The Wheelchair: The Agent to New Embodiment and New Role in the Living Experience of a Person with Paraplegia

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Abstract

For the person with paraplegia, the wheelchair is not merely a thing or a mobility aid to help people who cannot walk. The wheelchair is a mediator that allows persons with paraplegia to adapt to a new embodiment of themselves. The person with paraplegia is accepting and comfortable with the wheelchair as they imagine it is a new part of their body. The wheelchair is likely a representation of their legs, even though it is not a prosthetic device. In such a situation, a phenomenon occurs where a person with paraplegia experiences adapting their body from its existing embodiment to a new one, incorporating a wheelchair.

Design and technology are enabling wheelchairs to become agents for persons with paraplegia, opening up opportunities in their daily activities and social interactions. When the wheelchair is to be a part of their body and living situation, the person with paraplegia has a unique identity that is intrinsic to two conditions: liberation and limitation. A person with paraplegia can go travelling where they like as long as they use a wheelchair; at the same time, they face the problem of accessibility because this world, until today, is built without considering the circumstances of a person who uses a wheelchair to walk.

This artistic research delves into the complex and often overlooked embodied experience of a person with paraplegia when they decide to rise from a paralysed condition, specifically through the lens of the design and technology of mobility devices. All the participants involved in this research are persons with paraplegia from a traffic accident, work accident, or disaster survivors. The methods used to determine how to shift embodiment include ethnographic interviews, participant observation, and somaesthetic interaction design.

Keyword: Embodiment; Mobility; Paraplegia; Wheelchair

Features of paraplegia

Paraplegia and wheelchairs look very common because they are just like representations of people with disabilities and mobility assistive devices. This situation assumes that people with disabilities are the objects of design and technology activities. In reality, it is not so; wheelchairs are more than just a tool or device for paraplegia; they are body parts inherent to people with paraplegia. People with paraplegia are a subject that, together with design and technology, aims to change the world. Design and technology manifest in wheelchairs, enabling people with paraplegia to shape the world more inclusively. Based on the uniqueness of the interaction between wheelchairs and people with paraplegia, this article will discuss the background of the interaction and its phenomenon in more detail.

The uniqueness of the interaction between a wheelchair and a person with paraplegia lies in the condition of the spinal cord injury experienced; the level of paralysis is determined by the height of the spinal cord injury, as shown in Figure 1. Spinal cord injuries caused by trauma can cause paralysis due to damage to the signal from the brain, spine, and whole body.

There are two types of paraplegia: complete and incomplete. Paraplegia in the complete type is characterised by the loss of all motor and sensory functions below the level of injury. In comparison, incomplete paraplegia is characterised by the remaining several working functions in the lower body that can be maintained. (Freund et al., 2011; Herrmann et al., 2011; Jankovic et al., 2018; Marino et al., 2003; Maynard et al., 1997)

Individuals with complete paraplegia generally have a high level of injury located in the high Thoracic (T2-T9) area, which makes it challenging to balance the body when sitting (must lean) and the inability to ambulate. Individuals with incomplete paraplegia typically have a relatively lower level of injury, located in the lower thoracic-lumbar (T10-L2/L3) area, allowing them to attempt to balance when sitting without leaning and to ambulate with assistive devices such as knee-ankle-foot orthoses (KAFOs) and walkers. Several studies have shown that the lower Thoracic (T10-T12) is a critical transition level between complete and incomplete paraplegia. (Hastings et al., 2015; B. A. Lee et al., 2016; Lenggenhager et al., 2012; Scivoletto et al., 2014; Weiss et al., 2010)

In a person with paraplegia, the sensorimotor system is disrupted, resulting in the loss of conscious muscle control and the inability to perceive sensations from the lower body. This situation is related to proprioception, or the ability to be aware of the position and movement of the body in space without requiring a visual process, such as being aware of body movement to the right or left. Disturbances in proprioception also greatly affect the ability to balance the body because people with paraplegia also do not have a reference for balance, in addition to being unable to maintain posture due to paralysis. (Dietz, 2002; Leemhuis et al., 2019; Takeoka, 2019)

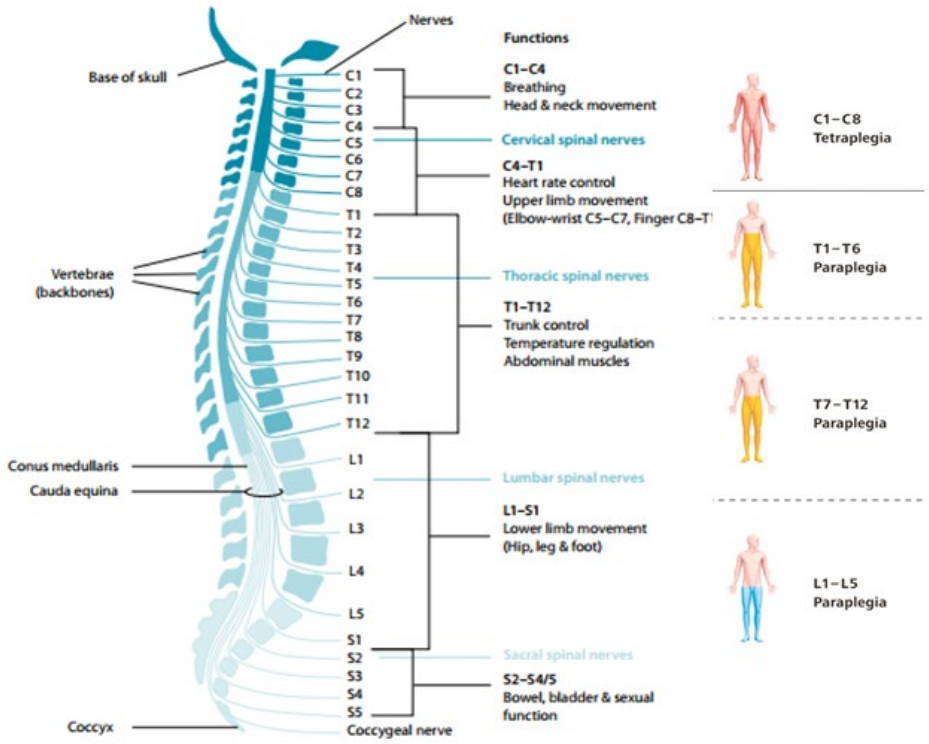


Figure 1. The primary functions of the spinal cord and paralysis due to injury
Source: (ISCOS; The International Spinal Cord Society, 2013, p. 5)

The main problem for people with paraplegia is mobility. The paralysis condition results in difficulty with ambulation or loss of the ability to move and balance the body, with or without aids, to the point where they cannot even drag their body or crawl. This condition differs from

people with leg amputation, who retain the ability to move because they do not have paralysis. Under these circumstances, individuals with paraplegia typically rely on their upper body and hands for ambulation and body balance, such as moving from a bed to a wheelchair or from a wheelchair to a toilet. Therefore, they cannot be separated from wheelchairs, and their sitting position must also lean back, either with a short backrest or a high backrest.

Methods

The activities in this study are based on the somaesthetic design framework (Hook, 2018), combined with ethnographic interviews and participant observation methods to delve deeper into the participants' experiences (Spradley, 1980, 2016). The participants involved in this study were people with paraplegia who had experienced spinal cord injuries due to traffic accidents, work accidents, or disaster survivors. This study involved five friends with paraplegia who were always connected in their daily lives. Some of the activities I participated in with them included visiting coffee shops to discuss various topics, taking a motorbike tour with them, visiting their homes to chat, serving as a buddy at an entrepreneurship exhibition for friends with disabilities, and discussing assistive technology via WhatsApp or Instagram.

The somaesthetic design framework is based on the work of the somatic system in the body. The somatic framework is used to explore the user's bodily experience in greater depth. The exploration of the user's physical experience in the somatic framework is obtained through in-depth interviews and participatory observations. The activities carried out are not explicitly categorised, but they are often repeated or frequently performed by the participants. Each participant engages in various activities, such as daily work tasks and social activities like visiting people with disabilities who require moral support, as well as preparing for the championship as a Paralympic athlete, among many other engaging activities that each participant undertakes. (Ferrando et al., 2023; W. Lee et al., 2014)

The exploration of activities carried out by participants with paraplegia is highly dependent on wheelchairs. Starting from how participants recognise wheelchairs, become accustomed to them, and then explore. The design and technology which manifest in wheelchairs have been inserted into the process of bodily experience. Thus, this study will also explore the role of design and technology in the physical experience of participants with paraplegia in greater depth.

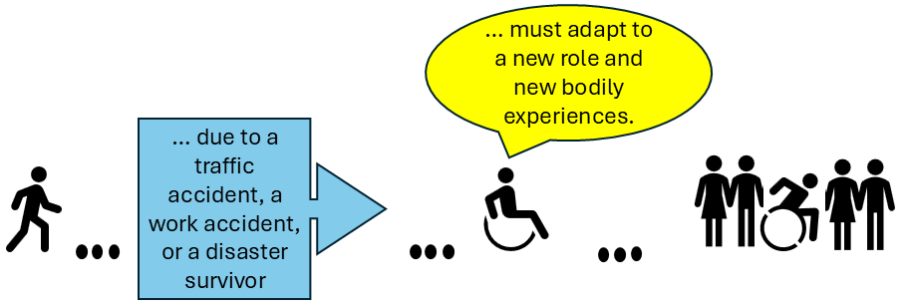


Figure 2. Research scenarios
Source: Research document, 2025

Understanding the new body

The first and second years after spinal cord injury are stressful and confusing times for people with paraplegia. This condition is experienced by all participants, with some experiencing it for up to three years. It is not easy to accept oneself with paralysis, and all participants experience mental devastation and think that their world is over. In addition to the confusion of imagining a new identity because of having a new body condition and socially

having a lack of self-confidence to socialise, they also must struggle to deal with their body condition to be able to carry out daily activities.

All participants with paraplegia still hope that the paralysis they experience is temporary and will recover. In addition to undergoing medical treatment and rehabilitation, they also try traditionally alternative methods with many variations so that conditions can return to the way they were before experiencing paraplegia. Muscle spasticity, which causes uncontrolled movements of the lower body and neuropathic sensations such as electric shocks or burning sensations, is considered by them as a progression of alternative treatment methods. However, waiting two to three years in an alternative way still does not change the situation; they remain sitting in wheelchairs with paralysis.

The situation of paraplegia with paralysis requires a new understanding of the body; their bodies are still visually intact, but they cannot feel the sensation of most of their bodies, such as feeling the tips of their toes. The absence of this sensation makes people with paraplegia unable to move their toes. Many of the participants still hope that their bodies will improve and they will be able to feel sensations in their lower bodies again. They train every day by trying to move the paralysed body part by focusing visually and thinking about the specific area they want to move. Often, they assume that they can feel but still cannot move their paralysed body.

The medical process experienced by participants who generally experience spinal injuries with fractures will undergo surgery and the installation of pins or often referred to as plate and screw fixation. After that, people with paraplegia will be given information that they are paralysed and must use a wheelchair for mobility. Then, they undergo an initial rehabilitation process that includes understanding their new condition, learning to mobilise the body, starting with getting up and sitting in bed, and then extending the sitting time. After getting used to it, they will learn to sit on the edge of the bed with their legs hanging. This initial training is so mentally painful that they feel like useless people because they struggle to get up. The support of family and close friends is very much needed in this initial phase because some participants said that they wished they would die rather than be in a state of paralysis.

In early rehabilitation, hand strengthening exercises are necessary because, after experiencing paraplegia, mobility is highly dependent on the use of the hands. Hand strength is needed for activities such as getting up, sitting, and moving. Even when using a wheelchair, it is used to pedal the wheelchair's push rim. The hands are used to push and hold the body so that it can lie down in a sideways position, serving as a starting point to get up and sit in bed. Then, the hands are also used to maintain a sitting position when not leaning back and serve as supports, conditioning the body to remain balanced. Not everyone with paraplegia is already accustomed to handling the load with the necessary hand strength. There are two participants whose jobs involve lumberjacking; they are accustomed to using their hand strength in their work. Both find it easier to adjust to using their hands for body mobilisation. In addition to hand exercises, people with paraplegia are also trained to stand, not to learn to walk, but for leg health, so that blood circulation is smooth and does not atrophy or shrink because it is never used. The aids used for standing are usually knee braces to tighten the knees and walkers, which are devices that support the body with the hands. The training is then continued by increasing the standing time from an average of one minute to three minutes, then to five minutes.

Efforts made to recognise the body's condition and overcome obstacles that arise are obtained from trial and error. Negotiation between thoughts, desires, and bodily conditions becomes quite complicated in the situation experienced by the participants. Movements must be as relaxed and natural as possible and must not be constrained by thoughts because if the movement is thought about, it will make the body stiff. The mind only determines the direction and stages that will be carried out; after that, the body will then make adjustments. An example of a trial-and-error process is when performing a transfer. It begins with trying, followed by evaluating the success or failure of the procedure. If successful, the procedure becomes a habit;

if it still fails, improvements and adjustments are made, both in terms of stages and body position. What often happens in adjusting the body for transfer is experiencing a sprain or muscle injury in the neck.

The situation experienced by the participants seemed to be an attempt to evaluate Descartes' thoughts on the relationship between the separate mind and body. (Descartes, 2009, pp. 19-20;55;60-61) The participants' experiences showed that the mind and body are connected. This situation is characterised by the participants' approach to overcoming difficulties and problems resulting from paralysis. Participants achieve this by attempting to use their bodies and then projecting, allowing perceptions about themselves and their surrounding environment to emerge. For people with paraplegia, awareness of body position, sensation, and movement systems have been disrupted. This condition then gives rise to a bodily experience that is not only different but completely new. Related to this phenomenon, the Rene Descartes perspective has been evaluated by the new bodily experiences of people with paraplegia. (Gallagher, 2005, pp. 17-39;133-152; Sebanz et al., 2006; Tucker, 2007, pp. 187–230)

Discussion: The Agency of New Embodiment

After going through the crisis, most participants will have a new spirit to be more active. Wheelchairs are the only thing that supports the movement and transfer of people with paraplegia. The World Health Organisation defines a wheelchair as a tool that supports mobility, featuring a seat and wheels, used by people who cannot walk. However, from the perspective of people with paraplegia, a wheelchair is not a tool; the wheelchair is inherent in them because movement and transfer are utterly dependent on the wheelchair. For people living with paraplegia, wheelchairs go beyond the general perception as mere mobility aids. It becomes an essential agent in reshaping their self-realisation, fundamentally changing their life experiences and encouraging the development of new life roles.

This transformation often involves a process of "merging with the wheelchair" (en-wheeled), where the wheelchair evolves from an external tool to an integral part of the individual's body schema and self-perception. This integration can be so profound that the wheelchair is experienced as an inherent part of the body, producing a different way of mobility. This condition signifies the fusion of humans, design, and technology to create a new functional unity. This latest embodiment is not just about a changed physical form but also encompasses different sensory experiences, enhanced spatial awareness, and a reevaluation of personal capabilities. Initially, the wheelchair may be met with resistance or viewed as a symbol of loss. However, over time and with experience, the wheelchair often becomes a conduit to renewed independence, enabling participation in social, professional, and recreational activities that might otherwise be inaccessible. This mobility is crucial in redefining life roles, allowing individuals to resume or start new careers, maintain relationships, and engage meaningfully with their communities.

The relationship with the wheelchair is profoundly personal. It can change throughout a person's life course, influenced by factors such as the nature of their injury, social support, access to resources, and personal resilience. Ultimately, the wheelchair plays a critical role not only in physical mobility but also in the ongoing process of negotiating a new sense of self and forging a fulfilling life experience in the face of profound physical change. It becomes a central element in narratives of adaptation, resilience, and re-imaginings of what it means to live a whole life.

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