The cognitive process of identity reconstruction after the onset of a neurological disability

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Abstract

Purpose: Rehabilitation professionals and researchers underscore the impact of an acquired disability on identity. However, the cognitive process by which identity is transformed is understudied. The present study aims to explore the cognitive process by which personal identity is reconstructed following disability onset. Methods: A template organizing style of interpretation was used to perform a qualitative analysis based on the Cognitive-Developmental Model of Social Identity Integration (CDMSII) using interview data from 10 participants with traumatic brain injury or traumatic spinal cord injury. Results: As suggested by the CDMSII, following the accident, participants initially tend to emphasize distinctions between their pre- and post-injury conditions. Eventually, individuals are able to create cognitive connections between pre-injury self-knowledge and how they understand their new condition. Finally, in the last stage of the identity integration process, the various identity components are recognized as part of the self. Organizing data based on the three stages of this theory was found to resonate with participants and aided the comprehension of how every stage in the identity reconstruction process is intertwined with the need for continuity through life. Conclusions: The CDMSII offers a useful heuristic for understanding long-term identity reconstruction and the present research emphasizes the importance of a sense of continuity following disability onset.

Key Words: Identity, spinal cord injury, temporal continuity, traumatic brain injury

History

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Implications for Rehabilitation

• A central concern in the adjustment process following disability onset is identity reconstruction. The Cognitive-Developmental Model of Social Identity Integration is useful to understand this process.
• This study highlights the importance of a sense of continuity throughout the identity reconstruction process following disability onset.
• Therapists should first help to identify core pre-injury identity characteristics in order to sustain a sense of continuity. Subsequently, the patient can be helped with the creation of meaningful links between significant pre-injury characteristics and the post-injury circumstances.
• The process of identity reconstruction following disability onset spans many years, therapists need to address this issue in a long-term perspective.

Introduction

Most people will, in their life time, face a negative major life event [1–3]. When unexpected and potentially traumatic life events occur, such as life threatening disease [4,5] or the onset of a disability, an individual’s sense of identity is often profoundly challenged [3,6,7]. The 2013 Boston Marathon Bombing left dozens of individuals seriously injured [8]. Similarly, although less publicized events, road traffic injuries represent one of the leading public health problems around the world [9], and occupational injuries cause hundreds of thousands of new disabilities every year [10]. These are only a few examples of unpredictable traumatic life events that can lead to permanent disability. Beyond physical rehabilitation, reintegrating identity through psychological recovery represents one of the most difficult and significant barriers for adapting to life following disability onset. The cognitive processes of this profoundly crucial aspect of recovery are the focus of the present study.

Rehabilitation psychologists recognize identity reconstruction as a central concern of the adjustment process following the onset of a disability [11,12]. In their meta-synthesis of qualitative research on the experience of recovery following traumatic brain injury (TBI), Levack et al. [13] identified the recurrent lack of appropriate measures for identity loss issues. Despite this, identity reconstruction is common subject matter for studies of acquired permanent disability, including TBI [13–16], traumatic spinal cord injury (TSCI) [17–19] and stroke [20,21]. Given that the
onset of a disability is often associated with a decrease in subjective well-being [22–24], it is important to better understand the identity integration processes associated with a loss of physical ability. Tedeschi and Calhoun [25] propose that the ability to experience positive changes in one’s sense of self is important for psychological growth following a traumatic event. While identity reconstruction in general has received substantial attention, the cognitive processes by which new identity characteristics are integrated as a result of disability onset remains understudied within psychology.

The aim of the present qualitative study is to investigate the cognitive processes by which identity is reconstructed following a traumatic accident that results in permanent, non-degenerative and non-life-threatening disability. Specifically, we focus on the cognitive process of identity reconstruction for individuals who have acquired a permanent disability through TBI or TSCI. The cognitive process of identity reconstruction

The self-concept is a multifaceted entity made of personal characteristics, feelings, images, social roles and statuses that an individual recognizes as being related to, or part of him/herself [26]. It is the combination of all these elements that forms an individual’s identity [27]. Most contemporary views of the concept of identity include a content component (i.e. memory structures that store experiences and thoughts related to the self) and a process component (i.e. activation of stored information in interaction with others) [28].

Theory and research concerning the cognitive process of identity reconstruction following major change is scarce. To our knowledge, there is only one theoretical model directly focused on explaining the cognitive processes underlying identity integration and development in adults. The Cognitive-Developmental Model of Social Identity Integration (CDMSII), developed by Amiot and coworkers [29], is based on a neo-Piagetian perspective of identity development. It relies on a developmental perspective of the self that increases in complexity as it develops [30,31]. This viewpoint posits that through development, fractionated self-components become coordinated through the creation of cognitive associations, to ultimately move toward self-integration [29,31].

Although the CDMSII [29] originally focused on social identity transformation in the long-term development and integration of social identities to the self, this cognitive-developmental perspective can also shed light on the process of personal identity reconstruction in the context of disability onset. For many authors, social identity and personal identity are intimately interrelated [32], with personal identity being the product of social experiences and interactions [27,30,33]. For example, individuals with a recently acquired disability will face new contextual demands and changes in their personal and social circumstances that require them to integrate new self-conceptions to their identities.

The CDMSII consists of four stages, the first being anticipatory categorization. It takes place before change occurs, as soon as an individual anticipates a change. In the context of an unexpected change, such as the onset of a disability following an accident, this stage cannot be part of the identity integration process.

The process of identity integration in the context of disability onset thus begins with categorization, the second stage of the CDMSII. At this stage, individuals notice the characteristics and differences in circumstances and social groups while adjusting to their life event. These include the specific rehabilitation demands, contextual life changes and characteristics of other rehabilitation patients or disabled individuals that contrast to pre-injury life and social relations. As such, the differences between pre- and post-injury circumstances are salient. In order to protect the self from the intrusion of characteristics associated with post-injury conditions, the pre-injury identity can even be strengthened. Thus, the characteristics associated with the new contextual circumstances are recognized, but perceived as external to the self.

The description of the categorization stage resonates with Yoshida’s [17] concept of the “former self”. In her study of individuals with spinal cord injuries, she proposes that following such traumatic experiences this “former self” is made of the non-disabled characteristics of the self. The “former self” thus serves as the basis for identity reconstruction. An affinity towards the pre-injury self, as noted by the CDMSII and Yoshida’s conceptualization, is also coherent with the common avoidance reaction acknowledged in the Dual Process Model concerning grief and adjustment to loss [34,35]. All three models recognize the presence of denial during the process of adjustment following loss.

Following the categorization stage, the compartmentalization stage takes place as individuals begin to recognize the multiplicity of identities related to pre- and post-injury circumstances. At this point, the individual starts to consider that he/she belongs to several groups. This progress arises as the individual increases contact with other disabled individuals, rehabilitation professionals and service organizations associated with the post-injury condition. This increased contact allows for the development of cognitive links between various self-components, and ultimately leads to more complex self-representations. However, at this stage the different self-components only coexist, and cannot be activated simultaneously. Activation of different identities remains context dependent. For example, an individual may start to take part in new activities, or adjust some pre-injury activities to accommodate for new physical limitations. As the post-injury activities and relations are semantically separate from those related to the pre-injury identity, comparisons between the different identities remain salient.

This intermediate stage of contextual experimentation and adhesion of new characteristics can account for the fact that the identity reconstruction process is not a linear journey [17]. After initially resisting new identity characteristics and considering them as contradictory to the self, the individual will occasionally experience new contextual demands and make some cognitive connections between pre-injury self-knowledge and the new understanding of the post-injury condition. By slowly becoming more familiar with the new post-injury reality, the individual will move closer to integrating conflicting identity characteristics by increasing the complexity of the self during this stage [29].

The final stage of the CDMSII is integration, and it arises once links are established between pre-injury and post-injury self-components, whereby the individual recognizes that both sets are simultaneously important to the self. By this stage, the individual has identified conflicting characteristics and can employ two ways to achieve identity integration. First, similarities can be found between the conflicting identities so that each of them contributes positively to the self-concept. For example, individuals who held positions of leadership at work, but can no longer work because of their disability could show leadership as volunteers in community organizations. In this way, individuals can create opportunities that allow them to express similar self-components that span pre- and post-injury self-concepts. The second method of identity integration is the creation of superordinate categories. In this case, the individual creates one or more broad and inclusive categories under which conflicting identities can be united. For example, an individual with a recently acquired disability may define oneself as a retired worker. This definition simultaneously accounts for the fact that the person had worked in the past, is currently not...
working, but has the possibility of getting involved in other activities.

Similarly, Corbin & Strauss [6] proposed an identity reconstitution process that culminates in an integration step. In their seminal study on biographical work and chronic illness, they define a sense of identity integration as “a feeling of wholeness about identity” (p. 274). While Corbin and Strauss arrive at the same final stage, they focus exclusively on the essential contribution of others to achieve integration. Amiot and coworkers [29] describe social support as an antecedent that facilitates identity integration, but also highlight the details of the cognitive processes that occur before and during integration. For a visual illustration of the CDMSII, refer to Figure 1.

In contrast to other inductive descriptions of the identity reconstruction process following disability onset [6,17], we propose to view the process through a theoretical cognitive model rooted in a developmental perspective in order to account for the long-term identity reconstruction pathway. Given that the CDMSII focuses on the cognitive process of identity integration, we believe that it is particularly instrumental in explaining the process by which new identity characteristics are durably integrated into the self. A specific understanding of the cognitive aspects of the adjustment process thus represents an accessible dimension of the experience, which may directly aid the development of future psychological evaluations or intervention tools in rehabilitation. Furthermore, the CDMSII provides a framework that can be easily operationalized for further research.

To understand how the three latter stages of the CDMSII shed light on the process of identity reconstruction, interview data of individuals with an acquired disability following TBI or TSCI were examined.

**Methods**

**Participants**

Participants (n = 10; see Table 1) were contacted through various organizations devoted to providing services and activities for disabled individuals. To be eligible for inclusion, participants had to: (1) have experienced a sudden onset of a disability following an accident; (2) live with a permanent physical or cognitive impairment; (3) not be in acute rehabilitation stages; (4) be in a stable physical and psychological condition and (5) be able to respond to a semi-structured interview in French or English. Thus, participants with TBI were pre-screened by a psychologist to ensure their ability to complete the semi-structured interview. As the focus of the present research was not on a specific condition, but rather on the process of identity reconstruction following the onset of a disability our sample was comprised of individuals with either TBI or TSCI.

**Procedure**

The first author and research assistants conducted and tape recorded semi-structured interviews. The first author transcribed them verbatim. Interviewers met each participant individually at their preferred time and location. Field notes were taken concerning the context of each interview and the content of informal discussions with the participants. We collected this

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![Figure 1. The main stages of the Cognitive-Developmental Model of Social Identity Integration. Adapted from Amiot, de la Sablonnière, Terry and Smith, 2007.](null)

**Table 1. Participants characteristics.**

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Gender</th>
<th>Trauma</th>
<th>Age</th>
<th>Time since injury (years)</th>
<th>Pre-injury occupation</th>
<th>Post-injury occupation</th>
<th>Pre-injury marital status</th>
<th>Post-injury marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>TSCI</td>
<td>47</td>
<td>4</td>
<td>General contractor</td>
<td>University student</td>
<td>Common-law partner</td>
<td>Unchanged</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>Severe TBI</td>
<td>52</td>
<td>7</td>
<td>Waitress</td>
<td>IE</td>
<td>Common-law partner</td>
<td>Unchanged</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>TSCI</td>
<td>34</td>
<td>17</td>
<td>Student</td>
<td>Creative director</td>
<td>Engaged</td>
<td>Common-law partner (new)</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>TSCI</td>
<td>61</td>
<td>2</td>
<td>Teacher</td>
<td>LTD employee</td>
<td>Married</td>
<td>Unchanged</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>Severe TBI</td>
<td>42</td>
<td>5</td>
<td>Service coordinator</td>
<td>IE</td>
<td>Engaged</td>
<td>Married (new)</td>
</tr>
<tr>
<td>6</td>
<td>M</td>
<td>TSCI</td>
<td>44</td>
<td>11</td>
<td>Foreman</td>
<td>IE</td>
<td>Married</td>
<td>Single</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>TSCI</td>
<td>33</td>
<td>7</td>
<td>Truck driver</td>
<td>IE</td>
<td>Single</td>
<td>Single</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>Severe TBI</td>
<td>35</td>
<td>11</td>
<td>Engineer</td>
<td>IE</td>
<td>Common-law partner</td>
<td>Single</td>
</tr>
<tr>
<td>9</td>
<td>M</td>
<td>TSCI</td>
<td>44</td>
<td>20</td>
<td>Plastic machinist</td>
<td>IE</td>
<td>Single</td>
<td>Married</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>Severe TBI</td>
<td>33</td>
<td>9</td>
<td>Law student</td>
<td>IE</td>
<td>Single</td>
<td>Married</td>
</tr>
</tbody>
</table>

TSCI, traumatic spinal cord injury; TBI, traumatic brain injury; IE, incapacitated for employment; LTD, long-term disability.

*Complete paraplegia; *Incomplete tetraplegia.
material as a means to allow for reflexivity during analysis. Prior to the interview, participants were informed about the topic of the research and signed a consent form. They were notified that they could take a pause, end the interview at any moment or withdraw from participation at any time without having to justify their decision. Participants were informed that if the interview caused them any discomfort or distress, they could be referred to a clinical consultant. This study received the ethical approval from the Université de Montréal.

The semi-structured interview covered the description of the circumstances of the accident; a retrospective description of identity characteristics prior to the accident; a description of the participants’ current view of their identity characteristics and a discussion about the differences and similarities between the two identity descriptions. Participants who reported changes in their self-concept were encouraged to explain how these changes had happened. Participants who reported that their identity had not changed following the injury were encouraged to explain how they managed to maintain a consistent identity. In order to detail participants’ identity characteristics, interviewers prompted participants, when necessary, to elaborate on their significant traits, important activities, goals or other central aspects of their sense of self. All the participants were prompted at some point, without distinction between TBI or TSCI participants.

The semi-structured interview did not refer to the stages of the CDMSII, nor was any explanation of the Model given to participants. Our theoretical affinities were “bracketed” [36] during the interview process to ensure that participants’ responses were spontaneous and personal. For the benefit of the qualitative analysis, we maintained a disjunction between the interview questions and the object of the analysis [37].

Data analysis

The analysis was led by the template organizing style of interpretation as outlined by Crabtree and Miller [38], and was performed by the first author with collaboration of the second author. The use of this method is coherent with our research project as the study aimed to explore a specific facet of participants’ experiences [38]. The present study thus draws on a postpositivist qualitative research paradigm in assuming that reasonably consistent expressions of a phenomenon can be found across individual experiences. The main coding procedure was performed using the following definitions of the CDMSII stages (adapted from Amiot et al.’s [29] original article):

**Categorization**

Emphasis is placed on the distinctions between the pre-injury condition and current condition, with regards to the social environment and personal characteristics. The individual’s pre-injury characteristics are highly salient and valued. There is no sense of connection with the life or group associated with the post-injury characteristics.

**Compartmentalization**

The individual begins to make some cognitive connections between the pre-injury self-knowledge and the new understanding of the post-injury condition. There is more complexity and more nuances in the self-representation. The distinct characteristics associated with the pre- and post-injury conditions, however, remain segregated and context dependent.

**Integration**

The various identity components are recognized as part of the self, and coherent links have been established between them. Similarities between pre- and post-injury characteristics are acknowledged, or higher order categorization is used to integrate different identity components.

During the final analysis of the interview transcripts, we systematically identified the excerpts that were relevant to these definitions. For each participant, we grouped the excerpts that corresponded to each of the stages and checked whether the chosen excerpts remained representative of the participant’s overall account. Then, for each stage, the quotes from all participants were grouped together. This allowed us to evaluate whether the excerpts relevant to each stage definition were coherent across the whole data set, and whether the entire coding was coherent with the stage definitions. A consensus process was then performed by the two authors with the collaboration of a post-doctorate student. The purpose of this consensus process was to corroborate the concordance of the sorted segments with the essence of the theory to limit the possibility of fabricating evidence [38].

We then analyzed the theory-driven sorting of the participants’ accounts in search for additional associations or patterns in the data [38]. We performed this interpretive stage of the analysis in order to reflect on what can be learned about the participants’ experience through the lens of the CDMSII.

The analysis is the result of an iterative and reflexive process of data exploration. Performing such an initial iterative exploration of the data, including preliminary analysis cycles, reduces the risk of missing information that would be relevant to the research question and/or central to participants’ experiences [38]. In addition, following the analysis, we reviewed the text that was not captured by any of the codes in order to ensure that we did not discount any competing or concurrent evidence for understanding the identity adjustment process. We used N-vivo 8 software to facilitate the analysis of the interview transcripts.

Results

The analysis of participants’ narratives revealed an unexpected substantial correspondence with the predicted identity adjustment process outlined by the CDMSII. Organizing the data through the Model’s stages yielded an understanding of the extent and the means by which individuals preserve continuity in their identities following TBI or TSCI. Thus, through their narratives of adaptation and change, the participants showed a concern towards identity preservation and continuity in their sense of self.

The aim of this section is twofold. We report how the CDMSII can be instrumental to understand the cognitive identity reconstruction process in the context of TBI or TSCI. In addition, we also extend the theory-driven analysis by unfolding how the superordinate theme of continuity was embedded in the sequence of the CDMSII.

**Categorization stage – protecting the self**

A sense of longing to return to the pre-injury life is common following the onset of a disability. The first steps of the adjustment process can be understood through the categorization stage of the CDMSII.

In his pre-injury description, Participant 10 highlighted that he was exceptionally physically fit prior to his severe TBI. This characteristic was clearly central to his sense of self as he explained how he survived.

According to the doctors, it’s my health and physical fitness that saved my life. [..] In a way, it’s sport that saved me, it’s health. [..] When I was at the rehab institute, I was spending 4 days out of 5 doing physical exercises to regain all the fitness I had before. So for me that was key. (10)
The vast majority of the participants’ accounts (9 out of 10) included, in various proportions, a current or retrospective form of categorization, as defined by the first stage of the CDMSII. It seems to be nearly inherent, in such context of change, to make comparisons between pre-injury characteristics and post-injury characteristics, and to value pre-injury characteristics without any sense of connection with the post-injury characteristics. The interview guidelines first asked participants to describe themselves separately before and after the accident (i.e. an account of identity characteristics before the accident, and another account for present sense of identity). However, participants spontaneously made comparisons between the pre- and post-injury characteristics in their accounts. These temporal comparisons were also coded as “categorization”. The account of Participant 5 exemplifies this trend:

I had an excellent job... I felt great, much appreciated in my work... uh, so I could identify with that. Now, I’m still looking for... I’m looking for some passion, because I was... I consider my work as my passion. In the past, it was my passion. I’m looking for a new passion to try to rebuild this identity. (5)

Although participant 5 can no longer work, she spoke about her passion for her former work using the present tense, and subsequently corrected herself to use the past tense. She even referred to her previous work as a passion that she strives to regain in order to rebuild her identity, thereby emphasizing how much she associates being passionate with her pre-injury professional occupation.

Another participant spontaneously started her post-injury identity description by stating that it is “very different” from her pre-injury condition. She admitted that she is not ready to acknowledge what seems to be her current representation of a disable person.

Um... (slight laugh) Oh very different, active wise, and I’m not working. Um... but I still, I still try to push myself, not, not just, I don’t want to sit around all day doing nothing. [...] Yeah, at this point, I’m not ready to, to, you know, being an old lady and sit around and, do nothing all day or something, I’m not ready for that yet. So I’m trying, I’m trying to keep, keep doing as much as I can, yeah. (4)

Being active and busy seems to represent a central and salient pre-injury characteristic to her. She lacks a sense of connection with what she views as the post-injury characteristics and circumstances. At the same time, she is attempting to maintain a connection with her pre-injury way of life. By “doing as much as [she] can”, she is expressing her need for continuity in her post-injury life. Perhaps her determination to maintain a connection with her pre-injury life is an identity characteristic that could eventually serve her sense of continuity. In the long term, she might consider that this determination has been present before and after her injury, and it could become a useful basis to nurture a sense of integration. However, at the time of the interview, she did not seem to be able to consciously pinpoint this strength.

As described in the categorization stage, participants show “no sense of connection with the life or group associated with the post-injury characteristics”. When individuals experience the sudden onset of a disability, they often initially reject associations with the post-injury condition as much as possible, where there seems to be nothing that can be used to nurture their sense of self. Participant 3, for example, reported how at first she was insisting to use a manual wheelchair even if it was not the most appropriate device for her incomplete tetraplegia, because she “felt too handicapped” with the electric wheelchair.

Additionally, some participants overtly recalled moments when they engaged in categorization during the acute phase following their accident:

...that’s it, you know, at first it’s... you try to get back, you would like to restart... . . . get in again... . . . take back your... . . . a job and eh, restart as soon as possible... but as the months pass by you realize uh, that nothing is the same as before. (6)

Participants with more excerpts coded as integration reported having engaged in “categorization”. Indeed, most participants spontaneously spoke about how their first thought after their accident was to regain all their pre-injury characteristics and activities that were self-defining.

According to participants’ accounts, the initial mechanism that is used in the face of a sudden change corresponds with the categorization stage. As Participant 6 had related, an individual’s initial reaction following a disabling accident is to try to continue where things were left off before the accident. The characteristics prior to the accident are an important reference point that is used to grasp the distinctions between the pre- and post-injury condition. This reference point sets in motion the process of identifying what is central to the recently-disabled individual’s sense of self.

In sum, the selected excerpts exemplify how participants initially identify themselves primarily using pre-injury references (categorization) without being able to relate to how core identity characteristics can serve their adjustment process. At this stage, the need for continuity is expressed through the reaction of valuing pre-injury characteristics and not connecting with any of the post-injury circumstances, characteristics or groups. Hence, the categorization stage can be understood as a normal reaction to a threatened identity and as a primary means of maintaining a sense of continuity.

Compartmentalization stage – experiencing novelty

The compartmentalization stage is also useful to describe the adaptation process following the onset of a stable and permanent disability. The majority of the participants’ accounts (8 out of 10) included excerpts that were coded as compartmentalization. Extracts corresponding to the compartmentalization stage show emerging complexity in participants’ sense of self, while some tension between the pre- and post-injury identities remains. Participant 9 illustrates this trend:

Well, me, eh... it’s a big difference because I can’t do as much as I could before. Except that... I go out more than before because I’m more conscious... listen... there are things to do other than work uh. I liked to work, even now, I still like it, but I can’t... so I move on to other things... (9)

Participant 9 illustrates his effort to make cognitive connections between his pre- and post-injury identities: although he states that he liked to work prior to his injury, he felt the need to immediately mention that he still likes to work. It seems that he makes sense of his current condition as a non-worker by acknowledging that there are ways to remain occupied even if it is not through paid work.

This emerging complexity reveals how Participant 9 emphasizes a possible connection between how he used to know himself and his current condition. Continuity is no longer solely preserved through recognizing and valuing pre-injury self-knowledge. It is now understood through more complex attitudes towards possible...
links between pre- and post-injury characteristics. Participant 5 displayed a similar attempt to make such connections:

[...] anyways, I don’t have a choice about these limitations, so even if I sit in a corner crying for days, these limitations will remain the same. So I’m better off saying ‘ok, with what I have, I can’t work anymore even if I want to’, so then I’ll just go to university, I’ll take a Spanish class even if my short term memory is not so good, I don’t mind, it doesn’t matter, it’s funny, and I enjoy it. I’d like to become a student, not so much for the results, but for the enjoyment, and to find my identity. (5)

In this case, Participant 5 is trying to accept that she can no longer work by searching for an identity anchor to make connections between her pre-injury self-knowledge and her understanding of her post-injury condition. She recognizes that she strongly identifies with her former work, and she is trying to find a new setting where she can find a way to connect with some core identity characteristics. Therefore, she seems to be looking for an activity that can fulfill her need for continuity, and this serves as more than a means to stay occupied. She is aiming at not simply finding any activity, but finding an activity through which she can express a part of her identity. Although she is incapacitated for work, she is searching for a way to stay active in an environment that resembles her former job.

In a similar attempt to preserve a sense of continuity, Participant 8 spoke about his longstanding interest in sports. He currently engages in adapted skiing and bicycling, and he still enjoys high speeds and often takes risks, but maintains a more conservative attitude than he had prior to his accident. While describing these connections between his pre-injury self-knowledge and his current activities, he felt the need to contextualize his emotional reaction:

Hum, in terms of sports, I can, since that… since that I grieved from… ok, I’m sorry, I’m doing a parenthesis. It’s been elev… almost eleven years since the accident. I quite did the, the grief of my old life, […] I accept my actual limitations, I accept them and I do… (moment of emotion, tears in the eyes)… and, as I say, as I say with a smile now, well, not with a smile, but I do the best I can with what I have. (8)

Participant 8 is able to make connections between his pre- and post-injury conditions with some nuances in his self-representation. However, while he reports having accepted his current condition, the topic still evokes emotion, suggesting that some tension remains salient. His willingness to discuss the sports he is currently doing suggests that he is capable of acknowledging his current condition and he enjoys his abilities in certain contexts. He explicitly recognizes some overlap between pre-injury identity characteristics and his current capacities in adapted sports. In doing so, however, he also contextualizes his narrative by mentioning that he "does his best with what he has", which illustrate some remaining unresolved conflicts in his post-injury self-representation.

Along a similar train of thought, Participant 4 illustrates how a characteristic and its opposite can be expressed depending on the context. When she describes the differences between her pre- and post-injury conditions, she notes that her "lack of independence" is responsible for much of the changes that she notices between her pre- and post-injury self-descriptions. Later, when asked if she felt she had gained or lost identity characteristics following her accident, she asserted that "the independence is still there, for sure" (4). This tension in her discourse shows how in some situations she experiences herself as being dependent (an unwanted negative label), while in other situations, she states that she still has the independence that she values as a self-defining characteristic.

These excerpts illustrate that participants can recognize various self-defining components as being part of their identities. Despite these participants’ obvious efforts to establish links between their pre-injury and current conditions, there seems to be various self-component features that remain segregated and context dependent, rendering the sense of wholeness within the self to be problematic.

Integration stage – feeling whole again

We found substantial correspondences with the integration stage in the narratives of only three of the participants. Three participants showed no sign of identity integration, and four participants expressed little that resonated with the integration stage. The usefulness of a code is not linked to its frequency of correspondence, but relies on the ability of the corresponding excerpts to enlighten the phenomenon. We believe that the fact that only a minority of participants had expressed a sense of identity integration suggests that this stage takes a long time to reach (length that is variable amongst individuals), or may never be reached by some in the case of TBI or TSCI. Thus, it is important not to underestimate the adjustment time required after a disability onset.

According to the CDMSII, individuals can achieve an integration of new components into the self by finding similarities between the pre-injury and the current identity characteristics. The following excerpt from Participant 3 exemplifies this process:

I don’t know, you are what y… You are what you were you know. It’s… it’s… if you were someone who, who, eh, who had nerves you know, and who… who had drive. I remember when I was young eh, I didn’t have, I didn’t have an easy childhood and eh… an easy adolescence. So, but I remember being a fighter you know. I remember I would wake up and go work, and do this and eh… I was never someone who gave up eh, easily. So that just goes on. (3)

In this excerpt, the participant acknowledged and described some similarities in the way she had dealt with adversity prior to, and following, her accident. She recalled having been a hard worker and full of determination, and she asserts that those characteristics are still part of her identity after her injury.

This excerpt resonates with the struggle of participant 4 (presented previously in the categorization section), who was trying with determination to stay active. If we compare the two participants, it becomes clear that participant 4 had not reached a point where she is able to recognize and integrate her determination as a pre- and post-injury defining characteristic, as participant 3 has done.

Acknowledging these similarities does not imply that the accident is ignored. Continuity and change coexist; the pre-injury characteristics and the transformed part of the self can both be recognized and integrated to form a unified sense of self. Participant 6 explicitly expresses the paradox of continuity and transformation and seems to have integrated it with confidence:

[...] the core of the person is still the same, for a person who was negative before his accident, the accident will not make him any less negative. For sure, the person will be transformed, but a whiner will always be a whiner. (6)
While finding similarities between pre- and post-injury characteristics seems to be an effective method of identity integration, it is not the only one. Another way to resolve conflicts between identities and reach integration is to create higher order categorizations that can encompass the different identity characteristics. Participant 7 illustrates this solution for integration:

No there was no revelation or whatever, it’s just eh, it happens like someone who loses his job, like someone. . . . I don’t know, things happen, all kinds of things eh, divorce or…[.] Of course it changed my life for sure, your life never happens like you think it will happen but…[.] I’m just the same as I was before (slight laugh, like puzzled), I don’t see eh…(Interviewer: Ok. What does identity mean to you then?) It would be me. It’s myself, it’s how I am, it’s not my wheelchair, nor is it the job I had before, it’s really eh… Me as an individual. (7)

This excerpt illustrates the superordinate categorization process. A broader category has been created to include the conflicting characteristics. Participant 7 uses the superordinate category of “a person” to describe himself. This allows him to bypass his wheelchair and his inability to work in order to maintain a unitary sense of self.

His search for continuity through the creation of a higher order self-representation could be understood as twofold. On one side, he recognizes himself despite the event that has happened to him; his self-representations have been carried throughout and above life hazards. At the same time, he is expressing a belonging to the human condition through a sense of connection with other persons’ suffering. His life is like any other life; his life is made of the same unpredictable, changing and challenging nature as everyone else’s. His life is in continuity with what life is made of for everyone.

Process overview

The CDMSII provides a framework that allows us to better understand how individuals can integrate new identity characteristics and preserve a sense of continuity following the onset of a disability. However, when looking at each participant’s coding summary, we noticed that a single stage prevails in each participant’s data analysis. Despite the cross-sectional understanding of the cognitive identity integration process, it is relevant to note that participants who have reached the integration stage recalled having engaged in thoughts associated with the categorization stage in the period immediately following their accident. One participant even spontaneously compared her former engagement in categorization to her current sense of integration.

My disability, I got over it. When I say it’s all set, it’s that I found that the first ten years of my life I really had a lot of low moments because of it. I was also much more into “ah, me before, I was like that”, “and before, and before” and, idealizing the past. That’s not really there anymore. Um… Where am I now…? You know, there was… there’s no tears anymore, there isn’t. Instead, I build on my disability in the sense that, it’s my trademark, you know it’s what makes me unique. (3)

It is interesting to note that Participant 3 retrospectively refers to the stage of categorization while narrating the first 10 years following her accident. This suggest once again that the stages of categorization and integration are part of the same adaptation process following the onset of a disability; however, it may take a long time (10 years in her case) to reach a sense of integration.

Participant 3 is definitely, within the sample of the present study, the individual with the most explicit discourse of identity integration. Nonetheless, during the analysis we found that a sense of tension remained about whether she has integrated her disability into her identity. On one side, the excerpt presented above suggests that she has integrated her disability as her trademark. At the same time, she also stated:

You know, you come to terms with the idea, you get used to it, and uh… Often, it’s when people stare at you that you remember that you’re handicapped. (3)

This statement can be understood as if “being disabled” is not a characteristic that is part of her self-representation. At the same time, it could be argued that the “disabled” characteristic is so well integrated and fluid with her other identity characteristics that she hardly thinks of it anymore. In fact, no other participant has mentioned any similarity or made higher-order categorization using the characteristic “disabled”.

This finding resonates with Watson’s [39] view on “reconstruction of normality in construction of self-identity” (p. 519) in the context of a disability. Initially, the disabled condition is salient and resisted, with individuals attempting to stay away from the label of being “disabled”. As time passes however, the refusal of being “disabled” seems to move from an attitude of resistance towards something that represents an unfortunate and doomed struggle, to a condition that strives towards normalcy without emphasis on the disability. Participant 2 illustrates this:

I really liked the person I was in the past. […] I liked myself. I was comfortable with myself. (Interviewer: Do you think that has changed?) No but at one point… I had to put myself back on track, I told myself ‘this is where you are’. You have the right to be different, listen uh, I had an accident, so what? It doesn’t make me different from others; it has made me into someone with more. It’s funny uh. Today I see my accident as a bonus. (2)

Participant 2 recognizes who she was prior to her accident, while also asserting that she remained the same but with something more. In order to achieve this state, she acknowledges that she had to make a conscious effort to recognize her post-injury condition as compatible, not conflicting, with her previous esteemed self. She clearly recognizes the new contextual demands and characteristics associated with her disability as compatible with her pre-injury sense of self.

The excerpts associated with the integration stage also resonate with what can be understood as psychological growth. As Tedeschi and Calhoun [25] suggest, positive changes in the sense of self represent one of the conditions that must occur in order to attain a feeling of growth. We argue that these positive changes are progressively constructed during the whole reconstruction process. The CDMSII can help to understand how individuals cognitively move from the initial psychological shock of acquiring a disability, to the “feeling of wholeness about identity”, as put by Corbin & Strauss [6] (p. 274). By finding similarities between the pre- and post-injury identity characteristics, or by finding a super-ordinate category that can encompass both the pre- and post-injury identity characteristics, individuals can integrate their different identity characteristics to maintain a single continuous sense of self.

Discussion

Each year, dramatic accidental life events impact millions of individuals. Yet, a clear understanding of the cognitive process
associated with how people integrate change in their identity is understood in psychology. In the current qualitative analysis, we aimed to explore how a cognitive-developmental approach can enlighten the identity reconstruction process following the onset of a disability. Through interviews with participants, we gathered data on their present and recalled sense of self, as well as their understanding of their process of adjustment. Building on the work of Amiot et al. [29], we used the Cognitive-Developmental Model of Social Identity Integration (CDMSII) to consider the participants’ accounts. Specifically, the theory-driven analysis yielded a comprehension of the intertwined nature of the cognitive process of identity integration and the need for continuity.

As a framework to consider the participants’ cognitive identity reconstruction process, we found that the CDMSII offers a useful heuristic as it led to two important results. The first result refers to the presence of the three stages of the identity reconstruction process in the discourse of the participants. Recently disabled individuals initially tend to emphasize the distinctions between their pre- and post-injury conditions. In this categorization stage, individuals’ pre-injury identity characteristics are highly salient and valued, and there is no sense of association with the post-injury characteristics, circumstances or social group. Individuals view their situation as a transition period, and strive to regain their pre-injury life and identity characteristics. Eventually, in the compartmentalization stage, individuals create some cognitive connections between how they used to know themselves and how they understand their new condition. Self-representations now include some nuances; new identity characteristics are occasionally acknowledged in certain situations, however, they remain mostly segregated from the pre-injury self-representations. Finally, in the last phase of the identity reconstruction process, the integration stage, the various identity components are recognized as part of the self. Coherent cognitive links are established between the pre- and post-injury self-representations as a means to resolve the intra-individual conflicts caused by the disability onset. By this phase, individuals have found similarities between pre- and post-injury identity characteristics, or have made higher order categorization to integrate different identity components. Thus, as Rybarczyk & Behel [12] also propose, individuals who acquire a disability can eventually integrate new identity components into their sense of self.

The second important result is the emergence of the need for continuity as the main superordinate theme across the identity reconstruction process. The analysis yielded a comprehension of how the identity integration process is embedded within individuals’ overarching search for a sense of continuity through life despite the disability onset. This superordinate theme reveals a paradoxical tension between a drive towards adaptation in the face of disability onset, and the need to maintain a feeling of continuity through life. The idea that an individual’s identity is strongly linked to his/her ability to experience a sense of continuity through life has already been proposed [40–42]. The importance of feeling like the same person over time is increasingly recognized as a basic identity principle [40,42–46]. When one’s sense of continuity is challenged, identity is directly affected and an adjustment is required [43]. Moreover, in the general population, positive affect is associated with stability over time in self-representation [47]. Chandler and Proulx [48] outlined that a sense of sameness can be maintained through the process of change. Thus, the present study suggests that every stage of the adjustment process following disability onset, as describe by the CDMSII, serves on its own terms the need for continuity by bringing about the best possible option in a given time to this need for continuity.

Implications

The intertwined nature of the need for continuity and the process of cognitive identity integration have some theoretical and practical implications. From a theoretical standpoint, besides deepening the understanding of the links between identity and the sense of continuity, the wider research field on adaptation to loss benefits from a more comprehensive integration of identity issues with other conceptualizations. For instance, identity concerns are mentioned in the conceptualization and research of the processes of growth after trauma [25,49], as well as in the Dual Process Model of coping with bereavement [34,35]. Clinical work on the concept of resilience also contributes a number of insights and possible links with identity issues in the context of adaptation to loss [1,3]. Future research should explore whether the cognitive process of identity integration is an antecedent, a constituent, a consequence or a parallel process of those conceptualizations of adaptation to change.

The path towards successful adaptation in the context of a disability also remains an issue of great interest for clinical practice in rehabilitation. Indeed, focusing solely on deficit remediation is often insufficient in helping recently injured individuals to cope with a disability [50]. Understanding the adaptation process using the CDMSII may help to appreciate early reactions to disability, such as the desire to return to pre-injury activities and occupations, and view them in the context of a long-term process. Such reactions may in fact have important identity and adaptation functions. We found that most of the participants viewed their pre-injury self as positively contributing to how they know themselves currently. If change can only happen within a framework of continuity [48], an individual with a recently acquired disability must first conceptualize new meaning out of the identity-defining characteristics with which he/she is already familiar before integrating them within the post-injury context. As such, rehabilitation professionals may best expect to facilitate patients’ adaptation by supporting the search for core identity characteristics through categorization.

We argue that taking care of identity matters represents a useful tool to redirect the focus of the recently injured individual towards an internal, and more controllable, piece of the puzzle in the adjustment process following disability onset. The present study suggests, along with others [3,48,51], that the individual’s experience of change is intertwined with a complex preoccupation with maintaining continuity in the self throughout life. We found that this is particularly important at every stage of the process of identity reconstruction in a context of disability onset.

Limitations

Despite the useful heuristic of the CDMSII for understanding identity reconstruction and the need for continuity following disability onset, the present study has some limitations. First, for most of the participants, several years have elapsed since their accident. The long-term retrospective account of the participants’ adjustment process implies both advantages and caveats. It could be argued that a positive cognitive bias [52,53] may have operated in the account of the participants, leaving open the possibility of underestimating the nature or the amplitude of the change. However, because we were interested in the entire cognitive process of identity reconstruction, individuals who can reflect on their experience from a long-term perspective were best suited for our inquiry.

The retrospective nature of the study has also limited the possibility of fully capturing the context dependent activation of new identity characteristics during the compartmentalization stage. The dynamic nature of this stage would warrant specific attention. Future longitudinal studies or research with multiple
Finally, the impact of cognitive impairment must be kept in mind when considering the results of the present study. Cognitive impairments following TBI can be diverse in type and gravity, and can also arise in association with TSCI [54]. The TBI participants of the present study all had relatively high pre- and post-injury levels of cognitive functioning, with preserved self-awareness. None of the TSCI participants reported having any brain damage. The level of pre-injury cognitive functioning has been shown to positively impact the post-injury distress level and effectiveness of coping abilities [55]. Moreover, cognitive resources following TBI can be impeded to an extent where the individual is left with only altered capabilities to cope cognitively [50]. When the “very circuitry that gives rise to the sense of self” [50] (p. 396) is damaged, it is important to note that a strategy derived from an understanding such as the CDMSII may be of little use. Caution must therefore be exercised in applying the present findings to individuals with severe cognitive impairments. Still, the present study found no preliminary indications of a fundamental distinction in the long-term identity reconstruction process between TBI and TSCI participants. Indeed, conducting a study with a mixed sample of individuals with various injury types has been done in the past, and has led to valuable findings [6]. In qualitative inquiries, looking at a phenomenon under different contexts to find similarities is a potential strategy that can eventually lead towards generalization [56].

Conclusion

Bearing in mind the previously outlined limitations, we argue that the CDMSII provides a valuable broad-spectrum framework to better understand the long-term adaptation process following the onset of a disability through TSCI and TBI. A general perspective on identity adjustment, including a concern for the need for continuity, is important given that identity adjustment following the onset of a disability spans many years [50,57]. In the light of the present findings, we propose that the CDMSII could eventually complement rehabilitation interventions or serve as a basis to develop an identity reconstruction measure.

Despite the fact that identity reconstruction is a common topic in rehabilitation literature, previous research has seldom elaborate upon the cognitive processes by which identity can be reconstructed following the onset of a permanent disability. “One of the most important intrapersonal functions that the self-concept serves is the regulation of affect” [26] (p. 317). Thus, in an effort to improve the well-being of individuals undergoing long-term rehabilitation, approaching this adjustment process from the point of view of cognitive identity integration is a promising and necessary avenue.

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Declaration of interest

The authors report no declarations of interest.

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