VOLUME I

RESEARCH COMPONENT

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A Thesis submitted to the University of Birmingham in partial fulfilment
of the requirements for the Degree of Clinical Psychology Doctorate

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Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Clinical Psychology Doctorate (Clin.Psy.D) at the University of Birmingham. It is comprised of a research component (Volume I) and five clinical practice reports (Volume II).

Volume 1 of the thesis consists of the research component in the form of two papers. The first paper in Volume I is a review of the literature, which examines the processes related to identity following a traumatic brain injury. The second paper is an empirical study to investigate the relationships between awareness, identity and social desirability in dementia. Both papers have been prepared for submission to Neuropsychological Rehabilitation (see Appendix 2 for submission guidelines).

Volume II is comprised of five clinical practice reports that present work undertaken in the areas of older adult, adult and child and adolescent mental health, learning disabilities and neuropsychology. The first report presents the case of a 69 year old man with anxiety from cognitive behavioural and systemic approaches. The second report describes a service evaluation designed to assess whether a newly established team for older adults was achieving its aims in reference to the recovery model. The third report presents the case of a 45 year old man who was exhibiting challenging behaviour. The fourth report describes the neuropsychological assessment of a 66 year old male who was found to have progressive prosopagnosia. An abstract for the fifth report presents the case of an 18 year old woman who was experiencing severe symptoms of obsessive compulsive disorder. Solution-focussed assessment, formulation and intervention are presented.

Dedication

In loving memory of my father

28.12.1952-27.02.2009

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LITERATURE REVIEW

WHAT DOES QUALITATIVE RESEARCH TELL US ABOUT THE PROCESSES ASSOCIATED WITH A POSITIVE IDENTITY FOLLOWING A TRAUMATIC BRAIN INJURY

Abstract

Following a traumatic brain injury, individuals may experience a profound disruption in identity. Rehabilitation professionals have a key role to play in providing interventions to address the psychosocial consequences of such injuries on the individual's sense of who they are. Before useful interventions can be designed, it is important to learn what processes people undergo when they construct their identity following a traumatic brain injury. Whilst the perspectives of professionals, family members, friends and carers have much to teach us about this process, it is the voice of the survivor which offers the most valid and meaningful understanding. Numerous researchers have sought to represent the view of the survivor through the use of standardised questionnaires and other quantitative methodologies. However qualitative research offers an opportunity to achieve rich and thick descriptions of survivors' experiences through an inductive method which privileges the view of the survivor over pre-existing theories and frameworks.

This literature review examines the processes involved in the development of identity following a traumatic brain injury, as conveyed via twelve peer-reviewed articles that used a qualitative methodology. The studies are evaluated in respect to their trustworthiness and usefulness and the findings discussed. Broad overarching processes of coming to know the loss, construction of a coherent narrative and construction of a positive identity were identified as integral processes. Activities and behaviours which contribute to these processes are also discussed. Implications for clinical practice are outlined based on the synthesis of the available research and in light of the quality of the evidence base.

Keywords: traumatic brain injury, identity, qualitative, process, literature review

Introduction

According to a report by Kay and Teasdale (2001), approximately 1 million people each year in the UK present at hospital with a traumatic brain injury (TBI), an injury to the brain caused by an external force. Since the estimated cost of hospitalisation after TBI stands at £15,500 per admission, there is an obvious need for ensuring the effectiveness and efficiency of rehabilitative interventions (Levack Kayes & Fadyl, 2010). In order for rehabilitation services to deliver useful interventions, it is necessary to develop a shared understanding of how people who have had a TBI experience make meaning of the event and its impact on their lives.

TBI produces a profound alteration in mind and body which disturbs the individual's appraisal of who they are (Baumeister, 1997) (see below). This might be expected, given that identity is constructed through a dynamic, evaluative process that demands intact cognitive, emotional and social functioning abilities which are likely to have been affected by the TBI (Muenchenberger , Kendal & Neal, 2008). A focus for rehabilitation post-injury might therefore be the re-construction of identity and an exploration of how individuals view themselves in relation to their past and current selves via psychological therapy (Nochi, 1998a). In order to address these issues, it is first necessary to be aware of how individuals with TBI understand and interpret their experiences and the processes they engage in to make meaning from their experiences and (re) develop a sense of self. The purpose of this literature review is to consider what conclusions can be drawn from the existing evidence base about the processes underpinning the experience of the self following TBI within the context of an evaluation of the quality of the research evidence.

Scope and definition of terms

Traumatic brain injury. This literature review focuses on TBI to the exclusion of other, non-traumatic acquired brain injuries (ABI), brain injuries occurring prior to birth or mixed samples. Whilst it is acknowledged that TBI is a subtype of ABI, the different pathological mechanisms underpinning the conditions result in important differences in post-injury life in biological, psychological, and sociological terms. For example, individuals who have had a stroke (a type of ABI) are likely to be older, present with impaired focal neurological function, and experience depression. In contrast, those with a TBI are likely to display global neurological functioning deficits and experience irritability rather than depression (Nair, Lehmann & Williams, 1993). A review of post-injury experience among those with the broader definition of ABI is beyond the scope of this review. However, for the purpose of this review, the broader term of "brain injury" was employed in the search to facilitate retrieval of the maximum number of articles. The abstracts and/or articles were then examined accordingly to identify those describing a TBI sample.

Identity. The terms identity, personality, self and self-concept are used interchangeably in the literature but reflect different epistemological underpinnings (Segal, 2010). For consistency with other research, it was decided that the term "identity" would be utilised throughout this review to depict the person's understanding of who they are. As explained by Baumeister (1997): "The concept of identity rests on two notions; sameness (continuity) and difference. Identity means being the same person you were yesterday or ten years ago; it also means being different from someone else" (pp. 248).

Process. For the purpose of this review, psychological processes are defined as the activities and behaviour people engage in when constructing identity after TBI. Levack et al (2010), in their recent meta-analysis of outcome measurement in TBI rehabilitation, revealed some of the issues related to the experience of identity disruption. Whilst their exploration is a helpful starting point to understanding the impact that TBI can have on identity, it is also necessary to understand the processes involved and the activities that people engage in to resolve their issues with identity. Indeed, Levack et al (2010) cite the need for deeper exploration of the identity issues raised in their paper as an important area for future investigation.

Qualitative research. According to Denzin and Lincoln (1994) the focus of qualitative research is on process and meanings. Appropriate methods of data collection for qualitative studies may include participant observation, interviews, focus groups, historical research and life stories (Law et al, 1998). There is no limit to what might constitute qualitative data and the term can be used to depict any data not quantitative in nature; that is, not reduced into numerical form (Thorne, 2000). All qualitative data sources were considered appropriate for this review. As per Levack et al (2010) and their meta-analysis, to qualify as a qualitative study in this review, articles had to explicitly utilise qualitative methods for both data collection and analysis in order to be included.

Method

Search Strategy

A computerised search of the literature was conducted using the databases PsycINFO and Ovid Medline. The search was limited to studies involving adult participants published between 1950 and 2nd March 2011. The search strategy focussed on the three significant components of the topic of interest:

1. individuals who have had a traumatic brain injury (search terms traumatic brain injur*, TBI, brain injur*)

AND

2. the research methodology of interest (search terms qualitative research, qualitative methods, grounded theor*, interview* (exploded subject heading: all narrower types of interviews included), narrative*, discourse analys*, life stor*, IPA, interpretive phenomenological analys* thematic analys*, content analys*, qualitative, life experience*, autobiography, story telling)

AND

3. the phenomena of interest (search terms self, self concept*, self-concept*, identit*).

The search strategy was applied to subject headings and title/abstract keywords. The inclusion criteria were adapted from a recent metasynthesis of qualitative research reporting recovery and outcome following TBI published by Levack et al (2010). To be included in the review studies were required to meet the following criteria:

1. be published in a peer-review journal
2. be published in English

3. report an original qualitative study
4. use as data the reported beliefs and experiences of people who had a TBI (phenomenological rather than ethnographical)
5. do so without merging the analysis of that data with analysis of views of people who do not have TBI e.g. family members, professionals, or those with different types of health issues
6. report specifically on perspectives regarding the self following TBI
7. use qualitative methodology in both data collection and analysis

Fifty nine references were generated from the search terms combined. Through examination of the abstracts or articles where necessary, papers were excluded as not meeting the inclusion criteria for the reasons outlined in Table 1. The reference section of each of the articles was scrutinised to identify further studies and yielded one further paper (Crisp, 1993). Twelve papers are consequently included in this review.

Table 1. A Table Demonstrating the Papers Excluded and the Rationale

Number excluded	Basis	Further detail
16	irrelevant to topic under investigation	1 exploration of adjustment and coping but not the impact on identity of TBI 1 case report on "borrowed identity syndrome" 1 paper on recovery and feeling well post-TBI 1 looking at neurobehavioural outcome in children 1 study of communication and friendship after TBI 1 study of the efficacy of self-regulation and goal setting in

		rehabilitation 1 exploration of service provider perspectives in polytrauma 4 papers researching awareness in brain injured populations 1 investigation into the communication abilities of those with brain injury, 1 investigation of rural identity and quality of life 1 study of the role of spirituality in those with spinal injury 1 study of threat avoidance and appraisal in a brain injured sample 1 investigation of service user perspective on service delivery
8	duplicate references	
3	mixed sample (not pure TBI)	1 stroke 1 acquired brain injury 1 mixed sample
11	Sources other than peer review journal	
10	excluded on methodological grounds	3 studies involving informant perspectives rather than subjective only accounts 2 studies examining the efficacy of an intervention 2 review articles 1 study on the co-construction of identity rather than subjective experience and 2 employing mixed or quantitative methodology (one utilised psychometric questionnaires and the other a meta-analysis)

Synopsis of papers, evaluation of quality and thematic analysis

A brief synopsis of the reviewed papers and overall ratings of quality are displayed in Table 2. Qualitative research does not conform to the positivist concepts of reliability and validity in the way the quantitative research does, as it is founded not on the assumption that there is any one truth; rather that there is a multiverse of truths (Shenton, 2004). Despite this, the trustworthiness of naturalistic research can be assessed using criteria to appraise credibility, transferability, dependability and confirmability which correspond to internal validity, external validity, reliability and objectivity, respectively, whilst continuing to reject the positivist paradigm (Guba, 1981). The traditional and alternative criteria for judging quantitative as compared to qualitative research, and strategies for meeting those criteria, are outlined in Appendix 1. Based on the alternative criteria, a 4-point system was then utilised to grade the quality of the research evidence based on Walsh & Downe (2005) and Downe (2008). Studies containing no or few threats to quality were rated A, those with minor flaws that were unlikely to affect overall quality were given a B grade, studies with flaws which might affect the overall quality were given a C grade and a D grade reflected significant threats to quality. Although the methodological shortcomings of the paper are referred to later in the Results section this review, the reader should keep these overall ratings in mind, and the criteria against which they are judged (Appendix 1), when considering the evidence for and against the themes discussed. Since all the studies were evaluated not to have flaws that significantly undermined the quality or jeopardised the usefulness of the overall investigation, they were all included.

Table 2. A Synopsis of the Twelve Qualitative Papers Selected for Review and the Quality Ratings Awarded

Author	Year	N	Type of data collection	Type of analysis	Quality grading
Crisp	1993	10	Unstructured & semi-structured interview	Thematic analysis	C
Gelech & Desjardins	2011	4	Life history and semi structured interview	Narrative analysis	B
Hoogerdjik et al	2011	4	Open ended interview	Narrative analysis	B
Klinger	2005	7	In-depth semi-structured interview	Constant comparative method/heuristic/thematic analysis	B
Muenchenberger et al	2008	6	Interpretive qualitative research using life story interview	Thematic analysis	A
Nochi	1998a	10	Semi-structured interview, email postings on an internet forum, observation and field notes	Grounded theory	B
Nochi	2000	10	In-depth semi-structured interview,	Grounded theory	B

			observation and field notes		
Nochi	1998b	10	Semi-structured interview, email postings on an internet forum, observation and field notes	Grounded theory	B
Nochi	1997	4	In-depth open ended interview, observations, field notes	Inductive, informal thematic analysis (Grounded theory)	B/C
Price-Lackey & Cashman	1996	1	Open ended interview - life story interview	Narrative analysis	C
Roscigno and Van Liew	2008	1	Retrospectively written journal entries and phone calls/ face to face open ended interview	Grounded theory	C
Sabat et al	2006	1	Life history interview	Narrative analysis	A

The studies were analysed and synthesised according to the principles of thematic analysis outlined in step by step detail by Braun & Clarke (2006). This involved becoming familiar with the studies through repetitive reading of the articles. This was followed by the generation of initial codes through repetitive cycles of reading and re-reading the papers to ensure that all potential codes were identified. The initial codes were noted in the margins of the papers and depicted any process involved with identity. Once the initial code generation was completed to saturation, the codes were searched for encapsulating themes to collapse the codes into broader units which again continued until saturation. Following the development of these overarching themes, the themes were reviewed and checked against the papers to ensure that the themes represented all of the data. The themes were subsequently defined and named below.

Results

Table 3 outlines the themes that were generated from the data and the papers which cited them. The themes are subsequently discussed in more detail below.

Table 3. A Table Outlining the Themes and Corresponding Citing Papers

Theme	Papers
Deconstruction/Disruption/Contraction/ Compartmentalisation	Crisp (1993) Gelech & Desjardins (2011) Hoogerdjik et al(2011) Klinger (2005) Muenchenberger et al (2008) Nochi (1997) Nochi (1998a) Nochi (1998b) Nochi (2000) Price-Lackey & Cashman (1996) Roscigno & Van Liew (2008) Sabat et al (2006)
Reconstruction/Assimilation/Continuity	Crisp (1993)

	Gelech & Desjardins (2011) Hoogerdjik et al(2011) Klinger (2005) Muenchenberger et al (2008) Nochi (1997) Nochi (1998a) Nochi (1998b) Nochi (2000) Sabat et al (2006)
Resistance/Rejection/Re-humanisation	Crisp (1993) Gelech & Desjardins (2011) Hoogerdjik et al(2011) Muenchenberger et al (2008) Nochi (1997) Nochi (1998a) Nochi (1998b) Roscigno & Van Liew (2008) Sabat et al (2006)
Re-alignment/Re-configuration	Crisp (1993) Gelech & Desjardins (2011) Hoogerdjik et al(2011) Klinger (2005) Muenchenberger et al (2008) Nochi (1997) Nochi (1998a) Nochi (1998b) Nochi (2000) Price-Lackey & Cashman (1996) Roscigno & Van Liew (2008) Sabat et al (2006)
Acceptance	Crisp (1993) Gelech & Desjardins (2011)

	Klinger (2005) Muenchenberger et al (2008) Nochi (1997) Nochi (2000) Roscigno & Van Liew (2008) Sabat et al (2006)
Transcendence/Moral awakening/Growth/ Expansion/Enlightenment	Crisp (1993) Gelech & Desjardins (2011) Klinger (2005) Muenchenberger et al (2008) Nochi (1997) Nochi (1998a) Nochi (1998b) Nochi (2000) Price-Lackey & Cashman (1996) Roscigno & Van Liew (2008) Sabat et al (2006)
Being optimistic/Looking Forward/Hoping	Crisp (1993) Gelech & Desjardins (2011) Hoogerdjik et al(2011) Klinger (2005) Muenchenberger et al (2008) Nochi (1997) Nochi (1998a) Nochi (1998b) Nochi (2000) Price-Lackey & Cashman (1996) Roscigno & Van Liew (2008) Sabat et al (2006)
Course of identity development	Crisp (1993) Gelech & Desjardins (2011) Hoogerdjik et al(2011)

	Muenchenberger et al (2008) Nochi (1997) Nochi (1998a) Roscigno & Van Liew (2008) Sabat et al (2006)

Deconstruction/Disruption/Contraction/Compartmentalisation

One of the most prevalent themes to emerge out of the studies, in that it was mentioned by all the papers, was the notion of exposing or dismantling identity or separating the injury from identity in order to make meaning. This theme was cited by all the papers. Several of the participants commented on the importance of acquiring knowledge about the accident in order to understand who they were, given that the neurocognitive consequences of the TBI (e.g. amnesia) often disrupted the continuity of the person's knowledge about themselves and remembering a pre-injury life is closely associated with a sense of identity (Nochi 1997; 1998a). Subsequently, survivors frequently relied on others' accounts of events to fill in the gaps in their self-knowledge about the accident itself. Other papers talked of how the individual with TBI might seek to obtain an understanding of their post TBI as compared to pre TBI functioning. Some individuals either actively sought opportunities (Price-Lackey & Cashman, 1996) or relied on experiences as they presented themselves (Hoogerdjik et al, 2011; Muenchenberger et al, 2008; Sabat et al, 2006) to test their capabilities, expose their difficulties and to understand the impact of the accident in terms of their functioning. In the majority of studies (Gelech & Desjardins, 2011; Hoogerdjik et al, 2011; Klinger 2005; Roscigno & Van Liew, 2008; Nochi 1998a; Nochi, 1998b; Sabat et al, 2006), participants reported that this comparison ultimately resulted in a negative comparison and dissatisfaction with their current identity. It led some to wonder whether life "could be meaningful" after a TBI (Crisp, 1993) and contributed to the sense of grief, loss, insecurity, loneliness and discontinuity (Crisp, 1993; Gelech & Desjardins, 2011; Hoogerdjik et al, 2011; Klinger , 2005, Nochi, 1997, 1998a/b, 2000; Price-Lackey & Cashman, 1996; Roscigno & Van Liew, 2008; Sabat et al, 2006) which peppers the literature and the medical discourse on life after TBI. Conversely, Klinger (2005) reported that her participants used this comparison more positively, and actively attributed lost abilities to their "past self" and competencies to their "current self" in an effort to re-develop their identity. Klinger's (2005) research design allowed for flexibility in her analysis when the author recognised that the views of her participants did not resonate with the theoretical assumptions she had made. By abandoning a deductive approach, she has bolstered the trustworthiness of her findings and so this is a valid theme. Muenchberger et al (2008) frequently refer to the process of pre-post identity comparison as the catalyst for identity change. Their research design was the only one to actively recruit participants at different post injury intervals to represent the time-course of identity development. Given the steps they employed to ensure trustworthiness such as member checking, inter-rater coding and purposeful searching for contradictory themes during the analysis phase, this paper is considered a good example.

The deconstruction or more specifically, compartmentalisation, of identity was a common thread in the research. Many participants spoke of the TBI as having "severed the life course" (Muenchenberger et al, 2008) or resulting in a distinction between a pre and post TBI identity which individuals used to assign meaning to their circumstances. In addition to the temporal distinction, other participants referred to the separation of public and private identities (Crisp, 1993, Gelech & Desjardins, 2011, Roscigno & Van Liew, 2008, Nochi 1998a; 1998b). This dissociation allowed individuals to manage the negativity they experienced from others through attributing deficits or impairments to a public identity and by maintaining a core sense of private identity (see below). Nochi (1998b; 2000) reported that for those who have successfully re-constructed their self-narrative, the dissociation of identity from TBI was a necessary step for the later consolidation of disabilities into identity. For Sabat et al (2006), Price-Lackey and Cashman (1996) and Roscigno and Van Liew (2008), the development of identity post-TBI can only truly be understood in the context of the individual's identity pre-TBI and how they were constructing themselves prior to the accident, suggesting that the process of identity development does not begin in the aftermath of a TBI but simply takes a different trajectory following the event. Whilst Price-Lackey & Cashman's, Roscigno and Van Liew's and Sabat et al's findings cannot be generalised to other types of injury or participant demographic due to their case study design, their consensus on this point may be said to endorse one another's perspective and give support for this view, particularly given the methodological rigour employed by Sabat et al (2006). For example Sabat et al's (2006) use of data triangulation and videotaping to allow non-verbal communication of their participant to form part of their dataset contributes to their study being judged the most trustworthy in this review.

Reconstruction/Assimilation/Continuity

This theme was cited by the two A grade papers, five B grade papers, the B/C grade paper and one C grade paper. There is a lack of recognition in the literature of the competing themes of continuity and discontinuity. Whilst many researchers refer to conflict between pre and post or new and old selves, there is also a sense of continuity or stability in identity that continues to exist despite a TBI (Nochi 2000). The contradiction is not explicitly acknowledged in the literature and makes understanding the processes related to identity after a TBI difficult to understand. For example, Klinger (2005) highlights the importance of retaining what is left of the old identity but later reports that acceptance of the loss of the old identity and establishment of a new identity is an integral step in the process of developing identity. Evidence for a sense of continuity and its importance in developing identity in the context of TBI is cited by all of the papers. Gelech and Desjardins (2011) found evidence for a loss of identity but also highlight that some individuals actively highlight consistencies in their character to maintain a continuous core inner identity. Through establishing those parts of the pre-injury identity that are capable of repair, the individual is said to be able to construct an identity that is stable and consistent and through which they are able to re-establish themselves as someone capable of making a contribution to society. Gelech & Desjardins (2011) findings are not jeopardised by any major flaws but would have been rated as more trustworthy had the authors employed member checking to verify their themes post-analysis. However, the involvement of two experienced qualitative researchers in coding the data adds support to their interpretation. Muenchenberger et al (2008) refer to the "reclaiming" of identity post-injury. Crisp (1993) asserts that those who adjusted well to post-injury life were those who viewed themselves as consistent and who assimilated the TBI into their sense of identity. Nochi (1997, 1998a, 1998b) talks of the importance of a coherent narrative and that over time, filling the void in self-knowledge becomes less important in relation to constructing identity as a consistent story is manufactured from other people's testimonies. However, it is important to note that along with the testimonies of participants, Nochi included personal observations in the dataset in all of his investigations. Subsequently, he may have introduced a level of bias into his studies which he fails to acknowledge or address. Although Nochi is the most prolific of writers in this area, this data collection method may have threatened to jeopardise the trustworthiness of his work. However, the use of a senior researcher to verify the themes he generated goes someway to asserting their dependability. Hoogerdjik et al (2011) talk of drawing on the facets of the pre-injury identity in order to aid recovery and achieve ambitions. They explain that individuals may experience conflict as the “new self” is not yet an accepted part of the current identity but the “old self” is not totally extinguished either. Although they did not include triangulation of sources in their methodology, Hoogerdjik et al (2008) did conduct interviews over two different time points which facilitated a follow up and clarification on some points from the initial interview which contributes to the overall trustworthiness of their findings and a rating amongst the most dependable of papers in this review.

Resistance/Rejection/Re-humanisation

One of the most striking and emotive discussions in the literature centres on the incongruence between the subjective identity of those who have sustained a TBI and the frequently negative view others have about them. This was highlighted by the two A grade papers, five B grade papers, the B/C grade paper and a C grade paper. According to Gelech and Desjardins (2011) maintaining a sense of continuity between the pre and post identity only goes some way to resisting the implication of a disruption to the core identity as a result of the TBI. An active process of re-legitimisation and re-humanisation appears necessary to reject and resist the derogatory perceptions of others; professionals and non-professionals alike. This resistance is against the view of a “truncated self” (Gelech & Desjardins, 2011) or the implication that negative consequences of disability spread to the entire identity which is a view perpetuated by others. The purpose is to reject attempts to discredit the individual’s uniqueness or reduce those with a TBI to the lowest common denominator. Incongruence between subjective and objective perceptions is a major threat to sense of identity. Nochi (1998a) described there being three types of identity loss or deconstruction: A loss of self-knowledge, a loss of self by comparison between pre and post TBI identity and a loss of identity in the eyes of others. These themes were generated from the analysis of participant observations, postings on internet forums used by the survivors of TBI, interviews and Nochi's own notes. The triangulation of sources lends credibility to these findings although it is important to reference again the potential bias introduced by Nochi's perspective in the dataset. Sabat et al (2006) describe how the resistance process represents a rebellion against the expectations society has of those with a disability. Roscigno and Van Liew's (2008) case study described the infantalisation and marginalisation experienced as a result of the TBI and how the participant sought to fight these misperceptions through overcoming physical limitations and challenging other's beliefs. These views are that of an individual as a product of a case study utilising retrospective journal entries. It is important to acknowledge that they may not generalise to all survivors of TBI. However, Crisp (1993) found that those who were well-adjusted to their TBI had also rejected this devaluation in his investigation which classified people as either entrenched, strugglers, strivers or optimisers. Crisp's study was the first to privilege survivors' voices over others' and affords a useful preliminary insight into the processes relating to identity post TBI and possible typologies of resulting identities. However, it is compromised by failing to include a constructive critique of the methodology employed. Furthermore, whilst the design did ensure a certain level of confirmability through member checks, this could have been extended by employing triangulation of sources. Despite some minor flaws, Crisp's effort should be considered a valuable first foray into this area. Muenchenberger et al's (2008) study, questioning social norms and priorities was integral to managing a sense of identity. Resistance and rejection were common processes in many survivor narratives (Hoogerdjik et al, 2011, Nochi, 1997, 1998a/b). Nochi (1998a) described how employing strategies that maintain a sense of identity, such as emphasising similarities between those with TBI and other people and minimising differences, de-emphasising similarities between those who have sustained a TBI and those with mental illness and controlling self-presentation, could aid in the resistance of pathological labels and endorse the view of the person as unique and individual. Since these activities were cited by people from different data sources (internet postings, interviews and observations) and then member checked, Nochi's conclusions are afforded good standing, despite his use of his own notes in the dataset.

Re-alignment/Re-configuration

Taking the resistance process further, many participants were reported as actively engaging with a re-configuration of their belief systems and life priorities, as cited by the two A grade, three of the B grade and the B/C grade paper. Nochi (2000) described this process as dissociating from other's views and values and a redefinition of "normal". Constructing a positive identity was associated with transforming the way people with TBI looked at things, placing an emphasis on the positive and redefining personal goals (Crisp, 1993, Gelech & Desjardins, 2011, Muenchenberger et al, 2008, Nochi, 1997, Sabat et al, 2006). Nochi (1998b) operationalised this process in more detail than other researchers, citing the redefinition of normality, emphasising strengths, sharing self knowledge to convey the appearance of normality, distinguishing functional changes from changes in self or identity, and replacing the term TBI for a less derogatory and more empowering and meaningful one e.g. survivor. Nochi (2000) saw this as constructing a positive identity because of rather than in spite of TBI. For some, the re-alignment process also involved the acknowledgement that certain elements of their identity had been lost and that not all roles or relationships could be regained (Gelech & Desjardins, 2011). This acceptance was integral for many participants before re-prioritisation could occur.

Acceptance

Many of those who had redeveloped their identity reflected that they had made a conscious decision to accept their circumstances and look to the future (Sabat et al, 2006). This theme was identified by the 2 A grade papers, four of the B grade papers, the B/C grade paper and two C grade papers. This might be achieved following a period of perspective taking such as when drawing comparisons (Nochi, 1997, 2000). Some achieved acceptance by actively seeking to conform to society (norms, values, milestones) in order to gain acceptance of others and reduce the incongruence between the subjective and objective identity (Klinger, 2005, Muenchenberger et al, 2008). Acceptance might also be reflexively influenced by the process of sharing the experience of surviving TBI with others (Crisp, 1993, Gelech & Desjardins, 2011, Roscigno & Van Liew, 2008) and challenging the prevailing discourse through dialogue in what Sabat et al (2006) refer to as a quest narrative.

Transcendence/Moral awakening/Growth/ Expansion/Enlightenment

In an effort to make meaning from the experience of TBI and to establish a sense of identity, many participants referred to the process of spiritual growth or enlightenment. Two A grade, five B grade and the two C grade papers identified this theme. For some, this was a re-awakening of their relationship with a spiritual figure (Crisp, 1993, Gelech & Desjardins, 2011, Sabat et al, 1996) which may have began with prayer or a bargaining with a God to be a better person should they recover from the TBI. For others, this moral awakening moved the individual from complacency to appreciation (Sabat et al, 1996). There was a transformation of loss into moral gain and, according to Gelech & Desjardins (2011), an acknowledgement of the impermanence and emptiness of social markers such as work, marriage and relationships. This acknowledgement led their participants to sacrifice the public identity as amoral and to give new credence to the private identity in an effort to construct the TBI experience as a moral growth process. Some participants felt that God had a better plan for them (Sabat et al, 1996) or used their spirituality as a filter through which to view the TBI (Roscigno & Van Liew, 2008). For the participant in the study by Price-Lackey & Cashman (1996), the fact that the participant had survived the TBI was viewed as conveying a sense of purpose in life and used to construct meaning and a consequential identity. In this way, TBI was viewed as an "agent for change" (Nochi, 1998a); an event that brought about a better life or what Nochi (2000) termed "the grown self". This better life allowed the construction of a morally grown identity whereby the individual exhibited a change in attitudes and behaviours such as improved tolerance and appreciation (Klinger, 1995). For many participants, this transcendence above the morals and values of others was an end point in the process of identity construction, whereby the individual had superseded the beliefs and values of society and had become a better person (Crisp, 1993, Gelech & Desjardins, 2011, Klinger, 2005, Nochi, 1998a, Nochi, 2000, Price-Lackey & Cashman, 1996, Roscigno & Van Liew, 2008, Sabat et al, 2006). However, Muechenberger et al (2008) view this process as being re-visited repeatedly over the course of identity construction after TBI. Rather than signifying an end point, to their participants this represented a type of expansion of identity which is characterised by small goals for psychological well being and personal growth. What is clear about this process is how the TBI is constructed positively in the narratives of survivors and how this contradicts the dominant narrative of TBI as a continuous loss and threat to identity.

Being optimistic/Looking Forward/Hoping

All of the papers in the review highlighted this theme. Whether it be a pre or post TBI characteristic, the ability to be optimistic and have hope appeared to be one of the main determinants in the construction of a positive identity following TBI and cited by all authors. While optimism conveys, to some extent, dissatisfaction with the current identity, there were some differences in the literature as to whether participants were seeking to become akin to their pre-injury identity (e.g. Nochi, 1997, 1998) or whether they hoped to make the most of their current identity. In Nochi (2000), four narratives emerged which demonstrated the construction of positive current identities either: in comparison to those less fortunate; or in contrast to the pre TBI self which was more negatively appraised in comparison with the current “grown” self now, or when judging themselves more positively in comparison to others or when considering their value in the world as someone with a TBI who can make a contribution despite prevailing stigmatised views. Nochi’s (2000) methodology generated themes which differed from the author’s previous studies by actively recruiting those who had adjusted well and who had a positive or neutral view of their identity post TBI. Nochi (2000) concluded that the construction of numerous positive narratives allowed individuals to move flexibly between them and therefore to develop a positive and coherent identity. For Hoogerdjik et al (2011) there was an exploration of multiple possible selves and a sense of opportunity. In addition to optimism as an internal resource, there were times when relationships brought hope and were positive rather than malignant influences such as when others misinterpreted their impairments for the signs of social deviance or judged them on the basis of their deficits rather than their capabilities (Roscigno & Van Liew, 2008). For some of the participants in the study by Crisp (1993), the existence of satisfying personal relationships outweighed problems arising from the disability and mediated the difficulties. Maximising opportunities led to chances to regain identity and focus on possibilities (Muenchenberger et al, 2008). A positive and forward looking attitude allowed individuals to move forward in their journey by valuing their past, having a meaningful present and a hopeful future (Muenchenberger et al, 2008). Although this was generally perceived as a positive process, for one participant, the potential he was presented with was intimidating and he reported feeling "constrained by too much freedom" (Muenchenberger et al, 2008). Muenchenberger and colleagues describe this tension as one of three phases of continuous, cyclical and dynamic identity construction whereas other researchers view identity development as a linear or temporal process. This will be outlined below.

Course of identity development

Only eight papers, the two A grade, four of the B grade, the B/C grade and one of the C grade papers implied a direction to the processes involved in identity development. The predominant framework in the literature is indicative of a linear process of identity development (Crisp, 1993, Gelech & Desjardins, 2011, Nochi, 1997, 1998a, Roscigno & Van Liew, 2008, Sabat et al, 2006). The processes are broadly encapsulated by themes of loss, learning about the accident and constructing a coherent self-narrative, challenging threats to identity (internal and external), and constructing a positive identity. Not all authors have sought to identify the phases of identity development but have identified key mechanisms or features of the process (Crisp, 1993, Nochi, 1998b, 2000, Sabat et al, 2006). However, a major point of consensus is that in order for the process to be meaningful to the survivor, it must be individual and within the context of the individual (Hoogerdjik et al, 2011) rather than defined by medical timeframes or goals (Muenchenberger et al, 2008). It must represent the needs and wants of the individual rather than the expectations of society and is a protracted process which continues long after functional rehabilitation services have completed their interventions (Hoogerdjik et al, 2011, Roscigno & Van Liew, 2008). Hoogerdjik et al's (2011) work contains a useful separation between the themes generated from the data and the reflections of the researcher. Unlike Nochi, the authors demarcate their perception from the perceptions of survivors. This aids the trustworthiness of the paper. The authors also conducted interviews across different time points and allowed for clarification on points which adds to the credibility of their findings. However, no further member checks were conducted, nor was triangulation of sources employed, and so the findings are to be considered within the context of its minor flaws. Muenchenberger et al (2008) have challenged the notion that identity development post-TBI is a linear process and instead posit that there is a cyclical course of identity contraction, expansion and equilibrium. This represents the interplay between positive and negative, certainty and uncertainty and stability and chaos. In this framework, there is no end point, just an "ease with unease" and identity phases can last for decades before a challenge to identity presents an opportunity for expansion. Whilst this framework might imply that individuals remain in limbo and with no clear recovery goal in sight, it highlights the importance of putting the injury into the individual's personal context and maintaining a balance at the interface of challenge and capability (Muenchenberger et al, 2008). Linear models may fail to recognise the repeating cycle of identity development and imply a shared trajectory between individuals that has a designated endpoint. Whilst linear models are more prevalent in the literature, it is likely that they underestimate the complexity of such a dynamic and multifaceted process. Muenchenberger at al's (2008) proposal of a non-linear theme does go against the grain of many studies reviewed here but this view is credible given the methodological rigour the authors utilised in their research design and through the recruitment of participants across different time points rather than cross-sectionally in order to obtain more of an understanding of the process. However, despite the shortcomings of some of the papers which cite linear models, the greater proportion of evidence, including the other A rated paper, supports a linear model.

Discussion

The aim of this review was to synthesis the processes involved in the development of identity following TBI according to published qualitative research findings. The review identified numerous themes; these were: Deconstruction/Disruption/Contraction/Compartmentalisation; Reconstruction/Assimilation/Continuity; Resistance/Rejection/Re-humanisation; Re-alignment/Re-configuration; Acceptance; Transcendence/Moral awakening/Growth/ Expansion/Enlightenment; and Being optimistic/Looking Forward/Hoping. The predicted course of these processes was also discussed. These themes will be summarised and their clinical implications shall be outlined below.

Clinical implications

Deconstruction/Disruption/Contraction/Compartmentalisation described the process of becoming acquainted with both the accident itself and the consequences of the accident. It was one of the richest themes generated from the data and fits with the prevailing view of TBI as being exemplified by loss, grief and disruption. It was typified by the search for information, acquired from others, to fill the gap in an individual's self knowledge about the event and in exposure to activities which afforded an opportunity to compare pre and post

TBI capabilities to acquire an understanding of the event's implications. Compartmentalising or dissociating the injury from identity was seen as an integral part of the process of identity development post TBI. This process may be achieved through empowering people with TBI to take small steps towards discovering what their capabilities are in a supported manner and at a pace determined by the individual. Continuing to ensure that rehabilitative programs are truly person-centred and seek to actively engage the person with devising the programme themselves will increase adherence, relevance and meaningfulness to the individual.

The theme of Reconstruction/Assimilation/Continuity discussed the process of rebuilding an individual's sense of identity. This was another well represented theme (10 papers) which identified that incorporating the TBI into their understanding of the self was helpful to individuals. This was possible because of activities such as highlighting consistencies between pre and post identity and the construction of a coherent narrative. This might be achieved clinically through emphasising the similarities between pre and post TBI identity, minimising the differences, and assisting the person where possible to draw on pre-injury characteristics and experiences to help shape the new identity. Activities such as these which promote the assimilation of TBI into the current identity are endorsed.

Resistance/Rejection/Re-humanisation was an evocative theme which encapsulated the incongruence between the way that the person with TBI views themselves and the views of others. This theme, cited by 10 papers and richly conveyed, revealed the stigmatisation experienced by people with a brain injury but also their determination to question, resist and reject other's definitions and labels. Emphasising the individuality and uniqueness of the person with TBI and rejecting being reduced to the lowest common denominator were key concepts within this powerful theme. In order to facilitate this process, it is recommended that formulations of brain injury that include the contributions of psychosocial factors, particularly interpersonal ones, are communicated to and understood by professionals, family members and the individual with TBI. This is with a view to the construction of a meaningful, accurate and shared representation of the impact of the TBI on identity and in order to enable the person with TBI to challenge some of the stigma they may face as a result of a lack of understanding. Furthermore, opportunities to practice role play scenarios which challenge prejudice and help the individual to develop tips on coping with practical and emotional issues are suggested.

Re-alignment/Re-configuration described the process of re-evaluating goals and values. It was the least well supported theme and was not richly described in the literature. However, it was clear that for some, identity development involved re-configuring life goals. For others, it was necessary to redefine their understanding of ‘normal’. Re-alignment/Re-configuration may be realised through active goal planning with the individual in a way that facilitates the redesign of life goals in a positive way that fits with the individual’s revised belief system and in the context of their TBI. Encouraging the individual to question the origins of some of the values and the depth with which they hold them may provide a helpful starting point in introducing flexibility into the goals, as advocated by narrative therapy (Morgan, 2000).

Acceptance was the process of a conscious effort to come to terms with their situation rather than a resignation to it. Some achieved this through actively attempting to conform to society’s value system whilst others chose to use their TBI experience to challenge society’s values and devise a new set for themselves. This theme was not as richly described or as well supported as the others but was cited by the two A grade papers. Acceptance of the TBI into their narrative may aid individuals with the further development of the identity post injury. Where possible, perhaps through talking therapies such as narrative therapies or cognitive behaviour therapy, individuals should be supported to reconstruct their TBI as having positive meaning and generate numerous narratives. This may involve systemic/narrative therapy techniques such as externalisation (Morgan, 2000) or other approaches such as cognitive reframing and Socratic questioning (Hoffmann, 2011) to challenge dominant notions of loss and to encourage a positive assimilation of the TBI into their sense of identity.

Transcendence/Moral awakening/Growth/ Expansion/Enlightenment highlighted the importance of the spiritual journey of the person with TBI. Whether participants felt that their survival of the TBI gave them purpose or whether they felt the TBI enabled them to have a renewed or improved purpose in life, there was evidence of moral awakening of some sort in eight of the 12 papers. Recognising the spiritual or religious aspect of TBI is an important aspect of the construction of coherent narratives about the self. The theme of Transcendence/Moral awakening/Growth/ Expansion/Enlightenment emphasised that the spiritual aspect of identity that TBI can be reignited or discovered anew. It may act as a filter through which to understand the TBI or life in general. Subsequently, opportunities to explore these issues, perhaps with chaplains or other spiritual figures are recommended.

Being optimistic/Looking Forward/Hoping was the other theme discussed by all of the papers. Having hope and a positive outlook seemed to be one of the most important aspects in the development of a coherent identity post TBI and this was achieved through drawing upon existing optimistic characteristics and developing new attitudes towards hope and a better future. In addition to the internal resources at an individual’s disposal, the support of others, in terms of both personal and professional relationships, afforded another source of sanguinity and hopefulness about the future. The responsibility for Being optimistic/Looking Forward/Hoping can be shared between both the individual and those around them in personal and professional systems. Pursuing activities or opportunities which foster a sense of optimism, such as solution focussed therapeutic techniques (de Shazer, 1985), may provide useful to rehabilitation professionals. Whilst care must be taken not to minimise or dismiss the feelings of the individual or to invalidate their experience, encouraging a positive outlook may be the most effective process involved in the development of identity post TBI.

Finally, the course of identity development in terms of linear and temporal trajectories was discussed. Whilst the A rated paper of Muenchenberger et al (2008) described a cyclical framework as a result of purposively sampling participants at different stages in their recovery, the most commonly represented view was that of a linear arrangement. However, whether a linear trajectory began before or with the event of the TBI and whether the course was different or simply altered as a result of the TBI was a matter of debate. The strength of support for the linear model was taken as evidence that this is how people with TBI understand the development of their identity post TBI. There was an emphasis on the importance of individualised, process-led and personally determined activities and timeframes rather than medically dictated ones for movement along the processes.

In summary, the literature encourages those with TBI to assimilate the TBI into their identity, rather than their identity into the TBI. The notions of continuity, growth and optimism have overpowered the dominant view of loss, and strategies to maximise these processes such as relying on both internal and external resources have been identified. Finally, the value of constructing numerous coherent positive narratives which allow flexibility of movement between them has been outlined. As per the current approach in rehabilitation services, individuals should be supported to create a new self and at their own pace.

The work outlined above has sought to convey the subjective experience of identity development following a TBI. The paradigm shift away from medical explanations of identity or “personality change” and towards interdisciplinary models which privilege subjective experience over informant or professional accounts have contributed to the view that identity development is an interactive process involving people, society, culture and environment (Nochi, 1997, 1998a, 1998b, 2000). These findings lend support to the biopsychosocial model of identity proposed by Yeates, Gray and McGrath (2008) which emphasises that identity is not a unitary construct but the product of diverse interacting and interdependent mechanisms. The theme of resistance and rehumanisation in particular, exemplifies the influence of psychological and psychosocial processes above biological/neuropsychological ones in the construction of a positive identity. Analogous to Kitwood (1997) and his proposition of a malignant social psychology that creates excess disability in dementia, those with TBI experience negative interactions with others which threaten their identity. As Clare (2003) explains with relevance to dementia and Ownsworth, McFarland and Young (2002) refer to in their study of those with TBI, threats to identity are predominantly experienced in interactions with others rather than an as a result of some internal process. The studies outlined above have cited examples of processes that aim to manage external threat to identity and to construct a positive sense of identity.

Methodological limitations

The papers cited in this review have represented the accounts of those who are aware of their TBI and the impact it has had on their sense of identity. Inherent in working with those who have the experience of particular processes related to identity post brain injury is the assumption that the individual has awareness into their injury and its consequences. Nochi (2000) highlights that those who are unaware of their difficulties are likely to have a different narrative from those who do have awareness. For example, those who are aware of the TBI are obliged to use it in different ways to link their identities to their characteristics. The findings of the papers are only representative of a specific group of individuals within a specific context. Furthermore, the interview method relies upon cognitive functioning ability, receptive and expressive communication ability, concentration ability, insight and reflexivity. Whilst Crisp (1993) Klinger (2005), Nochi (1998a, 1998b) Roscigno and Van Liew (2008) and Sabat et al (1996) utilised props and other non-verbal sources to aid their participant's expression, their participants are still representative of a group of individuals who were able to articulate their responses. Further work to give voice to those with different experiences of the process of identity construction is warranted.

This review aimed to explore those processes involved in identity construction following TBI through an examination of the contribution made by qualitative research. In order to do so, the criteria of Shenton (2004) were applied to assess the quality of the research. This technique privileged the assumption that one "truth" can be obtained from research, through measures such as member checking, over traditional qualitative approaches which support the notion of a multiverse and multiple truths (Dixon-Woods et al, 2003, Sale & Brazil, 2004). It is important that this epistemological conflict be acknowledged, even if there is no straightforward resolution.

The articles were analysed according to the principles of thematic analysis and the step by step guide produced by Braun & Clarke (2006). This method was chosen due to its simplicity, frequent use in the analysis of qualitative data and the clear instructions provided by Braun & Clarke (2005). Whilst every effort has been made to give a true account of the data, it should be noted that no second rater or experienced researcher can verify that the themes identified and cited in this account are valid. As Braun & Clarke (2006) attest, thematic analysis is frequently utilised but is often done so poorly. By adopting a method with explicit instructions, it is hoped that this review has produced credible conclusions.

Finally, it is important to consider the position of the author of this review. As a clinical psychologist in training with particular interest in dementia, it can be said that I have come to this topic with a fresh set of eyes; ignorant of extant theories and subsequently less likely to privilege one viewpoint, theme or framework over another. Whilst my clinical expertise relate to persons with dementia rather than those with TBI, I have been able to use my prior experience of designing and conducting qualitative research to analyse the trustworthiness and usefulness of the studies included in this review. During the process of writing this review, I have been struck by the amount of consensus across the literature and the sense of empowerment the authors have cultivated by giving their participants a voice and recognising the lessons clinicians have to learn from survivors' experiences. However, I have also been made aware of the challenge clinicians and survivors face in their shared objective of challenging the dominant narrative amongst rehabilitation professionals, friends and family and society as a whole. It is hoped that, in bringing the existing research together and highlighting the key processes involved in the development of numerous possible and positive narratives, this review will make a contribution to that aim.

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EMPIRICAL PAPER

AN INVESTIGATION INTO THE RELATIONSHIP BETWEEN MEMORY PROBLEMS AND OUR PUBLIC AND PRIVATE SELVES

Abstract

A lack of awareness of memory problems can be one of the symptoms of dementia. This lack of awareness can only partially be attributed to the neurocognitive consequences of the dementia process and research is continuing to elucidate the psychosocial factors which impact on unawareness. Research with other clinical populations has suggested that some unawareness may be due to people wishing to present themselves in a socially favourable way and therefore masking their awareness rather than being entirely unaware. Since awareness of abilities and attributes depends on the integrity of the same type of memories as those used to construct identity, unawareness may also have important connections with the identity of the person with dementia. Research has shown that those who are unaware report a more positive and more definite identity (Naylor & Clare, 2008).

This investigation sought to explore the relationships between awareness, identity and social desirability in dementia. Twenty eight participants with dementia and 28 relatives who acted as informants were recruited and completed measures of social desirability, identity and unawareness. Pearson Product Moment Coefficients were used to explore relationships between the variables. The findings showed that the relationship between unawareness and strength of identity failed to reach statistical significance and there was no relationship with whether identity was rated as positive or negative. Unawareness was unrelated to social desirability and only identity direction (positive or negative), not strength per se, was related to social desirability. The study concludes that it was not sufficiently powered to fully explore the relationships between the variables and that future investigation is warranted.

Introduction

People with dementia are typically thought of as being unaware of their memory problems although this is not always the case. This unawareness may reflect cognitive, neurological and/or physical deficits and the varying contributions of these factors is echoed by the different terms applied in the literature to describe it (anosognosia, lack of insight, unawareness, metacognitive unawareness) (Ansell & Bucks, 2006). Unawareness is not stable and may vary according to extent, type, domain affected, how it varies over time and its relationship to the progression of the dementia (Ansell & Bucks, 2006). The lack of consensus as to what unawareness is, and its variable nature, present numerous challenges to those seeking to define, measure or explore it (for a review of these issues see Clare, 2000a; 2000b). For the person with dementia, failure to be aware of difficulties in memory functioning may have negative consequences. For example, unawareness has been shown to be related to poorer clinical outcomes (Clare, Wilson, Carter, Roth & Hodges, 2004: see below). Understanding this variability may afford a better understanding of unawareness with the aim of reducing the negative impact on the person with dementia and those around them.

Research has shown that in order to be aware of any functioning difficulties we may have, we must: have an accurate record of past performance; be able to compare past and present functioning, and be aware of any mismatches. The Cognitive Awareness Model (CAM; Morris & Hannesdottir, 2004) predicts three separate mechanisms by which unawareness may occur. Of particular relevance to this discussion is ‘mnemonic unawareness’ which is hypothesised to result from a problem in updating the personal knowledge database (PDB); the store of information about task successes and failures. Similarities have been drawn between the PDB and the personal semantic component of autobiographical memory. The CAM model therefore links awareness and autobiographical memory. Since the personal semantic store is the repository for personally relevant information, such as knowledge about our characteristics, the PDB is implicated in the construction of identity (Naylor & Clare, 2008). The CAM model subsequently also suggests a connection between memory, unawareness and identity.

The contents of autobiographical memory therefore contributes to the construction of a self-concept; “A body of information consisting of knowledge, beliefs and attitudes” about who one is (Galin, 1992, p. 158). Although the terms self-concept and identity are used interchangeably throughout the literature, self-concept is commonly accepted to denote the ideas that an individual has about themselves, such as their traits and attributes, and is typified by questions such as “what kind of person are you?” Conversely, identity is the shared definition of an individual; the “who are you?” Fitts & Warren (1996) consider identity to be a subcomponent of self-concept. In the interests of continuity, the term identity will be used throughout this investigation.

Theorists from philosophy and social and cognitive psychology have long proposed there to be an association between autobiographical memory and identity. Addis & Tippett (2004) argued that if this were the case, then a loss of autobiographical memory, such as in dementia, would be expected to be detrimental to identity. Using the identity subscale of Tennessee Self Concept Scale 2nd edition (TSCS II: Fitts & Warren, 1996), the authors showed that participants with dementia not only experienced a disruption in their sense of identity (with participants reporting a less definite and less positive sense of identity) relative to controls but also that memories from early adulthood (16-25 years) were the most critical in constructing identity. These memories have been shown to be particularly susceptible to impairment in dementia (Mograbi, Brown & Morris, 2009).

Since autobiographical memory has been shown to store personally relevant semantic and episodic memories, it follows that damage to autobiographical memory might result in degraded memories (essential for establishing a continuous identity) and therefore an impairment in updating the store with new information (essential for constructing an accurate identity and in establishing an awareness of difficulties in functioning). It might therefore be predicted that in dementia, where both identity and awareness might be disrupted because of the effects of the disease process on autobiographical memory, individuals displaying high levels of unawareness might be expected to report having a poorer sense of their identity, parallel to the findings of Addis & Tippett (2004).

Naylor and Clare (2008) conducted such an investigation. Participants with either Alzheimer's disease or vascular dementia were asked to complete the same measures of autobiographical memory and identity that were utilised by Addis & Tippett (2004) and an additional measure of unawareness of memory functioning. Due to the theoretical associations between the three constructs predicted by the CAM model and outlined above, the authors predicted that there would be a relationship between better autobiographical memory performance, a stronger sense of identity and a higher level of awareness of memory functioning. In relation to autobiographical memory, performance was shown to decline linearly over time across lifetime periods in this sample, as in the findings of Addis and Tippett (2004). However, due to some adaptations to the mid-life section that were made to the standardised test because of the ages of the participants, the findings from this section of the test may be unreliable and the findings therefore need to be interpreted with caution. In terms of the predicted positive relationship between memory and identity, the results revealed that there were no significant correlations and subsequently, the findings of Addis and Tippett (2004) were not replicated. Naylor and Clare (2008) reported a positive trend relationship between better memory performance for recall of early adult memories and a more definite sense of identity; however this failed to reach statistical significance. The authors concluded that the relationship between memory and identity is more convoluted than theory would suggest. However, the results did demonstrate a statistically significant association between awareness and memory, in that those displaying a higher level of awareness displayed better recall for mid-life memories but only on the mid-life section of the test. However, these results are difficult to interpret given the departure from the standardised administration. No other associations between awareness and memory, despite the strong theoretical links posited by the CAM model, were reported. The authors used the same measure of identity as Addis & Tippett (2004) to investigate the direction (how positively-negatively) and the definiteness of their responses (how certain) of identity. The predicted positive relationship between awareness and identity was not supported. Rather, the opposite was found, in that those with a poorer level of awareness of their memory functioning reported a more positive and more definite sense of identity. According to the CAM model, this would be expected if the person is accessing a PDB which is no longer being updated and the individual is therefore basing their appraisals of their memory functioning on outdated information. Naylor & Clare (2008) explained that the individual would subsequently not be prompted to assimilate changes into their knowledge about themselves (identity) and therefore might have a more definite sense of identity but a compromised awareness of their functioning. Given these results, it is clear that the hypothesised triad between memory, unawareness and identity is not straightforward.

The CAM model focuses on cognitive impairment as the sole explanation for unawareness. If a biological mechanism was the direct cause of unawareness, the level of unawareness would be expected to increase over time. In fact, the opposite has been found to be true in some cases (McDaniel, Edland, Heyland and the CERAD investigators, 1995). Biological models also fail to recognise the role played by the social and psychological context of the individual in unawareness in dementia. The limitations of such an approach are outlined by Jetten, Haslam, Pugliese, Tonks and Haslam (2010):

"…such accounts, based on separating the body and the mind, only account for part of this relationship because they ignore the importance that psychosocial factors play in determining the way dementia unfolds" (p. 408).

As an alternative explanation for their findings, Naylor & Clare (2008) pointed to studies that highlight the role of social and psychological variables, such as psychological defences or personality related factors, in the construction of unawareness (Clare, 2003; Pearce, Clare & Pistrang, 2002; Seiffer, Clare & Harvey, 2005). In recognition of this body of evidence, the most comprehensive model of unawareness takes a biopsychosocial approach and acknowledges the interaction between biological, psychological and social influences on unawareness in AD and similarly in brain injury (Ownsworth, Clare & Morris, 2006). The psychosocial aspects of unawareness are given prominence in this model because, in early AD "psychological and social factors would typically account for a much greater proportion of any observed awareness" (Ownsworth et al, 2006, p. 430). The psychological factors cited in the biopsychosocial model include coping style and personality and social factors which include interactions with others and the influence of social and cultural representations of dementia. The biopsychosocial model incorporates these psychosocial influences and presents them in the context of the "subjective experience of the self" (Ownsworth et al, 2006, p. 429).

Since the level of unawareness may therefore mirror the altering contributions of neurological, psychological and social factors at any given time, Seiffer et al (2005) sought to distinguish the role of personality on unawareness from coping style. They suggested that unawareness could be considered a defence mechanism akin to the psychoanalytical concept of denial or as an actively employed avoidant behavioural coping strategy and attempted to identify their relative contribution to awareness. Their findings showed that the only personality-related variable that was associated with unawareness was conscientiousness. Avoidant behavioural coping was not associated with either unawareness or conscientiousness which led the authors to conclude that unawareness was attenuated by conscientiousness and that this was an unconscious defence mechanism. They posit that the highly conscientious individual is unaware of their difficulties with functioning and therefore cannot report them. Conscientiousness is highly correlated with impression management (IM), one of two subcomponents of social desirability (Uziel, 2010). Social desirability is the tendency to present oneself in a favourable light. IM represents an individual's conscious efforts to deceive others whereas the other subcomponent, self-deception, reflects individual's actual beliefs about their positive qualities (Paulhus, 1984). There are two opposing approaches to viewing IM: some take a *defensiveness* view which considers IM to reflect defensive, maladaptive and avoidant attempts to present the self favourably in order to protect the self from rejection by others and the *adjustment* approach which hypothesises that IM is an active and adaptive mechanism which reflects psychological adjustment and well-being (Uziel, 2010). Defensiveness accounts predict that those who employ this strategy are defensive, avoidant and behaviourally inhibited and are preoccupied with protecting their identity from vulnerable self-esteem, resulting in anxiety, stress and social maladjustment. Adjustment advocates predict that IM promotes emotional stability and reflects high levels of self-esteem or positive evaluations of identity (Borkenau & Ostendorf, 1992). The former approach was applied by Seiffer et al (2005) to explain their findings.

Ownsworth, McFarland and Young (2002) sought to clarify the relative contributions of neuropsychological and psychological factors in unawareness in those who have sustained an acquired brain injury. Specifically, they were interested in systematically clarifying the relationships between personality-related denial, coping-related denial and post-injury personality change. They drew a similar distinction to Seiffer et al (2005) between personality-related denial (defensiveness) which impacts on unawareness via pre-morbid personality characteristics, acting as a buffer to emotional stress, and coping-related denial (reduced symptom reporting) which represents an adaptive coping mechanism that is employed to avoid social stigma. Using the Marlowe-Crowne Social Desirability Scale (MCSDS: Crowne & Marlowe, 1960) as a measure of personality related denial, they found that those who scored highly also showed a higher level of coping-related denial. Ownsworth, et al (2002) concluded that those with a tendency to present themselves in a socially desirable way used this as a strategy to cope with their injury to manage the threat to their self. Subsequently, it is possible that those with dementia may utilise similar coping mechanisms and, as a result, may mask awareness of their illness by underreporting their difficulties in favour of presenting themselves in a desirable light. Qualitative interviews conducted with those who have dementia have also supported the notion that denial of deficit is an active strategy employed to protect the individual from psychological distress caused by acknowledging their functioning difficulties (Clare, 2003; O'Callaghan, Powell & Oyebode, 2006). O'Callaghan et al (2006) suggest that the fact that their participants were able to articulate cognitive and behavioural processes relating to denial, such as minimisation of difficulties, demonstrates that these were active and conscious processes which help people to cope with their difficulties rather than unconscious processes employed to protect the self from making 'unbearable truths' accessible to consciousness. Investigations such as these contradict the suggestion of Seiffer et al (2005) that unawareness is the result of an unconscious denial mechanism designed to protect the self from threat. This difference in viewing IM as an unconscious or conscious mechanism is echoed throughout the literature. However, there is agreement between the approaches that IM reflects an inter-, rather than intra-, personal sensitivity. What differs between the denial and IM approaches is the degree of control the individual exerts (Uziel, 2010).

Having reviewed the evidence base for both perspectives, Uziel (2010) concludes that there is an overwhelming case for IM to be considered as an adaptive conscious mechanism, more akin to coping-related denial. This coping strategy has been shown in other clinical populations to afford the individual numerous benefits such as coping with socially induced stress (Blackhart, Eckel & Tice, 2007), moderating negative feelings and reducing negative emotions such as depression and anxiety (Clark, Crewdson & Purdon, 1998). IM has also been shown to be related to better mental and physical health (Gravdal & Sandal, 2006). IM may therefore be employed as a strategy to counteract the social threats to identity and/or to protect an individual's sense of identity by influencing awareness about functioning difficulties and may be associated with better, rather than poorer, clinical outcomes. Indeed, those with TBI who were engaging in socially desirable responding were shown by Ownsworth, Fleming, Strong, Radel, Chan & Clare (2007) to have the most favourable emotional adjustment and psychosocial outcomes as compared with other types of psychosocial coping such as reduced symptom reporting.

Clinically however, those with dementia who display poor awareness have demonstrated poorer clinical outcomes and are: less likely to benefit from treatment (Clare et al, 2004); are more likely to deny their deficits and engage in risky behaviours such as driving (Woods & Pratt, 2005); and are less likely to comply with medical treatment and be at elevated risk of an accidental overdose (Arlt et al, 2008).

Nevertheless, if for some individuals socially desirable responding is used as a buffer to threats to identity, whether consciously or unconsciously, it is questionable whether interventions aimed at improving awareness of memory difficulties are ethical or even likely to be effective. Research elucidating the mechanisms and motivations behind unawareness will be useful in identifying appropriate areas for clinical intervention and methods of doing so.

Given that evidence does exist which supports accounts of IM being a form of defensive denial (see Uziel, 2010), it may be the case that interventions focussed on behavioural approaches to problem-solving and coping skills, rather than emotional or process issues which may be too threatening to the individual to discuss, would be more efficacious (Seiffer et al, 2005). It is therefore important to understand more about the psychosocial factors which impact on unawareness in order to understand the function they perform before person-centred treatments can be suggested. Furthermore, since those who care for people with little awareness report higher levels of caregiver burden (Seltzer et al, 1997), formulating the unawareness from a biopsychosocial perspective and communicating this to caregivers may offer further insight into the complexities of unawareness and dementia and afford them a better understanding and offer support. Taken together, these issues highlight the importance of understanding the factors influencing unawareness in those with dementia.

Whilst impression management, in its many guises, has been widely researched in areas such as organisational psychology or with other clinical populations such as those with a brain injury (Ownsworth et al, 2002), lung cancer and heart disease (Levine & Zigler, 1975), none have used a measure to directly assess IM, hereafter referred to as social desirability, in those with dementia. Since the extent to which identity and awareness continue to exist in those with dementia is a matter of debate, and there are important implications for how people cope with their illness, relate to others and what interventions are appropriate for them related to these issues (Caddell & Clare, 2010), this study seeks to explore the relationships between, unawareness, identity and social desirability in dementia. The present study will explore whether those who engage in socially desirable responding are less likely to disclose being aware of their difficulties with memory functioning (show unawareness) and to investigate the impact of this method of coping on an individual's identity in terms of definiteness (certainty), vagueness, and direction (extent to which they see their identity as positive or negative).

Aims

This research aimed to investigate the relationship between awareness, identity and social desirability in early dementia. Three main research questions were addressed:

1. Is there a relationship between unawareness and identity?
2. Is there a relationship between unawareness and social desirability?
3. Is there a relationship between identity and social desirability?

Method

Design

Relationships between unawareness of memory functioning, identity and social desirability in dementia were explored using a correlational design. Formal sample size calculation was conducted using G*Power (Erdfelder, Faul & Buchner, (1996) and based on the results reported by Naylor & Clare (2008). According to that study, the amount of variance explained by the measure of identity calculated by multiple regression was R^2=0.25, which generated a Cohen's f2 effect size of 0.33. In order to detect results with a similar effect size (between 0.275 and 0.375; considered a medium to large effect) at a significance level of alpha = 0.01, a sample size of between 42 and 56 would be required and recruitment of a sample of this size was the aim of this study. Favourable ethical opinion was received from South Birmingham Research Ethics Committee (Appendix 3).

Participants

Inclusion criteria. Participants had recently been diagnosed by clinicians at a specialist memory assessment service serving a large urban population in the UK as having dementia of either the Alzheimer's, vascular or mixed type, following multidisciplinary assessment based on medical history and examination, neuropsychological assessment, functional assessment and in some cases electroencephalogram (EEG) or computed tomography (CT) scan. Only those with a clinician verified diagnosis and in the early stages of the disease, as determined by a score of 18 or above on their most recent Mini Mental State Examination (MMSE, Folstein, Folstein & McHugh 1975) were considered suitable to participate. Those considered as lacking capacity to participate by clinicians did not satisfy the eligibility criteria and were therefore not invited to participate. Participants were required to be fluent in English since the questionnaires are only available in English. It was also necessary for the participants to have an informant who could participate in the study.

Exclusion criteria. Participants with frontal dementia, a history of major head injury, acquired language problems to prevent communication, neurological abnormality other than dementia, alcoholism or drug dependence, psychiatric illness or prolonged use of psychiatric medication were excluded.

Twenty eight people with dementia took part in the study. There were 17 males and 11 females whose ages ranged from 67 to 92 (M = 79.75. S.D. = 5.78). Nineteen participants had a diagnosis of vascular dementia, two had a diagnosis of Alzheimer’s disease and seven had a diagnosis of mixed Alzheimer’s disease and vascular dementia based on the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV, American Psychiatric Association, 1994). MMSE scores ranged from 18 to 29 (M = 24.04, S.D = 3.26). Twenty eight informants were recruited. Twenty six of these were the spouse of the person with dementia, one was a daughter and one was a sister. All the participants were living independently either with their spouse or alone.

Procedure

Those identified as satisfying the eligibility criteria by the clinical care team were invited to participate by the lead clinician. A Participant (Appendix 4) and a Carer (Appendix 5) Information sheet were sent after this identification, along with a covering letter (Appendix 6) from the lead clinician explaining the reason they were being contacted. Those who expressed initial interest were then contacted by the researcher. Participants and informants were visited in the participant's home by the researcher to complete the questionnaires after giving written informed consent (Appendix 7). All but one of the participants completed their questionnaires at one testing session. There was a one week delay in completing the remaining participant's questionnaires. Participants had already completed a Mini Mental State Examination (Folstien et al, 1975) as part of the diagnostic procedure so this was not repeated. Participants consented to this information being accessed from their care records. The following standardised assessments (Appendix 8) were administered verbally and in the following order: Marlowe Crowne Social Desirability Scale (MCSDS, Crowne & Marlowe, 1960), the Tennessee Self-Concept Scale Second Edition (TSCS II, Fitts & Warren, 1996), the Memory Awareness Rating Scale Memory Functioning Scale Subject version and finally Memory Awareness Rating Scale memory Functioning Scale Informant version (MARS MFS S and MARS MFS I, Clare et al, 2002). Demographic information such as age and diagnosis, along with MMSE score, was recorded on a Demographic Information Sheet (Appendix 9).

Measures

The MCSDS is a 33 item questionnaire which measures social desirability by asking individuals to rate whether particular attitudes or traits relate to them personally. Participants are asked to respond with "true" or "false. Eighteen of the items are positively oriented (socially desirable behaviours which have a low probability of occurring) and 15 negatively (socially disapproved behaviours which have a high probability of occurring). The items are dichotomously scored (true=1, false=0), with the reverse for the negative items, and are used to derive a score which indicates the level of socially desirable responding. A higher score on the MCSDS indicates a higher degree of social desirability. There are no accounts in the literature of the MCSDS being used with those who have a diagnosis of dementia and this study may therefore represent the first to do so. It has, however, been utilised in over 2500 studies (Uziel, 2010) and has been used successfully with people with a brain injury (Ownsworth et al, 2002) and older people such as the carers of those with dementia (O'Rourke, Haverkamp, Rae, Tuokko, Heyden & Beattie, 1997).

The TSCS II (Fitts & Warren, 1996) is an 82 item scale measuring various components of the self-concept. The 21 items of the identity subscale were administered to yield an identity direction score. Participants were asked to rate how representative a statement was of their sense of identity according to a 5 point scale. An identity direction score was calculated from the sum of the 21 identity subscale items (maximum score = 105). A higher score indicates a more positive identity. This method is in keeping with previous research (Addis & Tippett, 2004; Naylor & Clare, 2008). Scores were converted to T scores as indicated by the manual. An identity score of below 40T is indicative of an actively negative view of the self. Alternatively, it is also possible to deduce how definite someone is about their identity by calculating scores based on the response distribution. This involves counting the number of definite responses (“always true” (5) or “always false” (1)) and the number of vague responses (“partly false and partly true” (3)). These scores were used to assess how definite and conversely, how vague, an individual’s view of their identity was and so separate identity definiteness and identity vagueness scores were obtained. Addis & Tippet (2004) demonstrated that it is possible to obtain a response distribution score from only the 21 items of the identity subscale rather than having to administer the entire 82 item scale. In order to minimise the potential fatigue, stress and burden to participants, this method was adopted. Addis & Tippet (2004) and Naylor & Clare (2008) utilised the TSCS II scale due to its reported good internal consistency, test-retest reliability, construct validity and discriminant validity (Fitts & Warren, 1996).

The MARS was used to assess awareness. The MARS MFS S asks the participant and the MARS MFS I asks an informant to rate how well the person with dementia would perform on a range of everyday memory tasks. A discrepancy rating (MARS MFS D) is then calculated. A lower discrepancy reflects the participants’ assessment is similar to their informants’ assessment, suggesting greater awareness of functioning whereas a high discrepancy score is indicative of poorer awareness. Clare (2002) reports that the MARS has good internal consistency, test-retest reliability and construct validity.

Results

Preparation for Analysis

Analyses using the one sample Kolomogorov-Smirnoff test (Appendix 10) were performed on all variables. All the variables were found to be normally distributed and met the assumptions for parametric tests.

Table 1 shows the means and standard deviations (SD) for all the measures. As the MCSDS has not been used with people with dementia before, it was tested for internal reliability. The 33 items showed an acceptable internal consistency coefficient; alpha = 0.72. The current sample obtained a mean score on the MCSDS within one standard deviation of that of carers of those with dementia (O'Rourke et al, (1996)) (M= 20.4, s.d. = 5.17).

The 21 items of the TSCS II identity subscale also demonstrated good internal consistency (alpha = 0.75). In comparison to age stratified means on the TSCS II (M = 49.0, s.d. = 9.9) cited by Fitts & Warren (1996), the current sample obtained a comparable identity direction score. However, it should be acknowledged that the current sample were still less positive about their identity than that expected of those of a similar age and also less positive than that reported by the participants of Naylor & Clare (2008) (M = 50.2, s.d. = 9.5). Although the variables of definiteness and vagueness were normally distributed, medians and interquartile ranges are reported to allow direct comparison between the findings of the current study and those of Addis & Tippet (2004). In contrast to Addis & Tippett's (2004) participants, the current sample exhibited fewer definite responses than those reported by participants with Alzheimer's disease (Mdn = 9, interquartile range = 7.5) or controls (Mdn = 10.5, interquartile range = 14.5). Furthermore, the current sample made fewer vague responses in comparison to those with Alzheimer's disease (Mdn = 4, interquartile range =5, or controls (Mdn = 3, interquartile range = 3) (Addis & Tippett (2004)).

In relation to the level of unawareness, the current sample were more aware than those in the sample of Naylor & Clare (2008) (M = 14.5, s.d. = 14.8). The current sample were marginally less cognitively impaired than Naylor & Clare's (2008) sample (M = 22.4, s.d. = 3.61) but were more than one standard deviation less cognitively impaired than Addis & Tippet's (2004) Alzheimer's disease sample (M = 19.85, s.d. = 3.15). According to the diagnostic cutoffs of the MMSE (Folstein, Folstein & McHugh, 1975), the current sample would be classified as within the "mild" range.

Table 1 Mean scores of social desirability, identity direction, awareness, identity definiteness and cognitive functioning

Measure	N	Maximum possible score	Mean	SD
MCSD	28	33	24.21	4.23
TSCS II identity direction	28	100*	45.67	8.06
TSCS II identity definiteness (median and interquartile range)	28	105	7.5	7.5
TSCS II vagueness (median and interquartile range)	28	21	2	3
MARS MFS D	28	52	9.61	11.56
MMSE	28	30	24.04	3.26

* denotes T score

In order to look at the relationships between the variables, Pearson product moment correlations were performed (Table 2). The analysis looked at relationships between awareness, identity, social desirability and cognitive functioning.

Table 2 Correlations between the MMSE scores measures of social desirability, identity and unawareness

		MMSE	MCSD	TSCS direction	TSCS definiteness	TSCS vagueness	MARS D
MMSE	Pearson Correlation	1	-	-	-	-	-
	Sig. (2-tailed)		-	-	-	-	-
MCSD	Pearson Correlation	-0.366	1	-	-	-	-
	Sig. (2-tailed)	0.055		-	-	-	-
TSCS direction	Pearson Correlation	-0.079	.486**	1	-	-	-
	Sig. (2-tailed)	0.689	0.009		-	-	-
TSCS definiteness	Pearson Correlation	0.155	0.255	.754**	1	-	-
	Sig. (2-tailed)	0.432	0.191	0		-	-
TSCS vagueness	Pearson Correlation	0.104	-0.263	-.447*	-.398*	1	-
	Sig. (2-tailed)	0.597	0.177	0.017	0.036		-
MARS D	Pearson Correlation	-.418*	0.256	0.243	.449*	-.419*	1
	Sig. (2-tailed)	0.027	0.189	0.212	0.017	0.026	

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

The first research question investigated a relationship between unawareness and identity, as reported by Naylor & Clare (2008). As can be seen above, no relationship was found between identity direction and unawareness. On the other hand, a positive relationship between unawareness and identity definiteness narrowly missed statistical significance suggesting that those who were less definite were more aware. However, a negative relationship was found between unawareness and identity vagueness which also missed statistical significance. This suggests that those who were more unaware were more definite and less vague about their identity.

The second research question examined whether there is a relationship between unawareness and social desirability. As demonstrated above, no relationship was found between unawareness and social desirability. However, social desirability was found to be positively correlated with direction of identity.

The third research question explored the existence of a relationship between identity and social desirability. As displayed in the above table, a statistically significant positive correlation between identity direction and social desirability was reported. However, there was no relationship between identity definiteness and social desirability.

Although not part of the main research investigation, level of cognitive ability and level of unawareness showed a negative trend but failed to reach statistical significance ($p = 0.027$). As expected from the technical data in the manual for the TSCS II provided by Fitts & Warren (1996), identity direction correlated positively with TSCS II definitenesss.

Discussion

This investigation explored relationships between unawareness, identity and social desirability in individuals with dementia. The first aim was to explore the relationship between unawareness and identity; however the results of this study only showed a positive trend towards a relationship between unawareness and identity definiteness (those who were less aware were more definite). This result fails to replicate the findings of Naylor & Clare (2008) who found those who were more unaware were more definite and more positive about their identity. This may be due to the fact that the current sample was more aware than Naylor & Clare's sample. As in Naylor & Clare's (2008) sample, the standard deviation is greater than the mean MARS MFS D score and thus, like their study, the present findings must be interpreted with caution.

The finding of a positive trend between unawareness and identity definiteness may be interpreted as suggesting that those who have awareness of their functioning difficulties might (understandably) experience a lack of certainty about their identity, whereas those who are unaware may report a more definite sense of identity. However, it is important to emphasise that this result denotes a trend and not a finding that reached statistical significance. Nevertheless, many empirical studies support the notion that dementia impacts on sense of identity (see Cadell & Clare, 2003 for a review). The finding of a positive trend between unawareness and definiteness can be explained in neuropsychological terms by the CAM model (Hannesdottir & Morris, 2004) which would attribute a higher level of unawareness and a more definite sense of identity to difficulties with autobiographical memory. This model suggests the person with dementia may be relying on outdated information within their PDB to produce a response and so they remain more definite.

The second research question investigated the relationship between unawareness and socially desirable responding but there was no relationship found here. Interestingly, the scores on the MCSDS demonstrated that the participants in this investigation were engaging in socially desirable responding at a level comparable to their peers (O'Rourke et al, 1996), yet their scores on the TSCS II suggested they were slightly less positive about themselves than previous research (Naylor & Clare, 2008). The MCSDS asks participants to respond "true" or "false" to 33 statements about attitudes and traits. Many of these items may be more applicable to an individual's past than their current identity or require the participant to rely on autobiographical memory from an earlier period in their lives rather than recently acquired information. For example, the statement "It is hard for me to go on with my work if I am not encouraged" may be understood as relating to a time when the participant was in paid employment rather than their current retired status. The responses on the MCSDS might therefore not reflect true current attitudes towards socially desirable responding but instead, memories of incidences of socially desirable responses from the past. It is conceivable therefore, that socially desirable responses may have been being made on the basis of earlier autobiographical memories in addition to accessing an out of date PDB. Scores on the MCSDS would then be predicted to be at a level comparable to participants' peers whereas their scores on the TSCS II might reflect current attitudes towards identity depending on their awareness of their memory functioning.

The final research question examined the relationship between social desirability and identity. The results show a strong positive correlation between socially desirable responding and identity direction but no such relationship with identity definiteness or vagueness. The relationship between socially desirable responding and a more positive identity is expected given that a more positive identity is more desirable. The levels of socially desirable responding elicited in this sample were not considerably different to those reported in a group of carers of those with dementia (O'Rourke et al, 1996). It therefore appears that unawareness was not affected by participants' impression management concerns. Since the

MCSDS has been shown to load more onto the impression management factor, rather than the self-deception enhancement factor, of socially desirable responding (Uziel, 2010), any relationships between unconscious mechanisms such as denial may not have been revealed. Subsequently it has not been possible to explore whether the sample were responding in a socially desirable way due to personality related factors that predate the dementia. Further work is needed to investigate any possible relationships between unawareness and social desirability in dementia.

In this study, a strong association between direction and definiteness was reported which concurs with the work of other researchers (e.g. Baumeister, Tice & Hutton, 1988; Campbell et al, 2003) and is to be expected, given that the greater the number of more definite answers for positive items, the more positive their identity. Furthermore, a negative trend between identity direction and vagueness was reported. Given that a more positive identity is the product of more positive and definite responses and fewer vague responses, this is also as expected.

Finally, a negative trend between unawareness and cognitive ability was reported. Whilst some research cites examples of unawareness diminishing as dementia progresses (McDaniel et al, 1995), it is more commonly reported that unawareness and cognitive ability share the same trajectory. The potential reasons for this discrepancy are outlined in reviews by Clare (2004a; 2004b) such as a lack of conceptual clarity about what awareness it and how it should be measured.

Methodological limitations

The findings of this study must be considered in light of its methodological shortcomings. Foremost, the statistical analysis was underpowered by a small sample size. Although comparable to both Addis & Tippet (2004) and Naylor & Clare (2008), there were insufficient participants to accept findings at less than the 1% level of chance. Furthermore, there were a disproportionate number of participants who had vascular dementia in the sample. Whilst an independent t test conducted on the means of the different diagnostic groups did not reveal any significant differences, it is possible that the overrepresentation of vascular dementia relative to Alzheimer's disease may contribute to the lack of correspondence between the current study and that of Naylor & Clare (2008). Furthermore, it appears that the current sample were more aware of their functioning difficulties than that of Naylor & Clare (2008). It might be the case that a relationship between social desirability and unawareness may be revealed in a more cognitively impaired sample. This provides an area for future investigation.

Whilst the research literature cites examples where individuals who have sustained a brain injury have successfully completed the MCSDS, no studies could be found where it had been used with people who have dementia. Although this study may go some way to demonstrating its utility in this population, it should be noted that for three female informants, the question about driving "I never make a long trip without checking the safety of my car" was not applicable as they had never driven. In these cases the participants were asked to answer according to how they would expect to behave if they did own a car. Whilst no differences were found in relation to the internal reliability of the MCSDS in this sample, the females' answers may therefore be less indicative than the others of their overall level of social desirability. Future research may benefit from using a measure of social desirability less sensitive to the effects of age bias.

There are also few examples in the literature of the use of the TSCS II those with dementia. As a result, the suitability of the TSCS II in the assessment of identity in those with dementia is still to be established. Given that all the participants were able to complete the questions and the measure showed good internal consistency and reliability, there is nothing to suggest that the results obtained were not reliable and valid. However, further studies are needed to conclusively establish its reliability and validity.

In the current study, unawareness was assessed using the discrepancy between self and informant ratings akin to the methodology of Naylor & Clare (2008). Subsequently, the flaws identified by Naylor & Clare (2008) in their investigation are applicable to the current study. Specifically, these relate to the choice of unawareness measure (discrepancy rather than objective report by clinician) and the lack of generalisability of the findings to other types of unawareness of functioning such as unawareness of executive difficulties. Naylor & Clare (2008) note that there is evidence that the self-rated versus objective task performance measure of awareness can sometimes provide more accurate measures of unawareness than the method applied here (Dalla Barba et al, 1995). However, this alternative self versus objective method is more analogous to the type of cognitive unawareness described in the CAM model in relation to the performance of the PDB which was not the focus of the current study. By exploring the views of the person with dementia and the person with the most contact with them, it is believed that a more meaningful understanding of unawareness as it relates to identity has been obtained.

Clinical implications

Whist the current study may have failed to demonstrate a direct relationship between social desirability and unawareness, this is not to say that those who were reporting being unaware were truly so. Ownsworth et al (2007) conducted research with people who had sustained an acquired brain injury and attempted to identify typologies of unawareness and compare clinical outcomes on measures of adjustment and psychosocial functioning. Those classified in the ‘defensive group’ had scores above the norm (Reynolds, 1982) on the MCSDS, and scored lower on measures of symptom reporting and awareness. Their awareness deficits were subsequently attributed to psychological rather than neuropsychological processes. Whilst evidence has been reported that high levels of defensiveness are associated with poorer outcomes (Ownsworth, 2005), those in Ownsworth et al’s (2007) study who had a high defensiveness style were found to have better psychosocial functioning and emotional adjustment than the neuropsychological awareness typologies and the remaining psychosocial awareness typology, ‘high symptom reporting group’. The authors concluded that high defensiveness (socially desirable responding) is associated with more favourable outcomes post-TBI. Whilst the current study failed to demonstrate an association between unawareness and social desirability, this may be due to confounding factors rather than the absence of such a relationship. If socially desirable responding does underpin psychological unawareness but affords protection from emotional maladjustment and psychosocial functioning difficulties, it may not be ethical or effective to attempt clinical interventions to improve awareness in these individuals.

Ownsworth et al (2002) highlighted the indirect effect that personality and coping related denial may have on measures of awareness. They concluded that assessments of unawareness should include measures of social desirability in those with brain injury. Despite the limitations cited regarding the current study, it is recommended that this be extended to those with dementia. Whilst social desirability has been considered in its many guises as being implicated in unawareness in dementia, no studies have explored this using a measure of active coping (as considered by impression management proponents,) such as the MCSDS (Uziel, 2010). Furthermore, given the potential for more than one type of socially desirable responding to be influencing awareness, it may be clinically useful to determine self deception enhancement from impression management using a measure with more specificity than the MCSDS.

Finally, interventions which focus on supporting the highly sociable responder to address the threat to self and/or social stigma of dementia may be indicated as an area of future research. These may take the form of helping people to adjust to the symptoms of dementia and the emotional impact of these or perhaps a focus on dealing with the responses of others. Furthermore, individuals who have contact with those with dementia, both personally and/or professionally, may benefit from learning about the biopsychosocial formulation of unawareness which includes psychosocial influences such as denial and social desirability. Given that unawareness in such cases may be the product of psychological factors, these approaches are likely to be more advantageous than attempting neuropsychologically based interventions such as error monitoring.

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PUBLIC DOMAIN BRIEFING PAPER

AN INVESTIGATION INTO THE RELATIONSHIP BETWEEN MEMORY PROBLEMS AND OUR PUBLIC AND PRIVATE SELVES

Emma Henderson

Background

There is a wealth of both anecdotal and research evidence demonstrating the affect illness can have on a person's sense of identity. Studies investigating how identity is affected in brain disorders such as traumatic brain injury (TBI) and dementia have shown how mental processes, and individual differences in personality or the social environment, can play a role in shaping identity. By understanding the role of psychological and social factors in how identity changes and develops in the context of brain injury and dementia, researchers hope to design effective treatments to help people cope with and adjust to these illnesses.

Literature review

Given the impact that TBI has on identity, people who have sustained such an injury have much to teach us about the processes involved in the development of identity post-injury. This literature review examines the findings of twelve qualitative studies which have explored the processes involved in identity following a TBI. The findings are evaluated in the light of the methodological limitations of each study. The literature review concludes that identity development is hugely influenced by the social context of the person with TBI. As such, friends, family, professionals and society have a role to play in challenging the dominant story, or narrative, of loss in TBI and also in supporting the development of a coherent identity. The idea that TBI can be viewed as a positive rather than negative event also emerged from the participants' stories. Incorporating the TBI into the person, rather than the person into the TBI, seemed a key process. It is recommended that treatments focus on helping people with TBI to create numerous positive narratives, or stories, of their identity so that they can move flexibly between them rather than having one dominant and inflexible story about who they are.

Empirical paper

People with dementia often report being unaware of their memory problems. Whilst some evidence supports a biological explanation, or attributes the unawareness to the interaction between biology and difficulties with mental functioning (Hannesdottir & Morris, 2004), other research has suggested that unawareness may be the result of psychological processes. For example, Naylor & Clare (2008) found that people with dementia who reported being unaware of their memory difficulties also reported a more positive and more definite sense of identity. The authors concluded that unawareness and sense of identity are related to one another. They also suggested that unawareness may be the product of psychological processes called upon to act as a buffer to emotional distress. Interestingly, people with brain injury have been shown to use psychological processes, such as denial and socially desirable responding (presenting the self in a favourable light), when they report unawareness of their difficulties (Ownsworth, McFarland & Young, 2002). It may therefore be the case that unawareness in dementia may be due to a masking of awareness rather than an actual unawareness. Those who report being unaware of their difficulties have been shown to have poorer responses to treatments, increased mental health issues and their carers are more likely to experience high levels of stress and burnout. Understanding more about the psychological factors that underpin unawareness will allow for more effective treatments to be designed to tackle the negative effects of unawareness outlined above. Whilst the impact of social desirability on awareness has been investigated in people with brain injury, it has not been explored in people with dementia. The aim of this study was to explore the relationship between unawareness, identity and social desirability in people with mild to moderate dementia.

Participants

Twenty eight participants, seven males and eleven females, were recruited from a regional memory disorders service. Two people had a diagnosis of Alzheimer's disease, nineteen had a diagnosis of vascular dementia and seven had mixed Alzheimer's and vascular dementia. A relative of each participant was also recruited as an informant to give their perspective of the person with dementia's level of awareness.

Procedure

Participants were visited in their own homes and completed questionnaires on: socially desirable responding; identity characteristics and how definite they were about these; and awareness. The informant for each participant also completed a questionnaire about their relative's awareness. The discrepancy between the two scores was taken to indicate the level of unawareness, with greater discrepancies suggesting higher levels of unawareness. With consent from the participant, the score they obtained from their most recent mental functioning assessment was taken from their clinical notes and used as an indicator of mental functioning.

Results and conclusion

Many relationships failed to reach statistical significance due to a lack of sufficient power in the calculations. Unlike previous findings, identity was not found to be related to awareness. Neither was a relationship found between social desirability and awareness. However, a statistically significant relationship was found between social desirability and the degree to which someone views their identity positively. This finding is expected as socially desirable responses would be expected to be related to having more positive characteristics. Given the insufficient power in the calculations, further investigations are recommended to more fully understand the relationships between unawareness, identity and social desirability. It is also recommended that social desirability be considered by clinicians undertaking assessments of awareness.

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Appendix 1

Criteria for Assessing the Quality of Quantitative Versus Qualitative Research Based on Shenton (2004)

Traditional Criteria for Judging Quantitative Research	**Alternative Criteria for Judging Qualitative Research**	**Strategies for Judging Qualitative Research**
internal validity	credibility	• the adoption of research methods well established • the development of an early familiarity with the culture of participating organisations prolonged engagement/rapport building • random sampling • triangulation • tactics to help ensure honesty in informants • iterative questioning • negative case analysis • frequent debriefing sessions • peer scrutiny of the research project • the researcher's "reflective commentary" • background, qualifications and experience of the investigator • member checks • thick description of the phenomenon under scrutiny • examination of previous research findings
external validity	transferability	• extent to which the findings of one study can be applied to others • responsibility of the investigator to ensure that sufficient contextual information about the fieldwork sites is provided to enable the reader to make such a transfer: a) the number of organisations taking part in the study and where

		they are based; b) any restrictions in the type of people who contributed data; c) the number of participants involved in the fieldwork; d) the data collection methods that were employed; e) the number and length of the data collection sessions; f) the time period over which the data was collected
reliability	dependability	• if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained • the research design and its implementation (plan and execution) • the operational detail of data gathering • reflective appraisal of the project, evaluating the effectiveness of the process of inquiry undertaken.
objectivity	confirmability	• confirmability is the qualitative investigator’s comparable concern to objectivity • work’s findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher • “reflective commentary

Appendix 2

Submission instructions for authors for Neuropsychological Rehabilitation

Appendix 4

Participant Information Sheet

Title of Project: The relationship between memory problems and our public and private selves

Introduction

My name is Emma Henderson and I am studying at the University of Birmingham to become a clinical psychologist. I am carrying out a study looking into things that impact upon a person with memory problems. I am inviting you to take part in this research. 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.

What is the aim of this research?

This research is looking into how people with a memory problem view themselves. This may help us to support people with memory problems better in the future.

Why have I been invited to take part?

You have been invited to take part because you are currently under the care of the Birmingham Memory Assessment and Advisory Service and have a memory problem.

Do I have to take part?

It is up to you to decide. If you are interested in taking part I will telephone you to discuss the study in more detail. We will talk about the study and go through this information sheet. If you agree to take part I will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I agree to take part?

I will visit you at home to ask you some questions about your memory and your view of yourself. The questions are taken from questionnaires which have been used in research studies many times before. They ask you to rate how well a sentence describes you. I will also ask for permission to speak to a carer or someone who knows you well to ask them separately about your memory. It will take around an

hour and a half, or a bit longer if you would like to take breaks, to answer any questions you may have on the day about the research, sign the consent form and answer all my questions. When all the questions have been answered you will have finished being in the study.

Expenses and payments
Taking part in this research is voluntary so you will not be paid for doing so.

What are the possible benefits or risks of taking part?
We cannot promise the study will help you but the information we get from this study will help improve the treatment of people with memory problems. We are not aware of any disadvantages to you taking part. If you find answering the questions difficult or tiring you can stop for a break at any time.

What happens when the research stops?
When you have answered all the questions this is the end of you being involved in the research. If you like, you can ask for a copy of the results at the end of the study using the contact details below.

Will my taking part in the study be kept confidential?
Yes. You will not be able to be identified from the information you give and all information will be kept confidential including taking part.

What will happen if I do not want to carry on with the study?
You are free to leave the study at any time without giving a reason. Your care will not be affected in any way.

What will happen to the results of the research study?

The results will be published as part of my training as a Clinical Psychologist. This research may also be written up and published in a scientific journal

What happens if I have any concerns about the research?
Any concerns can be addressed either with me or Theresa Powell, Research Supervisor, The University of Birmingham, 0121 414 XXXX

Who is organising and funding the research?
The University of Birmingham.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed by South Birmingham Research Ethics Committee.

I will contact you in a few days to talk to you about the research and to ask if you would like to take part. Thank you for reading this Participant Information Sheet.

Emma Henderson (Clinical Psychologist in Training) 0121 414 XXXX

Appendix 5

Relative/Carer Information Sheet

Title of Project: The relationship between memory problems and our public and private selves

My name is Emma Henderson and I am studying at the University of Birmingham to become a clinical psychologist. As part of my studies I am looking into things which impact on people with memory difficulties. I am inviting you to take part in this research.

- What is the aim of this research?

This research is looking into how a person's view of themselves affects people with memory problems. This may help us to support people with memory problems better in the future.

- Why have I been invited to take part?

You have been invited to take part because someone you know is under the care of the Birmingham Memory Assessment and Advisory Service and has a memory problem.

- Do I have to take part?

You do not have to take part and if your decision will not affect your or the person with the memory problem's future care in anyway.

- What will happen to me if I agree to take part?

If you agree to take part, I will visit you and the person with the memory problem in their home where I will ask you some questions about their memory difficulties. The whole visit will last around an hour and your questions will take around 10 minutes. You will be welcome to take breaks if you wish. I will ask the person with the memory problem if it is ok before inviting you to take part. You will be asked to sign a form to say you are take part.

- Expenses and payments

Taking part in this research is voluntary so you will not be paid for doing so.

- What are the possible benefits or risks of taking part?

There are no disadvantages to you taking part. If you find answering the questions difficult or tiring, you can stop for a break at any time. There will be no direct benefit to you, although taking part in research can be very satisfying and enjoyable.

- What happens when the research stops?

When you have answered all the questions this is the end of you being involved in the research. If you like, you can ask for a copy of the results at the end of the study using the contact details below.

- Will my taking part in the study be kept confidential?

Yes. You will not be able to be identified from the information you give and all information will be kept confidential including taking part.

- What will happen if I do not want to carry on with the study?

You are free to leave the study at any time without giving a reason. Your care and the care of the person with the memory problem will not be affected in any way.

- What will happen to the results of the research study?

The results will be published as part of my training as a Clinical Psychologist. This research may also be written up and published in a scientific journal

- What happens if I have any concerns about the research?

Any concerns can be addressed either with me or Theresa Powell, Research Supervisor, The University of Birmingham, 0121 414 XXXX

- Who is organising and funding the research?

The University of Birmingham.

- Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed a Research Ethics Committee based in the West Midlands.

I will contact you in a few days to talk to you about the research and to ask if you would like to take part. Thank you for reading this Information Sheet

Emma Henderson (Clinical Psychologist in Training) 0121 414 XXXX

Appendix 6

Invitation letter

November 2011

Dear Sir/Madam

My name is Emma Henderson and I am carrying out some research as part of my training to become a Doctor of Clinical Psychology.

You have been given this letter by your clinician because you may be in a position to help me with my research. I was wondering whether you would allow me to telephone you so that I can tell you about it.

Agreeing to be telephoned does not commit you to taking part in the research.

If you're happy for me to call you I can explain what the project is about, what it involves, and what it would mean for you if you said yes to taking part. At the end of the conversation you can still take your time to decide whether to opt in or out. If you don't wish to take part you don't have to give a reason and your future health care will not be affected in any way. Should you decide to take part but change your mind later on you can withdraw at any time without giving a reason and again, without your health care being affected.

If you don't mind me giving you a call, please give your name and phone number below and put this letter in the post in the pre-paid envelope provided. You don't need a stamp. Alternatively you can call and leave a message on 0121 414 XXXX and I will get back to you.

Many thanks,

Emma Henderson
Clinical Psychologist in Training

Name:

Telephone number:

Appendix 7

Participant Consent Form

Title of Project: The relationship between memory problems and our public and private selves

Participant Identification Number:...

Please tick box

1. I confirm that I have read and understood the sheet dated 21/1/2011 (version 1.0) giving information about the above study. ☐
2. I have had a chance to think about the information, ask questions and have had these answered. ☐
3. I understand that taking part is voluntary and that I am free to withdraw at any time without giving any reason, without my medical or social care or legal rights being affected. ☐
4. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham. ☐
5. I understand that I will not be identified by any of the data I provide in this study. ☐
6. I give permission for the researcher to look at my healthcare notes ☐
7. I give permission for a relative or someone else I know well to be recruited to give their view of my memory ☐
8. I agree to take part in the above study. ☐

....	....	....
Name of participant	Date	Signature
....	....	....
Name of researcher	Date	Signature

Relative/Carer Consent Form

Title of Project: The relationship between memory problems and our public and private selves

Participant Identification Number:..

Please tick box

1. I confirm that I have read and understood the relative/carer information sheet dated 21/1/2011 (version 1.0) for the above study. ☐
2. I have had the opportunity to think about the information, ask questions and have had these answered. ☐
3. I understand that taking part is voluntary and that I am free to withdraw at any time without giving any reason, without my medical or social care or legal rights being affected. ☐
4. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham ☐
5. I understand that I will not be identified by any of the data I provide in this study. ☐
6. I agree to take part in the above study. ☐

....	....	....
Name of participant	Date	Signature
....	....	....
Name of researcher	Date	Signature

Appendix 8

Measures

Marlowe Crowne Social Desirability Scale
Tennessee Self Concept Scale
Memory Awareness Rating Scale Memory Functioning Scale (Subject)

Memory Awareness Rating Scale Memory Functioning Scale (Informant)

Appendix 9

Demographic Information Sheet

An Investigation into the Relationship Between Memory Problems and our Public and Private Selves

Date:

Participant Identification Number:

Diagnosis:

Gender:

Age:

MMSE score:

Appendix 10

A table displaying the results of the Kolomogorov Smirnoff test for normal distribution of variables

Variable	Significance (p)
Age	0.98
MMSE	0.76
MCSDS	0.60
TSCS II	0.96
MARS	0.97

The significance level is p=0.05