

Male Partner Experiences of Females with an Acquired Brain Injury: an Interpretative Phenomenological Analysis

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9th June, 2014

Submitted in partial fulfilment of the Doctorate in Clinical Psychology

Acknowledgements

Firstly, I would like to thank the participants for giving up their time to share their experiences with me. Your personal stories were moving, and I was touched by your individual accounts of loss, despair and adaptation. I sincerely hope this research gives voice to your heartfelt experiences and informs others of the hidden nature of life following an acquired brain injury.

I would like to express my sincere gratitude to my supervisors, Dr Gundi Kiemle and Dr Stephen Mullin. Thank you for your invaluable guidance, dedication and encouragement throughout the whole research process. I will remain forever grateful for your kind support.

Thank you to the local brain injury support groups for kindly distributing recruitment flyers and announcing my research at their support groups, and thank you to the local NHS Trust for providing a venue and allowing the research to go ahead.

Finally, a huge thank you to my family and friends for being supportive and accepting throughout the final few months, and to Brett, for listening, caring and understanding.

Table of Contents

Acknowledgements	ii
List of Appendices	vii
List of Tables	viii
List of Figures	ix
Introductory Chapter	1
Thesis Overview	2
References	3
Chapter One: Systematic Literature Review	5
Abstract	6
Keywords	6
Introduction	6
Method	9
Search strategy	9
Search terms	9
Exclusion/Inclusion criteria	11
Search results	11
Data extraction, analysis and synthesis	12
Quality appraisal	16
Results	17
Participant Characteristics	17
Qualitative synthesis	18
Loss and change; of old self, of old us	18
Role transition	18
Altered sexual experience	20
Cognitive and emotional change	22

Resilience and relationship strength	24
Discussion	25
Interpretation of the results	25
Inconsistencies within the literature	27
Clinical implications	28
Quality assessment	29
Limitations of the review	30
Recommendations for future studies	30
Conclusion	31
References	32
 Chapter Two: Empirical Paper	 36
Abstract	37
Keywords	37
Introduction	37
Method	40
Research approval	40
Participants	40
Sampling procedures	41
Interview content	42
Procedure	42
Methodology	43
Data analysis	44
Quality and validity	45
Position of the researcher	45
Results	46
Entering the unknown world of ABI	47
Pre-injury naivety	47

An emotional roller-coaster	48
ABI sequelae; hidden to the outside world	49
Imprisoned by the ABI	50
Entwined lives; ‘joint disability’	50
Playing ‘happy families’	51
'She's not the person I married'	52
'There's no real escape'	53
Compassion without self-compassion	54
Helplessness and powerlessness	54
Abandonment of the self	55
Male partners; the silent victims	57
Holding on to hope	58
A lifelong commitment; endlessly understanding	58
Inner resilience and strength	59
Acceptance and adaptation; 'bad things happen to nice people'	60
Forever indebted; the importance of support	62
Discussion	63
Entering the unknown world of ABI	64
Imprisoned by the ABI	64
Compassion without self-compassion	65
Holding on to hope	66
Strengths and limitations	66
Clinical implications	68
Future Research	69
Conclusion	70

References 71

Appendices 74

Word Count 24 936

List of Appendices

Appendix 1	‘Brain Injury’: Instructions for Authors	75
Appendix 2	Division of Clinical Psychology Research Committee Approval Letter Consent Form	76
Appendix 3	Research Ethics Committee Approval Letter	77
Appendix 4	Participant Descriptions	84
Appendix 5	Recruitment Flyer	86
Appendix 6	Recruitment Letter	87
Appendix 7	Interview Schedule	88
Appendix 8	Participant Information Sheet	91
Appendix 9	Consent Form	95
Appendix 10	Participant Debrief	97
Appendix 11	Excerpts from the reflective journal	99
Appendix 12	NVIVO print screen of a superordinate theme, with corresponding quotes	101
Appendix 13	Table of main themes, subthemes and super-ordinate themes (with associated participants)	103
Appendix 14	Participant 4 (Nick); Example of Exploratory Coding	109

List of Tables

Chapter 1 Systematic Literature Review

Table 1 Descriptions of the six papers included for review and quality appraisal	13
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Chapter 2 Empirical Paper

Table 1 Participant Demographics	40
Table 2 Transcript extract to illustrate the analytic process (David)	44
Table 3 Table of main themes and subthemes	46

List of Figures

Chapter 1 Systematic Literature Review

Figure 1 Flowchart to represent the search strategy and identification of inclusion paper	10
Figure 2 Diagrammatic synthesis of the six papers included in the review	21

Introductory Chapter

Thesis Overview

Thesis Overview

Relationships following acquired brain injury (ABI) are extremely vulnerable to strain and breakdown (Burridge, Huw Williams, Yates, Harris, & Ward, 2007; Kreutzer, Gervasio, & Camplair, 1994). Spouses are faced with the challenge of adapting to the emotional, cognitive and behavioural changes in their loved one; an often distressing, overwhelming and unpredictable experience. With the spouse more likely to take the lead role as caregiver, they are left suffering the burden associated with such major role change (Chwalisz & Stark-Wroblewski, 1996).

Acquired brain injury may result in damage to the frontal lobe, temporal lobe and the limbic and pituitary system; areas known to be associated with sexual function (Oddy, 2001). Additionally, loss of confidence, memory impairment, anxiety and fear of failure to perform sexually, may indirectly impact on a couple's ability to mutually enjoy sexual intimacy (Moreno, Arango Lasprilla, Gan, & McKerral, 2013). To date, the published literature in the field of sexual intimacy following ABI is primarily limited to quantitative studies which report divorce and separation rates (Godwin, Kreutzer, Arango Lasprilla, & Lehan, 2011). The qualitative experience, from the viewpoint of the person with an ABI and their intimate partner, is so often missed. The first paper within this thesis, a systematic review of intimacy post-ABI, narrows this gap within the current literature base by synthesising the results of six qualitative papers.

Acquired brain injury can transform the lives of family members (Bowen, Yeates, & Palmer, 2010). Partners have been referred to as the 'hidden patients' following ABI (Fengler & Goodrich, 1979) as they, too, are required to make huge, yet unnoticed, changes to their lives. Published literature exploring partners and spouses following ABI, to date, has overlooked the viewpoint of the male partner. Their experience of role change, intimacy and resilience is not represented, nor have their personal stories been told. The second paper within this thesis explores just that, the male partner's lived experience, following their female partner's ABI. Adhering to the analytic methodology of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009), the males'

accounts are presented in the form of a coherent and insightful narrative of the experience of the male partner.

Together, the two papers highlight the need for services to support the couple jointly, without disregarding the needs of the uninjured partner. The importance of support for the couple throughout the entire rehabilitation process is highlighted, as so often partners' needs remain unmet. Sexuality following ABI needs to be openly explored, with relationship counselling and couples therapy routinely offered. Further studies exploring the male partner experience following their female partner's ABI would add richness to the themes presented here.

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Chapter 1

Systematic Literature Review

Exploring the impact of acquired brain injury on intimate couple relationships: a qualitative synthesis

Manuscript prepared for submission to 'Brain Injury'

Exploring the impact of acquired brain injury on intimate couple relationships: a qualitative synthesis

Abstract

Primary objective: To systematically review and synthesise qualitative data which explores intimacy and sexuality between heterosexual couples following an acquired brain injury.

Methods: Electronic database searches were conducted; SCOPUS, psychINFO, MEDLINE, CINAHL, Cochrane and psychARTICLES. Terms relating to ‘couple’, ‘experience’, ‘intimacy’ and ‘brain injury’ were combined with “AND” relations. Results were limited to qualitative, English language, peer-reviewed literature. Quality of the literature was systematically assessed.

Results: A total of six studies, which met stated criteria, were selected. Two master themes emerged from the qualitative synthesis of the six studies; ‘loss and change; of old self, of old us’ and ‘resilience and relationship strength’. ‘Loss and change; of old self, of old us’ was further sub-divided into three themes; ‘role transition’, ‘altered sexual experience’ and ‘cognitive and emotional change’.

Conclusions: This review demonstrates a lack of focus on the intimate lives of couples following ABI. The findings are consistent with the limited qualitative data available in relation to ‘loss and change’ post-ABI. Synthesising the six papers extends our understanding of intimacy and sexuality post-ABI, highlighting the continued commitment and mutual appreciation shared by couples affected by ABI. Health care professionals need to work to support continued sexual expression and intimate communication.

Keywords: Acquired brain injury, intimacy, sexuality, couples, qualitative.

Introduction

The impact of acquired brain injury (ABI) on intimate relationships can be significantly damaging for the couple. Cognitive, emotional, physical and communication difficulties following ABI may

adversely impact on an individual's ability to maintain certain roles within a relationship, creating a very challenging period of transition [1]. Physical and cognitive sequelae, such as sensory-motor, memory or initiation impairment, may interfere with the expression of sexuality and an individual's ability to communicate love and affection towards their partner [2].

Cognitive, emotional, physical and behavioural changes can have a huge impact on family members [2]. The most vulnerable to such changes is the spouse or partner [3], reporting more subjective strain, psychological distress and burden [4]. Increased dependence on the partner can make it very difficult for the couple to continue to enjoy a mutually satisfying sexual relationship [2]. Some partners have reported to feel as though they are 'living with a stranger' following ABI and just want their 'old' wife or husband to return. For others, intimacy, in particular sexual intimacy, can 'feel wrong' [3, 5]. Lezak [6] suggested that partners of those who have sustained an ABI may find themselves living in a 'social limbo'; staying with their partner may well impact on their social life, yet leaving the relationship may result in harsh social criticism and feelings of intolerable guilt.

Quantitative studies tend to focus solely upon negative aspects of the relationship, gathering statistical information on marital breakdown, distress, sexual dysfunction and burden. Godwin, Kreutzer, Arango, Lasprilla and Lehan [7] highlighted the vulnerability of marital relationships following ABI, reporting divorce rates ranging from 15% to 78% across all levels of injury. However, variable inclusion criteria and disparate methodological approaches create a challenge when attempting to pinpoint the relationship between potential correlates and marital outcome.

By delving deep into the qualitative world of the participant, and attempting to capture the personal and phenomenological experience of intimacy and sexuality following ABI, relationships between variables can be abandoned, and the intimate partnership explored. Previous reviews in the field of sexuality and marriage following ABI [2, 7] have primarily reported factors which relate to the strength or dissolution of relationships. Little is known about the qualitative experience of intimacy

and sexuality following ABI from the perspective of both the person with the brain injury and their intimate partner.

In other areas of neurological research, couple intimacy and sexuality have been widely investigated. Following a diagnosis of dementia, spousal burden of care and change in role were considered the reasons for a decrease in sexual activity [8]. In a separate study, hand-holding, massaging and hugging were reported as substitute activities for sexual expression [9]. For men diagnosed with MS it was found that the diagnosis resulted in a loss of self-identity and sexuality. Men reported a loss of confidence in the ability to perform sexually, however they valued the care and intimacy provided by their partners. Female partners felt responsible for the initiation of sexual activity and took over the roles traditionally held by the male [10].

To deepen and expand professionals' understanding of intimacy and sexuality post-ABI, it is important to search the literature for the personal subjective accounts of intimacy following ABI. The impact on physical, emotional and sexual intimacy between couples needs to be understood and addressed in the early stages of rehabilitation, without neglecting the needs of the partner.

The purpose of this qualitative review was to evaluate the quality of current studies in the field of intimacy and sexuality between couples following ABI. Following close scrutiny, the primary aim was to synthesise the perspectives of both the partners and persons with brain injury in order to address the question 'How does ABI impact on intimate couple relationships, from the viewpoint of persons with ABI and their intimate partners?' Gaps in the current literature base were identified and the implications of these findings for supporting couples following ABI were acknowledged and addressed in the discussion.

For the purpose of this review, the definition of acquired brain injury was taken from the Headway UK website; "A non-progressive acquired injury to the brain with sudden onset." [11]. This includes traumatic brain injury (TBI), stroke, brain tumour, haemorrhage, viral infection and anoxia/hypoxia

(deprivation of oxygen supply to the brain). Despite there being differences between the causes of ABI, the sudden life changing impact on the couple and how this influences the intimate relationship, is the primary focus of this review.

Methods

Search strategy

An initial scope of the literature was conducted in order to gain a brief overview of existing literature on the topic. To ensure that a comprehensive search was accomplished, SCOPUS, psychINFO, MEDLINE, CINAHL, Cochrane and psychARTICLES were searched on 20 October 2013 using a number of keywords and terms thought to capture the question under review. Only literature analysed using qualitative methods was included. Results were limited to English language, peer reviewed journals. No timeline was applied, yet it was found that articles pre-1990 lacked quality, and the findings were outdated. References which appeared to meet the criteria were exported to a reference management programme and titles and abstracts screened. Once narrowed down, full texts were scrutinised. In addition, reference lists of full text articles were manually scanned for relevant papers and leading authors and researchers in the field of intimacy and ABI were contacted for any missing articles.

Search terms

The PICO (Population, Interest, Context) tool was used to focus the research question and verify the search terms. The keywords underpinning the phenomena of interest were separated into ‘experience’ and ‘intimacy’ to ensure, for example, that papers captured the personal experience of change rather than sexual dysfunction alone.

Population: Couple, spouse, partner, marital OR marriage, relationship.

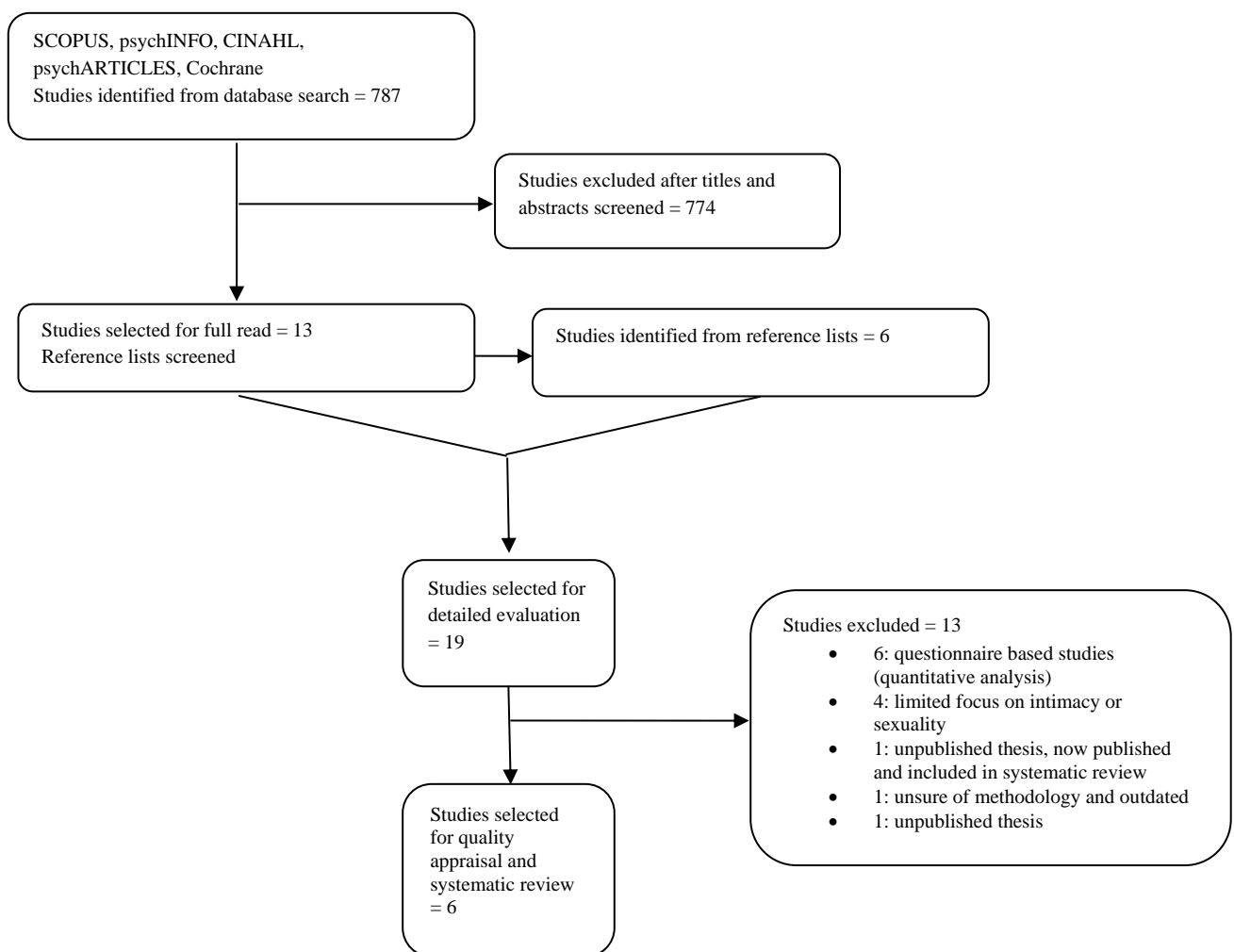
1st phenomena: Intimate OR Intimacy, sexuality, closeness.

2nd phenomena: Experience, change, adjustment, transition.

Context: Neuro*, acquired brain injury, traumatic brain injury, head injury, stroke, subarachnoid haemorrhage.

Literature including the terms “partner violence” or “cancer” were removed by the addition of the “NOT” relation to the search string.

Figure 1. Flowchart to represent the search strategy and identification of inclusion papers



Exclusion/Inclusion criteria

Qualitative articles, or those with a strong qualitative component, were included, excluding questionnaire based closed-question studies. Articles focusing solely on sexual dysfunction following ABI with no mention of the personal relationship or experience were excluded. Acquired brain injury was defined as an injury caused to the brain after birth with a sudden onset. Spinal cord injuries, MS and degenerative neurological impairments (such as dementia) were excluded from the review. Articles were also excluded if their focus was primarily on caregiver burden, role transition (not specifically linked with intimacy) or marital stability, with only marginal reference to intimacy and sexuality between couples. Literature focusing on divorced or separated couples was also excluded.

The review was limited to English language, peer reviewed qualitative articles. Papers with a dual focus (for example, 'intimate relationships' and 'rehabilitation needs' following ABI) were included, yet only the results relevant to the research question were reviewed.

Search Results

Studies were specifically included if they qualitatively explored the impact of ABI on intimacy and sexuality. A total of 19 studies were selected for detailed evaluation. Of the 19 studies evaluated, 13 did not meet the review's specific inclusion criteria. Six studies used questionnaire based methods to evaluate participant intimacy and sexuality [12-17]. Two of the identified studies were unpublished theses; yet one of these had been published since and was therefore included in the synthesis [18]. Four papers, despite unveiling interesting finds, did not fully address the review question; they focused on caregiver burden, spousal care giving, marital adjustment and role transition, without a direct link to intimacy [19-22]. Finally one paper was excluded on the basis of its unclear methodology and year of publication [23]. The paper did not explicitly state the method used, was brief and outdated.

Of the six studies meeting inclusion criteria, three of the studies focused on the impact of traumatic brain injury and the remaining three explored the impact of stroke. Four of the studies focused on the account of persons with ABI and their partners, one paper specifically focused on female partners and one focused on male and female stroke survivors; giving an equal representation of both persons with ABI and partners.

Data extraction, analysis and synthesis

A typology of reviews defines qualitative systematic reviews as a method of integrating or comparing the findings from a number of qualitative studies to create a new “interpretative translation” or narrative of the literature [24]. It looks for ‘themes’ or ‘constructs’ which are evident across the papers, with the overall aim of expanding knowledge of a particular phenomenon [24]. Systematic reviews of qualitative literature are within their infancy and therefore debate exists as to the precise method to be followed.

For the purpose of this review, the method outlined in Aveyard [25], an adaption of the meta-ethnographic [26] and meta-study [27] approaches, was followed. The first step required an in-depth knowledge of the six papers; their strengths, limitations and value. Data regarding the study aim, design, participants, method, main findings, conclusions and quality assessment were extracted and organised into a table to concisely summarise the six papers (only findings relating to this research question were included).

Table 1. Descriptions of the six papers included for review and quality appraisal

Authors	Participants	Aim, Design and Method	Main Findings, Themes	Conclusions and Implications	Quality Assessment
Gosling, J. Oddy, M. (1999)	Eighteen heterosexual couples; male sustained TBI 1-7 years ago. Mean age of men; 42.1 Mean age of non-injured women; 39.2. <i>Location</i> ; UK. <i>Recruitment</i> ; Head Injury Rehabilitation Service and local Headway branches	<i>Aim</i> ; To investigate the quality of the marital and sexual relationship (female non-injured partner perspective). <i>Design</i> ; Mixed methods; interviews and questionnaires (exploring relationship change and sexual satisfaction). <i>Method</i> ; Seven open ended questions relating to female partners' perceptions of the relationship and anticipation for the future. Themes identified.	<i>'Role change'</i> <i>'Partners' perception of patients' feelings'</i> ; grateful vs lack of emotional expression. <i>'Relationship changes'</i> ; no longer equal, sexual changes, 'boring', 'flat', 'feels wrong'. <i>'Positive aspects of relationship'</i> ; commitment, friendship and mutual affection (some women felt stronger with more control). <i>'The future'</i> , uncertainty. <i>'Other concerns'</i> , effect on children, stress and stigma.	<i>Conclusions</i> ; New responsibilities, 'maternal role' incompatible with intimate sexual relationship. Loss of equality in relationship and companionship. Lack of expression of emotional and physical affection leading to feelings of uncertainty. Positive feelings related to feeling committed and 'in it together'. <i>Implications</i> ; To help the partners of males with a TBI with the emotional and practical aspects of life following injury. To support the injured male with expressed emotion, encouraging mutual discussion of the couple's commitment to each other.	<i>Criteria met</i> ; Inclusion/exclusion criteria and recruitment reported. Ethical approval sought. Credibility check; two raters used. Participants situated (generally not individually). Participant characteristics homogeneous; all male participants had sustained a severe TBI (all unemployed) between 1 and 7 years ago. <i>Criteria unmet</i> ; Methodology unclear; analysis unclear (categories to themes?) Authors' theoretical perspective unclear. No participant interview extracts reported. The qualitative analysis appeared to be an 'add on' to the quantitative analysis; focusing on one type of design would provide a richer analysis.
Lemieux, L. Cohen-Schneider, R. Holzapfel, S. (2001)	Six couples, one partner aphasic following stroke (sustained 17 to 33 months ago). Five males and one female with aphasia. Mean age of aphasic subject; 65. <i>Location</i> ; Toronto <i>Recruitment</i> ; Pat Arato Aphasia Centre (PAAC)	<i>Aim</i> ; To investigate how stroke changed sexuality for aphasic people and their spouses. <i>Design</i> ; Pilot study. "Supported conversation for aphasic adults" method. Structured interviews. <i>Method</i> ; - Eight questions asked to the couple to begin. - non-aphasic spouse responded to 35 item questionnaire - 25 item face to face structured interview with the aphasic spouse. - Five questions were asked jointly to end. Data analysed and emergent themes identified.	<i>'Changes in sexual behaviour'</i> ; reduced frequency of intercourse for all couples. For some, other sexual activities increased. <i>'Changes in attitudes'</i> ; emotional lability and role of 'caregiver' interfered with sexual activity. Importance of sex stayed the same. Desire for sex reduced more in partner. <i>'Impact of aphasia on sexuality'</i> ; harder to verbally initiate and talk about sexual desire. Spouses reported their partner could no longer express feelings or engage in intimate conversation. Couples held the belief that improved communication skills would improve sex life.	<i>Conclusions</i> ; Aphasia limits the ability to initiate sexual activity. Partners missed the emotional intimacy that comes from talking about sex and their relationship. <i>Implications</i> ; Related to the role of the physician in exploring sexuality and providing information. Increasing access to aphasic-friendly communication tools/questionnaires. Couples wanted to be asked during rehabilitation about their sexuality. Sexuality should be broached in acute care, in rehabilitation or when the patient returns home.	<i>Criteria met</i> ; Aims and gap within the literature identified. Questionnaires developed and pretested. Ethical approval sought. Interview questions reported. Inclusion/exclusion criteria stated. Reliability checked by repetition of question. Themes reviewed with participants. Three investigators analysed data. Participants situated generally not specifically. First study to focus on aphasic patients. <i>Criteria unmet</i> ; Methodology and authors' theoretic perspective unclear. Method of analysis not clear (themes identified, how?) Very small sample (pilot study). Gender difference; partners predominantly female. Is it the aphasia specifically, or the stroke which impacts on sexuality? (non-aphasic stroke survivors may also be unable to express sexual desire) Loosely qualitative; more questionnaire based with closed answers.

<p>Layman, D.E. Dijkers, M.P.J.M. Ashman, T.A.</p> <p>(2005)</p>	<p>Twenty-one participants (male and female); eight with TBI, seven partners of people with TBI and six comparison group. All over the age of 50.</p> <p>Location; New York</p> <p>Recruitment; Research and Training Centre database of past research participants with and without TBI.</p>	<p>Aim; To explore the partner relationships of older couples following TBI.</p> <p>Design; Semi-structured interviews.</p> <p>Method; Content analysis approach. The study sought to answer the following;</p> <p>-What are the experiences of older partners of individuals with TBI?</p> <p>-In what way does the TBI impact upon older couples when the injury is sustained later in life?</p> <p>-Are the problems faced, similar to those of younger couples?</p>	<p>'Relatedness'</p> <p>'Communication'; positive and negative aspects.</p> <p>'Levels of dependence and inter-dependence'</p> <p>'Role change'-spouse to parent; more burdensome for females.</p> <p>'Sexual intimacy'- decrease in frequency (yet all comparison group also reported a decrease). Decrease in satisfaction primarily in TBI groups (yet attributed this to age).</p> <p>'Relationship persistence'</p> <p>'Critical incidents'; closer than before, relationship stronger.</p> <p>'Reasons given for relationship persistence'; mixed accounts, from feeling vulnerable, beliefs about divorce and acceptance and love.</p>	<p>Conclusions; Relationship change was attributed to age, with growing older making it difficult to differentiate TBI consequences from other health/physical/psychological issues. Participants with a TBI and partners reported decreased sexual satisfaction, yet attributed this to age related factors. The authors state that for the older couple (in comparison younger) issues of sex and sexuality are less significant following TBI, but they are unsure how much age masks the effects of TBI on intimacy. Female partners found it more difficult to adapt to their new role. Male partners found satisfaction and inter-dependence in their new role. (Note; this was similar in the comparison group).</p> <p>Implications; focused on counselling and attending to the 'here and now' with older couples.</p>	<p>Criteria met;</p> <p>Explanation for reason for the study; qualitative approach justified.</p> <p>Inclusion criteria noted.</p> <p>Participants situated (generally not individually). Content areas, guiding the interview, are presented. Process of analysis and coding described, reliability analysis conducted on three randomly selected interviews.</p> <p>Criteria unmet;</p> <p>Methodology vague and authors' theoretical orientation unclear.</p> <p>The results are difficult to follow and at times incoherent; there are too many groups with not many summaries or conclusions being made.</p> <p>It is unclear why a comparison group was used (using a reference point for the comparison group added an extra layer of ambiguity to the findings).</p>
<p>Thompson, H.S. Ryan, A.</p> <p>(2009)</p>	<p>Sixteen stroke survivors living with their non-injured spouse; nine males and seven females. Mean age of participants; 56</p> <p>Location; UK</p> <p>Recruitment; Stroke nurse specialist register</p>	<p>Aim; To explore the impact of stroke on spousal relationships, from the perspective of the person with stroke.</p> <p>Design; Qualitative interview study.</p> <p>Method; Content data analysis. Topics included; life before stroke (work, role and relationship), life after stroke (physical, emotional, social) and coping strategies.</p>	<p>'The dichotomies of pre and post stroke self'</p> <p>'Anger and irritability'; feelings of guilt, low self-esteem and despair,</p> <p>'Frustration (dependence and over-protective care)'</p> <p>'Sexuality, sexual functioning and desire'</p> <p>'Sexuality'; resembles a patient-carer relationship.</p> <p>'Physical appearance'</p> <p>'Sexual desire and sexual functioning'; reduced frequency, impact of medication and fear of stroke. Best friend.</p> <p>'Perceived loss of control'</p> <p>'Loss of role, identity and sense of self',</p> <p>'Socialising' (fatigue, swallow, anxiety).</p> <p>'Stroke – a life changing event'; not always visible impairment, difficult for others to understand.</p>	<p>Conclusion; The study concludes that stroke impacts on the physical, psychological, social and emotional dynamics within a spousal relationship.</p> <p>Implications; focus on the need for services to understand and recognise difficulties within the spousal relationship following stroke. Guidance lacking for psychosocial issues. The study acknowledged a need to increase nurse education and provide statutory counselling services.</p>	<p>Criteria met;</p> <p>Rationale provided for using qualitative design. Ethical approval granted. Confidentiality and emotional distress discussed. Topics of interview covered. Thorough description of data analysis. Saturation reached, by 14th interview, no new themes. Bias acknowledged. Direct quotations used. Peer-reviewed by supervisor to check interpretations. Balance of male and female participants.</p> <p>Criteria unmet;</p> <p>Cognitive impairment excluded (how did they screen for this?); no reason for this exclusion was provided. Transferability of findings is questionable; recruitment within small rural part of Northern Ireland where cohabiting outside marriage is not the norm (only married couples included). The discussion appears weak in relation to the wealth of findings. A more interpretative analysis would enable greater insight into the participants' lives.</p>

<p>Schmitz, M.A. Finkelstein, M.</p> <p>(2010)</p>	<p>15 stroke survivors and 14 non-injured partners (did purposely not recruit couples; although some couples did take part, they were interviewed independently). Median age of partner; 65 Median age of stroke survivor; 66</p> <p>Location; Minnesota</p> <p>Recruitment; stroke support groups, stroke programme coordinators and care providers</p>	<p>Aim; To explore the experience of sexual issues and rehabilitation needs following stroke from the perspective of survivors and partners.</p> <p>Design; Semi-structured interviews.</p> <p>Method; Qualitative thematic analysis. 10 interview questions with a focus on; sexuality after stroke, the experience of how rehabilitation professionals addressed sexuality issues and preferred rehabilitation settings following stroke</p>	<p>Two of the seven themes related to effects of stroke on sexuality (the remaining five related to rehabilitation needs).</p> <p>'Sense of loss and functional changes affect sexuality'; decrease in sexual desire/activity linked to physical/emotional change. Loss resulted in frustration, fear and isolation. Changes in physical/sexual functioning affected confidence and sense of self. Fear that sexual activity may cause another stroke. They affirmed a continued strong need for touch and emotional connection. Others described isolation.</p> <p>'Relationship changes affect sexual functioning'; changes were complex, disrupting defined gender roles and patterns of interaction. Caregiver vs sexual partner (unmet needs). Emotional tension between demands of care giving and sexual intimacy.</p>	<p>Conclusions; The results suggest that sexuality following stroke is largely ignored. Stroke survivors feel a deep sense of loss. Sexuality is complex and affected by a range of physical, psychological and social factors. There should be a focus on the bio-psycho-social factors affecting sexuality, not merely 'sexual dysfunction'.</p> <p>Implications; Focus on rehabilitation programmes, staff education and available resources. Staff must consider both the individual and the couple. Participants affirmed that sexuality was a vital part of their life that warranted attention as part of rehabilitation.</p> <p>Themes related to rehabilitation will be highlighted in the discussion.</p>	<p>Criteria met;</p> <p>The study did not include those previously or currently treated by the principal investigator to eliminate bias. Confidentiality discussed. Ethical approval granted. Interview questions appear within the paper. Methodology discussed. Peer-reviewed for verification of themes.</p> <p>Criteria unmet;</p> <p>The study is largely related to rehabilitation, however there are some important themes to come out of the study (relating to this review question); the impact of 'loss' and 'role change' on sexuality. The primary focus of the paper is on individual sexuality and not relationship dynamics, however, the findings answer the question posed in this review and therefore the paper was included.</p>
<p>Gill, C.J. Sander, A.M. Robins, N. Mazzei, D. Struchen, M.</p> <p>(2011)</p>	<p>Eighteen persons with TBI and their intimate non-injured partners, mean length of time post-injury; 4.78 years. Age range of persons with TBI; 21-59 Age range of non-injured partners; 27-61</p> <p>Location; Chicago and Houston</p> <p>Recruitment; Brain injury programmes, support groups, rehab centres, previous participant in studies</p>	<p>Aim; To explore the experience of intimacy from the perspective of the person with TBI and their partner; explored the facilitators and barriers to intimacy. Ultimate objective was to inform services on how best to educate and support people with TBI and their partners in relation to intimacy.</p> <p>Design; Qualitative interview study.</p> <p>Method; Grounded theory approach. Participants interviewed separately. 25 primary questions focused on the impact of TBI on intimacy.</p>	<p>'Barriers to intimate relationships'</p> <p>'Physical, cognitive and emotional changes (to intimacy)'</p> <p>'Emotional reactions'; e.g. guilt, inadequacy, confidence.</p> <p>'Different person, negative feelings'</p> <p>'Sexual strains and incompatibilities'</p> <p>'Role change or conflict'; parent and child</p> <p>'Communication difficulties, uncertainties'</p> <p>'Balance/role strain'</p> <p>'Family factors'</p> <p>'Isolation'.</p> <p>'Factors related to relationship strength'</p> <p>'Unconditional'</p> <p>'Communication, being understanding',</p> <p>'Pre-injury relationship foundation',</p> <p>'Grateful for survival'</p> <p>'Spending time together/friendship'</p> <p>'Social support, family bonds'</p> <p>'Spirituality'</p> <p>'Prior experience'</p> <p>'Coping skills'.</p>	<p>Conclusions; The study explored under-represented perspectives in TBI research (sex same couples, racial and cultural groups, post injury relationships, male uninjured partners and females with TBI). Couples focused on and savoured the positive experiences in order to overcome the loss following TBI. The results indicate that intimacy is complex. Stress and caregiver burden result, yet unconditional love, appreciation and commitment made it all worthwhile. Intimacy was perceived as more than just sex; meaning that more things can go wrong. Communication was a predominant theme (both positive and negative changes).</p> <p>Implications; Focus on increased support, education and counselling for couples around issues related to intimacy.</p>	<p>Criteria met;</p> <p>The research is informed by the social model of disability, moving away from a deficit/symptomatic focus. Epistemology highlighted. Confidentiality and ethical concerns are accounted for. Transcripts checked for accuracy. A second investigator coded a random selection of interviews to ensure credibility. Interview questioned noted. Direct quotations used.</p> <p>Criteria unmet;</p> <p>The sample size is small but sufficient for the design, yet is possibly too diverse (for example five couples got together after the TBI and are being compared with pre-injury relationships). Were the participants too heterogeneous to draw valid conclusions? Therefore it is difficult to say if themes may differ if the focus was on a particular participant characteristic.</p>

The second stage involved comparing and contrasting the papers by integrating and interpreting the six studies to form a coherent whole [25]. Codes were assigned to the main findings of each paper and transferred to a table with corresponding quotes or references to the text. Codes which corresponded to one another were then clustered. This enabled similarities and differences in the findings to be located. Codes naturally fell into four higher-order categories; three referring to the negative impact of ABI ('role change', 'altered sexual experience' and 'cognitive and emotional change') and one referring to 'resilience and relationship strength'. The three higher-order themes, referring to the negative impact of ABI, centred around 'loss' and 'change' following ABI in relation to the self and the interconnected couple. A number of codes were only evident in one of the papers due to the specific focus of the research question and type of participant; these will be discussed in the findings.

Quality appraisal

Each of the six papers underwent an in-depth reading and quality assessment of the content. The Critical Appraisal Skills Programme (CASP) [28] tool for appraising qualitative studies was utilised. The tool follows a set of ten questions covering aspects of the following; aims, methodology, design, recruitment, data collection, researcher-participant relationship, ethical considerations, data analysis, credibility and value of the data and its relevance to existing literature.

Due to the widespread debate regarding what constitutes a good piece of qualitative research, it has been argued whether a strict set of criteria to assess quality should exist at all. Dixon-Woods, Booth and Sutton [29], in their review of existing qualitative syntheses, highlight the variability of reported quality appraisal methods utilised in reviews; from no mention of appraisal (either no justification given or due to inclusion of all studies), to checklists used in a procedural and systematic manner. Papers utilising full quality appraisal tools often failed to account for the findings later in the synthesis [29].

Quality is not an exclusion criterion within this review, however, the judgements of quality will be incorporated within the synthesis and those papers deemed to be of higher quality will be given precedence.

Following quality assessment, the Gill et al [18] and Thompson and Ryan [30] papers provided the highest quality replicable research into the experience of intimacy following brain injury; complying with all ten CASP criteria. These two papers will be given precedence. The two earlier papers, Gosling and Oddy [5] and Lemieux et al. [31] offered a brief and comparable insight, however, qualitative richness appeared to be missing. Quality will be further explored in the discussion in line with the CASP framework criteria and the Elliott, Fischer and Rennie [32] publishability guidelines.

Results

Participant characteristics

Comparison of participant characteristics showed large variability across the six studies. Three of the studies recruited couples following ABI making a total of 38 couples [5, 18, 31]; 32 following TBI [5, 18] and six following stroke [31]. Of the 38 couples, only seven of the participants with an ABI were female. One study focused on the perspective of the person with stroke, recruiting nine males and seven females [30]. Two studies recruited both persons with an ABI and partners (not a couple specifically, although some couples did both volunteer) [33-34]. One recruited 15 people with stroke (6 female and 9 male) and 14 partners of people with stroke (7 female and 7 male) [33]. The second study recruited eight persons with TBI (5 female and 3 male), seven partners (2 female and 5 male) and six comparison group participants (3 female and 3 male) [34].

Three of the studies focused on intimate relationships following stroke [31-33] and three studies focused on intimate relationships following TBI [5, 18, 31]. One of the stroke studies focused specifically on couples affected by aphasia [31] and one of the TBI studies focused specifically on the

older couple [34]. A wide range of ages of participants (21-84 years) and severities of ABI (mild, moderate and severe) were represented across the six studies and relationship length ranged extensively from six months to 61 years.

Qualitative synthesis

Two master themes emerged from the synthesis of the six studies; '*loss and change; of old self, of old us*' and '*resilience and relationship strength*'. '*Loss and change; of old self, of old us*' was further sub-divided into three themes; '*role transition*', '*cognitive and emotional change*' and '*altered sexual experience*'; presented in figure 2 as interconnected. The master themes (and corresponding themes) are presented below, using original quotations and original authors' interpretations. Differences between the studies are also highlighted and discussed. Codes and themes were shared and validated with the academic supervisor who had extensive clinical knowledge in sexuality and sexual dysfunction, physical health and psychological therapy.

'Loss and change; of old self, of old us'

Role transition

Across all six papers, role change was evident in the accounts of both the person with the ABI and partners of those who had sustained an ABI. Role transition was almost exclusively discussed in terms of the negative impact on the relationship.

Both persons with ABI and partners felt that traditional gender roles were challenged following ABI. One male who had sustained a TBI was quoted as saying '*as a man, some of those difficulties make you feel, you know, like less than a man, like not a complete person*' [18]. Similarly a male, following stroke, described his experience; '*I would always be a passenger now all the time – it's really you're*

not as much as a man as you were before' [30]. With their gender identity and self-perception in question [30], males reported feelings of inadequacy [34], guilt and shame [18].

Across all six papers, partners reported feeling as though they now occupied a parental or caregiver role; one which no longer felt equal due to extra care giving responsibilities [5, 30]. Gosling and Oddy [5] reported that 13 out of the 18 female partners felt that they now had '*total responsibility*', with 10 participants reporting that their relationship to their husband was more like that of a '*mother*'. Similarly, a female stroke survivor reported '*it's not a husband and wife role anymore. It's a carer and a patient and it's not very pleasant and it's not fair*' [30].

For partners, occupying the role of caregiver appeared to be dissonant with that of a sexual, romantic role. In the study addressing how stroke altered sexuality for aphasic individuals and their partners [31], it was identified that '*assuming the role of caregiver reduced sexual desire for spouses*'. Similarly, in a separate study, a male partner following stroke was quoted as saying '*it's hard to get rid of that role (caregiver) and be a husband again*' [33].

Following ABI, the injured partners reported feeling '*treated like children*' [18] due to an increase in dependence on their intimate partner. This was found difficult to accept, especially when care was perceived as '*over-protective*' and '*demoralising*'; '*There's nothing says I can't do it – you know I'm fit enough. I want to do the hedges, want to tidy the place up, want to do this, if I go to do anything heavy the missus is giving off to me*' [30]. One partner, following his wife's TBI, acknowledged his need to care for his wife; '*I'm stupidly over-protective about making sure she doesn't get injured*' [34].

Similarly to previous studies looking at burden and role strain following ABI, partners referred to their lives as a '*juggling act*', balancing new responsibilities with work, family life and the needs of their partner [18]. One female partner summarised her personal struggles to remain organised, highlighting the impact it has on intimacy; '*I'm doing a lot, just a lot of issues you're trying to deal*

with all at the same time. . .I need someone to come in and organize my life because my life has been wrapped around a whole other situation for a whole year. . .I just don't have time to keep up with the small stuff. I'm focusing on the big stuff. So does that sound like I have a lot of time for intimacy?' [18].

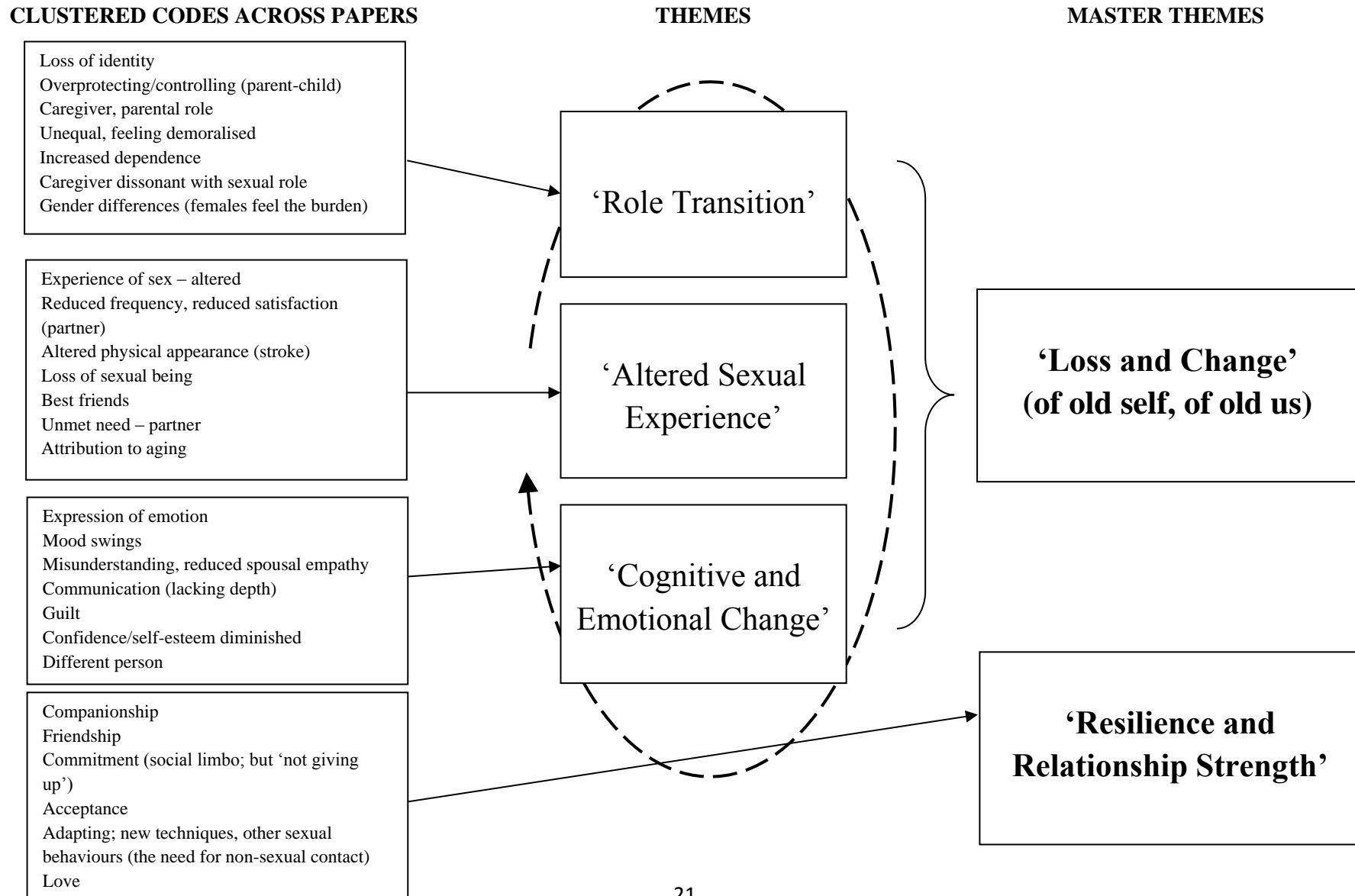
The Layman et al. [34] paper, exploring the impact of TBI on the older couple, highlighted a slightly different perspective on burden following ABI. Male partners expressed enjoyment in looking after their wife and did not refer to their new role as parental or burdensome. Retirement from work may explain this difference in finding. However, the same study reported that females expressed increased strain and burden, thus potentially highlighting a gender difference in perceived stress following ABI.

Altered sexual experience

All six papers reported reduced frequency of sexual activity following acquired brain injury; this was discussed in terms of decreased sexual desire [18, 30, 31, 33] and reduced sexual satisfaction [5, 18, 30, 31, 34]. Some partners described feeling '*disappointed*' [33] and frustrated regarding their unmet sexual needs [18].

The impact of physical changes following ABI were discussed across several of the studies [5, 18, 30, 33]. A male stroke survivor described his experience; '*Well I was hoping that we could make love as we did in the past, but I don't get erections anymore like I used to and my paralysis on the left side means that we can't. The positions we used aren't viable now, so I had to change that. And then we tried different approaches and that didn't work...*' [33]. Thompson and Ryan [30] identified a theme relating to post-stroke appearance highlighting how facial asymmetry and drooling resulted in feelings of inadequacy and the reluctance to engage in sexual contact with intimate partners. Fear of recurrent stroke or harm [30, 33] was also noted as impacting upon sexual desire as described by a male partner; '*I was afraid that touching or whatever would hurt her, would cause her to have another stroke*' [33].

Figure 2. Diagrammatic synthesis of the six papers included in the review



Altered sexual experiences following ABI resulted in the absence of emotional closeness and feelings of loss and rejection from their partner with an ABI; *'It's the lingering and holding. . .we don't have that anymore and that's what I miss the most'* [18]. Similar to previous studies in the field, partners highlighted feeling as though they were *'sleeping with another person'*, which for them, felt distressing and morally wrong [18]. Partners discussed occupying the role of *'best friend'* [30] rather than that of an intimate, sexual lover.

From the perspective of the person with a brain injury, issues of guilt, loss and fear of failure to perform were captured by this participant excerpt; *'The major piece is how it feels to me in my head. That I just don't think that I can be a successful lover any more, and I hate that...I don't want to sign up for experiences of failure – and I had a lot of that since I had my stroke...'*[33].

Layman et al.'s [34] study again highlights a slightly different outlook on sexuality in the older couple following TBI. They, too, report a decrease in sexual activity following ABI, yet most attribute this reduced frequency to age related health factors; *'No I think you have to understand [that] when you get to certain ages, and with certain medications, physical conditions demand that you sometimes have a decreased sexual desire or if you had the desire you, you can't make it.'* This misattribution to aging may function to make reduced sexual desire easier to live with; something which the other studies have not focused upon due to younger participant samples.

Cognitive and emotional change

All of the six studies reported changes in communication, expressed emotion and mood following acquired brain injury. The inability to express or convey emotions or feelings to their partner resulted in the brain injured persons feeling distanced [30] and often isolated [33]. In the study of aphasic stroke survivors and their partners, participants described the *'missed emotional intimacy'* which comes from talking about sexual experiences and the sharing of intimate conversations. In a separate

study, partners following TBI also discussed feeling uncertain about their partners' true feelings due to lack of emotional expression; this was sometimes interpreted as them being '*ungrateful*' [5]. A partner stated '*I think an intimate moment is when you pour your heart out. And we can't do that anymore*' [18].

Due to reduced emotional expression and cognitive change, spontaneous acts of intimacy were also affected; '*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..*' [18]. Coupled with role change and failure to perform sexually, individuals following ABI described low confidence [18, 33], self-esteem [30] and a diminished sense of self [33]. Such emotions were often attached with '*feeling a burden*' and guilty that their partner was '*lumbered*' with them [30].

Several of the studies highlighted the impact of mood swings [5, 30, 34] and emotional lability [31] on the intimate relationship; '*Well I'd just snap you know and not talking properly to people (spouse and family). And then I'd sit back and think why did I do that? But it doesn't make any difference, I keep doing it.*' [30]. Memory impairment [34] and the inability to inhibit outbursts [30] were reported to impact on mood and spousal discord.

The hidden disability of ABI was highlighted across several papers. At times, the impact of ABI was reported to be misunderstood by partners and '*spousal empathy*' was sometimes lacking [30]. A number of partners had questioned whether the relationship was '*really worth*' the effort they put in with one partner reporting that '*she's a whole different person than she was before her injury*' [18]. However, not all changes in communication, behaviours and emotions were perceived as negative. One partner described positive changes in her husband's drinking habits and family involvement [18], another reported her partner to be '*less verbally abusive now*' [34].

‘Resilience and relationship strength’

Despite the majority of the literature focusing on loss and the negative impact of ABI on intimate relationships, several of the papers did explore factors related to relationship strength [5, 18, 34]. Two further papers out of the six [30, 31] did highlight the need for continued touch and emotional connection as a way of adapting and coping with reduced sexual frequency, yet failed to explore relationship strength in any depth. Gill et al. [18] highlighted that unlike the negative factors following ABI, there was overlap and similarity between survivor accounts and partner accounts when discussing relationship persistence, endurance and growth.

A sense of mutual commitment [5] was evident across the papers. Appreciation for their partner’s commitment was evident in this account; *‘It’s amazing. You know, a lot of partners leave when this happens, and she stuck it out through thick and thin...’* [18]. Another participant acknowledged times when he does not feel emotionally close to his partner, yet pointed out his lasting commitment; *‘There are moments when we’re drifting apart, but when people say they’re drifting apart that generally means that the marriage is in trouble. Our marriage is not in trouble’* [34].

Lezak [6] described the dilemma of ‘social limbo’, which was evident in this quote taken from a female partner; *‘I can’t see myself as somebody who would leave somebody because of circumstances beyond his control, and a TBI is circumstances beyond his control. I’m not sure I really believe in divorce. And so—do I walk around feeling stuck some of the time? Yeah, I do. Could I live with myself if I did something proactively to unstick myself? I’m not sure I could’* [34]. The partner expressed a feeling of ‘stuckness’ within a no-win situation; battling between societal expectations of partners, and personal feelings of guilt following disability within marriage.

Despite highlighting the negative connotation of the ‘best friend’ role above, friendship and spending time together was seen as a positive factor relating to relationship success [5, 18]. Over half of the participants spontaneously made reference to love in the Layman et al. [34] study when providing

reasons for relationship persistence. Engaging in activities together demonstrated friendship, love and commitment to their partner; *'I try to do little surprises for him and that makes me happy because that is what we used to do before all this'* [18].

Unconditional acceptance was a theme across two of the papers, which resulted in deep appreciation for their partner. One un-injured female talked about accepting her partner's imperfections and just getting on with it; *'...when he's sitting there and working on his little letters to the newspapers, and he's got this commitment to making something work, you keep reminding yourself of this positive stuff that you find so attractive about that person, and you minimize the stuff that irritates you. I think you can start to say: "Well, we all have pros and cons to our personalities. So this guy got smacked in the head, you know. Well so ... let's deal with that"'* [34].

Discussion

Interpretation of the results

The findings of this review are consistent with existing literature in the field of ABI in which a prominent theme of 'loss and change' post-ABI is evident. The themes add depth to the vast amount of quantitative studies within the field. What remains unique about this review is the qualitative exploration of how 'loss and change' following ABI can and does impact on intimate couple relationships. Similar to other areas of health research, e.g. dementia [9, 35] and cancer [36], the theme of mutual commitment, affection, resilience and strength was unveiled across several of the papers. Much of the focus of past research has been on relationship breakdown and divorce rates, however, exploring experiential accounts of intimacy following ABI allows for a new and perhaps more hopeful perspective on sexuality, commitment and togetherness.

As presented diagrammatically in figure 2, the first three themes are closely inter-related and unveil the impact on intimacy of 'loss and change' following ABI. Role change has been well documented

in the field of ABI [1, 3, 37]. This review, however, specifically identifies the impact of this change on intimacy and sexuality. Following ABI, gender roles are challenged, extra responsibilities are handed to the partner and persons with an ABI reported to feel as though they were being treated like a child. Inequality within a relationship, coupled with feelings of shame, guilt and inadequacy were found to negatively impact on intimacy. Partners expressed burden, role strain and reported that newly acquired caregiver roles did not ‘fit’ with the role of sexual partner.

Loss of physical independence together with increased emotional lability, cognitive difficulties and sexual dysfunction or disinterest was reported to leave the individual feeling vulnerable and unable to contribute sexually to the relationship. In previous quantitative literature focusing on emotional change, anger following ABI has been associated with higher divorce rates [38] and emotional lability has been shown to impact on partner wellbeing and relationship satisfaction [1, 39]. This review uncovered the personal accounts of altered sexual experiences and the impact of emotional and cognitive change specifically on the relationship. The papers qualitatively reported the impact of post-stroke appearance, paralysis and fear of further strokes on intimacy and sexuality. Failure to perform sexually was reported to impact on the couple relationship and communication impairment created barriers to expressed emotional intimacy and the initiation of sexual desire.

Quantitative literature in the field of ABI commonly focuses on the difficulties following ABI rather than exploring the positive experience of caring, resilience and coping strategies [2, 7]. Understandably this reflects the life changing nature of ABI; however, personal growth, new learning and positive transition must not be neglected. Three of the papers in this review focused on relationship strength following ABI; commitment, appreciation for their partner, friendship and love. Both partners and persons with ABI reported similar feelings of connectivity towards their loved one, demonstrating mutual adaptation and acceptance of the ABI. There is a huge gap in the ‘positive’ adaptation literature surrounding ABI; these personal accounts demonstrate that it is present yet not researched. Further exploration would support professionals to understand what keeps relationships

strong and resilient, providing increased knowledge and support for sexuality counselling and couples therapy following ABI.

Inconsistencies within the literature

The majority of the findings across the six papers were comparable, thus providing sufficient overlap to enable qualitative synthesis. However, as highlighted in the results, a number of inconsistencies were revealed.

Interestingly, retired male partners, now caring for their wife, did not perceive the change in role as strenuous or burdensome and in fact reported enjoyment in their new-found responsibilities [34]. Unlike the female partners, this role was new to the males and therefore presented as a novel challenge, one which did not feel too stressful or demanding. The role may have been seen as owed to their female partner, i.e. it was their duty to pay back support, care and a life time of domestic chores. However, this finding was not reported in the context of intimacy and sexuality and it may be that such males no longer engaged in sexual activity alongside their caring duties.

In the same study [34], participants attributed the loss of sexual activity to aging and health related factors rather than the ABI. Older couples following ABI appear to provide age-related explanations for reduced sexual desire and satisfaction.

Participants in the aphasia and sexuality study [31] reported a belief that increased communication would improve their sex life. The participants attributed decreased sexual desire and sexual satisfaction to the aphasia rather than other aspects of the stroke (emotional, cognitive, behavioural sequelae). For the participants within this study, the focus was on communication and therefore other difficulties following ABI were not acknowledged. However, as previous literature points out, it is likely that a number of factors are attributable for the decrease in sexual desire.

In the Gill et al. [18] study, couples in new relationships post-ABI were included. Such couples questioned where to set boundaries in terms of care-giving duties, questioning whether the partner should have to do so much? Further research in the area of new couples and sexuality may provide more insight into this under investigated area.

Clinical implications

The findings have implications for healthcare professionals and services which support individuals and couples following ABI. As highlighted by quotations from the six papers, persons with ABI and their partners are able to articulately identify their post-ABI relationship need (physical, psychological and social) and therefore should be active participants in their own rehabilitation. Systemic rehabilitation is key. The couple should be approached as an equal partnership, supported to increase communication, express emotional intimacy and combine their resources to enable them to jointly cope with the after-effects of ABI.

As highlighted earlier, Schmitz and Finkelstein [33] explored rehabilitation needs in addition to post stroke sexuality, identifying a number of themes for healthcare professionals and services to address. Participants reported that they found it difficult to talk about sex; however sexuality was an important part of their lives. Only one out of 29 participants in the study reported that they had been asked about sexuality by a rehabilitation/medical professional. Participants expressed a wish for the professional to initiate conversation about sexuality as they felt unable to do so themselves. Another theme related to the wish for personalised education about sex following stroke; the safety of sex, communication barriers and treating sexual dysfunction. Participants expressed that information about sexuality should not be provided in the acute phase but when the stroke survivor is about to return home. Feeling comfortable and relaxed with the professional was also highlighted as key to discussing issues of intimacy and sexuality.

Post-ABI sexuality appears to be largely ignored by professionals; whether this is due to personal feelings of discomfort, lack of training or whether sexuality is not deemed to be of high importance during rehabilitation. As explored in the six papers, continued intimacy and mutual commitment following ABI is vital for recovery; without it, a sense of both loss and change is further exacerbated. These unmet rehabilitation needs must be addressed by the health care professional, protected time needs to be given to the couple for discussing sexuality needs and support should be tailored to the couple's needs and provided at the most appropriate time for them.

Quality Assessment

The Gill et al [18] and Thompson and Ryan [30] papers, overall, provide the highest quality research into the intimate lives of partners and persons with ABI. The method sections were clear, accurate and provided a template for replication. The direct quotations presented allow the reader to understand and empathise with the personal experience of the participant. The Layman et al. [34] study, despite providing a wealth of rich quotations, left the reader feeling confused. The use of a comparison group did not appear to strengthen the findings and instead added an extra layer of ambiguity and confusion [32]. Despite this criticism, many of the quotations were interpreted and used within this review as they appeared to encapsulate the themes well.

The two earlier papers [5, 31] offer a brief insight into intimacy post-ABI, however quotations were not provided, methodology was not described and the authors' theoretical orientation unacknowledged. The results were utilised, however, qualitative richness was lacking and therefore the other papers were given precedence over these findings. The Schmitz and Finkelstein [33] paper, despite a heavy focus on rehabilitation needs, provided a brief yet rich account of loss and change post ABI. The rehabilitation themes were utilised in the clinical implications section and address the need for professionals to address sexuality and provide education during the post-acute phase.

Limitations of the review

Despite thorough attempts to conduct a comprehensive search of the literature, studies may have been missed due to only including English language papers from peer-reviewed journals. Significant heterogeneity was evident across the six papers with participants differing in terms of the cause of the brain injury, severity of the brain injury, age of participant, age at time of ABI and especially length of relationship. Each paper focused primarily on different participant characteristics; older persons [34], aphasic stroke survivors [31], female partners following TBI [5], couples following TBI [18], stroke survivors [30] and stroke survivors and partners of stroke survivors [33]; yet perhaps not surprisingly it was found that similar themes were present despite the study focus. A limitation of this, however, was the focus of the questions across each study (i.e. failing to explore relationship strength). Due to the lack of studies present within the current literature, only participants who had sustained a TBI or a stroke were represented. All six studies identified were acknowledged and none were excluded on the basis of quality. This was accounted for by giving greater precedence to the higher quality studies. The systematic review was conducted by a single researcher, potentially impacting on the credibility of the interpretations. However, the supervisors had extensive clinical knowledge in sexuality and sexual dysfunction, physical health and ABI.

Recommendations for future studies

There is insufficient research exploring the intimate connection between partners and persons with ABI [1]. Further exploration of the personal accounts of post-ABI intimacy would add to the sparse literature base currently available. The six papers included within this review recruited individuals following stroke and TBI. Exploring other causes of ABI (tumours and subarachnoid haemorrhage) and their impact on sexuality would add to the existing literature.

Gill et al. [18] attempted to expand the literature base by including gay couples, couples who had begun their relationship after the TBI and couples from mixed ethnic backgrounds. Studying these

groups individually would allow for differences between the groups to be highlighted and individuals represented.

Male partners of females who have sustained an ABI are also a forgotten group and under-represented within the literature. Studies focusing on the partners/spouses following ABI tend to recruit females (due to the higher proportion of male TBI survivors), and the findings are generalised to both sexes, which may not be an accurate reflection of individuals' lived experience. Focusing specifically on the male partner experience would capture 'loss', 'change' and 'commitment' following their wife's ABI [40].

Despite three of the studies demonstrating some, albeit limited, focus on the positive aspects of intimacy post ABI, other areas of health and neurological research (e.g. dementia and cancer) provide a richer view of relationships following trauma and ill health. The current ABI literature base has been left behind, focusing on factors linked to divorce and relationship breakdown. Exploring the experiential accounts of persons living with ABI and their intimate partners would produce a much richer literature base, and healthcare professionals would benefit from the knowledge and feedback from those who have lived through the experience of ABI.

Conclusion

This review of six papers exploring intimacy and sexuality following ABI highlighted a surprising lack of focus in the extant ABI literature on the intimate couple relationship following the sudden and unexpected impact of brain injury. Many gaps within the current literature base need to be filled. The review uncovered how 'loss and change' following ABI engulfs the accounts of participants, specifically in relation to role transition, sexual experience and emotional and cognitive change. Despite the need for further exploration of relationship strength, the review exposed the mutual commitment and unconditional acceptance and appreciation expressed by couples following ABI.

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Chapter 2

Empirical Paper

Male Partner Experiences of Females with an Acquired Brain Injury: an Interpretative Phenomenological Analysis

Manuscript prepared for submission to 'Brain Injury'

Male Partner Experiences of Females with an Acquired Brain Injury: an Interpretative Phenomenological Analysis

Abstract

Purpose: Acquired brain injury does not only impact on the survivor, but on the partner and the relationship as a whole. The present study aimed to investigate the male partner experience of living with a female with an acquired brain injury; exploring role change, intimacy and future expectations.

Method: Semi-structured interviews were conducted with six male partners. Interviews were transcribed verbatim and analysed in-depth using Interpretative Phenomenological Analysis (IPA).

Results: Four main themes captured the male partner's lived experience; 'Entering the unknown world of ABI', 'Imprisoned by the ABI', 'Compassion without self-compassion' and 'Holding on to hope'.

Conclusion: The accounts uncovered the male partner's journey following ABI; the unpredictability, sorrow, frustration and finally acceptance and commitment to their partner. They identified the limited support available for partners following ABI; the sense of feeling forgotten by services and the need for information and support in the acute stages. Rehabilitation needs to take a systemic and longer term focus, supporting both the survivor and their partner through the journey of ABI.

Keywords; Acquired brain injury, male partners, qualitative research, relationships

Introduction

After an acquired brain injury is sustained, close family members are of upmost importance to the survivor and their journey through rehabilitation. Historically, brain injury rehabilitation has focused primarily on the individual, neglecting relational needs [1]. Yet as the literature indicates, brains are in continuous contact with the world around them and deficits are more prominent when interacting

with others than when alone [2]. Cognitive, emotional, physical and communication difficulties may adversely impact on an individual's ability to maintain certain roles and relationships, creating a very challenging period of transition [1].

The negative impact on relationships post ABI has been researched at great length. Due to the consequential sequelae of brain injury, families are more at risk of anxiety and depression [3], marital breakdown [4] and social isolation [5]. The most vulnerable to such changes in behaviour and cognition is the spouse or partner [6], reporting more subjective burden due to major role change [7]. In contrast, parents find the transition slightly easier due to taking on a previously held role [8]. Some couples do not identify with the term 'carer', finding it difficult to combine 'carer' and 'partner' responsibilities. If the new role feels forced, then this can be very damaging for the individuals involved [9].

The majority of published studies focus on the uninjured female's experience of ABI. To date, there appears to be no studies which focus solely on the role of the male partner and often the literature generalises findings to both genders (irrespective of the participant's sex). However, qualitative studies on dementia which look at male partner experiences are much easier to locate and can offer an insight into the experience of 'male role transition'. In a study by Harris [10], in-depth interviews of male caregivers (caring for their wives with Alzheimer's disease) revealed themes such as social isolation and coping strategies. The males reported that control over care-giving was crucial to role identification and diminished any sense of helplessness. More recently, Russell [11] identified comparable themes adding that a sense of commitment, responsibility and devotion was consistently expressed by male participants caring for their wives with dementia.

Although the social and emotional aspects of ABI appear to be relatively well documented, studies of intimacy between partners are limited. Intimacy is comprised of emotional, physical and sexual components and each can be affected following an ABI [12]. Wives have described feeling as if they are in a child-parent relationship due to the change in roles in the household [13]. In relation to sexual

intimacy, Ponsford [14] found that post ABI, over half of the participants reported a decrease in sexual activity. Quantitative studies tend to focus solely upon negative aspects of the relationship, gathering statistical information on marital breakdown, distress, sexual dysfunction and burden. In the recent literature on intimacy following ABI, two major themes were highlighted using a grounded theory approach; 'barriers to intimate relationships' and 'factors related to relationship strength'. Barriers to intimacy included role strain, emotional, physical and sexual change, and the positive themes encompassed unconditional love, communication, coping skills and commitment [15].

Qualitative studies within the field of ABI allow for a more in-depth exploration of relationship factors, enhancing our understanding of the lived experience of life post ABI. Such research will contribute to clinical practice by informing those working with families, about the nature of role transition, interpersonal dynamics, personal challenges (the non-injured person's perspective) and the coping strategies utilised in households following ABI. By exploring the male partner's experience, rehabilitation can take a more systemic approach, supporting the male in understanding his new role, normalising anxieties and supporting realistic future expectations.

The overall objective of the current study was to explore male partner experiences of living with a female with an ABI. In the interests of homogeneity for an IPA study, only male partners were included. The aims were to explore the partners' experiences of the impact of the ABI on roles in and outside of the home, e.g. domestic, social, work, finance, parenting (role accountability); the impact of the ABI on the relationship, including sexual, physical and emotional aspects; and the male partners' hopes and expectations for the future.

Method

Research approval

The study was approved by the Division of Clinical Psychology Research Committee (Appendix 2) and the University of Liverpool Committee on Research Ethics. NHS ethical approval (Appendix 3) and research governance approval was granted.

Participants

Six male participants, aged between 49 and 67, were recruited for the study. All participants were white British. Length of relationship ranged from 19 years to 40 years; five of the participants were married (the sixth was cohabiting) and four of the participants had children with their partner. Length of time since their partner sustained an ABI ranged from two years to 15 years. Five of the females had sustained a subarachnoid haemorrhage (SAH) and one female had sustained a head injury. Participant descriptions are noted in Appendix 4.

Table 1. *Participant Demographics*

Participant number	Pseudonym	Age	Length of relationship (<i>R</i>) / marriage (<i>M</i>) (years)	Cause of ABI	Number of years since partner's ABI
1	David	49	26 (<i>R</i>) 23 (<i>M</i>)	SAH	2
2	Simon	50	32 (<i>R</i>) 18 (<i>M</i>)	Head Injury	15
3	Peter	51	19 (<i>R</i>) 18 (<i>M</i>)	SAH	5
4	Nick	49	25 (<i>R</i>) 23 (<i>M</i>)	SAH	5
5	Tim	67	40 (<i>R</i>)	SAH	7
6	John	63	38 (<i>R</i>) 36 (<i>M</i>)	SAH	7

Sampling procedures

A purposive sampling method was used to identify the six participants. The recommendation of four to ten participants (determined by data richness) for a professional doctorate was followed [16]. All participants satisfied the inclusion criteria, i.e. male partners of females who had sustained an ABI (either a head injury or subarachnoid haemorrhage), cohabiting with their partner, known their partner for at least two years before the ABI and English speaking. Participants were excluded if they had separated from their partner, formed the relationship following the ABI, had not known their partner for two years before her ABI or if their partner had sustained an ABI from an alternative cause (e.g. stroke, tumour or infection). IPA research should aim to be homogeneous [17]; therefore only male partners were recruited and a tight inclusion criteria set.

Participant 2, Simon, may have potentially comprised the homogeneity of the sample as both the cause of his wife's ABI and the length of time since her brain injury differed to the other participants. However, following in-depth reading, re-reading and analysis, Simon's narrative did not differ significantly from the accounts of the rest of the sample and therefore he was included in the analysis.

Participants were recruited through regional brain injury support groups, and from a regional NHS ABI service. Recruitment flyers (Appendix 5) and emails were sent to local ABI support groups and the author attended a regional meeting to present the research. Flyers were displayed in the ABI service department and recruitment letters (Appendix 6) were sent to potential participants detailing the study. Five of the participants were recruited via head injury support groups and one via recruitment letter. A seventh participant was interviewed, yet did not meet the inclusion criterion of cohabiting with his partner. This interview was not included in the analysis, as several of the interview questions did not apply.

Interview content

Data were collected using semi-structured interviews to provide participants with the flexibility and space to explore their subjective experience. Following the guidance in Smith, Flowers and Larkin [16], an interview schedule was developed in line with the aims and objectives of the study. Questions explored the following areas, role change, the personal relationship, challenges, coping and resilience, the future and support. Questions were open-ended and expansive, for example, ‘How have the roles changed within the household following your partner’s brain injury? (domestic, social, work, financial, parenting), ‘How would you describe your close personal relationship with your partner?’ and ‘What do you feel have been the most challenging experiences for you?’ (full interview schedule in Appendix 7).

The first two interviews were conducted as pilot interviews to assess the content and suitability of the interview schedule. No changes were made and therefore the two pilot interviews were included in the analysis.

Procedure

Participants contacted the researcher via email or telephone if they wished to find out more information. A participant information sheet (Appendix 8) and consent form (Appendix 9) were emailed in response. If the potential participant agreed to take part, an interview was arranged. Interviews took place at the participant’s home address or at the NHS ABI service location. Participants were given the opportunity to ask any questions before signing the consent form and completing a demographic information sheet (detailing age, length of relationship, year of partner’s ABI and gender and age of any children).

Due to the potentially distressing nature of the research, the participants were fore-warned of the personal nature of questions and encouraged to discuss only what they felt comfortable discussing.

Interviews ranged from around 60 minutes to 120 minutes. The order of the interview schedule was not rigidly adhered to, to promote participant self-discovery and exploration. Following the interview the participants were debriefed and handed a ‘Thank you for participating letter’ detailing local support groups and helplines (Appendix 10).

Interviews were recorded using a Dictaphone and transcribed verbatim. Two of the interviews were transcribed by the lead researcher and the remaining four by a paid transcriber under a confidentiality agreement. These four interviews were listened to by the lead researcher and edited to ensure consistency in transcription style.

Participant anonymity was protected and pseudonyms used in this paper. Quotes were carefully selected to preserve anonymity.

Methodology

The data were analysed using Interpretative Phenomenological Analysis (IPA) [16]. With a focus on interpretation of experience and meaning-making, IPA aims to understand how individuals make sense of their personal and social world [18]. Drawing upon phenomenology, hermeneutics and idiography [19], IPA goes ‘back to the things themselves’ [16], exploring the objects of experience before interpretation or meaning is applied. Recognising that there is no direct route to experience, IPA remains ‘experience-close’ [18] to the phenomena while immersing in a ‘double hermeneutic’; in other words, the researcher attempts to make sense of the participant’s own sense-making. The analytic process is thus iterative and dynamic. The theoretical standpoint is well positioned to facilitate the interpretation of the male partner experience of living with a female partner with an ABI. The author engaged in a process of reflexivity throughout, noting ideas, reflections and questions in a reflective journal (Appendix 11).

Data analysis

The analytic procedure detailed by Smith, Flowers and Larkin [16] was followed. Transcripts were read and re-read to ensure immersion within the data; with each further reading involving a deeper level of analysis and abstraction. Transcripts were examined for descriptive, linguistic and conceptual comments [16] and emergent themes identified. The qualitative data analysis software, QSR International NVivo 10 [20] assisted with the management of a large number of emergent themes (Appendix 12). Emergent themes were clustered together to form super-ordinate themes for each participant.

Table 2.

Transcript extract to illustrate the analytic process (David)

Quote	Exploratory Coding	Emergent Theme	Superordinate Theme	Subtheme	Main Theme
“so we do lots of things together, and as I said, the gym was always our thing”	They live entwined, closely connected lives; they share a social life – joint impact of ABI? The gym ‘was’ (past tense) something they did together, symbolised togetherness – now this has been taken away? How does he feel? - couple identity lost.	Loss of shared activity; ‘our thing’	Entwined lives; then and now	Entwined lives; ‘joint disability’	Imprisoned by the ABI

This process was repeated for the remaining five transcripts, ensuring that each transcript was viewed independently and preconceptions set aside. Themes were then compared across the whole sample, searching for convergent and divergent patterns in the data and identifying higher-order categorisation. The process remained iterative, meaning that the researcher remained close to the

interview data. Themes were renamed and rearranged, ensuring that the final main themes encapsulated a transparent and clearly defined interpretation of the participants' experiences.

Quality and validity

Quality and validity were ensured by sharing transcripts, reflections, individual analyses and the final analysis with supervisors. Three transcripts and the corresponding three individual analyses were shared with the academic supervisor, who provided support for the analysis. This focused on developing from exploratory codes to emergent themes, and then to increasing levels of interpretation to super-ordinate themes and sub-themes. Both the academic supervisor and clinical supervisor had sight of the final themes, subthemes and corresponding super-ordinate themes. The clinical supervisor supported with reflections following each interview.

The final validity checks were not completed with the participants themselves as it was deemed that interpretations, made by the researcher, may appear too abstract for participants to legitimately comment on without them being presented with a full account of the abstraction process. The reflexive journal was also used to ensure that personal experiences and evoked feelings were not imposed on interpretations and instead logged and acknowledged.

Position of the researcher

Reflexivity is the process of attending to the influence the researcher imposes upon the research process; their background, experience, beliefs, prior assumptions and epistemological stance. The researcher is a 27 year old female trainee clinical psychologist with experience of paid and voluntary work in the field of neuropsychology, specifically ABI. The researcher is a strong advocate of person-centred, collaborative neuropsychological assessment and views the client as a 'person-in context', taking a systemic and relational approach to neuropsychological rehabilitation [21]. The researcher identifies with the 'contextual constructivist' position which suggests that personally

meaningful knowledge is built upon a previous knowledge foundation within a cultural context (class, religion, language); closely resembling Piagetian assimilation and accommodation [22].

Results

The aim was to explore the male partner experience of females with an ABI. Following analysis, four main themes emerged, each comprised of three or four separate subthemes (Table 3).

Table 3.

Table of main themes and subthemes

Main Themes	Subthemes
1. Entering the unknown world of ABI	<ul style="list-style-type: none"> • Pre-injury naivety • An emotional roller-coaster • ABI sequelae; hidden to the outside world
2. Imprisoned by the ABI	<ul style="list-style-type: none"> • Entwined lives; 'joint disability' • Playing 'happy families' • 'She's not the person I married' • 'There's no real escape'
3. Compassion without self-compassion	<ul style="list-style-type: none"> • Helplessness and powerlessness • Abandonment of the self • Male partners; the silent victims
4. Holding on to hope	<ul style="list-style-type: none"> • A lifelong commitment; endlessly understanding • Inner resilience and strength • Acceptance and adaptation; 'bad things happen to nice people' • Forever indebted; the importance of support

1. Entering the unknown world of ABI

The first main theme portrays the unpredictability, unplanned and life changing impact of ABI which is so often hidden from the outside world. With experience comes knowledge, yet inevitability the journey of ABI is far from plain sailing.

Pre-injury naivety

Participant accounts unearthed a sense of innocence and naivety prior to the brain injury, a lack of personal experience, a lack of information and a sense of stepping into the unknown; *'I realised very quickly that it was going to be a very life changing thing'* (Peter:3:84-85). Participants talked about ABI as being *'out of the blue'* (David:1:22-23, Nick:1:13) creating a reaction of *'shock'* (Nick:3:83) and disbelief, questioning why?; *'there was no warnings she was only forty, no headaches no nothing no pre no signs whatsoever, erm she was fit she would go to the gym most days you know'* (Nick:1:10-12). Nick is left searching for meaning in an uncertain world; he is left living his life with unanswered questions and unresolved feelings.

The more you read, the more I speak to people, the more you realise they don't, they've not really the foggiest you know, they just wait and see what happens. There was no way of saying she's this is going to happen and that's going to happen, it's just a case of suck it and see, so that was my experience and it still is, you know. (Nick:8:294-298)

With uncertainty comes unpredictability *'I don't remember thinking or planning anything for this past three years'* (Peter:29:1101-1102), and unpreparedness *'it's bizarre you know 'cause that's something that you're not ready for and it doesn't half freak you out.'* (Nick:31:1201-1203). Here, the ABI has taken centre stage and no longer do the male partners feel able to anticipate what will happen next. The ABI is outlandish to the newcomer, and remarkably, remains an ongoing mystery to all concerned.

An emotional roller-coaster

Male partners described the highs and lows of life following ABI; days of growth and progress, and days of heartache and despair; *'she went from up and went back down again'* (Nick:3:95-96).

I would say you are going to go through an awful lot. You are going to have emotional feelings, different feelings, you are going to have feelings of hatred, you are going to have feelings of love, you are going to have feelings of sorrow (John:19:718-721).

John offers a powerful account of his own emotional journey when asked what he would say to a male partner new to ABI. John remains truthful and unafraid to report feelings of hatred towards his wife. Hatred for who she has become, and sorrow for the person she has left behind. Yet within this account love exists in parallel to hatred and sorrow, a forever lasting adoration for the woman he married; *'she condemns me quite a lot since her brain haemorrhage, she has a lot of go's at me, but like I say I love her to death'* (John:4:152-153).

The roller-coaster ride of ABI is unrelenting for male partners; despite feeling leisurely at times, it can suddenly pick up speed, wakening the rider with reality.

So in the end we have all this and then last year, sorry two years ago in the January and February she had radio surgery to deal with the AVM [Arteriovenous malformation] because that's still there you know, it's not finished, it's still there and still posing a risk (Peter:6:215-218).

Unfortunately for Peter the journey remains unfinished, the risk continues to hang over them and they find themselves at the start of the second leg, feeling uncertain and unable to predict what the future may hold.

ABI sequelae; hidden to the outside world

Participants spoke about the impact of the emotional, behavioural and cognitive effects of ABI on their female partner. Debilitating fatigue, memory loss and executive dysfunction can create a ceaseless battle between the family and the brain injury. Yet those who are not familiar with ABI remain ignorant to the chaos it can cause; the ABI is to remain behind closed doors, hidden to life outside the family home.

Because she is, well you saw her yourself before, physically she is absolutely fine err you know and the restrictions are very much psychological, some physical but invisible.
(David:12:445-447)

David illustrates the hidden nature of ABI succinctly, reporting that his wife's limitations remain invisible to the outsider. His wife feels the pressure of societal expectations of 'illness' and 'injury' where visibility equates to acceptability; *'if you were on crutches you know, if you're injury was of a different type and you were left wheelchair bound or something, you'd broken your back, no one would turn around and say you should be able to do such and such'* (David:12:460-463). Left feeling guilty of faking illness, David's wife tires herself attempting to overcome societal pressures; *'...she'll try and do things that were never possible. And I say, why do you do that, you know, because that was always going to be a non-starter...'* (David:12:457-459).

When outside the family home, male partners support their wife's independence, promoting a continued façade of normality; *'there are little signals between us, if we are walking and I squeeze her hand we are by the curb. If I squeeze her hand again, it's like let's go'* (Simon:10:371-373); this way, attention is not drawn to the ABI and it continues to remain silently concealed.

2. Imprisoned by the ABI

The second main theme uncovers the restraining nature of ABI, life is no longer free and open to spontaneity; instead, male partners report ‘shared’ isolation and confinement, in conflict with a woman no longer recognisable as their own wife.

Entwined lives; ‘joint disability’

The down side of it now means that everything that we now can’t do impacts on us both.

(David:13:478-479)

Emotional and physical connectedness feels comforting and secure when a couple is young, free and in good health, yet living a life of joint dependency and reliance can be a little too close for comfort.

As you say, the die was cast years ago, that our social lives revolve around each other, we don’t have networks of independent separate interests and may be with hindsight, that might have been a more productive way to go round things. (David:13:472-476)

David reflects back on his life of interconnectedness with his wife; ‘the die was cast’ and their future determined long before the ABI. They were happily and enjoyably living inseparable lives, yet now, his wife’s deficits have become his own deficits, they share the ABI. Other participants too, report the loss of a shared social identity; *‘I had to learn I wasn’t young, free and single anymore, so both of our social lives just, you know, dipped’* (Simon:3:100-102); *‘We used to entertain an awful lot, all that’s gone now’* (Tim:8:291). The social self is now absent, and the restricting nature of ABI has taken its place.

The majority of the participants reported a loss of intimacy following the ABI. In many cases, (honest) views remained implicit and unspoken (both during the interview and in life) to protect their

partner from guilt, and instead participants portrayed a sense of shared responsibility for the loss of sexuality; *'rarely, occasionally, it's not you know, I think it's almost like unspoken'* (David:14:540-541). Some participants exposed an indifferent outlook, *'it just takes a back seat. It's not as much a part of our lives'* (Peter:26:995-996), while others uncovered underlying resentment at the loss of sexual togetherness; *'there isn't one, there isn't one, simple as that, it's a dead simple question that, nothing there'* (Nick:19:709-710).

Several male partners expressed a wish for the 'little things' to return, the kisses, cuddles and affectionate encounters. They could tolerate the loss of sex, if only their partners were intimately present; *'they are the little things that I miss more than anything'* (John:15:572-573).

Playing 'happy families'

The importance of maintaining normality was emphasised in Peter's account of 'normal family life'. To the outside world, he wants life to appear picture-perfect. For him, a normal life is an easy life.

I've tried to make sure that I have you know sleep overs and stuff like that. I've tried you know, we still do all of that so, so probably Sarah's found that if she ever says can Rachel come for a sleep over the answer's always yes, and if something else is happening you know I'll work round it. I'd rather solve that for life to be normal. (Peter:14:517-521)

Behind closed doors, the male partners juggle the demands of family life with an ABI. Single-handedly, they face the challenge of promoting patience, cohesion and a shared acceptance of 'mum with the brain injury'. Despite their best efforts, the non-acceptance of 'new mum' creates an unpleasant dilemma for the male partner. Trapped between his wife and child, he relentlessly attempts to reunite the mother-child attachment;

I don't know how you'll fix that [mother-child attachment], I mean I'm hoping at some point

they'll grow up [...] I don't know how to explain, they just, they didn't handle it well. I've tried everything with them but it seems like they've just cut off and gone. (Nick:6:222-226)

'She's not the person I married'

This subtheme, as illustrated by a quote from Nick (19:722), reveals undesired change and transformation of his partner following her ABI. To look at her, he still loves her, she remains visually the same woman he married. However her change in personality following the ABI has left her without identity, without personhood and without a name; *'there is emotion I suppose 'cause I love her, I love the woman, but I don't love that, 'cause I don't think that's my wife'* (Nick:19:734-735).

The debilitating sequelae of ABI (cognitive, emotional, behavioural and physical) can leave the person with an ABI as *'something else'* (John:17:647), as if *'someone had taken her and brought her back'* (Nick:6:217-218). She may no longer react, behave or think the way she did before the ABI; *'in some ways she can appear quite child-like'* (Simon:18:662); creating a relentless challenge for the male partner who feels as though he is slowly losing close personal contact; *'I feel like sometimes we drift apart a bit'* (Peter:24:905).

That person's trapped, it's like having [...] somebody else in there saying to you be aggressive, be nasty, be this, be that you know, but it's not you (John:19:727-729).

John attempts to understand his wife's ABI in terms of being *'taken over by another spirit'* (John:17:646). This malicious spirit has taken control, demanding her to be someone she is not. John knows the evil spirit is to blame, it has trapped his wife and taken over the person she once was. Yet John now needs to adapt to living life with the spirit, with a person he did not choose to live with and with a person he is struggling to transform back into his wife. Both he and his wife are left imprisoned, unable to escape the ABI.

'There's no real escape'

This subtheme, illustrated by a quote from Tim (8:305), captures the monotony, flatness and individual imprisonment of the male partner following ABI; *'I don't know it's just the same routine every day just tablets, looking after Dot, tablets, looking after Dot, you know'* (Tim:5:158-159). As a result of *'basically 24 hour looking after her'* (Simon:1:10), the male partner feels trapped and unable to truly escape from the wrath of ABI.

So all you're doing it's just, you're, it's just like Groundhog Day, which is a bit like my life at the moment, Groundhog Day (Nick:5:177-178).

Nick reports that his life resembles 'Groundhog Day'; each morning he awakes to the exact same series of events, day in day out. The same conversations with his wife, the same disagreements with his children and the same household chores his wife can no longer complete. An occasional drink with friends may provide a temporary glimpse at freedom from ABI, yet there remains no real way to escape it.

I used to be the one that was always smiling, I used to get in trouble for laughing and smiling even when I was in trouble I'd smile you know, that's all gone now, you know, it's everything is quite serious in my life (John:8:276-279)

John discusses the loss of 'fun' in his life following his wife's ABI. Naturally a cheerful person, the seriousness of ABI life has now taken control, capturing and locking away the fun which was once so familiar to him. He has been left without happiness in a serious world.

Several participant accounts unearthed a sense of feeling socially trapped following ABI; as Lezak [23] described, spouses live 'in social limbo', unable to grieve for the loss of their partner, and unable

to move on, fearing guilt and recrimination from others.

I think it was just getting to that point and then this happened and then unfortunately, not unfortunately really, but I felt a little bit trapped then, you know. I thought well I can't leave her, it wouldn't be the thing to do really (Tim:12:444-447)

Tim reported that his relationship was naturally coming to an end before the ABI, yet he felt that the ABI left him with no choice but to stay with his lifelong partner, emotionally and socially forced to remain by her side. Other participants reported how life is just '*rubbish*' (Nick:19:739) and '*despised*' (John:10:368), however, they are left with no choice but to '*get on with it*' (Nick:19:739-740), they love their partners and '*would feel awful*' (Tim:13:467) if they were to leave.

3. Compassion without self-compassion

The third main theme focuses primarily on the lack of compassion the male partners express inwardly towards themselves. The male partners are also victims of the harsh reality of life following ABI, yet they appear to shrug off any personal act of kindness, abandon their own needs and focus heavily on personal failings.

Helplessness and powerlessness

Due to the sudden and unpredictable nature of ABI, male partners are left feeling helpless and ineffectual in a situation they wish to, but never can, take control of; '*I hate it because you know I'm powerless*' (David:17:638).

I feel completely helpless errr whilst I have lots of skills and experience and training to deal with somebody else in that situation, it almost makes me feel worse, because I can't do it with Sally, you know (David:18:663-664)

Feeling vulnerable and defenceless, David, despite his professional expertise in dealing with crises, feels helpless when faced with a personal situation too close to home. His skills and experience become redundant as intimate emotions flood rational thought, leaving him with a sense of failure. The males are left feeling as though they '*let her down*' (John:18:697), despite an outward appearance of commitment and dedication.

Several of the participants described feeling abandoned by services following the acute phase of recovery, '*the neurosurgical team just dropped us like a ton of bricks*' (Peter:4:116). Without the support and knowledge, male partners were left feeling overwhelmed and helpless; '*it literally was, we've done our job, yours, you're not our responsibility any more*' (Simon:2:65-66).

A bit of warning of what to expect you know [...] we didn't even get this could happen we didn't get anything [...] there was nothing like there will be behavioural issues. I'm sure that everybody has those issues and there was none of that either, there was no warning for that.
(Nick:31:1175-1180)

Nick felt alone; no warning, no information, and no reassurance from professionals. A sense of anger underpins this account. Nick wants knowledge, yet the professionals remain reluctant to provide information which may prove inaccurate in the long run. Nick desires predictability (to reduce helplessness), within unpredictable life circumstances.

Abandonment of the self

Despite demonstrating love outwardly towards their female partners, the males tended to lack concern for their own needs, abandoning self-compassion and keeping their thoughts and feelings locked secretly away; '*she's got enough problems as it is without me you know burdening her with my problems*' (Tim:16:584-585). The male partners expressed a '*you just get on with it*' (Simon:3:102)

attitude; where providing support is seen as their personal ‘duty’ (Tim:13:477), and asking for help is a sign of weakness; ‘*maybe some of it’s me, I’ve not been very good at asking*’ (Peter:20:766-767).

I have never asked for help. I am sort of again it’s a different era, there was never help whatever you did you did it yourself. If you didn’t have money, if you didn’t work you didn’t have money, there was no sort of benefit system. So it instils in you a different way you look at life (Tim:15:548-551)

Tim describes here his outlook on life; ‘real’ men don’t ask for help, they can solve their own problems. Tim respects his British ‘stiff upper lip’ education, the weight of his partner’s ABI is to remain on his shoulders, and his shoulders alone.

The male partners reported dedication to their female partner and her rehabilitation needs, which often meant leaving work, taking a new job or reducing their hours to be at home; ‘*we just went from being a normal couple, to me giving up my job, moving in and looking after her*’ (Simon:1:11-12). Personal pleasures were sacrificed, ‘*I don’t go to the gym anymore because if I’m at home I am looking after Sally*’ (David:11:405-406), and male partners appeared to power through the tough times, neglecting their own emotional health needs, despite them being visible to others; ‘*I haven’t had any time off either so, I have had time off but very little, I think people expected me, in fact I was sent home*’ (Peter:13:476-478).

My coping strategies are to try and meet her needs and anticipate her needs [...] I get it right 90% of the time I think, it’s when I fail it’s catastrophic. You know and it’s my failing, it’s me, I’ve sort of failed to anticipate correctly, cos Sally can’t help it, you know she she desperately wants to not feel the way she does (David:19:704-709)

David blames himself for failing to predict his wife’s behaviour and pre-empt situations which may cause conflict. He places unrealistic expectations on himself. David neglects to comment on the

successes, achievements and selfless nature of his kindness, anticipatory patience and preparedness for circumstances which may arise. Compassion for his wife flourishes, while self-compassion remains deficient.

Male partners; the silent victims

Several of the male partners expressed a sense of feeling abandoned and forgotten; their female partners needs come first, and the support stops there; '*nobody's ever asked me any questions before about what I feel, ever*' (Nick:20:741-742). As pointed out in an early subtheme, ABI creates a sense of 'joint disability' where both the male and female feel imprisoned and limited in their new roles. However while the injured female draws much needed medical attention, the males feel forced to remain silent, appear positive and strong; for they are healthy after all. The impact on the male is thus brushed aside; they remain the forgotten victims of ABI.

While most of the males complied with keeping their emotions silent, John requested that this changes; partners should be given the chance to be open and honest, vent their frustration and share experiences with like-minded adults; a service specifically for the 'forgotten ones'.

It would be a great thing if there was somewhere for partners to go and have a cup of coffee and a biscuit and have a chat about their experiences you know, and get that frustration out.

(John:20:744-746)

Not only did the male partners feel forgotten by services, but they also at times felt unappreciated, unacknowledged and taken for granted by their families and partners; '*I'm not your slave*' (Simon:12:440). Simon reports feeling treated like a slave; he is told what to do and disrespected. His own needs are neglected and instead he must obey and meet the needs of others. Simon will happily attend to the needs of his wife, yet being ordered by other family members is something he refuses to bow down to.

4. Holding on to hope

The final theme captures the optimism, positivity and sheer commitment of the male partners through their journey of ABI. Despite the hardships they have faced, despite feeling trapped and unheard, the male partners remain loyal, expressing patience and understanding of their partners' '*rotten luck*' (David:10:352).

A lifelong commitment; endlessly understanding

All participants envisaged a future with their female partner; '*we will just grow old together I suppose*' (Simon:18:690), committed and devoted to the woman they fell in love with, '*I'm not going anywhere*' (Nick:19:733), and never giving up, '*don't give up on your partner, that's what I would say*' (John:20:750-751).

I think I'm lucky to have her that's what I honest and truly think how lucky I am in life that I had Anne before the haemorrhage, I've got Anne after the haemorrhage and that's my blessing, but I won't give up on her (John:15:581-583)

As discussed in the previous theme, male partners felt a sense of duty to their partner, the ABI was not their fault, nor should they be left to deal with the misfortune alone. 'Giving up' is suggestive of defeat, the males do not want to be perceived as weak and therefore their commitment remains strong and resilient.

Participants also appeared to show admiration for their female partner's achievements prior to and succeeding the ABI, '*a remarkable woman*' (Tim:3:93).

She does charity work in [name of head injury support group], in the shop, she volunteers

there, she's now doing volunteer work in the children's charity shop near where we live and she wants to do all these sorts of things, and as I say, she's great in so many ways (John:8:300-303)

The admiration and respect keeps their love strong, providing snippets of the person they committed themselves to many years ago; *'we spend our time, when we are not forced to be apart, together'* (David:13:498).

The male participants also demonstrated a strong desire to be there at her beck and call, keeping their female partners relaxed, happy and settled.

My whole life is just I am like a little dog actually I want to please her, all I want is for her to be happy, that's all I want (John:19:709-710)

John refers to himself as a little dog, following its owner around, wanting to please the owner and wanting to make the owner happy. The dog remains quiet unless the owner gives a command; as illustrated in an earlier theme, abandoning his own needs in order to meet the needs of his wife.

Inner resilience and strength

Participants discussed a number of adaptive coping strategies which they employ to support them to remain strong and provide time out from the ABI; *'I get up early'* (David:21:812), *'I spend a lot of time in the garden'* (Tim:9:318), *'I go for walks'* (Simon:8:307).

I'm going to the football tonight. I mean that's a nice release you know because I mean I have been a season ticket holder there for, I don't know, twenty odd years or something, so that's a bit of escapism for me (Tim:8:302-304)

Tim describes football as a form of ‘escapism’, a release from the pressures of home life and relief from the unpleasant reality of ABI. Football offers a temporary ‘fantasy’, a daydream, a life free from the imprisonment of ABI. David too talks about escapism from the ABI with his wife, *‘the cottage has always been our sort of refuge’* (David:18:684). The cottage provides a temporary illusion of normality. It is a place where they can be free with their emotions and free from reality, a place where nothing reminds them of the ABI.

Similar personality traits were evident across the participants. A number of males occupied caring professions *‘with being a qualified social worker and the training that you have and all the courses you go on over the years it’s probably quite useful’* (Peter:23:858-859) and several of the males described themselves as *‘pragmatic’* (Nick:8:293, David:7:239). Facing personal dilemmas in a systematic and logical fashion by drawing upon previous experience has encouraged the male partners to remain strong, resilient, and above all, committed to supporting their wives.

John spoke about his faith as a strong protective factor; protecting both his own life and the joint life he shares with his wife; *‘I just have such a strong faith’* (John:16:609). John expressed a wish for his life to end, his sense of ‘stuckness’ far outweighed the other male participants; *‘I am looking forward to death because I hate this life, that’s it in a nutshell’* (John:10:367-368). Praying, and talking to God each night made him stronger, more determined and more committed to his wife; *‘you are there to love for that person and your respect for that person will get you through’* (John:20:742-743).

Acceptance and adaptation; ‘bad things happen to nice people’

The subtheme, illustrated by a quote from David, depicts the acceptance and understanding of the male partners and their adaptation to living a life with the unforeseen challenges of ABI; *‘if it’s an unpredicted outcome, it’s not your fault, don’t worry about it, we’ll deal with it’* (David:20:756-757). Commonly, participant accounts unearthed a sense of understanding, empathy and a non-blaming, externalised attitude towards the ABI; *‘I know it’s because of the brain injury’* (Simon:5:178). Despite

the distressing changes, the male partners are willing to take on newly acquired roles within the household in order to support and stand by their partner; *'my role is you know it's just being Mrs Doubtfire (laughs)'* (Nick:358-359).

You know, life's like that, and as far as our future is concerned, if you want to make the Gods laugh, tell them what your plans are. That's the old saying and I really believe that, we had plans, so we'll make some new plans, you know. (David:23:868-871)

How much are we in control of our lives? As David points out, not as much as we would like to think. Plans are made, yet so easily destroyed. Here, David is accepting of uncertainty, adapting, evolving and changing plans to fit with his new life where brain injury takes centre stage. Ultimately, God controls our future and people suffer undeservedly. The shift from leading a bitter life to leading one accepting of uncertainty is a difficult manoeuvre, yet one which will allow a couple to remain strong, united and resilient to threat.

Occasional snippets of the 'old her' provided the male partners with the determination to remain supportive and committed to their partner's long term rehabilitation goals; *'I feel as though I have got a lot of her back, she's got a lot of herself back'* (Peter:23:895-896); *'this is the Sally I remember, this is the Sally, that was a flash of the old Sally'* (David:18:680-681). The ABI initially seized the female partner's identity, the person she was, and the person they knew. However, the occasional glimpse of a long lost trait is enough to provide optimism and hope for recovery.

Participants discussed their own role in recovery, the need for them to work at it, adapt and remain committed. For Peter (25:969), the importance was placed on continuing to do *'adult to adult'* activities in order to remain connected intimately. David (12:453-454) expressed his own need to *'sit down with someone who might just understand the nature of it'*, accepting that his own emotional health has taken a back seat over the last several years post ABI.

You got to learn things, you know, and you got to keep the house clean, you got to do all that yourself. But that's now second nature. So, Sandra does the dusting and the bathroom and I do everything else. (Simon:5:160-163)

For Simon, his new responsibilities have become 'second nature', almost habit due to being so long practised. He has accepted his new domestic role within the household; understanding of the apparent imbalance post ABI and appreciative of what his wife can still achieve.

Forever indebted; the importance of support

Male partners expressed full appreciation, respect and acknowledgment of the support from family, work and ABI services throughout their partners' time of need. For a number of the male partners, support from the ABI support group had been a 'life changer' (Simon:14:536), people there are understanding of their female partner, 'you don't have to explain anything to anyone up there' (Simon:14:537-538), and as one male partner expressed, you can 'chat with other people, male or female, who are going through this situation' (John:11:426-427). The support group provides a chance to escape from the world of ABI obliviousness and enter an understanding, caring and supportive environment; 'going back to your point about what I'd say to someone in my position is, grab all the support groups you can' (David:24:931-933).

Male partners were also appreciative of family acceptance of ABI. John is thankful of the kindness his family show, despite his wife's aggressive and hostile tendencies.

My family are a very close family they understand Anne and they also they want to come and see her they want to know, even now they want to come and see her and want to know how she is (John:6:221-223).

Yet not all partners felt that they had found the support they were looking for, the support they

believed would help their female partner come to accept her ABI. A postcode lottery is too often at play when it comes to ABI services.

I spoke to several people but there was nothing, there was nothing out there. I mean I wish we could find something now for her to go during the week, you know, something just a couple or once a week, would get her out and speaking to other people (Nick:29:1106-1110)

Support for Nick's wife would give him the free time to meet his own personal needs; time to recuperate, relax and restore his patience, resilience and positivity.

Discussion

The study explored the experience of males following their female partners' acquired brain injury, discovering how the males have made sense of their lived experience. The study was guided by a set of aims and interview questions, and the application of IPA uncovered four main themes; '*Entering the unknown world of ABI*', '*Imprisoned by the ABI*', '*Compassion without self-compassion*' and '*Holding on to hope*'.

Participants offered their emotive accounts of living with a partner with an ABI, their personal journey and how they had adapted to their 'new' life. Males expressed a sense of feeling trapped and imprisoned by the ABI, restricted, disabled and living as though they too, had sustained the injury. They felt emotionally and practically trapped, unable to express their true feelings to their partner and others around them. To them, their wife had been lost, taken over and/or replaced by an evil being. They were left living a monotonous life with no joy or smiles, feeling helpless, a failure and forgotten by the world. Despite the imprisonment, males were able to overcome this with hope, commitment and personal growth. The men gave accounts of coping and 'just getting on with it'. Their resilient and pragmatic personality traits kept them strong, they did not blame their partner, nor did they wish

to leave her to tackle the ABI alone.

‘Entering the unknown world of ABI’

Participants described a sense of uncertainty and unpredictability following their partners’ sudden and unexpected ABI. Bowen, Yeates and Palmer [1] suggest that the relatives of people with an ABI may experience anxiety due to not knowing what exactly caused the brain injury, thus leaving them with a sense of uncontrollability, unable to tolerate uncertainty.

The male partners were taken on an emotional rollercoaster through grief, love and hate and contended with the ignorance of society to ABI. Generally, society does not recognise the debilitating sequelae of ABI, the impact on the male partner and the family as a whole. Their partner is alive; they should be happy, celebrating. Experiencing a profound sense of loss, feeling isolated and unable to publically mourn, can lead to what Doka [24] termed ‘disenfranchised grief’; loss unacknowledged and undervalued by society.

‘Imprisoned by the ABI’

Participants reported a sense of feeling emotionally entwined and interconnected with their female partner. However, interdependence pre-ABI resulted in a post injury entwined disability; emotionally, intimately and practically. The female partner’s increased dependence can make it very difficult for the couple to continue to enjoy a mutually satisfying sexual relationship [25]. For partners following ABI, the role of ‘caregiver’ can be seen to be dissonant with that of a sexual, romantic role [26]; as highlighted in the current study. The male partners, although expressing underlying resentment, did not want to open up to their wives for fear of placing blame or appearing selfish and inconsiderate. Therefore, their needs were left unmet; the ABI continued to remain in command.

As highlighted in previous literature, the male partners felt as though they were now ‘living with a stranger’ [6]; their partner was no longer the same person, captured and returned as something else. They felt as though their life was like ‘Groundhog Day’, monotonous, repetitive and wearisome, with no escape route. Lezak [23] suggested that partners of those who have sustained an ABI find themselves living in a ‘social limbo’; remaining with their partner impacts on them socially, yet abandoning the relationship leaves them open to harsh social criticism and intolerable guilt.

‘Compassion without self-compassion’

Males expressed feeling helpless and powerless, unsure of what to do, and feeling as though they had let their female partner down. They were able to express compassion and love towards their partner, yet failed to direct love inwardly towards themselves. This theme presented as more subtle than the others, often being expressed in the participant’s intonation, silences and emotive speech. Participants felt alone, however did not feel able to request or accept the help of others; admitting the need for support appeared taboo. The males saw themselves as ‘copers’ and help seeking behaviour was associated with feelings of shame. This finding links closely to the Kingerlee [27] model of ‘male distress’ where the male belief ‘I must not be weak’/‘I must not show my feelings’ governs the male’s behaviour and psychological response to a critical incident; in this case, their wife’s ABI.

Male partners reported that no information was available for them; they did not know what was happening or what to expect. In their experience, no reassurance was offered by professionals, further exacerbating the males’ sense of helplessness and weakness. Chwalisz and Stark-Wroblewski [28] also reported that their participants expressed distress associated with lack of information from professionals following ABI. Feeling alone and ‘left in the dark’ appeared to create further distress for the male partners who felt forced (by personal beliefs) to portray a calm and caring exterior at all times.

‘Holding on to hope’

Males expressed everlasting commitment to their female partners, a sense of never giving up, growing old together, remaining forever by her side. They admired their partner, respected what she had achieved throughout her life (pre-ABI) and empathically understood her current loss. The ABI was not her fault, and therefore the male partners’ everlasting commitment may reflect their acknowledgement of this. Russell [11], exploring elderly men who care for their wives with dementia, similarly identified the themes commitment, responsibility and devotion.

Various coping strategies were described which enabled the males to manage and adjust to living life with an ABI. Similar to the three types of coping identified by Endler and Parker [29], males engage in ‘task-orientated’, ‘emotion-orientated’ and ‘avoidance-orientated’ coping. Males spent time gardening, looked to their faith, focused pragmatically on the situation or escaped to watch the football with friends. Coping strategies enabled the male partners to remain strong, committed and resilient.

Despite feeling that support was not available exclusively for the male partner, they expressed their appreciation for the support for their female partners, from family, friends and services. Without this support, they acknowledged that they would not have been able to cope alone. One male partner felt that the area he lived in lacked the services he desired for his wife. ABI services present sporadically across the UK, with some families isolated from the much needed care provision.

Strengths and Limitations

The study gave voice to the male partners of females who had sustained an ABI, their stories were heard and their personal sense making captured. There is currently no published literature in the field of ABI exploring solely the male partner experience, therefore it is hoped that this study adds value and depth to the current literature base. Most of the literature focuses on the negative aspects of life

post ABI, marital breakdown, distress and burden. The couples who remain together are often neglected, their experience unstudied and their resilience uncaptured. This study instead gave the males who stayed an opportunity to express their lived experience, the highs and lows, their personal journey of commitment.

A homogeneous sample allowed for the in-depth exploration of an under-researched group of individuals to identify the commonalities, and also possible discrepancies, amongst their accounts. The researcher remained reflective throughout the process to ensure preconceptions were set aside, and provided interpretations which were grounded with participant quotations. All four themes captured each of the six participants' experiences.

The position of the researcher may have presented a barrier to information sharing. The researcher was a 27 year old female, therefore much younger and a different sex to the male participants in the study. Several of the male participants talked in code when discussing sexual intimacy. This impacted on the researcher's use of direct questions as she, at times, felt unable to explore comfortably the topic of intimacy when the male appeared upset. The researcher was new to IPA, potentially impacting on the interview technique and questioning style.

The males appeared very understanding of their female partners' ABI, they were non-blaming, understanding and empathic. In conducting research it is important to consider the possibility of 'social desirability' in the male partners' responses to questions about personal lives, challenges and coping. However, the male partners' accounts were consistent and rich leading the researcher to believe that the males did not modify their experiences or sense-making to appear more desirable to the listener. The researcher also questioned whether the cause of the ABI had something to do with the male partner's commitment. The ABI was 'out of the blue' and uncontrollable; might it have been perceived differently if the female had influenced the cause of the ABI?

Recruitment invited male partners to come forward and consent to taking part in the research,

therefore encouraging a certain type of person, one which is willing to partake in research and express their story. It was found that five of the male partners were white, middle class males in financially stable jobs or secure retirement; several within caring professions (similarly highlighted in Gill et al. [15]). It may be hypothesised that financially stable males, working in the caring sector, are more likely to stay with their female partner. Alternatively, this may be interpreted as a recruitment bias; these types of individuals are more likely to volunteer their time and articulately relay their experience.

As purposive sampling was utilised, the author could not personally select the males taking part in the research. This resulted in five males whose partners had sustained a subarachnoid haemorrhage (SAH) and one male whose partner had sustained a TBI from a fall. An inclusion criteria of SAH and TBI was selected due to the similarities between the ABI sequelae and therefore the results should not be impacted by the bias towards SAH participants.

Clinical Implications

A common theme across participant accounts was the lack of information they felt they received from professionals (acute and post-acute). Males felt dismissed, forgotten and unacknowledged, leading them to live with increased uncertainty in an already vulnerable position. Male partners acknowledged that medical professionals are often unable to provide definite answers about the future prognosis of brain injury. However, support and general information about what to expect should be offered in the early stages of their partner's recovery. Professionals need to be available to contain worry and empathically appreciate the position of the partner.

The males acknowledged their 'just get on with it' attitude and their wish to be seen as strong and able to cope alone. With this in mind, professionals may need to offer support at different stages of the rehabilitation process to ensure that males are given the opportunity to accept the support they may rightly need. Initially, the male partner may be struggling with a variety of emotional reactions,

keeping himself together for his children and partner. However, further down the line he may start to accept that he can no longer keep his feelings hidden without them impacting on his close personal relationship. This may be the time when services need to offer support; by remaining in contact with families post-ABI, services can ensure that families and partners are supported throughout their journey, rather than exclusively at the start. A routine assessment at various time points (one year, two years and four years) would enable the male partner to voice concerns and express his needs without having to initiate access to support himself. However, most acute services are not able to keep patients 'on their books' for years to come, and discharge them once they are relatively stable.

Most importantly, however, rehabilitation should take a systemic approach, working with both the male and female partner following ABI. Both experience the joint impact of brain injury and both feel jointly disabled by the debilitating sequelae which follow. Providing rehabilitation to the partnership may serve to strengthen the relationship rather than isolate the partner. The couple can work as a team, sharing strengths and coping with the long term impact of ABI. The quantitative literature highlights the high separation rates; services should aim to follow a systemic framework, providing couples therapy, sexuality counselling and working with the whole family system in supporting the transition towards acceptance.

Future Research

As this is the first study to focus on the male partner's experience following ABI, further replica studies would add to the richness of findings from this study and encourage services to acknowledge the male partner during the process of recovery. Studies focusing on same sex couples following ABI should also be considered. Gill et al [15] included same sex couples in her study of intimacy following ABI, however their individual accounts were lost amongst the other participants' experiences.

Half of the participants in this study addressed family life and the impact on their children. Further

exploration of the impact on the child, from the child and parent perspective, would provide an insight into how children interpret and adapt to life following a parent's ABI. In a recent qualitative study exploring the child's experience, it was found that children make a special effort to hide feelings of loss or grief in order to protect their ill parent [30]. Further focus on the child's experience would add to the literature around systemic rehabilitation and encourage a whole family approach to recovery post ABI.

Qualitative studies exploring the male partner's account following stroke, tumour and TBI would further expand the current and limited literature base. Males who have recently separated from their female partners may provide insight into the difficulties and challenges post-ABI and what led them to make the decision to leave their partner. In terms of clinical implications, such findings would support professionals to understand the impact on the family system and offer the most appropriate support for the couple/family at the most appropriate time for them.

Conclusion

This IPA study, exploring the lived experience of males following their female partner's ABI, adds to the currently neglected literature base on male partners following brain injury. To date, male partners have remained the hidden victims of ABI, often suffering in silence with no support to address their loss, sorrow and underlying resentment. Despite their inner frustrations, they appear to overcome this with resilience, strength and commitment to the one they love. Males should be offered support from services and provided with education and information regarding their partner's brain injury. Rehabilitation should take a systemic stand-point. The male is 'jointly' limited by his partner's ABI and therefore the couple should be encouraged to work together as a team to cope with, and accept, the impact of the ABI on their life and future together. Research into the male partner's experience needs to be further expanded for the male partner role to be recognised and incorporated into the process of recovery.

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Appendices

Appendix 1.

‘Brain Injury’; Instructions for Authors

Please see <http://informahealthcare.com/page/bij/Description#Instructions> for full details.

General Guidelines

Please write clearly and concisely, stating your objectives clearly and defining your terms. In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the journal and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers. For all manuscripts, gender-, race-, and creed-inclusive language is mandatory. Use person-first language throughout the manuscript (i.e., persons with brain injury rather than brain injured persons).

File preparation and types

Documents must be double-spaced. References should be given in Council of Science Editors (CSE) Citation & Sequence format.

Abstract

Structured abstracts are required for all papers. The abstract should not exceed 200 words.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig). Each table and/or figure must have a title that explains its purpose without reference to the text.

Notes on Style

All authors are asked to take account of the diverse audience of *Brain Injury*. Clearly explain or avoid the use of terms that might be meaningful only to a local or national audience. *Brain Injury* uses conservative British, not US, spelling, i.e. behaviour (behavioural) not behaviour. Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.

Brain Injury is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case.

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Indicate in the text with Arabic numbers inside square brackets.

Appendix 2.

Division of Clinical Psychology Research Committee Approval Letter



D.Clin.Psychology Programme
Division of Clinical Psychology
Whelan Building, Quadrangle
Brownlow Hill
LIVERPOOL
L69 3GB

Tel: 0151 794 5530/5534/5877
Fax: 0151 794 5537
www.liv.ac.uk/dclipsychol

26th September, 2012

Cara Brunsden
Clinical Psychology Trainee
Doctorate of Clinical Psychology Doctorate Programme
University of Liverpool
L69 3GB

RE: PARTNER EXPERIENCES OF FEMALES WITH AN ACQUIRED BRAIN INJURY: AN INTERPRETIVE
PHENOMENOLOGICAL ANALYSIS

Trainee: Cara Brunsden
Supervisors: Gundi Kiemle, Stephen Mullin

Dear Cara,

Thank you for your response to the reviewers' comments of your research proposal submitted to the D.Clin.Psychol. Research Review Committee (supervisor approvals dated 06/09/12 and 14/09/12).

I can now confirm that your amended proposal (*not dated*) meet the requirements of the committee and have been approved by the Year 1 Committee Chair.

Please take this Chairs Action decision as *final* approval from the committee.

You may now progress to the next stages of your research.

I wish you well with your research project.

A handwritten signature in black ink, appearing to read 'Catrin Eames'.

Dr Catrin Eames
Chair Year 1 D.Clin.Psychol. Research Review Committee.

				A member of the Russell Group
Professor James McGuire Programme Director jmc@liv.ac.uk	Dr Jim Williams Clinical Director j.williams@liv.ac.uk	Dr Joanne Dickson Research Director jdickson@liv.ac.uk	Dr Laura Golding Academic Director L.golding@liv.ac.uk	Mrs Sue Knight Programme Co-ordinator s.knight@liv.ac.uk

Appendix 3.

Research Ethics Committee Approval Letter



Health Research Authority

National Research Ethics Service

NRES Committee North West - Greater Manchester West

HRA NRES Centre Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile: 0161 625 7299

04 March 2013

Dr Gundi Kiemle
Senior University Clinical Teacher
University of Liverpool
D.Clin.Psych. Programme
Division of Clinical Psychology
The Whelan Building, Brownlow Hill, Liverpool
L69 3GB

Dear Dr Kiemle

Study title:	Partner experiences of females with an acquired brain injury; An Interpretative Phenomenological Analysis
REC reference:	13/NW/0114
Protocol number:	UoL000930
IRAS project ID:	117210

The Research Ethics Committee reviewed the above application at the meeting held on 01 March 2013. Thank you for attending to discuss the application along with Miss Cara Brunsten.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator, Miss Shehnaz Ishaq, nrescommittee.northwest-gmwest@nhs.net

Ethical opinion

1. The Committee commented that it is not clear from the title of the study on the supporting documents that it is specifically aimed at male partners of female patients with an acquired brain injury. Miss Brunsten agreed to amend the study title on the supporting documents to reflect that it is aimed at male partners.
2. The Committee referred to question A33-1 on the IRAS NHS REC form and noted that 'only those fluent in the English language will be able to partake in the study; this is due to the research budget and the detailed analysis which requires English to be the participants first language.' The Committee commented that people can have English as a second language and can be fluent in it. Miss Brunsten agreed that this was worded incorrectly; she commented that participants should be fluent in the English Language regardless of whether or not it is their first language.

A Research Ethics Committee established by the Health Research Authority

3. The Committee pointed out some amendments needed to the Information Sheet and Consent Form as set out below. Miss Brunsden agreed to amend the Information Sheet and Consent Form accordingly.

You were both thanked for attending. You were advised that the study must not start until it has received a favourable opinion and that NRES is seeking feedback from applicants on their experience of the research ethics process which might help to improve future service. The final opinion letter will give details on how to go about this.

You both left the meeting room.

The Committee considered the responses.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Other conditions specified by the REC

1. Please revise the study title on the supporting documents to read as follows 'Male partner experiences of females with an acquired brain injury.'
2. Please revise the Information Sheet as follows;
 - a. Under the heading 'Do I have to take part?' second sentence, insert the words 'with you' after 'sheet' and before 'before starting' so it reads 'I will review the participant information sheet with you before starting the interview.....etc'

- b. Under the heading 'What will happen to me if I take part?' 3rd paragraph, after the second sentence, insert the following sentence 'Once the data has been anonymised it will not be possible to withdraw as the data will not be identifiable and we will not be able to link back to your details.'
 - c. Under the heading 'What are the possible disadvantages of taking part?' remove the word 'inconvenience' as the Committee felt that the 90 minute interview is inherently inconvenient.
 - d. Under the heading 'What will happen to the results?' insert the word 'wish' in between 'not' and 'to' so it reads '...state you do not wish to receive this....'z
3. Please insert the following standard mandatory statement on the Consent Form 'I understand that relevant data collected during the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.'

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Advertisement	2	05 February 2013
Covering Letter		29 January 2013
Evidence of insurance or indemnity	Marsh Ltd	02 August 2012
Interview Schedules/Topic Guides	4	30 January 2013
Investigator CV	Dr Gundi Kiemle	
Investigator CV	Cara Brunson	
Other: Sponsorship Approval Letter		05 December 2012
Other: Approval from D.Clin.Psych Research Review Committee, Liverpool University		26 September 2012
Other: Participants thank you letter	2	05 February 2013
Participant Consent Form: Consent Form	2	16 January 2013
Participant Information Sheet: Participant Information Sheet	2	16 January 2013
Protocol	3	08 May 2012
REC application	3.4	
Summary/Synopsis	2	08 May 2012

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/NW/0114

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Signed on behalf of:
Dr Lorraine Lighton
Chair

Email: nrescommittee.northwest-gmwest@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Mrs Lindsay Carter, University of Liverpool

Mr Anthony Hodgson, 5 Boroughs Partnership NHS Foundation Trust

Miss Cara Brunsden, University of Liverpool

NRES Committee North West - Greater Manchester West

Attendance at Committee meeting on 01 March 2013

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Joshua Adedokun	Consultant in Anaesthesia and Pain Medicine	No	
Mr Ian Beaumont	Director, Quality Control North West	Yes	Vice-Chair
Mrs Maureen Benbow	Senior Lecturer	Yes	Co-opted member from NRES Committee Northwest - Cheshire
Dr Peter Donnelly	Lay Member	Yes	
Mr Mark Garrod	Project Consultant and Pension Fund Trustee	No	
Mr Michael Hamor	Lay member	Yes	
Mr Richard Hovey	Lay member	Yes	Co-opted member from NRES Committee Northwest - GM South
Dr Lorraine Lighton	Consultant in Communicable Diseases	Yes	Chair
Dr Barry Miller	Consultant Anaesthetist	Yes	
Mrs Patricia Morgan	Lay Member	No	
Mr Peter Owen	Lay Member	Yes	
Mr Iestyn Shapey	Specialist Registrar - General Surgery	Yes	
Dr Gideon Smith	Consultant in Public Health Medicine	No	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Shehnaz Ishaq	Committee Co-ordinator



Health Research Authority

National Research Ethics Service

NRES Committee North West - Greater Manchester West

HRA NRES Centre Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821

Facsimile: 0161 625 7299

14 March 2013

Miss Cara Brunsten
Trainee Clinical Psychologist
Doctorate of Clinical Psychology
Whelan Building, The Quadrangle
University of Liverpool
L69 3GB

Dear Miss Brunsten

Study title: Partner experiences of females with an acquired brain injury; An Interpretative Phenomenological Analysis
REC reference: 13/NW/0114
Protocol number: UoL000930
IRAS project ID: 117210

Thank you for your email of 13 March 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 04 March 2013

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		12 March 2013
Participant Consent Form	3	03 March 2013
Participant Information Sheet	3	12 March 2013
Protocol	4	13 March 2013
Summary/Synopsis	3	13 March 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Advertisement	2	05 February 2013
Covering Letter		29 January 2013
Covering Letter		12 March 2013

A Research Ethics Committee established by the Health Research Authority

Evidence of Insurance or indemnity	Marsh Ltd	02 August 2012
Interview Schedules/Topic Guides	4	30 January 2013
Investigator CV	Dr Gundi Kiemle	
Investigator CV	Cara Brunsden	
Other: Sponsorship Approval Letter		05 December 2012
Other: Approval from D.Clin.Psych Research Review Committee, Liverpool University		26 September 2012
Other: Participants thank you letter	2	05 February 2013
Participant Consent Form	3	03 March 2013
Participant Information Sheet	3	12 March 2013
Protocol	4	13 March 2013
REC application	3.4	
Summary/Synopsis	3	13 March 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/NW/0114	Please quote this number on all correspondence
------------	--

Yours sincerely



Miss Shehnaz Ishaq
Committee Co-ordinator

E-mail: nrescommittee.northwest-gmwest@nhs.net

Copy to: Dr. Gundi Kiemle
Mrs Lindsay Carter, University of Liverpool
Mr Anthony Hodgson, 5 Boroughs Partnership NHS Foundation Trust

Appendix 4.

Participant Descriptions

(some details removed to protect anonymity)

David

David (49) has been married to his wife for 23 years, they met 26 years ago. David and his wife have two sons together, aged 19 and 24. David's wife (Sally) sustained a subarachnoid haemorrhage in 2011 following severe headaches and nausea at the gym. Sally struggles with memory difficulties, poor coordination and a lack of confidence. David is in a public sector profession and has expertise in dealing with crisis situations.

Simon

Simon (50) has been in a relationship with Sandra for 32 years and married for 18 years. Simon proposed several months after the ABI and moved in with his partner. Sandra sustained her ABI in 1998 after falling and hitting her head following an epileptic seizure. She was unable to return to work in the public sector due to severe memory impairment. Simon works reduced hours (mornings) in administration so that he can look after Sandra. They have no children together; they were never on the agenda before the ABI.

Peter

Peter (51) married Jane in 1996, both had been married previously. They have three children together; a 17 year old girl, a 15 year old boy and an 11 year old girl. Jane was diagnosed with an arteriovenous malformation (AVM) in 2008 following several fainting episodes. The AVM was embolised several times, however following the third embolization in 2010, Jane sustained a bleed. The blood clot was removed, however, the bleed left Jane with no speech and loss of feeling down her right side. Peter works in the public sector and is a qualified social worker. Jane also worked in the public sector before her ABI.

Nick

Nick (49) has been married to Jill for 23 years. They have three children together; a 21 year old girl (who lives down the road), a 19 year old girl and a 16 year old boy. Jill sustained a subarachnoid haemorrhage in 2008. She collapsed at work following a bleed and later sustained a second bleed. Jill has very poor short term memory, dysexecutive syndrome (change in personality and lack of awareness), reduced mobility and left sided visual neglect. Nick has his own business which enabled him to work around his wife. Jill has full time care provided by both Nick and his sister.

Tim

Tim (67) has been in a relationship with Dorothy for over 40 years; they are not married and have no children together. Dorothy sustained a subarachnoid haemorrhage following severe headaches in 2006. Dorothy started to improve over the following year and was thinking about a return to work, however, she started to have epileptic seizures and progressively deteriorated. She has a poor memory, dysexecutive syndrome (change in personality/mood swings/impulsivity) and struggles with her mobility. Tim is retired and Dorothy requires 24/7 support.

John

John (63) has been married to Anne for 36 years; they have a 33 year old daughter and lost their son when he was 15 years old as a result of a brain haemorrhage. Following severe headaches, Anne sustained a subarachnoid haemorrhage in 2006. Her personality completely changed; John describes her as independent yet aggressive. John no longer works due to physical health difficulties. He has been a driver all his life and was a driver in the army.

Appendix 5.

Recruitment Flyer

Version 2

05/02/2013



UNIVERSITY OF
LIVERPOOL

VOLUNTEERS NEEDED

I am looking to recruit male partners of females who have sustained an acquired brain injury, to take part in a study about personal experiences of brain injury.



The male partner will be asked to take part in a 60-90 minute interview which will explore how the acquired brain injury has impacted on roles within the family (e.g. domestic, parenting and financial), relationships, and views and expectations for the future.

To take part the male partner must;

- Live with a female who has sustained an acquired brain injury (either head injury or subarachnoid haemorrhage).
- Have had a close personal relationship with the female partner for two years before the acquired brain injury.
- Be fluent in the English language.
- Be willing to discuss his personal experience of his partner's brain injury.

The interview will take place at a mutually convenient location and time; in a local NHS building or alternatively in his own home environment. Travel costs will be reimbursed.

If you are willing to take part or require more information please contact;
Cara Brunsden (cara.brunsdn@liv.ac.uk or
tel. 0151 794 5530)

Appendix 6.

Recruitment Letter

Dear Ms. (last name),

I am writing to tell you about a study being conducted by Cara Brunsten, Trainee Clinical Psychologist, at Liverpool University.

As a clinical psychologist in the NHS I am not only involved in care and treatment of patients but also actively involved in promoting research studies which increase our understanding of acquired brain injury.

Cara Brunsten is conducting a study which aims to explore the experiences of male partners who are caring for female partners with a head injury/subarachnoid haemorrhage. I am contacting some of my patients to tell them about the study to let them know what it involves. If you are living with a male partner who meets the criteria to take part in the study (see the enclosed flyer), they may be interested in finding out more.

Participation is completely voluntary, and it is entirely your partner's decision whether to take part. Anyone wishing to find out more information is asked to contact the researcher (Cara Brunsten) directly, which means that participants remain anonymous and neither I nor the service will know who is taking part in the study.

If your partner is interested in learning more about this study, please review the enclosed recruitment flyer from Cara Brunsten.

You do not have to respond if you are not interested in this study. If you do not respond, no one will contact you further.

Thank you for your time and consideration,

Yours Sincerely,

(Name and designation of local collaborator/investigator)

Appendix 7.

Interview Schedule



Version No. 4

INTERVIEW SCHEDULE

1. Can I start by asking you some questions about your partner's brain injury? Please tell me about your experience of your partner's brain injury.

- What happened?
- What caused the brain injury?
- When was the injury/haemorrhage sustained?
- How long have you been in a relationship and how long have you lived together?
- How long had you been together at the time of the brain injury?
- Do you have any children? (If there are any children, how old were the children at the time?)

2. How have the roles changed within the household following your partner's brain injury? (domestic, social, work, financial, parenting)

- How did this feel for you at the beginning? ...What about now?
- How has the brain injury impacted on the family (on family life, children, childcare, domestic routines etc)?
- What other changes have happened in the family/ in your life, as a result of your partner's brain injury?

3. What coping strategies did/do you use and what works best?

- Please can you give some examples of the different coping strategies you use, and in what way they are helpful?
- What about extended family support?
- What about time for yourself?

4. How would you describe your close personal relationship with your partner?

- Please can you tell me about any changes in your emotional relationship with your partner (e.g. emotional closeness)?
- What about changes in your physical relationship?
- How has the brain injury impacted on your sexual relationship and sexual intimacy?
- Please can you give me some examples of things that have happened, which illustrate these changes.
- How have you coped with this? What are the strengths?
- What's been difficult?
- What is your experience of your partner's attitude towards any change in your relationship?

5. What keeps you strong? Positive?

- Can you give me some actual examples (based on your experience)?

6. What do you feel have been the most challenging experiences for you?

- How are you approaching these challenges?

7. How do you see yourself in the future?

- How is this different to how you viewed your future before the acquired brain injury?

8. What support have you received?

- Support from family and friends?

- Support from services (statutory or voluntary)?
- Other forms of support?
- What has been helpful, and how? What has not been helpful, and why?
- What would you want to have been done differently?

9. What would you say to a male whose partner recently sustained a brain injury?

10. Thank you for agreeing to take part in this interview, is there anything you would like to add? Anything I have missed which you feel is important? Any Questions?

Appendix 8.

Participant Information Sheet



Version No. 3

PARTICIPANT INFORMATION SHEET

Male partner experiences of females with an acquired brain injury

I would like to invite you to take part in my research study. My name is Cara Brunsden and I am conducting this research as a Trainee Clinical Psychologist, as part of my Doctorate in Clinical Psychology at the University of Liverpool. Before you decide, I would like you to know more about what the study will involve and why the research is being carried out.

Please give yourself time to read the information sheet. If something remains unclear, contact details are provided at the end.

What is the purpose of the study?

The purpose of the study is to explore male partner experiences of living with a female with an acquired brain injury (ABI). The study will aim to discover how the ABI has impacted on roles within the family (e.g. domestic, parenting and financial), relationships, and views and expectations for the future. Male partners are an under-researched group in the field of brain injury and therefore it is important that male partner experiences are explored further.

Why have I been invited?

Between four and ten males will be invited to take part in the study. You have been invited because you live within the North West, and you are a male who lives with a female partner who has sustained an acquired brain injury (either a head injury or subarachnoid haemorrhage). You are eligible to take part in this study if you have been in a close personal relationship with your partner for at least two years before she sustained an acquired brain injury. You must also be currently living with your partner.

Do I have to take part?

Taking part in this research is entirely voluntary. I will review the participant information sheet with you before starting the interview, giving plenty of time for questions to be asked. If you agree to take part, you will be required to sign a consent form. You are free to withdraw at any point without giving a reason.

What will happen to me if I take part?

If you agree to take part in the study, you will be contacted to arrange a date for interview. This will be conducted at a mutually convenient location and time. You will be reimbursed for any travel expenses.

The interview will be 1:1 and will last approximately 1 hour 30 minutes. Before the interview begins, the participant information sheet will be reviewed and you will have the opportunity to ask questions. The interview will be audio recorded using a digital recorder. All information will remain confidential and anonymous. At interview, I will ask you if you are willing to be contacted at a later date to discuss the initial findings. If you agree, I may contact you by telephone to arrange either a face:face or telephone appointment. This would be a briefer interview (up to half an hour). The research will be completed by September 2014.

You have the right to withdraw after the interview has taken place. If you decide you no longer wish to take part, you can contact me by email or telephone (details given at the end). Once the data has been anonymised it will not be possible to withdraw as the data will not be identifiable and we will not be able to link back to your details. Any personal information will be destroyed at the end of the study. Audio recordings will be stored securely for 5 years after the research has ended.

What are the possible disadvantages of taking part?

It is not anticipated that you will experience any danger or discomfort by taking part in this study. In the event that you do feel considerable distress from talking about sensitive and personal issues, the debriefing sheet, given at the end of the interview, will contain the numbers of a variety of services (e.g. Samaritans, Headway, and local Psychological Services) who can offer further support and advice.

What are the benefits to taking part?

There are no direct benefits to taking part, although you may find it interesting, you can ask questions and the researcher will be able to point you in the direction of support services in the local area. The research aims to explore male partner experiences of living with a partner with a brain injury. Therefore the research will potentially benefit NHS services; supporting and enhancing the provision of services to families and male partners in your position.

Will my data be confidential?

All information you provide is confidential. All data collected will be stored securely. Supervisors, the transcribers and the examiner of the dissertation will have access to collected data. Paper copies of participant information will be locked in a secure compartment and destroyed immediately after the study ends. Audio recordings will remain anonymous and stored securely in a password protected computer file. Each participant will be given a unique identification code (known only to the researcher) which will be used for transcription and analysis. Direct quotations will be used in the dissertation write up and any publications arising from this; yet quotations will not be identifiable.

The University will keep all electronic data for a period of 5 years following completion of the research, after which they will be destroyed.

I will discuss confidentiality in detail with you at the beginning of the interview. If information is disclosed which I feel may highlight a significant risk of harm to either yourself or others, it is my duty as a Trainee Clinical Psychologist to report this to my supervisor.

What will happen to the results?

The results will be reported in the form of a major research dissertation to fulfil part of the requirements of the researcher's Doctorate in Clinical Psychology. The research will be completed by the end of September 2014. Findings will be submitted for publication in a peer-reviewed journal.

A summary of the study and its main findings will be sent to all participants, unless you explicitly state you do not wish to receive this.

Who is funding the research?

The research is sponsored by the University of Liverpool.

Who has reviewed the study?

The study has been reviewed by the Doctorate in Clinical Psychology Research Review Committee and University Sponsorship has been granted.

All research in the NHS is looked at by independent group of people called a Research Ethics Committee in order to protect your interests. This study has been reviewed and given favourable opinion by Greater Manchester West Research Ethics Committee.

Further information and contact details.

If you have any questions about the study or require further details, please contact the researcher:

Email. cara.brunsdan@liv.ac.uk Tel. 0151 794 5530/ 0151 794 5534

Alternatively you can contact the supervisors;

University Research Supervisor

Dr. Gundi Kiemle

Email. g.kiemle@liverpool.ac.uk

Tel. 0151 794 5534

NHS Research Supervisor

Dr Stephen Mullin

Email. stephen.mullin@nhs.net

Tel. 01942 264 635

What if there is a problem?

If you have a concern about any aspect of the study and do not wish to speak to the researcher or supervisors, you can contact:

Joanne Dickson PhD

Research Director

Doctorate of Clinical Psychology Programme

Division of Clinical Psychology

University of Liverpool

Email: j.dickson@liv.ac.uk

Tel: 0151 7945530

Thank you for taking the time to read the participant information sheet

If you agree to take part in the research, please contact Cara Brunsten either by phone (0151 7945530) or email (cara.brunsten@liverpool.ac.uk)

to arrange an interview time and date.

This is your copy to keep. If you agree to take part in the study, you will be given a signed consent form to take away.

Appendix 9.

Consent form



Participant Identification Number:

Version No. 3

CONSENT FORM

Male partner experiences of females with an acquired brain injury

Name of Researcher: **Cara Brunsden** Name of Supervisors: **Dr Gundi Kiemle, Dr Stephen Mullin**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 12.3.2013 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I understand that all information I provide will be dealt with in a confidential manner. ☐
4. I agree to the interview being audio recorded. ☐
5. I agree to the use of anonymised quotes in publications. ☐
6. I agree to the researcher contacting me to discuss initial results (either face:face or by telephone). ☐
7. I understand that relevant data collected during the study, may be looked at by individuals from The University of Liverpool, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐
8. I agree to take part in the above study. ☐

<hr/>	<hr/>	<hr/>
Name of Participant	Date	Signature
<hr/>	<hr/>	<hr/>
Name of Person taking consent.	Date	Signature

Appendix 10.

Participant Debrief



Version No. 2

05.02.2013

THANK YOU FOR PARTICIPATING

It is important to understand the lived experience of families who have been affected by acquired brain injury. Acquired brain injury can understandably impact on roles within the family, most significantly, the role of the spouse or partner. The partner is required to adapt to new and unexpected circumstances, often resulting in a stressful and demanding time of change. By taking part in the interview process, you have been able to voice your opinion and personal experiences of change following acquired brain injury. Helping services to understand the lived experience of brain injury, from a male perspective, may enhance the understanding of professionals working with families post brain injury, improving family intervention and support.

It is often difficult to answer personal questions and voice your individual experience of brain injury. Your generosity and willingness to participate is much appreciated. If answering any of the interview questions led you to feel upset or distressed and you would like to talk in further detail about your thoughts, there are a number of contact details listed on the back of this sheet which may be of interest.

Thank you again for your kind participation in this research.

A summary of the study and its main findings will be sent to all participants. Please let the researcher know if you do not want to receive this.

**If you have any further questions or concerns please feel free to contact me
(cara.brunsdon@liv.ac.uk), Gundi Kiemle (g.kiemle@liv.ac.uk), or Stephen Mullin
(stephen.mullin@nhs.net) for more information.**

If this does not result in your satisfaction, please contact:

Joanne Dickson PhD
Research Director
Doctorate of Clinical Psychology Programme
Division of Clinical Psychology
University of Liverpool
Email: j.dickson@liv.ac.uk
Tel: 0151 7945530

Headway UK

Headway UK is a national charity set up to support those who have been affected by brain injury. A network of local branches, across the UK, offers a wide variety of services and support.

Website	www.headway.org.uk
Telephone Number	0808 8002244

BASIC (Brain and Spinal Injury Centre)

BASIC provides counselling, information and support services for patients and their families following brain or spinal injury.

Website	www.basiccharity.org.uk/
Telephone Number	0870 750 0000

Samaritans (24 hour helpline)	08457 90 90 90
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North West Improving Access to Psychological Therapies (IAPT) Teams

Service which provides brief therapy and guided self help for people suffering with anxiety and depression

Telephone numbers for all North West IAPT teams can be found at the following web address;

www.iapt.nhs.uk/services/services/north-west-nhs-iapt-services/

(Some teams across the NW accept self referrals and others require a GP referral letter)

Appendix 11.

Excerpts from the reflective journal

Reflections following Participant 1 interview 12.07.13

- Very understanding, patient, articulate ‘done his homework’ in relation to supporting his wife as best he can. Self-critical at times – what he does is ‘not enough’ (conscious of praising himself). Adaptable and flexible.
- Some possible underlying resentment? Occasional change in tone of voice – not apparent from reading transcript, still saying words which reflect patience.
- In need of support and help – acknowledged in interview and came to realisation at end that he may need to talk to someone. The interview was a chance to explore his feelings and move towards asking for help.
- Very tuned into his wife, knows her triggers and anticipates these.
- Very close partnership
- Open and honest interview
- Proud of what he has achieved/where they are; ‘life goes on’ attitude.
- Interviewer – difficult to hold back from being a ‘therapist’. Wanted to help. Drew interviewer in to personal world – felt emotionally drained. Felt like I didn’t ‘help’ him and left feeling that I should have remained in contact with him for support.

Reflections following Participant 3 Interview 12.09.13

- The participant only realised his multitude of roles as the interview progressed, coming to the conclusion that he is not a ‘therapist’ and needs to stop acting like one at times – he needs to be more of a husband.
- Realisation of the need to talk to someone – but reflected on this, never wanted to burden friends.
- Anger towards eldest child, but conflict between being proud dad and expecting more.
- Change in the way he views work – used to be career driven, now forced to be a family man, priorities changed. Takes on much more of a parenting role.
- Participant highlighted how the three years have been a rollercoaster with more challenges to come.
- Very articulate, upsetting interview felt by the interviewer. Very patient and loves his wife dearly, speaks very highly of her. Loves his family very much.
- Interviewer – felt that he wanted to tell his story and share with others, not had the chance to do this.
- Strong, not weak (doesn’t want to be perceived as weak/can’t be weak) but upset deep down.
- Described himself as the middle-man, the ‘negotiator’ and ‘peacemaker’.
- What does he do for himself? – family and wife always in mind.

Reflections following P2 noting and emergent themes 7.02.14

Several missed opportunities for further questioning, only evident when re-reading the transcript. Information hidden; 18 years since ABI – portrayed a sense of normality at interview, however his use of language indicates otherwise. How does he truly feel about things? Very hidden emotions...where is the resentment? The resentment appears to be towards others and not his wife; the doctors, her family etc.

I am left feeling confused. He says he doesn't like commitment (e.g. to a child) however he is committed to his wife? He chose to propose following the ABI – a commitment? Emergent themes difficult to define initially. I cannot interpret the hidden emotion when none is overly present in his use of language...how does he feel??! Difficult to remain impartial when left feeling confused. I am constantly questioning the underlying emotion in this very 'normal' account of life. Am I trying to find something that is not present? I must remain aware of this...and not over-interpret the transcript. He laughs and is sarcastic...are these underlying feelings, attempting to escape?

Reflections following P4 noting 19.3.14

Coughs to hide difficult feelings and emotions. Some jumbled messages, difficult to articulate story. I didn't realise how rich the interview was until reading and re-reading the transcript due to mumbled messages. Felt chaotic to sit with at the time; unresolved feelings transferred to interviewer. I was overwhelmed following the interview and after listening again to the recording; Nick was doing two trips a day (to the hospital and hospice!) he is a saint! How did he get through it?

Felt alone and without support, no information provided – key theme. Is this interview harder to listen to (more emotional) due to Nick appearing to still be grieving?? (along with his children?) – has he fully accepted the ABI? Very little positivity and coping.

I get a sense that he may not 'stick it out', it is tough for him. His wife's personality change is significant here. She is a changed person now. Evident throughout the account. How can he fully accept his wife when she is different and doesn't see it herself?

Acknowledges that no one has ever asked him about sexual intimacy, he just got on with it alone. He hides his emotions; but hates it. He feels trapped?? He has no choice but to stay (like 'social limbo'). Talks about two choices; stay or leave (simple as that?!)

What is it that makes them (male partner) stay...their personality? Pre-injury relationship? Financial situation? Profession? Guilt?....Nick is a 'doer' and does not want to be seen to be giving up.

Appendix 12.

NVIVO print screen of a super-ordinate theme, with corresponding quotes

The screenshot shows the NVIVO interface. On the left, a tree view displays 'Sources', 'Nodes', 'Classifications', and 'Collections'. A blue box labeled 'Super-ordinate Theme (P4)' points to the 'Nodes' section. Another blue box labeled 'Emergent Themes (P4)' points to a list of emergent themes. The main area shows a table of quotes and their counts.

Quote	Count 1	Count 2
'I don't think that is my wife'	1	12
adjustment following ABI; his wife is now different	1	1
'it looks like Jill but it isn't Jill'; personality change	1	1
loves his wife; but doesn't love the person she has become	1	1
post-injury change in behaviour; wife has smacked partner	1	3
she is the same but different; 'forget what you had'	1	1
'she looks the same, well she doesn't' (change of mind)	1	1
'she's not the person I married'	1	1
wife as stolen and replaced	1	2
wife has been 'taken over'	1	1

Reference 1

I mean she still is she looks well she doesn't even look the same any more but you know she looks the same

Reference 2

she was not even close, like someone had nicked her,

Reference 3

I know that sounds a stupid thing, someone had taken her and brought her back

Reference 4

you know it looks like Jill but it isn't Jill her personality and everything was so different

Reference 5

she's given me a smack a few times which she never did before ever you know its not the end of the world but she's just so different than what she was

Reference 6

than just the behaviour problems and its difficult,

Reference 7

you know and just struck off I mean she's hit me which which she'd never done before.

Reference 8

she's not the person I married that's definite you know

Reference 9

there is emotion I suppose 'cause I love her I love the woman but I don't love that, 'cause I don't think that's my wife

Reference 10

going back to what you said the biggest it's that first there is a lot of other things but the biggest one is that because you've got to adjust to you know some things that are said and its everyday I mean it could be tonight it could be tomorrow its every single day without fail

Reference 11

I would certainly be warning people listen just forget what you had you've got what you've got now and its it will be a different person it will look like her but she'll do things that you'll never believe that she would have done

Reference 12

flippin eck wouldn't believe my ears sometimes and then you know just nastiness it's like it's like somebody's just took her over

Appendix 13.

Table of main themes, subthemes and super-ordinate themes (with associated participants)

Participant Colour Code

Participant 1 (David)

Participant 2 (Simon)

Participant 3 (Peter)

Participant 4 (Nick)

Participant 5 (Tim)

Participant 6 (John)

Main Theme	Subtheme	Super-ordinate Theme
Entering the unknown world of ABI	<i>Pre-injury naivety</i>	<p>ABI as 'out of the blue'</p> <p>The immediate impact; decisions to be made</p> <p>Epilepsy; unknown and unexpected consequence of ABI</p> <p>ABI as unpredictable, unwanted</p> <p>ABI as 'out of the blue'</p> <p>Pre-injury naivety</p> <p>Unprepared and living with uncertainty; the search for information</p> <p>Waiting; the unattended injury</p> <p>Unaware of what's to come; symptoms preceding ABI</p> <p>The insertion of a 'brillo pad'; emergency operation</p> <p>ABI as dismissed (by all) despite signs of something wrong</p>
	<i>An emotional roller-coaster</i>	<p>ABI; 'altered everything'</p> <p>The long treatment process</p> <p>The journey, the experience (ongoing)</p> <p>The diagnosis; an anti-climax</p> <p>Learning; every ABI is different</p> <p>The seriousness of the brain injury; it happened so quickly</p> <p>ABI as a journey</p> <p>'Progress' before becoming 'progressively worse'</p> <p>'It was life threatening'</p> <p>An emotional roller-coaster</p>
	<i>ABI sequelae; hidden to the outside world</i>	<p>The hidden disability</p> <p>Psychological impact of ABI and associated trauma (wife)</p> <p>Sensory sensitivities following ABI (wife)</p> <p>Cognitive effects of ABI (wife)</p> <p>ABI; hidden from others</p>

		<p>Wife's 'breakdown'</p> <p>Wife's additional health complications; adding to the impact</p> <p>Fatigue following ABI (wife)</p> <p>Cognitive difficulties following ABI (wife)</p> <p>Impact of ABI; depression (wife)</p> <p>Symptoms of ABI as 'bizarre'</p> <p>Impact of ABI on mood and emotion (wife)</p> <p>The cognitive sequelae of ABI; memory and dysexecutive syndrome</p> <p>The negative sequelae of ABI</p>
Imprisoned by the ABI	<i>Entwined lives; 'joint disability'</i>	<p>Entwined lives; 'joint' (dis)ability</p> <p>Entwined lives; then and now</p> <p>Loss of physical intimacy; 'a perfect storm'</p> <p>New responsibilities; loss of equal partnership</p> <p>Remaining empathic amidst a sense of loss; life's personal pleasures</p> <p>Sense of loss; future travel</p> <p>Wife's emotional neediness and dependence</p> <p>Emotional dependence; wife's need for closeness</p> <p>The 'old life'</p> <p>Sex; no longer a priority</p> <p>ABI as a barrier to intimacy</p> <p>Unwanted roles (partner)</p> <p>A constant reminder of the 'old life'</p> <p>Shared plan of the future; pending</p> <p>Loss of shared social life</p> <p>Wife's loss of independence; the need to rely on her husband</p> <p>Loss of sexual intimacy; 'there is nothing there'</p> <p>Wife as sexually uninterested</p> <p>Lost 'quality of life'</p> <p>Female partner as vulnerable; never left alone</p> <p>Retirement; not the life he envisaged</p> <p>Loss of the 'good old life'</p> <p>Loss of interconnectedness; misses 'the little things'</p>
	<i>Playing 'happy families'</i>	<p>Negative impact of ABI on family life</p> <p>Being the dad (and the mum)</p> <p>Life as a juggling act</p> <p>Protecting the family, promoting normality</p> <p>Home life takes precedence</p> <p>Family (im)patience</p> <p>Youngest daughter and son; adapted well</p>

		<p>The struggles of joint parenting; 'wife involved in a different way'</p> <p>Loss of the daughter they knew; emotionally absent</p> <p>ABI as causing conflict within the home</p> <p>Children; unable to accept mum as their mum</p> <p>Family dynamics; 'stuck in the middle'</p> <p>Impact of executive dysfunction on the family; hurtful yet unaware</p>
	<i>'She's not the person I married'</i>	<p>Denial of disability (wife)</p> <p>Wife as a changed person</p> <p>Loss of identity (wife)</p> <p>The debilitating impact of ABI</p> <p>The same, but different; 'I miss her'</p> <p>The physical impact of ABI (wife)</p> <p>Loss of purpose (wife)</p> <p>'I don't think that is my wife'</p> <p>The 'degeneration' of his partner</p> <p>The debilitating sequelae of ABI</p> <p>Loss of identity; no longer the 'old Dot'</p> <p>No longer his wife; 'taken over by another spirit'</p> <p>'She is very sharp with her tongue'; the consequences of her behaviour when out alone</p> <p>Exacerbated (negative) personality traits following ABI</p>
	<i>'There's no real escape'</i>	<p>ABI causing conflict and upset; waiting for 'the storm' to pass</p> <p>Challenges and struggles</p> <p>'I'm stuck dealing with it'</p> <p>The frustration of patience</p> <p>You've just got to get on with it; no other choice</p> <p>'I'm bitter'; life is just different</p> <p>Life feels like 'Groundhog day'</p> <p>'It's like living on my own, but someone is there'</p> <p>Hidden resentment; 'I could do without all this'</p> <p>Stuckness; 'no real escape'</p> <p>Daily routine as monotonous</p> <p>The daily challenge of ABI</p> <p>Detached from the experience</p> <p>A sense of feeling ashamed; I wish I could ban my family from the house</p> <p>The absorption of life's fun</p>

		<p>Making 'my life hell'</p> <p>I hate this life, yet I love my wife</p> <p>'I love her to death but I can't live with her'; the impact of personality change on the relationship</p>
(Compassion) without self-compassion	<i>Helplessness and powerlessness</i>	<p>A sense of helplessness</p> <p>Feeling alone; 'cut adrift'</p> <p>Frustration at others; 'No matter how much you try to explain it, they don't really get it'</p> <p>Lose lose; 'nothing I can say will be helpful or right'</p> <p>Sense of feeling alone</p> <p>Risk and medical negligence</p> <p>Partner; dismissed and unheard</p> <p>Treatment; a sense of helplessness</p> <p>The experience of hospital; unanswered questions, unheard</p> <p>Friends drift away</p> <p>Separate lives, different paths (pre and post ABI)</p> <p>I can't win</p>
	<i>Abandonment of the self</i>	<p>Self-blame; personal failings and mistake making (remaining human)</p> <p>Wife's needs as more important than work</p> <p>Wife takes priority</p> <p>Hiding information; protecting wife from worry</p> <p>Anticipating and meeting wife's needs</p> <p>Providing explanations; understandings his wife's needs</p> <p>I can cope (alone)</p> <p>Unspoken communication; a fear of placing blame</p> <p>Wife comes before work</p> <p>I can do it (all) myself</p> <p>'My life revolves around her needs'</p> <p>Life has changed, I have changed</p> <p>Self-doubt, feeling helpless and inadequate</p> <p>Left alone, feeling 'empty'</p> <p>'I just want her to be happy'</p> <p>Admiration and respect (despite feeling unadmired and not respected)</p>
	<i>Male partners; the silent victims</i>	<p>Underlying resentment</p> <p>Underlying resentment; unappreciated</p> <p>Underlying anger; none-existent family emotional support</p> <p>Feeling unappreciated and unacknowledged</p>

		<p>Unanswered questions, unspoken feelings</p> <p>The need for support; partners as the forgotten victims</p>
Holding on to hope	<i>A lifelong commitment; endlessly understanding</i>	<p>Emotional attunement and connectivity</p> <p>Commitment as everlasting</p> <p>Wife remains vulnerable</p> <p>Wife's determination as promoting rehabilitation</p> <p>The future desire for togetherness</p> <p>Remaining committed</p> <p>Remembering 'it's not her fault'</p> <p>The meaning of a 'long term relationship'; she needs me</p> <p>Admiration for the person she was; 'a remarkable woman'</p> <p>A duty to (care for) his partner</p> <p>Remaining there for one another</p> <p>A lifelong commitment; 'for better or for worse'</p> <p>Wife has had 'a hard life'</p>
	<i>Inner resilience and strength</i>	<p>Coping; optimism and positivity</p> <p>Coping; time to self</p> <p>Coping; well balanced and resilient personality</p> <p>Coping; anticipating needs of wife</p> <p>The need for 'me time'</p> <p>The importance of support and 'me time'</p> <p>The importance of 'escapism' from the ABI</p> <p>Understanding and respect (for others)</p> <p>His faith keeps him alive</p>
	<i>Acceptance and adaptation; 'bad things happen to nice people'</i>	<p>Signs of progress; 'a flash of the old sally'</p> <p>Adapting and acceptance; new plans, new ideas</p> <p>'Bad things happen to nice people'; non-blaming and unpreventable nature of ABI</p> <p>Remaining optimistic; signs of progress</p> <p>'Normality'</p> <p>Acceptance; 'just got on with it'</p> <p>New learning and responsibilities</p> <p>Learning and adapting; 'knowing yourself'</p> <p>'Adult time' as important for the relationship</p> <p>What more can people do; recovery reaching a plateau</p> <p>Change of role; 'Mrs Doubtfire'</p> <p>The ABI as responsible (for life as it is)</p>

	<p><i>Forever indebted; the importance of support</i></p>	<p>The importance of support groups Acknowledging the need for support Work as supportive Others providing support Shared experiences New opportunities as important Support from others Community ABI team; saved our lives Acknowledging the need for support groups The importance of support from others (thankfully) Family remain understanding</p>
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Appendix 14.

Participant 4 (Nick); Example of Exploratory Coding

200	Interviewer: were they all living here at the time of the brain injury?	
201	Respondent: yeah erm <u>I think it's one of those 'cause I'm away so much as well</u>	Trying to understand what has happened – family dynamics. Nick was always
202	<u>they were obviously very close but the girls were just getting to the point where</u>	away and they were very close to mum, then this happened...
203	<u>they are like girly stuff with their mother and that you know just she's 22 nearly</u>	They were getting to the point where they enjoyed girly stuff with mum, and
204	<u>now Carla so she was like 16 or 17 yeah thereabouts almost 17 and that was</u>	that was taken away.
205	<u>she took it bad but they can't shut off I did try and get, is it erm <name of</u>	Carla, 'took it bad', they can't shut off from what happened to mum.
206	<u>clinical psychologist> at erm at <specialist hospital>? I can't remember her</u>	Nick asked the clinical psych to come and talk to the girls but that didn't work.
207	<u>second name she's foreign she's got an accent and I can't remember she came</u>	
208	<u>here actually erm 'cause the girls they wouldn't even entertain going anywhere</u>	In hindsight, should have tried harder to get the girls to accept mum's ABI, but
209	<u>it didn't work obviously given looking back we probably should have done a</u>	they refused to talk to anyone about it.
210	<u>little bit more with that one really but they just refused to go and see anybody</u>	
211	<u>but even now they</u>	
212	Interviewer: what do you mean sorry can you explain that a bit more	
213	Respondent: erm <u>they couldn't handle it they just didn't want to speak to her</u>	They couldn't handle 'it'?? Mum or the ABI? The changes? They didn't want to
214	<u>'cause as far as they were concerned it's not their mum 'cause she was such a</u>	talk to mum, because she wasn't the same.
215	<u>massive different person I mean she still is she looks well she doesn't even look</u>	She was (and still is) a 'massively different person'. Contradicts self, she looks
216	<u>the same any more but you know she looks the same but she was not even</u>	the same, well no she doesn't.
217	<u>close, like someone had nicked her, I know that sounds a stupid thing, someone</u>	Nick describes someone taking her, stealing her, and replacing her...
218	<u>had taken her and brought her back and you know it looks like Jill but it isn't Jill</u>	She looks the same, but it isn't her... her personality, changed.
219	<u>her personality and everything was so different and the kids really haven't even</u>	
220	<u>now they (sighs) a lot of is they've lost they don't give her respect it's hard you</u>	The children don't respect her. (sighs – this is tough for him).
221	<u>know and then they'll have a big massive fight and Daniel will text I just want</u>	The children will fight with mum, and then text dad saying that 'just want mum
222	<u>my mum back, and that cuts me in two you know but I don't know how you'll fix</u>	back' (the old mum is gone and the children can't accept the new mum they
223	<u>that I mean I'm hoping at some point they'll grow up and now she's had the</u>	have). This 'cuts dad in two'...very upsetting for him. Dad is unsure what to do,
224	<u>baby they'll but they still don't, I don't know how to explain they just they didn't</u>	feels lost?? How do you fix that? Hoping the children will grow up and see things
225	<u>handle it well I've tried everything with them but it seems like they've just cut</u>	differently...
226	<u>off and gone</u>	Children haven't handled it well, Nick has tried everything to help them...but
227	Interviewer: yeah	nothing has worked and they have cut themselves off.
228	Respondent: <u>my mum's not my mum that's not my mum I'll say</u>	'That's not my mum' (so why should they go back to normal...)
229	Interviewer: so what kind of things have you tried	
230	Respondent: well <clinical psychologist> came, <u>just we tried to take them</u>	Tried to take them somewhere for support, but they won't accept it.
231	<u>somewhere they wouldn't go to the doctors <clinical psychologist> tried with</u>	
232	<u>them but other than getting them to go and see somebody like counsellors or</u>	

