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# The Social Consequences of Stigma-Related Self-Concealment after Acquired Brain Injury

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Short title: Stigma-related concealment

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### **Abstract**

Social relationships often decline after brain injury. Although much of this is due to psychosocial impairments caused by the injury, the reactions to the injury of others in the person's wider social network, along with the response of the person with the injury to those reactions, also need to be considered. Anxiety about stigmatizing reactions from others may lead some to conceal information about their brain injury. This study investigated some of the social consequences of such concealment. Sixty-five participants with acquired brain injury completed the Anticipated Stigma and Concealment Questionnaire, the Social Avoidance and Distress Scale, the UCLA Loneliness Scale, the Rosenberg Self-Esteem Scale, the Social Integration subscale of the Community Integration Questionnaire, and the Enacted Social Support Questionnaire. As hypothesized, concealment was associated with social anxiety, social avoidance, loneliness and lower self-esteem; and social anxiety mediated the impact that concealment had on social avoidance, loneliness and reduced community activity. However, the expectation that concealment would also be associated with reduced use of social support was not supported. Concealment may have negative consequences, but inappropriate disclosure can also be harmful. Services should support individuals to make optimal decisions about disclosing information about the brain injury to others and also help them address psychological barriers to disclosure.

**Keywords:** stigma, loneliness, social anxiety, self-esteem, self-disclosure, brain injury

## **The Social Consequences of Stigma-Related Self-Concealment after Acquired Brain Injury**

In the context of a wide range of physical and mental health difficulties it has been observed that a strong network of social relationships makes a vital contribution to happiness and well-being, to physical and mental health, and to coping effectively with illness and adversity (e.g. Feeney, 2015; Paterson, Robertson, & Nabi, 2015; Santini, Koyanagi, Tyrovolas, Mason, & Haro, 2015). Similar findings have been reported in acquired brain injury (ABI): Better quality relationships are associated with better mental health and well-being (e.g. Douglas & Spellacy, 2000; Haslam et al., 2008; Jones et al., 2011; Kendall & Terry, 2009) and with better progress in the recovery of functional abilities and community reintegration (McColl et al., 1998; Palmer & Glass, 2003; Sander et al., 2002).

Unfortunately, ABI often has a negative effect on relationships. Relationships within the family can decline in quality (Blais & Boisvert, 2005; Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011). Outside the family, relationships with friends that pre-date the injury may break down (Hoofien, Gilboa, Vakil, Donovick, 2001; Morton & Wehman, 1995; Salas, Casassus, Rowlands, Pimm, & Flanagan, *in press*); the person with the ABI may struggle to form new relationships (Morton & Wehman, 1995; Salas et al., *in press*); and those that are formed can feel superficial and unsatisfactory (Crisp, 1993; Shorland & Douglas, 2010; Salas et al., *in press*). Loneliness is widely reported (Douglas & Spellacy, 2000; Hoofien et al., 2001; Morton & Wehman, 1995; Karlovits & McColl, 1999; Shorland & Douglas, 2010).

Given the positive benefits of relationships, it is important to understand why they often deteriorate in the aftermath of a brain injury. To a large extent, this may be due to the behaviour of the person with the injury. Psychosocial impairments arising from the brain injury can give rise to behaviours that alienate others (e.g. aggression) and to difficulties in

enacting interactive behaviours that establish, nurture and sustain relationships (Bodley-Scott & Riley, 2015; Bond & Godfrey, 1997; Shorland & Douglas, 2010; Wood, Lioffi, & Wood, 2005; Yeates, 2013). However, the responses of others to the brain injury, and the reactions of the person with the ABI to those responses, may also contribute to the deterioration in relationships. For example, spouses differ widely in their response to ABI, even to injuries associated with a similar range of impairments, and those responses may serve to weaken or strengthen their relationship to the person with the brain injury (Bodley-Scott & Riley, 2015; Gill, Sander, Robins, Mazzei, & Struchen, 2011; Riley, 2016). Relationships with the wider circle of non-immediate family, friends, acquaintances and the general public also need to be considered from this perspective. Stigma is a potentially useful construct for exploring the responses of this wider circle to the injury, and the reactions of the person with the ABI to those responses.

### **Stigma**

Stigma is a complex construct referring to negative and rejecting attitudes towards a group in society that is distinguished by some characteristic (Link & Phelan, 2001). Different aspects of the construct include the possession of stigmatizing attitudes towards those with the characteristic (*stigmatizing attitudes*); stigmatizing behaviour towards those with the characteristic (*enacted stigma*); the expectation of such behaviour by those with the characteristic (*anticipated stigma*); and the translation of stigmatizing attitudes into negative attitudes towards oneself (*internalized stigma or shame*) (Nyblade, 2006).

There is some evidence of these different categories of stigma in relation to ABI, and its role in undermining social relationships after ABI. The general public can be rejecting and prejudicial in its response to brain injury and the difficulties that the person may have (i.e. *stigmatizing attitudes* and *enacted stigma*) (Jones, Jetten, Haslam, & Williams, 2012; Karlovits & McColl, 1999; Nochi, 1998; Riley & Hagger, 2015). For example, participants

in the study by Riley and Hagger (2015) described being ridiculed by children in the street and by colleagues at work because of their disabilities. There is evidence of *anticipated stigma* (Baldwin, Powell, & Lorenc, 2011; Karlovits & McColl, 1999; Nochi, 1998; Riley, Brennan, & Powell, 2004; Riley & Hagger, 2015; Shorland & Douglas, 2010). For example, some of the participants in the study by Baldwin et al. reported a reluctance to use memory aids such as post-it notes because of concerns about the negative reactions that their use might elicit in other people. *Internalized stigma* has also been reported, with people reporting that they feel ashamed and embarrassed about their ABI (Crisp, 1993; Riley et al., 2004; Riley & Hagger, 2015; Simpson, Mohr & Redman, 2000). *Stigmatizing attitudes* and *enacted stigma* may undermine relationships after ABI by making others unwilling to associate with people with an ABI and by impairing the quality of the interactions that they do have; and there is evidence that people with ABI can be anxious and avoidant of social interaction because of *anticipated stigma* (Curvis, Simpson, & Hampson, *in press a*; Jones et al., 2012; Riley et al., 2004; Riley & Hagger, 2015; Simpson et al., 2000).

### **Concealing a stigmatized identity**

Brain injury is typically a concealable aspect of the individual's identity in the sense that the person has a choice about how much information relating to their injury they disclose to others (Jones et al., 2012; Riley & Hagger, 2015). Indeed, in many cases, the injury does not leave any lasting visible signs, and even the fact that one has had a brain injury can be concealed. Research on other concealable stigmatized characteristics unrelated to brain injury, such as sexual preference and mental health difficulties, has investigated the motivations behind the decision to conceal or disclose, and the consequences of that decision (Chaudoir & Fisher, 2010; Pachankis, 2007). Concealment can have several negative effects on social functioning. It may lead to stress and anxiety in social situations because of the threat of the characteristic being exposed or discovered (Birchwood et al., 2006; Chaudoir &

Fisher, 2010; Pachankis, 2007; Smart & Wegner, 1999). This anxiety may, in turn, lead to social withdrawal and isolation as the person avoids situations in which there is a threat of being exposed (Birchwood et al., 2006; Pachankis, 2007; Remennick, 2000). Disclosure of important personal information plays a central role in establishing, strengthening and maintaining close relationships with others, and so concealment may act as a hindrance to nurturing such relationships (Chaudoir & Fisher, 2010; Collins & Miller, 1994; Sprecher & Hendrick, 2004). Related to this, information about the identity needs to be disclosed in order to access support that focuses on it, and so concealment may result in restricted access to emotional, practical and informational support from others that enables the individual to address the challenges arising from the stigmatized aspect of their identity more effectively (Beals, Peplau, & Gable, 2009; Chaudoir & Fisher, 2010; Zea, Reisen, Poppen, Bianchi, & Echeverry, 2005). Concealment may also restrict access to the benefits that arise from identifying oneself, through disclosure, with others who share the stigmatized identity. Sharing a social identity may reduce internalized stigma through the validation of one's identity by others in the group that one identifies with, and can facilitate a more resilient response to the stigma attached to the identity in wider society (Cass, 1984; Crocker & Major, 1989; Matheson & Anisman, 2012; Pachankis, 2007). The subsequent reduction of internalized stigma and the sense of social inclusion would be expected, in turn, to enhance psychological well-being and self-esteem (Leary, Tambor, Terdal, & Downs, 1995). Indeed, from the perspective of social identity theory, one's identification with social groupings is a primary determinant of one's sense of self and thereby of self-esteem (Hogg & Abrams, 1990). Evidence generally supports a link between concealment and lower self-esteem. For example, lower self-esteem has been reported to be associated with higher rates of concealing HIV status (Zea et al., 2005), mental health difficulties (Ho et al., 2015) and sexual identity (Jordan & Deluty, 1998).



Research has also investigated the motivations behind the decision to conceal or disclose (Chaudoir & Fisher, 2010). These decisions are primarily driven by a focus on some of the specific consequences identified in the previous paragraph (e.g. not wanting to experience *enacted stigma*, or wanting emotional support from others) (Omarzu, 2000). However, it has also been suggested that a contribution is made by the general tendency to be avoidant-focussed or approach-focussed in one's goal-directed behaviour (Chaudoir & Fisher, 2010). Those who are generally motivated by the achievement of positive outcomes are more likely to disclose in order to achieve the benefits associated with disclosure; whereas those who are generally motivated by the avoidance of negative punishing outcomes are more likely to conceal in order to avoid the costs associated with disclosure. These approach and avoidance systems have also been related to self-esteem. Evidence suggests that those with low self-esteem are primarily avoidant-focussed, whereas those with high self-esteem are primarily approach-focussed (Heimpel, Elliot, & Wood, 2006). This implies that those with low self-esteem may be more motivated to conceal their faults, whereas those with high self-esteem may focus on whether disclosure will be of benefit (Baumeister, Tice, & Hutton, 1989; Wood & Forest, 2016). Thus, self-esteem and concealment may have a mutual impact: Low self-esteem may motivate concealment, and concealment may, in turn, prevent access to the enhancement of self-esteem that may derive from sharing a social identity with others in the stigmatized group.

### **Concealment of an ABI**

Evidence about the consequences and motivations associated with concealment of an ABI is sparse and derives from qualitative studies. In terms of motivation, participants in qualitative studies have reported concealing information about their ABI because of concerns about the reactions of others (*anticipated stigma*), and because of their sense of shame and embarrassment (*internalized stigma*) (Nochi, 1998; Simpson et al., 2000; Shorland &

Douglas, 2010). In their qualitative study, Riley and Hagger (2015) investigated the issue of motivation more extensively. As well as concern about the reactions of others and shame, participants also described, as reasons to conceal, wanting to avoid the stress and upset that could be associated with disclosure (because any talk about their injury had the potential to be upsetting), and wanting to fit in and not to draw attention to themselves as different. Reasons given for disclosure included wanting to obtain social support, alleviating the stress of concealment, wanting to forestall misattributions about their difficulties (e.g. that their difficulties are due to laziness or stupidity), and wanting to give others the benefit of their experience. Evidence about the consequences of concealment is even more limited, but is consistent with the research relating to other concealable identities. Some participants in qualitative studies have described how concealment and the threat of exposure create stress in social situations (Crisp, 1993; Riley & Hagger, 2015). They have also described how they have obtained valuable social support through disclosure (Riley & Hagger, 2015), how concealment has been a barrier to the formation of friendships, and how disclosure has enhanced the quality of friendships (Shorland & Douglas, 2010). In the study by Salas et al. (*in press*), participants highlighted that identifying with others with a traumatic brain injury (which is obviously dependent on a willingness to disclose) gave them a sense of belonging and connectedness that was otherwise lacking in their relationships with people who did not have a brain injury.

### **The present study**

The aim of the present study was to investigate the contribution of concealment to the decline in social functioning that can occur after ABI. The review of earlier research has suggested that concealment may contribute to stress in social situations, to subsequent avoidance of social situations, and to reduced access to social support. Because of the avoidance and the negative impact that concealment may have on friendships, loneliness may

be more frequent and general engagement in community activities may be reduced. Concealment may also hinder a person from identifying with others with an ABI, and this may prevent them accessing the benefits of group identification that include an enhancement of self-esteem and a sense of belonging and connectedness (i.e. the opposite of loneliness). Those low in self-esteem may also be more motivated to conceal. It was therefore hypothesised that a preference for concealing information about an ABI would be associated with more social anxiety, more social avoidance, less social support, greater loneliness, reduced engagement in community activities, and lower self-esteem. It was also hypothesised that the relationship between concealment and avoidance would be mediated by anxiety (implied by the suggestion that concealment leads to anxiety which subsequently leads to avoidance); and that the relationship between concealment and both loneliness and reduced engagement in community activities would be mediated by social anxiety/avoidance (implied by the suggestion that the anxiety and avoidance related to concealment contribute, to some extent at least, to loneliness and reduced engagement).

## **Method**

### **Participants and recruitment**

Ethical approval was given by the ethics committee of the University of Birmingham, U.K. Participants were recruited from two centres run by Headway, which is a non-governmental organization providing support for people with acquired brain injuries and their families. Participants were required to have had an acquired brain injury; to be at least 12 months post-injury; to be between the ages of 19 and 70; to have been at least 18 years of age when the injury occurred; and to have a level of cognitive ability and command of the English language that was adequate to provide informed consent and to complete questionnaires. Staff at the centres initially approached those meeting these criteria and

provided them with an information sheet. They were invited to contact the researchers if they were interested in taking part. Data were collected at the centres. Some participants required the questionnaires to be read to them and/or their responses to be recorded for them.

Power analysis was conducted using G\*Power (Faul, Erdfelder, Lang, & Buchner, 2007). It was anticipated that the hypothesized associations would involve a mix of large ( $>.5$ ) and medium (between  $.3$  and  $.5$ ) correlations. For example, larger correlations were expected between the measures of social anxiety and avoidance on the basis of previously reported research (Watson & Friend, 1969) and because of the strong empirical and theoretical connections between anxiety and avoidance, but more modest correlations were expected between the measure of concealment and social anxiety because numerous other factors are likely to contribute to social anxiety, thereby diluting the contribution of concealment. The intention was therefore to power the study sufficiently to detect moderate correlations. The analysis indicated that a sample of 64 would be required to detect a medium correlation ( $r = 0.3$ ), with alpha set at  $.05$ , and power set at  $.80$ . In terms of the mediation analysis, the relationships were likewise expected to involve a combination of large and medium effects. Fritz and MacKinnon (2007) calculated that, for the bias-corrected bootstrap method that was used for the mediation analysis and with alpha set at  $.05$  and power set at  $.80$ , a sample size of 54 is required to detect a mediation involving large and medium associations. The targeted sample of 64 was therefore also judged to be sufficient for the mediation analyses. Whether the sample size was, in the event, adequate for these analyses is considered later.

In the event, 65 people took part. Demographic information about the participants is contained in Table 1. Information was not collected about the severity of the injury. However, given that all participants were continuing to receive rehabilitative input from

Headway at least 12 months after their injury, participants were considered more likely to have sustained a moderate or severe brain injury than a mild one..

### Measures

The scale used to measure concealment was a subscale of a questionnaire devised and evaluated by Hagger (2011). For the purposes of this study, the subscale was labelled the *Anticipated Stigma and Concealment Questionnaire (ASCQ)*. Each item focuses on a potential negative reaction from others to disclosure about the injury (e.g. ‘other people might think I was mad or dangerous’) and asks whether the respondent has concealed information about their injury because of this. Responses are selected from ‘definitely false’, ‘false’, ‘not sure’, ‘true’ and ‘definitely true’. The questionnaire has 10 items (Appendix 1) and has been reported to have good internal reliability (0.87) and test-retest reliability (0.79), and construct validity (evidenced by a significant moderate correlation with the Brief Fear of Negative Evaluation (Leary, 1983) ( $r=.42$ )) (Hagger, 2011). Higher scores indicate more concealment.

Because of the difficulty in locating a measure of received social support that was appropriate for use in ABI, a measure was devised for the purposes of the current study. This nine-item questionnaire was labelled the *Enacted Social Support Questionnaire (ESSQ)* (Appendix 2). It asks about the frequency with which the participant has received practical, informational and emotional support from members of their wider family (i.e. those the participant did not live with), friends, and neighbours/ acquaintances. Responses are selected from ‘most days’, ‘most weeks’, ‘once or twice a month’, ‘a few times a year’ and ‘never’. Higher scores indicate greater frequency of social support.

Established scales were used to measure other constructs. The *Rosenberg Self-Esteem Scale (RSES)* was used to measure self-esteem. This has been widely used in ABI (e.g. Cooper-Evans, Alderman, Knight, & Oddy, 2008; Curvis, Simpson, & Hampson, *in press b*; Riley, Dennis, & Powell, 2010). Responses were scored from 0 to 3, and were scored so that

high scores indicate greater self-esteem. The *Social Avoidance and Distress Scale* (Watson & Friend, 1969) was used to measure distress and anxiety in social situations (SADD) (15 items) and social avoidance (SADA) (13 items). Responses are selected from ‘true’ or ‘false’, and scored as 1 or 2. Higher scores indicate more anxiety and avoidance. General engagement in community activities was measured by the *Social Integration* subscale of the *Community Integration Questionnaire* (CIQ-SI) (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993), and loneliness by the *University of California, Los Angeles Loneliness Scale* (UCLA-LS) (Russell, 1996). Higher scores indicate more community activity and more loneliness respectively.

[Table 1 about here]

### Results

All participants provided full data sets. Means, standard deviations and ranges are shown in Table 2, which also provides the Cronbach’s alpha for each questionnaire calculated from this data set. The alpha for the CIQ-SI was poor, with the items on managing personal finances and shopping showing item-total correlations below 0.2. Compared to non-brain-injured samples, the means for this ABI sample were lower on the RSES (0.8 standard deviations below the mean of a sample drawn from the general population – Sinclair et al., 2010) and on the CIQ-SI (0.5 SD below the mean of a sample matched on demographic variables with a traumatic brain injury sample – Migliorini, Enticott, Callaway, Moore, & Willer, 2016), and higher on the combined SADD/SADA total (0.4 SD higher than the mean of a sample of students – Stopa & Clark, 2001, who scored it 0 or 1 rather than 1 or 2), and UCLA-LS (1.3 SD higher than the mean of a sample of older people - Russell, 1996).

[Table 2 about here]

Prior to further analysis, SADA and SADD scores and the combined total of these two scores (used in the mediation analysis) were transformed using a logarithmic

transformation to correct moderate-to-severe positive skewing. Results of the correlation analysis are shown in Table 3. As predicted, concealment showed a significant positive correlation with social anxiety (SADD), social avoidance (SADA) and loneliness (UCLA-LS). Also as predicted, those with higher concealment scores reported lower self-esteem (RSES). Correlations of the ASCQ with the SADD and SADA were relatively small according to the classification of Cohen (1988) (i.e.  $<.3$ ), but medium with the UCLA-LS and the RSES (i.e. between  $.3$  and  $.5$ ). However, concealment was not significantly correlated with either general engagement in social activities (CIQ-SI) or social support (ESSQ). Indeed, the correlation between the ASCQ and ESSQ was positive, rather than the hypothesized negative correlation.

[Table 3 about here]

It was also hypothesised that the relationship between concealment and avoidance (SADA) would be mediated by anxiety (SADD); and that the relationship between concealment and both loneliness (UCLA-LS) and reduced engagement in community activities (CIQ-SI) would be mediated by social anxiety/avoidance. The study was sufficiently powered to conduct bias-corrected bootstrap mediation analyses in which the predictor variable has a moderate correlation with the mediator and the mediator has a large correlation with the outcome variable (or the predictor has a large correlation with the mediator and the mediator a moderate correlation with the outcome) (Fritz & MacKinnon, 2007). Consequently, these three hypotheses were tested using three separate mediation analyses rather than testing a model involving all the variables, which would have required a much larger sample. Likewise, to maintain the power of the analyses, the combined total of the SADA and SADD scores was used as the mediator variable (in preference to keeping these variables separate) in the analyses involving the UCLA-LS and CIQ-SI as the outcome variables. On the basis of the correlation analysis, it was possible to assess whether the

assumptions of the a priori power analysis were met. Although the correlations between the mediator variable (SADA or SADA/SADD total) and the outcome variables were all medium or large (i.e. greater than .3) (Table 3), those between the predictor (ASCQ) and the mediator (SADA or SADA/SADD total) were small (i.e. less than .3). The mediation analyses were thus somewhat underpowered and the results should be interpreted with caution.

AMOS was used to conduct the mediation analyses. The results are shown in Figure 1, and Table 4 contains the estimates (and 95% confidence intervals for the estimates) of the standardised direct and indirect effects, together with the p-values for the estimates. The indirect effect represents the impact that the predictor variable has on the outcome variable via the mediation of the other variable in the model; the direct effect represents the impact that is not mediated by the other variable. The standardised effect is the increase in standard deviations of the outcome variable for each standard deviation increase in the value of the predictor. Transformations of the SADA, SADD and SADD/SADA total scores were used in the analyses; Figure 1 shows the values of the standardised effects altered to raw score equivalents in order to assist in their interpretation. For example, the direct effect of the ASCQ on the UCLA-LS was 0.229 (Figure 1). This means that, when the value of the ASCQ increased by 1 standard deviation, the value of the UCLA-LS increased by 0.229 standard deviations. The analysis supported all three hypotheses: The association between concealment (ASCQ) and avoidance (SADA) was significantly mediated by social distress (SADD); the association between concealment and loneliness (UCLA-LS) was significantly mediated by distress and avoidance (SADD/SADD total); and the association between concealment and community activity (CIQ-SI) was likewise significantly mediated by distress and avoidance (SADD/SADD total). However, the mediated effects were relatively small, particularly the effect on community activity (Figure 1). It should also be noted that the direct effect of concealment on loneliness was also significant (Table 4), indicating that a



significant part of the relationship between the two was not mediated by distress and avoidance.

[Figure 1 about here]

[Table 4 about here]

### **Demographic analysis**

ANOVA was used to compare the questionnaire means of different demographic groups (defined according to the categories in Table 1) using the Tukey test to adjust for multiple comparisons, and correlations were calculated between the questionnaire scores and the two continuous demographic variables (i.e. participant age and time since injury). There were no significant correlations between any of the questionnaire scores and participant age or time since injury. Males were significantly less likely to conceal than females and those who were married or had a partner were significantly less likely to conceal than those not in a spousal relationship/partnership (males = 23.7 vs. females = 33.1;  $F = 10.76$ ,  $p = .002$ ; married/ partnership = 21.8 vs. not married/partnership = 27.9;  $F = 5.22$ ,  $p = .026$ ). Those who had received higher education reported more community activities on the CIQ-SI (9.64 vs. 8.08;  $F = 4.07$ ;  $p = .048$ ), and those in paid or voluntary work had higher self-esteem than those not in work (22.1 vs. 17.2;  $F = 6.35$ ;  $p = .014$ ). No other comparisons were significant for the categorical demographic variables. The sample was too small to support further exploration of whether any of the demographic variables moderated the relationships between the questionnaire variables (e.g. whether the effect of concealment on loneliness mediated by social anxiety and avoidance was larger for males or females).

### **Discussion**

The aim of the present study was to investigate some of the potential negative social consequences of concealment in ABI. As hypothesized, a preference for concealment was associated with more anxiety in social situations, more avoidance of such situations, more

loneliness and lower self-esteem. However, the relatively small size of the correlations should be noted. Moreover, there was no support for the expectation that it would be correlated with reduced frequency of social support or reduced engagement in general community activities (although there was a significant mediated effect on community engagement).

The association with social anxiety supports the findings of qualitative studies in which participants with ABI have described the stress associated with concealment and the risk of exposure, and the relief when this is removed through disclosure (Crisp, 1993; Riley & Hagger, 2015). Compared to some other concealable stigmatized identities, the anxiety about exposure in ABI may be heightened by the fact that it may often be difficult to completely conceal all the effects of the brain injury in a social interaction. For example, it is easier to conceal a sexual preference in a conversation than it is to conceal the fact that one is not understanding or not retaining a conversation. Related to this, Pachanskis (2007), in a general model of the process of concealment, suggested that the fear of exposure may lead to a preoccupation with the threat and increased vigilance for signs that the other person may suspect the identity, and to efforts to both conceal the identity and to present evidence to the contrary. The resultant cognitive overload may disrupt social performance, further adding to the stress of the situation. This seems a particularly relevant possibility to consider in the case of ABI, where such an overload may further compromise already impaired cognitive and social competencies.

In line with research on other concealable identities (Birchwood et al., 2006; Pachankis, 2007; Remennick, 2000), it was suggested that the anxiety of being discovered may, in turn, lead to social withdrawal and isolation as the person avoids situations in which there is a threat of being exposed. Support for this connection was provided by the results of the mediation analysis, in which the association between concealment (ACSQ) and avoidance

(SADA) was significantly mediated by social anxiety (SADD). The suggestion is also supported by other studies in which participants have stated directly that anxiety about the exposure of one's disabilities to others has led them to avoid social situations (Riley et al., 2004; Riley et al., 2010; Riley & Hagger, 2015).

As predicted, a preference for concealment was associated with greater loneliness. There may be several ways in which the two are connected. One possibility, which was supported by the mediation analysis, is that concealment leads to anxiety-related social avoidance which, in turn, creates a sense of loneliness. However, the direct effect of concealment on loneliness was also significant in the mediation analysis, indicating that this possibility did not explain all of the relationship between concealment and loneliness. Another possibility is that concealment acts as a barrier to the establishment and maintenance of friendships (and thereby increases loneliness) because of the importance of disclosure to establishing and maintaining closer personal relationships (Chaudoir & Fisher, 2010; Shorland & Douglas, 2010). Concealment may also prevent the individual from assuming a social identity as a person with a brain injury, and thereby prevent access to a sense of belonging and connectedness that comes from a shared social identity (Salas et al., *in press*).

The significant correlation between low self-esteem and concealment matches findings in other types of stigmatized identities (Ho et al., 2014; Zea et al., 2005). Two explanations of this link were suggested in the Introduction: Those with low self-esteem may be more motivated to conceal in order to avoid the losses associated with disclosure; and a willingness to disclose may provide a gateway to a social identification with others with a brain injury which, in turn, may reduce internalized stigma and thereby enhance self-esteem. Consistent with the suggestion that those with low self-esteem will be more motivated to avoid negative outcomes, Riley et al. (2010), in a study involving participants with ABI, found that those with lower self-esteem were more likely than those with higher self-esteem

to respond to situation-specific anxiety by avoiding that situation. The connection between a shared stigmatized identity and enhanced self-esteem has been further elaborated in an aspect of social identity theory which proposes that, once they have identified themselves with a social group, group members will focus on, and enhance, the positive differences between their group and other groups, and that this establishes a positive identity for the group and thereby enhances the self-esteem of group members (St Claire & Clucas, 2012; Hogg & Abrams, 1990). Evidence is generally supportive of this idea, but there have been some inconsistent findings (Rubin & Hewstone, 1998).

It was hypothesized that, because of its potential impact on social avoidance and friendships, concealment would be associated with a reduction in general community activities (measured by the CIQ-SI). There was some limited support for this: ASCQ scores had a significant effect on CIQ-SI scores through the mediation of social anxiety and avoidance (SADD/SADA total). However, the effect size was relatively small, and the direct correlation between the ASCQ and CIQ-SI scores was not significant. This may be a reflection of the fact that many other factors contribute to engagement in social activities in the community (e.g. transport and financial issues, living arrangements). Accordingly, any association between concealment and such activities is likely to be relatively small. In addition, the CIQ-SI showed poor internal reliability in this study (Table 2) and this would have reduced the effect size and increased the probability of Type-II errors. The subscale contains items on the management of personal finances and shopping that do not contain a strong social component, and, with item-total correlations below 0.2, these were the main contributors to the poor reliability. Doninger et al. (2003) similarly reported poor psychometrics for this subscale and that the item on the management of personal finances was a poor fit with the underlying construct.

The study failed to find the expected association between concealment and accessing social support. Indeed, the correlation was in the opposite direction to what was expected (albeit non-significant). The expectation of an association was based on the suggestion that information about the stigmatized identity needs to be disclosed in order to access support relevant to dealing with the challenges posed by the identity (Beals et al., 2009; Chaudoir & Fisher, 2010; Zea et al., 2005). However, the ESSQ asked about receiving social support in more general terms. A fairer test of the hypothesis would have been provided by asking more specifically about support received as a result of disclosure, rather than support received generally. Accessing social support outside the immediate family is also likely to be heavily dependent on the actual need for that support. For example, those living with a partner or spouse may be less likely to need such support than some of those with other living arrangements; and those living alone may be more competent in dealing with the impact of the brain injury than others and so also have less need for this type of support. The need for support would need to be controlled for in order to obtain a clearer picture of the relationship between concealment and accessing support. Another potential connection between concealment and reduced social support may be mediated through social identity. A reluctance to disclose may result in not sharing a social identity with others who have an ABI. As a result, the person may miss out on the perceived social support that derives from the sense of connectedness and belonging associated with group identity and from the specific enacted social support that those who have lived through the same experience may be able to provide (Clare, Rowlands, & Quinn, 2006; Hogg & Abrams, 1990; Sani, 2012). A more thorough investigation of the links between concealment and reduced social support would also need to address this possibility.

### **Limitations**

Some other limitations of the study should be noted. The use of convenience sampling indicates the need for caution in generalizing the findings. The reliance on self-report measures created an opportunity for response biases to influence the results. Because of the study's non-experimental nature, conclusions about causal relationships are not possible. The significant correlations observed in the study may have arisen for reasons other than those suggested. For example, anticipated stigma may contribute directly to social anxiety and avoidance regardless of any motivation to conceal (Riley et al., 2004; Curvis et al., *in press a*), and anticipated stigma is the primary motivation for concealment (Riley & Hagger, 2015). The correlation between the concealment and social anxiety observed in this study may thus have occurred, not because concealment creates anxiety, but because those who anticipate more stigma in social situations may be more likely to be both socially anxious and more motivated to conceal. Another example concerns self-esteem. It was suggested that low self-esteem may contribute to concealment because those with low self-esteem are more focused on protecting themselves from the negative effects of disclosure, and that concealment may contribute to low self-esteem by preventing the person access to the validation of their self-identity through group-identification, which is dependent on disclosure. However, because of the heavy dependence of self-identity on one's public identity (Lucksted & Drapalski, 2015; Ownsworth, 2014), it may be that those who anticipate more negative reactions from others (i.e. anticipated stigma) are more likely to have low self-esteem because of the internalization of the stigma (i.e. internalized stigma). Assuming those who anticipate more negative reactions from others are likely to be more motivated to conceal, the correlation observed in the present study between low self-esteem and a preference for concealment may be due to both being the product of anticipating more negative reactions from others. These examples relating to social anxiety and self-esteem illustrate that, when dealing with complex psychosocial processes of this nature, simple

unidirectional causal relationships between variables are likely to be the exception rather than the rule, and that most variables are likely to have complex mutual impacts on one another.

The complex multi-factorial nature of these relationships may also partly explain why, apart from some more closely connected variables such as social avoidance and loneliness, many of the correlations observed in the present study were relatively modest in size (Table 3).

Another limitation of the study related to this issue of complexity is that not all of the relevant variables were measured. For example, social identity was hypothesized to play a mediating role between the preference for concealment and some of the social outcomes, but no measure of social identity was taken. A final issue is that the relatively small size of the sample precluded a more thorough investigation of the relationships amongst the assessed variables. The *a priori* power analysis aimed to provide adequate power only for three-variable mediation analyses. The study did not have sufficient power to test more complex models of how the variables might be related. Indeed, *post hoc* power analysis indicated that the study was somewhat underpowered for the mediation analyses that were conducted. The sample was also too small to support further exploration of whether any of the demographic or injury-related variables moderated the relationships between the questionnaire variables. In this context, a particular limitation to note is the mixed aetiology of the brain injuries of the participants, the lack of information about the specific subtypes of stroke and tumour, and the relatively small numbers belonging to the different categories of traumatic brain injury (Table 1). This limits the extent to which the findings can be generalized to specific subgroups within the broader category of acquired brain injury. Larger samples in future research would enable a more thorough investigation of the relationships amongst the psychological variables and the relevance of demographic and injury-related variables.

## **Implications**

Good relationships with those outside the immediate family are likely to be major contributors to how well a person copes with an ABI, and to their general happiness and well-being. It is therefore important to understand why these relationships can deteriorate after ABI. Although much of this may stem from the psychosocial impairments created by the injury, it is also relevant to explore how the responses of others to the brain injury, and the reactions of the person with the ABI to those responses, may contribute to the deterioration in relationships. In this context, the results of the present study suggest that anticipated stigma and associated concealment merit further investigation. This study supported suggestions that they may contribute to social anxiety, avoidance, loneliness, reduced self-esteem and lower engagement in general social activities. Their contribution to accessing social support needs to be explored using more effective measures and controls for confounding variables. There is also a need to explore whether they affect the closeness of personal relationships (Chaudoir & Fisher, 2010; Shorland & Douglas, 2010). Social avoidance only partly explained the association between concealment and loneliness, and it would be worth investigating whether the association is also mediated by a reduced level of closeness in personal relationships and by an unwillingness to adopt a shared social identity with others with an ABI. The impact of a shared social identity on self-esteem and other social outcomes also needs to be explored. Various suggestions about this have been made in the non-ABI literature. Sharing a social identity may benefit self-esteem by reducing internalized stigma and facilitating a more resilient response to the stigma attached to the identity in wider society (Cass, 1984; Crocker & Major, 1989; Matheson & Anisman, 2012; Pachankis, 2007). From the perspective of social identity theory, self-esteem may be enhanced through the group process of emphasizing the positive differences between one's own social group and others (Hogg & Abrams, 1990; St Claire & Clucas, 2012), and, more generally, through promoting a sense of social inclusion and connectedness that meets a fundamental human



need and promotes a sense of self-worth (Hogg & Abrams, 1990). Another issue that would be worth exploring is the impact that concealment has on the reconstruction of self-identity after ABI. The changes to the individual that typically accompany ABI require varying degrees of adjustment to one's self-identity: The person has to understand what has changed and what is the same, and then integrate these into a revised self-identity (Gracey & Ownsworth, 2012; Ownsworth, 2014). It has often been suggested that our understanding of ourselves primarily derives from, and is sustained by, our interactions with others: It is through interpreting how others behave towards us that we understand who we are (Ownsworth, 2014). From this perspective, social interactions are vital to developing self-understanding and revising the sense of self after an ABI (Douglas, 2012; Gracey & Ownsworth, 2012). For example, developing narratives about the brain injury for other people helps the person integrate the changes into a coherent story that aids their own understanding (Douglas, 2013; Easton & Atkin, 2014). It is possible that a preference for concealment and reluctance to disclose might interfere with these processes.

Issues around stigma, disclosure and concealment also merit attention in the provision of rehabilitation services to those with an ABI. Individuals may need support in addressing these issues. This is not simply a matter of encouraging people to disclose more about their brain injury. Disclosure in the wrong circumstances can also have a negative impact; for example, by exposing the person to enacted stigma from others (Jones et al., 2012; Riley & Hagger, 2015; Zea et al., 2005). Rather, people may need support in discriminating between situations in which it is to their advantage to disclose and those in which it will disadvantage them. Furthermore, they may need support in addressing the psychological obstacles to beneficial disclosure such as anticipated and internalized stigma. Greater understanding of the motivations and consequences associated with concealment and disclosure should enable services to provide more effective support in these respects.

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Table 1

*Demographic information*

Demographic variable	
Gender	50 males, 15 females
Age	Mean = 47; SD = 12; Range = 27 to 70
Education	37 completed the statutory minimum only; 28 completed some form of further education
Relationship status	22 married/partner; 4 widowed; 13 separated/divorced; 26 single
Living arrangements	21 were living alone; 5 lived with carers or in shared supported accommodation; 22 lived with partner or spouse; 17 lived with other family members (e.g. parents)
Employment at time of injury	16 in professions or higher management; 22 in skilled occupations or administrative roles; 20 in semi-skilled; and 7 homemakers or in education
Current employment	9 in some kind of paid or voluntary employment; 56 not working
Time since injury	Mean = 12; SD = 9; Range = 1 to 35
Type of injury	41 traumatic brain injury (25 road accident; 7 assault; 9 other); 13 stroke; 11 brain tumour

Table 2

*Descriptive statistics*

Questionnaire	Mean	Standard deviation	Actual range	Possible range	Cronbach's alpha
ASCQ	25.8	10.5	10-49	5-50	.863
SAD Distress	19.4	4.2	15-28	15-30	.889
SAD Avoid	16.9	3.7	13-26	13-26	.887
SADD/SADA	36.3	7.8	28-54	28-56	.939
UCLA-LS	40.0	11.8	22-67	20-80	.899
ESSQ	21.7	8.1	9-41	9-45	.852
RSES	17.9	5.7	0-29	0-30	.872
CIQ-SI	7.1	2.3	1-12	1-12	.421

ASCQ - *Anticipated Stigma and Concealment Questionnaire*; SAD Distress – distress scores from *Social Avoidance and Distress Scale*; SAD Avoid – avoid scores from *Social Avoidance and Distress Scale*; SADD/SADA- combined total of SADD and SADA; UCLA-LS - *University of California, Los Angeles Loneliness Scale*; ESSQ - *Enacted Social Support Questionnaire*; RSES - *Rosenberg Self-Esteem Scale*; CIQ-SI - *Social Integration* subscale of the *Community Integration Questionnaire*

The table shows statistics for the raw SADD, SADA and SADD/SADA total scores. Means for the transformed SADD, SADA and SADD/SADA scores were 3.0, 2.8 and 3.8 respectively and standard deviations were 0.21, 0.21 and 0.20 respectively.

Table 3

*Correlations of questionnaire totals*

Questionnaire	ASCQ	SADD	SADA	SADD/ SADA	UCLA- LS	ESSQ	RSES
SADD	.255*						
	.040						
SADA	.253*	.888**					
	.042	<.001					
SADD/SADA	.261*	.975**	.968**				
	.036	<.001	<.001				
UCLA-LS	.403**	.528**	.590**	.571**			
	.001	<.001	<.001	<.001			
ESSQ	.156	-.326**	-.332**	-.340**	.205		
	.216	.008	.007	.006	.101		
RSES	-.333**	-.219	-.379**	-.302*	-.490**	.170	
	.007	.080	.002	.014	<.001	.176	
CIQ-SI	-.185	-.355**	-.409**	-.390**	-.541**	.219	.344**
	.141	.004	.001	.001	<.001	.079	.005

\*p&lt;.05; \*\*p&lt;.01

ASCQ - *Anticipated Stigma and Concealment Questionnaire*; SADD – distress scores from *Social Avoidance and Distress Scale*; SADA – avoid scores from *Social Avoidance and Distress Scale*; SADD/SADA- combined total of SADD and SADA; UCLA-LS - *University of California, Los Angeles Loneliness Scale*; ESSQ - *Enacted Social Support Questionnaire*; RSES - *Rosenberg Self-Esteem Scale*; CIQ-SI - *Social Integration* subscale of the *Community Integration Questionnaire*

Table 4

*Direct and indirect effects of predictor on outcome variables in the mediation analyses*

	Direct effects			Indirect effects		
	Estimate	95% CI	p-value	Estimate	95% CI	p-value
Analysis 1: ASCQ to SADA via SADD	.000	-.001 to .002	.607	.003	.000 to .006	.040
Analysis 2: ASCQ to UCLA-LS via SADA/SADD	.010	.003 to .023	.003	.005	.000 to .009	.038
Analysis 3: ASCQ to CIQ- SI via SADA/SADD	-.005	-.035 to .006	.433	-.005	.000 to -.009	.035

ASCQ - *Anticipated Stigma and Concealment Questionnaire*; SADD – distress scores from *Social Avoidance and Distress Scale*; SADA – avoid scores from *Social Avoidance and Distress Scale*; SADD/SADA- combined total of SADD and SADA; UCLA-LS - *University of California, Los Angeles Loneliness Scale*; CIQ-SI – *Community Integration Scale- Social Integration*

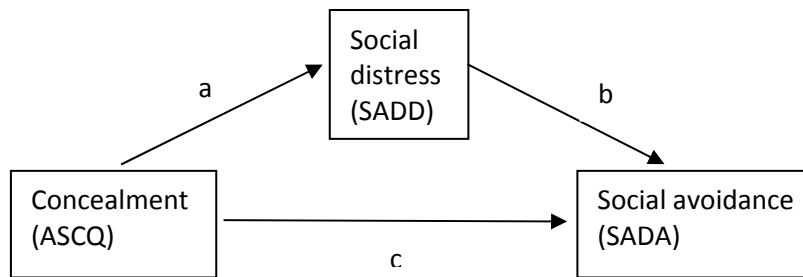
Estimate represents the standardized effect of the predictor on the outcome;

95% CI = 95% confidence intervals for the estimate

Figure 1

*Mediation analyses*

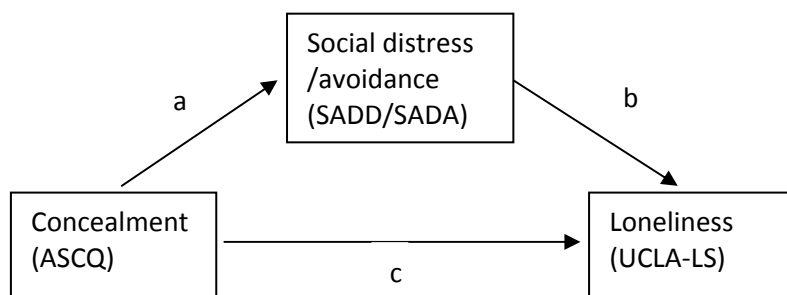
Analysis 1:



Standardised indirect effect (ab): .063 (p=.040)

Standardised direct effect (c): .006 (p=.607)

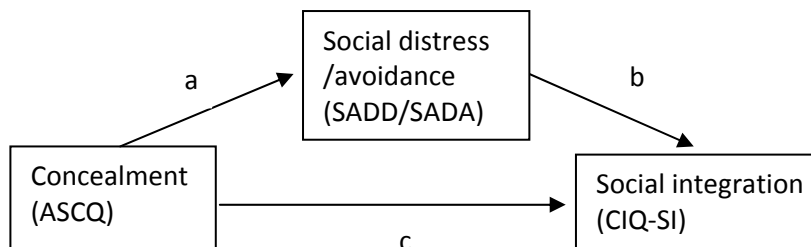
Analysis 2:



Standardised indirect effect (ab): .109 (p=.038)

Standardised direct effect (c): .229 (p=.003)

Analysis 3:



Standardised indirect effect (ab): -.021 (p=.035)

Standardised direct effect (c): -.020 (p=.433)

ASCQ - *Anticipated Stigma and Concealment Questionnaire*; SADD – distress scores from *Social Avoidance and Distress Scale*; SADA – avoid scores from *Social Avoidance and Distress Scale*; SADD/SADA- combined total of SADD and SADA; UCLA-LS - *University of California, Los Angeles Loneliness Scale*; CIQ-SI – *Community Integration Scale- Social Integration*



**Appendix 1***Anticipated Stigma and Concealment Questionnaire*

All questions took the form of a statement prefixed by “There are times when I keep quiet about my injury because” (e.g. “There are times when I keep quiet about my injury because: Other people might think I was mad or dangerous”). Response options were ‘definitely true’, ‘probably true’, ‘not sure’, ‘probably false’ and ‘definitely false’.

Items:

1. Other people might think I was mad or dangerous
2. The other person might get annoyed if I talk about it
3. The other person might start to talk down to me or patronize me
4. The other person might think badly of me
5. People might start to watch closely what I do and say
6. The other person might gossip about me to others
7. I might be made fun of
8. The people I am with might take advantage of me
9. The other person might think I was stupid
10. The other person might be fed up of hearing about it

## **Appendix 2**

### *Enacted Social Support Questionnaire*

Response options are ‘most days’, ‘most weeks’, ‘once or twice a month’, ‘once or twice a year’ and ‘never’. These are scored from ‘most days’ (5) through to ‘never’ (1), and so higher scores indicate the receipt of more social support. Examples are given in the instructions of each type of support: Examples given of practical help include such things as being driven to appointments and help with jobs around the house; examples of advice or information include suggestions about how to deal with a problem or help with understanding something; and examples of moral and emotional support include providing encouragement and motivation when it is needed, and cheering someone up when they are feeling low.

Items:

1. In the past year, how often have you received practical help from family members (not including those you live with)?
2. In the past year, how often have you received practical help from your friends?
3. In the past year, how often have you received practical help from your neighbours or acquaintances?
4. In the past year, how often have you received advice or information from family members (not including those you live with)?
5. In the past year, how often have you received advice or information from your friends?
6. In the past year, how often have you received advice or information from your neighbours or acquaintances?
7. In the past year, how often have you received moral or emotional support from family members (not including those you live with)?
8. In the past year, how often have you received moral or emotional support from your friends?

9. In the past year, how often have you received moral or emotional support from your neighbours or acquaintances?