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Body and Self-Identity in Stroke Rehabilitation

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Introduction

The experience of stroke is variously described in several studies as a rupture in everyday life, a change that is constantly present, and as a new aspect of life to which the individual has to relate [1-14]. The stroke is described as a sudden and overwhelming reversal [1,2,8,13], and an essential severance [5,10] that separates stroke survivors from their earlier life and forces them into a new and foreign existence [1,4,6,10]. For some, it takes a long time before they understand that something serious and inexorable has taken place and before they understand the extent of the consequences [1,10]. A stroke has also a significant influence on mood (underlying state of mind) [7], personality [6,10], capabilities [5,10], activities [2,6] roles and social relations [4,14] and on self-identity [3].

Self-identity refers to the awareness of the qualities that distinguish the self from others. These qualities are unique and persisting, and are the basis of the experience of inner sameness and continuity [4]. Although one's self-identity is generally considered to be steady, it also constitutes an on-going personal and social construction. Self-identity is closely linked to, and affected by, a person thoughts and feelings about himself or herself, and to the sense of self that is derived from interacting with others and with one's environment [5,6] The outcome of stroke is dependent on neuropathology (i.e. the cause of brain damage, severity, location, recurrence, effects on functioning, treatment type and effectiveness) but also on pre-injury characteristics (age, gender, health, occupation, cognitive and physical abilities, social resources), psychological factors (personality, coping strategies, motivation and goals) and social environment (access to, among others, physical, financial, information and social support resources) [7]. With this in mind, following stroke self-identity can be affected in numerous ways, and is continuously constructed and verified by experiences and perceptions of activities [8,9]. For the survivor of stroke, this means that a mismatch between performance and existing self-knowledge might disorganize the sense of self-identity [10,11].

This commentary proposes that self-identity and the body shape each other [12]. Experience and perception are grounded in the body. That points to a need for a description of how the body is perceived.

In neuro-rehabilitation, the body is traditionally referred to in medical terms. This practice is so conditioned that it can lead to health professionals neglecting the manifold of potential and values of the body [13]. We choose, therefore, to apply a phenomenological understanding of body in neuro-rehabilitation, which claims that the body is always both an object (we have a body: we can touch and reflect upon it) and a subject (we are a body: we are situated in the world through our body) [14]. Humans are not only capable of different movements and functions through bodily processes. Humans are those processes. That is what constitutes that person. The proprioceptive system, i.e. the coherence between the sensorial system and the motor system, accomplishes complicated bodily functions, but at the same time, it is the foundation of one's self-identity, and allows us to interact with others and with one's surroundings [15]. A phenomenological approach proposes that, in rehabilitation after a stroke, it is expedient to consider the body as two different, but closely related, systems: body image and body schema, where body image is a system of attitudes, perceptions and beliefs pertaining to one's own body, and body schema consists a system of sensory-motor capacities that function both with and without awareness. Ordinarily, these two systems interact and coordinate, but when brain damage occurs, the systems can be affected in different ways [16,29].

Special attention is devoted to the body by all those who experience sickness, injury or an alteration in their ability to function. This is described through a variety of experiences in different studies. Such attention becomes even more pronounced when individuals are subjected to medical treatment in which the body is examined, measured and assessed. For those who have suffered stroke, this can be amplified if they are subjected to treatment by professionals in whom their paralysed limbs are handled as objects, or manipulated and controlled through treatment [17]. For at least two years after the attack, stroke individuals describe how they are uncomfortably aware of their body, finding it unreliable and apt to land them in situations of bodily embarrassment [6,10,18]. For individuals who have suffered a stroke, bodily changes appear to constitute an overriding theme during the first months after their attack. During the period from about two to six months after the stroke, attention is directed more towards the way the body functions and to finding new ways to deal with everyday actions. According to Eilertsen & Kirkevold, there follows a period of about six to twelve months, in which the individual attempts to arrive at an understanding of the body's changes [19]. In Kvinge and Kirkevold's study, stroke individuals describe how they gradually came to feel more confident with a body that they could no longer take for granted [32].

In a study by Ellis-Hill et al. [6], stroke individuals describe a number of different ruptures: before/after the attack, body/self, right/left side of body. The body becomes separated from the self and takes on the form of an object. This separation also makes itself felt on the personal level, where the body is experienced as being passive and foreign: "the mind is telling the body-which does not listen-what to do" [16]. Faircloth et al. find, however, that a body/self-dualism is not simply a question of "mind over matter", and an expression of traditional Cartesian thought processes. Rather, what we have here is an inner dialogue wherein both the experimental, meaningful, biographical body and the self-speak and listen. An on-going and everyday constant dialogue occurs between the body and the self. Based on the respondents' narratives, Faircloth et al.'s study shows that survivors deal with changes to the body and to their capabilities in three ways-through the above-mentioned body/self-dialogue, through

testing the body in various everyday practices and through creating cohesion in their "biographical" body (understood as a historical and contextual knowledge resident in the body) [20].

The descriptions make it clear that stroke individuals are particularly attentive to ways in which the body can find new ways forward and body image and body schema are important in the process of arriving a new understanding of body and self.

Stroke individuals wonder whether they are the same person they were formerly, whether they still belong where they are used to being, and whether they can maintain their former way of life and social status [14]. Over a prolonged period, they struggle with their different bodily, emotional and mental changes in an attempt to find a present self [3,21]. For some, this is based primarily on a comparison between themselves and their life prior to the attack, together with a desire to return to a former life, but frustration with themselves and with slow or non-existent progress also plays a role [5]. For others, this struggle is turned into part of a process of change, in which "a new identity is negotiated" in relation to altered capabilities [7, 17]. The process of coming completely to terms with their condition and their new situation, is difficult and takes a long time, and it is normal for situations to arise that either split body-self or demand revision of possible self-perceptions, even a number of years after the attack [22]. In addition to loss of continuity in relation to the person they were formerly and what they now are, Heller et al. [36] describe a loss of the image others have of the person, which can lead to the risk of losing one's partner, job, etc. into the bargain. Borg [10] talks about the need to open up new ways and of letting go of aspects of the old life before changes can take place in the conduct of daily life that extend beyond what it was and who one was before the stroke.

Altered self-identity and different views of the individual are factors that ought to be considered in the rehabilitation process. It is valuable for professionals to see the individual in the context of his/her family, close relatives and the surrounding society [36]. The entire process of redefinition of self-identity appears to take place in all the interactive situations in which the individual is involved, both during and subsequent to hospitalisation. The process of redefinition of self-identity must, therefore, be seen as a core area in rehabilitation of individual and their specific situations' too, and as a long-term aim. It is significant to individuals' future perception of themselves and to the process of becoming at one with themselves and with their condition.

A recent study on stroke individuals' self-identity suggests that it is important to review post-stroke rehabilitation programs and address issues regarding not only activities but also the aspect of self-identity [17]. The body viewed as a foundation for self-identity as described above, it becomes significant to investigate how rehabilitation after brain injury can contribute to stroke individuals' self-identity. The rehabilitation starts as soon as possible after the stoke, with a great deal of focus on motor functioning. In addition another novel study advocates a change of focus from elementary concepts to the delivery of complex services at various stages after stroke. The study proposes that both building up capacities and repeating task-oriented activities are focused on. We support this idea; especially if the body capacity implies that the health professionals perform an approach focusing on self-efficacy, empowerment and insight into their own bodily capacity.

This commentary furthers the idea of phenomenological methodology and that a bodily approach could also open up a fundamental way to support, challenge and develop self-identity. This is ever as important as stroke survivors not only struggle with what they can do, but also who they are [24].

Research on neurorehabilitation should therefore focus on the didactical and pedagogical strategy applied by the health professionals. How do they, in their relations with stroke individuals, direct the body as an object and how could that be changed? This approach calls for the stroke individuals to be aware and reflective about his or her, own body [29]. It should also focus on whether there is an approach that directs the body as a subject, and thereby facilitate stroke individuals' experiences and perceptions, which is important for learning and reconstruction of positive self-identity [25].

According to the ICF [25], rehabilitation must include patient participation and a patient-centered approach is considered essential in neurorehabilitation [26,27]. A patient-centered approach involves acknowledgement of the stroke individual as a unique person, with multidimensional experiences, assessments and reactions [25,28,29] and recognition that it is essential in rehabilitation to support, challenge and develops self-identity. But, at the same time, this is not an easy target. Health care as a field has its specific values and practices [30,31], which provide a certain platform for how to recognize stroke individuals' resources. Self-identity is shaped by social and cultural expectations [25] and it is interesting to investigate how interactions are negotiated in neurorehabilitation.

This commentary suggest that further research should be conducted on how specific professions can contribute to supporting, challenging and developing approaches and innovative rehabilitation strategies, that would facilitate stroke individuals' self-identity.

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