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Re-imagining Embodiment and the Self in People with Traumatic Spinal Cord Injuries: A Narrative Approach

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Traumatic spinal cord injuries from accidents cause physical and social suffering, pain and loss. After an initial period of physical and psychological trauma, the individual begins to cope and successfully *crosses over*. Crossing over as a term used in the spinal cord injury register refers to positive adaptation—physical, psychological and social. This paper is based on a qualitative narrative study of the lived experiences of individuals negotiating spinal cord injuries in the Indian context wherein the disability is no longer the location of inability, tragedy, pain, and loss, but one of creative possibilities. As individuals re-imagine embodiment and self, a space of infinite possibilities opens, thereby creatively re-engaging the embodied self and taking on new role identities.

Keywords: embodiment, self, narrative, disability, re-imagination, spinal cord injury

Disability is, among other things, a space that allows for various possibilities and re-imagining new ways of being in the world. This space allows for rethinking and remaking *embodiment*, defined as the focus on the lived experience of the body, and *selfhood*, which is challenged by disrupted bodies. In this paper, embodiment refers to the primal experience of the material body, including the molecular level and all the inner senses, in terms of ecological location, movement, sensation, navigation and proprioception; the *embodied self* is the primal self as the body is the primary source of engagement with the world (Welsh, 2007; see also Merleau-Ponty, 1945/1996). *Self* is discussed as a psychological phenomenon related to cognition and reflection, encompassing self-consciousness, self-awareness, self-reflection, self-concept, and so forth. The range of possibilities within this space is facilitated by an active psychological and embodied self that we term the *adapting self*. It is based on a study that sought a narrative capture of the lived experiences of subjects who have positively adapted to spinal cord injuries (SCIs), and thereby the focus is on the body

as experienced subjectively (*lieb*, rather than *körper*; Husserl, 1913/1962).

SCIs are usually the result of traumatic accidents such as motor accidents or high-impact falls. SCIs entails fractures in the vertebral column that usually heal, but the injured spinal cord does not heal or regenerate, thereby causing loss of sensation, movement, and mobility: either *paraplegia*—lower limbs—or *tetraplegia*—upper and lower limbs. SCIs are one of the most traumatic injuries requiring a lengthy period of treatment, rehabilitation, and transition back to everyday routine and living activities. Injury in the cervical area leads to loss of use in the arms, trunk, and legs (tetraplegia or *tetraparesis*; Cole, 2004). Injury in the thoracic, lumbar and sacral regions leads to loss of sensation and movement in the legs, but the arms still work (paraplegia or *paraparesis*; Cole, 2004).

Interrelated Matrix of the Body and the Self

This study considers the body and the self as an interrelated matrix because of which there

is a sense of unitary being. The body and self are enmeshed and experiences accruing to the body also feed into the individual's experience and sense of self. Contrary to the Cartesian dictum, in daily life human persons first *are*, and are therefore able to do many things, both mental and physical (Menon, 2014). Thus, a bodily disruption also keenly impacts who one is as an individual, how one reacts and responds to these experiences, and ultimately how one copes and adapts. The self is both object and subject as in known and knower (James, 1890/2007). The self is an active agent trying to make sense of life experiences. The self can be said to be the experiencer, organizer, and synthesizer of experiences. The self is a subjective experiencer capable of self-reflection, including reflecting on oneself with a degree of objectivity.

The self as the knower and the known is critical in reflecting upon life experiences, actions, and thoughts (James, 1890/2007). The self negotiates life experiences and maintains a sense of stability and continuity in the life-course. The psychological model of the self is a comprehensive, dynamic, unifying system with interactive multiple layers that include embodiment, sociality, culture, emotion, memory and narrative. Thereby the self is a complex matrix of the mind, body, society, and culture.

In people's experiences of SCI, the altered body also impacts the self. The self's awareness of the body adjusts to the altered state, and this sets into motion the process of coping, adapting, and reconciling. The embodied self as it is experienced through the vehicle of the body undergoes shifts in terms of transformed self-concept. "Self-concepts are cognitive *structures* that can include content, attitudes, or evaluative judgments and are used to make sense of the world, focus attention on one's goals, and protect one's sense of basic worth" (Leary & Tangney, 2012, p. 72; italics in original).

According to Burke and Stets (2003), human beings develop a concept or a view of who they are as they present themselves to others and to themselves (Burke & Stets, 2003), "the sum total of our thoughts, feelings, and imaginations as to who we are" (p. 5; cf. Rosenberg, 1979). In line with Gecas and Mortimer (1987), we view the self-concept as a "multidimensional phenomenon"

(p. 141) comprising a range of psychological elements used by individuals to define themselves; these might include "attitudes, beliefs, values and experiences, along with their evaluative and affective components" (p. 141).

Drawing from the cognitive notion of a *conceptual self* (Neisser, 1991) refers to the self-concepts each person carries. These self-concepts are inherently embedded in sociality and are variously shaped through cultures and societies. In this sense, the conceptual self is self-knowledge of existing self-concept and also a process of *self-making* by way of which one tries to become what one thinks of oneself. Self-making refers to the process of the creation of the self, including the various activities by which personal and social selfhood are acquired (Baerveldt & Voestennans, 1996). The conceptual self involves the "capacity to engage in abstract, self-thought" (Leary, 2007, p. 41). Both self-concept and self-making receive cues from the social environment wherein the conceptual self is constituted and constructed by sociocultural processes.

The Embodied Self

Embodiment is the process of the *lived body* (Merleau-Ponty, 1945/1996) in which the body is the first and foremost environment available. It is through the body one lives, communicates, experiences the world, and interacts with others. According to Merleau-Ponty (1945/1996), "the permanence of one's own body, if only classical psychology had analyzed it, might have led it to the body no longer conceived as an object of the world, but as our means of communication with it, to the world no longer conceived as a collection of determinate objects, but as the horizon latent in all our experience and itself ever-present and anterior to every determining thought" (p. 92). The term *body* at the basic level refers to the biological organism as a sum total of all biological, molecular processes, and hence is the *material body* or the *corporeal body*, defined as the physical structure. However, the idea of using the term *embodiment* is to focus on the lived or subject-body rather than the object-body (Sampson, 1998). The lived/subject body is an active knower and experiencer and the

locus of all experience (Merleau-Ponty, 1945/1996). The object-body on the other hand refers to the body as dormant and passive as against the acting body (Williams & Bendelow, 1998).

The sense of body and the mind are intertwined (Merleau-Ponty, 1996; see also Menon, 2014). The self is the subjective experiencer capable of self-reflection (reflecting on oneself as an object). One experiences the self through the medium of the body (which is what is meant by the embodied self). The embodied self refers to a grounding of the concept of the self in the physical body. Far from the self being a purely psychological, mental entity, it is embedded in a corporeal framework.

From the psychodynamic perspective, the body forms the basis of the self (Krueger, 2002). Meissner (1997) named the physical body and the *body self* as crucial components of the self. The embodied self includes both experiences of the psyche as well as bodily experiences of sensation, movement, and so forth. All actions involve the body: the body is an integral component of self-organization and ultimately of self-representation. Serious illness is a loss of the “destination and map that had previously guided the ill person’s life” (Frank, 2006, p. 1). This study uses the terms *destination* and *map* to show how people with SCIs have to deal with and reconfigure these orientational aspects of their bodies and lives.

The Disruptions and Re-imaginings of Embodiment

The embodied self copes, re-adjusts and successfully adapts to an altered condition. As expressed by the phenomenological philosopher Maurice Merleau-Ponty (1945/1996), “the body is the vehicle of being in the world” (p. 82). The embodied self is experienced through the body, and thus there is remaking in terms of engaging with the body and self post-SCI. Embodiment and self are re-imagined within an altered body with new ways, as crafted by the individual, of meaningfully engaging with the sociocultural world. With such re-imagination and ensuing responses, role identities—personal, social and professional—may change accordingly. Positive adaptation implies self-acceptance of the altered body and the self, including the physical, social and

psychological pain and loss. According to Frank (1995), loss for people with SCIs is not just limited to sensory or mobility abilities but also a loss of the old map and destination.

Traumatic spinal cord injuries present a disruption in the baseline embodiment. The body and its engagement with the psychological self and the world are taken for granted until a break in the usual state of mind and body forces an individual to engage in conscious reflection (Martin, Sugarman, & Hickinbottom, 2009). The injury presents an opening and a possibility to think about embodiment in a whole new way. People with SCI often engage in deep conscious reflection on embodiment, finding new ways to deal with the disrupted state and newer ways to make meaning of an altered body and world. SCI implies a radical shift in the body’s interaction with the physical environment. Taking Merleau-Ponty’s (1945/1996) *phenomenology of perception* approach, the body is the source of the self and the world. While the self is constituted by the body, and the self is experienced through the body as an embodied self, it is also equally important to note the possibility that the self is not wholly constituted by the body or other biological, physiological determinants. The psychological self is definitively constituted by embodiment but is neither wholly defined nor limited by the material body. Embodied disruption in SCI alters the old routines and ways of doing things but does not limit possible ways of doing things differently. This is the inventive space where possibilities are imagined and creative actions are envisioned.

SCI also implies new learning both for the person and those around her or him—family and friends. We use the term *learning* because the person has to learn to pay attention to her or his bodily needs and acquire new skills in movement and navigation. To use Murphy’s (2001) phrase, “the former sense of embodiment” (p. 256) becomes meaningful in the context of SCI. The body may be devoid of sensation or movement, but one must pay attention and take care of the body (Cole, 2004). The body is brought to attention and reflective consciousness only during a disruption. Disruption in SCI brings to reflective consciousness the primacy and criticality of embodiment. Disruption

brings with it new experiences of embodiment, for example, people with SCI must get used to a different way of navigation using the wheelchair. People with SCI find novel ways to re-engage the body with the ecological and social worlds. Prior to re-engaging the body with the outside worlds, individuals must re-engage the self with the body first, coping and reconciling with an altered state of embodiment and altered perceptions.

Reflective Narratives on Embodiment: Method and its Limits

The narratives in this study are critical reflections on embodiment and the range of transformations and adaptations in experiences of SCI. The narratives embody *personal agency* and *subjectivity* as individuals work towards coping, reconciling, and re-engaging with the world post-SCI. Personal agency refers to the self-determination of individuals living and negotiating within societies. Personal agency is the capability of intentional decision making and purposeful action. Subjectivity refers to the subjects' perspectives, thoughts, desires, beliefs, and emotions. Ortner (2006) defined subjectivity as "modes of perception, affect, thought and desire" (p. 107). The narrative is best suited to understanding the making of the human self as it can be said to be essentially a storied account of an individual's *lifeworld* and experiences. The narratives of P3, P5, P16, and Gupta are reflective and present a unified, coherent understanding of distinct lifeworlds, the travails of SCI and the ensuing transformations and adaptations. Narrating disruptions of the body imply a space presenting inventive and creative possibilities.

The underlying study focused on the narratives of 20 participants with acquired traumatic SCIs. For the four participants considered in this paper, ages ranged from 30–50. To protect the privacy of the participants, names were omitted and coded. This study focused on the life-story narratives of participants P3, P5, and P16, as well as Shivani Gupta (2014), whose name has been used since her narrative, *No Looking Back*, is a published book circulating in the public domain. We used both the published narrative and the personal conversation with her as data.

Participants were selected using a purposive sampling method (Given, 2008). The initial samples were chosen following the suggestions of two consultants working in the field of disability and equal opportunities for people with disabilities. As an accessibility consultant and auditor, the first individual had considerable experience and a large number of acquaintances in the disability sector. She provided contacts about other individuals who would be able to share their own experiences about disability. The second informant worked in a Non-Governmental Organization (NGO) for visually impaired people and was able to provide contact information concerning people with visual impairments. The initial sampling provided by the two consultants produced a snowballing effect (Oliver, 2006) as each new participant provided new contacts of friends/acquaintances who could participate in the research project and share their personal narratives with the researcher. According to ethical research norms (Denscombe, 2006), prior consent was obtained from all participants to record their interviews. While the focus was on allowing narratives to freely emerge from conversations, we guided the interviews through semi-structured questions and prompts. Questions posed included: What did you feel about your body after the injury? What were the strategies you used to cope with a "different body" post-SCI? What life changes did you have to make post-SCI? What kind of support did you get during rehabilitation and coping?

The resulting data were analyzed using thematic content analysis (Riessman, 2006). Of the resulting 10 major themes and 5 specific themes, the four considered in this paper are *conceptual self*, *embodied self*, *disruption*, and *relearning*.

While conventional psychology seeks to objectively separate the subject from the researcher, critical psychology seeks to include the subjectivity of the researcher into the research project, emphasizing the links between participants and researchers (Parker, 2007). Consequently, our ways of interpreting and using data are also reflected in the results presented in this study. As Parker (2007) put it, critical psychology attempts to move away from objective knowledge to subjectively produced, personal knowledge, which locates the individual in personal and social worlds. Critical Narrative

Analysis (CNA) is one of the qualitative methods used in psychology that seek to recover and construct meanings as an interpretive enterprise (Emerson & Frosh, 2004). CNA allows for meaning to emerge both from the narrator and researcher. The narrative mode of inquiry through CNA assumes the storied nature of human experience (Sarbin & Kitsuse, 1986; cf. McAdams, Josselson, & Lieblich, 2006). Thus, as against quantitative or empirical approaches, the focus of the study is also on qualitative, hermeneutic and idiographic approach to the meaning making of human experiences. As such, the thematic content analysis has been conducted with a sensibility to implicit meanings.

While qualitative research methods and data yield a rich, nuanced study, there are certain limitations. One such limitation is researcher subjectivity, since the data is open to interpretation in a qualitative method, which may be influenced by a researcher's beliefs and ideas about the topic under study. Another limitation is the non-replicability of most qualitative research studies; unlike quantitative research or experimental research which can be replicated under similar conditions, qualitative research is usually contingent to time, place, and certain circumstances. In this study, adaptation is studied specifically relating to post-SCI. While a similar study could analyze adaptations in other disabilities or diseases, adaptation in SCI has its own unique meaning and interpretation. This study is, again, contingent to time and certain circumstances in the live trajectories of participants.

The Conceptual Self in Individuals with SCI:

Results

The body is usually taken for granted, and one often goes through life without reflecting on it deeply, but a disruption in the baseline bodily state reveals the importance of reflective consciousness. The participants discuss how after an SCI one cannot take anything for granted, from being cautious and conscious about how one sits, transfers from a wheelchair, navigates, eats, drinks, and other daily activities. All participants had similar experiences of prolonged hospitalization, insertion of tongs or calipers into the skull, and lengthy rehabilitation.

Gupta is in her forties and became a paraplegic wheelchair user at the age of 22 in a car accident in 1992 that damaged her spine. She was a hotel management graduate and had just begun her career as a guest relations officer when the accident changed her lifeworld and life-course. Writing about her hospitalization, trauma, pain, and uncertainty of what would happen to her, Gupta shared a range of issues from medicalization to depersonalization in the hospital setting. During her hospitalization she wrote that life came to a standstill.

Her spinal injury was a spinal compression at the level of cervical vertebrae 6 and 7 (C-6/7), with a hairline fracture at C1. She had to go through the traumatic experience of being fitted with a steel tong in the skull. Her frustrations of being an object in the hospital and dependent upon aides for basic activities clearly illustrates the stark difference in the life of a person with a spinal cord injury who was used to being independent. She had no sensation below her shoulders, and she wrote about how the sensation of touch is taken for granted, its importance only realized when it has been lost.

Gupta (2014) was rehabilitated in the hospital and had to re-learn how to sit, control her bladder and engage in physiotherapy to strengthen her limbs. She said "there were no aspirations, no ambitions—I needed to relearn simply how to live" (Gupta, p. 41). She was medically repaired but needed rehab to get back to life. P16 was in his late thirties and has been negotiating a traumatic SCI since he was a teen when he had a high impact fall. Narrating his story, P16 spoke about how the initial days were very tough. Many individuals find themselves in a state of loss because the body has changed beyond comprehension. The embodied self must come around to accepting this altered state wherein the body has to cope with a loss of sensation and most importantly movement and mobility. P3, a professor in a college in New Delhi, had an SCI in a traumatic motor accident. She is now in her fifties and has successfully crossed over. P3 stated, the first thing that hits a person with SCI is the fact that he or she is not going to walk again and will have to use a wheelchair. While there is loss in some dimensions, there are also ways of working around these losses. P3, P5, P16 and Gupta

shared a unanimous opinion that the only way to work around the loss is to accept the situation and see what best can be done to deal with it. P16 said that it took him five years of anger, frustration, and depression before he came out of it. His struggles were the struggle of the embodied self coming to terms with an altered body, as well as trying to salvage a self-image.

P16 and Gupta shared a similar experience of undergoing a phase of heavy blurring of self-image and body-image. We use the terms self-image and body-image to refer to how an individual sees or visualizes the body and self in a sociocultural matrix. Cash (2004) stated that body-image refers to the “multifaceted psychological experience of embodiment, especially but not exclusively one’s physical appearance” (p. 1). Gallagher (2005) and Gallagher and Meltzoff (1996) have defined body-image as a system of (sometimes conscious) perceptions, attitudes, and beliefs pertaining to one’s own body. Visualizing the self- and body-image requires intersubjective awareness.

P16 and Gupta had to reconcile the fact that the wheelchair was going to become a part of their self- and body-image. Since the body needs a wheelchair to make up for a loss of mobility and to be functional, the body-image undergoes a shift from an image of upright posture, and an ability to stand and walk, to a new way of navigation. Consequently, the self-image also alters in tandem with the body-image. Ultimately the embodied self realigns to an altered way of corporeal being. Gupta candidly shared that her first glimpse of herself in a wheelchair in the mirror sent her reeling, and she almost disavowed the reflection as she worried about her image in public. She wanted to hide and somehow could not accept this image of herself in a wheelchair. It was at this stage that she understood her life was not just relearning how to live, but also rediscovering who she was. Ultimately, she had to get over her fears of being seen as helpless and dependent because she wanted to relearn how to live and live well within whatever body parameters were given.

The theme that the wheelchair and the changes it effects in the self- and body-image is common to all the participants. P3 put it humorously,

stating that she was a “compulsive wheelchair-user.” P5 talked about how people view him as a “nuisance” when he is out on the streets because vehicle users have to make way for him. P16 said his friends were initially shocked to see him in a wheelchair, but ultimately they understood that he as an individual/person was the same. All participants shared similar experiences of relearning how to live post-SCI. The body is no longer in a baseline state and the individual must make adjustments at different levels in order to get back to the business of living, although differently. The embodied self undergoes an acute transition during and post-SCI.

Rehabilitation in SCI involves re-engaging with the concept of mobility and navigation. Both mobility and navigation have to be effected through the medium of the wheelchair. The embodied self must adjust the line of vision, which is different from the location of the wheelchair, and must relearn navigating spaces through the wheelchair. The concept of spatiality must be re-imagined wherein the individual negotiates space differently. While space is hardly brought to reflective consciousness when one has mobility, it becomes a symbol of accessibility/inaccessibility when one is negotiating from a wheelchair. As P3 put it, one must pre-empt situations and when going to a new place one has to get prior information about accessibility. Navigating spaces and negotiating mobility in a wheelchair gives individuals new competencies. As P5 put it humorously, he has developed very strong arm muscles by negotiating his wheelchair and he likes to challenge people to arm wrestling. In all these cases—P3, P5, P16, and Gupta—participants had developed new navigating skills and competencies to rise to the challenges of spatiality and accessibility. The embodied self creatively rises to the challenge of adapting to an altered corporeal environment, and a changed spatial environment.

What is also significant about the transitions in the embodied self in SCI is the fact that the body per se has to be given proper care and attention. One cannot afford to neglect or ignore the body at any given point in time. The embodied self’s perceptual experiences undergo a major shift. Sense perception, feeling, movement, and mobility are no longer the same. The body’s travails include

pressure sores, loss of bladder control, frequent urinary tract infections, and occasional respiratory issues. The embodied self must grapple with physical discomfort and also psychologically reconcile that these issues are not going to go away. As put by all the participants, crossing over begins and happens successfully when one realizes that acceptance is the only way to go forward.

Though P3 noted that one needs help with body functions, and this is not what one would like to do, there is no other way to be when dealing with a SCI. Acceptance that one has to depend on help for daily life activities is a part of SCI. The embodied self has to significantly adjust to this way of being. The fact that one requires assistance is not easy to accept; P16 shared that he has his care-giver with him all the time, even when he goes out to meet his girlfriend. Independence is now a different concept for people with SCI. While mainstream society excessively valorizes the concept of independence, people with SCI significantly renegotiate the concept to mean doing things as best as they can, with assistance whenever required. A significant relearning in SCI is interdependence, which is not something that one has to be ashamed of, but rather one accepts that one cannot do certain things, and that there are ways of doing things differently.

P5 is also an academic researcher and professor, and his self-concept is linked to his profession. P5's self-concept has also undergone certain shifts post-SCI that can be explained in terms of his negotiations with accessibility/inaccessibility. Accessibility is a significant issue with P5 and he expressed that sometimes he finds it difficult to negotiate certain buildings and feels that he can become a "nuisance." If the building is not accessible he steps back rather than allowing people to carry him. He reported feeling that people are curious but also helpful and put it that one would rather do things by themselves. P5's self-concept has been revised in terms of his interdependence. He shared that he sees himself through social cueing as he makes the statement that his wheelchair is sometimes seen as a "nuisance" on roads. We interpret parts of P5's talk within a matrix of pre- and post-injury self-concept.

P5 has adapted positively to his injury though slight hints of a not-very-happy situation

are identified in his language. Phrases such as, "confined to a wheelchair," "learns a lot of tricks to get by and manage," and "it strips one's self confidence," indicate a self-concept that has undergone a certain blurring due to the current state—though overall P5 appears to be extremely positive and well-adapted. We locate these feelings and emotions in the discourse of ableism/disablism because society has not been able to provide adequate facilities and access. According to Wolbring (2008), "ableism is a set of beliefs, processes and practices that produce—based on abilities one exhibits or values—a particular understanding of oneself, one's body, and one's relationship with others of humanity, other species and the environment, and includes how one is judged by others" (p. 252-253). Ableism reflects the sentiment of certain social groups and social structures that value and promote certain abilities, for example, productivity and competitiveness, over others, such as empathy, compassion, and kindness. Ableism directed at people with disabilities leads to disablism (Wolbring, 2008, p. 253). Simple provisions such as ramps, lifts, accessible restrooms, and easy seating will ensure a lot more independence in movement. The hard fact that P5 feels excluded from various activities and events due to lack of access is evidence of structural disablism resulting in a feeling of psychological exclusion.

P16 also presents a renegotiated self-concept post-SCI. While his initial five years were reported as very tough as he went through anger, frustration, and depression, he currently appears well-adjusted with a strong positive self-concept. He shared that it took him time to adjust to his body and accept it. Finally, he realized that he had no choice but to accept it and this led to his crossing over positively. He apparently does not allow social cueing to blur his self-concept. Talking about people's stares at his wheelchair, he said this does not bother him. In a way his self-concept is still linked to his sense of fun and adventure. He has done it all in his wheelchair. He reported that he still goes trekking with his friends and feels it is acceptable to receive help. He also has a girlfriend and his sense of who he is now is closely tied to his relationships. P16's strong self-concept comes from his belief that disability should

not be the dominant theme of one's life. Though the disability is there and inevitable, and has to be accepted, he indicated that he feels he is not defined by it. He has other activities and interests in life, and has had to revise his self-concept post-SCI more so in terms of being amenable to having a constant care-giver and taking help.

Gupta's (2014) narrative and published text clearly embodies her revised self-concept post-SCI. As she put it, "there were no aspirations, no ambitions—I needed to relearn simply how to live" (p. 41). She was medically repaired but needed rehab to get her back to life. In the initial phase of rehab, she spoke about her self-esteem taking a deep dive. The idea of learning to depend on others and not being able to do everything on her own affected her self-concept. She wrote about wanting to hide. More than relearning to live at this stage it was more of rediscovering who she was:

I changed that day. I changed forever—
I was no longer the carefree person who dreamt
of having her own family.
I didn't know yet who I was now; neither did I
know how I was supposed to go on.
The one thing I knew was that tomorrow wasn't
going to be a better day.
My life from now on was about rediscovering
myself—
Struggling to let go of all that I had lost;
Learning to appreciate what I had left.
(p. 45)

Self-perception is a process that regulates individual behavior and actions based on one's interpretations of events and experiences (Bem, 1967/1972; cf. Riding & Rayner, 2001; Menon, 2014; Laird, 2007). The above poem beautifully captures the struggle of the self in disability. The struggle to re-imagine a self and the struggle to reinvent a life that is a constant tension between public perception and self-perception. The self is no longer the same after a traumatic spinal injury. The body is not the same and has to adapt to several changed situations. One relearns the simple business of living and negotiating daily activities after such a trauma.

Gupta's self-concept also had to reconcile images of helplessness about disability. She became

self-conscious of her disability but gradually renegotiated for herself a new way of life including a new career because she could no longer continue in her pre-SCI career in the hospitality industry. Gupta's self-concept received a positive boost as she started working with the Indian Spinal Cord Injuries Center, New Delhi after a training course as a peer counselor at the Duke of Cornwall Spinal Treatment Center, UK. As she went on to establish her own organization, AccessAbility, with her husband Vikas, Gupta's self-concept took on strong positive overtones and reflects who she has become as a person and a professional.

All of the above individuals from P3 to Gupta have clearly negotiated a different self-concept post-SCI. The conceptual self feeds into self-knowledge and allows for a revision of self-concepts. One is never the same after a traumatic accident, but one can also find positivity and strength in going over who one has become after a trauma. The very fact that individuals cross over and relearn the business of life makes for positive self-conceptualization. Coping with a changed self-concept is inevitable as one reassesses the feeling of *who am I now in this state of body and mind*.

Individuals often have a fair idea of their life course and life goals, both personal and professional, and a disruption in the form of an illness or disability often requires a remapping of life goals with altered embodiment. This study uses the term *disruption* to indicate a break or rupture in the old way of being. Though the term traditionally has negative implications of something undesirable, disruption can also have positive meanings and can enable individuals to re-think, re-examine, and reconfigure their life maps and destinations—a process that can often add more meaning to their lives. For example, people with spinal cord injuries such as Gupta have used the disruption in their lives and bodies to not only find new ways of being in the body, but also find new life goals to engage meaningfully and lead richer lives.

Experiences of disability and changes in body functioning bring about major cognitive changes in terms of perception, relearning, and thinking (Menon, 2014). The embodied self and the psychological self inevitably cope and adjust

to altered environments. Such adaptation is central to living and moving on with life. All the above individuals' narratives reflect embodiment of positive adaptations that show the way forward for life to go on.

Conclusion

As a source of self-knowledge, the conceptual self negotiates self-concept and provides the process of self-making as one goes through changes and upheavals in the life course. The conceptual self can be said to be constituted not only by the sociocultural environment, but also by the body ecology and psychological environment within the individual. An altered body, in terms of the injury and related changes, is read and processed by the conceptual self as the individual comes to terms and reconciles along with reassessment of his or her self-concepts in facing a changed environment.

It is inevitable for an individual to reassess self-concept following a major life changing event, be it a major illness or a traumatic accident such as SCI. As the title of Gupta's (2014) text reads, *No Looking Back*, it is suggested that SCI brings with it major life changes and alterations. While a disabling accident is usually viewed as a tragedy, the narratives of the individuals in question tell a different story. Though the initial coping period of rehabilitation is traumatic—physically and psychologically—the individuals have made it through this period and crossed over into a state of adaptation. Narrating her experiences, P3 said that she was always a happy and cheerful person and this has not changed. She said she has the ability to accept things that she cannot change, and she believes no one has a perfect life. P3 had a strong self-concept even before the injury and her positive self-perception is closely tied to her role as an academic researcher and professor. Post-SCI, her professional role has not changed much and she has moved forward in her role. She spoke of renegotiating her feelings of who she was and is post-SCI. While her self-concept pre-SCI was linked to her total sense of independence, post-SCI she has had to realign her expectations and understand that she needs help. Her husband taught her that it was acceptable to ask for and receive help. The idea of receiving help,

of being interdependent, is linked to an individual's self-concept as dependent/independent. Modern cultures and communities often overemphasize the idea of individual independence ignoring the fact that all human beings are interdependent for most life activities.

The participant narratives from this study suggest that SCIs make apparent the importance of embodiment, and require one to pay acute attention to the body. The interpretative analysis of the subjects' narratives suggests that the onset of a major or life-threatening illness or disability is a disruption not only of the body but also of the self that has to adjust and reconcile to altered states of being—both physical and psychological states. The fact that the self undergoes several changes post-illness or disability has been reported by those with relevant lived experiences, such as anthropologist Robert Murphy (2001) in his book, *The Body Silent*. A chapter in the book titled, "The Damaged Self," offered clear perspectives on the blurring of the self and identity in disability and illness. In the narratives considered in this study, the embodied self has been through a significant blurring, but has come around to reconciling, coping, adjusting, adapting, and most importantly accepting the altered body. If there is a profound learning for the embodied self in SCI, it is the fact that the body must be attended to consciously and the auto-pilot body is no longer a fact of life. We conclude based on our qualitative data that the self-image feeds off of the body-image. Attitudes and perception towards the body also play a determining role in the self-image.

The starting point for the phenomenological study of embodiment and self is a reflection on how individuals negotiating SCI re-engage with their bodies, selves, and the environment—ecological, sociocultural, and psychological. Drawing on the phenomenological experiences of the body and the self in SCI, the study suggests that the embodied self and the conceptual self go through critical transformations that can lead to coping, reconciling, and adapting positively. The conclusion we wish to draw from the above life-story narratives is that disability as disruption, though implying a rupture/break, also serves as a space for reflection on embodiment and selfhood. Illness and disability

acutely draw one's attention to the body and the self as the individual goes through a range of situations. A traumatic accident such as an SCI calls for reengaging both body and self within changed environments; for example, what was once an easily negotiable environment for the body now poses new barriers, as with steps or uneven terrain. Role identities also change, as in the case of Gupta who found new meaning in engaging in peer counseling others with SCI and ultimately established her own organization engaged in access audits.

These narratives of lived experiences of individuals with SCIs in the Indian context indicate a creative re-engagement of the body within the given ecological and sociocultural environments. Though there is a disruption of the body in terms of movement, navigation, sensation, and other abilities—as with the independent performance of personal activities—the active psychological self along with the embodied self can reconcile to the disruption, finding ways to do things differently. Positive adaptation begins with self-acceptance of an altered body- and self-image. Role identities may undergo a shift to make way for a different way of being in the body and world.

Positive adaptation happens when the self moves beyond the limitations of the body, yet remains connected and engaged with the body needs. Adaptation is a fine balance of the embodied self and psychological self finding new meaning in life and accepting the altered body. Disability as a space allows for creativity in finding new ways of being and doing things. Examples of this creativity include P5's challenge to arm wrestling, or P16's trekking adventures in the forests of Mumbai or Pune. Adaptation also implies a reevaluation of abilities. Individuals go beyond disability to focus more on abilities and what can be done rather than what cannot be done. This is the crux of positive adaptation. The range of possibilities within this space is facilitated by an active embodied and psychological self that we term the *adapting self*.

The adapting self can be said to be a self-process that is constantly active, alert, and attuned to the body and the physical environment. Self-processes are essential for driving engagement in learning and for human potential. Self-processes

are dynamic and interactive. We consider the self to be a multidimensional, interactive, dynamic, and constantly changing process (McInerney, Marsh, & Craven, 2008). The adapting self in the participant narratives enables a process of reconciling and remolding the individual's embodied self and psychological self in tune with the changed circumstances and situations. The adapting self is agentive—capable of making choices and taking actions—thereby allowing the individual to act according to the situation. The implication of the self being agentive encompasses the idea of individual responsibility for his or her life. We posit that the adapting self is integral not only to coping and reconciling with experiences of disability but also to the sense of wellbeing.

Wellbeing is dependent on the inner disposition of the individual, his or her sense of autonomy, virtues and passion for common good. Wellbeing mostly is experienced in our lives when we find a meaning and purpose to living. In almost all of wellbeing studies the two life traits that clearly emerge are "meaning" and "purpose." (Menon, 2014, p. 16)

Each of the participants in the study have gone beyond all physical limitations to rediscover a new meaning and purpose in his or her life. While P3 and Gupta (2014) found a greater purpose in peer-counseling, P16 has challenged his own body and found new ways of participating in activities such as trekking. While SCI typically brings on a temporary blurring of the embodied self and psychological self, the above individuals have gone through a process of loss, pain, emotions of anger, frustration, and depression, but have finally returned to a new baseline state. As the embodied self reconciles to the changed body, the psychological self copes with a blurred body- and self-image as individuals revise their sense of who they were and who they will be post-SCI. Ultimately it is crucial for every such individual to find a new space of adaptation, thereby meaningfully reengaging with life, finding new goals, and moving ahead in their personal and professional lives. Positive adaptation is all about a new way of being and a new way of doing things within the given matrix of the changed body and bodily functioning.

Notes

1. The case studies presented in this study are drawn from Namitha Kumar's doctoral research and the field work data collected in India between July 2012 and February 2013. Sangeetha Menon was the supervisor for the doctoral thesis.

References

- Baerveldt, C., & Voestennans, P. (1996). The body as a selfing device: The case of anorexia nervosa. *Theory & Psychology, 6*(4), 693–713. <https://doi.org/10.1177/0959354396064008>
- Bem, D. J. (1967). Self-perception: An alternative interpretation of cognitive dissonance phenomena. *Psychological Review, 74*(3), 183–200.
- Campbell, F. (2008). Refusing able(ness): A preliminary conversation about ableism. *M/C Journal, 11*(3). Retrieved from <http://journal.media-culture.org.au/index.php/mcjournal/article/view/46%2C>
- Cash, T. F. (2004). Body image: Past, present, and future. *Body Image, 1*, 1–5. [https://doi.org/10.1016/S1740-1445\(03\)00011-1](https://doi.org/10.1016/S1740-1445(03)00011-1)
- Cole, J. (2004). *Still lives: Narratives of spinal cord injury*. Boston, MA: MIT Press.
- Denscombe, M. (2006). Writing research. In V. Jupp (Ed.), *The Sage dictionary of social research methods* (pp. 324–326). Thousand Oaks, CA: Sage.
- Descartes, R. (1967). Discourse on the method of rightly conducting the reason and seeking truth in the sciences. In *The philosophical works of Descartes* (Vol. 1; E. S. Haldane & G. R. T. Ross, Trans.). Cambridge, UK: Cambridge University Press.
- Emerson, P. & Frosh, S. (2004). *Critical narrative analysis in psychology: A guide to practice*. New York, NY: Palgrave Macmillan.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics* (2nd ed.). Chicago, IL: University of Chicago Press.
- Gallagher, S., & Meltzoff, A. N. (1996). The earliest sense of self and others: Merleau-Ponty and recent developmental studies. *Philosophical Psychology, 9*(2), 211–233. <https://doi.org/10.1080/09515089608573181>
- Gallagher, S. (2005). *How the body shapes the mind*. Oxford, UK: Oxford University Press.
- Gecas, V., & Mortimer, J. T. (1987). Stability and change in the self-concept from adolescence to adulthood. In T. Honess & K. M. Yardley-Matwiejczuk (Eds.), *Self and identity: Perspectives across the lifespan* (pp. 265–286). New York, NY: Routledge.
- Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. London, UK: Sage.
- Gupta, S. (2014). *No looking back: A true story*. Delhi, India: Rupa India.
- Husserl, E. (1962). *Ideas: General introduction to pure phenomenology*. New York, NY: Collier. (Original work published 1913)
- James, W. (2007). *The principles of psychology* (Vol. 1). New York, NY: Cosimo. (Original work published 1890)
- Jupp, V. (Ed.). (2006). *The Sage dictionary of social research methods*. Thousand Oaks, CA: Sage.
- Krueger, D. W. (2002). *Integrating body self and psychological self: Creating a new story in psychoanalysis and psychotherapy*. New York, NY: Routledge.
- Laird, D. J. (2007). *Feelings: The perception of self*. Oxford, UK: Oxford University Press.
- Leary, M. R. (2007). How the self became involved in affective experience: Three sources of self-reflective emotions. In J. L. Tracy, R. W. Robins, & J. P. Tangney (Eds.), *The self-conscious emotions: Theory and research* (pp. 38–52). New York, NY: Guilford Press.
- Leary, M. R., & Tangney, J. P. (2012). *Handbook of self and identity* (2nd Ed.). New York, NY: Guilford Press.
- McInerney, D., Marsh, H. W., & Craven, R. (2008). Self-processes, learning, and enabling human potential. In H. Marsh, R. Craven, & D. McInerney (Eds.), *Self-processes, learning, and enabling human potential: Dynamic new approaches* (pp. 3–14). Charlotte, NC: Information Age.
- Martin, J. S., Sugarman, J. H., & Hickenbottom, S. (2010). *Persons: Understanding psychological selfhood and agency*. New York, NY: Springer.
- McAdams, D. P., Josselson, R., & Lieblich, A. (2006). *Identity and story: Creating self in narrative*. Washington, DC: American Psychological Association.

- Meissner, W. (1997). The self and the body: I. The body self and the body image. *Psychoanalysis and Contemporary Thought*, 20(4), 419–448.
- Menon, S. (2014). *Brain, self and consciousness: Explaining the conspiracy of experience*. New Delhi, India: Springer India.
- Merleau-Ponty, M. (1962). *Phenomenology of perception*. Delhi, India: Motilal Banarsidass. (Original work published 1945)
- Murphy, R. F. (2001). *The body silent*. New York, NY: W. W. Norton.
- Neisser, U. (1991). Two perceptually given aspects of the self and their development. *Developmental Review*, 11(3), 197–209.
- Oliver, P. (2006). Snowball sampling. In V. Jupp (Ed.), *The Sage dictionary of social research methods* (pp. 281–282). Thousand Oaks, CA: Sage.
- Ortner, B. S. (2006). *Anthropology and social theory: Culture, power, and the acting subject*. Durham, NC: Duke University Press.
- Parker, I. (2007). *Revolution in psychology: Alienation to emancipation*. Ann Arbor, MI: Pluto Press.
- Riding, J. R., & Rayner, G. S. (2001). *International perspective on individual differences: Self perception* (Vol. 2). Westport, CT: Ablex.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. New Delhi, India: Sage India.
- Rosenberg, M. (1979). *Conceiving the self*. New York, NY: Basic Books.
- Sampson, E. E. (1998). Establishing embodiment in psychology. In H. J. Stam (Ed.), *The body in psychology* (pp. 30–53). London, UK: Sage.
- Sarbin, T. R., & Kitsuse, J. I. (1986). *Constructing the social*. London, UK: Sage.
- Scheper-Hughes, N., & Lock, M. M. (1987). The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly*, 1(1), 6–41.
- Stets, E. J., & Burke, J. P. (2003). Sociological approach to self and identity. In M. Leary & J. P. Tangney (Eds.), *Handbook of self and identity* (pp. 128–152). New York, NY: Guilford Press.
- Welsh, T. (2007). Primal experience in Merleau-Ponty's philosophy and psychology. *Radical Psychology*, 6(1). Retrieved from <http://www.radpsynet.org/journal/vol6-1/welsh.html>
- Williams, S. J., & Bendelow, G. (1998). *The lived body: Sociological themes, embodied issues*. London, UK: Routledge.
- Wolbring, G. (2008). The politics of ableism. *Development*, 51(2), 252–258. <https://doi.org/10.1057/dev.2008.17>

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