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Experiences that challenge self-identity following traumatic brain injury: a meta-synthesis of qualitative research

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Experiences that challenge self-identity following traumatic brain injury: a meta-synthesis of qualitative research

Purpose: To systematically review and synthesise the qualitative literature on experiences that challenge self-identity following traumatic brain injury (TBI). *Method*: Four electronic databases were searched systematically for qualitative research published between 1965 and August 2017, investigating subjective experiences of identity change following TBI. Papers which met the inclusion criteria were evaluated using the Critical Skills Appraisal Programme (CASP) tool and synthesised using guidelines by Thomas and Harden (2008). *Results*: Of the 1965 papers retrieved, 36 met inclusion and quality criteria. Synthesis resulted in six themes: (1) awareness of change in physical, cognitive, emotional and social functioning; (2) autobiographical memory loss; (3) responses of other people that highlight change; (4) loss of autonomy; (5) comparing old me and new me – loss of valued roles and activities; (6) social rejection and stigma. *Conclusions*: An in-depth understanding of the experiences that challenge self-identity after TBI can inform rehabilitation to support individuals to negotiate these processes with less distress and more successfully.

Keywords: Traumatic brain injury, self-identity, qualitative research, meta-synthesis, review

Introduction

On the basis of observing soldiers who had sustained traumatic brain injuries (TBI), Goldstein [1] developed the concept of the "catastrophic reaction". Environmental demands (such as being asked to complete a task that has become challenging because of the injury) may induce a sense of incoherence (in which different parts of the self do not function in an integrated and expected fashion) and a sense of discontinuity (which involves disruption to the experience of the self as a conscious, remembering and persisting subjective perspective on the world) [2]. These challenges to the sense of self can then trigger a state of extreme distress and shock, in which the person becomes unable to use even their intact abilities. To protect the self, the individual subsequently avoids situations that may result in failure and restricts activity to familiar and orderly routines. What Goldstein [1] observed is an example of an experience that challenges self-identity after TBI, and an example of a response to that challenge that is distressing and not particularly helpful. The aim of the present review is to synthesise the qualitative literature about identity change after TBI in order to provide a broader account of the types of experience that challenge self-identity. Such an account may be of clinical use: understanding what the challenging experiences are may help clinicians support people to negotiate these experiences in a less distressing and more productive way.

The concept of self-identity encompasses our knowledge and understanding of ourselves, our relationships and social roles, and our self-evaluation [3]. A number of factors contribute to our sense of self: understanding our personality (conceived as relatively stable and consistent patterns of thinking, feeling and behaving); understanding our motivations (including our goals, preferences and values); understanding our abilities, limitations and potential; knowing the roles we play within the social environment and our social connection with others; knowing our personal history; and an evaluative component (self-esteem) [3]. Self-identity can therefore be conceptualised as being constructed both subjectively focusing on what makes us unique and different from others, and socially through our interactions and group memberships [3,4].

TBI can result in profound changes to physical, cognitive, emotional, and behavioural functioning [3,5]. Physical changes, such as changes in gait, voice or body shape, can result in people with acquired brain injuries (ABIs) including TBI being less recognisable to themselves and others [6]. Retrograde amnesia can result in loss of access to an accurate self-history on which to base conceptualisations of a continuous self [6]. Cognitive changes (such as changes in memory, attention and concentration, planning and problem-solving and inhibition), emotional changes (including depression, anxiety and ability to regulate mood), and behavioural changes are frequently identified in judgements of personality change [6,7] which are common following TBI [8]. Any one of these changes can influence reintegration into society and the ability to fulfil self-defining roles in relation to living independently, work, intimate relationships and parenting [3,9,10]. Unsurprisingly then, experiences of identity change and crisis are commonly reported by people with acquired ABI including TBI [6]. The concept of identity change has been used to refer to disruption in the continuity of a person's subjective sense of who they are post-injury and is considered to be a key feature of TBI [3,5,11–14].

Quantitative studies measuring self-concept (a construct closely related to self-identity but which focuses on one's overall perception of self and perceived attributes or competency in a number of domains [15]) report that after TBI survivors typically rate their current self significantly more negatively than their pre-injury self and these negative evaluations are associated with a range of poor outcomes [16–19]. Greater perceived identity change (i.e. greater discrepancies between past and present self-ratings: "who I am now" versus "who I was before the injury") are associated with self-reported distress [19]; anxiety [20]; depression [17,20,21]; grief, poor adjustment and poor self-esteem [17]; and poor subjective quality of life [21] in people with ABI.

Conversely, positive identity experiences may be a protective factor following ABI including TBI. Jones and colleagues [22] reported that a strong personal identity (measured by ratings on the statement "Having had a brain injury has made me a stronger person" [22] [p.358]), survivor identity ("I think of myself as someone who has survived a brain injury") and social identity (measured by ticking off a list of "the relationships in your life that have improved since injury") were positively associated with life satisfaction in people with ABI. Mediational analyses indicated that personal and survivor identity, and social networks acted as a buffer against the negative effects of severity of injury on life satisfaction [22]. Walsh and colleagues [23] provided evidence that group membership facilitates social support and engagement in activities which becomes internalised into social identities of "self-as-doer" in people with ABI [23] [p.1]. These “self-as-doer” identities in turn predicted post-injury well-being [23].

Despite recognition of the importance of identity adjustment and reconstruction in rehabilitation [5,12,15,24–27], there has been little progress in the development of effective interventions. A review of intervention studies specifically targeting self-concept [15] found mixed support for their efficacy. The authors highlighted the need for theory-driven interventions to support positive identity experiences after TBI [15]. One step towards the development of more effective theory-based interventions is to establish a better understanding of the experiences faced by people with a TBI that challenge their self-identity. Knowing what these are and how people react to them could provide the basis for developing interventions that support people in dealing with these experiences in a way that is less distressing and more constructive than Goldstein’s [1] catastrophic reaction.

Qualitative research is uniquely able to explore in-depth subjective experiences and the meanings participants give to them [Willig, 2013] contributing to a nuanced and detailed understanding of experiences that challenge self-identity after TBI from the person with TBI’s own perspective. The focus of qualitative research on contextual factors [Willig, 2013], is likely to shed light on social and psychological processes such as changes in social roles, relationships, and dependency which are increasingly understood as central to one’s sense of self after TBI [3]. There is a growing body of qualitative research that has explored the issue of self-identity following TBI. Some of the studies contain material about identity-challenging experiences. The aim of this review is to provide an account of these experiences based on a meta-synthesis of these studies. Although a previous meta-synthesis of survivors’ experiences of recovery following TBI [28] identified some themes that relate to identity change, the review was broader in its scope and therefore did not include sustained and in-depth review of experiences and processes that challenge self-identity in TBI. The current meta-synthesis is therefore unique in its focus.

Method

Literature searches

A systematic literature search was conducted by the first author (DV) using the electronic databases PsycINFO, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science from 1965 to August 2017. PsycINFO was chosen for its coverage of the psychological literature; MEDLINE and CINAHL for their coverage of the health literature; and Web of Science for its extensive coverage. Combined keyword and subject heading searches were used to locate relevant articles. Searches were limited by peer review, human subjects and English language. Table 1 lists the search terms used and their combination. Following recommendations for locating qualitative research [29,30], citation tracking, hand-searching reference lists of relevant articles, and forward citation searching using the general search engine Google Scholar were used to locate additional reports.

[Table 1 near here]

Inclusion and exclusion criteria

Studies were included if they: (1) were published in a peer-reviewed journal; (2) were published in English; (3) reported an empirical qualitative study; (4) used as data the reported experiences of working age adults with TBI (>16 years); (5) contained findings relating to subjective experiences that challenge self-identity, defined as an experience where the person with TBI perceives that they are receiving information that they have changed as a person in some important way.

Using Noblit and Hare's [31] definition of qualitative research, the study was included if it sought to generate understanding of participants' subjective experiences and used an interpretative framework. Mixed methods studies were considered for inclusion if the qualitative data and analysis were distinct. Studies were excluded where the majority of participants had TBI but other participants had other forms of ABI. Studies that contained data from other participants (e.g. family members) in addition to participants with TBI were considered for inclusion only if the paper identified whether the data had come from people with TBI or another source, reported direct quotations from people with TBI, and focused on the experiences of people with TBI. All studies which contained data relevant to experiences that challenged self-identity were included even if this was not their stated focus [32].

The title and abstract of each article, and where necessary the full article, were screened against the hierarchy of inclusion criteria by the primary reviewer (DV) and checked by one of two reviewers (HC, KW). Differences in agreement, which occurred for less than 1% of articles screened (*n*=19), were resolved by consensus and/or arbitration of the third reviewer (GR; *n*=5).

Quality appraisal

Studies meeting initial inclusion criteria were critically appraised independently by two of three reviewers (DV, HC and KM) using the Critical Appraisal Skills Programme (CASP) qualitative checklist [33]. The CASP was selected from a range of quality assessment tools because it addresses the principles and assumptions of qualitative research (Tong, Flemming, McInnes, Oliver, & Craig, 2012); is suitable for use across a range of qualitative methodologies (Tong et al., 2012); and is one of the tools that is recommended by the Cochrane collaboration (Noyes, Popay, Pearson, Hannes, & Booth, 2015). Studies were only excluded based on quality if they failed to meet minimum requirements of a qualitative study

[34] assessed using the two screening questions of the CASP: (1) Was there a clear statement of the aims of the research?; (2) Is a qualitative methodology appropriate? The remaining eight CASP criteria (which assess appropriateness of the research design, recruitment, and data collection, consideration of the researcher-participant relationship and ethics, rigour of data analysis, clarity of findings, and the value of the research) provided broader information about reported study methodology for appreciation of its contribution to the synthesis, specifically to avoid over- or under-reliance on certain studies [34]. This decision was based on guidelines for synthesis of qualitative research which highlight the lack of consensus within assessment of quality in qualitative research both in terms of criteria by which to assess quality and reviewer agreement on quality (Pope et al., 2007; Sandelowski & Barroso, 2007; Thomas & Harden, 2008; Tong et al., 2012), and the risk of losing conceptually useful papers based on minor errors or omissions in reporting (Cambell et al., 2011; Noyes, Booth, Hannes, Harden, Harris, Lewin, Lockwood, 2011).

Data extraction and synthesis

Meta-synthesis is a method for integrating and interpreting findings dispersed across individual qualitative studies [35]. It aims to not only review data but reinterpret it to provide an enriched understanding of the topic [31,35]. The combined rigour, transparency and avoidance of bias of traditional systematic reviews, with the focus on complexity and context of qualitative research, means that meta-syntheses are considered uniquely placed to contribute to evidence-based practice and policy [34,36,37]. Data were first extracted on the general characteristics of each study including study focus, methodology, sample, data collection and setting. Next, the findings section of each study was extracted for synthesis. When an article met the inclusion criteria but not all findings were relevant to the research question, only relevant findings were extracted [38,39]. Thomas and Harden's [38] methods for thematic synthesis of qualitative research were followed: (1) the findings sections were read repeatedly and coded line by line for meaning; (2) descriptive themes were developed by looking for similarities and differences between codes within and across studies, and by arranging codes hierarchically; (3) higher level analytic themes that went beyond the themes presented within each individual article were developed. The first reviewer (DV) coded all the included studies and developed the initial themes. HC separately coded five studies (13.9%) and checked the codes against the emerging themes. The two reviewers then met to discuss the themes. This process confirmed that the emerging themes were present across papers reviewed by both reviewers and no new themes were identified that were not already represented within the emerging themes. The first reviewer (DV) then checked that the final themes included were present across studies to ensure that a small number of papers did not influence the themes to an undue extent.

Findings

Results from search strategy

Electronic database searches located 2422 papers. The removal of duplicates and application of inclusion and exclusion criteria left 32 remaining papers for inclusion (Figure 1). Additional searches resulted in the addition of five papers.

[Figure 1 near here]

Quality appraisal

Of the studies which met the initial inclusion criteria, one study [40] was excluded on the basis that it did not meet the minimum criteria for inclusion based on the CASP screening questions. Specifically, qualitative methodology was not considered appropriate for the study’s research questions. There was 100% agreement between reviewers regarding the inclusion or exclusion of papers based on the quality criteria. Consensus decisions on detailed critical appraisal of the remaining studies are presented in table 2. In 266 of the 288 quality decisions (92.4%), reviewers achieved complete consensus when independently categorising the studies as "yes", "no" or "unclear". Cohen's kappa was .84 indicating "near perfect agreement" [41].

[Table 2 near here]

Study characteristics

Table 3 shows the characteristics of the studies included. Two articles [44,45] presented data from one study, while a further three articles [62–64] had overlap in the data but different numbers of participants with the later articles reporting an extended version of the study. As the articles reported different themes and included different quotations, they were treated separately but care was taken not to allow undue influence of these participants on the synthesis findings. Accounting for overlaps, the studies collectively presented data from 386 participants (274 men, 112 women) with mild to very severe TBI, ranging in age from 17 to 81 years. Participants were recruited from hospitals, outpatient clinics, residential services, support groups, charities and the community, and ranged from 21 weeks to 40 years post-injury. Most studies used individual interviews as the method of data collection and several qualitative approaches were used including interpretative phenomenological analysis (IPA), grounded theory (GT), narrative and ethnographic approaches.

[Table 3 near here]

Study findings

Synthesis resulted in six themes: (1) awareness of change in physical, cognitive, emotional and social functioning; (2) autobiographical memory loss; (3) responses of other people that highlight change; (4) loss of autonomy; (5) comparing old me and new me – loss of valued roles and activities; (6) social rejection and stigma. It is noted that some studies are of poorer quality based on the CASP criteria. However, each theme is based on findings across several studies, which provides some triangulation.

Awareness of change in physical, cognitive, emotional and social functioning

Aligning with Goldstein's [1] observations, awareness of functional loss and changes, often triggered by struggling to complete tasks, may challenge the sense of self. Injury-related physical or cognitive changes, which might not be immediately apparent, affected self-knowledge about capabilities and participants' ability to define themselves: "She (OT) saw me shower, when I was on my own… Just to prove to myself that I could do it, because I had no idea what I could do any more" [45,p.78]. This included awareness of physical changes that could challenge self-concept: "...even the f... way I talk – it's so slow and I sound like I'm drunk or angry, it just makes me feel so small..."[68,p.233]. Affective or behavioural changes, such that individuals responded in ways inconsistent with their self-concept, threatened a coherent sense of identity: "Yes, you are not the same [as before the injury], you do not react in the same way anymore" [77,p.5].

These experiences could result in feeling changed in a radical and global sense: "I'm not normal: it will never be like I was before. I think differently and I feel different" [52,p.125]; and a sense of being alienated from the self: "I don't know this person any more. She is not reliable and cannot be trusted as my best friend" [63,p.872]. Without accurate knowledge about one's qualities and capabilities, the self was experienced as unpredictable: "I live my life without a certainty I must admit, of most things without a certainty of making the right decisions or thinking the right way or doing the right thing..." [61,p.985–986]. Some participants experienced fundamental loss of knowledge about the self: “I felt as though I didn’t even know that I had a personality to start with. I felt really sort of empty” [72,p.247]. The extent to which perceived changes in capabilities or attributes were experienced as threatening to sense of self was influenced by the personal qualities that the person with TBI valued before the injury: “I have lost my identity [...] that which I value so much – my mind – it doesn’t work like it used to” [43,p.411], or by the ways that they defined themselves: “I was always brought up that ‘if you start a job you finish it’ and that’s what I can’t do at the moment” [54,p.1575].

Again, consistent with Goldstein’s [1] observations, the response to these challenges is often withdrawal and avoidance. For example, some participants withdrew from social contact for fear of making mistakes or receiving feedback that might highlight changes in their self-identity:

> I didn’t do anything and um, that would make me question who... who I was and what I could do because it is to hang on to the idea that... that I was the old-me. You... you don’t want to do anything that would make that idea shake so you... err... you... I realised that I had made a prison for myself. I didn’t go out, I didn’t see people I knew I didn’t um, you know, um, I was all very, err [short pause] err, I didn’t want to disturb the idea in my head that I was, err, still exactly the same after the accident [48,p.206].

Other participants described difficulty acknowledging perceived changes:

> I'm bloody slower… I work slower… I hate saying that… I'm very evasive to admitting to that… It frustrates me knowing what my abilities used to be… We know what we were like before the accident and that's the worst bloody thing… Hardly a day goes by that I don't think about it… [46,p.398].

Autobiographical memory loss

Autobiographical memory loss, disrupting access to self-history and a continuous life-story, had a profound influence on people with TBI knowing who they are as a person:

> I don't remember myself in my later years with this amnesia. I remember myself most clearly at 17 years old. I don't remember being engaged but I remember (my girlfriend). I remember working in one office but not being supervisor. I am now only just getting to know this person in the mirror. I don't even look anything like I remembered. I don't feel, somehow, like I am anything like I was [58,p.76].

Loss of autobiographical memory was experienced as being a stranger in one's own life:

> I got home after the accident; it was literally like I'd stepped into somebody else's shoes. I didn't know my wife, I didn't know where home was, and I thought the garage was a mess, and it was, I guess, just as I'd left it. So yeah, it was literally like I'd stepped into someone else's shoes [60,p.5].

For some participants, it had an impact on their global sense of personhood:

> I don't remember anything about my life before the accident. [W]hen I woke up, I couldn't identify my mother, my brothers, and sisters, I couldn't identify anything. ...I didn't know I was an almost 18-year-old girl. ...I didn't know what one should do as a human being [55,p.44].

Loss of accurate self-history could leave participants not knowing how to approach daily life and challenges:

> cause you're brought up with the 'self' you know, you dealt with everything and it doesn't matter how old you are, the history you've had gets you to the point that you're at now and then to become something totally different [61,p.985].

Responses of other people that highlight change

Although a minority of participants described experiences of being treated the same as they were before by close others, for many the changed responses of close others was a major challenge to self-identity. These responses could signal a change in the person with TBI which they might not be aware of: "... I feel that there is something about me th... that there is something that my wife doesn’t feel is right and that, is, maybe something about me that is... that I... I need to change...” [48,p.201]. The attitudes and actions of friends and family towards the survivor included treating them with pity, wariness, or like a child:

> I feel that because of the head injury other people, mostly relatives and those who don’t know me or just met me, treat me like a small child. I feel that some of my older relatives think of me as “little Kevin.” … I notice people who work with the elderly or small children will raise the pitch in their voice. I notice people who do not know me very well will talk to me with a high pitch. … Those same people will explain to me what I need to do as if I am a 3-year-old [71,p.215].

Often it was family or friends who had known the person before the injury who pointed out changes in their personality or capabilities: “the old man [father] reckons I didn’t have a clue where to start and he goes, ‘gee that’s no good’ because I used to... put things together pretty easy” [65,p.1605].

Frequently, the responses of other people contradicted the person with TBI’s own felt sense of being the same: “How I get on with people I don’t think has particularly changed but I think people must obviously have a different view of me because they’re assessing, you know, does he really understand” [44,p.360]. Treatment by others, including employers highlighted discrepancies between self and other perception. For example, one participant described returning to work: “I personally thought it went really well. but then work suspended me on grounds of not being able to do the job, so there was my perception and their perception and they were completely different...” [53,p.135]. These discrepancies undermined participants’ sense of a continuous identity prompting them to question their self-image: “maybe I’m not seeing myself properly” [53,p.135].

Responses of professionals, which indicated change or damage to self, which included results of neuropsychological tests, could also threaten notions of a stable and intact self:

> Yeah, like I think, I think I’m okay. But yet I have tests, I have cognitive tests and they all prove that, no, you’re not what you used to be. I had tests done, you know, and he said, ‘Well according

> to what we have on your information, your standards and stuff, you're down considerably'. But I don't consider myself a dimwit really [49,p.67].

These authoritative discourses frequently caused participants to question their self-knowledge and defer to medical and professional knowledge: "I don't feel anything wrong with my brain, [but] they insist I'm brain injured. Well wouldn't they know?" [49, p.67–68]. They could be co-opted by family and friends in ways that undermined the credibility of the participant's own self experiences:

> [another challenge] is when you actually get over certain things but people around you are still thinking that you're still the person that's got the injury and that injury will always be with you because doctors or support workers or whoever, have told the people around you that this is how they will react, they'll be like this forever, they'll be this way, they can't they're just thinking that they can [61,p.988].

Feedback from other people was considered especially influential to appraisals of identity change due to changes in awareness post-injury resulting in people with TBI being more reliant on that feedback: "...my benchmark for how I am doing, I read off the feedback of other people" [69,p.649].

Loss of autonomy

People with TBI highlighted loss of autonomy post-injury as undermining of their self-identity through its impact on their sense of personhood and their social standing: "We planned to be together alone at night. ...We were found [by staff members] and separated. Do you know how that makes me feel? I'm 46 and she's 43. I feel like we're children" [51,p.541]. This included lack of involvement in decision-making about personal aspects of their daily lives: "I haven't recovered. I can't even do my own hair. No sense of control…I don't even choose what I wear"[43,p.413], and their body: "Now that I have diabetes they're really watching out for me. Which is a good thing for my own health, but I don't feel like I am in control of my own body, of my own self" [49,p.70].

Some participants acknowledged that in the early post-injury stages, it could be appropriate for other people to take responsibility for their care: "In the early stages I had no problem with the hospital calling the shots" [45,p.81]. However, it could still profoundly influence self-identity: "And suddenly after the injury I was forced to take help, myself, despite you are an adult, that is also—that takes naturally on the subconscious, somehow. That you can't do things by yourself, as you used to do earlier…" [76,p.286]. For some, lack of decision-making opportunities could result in a revision of self-identity so that people with TBI identified themselves with "sick role" [61,p.985] and could prompt passive self-positioning: "I just walk away and leave it, and go, 'it's up to you'" [57,p.2253].

Comparing old-me and new-me – loss of valued roles and activities

Comparisons between pre- and post- injury self, typically prompted by return to pre-injury environments or the attempted resumption of pre-injury roles and activities, contributed to judgements of identity change following TBI. Difficulty accessing pre-injury self-defining social roles was frequently cited in appraisals of identity change:

> Part of what exacerbated my profound sense of loss of self was the loss of my role as a valued member of the healthcare team. [...] A fundamental part of how I defined myself was associated with my previous work. I defined myself – and my sense of competence and compassion – in that role [59,p.242].

Typically, comparisons between pre- and post-injury roles highlighted loss of status; after the injury people with TBI occupied what they perceived to be devalued roles both occupationally: "I went from being, I suppose, a motivational lecturer to doing mail runs" [65,p.1604] and in relationships: "Well it's like instead of say being you know, the old fashioned head of the household, it's like I'm just a—well not quite a nothing, but just don't have a lot of status" [60,p.5–6]. These changes affected self-worth so that some people with

TBI appraised themselves to be a “lesser person” [45,p.80] after the injury: “you feel worthless, you aren’t profitable you just feel a spare part sitting there doing nothing” [50,p.753].

Without access to pre-injury roles, people with TBI struggled to define their identity: “If I'm nor a writer, if I'm nor a doer, who can do things for other people because I no longer have the capacity. If I'm nor any of those things, then who am I as a person?” [70,p.311]. In the absence of new roles by which to define their identity, some participants described having no clear sense of who they are:

> When they ask me what I do, for the last couple of years I have said ‘nothing’. After that 75% of people don’t want to talk to you. But if you are working, then you are one of the guys. If not, who knows what you are [58,p.77].

Other people with TBI defined themselves by the brain injury and its consequences: “I’m no longer Miss M. the teacher. I’m Barb the resident at [long-term care facility]” [49,p.66] or by absence itself: “nothing unable man” [42,p.393].

Discrepancies between participants’ potential/imagined pre- and post-injury futures also contributed to appraisals of identity change. Participants discussed loss of what they “could-a been; should-a been” [56,p.12] because of the head-injury:

> I should have already fallen in love and gotten married, had a family, gone down that route. I know I would have been in an executive level position at work by now. [...] It just feels like part of my life was not fulfilled [51,p.540].

Social rejection and stigma

A common experience was that, after initial shows of concern and support, friends and even family withdrew and social life contracted. The rejection inherent in this response prompted appraisals of reduced self-worth and a revaluation of one’s social identity:

> Friends just don't happen for me no more. Before my brain injury, you ask who was on the 'A' list all the time in the social things, well, I was in there and now I'm not. Now I'm on the loser end of things. I dunno what it is, but they're not interested at all [49 p.66–67].

An experience which could lead to a particularly negative revaluation of self was being treated as part of a homogenous, marginalised group: "I guess one of the fears now is this. If I say, 'Oh, I had a head trauma', then people are going to think that I'm, you know, beyond whole person" [64,p.670]. Labels like brain injury or disability were considered by some participants to contribute to the process of undermining their individuality: "I don't, I don't like the word 'disability'. I, I just, you know, that's just society's way of saying, you know. They [people with TBI] are more unique" [62,p.547]. They were considered by some participants to be a barrier to other people getting to know them: "I don't like the term 'TBI' because it just puts another stigma. It puts things on people. It's just a title (...) [Suppose I say] 'I have TBI', and that's going to stop people from getting to know me" [63,p.873]. Participants identified more subtle forms of stigma in professional discourses and practices that were identified as contributing to denial of personhood: "If you're a client, you're not a person. You're looked at in a very clinical way" [51,p.541]. One participant's description powerfully captured the experience of having one's personhood stripped away within institutional environments: "To the staff we are all the same, one body is just like the next"[49,p.69].

Discussion

This meta-synthesis draws together findings dispersed across the qualitative literature concerning the kinds of experience that challenge self-identity after TBI. Some of the experiences had a more introspective focus (specifically, awareness of changes in function, autobiographical memory loss, and comparisons of old-me and new-me) whereas in others there was a more explicit social dimension (responses of others highlighting change, restrictions on autonomy, social rejection and stigma). The critical role played by others is to be expected. Our understanding of ourselves primarily derives from, and is sustained by, our interactions with others: it is through interpreting how others behave towards us that we understand who we are [3]. From this perspective, social interactions are central to developing self-understanding and revising the sense of self after an ABI [24,78].

The experiences that challenge self-identity also appeared to vary in their time of occurrence. It was apparent that some could occur in the earliest stages of recovery (e.g. awareness of changes in function) but others occurred at a later date (e.g. social rejection and stigma). Some could also be tied to particular milestones in the recovery process; for example, comparisons between pre- and post- injury self appeared to be typically prompted by a return to pre-injury environments or the attempted resumption of pre-injury roles and activities. The occurrence of, and reaction to, the experiences that challenge self-identity are also likely to depend on the type and severity of impairments (e.g. the presence and severity of autobiographical memory loss), and the degree of awareness about impairments which may have a neurological basis as well as being a psychological mechanism to cope with changes that threaten self-image [3]. Further investigation of how these factors influence the occurrence and reaction to challenging experiences would be useful. Such information could assist clinicians in choosing the right time to support people in dealing with the challenging experiences.

The rationale for the current review was based on the idea that, in the absence of well-developed and effective interventions focused on self-identity, knowing more about the experiences that challenge self-identity and how people react to them could provide the basis for developing interventions that support people in dealing with these experiences in a way that is less distressing and more constructive than Goldstein's [1] catastrophic reaction.

Taken together with other literature, the findings of the review suggest some initial ideas about how this support might be developed in the future.

In relation to *awareness of change in physical, cognitive, emotional and social functioning,* clearly the provision of experiences likely to trigger such awareness, and accompanying education about the impact of TBI, needs to be conducted in a sensitive manner. A graded approach in which the person is given the opportunity to come to terms with a few changes at a time may be preferable to flooding the person with an overwhelming amount of experience and information [79,80]. The experiences and education need to be provided in a context that is emotionally supportive and in which the person has an opportunity to reflect on their reactions [79]. An appropriate balance between realism and hope for improvement also needs to be struck [3]. It may also help to counterbalance the shock of change if areas of functioning that remain intact are highlighted. This may help prevent the appraisals of radical and global change to self, and mistrust of the self as a whole, reported by some participants in the reviewed papers. These interventions need to be provided by the whole rehabilitation team and special attention needs to be given to events that are particularly likely to confront people with the reality of change, such as functional and neuropsychological assessments, and initial visits or return home. Fleming and Ownsworth [79] highlight the relevance of counselling techniques to work through grief and re-establish self-identity and self-mastery particularly for people with psychologically-based loss of awareness after ABI. Clinicians also need to address the possibility of avoidance, in terms of the person avoiding both thinking about change and avoiding situations that confront them with the reality of change. This should be part of a more general effort in rehabilitation to help people address withdrawal and avoidance, and the threat-related anxieties that underlie this [81–83]. Clinicians should also be aware of the psychological comfort that may be gained from routine and orderliness.

The theme of *responses of other people that highlight change* also underlined the importance of providing feedback about change in a sensitive manner. Medical discourses focus on damage, loss and disability; conceptualise the individual as a collection of clinical problems rather than as a whole person; and highlight 'personality change' and being 'a different person' [6,84]. These discourses are often taken up by family members [84,85]. With the focus on damage and deficiency, such discourses may damage the individual's self-concept and self-esteem [86]. They may also undermine relationships between the person with the TBI and their clinical and family support [76], particularly if the person is unaware of the changes that are highlighted in this way or if the person feels a sense of continuity with their past self [49,80]. These discourses may be less helpful than ones that focus on specific changes in the context of an emphasis on areas of functioning that remain intact and on the continuity between the past and current self.

The paternalism associated with the traditional medical model of care [87] may be a major contributor to the practices that gave rise to the experience of *loss of autonomy.* Autonomy is key to the sense of personhood, and being deprived of it can have a damaging impact on self-identity [88]. The importance of promoting autonomy in health care is widely recognised and underlies major policy initiatives to ensure that care is 'person-centred' [89,90]. However, in these policy contexts, the concept of person-centred care has often been narrowed down to the idea that patients should be involved in decisions about their health care [91]. Rehabilitation services often do have an emphasis on involving patients and families in these decisions through the medium of goal-setting [92]. However, clinical services for people with TBI might usefully be guided by the richer concept that was originally developed in dementia care and that goes beyond just involving people in healthcare decisions [88]. Brooker [93] described four central components of person-centred care, summarised in the acronym *VIPS.* The *Valuing* component is about valuing the personhood of people with dementia and according them the same moral and social status as everyone else in society. The *Individual* component is about treating the person with dementia as an individual with a unique personal history and personality, and their own wishes, values and goals. The *Perspective* component refers to the need for the carer to try to understand the world from the perspective of the person with dementia, and to respond with empathy. The *Social* component is about creating a positive social environment and experience. Methods are available for evaluating clinical services in terms of how well they promote these components [94,95]; so too are guidelines about how to improve services in this respect. This richer notion of person-centred care also has application in considering the care provided by families, and helping families to deliver more person-centred care may have significant benefits for the self-identity of the person with TBI [96].

Person-centred care also implications for how society in general deals with people with TBI. The valuing component implies dealing at a societal level with the stigma often faced by people with a TBI [97]. This may help address the damaging impact of stigma on self-identity as well as other negative consequences such as social withdrawal and avoidance [83]. There is also a need to help people with a TBI to deal with the stigma they face. This includes helping them to decide when and to whom they should disclose information about their injury to others in society [97]. Consideration of the individual's social identity may also be useful. Identifying oneself with others who share the stigmatized identity can facilitate a more resilient response to stigma by establishing a more positive and robust self-identity [98,99]. The loss of friendships after TBI is a common experience [100–102]. The present review suggests that this too may have a negative impact on self-identity. Despite its frequency, interventions to try to prevent the loss are infrequently reported. An exception is circle of support where a purpose-built friendship group is established by workers or volunteers to replace or strengthen natural friendship networks that might have dropped off after TBI. The aim is to increase social support, community integration and participation following TBI [103]. An evaluation of a similar supported relationships intervention found that three participants with TBI reported increased number of integrated social contacts compared to baseline during a four-week intervention period and four weeks of follow-up. Compared to baseline, the participants engaged in a greater variety of activities and interacted with a larger number of people during the intervention and follow-up phases [104].

Autobiographical memory loss is often overlooked in rehabilitation services and, because of the difficulties in reliable evaluation, may not even be assessed in any systematic way. Yet the findings of this review suggest that it may have an important impact on self-identity in cases where the loss is significant. The value of life-story work [105] as a way of helping people to adjust to a disrupted and fragmented sense of self merits investigation.

The enablement of people to return to valued roles and activities after a TBI is a well-established aim of rehabilitation [106]. This should help address the issues identified under the theme of *comparing old-me and new-me*. Indeed, some of the reviewed studies describe how a return to employment and other meaningful activities helped support the development of a more positive and robust self-identity that was not defined by the injury [49,60,61]. However, the review highlighted that the value placed on the role or activity was a key determinant of how much its loss affected self-identity. A return to what are generally considered important roles and activities may not be as useful as a return to what was of particular value to the individual. Acceptance and commitment therapy may be a useful approach in addressing this particular issue [107–109]. Key components of the approach include an assessment of what is valuable to the individual and whether their life is being lived according to those values, and efforts to help the individual live their life in accordance with their values [107–109]. Sometimes a return to valued roles and activities is difficult. In such cases a person might be helped by supporting them in re-prioritising what is important to them [107–109].

Limitations

This meta-synthesis was limited by the inclusion of studies whose primary focus was not experiences that challenge identity. This meant that some papers lacked sustained exploration of this issue and this might have required a greater degree of interpretation on the part of the reviewer. However, the latter could be considered a general limitation of qualitative meta-syntheses which are an interpretation of an interpretation [35]. To mitigate for this, each theme included in the final analysis was based on findings across several papers (a minimum of nine) including some conceptually rich studies (Lewin et al., 2015). Taken together these provided a richer base for the themes presented in the meta-synthesis. All themes were supported by a range of quotations to illustrate the themes and to ensure they were grounded in the empirical data (Tong et al., 2011).

While most of the studies included in the synthesis were assessed as meeting quality criteria in relation to design and methods, the majority did not report information considered important to robust qualitative research around reflexivity and the participant-researcher relationship. Given that self-identity is understood as being formed within our social relationships [3], this is an important omission. A number of other meta-syntheses have also reported reflexivity to be less well-represented in qualitative research (e.g. Campbell et al., 2011). Detailed reporting of the data analysis process was also missing from several studies. There is debate over the value of applying strict quality criteria within meta-synthesis [37], however we highlight this issue here in acknowledgement that any findings reported are limited by the quality of the papers included.

The meta-synthesis could have been expanded by inclusion of studies comprising mixed ABI samples. However, the inclusion of additional studies might have resulted in an unmanageably large dataset negatively influencing the depth of analysis [110]. Furthermore, it is likely that identity experiences following TBI compared to other forms of ABI (e.g. stroke) might be unique given the life-stage and cognitive deficits more typically associated with TBI. Future reviews could usefully synthesise the qualitative literature in relation to identity experiences following other forms of ABI.

This meta-synthesis focused on the subjective experiences of individuals with TBI. This resulted in the exclusion of papers (e.g. [84,111]) where the focus was on discourses between people with TBI and others. These papers provide helpful fine-grained analysis of how identity can be constructed interpersonally and contribute to our understanding of processes contributing to identity change.

Although the findings were drawn from participants in nine countries, these were overwhelmingly economically developed, Western, majority White countries. These findings may therefore not represent the views of people with TBI from different cultural or ethnic backgrounds. This limitation might in part result from applying an English language exclusion criteria. Future research could usefully explore the experiences of people with TBI from non-White, collectivist or economically less-developed countries to identify the points of intersection and divergence with the themes identified in this meta-synthesis.

In conclusion, this review has synthesised the qualitative research on key experiences that challenge self-identity in people with a TBI. By synthesising findings into one single paper, this review makes information more accessible to clinicians working within neuro-rehabilitation. They can use the findings to support them in supporting people with TBI and their relatives to negotiate their identity experiences with less distress and more successfully.

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Table 1. Electronic database search strategy

Table 2. Critical appraisal of study quality using the CASP tool

Table 3. Characteristics of studies included in the meta-synthesis

Figure 1. Flow chart for inclusion of studies in the meta-synthesis

Table 1. Electronic database search strategy

Search number	Construct	Keyword terms (variations)	Subject terms (database)
1	Identity	Selfhood* (selfhood/s) Self-concept* (self-concept/s) Self-perception* (self-perception/s) Selves Personhood* (personhood/s) Personality change* (personality change/s) Identit* (identity/ies) Subjectivit* (subjectivity/ies) Combined with *or*	Self Concept, Self Perception, Subjectivity, Narratives, Personality Change, Identity Crisis, Identity Formation, Life Experiences (PsycINFO); Self Concept, Identity Crisis, Personhood (MEDLINE); Self Concept, Identity (CINAHL)
2	Traumatic brain injury	Brain injur* (acquired brain injury/ies, traumatic brain injury/ies) Head injur* (head injury/ies) ABI TBI Craniocerebral trauma* (craniocerebral trauma/s) Combined with *or*	Traumatic Brain Injury, Head Injuries (PsycINFO); Brain Injuries (MEDLINE); Brain Injuries, Head Injuries (CINAHL)
3	Searches 1 and 2 were combined with *and*		

Table 2. Critical appraisal of study quality using the CASP tool

Criteria	Brenner et al. [42]	Chamberlain [43]	Conneeley [44]	Conneeley [45]	Crisp [46]	Douglas [47]	Freeman et al. [48]	Gelech & Desjardins [49]	Glover [50]	Gutman & Napier-Klemic [51]	Hoogerdijk et al. [52]	Howes et al. [53]	Jones & Curtin [54]	Jumisko et al. [55]	Klinger [56]	Knox et al. [57]	Krefting [58]	Lawson et al. [59]	Levack et al. [60]	Muenchenberger et al. [61]	Nochi [62]	Nochi [63]	Nochi [64]	O’Callaghan et al. [65]	O’Callaghan et al. [66]	Padilla [67]	Parsons & Stanley [68]	Petrella et al. [69]	Price-Lackey & Cashman [70]	Roscigno & Van Liew [71]	Roundhill et al. [72]	Sabat et al. [73]	Shotton et al. [74]	Soeker [75]	Strandberg [76]	Sveen et al. [77]
Research design appropriate to address aims?	✓	?	✓	✓	?	✓	✓	?	x	x	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓
Recruitment strategy appropriate to address aims?	✓	?	✓	✓	?	✓	✓	✓	?	?	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	x	?	✓	?	✓	✓	?	?
Data collected in way that addressed research issue?	✓	✓	✓	✓	✓	✓	✓	✓	?	?	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓
Researcher-participant relationship considered?	?	?	✓	✓	x	✓	✓	x	x	?	✓	x	?	?	✓	?	?	✓	x	?	?	x	?	x	x	?	?	x	x	?	✓	x	x	?	?	x
Ethical issues considered?	?	✓	✓	✓	x	✓	✓	?	x	x	✓	✓	?	✓	x	✓	x	✓	✓	✓	x	x	x	?	x	?	✓	x	x	✓	✓	✓	✓	✓	✓	?
Data analysis rigorous?	✓	✓	x	✓	?	✓	✓	✓	x	x	?	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	?	x	✓	x	✓	?	✓	✓
Clear statement of findings?	✓	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	✓
Valuable research?	✓	✓	?	✓	✓	✓	✓	✓	?	?	✓	✓	✓	?	✓	✓	✓	✓		✓	✓	✓	✓		✓	?	✓	✓	?	✓	✓	✓	✓	✓	?	✓

Table 3. Characteristics of studies included in the meta-synthesis

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Brenner et al. [42]	To understand precipitants and preventative factors of suicidal behaviour in veterans with TBI.	Hermeneutic phenomenology	*N*=13, 12 men, 1 woman; 33-65 years, mild to severe TBI caused by road traffic accident (RTA; *n*=8), fall (*n*=1), blast (*n*=1) or assault (*n*=3); 2-39 years post-injury; living and employment status not reported.	USA. Veterans seen by the local TBI interdisciplinary team with known history of TBI and suicidality.	Interviews using a hermeneutic approach. One interview with each participant; 30-60 minutes duration; location not reported. Interviews audio-recorded and transcribed.
Chamberlain [43]	To explore the experience of surviving TBI. To explore the experiences of self within survival and recovery.	Qualitative content analysis	*N*=60; 40 men, 20 women; 18-81 years; mild to critical TBI caused by RTA (47) or unstated (*n*=13); one year post-injury; living with family (*n*=50), nursing home (*n*=7) or other (*n*=3); in employment (*n*=25). One family member per participant also interviewed.	Adelaide, Australia. Individuals admitted to Intensive Care Unit at participating hospitals one year previously.	Interviews. One interview with each participant (together with family member); 45-60 minutes duration; interviews conducted in participant home. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Conneeley [44]	To gain insight into the issues perceived as relevant for individuals with TBI re-entering their social environment.	Qualitative methodology – not reported	*N*=18; 13 men, 5 women; 17-60 years; severe TBI caused by RTA (*n*=12), assault (*n*=3), fall (*n*=1), accident at work (*n*=1) or sporting injury (*n*=1); one year post-injury; all discharged to home environment with family support; employment status not reported. Significant other and professional staff also interviewed.	UK. Patients consecutively discharged from the ward of a neurological rehabilitation unit.	Semi-structured interviews. Three interviews with each participant: on discharge, six months and one year post-discharge; duration not reported; interviews conducted in participant home or at the rehabilitation hospital. Significant other and professional staff also interviewed.
Conneeley [45]	To explore the journey of individuals with TBI and their families over a period of one year following discharge from a neurological rehabilitation ward.	Interpretative phenomenological approach (IPA), thematic analysis (TA)	*N*=18; 13 men, 5 women; 17-60 years; severe TBI, caused by RTA (*n*=12), assault (*n*=3), fall (*n*=1), accident at work (*n*=1) or sporting injury (*n*=1); recruited on discharge from post-acute neurological rehabilitation ward; all living in the community supported by a family member; employment status not reported. Significant other and professional staff also interviewed.	UK. Participants recruited through neurological rehabilitation ward as they were discharged.	Semi-structured interviews. Three interviews with each participant: on discharge, six months and one year post-discharge; duration not reported; most interviews conducted in participant home. Significant other and healthcare professional also interviewed. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Crisp [46]	To explore the experience of living with TBI and the meaning it has for the person with TBI. To explore psychosocial responses to TBI.	Comparative analysis	*N*=10; 6 men, 4 women, 22-50 years; mild to severe TBI, cause not reported; 3-20 years post-injury; all living in the community; in paid full-time employment (*n*=4), full-time students (*n*=2), part-time volunteers (*n*=2), unemployed (*n*=2).	Victoria, Australia. Participants recruited from Headway and via rehabilitation professionals working with individuals with TBI.	Unstructured and semi-structured interviews. 7-10 interviews with each participant; 40-75 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed.
Douglas [47]	To explore the way in which adults who have sustained a severe-very severe TBI conceptualise themselves several years after the injury.	Grounded theory (GT)	*N*=20; 16 men, 4 women; 21-54 years; severe to very severe TBI caused by RTA; 5-20 years post-injury; all living in the community with various levels of paid and unpaid support; no participants in paid employment, volunteers (*n*=4), in vocational training programmes (*n*=2).	Australia. Participants recruited from metropolitan community disability agencies that provide services to people with TBI.	In-depth interviews. One interview with each participant; 90-180 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed. Field notes.
Freeman et al. [48]	To explore the experience of male survivors of TBI in relation to perceived changes in personal and social identity. To provide an understanding of the individuals' sense of self and sources of emotional distress and growth.	TA	*N*=9; all men; 22-59 years; moderate to severe (or severity unknown *n*=3) TBI caused by RTA (*n*=8) or work-related fall (*n*=1); 17 months – 21 years post-injury; all living in the community; in employment (*n*=7), of which voluntary (*n*=2), reduced capacity (*n*=3), all in employment prior to injury.	UK. Participants had been referred to, assessed by or received neuropsychological rehabilitation from the Oliver Zangwill Centre for Neuropsychological Rehabilitation (OZC)	Semi-structured interviews. One interview with each participant, 58 minutes duration on average; interviews conducted at OZC (*n*=7) or participant home (*n*=2). Interviews audio recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Gelech & Desjardins [49]	To explore the construction of self following ABI.	Thematic, syntactic and deep-structure analysis	*N*=4; 3 men, 1 woman; 37-55 years; moderate to severe TBI caused by RTA; 4-21 years post-injury; living independently (*n*=2), in assisted living (*n*=2); no participants in employment, all employed prior to injury.	Saskatoon, Saskatchewan, Canada. Local rehabilitation centre.	Life history and semi-structured interviews. Two interviews with each participant; 35-90 minutes duration; interviews conducted in rehabilitation centre or participant home. Interviews audio-recorded and transcribed.
Glover [50]	To explore perceptions of quality of life following TBI; the effects of the injury on family, social and working life; and the effects of attending Headway on quality of life.	Qualitative case history and framework analytic approach	*N*=4; all men, 34-53 years; TBI caused by RTA (*n*=2), fall (*n*=1) or other (*n*=1); severity of injury not reported; 6-11 years post-injury; living situation and employment status not reported.	Essex, UK. Headway.	Conversational interviews. Number, duration and location of interviews not reported. Interviews audio-recorded.
Gutman & Napier-Klemic [51]	To explore the disruption of gender identity and gender role after TBI.	GT	*N*=4; 2 men, 2 women; 33-46 years; TBI caused by RTA; severity of injury not reported; 10-18 years post-injury; living in a residential facility; in employment (*n*=3), all employed pre-injury.	Northeast USA. Residential facility for people with head-injury.	Open-ended interviews. Six interviews with each participant; 60 minutes duration; interviews conducted in private informal settings such as the participant's residence or a recreational room at the facility. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Hoogerdijk et al. [52]	To explore how individuals with TBI make sense of their adaptation process and the performance of occupations within the process.	Narrative analysis	*N*=4; 3 men, 1 woman; 33-61 years; TBI, cause not reported; severity of injury not reported; 20-27 months post-injury; all married and living with partner; in employment (*n*= 1).	Netherlands. Participants discharged from inpatient treatment programme at a rehabilitation centre at least six months previously.	Interviews. Two interviews with each participant; 50-90 minutes duration; interviews conducted in participant home. Interviews audio-recorded and transcribed.
Howes et al. [53]	To investigate the experiences of women with TBI.	IPA	*N*=6, all women; 30-51 years; mild to severe TBI, cause not reported; 7 months to 15 years post-injury; living situation and employment status not reported.	UK. Participants recruited via referrals made to a Clinical Neuropsychologist at a district general hospital.	Semi-structured interviews. Two interviews with each participant; duration not reported; interviews conducted in a private consultation room at the hospital. Interviews audio-recorded and transcribed.
Jones & Curtin [54]	To explore masculine identity and participation of men with TBI living in rural Australia. To explore the impact of role changes on identity and participation satisfaction.	GT	*N*=21; all men; 24-66 years; severe-extremely severe TBI caused by RTA (*n*=14), fall (*n*=4) or assault (*n*=3); 2-31 years post-injury; living situation not reported; unemployed (*n*=8), retired (*n*=4), voluntary or unpaid work (*n*=2), in paid work (*n*=7).	New South Wales, Australia. Participants recruited from one of eight rural Brain Injury Rehabilitation Programmes.	Semi-structured interviews. One interview with each participant (together with partner or support person); 60-90 minutes duration; interviews conducted in participant home or convenient location. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Jumisko et al. [55]	To explore the meaning of living with TBI as narrated by people with moderate or severe TBI.	Phenomenological hermeneutic method	*N*=12, 10 men, 2 women; 23-50 years; moderate to severe TBI caused by RTA (*n*=7), fall (*n*=3) or assault (*n*=2); 4-13 years post-injury; living with parent (*n*=2), partner (*n*=2), alone or with children (*n*=8); employment status not reported.	Sweden. Participants recruited by a psychologist and a nurse working in two different hospitals.	Interviews. Two interviews with each participant; 60-75 minutes duration; interviews conducted in participants home (*n*=11) or work place (*n*=1). Interviews audio-recorded and transcribed.
Klinger [56]	To explore experiences of the process of occupational adaptation after TBI. To explore occupation and identity following TBI.	Constant comparative method	*N*=7; 6 men, 1 woman; 29-45 years; TBI caused by RTA (*n*=4), accident at work (*n*=2) or assault (*n*=1); severity of injury not reported; 2-16 years post-injury; living situation not reported; in employment (*n*=1), unemployed (*n*=6).	Ontario, Canada. Participants recruited via the director of a local brain injury association and by the director of a clubhouse programme for individuals with TBI.	In-depth, semi-structured interviews. One interview with each participant; 90 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed.
Knox et al. [57]	To explore how participation in decision making contributes to self-conceptualisation in adults with severe TBI.	Constructivist GT	*N*=8; 6 men, 2 women; 18–55 years; moderate-severe TBI caused by RTA (*n*=5), sporting accident (*n*=1), fall (*n*=2); 7-29 years post-injury; all living in the community; not in paid employment (*n*=6), employed part-time (*n*=2). In full time employment or study at time of injury (*n*=7).	Eastern Australia. Participants invited through community-based rehabilitation clinicians, brain injury services and support groups in eastern states of Australia.	Unstructured in-depth interviews. Two to three interviews per participant, total of 20 interviews; 45-155 minutes duration; location of interviews not reported. Interviews audio recorded and transcribed. Interviewer field notes.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Krefting [58]	To explore the life experiences of people with TBI and their family to gain an understanding of disability.	Ethnographic study. Thematic and content analysis	*N*=21; 14 men, 7 women; 17-41 years; moderate to severe TBI, cause not reported; 2-22 years post-injury; all living in the community; in employment (*n*=1), supported by income from insurance settlement, social security or allowances from parents (*n*=20). Family members and neighbours, teachers, friends also interviewed.	Urban community, Southwest USA. Participants recruited via leaders of the local branch of the National Head Injury Foundation or by others in the study.	Non-structured interviews with individual, family members and friends. 80 interviews in total; 60-240 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed. Participant observation at family support group meetings, treatment sessions, and family time. Document review.
Lawson et al. [59]	To provide an autoethnographic exploration of the lived experience of rehabilitation following brain injury.	Autoethnography	*N*=1, female; age and time post-injury not reported; moderate TBI caused by RTA; living in the community; employment status not reported.	Montreal, Canada. Participant recruited through social connection.	Four years of poetry and journal entries, interview. Number, duration and location not reported.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Levack et al. [60]	To explore experiences of change and reconstruction of self-identity following TBI to develop a theoretical framework for measuring identity following TBI.	GT	*N*=49; 34 men, 15 women; 21-79 years; clinical data regarding severity of TBI not reported, self-reported mild-severe TBI caused by RTA (*n*=28), fall (*n*=11), sport accident (*n*=3), assault (*n*=3), work accident (*n*=2), medical misadventure (*n*=1) or aeroplane accident (*n*=1); 6 months to 36 years post-injury; living situation not reported; in part-time employment or study after accident (*n*=8), unemployed (*n*=31), retired (*n*=8), home-maker (*n*=2).	New Zealand. Participants recruited from eight urban and rural regions via local TBI community support organisations.	Focus groups. One focus group per region, (*n*=4-9 participants per focus group), two researchers present, 90-120 minutes duration, held in local regional centres; participants invited to bring support person to facilitate the participant in expressing their views, views expressed by the supporters were not included in analysis. Focus groups audio recorded and transcribed.
Muenchenberger et al. [61]	To explore turning points and processes which define the experience of identity change for people with TBI.	Interpretative qualitative research design using a phenomenological approach. TA	*N*=6; 4 men, 2 women; 22-42 years, TBI caused by RTA; severity of injury not reported; 1-25+ years post-injury; living situation not reported; participants had attained 'positive productive outcomes' following brain injury (e.g. return to work, study).	Australia. Participants had received formal inpatient and outpatient brain injury rehabilitation but were not current rehabilitation clients.	In-depth narrative/life-story interviews with critical incident technique. Two interviews with each participant; duration and location of interviews not reported. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Nochi [62]	To explore the self-images of people with TBI and how they experience psychological distress.	Constant comparison	*N*=4; 3 men, 1 woman; 24-40 years; TBI caused by RTA (*n*=3) or fall (*n*=1); severity of injury not reported; 3-12 years post-injury; all living in the community independently (*n*=3) or with parents (*n*=1); in employment (*n*=3) or study (*n*=1).	New York, USA. Participants recruited from an independent living centre or TBI support group.	In-depth interviews and observations. Two interviews with each participant; 30-45 minutes duration; interviews conducted in participant home, independent living centre or university. Interviews audio-recorded and transcribed.
Nochi [63]	To explore experiences of self after TBI.	GT	*N*=10; 6 men, 4 women, 24-49 years, TBI, caused by RTA (*n*=8), sports injury (*n*=1) or fall (*n*=1); severity of injury not reported; 2-12 years post-injury; all lived in the community alone or with family; in full-time employment (*n*=3), in part-time employment (*n*=3), in graduate study (*n*=1), unemployed (*n*=1).	Northeast USA. Participants recruited from a TBI support group (*n*=7). Additional data collected from e-mail written on the TBI Support List on the internet (*n*=3).	Semi-structured interviews conducted with the seven participants recruited from the support group. Two or more interviews with each participant; 45-60 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed. Participant observation. Also reviewed text from TBI e-mail discussion board for three participants.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Nochi [64]	To explore loss of sense of self experience in relation to the sociocultural context. To identify the images or labels that individuals with TBI feel they receive from society by examining their self-narratives.	GT	*N*=10; 8 men, 2 women; 24-54 years; TBI caused by RTA (*n*=8), sporting injury (*n*=1) or fall (*n*=1); severity of injury not reported; 3-28 years post-injury; all participants were living in the community; in employment (*n*=4), in study (*n*=2), unemployed (*n*=4). Additional data obtained from 13 participants, 5 men, 8 women, 2-61 years; 1-34 years post-injury.	Northeast USA. Participants recruited from a TBI support group. Additional data collected from e-mail written on the TBI Support List on the internet.	Semi-structured interviews. Two to three interviews with each participant; 45-60 minutes duration; interviews conducted in place familiar to participant. Interviews audio-recorded and transcribed. Participant observation. Also reviewed text from TBI e-mail discussion board of 13 additional participants.
O'Callaghan et al. [65]	To explore self-awareness and insight and the concept of readiness in relation to experiences of engaging with therapy in people with TBI.	Qualitative research – interpretative paradigm	*N*=14, 8 men, 6 women; include age range 18-65 years; moderate to severe TBI; cause not reported; time post-injury not reported; living situation and employment status not reported. Significant others (*n*=9) also interviewed.	Australia. Participants had responded to a survey in an earlier stage of the research and expressed an interest in being interviewed.	Unstructured interviews. One interview with each participant together with significant other if present; 45 minutes to 2.5 hours duration; conducted in location of participant's choosing (home or local café). Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
O'Callaghan et al. [66]	To explore experiences of gaining awareness of deficits after TBI.	IPA	*N*=10; 7 men, 3 women; 21-60 years; moderate to severe TBI caused by RTA (*n*=6) or fall (*n*=4); 6 months - 5 years post-injury; living at home with family (*n*=7), with support (*n*=3).	Birmingham, UK. Patients attending an outpatient post-acute rehabilitation service.	Semi-structured interviews. One interview with each participant; ~60 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed.
Padilla [67]	To investigate the lived experience of disability for a woman who sustained a head injury 20 years ago.	Phenomenology	*N*=1; female; ~40 years; TBI caused by train accident; severity not reported; 21 years post-injury; living at home and working.	Nebraska. Participants recruited through social contact.	Interviews and e-mail conversation. Eleven interviews and 72 e-mail message exchanges; 60-90 minutes duration; interviews conducted in participant work place or home. Two interviews audio-recorded and transcribed; interview notes for remaining interviews.
Parsons & Stanley [68]	To explore the experience of occupational adaptation and strategies used by people with ABI living in a rural area.	Phenomenological approach	*N*=2; both men; 30 and 44 years; mild to moderate TBI, caused by RTA; 1 and 15 years post-injury; both living in their own home in rural Australia; employment status not reported.	Rural South Australia. Participants recruited via Brain Injury Rehabilitation Services.	Semi-structured interviews. One/two with each participant; 60 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Petrella et al. [69]	To explore the process of returning to productive activities from the perspective of people with longstanding ABI. To understand how intrinsic and extrinsic factors enable or limit productive involvement over time.	GT, constant comparative method	*N*=6; 4 men, 2 women; 33-78 years; severe TBI caused by RTA; 13-15 years post-injury; all living in the community; part-time student and volunteer (*n*=1); part-time employment (*n*=1), working in a vocational rehabilitation programme (*n*=4).	Ontario, Canada. Participants recruited from an outreach community programme for people with brain injuries.	Semi-structured interviews. Two-three interviews with each participant; 18-90 minutes duration; interviews conducted in participant home. Interviews audio-recorded and transcribed.
Price-Lackey & Cashman [70]	To explore how a person experiences and adapts to head injury focusing on occupational satisfaction and adaptation.	Narrative analysis.	*N*=1; female; 43 years; moderately severe TBI caused by RTA; 5 years post-injury.	California. Recruitment not reported.	Life history interviews. Two interviews; 3 hours and 4 hours; one year apart; location of interviews not reported. Interviews audio-recorded and transcribed.
Roscigno & Van Liew [71]	To highlight one man's personal writings about his life after experiencing severe TBI. To provide preliminary understanding of the nature of social interactions for people with TBI. To explore the social processes that influenced the assignment of meaning to his life.	Symbolic interactionism	*N*=1, male, 35 years, severe TBI caused by RTA; 18 years post-injury; living and employment status not reported.	USA. Recruitment not reported.	Written journal, written retrospectively. In person and telephone discussions. Duration and location of 'discussions' not reported.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Roundhill et al. [72]	To explore the process of loss. To explore how individuals experience grief following TBI and how they view themselves and their lives in light of these losses.	IPA	*N*=7; 6 men, 1 woman; 32-60 years; severe TBI caused by RTA (*n*=6) or assault (*n*=1); 3-40 years post-injury; living situation and employment status not reported.	UK. Participants recruited through Headway.	Semi-structured interviews. One interview with each participant; duration and location of interviews not reported. Interviews audio-recorded and transcribed.
Sabat et al. [73]	To explore the construction of identity pre and post TBI.	Life history methodology and narrative analysis	*N*=1, male, 31 years; severe TBI caused by explosion; 12 years post-injury; living situation and employment status not reported.	KwaZulu, South Africa. Participant recruited from rehabilitation institution for individuals with stroke and head injury.	In-depth semi-structured interviews. Three interviews with each participant; 90 minutes duration; interviews conducted at rehabilitation institution. Interviews audio-recorded. Document review of personal journal and photograph album.
Shotton et al. [74]	To explore appraisal, coping and adjustment in individuals with a TBI.	IPA	*N*=9, 7 men, 2 women; 21-59 years; moderate to severe TBI caused by RTA (*n*=4), fall (*n*=3) or assault (*n*=2); 2-6 years post-injury; unemployed (*n*=3), attending day centre (*n*=1), in education, (*n*=4), employed (*n*=1). All employed prior to brain injury.	UK. Participants recruited via database of neurological rehabilitation unit.	Semi-structured interviews. One interview with each participant; 54-87 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed.

References	Focus/aims of study	Methodology	Participants	Geographical location and setting	Data collection
Soeker [75]	To explore the difficulties in resuming and maintaining worker roles, adaptation following TBI, and the relationship between competence and identity in TBI.	Data analysis methods described by Morse and Field (1996): comprehending, synthesising, theorising and recontextualising	*N*=10, 9 men, 1 woman; 31-64 years; mild to moderate brain injury, cause not reported; time post-injury not reported; living situation not reported; all in employment.	South Africa. Participants recruited from statistical records of Hospital Occupational Therapy Department and Road Accident Fund Organization.	In-depth interviews. One interview with each participant; 60 minutes duration; location of interviews not reported. Interviews audio-recorded and transcribed.
Strandberg [76]	To explore how individuals with TBI experience the changeover process that arises after the trauma.	Critical interpretation perspective. Qualitative content analysis	*N*=15; 10 men, 5 women; 19-53 years; mild to moderate TBI caused by RTA (*n*=11), fall (*n*=3) or assault (*n*=1); 5 months to 17 years post-injury; living situation and employment status not reported.	Örebro, Sweden. Outreach team of University hospital of Örebro.	In-depth interviews. One interview with each participant; 1-2 hours duration; interviews conducted in participant home, workplace or at the university. Interviews audio-recorded and transcribed.
Sveen et al. [77]	To explore TBI as a biographical disruption and to study the reconstruction of everyday occupations and work participation in people with mild TBI.	Qualitative content analysis	*N*=20, 8 men, 12 women; 22-60 years; mild TBI resulting from RTA (*n*=9), fall (*n*=7) or other (*n*=4); 21-46 weeks post-injury; all living in the community, cohabiting (*n*=15), alone (*n*=5); in partial or full employment (*n*=12). All in employment or studying at time of injury.	Norway. Participants recruited from a return to work outpatient rehabilitation programme.	Focus groups. Seven groups, 2-4 participants per group; two researchers per group; duration not reported; conducted as part of return to work programme. Focus groups audio recorded and transcribed.

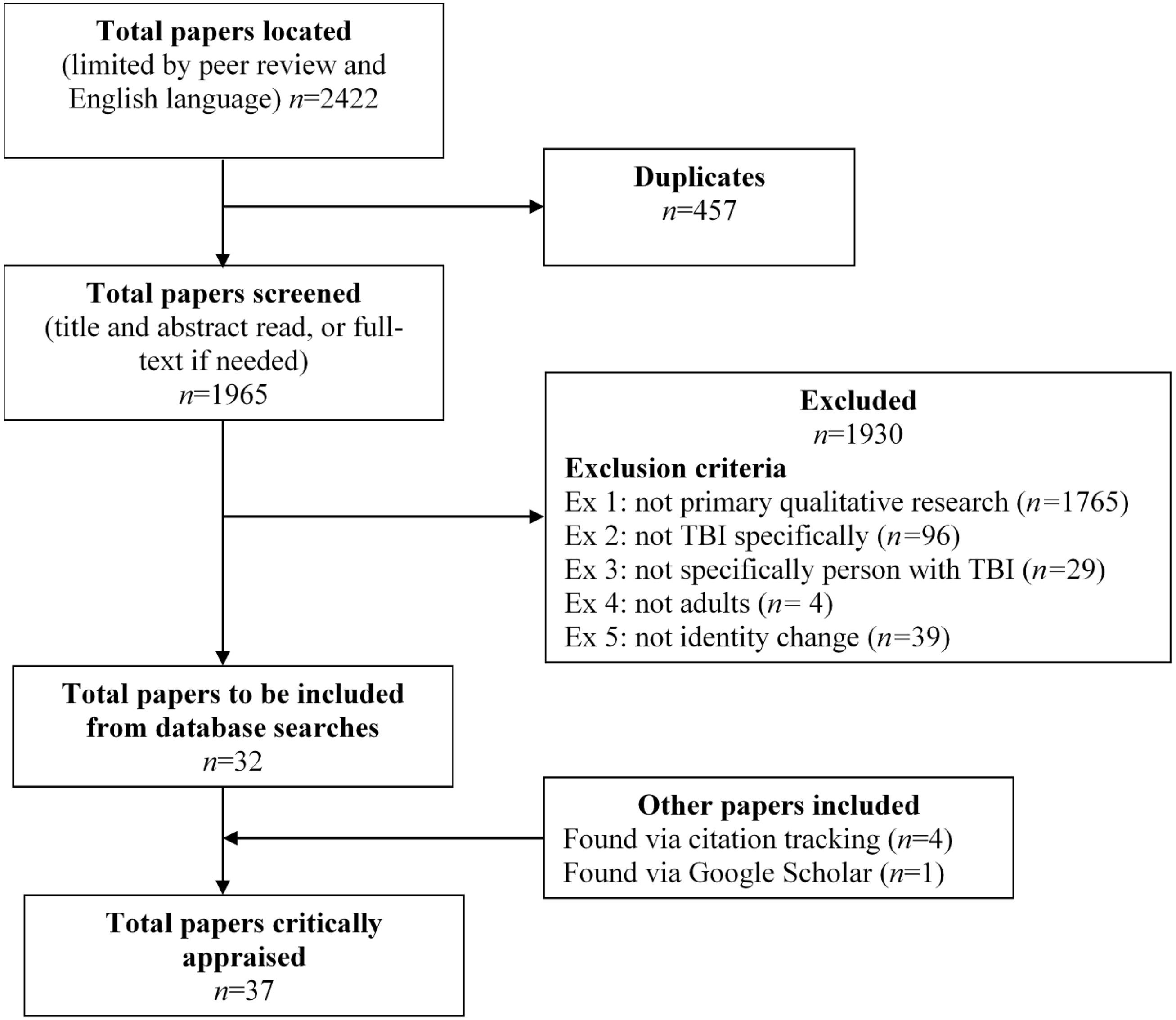
Total papers located
(limited by peer review and English language) n=2422
Duplicates
n=457
Total papers screened
(title and abstract read, or full-text if needed)
n=1965
Excluded
n=1930
Exclusion criteria
Ex 1: not primary qualitative research (n=1765)
Ex 2: not TBI specifically (n=96)
Ex 3: not specifically person with TBI (n=29)
Ex 4: not adults (n= 4)
Ex 5: not identity change (n=39)
Total papers to be included from database searches
n=32
Other papers included
Found via citation tracking (n=4)
Found via Google Scholar (n=1)
Total papers critically appraised
n=37

Figure 1