

The experience of adjustment to relationship changes
in men whose female partners have an acquired brain
injury (ABI).

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LIST OF ABBREVIATIONS

'ABI': Acquired Brain Injury

'TBI': Traumatic Brain Injury

ABSTRACT

Background: An ABI and its consequences affect not only the injured person, but also those in relationships with that person, particularly partners and other close relatives. Previous research suggests that an ABI may impact more negatively upon partners than other relatives, but little research has specifically explored the experiences of men. This study explored the experience of adjustment to relationship changes in men whose female partners have an ABI. In particular this study was interested in what changes in their relationship with their partner men have experienced, and how they have adjusted to these changes.

Method: A qualitative approach was taken and eight men were interviewed. The data was analysed using thematic analysis from a critical realist epistemological perspective.

Findings: Five themes were identified within the data: 'Initial reactions to the brain injury', "She's a lot the same, but she's not the same", 'Relationship changing', 'Responsibility and burden', and 'Coping and support'. Men had experienced wide-ranging and numerous changes in their relationships which impacted upon them emotionally and practically. 'Just getting on with it' was a widely used way of coping, as well as drawing on different sources of support. However, there was an overall sense that men had been left to navigate a frightening and unknown territory without much support or guidance.

Conclusions: This study adds to the current literature on the previously neglected and unheard experiences of men whose female partners have an ABI. Future research could explore different aspects of men's experiences utilising more in-depth qualitative methodologies. Couples' experiences could also be explored by interviewing couple dyads together. Several clinical and policy-level implications have been identified, including increasing ABI awareness, information provision, routine access to support for partners, further curiosity about men's support needs, and working systemically in brain injury services.

1. INTRODUCTION

1.1 Preface

It is now widely acknowledged that an acquired brain injury (ABI) and the consequences of that injury affect not only the injured person, but also the system of people in relationship with that person (e.g. Gervasio & Kreutzer, 1997; Wood & Yurkadul, 1997; Bowen, Yeates & Palmer, 2010). Following an ABI, the injured person may experience cognitive, emotional, behavioural, social and physical difficulties or changes. These 'individual' difficulties will inevitably have an effect on the wider system around the injured person, in particular those closest to them, such as partners or other close relatives. Yeates (2009) has argued that brain injury sequelae may actually be more apparent when the injured person is with others than when they are alone. Many consequences of a brain injury may be seen to be located in the spaces *between* people rather than solely *within* the injured person (Bowen, Hall, Newby, Walsh & Yeates, 2009). Hence, adjusting to changes may be challenging for many members of the family system.

Currently there is little research exploring the experiences of men whose female partners have sustained an ABI. The aim of this study is to find out about men's experiences of changes in their relationship with their partner since the ABI, and how they have adjusted to those relationship changes. I will begin this chapter by describing the contexts that influenced how I came to do this research. I will then present some definitions of ABI and a description of prevalence and sequelae, before moving on to review the existing literature about the impact of ABI on those in relationship with the injured person, noting gender differences in experience, coping and adjustment. The focus then narrows to look at the effects of ABI on partner relationships. After summarising the existing research and noting the gaps in the literature, I will introduce the rationale for this study. Finally, I will outline my research question and specific aims.

1.2 How I came to this research

It is very difficult to come to research from a position of neutrality as any research question will have been shaped by the experiences, interests, values and assumptions of the researcher. It is likely that those same experiences and

assumptions that led a researcher to come up with the study in the first place will also impact upon which topic areas are privileged during the analysis and write-up of the research. In the methodology chapter I will reflect further upon my own assumptions and experiences. Given these issues, and in order to include the social aspects of the research, I have chosen to write in the first person rather than referring to myself as 'the researcher' (Webb, 1992).

My interest in the area of brain injury is informed by my experiences of working in several brain injury services prior to training, including a long-stay residential rehabilitation unit, a short-stay inpatient behavioural rehabilitation unit, and a community neuro-rehabilitation team. During my work I was struck by the huge changes in life circumstances that the injured people I was working with were going through. I often wondered about what it might be like for someone whose partner or relative has had a brain injury, and what changes and adjustments they must also be having to make. I noticed that the primary focus of the rehabilitation work was on working with the individual to make improvements in their functioning after the brain injury, with much less focus upon the role that partners and relatives might have to play in the rehabilitation, and even less attention given to the emotional needs of partners and relatives. There were a few family and carer support groups on offer, but these groups were not always well attended.

Within the existing literature I found that there was relatively little research that focused on the emotional experiences of partners and relatives of people with brain injuries, with a bias towards quantitative research, and mostly research involving female partners of men with brain injuries. I wondered whether this might be a reflection of the gender bias in numbers of people who acquire brain injuries, but I also wondered whether male partners are given opportunities to share their stories. Anecdotally, myself and colleagues had noticed a female bias in those relatives who did attend support groups, which led me to question whether support groups were adequately meeting the needs of male partners. Published work in this area also points towards the experiences of male partners as an area requiring further research (e.g. Bowen, Yeates & Palmer, 2010). I was very keen to explore these ideas further and to give male partners a voice and the opportunity to share their experiences.

1.3 Literature search strategy

I conducted electronic literature searches on many of the major psychology and medical databases, including Science Direct, MEDLINE, One File, Cambridge Journals Online, American Psychological Association, and Informa Healthcare. I used several different search terms in various combinations, for example, brain injury, TBI, ABI, stroke, brain tumour, encephalitis, spouse, partner, husband, men, family, carer, adaptation, relationship, qualitative. I did not use 'wild cards' within my search. Initially my search covered relatively recent papers (i.e., from the year 2000 onwards), however, it was later broadened to cover all years, and some of the qualitative literature reviewed came from as early as 1978; I deemed the content of these early articles as relevant and useful to the current study.

Additional search strategies were also used, including reviewing the reference lists of relevant books and articles, and consulting with colleagues in the field (many of whom are also researchers and authors) to identify additional research, including that which may be ongoing, or planned for the future.

I used these search strategies to conduct a narrative review of the literature, rather than a systematic review or meta-analysis, hence my review is not necessarily exhaustive, and very tightly-defined inclusion and exclusion criteria were not applied to the review. Instead, I made the decision to include or exclude literature initially based on reading the title and abstract to deem whether the paper was relevant. Later, papers were selected or discarded to fit with the structure of my literature review, which began with an overview of acquired brain injuries and their sequelae, with the focus systematically narrowing to the effects of brain injuries on relationships, parent vs partner relationships, partner relationships, and finally the experiences of non-injured male partners.

1.4 Background

1.4.1 Acquired brain injury

An acquired brain injury (ABI) is an injury caused to the brain since birth and that is not hereditary, congenital or degenerative (Headway, 2012a). The causes of

ABI are wide and varied, and include traumatic brain injury (TBI), stroke, encephalitis, aneurysm, haemorrhage, hypoxia/anoxia and tumour.

Gathering accurate data about the prevalence of ABI is problematic, as varied assessment methods are used to diagnose ABI. The United Kingdom Acquired Brain Injury Forum (UKABIF, 2012) have outlined some of the difficulties, including the fact that statistics are usually based on the presenting problem at A&E, with often the primary diagnosis only being recorded, sometimes meaning that a brain injury goes initially unrecorded. The most accurate data is collected for traumatic brain injuries but other causes of brain injury, such as infections, may be left out. Primary Care Trusts within the UK also differ in their classification systems for ABI.

So although prevalence data tends to be hugely varied, some general statistics about brain injury in the UK are presented here. According to Headway (2012a), it is estimated that there are around 500,000 people living with long-term disabilities following a traumatic brain injury. There are up to 500,000 people who have had encephalitis or meningitis at some point in their lives, and over 450,000 people living with severe disability following a stroke. Around 13,000 people are diagnosed with a brain tumour each year, although the number of people currently living with disability or other sequelae following brain tumour is unknown. Therefore, although it is difficult to obtain accurate overall figures, clearly a significant number of people are living with ABI.

With traumatic brain injury, there is a clear gender difference in incidence rates, with men being two to three times more likely to suffer a traumatic brain injury than women (Headway, 2012a). In general, men are more likely to suffer from strokes than women, with the exception of subarachnoid haemorrhage, where the incidence is considerably greater in females than in males of the same age (e.g., Zhang, Chapman, Plested, Jackson & Purroy, 2011). According to the Office for National Statistics (2008), men are slightly more likely to be diagnosed with a brain tumour than women, with an incidence rate of 8.1 per 100,000 per year in men compared with 5.5 per 100,000 per year in women. Overall, men seem to be more likely to acquire brain injuries (with the exception of subarachnoid

haemorrhage), but it is difficult to gather accurate data about gender differences in incidence and prevalence rates due to many of the methodological issues already described.

1.4.2 *Sequelae of acquired brain injury*

Depending on the type, location and severity of an ABI, a brain-injured person is likely to experience changes and impairments in their cognitive, emotional, behavioural, social and physical functioning. Cognitive changes might include difficulties with memory, understanding and processing information, concentration, problem solving, and using language; executive functioning may also be affected, resulting in difficulties in planning and sequencing, and mental flexibility; emotional and behavioural changes may include depression, anxiety, apathy, fatigue, emotional lability, irritability, aggression, sexual disinhibition, and impulsivity (e.g. Braine, 2011; Headway, 2012b). Although many people make a good recovery after ABI, some may be left with physical problems which impact upon their daily life. As a result of these cognitive, emotional, behavioural, and physical changes, people with brain injuries may experience social changes such as unemployment, loss of role and status within their social network, reduced access to opportunities, and social exclusion.

ABI does not just affect individuals, but can transform the lives of entire families (Headway, 2012a), with the terms *silent epidemic* and *hidden patients* being applied to the families and partners of people with brain injuries (e.g., Braine, 2011; Fengler and Goodrich, 1979). When a person sustains a brain injury, or a diagnosis is made, the whole family often have to make significant adjustments, usually without any prior experience or any sense of prognosis to prepare them (Bowen et al., 2009). Zeigler (1987) has suggested that after a brain injury, roles within that person's family may be very quickly, and often permanently, changed.

1.4.3 *Impact of ABI on family members*

The changes in an individual following a brain injury can have a ripple effect on others in their close family system, particularly with different roles often being taken on within a family or within a couple. A common theme in the existing literature is the new dual relationship that family members might have with their

relative with an ABI; many relatives take on the role of 'carer' after their loved one has had a brain injury, including formal caring responsibilities such as personal care in the case of more severe brain injury. Taking on new roles may have an impact on a family's financial situation, particularly if the injured person is now unable to work, and if their relatives are required to give up work in order to take on their new caring responsibilities. Carnes and Quinn (2005) have noted that if a family remains financially secure following a brain injury, then they are likely to function better as a family.

Taking on a more caring role can also impact upon relatives' mental health and wellbeing, as it has been reported that family members are more likely to experience high levels of stress if their relative's initial injury is more severe (Brooks, Campsie, Symington, Beattie & McKinlay, 1986). More recently, a study found that family members of people with brain injuries demonstrated significantly higher levels of psychological distress when compared with a healthy, 'non-patient' control group (Carnes & Quinn, 2005). Cumming, Cadilhac, Rubin, Crafti and Pearce (2008) found a high prevalence of clinical depression in family caregivers of stroke survivors.

Following a brain injury, family members may feel responsible for their relative who has an ABI. Logstrup (1994) has noted the perceived ethical obligation, and sense of social expectation, that family members should be there as a close relative of a sick person, and similarly Kneafsey and Gawthorpe (2004) have written about close relatives taking on additional responsibility for the person with a TBI, in such a way that was not necessary prior to the accident. Often these new and different responsibilities are not something for which relatives were prepared (Jumisko, Lexell & Soderberg, 2007). Relatives may need to be constantly available and continually on stand-by for the injured person (Engstrom & Soderberg, 2011).

Family members are often required to make huge adjustments following a relative's brain injury, including adjusting to their own new way of life, particularly if this now involves caring responsibilities, but also adjusting to any changes they notice in the injured person and in their relationship with the injured person.

Family might have to relinquish the life that they had planned and try to find a new way to live with their loved one who has been changed by the brain injury (Jumisko, Lexell & Soderberg, 2007). Engstrom and Soderberg (2011) describe close relatives' daily lives as being changed forever and the necessity for relatives to be strong despite perhaps feeling alone in their changed situation. Tennant (2004) reported that family carers of people with ABI had difficulties accepting the life-changing nature of brain injury and the fact that daily life would never be the same as it was before, when the person was healthy and unaffected by a brain injury (Engstrom & Soderberg, 2011). The survey also noted that family members often found it disturbing that their relative's personality had changed, with some family carers describing feeling as if they were living with a different person.

Being provided with information about the consequences of brain injury is something that many family members find useful, and information can help family members to understand what is going on for their loved one and to find ways to support their relative after an ABI (Coco, Tossavainen, Jaaskelainen & Turunen, 2011). However, having this information does not necessarily lessen the impact on family members of their relative's 'hidden disabilities'; the National Service Framework survey (2004) found that many family members struggled to deal with the disabilities that were harder to see, such as cognitive and emotional impairments, despite being given information about these effects, and they also found it hard to convey and explain these hidden difficulties to other people.

The majority of research in the area of relationships after brain injury has utilised heterogeneous samples combining the experiences of the families (usually parents) of people with brain injuries, and the partners of people with brain injuries, without distinguishing between the types of relationships (Blais & Boisvert, 2005). Although this provides the reader with general information about the impact of ABI on relationships, and on those in relationship with the ABI survivor, it does not consider the many qualitative differences that there may be between types of relationships.

In fact, it has been found that ABI has a differential impact on parents and partners, with most research in this area suggesting that ABI has a more negative impact on partners than parents (e.g., Gervasio & Kreutzer, 1997; Kreutzer, Gervasio & Camplair, 1992; Florian, Katz & Lahav, 1989). The nature of partner relationships is usually very different from relationships between parents and children *prior* to an injury, therefore the impact of a brain injury will be experienced differently by people in different relationships with the injured person. For example, partners might experience role changes within their relationship, a loss of companionship and emotional support, and a loss of sexual intimacy and empathic communication with their partner (Blais & Boisvert, 2005). In contrast, parents of a person who has an ABI may be more familiar with the caring role they may be required to take on, and so the nature of their relationship loss may be different (Gervasio & Kreutzer, 1997). Bowen, Hall, Newby, Walsh, Weatherhead and Yeates (2009) have suggested that parents of adults with brain injuries tend to adopt a nurturing and protective role more easily as it is more natural for them, but for spouses this is a relatively new role to have to take on (Gan, Campbell, Gemeinhardt & McFadden, 2006).

1.4.4 Gender differences in coping and adjustment

It has been suggested that men and women may show differences in the coping strategies that they adopt in response to a partner or family member's ABI, for example women have described support groups as helpful, whereas men tend to use individual coping strategies such as suppressing their feelings (Willer, Allen, Liss & Zicht, 1991). In addition, Willer et al. (1991) found that non-injured husbands tended to cope by maintaining a sense of humour, encouraging their injured wives to attend support groups, and defining new roles for themselves and their wives, and non-injured wives found it helpful to become more assertive, to participate in support groups, to encourage their injured husbands to be more independent, to develop a realistic outlook on their situation, and to keep aside some personal time alone. Sander (2005) has also suggested that male and female relatives of people with brain injury tend to employ different coping styles.

More generally, empirical literature with regard to family members taking on carer roles has shown gender differences in how men and women caregivers cope with

new challenges that are related to ill-health and long-term conditions in their relatives (e.g. Yee & Schulz, 2000). It has also been suggested that men find it more difficult than women to ask for psychological help (Perlick & Manning, 2007).

Gender differences have not only been suggested in the ways that relatives cope, but also in the distress experienced by relatives and their adjustment to the changes that have come about as a result of their loved one's brain injury. Overall, the literature suggests that men whose family members or partners have an ABI may experience more distress and find it more difficult to adjust. For example, male partners of women with TBI may be more distressed than females whose husbands have a TBI, with men showing higher elevations on the Brief Symptom Inventory Global Severity Index than women (Gervasio & Kreutzer, 1997). Alexander and Wilz (2010) have suggested that following a stroke, non-injured female partners adjust better to emotional and cognitive changes in their partners than did non-injured male partners. These authors also postulated that the mental and physical distress experienced by non-injured male partners is more closely related to the stroke-related changes in their female partner than vice versa; this could suggest that men find it more difficult to adjust and adapt to changes in their wives than women in similar situations.

More general literature related to gender roles points to differences in the ways that girls and boys are socialised during their upbringing (e.g. Wooley, 1991; Dornes, 2006). Alexander and Wilz (2010) have drawn upon this psychosocial literature to try to explain the gender-related adjustment differences they found in their study. For example, traditional social norms encourage us to bring up our children in certain ways, so girls are encouraged to pay more attention to other people's feelings and to meet other's emotional needs, hence adult women may be more 'used' to noticing others' feelings and finding ways to respond to them. Boys are less socialised to notice and attend to emotions. Alexander and Wilz (2010) suggest that female non-injured partners of men with stroke may be more flexible than male non-injured partners in managing the emotional and cognitive changes in their partner.

Conversely, it has been estimated that the likelihood of a marriage becoming unstable or breaking down is greater for males with TBI than for females with TBI (Arango-Lasprilla, Ketchum, Dezfulian, Kreutzer, O'Neil-Pirozzi, Hammond & Jha, 2008), which could suggest that non-injured men are more likely than non-injured women to try to adjust to changes and try to keep a marriage going after their spouse has had an ABI. In addition, Linn, Allen and Willer (1994) have reported that anxiety levels were higher in female spouses of men with brain injuries than in the reverse. This could reflect that the 'actual' burden on female spouses is greater than the burden on male spouses, with women taking on more of the caring roles, or it could be that women's *perception* of the burden is greater. Furthermore, in general, women may be socialised into responding to change and stress in an anxious way, or it may be seen as more socially acceptable for women to display and report anxiety than for men. Alternatively, Arango-Lasprilla et al.'s (2008) findings, and Linn et al.'s (1994) results could indicate that the burden and stress on male and female non-injured partners is similar, but that women are more likely than men to openly acknowledge their distress.

Social gender norms and expectations appear to have a role in shaping the experience of non-injured family members. For example, Gill, Sander, Robbins, Mazzei and Struchen (2011) found that male partners of women with TBI felt inadequate if they could not fix all of their partner's difficulties and problems, and were reluctant to ask for any outside help. Female partners of men with TBI found it harder to adjust to any new roles and responsibilities that they considered to be 'men's work'. Jones and Curtin (2011) found that if non-injured men had been involved in some domestic and caring (perhaps more traditionally 'female') roles prior to their partner's brain injury, they were less likely to have difficulties in adjusting to taking up these roles on a more regular, or full-time basis. It seems that the more strongly that socially endorsed gender roles were adhered to within a family prior to a brain injury, the more difficult it is for family members to adjust to and take on new roles that are outside of their gender's remit.

Overall, existing literature related to family members supporting a relative post-ABI (or during another illness or long-term condition) points to several possible differences in the ways in which the genders cope with and adjust to changes in

their circumstances. For example, within the literature, men tend to suppress their feelings and find it hard to ask for psychological help, and women tend to talk about their feelings in forums such as support groups, and more openly acknowledge or report psychological distress. How 'well' someone is able to cope and adjust also seems to have an impact on the level of distress reported by the non-injured family members.

1.4.5 Impact of ABI on partners

The focus of this literature review now moves to the impact and experience of ABI on partners. Some of the studies reviewed have looked only at marital relationships whereas others have included the experiences of unmarried couples. The current study is concerned only with heterosexual relationships and will use the terms 'male partner' or 'female partner' to encompass the spectrum of marital and non-marital relationships. Gervasio and Kreutzer (1997) have found that partners experience more difficulties in adjusting to their loved one's brain injury than any other relatives, and suggest that researchers and clinicians dedicate increased attention to the psychological needs and 'symptoms' of partners. Anderson, Parmenter and Mok (2002) also note that psychological distress in partner-caregivers is a worthy area of investigation in its own right.

1.4.5.1 Relationship breakdown

Many existing studies highlight the increased risks of relationship breakdown following an ABI in one of the partners (e.g. Oddy, Humphrey & Uttley, 1978; Anderson-Parente, DeCesare, & Parente, 1990). Wood and Yurdakul (1997) found that within a sample of 131 couples, only 42% of couples were able to sustain their relationships longer than five years after one partner's brain injury. It has been suggested that relationships are more likely to last for couples who marry post-brain injury, in older couples who have been together for a longer period of time, or in couples where the injured partner has suffered milder brain injuries with less accompanying complications or trauma (Charles, Butera-Prinzi and Perlesz, 2007). There is less research which explores the experiences of couples who stay together.

1.4.5.2 Relationship changes

Of those couples who do stay together, research has tended to focus upon problems and difficulties rather than any positive changes or experiences which have come about as a result of one partner's brain injury or positive aspects of caring for a partner (Harris, Godfrey, Partridge and Knight, 2001). This likely reflects the huge changes that couples undergo after a brain injury, and this cannot be underestimated or down-played. However, the current research will also be looking for exceptions to the problem-saturated narratives about experiences of relationship changes. Braine (2011) has noted that the nature of caring for a partner with a brain injury needs to be viewed as a whole experience with the potential for growth, learning, and positive changes, rather than viewed purely as having negative aspects.

Yeates (2011) has likened the acute and post-acute changes in one partner as a result of brain injury to a 'landmine' within the couple's relationship. Such a life-changing event can shatter what were well-established identities and roles within the relationship pre-brain injury, leaving both partners experiencing difficulties. In the non-injured partner, such difficulties might include reduced marital and sexual satisfaction as compared with before the injury (Gosling & Oddy, 1999), feeling more depressed and generally less happy with life compared to a control group matched for age, sex and social class (Carwath & Johnson, 1987). Non-injured partners may experience loss of intimacy and loss of a mutually supportive partnership (Coombs, 2007), and thoughts about separation or divorce (Chwalisz & Stark-Wroblewski, 1996). Some 'direct' ABI sequelae such as difficulties with 'theory of mind' or perspective-taking (Havet-Tomassin, Allain, Etcharry-Bouyx & Le Gall, 2006) may be interpreted or experienced as a lack of empathy or sensitivity within a couple relationship (Bowen et al., 2009). Similarly, deficits in selective emotion recognition as a result of an ABI (Goldman & Sripada, 2005) could be experienced within a couple as a lack of attunement, which could lead to the breakdown of intimacy and connectedness within a relationship (Yeates, 2011).

Conversely, it has been suggested that a non-injured partner is more likely to positively adjust to relationship changes and experience higher relationship

satisfaction if they adopt an effective attitude towards problem-solving, do not make use of avoidance coping strategies, and if they perceive their partner to have communication skills (Blais & Boisvert, 2007). In terms of sexual relationships, Kreutzer, Dahlf, Gudjonsson, Sullivan and Siosteen (1998) found that physical independence and maintained sexual ability in the partner with ABI were good predictors of a couple's ability to adjust to changes in their sexual relationship post-ABI.

The two studies briefly outlined in the paragraph above suggest that there may be specific qualities about each of the partners in a couple relationship that contribute to either 'good' adjustment or maladjustment to ABI-related changes. Given this suggestion, it would be reasonable to expect that the more severe an ABI, the more distress the non-injured partner would experience, and the more difficult it would be to adjust. However, the literature presents conflicting findings. Peters, Stambrook, Moore and Essex (1990) found that the greater the severity of a TBI, the poorer the relationship adjustment and greater distress experienced in the non-injured partner; similarly, Anderson et al. (2002) found that high levels of social, behavioural and communication problems in partners with ABI resulted in high levels of psychological distress in their non-injured partners. However, Livingston (1987) reported that injury severity was unrelated to relatives' or partners' psychological adjustment.

Additionally, there is some equivocation about whether time post-brain injury influences psychological adjustment and distress in non-injured partners. Some studies suggest that stress and burden in partners do not reduce over time (Tate & Broe, 1999), and that the burden on the non-injured partner only becomes apparent several years after a brain injury (Buchanan, 1992), whereas other research indicates that adjustment improves with time post-ABI (Sander, High, Hannay & Sherer, 1997).

1.4.5.3 Responsibility and social isolation

Partners whose loved one has an ABI may experience increased pressure and responsibilities within the relationship, often taking up new roles, including the role of carer for their injured partner. Zeigler (1987) describes the changes that

go on within a couple as 'dramatic', noting that the non-injured partner may have to take on sole responsibility for many daily tasks that might previously have been shared between the couple. Zeigler suggests that shared decision making may not always be possible when one partner has an ABI, and that the non-injured partner may have to regularly encourage and prompt their partner to do things, which can be emotionally and physically draining.

Following an ABI, both members of the couple may become progressively more socially isolated over time (e.g. Elass & Kinsella, 1987) which could be particularly difficult for the non-injured partner who may experience others as unsupportive or not understanding (Chwalisz & Stark-Wroblewski, 1996). Florian, Katz and Lahaz (1989) found that for many couples, the non-injured partner may be left to cope with any difficulties or changes on their own as family and friends often slowly withdraw their contact and support over time.

1.4.5.4 Experience of loss

Within the existing literature, a particularly prevalent theme is that of loss. Many non-injured partners have described their relationship as having changed in a disturbing way (Gosling & Oddy, 1999), and report feeling that their injured partner had changed in many profound ways (Gill, Sander, Robbins, Mezzei & Struchen, 2011). With these profound changes, non-injured partners may feel as if they are married to a stranger or a 'monster' (e.g. Zeigler, 1987; Wood, 2005). Many partners have reported feeling as if they are "married but don't really have a [spouse]" (Mauss-Clum & Ryan, 1981, p168) and perceiving their injured partner as no longer being the person they married (Eames & Wood, 1989).

From both anecdotal descriptions and within published research, there is an overwhelming sense of couples feeling disconnected from each other as a result of an ABI, often with the non-injured partner experiencing the disconnection most strongly. Gill et al. (2011) found that partners can be left feeling devastated by the experience of disconnection because they have lost the partner who they once shared everything with, and may feel like they want to withdraw from the relationship. Most of the existing literature describes changes within the person with ABI and how these changes are perceived and experienced by the non-

injured partner, but a few authors have started to consider the changes that occur within both members of the couple. For example, Yeates (2011) considers that after an ABI, both partners change dramatically, and aspects of the partnership may even be lost. The neurological changes in the injured partner's brain are experienced in a private, unique way by their non-injured partner, often in a way that others seem to be unable to understand, or in ways that only make sense to the partners within that couple. Feigelson (1993) has suggested that noticing and experiencing significant changes in the injured partner's personality or character may bring up particular anxieties and lead to a fragmented or disturbed sense of self for the non-injured partner.

The nature of the losses that may come about as a result of an ABI are generally not socially recognised. For someone whose partner has an ABI, experiencing a profound loss but feeling unable to publicly mourn or acknowledge this loss can lead to what Doka (1989) has termed 'disenfranchised grief'. Social customs generally only allow us to mourn the loss of a loved one when the body is no longer alive, meaning that partners' grieving in this situation is made socially impermissible (Lezak, 1988). Zeigler (1987) noted the difficulties that partners may have in dealing with the loss of the person they married, or aspects of that person, without death, which for many partners is an ongoing, non-finite experience of loss (Bruce & Scholtz, 2001; Braine, 2011). This ongoing sense of loss means that partners may start to live in a sort of 'social limbo' (Lezak, 1988), feeling unable to participate in couple-orientated activities with their injured partner, but also feeling tied to their partner and unable or not permitted to find another relationship.

1.4.5.5 Feelings of guilt and obligation

The previous section has touched upon some of the feelings of guilt and obligation that partners may feel in terms of staying in a relationship with their injured partner. Lezak (1988) has highlighted the moral dilemmas that non-injured partners might experience, feeling as if they could not separate from their partner without feeling guilty, responsible for their partner's care or wellbeing, and afraid of what others and society might think of them. Many partners may feel anxious or guilty about what might happen to their injured partner in the future if they

leave them (Zeigler, 1987; Jacobs, 1989). Porter (1994) notes the influence of marital vows for some couples, with non-injured partners feeling obligated to stay with their partner 'for better or worse'. These feelings combined with their memories of the relationship prior to the ABI, likely contribute to many partners feeling obligated to stay in the relationship.

1.5 Summary and gaps in the literature

As stated previously, ABI affects not only the injured person, but also the system of people in relationship with that person. Any 'individual' difficulties that the injured person experiences as a result of the brain injury (such as cognitive, emotional, behavioural and physically brain injury sequelae) will also affect the people around them. People of particular significance within a family system are likely to be partners and parents.

Existing research highlights the potential impact of brain injury on the mental wellbeing, coping and adjustment of family members. Much of the research has looked at the experiences of family members together, without considering the qualitative differences between the nature of each type of relationship. It has been suggested that ABI may have a more negative impact on partners than on parents of people with ABI (e.g. Gervasio & Kreutzer, 1997). This could be because partners often have to make a larger adjustment and take on very different roles within the relationship with their injured partner, whereas for parents their change in role may be more minimal, and they may be more familiar with the caring and protective roles they need to adopt (e.g. Bowen et al., 2009). Blais and Boisvert (2005) recommended that future studies should focus on either partners' or parents' experiences, rather than continuing to conduct studies employing heterogeneous samples.

Shifting the focus towards the experiences within couple relationships after ABI, it is interesting to note that many studies report an increased risk of relationship breakdown after ABI (e.g. Anderson-Parente et al., 1990). This finding leads one to consider those couples who do stay together after a brain injury; what might it be like for them, and what might it be about those couples that helps them to stay

together? Much existing research focuses on the wide-ranging and numerous difficulties that couples might experience if they do stay together. For example, partners of people with ABI may experience significant changes in their relationship and to their roles within the relationship, feelings of loss and disenfranchised grief (e.g. Yeates, 2011; Doka, 1989; Lezak, 1988), social isolation (Florian et al., 1989), feelings of responsibility for their injured partner (Zeigler, 1987) and feelings of guilt and obligation to stay in the relationship (Lezak, 1988). Braine (2011) notes the particularly negative focus of existing research and suggests that the experience of being in a relationship with a person with ABI should be viewed in a more rounded way.

Within the general psychosocial literature, it has been suggested that there are gender differences in the ways in which people cope with the impact of family illness and disability, and this applies to coping with the effects of brain injury. This suggests that it could be useful to examine and explore the experiences of different genders separately, rather than conducting research with men and women together.

Of those studies which do look at the experiences of one gender specifically, their uninjured participants have usually been women. It could be hypothesised that, because overall men seem to be more likely to acquire brain injuries (e.g. Headway, 2012c), there are less female brain injury survivors around, and therefore less male non-injured partners to take part in research. Several authors have pointed out this gap in the literature; for example, Braine (2011) acknowledges that her research sample was composed of female carers for men with brain injury, and considers that her findings may have been different among males, such as fathers or male partners. Similarly, Bowen, Yeates and Palmer (2010), following an extensive review of the literature, conclude that most research focusing on partners' experiences after brain injury has been conducted with women, and that there is a need for more research that explores male partner experiences. Bell and Pepping (2001) also state that women with brain injury are inadequately represented in the literature. Within my own literature review, I noted that much of the early research (e.g. in the 1980s and early 1990s) refers only to the wives of brain injured men, and seems to make the

assumption that female partners are the only people affected by brain injury in their partners, and therefore the only participants to be recruited and studied. Little attention has been paid to the experiences of male partners (e.g. Perlesz, Kinsella & Crowe, 1999).

1.6 Rationale and aims for this study

Although the existing literature presents some interesting and important findings, there is a significant gap in the knowledge of the experiences of male partners. Gill et al. (2011) have acknowledged that less attention has been given to exploring intimate interpersonal relationships after brain injury, and have recommended that future research exploring intimacy and relationships after brain injury may benefit from targeted sampling, such as looking at the experiences of a specific gender. Given that it has been suggested that partners are more negatively affected by their loved one's brain injury than parents, and that different coping strategies may be used by men and women, it is important that the experiences of male partners are explored in more detail.

The aim of the current study is to add to the current research literature relating to the experiences of men whose female partners have acquired a brain injury. In particular this study is concerned with the process of adjustment to relationship changes experienced by men in the aftermath of their partner's brain injury. More specifically, the research aims to:

- Explore men's experiences of changes in the intimate couple relationship following their female partner's ABI.
- Gain an understanding of how men have adjusted to relationship changes, and what factors they describe as important in helping them to adjust.

The study will be using a qualitative approach to explore the often unheard or unacknowledged experiences of being a man whose female partner has an ABI. Generally, it has been suggested that using qualitative methodology can enhance the relevance of psychological knowledge (e.g. Denzin & Lincoln, 1994; Harmon, 1982), and that qualitative interviewing allows for data collection that paints a

broad description of complex situations (Patton, 2002). More specifically, Chwalisz and Stark-Wroblewski (1996) have recommended that qualitative methods should be used in future research about the experiences of partners of people with brain injuries, and in particular they suggest using interviews to capture more detailed information. It is hoped that by employing a qualitative methodology involving individual interviews with men, I will come to a greater understanding of the experiences and adjustment for men who share the experiences of their partner suffering an ABI during the course of their relationship.

Having a greater understanding of what is important in helping men to adjust to relationship changes may help to build further research in this area. The current study aims to produce findings that will be of clinical use to professionals who are working with couples in brain injury services. This is particularly important since previous research has suggested an increased risk of relationship breakdown in couples following ABI, and negative experiences such as relationship dissatisfaction, and experiences of loss and isolation for couples who do stay together post-ABI.

1.7 Research question

Given the background of this study and its aims, the main research question was framed as:

- **What are the experiences of adjustment to relationship changes in men whose female partners have an acquired brain injury?**

In addition to this overarching question, additional areas to be clarified and explored included:

- What changes in their relationship with their partner have men experienced since their partner's ABI?
- How have men adjusted to these relationship changes?

2. METHODOLOGY

2.1 Qualitative design

This study utilised a cross-sectional qualitative research design. As stated in the introductory chapter, there has been little research exploring the experiences of men whose female partners have sustained an ABI. Given that little is known about men's experiences, the current study is positioned as exploratory in nature and as a possible prelude to future research that may focus on specific aspects of men's experiences. Barker, Pistrang and Elliott (2002) suggest that qualitative methodology can facilitate in-depth study of personal experiences and is well suited to exploratory research. It was considered appropriate to use semi-structured interviews to explore those issues of significance and interest that are raised by participants, indeed, Smith, Flowers and Larkin (2009) suggest that the flexibility of semi-structured interview approaches tends to yield rich data.

2.2 Thematic Analysis

Thematic analysis was my chosen methodology, which is a way of identifying, analysing and reporting themes within data, and can provide a rich and detailed account of research data (Braun & Clarke, 2006). Thematic analysis is said to offer an accessible and flexible form of analysis and is not strongly associated with any particular theoretical orientation. This fits well with the current research which is concerned with exploring the experiences of participants and the issues that they consider to be salient, rather than developing a theoretical model, such as might be the aim with an alternative approach like Grounded Theory.

The current study is concerned with acknowledging the ways that men whose female partners have had a brain injury make sense of their experiences of changes in their relationships. At the same time, I see it as important to situate men's experiences within a social context, and to reflect upon how broader contextual factors impact upon the way men make meaning of their experience. This standpoint could be described as a 'critical realist' epistemology (Willig, 1999). Thematic analysis is compatible with both realist and constructionist epistemologies, as well as those epistemologies which sit between the two, such as critical realism. Harper (2011) describes critical realist researchers as having

an awareness of the importance of studying qualitative data in detail, as well as considering it important to go beyond the text and set participants' responses to research questions in a broader historical, cultural and social context.

Braun and Clarke (2006) consider it essential as a researcher to decide on what type of analysis you wish to conduct, and what types of claims you wish to make on the basis of your data. Analysis could be concerned with providing a rich thematic description of the entire data set, which may be useful if investigating an under-researched area, or if you are interviewing participants whose views on the topic are not known. Alternatively, analysis could focus upon one particular theme within the data, and might relate to a pre-determined research question and the researcher's particular interests. The current research is interested in what relationship changes men have experienced after their female partner's brain injury *in general*, and *more specifically* is interested in how men have adjusted to relationship changes. In order to address these research concerns, thematic analysis will be both inductive *and* theoretical, that is, both data-driven (looking at what themes arise when men talk about their experiences more generally) and analyst-driven (when looking for themes which map onto the research question concerned with adjustment).

In summary, given that thematic analysis provides a flexible approach to data analysis that is compatible with many different theoretical orientations, the current research will utilise this methodology to search across several interviews to find themes or repeated patterns of meaning.

2.3 Participants

2.3.1 Recruitment

It is appropriate to use a small number of participants when employing a qualitative approach (Silverman, 1997) as interviews usually generate a large quantity of verbal data which then requires detailed analysis (LoBiondo-Wood & Haber, 2002). By collecting extensive data from each individual participant, the researcher is able to examine meanings and experiences, and to gain an

“insider’s” perspective (Smith, Flowers & Osborn, 1997). Participants were recruited within the context of a specified research timetable, so it was important to collect a manageable amount of sufficiently rich data. For these reasons, this study aimed to recruit between 8 and 12 participants.

Purposeful sampling was necessitated by the requirement for a small number of participants who have had experiences of a similar life event (Mays & Pope, 1995). In order to do this, the researcher contacted several TBI family and carer support group co-ordinators within the UK, by email and by phone, to provide information about the study, and were asked to attend support groups wherever possible. At this stage, the research was concerned with the experiences of men whose female partners had sustained a *TBI*, but I was informed by many of the support group co-ordinators that they did not have contact with many men who fitted this description. It was then decided that the criteria should be extended to include *ABI*, and I contacted several other ABI family and carer support group co-ordinators as well as other relevant organisations.

In addition to contacting the TBI and ABI organisations, I also emailed colleagues who worked in the field, asking if they had any contact with men who met the research criteria through private or other non-NHS work. The study was also advertised through social networking sites including Facebook and Twitter.

Later in the recruitment process, I decided to also apply for NHS ethical approval as contact had been made with colleagues who said they knew of men who fitted the research criteria, but through their work in the NHS. As recruitment had been slower than hoped, it seemed sensible to make this application and once ethical approval had been granted (and the research had been registered with the relevant Research and Development departments), I followed up these links.

The exact recruitment process was slightly different for each participant, but in general, organisations and professionals provided potential participants with my contact details, or offered to contact potential participants on my behalf. I also attended some TBI and ABI family and carer support groups to provide general information about the research to members of the group, who were either

potential participants, or who knew of people who might be interested in taking part. Potential participants were contacted either by phone or by email, and were given an information sheet (Appendix 1), as well as the opportunity to ask any questions about the research. Participants who continued to express an interest were contacted again by myself and screened according to the inclusion and exclusion criteria (see sections below). If it was appropriate to do so, an interview was arranged in a mutually agreed location in which participants felt comfortable, such as their own home, or a local brain injury service. All participants were required to give their informed, written consent prior to commencement of each interview (see Appendix 2 for consent form).

2.3.2 Inclusion criteria

The recruitment process aimed for a reasonably homogenous group of participants, however there were of course some differences between participants in terms of their individual situations. Although the findings will be considered in relation to any differences between participants, it is thought that many of the types of experiences described by the men in this study will also be shared by other men in similar situations. The study initially aimed to recruit men whose female partners had sustained a traumatic brain injury (TBI). However, due to the recruitment challenges described above, the inclusion criteria were later extended to include men whose female partners had experienced an acquired brain injury (ABI), which includes stroke, anoxic/hypoxic brain injury, brain haemorrhage, aneurysm, encephalitis, and brain tumour.

This study required that participants were in a relationship with their female partner at the time of the ABI, and should still be in that relationship at the time of participation in the research. Research suggests that carer burden and changes in couple relationships may not be fully apparent until 3-12 months post brain injury (Brooks, Campsie, Symington et al., 1986) hence this study recruited participants whose female partner sustained a brain injury at least 12 months ago.

Recruitment focused on men who were aged between 18 years and 65 years at the time of their female partner's brain injury, reflecting the state pension age in the UK, and to cover a significant proportion of the adult life span.

2.3.3 Exclusion criteria

Given the above inclusion criteria, men whose female partners had sustained a brain injury in the last 12 months were excluded from the study. Men who were outside of the specified age range at the time of their partner's brain injury were also excluded (i.e. under 18 years, or above 65 years).

2.3.4 The sample

Participants comprised of eight men, ranging from age 32 to 66 years. See Table 1 for more detailed demographic information.

Participants *	Participant age & ethnicity	Partner age & ethnicity	Duration of relationship	Description of partner's brain injury	Time since injury
Participant 1 ('Tom')	55 White South African	54 White South African	25 years	Subarachnoid haemorrhage	4 yrs 7 months
Participant 2 ('Desmond')	45 White British	38 White British	5 years	Stroke	2 yrs 4 months
Participant 3 ('Daniel')	55 White British	45 White British	5 years	Traumatic brain injury	1 yr 10 months
Participant 4 ('Jim')	32 White British	33 White British	10 years	Encephalitis	5 yrs 9 months
Participant 5 ('Charles')	66 White British	64 White British	45 years	Cardiac arrest → hypoxic brain injury	9 yrs
Participant 6 ('Ivan')	48 White British	44 White British	18 years	Brain tumour → stroke	1 yr 2 months
Participant 7 ('Darren')	62 White British	64 White British	42 years	Traumatic brain injury	2 yrs
Participant 8 ('Peter')	60 White British	49 White British	27 years	Subarachnoid haemorrhage	13 years

Table 1. Demographic profile of participants and their partners

* All names of participants have been replaced with pseudonyms to retain anonymity

2.4 Ethical issues

2.4.1 Ethical considerations

Ethical approval for the research was granted by the University of East London Ethics Committee (see Appendix 3) and a London-based NRES Committee (see Appendix 4).

2.4.2 Informed consent

Participants were given an information sheet (Appendix 1) detailing the aim and purpose of the research. This included participation requirements, confidentiality, and the right to withdraw from the study at any time without their treatment being affected. I also talked through the information sheet and gave participants the opportunity to ask any questions prior to commencement of each interview. Each participant signed a written consent form which was also signed by the researcher (Appendix 2).

2.4.3 Confidentiality

Participants were informed by myself and in the information sheet about confidentiality and its limits (Appendix 1). Any identifying information was removed from research report, with participants' names replaced by pseudonyms. Each participant was also assigned a code to facilitate the storage and organisation of participant material post-interview. These codes and completed consent forms were kept securely at my home address, separately from audio-recordings, transcribed data and demographic details which were also kept at the researcher's home address. I was responsible for all transcription of the audio-recorded data, with only myself, my academic supervisors and examiners having access to the transcribed data.

I informed participants that audio-recordings would be destroyed after examination of the doctorate research has been completed and that anonymised data would be kept for three years after research submission for the purpose of publication, after which it would be destroyed.

2.4.4 Potential distress

Given the subject area being discussed during research interviews, there was a possibility that participants might become emotionally distressed when talking about their experiences since their partners' brain injury. Participants were assured, both verbally by myself and in the information sheet (see Appendix 1) that they could stop the interview at any time, and could withdraw from the research at any time. Participants were also offered breaks and if it was deemed necessary and appropriate, offered contact details for suitable supportive organisations. It was hoped that these practices would reduce the likelihood of participants experiencing distress during interviews. Nonetheless, some research participants have described the process of reflecting on their experiences as therapeutic (Birch & Miller, 2000), and it was hoped that this may be the case for the participants in this study.

2.5 Data collection

2.5.1 Interviews

In order to capture the men's personal experiences of changes in their relationships, interviews were conducted using a semi-structured narrative interview schedule (Appendix 5). Given the open, exploratory nature of the research, it was decided that interviews should also be very open and exploratory, so the interview schedule was based on Wengraf's (2001) ideas about 'biographic narrative' interviewing. Wengraf has described a design which starts from a single initial narrative question, which has a particular focus, such as part of an individual's life story. This fitted well with the current research as it has a particular focus on men's life stories since their female partner's brain injury.

Prior to developing an interview schedule, I considered broad areas of interest, shown in Table 2.

What changes in their relationship with their partner have men experienced since their partner's brain injury

How men have adjusted to these changes in their relationship with their partner

What ideas men have about what 'good adjustment' is

What men think has been important and helpful in contributing to their adjustment to these relationship changes

Table 2. General areas for consideration during the interview process.

In order to gather demographic data, I also needed to ask participants some background information about their partner's brain injury, how long it had been since their partner's brain injury, and the overall duration of their relationship as a couple.

The first part of a narrative interviewing design begins with the researcher asking a 'single question aimed at inducing narrative', with the researcher noting down topics that the narration is about. This continues until the participant indicates that they have no more to say. There is then a short break where the researcher reviews their notes and prepares additional questions to find out more about the topics which were raised in the first part of the interview. The researcher follows the order in which the topics were raised by the participant, and uses the words that were used by the participant. Wengraf terms these questions 'topic questions aimed at inducing narrative'.

I held in mind the above areas of interest during the interview process (shown in Table 2), and this likely influenced and biased which topic areas I considered to

be significant, and therefore, which topics I privileged by asking more about using 'topic questions aimed at inducing narrative'. This bias will be further discussed in the reflexivity section of this chapter.

As previously described, the location of the research interviews were mutually agreed between myself and each participant. Six participants chose to be interviewed in their own homes, and two participants chosen to be interviewed in private rooms at their places of work. Interviews lasted between 30 and 90 minutes, and were audio-recorded using a digital recorder. Interviews were then transcribed by myself, with all identifying information removed or replaced with pseudonyms.

Immediately after each interview, participants were offered the opportunity to reflect on their experience of participating in the interview, as well as debriefing about the research and the opportunity to ask me any additional questions. On completion of the study, participants were also offered feedback on the overall research findings, either verbally or in writing.

2.6 Data analysis

Data from the interviews was analysed using thematic analysis (as described by Braun & Clarke, 2006). This was a recursive process, which involved looking for patterns of meaning within each interview, and then moving back and forth between the interviews to identify which of those patterns occur repeatedly across the data set.

The process of data analysis began with the listening to and transcribing of each audio-recorded interview. During transcription, I began to listen out for and note down ideas and topics that were of interest and that seemed to occur in many of the interviews. The interviews were transcribed in the order in which the interviews took place, i.e., starting with participant one working through to participant eight.

Following transcription, I read through all eight transcripts to further familiarise myself with the data, making notes on the right hand side of the transcripts to document my initial thoughts and ideas. It should be noted that this initial process started with the reading of the transcript for participant one, but then did not follow in numerical order. I then chose to move onto reading the transcript for participant four as this appeared to be a richer set of data, before moving back to reading the transcripts in numerical order. Although I made conscious efforts not to be too rigid in my thinking and to read each transcript with 'fresh eyes', it should be acknowledged that my prior ideas about the topic, as well as the reading order, probably did shape the ideas that most caught my interest and were privileged during the analysis process.

The transcripts and initial notes were then re-read and I used the left hand side of the transcripts to note down codes. For an example of an annotated transcript see Appendix 6. This involved a process of constant comparison between transcripts, resulting in a long list of codes being produced (Appendix 7). The next stage involved making connections between the codes, and grouping them together to form more general, overarching themes. In order to do this, the codes were printed onto pieces of paper and then moved around and organised into 'theme-piles' (e.g. Braun & Clarke, 2006). By the end of this process, I had collated a collection of themes, each comprised of several sub-themes, but I took care not to discard any of my initial codes at this stage (see Appendix 8 for initial table of themes and sub-themes).

As recommended by Braun and Clarke (2006), this collection of themes and sub-themes was refined by collating the data extracts within their corresponding themes to assess the level of 'fit'. I considered Patton's (1990) criteria for refining thematic categories, that is, whether the data extracts fitted together in a meaningful pattern within a theme, and whether there were sufficient differences between themes. Following consultation and discussion with my supervisor, I produced definitions and descriptions of what each theme and sub-theme was capturing. This enabled me to further refine my themes, as I considered the most important aspects of each theme, and also helped with the process of giving my

themes clear and concise names. For an example of these final stages of the analytic process see Appendix 9.

2.7. Reflexivity of the researcher

Reflexivity is the process of attending to the influence of the researcher upon the whole research process. Malterud (2001, p.483-484) states that:

“a researcher’s background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions”.

A researcher’s background and position include their professional, personal, political and cultural values, beliefs and assumptions. Within the introductory chapter, I have briefly described how I came to do this research, and here I will further elaborate upon my own assumptions and experiences for the purposes of reflection.

I am a 27 year old White British female who is undertaking this research for the purposes of the doctorate programme in clinical psychology. As a trainee at the University of East London, I have engaged with teaching that comes from a social constructionist perspective, and within the programme there is an emphasis on systemic and narrative psychological approaches, rather than upon individualistic approaches. Being in this teaching environment has had an influence upon my own values and assumptions, and I have reflected upon my own epistemological position throughout training. I identify with ‘light’ social constructionist ideas, wanting to validate and acknowledge the reality of individuals’ experiences, but also acknowledging how social context shapes the way individuals’ experiences are constructed. One way of framing this epistemological standpoint is as ‘critical realist’.

Prior to clinical training I had experience of working with people with brain injuries and their families in support worker and assistant psychologist capacities. These

experiences influenced my assumptions about the effects of brain injury on an individual and on those in relationship with that individual. Through these posts I developed working relationships with several other professionals, and the most memorable relationships were with clinical psychologists who viewed relational aspects of neuro-rehabilitation as important. Maintaining these relationships and continuing to have conversations about relational approaches to rehabilitation influenced my choice of research topic. These conversations led me to formulate my own areas of interest (shown in Table 2), and I think it is important to be transparent about my own interests, as this certainly would have influenced those follow-up questions, or 'topic questions aimed at inducing narrative' that I asked the participants. During the research process I kept a research journal to record and reflect upon my own views about, and influence upon, the data collection and analysis. I used these reflections during the process of analysis, particularly when making notes during my reading of the transcripts, and when noting down initial ideas and codes.

3. RESULTS

This chapter will present the findings of my thematic analysis of the experience of adjustment to relationship changes in men whose female partners have an acquired brain injury (ABI). I aim to provide a rich account of men's experiences, illustrating the issues that seem to be the most salient for this particular group of men. Five themes form the basis of this chapter:

- 1. Initial reactions to the brain injury**
- 2. "She's a lot the same, but she's not the same"**
- 3. Relationship changing**
- 4. Responsibilities and burden**
- 5. Coping and support**

I have presented verbatim quotes from the participants to illustrate aspects of each theme and sub-theme, using pseudonyms to retain anonymity. I will provide some indication of which aspects were found to be common across men's accounts, and which aspects were representative of an alternative story, or were more idiosyncratic.

Overall, all the men interviewed were able to give an account of their experiences since their partner's ABI, and most said that they could have talked about the topic for longer if given the opportunity. Participants commented that they had found talking therapeutic in some way, and had enjoyed reflecting on their experiences, for example:

"It's good actually to talk, I was looking forward to you coming, you know"
[Peter, Line 488]

I acknowledge that there are some differences between the lived experiences of the men interviewed and in the extent and nature of their partners' ABIs; however there were themes that were common across the whole dataset.

The order in which the themes are presented reflects the order in which the participants tended to talk about their experiences, perhaps illustrating the

process that they were going through, from a certain start-point, usually just before their partner’s ABI. It seemed that for many men, their process was still continuing, but some talked as if the experience finished at the time of the interview. There was an overall sense that the process these men had gone through, and some felt were still going through, was like a journey. For example, Darren provided a succinct overview of his experiences:

“It’s been a hell of a journey” [Darren, Line 159]

I will now describe and explore the five themes and their associated sub-themes (see Table 3 for overview).

Themes	Sub-themes
1. Initial reactions to the brain injury	1.1 <i>Finding out about the brain injury</i> 1.2 <i>Making sense and finding explanations</i>
2. “She’s a lot the same, but she’s not the same”	2.1 <i>Hidden nature of difficulties</i> 2.2 <i>Changes in character</i>
3. Relationship changing	3.1 <i>Changes in the nature of the relationship</i>
	3.2 <i>Making comparisons to before the ABI</i>
4. Responsibilities and burden	4.1 <i>New responsibilities</i>
	4.2 <i>Isolation and others not understanding</i>
	4.3 <i>Emotional impact of changed situation</i>
5. Coping and support	5.1 <i>Getting on with it</i>
	5.2 <i>Sources of support</i>

Table 3. Table of themes and associated sub-themes

3.1 Initial reactions to the brain injury

All of the participants began their accounts by describing the circumstances in which their partner’s ABI occurred, and the ways in which they tried to make sense of what was happening. They also recounted what it felt like to realise that something was wrong with their partner. There was a sense that the men needed to tell the story of how it all started, to set the context and to ensure that I, as the

researcher, had an understanding of their situation before they could begin to talk about how their relationship with their partner had changed.

This theme is comprised of two sub-themes: 'Finding out about the brain injury', and 'Making sense and finding explanations'.

3.1.1 Finding out about the brain injury

For Ivan, this was a fairly gradual process, with him noticing several signs, symptoms and behaviours, over time, which were out of the ordinary for his partner:

"We first noticed her eyesight was going a bit funny about the turn of the year... then her memory started going a bit funny" [Ivan, Line 19]

In other scenarios, men did not have any indication that anything was wrong until just before the ABI happened, with their partners describing or presenting with signs or symptoms, and then requiring urgent medical attention:

"she was getting on a plane...suffering a migraine, without going into detail, had the migraine and then found out about the subarachnoid haemorrhage" [Tom, Line 19]

"she woke me up and said I don't feel very well, before I got around to the other side of the bed, she was, she lost consciousness and her heart had stopped" [Charles, Line 31]

Desmond talked about knowing something was wrong with his partner, but it being difficult for him to make sense of this as the signs and symptoms he saw in his partner were not the signs that he thought he should be looking out for. He expressed surprise that his partner's situation was not like 'the advert on the telly for stroke':

"she had gone downstairs, she came back upstairs, erm and she just couldn't speak, you know she had none of the, you see the advert on the telly for

stroke, nothing like that whatsoever, there was no sign, but she was laughing, seemed quite normal, quite well happy in a way, just couldn't stop laughing for some reason, but she couldn't say anything else" [Desmond, Line 25]

For Daniel and for Darren, there was no time to notice that something was wrong as their partners suffered TBIs. In these cases, the process of discovering something was wrong was very sudden, with the first sign being a phone-call and then visiting their partner in hospital. Neither of these men initially placed much significance onto this, both believing that their partner would recover quickly, and neither having much prior knowledge about what the impact of a brain injury could be:

"I didn't know at that time that she'd had a brain injury, she was in A and E and she wasn't speaking at all and I didn't for one minute think it was a brain injury"

"I went back to see her the next morning and she'd been moved to the neurological ward, and I thought bloody hell, and erm, so it was all a bit of a shock really" [Daniel, Lines 41 and 46]

"I got the call here...when I got to the hospital and I actually saw her lying there on the bed, erm I didn't think anything of it, but then it became very clear over the next hours, that actually she was quite, very seriously injured" [Darren, Line 30]

3.1.2 Making sense and finding explanations

In response to noticing these signs and symptoms, many men described trying to make sense of what was happening. It is possible that in seeking explanations, the men hoped that their feelings of confusion and experience of uncertainty would be alleviated. Peter and Jim both referred to their initial relief as medical investigations started to take place:

"I said, look, I'm pretty sure that something is really badly wrong here, Anna is behaving bizarrely, could you please look into it urgently. Fortunately the

registrar believed me, and she was put in for an MRI scan almost straight away after that” [Peter, Line 46]

“so she goes to the doctors and they send her to hospital, think it might be meningitis and it’s not, so we’re relieved, then she goes back home” [Jim, Line 7]

In contrast, it took time for Ivan to experience any relief as he needed to repeatedly fight for recognition from professionals that something was wrong with his partner, leaving him feeling frustrated and lacking in satisfactory explanations for some time:

“I kept taking her to the GP and the GP said she’s stressed, so eventually I ended up taking her to a private psychiatrist, had a scan, and discovered she had a rather large tumour in her head, yeah, in fact we had taken her to A and E and they said well she’s stressed, and saw the local mental health people and they said she’s fine” [Ivan, Line 22]

Desmond and Jim referred to their own prior knowledge or experience of ABI to help them try to find an explanation for what was happening to their partner:

“I didn’t know what was wrong with her, she said she had a headache, I just sat her on the bed, erm did a few like basic tests, like put your arms out straight, you know, stand on one leg, the usual, touch your nose, everything seemed normal” [Desmond, Line 31]

“I thought sometimes when you’re feverish, you know, you sort of speak in tongues, and you sort of say funny, funny things” [Jim, Line 12]

3.2 “She’s a lot the same, but she’s not the same”

Throughout their accounts men talked about the changes that had happened in their partner as a result of the ABI. Men typically tended to locate the difficulties within the partner, but also referred to the relational effects of the ABI – these are described in more detail in the next theme (‘Relationship changing’).

This theme is comprised of two sub-themes: 'Hidden nature of difficulties', and 'Change in character'.

3.2. 1 Hidden nature of difficulties

Many men referred to the hidden nature of their partners' disabilities or difficulties resulting from the ABI, such as cognitive impairments or memory problems. Tom and Daniel suggested that other people might not be able to tell that their partner had had a ABI:

"If you met her you would think she was someone who had had a car accident and had broken her legs, and in other words she speaks fine, she laughs, makes jokes, coherent etc etc" [Tom, Line 316]

"I don't think, if you'd met her not knowing, I don't think you would've thought she'd had a brain injury" [Daniel, Line 86]

Jim talked about other people not understanding his partner's difficulties because they are hidden:

"there's a kind of a stigma to it, about having a brain injury, if she bust her leg permanently, she'd always be in a wheelchair, always having her crutches, people would just like see it... because people don't see the brain injury, and her crutches as such are her mobile phone and her notebook, her diary that she always takes with her, they might not appreciate what her problems are" [Jim, Line 372]

Similarly, Desmond felt that others did not understand his partner's difficulties because they are not visible. He made reference to the idea that difficulties resulting from a stroke should be very apparent, and the fact that this was not the case for his partner made it harder to know what was wrong:

"you mention the word 'stroke', the first thing you think of is like you see on the telly, you know, the arm all floppy and everything else, but they see Jane"

and think what's the matter with you, you look absolutely fine, they don't see what's going on inside, you know, they don't seem to understand what's going on inside her head" [Desmond, Line 185]

3.2.2 Changes in character

In addition to men's impressions that other people could not 'see' the changes in their partners, for men themselves there seemed to be a discrepancy between their partner's outward appearance, and their changed or 'new' character or personality:

"she might be physically looking quite similar, but just poles apart from the things you'd normally interacted with" [Charles, Line 259]

Many men's accounts reflected a subtlety in the changes they had noticed and there was a sense that these men found it quite difficult to put these experiences into words in a quantifiable way:

"she's a lot the same, but she's not the same" [Tom, Line 403]

"It really changed who she was, quite fundamentally, but still er, you know, loving and kind person, and she's very attractive, and she's a different person but not different in such a way that, like 'who are you', don't recognise you, it's like, ok you haven't got these characteristics anymore" [Jim, Line 645]

Peter's experience of the changes in his partner were less subtle, and he described it as 'disconcerting' to see his partner's character changing as a result of the ABI:

"it's a completely different kind of character, you know, that had never been there before, from a very shy, almost introverted person to someone who's very out there, and I think probably the most disconcerting thing for me as her partner is, whilst she looks the same, she's a different character"

"so as a partner, it's odd cos sometimes I feel I'm living with a stranger who's becoming stranger" [Peter, Lines 147 and 156]

Desmond and Jim made reference to an exaggeration of some of their partner's previous characteristics since the ABI. These men tended to talk about characteristics which they viewed as problematic in some way, such as being tired, 'paranoid' or late, as described in the examples below:

"since the stroke she's become more paranoid, you know, she was a little bit of a worrier before but now, good god, she worries about anything and everything"

"everything she does now, she used to do before, but greatly exaggerated now since she's had the stroke" [Desmond, Lines 85, and 360]

"she was very tired...I mean she's always been one of those people who likes a lie in and that sort of thing, but it got a bit silly, just feeling really, really tired and washed out and knackered" [Jim, Line 102]

3.3 Relationship changing

When the participants talked about their relationship with their partner since the ABI, it generally seemed to be with a feeling of sadness and a sense of yearning for the relationship they had together in the past. Most men made reference to changes in the overall nature of their relationship and the ways in which they and their partner relate to each other now, as well as general changes in their lifestyle, as compared with before the ABI, for example:

"since then I guess we've had a different life that's for sure" [Charles, Line 81]

This theme is comprised of two sub-themes: 'Changes in the nature of the relationship', and 'Making comparisons to before the ABI'.

3.3.1 Changes in the nature of the relationship

As with the previous theme ("She's a lot the same, but she's not the same"), the aspects of their relationships that were changing were often difficult for the participants to describe clearly, or to quantify. Desmond was the only participant to explicitly name the significantly negative impact of the ABI on his relationship, in terms of pushing him and his partner apart:

“some people that I’ve known in the past, if something major happens within their lives they can say that’s brought them closer together, but personally I think it’s pushed us further apart” [Desmond, Line 133]

The fact that only Desmond voiced this experience could indicate that this was not the case for the other participants, in fact, for Daniel this was certainly true:

“really I haven’t had to adjust very much at all, erm, and I don’t think the brain injury has had that much effect on our relationship” [Daniel, Line 376]

Alternatively, if other men did now experience their relationships in this way, the fact that they did not describe the difficulties in this way could reflect how painful it might be to acknowledge this experience.

The men talked about the absence of or changes in various aspects of their relationships, which seemed to result in a huge sense of loss and mourning for the relationship that was. Some men referred to the absence of adult companionship that they used to get from their relationship with their partner, for example:

“I started to think to myself I could face my life alone” [Darren, Line 90]

“prior to the subarachnoid haemorrhage, I can truly say this was the love of my life, you know, this was something really amazing and special, and our compatibility was 100%, and I miss that” [Peter, Line 201]

The men said that since the ABI they felt that the intellectual connection they once shared with their partner was now no longer there:

“we still certainly don’t relate as we used to and that’s been the biggest loss, erm, ours was quite an intellectual relationship if you understand what I mean” [Tom, Line 130]

“She’ll almost never start a conversation, so very little starting of a conversation, and it can’t last too long before she’s clearly had enough of it,

so it's not developed in the way it would have been, and that's a huge, huge issue" [Charles, Line 325]

Since their partners' brain injuries, the men also described the loss of their sexual relationship. For some men, due to their partner having had a more severe ABI, there was now a complete absence of sexual interaction, such as in Ivan's case, whose partner was being cared for in a residential setting at the time of the interview:

"I suppose going from being a married man to single, celibate has been quite hard at times, erm, I obviously miss that side of it" [Ivan, Line 225]

For Tom, although his partner was now living back at home, the nature and severity of her ABI were such that she now needed to use a wheelchair, and a sexual relationship was no longer possible. He talked about the possibility of having an affair in order to meet his sexual needs, but this was not something that he had seriously considered:

"I talked a bit with the chap at [carer's organisation] and bizarrely the conversation went as far as, well you might need to start, you might need to have a girlfriend and start an affair because you are not going to get adult interaction with her, not of the level you had beforehand, but anyway I mean that hasn't happened and I haven't felt the need for that to happen" [Tom, Line 141]

For other men, such as Peter, since their partner's ABI, they still had sexual contact with their partner, but there had been a change in the nature of their sexual relationship, and a loss of their previous sexual connection:

"It's slightly artificial, it's slightly at arm's length, which is, you know, it's hard to square that one. We still, I mean we still have a good physical relationship, but it's erm, it can seem a little abstract" [Peter, Line 301]

Charles described his concerns about what the loss of his sexual relationship with his partner might mean for their future, and whether or not they would still be classified as 'a couple' if sexual intimacy was no longer a part of their relationship:

"I do find that worrying in some ways because it's one of the things that is different from everybody else, that's what makes you a couple, and I kind of worry for the long-term whether that doesn't cause you to change that kind of relationship" [Charles, Line 267]

3.3.2 Making comparisons to before the brain injury

Men's experiences of aspects of their relationships having changed or now being absent were often manifested in them making frequent comparisons with life before the ABI.

In many men's accounts there were descriptions of not only an absence of certain aspects of their relationships, but also feeling as if the woman they had been in a relationship with before was now absent. This led to men experiencing overwhelming feelings of loss, and the disturbing feeling that they were now in a relationship with somebody different:

"I often feel like I've had my wife stolen from me a lot of the time"

"well it just felt like, erm, well the old Louise has died, I don't think she'll ever be, she'll never be 100%" [Ivan, Lines 92 and 300]

"I think you can't underestimate how hugely different life is, and you really do wake up in the morning and it's not the woman you married" [Charles, Line 257]

"it's a fair sort of thing to say, old Eleanor, new Eleanor, I don't think I see old Eleanor all that much" [Jim, Line 630]

A common theme across the data set was that these were couples who led fairly independent lives, and men viewed this as a strength within their relationship.

Following an ABI, many of the partners had become less independent, resulting in a change in the relationship dynamic:

“before it all happened we’d have, typically we’d have a couple of nights a week where, oh you’re out with the girls, or I’m out with the guys, or you’re out with work, or whatever, but that sort of stopped” [Jim, Line 160]

“we’ve always, you know, in the past had lots of different interests and that was part of the secret of the marriage I suspect, and you know, she’d go off and do her things and I’d go off and do my things” [Charles, Line 341]

When making comparisons between the relationship now and the relationship prior to the ABI, some men expressed a longing or a yearning for things to back the way they were. This was particularly apparent in Jim’s account:

“...we were a very, very equal partnership”

“...her confidence has gone and I realised that I was having to lead and instruct everything”

“I’d rather she was at the front and just going for it and being like she was”

“I preferred it when she was, quite simply, I liked that sort of ballsy-ness, you know, I really admired that”

“I would love to have that challenge again, at times it can get a bit easy for me” [Jim, Lines 176, 191, 293, 498 and 603]

Some men experienced the comparison between the relationship now and the relationship before the ABI as quite painful, finding memories of the past difficult to deal with. Tom and Darren both felt that, due to the severity of their partners’ brain injuries, there was a significant difference between their partner ‘before and after’, likely meaning that drawing comparisons was a more painful experience for them:

“I find it difficult sometimes to look at pictures of her around the home and us together and with the children... things to do with memories, I do find quite difficult” [Darren, Line 155]

*“I will always have the ‘before’ part of the comparison and that doesn’t help”
“actually it’s quite a hindrance to have the ‘old’ kicking around in your head”
[Tom, Lines 793 and 796]*

For other men, remembering the strength of their relationship, and mutual commitments such as family values, prior to the ABI was helpful in keeping them together as a couple now, despite the difficulties they were experiencing:

“I think we had a hugely strong marriage, I think we both have a huge sense of family, and you know, a recognition that the most important thing in our lives are our children” [Charles, Line 555]

“we’re committed to keeping our relationship working and it’s very hard work sometimes, but we do want it to work, partly for our son, but also we had such a lot of investment in that relationship before” [Peter, Line 198]

3.4 Responsibilities and burden

There was an overwhelming sense of men’s new responsibilities and feelings of isolation within all of the participants’ accounts of their experiences, no matter what the nature or severity of their partner’s ABI was, including for those men who described their partners as having made a ‘good recovery’. Men’s accounts seemed to reflect the fact that the effects and impact of ABI are relatively unknown by the general public, and that there is a lack of societal knowledge or understanding of ABI. Living with the after-effects of their partner’s ABI within this context left men feeling isolated and misunderstood, and with a hugely increased sense of responsibility for their partner and her well-being.

This theme is comprised of three sub-themes: ‘New responsibilities’, ‘Isolation and others not understanding’, and ‘Emotional impact’.

3.4.1 New responsibilities

In the early days after their partners’ brain injuries, some men described the initial sense of responsibility that they felt, and pressure at times, to make decisions

about their partner's medical treatment and care. Peter and Jim each described their initial reactions to being asked to make those decisions, with Peter wondering if he was the right person to take on the responsibility, or whether it should have been his partner's mother:

"I had to shoulder a lot of tough decisions, like will you sign the permission for an operation, she may not live, you know, you've got to sign and say it's ok, and they weren't asking her mum that, they were asking me, so there was quite a lot of pressure early on to kind of deal with stuff" [Peter, Line 469]

In Jim's case, he felt that it made sense for him to have been asked to take on the responsibility given the duration of his relationship with his partner, but found it difficult to handle this responsibility:

"sort of straight away it was kind of a, it was responsibility on me, because we'd been together long enough, it was principally on me, trying to just take on all this stuff and not really knowing what, you know, what on earth was going on" [Jim, Line 65]

The men talked about the experience of juggling a number of different practical tasks since their partner's ABI. For Tom, it was frightening to have to take on these new responsibilities in such a short space of time:

"the scariest thing was that suddenly I had to consider and arrange two hundred different things from medical through to council support through care through... you name it" [Tom, Line 411]

Ivan had the similar experience of feeling as if he had many different tasks to negotiate at once, compounded by the fact that he felt unsupported by the medical system. This was very difficult for him to do at the same time as dealing with the fact that his partner was now seriously ill:

"it's hard enough if you've got a loved one who's ill, seriously ill, anyway, but when you've got to put up with all that kind of stuff on top of it, you could do

with some people being, you know, more open, when you feel like you're fighting the system and dealing with that at the same time it's very hard" [Ivan, Line 319]

The sense of responsibility often came from the fact that men had moved from being part of a joint and equal partnership where decisions were shared, to now being the person in control and responsible for decisions on behalf of the couple. Jim talked about feeling as if he had to lead his partner through every decision, including bigger decisions about their future, but also smaller, everyday decisions:

"it was a couple of years, it was like, I'd really have to lead her through and I'd have to be the one to make plans, erm she wouldn't really have the gumption to think this is what we'll do" [Jim, Line 200]

Charles also referred to the sense of responsibility that he now felt in making decisions, and not always feeling confident that he was really able to look after their joint interests on his own. He gave the particular example of financial decisions which, prior to the ABI, he and his partner would have made together:

"now she finds it really hard to try to, you know, talk about money, erm that I find quite hard, cos although I think I'm making all the decisions in our joint interest, it's much more difficult when you're not really talking it through" [Charles, Line 112]

Tom referred to the independent lives and equal partnership that he and his partner shared prior to the ABI, and the dramatic adjustment that he has had to make in now shouldering the responsibility for many decisions:

"the other thing which was new for me, by virtue of our circumstances and which has changed 180 degrees, erm I guess largely because we didn't have kids we lived fairly independent lives, and so with the stroke of a wand I am now constantly responsible" [Tom, Line 149]

Another salient issue that was raised by the men interviewed was the financial impact, and in some cases burden, since their partner's ABI. For some men, it was the case that their partner was still able to work, but due to difficulties resulting from the ABI, she was no longer able to do the same job as before, such as in Desmond's case:

“she was in sales and she couldn't do that anymore, she had to take a lesser job in the company, basically half her pay gone, so that's been hard financially, and of course you don't get help, benefit or anything like that these days” [Desmond, Line 80]

For other men, their partner's ABI was more severe, meaning that she was completely unable to work. Because these men were required to provide care for their partner, or were spending a lot of time visiting her in hospital, their own work-lives had been affected, often meaning that their income was reduced significantly, as well as losing their partner's previous income:

“in fact I'm not working full-time, when we were both working full-time at one stage, so our income is considerably less than it was” [Ivan, Line 100]

Tom's account suggests that, prior to his partner's brain injury, their political views and social status were 'taken for granted', but since her brain injury and the change in their financial circumstances, his awareness of their socio-political position has been brought to the forefront:

“having been part of a life that was I suppose upper middle class, certainly blue Conservative if I bothered to vote, and those kind of people, that's where we came from. Now we sit very much on the other side of the house, you know, we sit as beneficiaries of the state, and therefore I can't take any Conservative points of view any longer”

“our income went from X to X minus ten” [Tom, Lines 234 and 294]

Desmond named the fact that finances had been a deciding factor in him staying in a relationship with his partner, but seemed rather reluctant in doing this, implying that it should have been 'better' reasons that had helped him to stay in the relationship:

"it's been hard to try and persevere like, you know, trying to find the old Jane to come back again, that's never gonna happen, but I think, harsh as it might sound, that the past year or so, it's financial reasons that have kept us together, sometimes financially it keeps you together and it shouldn't do"
[Desmond, Line 371]

Tom also named other practical reasons as helping him to decide that staying in the relationship was the most desirable option for him, having weighed up his options regarding whether to stay or to leave:

"when I put all the pros and cons together into the basket, and some of those are hardware like the house, and some of those are software like sex, when I put all of those pros and cons together, for me, staying is a better option than going" [Tom, Line 480]

Men's sense of responsibility extended from decision-making to feeling as if they now had to 'push' their partners to do things to fill their time, and feeling responsible for their partners' well-being. Charles and Jim and both described the sense of duty they now felt to encourage their partners to do things:

"she finds it difficult to get up in the morning, I think because it's safe in bed and the day is a challenge, so normally I try and make sure something's happening in the morning" [Charles, Line 294]

"I feel like I'm on duty almost, you know, like is she alright, is she ok, is she talking to someone, has she got someone to be with"

“feeling the need to look after her more than, I might you know be more protective and push her towards things and guide her, I need to push her more to things” [Jim, Lines 615 and 662]

In men’s accounts, partners were frequently compared to children, which contributed to their sense of responsibility. Many of these men’s relationships had changed from being mutual and ‘equal’ to relationships where their partner was now more dependent on them. There were often changes in roles, for example men feeling more like parents than partners:

“I feel like I’m a father, looking after her all the time, have to help her with everything really, going to the toilet or stuff like that which you don’t expect to be doing that to your wife when she’s only 44, expecting to do that maybe when you retire, a bit dodderly maybe, but not at that age” [Ivan, Line 96]

“98% of the time this is about 24/7 having to worry about somebody else and again you think the baby scenario” [Tom, Line 157]

For Charles, his partner’s child-like behaviour, which he called ‘tantrums’, were sometimes a source of frustration for him, with him feeling as if he needed to give advice and guidance to his partner about how to behave:

“every now and again she’ll have what I can only describe as a tantrum, and I find those very difficult to react to because, you know, you want to say oh for god’s sake, grow up!” [Charles, Line 544]

For Daniel, the caring role that he took on was that of over-seeing his partner’s discharge home, and he talked about being ‘named’ as her carer by the hospital professionals:

“at first they let her stay here just for the day, and then they let her out for weekends and we got on fine, she was a bit sort of cautious about doing things and I had to be her informal carer as it were” [Daniel, Line 69]

Although Darren's partner was being formally cared for by staff in a residential setting, he describes his sense that his role in life now is primarily about caring for and supporting his partner:

"I would like to think that life will always be surrounding her for as long as she's alive, and I will support her as much as I can to try and get better, much better, encourage her and push her and give her as much as I can, physically or through providing extra support to her, to try and help her, give every opportunity for her to recover" [Darren, Line 132]

Within many of the men's accounts, their additional responsibilities also included a sense of 'duty' to stay in the relationship. It seemed that these men held certain values about how they should behave in the situation they found themselves in, and these values had a great impact on their decision to stay in the relationship with their partner:

"it's very common for there to be a divorce or a separation, and I cannot think about that, I don't think about that, you don't just give up on 40 years very lightly, I call it a 'duty', am I right to call it a duty, it sounds very matter of fact, very odd, but in a way it is..." [Darren, Line 13]

"her sister said to me, no one will feel the worst of you if you leave her cos she has changed, and I said I can't do that, I couldn't, for one thing it would be a, even to do it would be a cowardly thing to do, and it's not what I wanted to do either" [Jim, Line 438]

3.4.2 Isolation and others not understanding

Men talked about their common experience of others not understanding their situation and what it was like to experience the changes in their partner and their relationship. This led to men feeling isolated and increased their sense that they were now responsible for their partner and for many decisions related to them and their partner. In Tom and Desmond's experience, they found that others found it very difficult to understand their situation, even though these other people clearly wanted to help and provide support:

“good friends, carers, members of the public, are all very willing, but they are all desperately ignorant” [Tom, Line 165]

“we’ve got the Stroke Association going into her work and try and talk to them about it, and they’ve tried to explain what it’s like and she’s had various meetings with managers, and you can tell them what you like but they just don’t get it” [Desmond, Line 196]

In order to manage the fact that other people find it hard to understand and to provide appropriate support, Ivan and Tom felt it was simply easier if they became an expert in how to live with and support their partner, rather than expecting others to do the same:

“I’ve had to do it all myself, I mean if I want to find out something then I will do it, the worrying thing is I find I’m kind of telling the doctors what to do, I’m kind of leading them” [Ivan, Line 143]

“it’s just easier now if I tell people what to do”

“I am now the expert on what is best for her” [Tom, Lines 205 and 211]

Living with their partner after the ABI, without the complete understanding of other people, left many of the men feeling isolated and lonely. Throughout his account, Jim referred to his positive experiences of social support, but also alluded to the pervasive nature of his isolation despite receiving support from others:

“I couldn’t say I didn’t have support from Eleanor’s parents and my mum, they were great, but there was a lot of sort of loneliness” [Jim, Line 77]

Peter felt an acute sense of loneliness and isolation resulting from others’ lack of understanding of what it was like to be him, in a relationship with a partner who was now very different from the woman he first met:

“the loneliness is one of the hardest things, it’s that isolation and there is no one on the whole estate I could have this conversation with, cos they wouldn’t know what the hell you were talking about” [Peter, Line 488]

In addition to others not understanding, there seemed to be a shared experience of having completely lost friendships, or having lost the full support of friends, as a result of their partner’s ABI. Jim talked about his partner’s friends not being as supportive as he would have liked, or would have expected, and the practical impact this had on him in terms of him needing to provide additional support to his partner:

“all of these people had known that she’d been unwell, but it was noticeable that hearing from these, some of these friends, became less and less frequent, erm, as time went on, and that really, really angered me because it felt then for her, what should’ve been a really great support network for her wasn’t as strong as it might have been and so I felt obliged to pick up the slack a bit, a bit more” [Jim, Line 121]

In relation to this, Tom described a gradual reduction in contact with and support from particular groups of friends. This was in contrast to Jim, who had not expected this to happen; Tom had received prior advice from a professional and so the experience of losing friends came as less of a surprise to him:

“one of her therapists had said you’ll find your friends, and this has happened, there will be a few who adjust and stay as friends, of which there have been four that come to mind, there will be a few down the other end of the bell curve that just won’t be able to cope with it and will drop off, and then there will be the big chunk in the middle who feel they need to keep going, but actually you start drifting apart, and that’s exactly how it’s happened with us” [Tom, Line 56]

Ivan told a similar story, with him experiencing some friends as incredibly supportive and tenacious, and other friends as gradually reducing their contact with him since his partner’s ABI:

“I’ve had a few friends who’ve been very good, you get a lot of friends when you’re going through something in the first couple of weeks who tend to fall away, there’s a few die hards” [Ivan, Line 231]

3.4.3 Emotional impact of changed situation

The burden of the new roles and responsibilities, the feelings of being isolated and misunderstood, and the many changes and losses experienced as a result of their partners’ ABIs inevitably had an emotional impact on these men. Within their accounts men talked about a number of different emotions, including anger, sadness and despair, feeling overwhelmed, frustrated, and feeling a sense of ‘entitlement’. Some men also felt as if they were in ‘limbo’, resulting in them feeling frustrated, anxious and unsure about their future.

Peter described feelings of anger about his situation, particularly in relation to the losses he had experienced:

“if I had an overriding emotion about what happened it’s anger really, and I’m quite angry because we had something really special and it was taken away, just like that one day” [Peter, Line 203]

Tom was also angry about his situation, having a significant impact on his mental well-being for which he felt he needed to seek professional support:

*“in November I had a nervous breakdown cos I was trying to do too much”
“having always been a, erm, a very sanguine person, I started suffering really badly from rage, to the point where it was affecting my physically, and so I have been and am still going to some counselling for that” [Tom, Lines 35 and 240]*

Darren and Ivan talked about feeling dissatisfied with how their partners were treated in hospital, with Darren experiencing sadness and despair, and Ivan experiencing sadness and anger. Men’s experiences of contact with and support from professionals will also be further explored in the theme ‘Sources of support’:

“there was a terrible period, a period where actually I got upset, erm and I think she went backwards in the hospital, quite considerably, because they didn’t know how to deal with her, they hadn’t got the resources, they’d put her in a respiratory ward, and they hadn’t got the resources there, so there was more despair there” [Darren, Line 60]

“there’s been a lot of tears, a lot of anger as well, I’m angry about the way she was treated when she went into hospital” [Ivan, Line 315]

Although Jim spoke about the impact that his partner’s ABI had on him, he gave the impression that there were not many occasions when he felt emotionally overwhelmed by the situation:

“I can only remember one time where I lost it, I was just home on my own, you know, I’d been used to, erm, I’d either lived at home or lived with mates or lived with Eleanor, I’d never lived alone, I effectively had 3 weeks living alone and just one night, I was just doing the washing up or something, I just burst into tears and just cried and cried and cried, then 15 minutes later I was alright” [Jim, Line 72]

Certain aspects of their partner’s behaviour that were now present as a result of the ABI were sources of frustration for Desmond and for Charles:

“if she moves stuff or puts something down somewhere, or she can’t find it, it’s never her fault, it’s always someone or something’s fault, it’s always me, it’s always me, it’s always something I’ve done” [Desmond, Line 256]

“so when you wake up in the morning, most of us are motivated by about 15 tasks we’ve got to get through, she’s motivated by no task whatever really, so that’s, that has an impact and that can be quite frustrating” [Charles, Line 134]

In response to their situation, some men referred to a feeling of entitlement, almost as some compensation or some consolation for the fact that their life with

their partner had been so dramatically altered. Tom described one way that he tried to compensate himself for what had happened to him and his partner:

“I have learned to play the guilt card... I make full use of her disability to get us good seats etc etc and I figure that’s kind of a bit of a quid pro quo, you know”
[Tom, Line 216]

Similarly, Jim felt that he deserved to go out and have fun, and he described the sense of injustice that he felt in response to his changed life circumstances:

“it’s like I’m gonna go out cos I’ve had a tough time here as well, and you know, almost why should I be punished for what’s happened to Eleanor”
[Jim, Line 415]

Other men also referred to their changing lifestyle, and for some, the impact of their partner’s ABI was that their life had to be put ‘on hold’, with many of their expectations or plans for their future delayed, adapted or even abandoned. Ivan used the word ‘limbo’ to reflect the ‘stuck-ness’ and uncertainty that he had been experiencing ever since his partner’s ABI, which was impacting on his ability to plan for the future:

“well you know, limbo, that’s the other thing, you can’t really plan, limbo is a very good word, you don’t really know what’s going to happen, and my life’s been on hold for over a year basically, and I don’t know what’s going to happen” [Ivan, Line 215]

For Jim, because of his partner’s recovery, he was now able to continue with the life he wanted to lead, although this was later down the line than he would have wanted:

“the illness probably put our lives on hold for a while, if I could’ve written it down we probably would’ve had kids two or three years ago, but I couldn’t, we didn’t, I guess everything’s sort of maybe slightly delayed” [Jim, Line 534]

3.5 Coping and support

The men interviewed had adopted a variety of different methods to cope with the challenges and life changes since their partners' brain injuries. They also drew upon different sources of support and described their experiences of how helpful they found this support. Many men made suggestions regarding how they felt professionals could do things differently. This theme is comprised of two sub-themes: 'Getting on with it' and 'Sources of support'.

3.5.1 Getting on with it

One way of coping that was described by almost all of the men was an acknowledgement that their situation was now very different from previously, a feeling that there was not much they could do to change or alter their current situation, and then to 'just get on with it'. Jim described the stance of acceptance that he adopted, and drew on his past experience of dealing with difficult situations to help him to cope now:

"sometimes you have to accept that life hits you... my dad died when I was 16... it's like, well things can't get much worse than this, so it just kind of gave me the approach like, well things can be really, really, really bad, fight them off, shake them off, and try and do the right thing, do the right thing by Eleanor, you know, try and be there for her" [Jim, Line 469]

Darren also drew upon his prior ways of coping, and described 'giving himself a talking to' when he felt that he was not managing his situation as well as he felt he should be:

"I've always thought I've just got to get on with it, I've always had a positive, tried to always have a positive outlook on life"
"when I get down, I think, goodness, don't be so stupid, you've got so much going for you, just get on with it, and stop messing around" [Darren, Lines 424 and 443]

For Ivan, there was almost a resignation to the fact that he could not change what was happening to his relationship and his lifestyle:

“I just have to get on with it I suppose” [Ivan, Line 222]

Initially, Tom found it very difficult to acknowledge the dramatic change in his and his partner’s situation, and his way of coping was to continue with life as it had been before, and to switch off from what was happening and the adjustments that he needed to make:

“for about the next three months I tried to live life like we’d lived it” [Tom, Line 33]

It seemed that for Tom, over time he was gradually able to adjust to the changes and he talked about establishing routines as a way of coping:

“my every moment of worry, which is where we started, has now reduced considerably, for as long as life has routine and balance” [Tom, Line 291]

Peter’s way of coping was to try not to focus on the changes and challenges of his new situation:

“in order to function in daily life you kind of bury it and get on with it” [Peter, Line 218]

Daniel’s experience was that he did not need to use many ways of coping as his partner made such a good recovery, despite some initial uncertainty about how things might progress:

“no one was quite sure how, well we sort of knew that there wasn’t a big problem, because it was obvious when she came out of [rehab unit], but no one quite knew how it was going to work, but because it basically worked ok, there wasn’t much need to readjust... I think they were very pleased with the speed with which she recovered” [Daniel, Line 241]

Men also talked about seeing the positives in their situation as compared to other people's situations, and almost all of the men described an attitude of 'this could have been worse', counting themselves lucky in some respects. By doing this, it seemed that men found it easier to cope with their altered lifestyle and relationship with their partner. Peter gave an account of the different scenarios that he was faced with during his partner's recovery, and how he considers them as lucky compared to what the outcome could have been:

"I get consolation from the fact that, if you think about the scenario that we were looking at, when Anna didn't die, you know, we were then faced with the prospect that she may be a cabbage, and that was horrifying, that was a very, very difficult scenario because I didn't know how I would cope with that, and we've been very fortunate because that hasn't happened... in a way we're very fortunate erm it could have been so much worse" [Peter, Line 331]

Charles also talked about the way he sees his situation as compared with others:

"I think, you know, there's plenty of people better off and plenty of people worse off and I'm probably somewhere in the middle" [Charles, Line 595]

Some men referred to the nature and severity of their partner's ABI and compared this with what they perceived as worst case scenarios. For example, several times during his account, Desmond referred to other people he has known who have suffered strokes, and the fact that he sees his partner as better off in comparison:

"it's not as bad, like I say, mum had a stroke a few years ago and she's a bit dithery, but my ex-wife's father in law, he had a massive stroke that left him quite seriously, erm, mobility-wise and so on and so forth" [Desmond, Line 109]

The men talked about having let time pass, and that this had helped them to cope with and adjust to the new way of life that they might now have to lead:

“in 2009 there was a change in my attitude, quite amazing which kind of went ok, well I’d understood this notion of the only thing to do is let time pass and that I think is essentially what the 2008 period was, I must’ve been in shock”
[Tom, Line 51]

“you just get used to it like everything really, it’s like a process of mourning really, I think, although she’s improving” [Ivan, Line 107]

Daniel described the positive aspects of having his partner come to live with him after the ABI, and compares her situation to that of someone who might have suffered a more severe ABI:

“it was quite good for me as well because I could sort of, you know, make sure she was alright cos I love her, so it was great having her living here from that perspective, erm but it wasn’t as necessary as I can imagine in some circumstances, you know, like if someone was suffering the after-effects of a stroke or something, a bad stroke” [Daniel, Line 190]

In addition, in order to cope with the new challenges and changes in his relationship with his partner, Daniel also described some positive changes that had come about:

“well in some ways it’s beneficial because was drinking far too much, you might say she was probably an alcoholic, and she’d probably had far too much to drink and slipped over, no one quite knows, so it’s stopped her drinking, so it’s quite positive in that sense as well” [Daniel, Line 272]

For those men who were able to continue to work, this proved an invaluable resource, perhaps serving to maintain some sense of normality, and providing a source of achievement, status and possibly support. Work was also a useful way of coping, likely providing a distraction from the challenges they were experiencing in most other areas of their lives, again with the attitude of just getting on with it:

“I’ve managed to get back into a little consulting which is good for me” [Tom, Line 214]

“I have to get over it and get on with it for the sake of her, using my work as an outlet, erm if I hadn’t got my work, I don’t know, I think I would’ve cut my wrists by now” [Darren, Line 112?]

3.5.2 Sources of support

Men drew on a number of different resources in order to feel supported. Some made use of the practical support that was available to them and their partners. For example, Jim described trying to use technology to enable his partner to continue working after the ABI:

“we’ve tried all sorts of things, support at work, all sorts of organisations, someone actually in work with Eleanor, trying to help her through the working day, erm they gave her a Dictaphone, a palm pilot thing, all sorts of things to try, her making notes and that during the day” [Jim, Line 137]

Tom also described the practical adaptations he had made, which made it easier for him to cope with the everyday challenges presented since his partner’s ABI:

“we got a ramp made, so suddenly I got a motability vehicle which made all the difference” [Tom, Line 73]

Peter described finding relaxation and talking to others useful ways of coping with the anger and tension that he has experienced since his partner’s ABI, however he also acknowledged that more help and support would be beneficial to him:

“that anger, for me, causes a lot of tension, I end up quite tense physically, erm and I try relaxation exercises”

“yeah well speaking about it helps, I would ideally like more help” [Peter, Lines 206 and 413]

Ivan felt supported through practising his religion:

“I have faith, I’m a Christian, I’ve been praying a lot and that’s helped me, and through it all I’ve struggled at times, even with my faith” [Ivan, Line 227]

Men also talked about drawing on the support of their family and friends. The quality of this support tended to be related to the amount of contact they received, and the physical proximity of family and friends. Those men who did not have any family locally referred to the additional sense of responsibility and isolation that this left them with, as has been explored within the theme ‘Sense of responsibility:

“it’s pretty much mostly me, we haven’t got any family round the corner” [Jim, Line 405]

For some men, the majority of their social support came from their adult children:

“we’ve got two magnificent daughters, so we see them pretty much every week, erm and they get terribly involved, so fantastic family support” [Charles, Line 124]

“the kids really, particularly daughter, she speaks to me every day” [Darren, Line 401]

These same men also described the support they received from friends and others in their local area, and how this, combined with the support of their family, was very helpful to them:

“we’re very lucky in that we have some wonderful friends in the road, the sort of ladies in the road always come round and have a coffee with her” [Charles, Line 178]

“there’s a couple of, two sets of friends that have been very, very good in this really” [Darren, Line 400]

However, even men who did talk about having family around to provide support, continued to feel as if they were not really held in mind, and this support did not always adequately meet their emotional needs:

“I talk to my sister and certain friends”

“not many people ask how I am” [Ivan, Lines 106 and 264]

“the only person I’ve got is Anna’s mum” [Peter, Line 454]

The men seemed to have mixed experiences of the professional support and advice they received. In describing those aspects of the professional support they thought were positive and useful, they tended to name specific professionals who had stood out as being particularly helpful, or whom they had formed a good relationship with:

“we’ve tried carers and in fact, we had one girl, she was a graduate nurse, she had a young boy, she was brilliant, she had all sorts of clever ideas”
[Charles, Line 404]

“the one person who has been very helpful in all of this, is the case manager, she I could talk to her about anything, and she shared the battles with me”
[Darren, Line 382]

Men referred to their experiences of attending support groups and these groups were mostly viewed as unhelpful, or not relevant, because what was discussed in the groups was generally not what men wanted to discuss:

“sometimes I find the meetings pointless... all they seem to do there is you sit down in a circle, erm they’ll talk about what’s happened in the past week, nothing major... I think well that’s not helping anything, you know, that’s not helping matters at all, and I don’t know, I can’t see the point of them myself”
[Desmond, Line 289]

As an alternative, Desmond said that he wanted reliable, 'expert' advice, which he felt should come from professionals who had knowledge and experience of ABI, which is understandable in the context of a society which privileges professional knowledge:

"they probably need someone there with more information cos everyone's firing questions off each other but no one really, everyone's just guessing, giving the answers to their own personal experience, rather than having someone in the medical professional to give them a definition, a proper answer" [Desmond, Line 317]

In contrast, Tom talked about valuing the experience of others in a similar situation to himself, and finding information from them more useful than most of the information he had received from professionals:

"consultants of every sort are only ever consultants, whereas people who are in the same circumstance as you, which is the 24/7-ness of caring, means I've always been a bit reticent in how I dish out my respect, all the carers I know have taught me some little thing, so there is a massive difference if you're caring for someone 24/7" [Tom, Line 628]

Tom also referred to the 'tea and sympathy' nature of many of the support groups he found to be available, and in contrast the group he now attends has a different kind of feel, and a different agenda:

"I'm not really fussed about the tea and coffee and sympathy, I just want the information, the group that I'm currently in, and we meet kind of once a month, but we don't talk about how sorry we're feeling for ourselves, but how to prevent issues" [Tom, Line 591]

Men often found it a struggle to get the care and support that they wanted and needed for themselves and for their partners, and described the experience of fighting professionals for what they thought should have been more readily available:

“I’ve had to fight the system as well as put up with obviously big changes in her which is not good, so finally she’s got, the new GP she’s got at the moment is quite good, been quite helpful, I just find there’s been a lot of fighting faceless bureaucracy” [Ivan, Line 116]

“it became clear that I would always have a fight for her”

“so really the fight with [nursing unit] and the PCT started, in October of last year, and that’s been a continual fight” [Darren, Lines 92 and 95]

In addition, Darren was dissatisfied with the amount of information he received, not knowing what was happening and feeling as if information or knowledge was being held back from him:

“sometimes I did feel there wasn’t enough information, but sometimes you had to pull it out, and one of the infuriating things is, I did find this, I find it strange, I find it horrible, that people will not give you an opinion, or not give you a view” [Darren, Line 505]

Instead, the men made suggestions that professionals could have given them more information from the very start of their journey, although perhaps with unrealistically high and idealistic expectations of professionals’ knowledge, given the uncertain nature of the prognosis of brain injuries:

“I think if we’d had more idea of what to expect to start with, erm that would’ve been useful to know, and that you were kept informed better, would be good” [Ivan, Line 332]

“if I’d had a single source of information that covered even 70% of what I needed to know pretty instantly, that would’ve been great, but it doesn’t exist” [Tom, Line 557]

There was an overwhelming sense of a lack of adequate support and provision for these men as partners of women who had suffered brain injuries, leading to men feeling as if their needs and experiences were not being acknowledged by many of the professionals working in the field:

“there’s nothing out there for the partners, you know, it’s, if you like you might have one half that’s had the physical injury, but you both suffer, you’re both suffering, and you’re both going through, in a way, the same thing, but there’s nothing out there for that person, you know, wife, husband, boyfriend, girlfriend, whatever it is, there’s nothing out there for that, there’s no one, you know, you can physically talk to about what it’s like” [Desmond, Line 603]

There were suggestions that there should be more acknowledgement of the needs of partners, and the idea of breaking the taboo of help-seeking by making a referral to psychology or psychiatry a routine part of the after-care following an ABI:

“we need more help, and I would’ve liked to have seen that acknowledged earlier, I’d like to have been referred and perhaps, even if it was just kind of like an annual check-up or something” [Peter, Line 397]

Finally, throughout the interviews the men showed a willingness to share their experiences in order to help others in similar situations to themselves, and some named this as one of the reasons they had chosen to participate in the research:

“one of the things I’ve been thinking of is actually to try and put something back into the neuro world... when I retire, it might be quite nice to do something like that, to put something back into it really” [Darren, Line 469]

There was a sense of the participants wanting to share what they had learnt along the way so that others could immediately benefit from what had taken them months or even years to learn about. In particular, Peter described the experience of his partner continuing to change and her ‘new character’

developing in ways that he never could have anticipated prior to the brain injury, and he wanted to 'warn' others in the same situation of this possibility:

"I think if you were trying to make this research for people who were going through similar situations, I would warn them that it's not just that they've changed, it's that they're gonna carry on changing, it's like they've taken a different trajectory, because they've become a different character, they evolve along that character, and that's something I was not prepared for" [Peter, Line 359].

4. DISCUSSION

4.1 Overview

This study aimed to explore the experience of adjustment to relationship changes in men whose female partners have an ABI. Participants attempted to name the almost indescribable experience that something was not quite right and the sense of disconnectedness they now felt. These changes led to feelings of new and increased responsibility, and increased burden in many respects, including the emotional impact and the practical, everyday tasks that men now faced. The men gave accounts of coping by ‘just getting on with it’ and drew on some different sources of support, but in general it seemed that they had been left to navigate what was a frightening and unknown territory without much support or guidance. Nonetheless, they presented as resilient, generally responding to an unexpected ‘landmine’ in their relationship (Yeates, 2011) with resourcefulness and strength.

The specific aims of the study were to explore what changes in their relationship with their partner men have experienced since their partner’s ABI, how men have adjusted to these relationship changes, and what they feel has been important in contributing to their adjustment. In this chapter I will discuss and explore the study’s findings in relation to the existing literature. I will then consider the strengths and limitations of this study, and the implications of the findings for clinical practice, and future research. Issues of reflexivity will be discussed before final conclusions are presented.

4.2 Summary and discussion of main findings

As shown in Table 3, through thematic analysis I was able to identify five themes: initial reactions to the brain injury, “she’s a lot the same, but she’s not the same”, relationship changing, sense of responsibility, and coping and support. I will now discuss these themes in relation to my research question and specific aims.

4.2.1. What changes in their relationship with their partner have men experienced since their partner's ABI?

One of the themes, 'Relationship changing', comprised men's descriptions of their experiences of changes in their relationship with their partner. Following their partner's ABI, participants experienced a variety of losses within their relationships, most notably feeling as if they had lost the person their partner once was, and the loss of the connection and intimacy that they had previously shared. The sometimes subtle nature of these changes and losses, combined with the fact that their partner had 'survived' the ABI and was, therefore, alive and well, meant that the distress that men experienced was often not socially recognised or permitted, a poignant demonstration of Doka's (1989) ideas about 'disenfranchised grief'. The fact that many others did not understand what these men were going through, and the expectation, both from others and from themselves, that they should be relieved because their partner had not died, added to the feeling that their distress was not always acceptable or warranted. Some of the men used the word 'limbo' or alluded to the experience of feeling in limbo within their accounts, reminiscent of Lezak's (1988) description of partners feeling as if they were in 'social limbo'.

Changes to sexual relationships were mentioned as part of more multi-faceted accounts of what had changed in their relationship overall. For this particular group of men, whether their sexual relationship had changed, or had been lost completely seemed to be dependent on the severity of partners' ABIs; with the most severe injuries resulting in more physical and cognitive difficulties as well. The men whose partners required assistance with personal care tasks such as toileting found themselves in an ambiguous position, since the role of a sexual partner can be incompatible with the role of a carer (e.g., Gosling & Oddy, 1999). Blais and Boisvert (2005) have suggested that much of the existing research focuses on relationships where one partner has had a severe brain injury, and there is not so much literature to be found about the non-injured partner's experience of sexual relationships if their brain-injured partner has a less severe injury. Gill et al. (2011) interviewed men and women whose partners had ABIs and found that many partners' accounts were about their injured partners' functional losses, erectile dysfunction, and lack of interest in sex or disinhibition

and, therefore, increased interest in sex. Men in the current study whose partners had less severe ABIs spoke less about functional changes, or the frequency of their partner wishing to have sex, but more about the sexual relationship not being the same as it was prior to the injury which they found disconcerting. For example, some men now experienced their sexual relationship as 'artificial' and as lacking in the connection they had previously shared.

Men also described a more general sense of disconnectedness they now felt with their partner, and the disconcerting experience of feeling as if they were living with a stranger. Many authors have talked about non-injured partners feeling as if they were in a relationship with somebody different and not the person they married (e.g. Eames & Wood, 1989; Gill et al., 2011), with the emotional and intimate side of the relationship feeling wrong or strange (Gosling & Oddy, 1999). Gregory (1998) has suggested that everyday language may not be adequate in capturing the types of experiences that these partners have tried to describe, and this was apparent in the men's accounts in this study where they sometimes struggled to describe the subtleties of their experiences, using phrases such as 'she's a lot the same, but she's not the same', or 'she's a different person but not so different'.

There were many stories of mutual independence and equality within the pre-injury relationships which had now been replaced with less reciprocal 'responsible to dependent' relationships, further contributing to men's sense of disconnectedness. They gave examples of now needing to lead the way and take the initiative in their relationship in a way that they had not needed to before, and not feeling cared for or looked after by their partners. The lack of reciprocity might also have increased their sense of responsibility; furthermore, Reid, Moss and Hyman (2005) have suggested that caregiver burden is increased when there is a lack of reciprocity or balance in the care-giver/care-receiver relationship.

The men spoke of new responsibilities that they had taken on since the ABI, as captured in the theme 'Responsibilities and burden', such as decision-making, providing additional encouragement and guidance to their partner and, in some cases, providing physical care or seeing their partner being cared for in a hospital

setting. These changes in roles seemed to have an impact on the interactions between men and their partners. Framed within a model of transactional analysis, it could be suggested that interactions that had previously been 'reciprocal' and 'complementary' had now become 'crossed' and therefore less functional for the couple (e.g. Berne, 1961). This was particularly apparent in the accounts of those men who now compared their partner to a child.

Feeling more responsible and having lost the companionship of their partner led to participants feeling isolated, likely exacerbated by the fact that it is hard to truly capture their experiences in everyday language (Gregory, 1998). The social isolation that family members of those with brain injuries experience has been highlighted by many authors. For example, Chwalisz and Stark-Wroblewski (1996) interviewed spouse caregivers of people with brain injuries who also reported that others do not understand and may be unsupportive. Braine (2011) identified that care-giving partners experience loneliness, and Engstrom and Soderberg (2011) noted that for relatives of people with brain injury, most former friends disappeared, and this was the case for many men in this study. Community brain injury services are becoming increasingly concerned with, and focused, on tackling social isolation (e.g., Tyerman & King, 2008).

There was an inevitable emotional cost of the demands of the new roles and responsibilities, the experience of being isolated and misunderstood, as well as the numerous losses and changes that these men were experiencing. The men talked about experiencing anger, sadness, despair, feeling overwhelmed, frustrated, and feeling a sense of entitlement to compensate for their loss and distress. Similarly, Bowen, Yeates and Palmer (2010, p. 142) also note that commonly reported emotions for partners are "guilt, frustration, relief, 'utter sadness', loss, despair" and suggest that in these cases, "love is really pushed to its limits".

In men's accounts, they seemed to attribute many of these changes in their relationships to the changes within their partner, as a result of the physical damage caused to her brain by the injury. This is captured by the theme 'She's a lot the same, but she's not the same'. Yeates et al. (2006, 2007) have suggested

that attributing relationship changes to the injured person, or the brain injury itself, might be a necessary way that family members make sense of and cope with any unusual or hurtful actions or interactions that occur between them and their partner. This may also be true of the men interviewed in this study; that in order to manage difficult emotions and reactions to the relationship changes, they attribute the changes and difficulties to the brain injury itself, or liken their partner to a child, i.e. it is not their fault, it is because of the brain injury, or because they are like a child now. Wood (2005) has also noted the common description that family members give of their relative with a brain injury as like a child and needing to be looked after, also implying the role changes that might occur with a couple or family after an ABI.

In order to illustrate these changes in their relationships with their partners, the men compared and contrasted their relationships before and after the brain injury, often with a yearning for the relationship that was, and could have been. McGrath (2004) has suggested that life prior to a brain injury, including relationships, is often romanticised and idealised in relation to how things actually were before the brain injury. Yeates et al. (2006) add that the function of remembering and referring to these pre-injury life circumstances may be to provide stability and meaning when the current circumstances are difficult to manage and make sense of. It could be that this was the case for these men, that frequently making reference to the past relationship was a reassurance and reminder for them of why they were in a relationship with their partner. However, for some men, making that comparison was unhelpful, with memories of their relationship before the brain injury proving to be painful reminders of what they had lost.

As in other research, during the interviews men spoke about their changing relationships in terms of centrifugal forces driving them and their partners apart, such as the losses, disconnection, distress, isolation and burden, and centripetal forces bringing them closer together, or keeping them together as a couple (e.g., Moore, Stanbrook & Peters, 1993). Some centripetal forces were more practical, such as financial and housing issues, whereas others seemed more related to the men's values, such as sense of duty and the strength of their pre-injury

relationship, as also suggested by Gill et al. (2011). These men seemed to hold particular values about their duty as a partner, appearing to demonstrate qualities that fit with gender-stereotyped ideas of the roles a male partner should take on, and 'traditional' ideas about relationships (e.g., as a protector, staying together 'for better or for worse').

4.2.2. How have men adjusted to these relationship changes?

The men's accounts of how they had adjusted began with telling the story of how their partner's brain injury had occurred, describing the ways in which they noticed something was wrong, as illustrated in the theme 'Initial reactions to the brain injury'. For most of the men, it was not yet apparent that their relationship with their partner might change, but their accounts demonstrated some of the ways they reacted to, and started to adjust to, the shock of the new situation they were encountering. Bowen, Yeates and Palmer (2010) have suggested that relatives of people with brain injuries might experience anxiety due to not knowing exactly what caused the brain injury, and feeling out of control about what is happening to their partner. This was reflected in the current study, with participants describing their feelings of confusion and uncertainty, particularly as they did not have much prior knowledge or experience of brain injury to 'measure' their own experience by. By looking for explanations and seeking acknowledgement and medical attention from professionals, the men seemed to be already adjusting to the situation they found themselves in and trying to find ways to reduce their anxiety.

Various ways of coping were described, and these seemed to be key in helping the men to manage and adjust to their new situations. The ways of coping that men described seem to be congruent with Endler and Parker's (1994) three factor model of coping, which consists of 'task-focused' strategies, 'emotion-focused' strategies, and 'avoidant' strategies. For example, some men talked about 'task-focused' or problem-solving strategies such as using technology, making practical or physical adaptations, and drawing on resources such as relaxation or praying. These types of strategies seek to alter or eliminate the source of stress (Lazarus & Folkman, 1984).

'Emotion-focused' strategies mostly consisted of taking an alternative perspective of the situation, which the men tended to do by seeing the positive aspects of what had happened, and often adopting an attitude of 'this could've been worse' and of counting themselves lucky; Chwalisz and Stark-Wroblewski (1996) note that this sort of positive social comparison can help people to cope with difficult situations. Averó, Corace, Endler and Calvo (2003) suggest that by using 'emotion-focused' strategies, emotional distress is regulated or reduced, and this might be through taking a different perspective of the situation, or seeking emotional support. The men did also seek emotional support from friends, family and professionals, with varying degrees of perceived helpfulness, which will be explored later in this chapter.

'Avoidant' strategies (Endler & Parker, 1994) such as throwing themselves into their work to distract themselves from thinking about their situation, trying to live life just the way it had been before the ABI, and burying thoughts and emotions were all mentioned by this group of men. According to Averó, Corace, Endler and Calvo (2003), the use of 'avoidant' strategies can be helpful in the short-term but 'maladaptive' over longer periods of time. However, most men described using 'avoidant' strategies in the early days after their partner's ABI, with a gradual move towards avoiding less and instead problem-solving or taking a different perspective, suggestive of some process of adjustment. Furthermore, it should be noted that these are just some ideas about helpful and unhelpful ways of coping, and care should be taken not to pathologise or problematise the strategies that are used by one or both partners, as couples may have their own unique ways of coping (e.g., Bowen, Yeates & Palmer, 2010). It has also been suggested that in terms of ways of coping, men tend to be 'do-ers' and women tend to be 'feel-ers' (e.g. Hammond, Davis, Whiteside, Philbrick & Hirsch, 2011), however, in the current study there seemed to be more of a balance between men's use of 'task-focused', 'emotion-focused' and 'avoidant' strategies, which presents a challenge to the widely-held gender stereotype that men may be more practical than emotional.

As previously mentioned, in order to adjust to their situations participants sought support both socially and through professionals. Some men considered

themselves 'lucky; as they had support from family such as adult children, and local friends, but this seemed to be the case in only a minority of the men interviewed in this study. There were mixed views of the professional support that was available; some men were impressed with particular clinicians who had been helpful to them, however, other men were incredibly disappointed with the lack of support and advice they had received, as well as the quality of care for their partner.

There was a strikingly common complaint that professionals did not provide enough information to these men about what was happening to their partner, or about what to expect. They wanted more information right from the initial stages of their partner being diagnosed with an ABI, and ongoing access to practical and relevant information, perhaps within a single source for ease of access. Chwalisz and Stark-Wroblewski (1996) also found their participants reported stress associated with professionals' substandard practice and knowledge about brain injury. In addition, it could be considered that due to the difficulty in predicting prognosis in brain injury, family members may be frustrated in not receiving information about what to expect and, therefore, may 'attack' professionals who they see as holding that 'expert' knowledge and opinion. Within the accounts in this study, several men expressed frustration with professionals for not giving them enough information with the impression that they were withholding information or opinion without due cause.

Support groups were also another source of help and advice that the men drew upon, but were mostly seen as unhelpful or not relevant because the topics discussed in the groups were not the burning issues for these men. Some men described the support groups they had attended as 'pointless' and said that they did not want 'tea and sympathy', but instead they valued practical advice, information and support. Some men felt that this practical advice should come from 'expert' professionals. However, other men did not necessarily respect the views of professionals and preferred to meet with others in a similar situation as themselves, to share practical tips and information. This is supported by Morris and Morris (2012) who considered similar issues related to stroke peer support groups and found that group members perceived the groups to be the most

helpful when the others in the group were very similar to themselves. Most of the men interviewed in this study had not found a satisfactory support group to attend, leading to tentative suggestions that the group members may not be similar enough to these men (for example, if there is a female majority in a group) and there may be differences in the primary tasks of these support groups and men's ideas about what they would like to gain from attending a group.

When describing the helpful and unhelpful aspects of the available support and coping strategies, many men made suggestions about what professionals could have done differently. They described a lack of adequate and relevant support and provision for relatives of people with ABI, especially partners, and asked for more professional recognition of their needs. There was a common theme that admitting that you are not managing and asking for help was very much a taboo, linking with Kingerlee's (2012) model of male distress, which conceptualises the general lack of help-seeking amongst men as associated with feelings of shame that emotional distress and, therefore, asking for help, may engender in them. Men recommended that help and support should be offered to partners more routinely, particularly as often they did not know what support they were entitled to, or how to even go about asking for it. During the interviews, many of the men said their motivations for taking part in the research were partly a desire to be helpful to me as the researcher and to other people in situations similar to their own, which was also reported by participants in Chwalisz and Stark-Wroblewski's (1996) study.

Overall, the men's accounts of their experiences since their partner's ABI were indicative of their individual journeys through this "uncharted territory" (Steele, 2005) from a position of being in shock and continually looking for explanations and answers, to relative positions of feeling more accepting of the situation they now found themselves in, or feeling more adjusted. Within these stories there seemed to be perpetual 'ups and downs', with the men feeling more or less accepting of what was happening at different times, and facing new and different challenges at various stages of their journeys. A sense of time passing, as well as making use of various coping strategies and sources of support, seemed to contribute to their adjustment to the changes in their relationships.

Gracey, Evans and Malley (2009) proposed a Y-shaped model of adjustment and safety-seeking for people with ABI which suggests that immediately after a brain injury, a person is likely to be at a point of discrepancy between how they think things should be, and how they perceive things to be, resulting in distress. They then use coping strategies which may be more or less effective in helping them to feel safe and alleviating their distress. The authors extended the model to include the wider system around the person with ABI. These men's accounts of their adjustment to relationship changes could be conceptualised in a similar way, having initially been at a point of discrepancy between how they thought their relationship should be, and how they perceived their relationship to be since the ABI, resulting in feelings of distress, confusion and anger. Throughout their journeys the men made use of various coping strategies, some of which helped more or less to enable them to manage and cope with the situation they found themselves in, and to start to adjust to and accept things as they are.

4.3 Strengths and limitations of this study

4.3.1 Significance and strengths of this study

This study has provided some insights into the experiences of men whose female partners have an ABI, and has given the participants an opportunity to tell their stories, which were previously neglected and unheard. It is hoped that this study will add to the current literature on the experiences of partners of those with brain injuries and, as previously outlined, is one of few studies focusing specifically on the experiences of male partners, and focusing on relationship changes in particular. Many couples do break up following an ABI in one of the partners (e.g. Oddy, Humphrey and Uttley, 1978; Anderson-Parente, DeCesare, & Parente, 1990), and as noted by Perlesz, Kinsella and Crowe (1999), there is a lack of literature exploring the experiences of families who have adjusted and coped well since their family members' brain injury. It could be argued that this study adds to this under-researched area, considering the resilience that the men in my sample demonstrated through their accounts of their experiences, such as using a variety of ways of coping with their changed situations, and maintaining their

relationships with their partners, despite a lack of available and appropriate support of understanding from other people.

In my opinion, the use of a small sample size is a strength of this study as it has enabled a depth of analysis and it has allowed the voices of all eight men to be heard within my account in the Results chapter. The use of thematic analysis allowed for this in-depth exploration of these men's experiences, with time for each interview to be systematically analysed to ensure that the resulting themes and sub-themes captured their descriptions as fully as possible.

I will now consider my research in terms of Elliott, Fischer and Rennie's (1999) suggested guidelines for evaluating qualitative research. In terms of 'owning one's perspective', I have endeavoured to provide a transparent account of what brought me to this research, including sections to reflect on issues of reflexivity, and ensuring that my relevant personal and clinical background, values and assumptions are made clear to the reader. I have aimed to 'situate the sample' by providing demographic details about the participants in the study, and some brief details about the recruitment process; without compromising the anonymity of the men who took part, or their partners. Within the Results chapter, I have shown that the themes and sub-themes were 'grounded in examples' by illustrating the ideas with quotations from the participant interviews. I have also provided a step by step account of the process of analysis in the Methodology chapter and a worked example of the analytic process within the appendices.

As described in the Methodology chapter, the quality and 'credibility' of the themes derived from the data was supported by consultation and discussions with my supervisor who has extensive experience in conducting and supervising clinically related research. The themes and sub-themes are also supported by previous qualitative and quantitative data related to the topic, as explored earlier in this chapter. I have aimed to present an analysis of the data which achieves 'coherence and integration' by refining and summarising the themes, but by also providing a narrative account which reflects the similarities and differences

between the different participants' experiences, by providing illustrative quotes and identifying each participants' perspective and experience (using their pseudonyms). The 'specific research tasks' of this study have been presented in a transparent manner, without the aim of necessarily extrapolating the findings, but instead showing that these findings may have meaning if transferred to other men in a similar situation. The richness and depth of the data collected through individual interviews has previously been highlighted as a strength of this study, and has allowed for detailed analysis of these men's experiences.

Finally, it is hoped that this study will add to the reader's knowledge and understanding of men's experiences of relationship changes since their female partner's ABI. Throughout the early stages of this research, I consulted with several colleagues working with brain injury and the general sense was that doing this research would be of value and that these colleagues were awaiting the end result with interest. I hope that this account will provide some clinically relevant, useful and interesting information for clinicians working in the field.

4.3.2 Limitations of this study

It is worth noting that, although there was homogeneity within the sample recruited for this study, as all the participants were men who were still in relationships with their female partners who had an ABI, there were several heterogeneous aspects of the sample. For example, the ages of the eight men interviewed ranged from 32 years to 66 years, and the total duration of their relationships with their partners ranged from 5 years to 45 years. These differences were not taken into consideration during the process of data analysis, so it is unclear as to whether or not the age of the men or the duration of their relationship has any effect on their experience and their adjustment. In addition, the impact of participants' financial circumstances on their experience and adjustment could also have been looked into, particularly as most of the men talked about finances as significant. This information could have been collected alongside the other demographic information such as age, ethnicity and type of brain injury.

Furthermore, the men's partners had suffered a variety of different types of ABI, including subarachnoid haemorrhage, stroke (including as a result of surgery for a brain tumour), TBI, hypoxic brain injury, and encephalitis. Initially this study had aimed to recruit men whose partners had TBIs, but was widened to include all ABIs due to recruitment difficulties. The time since partners' ABIs also ranged from one year two months to 13 years, so some men had been living with the changes in their relationships for longer than others. Although this study identified many aspects of their experiences which were common across the sample, it could be argued that different types of ABI may have a differential impact on men, their partners, their relationships, and hence how they have adjusted, but this was not explored in this study.

In terms of recruitment, as described in the Methodology chapter, several avenues were pursued, beginning with contacting TBI family and carer support groups, and then widening the search to include ABI family and carer support groups, and NHS and non-NHS colleague contacts with brain injury survivors and their partners, as well as advertising the research through social networking sites. The final sample were mostly recruited via non-NHS colleagues, with only one participant having been recruited via a support group which his partner attended, one participant recruited through an NHS contact, and two participants having responded to social networking advertisements. In retrospect, I feel that pursuing the NHS recruitment options earlier in the process of research may have enabled me to recruit my sample more easily, and potentially to select participants on the basis of homogeneity of their experiences.

For the men who were recruited via the NHS and non-NHS contacts, it could be hypothesised that the group of men interviewed for this study tended to be 'success stories' and may, therefore, have been more willing to participate and to share their stories, than men who were struggling to adjust to their situation. During the recruitment process, I got the impression that my colleagues may have had particular men in mind before passing on the information about the research, and I wondered if those men might have been 'selected' in this way because they were coping so well, or because colleagues perceived them to be able to provide clear, eloquent accounts of their experiences. In the cases of

those men who responded to social networking advertisements, I got a slightly different impression, that these were men who felt the need to share their story either to help others, or because they felt that they had not received adequate support, and they may have viewed the research as a therapeutic opportunity for them in some ways. As a result of the recruitment avenues pursued, the final sample may have represented a group of men who had higher levels of motivation and less time-constraints or other demands, compared with other men in similar situations (as also suggested by Reid, Moss and Hyman, 2005), and there may be a 'hidden' group of men whose voices continue to be neglected because they are 'hard to reach' in terms of research, and accessing clinical services.

The chosen method of thematic analysis does facilitate the detailed analysis of the wider societal and other contextual discourses that may have influenced the ways that men experienced the phenomena of their partner having an ABI and the associated life and relationship changes. Although societal ideas about gendered ways of coping and gender roles have been briefly touched upon earlier in the Discussion chapter, this study may have been enhanced by the more in-depth exploration of these factors. In terms of the interview methodology, the open narrative question allowed for men to tell the stories of their experiences that seemed the most salient and important for the participants. However by using an open question, it could be argued that the intended primary focus on relationship changes and adjustment was somewhat lost. Due to the time-constraints of this research, it was not possible to carry out 'member checks' with the participants after the themes were gathered, which may have added credibility to the themes and enabled an additional layer of in-depth analysis to have taken place.

Alternatively, an Interpretative Phenomenological Analysis (IPA) methodology could have been employed in this study, given the focus on men's *experiences* of relationship changes and adjustment. Such a methodology would have allowed for the explicit acknowledgement of the double hermeneutic within the research process, that is, the participants making sense of their experiences, and myself, as the researcher, making sense of the participants making sense of their

experiences. Within an IPA framework, there would also have been scope for me to make my own reflections, within the analysis, about what the men may or may not have felt able to disclose within the interviews, given the multiple layers of context surrounding the interviews, for example, from the set-up and location of the interview, the influence of my age and gender on the interview, and the types of questions asked, to the wider societal discourses about what it is acceptable to disclose as a man, and expressions of emotion and distress.

Although the focus of this study was on men's experiences of relationship changes and adjustment, by interviewing these men on their own it could be argued that I missed out on the opportunity to further situate their experiences within the context of the couple dyad. Furthermore, although the primary purpose of research was about adding to the literature and existing understanding of the topic, by employing an alternative approach of interviewing couples together, a secondary therapeutic opportunity may also have been opened up, allowing both parties in the couple to witness each others' stories of their experiences of relationship changes and adjustment, as Bowen, Yeates and Palmer (2010) have suggested may be helpful.

4.4 Recommendations for future research

The findings of this study indicate that one of the most important recommendations for future research would be to further explore men's ideas about what support they would find helpful, as although men had mixed views about the professional support and advice they had received, there was no clear sense of what alternative types of support they would have liked. Findings from this type of research might usefully influence service development for the benefit of a group of men who might typically not access services or professional support.

In addition, replication of some of the aspects of this study may be useful with more homogeneous samples, for example, with men whose partners have TBIs as originally planned for this research, or comparing and contrasting the experiences of men whose partners have different types of ABI. Additional

studies might also compare the experiences of men of different ages and stages since their partner's brain injury. Recruitment of these different samples might be achieved by pursuing wider recruitment avenues, and with creative thinking to include the stories of harder to reach participants. More advertising of research within wider social media, as well as the longer-term follow-up of couples where the female partner has presented to hospital or an acute rehabilitation unit might be helpful.

This study suggests that further research should be conducted into the generally under-researched experiences of men, but perhaps employing an alternative qualitative methodology such as discourse analysis or Foucauldian Discourse Analysis to explore the ways in which men talk about and conceptualise their experiences after their partner's brain injury, and to allow for more detailed analysis and consideration of societal discourses and other contextual factors.

More focused research into the experience and process of adjustment after a partner's brain injury is indicated, making use of more focused interview questions to deconstruct men's ideas about what adjustment means and what 'good' adjustment looks like, as well gathering more detailed accounts of their own process of adjustment. Finally, given the acknowledgement that by interviewing men alone I have only seen one perspective, future research could focus on the experiences of the couple together by setting up a systemic interview with the couple dyad.

4.5 Implications for clinical practice

The current research findings have several implications for the clinical practice of professionals working with brain injury, and wider implications for service development and provision as well as relevant policies informing practice.

4.5.1 Wider implications

I was struck by men's accounts of the lack of awareness of brain injury and its effects within the general public. One recommendation is that further attention is paid to increasing awareness of brain injury amongst the general public;

initiatives such as 'Action for Brain Injury Week' run by Headway and recent newspaper articles (e.g., Wheaton, 2012) are starting to do this, but there is more work to be done. The portrayal of brain injuries in popular culture, such as on television shows, is often unrealistic, with the full spectrum of brain injury outcomes usually being ignored, in favour of more 'dramatic', 'black and white' outcomes such as being in a coma, or making a full and 'miraculous' recovery. These conflicting narratives about brain injury might lead to high expectations of recovery and other misconceptions about brain injury (Bowen, Yeates & Palmer, 2010). This was reflected in the findings of this study, with men feeling that others did not understand the subtleties of the challenges and changes they were faced with.

4.5.2 Information provision

Professionals working with ABI at all stages (from acute, to rehabilitation, through to many years post-injury) should endeavour to provide partners of people with ABI with as much information as possible about what is happening to their loved one. Gass and Brown (1992) recommend the clear provision of information to relatives about their family member's ABI, particularly feedback about neuropsychological assessments, and this can be applied to all clinically relevant information. Although the difficulty with providing accurate prognoses is acknowledged, increased transparency and communication regarding this position of uncertainty would likely improve partners' experience, and reduce their perception of professionals withholding information.

Information provision should be continuous and meet the ongoing needs of brain-injured people and their partners. For example, this study identified that men would have liked to receive information from 'day one' about what to expect, but some continued to struggle to understand what was happening several years down the line. Junque, Bruna and Mataro (1997) have suggested that relatives tend to require information about the effects of brain injury many years after it has occurred, perhaps due to psychological distress experienced by relatives because of the persistent effects of the brain injury on their loved one. This indicates that follow-up information-giving and ongoing access to information would be beneficial for partners and other relatives.

4.5.3 Routine access to support

Many men commented on the stigma associated with help-seeking, suggesting that a routine referral process for family members would enable partners, particularly male partners, to access help and support more easily. This may help to reduce the stigma and possible sense of shame that may come from admitting that you are struggling to cope and having to ask for help and support. Bowen, Yeates and Palmer (2010) have also pointed out that partners are frequently excluded by professionals as services are routinely organised around the brain-injured person in isolation, adding further support to the recommendation that partners and relatives must be included. Routine follow-up for couples several years after brain injury is also recommended, since the challenges couples face rarely stop at the point that rehabilitation stops; Wood and Yurdakul (1997) have suggested that at five to six years post-ABI, relationship separation rates are at their highest, with Yeates (2011) adding that couples may feel particularly isolated as services are rarely involved at this stage.

4.5.4 Further curiosity about men's support needs

This study provides further 'evidence' that many of the family and carer support groups are not meeting the needs of male partners, which is particularly problematic when the most common, and often the only, source of support which is offered to partners is professionals providing contact details for a support group. As previously described, it is recommended that researchers and clinicians undertake further investigation into the support needs and wishes of male partners. Clinicians could also contribute to this within their everyday practice by remaining curious about what individual men think might be helpful to them in managing the effects of their partner's ABI, and by thinking creatively about ways in which they can meet these needs. Given the issue of stigma raised by the participants in this study, it would be useful for clinicians to normalise and validate partners' need for support following their loved one's brain injury, particularly male partners.

4.5.5 A more systemic approach to rehabilitation

Brain injury services should aim to work with couple relationships as a routine part of the rehabilitation process, in addition to focusing on the 'direct' cognitive

and physical sequelae of ABI. Yeates (2011) has recommended that questions and conversations about intimacy, sexuality and other aspects of relationships should be covered by clinicians' assessments, and the current study also provides support for this recommendation, with most men commenting that they had never really been asked about the effects of the ABI on their relationship before. These conversations about closeness and about the effects on an ABI on a couple's relationship could be facilitated by the use of questions informed by systemic and narrative approaches, as also suggested by Bowen, Yeates and Palmer (2010).

4.6 Issues of reflexivity

Overall, during the interview process I was very aware of my privileged position as a researcher being able to hear these men's stories of their very personal and sometimes traumatic experiences. Prior to starting the interviews, I did have some concerns about how my own demographics might influence what men did and did not feel comfortable to share, given that I am a younger female in the relatively powerful position of conducting research as part of a doctorate level course. In addition, having been surrounded by societal discourses about gender in terms of coping and disclosure of feelings and personal stories, as well as having read research literature about gender differences in coping and adjustment, I may have brought some of these potential biases to the research process.

However, I was struck by the honesty within men's accounts and the sharing of some of the difficult dilemmas they have had to face, such as considering whether or not to stay in the relationship, and even whether or not to have an affair. Suggestions have been made about gender differences in disclosure being due to men's discomfort about sharing personal feelings, with Wood and Inman (1993) proposing that men may disclose less simply because they have less to disclose. I was surprised that neither of these ideas seemed relevant for the group of men I interviewed, with men actually disclosing quite a lot. The fact that the majority of these men shared such thoughts and dilemmas hopefully reflects a comfortable and safe space that I endeavoured to provide in all the interviews. In retrospect, I also feel that having the conversations in mutually agreed

locations, which for the majority were their own homes, helped to level any potential power imbalance, with myself positioned as a non-expert invited guest in their homes.

During the interviews I also became aware of the clash between my relatively new role as researcher with the role of therapeutic clinician, which I am more accustomed to. I found myself making a conscious effort not to fall into the role of a therapist, for example when men's accounts located the problem with their partners, I would have liked to have expressed some more curiosity about this and to have had some externalising conversations about the ABI. I also felt some discomfort with not hearing the voices of the men's female partners, particularly as I met some of them through the recruitment and interview process. I wondered what the women's ideas were about their partners taking part in the research, particularly in relation to their partners sharing personal stories about their relationships. The experience of conducting this research has added to my ideas about the type of psychologist I would like to be and has strengthened my conviction in the importance of working systemically and considering multiple perspectives.

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APPENDICES

APPENDIX 1 – Participant Information Sheet

‘The experience of adjustment to relationship changes in men whose female partners have an acquired brain injury (ABI)’

Emma Ferguson - Trainee Clinical Psychologist

Email: [REDACTED]

University of East London- Clinical Psychology Department

Water Lane, London, E15 4LZ

School of Psychology Research Ethics Committee Chair: Dr Mark Finn

My name is Emma Ferguson and I am training to be a Clinical Psychologist. As part of my training I am doing a research study looking at the experiences of men whose partners have had a brain injury. I would like to ask for your help.

What is the study about?

The study is about the process of adjustment in men whose partners have had a brain injury. I would like to talk to you about any changes in your relationship with your partner since their brain injury, and how you feel you might have adjusted to those changes. I would also like to talk to you about what you feel might be important in helping you to adjust to relationship changes.

Why is this study being done?

Currently there is little research exploring the experiences of men whose female partners have had a brain injury. This study will offer an opportunity for men to speak openly about their experiences since their partner’s injury, and to talk about some of the things that have helped them to adjust. I hope that this will help me and other health professionals to better understand what is important in helping men to adjust to relationship changes, and to learn about how we might work more effectively with couples and families in brain injury services.

What will it involve?

I would like to meet with men, like yourself, and talk with you about your experiences since your partner's brain injury. We can find a quiet, private place to talk; I can either come to your home, or meet with you in a room at a local brain injury support group or my university, whichever is the most convenient for you. I would like to tape-record our conversation, so that I can remember what you have said and then write an anonymous report on it. The conversation should take approximately 1 hour.

Do I have to take part?

No, it is up to you. If you do decide to take part, you can say as much or as little as you wish. I am only interested in what you want to say, not in making you say or do anything you do not want to. You can change your mind about taking part at any time. If you do not wish to take part or you change your mind at any point, this will have no effect on your relationship with your local services.

What will happen with the information that I discuss with you at the meeting?

After the individual meetings, I will write a report about what people have said. In the report, I might say exactly what you have told me, but I will not use your real name or any details which might identify you. The report may be published but I will discuss this with you before it happens and I will not use your real name or any other information that could identify you.

I will offer those who take part in this study a summary of the results and the opportunity to discuss any issues that come out of the meetings.

All of the information that I collect from people will be stored securely. This information will be destroyed at the end of the study.

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

Emma Ferguson

Trainee Clinical Psychologist- University of East London

APPENDIX 2 – Participant Consent Form

‘The experience of adjustment to relationship changes in men whose female partners have an acquired brain injury (ABI)’

Emma Ferguson - Trainee Clinical Psychologist

Email: [REDACTED]

University of East London- Clinical Psychology Department
Water Lane, London, E15 4LZ

School of Psychology Research Ethics Committee Chair: Dr Mark Finn

This form is for you to fill in to show that you have agreed to take part in this study. Please read each section and circle yes or no to say whether you agree.

Name of person taking part _____

Emma Ferguson has explained this study and I understand what she is asking me to do. I have read the information sheet myself or through an interpreter and I have been given a copy to keep.

Yes/ No

I understand that I do not have to take part and that if I do take part, I can stop whenever I like.

Yes/ No

I understand that the things I say may be written down and directly quoted in the final report. I also understand that this may later be published but my real name and any other details that may identify me will not be used.

Yes/ No

I agree to take part in this study by Emma Ferguson.

Yes/ No

I agree to the discussion being audio- recorded.

Yes/ No

Signed by the person taking part: _____

Date: _____

I, Emma Ferguson, have fully explained to the participant what is involved in this study.

Signed by researcher, Emma Ferguson: _____

Date: _____

APPENDIX 3 – Ethical approval from the University of East London

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.
 uel.ac.uk/psychology



Doctoral Degree in Clinical Psychology Direct Fax: 0208 223 4967

June 2011

Name of Student	Emma Ferguson
Title of Research Project	An exploration of the process of adjustment in men whose female partners have experienced a traumatic brain injury (TBI).

To Whom It May Concern:

This is to confirm that the above named student is conducting research as part of the requirements for the Professional Doctorate in Clinical Psychology. The Ethics Committee of the School of Psychology, University of East London has approved their proposal and they are, therefore, covered by the University's indemnity insurance policy. This policy should normally cover for any untoward event provided that the experimental programme has been approved by the Ethics Committee prior to its commencement. The University does not offer "no fault" cover, so in the event of untoward event leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the above named is a student of UEL the University will act as the sponsor of their research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Kenneth Gannon PhD
 Research Director

Dr Martyn Baker 020 8223 4411 M.C.Baker@uel.ac.uk
 Dr Maria Castro 020 8223 4422 M.Castro@uel.ac.uk
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Dr Nimisha Patel 020 8223 4413 N.Patel@uel.ac.uk
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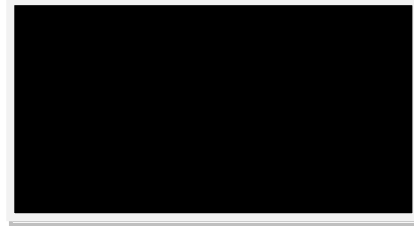
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APPENDIX 4 – Ethical approval from NRES Committee



Health Research Authority



17 January 2012

Miss Emma Ferguson
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
School of Psychology - University of East London
Water Lane
Stratford
E15 4LZ

Dear Miss Ferguson

Study title: The experience of adjustment to relationship changes in men whose female partners have experienced an acquired brain injury (ABI)
REC reference: 11/LO/1912
Protocol number: N/A

Thank you for your letter of 11 January 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by me (Committee Chair).

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation as revised, 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).

Non-NHS sites

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

It is the 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).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	1	03 November 2011
Evidence of insurance or indemnity		01 June 2011
Interview Schedules/Topic Guides	1	03 November 2011
Investigator CV		03 November 2011
Letter of invitation to participant	1	11 January 2012
Other: Email clarification from Emma Ferguson re: sponsorship		15 November 2011
Participant Consent Form	1	03 November 2011
Participant Information Sheet	3	16 January 2012
Protocol	1	03 November 2011
REC application	1	07 November 2011
Response to Request for Further Information	Emails from Emma Ferguson (11th and 16th January 2012)	11 January 2012

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

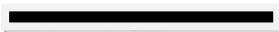
11/LO/1912 **Please quote this number on all correspondence**

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

Yours sincerely




Chair

Email: 

Enclosures: "After ethical review – guidance for researchers"

Copy to:


(Sponsor Contact)
School of Psychology, University of East London
Water Lane
Stratford
London E15 4LZ



APPENDIX 5 – Semi-structured Interview Schedule

interview schedule

Before interview:

- Read participant information sheet
- Sign consent form
- Checklist re brain injury information:

“Before we start, I just need to ask you a few practical questions”

What type of brain injury did your partner have?

How long ago was her brain injury?

How long have you been together as a couple overall?

Some explanation:

This interview will be split into 2 sections; in the first section I will ask you a very open question about your experiences, and in the second section I will follow up any topics that I’m interested in hearing more about.

1. Initial elaboration of story around topics (using a single question aimed at inducing narrative)

This interview is interested in *your* experiences since your partner’s brain injury.

Tell me about your partner’s brain injury, what changes have happened in your relationship since then, and how you have adjusted to those changes until now.

Short break

2. Briefer follow-up section of interview – asking additional questions about topics raised by the participant, in the order they raised them, using their own words (using topic questions aimed at inducing narrative)

Ideas I'm interested in hearing about:

- What changes in their relationship with their partner they have experienced since the brain injury
- How they have adjusted to these changes in their relationship with their partner
- What factors they feel have been important in contributing to their process of adjustment

Topics raised by participant

APPENDIX 6 – Example annotated transcript

Notes / Ideas		Codes
	1 erm and everything went ok, yeah she was alright. Erm but it's an odd scenario because	
	2 Chris is starting to develop a character, he's now you know growing up and er his	
Son reminds him of Sis' Anna	3 character is very like his mum before and that's a very bizarre experience because er	her lack of awareness
she doesn't know what she was like	4 Anna doesn't recognise that but I do, so I mean Chris and I have become very close,	
	5 and it's not an unhealthy relationship, it's very loving and it's nice, but it's a bit odd	
	6 sometimes because he reminds me of her, her before, he has a lot of her sort of	making comparisons to before the brain injury
finding it hard to cope / 'deal with'	7 sensitivity and kind of shyness and erm kind of gentle, I suppose feminine qualities	
	8 really although he's a little boy, and erm you know that's quite a difficult one to deal	
	9 with, you know, and it's only, the realisation of that is really probably only in the last	
	10 six months, you know as he starts to be more of a little character. You know pre-five,	
	11 erm I think a lot of children they are just children, but he's now developing this	
Reminds of past, 'Sis' Anna	12 character, and you suddenly think god that's so like Anna. Erm so that's the latest,	
	13 that's where we're up to at the moment really, and we're committed to keeping our	Reasons for staying together
commitment to relationship	14 relationship working and it's very hard work sometimes, but we do want it to work,	- kids, strength of relationship.
	15 partly for Chris, erm but also just erm we had such a lot of investment in that	
Sadness, loss, love	16 relationship before, you know, we, you know, before, prior to the subarachnoid	Loss of person connection
	17 haemorrhage erm you know I can truly say this was the love of my life, you know this	Emotion - anger
	18 was something really amazing and special, and our compatibility was 100% erm and	
	19 I miss that, and if I had an overriding emotion about what happened it's anger really,	
angry feelings - Stock of it all.	20 and I'm quite angry because we had something really special and it was taken away,	
	21 just like that one day, and erm that anger for me causes a lot of tension, I end up	ways of coping - therapy, relaxation.
	22 quite tense physically erm and I try relaxation exercises and I've tried lots of talk	
	23 therapies, you know I've talked to quite a few people, a clinical psychologist in fact at	
	24 the hospital which is our local erm health centre and erm I've talked to an independent	
	25 erm kind of sort of, what's the word?	
	26 Int: is it like a counsellor or something like that?	
	27 P8: counsellor, counsellor's exactly the right word. I've talked to an independent	Emotion - anger
things help but don't take away pain/ reality of situation	28 counsellor, but it, it all helps a bit but I still feel, you know there's an underlying anger	
	29 and underlying resentment I suppose. And I've dried up, sorry!	
	30 Int: no you've said a lot, that's really useful. What's it like talking about this?	
	31 P8: it's traumatic	
	32 Int: is it	
	33 P8: yeah, because in order to function in daily life you kind of bury it and get on with it	ways of coping - just get on with it
	34 Int: ok, I'm just wondering if you've ever really told the story in one go before	
Talking about talking	35 P8: oh yeah, it's very challenging and it continues to be very challenging and erm and	making comparisons to before the brain injury
	36 every day is a challenge, and you know every day there's a reminder that there's	loss of connection
	37 something not quite right here <Int: yeah> and possibly, and I think this is quite	

"Sensory
"not quite"
of "not quite"
→ loss of
connection?
→ "not quite"
disturbance?"

new friendships
but may
could cope
to be able
brain
wiring

diff. activities
(personality)

preferred
shy-er
invention
of Anna

no-one
to talk to
? research
for telling
poor in
the
research
- therapist

38 important. We've moved, when this happened we were based in London, and we're
39 now in the [redacted] erm there's nobody here who knows Anna 1, nobody
40 within our neighbourhood or even within the county who knows Anna 1, except
41 myself and Anna's mother, and Anna's mum has been a great sounding board really
42 because she is the only other person in the world who understands what's going on,
43 so we talk to each other quite a lot, and she asks me how Anna is, and she's quite
44 angry, she's quite erm she wishes she had her daughter back, she's got a different
45 daughter, so I mean that's the best line of communication is actually with her mum,
46 because her mum knows, she understands the difference <Int: mm> most people,
47 and since we've moved up here Anna's acquired a new set of friends, through her
48 political activities mostly, and those relationships are based on the Anna now, and
49 they have no reference point to anything else, so I feel very isolated a lot of the time
50 because if I question anything, it's kind of what's wrong with you, what's your
51 problem, because I'm referring to someone they'd never met, they don't know what
52 I'm talking about so that's quite hard

Int: I wonder with those friends, are they the types of people that Anna 1 would have
54 been friends with, or are they quite different?

P8: they're very different <Int: yeah so that must be...> yeah they all have that same quite
55 outgoing, erm quite sort of erm in your face attitude, which is fine you know, and
56 they're interesting, and I'm on good terms with those friends but they're, they're not
57 perhaps people that Anna would have associated with before, the other Anna, so I'm
58 feeling more and more alienated because it's kind of erm I've got a nostalgia for
59 something that's only relevant to me, it doesn't have any focus point. I mean so
60 talking like this is great actually because it erm you know when your colleague
61 suggested that you might wanna talk I was actually really pleased because erm the
62 last time, because we're still seeing a counsellor, do you know about that?

Int: no
64

P8: oh!
65

Int: I don't know much at all about your circumstances, erm [redacted] just erm, I was in
66 touch with her through my research anyway <P8: oh ok> and she said she knew your
67 family
68

P8: yeah [redacted] is still counselling us, erm we see her perhaps once every couple of
69 months, she's been very helpful and very supportive, erm I can't remember why I
70 was telling you that
71

Int: erm because you're still receiving counselling, oh you said something about talking
72 like this being helpful
73
74

- isolation
- support
- emotion
- loss of person

Changes in friendships

- isolation
- others' understanding of brain injury

- Making comparison to before brain injury

- isolation
- Making comparisons

- ways of coping
- talking

ways of coping
- preferred support

APPENDIX 7 – List of initial codes generated for all transcripts

Adjustment – accepting things as they are
Adjustment – as she recovers
Adjustment – as time passes
Adjustment – making allowances
Caring role
Change in nature of relationship
Change of identity/status
Changes in friendships
Comparison to a child
Comparison to worst case scenarios/ counting self lucky
Confusion
Emotion – anger
Emotion – anxiety/ fear
Emotion – frustration
Emotion – guilt
Emotion – loneliness
Emotion – love
Emotion – sadness, despair
Emotion – shock
Exaggerated version of before
Expert on her and the brain injury
Fighting for care
Financial impact
Helping/advice to others in similar situation
Her continuing to change into different person
Her lack of awareness
Hidden disability
How noticed things weren't right
Impact on his mental health – incl. self-esteem
Isolation
Keen to retain sense of normality
Lack of information
Life put on hold
Looking for explanations
Loss of connection
Loss of person – to relate to
Loss/change of sexual relationship
Making comparisons to before the brain injury
Misunderstood
Needing a break
New lifestyle
No-one else can care for her
Others' understanding of brain injury
Overwhelming
Practical/ physical adjustments
Prior knowledge or experience of brain injury
Professional support and advice
Reasons for staying together – age

Reasons for staying together – best option
Reasons for staying together – children
Reasons for staying together - other people
Reasons for staying together - strong marriage
Reasons for staying together - their shared history
Recommendations for professionals
Same but different
Seeing her character in their child
Seeing positives
Sense of duty
Sense of entitlement
Sense of responsibility
Sense of unfairness/injustice
Social support
Symptoms/signs
Uncertainty
Unexpected
Ways of coping – avoidance
Ways of coping – carry on like before
Ways of coping – depersonalising her
Ways of coping – developing sense of balance
Ways of coping – faith
Ways of coping – finding information
Ways of coping – focusing on children
Ways of coping – gendered ideas about how men cope
Ways of coping – get on with it
Ways of coping – hope for recovery
Ways of coping – making sure she's doing things
Ways of coping – practical strategies
Ways of coping – reassuring self
Ways of coping – relaxation
Ways of coping – routine
Ways of coping – talking to others
Ways of coping – using respite
Ways of coping – using work

APPENDIX 8 – Initial themes and sub-themes

Theme	Sub-themes	Categories within sub-themes
How it all started	Symptoms/ signs things not right	
	Looking for explanations	
	Shock/ All so unexpected	
	Confusion and uncertainty	
Prior knowledge or experience of brain injury		
Changes in brain-injured partner	Hidden disability – looks same but is different	<i>Continues to become more different over time</i>
	Exaggeration of previous characteristics	
	Comparison to a child	
	Her lack of awareness of changes	
Changes to relationship	Overall sense of loss	- <i>Person to relate to</i> - <i>Sexual relationship</i> - <i>Connection</i>
	Making comparisons to before brain injury	- <i>Comparing her to before</i> - <i>Comparing relationship to before</i>
	Change in nature of relationship	
	Reasons for staying together	- <i>Sense of duty</i> - <i>Best option</i> - <i>Shared history,</i> - <i>Children</i> - <i>Age</i>
Emotional impact on him	Frustration	
	Anger	
	Sadness	
	Anxiety/ fear	
	Sense of unfairness, injustice and entitlement	

Practical impact on him	Financial impact	
	Changes/loss of friendships	
	Change in lifestyle	- <i>New lifestyle</i> - <i>Change of identity/ status</i>
	Life put on hold	
Sense of responsibility	Guilt	
	Feeling overwhelmed	
	Caring role	
Others don't understand	Expert on her and on brain injury	
	No-one else can care for her	
	Feeling isolated and lonely	
Ways of coping	Emotional Strategies	- <i>Get on with it</i> - <i>"It could've been worse"</i> - <i>Seeing positives</i>
	Practical Strategies	- <i>Relaxation</i> - <i>Respite</i> - <i>Faith</i> - <i>Talking to others</i> - <i>Focusing on children</i> - <i>Finding information</i> - <i>Using work</i> - <i>Making allowances</i> - <i>Physical adjustments</i> - <i>Establishing routine</i>
	Adjusting	- <i>Letting time pass</i> - <i>As she recovers</i> - <i>Acceptance</i>
Sources of support	Professional support	- <i>Helpful professionals</i> - <i>Lack of information</i> - <i>Fighting for care</i>
	Social support	
	Recommendations	- <i>Recommendations for professionals</i> - <i>Advice/help to others</i>

APPENDIX 9 – Themes and sub-themes for all participants

Theme <i>(and description)</i>	Sub-theme <i>(and description)</i>	Data extract	Notes
<p>1. Initial reactions to the brain injury</p> <p><i>All participants began answering interview question by telling me about how they realised something was wrong. For TBIs, men received phone calls etc. For ABIs men saw signs and behaviours that were out of the ordinary for their partner. Men talked about feelings of confusion and anxiety about what was happening and how things would turn out. Men looked for explanations about what was happening and in some cases had to 'fight' for medical recognition that something was wrong. It seemed like they hoped by finding an explanation, their feelings of fear, uncertainty and confusion would be alleviated. Explanations most commonly first drawn upon</i></p>	<p>N/A</p>	<p>P1. "I'm sure one of the things that threw me when we started out here, having always been somebody who knew what was going on, to suddenly knowing nothing about what was going on was pretty scary I suspect"</p> <p>P1. "it was like going into a wall, quite literally, as in I wonder what that means"</p> <p>P1. "she was getting on a plane... suffering a migraine"</p> <p>P1. "then we found out about the subarachnoid haemorrhage"</p> <p>-----</p> <p>P2. "even though the doctors haven't said categorically what it was caused by, they said they are 95% sure it was caused by the type of pill she was on, the microgynon pill"</p> <p>P2. "I didn't know what was wrong with her, I just sat her on the bed, erm did a few like basic tests, like put your arms out straight, you know, stand on one leg, the usual, touch your nose, everything seemed normal"</p> <p>P2. "I phoned up a friend of ours who's a pharmacist, she said she could have a really bad migraine cos she'd had something similar before"</p> <p>P2. "off I went to A and E, erm...we got there about midday, it wasn't until 10 o'clock that night before she had a CT scan which is a long time, you know, they confirmed yes she's had a large stroke"</p> <p>P2. "yes I understand she had a stroke cos I've obviously known</p>	<p>- <i>Not knowing what was happening, feeling afraid and experiencing uncertainty</i></p> <p>- <i>No prior experience to draw upon re his partner's diagnosis</i></p> <p>- <i>Signs something was wrong</i></p> <p>- <i>Value of receiving a diagnosis</i></p> <p>- <i>Looking for explanations and causes of the ABI</i></p> <p>- <i>Looking for explanations</i></p> <p>- <i>Looking for explanations, drawing on 'expert' advice and prior experience of his partner's illnesses</i></p> <p>- <i>Value of medical opinion, dissatisfaction with speed of medical intervention, receiving a diagnosis</i></p> <p>- <i>Drawing on prior</i></p>

<p><i>were related to men's prior experience or knowledge of brain injury, which in different cases helped or hindered the process of sense making.</i></p>		<p>people who have had stroke in the past"</p> <p>P2. "she had gone downstairs, she came back upstairs, I can't tell you what time, erm and she just couldn't speak. You know, she had none of the, you see the advert n the telly for stroke, nothing like that whatsoever, there was no sign, no visible signs, nothing...she was laughing, seemed quite normal, quite well happy in a way, just couldn't stop laughing for some reason, and then but she couldn't say anything else"</p> <p>-----</p> <p>P3. "I can remember those five days, ringing up every morning saying is she alright, so it was a bit scary, so I was a bit less sortof worried about that"</p> <p>P3. "I didn't know at that time that she'd had a brain injury, she was in A and E and she wasn't speaking at all and I didn't for one minutes think it was a brain injury... I went back to see her the next morning and erm she'd been moved to the neurological ward and I thought bloody hell, and erm so it was all a bit of a shock really"</p> <p>P3. "no one was quite sure how, well we sortof knew that there wasn't a big problem, because it was obvious when came out of [rehab unit] but no one quite knew how it was going to work"</p> <p>-----</p> <p>P4. "I think it was til the Monday or even the Tuesday that a senior brain doctor eventually said this is herpes encephalitis and I was, well what on earth's that"</p> <p>P4. "her mum called and noticed there was something wrong as she was talking to [wife's name] and she's just not making sense"</p> <p>P4. "I thought sometimes when you're feverish you know, you're sortof speak in tongues, and you sortof say funny, funny things"</p> <p>P4. "it was very difficult just not understanding what on earth was</p>	<p><i>experiences to make sense of situation</i></p> <ul style="list-style-type: none"> - <i>Signs that something was wrong, trying to make sense by drawing on frame of reference re strokes but did not make sense to him as not congruent with his previous ideas about stroke</i> - <i>Fear, uncertainty</i> - <i>Not so worried to start with – then reality and enormity of brain injury came as a shock</i> - <i>Uncertainty, need to 'get on with things' to see how they go</i> - <i>Took a long time to find out what was wrong, and even then, didn't make much sense</i> - <i>Ways/people who noticed things were not right</i> - <i>Trying to make sense of symptoms, looking for explanations</i> - <i>Uncertainty, confusion, fear</i>
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		<p>happening, you know really that was, that was the scary thing for a few days”</p> <p>P4. “no-one knew what on earth was going on”</p> <p>P4. “she came home from work one day with an absolute splitting headache”</p> <p>P4. “she had a really bad headache and she was starting to talk funny”</p> <p>P4. “so she goes to the doctors and they send her to hospital, think it might be meningitis and it’s not, so we’re relieved, she goes back home”</p> <p>-----</p> <p>P5 “she woke me up and said I don’t feel very well, before I got around to the other side of the bed, she was er, she lost consciousness and her heart had stopped”</p> <p>-----</p> <p>P6. “I kept taking her to the GP and the GP said she’s stressed, so eventually I ended up taking her to a private psychiatrist, had a scan, and discovered she had a rather large tumour in her head, yeah in fact we took her to A and E and they said well she’s stressed, then saw the local mental health people and they said she’s fine as she could remember what day it was, that particular day was quite unusual for her”</p> <p>P6. “I was expecting her to be away for about a week, so not quite what I expected, well not really given any idea, I know they can’t tell, well everybody’s different, but we weren’t really given much indication of what to expect”</p> <p>P6. “we first noticed her eye sight was going a bit funny about the turn of the year... then her memory started going a bit funny”</p>	<p>- <i>Uncertainty</i></p> <p>- <i>Signs something was wrong</i></p> <p>- <i>Signs something was wrong</i></p> <p>- <i>Medical investigations – initially relieved, but still not finding an explanation</i></p> <p>- <i>Ways knew something was wrong, sudden nature</i></p> <p>- <i>Persistence, fight for medical recognition, dissatisfaction with explanations and diagnoses initially given, frustration at various different teams</i></p> <p>- <i>Uncertainty, lack of info about what to expect, how long it might take to recover from a brain injury</i></p> <p>- <i>Ways noticed something was wrong</i></p>
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		<p>P6. "well I suppose the start was that it was quite stressful to start with because her memory was going, before we knew what was wrong with her, er and I couldn't really understand it, asking the same question over and over again, all this kind of stuff which got kind of very stressful"</p> <p>-----</p> <p>7. "me never really understanding what it really meant, what was going on"</p> <p>-----</p> <p>P8. "[girlfriend's name] went upstairs to the studio and had her picture taken and then collapsed and erm fortunately the gentleman who was taking the picture, his day job was a policeman and he immediately spotted the symptoms of a brain haemorrhage, erm because she seemed kindof drunk and sortof really out of it as well as the fact that she'd physically collapsed"</p> <p>P8. "I said look I'm pretty sure that something is really badly wrong her, [girlfriend's name] is behaving bizarrely, could you please look into it urgently. Fortunately the registrar believed me, and erm she was put in for an MRI scan almost straight away after that"</p>	<p>- <i>Uncertainty, didn't know why she was acting as she was, caused strain on relationship at times because of lack of understanding</i></p> <p>- <i>Confusion, uncertainty, lack of knowledge</i></p> <p>- <i>How the brain injury happened, looking for explanations, drawing on others' experience and knowledge</i></p> <p>- <i>Fighting for medical recognition - relief</i></p>
<p>2. "She's a lot the same, but she's not the same"</p> <p><i>Men referred to the hidden nature of the difficulties or disabilities resulting from their partner's ABI, making it hard for others to understand. Often emphasised the 'normal' appearance of their partner. Men said their</i></p>	<p>N/A</p>	<p>P1. "if you met her you would think she was someone who had a car accident and had broken her legs, and in other words, she speaks fine, she laughs, makes jokes, erm coherent etc, that's very different from some very severely disabled folk who just exist"</p> <p>P1. "she's a lot the same, but she's not the same"</p> <p>P1. "the difficultly people have who engage with her infrequently if that she comes across absolutely normal"</p> <p>-----</p> <p>P2. "since the stroke she's become more she'll admit it herself, a lot more paranoid, you know, more paranoid, more, she was a little bit of</p>	<p>- <i>'Normal' appearance, comparing to others in worse situations</i></p> <p>- <i>Trying to put into words her change in character</i></p> <p>- <i>Others don't understand because she looks 'normal'</i></p> <p>- <i>Exaggeration of previous characteristics</i></p>

<p><i>partners looked the same or very similar but had undergone a change in character, whether fundamentally, more subtle, or an exaggeration of previous characteristics.</i></p>		<p>a worrier before but now, good god, she worries about anything and everything”</p> <p>P2. “the people that see her at work, she had the stroke and then went back to work, and looks exactly the same”</p> <p>P2. “as I say it’s a disability you can’t see, so which makes it even harder, like when she first went to the stroke club people looked at her and said what’s wrong with you, so it made her sortof alien in a way”</p> <p>P2. “before she’d just go up and talk to anybody randomly and just bla bla bla, but now she won’t.... that’s a big difference in her, she’s a lot more reserved now with regards to people”</p> <p>P2. “everything seems to have been exaggerated big time now”</p> <p>P2. “everything she does now, she used to do before, but greatly exaggerated now, since she’s had the stroke... everything seems greatly exaggerated now”</p> <p>P2. “her friend didn’t really understand too much about it and even now she’s still trying to understand what she’s going through, but she just can’t grasp it in a way, you know, what’s happening, because she looks so normal, you know, you would’ve think anything was wrong, you know this is why a lot of people find it hard”</p> <p>P2. “I mean now you can’t tell a difference, she’s just like you or me, you can’t tell any difference whatsoever, you would’ve even know she’d had a stroke”</p> <p>P2. “I mean to look at her and talk to her, there’s no difference whatsoever”</p> <p>P2. “she’ll have to pick a fault in something, she did it before, whereas now she has to find a fault with something when she comes home, she’ll find a fault you know, whatever, she has to find a fault,</p>	<p>- <i>Others don’t understand because she looks the same – then don’t make allowances</i></p> <p>- <i>hidden disability, feeling different even at stroke club, not same ‘extreme’ difficulties as he would expect from a stroke</i></p> <p>- <i>Comparing to before – she is now less confident and more shy</i></p> <p>- <i>Exaggeration of previous character</i></p> <p>- <i>Exaggeration of previous character</i></p> <p>- <i>Friends not understanding, even a friend who had prior experience of knowing someone who’d had a stroke</i></p> <p>- <i>‘Normal’ appearance – however this description is slightly incongruent with his previous reports of her having many difficulties</i></p> <p>- <i>Ditto for this extract</i></p> <p>- <i>More arguments since brain injury, she picks more faults</i></p>
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		<p>she has to pick an argument for something”</p> <p>P2. “she’s just like a normal, a normal everyday person, you know that sort of thing, and you can’t tell, she just gets on with life and seems perfectly normal”</p> <p>P2. “she’s like a, how do I describe, a Jekyll and Hyde, you, we’ll go out to friends, family, and go out and about and everything else and she’s a different person, nice as pie, you know... and yet as soon as we get in the car, soon as we get home, it’s like she’ll instantly change back and then just start moaning and groaning about anything and everything”</p> <p>P2. “she’s the worst one for lateness, she’s always late, always has been, that’s always been the same anyway, but she’s got worse since then”</p> <p>P2. “the Jekyll and Hyde thing I’d say is, was always probably there to a certain extent... but it’s obviously more exaggerated now she’s had the stroke, and so it’s always been there to a certain extent, but it’s but she can never see it, she can never ever, ever see it”</p> <p>P2. “you mention the word stroke, the first thing they think of is like you see on the telly you know, the arm, all floppy and everything else, but they see [girlfriend’s name] and think what’s the matter with you, you look absolutely fine, they don’t see what’s going on inside, you know, they don’t seem to understand what’s going on inside her head”</p> <p>-----</p> <p>P3. “I don’t think if you’d met her not knowing, I don’t think you would’ve thought she’d had a brain injury”</p> <p>P3. “you wouldn’t know, one wouldn’t know unless you knew that she’d had problems”</p> <p>-----</p>	<p>- <i>emphasis that she’s ‘normal’</i></p> <p>- <i>extremes in her character and moods now; seems to affect him and their relationship more than other friendships</i></p> <p>- <i>exaggeration of previous. Lateness is undesirable from his perspective?</i></p> <p>- <i>again, exaggeration of before, she’s not aware?</i></p> <p>- <i>Not like the telly advert, not as extreme, hidden disability, not completely making sense to him, others not understanding</i></p> <p>- <i>Hidden disability</i></p> <p>- <i>Only apparent to those who know her well?</i></p>
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		<p>P4. "it wasn't just an ordinary injury where it's like oh I can see you've got a broken leg or oh that scan says you've got a tumour, or... something you just couldn't understand"</p> <p>P4. "it you know, really changed who she, who she was, quite fundamentally, but still er you know, loving and kind person you know, and she's very attractive and you know, she's a different person but not different in such a way that, like who are you, I don't recognise you, it's like ok, you haven't got these characteristics anymore"</p> <p>P4. "She was very tired as well, I mean she's always been one of those people who likes a lie in and that sortof thing but it got a bit silly, just feeling really, really tired and washed out and knackered"</p> <p>P4. "there's kindof a stigma to it, about having a brain injury, if she, if she bust her leg permanently, she'd always be in a wheelchair, always having her crutches, people would like just see it... because people don't see the brain injury, and her crutches as such are her mobile phone and her notebook, her diary that she always takes with her, they might not appreciate what her problems are"</p> <p>P4. "it's a fair sortof thing to say, old [wife's name], new [wife's name], I don't think I see old [wife's name] all that much"</p> <p>-----</p> <p>P5. "she might be physically looking quite similar but just poles apart from the things you'd normally interacted with"</p> <p>-----</p> <p>P6. "she looks similar but not really the same personality and I think also her, a general thing about seeing people who are very ill, they can only think of themselves, a bit like a child I suppose, can't ask how you're doing"</p> <p>-----</p> <p>P8. "[girlfriend's name] 2 as we now started to call her, within 6</p>	<p>- Not a 'straightforward' injury, unclear trajectory, can't understand sequelae</p> <p>- Fundamental change in character, stating what's still similar, hard to put into words what's different, more of a sense that she is different as a person</p> <p>- Exaggeration of previous – tiredness as a negative or undesirable characteristic?</p> <p>- Hidden disability, stigma, others not understanding, suggestion that people might understand more if it was a visible disability</p> <p>- Idea of partner as version 1 and version 2?</p> <p>- Looks the same, different person, different interactions and responses?</p> <p>- Looks the same, different character. Comparison to a child – if you're ill, you cant consider others' feelings, including his?</p> <p>- Idea of partner as version 1</p>
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		<p>weeks of surgery she was working again, and in kindof a very unusual way, you know a way that was not characteristic of her previous behaviour, very erm controlling and very kindof erm uninhibited, erm wanting to be in charge which was kindof really strange and erm, that change in character has remained”</p> <p>P8. “it needs more understanding, it needs more recognition that, you know, you can end with a situation where you’re living with someone who looks the same but isn’t the same, is a different character and is becoming more different”</p> <p>P8. “it’s a completely different kind of character, you know that had never been there before, from a very shy, almost introverted person to someone who’s very out there, and I think probably the most disconcerting thing for me as her partner is whilst she looks the same, she’s a different character”</p> <p>P8. “it’s still an odd experience, especially as this person looks like the other person but patently isn’t”</p> <p>P8. “She’s often very perplexed, you know, she’s kindof, she’ll go ‘what?’ because she doesn’t know what I’m talking about, and if I refer back to the [girlfriend’s name] pre the subarachnoid, she has no idea who I’m talking about at all, who was that person you know, but she’s sitting there and she looks like that person, and that’s erm, that’s very strange.... you find you’re living with a different personality, erm it’s very odd”</p> <p>P8. “so as a partner, it’s odd cos I sometimes feel I’m living with a stranger who’s becoming stranger”</p> <p>P8. “something that I hadn’t anticipated, erm is that she’s on a trajectory and is carrying on on that trajectory, so she’s not, it’s not just different, but she’s becoming more different”</p> <p>P8. “she had trained as a musician and although she played quite good flute would never play in public, in front of other people, she</p>	<p><i>and version 2? Disinhibition, very different character to before the injury - seems he expected her character might return?</i></p> <p><i>- very important to him to tell me that her character has continued to change and evolve more into her new character</i></p> <p><i>- disconcerting and almost disturbing that she can look the same but be different</i></p> <p><i>- effect on him that she looks the same but isn’t</i></p> <p><i>- her lack of awareness of the fact that she’s different adds to his sense of discomfort and the strangeness</i></p> <p><i>- living with someone who’s a stranger</i></p> <p><i>- again, the point about her becoming more different and continuing to change</i></p> <p><i>- an example of how she is different – an extreme way</i></p>
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		<p>was always inhibited, too shy to play in front of people which had always puzzled me because she seemed to be able to do it quite well, but the second time she as in hospital she asked me to bring her flute into the hospital so although it was a bizarre request, I did and I took it into the ward during day time and erm she took the flute out of its box and then gave a serenade to the whole ward which was really, you know, unusual and unexpected because she'd always been so inhibited before"</p> <p>P8. "the following day I returned again to see [girlfriend's name] and erm I entered the ward and she greeted me stark naked and she walked the whole length of the ward stark naked, and erm didn't think that was at all unusual, for her that seemed a kindof normal behaviour, and obviously I was a bit thrown by that"</p>	<p><i>that he first noticed she might be different</i></p> <p><i>- another example of how her character had changed – the shock that he experienced</i></p>
<p>3. Relationship changing</p> <p><i>Men spoke of numerous changes in their relationship since the brain injury with feelings of sadness and yearning for the relationship that once was.</i></p>	<p>Changes in the nature of the relationship</p> <p><i>Many aspects had changed, including sexual relationship, intellectual interactions, connection, closeness etc.</i></p>	<p>P1. "I talked a bit with the chap at [carers organisation] and bizarrely the conversation went as far as well you might need to start, you might need to have a girlfriend and start an affair because you are not going to get adult interaction with her, not of the level that you had beforehand...but anyway I mean that hasn't happened and I haven't felt the need for that to happen but I do miss the intellectual stimulus"</p> <p>P1. "we still certainly don't relate as we used to and that's been the biggest loss, erm ours was quite an intellectual relationship if you understand what I mean"</p> <p>-----</p> <p>P2. "it [the worrying] has put a strain on the relationship, quite a big strain at some stages"</p> <p>P2. "some people that I've known in the past, you know, if something major happens within their lives they can say that's brought them closer together, but personally I think it's pushed us further apart"</p> <p>-----</p> <p>P4. "I would love, you know, to have that challenge again, at times it</p>	<p><i>- Loss of intellectual connection, loss of sexual relationship</i></p> <p><i>- Loss of intellectual connection, emphasised that this was important to them</i></p> <p><i>- Her worries have changed the relationship, it's now less relaxed</i></p> <p><i>- Significant negative impact of brain injury on the relationship</i></p> <p><i>- Less of an 'equal'</i></p>

		<p>can get a bit easy for me and I can get the opportunity to manipulate, that's probably not the right word, but to work, to work things my way you know"</p> <p>P4. "because she's spent so much time at home... what did you do today – got up, walked into town, went to Boots, got the meal deal, came home, watched countdown, and so that would make it difficult sometimes to actually, as a couple, talk, and before her illness we were the biggest pair of gasbags ever, we could talk about anything, absolutely everything, erm it became a struggle and I would find myself always trying to force the conversation"</p> <p>-----</p> <p>P5. "I do find that kindof, I don't know, I suppose worrying in some ways because it's one the sortof, even at the lowest level of intimacy, it's one of the things that is different from everybody else, that's what makes you a couple, one of the things that makes you a couple, and I kindof worry if, you know, for the long-term whether that doesn't cause you to change that kindof relationship"</p> <p>P5. "all your interactions are just no longer there, erm and to a degree I think at our age the physical side of our marriage was probably in decline anyway, but it's kindof probably pretty non-existent simply because I thick she finds it hard to do the normal responses"</p> <p>P5. "I think you can't underestimate how hugely different life is, and you really do wake up in the morning and it's not the woman you married"</p> <p>P5. "she'll almost never start a conversation, so very very little starting a conversation, and it can't last too long, before she's clearly had enough of it, so it's not developed in the way it would have been and that's a huge, huge issue"</p> <p>P5. "since then I guess er we've had a different life that's for sure, and lots of things she can't, she finds hard to do"</p>	<p><i>relationship, loss of banter and challenge, difference in connection</i></p> <p><i>- Less to talk about, loss of connection and conversation</i></p> <p><i>- loss of sexual relationship, his worries about loss of connection and change in their status as a couple? Are you a couple if your sexual relationship is lost?</i></p> <p><i>- Loss/ change of sexual relationship – attributes some of it to age, some of it to the brain injury</i></p> <p><i>- Loss of the woman he first got together with, loss of connection</i></p> <p><i>- Loss of conversation, connection</i></p> <p><i>- Fundamental difference in their relationship and life</i></p>
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	Making comparisons	P1. "so my wife and I...were quite high powered...both high powered	- <i>Their life before – focussed</i>

	<p>to before the brain injury</p> <p>Men's experiences of the changes in their relationships were manifested in frequent comparisons to life before the brain injury.</p> <p>Often these were couples who led fairly independent lives.</p>	<p>jobs"</p> <p>P1. "I will always have the before part of the comparison and that doesn't help... actually it's quite a hindrance to have the old kicking around in your head"</p> <p>-----</p> <p>P4. "we'd just got back from a lovely holiday in New York, we'd gone to New York for five days and erm things were just going so well really, both doing ok in our jobs, both loved what we were doing, erm so it hit us like a, like a train, totally out of the blue, you know the odds of someone of her age contracting a disease like that are incontestable, you know"</p> <p>P4. "before it all happened, we'd have, typically we'd have a couple of nights a week where, what you doing, oh you're out with the girls or I'm out with the guys, or you're out with work, or whatever, but that sortof stopped"</p> <p>P4. "I think the other big change in terms of dynamic, erm we were a very, very equal partnership... since then I've had to lead the way. Her confidence has gone and I realised that you know I was having to lead and instruct everything"</p> <p>P4. "it's just that I preferred it when she was, quite simply I liked, I liked that sortof ballsy-ness, you know I really admired that"</p> <p>P4. "I'd rather she was at the front and just going for it and being like she was"</p> <p>-----</p> <p>P5. "on some of the cognitive tests she performed quite low, which is, being a school teacher, so she was pretty clued up in life in general, and very clued up in note taking, and always a sort of person when she got up, even before she went to school, she'd make a note of all the things she had to do, and by the end of the evening they were either ticked or not, as the case may be, well we might all try and do</p>	<p>on work</p> <p>- Him making comparisons makes him feel sad and recognise the loss</p> <p>- Recounting memories from life and relationship before brain injury, unlikely and unfair nature of her brain injury given her age</p> <p>- Comparison to before, independence within their relationship, contrast to now</p> <p>- Was an equal relationship, now he is more responsible, loss of that connection</p> <p>- Loss of an aspect of her personality and their interactions that he enjoyed</p> <p>- Yearning for relationship before</p> <p>- Comparison to her intellect and ability before, what she was like before in terms of her job, respect etc</p>
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		<p>that but very few of us actually achieve it, but she actually achieved it”</p> <p>P5. “before we had a marriage that was completely open, erm and I think that one of our really good decisions is that we would, we would always just have one bank account so we’d never had any concept of my money, your money, kindof thing, erm it was money, erm so every decision that we made was always a joint decision”</p> <p>P5. “we’ve always, you know, in the past had lots of different interests and that was part of the secret of the marriage I suspect, and erm you know, she’d go off and do her things and I’d go off and do my things”</p> <p>-----</p> <p>P7. “I find it difficult sometimes to look at the pictures of her around the home, and us together and with the children, erm I do find that difficult sometimes. Erm I’m a lot better now that what I was, so things to do with memories, I do find quite difficulty, erm although as I said I’m a lot better now that what I was”</p> <p>P7. “[wife’s name] took a great deal of strength from each other, in her job as a teacher, and me hearing about her problems, and her hearing about my problems, I think the relationship, it just went from the bad old days of the mid 90s, it really got stronger and stronger, and I think erm that’s what’s held it together, and that’s why one of the things I think is so key to my attitude at the moment that erm I’ve got to do it for her, and I put that down really, to you know, the way the relationship has got stronger and stronger”</p>	<p>- <i>Comparison to before, decisions were made completely jointly, contrast to now</i></p> <p>- <i>Independence before which helped maintain their relationship</i></p> <p>- <i>Comparisons with before are painful, particularly as the situation is so difficult now</i></p> <p>- <i>How they supported each other before, comparison to before brain injury, what made their relationship work</i></p>
<p>4. Responsibility and ‘burden’</p> <p><i>There was an overwhelming sense of men’s new roles and</i></p>	<p>New responsibilities</p> <p><i>For some men this involving new caring roles, with many comparing their</i></p>	<p>P1. “I’m living with a six year old, and that has the benefits of a six year old’s charm but you can’t have an intellectual conversation with a six year old”</p> <p>P1. “it’s very easy to slip into viewing them as something, you know you have to look after her, a bit like you would view a baby aged three, so something that has to be looked after but you can’t really</p>	<p>- <i>Comparison to a child, conversations not the same</i></p> <p>- <i>Caring role, loss of adult interactions</i></p>

<p><i>responsibilities no matter what the nature or severity of their partner's ABI was. Others seem to have little understanding of ABI and its effects, leaving men feeling isolated and misunderstood, and responsible for many new tasks and roles. They felt responsible for their partners and their wellbeing.</i></p>	<p><i>partners to children. Others felt responsible for encouraging their partner to do things or find meaningful activities during their days. Financial and other household responsibilities that had previously been shared were now taken on by these men.</i></p>	<p>engage with”</p> <p>P1. “when I put all the pros and cons together into the basket and some of those are hardware like the house and some of those are software like sex, when I put all of those pros and cons together, for me staying is a better option than going”</p> <p>P1. “our income went from X to X minus ten”</p> <p>P1. “Having been part of a life that I can't describe it in English terms, but I suppose upper middle class, certainly blue Conservative if I bothered to vote and those kind of people, that's where we came from. No we sit very much on the other side of the house, you know we sit as beneficiaries of the state, and therefore I can't take any Conservative points of view any longer”</p> <p>-----</p> <p>2. “she was in sales and she couldn't do that anymore, she had to take on a lesser job in the company, basically just half her pay gone so that'd been hard financially, and of course you don't get help, benefit or anything like that these days”</p> <p>P2. “it's been hard I mean, to try and persevere like you know, trying to find the old [girlfriend's name] to come back again, that's never gonna happen, but I think, harsh as it might sound, that the past like year or so, it's financial reasons that have kept us together... sometimes financially it keeps you together and it shouldn't do but...”</p> <p>-----</p> <p>P4. “her sister said to me, no one will feel the worst of you if you leave her cos she has changed... and I said I can't do that, I couldn't, for one thing it would be a, for one thing it would be, even to do it would be a cowardly thing to do, and it's not what I wanted to do either”</p> <p>P4. “it's doing the right thing as well”</p>	<p><i>- practical responsibilities keep them together eg house, but also is the best option for him</i></p> <p><i>- Financial responsibilities</i></p> <p><i>- change in status and even political viewpoints as a result of financial changes and new caring responsibilities</i></p> <p><i>- Financial impact and new responsibilities and burden for him as a result of the brain injury</i></p> <p><i>- financial responsibilities keep them together</i></p> <p><i>- Responsibility to stay, doing the right thing, sense of duty</i></p> <p><i>- Sense of duty</i></p>
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		<p>P7. "it's very common for there to be a divorce or a separation, and erm I cannot think about that, I don't think about that, you know you don't just give up on 40 years erm quite, very lightly, I call it a 'duty', and I've often thought about well am I right to call it a duty, it sounds very matter of fact, sort of very odd, but in a way it is"</p> <p>-----</p> <p>P8. "[psychologist] said to me would you still be together if it wasn't for your son and I had to say no, you wouldn't do it, you know, you wouldn't put this much energy into sustaining your relationship, you just wouldn't do it, and erm it's a combination of things really, erm my age is a factor, you know the fact that I'm coming up to 61 means you know, I don't think I could cope with the trauma of separation so it's better to work out what we have than to contemplate another life, you know at 61 I can't start again"</p> <p>P8. "we're committed to keeping our relationship working and it's very hard work sometimes, but we do want it to work, partly for our son, erm but also just erm we had such a lot of investment in that relationship before"</p> <p>P8. "there's a lot of investment in a series of relationships which all work very well"</p>	<p>- <i>strong sense of duty</i></p> <p>- <i>responsibilities and investments in relationship and other people keep them together</i></p> <p>- <i>investment and responsibilities keep them together, especially their son</i></p> <p>- <i>other people who are linked with their relationship – responsibility not to jeopardise that</i></p>
	<p>Isolation and others not understanding</p> <p><i>For most men, others did not fully understand their situation and what it was like to experience the changes in their partner and in their</i></p>	<p>P1. "one of her therapists had said you'll find your friends, and this has happened, there will be a few who adjust and stay as friends, of which there have been four that come to mind, there will be a few down the other end of the bell curve that just won't be able to cope with it and will... drop off... and then there will be the big chunk in the middle who feel they need to keep going, but actually you start drifting apart, and that's exactly how it's happened with us"</p> <p>P1. "they [therapist] said you'll need to go and fish for new pools of friends, not necessarily disabled, although some of them are, but it's been interesting that we've acquired probably as many good new</p>	<p>- <i>professional advised that he may lose friends, loss of friends leading to isolation</i></p> <p>- <i>loss of friends but also acquiring new friends, but who are more likely to</i></p>

	<p><i>relationship. This led to them feeling isolated, and increased their feelings of responsibility.</i></p>	<p>friends as we lost so it's been interesting in that sense"</p> <p>P1. "I am now the expert on what is best for her"</p> <p>P1. "I thought I better get myself involved in how you live as a disabled person in this country... so almost inadvertently by becoming an expert...helped me form a picture as to how I want to live, within the constraints placed on me life"</p> <p>P1. "it took me erm probably two years, it was always easier not to take respite, because with respite, she's in the care by generally of strangers, and so when they did things...good friends, carers, members of the public, are all very willing but they are all desperately ignorant"</p> <p>P1. "it's just easier now if I tell people what to do"</p> <p>P1. "something I hadn't accounted for, that I would have to take the role of gently explaining to everybody that she's different"</p> <p>P1. "unless she goes to hospital there are probably only currently maybe two people that I can leave her with and not worry about her at all"</p> <p>P1. "we don't have any family here so there's only the two of us"</p> <p>-----</p> <p>P2. "we've got the stroke association going into her work and try and talk to them about it, and they've tried to explain what it's like and she's had various meetings with managers, and you can tell the what you like but they just don't get it"</p> <p>-----</p> <p>P4. "all of these people had known that she'd been unwell, but it was noticeable that hearing from these, some of these friends became less and less frequent erm as time went on, and that really, really angered me because it felt then that her, what should've been a</p>	<p><i>understand their situation</i></p> <p><i>- he knows best, others don't understand</i></p> <p><i>- immersing himself in world of brain injury to help him adjust and understand</i></p> <p><i>- would not accept help because others don't understand, has taken time to be able to explain things to them</i></p> <p><i>- he is the expert</i></p> <p><i>- others don't get it, he has to explain, expert role</i></p> <p><i>- not many others who can look after her → isolation</i></p> <p><i>- lack of social support</i></p> <p><i>- others not understanding even when given explanations and information</i></p> <p><i>- her friends not understanding and their loss of her friends, him feeling responsible to provide friends</i></p>
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		<p>really great support network for her wasn't as strong as it might have been and so I felt obliged to pick up the slack a bit, a bit more"</p> <p>P4. "one thing I noticed and it was less happening to me but it very much annoyed me that some of her friends didn't particularly step up to the plate"</p> <p>P4. "she lost some friends through no fault of her own as well, you know some of her friends just take it for what it is, others seem to not be willing to put in the hard work and have just sortof you know mugged her off which is very annoying but frustrating"</p> <p>P4. "I couldn't say I didn't have support from [wife's name]'s parents and my mum, they, they were great but there was a lot of sortof loneliness"</p> <p>P4. "it's pretty much mostly me, we haven't got any family round the corner"</p> <p>-----</p> <p>P5. "I think a sense of family, and then they too are hugely supportive to me, I mean we're just so lucky really erm that I think we are such a close knit family, and you know, we get so much support from them, it's just amazing, I mean how people do it without family, or if they're on their own, and their marriage is... I have no idea"</p> <p>P5. "we're very lucky in again that we have some wonderful friends in the road, the sortof ladies in the road always come round and have a coffee with her"</p> <p>P5. "we've got two magnificent daughters, so we see them pretty much every week, erm and they get terribly involved, so fantastic family support"</p> <p>-----</p> <p>P6. "I've had a few friends who've been very good, you get a lot of friends when you're going through something in the first couple of</p>	<p><i>for her, provide a social circle and support network</i></p> <p><i>- lack of support and understanding from her friends</i></p> <p><i>- lack of support and understanding from her friends</i></p> <p><i>- isolated and lonely in his particular experience of the situation</i></p> <p><i>- lack of social support that's always available</i></p> <p><i>- great social support experience</i></p> <p><i>- support from neighbours</i></p> <p><i>- support from adult children</i></p> <p><i>- some friends understand and supportive, loss of other</i></p>
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		<p>weeks who tend to fall away, there's a few die hards"</p> <p>P6. "I mean I've had to do it all myself, I mean if I want to find out something then I will do it, the worrying thing is I find is I'm kindof telling the doctors what to do, I'm kindof leading them"</p> <p>P6. "one thing that did really annoy me, sort of that I know more about her than anybody and nobody seemed to be terribly interested in what I had to say cos I could have probably helped...you think if you kept me in the loop you know, I could actually help you, cos I'm spending hours with her and I notice these little things, I know her obviously very well, her history and so on, there seems to be almost an arrogance there, where we know better, we're not interested in family members"</p> <p>P6. "a lot of people know her around here so once the knew what was wrong with her they looked out for her"</p> <p>P6. "I talk to my sister and certain friends"</p> <p>-----</p> <p>P7. "there are a couple of friends that without them, erm I try and make sure [wife's name] has a visitor every day, if it's not me it's somebody else, and there's a couple of, two sets of friends that have been very, very good in this really, and the kids really, particularly daughter, she speaks to me every day"</p> <p>P7. "we've still got a 4 bedroom, quite large house, erm which needs to be looked after, and I've got a lady that irons for me, and cleans the house once a week for me, without her I'd be lost, I've got a gardener, we've got a big garden, and we had that before, but without those two people life might be a lot more complicated than it is around the house"</p> <p>-----</p> <p>P8. "it's good actually to talk, I was looking forward to you coming,</p>	<p><i>friendships, isolation as a result</i></p> <ul style="list-style-type: none"> - <i>him as expert, feeling like even professionals don't fully understand her</i> - <i>isolated from medical process, felt not involved or not valued</i> - <i>support from neighbours</i> - <i>family and other support</i> - <i>supportive friends and adult children</i> - <i>support of employees who help him deal with practicalities and domestic chores</i> - <i>value of the research</i>
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		<p>you know, because the loneliness is one of the hardest things, it's that isolation and there is no one on the whole estate I could have this conversation with, cos they wouldn't know what the hell you were talking about"</p> <p>P8. "most people, since we've moved up here she's acquired a new set of friends, and those relationships are based on the [girlfriend's name] now, and they have no reference point to anything else, so I feel very isolated a lot of the time because if I question anything, it's kindof 'what's wrong with you, what's your problem' because I'm referring to someone they'd never met, they don't what I'm talking about so that's quite hard"</p> <p>P8. "the loneliness of that I tell you, the loneliness of that is, you can't describe, because you'll get people going 'what's wrong with you, what's your problem' and it's in their eyes, they won't say that, it's just in their eyes, 'what's your problem' and a lot of even close relatives don't see it, and all of her relatives are in denial"</p> <p>P8. "we've moved house, erm there's nobody here who knows [girlfriend's name] 1, except myself and her mother, and her mum has been a great sounding board really because she is the only other person in the world who understands what's going on"</p>	<p><i>interview in temporarily alleviating isolation and loneliness of the experience</i></p> <p><i>- new friends don't understand as they didn't know the prior version of his partner, he feels misunderstood</i></p> <p><i>- loneliness of feeling misunderstood</i></p> <p><i>- minimal support network, most people don't understand what he is even referring to except his mother in law</i></p>
	<p>Emotional impact of changed situation</p> <p><i>- The burden of men's new roles and responsibilities and their feelings of being isolated and misunderstood led to many emotional reactions. Sadness, despair, anger, frustration, unfairness,</i></p>	<p>P1. "I have learned to play the guilt card... I make full use of her disability to get us good seats etc etc and I figure that's kindof a bit of a quid pro quo you know"</p> <p>P1. "I started suffering really badly from rage, to the point where it was affecting me physically, and so I have been and am still going to some counselling for that"</p> <p>P1. "in November I had a nervous breakdown cos I was trying to do too much"</p> <p>-----</p> <p>P2. "if she moves stuff or puts something down somewhere, or she can't find it, it's never her fault... it's always someone or something's</p>	<p><i>- sense of entitlement, why should I suffer because of this situation</i></p> <p><i>- anger, seeking professional help</i></p> <p><i>- overwhelmed, anxiety, fear, responsibility</i></p> <p><i>- feeling of being blamed, frustration, anger?</i></p>

	<p><i>injustice etc.</i></p>	<p>fault, it's always me, it's always me, it's always something I've done"</p> <p>-----</p> <p>P4. "I can only remember one time where I lost it, I was just at home er on my own, you know I'd been used to erm I'd either lived at home or lived with mates or lived with [wife's name], I'd never lived alone. I effectively had 3 weeks living alone and just one night I was just doing the washing up or something, I just burst into tears and just cried and cried and cried, then 15 minutes later I was alright"</p> <p>P4. "if she was 100% before, she was 5% of what she was in the early days of the illness, got up to 70 or 75 quite sharpish, then gradually up to 90 but has never, sortof, she'll say it as well, she's never quite, she's never gonna be quite the same, it's plateaued now, it's not gonna get worse, not gonna get better, erm and so we've just had to adjust to this, you know, this is what it is, at times I've thought this is unfair, I got together with essentially a different person in 2002 to who sortof emerged from hospital in 2005"</p> <p>P4. "it's like I'm gonna go out cos I've had a tough time here as well, and you know, almost why should I be punished for what's happened to [wife's name], I've had to change and adjust certain things and be much more responsible for things around the house"</p> <p>P4. "the illness probably put our lives on hold for a whole, if I could've written it down we probably would've had kids two or three years ago but I couldn't, we didn't... I guess everything's sortof maybe slightly delayed"</p> <p>P4. "this ain't fair, she's a young woman, a tax payer, what can you do"</p> <p>-----</p> <p>P5. "so when you wake up in the morning, most of us are motivated by about 15 tasks we've got to get through, she's motivated by no task whatever really, so that's, that has an impact and that can be quite frustrating"</p>	<p>- <i>overwhelmed, sadness, loneliness, trying to hold it together, rarity of such an event when he 'lost it'</i></p> <p>- <i>sense of injustice that she's different, resignation to how things are now</i></p> <p>- <i>sense of entitlement – why should I suffer?</i></p> <p>- <i>had to wait, life on hold, limbo, not as planned, disruption</i></p> <p>- <i>injustice, unfairness, why us, why her?</i></p> <p>- <i>frustration, why can't she do things like she did before</i></p>
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<p>5. Coping and support</p> <p><i>Men had adopted a variety of different ways to cop with the new challenges in their lives and relationships. They also drew on various sources of support with mixed reports about how useful and</i></p>	<p>Getting on with it</p> <p><i>Acknowledgement that their situation was different and changed since before the brain injury but that there was not much they could do about it and they wanted to just get</i></p>	<p>P1. "for about the next three months I tried to live life like we'd lived it"</p> <p>P1. "I came out [of hospital] in January 2008 and basically lived life like a moron and when I say that I mean quite literally I sat in front of the television, all day every day, I didn't work, I didn't organise things, I kept us fed and that was it"</p> <p>P1. "I've managed to get back into a little consulting which is good for me"</p> <p>P1. "last year she... was in hospital for a month you know so it's, for</p>	<p>- ignoring the changes, avoidance</p> <p>- avoidance, survival</p> <p>- work as avoidance or distraction</p> <p>- seeing the positives, it</p>

<p><i>relevant this support was – both social and professional.</i></p>	<p><i>on with it.</i></p>	<p>her, life has been a bit of a challenge. But she’s remarkably, most people would say she’s remarkably good-spirited and luckily she wasn’t affected, her speech is not affected by the stroke”</p> <p>P1. “luckily she hasn’t been so severely damaged but I have experience of people like that through friends and that, where the carer views the person as a something vs a someone”</p> <p>P1. “my every moment of worry which is where we started has now reduced considerably, for as long as life has routine and balance”</p> <p>P1. “she was really lucky”</p> <p>P1. “we got a ramp made, so suddenly I got a motor-bility vehicle which made all the difference”</p> <p>-----</p> <p>P2. “I don’t worry about anything unless I have to worry about something, whereas I know a lot of men will just erm, women will show their feelings I believe more so than a man would show their feelings, you know, erm not saying to each other, but I’m saying like in general life, oh that’s fine, don’t worry about it, but inside they’re going “oh my god what’s going on” you know, it’s eating them up, but they won’t say it or show it for some reason, erm but no I think it’s just me, I’ve never been a big worrier, I just can’t see the point”</p> <p>P2. “I just take each day as it comes, you know, i don’t really plan for anything as such... and I’m not a worrier at all, I’ve never really worried about anything, yeah I’ll worry about it if I have to worry about it”</p> <p>P2. “I try to adjust to it, a lot of the time I just try and ignore it erm because no matter how much I’ve said to her what’s she’s doing and what she’s turning into or changed, how much she’s changed since the stroke, she refuses to accept it, so a lot of the time she comes home and starts going on about something, it’ll just go in one ear and out the other, but I’ll just try and ignore it and jus try and get on with it</p>	<p><i>could’ve been worse</i></p> <p><i>- could’ve been worse</i></p> <p><i>- establishing a routine to cope with challenges</i></p> <p><i>- seeing the positives</i></p> <p><i>- making practical adaptations to cope</i></p> <p><i>- not worrying, just doing it, thinks he’s not like other men who do worry but cover it up, what’s the subtext here? Is he really worrying or not?</i></p> <p><i>- just get on with it, don’t worry about things</i></p> <p><i>- avoid, get on with it</i></p>
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		<p>sortof thing”</p> <p>P2. “it’s not as bad, like I say, mum had a stroke a few years ago and she’s a bit dithery, but my ex-wife’s father in law, he had a massive stroke that left him quite seriously, erm mobility-wise and so on and so forth”</p> <p>-----</p> <p>P3. “I don’t think that much has changed er because I think she made such a good recovery”</p> <p>P3. “it was quite good for me as well because I could sort of you know, make sure she was alright cos I love her, so it was great having her living here from that perspective, erm but it wasn’t as necessary as I can imagine in some circumstances, you know like if someone was suffering the after effects of a stroke or something, a bad stroke”</p> <p>P3. “well in some ways it’s beneficial because she was drinking far too much, you might say she was probably an alcoholic, and she’d probably had too much to drink and slipped over, no one quite knows, so it’s stopped her drinking, so it’s quite positive in that sense as well”</p> <p>P3. “you had to sortof be aware that if she was concentrating on something, then she could do that, but not perhaps have a conversation about something else... so it’s very, very minor, I mean I did it, I wouldn’t say I always did it, I sometimes got it wrong, but you did it and that was it”</p> <p>-----</p> <p>P4. “I think the children are, it’s so difficult to think of what it was like without them now, but I would be slightly concerned about heading down something of a dead end, you know they’ve just renewed everything really, the whole sortof vigour and reason for sortof being together, it’s just changed the focus really, and yet I do wonder sometime well if it weren’t for these two... it’s a bit of a sobering thought really, think where we might, we might just have trundled</p>	<p>- seeing the positives, it could’ve been worse, she’s not as bad as these other people who’ve had strokes</p> <p>- good recovery made it easier to cope</p> <p>- seeing positives – enjoying having her around, it could’ve been worse</p> <p>- seeing positives – reduced or stopped her drinking which was problematic prior to brain injury</p> <p>- had to make adjustments but seemed like he just did them without too much bother or hassle</p> <p>- focus on children meant they just get on with things, have helped them to cope</p>
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		<p>along to nowhere really”</p> <p>P4. “I tried to encourage her to do things, partly for her good well-being, but probably partly for mine as well, so I can know that I’d feel better in myself if she was being stimulated and challenged and what have you”</p> <p>P4. “sometimes you have to accept that life hits you...my dad died when I was 16... it’s like well things can’t get much worse than this, so it just kindof gave me the approach like well things can be really, really, really bad, fight them off, shake them off, and try and do the right thing, do the right thing by [wife’s name], you know try and be there for her”</p> <p>P4. “we have to live a lot by lists and the kitchen calendar is a big thing, you know writing stuff on there, giving her little reminders and she uses her phone, her phone’s forever going off”</p> <p>P4. “we’ve tried all sorts of things, support at work, all sorts of organisations, someone actually in work with [wife’s name] trying to help her through the working day erm they gave her a Dictaphone, a erm a palm pilot thing, all sorts of things to try, her making notes and that during the day”</p> <hr/> <p>P5. “I think, you know, there’s plenty of people better off and plenty of people worse off and I’m probably somewhere in the middle”</p> <p>-----</p> <p>P6. “I have faith, I’m a Christian, I’ve been praying a lot and that’s helped me, and through it all I’ve struggled at times, even with my faith”</p> <p>P6. “I just have to get on with it I suppose”</p> <p>P6. “I’m not the most patient person, or I wasn’t, I’m now more patient than I was, so that kindof got, ended up sortof having rows and</p>	<p>- <i>getting her to do things helps him to cope and feel better</i></p> <p>- <i>acceptance, stoical, drawing on past experiences, it could’ve been worse</i></p> <p>- <i>practical ways of coping</i></p> <p>- <i>practical ways of coping</i></p> <p>- <i>seeing positives, could’ve been worse</i></p> <p>- <i>using faith to cope</i></p> <p>- <i>just get on with it</i></p> <p>- <i>making allowances,</i></p>
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		<p>things, feeling really bad about yourself because you knew there was something wrong with her.... once I knew what was wrong with her I could kind of, in a way it became less, well I knew she was seriously ill, kind of made allowances for her”</p> <p>P6. “you just get used to it like everything really, it’s like a process of mourning really I think, although she’s improving I don’t suppose she’ll ever be the same as she was”</p> <p>-----</p> <p>P7. “I feel a lot better than I did 12 months ago”</p> <p>P7. “I have to get over it and get on with it for the sake of her, using my work as an outlet, erm if I hadn’t got my work, I don’t know, I think I would’ve cut my wrists by now”</p> <p>P7. “I’ve always thought I’ve just got to get on with it, I’ve always had a positive, tried to always have a positive outlook on life”</p> <p>P7. “sometimes I’ve had a crisis of confidence, erm but that what I’ve done is just sit down and talk to myself, I used to talk to my wife about it but of course I haven’t got her now, I just talk to myself and say come on, don’t be stupid, pull yourself together and get on with it”</p> <p>P7. “when I get down I think, goodness, don’t be so stupid, you’ve got so much going for you, just get on with it, and stop messing around”</p> <p>-----</p> <p>P8. “I get consolation for the fact that you know, if you think about the scenario that we were looking at, when [girlfriend’s name] didn’t die, you know we were then faced with the prospect that she may be a cabbage, and that was horrifying, that was a very very difficult scenario because I didn’t know how I would cope with that, and we’ve been very fortunate because that hasn’t happened... in a way we’ve very fortunate, erm it could have been so much worse”</p> <p>P8. “in order to function in daily life you kindof bury it and get on with</p>	<p><i>accepting things, trying to be patient</i></p> <p><i>- getting on with it and adjusting and accepting things over time</i></p> <p><i>- letting time pass and heal</i></p> <p><i>- using work to avoid and distract</i></p> <p><i>- getting on with it, seeing positives</i></p> <p><i>- giving himself a pep talk, getting on with it, pull yourself together</i></p> <p><i>- seeing positives</i></p> <p><i>- seeing positives, it could’ve been worse</i></p> <p><i>- avoidance</i></p>
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		<p>it”</p> <p>P8. “that anger for me causes a lot of tension, I end up quite tense physically, erm and I try relaxation exercises”</p> <p>P8. “yeah well speaking about it helps, I would ideally like more help and unfortunately that’s really hard to acquire at the moment”</p>	<p>- <i>using relaxation to cope</i></p> <p>- <i>talking to others to cope</i></p>
	<p>Sources of support</p> <p><i>Men had mixed experienced with the support they had been offered and had received. They also made many suggestions of how they would have liked to have been treated and what support they would have liked to have been offered.</i></p>	<p>P1. “consultants of every sort are only ever consultants, whereas people who are in the same circumstance as you, which is the 24/7-ness of caring, means I’ve always been a bit reticent in how I dish out my respect... all the carers I know have taught me some little thing, so there is a massive difference if you’re caring for someone 24/7... I’m always, I’m afraid I am really cynical about professionals giving me advice”</p> <p>P1. “I went to [hospital] for so November, December, January, erm to be perfectly honest I don’t, when I look back, I don’t think it did anything for erm other than provide me to be honest with some breathing space... it was me going I’ve got to get away from it”</p> <p>P1. “I’m not fussed about the tea and coffee and sympathy, I just want the information... the group that I’m currently in, and we meet kindof once a month but we don’t talk about how sorry we’re feeling for ourselves, but how to prevent issues”</p> <p>P1. “if I’d had a single source of information that covered even 70% of what I needed to know pretty instantly, that would’ve been great, but it doesn’t exist, but of information from the council, but of information from NHS”</p> <p>P1. “the council has been very good with carers and stuff like that”</p> <p>-----</p> <p>P2. “they probably need somewhere there, with more information cos everyone’s firing questions off each other but no one really, everyone’s just guessing, giving the answers to their own personal</p>	<p>- <i>preferring and respecting the support of others in same position as him rather than professionals</i></p> <p>- <i>professional psychiatric support – not sure of the value, providing a break from it all?</i></p> <p>- <i>wants practical help not sympathy – has found a group which can provide this</i></p> <p>- <i>information in one place would be useful, and right from the start of him journey</i></p> <p>- <i>values care support from council</i></p> <p>- <i>he would like more professional ‘expert’ advice</i></p>

		<p>experience, rather than having someone in the medical profession to give them a definition, a proper answer”</p> <p>P2. “sometimes I find the meetings pointless... all they seem to do there is you sit down in a circle, erm they’ll talk about what’s happened in the past week, nothing major.... I think well that’s not helping anything, you know that’s not helping matters at all, and er I don’t know, I can’t see the point of them myself... I mean it’s just not organised very well at all really”</p> <p>P2. there’s nothing out there for the partners, you know, it’s, if you like you might have one half that’s had the physical injury, but you both suffer, you’re both suffering, and you’re both going through in a way the same thing, but there’s nothing out there for that person, you know wife, husband, boyfriend, girlfriend, whatever it is, there’s nothing out there for that, there’s no one, you know, you can physically talk to about what it’s like” <i>and</i> “there’s nothing out there that I know, that I’ve found anyway, that is helpful to like the other half if you like”</p> <p>-----</p> <p>P4. “the state, the NHS, you know various sorts of psychologists and support workers and that, then any time we felt like we were getting somewhere it would stop”</p> <p>-----</p> <p>P5. “erm I think [name of organisation] are thinking of running a course, erm my wife thinks it’s already actually going on in parallel, cos she said some of the other people’s husbands are going, or wives are going there”</p> <p>P5. “erm I think now I’ve been with it for 8 years, I appreciate I don’t know everything, and I’m sure I could do with some help, but I’d kindof want to know it was going to be helpful because otherwise it’s another 2 hours or 3 hours of my life”</p> <p>P5. “I think to myself I really do want to make sure this is either</p>	<p><i>rather than peer support</i></p> <p><i>- not sure of value of support groups, would prefer more information based groups</i></p> <p><i>- lack of support for him or anyone in his position, not sure if he feels his distress is acknowledged by anyone</i></p> <p><i>- inconsistent experience of NHS professional support</i></p> <p><i>- knows of a support group but hasn’t been to it</i></p> <p><i>- acknowledges he doesn’t know everything but not sure what would be helpful to him</i></p> <p><i>- would attend groups if he</i></p>
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		<p>useful, or I could be useful to someone else”</p> <p>P5. “I’d still love to find someone who had you know, some sort of, I don’t know, retired psychologist, or a retired, you know, person who was used to working with, you know, mental health etc, because that would be absolutely, I tell you there’s a crying need for it”</p> <p>P5. “the local people came around and they were alright, but it wasn’t, there was not any kindof follow up to the whole thing”</p> <p>P5. “we’ve tried carers, er and in fact we had one girl, she was a graduate nurse, she had a young boy, she was brilliant, she had all sorts of clever ideas”</p> <p>-----</p> <p>P6. “I went to a support group, they run a support group, well I went there for the first time lat month and that was quite useful, I think it’s if we’d had more idea of what to expect to start with, erm that would’ve been useful you know, and that you were kept informed better, would be good”</p> <p>P6. “I think the problem has been the sort of lack of communication, not knowing what’s going on, erm hospital are bad”</p> <p>P6. “I’ve had to you know, I’ve had to fight the system as well as put up with obviously big changes in her which is not good, so finally he’s got, the new GP she’s got at the moment is quite good, been quite helpful, I just find there’s been a lot of fighting faceless burocracy”</p> <p>P6. “nobody’s trying to get her well so, well they are hopefully now because I’ve been pushing and pushing to fight, erm so I’ve become a kind of occupational therapist in my spare time, er all sorts of things, spending lots of time on google, discovering about illnesses”</p> <p>P6. “not many people ask how I am”</p> <p>P6. “there’s no way you could have a proper relationship, it’s just</p>	<p><i>knew they’d be a good use of his time</i></p> <p><i>- feels the support that’s on offer is from the wrong people, or professionals who don’t really understand</i></p> <p><i>- lack of routine follow-up</i></p> <p><i>- positive care experience because of the particular individual and her skill</i></p> <p><i>- mixed view of support group – would’ve liked support earlier on and information earlier on</i></p> <p><i>- dissatisfied by lack of communication and information</i></p> <p><i>- feeling like he’s against the professionals and his partner won’t get adequate care unless he fights for it</i></p> <p><i>- feels isolated and like others do not want to fight his partner’s cause, he feels like he’s taking on all the roles</i></p> <p><i>- does not feel supported</i></p> <p><i>- feels undermined and like</i></p>
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		<p>other people making decisions you know, being sidelined really, and having to fight for any information on a , it's lie the state's taken her over, sort of find things out second hand"</p> <p>P6. "there's actually no kind of provision for relatives at all, hospitals just go out of their way to make it as hard as possible in my experience, there's no communication"</p> <p>-----</p> <p>P7. "it became clear that I would always have a fight for her, because I've always, she's always had the best in life, and there was no way that I was going to accept anything different to that, and erm that she should always have the best, and erm so really the fight with [nursing unit] and the PCT started, and that's been a continual fight"</p> <p>P7. "nobody seems to know, that's one of the things really I've found difficult is nobody could tell me what she may well end up lie, erm and I still find that very difficult that nobody will give me the view, or nobody will give me an opinion and I find that quite frustrating"</p> <p>P7. "one of the things I've been thinking of is actually to try and put something back into the neuro world... when I retired, it might be quite nice to do something like that, to put something back into it really"</p> <p>P7. "sometimes I did feel there wasn't enough information, but sometimes you had to pull it out, erm and one of the infuriating things is, I did find this, I find it strange, I find it horrible, that people will not give you an opinion, or not give you a view"</p> <p>P7. "the one person who has been very helpful in all of this, is the case manager, and I could talk to her about anything and she shared the battles with me that we've had with [name of hospital]"</p> <p>-----</p> <p>P8. "[name of psychologist] is still counselling us, erm we see her perhaps once every couple of months, she's been very helpful and</p>	<p><i>he is no longer involved in his partners life, his opinion does not matter</i></p> <p><i>- disappointed with lack of support for him as a partner</i></p> <p><i>- has been dissatisfied with the care his partner has and feels he has to fight for it</i></p> <p><i>- lack of information, reflecting uncertainty and difficulty in predicting prognosis with brain injury?</i></p> <p><i>- wants to give something back – altruism</i></p> <p><i>- lack of information, feels like he wasn't given the full story or professionals unwilling to give their opinion</i></p> <p><i>- names one individual who supported him and made him feel understood</i></p> <p><i>- values counselling</i></p>
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		<p>very supportive”</p> <p>P8. “a lady from [name of organisation] erm gave me some counselling at that point and talked to me about disinhibition and erm explained what was going on”</p> <p>P8. “I felt quite isolated because erm, she had actually undergone two sortof ten hour sessions of major brain surgery, she had a relationship with her brain surgeon, and they would meet, and have sortof of consultations about how’s it going, but I didn’t have any of that, and I think that’s an area that perhaps could be looked at, where erm you know the partner is erm is involved, kindof it there could be a referral or kindof an assessment process”</p> <p>P8. “I think if you had to give any advice, if you were trying to make this research for people who were going through similar situations, I would warn them of that more than anything else, it’s not just that they’ve changed, it’s that they’re gonna carry on changing, it’s like they’ve taken a different trajectory, because they’ve become a different character, they evolve along that character, and that’s something I was not prepared for”</p> <p>P8. “I think we left it too long, we though we could cope, we thought we could make it work, and it took us until probably 18 months ago to go back and say actually no we can’t do this, you know we need more help, and I would’ve liked to have seen that acknowledges earlier, I’d like to erm, I’d like to have been referred and perhaps erm even if it was just kindof like an annual, even if it was sortof like an annual check up or something”</p> <p>P8. “I’ve tried lots of talk therapies, you know I’ve talked to quite a few people, a clinical psychologist in fact, and erm I’ve talked to an independent counsellor... it all helps a bit but I still feel, you know there’s an underlying anger and underlying resentment I suppose”</p>	<p><i>- values one particular professional who provided relevant information</i></p> <p><i>- lack of routine follow up and support for him as a relative</i></p> <p><i>- wanted to make the research helpful for others in his situation – wanted to emphasise that their partner could carry on changing after a brain injury</i></p> <p><i>- stigma of asking for support and admitting you need help – could have been reduced by routine support being offered</i></p> <p><i>- counselling helps but does not alleviate everything</i></p>
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