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## The caregiving bind: concealing the demands of informal care can undermine the caregiving identity

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## **The Caregiving Bind:**

### **Concealing the Demands of Informal Care Can Undermine the Caregiving Identity**

#### **Abstract**

Disagreements and misunderstandings between informal caregivers and care-receivers have been widely reported, but the causes are unclear. The present article compares the views of people with acquired brain injury and their main informal caregivers (28 dyads, n = 56). First, we report a quantitative analysis finding that the majority of disagreements were about caregivers' identity. Caregivers saw themselves as less confident, less intelligent, more embarrassed, more independent and more overprotective than care-receivers rated them to be. Caregivers understood the care-receivers' ratings but disagreed with them. Second, we report a qualitative analysis focusing on how caregivers felt themselves to be perceived by significant others. Caregivers felt that the care-receiver, family members, the general public, health services and even friends often have negative views of them. The 'caregiving bind' is proposed as a cause of caregivers' negative identity. It arises when caregivers try to protect the care-receiver's identity by concealing the extent of informal care provision, with the unintended consequence of undermining the prospects of the caregiver receiving positive social recognition for the challenging work of caregiving. The caregiving bind has implications for therapy and points to the potential of friends and health services to provide caregivers with positive social recognition.

Keywords: UK; informal care; acquired brain injury; disagreement; misunderstanding;

identity

## Introduction

Acquired disability necessitating informal care causes role changes. The person with the disability becomes a care-receiver, often struggling for independence (Newsom & Schulz, 1998) and at risk of stigmatisation (Goffman, 1963). Simultaneously, family and friends become informal caregivers, a demanding (Simon, Kumar, & Kendrick, 2009) and usually unfamiliar role (Emslie et al., 2009). Adaptation to these role changes is complex. On the one hand, caregivers and care-receivers often work together to avoid stigma (Brittain & Shaw, 2007) and compensate for the disability (Johansson, Anderson & Ronnberg, 2005). On the other hand, each side experiences divergent practical, social and emotional demands (Bevans & Sternberg, 2012) which can fracture the relationship.

Caregivers and care-receivers have been found to disagree about care needs (Walters, Iliffe, See Tai & Orrell, 2000), risks and stress (Robinson et al., 2007), and level of knowledge (Bar-Tal, Barnoy & Zisser, 2005). Horowitz, Goodman and Reinhardt (2004) found caregivers rated care-receivers as more disabled than care-receivers rated themselves. Noble and Douglas (2004) found that family members wanted intensive interventions which were support focused, whereas care-receivers placed emphasis on interventions that fostered independence. Many disagreements centre on caregivers' identity, particularly their overprotectiveness (Ridley, 1989; Croteau & Le Dorze, 2006), embarrassment (Pot, Deeg, van Dyck & Jonker, 1998), independence (Gosling & Oddy, 1999), and confidence (Semple, 1992). We speculate that these disagreements may be due to the previously mentioned divergent practical, social and emotional demands.

We report research that systematically compares the perspectives of people with acquired brain injury and their main informal caregivers. The main finding is that caregivers' identity is often undermined. Our interpretation is that this may partly be caused by caregivers concealing the demands of informal care provision.

### **Acquired Brain Injury and Informal Caregiving**

Acquired Brain Injury (ABI) is defined as an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma (Brain Injury Association of America, 2011). It is estimated that the incidence of ABI is one per 500 people globally and occurs most often to those under 30 (Jones et al., 2010). ABI is the biggest cause of disability and dependency in young adults (Walsh, Fortune, Gallagher & Muldoon, 2012).

ABI often entails a mix of cognitive, behavioural, communicative and psychological problems that can disrupt employment, maintaining relationships, and relating to others (Verhaeghe, Defloor & Grypdonck, 2005). Personality changes are common (Yeates, Gracey, & McGrath, 2008). Caregivers have characterized people with ABI as hostile (Kreutzer, Gervasio & Camplair, 1994), angry (Farmer & Stucky-Ropp, 1996), child-like (Bowen et al., 2010), irritable (Thomsen, 1984), self-centred (Farmer & Stucky-Ropp, 1996), passive (Yeates, Henwood, Gracey & Evans, 2007), dependent (Ridley, 1989), and difficult to understand (Gosling & Oddy, 1999).

Informal caregivers are defined as people, operating outside of healthcare institutions, who provide daily and long-term support to a person with disability who is living at home (Turner & Catania, 1997). In the UK, informal care provision is

estimated to be worth £119 billion annually (Buckner & Yeandle, 2011). Although caregiving is a heterogeneous activity with variable outcomes (Carnes & Quinn, 2005), it often negatively impacts health (Braun et al., 2009), subjective well-being (McPherson, Pentland & McNaughton, 2000) and quality of life (Greenwood, Mackenzie, Wilson & Cloud, 2009). Caregivers may even experience more distress than care-receivers (Badr, Acitelli & Carmack-Taylor, 2007). Caregiving can also lead to role captivity and reduced social and leisure activities (Carnes & Quinn, 2005).

### **A Relational Approach**

The neuropsychological approach to ABI needs to be complemented by a focus on social relations (Walsh et al., 2012). ABI impacts all relationship types (Yeates & Daisley, 2013), especially family relations (Bowen, Yeates & Palmer, 2010). It is associated with increased divorce rates (Godwin, Kreutzer, Arango-Lasprilla & Lehan, 2011) and family functioning is crucial to rehabilitation outcomes (Sander et al., 2003; Sander et al., 2002). The few studies which have explored identity in these relationships by comparing the perspectives of people with ABI and their caregivers, usually family members, have found a range of disagreements (Yeates et al., 2007; Gill, Sander, Robins, Mazzei & Struchen, 2011; Jones & Morris, 2013).

We introduce a systematic relational approach grounded in the work of Mead (1934), Goffman (1959) and Laing, Phillipson and Lee (1966). Crucial is the distinction between disagreements and misunderstandings (Gillespie & Cornish, 2010). Disagreement occurs when both parties have differing views on the same object.

Misunderstanding occurs when one party attributes an incorrect view to the other party. Accordingly, there can be disagreement with understanding (i.e., awareness of disagreement), or agreement with misunderstanding (i.e., perceived disagreement with actual agreement) (Laing et al., 1966). Identifying disagreements and misunderstandings about identity necessitates asking each party what they think about themselves, the other party and what they estimate the other party to think. This approach is similar to systemic approaches, such as circular questioning, a technique for exploring patterns of relating (Nelson, Fleuridas & Rosenthal, 1986).

The relational approach addresses two limitations of the literature. First, the literature tends to examine disagreements without considering whether there is understanding (e.g. Horowitz et al., 2004; Yeates et al., 2007). Yet, research suggests that misunderstanding is often more problematic than disagreement (Sillars, Koerner & Fitzpatrick, 2005). Our first analysis will identify and distinguish disagreements and misunderstandings. Second, the literature assumes that misunderstandings between caregivers and care-receivers are problematic, requiring therapeutic intervention (e.g. Bowen et al., 2010; Robinson et al., 2007; Yeates et al., 2007). However, misunderstandings are not always accidental or even problematic, they can be inherent to the injury, or, deliberate creations aimed at identity protection (Gillespie, Murphy & Place, 2010). Accordingly, our second analysis examines the causes of the observed disagreements and misunderstandings.

We conceptualise identity in relational terms, emphasising perspective taking (Mead, 1934) and impression management (Goffman, 1959). Central to identity is social recognition, that is, how people feel themselves to be viewed by significant others

(Honneth, 1996). Thus, examining what people with ABI and their main caregivers think about themselves and each other will allow us to both identify misunderstandings and also unpack the role of these perceptions in producing the caregiving identity.

### **Methodology**

We used an adapted version of the Interpersonal Perception Method (Laing et al., 1966). Caregivers and care-receivers were asked to (1) rate themselves, (2) rate their partner, and (3) estimate how their partner will rate them on 14 identity items. We expected disagreements about the caregiver on five items: overprotectiveness (Ridley, 1989; Croteau & Le Dorze, 2006; Carnes & Quinn, 2005), embarrassment (Pot et al., 1998), independence (Gosling & Oddy, 1999), interest and confidence (Semple, 1992). We expected disagreements about the people with ABI on six items: passive (Yeates et al., 2007), self-centred (Farmer & Stucky-Ropp, 1996), irritable (Kreutzer et al., 1994), displaying child-like qualities (renamed the opposite, mature) (Bowen et al., 2010), aspontaneous (renamed, lazy) (Thomsen, 1984), and confused (Ponsford, Sloan & Snow, 1995). Finally, in order to give participants a chance to report positively on one another, we included three items on which we expected agreement (intelligent, kind and supportive).

The rating procedure was adapted for people with cognitive impairment using Talking Mats (Murphy, 2000) and iteratively modified through a pilot with five people with ABI. Items, in the form of picture symbols, were presented individually with accompanying explanation. Participants placed the symbols on a large (A3) mat

which had a 5-point scale on the top, from 'is not at all like' (0) to 'is very like' (4). Participants discussed their ratings with the researcher during the process.

The numerical ratings were used in Analysis 1. Disagreement was calculated by using the Wilcoxon matched-pairs signed-ranks non-parametric test to compare ratings about self and other. Misunderstanding was calculated by using the same Wilcoxon test to compare estimated ratings with actual ratings.

Video recordings of the discussion during the rating task were used in Analysis 2. The mean length of these recordings was 35.747 minutes for caregivers (SD = 13.953, range 15.414-66.733 minutes) and 32.916 minutes for people with ABI (SD = 15.668, range 19.147-88.461 minutes). Video data was transcribed and analysed using NVivo 9.

The research was conducted by HM during home visits. The first home visit introduced the research and informed consent procedures. The rating tasks were conducted on one or more subsequent visits. All ratings were confidential and done in the absence of the partner. Ethical approval was obtained from the UK National Research Ethics Service (09/S0501/26).

### **Participants**

Twenty eight people with acquired brain injury (PwABI) and their main informal caregivers (n = 56) were recruited in Scotland from NHS Brain Injury Rehabilitation Facilities (20 dyads) and Headway groups (8 dyads).



The inclusion/exclusion criteria for the PwABI were: 2+ years post ABI, aged 16-70, and without psychiatric co-morbidity or any history of substance abuse. ABI was sustained as a result of traumatic injury in 24 (85.71%) of cases (11 Road Traffic Accidents, nine falls, three assaults, one unrecorded). Of the four non-traumatic injuries, three were as a result of cardiovascular accident and one was the result of herpes simplex encephalitis.

The inclusion/exclusion criterion for caregivers was that they were identified as the main informal caregiver by the PwABI for 2+ years. No restrictions were placed on the type of relationship (i.e., spouse, parent, sibling, or friend) or cohabitation because caregivers are heterogeneous (Harper & Lund, 1990). Compared to a 2009/10 survey of caregivers in England (HSCIC, 2010), our sample of caregivers was weighted towards females (82% vs. 60%), spouse/partner relationships (50% vs. 26%), and parent caregivers (32% vs. 13%), while underweighted in children caring for parents (0% vs 33%). These discrepancies are likely due to: (1) the fact that ABI often affects young people, (2) ABI occurs at a male to female ratio of 2:1 (Howes, Benton & Edward, 2005) and thus, acknowledging same-sex relationships, we would still expect caregivers in our sample to be predominantly female, (3) we excluded PwABI who were age 70+, and (4) our sample only includes only the 'main' informal caregivers.

Table 1 reports measures of cognitive ability (ACE-R, with scores below 88 indicating 72% sensitivity for cognitive impairment in ABI samples (Gaber, 2008)) and anxiety and depression (HADS, with scores above eight indicating possible anxiety or depression). More caregivers scored eight or above on the HADS for

anxiety than depression (44.8% vs 17.3%). For PwABI, 30.4% and 43.5% scored eight or above on subscales for depression and anxiety respectively. Although a useful test to assess mood after injury, caution should be taken when interpreting scores for PwABI on the HADS using cut-offs for the general population (Whelan-Goodinson, Ponsford & Schonberger, 2009).

Kruskal-Wallis tests found no significant differences on ACE-R or HADS measures between spouse/partner, parent, sibling or friendship relationships (ACE-R,  $K=3.383$ , d.f. 3, sig .336; HADS anxiety caregivers,  $K=2.881$ , d.f. 3, sig .410; HADS depression caregivers,  $K=1.252$ , d.f. 3, sig .741; HADS anxiety PwABI,  $K=1.106$ , d.f. 3, sig .776; HADS depression PwABI,  $K=1.676$ , d.f. 3, sig .642).

Insert Table 1 here

### **Analysis 1: Identifying Disagreements and Misunderstandings**

Table 2 presents the median ratings of people with ABI on themselves, caregivers (CG) on their partner with ABI, and PwABIs' estimates of the ratings of their caregiver. Wilcoxon matched-pairs signed-ranks tests, with two tailed significance, are used to test: (1) Do PwABI and caregivers disagree in their views about the PwABI? (2) Do PwABI misunderstand the views that caregivers have about them?

Insert Table 2 here

Table 2 reveals considerable agreement about PwABI and an understanding of this agreement by PwABI. The only disagreement and misunderstanding concerns being self-centred: caregivers rated their partner with ABI as more self-centred (2 vs 1) and the PwABI misunderstood their caregivers, assuming that they would rate them as much less self-centred (0.5). This supports the previous research finding that caregivers view their partner with ABI as self-centred (Farmer & Stucky-Ropp, 1996), and adds the finding that PwABI may not be aware of this disagreement.

Table 3 presents the median ratings of caregivers (CGs) on themselves, PwABI on their caregivers, and caregivers' estimates of the ratings of their partner with ABI. Wilcoxon matched-pairs signed-ranks tests, with two tailed significance, are used to test: (1) Do caregivers and PwABI disagree in their views about caregivers? (2) Do caregivers misunderstand the views that their partners with ABI have about them?

Insert Table 3 here

On all but two items the scores given ranged from zero to four indicating significant heterogeneity, however, patterns also emerged. Caregivers tended to rate themselves as less confident (median 1 vs. 4), less intelligent (median 1 vs. 4), more embarrassed (median 2 vs. 0), more independent (median 4 vs 4), and more overprotective (median 3 vs. 2) than their partners with ABI rated them. Caregivers also misunderstood their partners, thinking their partners saw them as more interested (median 4 vs 4) and more irritable (median 2 vs. 1) than they actually did. Overall this supports findings about caregivers experiencing stress (e.g. Badr et al., 2007), lacking confidence (Semple, 1992), being embarrassed (Pot et al., 1998), and

overprotective (Carnes & Quinn, 2005). Importantly, the analysis adds the finding that caregivers tend to understand these disagreements.

## **Analysis 2: Exploring Caregivers' Feelings of Social Recognition**

The first analysis indicated that there is greater disagreement surrounding caregiver identity than PwABI identity and that caregivers tend to understand these disagreements. Accordingly, the second analysis uses the discussion data from the rating task to 'zoom in' on caregivers' identity, exploring how they feel significant others view them.

The transcripts of caregivers discussing their ratings with HM were coded for all instances of reported speech, that is, when caregivers spoke about what significant others had said (see, Gillespie & Cornish, 2010). Such coding has been used across health care settings (e.g. Hengst, Duff & Prior, 2008; Macintosh, Beech & Martin, 2012) to explore the heterogeneous points of view in participants' discourse. Specifically, this method reveals how caregivers feel that significant others view them, and thus provides insight into how their identity has been constructed. Five main groups were reported speaking (namely, care-receivers, family, friends, the public and health professionals), and their reported speech was coded as providing positive (six sub-types), negative (13 sub-types), or neutral social recognition (Table 4). AG (second author) independently coded two transcripts on both dimensions (38 codes in total) yielding good inter-rater agreement (Cohen's Kappa .743).

Insert Table 4 here

Caregivers quoted PwABI 58 times. Only 10% of the quotes provided positive recognition while 78% provided negative recognition for the caregiver. The voice of PwABI when quoted by caregivers was critical (16%), demanding (16%), pessimistic (10%), disinterested (9%), irritated (7%), and confused by the caregiver (5%). Below is an excerpt from Maureen (all names are pseudonyms) demonstrating demanding reported speech:

Maureen: It doesn't matter what else you were doing. 'I have to be at such and such a place at such and such a time'. 'Remember that, you must remember that' - because he writes in his diary, the wee soul. He tries hard to do things for himself. Erm, like tonight he's meeting, I'm putting him on the half five train for Jim. Five o'clock he'll start. 'Have you remembered, have you remembered, have you remembered?' And if the windows blew in I would still have to have him on the half five train.

(Maureen, age 56, caring for her husband, four years post fall, HADS A score, 10; HADS D score, 10)

Maureen characterises her husband with ABI as demanding, suggesting an asymmetry which is in stark contrast to the ideals of equality within a marital relationship. The relationship becomes polarized by "health and disability, giving and taking, powerful and powerless" (Krefting, 1990, p. 861). Care-receivers acknowledging the help that caregivers provide might, to some extent, rebalance a

relationship.

The PwABI was often described as childish. “She is really like a truculent 3 year old,” one caregiver said, and then proceeded to enact the voice of the PwABI saying “I can do it all by my own self.” Talking about the person with ABI as “childlike,” Bowen et al. (2010, p. 30) write, enables caregivers to explain “unusual and sometimes hurtful actions”.

Caregivers quoted family members 12 times. Only 8% provided positive recognition while 58% provided negative recognition. The voice of family members was critical (25%), patronizing (17%) and un-sympathetic (17%) of the caregiver’s efforts to support the person with ABI. Many of the critical comments came from the care-receiver’s side of the family, as illustrated by the following quotation:

HM: Finally, would you say you are too protective?

Sandra: No, I don't think I am, erm [pause]. Somebody said something the other day you know, ‘well you know if you just let Rach do this’. It was one of her family, ‘cos they really just don't understand what it's like, you know 24/7. ‘If you just let her do something’.

(Sandra, age 54, caring for friend, two years post encephalitis, HADS A score, 8; HADS D score, 2)

Sandra reported working hard, often behind the scenes for Rachel. Her effort was successful in the sense that Rachel's family perceived Rachel to be more independent than Sandra perceived her to be. But there is an unintended consequence of this success: Sandra feels criticised for being overprotective. This is compounded by the fact that Sandra, despite being the main informal caregiver, is not part of Rachel's family and disagreements between caregivers and family members about care can undermine caregivers' confidence (Semple, 1992).

Caregivers quoted friends 17 times. The majority of these quotations (59%) provided positive recognition to the caregiver, while 41% were negative. The voice of friends provided emotional support (35%) and practical help (24%) but was also patronizing (18%), avoiding (18%) or critical (6%). Positive comments tended to come from friends who were closer to the caregiver than the care-receiver. The following excerpt illustrates providing emotional support:

HM: Do you ever feel lonely?

Bernard: [...] I felt lonely. But it was also at that time that I realised that, erm, we weren't alone. [...] friends and people who we knew erm, socially, and, er, you know people at our golf club. Other members and so on, just came along and put out a hand and said you know 'take it easy' you know. Made a hell of a difference really. It really did.

(Bernard, age 70, caring for his daughter, three years post stroke, HADS A score, 9; HADS D score, 5)

Social isolation is a common outcome of brain injury for both caregiver and care-receiver and loneliness can ensue for caregivers (Braine, 2011). The number of friendships and thus sources of positive recognition lessens as time passes after the injury (Skaff & Pearlin, 1992). This is evident in Bernard's comment about feeling "lonely" and it is against that backdrop that even minor social contact can make "a hell of a difference." The phrase "take it easy" is directed at Bernard by his golfing colleagues, and it acknowledges, implicitly, that the support he is providing goes far beyond what is expected of most parents.

Caregivers quoted the general public 11 times, and each instance provided negative recognition. The voice of the public was stigmatizing (64%) and patronizing (36%).

The following excerpt illustrates stigmatizing reported speech:

Beth:           You look at Karl and you wouldn't be able- [to see his disability].  
If he was walking around with a big scar from there to there or  
whatever people would say 'Oh there's something' but because  
it's not visible, well obviously like his arm and his leg, but people  
don't understand [pause] and I do believe there's certain people  
who think 'oh, he's at it, he's kidding on' because they don't  
under-, and they can't see anything, a physical thing, and  
whatever, so it is, quite hard.

(Beth, age 38, caring for her husband, four years post fall,  
HADS A score, 15; HADS D score, 10)



Beth feels that some people think her husband is trying to obtain social benefits unlawfully. She finds this courtesy stigma “quite hard.” This case is both peculiar and interesting because the stigma comes not from the visibility of the ABI, but rather from its lack of visibility. She wants the disability to be *more* visible. Perhaps this lack of visibility also undermines her caregiving efforts.

People working in the health services were quoted 22 times. Twenty three percent of these quotations were providing practical help or emotional support, while 55% were negative, namely, disinterested (36%), confrontational (9%) and discouraging (9%).

The following excerpt was coded as disinterested:

Leona: [Discussing the family GP] I think she should have known you know, a bit more. I don't know, I think she was just trying to, it felt like "I don't know what to do with you so just go away and get someone else to look at you".

(Leona, age 44, caring for her husband, over two years post fall, HADS A score, 2; HADS D score, 0)

Health services were described by caregivers as something that they had to battle against (Reader & Gillespie, 2013). Services were accused of making misdiagnoses, providing inappropriate interventions, and failing to support the caregiver.

## The Caregiving Bind

What is the cause of the negative caregiving identity? One contributing factor may be anxiety or depression which is a common issue for caregivers (Ennis, Rosenbloom, Canzian & Topolovec-Vranic, 2013). However, we want to explore another contributing factor: maybe caregivers concealing the demands of caregiving, to protect the identity of the PwABI, might be undermining the social recognition processes that are needed for establishing a positive caregiving identity.

There is a shared goal within the care relationships for the PwABI to be independent. However, most PwABI require assistance with activities of daily living and this can undermine feelings of independence. Thus PwABI are caught between wanting practical support, but, not wanting the identity of requiring support (Power, 2008). Caregivers often ease this tension by concealing their care provision (Thomas, Morris & Harman, 2002) and distress (Farmer & Stucky-Ropp, 1996). For example, one caregiver spoke about working “behind the scenes”, re-washing the dishes and re-doing the ironing, “to protect his feelings” and “encourage his independence”. Other caregivers mentioned quietly looking after general household issues, finances and social arrangements. Encouraging feelings of independence also means creating the impression of independence for significant others (Krefting, 1990). Sandra, for example, mentioned that “there’s a lot of support needed for Rachel to look as though she doesn’t need support,” to ensure that she would arrive to meetings on time, appropriately equipped, and with well-rehearsed stories.

Successfully concealing care provision from care-receivers (Power, 2008) and friends and family (Krefting, 1990) can explain why caregivers view themselves more negatively than they are viewed by their partners with ABI, and why caregivers understand this disagreement. Simply put, the disagreement is not accidental, it is sometimes a deliberate creation by caregivers to protect the identity of the person with ABI. However, this concealment can undermine the caregiving identity in two ways.

First, the care-receiver and significant others will underestimate the physical and emotional drain on the caregiver, failing to provide the caregiver with social recognition. In response to the question “Do you think they [i.e., the PwABI] think you are supportive?” caregivers said: “She’d bloody better,” “Yeah, I bloody hope so!,” and “She’d better.” These statements perhaps indicate the desire for caregivers to receive social recognition for their efforts, but, this desire for social recognition conflicts with their efforts to conceal the demands of caregiving.

Second, successfully concealing the demands of caregiving will lead the care-receiver and significant others to overestimate the independence of the care-receiver, and thus involvement of the caregiver can lead to accusations of being overprotective. This is evident when Sandra reports a family member saying “well you know if you just let Rach do this” and reports Rachel saying “I can do it all by my own self.” Thus, concealing the demands of caregiving, not only undermines opportunities for positive social recognition, it also creates misunderstandings which can result in negative social recognition.

Main caregivers are heavily invested in caregiving, often at the expense of other social roles (Carnes & Quinn, 2005; Skaff & Pearlin, 1992). The identity literature suggests that successful integration of a new role into a positive identity requires positive social recognition (Maslow, 1954; Mead, 1934). As William James (1890, p. 263-4) vividly wrote:

No more fiendish punishment could be devised, were such a thing physically possible, than that one should be turned loose in a society and remain absolutely unnoticed by all the members thereof. If no one turned around when we entered, answered when we spoke, or minded what we did, but if every person 'cut us dead,' and acted as if we were non-existent things, a kind of rage and impotent despair would long well up in us, from which the cruellest bodily torture would be a relief.

Social recognition is the process through which identities are instituted in social reality (Goffman, 1959; Honneth, 1996). The caregiving bind arises when caregivers try to protect the care-receiver's identity by concealing the extent of informal care provision, with the unintended consequence of making their caregiving "non-existent."

## **Discussion**

The first analysis found many disagreements about the identity of caregivers. Caregivers saw themselves as less confident, less intelligent, more embarrassed and to some extent more irritable and overprotective than their partners rated them

to be. This pattern supports existing findings (Carnes & Quinn, 2005; Gosling & Oddy, 1999; Semple, 1992) and adds the finding that caregivers tend to understand these disagreements.

The second analysis found that caregivers experience minimal positive social recognition from their partner with ABI, family, the general public or health services. Positive social recognition was most likely to come from caregivers' friends. These findings extend research on the negative impact of caregiving on mental health (Badr et al., 2007; Braun et al., 2009), subjective well-being (McPherson et al., 2000) and quality of life (Greenwood et al., 2009), by revealing caregivers' negative experiences of social recognition.

The main contribution has been to interpret the findings in terms of 'the caregiving bind,' namely, caregivers concealing care-provision, to support the care-receiver's identity as independent, at the expense of undermining their own caregiving identity. This interpretation brings together findings on concealing the demands of caregiving (Gillespie et al., 2010; Harper & Lund, 1990; Power, 2008) with findings on the negative impact of caregiving for identity (Badr et al., 2007; Braun et al., 2009; Greenwood et al., 2009; McPherson et al., 2000). The findings support calls for a relational approach to ABI theory and rehabilitation which expands beyond individuals with ABI, to include their family and broader social relationships (Bowen et al., 2010; Yeates & Daisley, 2013).

If the caregiving bind exists, then what are the implications? Positive social recognition could come from care-receivers via greater openness within the

relationship and exploration of the engineered misunderstanding within a therapeutic setting. It has been suggested that they discuss “what they each see as different in themselves and each other” (Bowen et al., 2010, p. 134). Reconciliation could be facilitated by externalising the problem to confront it as a united pair (Yeates et al., 2007) and circular questioning to promote curiosity about different perspectives within the relationship (Bowen et al., 2010). Resolving misunderstandings may help to improve relationship quality and facilitate family adjustment (Bowen et al., 2010). Caregivers with a high sense of family cohesion and satisfaction are less likely to feel burdened (Perrin et al., 2013) and Family Resilience Theory emphasises that healthy patterns of family organisation, sharing of narratives and open communication lead to positive outcomes (Walsh, 2006).

While resolving misunderstandings is often helpful, it should be done with caution. Exposing the full extent of care provision to either the care-receiver or their friends and family will not necessarily provide an escape from the caregiving bind. In some cases it could undermine the identity of the person with the disability, making them appear more dependent, and, via courtesy stigma (Goffman, 1963; Wight, Aneshensel, Murphy, Miller-Martinez & Beals, 2006) also undermine the identity of the caregiver. An alternative option for resolving the caregiving bind, we suggest, is for the caregiver to obtain social recognition for their caregiving from alternative sources.

One potentially unproblematic source of positive social recognition for caregivers is health services. Health professionals are well placed to socially validate caregivers' efforts because they understand the demands of care-provision, yet they are not so

closely entangled with the identity of the PwABI that caregivers would feel the need to conceal anything. However, few caregivers experienced the National Health Service as supportive in this way. Financial pressures mean that few health professionals have the time or incentive to provide soft support which is invisible to targets (Ashworth & Kordowicz, 2010). It is possible that a few follow up telephone calls with caregivers would provide significant support (Wade, King, Wenden, Crawford & Caldwell, 1998). Social support groups for caregivers might also be a source of positive recognition outside of the care relationship (Locock & Brown, 2010). It is important that such interventions are available in the long term after injury (Ponsford & Schonberger, 2010).

Caution must be taken in generalising our exploratory findings due to the characteristics of the sample. The sample was homogeneous in being Scottish and heterogeneous both in relationship types and cause of injury. Unfortunately, the sample size did not permit breaking down results in terms of this heterogeneity. For example, the majority of critical care-receiver reported speech came from spouses rather than other relationship types. Maybe, romantic partners perceive more criticism of their efforts as there is a greater rupture in the relationship and a more marked relationship change than for example within parent/child relationships (Bowen et al., 2010). The limitations of our sample aside, we suggest that the concept of the caregiving bind could have broad applicability in informal care relationships.

Caregiving, we have argued, often entails a bind. Caregivers strive to live up to the ideal of being a perfect caregiver, of being selfless, and providing care without

reward. Caregivers concealing caregiving demands can lead care-receivers to feel more positive about themselves and make friends and family view the care-receiver as more independent. However, the unintended consequence is that care-receivers, family and friends underestimate the extent of informal care provision, making the caregiver's efforts invisible in the social arena. Unsurprisingly caregivers are widely misunderstood, but more significantly, this social misrecognition can undermine the emerging caregiver identity. Indeed rather than receiving recognition for their efforts, caregivers are sometimes rewarded by being taken for granted or accused of being overprotective. A possible solution to the caregiving bind could be to promote openness and explore the disagreements and misunderstandings in a therapeutic setting. Alternatively, where acknowledgement of the full extent of informal care provision might come at a cost to the identity of the care-receiver, alternative sources of recognition and social validation from outside of the care relationship should be cultivated.

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Table 1: Participant details

Caregiver's relationship to the PwABI	Spouse/ partner (14 dyads)	Parent (9 dyads)	Sibling (4 dyads)	Cohabiting friend (1 dyad)	Overall (28 dyads)
<b><u>PwABI</u></b>					
Age	51.57	38.78	49.75	52	47.21
Time since injury	9.31 years	6.38 years	7.33 years	2 years	7.84 years
Employed	5	3	1	0	9
HADS Anxiety (n=23)	6.50	7.71	5.67	9	6.87
HADS Depression (n=23)	4.92	5.71	7.33	8	5.61
ACE-R (n=18)	80.70	80.20	83.00	96	81.67
<b><u>Caregiver</u></b>					
Age	49.77	64.78	47.50	54	54.59
Employed	8	2	3	0	13
Co-habiting	12	6	0	1	19
HADS Anxiety (n=28)	7.36	7.22	6.75	8	6.86
HADS Depression (n=28)	4.21	3.56	4.00	2	3.62

Table 2: Disagreements and misunderstandings about PwABI

	PwABIs' rating of themselves	CGs' rating of their partner with ABI	Do PwABI and CGs disagree about PwABI?		PwABIs' estimate of CGs rating	Do PwABI misunderstand CGs' views about PwABI?	
	Median (range)	Median (range)	Z	Sig.	Median (range)	Z	Sig.
<b>Confident</b>	3 (0-4)	2 (0-4)	-.497	0.62	3 (0-4)	-1.753	0.08
<b>Confused</b>	2 (0-4)	3 (0-4)	-1.23	0.219	3 (0-4)	-.399	0.69
<b>Embarrassed</b>	1.5 (0-4)	1 (0-4)	-.945	0.344	2 (0-4)	-.979	0.328
<b>Independent</b>	3 (0-4)	3 (0-4)	-1.006	0.314	3 (0-4)	-.264	0.792
<b>Intelligent</b>	3 (0-4)	4 (0-4)	-.423	0.673	3 (0-4)	-.192	0.848
<b>Interested</b>	4 (0-4)	4 (0-4)	-1.786	0.074	4 (0-4)	-1.915	0.056
<b>Irritable</b>	2 (0-4)	1 (0-4)	-1.182	0.237	2 (0-4)	-1.589	0.112
<b>Kind</b>	4 (2-4)	4 (2-4)	-.577	0.564	4 (2-4)	-1.299	0.194
<b>Lazy</b>	0 (0-4)	0 (0-4)	-.221	0.825	0.5 (0-4)	-.213	0.831
<b>Mature</b>	4 (0-4)	3.5 (0-4)	-1.283	0.2	4 (1-4)	-1.476	0.14
<b>Overprotective</b>	2 (0-4)	2 (0-4)	-.165	0.869	2 (0-4)	-.302	0.763
<b>Passive</b>	2 (0-4)	3 (0-4)	-.132	0.895	2 (0-4)	-.646	0.518
<b>Self-centred</b>	1 (0-3)	2 (0-4)	-2.381	<b>.017*</b>	0.5 (0-4)	-2.134	<b>.033*</b>
<b>Supportive</b>	4 (0-4)	4 (0-4)	-.872	0.383	4 (0-4)	-1.459	0.145

Asterisk (\*) indicates statistically significant disagreement ( $p < .05$ )

Table 3: Disagreements and misunderstandings about caregivers (CG)

	CGs' rating of themselves	PwABIs' rating of their CG	Do CGs and PwABIs disagree about caregivers?		CGs' estimate of PwABIs rating	Do CGs misunderstand PwABIs' views about caregivers?	
	Median (range)	Median (range)	Z	Sig.	Median (range)	Z	Sig.
<b>Confident</b>	1 (0-4)	4 (1-4)	-2.19	<b>.029*</b>	3 (0-4)	-.299	0.765
<b>Confused</b>	0 (0-3)	0 (0-4)	-.350	0.726	0 (0-4)	-.461	0.645
<b>Embarrassed</b>	2 (0-4)	0 (0-4)	-2.738	<b>.006*</b>	0 (0-4)	-.918	0.359
<b>Independent</b>	4 (1-4)	4 (0-4)	-2.178	<b>.029*</b>	4 (1-4)	1.603	0.109
<b>Intelligent</b>	1 (0-4)	4 (2-4)	-3.136	<b>.002*</b>	4 (0-4)	-1.913	0.056
<b>Interested</b>	4 (2-4)	4 (0-4)	-1.485	0.138	4 (1-4)	-2.14	<b>.032*</b>
<b>Irritable</b>	2 (0-4)	1 (0-4)	-1.766	0.077	2 (0-4)	-2.61	<b>.009*</b>
<b>Kind</b>	4 (3-4)	4 (3-4)	-1.265	0.206	4 (2-4)	-1.291	0.197
<b>Lazy</b>	0 (0-3)	0 (0-3)	-.647	0.518	0 (0-3)	-.355	0.722
<b>Mature</b>	4 (2-4)	4 (3-4)	-1.513	0.13	4 (0-4)	-.758	0.449
<b>Overprotective</b>	3 (0-4)	2 (0-4)	-2.005	<b>.045*</b>	3 (0-4)	-1.681	0.093
<b>Passive</b>	2 (0-4)	2 (0-4)	-.323	0.746	2 (0-4)	-1.115	0.256
<b>Self-centred</b>	0 (0-2)	0 (0-4)	-.097	0.923	0 (0-3)	-1.087	0.277
<b>Supportive</b>	4 (3-4)	4 (3-4)	-.577	0.564	4 (1-4)	-1.725	0.084

Asterisk (\*) indicates statistically significant disagreement ( $p < .05$ )

Table 4: Quotations attributed to significant others by caregivers

Significant Other	Positive Recognition	Negative Recognition	Neutral Direct Quotations	Total Direct Quotations
PwABI	3 (Acknowledging support) 1 (Accepting of situation) 1 (Encouraging) 1 (Kind)	9 (Critical) 9 (Defiant) 9 (Demanding) 6 (Pessimistic) 5 (Disinterested) 4 (Irritated) 3 (Confused)	7	58
Family	1 (Being supportive)	3 (Critical) 2 (Patronizing) 2 (Uncomprehending)	4	12
Friends	6 (Being supportive) 4 (Providing practical help)	3 (Patronizing) 3 (Avoiding) 1 (Critical)	0	17
General Public	0	7 (Stigmatising) 4 (Patronizing)	0	11
Health Services	3 (Providing practical help) 2 (Being supportive)	8 (Disinterested) 2 (Confrontational) 2 (Discouraging)	5	22
Total	22	82	16	120