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Disclosure of a stigmatized identity: A qualitative study of the reasons why people choose to tell or not tell others about their traumatic brain injury

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Short title: Disclosure after TBI

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**Disclosure of a stigmatized identity: A qualitative study of the reasons why people choose to tell or not tell others about their traumatic brain injury**

**Abstract**

Objective:To investigate what goals influence the decisions of people with a traumatic brain injury to disclose (or not to disclose) information about their brain injury.

Method: Ten people with a traumatic brain injury were interviewed about disclosing information about their injury to others. Thematic analysis was used to analyse the data.

Results: The report focuses on disclosure to people other than immediate family and close friends. Reasons for not disclosing included concern about negative reactions from others, feelings of shame about the injury, wanting to avoid getting distressed, wanting to fit in, lack of interest from others, and the perception that the stress associated with the act of disclosing outweighed the benefits. Reasons for disclosing included obtaining emotional and practical support from others, the emotional release obtained from disclosure, the need to explain their behaviour to others, and giving others the benefit of their experience. Experience of negative and stigmatizing reactions from others was common. Participants varied in their willingness to disclose.

Conclusion: Disclosure can have important advantages and disadvantages. Some people with a TBI may need support in making optimal decisions about disclosure.

Key words: stigma, neuropsychological rehabilitation, self disclosure

**Self-disclosure of a stigmatized identity: A qualitative study of the reasons why people choose to tell or not tell others about their traumatic brain injury**

**Introduction**

Certain characteristics or experiences can be the target of stigma within society. They vary in how obvious they are to others. When they are less obvious, the individual has a choice about whether or not to disclose them. A large body of research has addressed issues surrounding the disclosure of concealable stigmatized identities such as those relating to sexual preferences, medical conditions, mental health and experiences of abuse [1-4].

This research has highlighted several advantages and disadvantages of disclosure. The main disadvantage is that it may expose the individual to stigmatizing and discriminating responses from others. For example, in a survey of gay, lesbian and bisexual individuals, Herek [5] found half of the sample had experienced verbal abuse because of their sexual orientation and a tenth had experienced employment or housing discrimination. On the other hand, several benefits have also been identified. *First*, disclosure allows individuals to gain access to emotional, practical and informational support from others that enables them to deal with the stigmatized aspect of their identity more effectively [6,7]. A particularly useful source of social support comes from identifying oneself, through disclosure, with others who share the stigmatized identity. Sharing a social identity may have a beneficial effect on self-esteem and wellbeing, and facilitate a more resilient response to stigma and other stresses arising from the characteristic [3,8,9]. *Second*, active concealment of a stigmatized identity may lead to stress and anxiety associated with the threat of the secret being discovered [3,10,11]. Conversely, disclosure can be beneficial because it alleviates this anxiety, and can assist the person in processing, and coming to terms with, emotionally troubling aspects of their identity [7,12-14]. *Third*, concern with keeping the stigmatized aspect of one’s identity secret may lead to social withdrawal and isolation because the person avoids situations in which there is a threat of their stigmatised identity being discovered [15,16]. *Finally*, disclosure of important personal information appears to play a critical role in establishing, strengthening and maintaining close personal relationships with others [17-21].

In order to support people with devalued identities to make optimal decisions about disclosure, it is important to understand how they make disclosure decisions. Again, there is a considerable literature in this area [1,13,22]. Previous research has focused on variables thought to influence the decision, such as the goals that people seek to achieve through disclosure or concealment; the personality of the person with the stigmatized identity; the characteristics of the confidant; the relationship between the confidant and the person with the stigmatized identity; situational cues; and the consequences of previous disclosures. Unsurprisingly, the goals that influence the decisions overlap considerably with the advantages and disadvantages that have been identified. People choose not to disclose in order to avoid social rejection, stigma and discrimination [13,23,24]. They chose to disclose in order to gain informational and practical support from others [25,26], to build stronger relationships [1,23,24], to gain approval for their identity [27,28], to gain relief from emotional distress through sharing it [20,22,28], and to be ‘true to themselves’, avoiding the stress and dishonesty involved in concealing their identity [1,29]. More altruistic motives have also been reported, such as protecting the confidant from distress or harm, and educating others about the concealable identity in order to bring about more positive social attitudes [1,23,30].

**Disclosure and traumatic brain injury**

Traumatic brain injury (TBI) shares some features with the concealable stigmatized identities that have been investigated in research about disclosure [31]. Like many other conditions involving disability, people with TBI have reported experiencing devaluing and stigmatizing reactions from others regarding their brain injury [32-34]. Furthermore, many of the effects of TBI are concealable. For example, cognitive difficulties are not immediately obvious to others, and they can be concealed by avoidance of tasks in which they are likely to be apparent. Even when the effects of the TBI are more difficult to conceal, the fact that they originate from a TBI is generally concealable. For example, although it might be difficult to conceal one’s unsteadiness when walking, one can usually conceal the fact that this is due to a TBI. The general public have relatively poor knowledge and understanding of the effects of TBI [35,36], and are unlikely to attribute difficulties to a brain injury in the absence of highly visible signs such as scars and bandages [36,37].

Based on these similarities, Jones et al. [31] have recently proposed that concealment and disclosure after TBI are likely to have similar costs and benefits to those identified for other concealable stigmatized identities. Although this is a highly plausible suggestion, supportive evidence is sparse. Jones et al. described the results of an unpublished study in which people with acquired brain injury who were more willing to disclose, reported fewer negative changes to their relationships, and higher levels of self-esteem and life-satisfaction. In a qualitative study, Crisp [38] reported that some of their participants who chose to conceal their difficulties felt burdened by this lack of outlet to express their feelings, but no further detail was provided. In another qualitative study by Shorland and Douglas [33], one of their participants reported that his difficulties in self-disclosure had been a barrier to the formation of friendships; and another reported that disclosure of the TBI had improved her friends’ understanding of her situation.

There is also a lack of evidence about the decisions made by people with TBI regarding disclosure. In the research that does relate to this issue, the topic is often peripheral to the main focus of the study and the evidence is not comprehensive or systematic. In an unpublished study, Jones et al. [41] found that those who expected to encounter more stigma and discrimination were less likely to disclose. In a qualitative study, Karlovits and McColl [32] reported that some participants used disclosure as a means of forestalling misunderstanding of their difficulties (e.g. misattributing them to drug abuse). Some participants in the qualitative study of Simpson, Mohr, and Redman [39] had lied about their injury to friends because they were ashamed of the TBI. One participant in the Shorland and Douglas study [33] was reluctant to disclose because of his concern that others would not understand, and, in the case of his male acquaintances, were not interested in hearing about his problems. He also spoke about the importance of choosing the right time for self-disclosure, and that it was possible to ‘frighten off’ people if they were told too soon in the acquaintance. However, the other participant in the study felt she had a duty to tell her friends about her TBI. Nochi [34] reported that one of the participants in his qualitative study feared that disclosure of the TBI would lead other people to think that she was mad or incompetent. In order to prevent judgements about her incompetence, another concealed her problems by preventing people from coming to her house. Another revealed work difficulties to her employer and asked to be judged on her end products rather than on how she completed the work, in an attempt to forestall criticism of her work performance. Another participant (a college instructor) disclosed her difficulties to her students in order to recruit their assistance in completing her job. A final participant in Nochi’s study (a student) said that she was reluctant to reveal her TBI to teachers in case they thought she was using it as an excuse for her difficulties.

**The present study**

In summary, research on other concealable stigmatized identities has suggested that disclosure can result in significant costs and benefits for the individual. Given the importance of these consequences, it is important to understand how individuals make decisions about disclosure, so that they can be supported in making optimal decisions. Research has also investigated the decision-making process, and suggested that there is a close overlap between, on the one hand, the goals of disclosing or not disclosing and, on the other, the costs and benefits of disclosure. Despite TBI being a socially devalued identity that can often be concealed, there is only a small amount of evidence about the costs and benefits of disclosure for this population and about the goals that guide their decisions about whether or not to disclose. Furthermore, the evidence has been provided by studies in which the topic of disclosure has been peripheral to the main focus of the study and consequently has not been gathered in a planned way.

The aim of the present study was to address this gap in the literature with a qualitative study that focused systematically on the goals that influence the decisions about disclosure made by people with a TBI. Having a fuller understanding of these goals may enable clinicians to support people with a TBI to make more effective decisions about disclosure that avoid the costs (e.g. stigma and discrimination) but reap the benefits (e.g. social support and closer personal relationships).

**Method**

Ethical approval for the study was given by the University of Birmingham ethics committee.

**Recruitment and participants**

All participants were recruited from two centres run by Headway, a non-governmental organization providing services to people with brain injury and their families in the UK. Participants were required to have sustained a TBI and to be judged capable by Headway staff of giving informed consent, and of taking part in an interview about their experiences of having a TBI. Capacity to consent was also assessed by the researcher prior to the interview. After the nature of the study had been explained to them, participants were asked to say what the study was about and what they would be expected to do. Giving satisfactory answers was taken as evidence of capacity to consent. Because of limitations on the time available for data collection, the sample size was pre-set at 10 and the first 10 volunteers who met the inclusion criteria were recruited. Demographic details are included in Table 1. Pseudonyms are used throughout.

[Table 1 about here]

**Interviews**

One-to-one interviews were conducted at the Headway centres. Interviews lasted between 30 and 60 minutes; an hour was set as the maximum time to avoid causing excessive fatigue to the participants. To establish the context for the main focus of the interview (i.e. disclosure), participants were asked about the general impact of the TBI on their lives. More specific questions then focused on telling, or not telling, others about having the TBI and the disabilities and difficulties arising from it. They were asked about disclosing to their families and close friends, as well as to neighbours, acquaintances, work colleagues and employers, and other people they may come into contact with. However, the current paper does not report the data relating to family and close friends. Such disclosure raised different issues because they were already aware of the TBI and its impact. To address potential difficulties with memory and abstract thinking, participants were encouraged to talk about specific autobiographical events in which disclosure was an issue [40]. All interviews were taped and transcribed verbatim.

**Data analysis**

Thematic analysis was used because this method is not tied to any particular theoretical perspective and therefore allows more flexibility in approach [41]. Following the recommendation of Braun and Clarke [41], the assumptions informing the present application of the method are made explicit. A phenomenological approach was taken: The focus was on the participants’ subjective experience of disclosure, and on understanding and describing it from their perspective, rather than on some objective reality or social construction separate from their experience. Consistent with this, there was no attempt to uncover any latent meaning that the statements of the participants might have, either within the interviews or within the data analysis. Instead, explicit interpretation was confined to considering the broader meaning and significance of the themes in relation to previous research. To emphasize this, interpretation is confined to the Discussion section. On the other hand, it is not assumed that the research simply involved ‘giving voice’ to the participants: It is acknowledged that the researchers have influenced the outcome of the research (unavoidably so) in terms of how the interviews were conducted, and the analysis and presentation of the findings. The aim of the present research was to enhance our understanding of the kinds of reason participants had for choosing to disclose or conceal. There was no interest in how frequently different reasons appeared in the interviews, or whether one reason was more frequent or important than another, questions that are more appropriately addressed using quantitative methodology. Finally, this aim of the research was used to provide a framework for developing the themes. The analysis focused on extracting data from the interviews that were pertinent to the aim, and did not attempt to address other issues present within the data.

The analysis followed a similar series of steps to those described by Braun and Clarke [41]. The first step involved reading each transcript several times, noting down any initial ideas. A set of potential themes was drawn up, and relevant parts of each transcript were copied into data files in NVIVO 7, representing each theme. Summary descriptions of the themes were drawn up. Each data extract in the file was then re-considered against the description of the theme to determine whether the description sufficiently captured the data. Extracts that provided a particularly clear or vivid illustration of the theme were highlighted for later inclusion in the write-up.

A number of steps were taken to establish the credibility of the analysis. Using interview transcripts, the two authors reflected together on how the interviews were being conducted, with a view to ensuring that the interviews were giving the participants adequate opportunity to describe their experiences. Each of the two authors independently conducted a formal analysis of the data. There were no substantial differences between the two analyses. Subsequently, they reflected together on the analysis, in order to ensure that the themes were coherent and adequately grounded in the data. In this report, excerpts from the interviews have been liberally used so that this grounding is transparent to the reader. A summary of themes (with any identifying information removed) was discussed with a group of clients at both Headway centres. At least one member of each group endorsed each of the themes that had been identified in the sense that they said that the reason given for disclosure or concealment was one that had influenced their own decisions. Nobody in the groups challenged any of the themes on the grounds of it being implausible or improbable. As stated earlier, there was no interest in how frequently different reasons appeared in the interviews, or whether one reason was more important than another, and so no attempt was made in these groups to quantify the extent of support. The endorsement by at least one individual, and the lack of challenge from the rest of the group, was considered sufficient to lend some credibility to the theme that had been extracted. One of the groups also discussed a distinct theme that had not occurred in the original interviews (namely, ‘wanting to fit in’ – see below).

**RESULTS**

The results are described in three sections. Sections 2 and 3 focus on the reasons given for and against disclosure. These are summarised in Table 2. Section 1 describes some themes arising from the data that provide a context for considering the reasons for and against disclosure.

**1. Contextual issues**

Most of the participants described negative reactions from work colleagues, neighbours and members of the public to their disabilities, both the overt physical disabilities and concealable ones that had been disclosed.

I found some of the chaps [at work] were taking the mickey, and, you know... insulting in a sexual way. So it really got on my nerves. I’m there to work not listen to that... I was getting teased, and [employer] wouldn’t do anything about it. (Harry)

When I went to the shops, like, I felt a bit like everybody’s looking, maybe they weren’t, but I felt as though they were. Then you do get some kids on a bike, scooting round and looking at you. You know, and then I started getting a bit aggressive... It bloody got to me a bit because they kept running circles round me on these bikes and calling me names. (Graham)

While the one time...this bloke up at the bar turned around and said ‘are you coming to put us off our drinks, you spastic?’ I just turned around and walked out and the Landlord come and got me, took me back in there and barred the person who said it.

 (Ian)

I went for a job at the hospital as a cleaning technician...The person who interviewed me...we didn’t talk about the head injury but, of course, it was on the appropriate forms and so forth. They appeared to be almost scared by it...they didn’t seem to be comfortable with the fact that there could be something wrong with my brain. (John)

They [people in general] treat, they treat you as if you...well I am an idiot I suppose. They treat you as an idiot. They look down on you, if you know what I mean, as if you’re second class. (Andy)

The exception to this general experience of stigma was Rebecca:

Most people react quite good and kind. I’ve never had any bad reactions. Hmmm, I have been very lucky. (Rebecca)

The experience of these negative reactions from others had led some of the participants to become socially reclusive, or to avoid the specific situations in which the stigma had been experienced. After the incident with the children described above, Graham confined himself to his house: *“Anyway, I just locked my own self away. Prior to coming here* [Headway], *eighteen months I haven’t been out my house”.* Harry described several incidents of being teased at a bowling alley after which he stopped going despite further invitations from a friend.

There was individual variation across participants in terms of their willingness to disclose information. Although most of them described situations in which they had chosen not to disclose something, three participants (Ian, Collin and Eric) said that they were not concerned to conceal anything about their disability.

So, I mean, yeah I would tell anybody anything if they asked me. Or even if I was put in a position like I am now just to explain something. I don’t mind it at all.

Actually in some ways this will…yeah this, I’ll be happy telling anybody anything. *Interviewer: Have you ever been in a situation where you’ve not wanted to tell somebody something?*

Mm...I’m trying to think...mm, no, not that I can remember, no. (Eric)

Some of the participants had obvious physical disabilities that could not readily be hidden from others. This did not mean, however, that they necessarily chose to disclose other hidden disabilities or to reveal that they had a brain injury.

I’ve always just told people I was in a car accident, because I really can’t remember anything. That’s as far as I can go...Most people either see this [pointing to walking stick], so they think I’ve got a problem with walking. And they look in my face and they see my eye [badly damaged]...so they know I can’t ever see properly.

*Interviewer: So you don’t mention anything about a brain injury?*

No, no...I know it is a brain injury but I don’t feel like it is to other people. I can add up and I can write. Not together, I never used to write very good. Now I can’t write very good at all. (Rebecca)

Some of the participants described changes over time in their disclosure behaviour. Frank and Don had both been unwilling to disclose in the earlier stages of their recovery, but now were more willing.

*Interviewer: Do you ever keep things back from people, because you’re not comfortable with saying something*?

Yes, I, I’m glad you brought that up. I used to do that a lot. But thank God I’ve got people that I can talk to now. (Don)

By contrast, John said that he was less likely to disclose than previously:

Within the first few years, people that I knew well, I would try and tell them quite a lot...So at that point I did try to explain things quite a lot. But now, other than a few people who show an interest, I don’t really explain very much at all. (John)

He explained this change in disclosure in terms of wanting to look ahead, thinking less about the brain injury and relegating the brain injury to a more peripheral role in his identity.

I think that the sort of head injury has become less important to me because it’s sort of ‘I’ve been there and done that’. And I’m trying to move on, rather than think about the past I suppose. (John)

I don’t very often consider myself as a person with a head injury because I’m used to it now. And I think it comes back to [the fact that] I’m not making comparisons to what I used to do...I guess that’s one of the reasons why I don’t explain my head injury very frequently now, because I don’t actually think about it very often. (John)

 **[Table 2 about here]**

**2. Reasons for not disclosing**

*Negative reactions from others*

A common reason given by participants for not disclosing their disability related to their concerns about negative reactions by others. Frank, who had been the target of ridicule in the past, chose not to disclose in order to avoid further ridicule:

Well I, sometimes I just keeps that [kind of information] to myself. And I think to myself, well, why should I tell other people about like - things what I can’t do - so they can laugh at me. (Frank)

John was concerned to avoid being judged or interrogated by others:

*Interviewer: How about if you meet somebody new?*

No, I don’t talk about it immediately...I don’t want to be sort of judged and questioned. ‘Why the hell didn’t you remember that?’, which is what I think to myself. Whether other people think that or not, I don’t really know. (John)

Some had tried to conceal their difficulties from employers, fearing that they would not be given a job or would lose an existing job.

I used to keep it under my hat, and used to say...lie about it going for jobs and that. I didn’t know how to work [cash] tills. I didn’t know how to work...sort money, and things like that. And used to like, um, didn’t know how to like...what change I should, shouldn’t hand back. And I would then used to give it back and I’d be praying all the time [that the customer would not notice]. (Frank)

But then I went up to [prospective employers]. I thought I’d, they’d give me a [job]... I didn’t, I didn’t tell them. And then I had my medical and I don’t know where they were getting it all from but they had all of it [information about his brain injury]. They couldn’t start me. (Graham)

*Shame*

Non-disclosure was sometimes chosen because the participants felt embarrassed or ashamed of their disability. For example, Frank did not disclose his difficulties with reading and writing because he felt ‘embarrassed’ about them. John said that, because of his embarrassment, he would explain about his problems to others only if he ran into difficulties:

My attitude is ‘ooh, yeah I’ll have a go at that’. And then if, and when, I find it more difficult, I will then explain why I found it more difficult. But I think it’s often afterwards rather than before. I guess in a way I’m almost sort of embarrassed about having a head injury. It’s a sort of...almost like a kind of black mark rather than a... certainly not something I’d want to show off about. (John)

*Avoidance of emotional upset*

Some participants generally tried to avoid thinking about their brain injury and its impact because it upset them. Consequently, they also avoided talking to others about it so that they did not get upset in front of them.

Sometimes I feel ‘What’s the point of explaining how I feel? Sod it’. I mean...I think...it’s only going to cause more heartache - I’ll just leave it as it is. You know, it’s easier to leave it than to start messing about saying how I feel. So I, I leave it all. (Graham)

*Others are not interested*

Collin’s experience of disclosure was that many other people, although they ask about it, did not really want to know too much about his situation. This made him more cautious about saying too much:

Normally people ask me [why I use crutches]. And they’re trying to walk away then when I start reeling off a story…they’ll start edging away from me. (Collin)

*Stress of disclosure outweighs benefit*

Because of the difficulties associated with disclosure, John said that there needed to be a good reason for disclosing the information and that sometimes disclosure was not worth the effort involved.

I don’t find it easy talking to people about my, effectively, my medical situation, because it’s not...I’m not always comfortable doing it and it, I feel it has to be worth it….I have to feel that they will appreciate knowing, such as the lady at the voluntary work who uses it to her advantage and also mine. That’s, it was worth going through the effort and saying something. But other people, it’s not as simple as ‘why bother?’, it’s...but it’s...is it worth going through the hardship, in a way, of telling somebody what the situation is? (John)

*Wanting to fit in*

As noted earlier, when the results were fed back to two groups of other people with a TBI, another reason described by these groups for choosing not to disclose was the desire to fit in. They want to be treated like everyone else, and therefore do not wish to draw attention to themselves as being different, as being ‘the person with the brain injury’.

**3. Reasons for disclosing**

*Social support*

Recruiting practical and emotional support from others was highlighted as a reason for some participants.

And they [people met through Headway] say like ‘If you got doubts and you want to speak, come and tap us on the shoulder and we’ll come and help you. That’s if you’re willing to do that kind of thing’. I said ‘yeah, I’d be glad to’. You know I want to do it...to try and better myself and meet better friends. And stay with them and then not lie to them. I’m with new friends now and they’re looking after me. And showed me things what I can’t do. (Frank)

[Talking about voluntary work] I try to make certain that she [the boss] knows as much about my situation as possible. Partly for practicalities, the fact that she needs to know what the situation is and she obviously needs to know all about the epilepsy and potential seizures and so forth. And the fact that if, I mean I’m okay memory-wise if I’m always doing the same shifts on the same days, but when something different is going to happen, like I’m filling in for somebody on a different day, she needs to know that my memory is not perfect with that sort of thing...So yes, with her I do make an effort to make sure that she knows, not sure it’s quite everything, but certainly a lot. (John)

I’ve got a friend who lives next door….He does the Samaritans. And I’ve been chatting to him [about personal difficulties] and he’s been, been quite helpful with me. (Harry)

*Emotional release*

Graham talked about the stress caused by keeping things to himself, and the importance of telling others as a means of getting rid of this stress:

If I get frustrated, I mean really frustrated - say there’s something deep in my mind and it keeps coming back now, you know, to the front. And then I can’t sleep because I’m still thinking about it, and I don’t need it there. Then I have to say something, because, at the end, it eats me away. So I’ll say like - this ain’t rude, is it? – ‘Shit or bust’ or what the hell it is. If it causes havoc, it causes havoc. Because what I leave there [pointing to head], it makes me ill. So if I needs to get me hair down at whatever…at least it’s gone and I haven’t got to think about that. (Graham)

Frank drew a strong contrast between his previous lying and concealment, and his present willingness to be more open and honest with other people. Part of this contrast was the stress caused by the dishonesty (e.g. his concern about his difficulties with money being discovered – see above) and the positive feelings he had about his new intentions of being honest about his disability and his needs.

You know I want to do it [to tell people that he needs help]...to try and better myself and meet better friends. And stay with them and then not lie to them. I’m with new friends now and they’re looking after me. (Frank)

*Need to explain*

The need to explain changes and difficulties was highlighted by some participants. When the causes for observable changes and difficulties are not obvious, others may draw their own conclusions that may not always be particularly positive. For example, difficulties in daily life may be misinterpreted as rudeness, stupidity or laziness. Explaining about the traumatic brain injury allowed participants to forestall these more negative evaluations.

I felt I needed to explain myself, because I was, well I felt I was quite different and I needed to justify why I couldn’t remember things and why I wasn’t particularly good at time-keeping. Now, before my head injury, I was. I needed to sort of justify why there had been the change. So at that point I did try to explain things quite a lot. (John)

*Giving others the benefit of one’s experience*

Ian, who had a history of criminal offences and whose accident occurred because of drink and drugs, told others about his accident and its impact on his life in the hope that he might prevent others from the same fate.

It’s good for them to know…and it stops them doing silly things...gets them on the straight and narrow, that’s a better way to put it. (Ian)

Some participants shared their experiences with other people with disabilities in order to provide useful information or give emotional support.

I used the fact that something that was affecting her was similar to something that affects me. I effectively said that I had to stop work...I actually said for the same reason [tiredness] - which is not entirely true, but it sort of is. I used something that she had said, as an opening to tell her about me…I think she was quite pleased to talk to somebody who wasn’t judging her. (John)

**Discussion**

Research on other concealable stigmatized identities has provided evidence about a range of goals that motivate disclosure and concealment [1,13,22]. This issue has not been directly addressed in the context of TBI by previous research and so the evidence that exists has been peripheral to the main aims of the study and has not been collated into a coherent account. The present study addressed this gap in the literature by investigating the reasons in a more systematic way.

There was an overlap between the goals highlighted in the present study and both those that appear in the general literature on other concealable identities and those that appear in the TBI literature. Considering, first, the reasons against disclosure, the fear of negative reactions from others appears in both the general literature [13,23,24] and in the literature specific to brain injury [31,34]. Collin’s perception that others were not really interested in his disclosure is similar to a participant in the study by Shorland and Douglas [33] who found it difficult to talk about his brain injury because he felt that others (particularly his male friends) were not interested. Choosing not to disclose because of feelings of shame about the TBI was also reported in the study by Simpson et al. [39]. Other reasons reported by the participants in this study for not disclosing have appeared less often in previous literature, either about TBI or about other concealable identities – specifically, the avoidance of emotional upset, wanting to fit in, and the perception that potential gains may be outweighed by the stress involved in the act of disclosing.

In respect of the reasons in favour of disclosure, disclosing to gain emotional and practical support is frequently reported in the general literature [25,26] and in the literature specific to brain injury [34]. A number of participants in the current study spoke about the stress of keeping things hidden, and the emotional relief when they were able to disclose (‘emotional benefits’). Similar reports have also appeared in the general literature [20,22,28]; and, in a TBI study, Crisp [38] reported that some of the participants who chose to conceal their difficulties felt burdened by this lack of outlet to express their feelings. In line with the theme of ‘need to explain’, Karlovits and McColl [32] reported that some of their participants with a brain injury used disclosure to forestall misattribution of their difficulties. ‘Giving others the benefit of one’s experience’ is another example of the more altruistic motives for disclosure reported in the general literature [1,23,30].

In summary, the themes identified in this study of ‘negative reactions from others’, ‘shame’ ‘emotional release’ and ‘giving others the benefit of one’s experience’ (Table 2) echo findings in both the general and the TBI literature. ‘Need to explain’ and ‘others aren’t interested’ echo findings in the TBI literature, but not in the general literature. It is difficult to find any similarities in either literature to the themes of ‘avoidance of emotional upset’, ‘stress of disclosure outweighs benefit’ and ‘wanting to fit in’. TBI can be associated with reduced emotional control. It is possible this is why the emotion-related goals (‘avoidance of emotional upset’ and ‘stress of disclosure outweighs benefit’) were issues for the participants in this study, but not for those with other concealable identities that are not associated with reduced emotional control. The specificity to TBI of the ‘need to explain’ may arise from the fact that TBI disabilities and their effects cannot always be concealed, and are therefore open to misinterpretation when others observe them; whereas stigmatized identities such as sexual preferences can be more effectively concealed.

The reasons given for not disclosing in the present study also overlap with the reasons given by people with a TBI for not doing other things. In a study investigating anxiety-related avoidance of social situations after TBI, Riley, Brennan and Powell [42] reported that this avoidance could be motivated by participants’ concerns about being patronised and talked down to, being laughed at or thought to be stupid, being treated differently, getting tearful and upset in front of others, and about other people thinking that there was something wrong with them. In a qualitative study of factors influencing the use of memory compensation strategies, Baldwin, Powell and Lorenc [43] similarly highlighted concerns about not wanting to appear stupid or different, fears of being negatively judged and evaluated by others, and feeling embarrassed about using the compensatory strategies.

*Consequences of disclosing or not*

The present study also provided evidence about some of the positive and negative consequences of disclosure. Again, these findings are similar to those in the general literature about concealable identities and to the TBI-specific literature. Consistent with some other studies [32-34], many of the participants in the present study had experienced negative and stigmatizing reactions from others to their TBI. Anxiety about these reactions had led some participants to avoid others and become socially withdrawn. This reaction has been reported in both the general literature [15,16] and in the TBI literature [39]. On the other hand, disclosure allows people to gain access to emotional, practical and informational support that allows them to deal with their situation more effectively [6,7]. Some participants in the present study similarly reported that they had gained valuable social support through disclosing to others. Finally, consistent with reports in the general literature [3,10,11], some participants described the stress of keeping the TBI and its associated difficulties a secret.

*Individual differences in willingness to disclose*

There was considerable variation amongst the participants in terms of their willingness to disclose (see ‘contextual issues’). Given the significant consequences associated with disclosure, it is useful to consider why this might be the case. In their review of disclosure, Chaudoir and Fisher [13] drew on the Reinforcement Sensitivity Model [44] which concerns individual differences in the focus on approach or avoidance goals. This model suggests two distinct brain systems; the behavioural approach system, which responds to cues signalling potential positive reinforcement by activating goal-directed behaviour, and the behavioural inhibition system, which is sensitive to cues of threat and responds to them by inhibition of behaviour, avoidance and escape. Evidence suggests that individuals differ in terms of the relative dominance of each system in determining behaviour – i.e. that some individuals are primarily motivated by the avoidance of threat, and others by the achievement of reinforcement [45-47]. In terms of individual differences in disclosure, Chaudoir and Fisher [13] suggested that those primarily motivated by the avoidance of threat may be less likely to disclose because of their preoccupation with avoiding the negative consequences of disclosing; whereas those primarily motivated by positive reinforcement may be more likely to disclose because of their focus on the potential benefits. From this perspective, individual differences in willingness to disclose are viewed as consequences of a broader personality trait relating to approach and avoidance motivation.

 Although the Reinforcement Sensitivity Model has not been studied specifically in the context of TBI, this central idea might also explain the overlap, described earlier, between the reasons given for non-disclosure in the present study and the avoidance of social situations [42] and reluctance to use memory compensation strategies [43]. The motivations in all three situations might arise from a broader underlying motivation to avoid threat. Threat avoidance is a very general underlying motivation and this makes it less amenable to clinical intervention. An explanation in terms of more specific threat-related motivations may be of more clinical use. Riley, Dennis and Powell [48] argued that the motivation to avoid threat-related situations may be related to self-esteem. When faced with a threat to self-esteem, those with low self-esteem are more likely to take steps to protect their self-esteem such as avoidance; whereas those with high self-esteem are more likely to take steps to bolster it [49.50]. Applying this to the present context, disclosure may pose a threat to self-esteem because it involved disclosing details that may elicit a stigmatizing or otherwise negative reaction, and those with low self-esteem may be more likely to avoid disclosure because of their concern to protect their self-esteem. By contrast, those with higher self-esteem may be motivated more by the specific gains to be achieved from disclosure.

*Limitations of the study*

Care should be taken not to over-generalize the findings. The participants had all experienced severe injuries, all but one were men and all were several years post-injury. Severity of injury, gender and time post-injury may all be associated with reasons for disclosing or concealing. The focus of this report was also on disclosure to people outside the participant’s immediate circle of family and close friends. Decisions relating to the disclosure of issues related to the TBI to family and close friends are likely to be motivated by a different range of reasons.

 Ideally in qualitative research, sample size should be determined by ‘data saturation’; that is, by continuing to interview more participants until no new themes emerge [51]. In the present study, this was not possible because of resource limitations. That data saturation had not been achieved is evident from the fact that a new theme (‘wanting to fit in’) emerged when the findings were discussed with other people with a TBI as part of the process of checking credibility. It should not be assumed, therefore, that the reasons uncovered in this study provide an exhaustive list of the motivations that influence disclosure decisions.

 Qualitative research with people with impaired cognition (e.g. in dementia, general developmental delay and brain injury) was slow to emerge because of concerns that difficulties with cognitive processes such as abstract thought and memory would prevent people from reflecting on, and articulating, their experience [40]. To address these issues, various recommendations have been made about conducting interviews with people with significant cognitive impairments [40]. The main recommendations used in the present study were to keep the interview relatively short, and to focus on talking about specific autobiographical events in which disclosure had been an issue, rather than asking abstract general questions. Also, one of the inclusion criteria was that the Headway staff considered that the individual was able to take part in a conversation about their experience. In the event, all the participants were able to generate data that were relevant and useful to the aims of the study. However, some of the general statements made by some participants may need to be treated more cautiously because they may have been influenced by memory impairments (e.g. Rebecca’s claim never to have experienced negative reactions to her disability from other people, or Eric’s claim never to have been reluctant to disclose things about his TBI).

*Conclusions*

As experienced by participants in the present study, disclosure can result in significant costs and benefits. It is therefore important for people to manage their disclosure effectively – to disclose in situations in which it is to their advantage and not to disclose when it would be to their disadvantage. Rehabilitation services could usefully support people in making optimal decisions about disclosure. The present study adds to a small body of evidence about the goals people with a TBI have in mind when they make these decisions. Understanding these goals should help services improve the support they provide about disclosure. Unwillingness to disclose even when it is to one’s advantage needs to be addressed as part of this support. Further research is required to understand individual differences in willingness to disclose.

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**Declaration of interest**

The authors report report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Table 1: Demographic details of participants

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Pseudonym** | **Age** | **Time since injury** | **Pre-injury occupation** | **Living arrangements (at time of interview)** |
| Ian | 41 | 8 years | Labourer | Supported accommodation |
| Don | 36 | 7 years | Painter | Supported accommodation |
| Andy | 61 | 3 years | Supervisor | Supported accommodation |
| Collin | 38 | 2.5 years | Driver | Living with wife and family |
| Eric | 36 | 8 years | Mechanic | Supported accommodation |
| Frank | 54 | 30 years | Labourer | Supported accommodation |
| Graham | 66 | 30 years | Labourer | Living with wife |
| Harry | 49 | 35 years | Labourer | Living with relatives |
| John | 45 | 14 years | Engineer | Supported accommodation |
| Rebecca | 61 | 6 years | Social worker | Living with family |

Table 2: Summary of reasons for and against disclosure

|  |  |
| --- | --- |
| **Reasons against disclosure** | **Reasons for disclosure** |
| * Negative reactions from others
* Shame
* Avoidance of emotional upset
* Others are not interested
* Stress of disclosure outweighs benefit
* Wanting to fit in
 | * Social support
* Emotional release
* Need to explain
* Giving others the benefit of one’s experience
 |