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An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

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CHAPTER 1: SYSTEMATIC REVIEW

Exploring identity change in adults following head injury: A qualitative systematic review

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Abstract

Background: Recovery following head injury (HI) extends beyond physical rehabilitation and there is recognition of the often pervasive psychological and social changes which impact on quality of life and wellbeing. There is growing interest in changes to identity as one of the psychological changes following HI.

Aims: This review systematically examines qualitative studies to determine the key concepts and processes in identity change in adults following HI.

Methods: Qualitative studies examining identity and HI were identified through searches of electronic databases, relevant journals and reference lists were conducted and key authors were also contacted. Eight studies were identified for inclusion, appraised using Walsh and Downe's (2006) quality rating criteria and synthesised using a meta-ethnography approach.

Results: Three, third-order concepts were identified relating to different stages of identity change following HI: being the same and being different, others as both a support and a threat to identity and reconciling identity with HI. The results suggest that social forms of self are heightened following HI, challenging stable perceptions of self and increasing the importance of social goals and the perceptions of other people. The results suggest that changes to identity following HI and perceptions of self can be reconciled through adaptations to self-narratives.

Strengths & Limitations: This review is the first systematic synthesis of qualitative studies on identity following HI in adults. It identified processes in identity adaptation that can inform healthcare providers working with this client group. Further studies are required before the results can be generalised to the wider HI population.

Conclusions & Implications of findings: There is a need to increase the awareness in healthcare professionals of the impact of HI on identity. Recommendations are made for working with this client group, such as professionals being aware of their communication style and use of language. Future research is needed to better understand and respond to identity change following HI and to improve functioning and wellbeing.

Keywords: Qualitative Systematic Review, Head Injury, Traumatic Brain Injury, Identity, Self

Introduction

The consequences of sustaining a head injury (HI) are significant to the victims as well as to those around them (e.g. Muenchberger, Kendall & Neal, 2008; Bond, Draegar, Mandleco & Donnelly, 2003). NHS Scotland's standards (2009) for this population stress the requirement for a comprehensive understanding of individuals' current as well as future rehabilitation needs following discharge from acute settings. The psychological and social changes that arise following a HI are arguably the most significant in terms of their long-term impact on recovery and wellbeing following the acute recovery period (Muenchberger et al., 2008). For a large number of people who are discharged home following rehabilitation, physical functioning can often improve; however, the impact of cognitive impairments or personality changes as a result of the HI can have a lasting impact on many areas of social functioning (employment, study, hobbies and interests) and can lead to social isolation, difficulties with adjustment and mood problems (Ponsford, 2002). These changes are difficult to assess and predict, can often be missed by clinicians and underestimated by relatives and the people with the HI themselves (McMillan & Oddy, 2002).

There is growing interest in the changes to identity experienced by adults following HI (e.g. Ylvisaker & Feeney, 2000; Gracey et al., 2008). A meta-synthesis of qualitative research examining recovery highlighted two themes relating to changes to personal identity following HI: reconstruction of a lost or disrupted sense of self and a sense of disconnection from society based on stigmatisation and discrimination from others (Levack, Kayes & Fadyl, 2010). This is worthy of further exploration because perceptions of identity can mediate wellbeing (Haslam et al., 2008).

Identity has been described as fluid, rather than as a fixed entity which can shift and alter. Brewer and Gardner (1996) propose three forms of self: individual, relational and collective, which change in salience depending on context and environment. Individual-self is defined as the unique attributes which separate the self from others; relational-self as the aspects of the self that are defined by interpersonal relationships and; collective-self as defined by social group membership. It is the collective-self that social identity theory (Tajfel & Turner, 1979) is concerned with. Based on this theory, individuals identify as members of particular social groups, for example with a nationality or sports team. Identifying with these social identities contributes to a sense of belonging to the social world and is linked with self-esteem and mental health (Haslam et al. 2008).

The link between identity with self-esteem and mental health is mediated through perceptions of the social groups as being of high or low status within society. When a social identity is low status or is stigmatised within the society to which it belongs, individuals may protect their self esteem by reconciling with the low status social group, engaging in action to alter the image of the group and how it is viewed (Brewer, 2001). Alternatively individuals may dissociate themselves from that social identity to protect their self-esteem. An example of this is given by Yardley, Donovan-Hall, Francis and Todd (2007) who found that a barrier to the uptake of a falls prevention programme by older people was resistance to self-identification as being old. Dissociating from a stigmatised group identity can be difficult for individuals, impacting upon their wellbeing and making it difficult for individuals to see themselves as belonging to other social groups (Haslam, Jetten, Postmes & Haslam, 2009) or to define themselves in other ways.

As yet, changes in identity are not routinely assessed following HI. It has been suggested that outcome measures are needed to assess changes to self and social identity, as are interventions which focus on these changes following discharge (Levack et al., 2010). Devising such measures and interventions may be difficult due to the subjective and idiosyncratic nature of identity (to which qualitative methodology lends itself well in eliciting personal meaning and subjective views). Examining identity in the HI population is further complicated by the highly heterogeneous nature of those with HI (NHS QIS, 2009). A systematic review of identity change following HI may inform further rehabilitation care for patients with HI and the future development of specialised assessment measures and interventions. Furthermore, a systematic review of the qualitative literature on identity change may help to overcome difficulties in generalising from individual qualitative studies (Ring, Ritchie, Mandava & Jepson, 2011) and identify common themes or issues.

Aims

- To explore the post-injury experiences of adults who have sustained a head injury.
- To appraise the quality of the qualitative literature in this area.
- To synthesise and discuss key concepts from the qualitative literature examining identity change in adults who have sustained a head injury.

Review Question

What are the key concepts and processes involved in identity change following head injury?

Method

The process of review was conducted in several stages involving a search and identification of suitable studies for inclusion in the review, appraisal of the quality of the studies identified and the synthesis of key concepts from the studies using a meta-ethnography approach (Noblit & Hare,1988).

Search strategy

Searches were carried out on the following electronic databases: Ovid: Medline (1946- March 2013) and Embase Classic + Embase (1947-2013 Week 13) and EBSCO: CINAHL, Psychinfo, Psychology and Behavioural Sciences and Biomedical Reference Collection: Comprehensive.

Identifying suitable qualitative studies can be challenging due to varying standards in the indexing of qualitative studies on databases and the aims of qualitative studies often being unclear from their titles (Ring et al., 2011). To improve the sensitivity of the search, a contents list search of three key journals (Brain Injury, Qualitative Health Research and Social Science & Medicine) from the past 5 years (2009 - May 2013) was conducted based on issue availability at the time of search (Brain Injury, 2009 - June 2013; Qualitative Health Research, 2009 - July 2013; Social Science & Medicine, 2009 - July 2013) to identify any further relevant papers. Reference lists of relevant papers were also scrutinised for additional papers. Key authors were also contacted regarding any other published papers which may have been suitable for inclusion.

Search terms

Key search terms relating to ‘head injury', 'identity' and 'qualitative methods' were taken from past studies and piloted to ensure sufficient scope for the search (see Table 1). The same search terms were used in both databases using 'AND' commands to link the terms from the three search topics.

Table 1: Search terms by topic area

Topic	**Search terms**
Head injury	Head injury OR Traumatic brain injury OR Cardiovascular trauma OR Craniocerebral trauma OR Neuro$*
Identity	Identity OR Self$* OR Personhood
Qualitative methods	Qualitative OR Interpretative phenomenological analysis OR Grounded theory OR Thematic analysis

* $ indicates truncation for alternative endings of the search term

Inclusion criteria

This review included: papers published in peer-reviewed journals, studies explicitly adopting qualitative methods in data collection and analysis, adult studies (age 18 and over), studies of head injury and studies exploring identity.

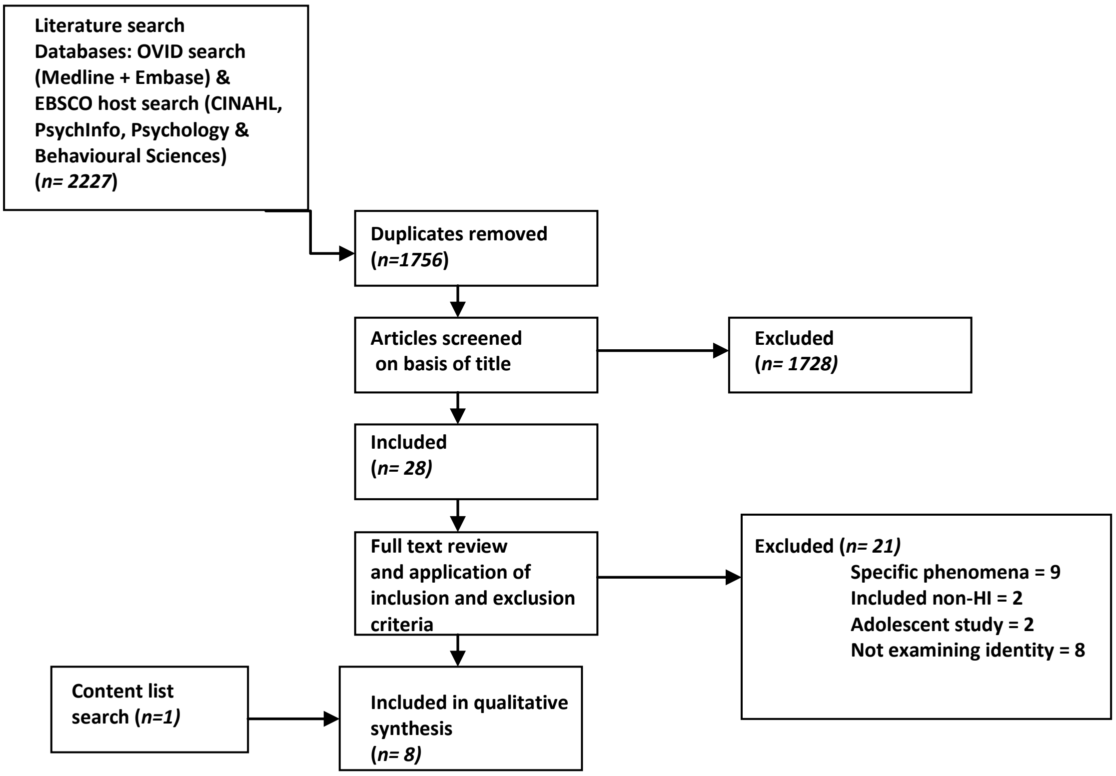
Exclusion criteria

This review excluded: non-English language studies, studies of individuals who experienced brain injury as a result of non-traumatic causes(including stroke or a degenerative brain condition), studies including non-HI participants (including mixed aetiology studies), book chapters, child or adolescent studies, studies relating to specific phenomena (for example, suicidality in veterans following HI) and studies employing quantitative methods (including mixed-method studies).

Results of search strategy

The results of the search are presented in Figure 1 as per guidance for the presentation of systematic review results (PRISMA, Liberati et al., 2009).

Figure 1: Flow chart of search results



Quality appraisal

There are varying opinions regarding how quality should be appraised in qualitative studies (Noyes, Popay, Pearson, Hannes & Booth 2010) which may be partly due to the nature of the methodology as being more difficult to quantify than in quantitative studies (Barbour, 2001). This review used a score-based rating tool (see Appendix 1.2) based on Walsh and Downe's (2006) summary framework of 12 essential criteria for assessing the quality of qualitative research (for example, if there is a clear statement of and rationale for the research question and whether the sample and sampling method was appropriate) (see Appendix 1.5 for a breakdown of scores for each reviewed paper).

Each paper was scored on 46 items based on the 12 criteria (with a score of 0 or 1 for each) and a percentage rating was given based on the final score out of a maximum of 46 points (good >75%, acceptable >50% and poor <50%; see Table 2). All of the papers were second rated by an independent reviewer (a Trainee Clinical Psychologist). Inter-rater reliability for the final scores was high (94.3%) and agreement for the overall quality categories was 100%. Disagreements about ratings were resolved through discussion until 100% agreement was achieved.

Table 2: Methodological outline & quality ratings of reviewed papers

Authors	**Country**	**Data collection**	**Setting**	**Participant Number**	**Quality Rating**
Douglas (2013)	Australia	Grounded theory	Community	20 (16 male, 4 female)	86% Good
Nochi (1998b)	Internet/USA sample	Grounded theory	Internet forum + a TBI support group	10 (6 male, 4 female)	84% Good
Muenchberger, Kendall & Neal (2008)	Australia	Phenomenological approach	Community	6 (4 male, 2 female)	82% Good
Nochi (2000)	USA sample	Grounded theory	Support group + previous participation in past study	10 (8 male, 2 female)	80% Good
Gelech & Desjardins (2011)	Canada	Thematic analysis	Rehabilitation Centre	4 (3 male, 1 female)	78% Good
Nochi (1998a)	Internet/USA sample	Grounded theory	Internet forum + a TBI support group	10 (6 male, 4 female)	76% Good
Nochi (1997)	USA	'Qualitative research methods'	Community	4 (3 male, 1 female)	74% Acceptable
Gutman & Napier-Klemic (1996)	USA	Grounded theory	Residential facility	4 (2 male, 2 female)	73% Acceptable

Method of synthesising themes

Meta-ethnography is commonly used to synthesise qualitative health care research (Noblit & Hare,1988) and was used to synthesise the themes extracted from the individual studies. In meta-ethnography, the process of synthesis is broken down into seven steps (Ring Noblit & Hare,1988; see Appendix 1.3). There are three methods of synthesis within this, involving exploration of similarities and differences between the individual studies, 'translating' concepts from the separate papers to create higher level 'third order' constructs (new interpretations based on the interpretations within individual studies) and establishing an overall picture of a topic through synthesis of the individual papers (Barnett-Page & Thomas, 2009).

The process of analysis began with reading and re-reading the results sections of each paper approximately five times to identify and note the key concepts and interpretations made by the authors in each paper. This involved the current reviewer both identifying concepts as labelled by the authors as well as interpreting and labelling new concepts based on the information and quotes within the papers (see Appendix 1.4 for a sample of notes). These key concepts and interpretations, labelled 'dominant themes', with supporting quotes were then extracted from the texts and typed electronically within the same document allowing comparison within and between papers. The dominant themes were then 'translated' (Ring et al., 2011) by grouping similarities across papers. These translations were used to create third order constructs, labelled by the current reviewer, and compared and contrasted to determine how the constructs relate to each other. This involved consideration of how dominant themes and third order constructs contribute to the mechanisms of identity change following HI.

Results of synthesis

The extracted list of dominant themes from the individual papers are presented in Table 3, as recommended by Noblit & Hare (1988). As presented in Table 3, the related term of 'traumatic brain injury' (TBI) was used within most of the papers; however the term head injury (HI) is used to present the results following the synthesis.

Table 3: Dominant themes from each paper

Authors	**Dominant themes**
Douglas (2013)	• Self-definition through personal attributes and goal statements • Feelings about self based on appraisals of functioning, outcomes and material ownership • Staying connected to others and society • Creating a new self-narrative
Gelech & Desjardins (2011)	• Public aspects of self - focus on negative change, loss and reduced functioning • Private aspects of self - stable inner self based on traits; threatened by others • Reinventing selfhood
Gutman & Napier-Klemic (1996)	• Differences between males and females in ability to retain gender identity post-TBI • Differences in the importance of activity in influencing gender identity • Differences in the role of activity in promoting social contact • Differences in the value placed on achieving societal goals
Muenchberger, Kendall & Neal (2008)	• Contraction of self - increased focus on loss and functioning, detachment from society • Expansion of self - decreased value placed on societal norms and recognition of positives of present self • Identity as tentatively balanced between states
Nochi (1997)	• Dealing with voids in memory gap between past and present, doubt affecting the stability of the sense of self • Recovery through increasing functioning to progress towards pre-injury self and redefining life priorities • Adjusting to life with TBI
Nochi (1998a)	• Labels from society which conflict with perceptions of self • Attributing behaviours to TBI and aligning self with TBI • Strategies to overcome labels
Nochi (1998b)	• Loss of self through loss of self knowledge • Loss of self in comparison to past self • Loss of self in the eyes of others
Nochi (2000)	• Revision of self-narratives to cope with TBI • Narratives of self as better than others; self as developed; recovering self; the present self; and the self within society

Three third order constructs were synthesised from the papers: being the same and being different, others as both a support and a threat to identity and reconciling identity with HI.

Being the same and being different

The first third-order construct relates to the challenges posed to identity from changes to physical and cognitive functioning:

'Survivors were able to maintain the sense of a stable inner self across the injury experience, despite threats to continuity..."I think I'm okay. But yet I have tests, I have cognitive tests and they all prove that, no, you're not what you used to be"' (Gelech & Desjardins, 2011, pg. 67).

While some conceptions of self can remain the same following HI, the synthesis suggests that this stability is often challenged by reminders that the person has changed and is different from before the injury. One reminder comes from an increased focus and importance placed on the inability to achieve societal goals, such as marriage or job promotion due to physical or cognitive changes:

'There's so much of my life that didn't go the way it should have.... I'm a man who has been battling to prove myself a man for the last 18 years because of this head injury. I should have already fallen in love and gotten married, had a family, gone down that route. I know I would have been in an executive-level position at work by now' (Gutman & Napier-Klemic, 1995, pg. 540-541).

This appeared to affect the studies' participants both in terms of how they understood their present circumstances and how they envisioned their future lives. It contributed to a separation of self into pre-injury and post-injury, with the discrepancy between these characterised as identity loss:

'It has been an extremely emotional roller coaster for me in realising that the direction that I wanted to pursue has been snatched away' (Nochi, 1998b, pg. 873).

Another reminder that they were different from before also came from an increased focus on physical ability following HI. Changes in physical functioning appeared to be the most obvious indicator that they were no longer the same as before:

'(After the accident) my whole life changed . . . I realised that a lot of the skills were gone, and I wasn't accepted socially as much. . .I knew there was something different' (Muenchberger, Kendall & Neal, 2008, pg. 985).

Similarly, another common theme was the concept that regaining aspects of physical functioning would signify regaining the pre-injury self and the ability to be the same as before the injury:

'Well, the best aspect is it gave you an identity back. That a person's back in the workforce. Then you can feel proud; say, "Yeah, I work at London Drugs". People think, "Good, he's a part of—a productive member again", you know? It's good' (Gelech & Desjardins, 2011, pg. 67).

To a lesser degree than physical functioning, changes in cognitive functioning also emerged as a threat to the participants' stable sense of self. Examples of this were memory loss relating to both the traumatic event and also key events or knowledge that caused them to feel uncertain about their sense of identity:

'Fred found that he did not remember even the faces of his parents. He said that this memory loss was one of the most bothering effects of his brain injury because he could not be sure that his father was really his father' (Nochi, 1998b, pg. 871).

The stability of self was also further threatened by a lack of knowledge of how they had changed out-with the physical changes to their functioning which they could see. The following example highlights a detachment and wariness in the participant's sense of self:

'I still, after two years, am trying to redefine myself. I don't know this person any more. She is not reliable and cannot be trusted as my best friend' (Nochi, 1998b, pg. 872).

Others as both a support and a threat to identity

Threats arising from physical and cognitive changes to the stability of the self was frequently paired with an increased reliance on others, passivity and a sense that others had better knowledge of them and their needs:

'For a younger person, they (nursing homes) are not the greatest things. But they are needed. You know, there is a bit, there is a bit of difference (between) wants and needs. Again, I didn't want it, but I needed it' (Nochi, 1997, pg. 543).

This theme of increased need for support from others, however, was equally matched with a recurring theme of others as a threat to the sense of self, as not understanding them, and as perpetuating the narrative that they were not the same as before:

'I have changed in other people's eyes for sure, cause every time my mom sees me she cries. Yeah. But I still feel like the same person. It makes me sad, uh, makes me angry' (Gelech & Desjardins, 2011, pg. 68-69).

Family and friends were frequently cited to have changed in their behaviour towards the participants and in their perceptions of them. This often resulted in the participants reporting withdrawing from others or isolating themselves from society (deviating further from valued societal goals). Although interactions with family and friends were often described as problematic, it emerged that the biggest threat to their identity came from medical, rehabilitation and other professionals. The sense that the self had changed and was drastically altered following HI was described as both originating from and being perpetuated by professionals:

'They (my family) feel I have changed because other people have told them it was going to be that way' (Gelech & Desjardins, 2011, pg. 68).

'I don't feel brain injured, so it's like, just a story to me. I don't feel anything wrong with my brain, (but) they insist that I'm brain injured. Well, wouldn't they know?' (Gelech & Desjardins, 2011, pg. 67-68).

Interactions with professionals and the use of medical language appears to push participants, often unwillingly, into incorporating the social identity of a patient (also described in the papers as disabled, adopting the sick role, as a head-injured person and as 'mental') into their sense of self:

'Getting out of the sick role (was a challenge) and I think I knew it wasn't me. It was never me. But I was told it was' (Muenchberger, Kendall & Neal, 2008, pg. 985).

This aspect of identity was frequently described as limiting participants from making progress with recovery, making it difficult to feel part of society or the same as others following their initial recovery period:

'I'm not able to do (make new friends) because, when you get into a new work place, you go in there as a head-injured person, and you go in there with a job coach. That makes them think differently of you because I have a job coach and I am head-injured. They might not really treat me the same as another person, ordinary person' (Nochi, 1997, pg. 545).

This 'head-injured' identity was described as a homogenous, low status group which challenged the individual, idiosyncratic aspects of identity. This medically-based group identity was difficult for participants to reconcile with due to the internal features of their difficulties following HI (such as changes to cognitive functioning). Furthermore, the adoption of this new, unwelcome social identity was often associated with the loss of other valued social group identities:

'Initially, mum wanted to take me to the head injury society . . . I said "what, I'm not like them" . . . I didn't want to be a part of a group that had a disability . . . and my disability was quite invisible to look at, and (being part of a society) kind of put me in the same category as people who had wheelchairs, and canes, and I didn't want that . . . because of that need for normality, to be so offended by your own disability and then to be thrown in a group (of people) with disabilities' (Muenchberger, Kendall & Neal, 2008, pg. 987).

'I'm no longer Miss M. the teacher. I'm Barb the resident at (longterm care facility)' (Gelech & Desjardins, 2011, pg. 66).

Being a member of this low status group also revealed another tension between the participants and others involving the desire for more emotional support versus a lack of privacy and autonomy due to paternalistic supervision:

'Really, there's no one to talk to. Talking to you now has been such a relief because I don't think I've discussed my feelings about what we've been talking about for - it's too many years now' (Gutman & Napier-Klemic, 1995, pg. 541).

'They were worried about me too much. They always threatened me, "If you go out, then you can't make it on your own!"' (Nochi, 1998a, pg. 671).

Reconciling identity with HI

The last third-order construct relates to descriptions of attempts by the participants to reconcile the similarities, differences and threats to their identity as a means of coping following HI. These have been divided into broad themes, or categories, of cognitive and behavioural strategies which are both facilitated by changes to self-narratives and selective use of language.

There were a number of adaptations to self narratives which reflected or were facilitators of cognitive change (changes to thinking). The first involved an appraisal of the self as fortunate, in terms of the potential for poorer functioning, and involved downward social comparisons with those perceived as less fortunate:

'My hand-writing is not the best, but it could be worse' (Nochi, 2000, pg. 1798).

'You know, I have pretty much life experience by 37...I feel bad for them (younger people with TBI) because they are never going to have, have girlfriends' (Nochi, 2000, pg. 1798).

Positive consequences of the HI also appear across studies, including increased insight into self and others as well as moral changes arising from having survived a trauma. Similarly, the value placed on aspects of the individual self were framed as more important and more morally worthy than social identities:

'Retards. That's how I used to see the disabled. People, now I see them as people... A person's world maybe revolves too much around financial and having. That can happen too. And, you know, it's easy to get involved in that' (Gelech & Desjardins, 2011, pg. 70).

These cognitive adjustments were often linked with behavioural changes. The most frequently reported behavioural changes related to socially-driven goals, such as returning to employment or previously enjoyed activities but also included maintaining a connection with people which for some had reduced following their HI:

'I have no friends anymore, only my family; Family, the way they are . . . they're just here and I know they're for me' (Douglas, 2013, pg 68; pg. 67).

The use of language and selective word choice was also found within the studies and appeared to be the means for participants to incorporate or distance themselves from their HI. Although this theme was extracted from a number of the papers included in the study, there is no clear consensus about what is acceptable terminology relating to HI and preferences varied between participants. Despite differences in semantics, the participants emphasised the use of language to help others to understand about the nature of their 'invisible' difficulties and to convey that they are the same as everyone else:

'I am tired of fighting people's perceptions of me as "stupid". I remember times that co-workers would come into my office and ask, "Do you have the answer to that question yet?" And no, I had only finished getting all set up to think about it' (Nochi, 1998a, pg. 676).

'I just have problems. It's better than saying he's got head injury or has disability or he's not right in the head, or whatever...Everybody in the world has problems' (Nochi, 1998a, pg. 673).

In terms of how the three constructs relate to each other, it was postulated by the reviewer that each construct loosely mapped onto three different stages of identity change following HI relating to different stages of adaptation and acceptance of HI within identity. Hence, struggling with being the same as well as being different involves a comparison of the current self with the pre-injury self (looking backwards); other people as playing a key role in supporting or challenging identity stability and their reactions as informing the individual about their present self (constructing the present self);

and the use of specific strategies to reconcile the self with the HI as a means of adapting to a changed sense of self (moving forward into the future).

Discussion

This systematic review synthesised qualitative studies examining identity following HI. Three dominant constructs emerged, of being the same and being different, others as both a support and a threat to identity and reconciling identity with HI which relate to three different stages of identity change following HI. These constructs are characterised by tension between the conflicting processes involved in identity change or adaptation which reflect theories of identity as an ongoing fluid process; perhaps made fraught by the nature of HI (as unexpected and as a trauma) and by societal perceptions of those with HI.

Theoretical implications of the synthesis

The results of this synthesis suggest that the experience of HI heightens, or increases the salience of social forms of self. The characteristics of the individual which are more stable, such as personality traits, are less emphasised in comparison. This fits with existing literature on identity salience (Brewer & Gardner, 1996; Terry, Hogg & White, 1999) and may explain the perceived discrepancy between feeling the same (in terms of individual traits) and feeling different (acquiring a new social identity). Themes within the studies reflect a resistance to being different with numerous factors perceived as threats to a stable sense of self. This may reflect the internal drive for people to keep perceptions of themselves consistent (Burke & Stets, 2000).

Based on this synthesis, it appears that increased salience of social identity also increases the importance of achieving societal goals. This in turn highlights to individuals their altered path or the barriers to achieving goals as a result of their HI (impaired physical and cognitive functioning) which further reinforces the feeling of being different. Much of the resistance to the acquisition of this new social identity relates to the status or perceptions of being a person with a HI; within the societies in which the studies were based, this was inferred to be low and inferior. Fitting with this is the need for a positive social identity (Turner, 1981); hence people are likely to avoid categorising themselves using medical labels that challenge their self-esteem and are likely to reject or refute a HI label. The acquisition of a HI identity is often met with resistance and, as found in the reviewed studies, was often described alongside negative emotions such as sadness and anger. Based on the existing literature on social identity, the low-status of a HI identity poses a threat to the self-esteem and well-being of those who have sustained a HI (Haslam et al., 2009). The loss of other previously valued social identities further impacts on well-being (Haslam et al., 2009), examples of which were found in some studies (including withdrawing from previously enjoyed activities or a reluctance to engage in social activities due to perceived stigma from others). Similarly, decreased value placed on social identity and societal goals, as mentioned in some papers, also led to avoidance and withdrawal from society, further impacting on the sense of self.

Unsurprisingly, the social nature of social identity affects the role of others in peoples' lives. In the HI population there is often an increased dependence on others due to physical and cognitive impairments. Social identity salience within a low-status group may heighten the importance, or meaning attached to, the reactions of other people and, as found within this review, an increased sensitivity or awareness of differences in how others perceive them after injury. This is reflected in how other people are both simultaneously perceived as both a support and a threat to identity.

Several strategies were used by participants to reconcile their identities with their experience of HI which often fell within the social domain: rejecting social forms of identification as shallow, employing downward social comparisons with others in worse circumstances and engaging in socially-based activities. Despite a perceived rejection of social identities in general, results suggest that by embracing other forms of social identity (either new or from before the HI) individuals can reconcile their HI with their sense of identity.

Clinical and practical implications

The results of this review and synthesis raise a number of points for consideration in clinical practice. Firstly, it would appear that identity change following HI can be fraught and associated with tension and negative emotion which impacts on social functioning, adjustment to HI and mood. The ongoing nature of identity construction suggests that this is a process that is likely to extend beyond the acute recovery period from HI and indeed, is perhaps most difficult for individuals when they return to functioning within society. It would appear that supporting individuals with identity change following HI should be considered as a rehabilitation need which it currently is not (NHS Scotland, 2009).

It also appears that the perceptions of those with HI as part of a low status, stigmatised group (based upon the reaction of others and societal perceptions) is a key component of many post-HI identities which is worthy of screening and psychosocial support. The nature of this support would need to be carefully considered due to the described heightened sensitivity in interpersonal relationships but perhaps would be most meaningfully delivered by professionals early in the post-injury process. This could help to model appropriate or meaningful interactions for other people (such as family members) to facilitate adjustment to the HI for the individual as well as those around them. Altering communication style or use of language (for example, to be more inclusive) may be an important intervention in itself. Taking this approach may be normalising for individuals struggling with identity change or adaptation following HI.

A key mechanism for individuals to reconcile the changes to their identity following HI is through adaptations to their self-narratives. It may be that measures or interventions for identity are based on this approach. Alternative ways of supporting the development and evolvement of self-narratives, in a sensitive manner acknowledging the fraught and tense nature of this process, outside of stigmatising encounters with others may help to facilitate identity change for individuals with HI. Individuals should be supported to view their social identities as multi-faceted and an asset rather than as a threat to their individual sense of self. This may help to promote functioning through socially valued activities, supported with an appreciation of the individual's strengths and limitations, and may help to promote adjustment and wellbeing following HI.

Strengths and limitations

This review is the first systematic synthesis of qualitative studies on identity following HI, which overall are rated to be of acceptable to good quality. Key processes in adaptation of identity following HI have been outlined and an awareness of these processes can assist professionals to be more sensitive in their interactions with adults with HI. The clinical utility of this synthesis is a strength and addresses the previously criticised lack of contribution from qualitative studies to healthcare practice (Barnett-Page & Thomas, 2009).

There are a number of limitations of this systematic review. Some of these relate to the process of synthesising qualitative papers (Ring et al., 2011; Pope, Mays & Popay, 2007). Some information is typically 'lost' from individual qualitative studies through the process of synthesis which reduces their richness of detail (Pope et al., 2007) and it may be that through the process of summarising the results, there could be misinterpretation or bias introduced through the reviewer eliciting third order constructs. Furthermore, the use of qualitative methodology terms in the initial search may have reduced the sensitivity of the search in capturing all available studies; although this was compensated for by the use of reference list and journal searches and by contacting key authors. In terms of the papers which were included within the review, it is recognised that half of the papers which were included were from one author (Nochi) which may bias the data set and themes and interpretations overall.

In relation to the quality of the papers included, all were deemed to be of at least acceptable quality; however the rating process highlighted that only two studies reported achieving data saturation and a different emphasis on themes may have emerged had there been larger samples (although the absence of reporting does not necessarily mean that saturation was not reached in other studies). Lastly, the results and recommendations of this review should be considered in relation to the sample on which the studies were based. All drew on Western cultures, where the concepts of identity and social identity may be different compared to other cultures. Similarly, there may be differences between Western cultures in which the studies were conducted (the UK, USA, Canada and Australia). Furthermore, the studies used participants who were able and prepared to speak about their experiences and they may not be represent all individuals with HI. This may be unavoidable in research on HI (NHS QIS, 2009). Similarly, the papers were included on the basis of their explicit exploration of identity following HI and it is not possible to infer the prevalence of these difficulties in the HI population, although this is expected in qualitative studies. It may be difficult to create generic screening tools for identity based on the results of this study due to a potential bias in the sample and the limited scope of this study.

Future directions

This review indicates a need to increase awareness of the impact of HI on identity. Professionals should be mindful of identity throughout the acute recovery phase and beyond and be sensitive in their use of language and communication. The development of screening tools and interventions to facilitate adjustment following HI is likely to be useful, however further research using qualitative methods where saturation has been achieved should be considered, if this is viewed by future researchers to indicate quality within a study (as by Walsh and Downe, 2006, in the quality appraisal tool used within this study). Future studies examining the link between social identity and wellbeing in the HI population is also recommended. These studies could be informed by the dominant constructs relating to identity change, or adaptation, elicited from within this study.

Conclusion

Difficulties in maintaining and adapting a sense of identity can arise following a HI. Three key constructs are identified relating to stages in the process of identity change following HI: being the same and being different, others as a support and a threat to identity and reconciling identity with HI. Further research is needed to better understand the relationship between identity and the rehabilitation needs of individuals with HI.

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CHAPTER 2: MAJOR RESEARCH PROJECT

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

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Plain English summary

An exploratory study of social identity in adults with severe head injury who reside in care homes

Background: A head injury (HI) can lead to many life changes for people such as in the ability to look after themselves, to work and take part in activities which they used to enjoy. For those with severe HI, these limitations can result in moving into a care home. Changes following HI can affect the person's identity or sense of who they are. One important aspect of identity is 'social identity' or a person's sense of belonging to social groups (for example family, sports or recreation groups). It has been suggested that HI (Gelech & Desjardins, 2011) and moving into a care home (Knight, Haslam & Haslam, 2010) can reduce a person's ability to see themselves as part of the same social groups as before. Changes to social identity affect self-esteem and wellbeing (Haslam et al., 2008); yet little is known about this for adults with severe HI who live in care homes.

Research Aims: The aim is to describe how adults with severe HI who live in care homes see themselves in terms of their social identity and how their relatives and care staff see them also.

Methods: Eight adults took part in this study: three with severe HI, two of their relatives and three care staff. Participants were identified using a NHS database and through liaison with care home managers. Written consent was obtained from all participants. Adults with Incapacity (who are legally deemed to be incapable of making decisions regarding their welfare) were excluded as were those with acquired brain injury as a result of non-traumatic aetiologies (for example, stroke). The researcher interviewed each participant individually using open-ended questions which were used flexibly to encourage the participants to talk freely about topics which were important to them. Interviews were recorded, typed up and anonymised. The typed transcripts were re-read several times to identify recurring themes within the interviews. These themes were then grouped together by similarity to identify over-arching, or super-ordinate, themes.

Main findings and conclusions: Three superordinate themes were found in relation to social identity. These were: (i) how the HI and living in a care home elicited views of the person as abnormal; (ii) the HI as separate from the individual person and; (iii) the person with the HI as seen as being like a child and an adult. There are similarities and differences within the themes between the views of the adults with severe HI, their relatives and their carers. The results indicate the importance of activity relating to valued social identities for adults with severe HI and of taking an individual approach in exploring meaningful activity for each person. The exploratory nature of this study and small sample size limits the ability of these findings to be applied more widely and further research is recommended.

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Scientific abstract

Introduction: The consequences of sustaining a head injury (HI) are varied. Recent research has begun to explore the experience of HI on identity which can, in turn, affect wellbeing. The move into a care home is also associated with changes to identity and wellbeing. Arguably changes to social identity (a form of identity based on membership to social groups) are particularly salient in this setting. Despite this, there have been no studies examining social identity in individuals with severe HI who reside in care homes.

Aims: This exploratory study examines the perceptions of adults with severe HI residing in care homes, their relatives and care staff using a social identity framework.

Methods: Eight participants from three group perspectives took part in this study (three adults with severe head injuries, two relatives and three staff carers) comprising two participant triads and one participant dyad. Semi-structured, open-ended interviews were completed and recorded with each participant on an individual basis. Transcripts were analysed using Interpretative Phenomenological Analysis.

Results: Three superordinate themes were found: doing as normality, HI as separate from the individual and being a child and an adult.

Discussion: Social identity processes of pre-injury identity loss and the acquisition of new social identities relating to the HI and being a resident in a care home are discussed. HI and the care home environment lead to perceptions of the PPs as part of a homogenous group which result in stigmatising interactions. The role of socially meaningful behaviour in mediating perceptions of the PPs is raised as well as the need to acknowledge issues relating to insight and current ability. It is unclear based on the results of this study whether needs relating to identity are met within care homes.

Conclusion: The importance of taking an individual approach to explore meaningful social activity for the PPs and the recognition of the importance of this in relatives and carers is highlighted. Further research into interventions for this population and care staff is recommended.

Introduction:

The consequences of sustaining a head injury (HI), a sudden unexpected trauma to the brain caused by an external force resulting in brain injury, are varied and can continue beyond the physical recovery period (Muenchberger, Kendall & Neal, 2008). Studies into head and brain injury suggest that one of these consequences relates to changes in identity with individuals reporting changes to how they view themselves and to how others view them also (Gelech & Desjardins, 2011). A metasynthesis of qualitative research identified two key themes of social disconnection (through the loss, amongst other things, of friends, employment and social networks) and lost or disrupted self-identity (Levack, Kayes & Fadyl, 2010). Other themes which have emerged in individuals with a HI and their significant others relate to deficits and dependency on others (Cloute, Mitchell & Yates, 2008). This may subsequently affect how significant others communicate with the HI individuals, often reinforcing their position as a 'passive party' (Cloute et al., pg. 656). For the individual, changes to identity can affect wellbeing and feelings of self-worth (Haslam et al., 2008).

Negative changes in identity may be particularly relevant to individuals who are discharged to care homes following their HI. These individuals are often at the most severe end of the spectrum, in terms of the severity of HI and cognitive impairment (Van Baalen, Odding & Stam, 2008). Studies in non-head injured populations suggest that the move to a care home is a significant life event for individuals and is often associated with losses of lifestyle, a home, material possessions, social role and autonomy (Reed & Morgan, 1999). Moving into a care home is suggested to impact on life satisfaction and wellbeing (Knight, Haslam & Haslam, 2010).

These negative changes in life satisfaction and wellbeing may be linked to changes in identity. Social identity may be particularly relevant in this setting where there are two distinct social groups of carers and residents. Social identity theory relates to an individual categorising themselves as a member of a particular social group (self-categorisation theory - Turner, Hogg, Oakes, Reicher & Wetherell, 1987; Tajfel & Turner, 1979), internalising the attributes of this group into their sense of self and defining themselves as a member of the social group. The basis of this theory and its relation to self-esteem is that one way that people learn about themselves is through comparison with others (social comparison theory - Festinger, 1954). The individual may seek out others (social groups) whom they perceive to be the same as them to validate their beliefs and attitudes. The opposite is true of behaviour - people will prefer to seek out those who are perceived to be less able or perform less well than them (downward social comparison) which boosts or is protective for the person's self esteem (Wills, 1981). However, it is not always possible to surround oneself in this way and where an individual is constrained to making upward social comparisons (perceiving others as more able) this can have a negative effect on their self-esteem (Wood, 1989). Belonging to a social group which is perceived to be of low-status in society (i.e. stigmatised groups) has similar consequences. Within a care home environment, differences between the social groups of carers and residents exist in terms of the power dynamics, levels of autonomy and decision-making abilities. Similar power imbalances are found in medical settings which foster a loss of control, increased obedience in patients (Contrada & Ashmore, 1999) and diminished their ability to see themselves in terms of other identities (Haslam, Jetten, Postmes & Haslam, 2009). A quantitative study by Haslam et al. (2008) examining social identity in stroke patients suggests that in addition to gaining the identity of a 'patient', past valued identities such as professional identities, memberships of recreational groups and community identities were lost through the process of moving into care due to disability. They suggest that this is related to lowered self esteem and mental health difficulties (Haslam et al., 2008).

Within the care home environment the need exists for one group (staff) to care for and take responsibility for facilitating the other group's (residents) needs and interests. In this setting, the emphasis is often to provide equal care to all (Knight et al., 2010). Standardised care may result in staff categorising all residents as a homogeneous group of 'recipients of care' (Knight et al., pg. 1395; Turner et al., 1987). This may result in a prioritisation of basic care needs common to all residents (such as attending to personal care) over individualised psychosocial interventions to promote wellbeing. This is important, as previous studies suggest that the ability to maintain social networks and contacts are often impaired by HI (Morton & Wehman, 1995). This means that to maintain past valued social identities the HI individuals rely heavily on the decisions and actions of powerful others who care for them.

As yet, there are no studies examining how adults with HI residing in care homes perceive themselves. This is worthy of investigation given that both having a HI and residing in a care home can have a negative impact on identity and wellbeing (Wood, 1989; Haslam et al., 2008; Knight et al., 2010). This is also important given the increasing pressure on disability and rehabilitation services to respond to and be evaluated by outcomes which are perceived to be relevant to the users of these services (Levack et al., 2010). Similarly, examining the perceptions of significant others are important in establishing the need for indirect interventions through staff or family members.

Aims and Research Questions:

Research Questions

- How do adults with severe HI residing in care homes perceive themselves in terms of their social identity?
- How do their relatives and carers perceive their social identity?

Aims

- To describe the key features of the perceptions of adults with severe HI residing in care homes and of their relatives and carers using a social identity framework.
- To examine whether needs relating to the identity of the HI person are met in care home settings by comparing perceptions of their past, current and future selves from their own and other's perspectives.

Methods

Ethical approval

The study was reviewed and approved by the NHS Scotland A Research Ethics Committee on condition of excluding Adults with Incapacity (Adults with Incapacity Act, 2000; see Appendix 2.9). The study was also reviewed and approved by NHS Greater Glasgow and Clyde Department of Research and Development and by the University of Glasgow.

Participants

Eight participants from three group perspectives participated in the study: three adults with severe HI residing in care homes (the Primary Participants, 'PP'), two of their relatives and three care staff. These participants comprised two participant triads (of PP, carer and relative) and one participant dyad (PP and carer) of related individuals (see Tables 1, 2 and 3 for detailed participant information extracted from care home records, medical notes and participant self-report). The participating PPs and carers were based in two care homes in the Greater Glasgow and Clyde area. As recommended for IPA studies, participants were recruited on a purposeful basis to establish a sample for whom the research questions were relevant (Smith & Obsborn, 2003). As participants were recruited on the basis of their group membership (as a PP, a carer and relative of the PP) they are identified by these groupings along with a letter (A, B, C) to identify the triad or dyad to which they belong.

The participant sample size was at the lower end of the projected range for this study; however the sample size is consistent with the guidance suggested by Turpin et al., (1997) for a feasible DClinPsy research project and is within the recommended range for a research study using IPA for a professional doctorate (Smith, Flowers & Larkin, 2009).

Table 1: Primary participant information

Participant pseudonym	Age	Gender	Previous employment	Pre-injury accommodation	Age at injury	Time since injury	Cause of injury	Time in care home
PP-A	51	Male	Rig-worker/taxi driver	Home with partner	46	5 years	Assault	2 years 4 months
PP-B	48	Male	Unemployed	Home with parents	15	33 years	Road traffic accident	1 year 7 months
PP-C	43	Male	Unemployed	Homeless	35	8 years	Road traffic accident	2 years 10 months

Table 2: Relative participant information

Participant pseudonym	Age	Gender	Relationship to Primary Participant	Frequency of contact with PP
Relative-A	58	Female	Sister	Approx. 2-3 days per week
Relative-B	65	Female	Cousin	Approx. once per fortnight

Table 3: Carer information

Participant pseudonym	Age	Gender	Job Title	Length of time spent caring for PP
Carer-A	45	Female	Senior Care Assistant/Key worker	Approx. 2 years 4 months
Carer-B	47	Female	Senior Care Assistant/Key worker	Approx. 2 years 10 months
Carer-C	53	Female	Named Nurse/Unit Manager	Approx. 1 year

Inclusion and Exclusion criteria

PPs were included on the basis of:

- English as their first language[1].
- Being age 18 or over.
- Having no significant comprehension difficulties impacting on their ability to participate in interviews as assessed by care home managers.
- Having sufficient communication abilities to participate in semi-structured interviews, with use of aids if required as assessed by care home managers.
- Having sustained a severe HI as judged by an NHS GG&C referral data base for the rehabilitation of people with a HI.
- Being a care home resident (with the residency necessitated by sustaining a severe HI).

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[1] This was necessitated by the qualitative methods used in the study which rely on the ability of the researcher to make interpretations from the discourse between the researcher and the participant. The ability to do so may be compromised if English is not the participant's first language; that is, interpretation of the transcription might not be valid because of idiosyncratic use of language by the participant or limitations in their vocabulary.

- PPs were excluded if they:
- Were known to display severe challenging behaviour (as assessed by care home managers) for the safety of the participant and researcher.
- Had been legally deemed to lack capacity regarding their welfare decisions (Adults with Incapacity Act, 2000)[2].

Inclusion criteria for relatives and care staff:

- English as their first language.
- Age 18 or over.

Recruitment process

All of the PPs were recruited via identification by the Field Supervisor (Staff Grade in Public Health) using a NHS Greater Glasgow and Clyde extra contractual referral database for the rehabilitation of people with HI. Inclusion and exclusion criteria were used to determine suitability for the study. PPs were approached by their care home managers and given a participant information sheet (see Appendix 2.1). PPs who provided verbal consent and permission for the researcher to contact their General Practitioners (see Appendix 2.2) then met with the researcher to discuss any questions or concerns and to provide written consent (see Appendix 2.3) prior to taking part in the research interview. In addition to the three PPs who took part in the study, two further identified potential participants were found to meet exclusion criteria and one other was unable to participate due to personal circumstances.

Relatives and care staff of the PPs who were interviewed were identified through liaison with the care home managers. Care home managers were encouraged to suggest staff members based upon the most amount of contact or time spent caring for the PP. Relatives and carers were initially approached by the care home manager with the participant information sheet in person and/or via letter (see Appendix 2.4 and 2.5). Those who consented in principal to participating in the study were then contacted to arrange a suitable time to meet to discuss any questions or concerns and to provide written consent (see Appendix 2.6 and 2.7) to participate in the study before the research interview. In addition to the two relatives who took part in the study, one other relative was not contactable by the care home manager and did not participate in the study (from dyad C).

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[2] As necessitated by the conditions of the study as stipulated by NHS Scotland A Research Ethics Committee (see Appendix 2.9).

Semi-structured research interview

Semi-structured interviews were conducted on an individual basis with each participant. The aim of qualitative research interviews is to encourage the participant to 'tell their stories in their own words' and to facilitate the conversation so that the researcher has minimal involvement in the dialogue (Smith et al., 2009). Topic themes were perceptions of the PP: prior to sustaining the HI; currently; and in the future. Interview questions were used as guides to facilitate discussion (see Table 4 for example questions and Appendix 2.8 for the full interview schedule); however were used in an open-ended and flexible manner to follow the concerns or narratives of the participant (Smith et al.).

Table 4: Example interview schedule questions by topic theme

Topic Theme: Perceptions of social self before sustaining HI

a) If you think back to before your head injury, how would you describe yourself?

b) What was your relationship like with (PP) before their head injury?

c) Can you tell me about any of the groups they belonged to before their head injury?

Topic Theme: Perceptions of social self at present

a) How would you describe yourself now?

b) Do you feel they have been able to maintain links with some of the groups they were part of before?

c) Can you tell me about your relationship with (PP)? What sort of things do you talk about together?

Topic Theme: Perceptions of social self in future

a) How do you see yourself in the future?

b) What are your hopes for them in the future?

c) What do you feel they would need to enable them to be this way?

All interviews took place in the PP's care home in private interview rooms to ensure a quiet space and confidentiality. The interviews were recorded using a digital recorder and ended based upon the interviewer's judgement relating to data saturation within the interview.

Analysis

The interviews were transcribed and anonymised for references to persons and places. A reflective diary was kept by the researcher throughout the data collection process, including thoughts and feelings elicited from the process of interviewing, to facilitate the development of themes and the researcher's subjective views of the data (Grbich, 1999).

The transcripts were then analysed as described in Smith et al. (2009) with an Interpretative Phenomenological Analysis (IPA) focus. IPA is an approach which examines individuals experiences of life from their perspective, whilst acknowledging the role of the researcher's beliefs and experiences in influencing the interpretations of these experiences (Smith et al.). IPA is influenced by the philosophical concepts of phenomenology (the study of experience), hermeneutics (relating to interpretation) and ideography (concerned with depth of analysis). It is the most appropriate method for this study due to its focus on personal meaning of individuals who share a common experience. In this study, the participants share experiences of head injury from three different perspectives (person with HI, relative and carer of a person with a HI). Multi-perspective qualitative studies allow for a richer, more detailed account of the studied phenomenon (Smith et al., 2009); however, are likely to require more participants than single perspective studies and can be more time consuming to analyse (Smith et al., 2009). They are most useful in seeking to understand and explore relationships and dynamics between related individuals and in comparing the perceptions of patients, carers and professionals (Kendall et al., 2010). Dyad combinations (of two related individuals) are more common within qualitative research; however, interview triads (of three related individuals) have been suggested to provided a greater breadth and depth of information (Kendall et al., 2010).

The process of analysis began with reading and re-reading the transcripts approximately five times and making initial notes over the course of re-reading (see Appendix 3.0 for an extract from an annotated transcript). These notes included descriptive comments focusing on the ideas and concepts conveyed by the participants, linguistic comments focusing on the word choice used in the participants' narratives and conceptual comments exploring developing ideas or themes. After the initial noting process, the notes were examined (one participant at a time) to extract emergent themes from their interviews, expressed as phrases interpreted by the researcher. These themes were then collated as a whole and grouped by similarities and differences. This grouping process led to perceived patterns within the data and the elicitation of subthemes and superordinate themes (higher level themes which group together subthemes). Following this, these similarities and differences were further examined by group perspective (PP, relative and carer), both through triangulation of data (the reiteration of the same piece of information between sources to verify themes; Elliot, Fischer & Rennie, 1999) within the same triad or dyad as well as between the three perspectives.

Researcher reflexivity

There is an acknowledgement that the interpretative aspect of the IPA approach involves the researcher bringing their own beliefs, concepts and ideas into their interpretations of the phenomenological data from the participants (Reid, Flowers & Larkin, 2005). The reflective diary was used to be mindful of these issues and an academic supervisor, who had experience of utilising

IPA in qualitative research, blind coded a section of the transcribed data to further increase the reliability of the primary researcher and the themes elicited from analysis.

A bias in interviewing-style leading to a bias in subsequent themes elicited may have been introduced from the limited experience of the researcher who was a Trainee Clinical Psychologist and as such was used to interviewing people for mental health assessment and treatment. The use of the interview schedule was used to minimise this potential bias as much as possible within the flexible, open-ended approach used. There may have been bias in the interpretation of sub-themes and superordinate themes through the researcher's completion of a systematic review in a related topic area, which may have influenced perceptions of the importance of particular themes over others (also addressed through blind coding of themes by an academic supervisor). Also the researcher's theoretical standpoint, of social identity, may have influenced theme interpretation due to the aims of the study.

Results

Three superordinate themes with related sub-themes emerged from the interviews (see Table 5 and Appendix 3.1 for a diagrammatic representation of the links between the themes). The terms ‘head injury’ and ‘brain injury’ were referred to inter-changeably within the interviews.

Table 5: Table of super-ordinate themes and dominant sub-themes

Super-ordinate themes	Sub-themes
Doing as normality	Nothing to do in care-homes
	Head injury as restricting activity
	Activity and appraisals of present life
	Head injury as separate/different from normal society
	Care homes as separate/different from normal society
	Care homes as care settings not homes
	Residents versus staff
	Care home residents as abnormal
	Care home residents with head injuries as in-between (as neither a competently functioning adult nor a care home resident)
Head injury as separate from the individual	Individual as core traits
	Head injury as aggressive behaviour
	Head injury as lost time
	Head injury as reducing the possibility for the individual to change
	Head injury as injustice
Being a child and an adult	Individual with head injury as a child and an adult
	Need for monitoring versus support

Doing as normality

For the PPs there is a strong emphasis on the ability to physically participate in activities, perform social roles and achieve social goals. These experiences or hopes are linked to positive emotions and attributed to times when they felt part of society or with feeling normal:

'I worked a hell of a lot. I worked all over the world. I worked off shore on the rigs and that, done quite a bit I suppose....through my young life I done a lot and I've done more things than other people have done. Which I'm quite lucky really' (PP-A).

'What I hope for the future? Get my own life back to normal. Get a job. Get a girlfriend. Aye and get my house. And that will be me' (PP-C).

This theme presents slightly differently but as frequently in the narratives of the care staff. For two carers, when asked to describe the PP, there was a strong and recurring focus on the PP's behaviour. The ability to perform self care tasks or participate in group activities are positively viewed by the carers:

'(PP-A) is a very very pleasant man. He takes part in all activities, he does a lot for himself....takes part in anything, as I say, does a lot for himself, he usually showers himself and gets himself dressed.' (Carer-A)

'How do I describe him as well...personal care as well. He does all his own shaving, he washes himself, he's good at actually doing that' (Carer-B).

Nothing to do in care-homes

The positive focus of the carers on the PPs' ability to perform tasks in the care home are at odds with the perceptions of the PPs and their relatives. For two of the PPs there is a clear emphasis on there being a lack of things to do within the care home, of repetitive days and a sense of restricted freedom. This difference in opinion can be compared between a PP and carer within the same triad:

'Well, a day in my life is - spend time in here, lie in my bed, go see my sister at the weekend, then come back here. So my life is - here, outside, here, outside, here, outside. I don't do nothing' (PP-A).

'He likes time out himself in the room with the computer, but as I say there's activities going on for the morning...he takes himself out so he's independent in that way also, but he'll come back and then maybe have his lunch....and then after that there's usually an activity going on in the afternoon also, and then he'll go in his room for a wee while...and then he'll come back and it'll be tea-time and then

he'll go back in and do his computer and then he'll come back and then maybe one of the care assistants will maybe have like cards or dominoes or something. So take part in that, so there's <u>*constantly*</u> *something going on, every single day of his life' (Carer-A).*

It seems that for the PPs and relatives, there is more of an emphasis on the quality of the activities available within the care home as being stimulating or personally meaningful to the individual rather than the quantity of activities:

'There's no stimulation in here. Quiet time? What? Church time, quiet time, rest time, relax time...how much relaxation do you need?...I feel if there was something to stimulate him. That he was interested in. For instance, if they were to bring in an old motorbike or an old car or something like that - I know that sounds ridiculous' (Relative-B).

<u>Head injury as restricting activity</u>

In addition to there being a lack of opportunity for meaningful activity within care homes there is also a theme of the PP's HI and/or physical injuries as posing further restrictions on their ability to engage in activities and in moving forward with their lives. This is found in the narratives of the PP's themselves but also in those of their relatives:

'It could be that - he sees what he's missing out on in life. Because he can't get up and maybe enjoy himself the way he used to' (Relative-A).

<u>Activity and appraisals of present life</u>

Restricted activity or opportunities for activity are often linked with the perception that quality of life is poor and for two PPs is characterised as being no life at all:

'It's not a life I've got, I'm just surviving. Ain't got a life...I don't do nothing' (PP-A).

'What kind of life is this? What I'm doing? What I do, one two three four five six seven days a week. Nothing else' (PP-B).

The association between activity and positive appraisals of life is further strengthened by the third PP; who in contrast to the two previous, feels his life has changed for the positive in some respects following HI. These positive changes largely centre on being able to participate in a range of personally and socially meaningful activities which he previously was unable to:

'I never went to college before...That's the first time. No I did go to college but I couldn't be bothered with it. Cause I didn't think it was important...and that's me passed my first thingmy (referring to a college exam), and I've never done something like that before' (PP-C).

Head injury as separate/different from normal society

Socially meaningful activity seems to be associated with normality for the participants. As well as the barriers to participation in activities for most of the PPs, there is also a perception that the PPs and/or the care homes are in a fundamental way separate or different from normal society. There are differences between the PPs in the extent to which they have internalised these perceptions. One PP describes his HI as an 'illness' compared to another PP who spoke at length about the societal perceptions of people with HI as a 'joke' (such as others mistaking him to be a drug addict). For this PP, his view was that people with HI are different from the norm and should be treated as such, but in a respectful way:

'They don't know the way to talk to you. They should treat you with respect and that and like "you only use this as an excuse, you've got a brain injury"...And I say, "well I hope yous end up with a brain injury and then you'll see in your lives, the difference"' (PP-C).

Care homes as separate/different from normal society & Care homes as care settings not homes

In addition to HI as separating them from the norm there is also the perception, from the majority of participants, that the care homes are also separate from normal society. There is an emphasis on care homes being care settings rather than homes:

'I think this is going to be a problem for (PP-A) cause they're gradually all moving into the society (moving out of the care home)' (Carer-A).

'I mean the place is fine but to me, they're like God's waiting rooms....You've to be here before you go upstairs. We're here to die...We're not put here for to have a good life, we're put here for people to look after us, right, before we peg it' (PP-A).

Residents versus staff

Another dominant sub-theme is of separate group identities within the care homes: of PPs or residents and carers. All of the PPs refer to this separation in a negative way: PP-C describes a distinction between staff and 'prisoners', whereas PP-A (who describes his HI as an illness) identifies a distinction between staff and patients. For the patient identity, group identification is associated with diminishing individual needs in favour of group needs; whereas identifying as a prisoner provokes a different sense of identity, that of injustice and being treated unfairly:

'There's quite a lot of things I do on my own to occupy my mind. I don't know, I don't really know, it's being selfish. Like (staff member) is up here doing activities upstairs. Now, there's nothing going on downstairs. I'd like something to be going on downstairs. But that's selfish, cause then there's just me downstairs. Now that's being selfish' (PP-A).

'We're like prisoners cause we've got a brain injury. Cause they think that, people who are carers, they say 'no', that's wrong...I would take it against my human rights, to try and stop me. Cause no-one can do that' (PP-C).

The separation between residents and carers is expressed differently by the carers but is more dominant in their narratives compared to the PPs. For two carers, this is mainly expressed through the dominant content of their knowledge of the PPs as relating to their daily routines, behaviours and self-care needs and limited knowledge of the PP's pre-injury lives. This is also expressed through repeated use of group-based language even when the interviewer asked about the PP as an individual:

'I wondered what it was about your relationship with (PP-A)? (Interviewer)

'No you've actually got that relationship with...well on this floor, I've actually got that relationship with all residents and I think it's the more important thing, coming into a nursing home or any kind of home is that they've got to gain trust and vice versa for the care assistant as well' (Carer-A).

For one carer who has a detailed knowledge of the PP there is still an important distinction to be made between residents and staff relating to clearly defined professional boundaries:

'Sometimes you get a bit too familiar and you think, you've got to remember <u>he's got a brain injury</u>. Deep down, overall, he's here because he's got a problem, he's not here just because he's got problems, he's got a brain injury and he needs to be here' (Carer-C).

Similarly Carer-B also expresses the need for staff to maintain a professional boundary, in this example using group language to perhaps protect from negative emotions or over-identification with the PP:

'I feel sad for any-, (PP-B) as well, I feel sad for anybody that...who's had a life, before...I don't know if they remember their life before, but...it must be quite hard to be trapped in a body that you have no power over, you know what I mean, it must be quite hard. So I think that's why the carers that are in here, they kinda sympathise...as well as doing your job....you're not in here to feel sorry for people, I mean you're here to look after the condition they're in at the moment' (Carer-B).

Care home residents as abnormal

For all of the carers and for one PP, this separation between carers and residents is associated with perceptions of residents as being different from normal:

'I don't think (PP-B) realises that he's actually got a brain injury. I think that (PP-B) thinks he's just like you or I' (Carer-B).

For PP-B a strong theme from his narrative, often matched with high expressed emotion, relates to a heightened awareness of how others perceive care home residents. This mirrors his own negative views of residents and he expresses disgust at how others categorise him in this same way:

(Describing a conversation with a shopkeeper) '"Oh I'm sorry I can't sell you any cigarettes or alcohol, cause you're from (nursing home)". What do you think of that? They were all off their head! They weren't allowed out!...They were all illiterate!' (PP-B).

Care home residents with head injuries as in-between

These perceptions, interpreted from the narratives of the carers and one PP, can be contrasted to the perceptions of the PP's relatives. For the relatives, there is a weaker perception of the PP as a resident (in terms of the negative connotations attached to this). This seems to particularly relate to the PPs' young age and physical appearance:

'I said the place he's in is absolutely disgusting for a young person to be in...the home was for...all people that was old, right. They were all bed-ridden' (Relative-A).

'(PP-B) is the category where he's not...he's a strange category because he looks and sounds okay, but he's actually not...he'll say 'everyone in here's off their head'...I think he's lonely' (Relative-B).

These perceptions are also shared by the PPs:

'I do feel different. I think I see things as well. Plus the fact is, I can do things whereas other people who may be younger or older but they can't do things. But it's not their fault, it's their illness. It's like being stuck in the middle. Like you want to do things but you don't want to in case someone else gets pissed off cause you're doing things that they can't do' (PP-A).

Head injury as separate from the individual

The second superordinate theme of HI as separate from the individual is derived from all of the participants. HI is interpreted as being perceived as a negative external force which influences the individual through aggressive behaviour, robbing them of time and memories and causing injustices in their present lives.

Individual as core traits

In their descriptions of the PPs, relatives and carers often make a distinction between the core traits of the person and a separation from their present behaviour or abilities:

'He's probably not much different from what he is, he's very outgoing, very much a lad's lad....He's always had a good heart...his disability holds him back from socialising' (Relative-A).

Head injury as aggressive behaviour

The most frequent sub-theme within this superordinate theme is specifically the separation of the individual person from their aggressive behaviour which is attributed by PPs and carers to the HI:

'Cause of my frontal lobe got damaged and that thingmies (affects) your behaviour...I've always said I have got a brain injury and cause of it they can tick you off in certain ways...cause it, then they, makes that bit in your brain...and you react to it' (PP-C).

'I mean he is a nice...he's a nice guy...I think it's because we sort of know his behaviour problems...we take every day as it comes with (PP-B) because of his brain injury' (Carer-B).

Head injury as lost time

For PPs and their relatives, there is a theme of the HI as removing time and memories which are lost and cannot be recovered. For PP-B in particular, his narrative is dominated by themes of the past, loss and of change and a sense that he does not belong in the present time - similarly mirrored in the narratives of his carer and relative:

'It was a pub, it was called (name). It's not there anymore...And then, two closes, well they two closes are away. Straight across the road, just a wee house building right? (Town) police station. Away! That's not there anymore! And then you keep going, right? Then you come to the shops and then there's another pub, then you go over a bridge, over the canal and first on your right...scrap yard, right? Well that's not a scrap yard now. It's a cafe! It's all been done up now, know what I mean? Different place, different place' (PP-B).

'We have spoken, (PP-B) and I and he doesn't remember anything about the accident....There's like a twenty-five, thirty year gap in the middle. He was there, but he doesn't remember it' (Relative-B).

Alongside these negative perceptions of HI was an acknowledgement of the power it has over the person in limiting their ability to change in the future, both through lost time as well as through their behaviour:

'Cause sometimes with a brain injury, the damage is done, it's kind of hard to re-track and bring in new things new things when, they're kind of trapped in the past sort of thing. And I find that is with (PP-B), I don't know if you could bring things into the future when he's kind of referring to the past' (Carer-B).

Head injury as injustice

While there is a sense of injustice associated with HI removing the possibility for future change and the difficulty in shaking off the label of HI, there is also the theme of injustice in society's perceptions of people with HI as a group. For PP-C, he appears proud to identify himself as a person with a HI and there was a sense during the interview that the injustice surrounding how HI is perceived gives him a sense of purpose and drive to make things different:

'It's something I want to do, is go into schools and learn people what a brain injury is all about. Cause I think young people, 'aye look at that mug', and...And they shouldn't do it cause it could be one of their family...I don't think there's a lot publicised about brain injury. I don't think there's a hell of a lot...cause people would just brush it aside. And it shouldn't. It could impact on anybody' (PP-C).

Similarly, both relatives express a dissatisfaction and sense of unfairness of what they view as insufficient services for young adults with HI:

'Something like sheltered housing would be great for (PP-A), but sheltered housing is no good because they wouldn't accept him because he's not over sixty-five. So it's...where does (PP-A) go to next?' (Relative-A)

Being a child and an adult

The third superordinate theme which emerges from all of the interviews relates to a conflict between perceptions of the PP as an adult with age-appropriate needs versus having a HI and being child-like with developmentally younger needs.

Person with head injury as a child versus adult

A sub-theme of HI as making the PP more child-like is often in conflict with the PP being recognised as an adult. This is most prevalent in the narratives of carers through explicit references to being an adult and being a child as well as through the use of child-based terms:

'He's just like a child in certain ways you know...he's a grown man there's not a thing in place to say you cannot drink (alcohol)...he's like a wee boy, you know - a teenage boy you know, sort of puberty and teenage and adolescence together' (Carer-C).

'He does have his wee tantrums' (Carer-A).

Similarly, within the narratives of the carers is also the theme of carers as being parental figures to the PPs. This was conveyed during the interviews in an affectionate and warm way:

'It's not as if you go "oh my god (PP-B) went out at such a time and he's not come back" - he does, he's quite punctual. He's quite good, so we don't have a worry that way with him' (Carer-B).

'He's constantly beside...wherever I am he wants to be there. I'm sort of his mother-figure' (Carer-C).

In contrast, the PPs refer to being treated like a child by carers as negative experiences:

'I didn't get on well with the workers. I felt they were telling me what to do and I don't like that. I hate it. I said 'I'm not a wain (Scots meaning child)' (PP-C).

For PP-A, he reports that, as individuals, the care staff are nice people but that when they view him by his disability and not as individual this is frustrating for him. Furthermore, this also appears to provoke thoughts relating to his pre-injury group status in order to categorise himself above the carers who look down on him:

'Especially carers, some of the...I mean they're good as gold, don't get me wrong...but they see this chair first before they see the person. So I mean, here the carers, they're lovely people don't get me wrong, but some of them talk to you like you were a kid, right. But that they don't realise as well as is, is that I used to earn three times as much as they do' (PP-A).

For relatives, and carers, this theme also emerges through more subtle dialogues relating to the PPs as having status through their clothes and dressing like adolescents. The two dominant concerns relating to being child-like relate to the PP as being vulnerable (specifically to financial exploitation from others) and to the need to protect the PP from loneliness. Loneliness or isolation is the most frequently cited barrier given by carers and relatives to the PP living independently in the community. This could be interpreted as implying that, as with younger children, the PPs are viewed as unable to create social opportunities or function in the social world without support:

'I says "and I know you, you'd be in the house all day, all night...but you will get fed up because you're not speaking to anybody or you're not talking to people, you're not out- you'd still get out and about with your chair and things like that, but you're totally - you've not come back into the home and speaking and having the banter"....that's what I would be worried about and then I think he would maybe go into depression. That would be my worry' (Relative-A).

Need for monitoring versus support

Related to this conflict between perceptions of the PP as a child versus being an adult is an appraisal of their subsequent needs as being either for security and monitoring (child) versus advice and support (adult). This conflict was often present within the same interviews and is a dominant theme in the narratives of all of the carers and relatives:

'We can't tell him what to do...he's a grown man, we can't tell him we can only advise him...I think he needs us, I think he needs the security of the twenty-four hour care...he needs that you know to monitor him as I say he would go AWOL…he's just like a child' (Carer-C).

'(PP-B) can get a couple of pints. Cause he's a man! He's not a boy...really, what (PP-B) needs is somebody to monitor him' (Relative-B).

For all of the carers, the need for security and monitoring is linked with the view that the care home is the best setting for the PPs. For the PPs, although less prevalent in their overall narratives, it is clear that they do not feel like children and seek adult support or advice. Similarly, unlike all of the carers, they do not view the care home as the best place for them or where they aspire to be:

'I suppose they could help me to try to achieve things...maybe they could help me to walk, to help me achieve my achievement. But it's up to - maybe they'll know better if I'll never be able to walk again. So it's up to them to say (PP-A) you'll never walk again and then I could achievement to be something else...I like honesty' (PP-A).

'I'll tell you what I'd love to do. Get myself a passport and go away over to Italy...I'd go over there and stay. Because there's nothing here. There's nothing here' (PP-B).

Discussion

This study had two aims: to describe the key features of the perceptions of adults with severe head injuries (HI) living in care homes using a social identity framework and to examine whether their needs relating to their identity are being met within the care home settings through a comparison of their past, present and future selves.

Aim 1: Describe the key features of the perceptions of adults with severe HI residing in care homes, their relatives and care staff using a social identity framework.

In relation to the first aim, three superordinate themes emerged from the interviews comprising three key features of perceptions of adults with severe head injury. The first key feature relates to deviating from normality - that is, a restricted ability and limited opportunity to participate in activities; having a HI and living in a care home produced a perception of the PPs as being abnormal and separate from normal society. This can be interpreted as a loss of social identity through the loss of previously valued pre-injury identities because of an inability to participate in the activities associated with them (for example, the loss of the identity of being a working man through being unable to return to employment). This supports the view that HI impairs the ability to maintain social activity but additionally, for the PPs, it emphasises the additional barriers to activity posed by the care home environment.

Similarly, the acquisition of new social identities could also contribute to feelings of differing from the norm. From a theoretical perspective it could be assumed that having a HI and residing in a care home are two new potential social identities. Interestingly, there are differences between the PPs in terms of the social identities they report as well as in the extent to which they have internalised and self categorise as members of these social groups (Turner et al., 1987). PP-A described a 'patient' identity which links both his perceptions of having a HI as being unwell and of care homes as settings where ill people wait to die. His internalisation of this identity was matched by this sense of passivity, hopelessness regarding the future and flat affect during the interview. In contrast, PP-B focussed on fellow care home residents as being abnormal and distancing himself from other care home residents. For PP-B there is a felt sense of being normal and residing with others who are not normal. In contrast again, PP-C described internalising the HI identity, characterised by a desire to change social perceptions of this, and a resistance to the identity of a resident, which he feels is like being a 'prisoner'. These three different perspectives on the potential acquisition of two social identities can be conceptualised as mediating self-esteem and wellbeing. Acquiring a patient social identity is linked to a reduced ability to see the self in terms of other identities, lowered self esteem and mood (Haslam et al., 2008). The power imbalances within the care home setting may lead to upward social comparisons with care staff (Wood, 1989) promoting conformity and obedience to more powerful others, similar to medical settings (Contrada & Ashmore, 1999). Two strategies employed to protect self esteem (as found in PP-B and PP-C) are to resist and conceal membership of the stigmatised social group (Goffman, 1963) or to reconcile with the social group by engaging in over identification with the social identity and engage in actions to alter how others view the group (Brewer, 2001). The first strategy is akin to denial which may have costs in terms of not being able to benefit from the supports, resources or advantages of identifying with the group. An example from the interviews was carer-B describing PP-B as somewhat of a loner or as an antagonistic figure within the care home, who rarely participates in organised group activities. In terms of social categorisation, PP-B may be aware of the low status of residents and avoids being categorised in this way through avoidance of other residents and through making derogatory comments about them. The second strategy could also have potential costs in terms of generating frustration from perceived injustices from the behaviour of others or the wider system. This was similarly reflected for PP-C in the descriptions of his frequent disagreements with authority figures from his carer.

In terms of the perceptions of others, there are similarities and differences between the care staff and relatives of the PPs; these are linked with the first superordinate theme of deviating from normality and the second superordinate theme of a separation of the self and the HI. Firstly, both relatives were reluctant to identify the PPs as similar to other care home residents, identifying the differences from them but also acknowledging the need for monitoring, support and company which independent living would not provide. This emerged within the theme of perceptions of the PPs as 'in-between', as not as severe in terms of decreased function and support needs as other care home residents but also as requiring support due to physical and cognitive deficits arising from the HI. Relatives appeared comfortable and more able to discuss the social identity of the PPs than the care staff and made use of individual rather than group-based terms. Relatives primarily described the HI as being an external force which had changed the PP for the worse in terms of daily function, personality and opportunities for the future, rather than as a set of group traits with which they could identify their relative.

In contrast, care staff appear to have a clearer perception of the PPs as a person with a HI and as a resident. This supports the proposal that social identity processes are particularly relevant within the care home setting. Themes of abnormality and being separate from normal society were much more dominant in care staff interviews compared with relatives, as well as examples of 'grouping' the PPs rather than discussing them as individuals. That is, for two of the carers their dominant narrative relating to the PPs centred on physical needs and day-to-day behaviours and their knowledge of the PP in terms of more individual aspects such as their pre-injury lives being very limited. Group language was used by all of the carers (with descriptions of ‘staff’ and ‘residents’) which reflects the perception of there being two social groups within the care homes, their belonging to staff and the PPs as residents. While there was an acknowledgement that the PPs were more able than other residents, for example in attending to their personal care, there was less of an emphasis on what separated the individual PP from the other residents. Like the relatives, however, there was a distinction between the PP as an individual and the HI as an external force, which for the carers is mainly attributed to aggressive behaviour.

These findings may reflect the different relationships between the PPs and their relatives compared with care staff. The relatives in this study have a good knowledge of the PP prior to their HI, including perceptions of the PP in terms of other, consistent, social identities (such as brother) reducing the likelihood that they would perceive them solely in terms of stigmatised social groups (Zajonc, 1968). Most of the staff have less knowledge and experience of the PP prior to their injury; however, the nature of the carers’ relationships with the PPs is not based on existing familial roles, but on their role as a paid carer for residents with care needs. Carers’ detailed knowledge of the daily routine of the PPs is unsurprising when this is viewed as necessary information for carers to carry out their professional role. This interpretation is consistent with suggestions that by perceiving all residents as a homogenous group, carers are prioritising basic needs and the efficient delivery of standard care which is one key element of their job remit (Knight et al., 2010). This focus on behaviour may also serve the carers by facilitating a social comparison that allows and maintains a sense of superiority or power over residents (Festinger, 1954;Turner et al., 1987; Willis, 1981). Similarly, as described by carer-B and carer-C, self-categorising as 'staff' rather than 'resident' allows a separation between the groups: in terms of day to day working that may facilitate their ability to carry out their roles effectively and to maintain a professional boundary that protects them emotionally by reducing sympathy or identification with the residents. It may be that over-identification with the PPs on an individual basis paired with the sudden, unexpected nature of HI could threaten staff by making them consider their own mortality and vulnerability to health events (Greenberg, Pyszczynski & Solomon, 1986).

Stigmatising interactions with care staff were described by all of the PPs who felt they were not often treated as individuals. Interestingly, what they describe as problematic in these interactions is not being treated as a 'resident' per se (i.e. as being like an older person with high physical care needs) but as a child. The 'child' identity is strongly resisted by PPs, who describe being treated in this way as frustrating and demeaning to their (adult) sense of self. It may be that being categorised as child-like is perceived as being even less powerful than the social identity of a resident and threatens their adult self-concept (for example, of independence) and self esteem. These interactions are also reflected in the narratives of the carers: that is, through having authority and power over the residents and being responsible for their care and welfare, interactions between staff and residents are described as like a parent to child. Although perceptions of PPs as children were found in the narratives of relatives, they were not reflected within the accounts of the PPs. It may be that the care setting or care tasks which the carers undertake as part of their job role promotes perceptions of child and parent in the residents and care staff.

Aim 2: Examine whether the individuals' needs relating to their identity are being met within care home settings through a comparison of the content of their past, current and future selves from their own and other's perspectives.

There appears to be a difference in perspectives about the needs and identity of the PPs. Carers and relatives spoke about needs in relation to the safety of the PPs. It is difficult to comment on practicalities and how realistic these concerns may be, however, there is an issue of professionals being over cautious in estimating risk to justify 'invasions, intrusions and manipulations' of the 'personhood' (Shweder, 1991, pg. 134) of those they care for. In addition to safety, all relatives and carers cite loneliness as a main barrier to independent living in the community for the PPs. There appears to be a shared perception that the PPs would struggle to be independent which could be interpreted as reflecting doubts that they would be able to initiate and maintain social contact with others. That is, there appears to be a perception that if PPs lived in the community, they would be very much alone. It may be that due to the PPs' current lack of opportunity or ability to engage in socially meaningful activity within or out-with the care homes, this makes it difficult for relatives and carers to perceive them as belonging to social groups. Similarly, it may be that the social groups which the PPs now belong to may not be viewed as important. It may be that participating in socially meaningful activity such as attending interest groups or taking part in activities that give the PPs a sense of shared group identity (even if this is on an individual basis, such as PP-B being able to fix up old motorbikes or participating in something similar) would enable others to perceive them as part of the social world.

In terms of what the PPs describe as their needs or hopes these include advice and support to improve physical functioning in order to regain previously valued skills relating to past social identities and social goals of independent living and relationships. These can be interpreted as relating to goals of moving towards normality (whether pre-injury normality or in terms of societal expectations or goals) and freedom; however this would need to be explored in more depth as a separate topic area (which it was not in the interviews) before any conclusions could be drawn. It is also worth acknowledging issues of insight and the potential for further improvement in functioning in determining what is realistic in terms of social activity (for example, returning to employment) or whether these could be reviewed with the person with the HI to adjust their expectations.

Limited further insights are gained from contrasting the PPs' past, present and future identities to determine whether needs relating to their identity are being met within the care homes. Whilst all report a large discrepancy between PPs' current and past selves, it cannot be concluded that simply adjusting their present lives to be more like their pre-injury lives would meet their needs relating to identity. That is, one PP reports having a better quality of life now compared to pre-injury, another a more fragmented sense of his past self (perhaps as a result of his young age at the time of injury), whereas the third describes a desire to return to previously enjoyed activities which gave him a sense of status and belonging in the social world. These findings further highlight the heterogeneous nature of HI and the need for an individual approach to determine what is socially meaningful and achievable for adults with HI residing in care homes. Adults with HI may need to be supported in adjusting their social identities on the basis of their limitations and what is available within their environment - an important part of this will be in supporting relatives and carers to recognise the importance of doing so also.

Strengths and weaknesses

This study provides a novel insight into the perceptions of adults with severe HI residing in care homes using a social identity framework. Although the sample size is within the recommended range for a doctoral research project (Smith et al., 2009; Turpin et al.,1997) and is appropriate in terms of the exploratory nature of the study, it is within the lower range for the majority of published qualitative studies (Turpin et al.). Furthermore, the sub-themes and superordinate themes presented within the results were selected on the basis of their recurrence across the majority of interviews and were therefore thought to have reached saturation; however, there were other sub-themes which were discarded which may have been more prominent within a larger sample size. The need for saturation in IPA studies is, however, debatable: in larger samples, eliciting themes based upon recurrence across participants is important but should be balanced by retaining an idiographic (individual) focus which is central to the IPA approach (Smith et al., 2009). The use of a multi-perspective design within this study is a strength because it provides a broad examination of the experience of head injury on related individuals (Kendall et al., 2010).

The aims of an IPA approach are to present in-depth, detailed accounts of human experiences, often within a small sample size than in quantitative studies (Smith et al., 2009) which this study provides; however, the acknowledged limitations of this approach are its limited ability to generalise to the wider population. Furthermore, all of the PPs were men, and although the majority of HI are male (Buchanan, Wang & Huang, 2003), this also restricts the generality of findings; as it has been suggested that there are gender differences in identity adjustment and the perceived importance of social activity (Gutman & Napier-Klemic, 1995). Similarly, the ethical conditions placed on the study (see Appendix 2.9) excluded the recruitment of Adults with Incapacity; who constitute a sizeable proportion of this population (Buchanan et al., 2003) further limiting how representative the sample is.

In terms of the other participants, the responses of care staff may have been biased because, despite being informed that their participation would not affect their employment, carers may have been aware of being identifiable to their managers and this might have influenced their responses during interview. Relatives were under-represented in the study due to difficulties with recruitment.

From a theoretical perspective, by examining the results using a social identity framework the participants have been presented in the results by their group identities (of PP or adult with HI residing in a care home, relative and staff carer). By doing so, this assumes that each participant speaks from these positions or group identities rather than from their individual perspectives (McCarthy, Holland & Gillies, 2003) which may not be the case.

Implications and future directions

The results of this study provide some support for the proposal that adults with severe head injury residing in care homes are doubly vulnerable to changes to their social identity in terms of influences from both the HI (e.g. Gelech & Desjardins, 2011) and residing in a care home (Knight et al., 2010). The results also reflect the complexities of this group, with its heterogeneity of outcomes. For the PPs, the results suggest key losses of social identity paired with the acquisition of new, stigmatised social identities. These processes were mediated by individual differences in the PPs' ability to engage in socially meaningful behaviour (such as attending college) and the extent to which they internalise or resist the new social identities. These individual differences in turn appear to mediate attitudes and behaviours which may reflect styles in coping and wellbeing, although this was not explicitly examined within this study. The results also reflect the fraught interactions which can occur within care homes and the tensions which can arise from PPs wishing to be treated as adults and care staff, perhaps as a result of performing their expected roles, categorising them as children. The social comparisons between carers and residents in terms of behaviour and power also diminish perceptions of the PPs as individuals which are subsequently experienced as demeaning and frustrating by the PPs, resulting in stigmatising interactions between the two social groups.

The results highlight the importance of engaging in socially meaningful behaviour and contact as well as the need for these needs to be assessed on an individual basis. Practically, it is acknowledged that there are limits to providing individualised activity timetables for adults within HI care homes; however, it has to be recognised that young adults with HI in care homes are likely to have different needs from older, frailer co-residents. Participation in these activities needs to be considered within the limits of their current functioning and available support, although improvement in self-esteem, well-being and normalisation is likely to reduce stigmatisation (Haslam et al., 2008). Social stigma may already exist to varying extents in care homes. When information is gathered routinely about interests, preferences and goals this could form the basis of an individualised approach that may go some way towards reducing perceptions of adults with HI as children and reducing stigmatising encounters with staff. The need for additional training for staff about attitudes and communication with regard to maintaining and developing social identity should be examined in future studies.

Conclusion

This study provides preliminary insights into the perceptions of adults with severe HI and highlights the role of social identity processes within care homes. The importance of meaningful social activity is suggested for this group as well as a consideration of the individual differences between adults with HI in terms of their needs and preferences. It is suggested that individualised opportunities for participation in social activity will increase identification with valued group identities and increase feelings of normality and belonging to the social world. This may improve quality of life and wellbeing within the adults with severe HI and also reduce stigma and challenging encounters within care homes. Further research is required to determine the benefits of this approach as well as the need for other interventions for adults with severe HI and their care staff.

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CHAPTER 3: ADVANCED CLINICAL PRACTICE I: REFLECTIVE ACCOUNT ABSTRACT

Professional uneasiness:

The influence of IAPT on developing professional identity

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Abstract

The introduction of the Increasing Access to Psychological Therapies programme (IAPT, Department of Health, 2008) has raised concerns regarding how changes to way in which psychological services are provided will influence the wider profession (Nel, 2009; 2010). This is the context in which I reflect on two experiences during my specialist placement of working with complex cases. The first of these experiences elicited feelings of unease and discomfort relating to my clinical practice. I consider how this led me to reflect on my development as a Trainee Clinical Psychologist in terms of my knowledge and skills in clinical practice, drawing on Atkins and Murphy's Model of Reflection (1993) and the Integrated Developmental Model (Stoltenberg, 1998) to facilitate the reflective process. These experiences and feelings of unease and discomfort are then analysed further in terms of the limitations of working within defined diagnostic parameters and adhering rigidly to approaches recommended within the evidence base, as per criticisms of IAPT. In drawing this together, I consider how reflecting on these experiences has contributed to my developing professional identity. The new perspective at the end of the reflective process results in a re-emergence of feelings of unease, no longer relating to my clinical practice, but to my developing professional identity. I conclude that these feelings will provide an ongoing basis for future reflection through my development as a Clinical Psychologist and that this will facilitate action within my clinical practice.

CHAPTER 4: ADVANCED CLINICAL PRACTICE II: REFLECTIVE ACCOUNT

A tentative balance:
The provision and remit of applied psychologists within teams

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Abstract

Increased recognition and value placed on psychological ways of working during a financial climate of restriction and cut backs has resulted in the need to review the remit of applied psychologists within the Scottish NHS workforce (Delivering for Mental Health, 2006; The Wells Report, 2011). This is the background in which I reflect on experiences and reflections on my current placement working in two different teams within the same medical setting. Drawing on Rolfe, Freshwater and Jasper's (2001) reflective model I consider the tentative balance between the provision and remit of psychological services in providing clinical sessions within teams and other, more indirect, ways of working such consultancy, teaching and training. Following this, I draw upon the Integrated Developmental Model (Stoltenberg, McNeill, & Delworth, 1998) to reflect on how this process of reflection relates to my current developmental stage of training. Using the model, I look back on my experiences over the course of training to reflect on my changing feelings and learning points while working as a psychologist within different teams. I reflect that my current perspective is a sum of these experiences which has been facilitated by increasing knowledge and awareness of professional issues over time, as well as the stability and security in my competence as a psychologist at present. Lastly, I consider how my reflections have led to changes in my behaviour at present and conclude that it will be important for me to reflect back on issues of service development and resource allocation further on into my development beyond qualification as a Clinical Psychologist.

Appendices

Appendix 1.1: Guidelines for submission to *Brain Injury*

Brain Injury

Instructions for Authors

Brain Injury publishes critical information relating to research and clinical practice, adult and paediatric populations. The Journal covers a full range of relevant topics relating to clinical, translational, and basic science research. Manuscripts address emergency and acute medical care, acute and post acute rehabilitation, family and vocational issues, and long-term supports. Coverage includes assessment and interventions for functional, communication, neurological, and psychological disorders.

Manuscript Preparation

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author(s) should be removed from files to allow them to be sent anonymously to referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".
Brain Injury considers all manuscripts at the Editors' discretion; the Editors' decision is final.
Brain Injury considers all manuscripts on the strict condition that they are the property (copyright) of the submitting author(s), have been submitted only to ***Brain Injury***, that they have not been published already, nor are they under consideration for publication, nor in press elsewhere. Authors who fail to adhere to this condition will be charged all costs which ***Brain Injury*** incurs, and their papers will not be published. Copyright will be transferred to the journal ***Brain Injury*** and Informa UK Ltd., if the paper is accepted.

General Guidelines

Please write clearly and concisely, stating your objectives clearly and defining your terms. Your arguments should be substantiated with well reasoned supporting evidence. In writing your paper, you are encouraged to review articles in the area you are addressing which have been previously published in the Journal, and where you feel appropriate, to reference them. This will enhance context, coherence, and continuity for our readers. For all manuscripts, gender-, race-, and creed inclusive language is mandatory. Use person-first language throughout the manuscript (i.e., persons with brain injury rather than brain injured persons). Ethics of Experimentation: Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement. Abstracts are required for all papers submitted, they should not exceed 200 words and should precede the text of a paper. See below for further information. Authors should include telephone and fax numbers as well as e-mail addresses on the cover page of manuscripts.

File preparation and types

Manuscripts are preferred in Microsoft Word format (.doc files). Documents must be double-spaced, with margins of one inch on all sides. Tables and figures should not appear in the main text, but should be uploaded as separate files and designated with the appropriate file type upon submission. References should be given in Council of Science Editors (CSE) Citation & Sequence format (see References section for examples). Manuscripts should be compiled in the following order: title page; abstract; main text; acknowledgments; Declaration of Interest statement; appendices (as appropriate); references; tables with captions (on separate pages); figures; figure captions (as a list).

Title Page

A title page should be provided comprising the manuscript title plus the full names and affiliations of all authors involved in the preparation of the manuscript. One author should be clearly designated as the corresponding author and full contact information, including phone number and email address, provided for this person. Keywords that are not in the title should also be included on the title page. The keywords will assist indexers in cross indexing your article. The title page should be uploaded separately to the main manuscript and designated as “title page – not for review” on ScholarOne Manuscripts.

Abstract

Structured abstracts are required for all papers, and should be submitted as detailed below, following the title and author's name and address, preceding the main text. For papers reporting original research, state the primary objective and any hypothesis tested; describe the research design and your reasons for adopting that methodology; state the methods and procedures employed, including where appropriate tools, hardware, software, the selection and number of study areas/subjects, and the central experimental interventions; state the main outcomes and results, including relevant data; and state the conclusions that might be drawn from these data and results, including their implications for further research or application/practice. For review essays, state the primary objective of the review; the reasoning behind your literature selection; and the way you critically analyse the literature; state the main outcomes and results of your review; and state the conclusions that might be drawn, including their implications for further research or application/practice. The abstract should not exceed 200 words.

Tables, figures and illustrations

The same data should not be reproduced in both tables and figures. The usual statistical conventions should be used: a value written 10.0 ± 0.25 indicates the estimate for a statistic (e.g. a mean) followed by its standard error. A mean with an estimate of the standard deviation will be written 10.0 SD 2.65. Contributors reporting ages of subjects should specify carefully the age groupings: a group of children of ages e.g. 4.0 to 4.99 years may be designated 4 +; a group aged 3.50 to 4.49 years 4 ± and a group all precisely 4.0 years, 4.0. Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. 'As seen in table [or figure] 1 ...' (not Tab., fig. or Fig). The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript: *Insert table 2 about here* Each table and/or figure must have a title that explains its purpose without reference to the text. Tables and/or figure captions must be saved separately, as part of the file containing the complete text of the paper, and numbered correspondingly. The filename for the tables and/or figures should be descriptive of the graphic, e.g. table 1, figure 2a.

Tables

Tables should be used only when they can present information more efficiently than running text. Care should be taken to avoid any arrangement that unduly increases the depth of a table, and the column heads should be made as brief as possible, using abbreviations liberally. Lines of data should not be numbered nor run numbers given unless those numbers are needed for reference in the text. Columns should not contain only one or two entries, nor should the same entry be repeated numerous times consecutively. Tables should be grouped at the end of the manuscript on uploaded separately to the main body of the text.

Figures and illustrations

Figures must be uploaded separately and not embedded in the text. Avoid the use of colour and tints for purely aesthetic reasons. Figures should be produced as near to the finished size as possible. Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC). All files must be 300 dpi or higher. Please note that it is in the author's interest to provide the highest quality figure format possible. Please do not hesitate to contact our Production Department if you have any queries.

Letters to the Editor

Letters to the Editor will be considered for publication subject to editor approval and provided that they either relate to content previously published in the Journal or address any item that is felt to be of interest to the readership. Letters relating to articles previously published in the Journal should be received no more than three months after publication of the original work. Pending editor approval, letters may be submitted to the author of the original paper in order that a reply be published simultaneously. Letters to the Editor can be signed by a maximum of three authors, should be between 750 and 1,250 words, may contain one table/figure and may cite a maximum of five references. All Letters should be submitted via ScholarOne Manuscripts and should contain a Declaration of Interest statement.

Notes on Style

All authors are asked to take account of the diverse audience of ***Brain Injury***. Clearly explain or avoid the use of terms that might be meaningful only to a local or national audience. Some specific points of style for the text of original papers, reviews, and case studies follow: ***Brain Injury*** prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'. ***Brain Injury*** uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc. Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'. Punctuation should follow the British style, e.g. 'quotes precede punctuation'. Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period. Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).

Brain Injury is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case. Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs. All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'.Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).

Brief biographical details of significant national figures should be outlined in the text unless it is quite clear that the person concerned would be known internationally. Some suggested editorial emendations to a typical text are indicated in the following with square brackets: ‘From the time of H. E. Armstrong [in the 19th century] to the curriculum development work associated with the Nuffield Foundation [in the 1960s], there has been a shift from heurism to constructivism in the design of [British] science courses'. The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. 'The African American presidential candidate, Jesse Jackson...' For the UK, African-Caribbean (not 'West Indian'), etc.

Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly. n (not N), % (not per cent) should be used in typescripts. Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

Acknowledgments and Declaration of Interest sections

Acknowledgments and Declaration of interest sections are different, and each has a specific purpose. The Acknowledgments section details special thanks, personal assistance, and dedications. Contributions from individuals who do not qualify for authorship should also be acknowledged here. Declarations of interest, however, refer to statements of financial support and/or statements of potential conflict of interest. Within this section also belongs disclosure of scientific writing assistance (use of an agency or agency/ freelance writer), grant support and numbers, and statements of employment, if applicable.

Acknowledgments section

Any acknowledgments authors wish to make should be included in a separate headed section at the end of the manuscript preceding any appendices, and before the references section. Please do not incorporate acknowledgments into notes or biographical notes.

Declaration of Interest section

All declarations of interest must be outlined under the subheading “Declaration of interest”. If authors have no declarations of interest to report, this must be explicitly stated. The suggested, but not mandatory, wording in such an instance is: *The authors report no declarations of interest.* When submitting a paper via ScholarOne Manuscripts, the “Declaration of interest” field is compulsory (authors must either state the disclosures or report that there are none). If this section is left empty authors will not be able to progress with the submission. Please note: for NIH/Wellcome-funded papers, the grant number(s) must be included in the Declaration of Interest statement. *Click here to view our full Declaration of Interest Policy.*

Mathematics

Click for more information on the presentation of mathematical text.

References

References should follow the Council of Science Editors (CSE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Further examples and information can be found in The CSE Manual for Authors, Editors, and Publishers, Seventh Edition. Periodical abbreviations should follow the style given by Index Medicus.
Examples are provided as follows:

Journal article: [1] Steiner U, Klein J, Eiser E, Budkowski A, Fetters LJ. Complete wetting from polymer mixtures. Science 1992;258:1122-9.

Book chapter: [2] Kuret JA, Murad F. Adenohypophyseal hormones and related substances. In: Gilman AG, Rall TW, Nies AS, Taylor P, editors. The pharmacological basis of therapeutics. 8th ed. New York: Pergamon; 1990. p 1334-60.

Conference proceedings: [3] Irvin AD, Cunningham MP, Young AS, editors. Advances in the control of Theileriosis. International Conference held at the International Laboratory for Research on Animal Diseases; 1981 Feb 9-13; Nairobi. Boston: Martinus Nijhoff Publishers; 1981. 427 p.

Dissertations or Thesis: [4] Mangie ED. A comparative study of the perceptions of illness in New Kingdom Egypt and Mesopotamia of the early first millennium [dissertation]. Akron (OH): University of Akron; 1991. 160 p. Available from: University Microfilms, Ann Arbor MI; AAG9203425.

Journal article on internet: [5] De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi A, Maleki M, Marcoux J, Feyz M. 2009. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. Brain Injury 23(11):853-865. http://www.informaworld.com/10.1080/02699050903283221. Accessed 2009 Oct 06
Webpage: [6] British Medical Journal [Internet]. Stanford, CA: Stanford Univ; 2004 July 10 - [cited

2004 Aug 12]; Available from: http://bmj.bmjjournals.com
Internet databases: [7] Prevention News Update Database [Internet]. Rockville (MD): Centers for Disease Control and Prevention (US), National Prevention Information Network. 1988 Jun - [cited 2001 Apr 12]. Available from: http://www.cdcnpin.org/

Appendices: Systematic Review

Appendix 1.2: Summary criteria for appraising qualitative research studies (Walsh & Downe, 2006)

Stages	Essential criteria	Specific prompts	Score (0/1)
Scope & purpose	Clear statement of and rationale for research question/aim/purposes	1. Clarity of focus demonstrated	
		2. Explicit purpose given (descriptive/explanatory intent, theory building, hypothesis testing)	
		3. Link between research & existing knowledge demonstrated	
	Study thoroughly contextualised by existing literature	4. Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both	
Design	Method/design apparent and consistent with research intent	5. Rationale given for use of qualitative design	
		6. Discussion of epistemological/ontological grounding	
		7. Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology)	
		8. Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims	
		9. Setting appropriate	
	Data collection strategy apparent and appropriate	10. Were data collection methods appropriate for type of data required and for specific qualitative method?	
Sampling strategy	Sample and sampling method appropriate	11. Selection criteria detailed, and description of how sampling was undertaken	
		12. Justification of sampling strategy given	
		13. Thickness of description likely to be achieved from sampling	
Analysis	**Analytic approach appropriate**	14. Approach made explicit (e.g. thematic distillation, grounded theory)	
		15. Was it appropriate for the qualitative method chosen?	
		16. Discussion of how coding systems/conceptual frameworks evolved	
		17. Evidence that the subjective meanings of participants were portrayed	

		18. Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance	
		19. Did research participants have any involvement in the analysis	
		20. Evidence provided that data reached saturation or discussion/rationale if it did not	
		21. Evidence that deviant data was sought or discussion/rationale if it was not	
Interpretation	Context described and taken account of in interpretation	22. Description of social/physical and interpersonal contexts of data collection	
		23. Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena	
	Clear audit trail given	24. Sufficient discussion of research processes such that others can follow 'decision trail'	
	Data used to support interpretation	25. Extensive use of field notes entries/verbatim interview quotes in discussion of findings	
		26. Clear exposition of how interpretation led to conclusions	
Reflexivity	Researcher reflexivity demonstrated	27. Discussion of relationship between researcher and participants during fieldwork	
		28. Demonstration of researcher's influence on stages of research process	
		29. Evidence of self-awareness/insight	
		30. Documentation of effects of the research on researcher	
		31. Evidence of how problems/complications met were dealt with	
Ethical dimensions	Demonstration of sensitivity to ethical concerns	32. Ethical committee approval granted	
		33. Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants	
		34. Recording of dilemmas met and how resolved in relation to ethical issues	
		35. Documentation of how autonomy, consent, confidentiality, anonymity were managed	

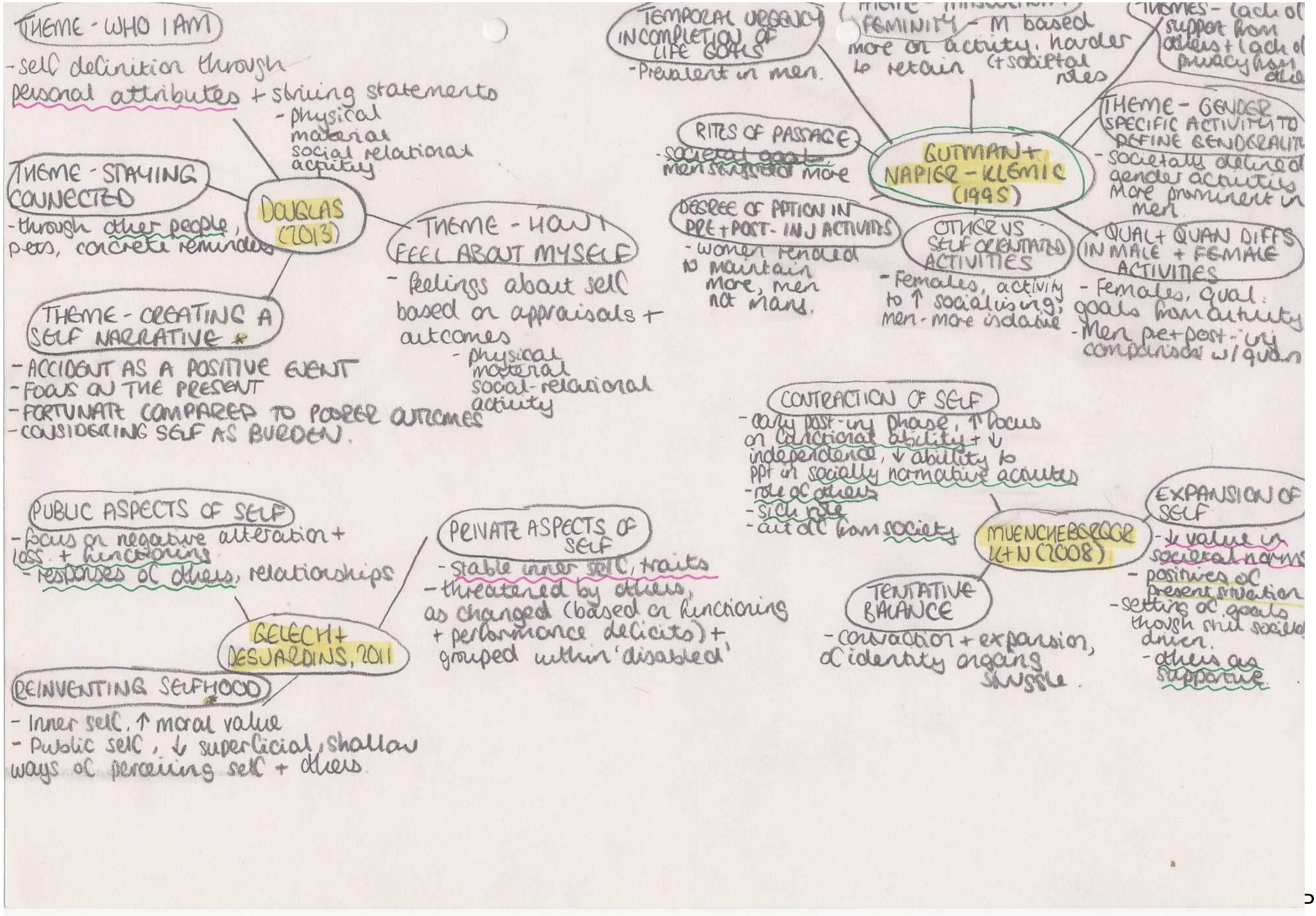
		36. Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies	
		37. Discussion of how explanatory propositions/emergent theory may fit with other contexts	
		38. Limitations/weaknesses of study clearly outlined	
		39. Clearly resonates with other knowledge and experience	
		40. Results/conclusions obviously supported by evidence	
		41. Interpretation plausible and 'makes sense'	
		42. Provides new insights and increases understanding	
		43. Significance for current policy and practice outlined	
		44. Assessment of value/empowerment for participants	
		45. Outlines further directions for investigation	
		46. Comment on whether aims/purposes of research were achieved	

Appendix 1.3: Stages of synthesis in meta-ethnography

The process of synthesising themes using a meta-ethnography approach is conducted in 7 steps which can be repeated or can overlap (taken from Noblit & Hare, 1988):

1. Get started (identifying area of interest).
2. Confirming initial interest, searching and selecting relevant studies (literature screening).
3. Reading studies and extracting data (involving repeated reading to identify the concepts and interpretations which are the raw data for the synthesis).
4. Determining how the studies are related (common themes and concepts. Compiling a list of the ideas, key concepts and initially speculating about how they connect to each other).
5. Translating studies (comparing themes against each other, examining similarities and differences and translating studies into one another, integrating/framing similarities and differences within a new interpretation).
6. Synthesising translations (creating third order constructs, taking translations from the previous step to identify overarching concepts).
7. Expressing the synthesis (discussion and write up).

Appendix 1.4: Extract from notes during synthesis



DOUGLAS (2013)

THEME - WHO I AM
- self definition through personal attributes + striving statements
  - physical
  material
  social relational
  activity

THEME - STAYING CONNECTED
- through other people, pets, concrete reminders

THEME - HOW I FEEL ABOUT MYSELF
- feelings about self based on appraisals + outcomes
  - physical
  material
  social-relational
  activity

THEME - CREATING A SELF NARRATIVE *
- ACCIDENT AS A POSITIVE EVENT
- FOCUS ON THE PRESENT
- FORTUNATE COMPARED TO POORER OUTCOMES
- CONSIDERING SELF AS BURDEN.

GUTMAN + NAPIER - KLEMIC (1995)

TEMPORAL URGENCY INCOMPLETION OF LIFE GOALS
- Prevalent in men.

THEME - MASCULINITY FEMINITY - M based more on activity, harder to retain (+ societal roles

THEMES - lack of support from others + lack of privacy from othe

RITES OF PASSAGE
- ~~societal goals~~ men struggled more

THEME - GENDER SPECIFIC ACTIVITY TO DEFINE GENDERALIT
- societally defined gender activities More prominent in men

DEGREE OF PARTICIPATION IN PRE + POST - INJ ACTIVITIES
- women tended to maintain more, men not many.

OTHER VS SELF ORIENTATED ACTIVITIES
- Females, activity to ↑ socialising; men - more isolative

QUAL + QUAN DIFFS IN MALE + FEMALE ACTIVITIES
- Females, qual. goals from activity
- Men pre + post - inj comparison w/ quan

GELECH + DESJARDINS, 2011

PUBLIC ASPECTS OF SELF
- focus on negative alteration + loss + functioning
  - responses of others, relationships

PRIVATE ASPECTS OF SELF
- stable inner self, traits
- threatened by others, as changed (based on functioning + performance deficits) + grouped within 'disabled'

REINVENTING SELFHOOD *
- Inner self, ↑ moral value
- Public self, ↓ superficial, shallow ways of perceiving self + others.

MUENCHBERGER K + N (2008)

CONTRACTION OF SELF
- early post-inj phase, ↑ focus on functional ability + ↓ independence, ↓ ability to ppt in socially normative activities
- role of others
- sick role
- cut off from society

EXPANSION OF SELF
- ↓ value in societal norms
- positives of present situation
- setting of goals though still socially driven.
- others as supportive.

TENTATIVE BALANCE
- contraction + expansion, of identity ongoing struggle.

Appendix 1.5: Table of quality ratings for reviewed studies

Paper/ Criteria	Douglas (2013)	Gelech & Desjardins (2011)	Gutman & Napier-Klemic (1995)	Muenchberger et al. (2008)	Nochi (1997)	Nochi (1998a)	Nochi (1998b)	Nochi (2000)
1. Clarity of focus	1	1	1	1	0	1	0	0
2. Explicit purpose	1	1	0	1	1	0	1	0
3. Link with existing research	1	1	1	1	1	1	1	1
4. Systematic approach to review	1	1	1	1	1	1	1	1
5. Rationale for design	1	1	0	1	1	0	1	1
6. Discussion of grounding	1	1	1	1	0	1	1	1
7. Rationale for method	1	0	0	1	0	0	1	1
8. Discussion of method	1	0	0	1	1	0	1	1
9. Appropriate setting	1	1	1	1	1	1	1	1
10. Data collection appropriate	1	1	1	1	1	1	1	1
11. Selection criteria detailed	1	1	1	1	0	1	1	0
12. Justification of sampling	0	1	0	1	1	1	1	1
13. Thickness achieved	1	1	1	1	1	1	1	1

14. Explicit approach	1	1	1	1	0	1	1	1
15. Appropriate method	1	1	1	1	1	1	1	1
16. Discussion of coding	1	1	1	1	1	1	1	1
17. Subjective meaning portrayed	1	1	1	1	1	1	1	1
18. Evidence of more than 1 researcher	1	1	1	1	0	1	1	1
19. Participant involvement in analysis	0	0	0	1	0	1	1	1
20. Saturation	1	0	1	0	0	0	0	0
21. Deviant data	0	0	1	1	0	1	0	0
22. Context of data collection	1	1	1	1	1	1	1	1
23. Spent time with data	1	1	1	1	1	1	1	1
24. Decision trail evident	1	1	1	1	1	1	1	1
25. Field notes	1	1	1	1	1	1	1	1
26. Description of interpretations leading to conclusions	1	1	1	1	1	1	1	1
27. Discussion of relationship between researcher & participant	0	0	0	0	1	1	1	1

28. Demonstration of research influence	1	0	1	1	1	1	1	1
29. Insight	1	0	1	1	1	1	0	1
30. Effects on researcher	0	0	0	0	0	0	0	0
31. Discussion of how problems resolved	1	1	1	0	1	1	1	1
32. Ethical approval	1	1	0	1	0	0	0	0
33. Integrity	1	1	1	1	1	1	1	1
34. Discussion of ethical dilemmas	0	0	1	0	0	0	0	0
35. Documentation of ethical processes	1	1	1	0	1	1	1	0
36. Existing literature in discussion	1	1	0	1	1	1	1	1
37. Discussion of theory in context	1	1	1	1	1	1	1	1
38. Limitations outlined	1	1	0	0	1	0	1	1
39. Resonates with experience	1	1	1	1	1	1	1	1
40. Results supported by evidence	1	1	1	1	1	1	1	1
41. Interpretation plausible	1	1	1	1	1	1	1	1
42. New insights	1	1	1	1	1	1	1	1

43. Significance for practice	1	1	1	0	1	0	1	1
44. Empowerment for participants	1	1	1	1	1	1	1	1
45. Outlines future directions	1	1	1	1	1	0	1	1
46. Aims achieved	1	1	0	1	1	1	1	1
Total score	40	36	34	38	34	35	39	37

Appendices: Major Research Project

Appendix 2.1: Participant information sheet

Mental Health and Wellbeing

University of Glasgow

Gartnavel Royal Hospital

1055 Great Western Road, G12 0XH

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

Participant Information Sheet

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask if there is anything that is not clear or if you would like more information.

Who is conducting the research?

The research is being carried out by Ying Teh, Trainee Clinical Psychologist from the University of Glasgow Institute for Health and Well Being, Gartnavel Royal Hospital.

What is the purpose of the study?

The study is being carried out as part of the requirements of the Doctorate in Clinical Psychology training course at the University of Glasgow. The study will explore the perceptions of individuals with a severe head injury who reside in care homes, their family members and the staff who care for them within the care homes. There will be a particular focus on how sustaining a head injury may have changed perceptions of or within the individual in terms of their group identity ("social identity"). Social identity is people's sense of who they are based on their membership of groups (e.g. occupation, social class, parent, football club they support etc). This research may contribute to helping to improve services for similar individuals.

Why have I been invited?

You have been invited to take part in this study as you are aged over 18 years old, have been identified as a person who has sustained a head injury and currently live in a care home or are a relative of or carer for such an individual. You were identified on the basis of your inclusion on a database called SCOTBASE held by NHS Greater Glasgow and Clyde. This database is used to record previous referrals for neurorehabilitation by NHSGG&C. If you are a relative or carer, you were identified by the relevant care home manager responsible for the care home resident.

It is vital in this study that all three types of people take part in the study, in order to be able to make sense of the information.

What does taking part involve?

If you are a care home resident: if you agree, you will be contacted by Ying Teh by telephone to arrange a suitable day and time to attend for a meeting at your care home. The meeting will last around one hour. You will discuss the information on this sheet and you will be able to ask any questions you may have.

If you are happy to take part in the study, Ying Teh will first ask you to sign a consent form which you will be given a copy to keep. She will then ask you questions about how you see yourself since the head injury. This interview will be recorded (to make sure that she carefully understands your experiences and the conversation, and to help to remember everything that is talked about). There are no right or wrong answers, the research just wants to find out what you think and to learn of your own experiences.

If you are a relative or carer: following receipt of your agreement to be contacted, Ying Teh will contact you, by telephone or in person if you prefer, to discuss the study and any questions you have. If you are happy to participate in the study, we will then arrange a suitable time to meet at the care home. This meeting will last approximately 30-60 minutes. During this meeting Ying will ask you questions about your perceptions of your relative or the person you care for. Please note that unfortunately no expenses will be available to participants or carers attending for a meeting.

Do I have to take part?

It is up to you to decide. Ying Teh will describe the study, go through this information sheet and answer any questions you have. You are free to withdraw at any time from the study, without giving reason. Choosing to participate or not participate in the study will not affect the standard of care you receive or your employment.

Who will know I am taking part in the study?

The care home manager who approached you will know that you are taking part in the study.

For care home residents, the research team will also be contacting you GP to let them know that you are considering taking part in this study. If they have any concerns about your participation you may be withdrawn from the study, for your own safety and wellbeing.

You should also be aware that following your consent to take part in the study, and as part of your participation, the researchers may have access to some of your personal data (such as your home address and telephone number). If you are a care home resident, the researchers may access your medical records for information relevant to the study. As with all data, this information will be kept confidential and any identifying information removed.

An exception to this is if at any point during the research process the research team is concerned about your emotional wellbeing: this information may be passed on to staff to ensure that you receive appropriate support. Relatives and members of staff will be encouraged to seek advice from their General Practitioner. If the researchers are concerned that you may be at risk of harm to yourself or others, they will be obliged to inform the relevant agencies. This will be discussed with you first.

All of the above will be discussed with you again, prior to obtaining written consent from you to take part in the study.

What will happen to my personal information?

Everything that you say during our interviews will be kept strictly confidential within the research team. The information will remain confidential and be stored securely on an password protected NHS-encrypted laptop and within a locked room.

The data will be anonymised and held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission. Your name, or other identifying information will not appear in any reports. With your permission, anonymous quotes of what you have said may be used in the report.

What will happen to the results of the research study?

The final results and conclusions of the study may be published in a scientific journal and will form part of the researcher's qualification in Clinical Psychology. Your name or identifying information will not be included in any publication.

What are the possible disadvantages and risks of taking part?

It is possible that our meeting may cover topics that are difficult or distressing to talk about. However, if you do not want to continue you can end the interview, or have a break, at any time. If you feel distressed at all following the interview, the researcher will be available to talk with you. Alternatively the researcher may also inform the care/support staff team in the event that you become distressed to ensure that you receive the support needed once the interview is completed. You may be encouraged to seek advice from your General Practitioner. As mentioned, if the researchers are concerned that you may be at risk of harm to yourself or others, they will be obliged to inform the relevant agencies. This will be discussed with you first.

The approximate time required to take part in the study, including the time required to discuss your potential participation and obtain your consent, is estimated to be up to an hour and a half. All meetings and interviews will take place in the residential care home and for relatives this will involve travelling to the care home. Unfortunately, travel expenses incurred from doing so cannot be reimbursed; however, every effort will be made to coincide any pre-planned visits to the care home with meetings with the student researcher.

What are the possible benefits of taking part?

It is hoped that by taking part in this research, you will be providing valuable information about the perceptions of individuals with severe head injuries who reside in care homes. This information will be useful in considering consistencies and differences in quality of life in these individuals. This will allow us to make recommendations about the care such individuals will receive. As this is a preliminary study, further research will be required in order to inform service development for other adults with head injury.

Who has reviewed the study?

The study has been reviewed and approved by the NHS Scotland A Research Ethics Committee, NHS Greater Glasgow and Clyde Research and Development and the University of Glasgow.

If you have any further questions?

We will give you a copy of the information sheet and signed consent form to keep. If you would like more information about the study and want to speak to someone please contact:

Ying Teh, Trainee Clinical Psychologist
Mental Health and Wellbeing, University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road, G12 0XH
y.teh.1@research.gla.ac.uk

Professor Tom McMillan
Mental Health and Wellbeing, University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road, G12 0XH
thomas.mcmillan@glasgow.ac.uk

What if you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint mechanism is also available to you.

Thank-you for your time and co-operation

Appendix 2.2: GP contact letter

Mental Health and Wellbeing
University of Glasgow,
Gartnavel Royal Hospital
1055 Great Western Road,
G12 0XH

Contact: Miss Ying Teh/Professor Tom McMillan
Email: y.teh.1@research.gla.ac.uk/ thomas.mcmillan@glasgow.ac.uk

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

RE: **Primary participants name, DOB, address**

Dear Dr -,

I am writing to inform you that **Primary participants name** has recently given permission to be approached to discuss their potential participation in the above research study and given consent to contact you as their GP. I have enclosed a copy of the participant information sheet for your information.

We would be grateful if you could read over the participant information sheet and following this, we would invite you to contact us if you have any concerns regarding **Primary participants name**'s participation in this study. This may result in the participant's withdrawal from the study as well as the removal of any data which has been collected relating to or from them. All potential participants are aware that we have contacted you in this regard.

Many thanks for your assistance with this.

Yours sincerely,

Miss Ying Teh
Trainee Clinical Psychologist

Professor Tom McMillan
Professor of Clinical Neuropsychology

Appendix 2.3: Primary participant consent form

Mental Health and Wellbeing
Academic Centre,
Gartnavel Royal Hospital
1055 Great Western Road,
G12 0XH

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

Primary Participant Consent Form

Please initial the BOX

I confirm that I have read and understand the information sheet dated 28/1/13 (version 4) for the above study and have had the opportunity to ask questions ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

In the event of withdrawing my consent, I understand that data which has already been collected with consent would be retained and used in the study; however, no further data would be collected or any other research procedures carried out. ☐

I understand that relevant sections of my medical notes and data collected during the study may be looked at by the study researchers and individuals from the Sponsor, regulatory authorities or from the NHS organisation where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

I understand that if I disclose anything that causes concern for the researcher (in terms of your safety or the safety of others) during the course of the interview then there is a duty of care to report such a disclosure to the appropriate agencies. ☐

I agree to take part in the above study ☐

--------------------------------------	-----------------	--------------------------
Name of Participant	Date	Signature
--------------------------------------	-----------------	--------------------------
Name of Researcher	Date	Signature

1 copy to the patient, 1 copy to the researcher, 1 Original for the patients' notes

Appendix 2.4: Relative letter

Contact: (Care home manager's name)

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

RE: **Primary participants name**

Dear relative,

I am writing to you to let you know that your relative, **Primary participants name,** has been identified as a potential participant for the above study conducted by researchers at the University of Glasgow. They have been invited to take part in this study as they are aged over 18 years old and have been identified as a person who has sustained a head injury and currently live in a care home (from previous referrals for neurorehabilitation by NHS Greater Glasgow and Clyde). We will be approaching your relative to see if they would be interested in taking part in this study.

This study is interested in hearing the views of care home residents, as well as the views of their relatives and carers. The views of all three sets of people are essential to this study as it is hoped that the research will be able to bring the different viewpoints together. It is for this reason that I would like to invite you to also participate in the study. I have enclosed additional information to help you to make your decision.

If you are happy for a member of the research team to contact you to discuss the study further, could you please sign the tear off slip below and return it using the enclosed self-addressed envelope **within 7 days**. Alternatively, feel free to contact the research team directly using the contact details and they will contact you as soon as possible. Please note that the research team will not have any access to any of your personal details prior to you contacting them.

If following the conversation with the research team you are happy to take part in the study, a researcher will arrange a suitable time to meet with you at your relative's care home. This meeting will take approximately one hour and can be, as much as possible, arranged to coincide with a visit you may have planned in the near future to your relative's care home. You will also be asked to sign a consent form to ensure you are happy to take part in this research study.

Many thanks for your assistance with this.

Yours sincerely,

(Care home manager's name)

Enc: Participant information sheet, self-addressed envelope

RE: An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

Name:____________________________

Relative's name: _________________________________

I am happy for a member of the research team to contact me to discuss participating in the above the research study/I would prefer to meet to discuss the study in person with a member of the research team/ I would like to opt-out of any further correspondence regarding my participation in this study (*delete as appropriate)*.

My contact details are as follows:
Telephone number_____________________
Email address__________________________

Please return this tear off slip using the self-addressed envelope to: Ying Teh/Professor Tom McMillan (Mental Health & Wellbeing, University of Glasgow, Gartnaval Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH).

If you would prefer to speak to the research team directly, please contact Ying Teh**, Email: y.teh.1@research.gla.ac.uk**

Appendix 2.5: Carer letter

Contact: (Care home manager's name)

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

RE: **Primary participants name**

Dear staff carer,

I am writing to you to invite you to participate in the above study conducted by researchers at the University of Glasgow. You have been invited as you have been identified by your care home manager as suitable to participate in the study.

This study is interested in hearing the views of care home residents, as well as the views of their relatives and carers. The views of all three sets of people are essential to this study as it is hoped that the research will be able to bring the different viewpoints together. It is for this reason that I would like to invite you to also participate in the study. I have enclosed additional information to help you to make your decision.

I would be grateful if you could take some time to read over the participant information sheet. If you are happy for a member of the research team to contact you to discuss the study further, could you please sign the tear off slip below and return it using the enclosed self-addressed envelope **within 7 days**. Alternatively, feel free to contact the research team directly using the contact details and they will contact you as soon as possible. Please note that the research team will not have any access to any of your personal details prior to you contacting them.

If following the conversation with the research team you are happy to take part in the study, a researcher will arrange a suitable time to meet with you at your care home. As stated in the participant information sheet, permission to take time from your working day to participate in this study with be arranged with your manager. You will also be asked to sign a consent form to ensure you are happy to take part in this research study. Please note that your decision to participate or not to participate in this study will not affect your employment in any way.

Many thanks for your assistance with this.

Yours sincerely,

(Care home manager's name)

Enc: Participant information sheet, self-addressed envelope

RE: An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

Name:___________________________

Care home name: _______________________________

I am happy for a member of the research team to contact me to discuss participating in the above the research study/I would prefer to meet to discuss the study in person with a member of the research team/ I would like to opt-out of any further correspondence regarding my participation in this study (*delete as appropriate)*.

My contact details are as follows:
Telephone number____________________
Email address_________________________

Please return this tear off slip using the self-addressed envelope to: Ying Teh/Professor Tom McMillan, at the above address. Many thanks.

If you would prefer to speak to the research team directly, please contact Ying Teh**, Email: y.teh.1@research.gla.ac.uk**

Appendix 2.6: Relative consent form

Mental Health and Wellbeing
Academic Centre,
Gartnavel Royal Hospital
1055 Great Western Road,
G12 0XH

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

Relative Consent Form

Please initial the BOX

I confirm that I have read and understand the information sheet dated 28/1/2013 (version 4) for the above study and have had the opportunity to ask questions	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	☐
In the event of withdrawing my consent, I understand that data which has already been collected with consent would be retained and used in the study; however, no further data would be collected or any other research procedures carried out.	☐
I understand that if I disclose anything that causes concern for the researcher (in terms of your safety or the safety of others) during the course of the interview then there is a duty of care to report such a disclosure to the appropriate agencies.	☐
I agree to take part in the above study	☐

-------------------------------------- ----------------- --------------------------
Name of Participant Date Signature

-------------------------------------- ----------------- --------------------------
Name of Researcher Date Signature

1 copy to the relative, 1 copy to the researcher

Appendix 2.7: Carer consent form

Mental Health and Wellbeing
Academic Centre,
Gartnavel Royal Hospital
1055 Great Western Road,
G12 0XH

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

Staff Carer Consent Form

Please initial the BOX

I confirm that I have read and understand the information sheet dated 28/1/2013 (version 4) for the above study and have had the opportunity to ask questions ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

In the event of withdrawing my consent, I understand that data which has already been collected with consent would be retained and used in the study; however, no further data would be collected or any other research procedures carried out. ☐

I agree to take part in the above study ☐

I understand that if I disclose anything that causes concern for the researcher (in terms of your safety or the safety of others) during the course of the interview then there is a duty of care to report such a disclosure to the appropriate agencies. ☐

I understand that my decision to take part in the study will not affect my employment ☐

--------------------------------------	-----------------	--------------------------
Name of Participant	Date	Signature
--------------------------------------	-----------------	--------------------------
Name of Researcher	Date	Signature

1 copy to the staff carer, 1 copy to the researcher

Appendix 2.8: Interview schedule

Interview schedule: For primary participants (PPs)

The interview schedules are based on relevant issues from the research literature.

Pre-interview questions, if known: age, age at injury, previous employment, living/accommodation circumstances pre-injury, time since injury, severity of injury and time spent in care home.

Perceptions of social self before sustaining head injury

1. If you think back to before your head injury, how would you describe yourself?
2. Can you tell me about the groups you belonged to before your head injury? *Prompt* - These can take any form, for example - family groups, professional groups, social groups or sporting groups.
3. How did people treat you before your head injury? Did that affect how you saw yourself? If so - how?

Perceptions of social self at present

4. How would you describe yourself now?
5. Have you joined any new groups?
6. Have you been able to maintain links with some of the groups you were part of before?
7. Is it important to you to maintain or regain these links? If so - why? If not, why not?
8. How do others around you treat you now? Does that affect how you see yourself? If so - how?

Perceptions of social self in future

9. How do you see yourself in the future?
10. How would you like yourself to be in the future?
11. How could others support you to be the person you want to be in the future?

12. Before we finish, is there anything we have not covered that you would like to share?

Example Probes

Can you tell me more about that?

What does that mean for you?

Could you give me an example of that?

How does that make you feel?

What do you think about that?

What is that like for you?

Interview schedule: For relatives

Pre-interview questions: age, relationship to individual, frequency of contact with the individual.

Perceptions of relative's social self before sustaining head Injury

1. How would you describe (PP's name) before their head injury?
2. Can you tell me about the groups they belonged to before their head injury? *Prompt* - These can take any form, for example - family groups, professional groups, social groups or sporting groups.
3. What was your relationship like with (PP) before their head injury?

Perceptions of relative's/client's social self at present

4. How would you describe (PP) now?
5. Have they joined any new groups?
6. Do you feel they have been able to maintain links with some of the groups they were part of before?
7. Do you think it is important to them to maintain or regain these links? If so - why? If not, why not?
8. Can you tell me about your relationship with (PP) now? What sort of things do you talk about together?

Perceptions of relative's/client's social self in future

9. How do you see (PP) in the future?
10. What are your hopes for them in the future?
11. What do you feel they would need to enable them to be this way?

12. Before we finish, is there anything we have not covered that you would like to share?

Example Probes

Can you tell me more about that?

What does that mean for you?

Could you give me an example of that?

How does that make you feel?

What do you think about that?

What is that like for you?

Interview schedule: For care staff

Pre-interview questions: age, job title, approximate length of time spent caring for individual.

Perceptions of relative's social self before sustaining head Injury

1. What do you know, if anything, about the person (PP) was before their head injury?
2. Can you tell me about any of the groups they belonged to before their head injury? *Prompt* - These can take any form, for example - family groups, professional groups, social groups or sporting groups.

Perceptions of client's social self at present

3. How would you describe (PP)?
4. Does (PP) belong to any groups now? If so, what are they?
5. Do you feel it is important to (PP) to maintain the links they had to previous groups? If so - why? If not - why not?
6. Can you tell me about your relationship with (PP)? What sort of things do you talk about together?

Perceptions of relative's/client's social self in future

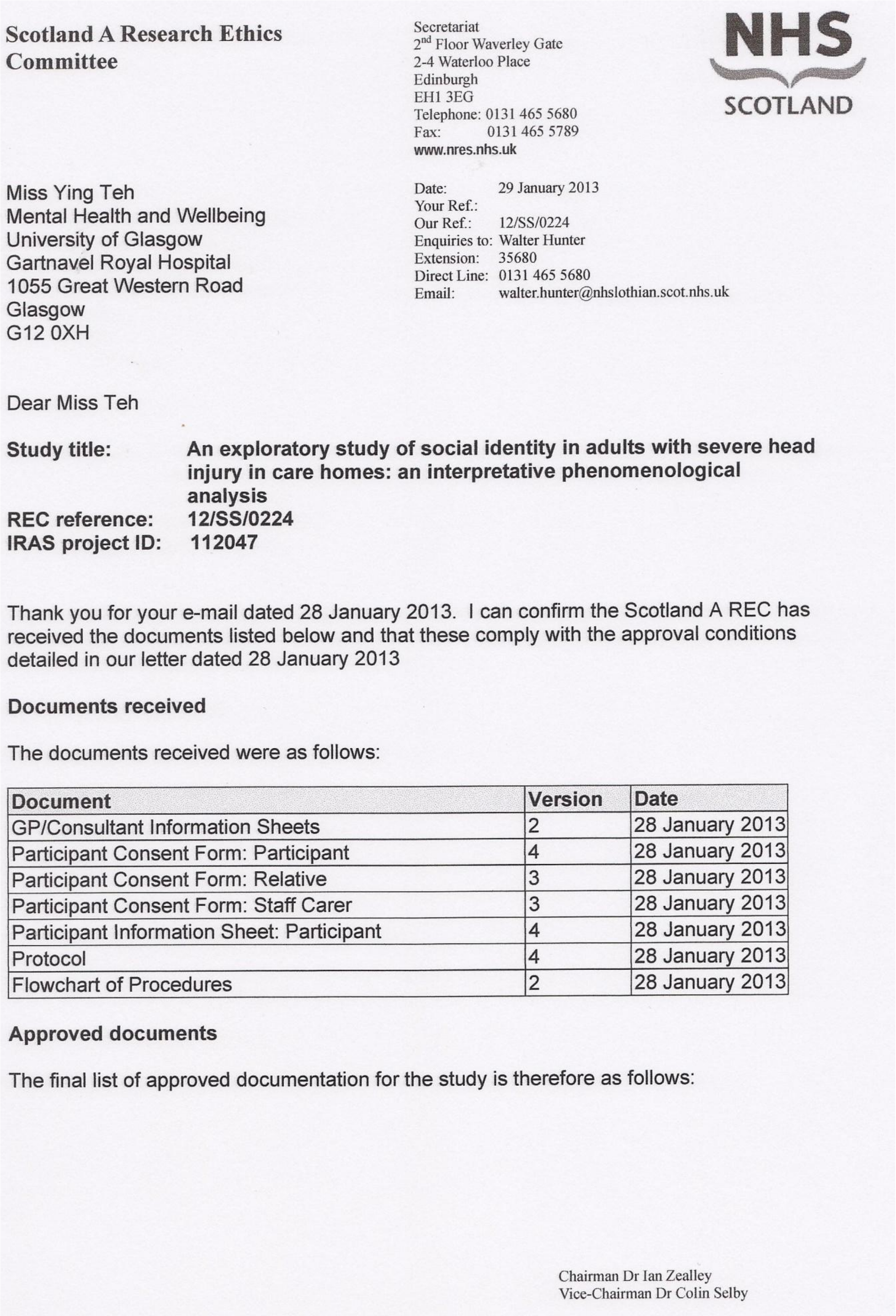
7. How do you see (PP) in the future?
8. What are your hopes for them in the future?
9. What do you feel they would need to enable them to be this way?

10. Before we finish, is there anything we have not covered that you would like to share?

Example Probes

Can you tell me more about that?
What does that mean for you?
Could you give me an example of that?
How does that make you feel?
What do you think about that?
What is that like for you?

Appendix 2.9: Ethical approval letters



Scotland A Research Ethics Committee

Secretariat
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
Fax: 0131 465 5789
www.nres.nhs.uk

Miss Ying Teh
Mental Health and Wellbeing
University of Glasgow
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Date: 29 January 2013
Your Ref.:
Our Ref.: 12/SS/0224
Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Miss Teh

Study title: **An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis**
REC reference: **12/SS/0224**
IRAS project ID: **112047**

Thank you for your e-mail dated 28 January 2013. I can confirm the Scotland A REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 28 January 2013

Documents received

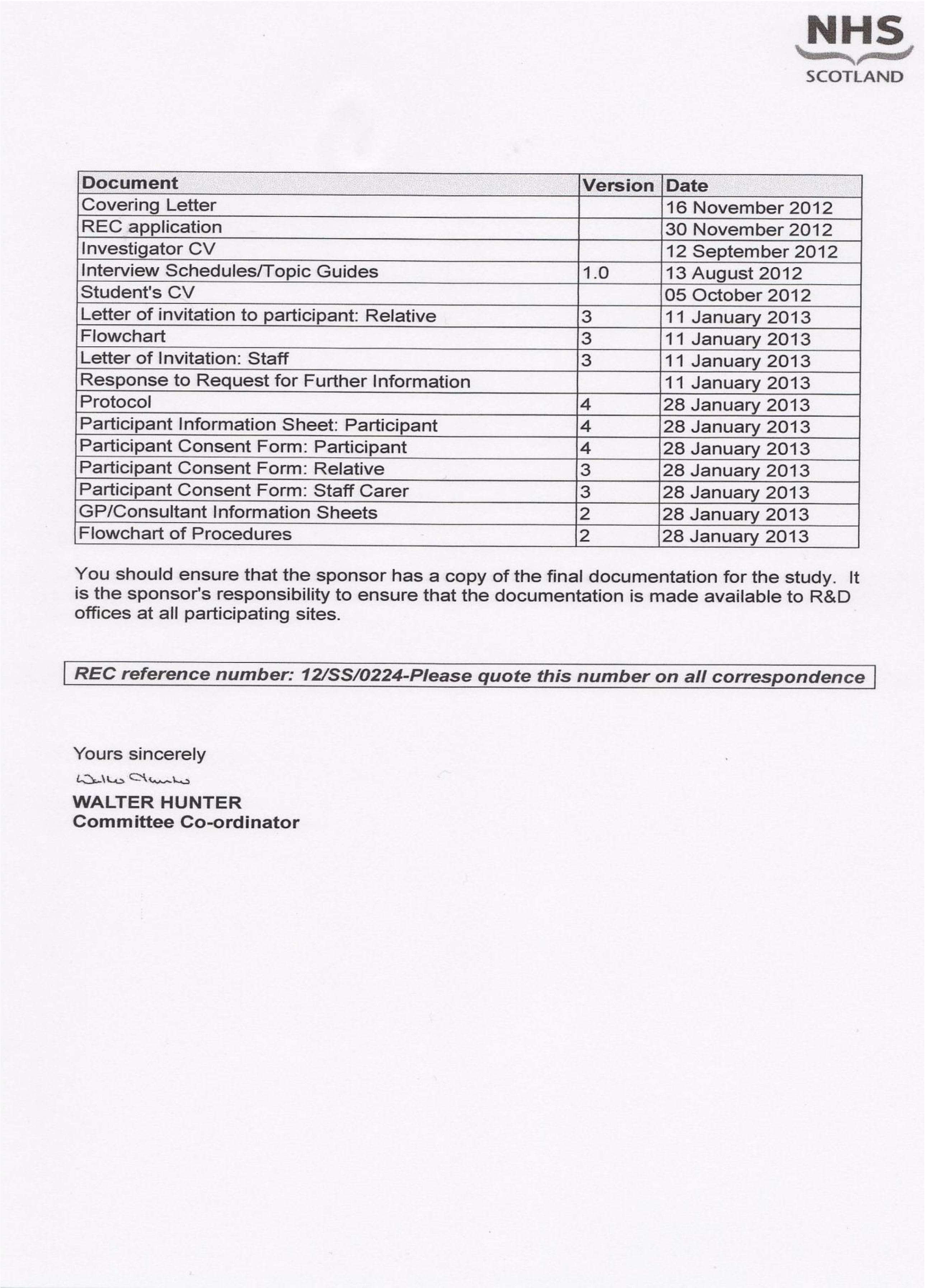
The documents received were as follows:

Document	Version	Date
GP/Consultant Information Sheets	2	28 January 2013
Participant Consent Form: Participant	4	28 January 2013
Participant Consent Form: Relative	3	28 January 2013
Participant Consent Form: Staff Carer	3	28 January 2013
Participant Information Sheet: Participant	4	28 January 2013
Protocol	4	28 January 2013
Flowchart of Procedures	2	28 January 2013

Approved documents

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

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby



NHS
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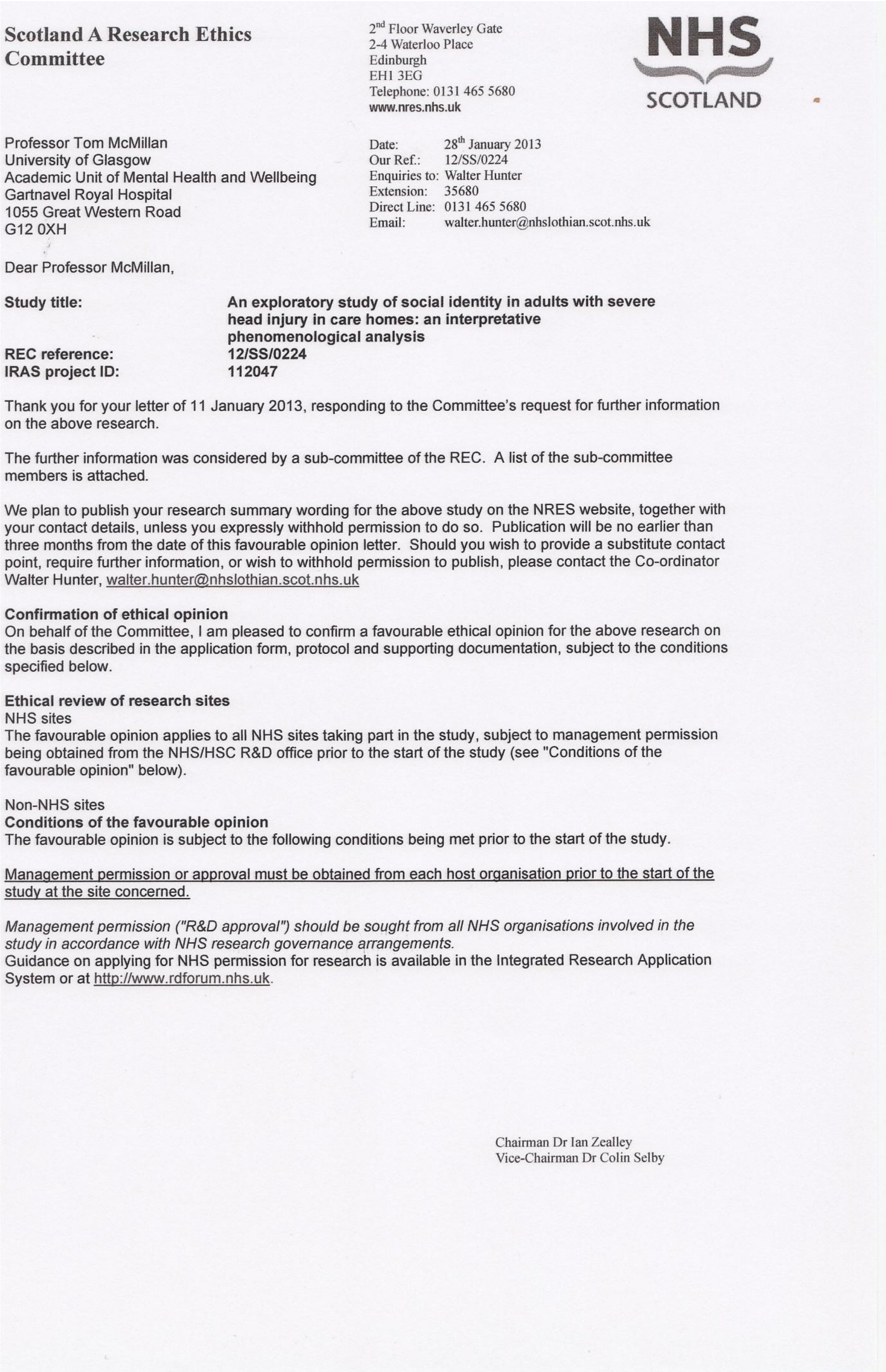
Document	Version	Date
Covering Letter		16 November 2012
REC application		30 November 2012
Investigator CV		12 September 2012
Interview Schedules/Topic Guides	1.0	13 August 2012
Student's CV		05 October 2012
Letter of invitation to participant: Relative	3	11 January 2013
Flowchart	3	11 January 2013
Letter of Invitation: Staff	3	11 January 2013
Response to Request for Further Information		11 January 2013
Protocol	4	28 January 2013
Participant Information Sheet: Participant	4	28 January 2013
Participant Consent Form: Participant	4	28 January 2013
Participant Consent Form: Relative	3	28 January 2013
Participant Consent Form: Staff Carer	3	28 January 2013
GP/Consultant Information Sheets	2	28 January 2013
Flowchart of Procedures	2	28 January 2013

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

REC reference number: 12/SS/0224-Please quote this number on all correspondence

Yours sincerely

WALTER HUNTER
Committee Co-ordinator



Scotland A Research Ethics Committee

2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
www.nres.nhs.uk

Professor Tom McMillan
University of Glasgow
Academic Unit of Mental Health and Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
G12 0XH

Date: 28th January 2013
Our Ref.: 12/SS/0224
Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Professor McMillan,

Study title: **An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis**
REC reference: **12/SS/0224**
IRAS project ID: **112047**

Thank you for your letter of 11 January 2013, responding to the Committee's request for further information on the above research.

The further information was considered by a sub-committee of the REC. A list of the sub-committee members is attached.

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

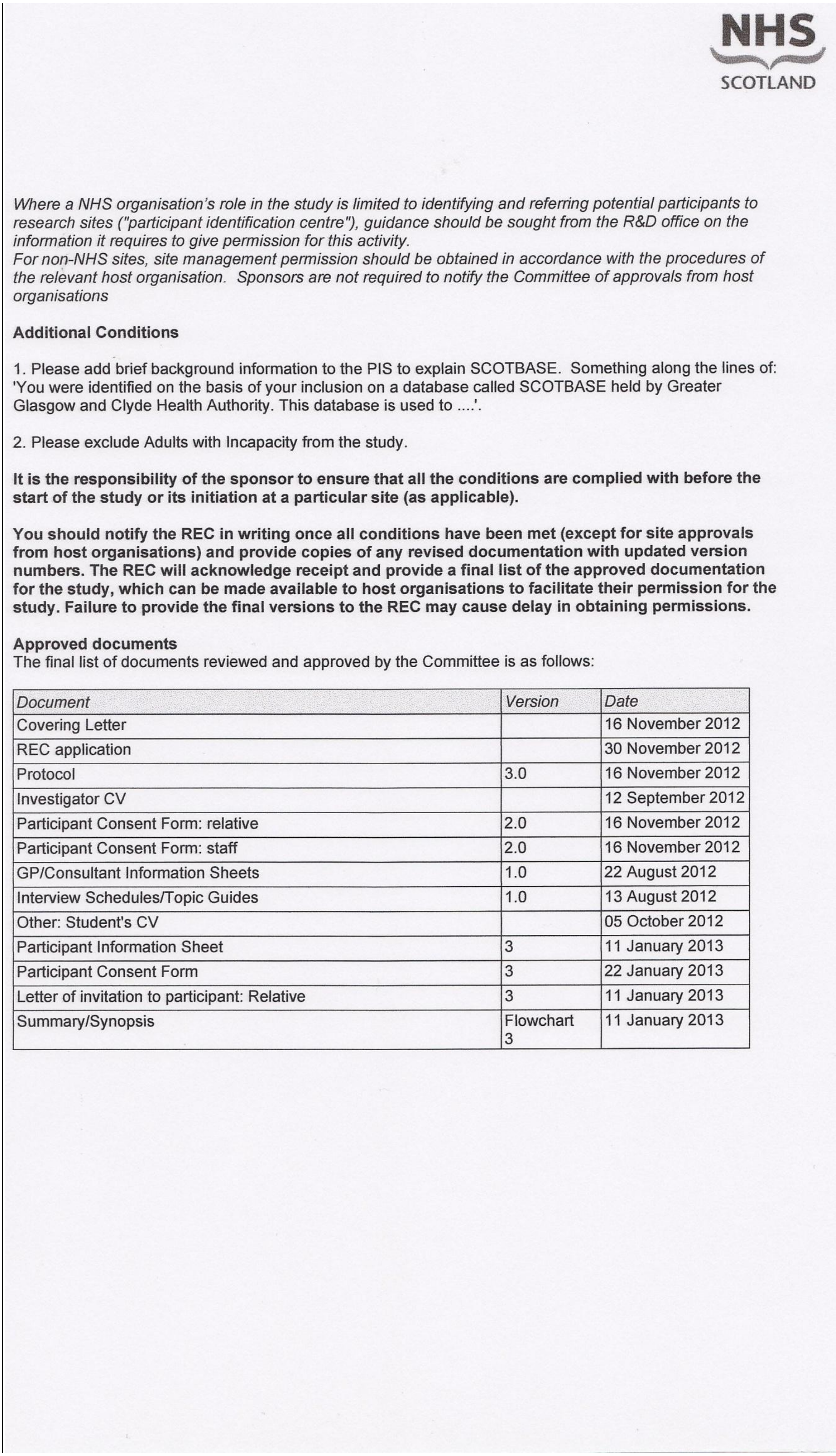
Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

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

Non-NHS sites
Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.



Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation. Sponsors are not required to notify the Committee of approvals from host organisations

Additional Conditions

1. Please add brief background information to the PIS to explain SCOTBASE. Something along the lines of: 'You were identified on the basis of your inclusion on a database called SCOTBASE held by Greater Glasgow and Clyde Health Authority. This database is used to ....'.

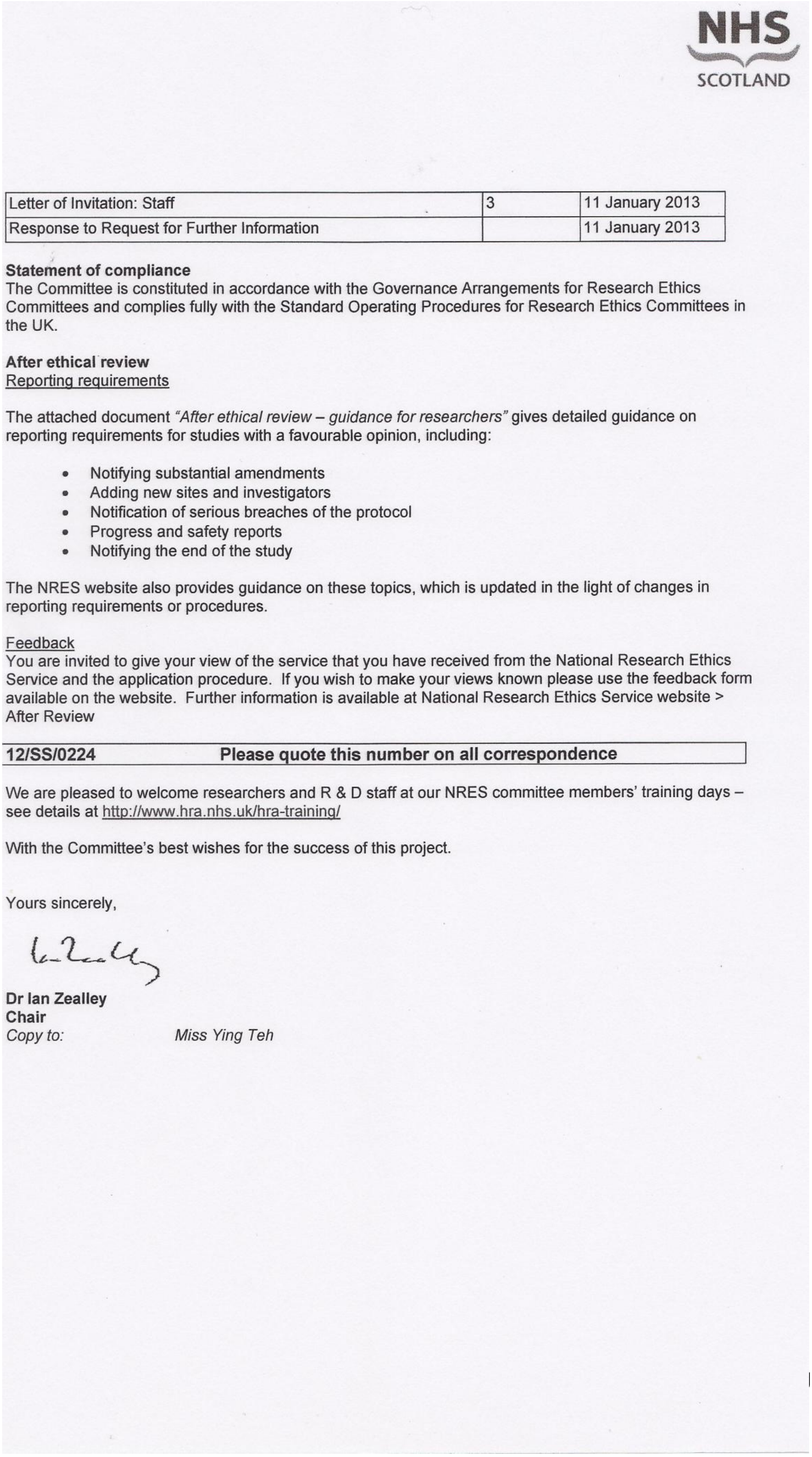
2. Please exclude Adults with Incapacity from the study.

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

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

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

Document	*Version*	*Date*
Covering Letter		16 November 2012
REC application		30 November 2012
Protocol	3.0	16 November 2012
Investigator CV		12 September 2012
Participant Consent Form: relative	2.0	16 November 2012
Participant Consent Form: staff	2.0	16 November 2012
GP/Consultant Information Sheets	1.0	22 August 2012
Interview Schedules/Topic Guides	1.0	13 August 2012
Other: Student's CV		05 October 2012
Participant Information Sheet	3	11 January 2013
Participant Consent Form	3	22 January 2013
Letter of invitation to participant: Relative	3	11 January 2013
Summary/Synopsis	Flowchart 3	11 January 2013



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Letter of Invitation: Staff	3	11 January 2013
Response to Request for Further Information		11 January 2013

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

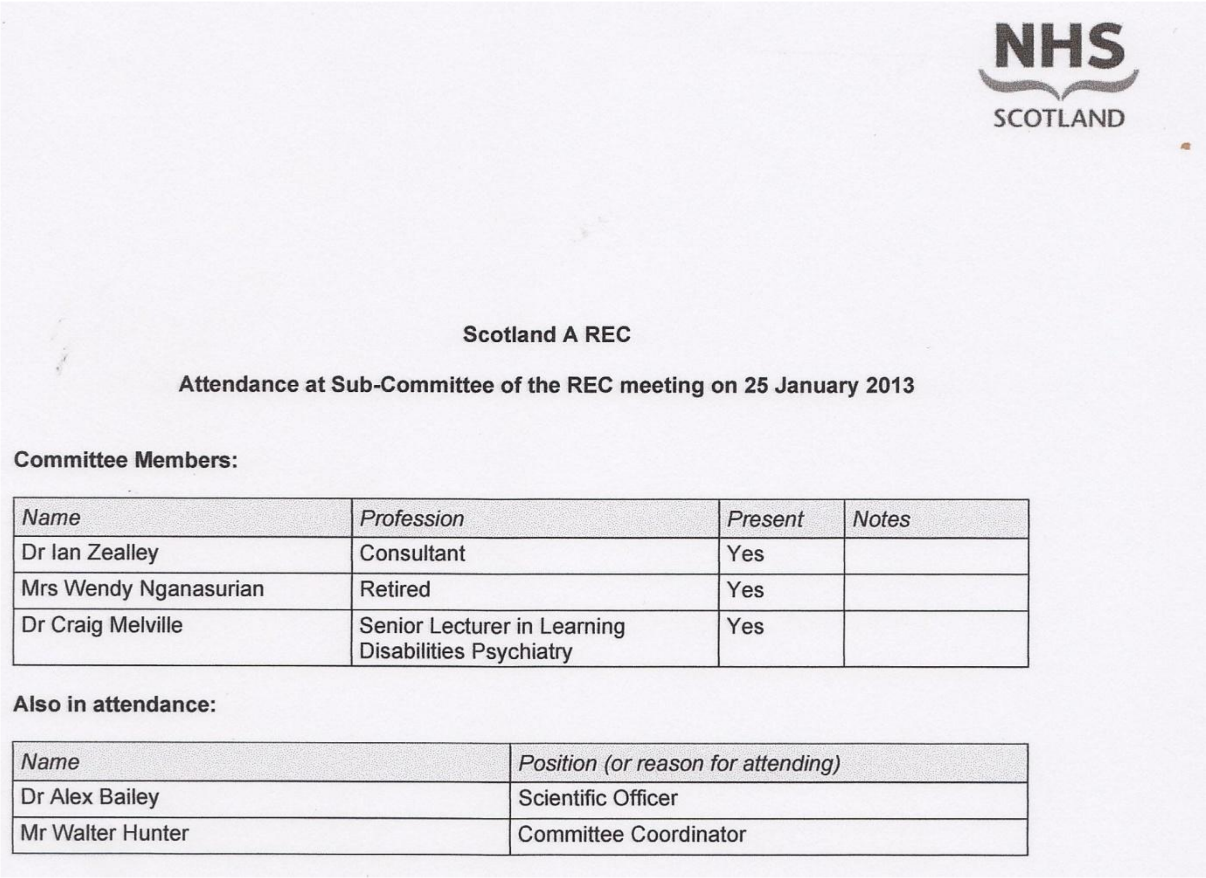
12/SS/0224 Please quote this number on all correspondence

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

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

Yours sincerely,

Dr Ian Zealley
Chair
Copy to: *Miss Ying Teh*



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Scotland A REC

Attendance at Sub-Committee of the REC meeting on 25 January 2013

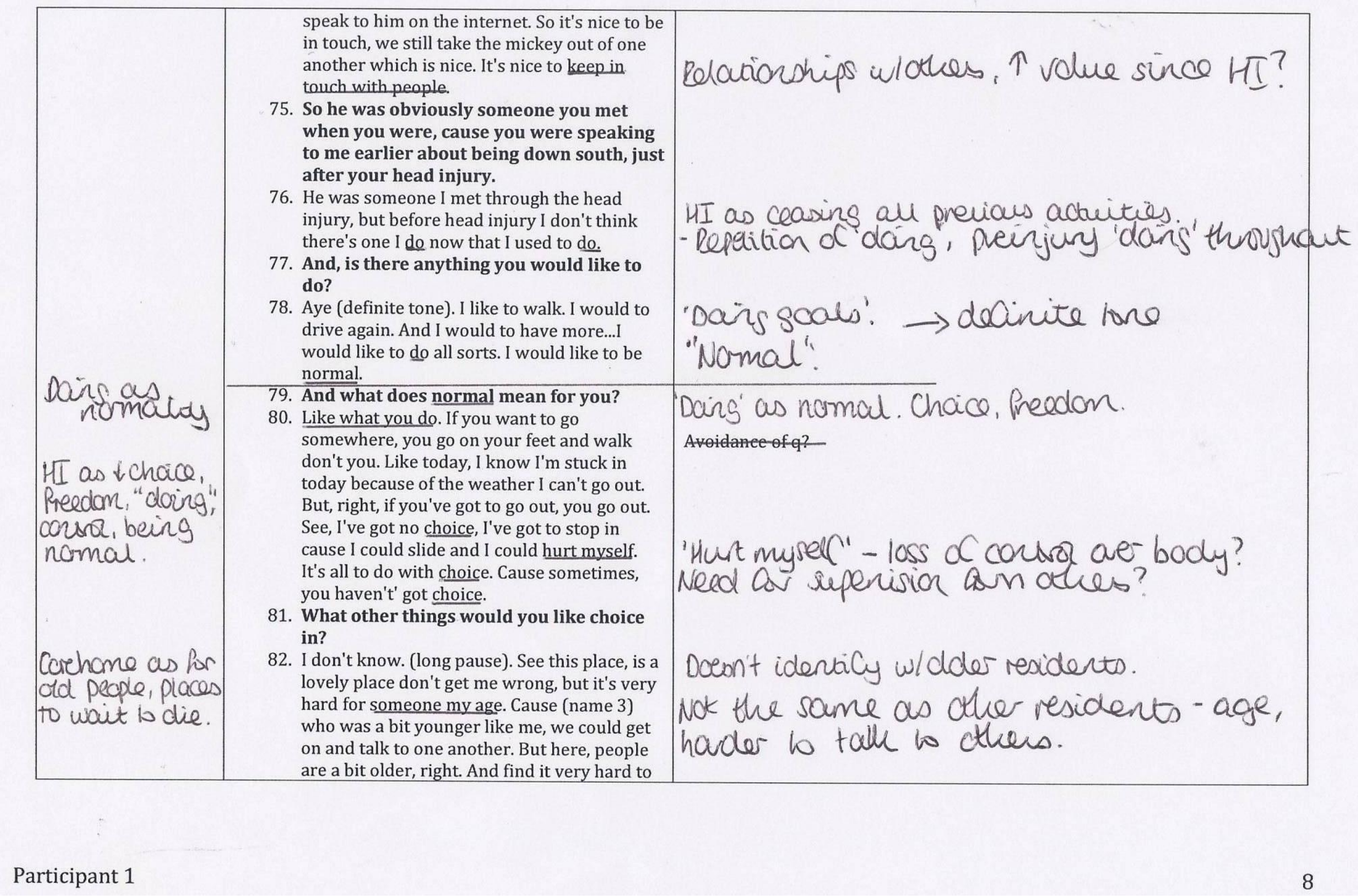
Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Ian Zealley	Consultant	Yes	
Mrs Wendy Nganasurian	Retired	Yes	
Dr Craig Melville	Senior Lecturer in Learning Disabilities Psychiatry	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Dr Alex Bailey	Scientific Officer
Mr Walter Hunter	Committee Coordinator

Appendix 3.0: Section of annotated transcript

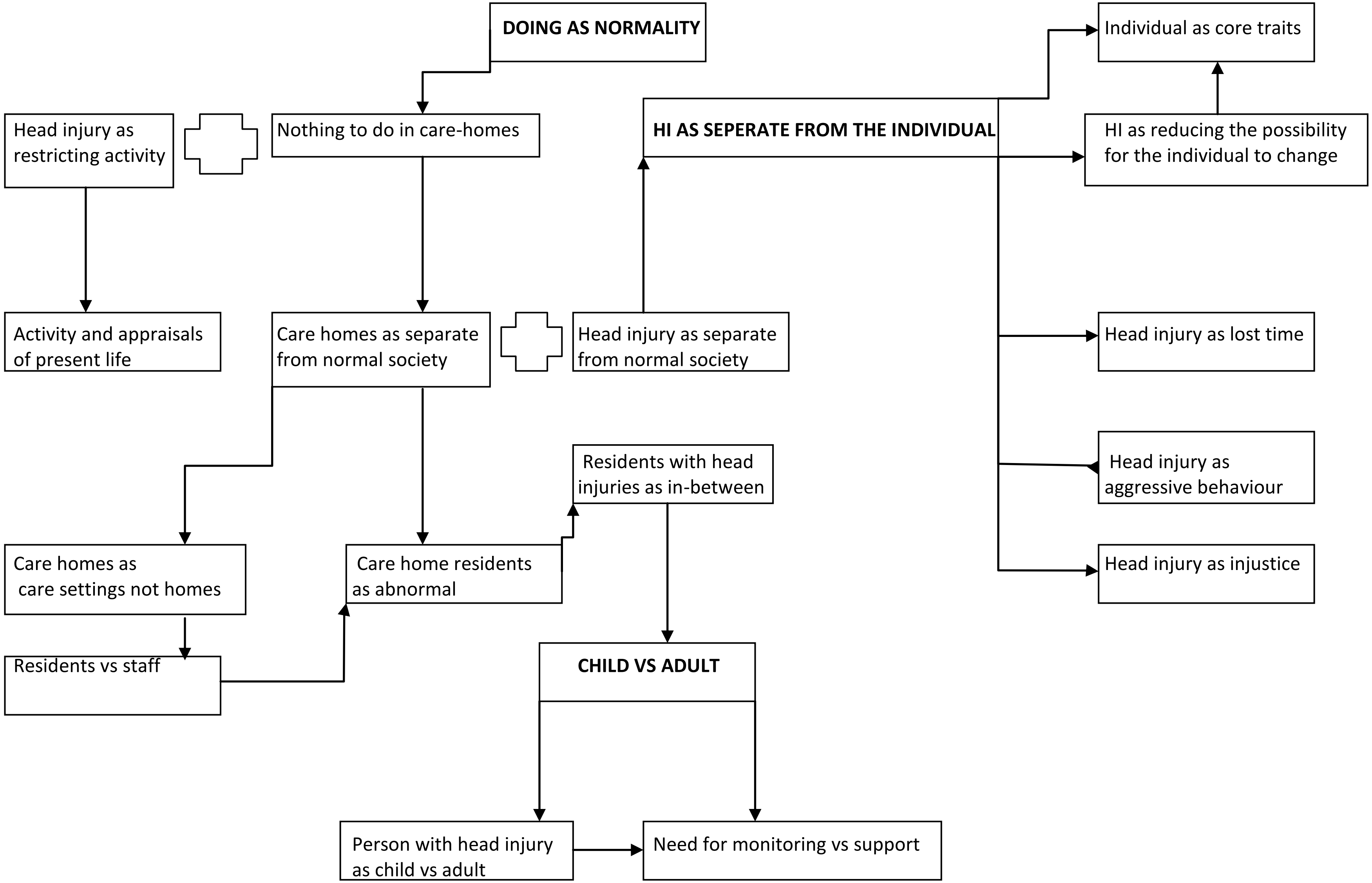


	speak to him on the internet. So it's nice to be in touch, we still take the mickey out of one another which is nice. It's nice to keep in touch with people.	Relationships w/others. ↑ value since HI?
	75. So he was obviously someone you met when you were, cause you were speaking to me earlier about being down south, just after your head injury.	
	76. He was someone I met through the head injury, but before head injury I don't think there's one I do now that I used to do.	HI as ceasing all previous activities. - Repetition of 'doing', preinjury 'doing' throughout
	77. And, is there anything you would like to do?	
	78. Aye (definite tone). I like to walk. I would to drive again. And I would to have more...I would like to do all sorts. I would like to be normal.	'Doing goals'. → definite tone "Normal".
Doing as normality	**79. And what does normal mean for you?**	'Doing' as normal. Choice, freedom. ~~Avoidance of q?~~
HI as ↓ choice, freedom, "doing", control, being normal.	80. Like what you do. If you want to go somewhere, you go on your feet and walk don't you. Like today, I know I'm stuck in today because of the weather I can't go out. But, right, if you've got to go out, you go out. See, I've got no choice, I've got to stop in cause I could slide and I could hurt myself. It's all to do with choice. Cause sometimes, you haven't't' got choice.	'Hurt myself' – loss of control over body? Need for supervision from others?
	81. What other things would you like choice in?	
Carehome as for old people, places to wait to die.	82. I don't know. (long pause). See this place, is a lovely place don't get me wrong, but it's very hard for someone my age. Cause (name 3) who was a bit younger like me, we could get on and talk to one another. But here, people are a bit older, right. And find it very hard to	Doesn't identify w/older residents. Not the same as other residents - age, harder to talk to others.

Participant 1

8

Appendix 3.1: Diagram of links between super-ordinate and sub-themes



Appendix 3.2: Major research proposal

Study Proposal/ Protocol

An exploratory study of social identity in adults with severe head injury in care homes: an interpretative phenomenological analysis

Abstract

Background:

The consequences of sustaining a head injury are significant. Recent research has begun to examine the consequences of sustaining a head injury on individuals' sense of identity, how significant others interact with them and how this can impact on the individual's wellbeing. The move into a care home is also associated with changes to wellbeing as well as identity, in terms of how the individual perceives themselves and in how others perceive them. Arguably changes to social identity are particularly salient in this setting (a form of identity based on membership to social groups). Despite this, there have been no studies to date examining social identity in individuals with severe head injury who reside in care homes.

Aims:

This exploratory study aims to examine the social identity of adults with severe head injury residing in care homes and how their relatives and care staff perceive them.

Methods:

Qualitative methods will be used to investigate three different perspectives within participants who have expertise in head injury (adults with severe head injury residing in care homes, their relatives and care staff). Thematic analysis will be used taking an Interpretative Phenomenological Analysis approach.

Applications:

Both sustaining a head injury and moving into a care home are significant events which can impact on wellbeing. By exploring social identity as a factor which influences these, the need to provide support for staff and family members to deliver appropriate psychosocial care can be determined.

Introduction:

The consequences associated with sustaining a head injury (HI), a sudden unexpected trauma to the brain caused by an external force, for individuals are often negative and can continue for many years after their physical recovery period (Muenchberger et al., 2008). Studies into head and brain injury suggest that one of these consequences relates to changes in identity: individuals report changes in how they view themselves and in how others view them (Gelech & Desjardins, 2011). A metasynthesis of qualitative research into traumatic brain injury identified two key themes of social disconnection (through the loss, amongst other things, friends, employment and social networks) and lost or disrupted self-identity (Levack, Kayes & Fadyl, 2010). Other themes which have emerged in individuals with a HI and their significant others relate to deficit and dependency on others (Cloute et al., 2008). This has been suggested to subsequently affect how significant others communicate with the individuals, often reinforcing the individual's position as the “passive party” (Cloute et al., pg. 656). Changes to identity have been shown to affect, amongst other factors, wellbeing and feelings of self-worth (Haslam et al., 2004; Haslam et al., 2008).

Negative changes to identity may be particularly relevant to individuals who are discharged to care homes following their HI. These individuals are often at the most severe end of the spectrum, in terms of the severity of HI and the extent of their cognitive impairment (Van Baalen et al., 2008). Studies of non-head injured populations have suggested that the move to a care home is a significant life event for individuals. This transition is often associated with negative changes for individuals, such loss of lifestyle, a home, material possessions, role and autonomy (Reed & Morgan, 1999). The impact for an individual of moving into a care home has been suggested to impact on life satisfaction, wellbeing as well as identity (Knight et al., 2010).

These negative changes to wellbeing and life satisfaction may be linked to changes in identity. Social identity may be particularly relevant in this setting: the power imbalance which exists in care home environments establishes two polarised social groups of staff and residents. Social identity theory relates to an individual categorising him/herself as a member of a particular social group (Tajfel & Turner, 1979), in this instance a staff member or a resident. Within a care home environment differences between these social groups exist in terms of the power dynamic, levels of autonomy and decision-making abilities. Similar power imbalances found in medical settings have been documented to foster a loss of control and increased obedience in patients (Contrada & Ashmore, 1999) and diminish an individual’s ability to see themselves in terms of other identities (Haslam et al., 2009). A quantitative study by Haslam et al. (2008) examining social identity in stroke patients suggested that in addition to gaining a 'patient' identity, past valued identities such as professional identities, memberships of recreational groups and community identities were lost through the process of moving into care due to disability. They suggested a relationship between this, lowered self esteem and mental health difficulties (Haslam et al. 2008).

There are important consequences of adopting a 'patient' social identity and losing other valued identities. Similarly, there are important consequences of being perceived as a patient which can negatively impact on further opportunities for the individual to develop or maintain protective identities. Within the care home environment the need exists for one group (staff) to care for and take responsibility for facilitating the other group’s (residents) interests. In this setting, the emphasis is often to provide equal care to all and to minimise the autonomy of residents, as this has been suggested to evidence failure to provide a duty of care (Knight et al., 2010). Standardised care can result in staff perceiving all residents as a homogeneous group, as ‘recipients of care’ (Knight et al., 2010, pg. 1395). This may result in a prioritisation of basic care needs common to all residents (such as attending to personal care) over individualised psychosocial interventions to promote wellbeing. This is important, as previous studies examining social identity processes in individuals with a HI suggest that the ability to maintain social networks and contacts are impaired by the HI (Morton & Wehman, 1995). This means that the ability or opportunity to be able to maintain past valued social identities for these individuals relies heavily on the decisions and actions of others around them.

As yet, there have been no studies examining how adults with HI residing in care homes perceive themselves. This would appear to be worthy of investigation given that both having a HI and residing in a care home have been suggested to have a negative impact on social identity and wellbeing. Examining social identity would be important in determining the potential for improving wellbeing. Similarly, studies indicate that having a HI and being a resident in a care home contribute to how others may perceive these individuals: that is, not as individuals at all but rather as a homogeneous, low-status group. Examining the perceptions of significant others would be important in establishing the need for promoting individualised, psychosocial care in staff members or, for family members also, interventions based on communication to facilitate positive self-identities for the wellbeing of the individuals with a HI. This is particularly important given the increasing pressure on disability and rehabilitation services to respond to and be evaluated by outcomes which are of perceived relevance to the users of these services (Levack et al., 2010).

Aims and Research Questions:

Research Questions

- How do adults with severe HI residing in care homes perceive themselves in terms of their social identity?

- How do their relatives and care staff perceive these individuals in terms of social identity?

Aims

- To describe the key features of the perceptions of adults with severe HI residing in care homes, their relatives and care staff using a social identity framework.
- To examine whether the individuals' needs relating to their identity are being met within care home settings through a comparison of the content of their past, current and future selves from their own and other's perspectives.

Plan of investigation:

Participants:

Three perspectives within the participant group will be examined, those of : adults with severe HI residing in care homes (the Primary Participants, "PP"), relatives of these individuals and care staff (from the care homes) who provide care for the individuals.

Information will be gathered regarding the background of the PPs by the student researcher: age, age at injury, previous employment, living/accommodation circumstances pre-injury, time since injury, severity of injury and time spent in care home. Information will also be gathered regarding the background of their family members (age, relationship to individual, frequency of contact with the individual) and care staff (age, job title, approximate length of time spent caring for individual).

Inclusion and Exclusion criteria:

Inclusion and exclusion criteria for adults residing in care homes:

- English as their first language[3].
- Age 18+
- No significant comprehension difficulties impacting on ability to participate in interviews.
- Sufficient communication abilities to participate in semi-structured interviews, with use of aids if required.
- Participants will have sustained a severe HI as judged by the Scotbase database (a NHS GG&C referral data base for the rehabilitation of people with a head injury).
- Care home resident (residency necessitated by sustaining a severe head injury).
- Participants who display severe challenging behaviour (as judged by care staff) will be excluded for the safety of the participant and researcher.

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[3] This is necessitated by the qualitative methods used in the study which rely on the ability of the researcher to make interpretations from the discourse between the researcher and the participant. The ability to do so may be compromised if English is not the participant's first language.

- Participants who have been legally deemed to lack capacity regarding their welfare decisions **(**Adults with Incapacity Act, 2000) will be excluded from the study.

Inclusion and exclusion criteria for relatives and care staff:

- English as their first language.[4]
- Age 18+

Design:

This study will take a qualitative approach using semi-structured interviews with all three participant groups (PPs, relatives and care staff).

Recruitment: Recruitment of PPs will utilise the Scotbase database (a NHS GG&C extra contractual referral data base for the rehabilitation of people with HI). The PPs will first be identified on an opportunity basis by the field supervisor (M.L) and will be compared against the inclusion and exclusion criteria for this study. Some of these individuals may have already consented to participate in previous DClinPsy research. The field supervisor will then contact the relevant care home managers, who in turn will ask the individual whether they would be interested in participating in a research study.

For the PPs who are able to provide consent and agree to participating in the research study, they will be asked if they would be willing to meet with the researcher (YT) within seven days to discuss the study further and consent to the research team contacting their GP. <u>All</u> PPs will meet with the researcher for a consent interview and will be given a participant information sheet.

Relatives will be identified through liaison with the care home managers. As with the patients, relatives will initially be approached by the care home manager in person and/or letter and those who are welfare guardians will also be asked to provide consent for their relatives also. Those who agree in principal to participating in a research study, will be sent a participant information sheet relating to the study and be invited to return the form within seven days if they are interested in taking part. Relatives will be given the option to speak with the researcher to discuss the study further before providing consent, if preferred.

The researcher will liaise with care home managers in identifying suitable staff members to participate in the study based upon the individuals and relatives who consent to participating in the

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[4] This is necessitated by the qualitative methods used in the study which rely on the ability of the researcher to make interpretations from the discourse between the researcher and the participant. The ability to do so may be compromised if English is not the participant's first language.

study. There are no set inclusion or exclusion criteria relating to the suitability staff members (other than English as their first language); however, care home managers will be encouraged to suggest staff members based upon the amount of contact or time spent caring for the individual. Written consent will also be obtained from staff members to participate and they will also receive a participant information sheet.

Research procedures:

Semi-structured interviews will be conducted on an individual basis with each participant. The aim of qualitative research interviews is to encourage the participant to 'tell their stories in their own words' and to facilitate the conversation so that the researcher has minimal involvement in the dialogue (Smith et al., 2009). A list of interview questions will be used to guide discussion during the interviews (an interview schedule). Questions will be devised by the researcher and will be informed by the literature on social identity and the study aims; however will be used in an open-ended manner and at the discretion of the researcher and may be followed up by further probe questions if necessary. These are in line with the aims of qualitative research interviews. Topic themes include perceptions of the individual with a head injury: prior to sustaining the head injury; currently; and in the future.

Interviews will be recorded on a digital voice recorder, then transcribed and anonymised for references to persons and places. A reflective diary will be kept by the researcher throughout the data collection process to facilitate the development of themes and the researcher's subjective views (Grbich, 1999). Data will then be analysed using thematic analysis (as described by Braun and Clarke, 2006) with an Interpretive Phenomenological Analysis (IPA) focus. IPA is an approach which aims to examine individuals' experiences of life from their perspective (Smith et al., 2009). It is influenced by the philosophical concepts of phenomenology (the study of experience), hermeneutics (relating to interpretation) and ideography (concerned with depth of analysis) (Smith et al., 2009). It is the most appropriate method for this study due to its focus on personal meaning in a particular context, of individuals who share a common experience.

Data analysis:

Data will be examined periodically during the process of data collection. This will follow a six phase process for the researcher of: (i) familiarising themselves with the data (transcribing the audio material and repeatedly reading the scripts to identify themes or emerging patterns); (ii) generating initial codes (of patterns within the data); (iii) searching for themes within the data; (iv) reviewing the themes; (v) defining and naming the themes; (vi) and producing the final report (Braun & Clarke, 2006). Stages two through to five will be shared in supervision with the academic supervisors to improve the reliability of the interpretations made. An academic supervisor will also blind code a section of the transcribed data to further increase the reliability of the primary analyst.

Justification of sample size:
It is not appropriate for power calculations to be made for qualitative studies as samples sizes are not predetermined as with quantitative studies. One of the primary aims of taking an IPA approach is to present in-depth accounts of human experiences and as such it prioritises detailed analysis of a small number of cases rather than superficial interpretations of a large number of cases (Smith et al., 2009).

It is anticipated that this study will have an estimated sample size of approximately nine to eighteen participants. This sample size fits with guidance suggested by Turpin et al., (1997) for a feasible DClinPsy research project (the authors propose a minimum of five participants and also highlight that most published qualitative studies have a sample of between eight and twenty participants). Similarly, Smith et al. (2009) recommend that a professional doctorate study should expect up to approximately ten interviews to take place overall. For this particular study it is also worth noting that difficulties may arise in recruiting suitable PPs. It is arguable that individuals within this population who are able tolerate, engage fluently and at length within a clinical interview may be in the minority. As this is an exploratory study, the feasibility of recruiting within this population for a qualitative study is unclear and may necessitate a conservative estimate of sample size. Therefore, in consideration of the aims of an IPA approach and the exploratory nature of this study, the anticipated number of participants may be at the lower end of this projected range.

Settings and Equipment:
Interviews with PPs and care staff will take place in independent sector care homes across Greater Glasgow and Clyde. Family members will be invited to attend their relative’s care home to participate in the study.

Equipment required constitutes a digital recorder, a transcription pedal and software and a password protected University of Glasgow laptop encrypted to NHS standards
which will be provided via the University's current facilities for qualitative research, as well as pens and paper.

Health and safety issues:

Researcher safety issues:
The researcher will be attending care homes alone; however, interviews will take place in 24-hour staffed units where members of staff will be present at all times. The researcher will inform staff of when they arrive, check how the PP has been that day (to assess risk or unsuitability for interview at that time), and will inform staff of when they leave. The researcher will familiarise themselves with the health and safety procedures in the care homes visited and follow these accordingly for both their

and the participant's safety. The researcher may also be potentially be exposed to emotional or sensitive information and will be mindful of this and discuss this in supervision as appropriate.

Participant safety issues:

During the interview process, fatigue and/or discomfort will be monitored by the researcher and breaks will be offered as required. Similarly, the researcher will use their discretion in determining whether it would be appropriate to split interviews over more than one session.

Through participation in the study there is also the potential for participant distress in relaying sensitive or emotional information. This will be discussed with participants when obtaining consent to participate in the study. There will also be the opportunity to discuss any issues arising during debriefing following the interview. Should concerns be raised that the participant is at risk of harm to themselves or others, the appropriate agencies will be contacted. Participants will be made aware of the requirements for this within the participant information sheets and consent forms.

Ethical issues:

All participants will initially be approached by the care home managers; for patients and care home staff, the care home manager will be in a position of power to them and participants may feel coerced into participating in the study. PPs will be informed that their decision will not affect the care they receive and this will be outlined in the information sheet. Similarly, relatives will also be reassured of this and care home staff will be reassured that their participation will not affect their employment. The recruitment process following this consists of being followed up by the researcher (YT) who will have had no previous contact with the participants. This provides further opportunities for the potential participants to be informed of what this study entails, ask questions or discuss concerns prior to giving written consent. It will be emphasised that participants can withdraw from the study at any time.

Ethical considerations have also been made in determining the estimated sample size to be recruited. As this is an exploratory study, the sample size is relatively conservative but still within the appropriate limits suggested for a qualitative study.

All participants will be made aware that by consenting to participate in the study, this will include consenting to have verbatim extracts in the final study report. Participants will be informed that their responses will be anonymised and identifiable information relating to person or place will be removed.

For staff members and relatives written consent to participate in the study will be sought and, as for all the participant groups, their right to withdraw this at any stage will be highlighted to them.

In seeking ethical approval, applications will be made to NHS GG&C Research and Development and to the appropriate NHS Research Ethics Committee (Scotland A Research Ethics Committee).

Data will be handled as outlined within The Data Protection Act (1998), The Freedom of Information Act (2000) and the NHS Confidentiality Code of Practice Guidelines (2003). Identifying information will be removed to preserve anonymity (within the limits of providing the context for verbatim extracts within the final report). Recorded interview data, anonymised for references to persons and places, will be stored as digital voice recording files uploaded on to a password protected University of Glasgow laptop encrypted to NHS standards. Recordings will be deleted once the data has been transcribed. Transcribed information will also be stored and analysed on the password protected University of Glasgow laptop encrypted to NHS standards. Paper copies of anonymised transcripts will be stored securely in Glasgow University's Mental Health and Wellbeing department. Data will be accessed by the researcher and academic supervisors only. The laptop will be securely stored in a locked room when not in use.

Financial issues:

Costs may incur from travel to and from the various care homes across Greater Glasgow and Clyde where interviews will take place. Travel costs have been agreed to be covered for the research team in principle by NHS GG&C. No travel costs will be available for the study's participants.

Costs will also arise from contacting potential participants. This will be (for a maximum of 18 participants) approximately:
18 sheets of headed paper (photocopied)
18 A4 envelopes
Freepost for 18 participants

Timetable:

Smith et al. (2003) suggest that for the depth of analysis required in taking an IPA approach, transcription will take approximately seven hours for every hour of audio recording made and that analysis of three cases can take over two months of full time work. As such, the timetable for this study is heavily weighted to take into account the lengthy time required for analysis using this approach.

- **April 2012**: Proposal submitted to University
- **May/June**: Apply for ethical approval

- **December:** Reapplication for ethical approval
- **February - June 2013**: Recruitment and analysis of data (ongoing throughout recruitment process)
- **June - August 2013**: Final write up and submission

Practical Applications:

The results of this study have implications for improving the wellbeing and quality of life of adults with severe HI in care homes. Implications include examining the need for the provision of individualised psychosocial care (such as interventions to encourage social group membership or maintenance) in care homes and psychoeducation or interventions for staff and/or the relatives of the individuals with HI.

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