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# Understanding Indian Spinal Cord Injury Rehabilitation Ecosystem

***Priyanka Rawal, Ph.D.; Prof. Gaur G. Ray, Ph.D.***

## Abstract:

**This work, describes the study carried out with 82 SCI (Spinal Cord Injury) individuals throwing light on the flow of these individuals from accident location to their settlement in their final living setting. Further, it divides this flow into three settings, Initial Care, Rehabilitation and Post-Rehabilitation Settings. Finally, observations about the interactions of the SCI individuals with these settings are noted to uncover various pain points that can be utilised in redesigning SCI rehabilitation in India.**

## Keyword:

**Spinal Cord Injury Rehabilitation, Spinal Cord Injury Ecosystem, Post-rehabilitation.**

## Article:

**Experts around the world put much emphasis on rehabilitation to prevent complications associated with SCI (Spinal Cord Injury) and support an individual in having a fulfilling and productive life. WHO defines rehabilitation as a "set of measures that assist individuals in achieving and obtaining optimal functioning in interaction with their environments" (WHO, 2011). Byrnes and colleagues state that the goal of a rehabilitation program is to promote optimal recovery and to prepare patients for self-care management after discharge from the program (Byrnes, et al., 2012) (Williams, 2008).**

**In short, rehabilitation means preparing SCI individuals for their environments. This makes it essential to understand the environments and the interactions of SCI individuals with it. One significant aspect of doing so is to understand the flow of SCI individuals in the SCI ecosystem, i.e., the movement of individuals from the time of injury to entering back into the society. Understanding this flow is basically mapping the user journey, a user research process in design used to provide meaningful insights into a user's life in and around the rehabilitation phase, to find their pain points, needs, and motivators.**

**Given the importance of the rehabilitation process, presenting a comprehensive picture of the flow of Indian SCI individuals becomes significant in identifying their needs. Such needs and insights will provide valuable inputs for better patient-centred care.**

**This article covers the insights from a part of my doctoral research study that discusses the flow of SCI individuals. In addition, some significant insights developed from the study are also discussed.**

**To grasp the ground realities of the SCI ecosystem and gain insights into its basic layout in the Indian context, a study was conducted with post-rehabilitation community homes and at private residences of SCI individuals in the cities of Pune and Mumbai, India. Eighty-two SCI individuals agreed to face-to-face interviews. The participant cohort consisted of civilians and veterans with SCI and their caregivers wherever available.**
**Based on the responses from these participants, it was concluded that they followed one of the possible paths to their final living setting, as depicted in figure 1.**

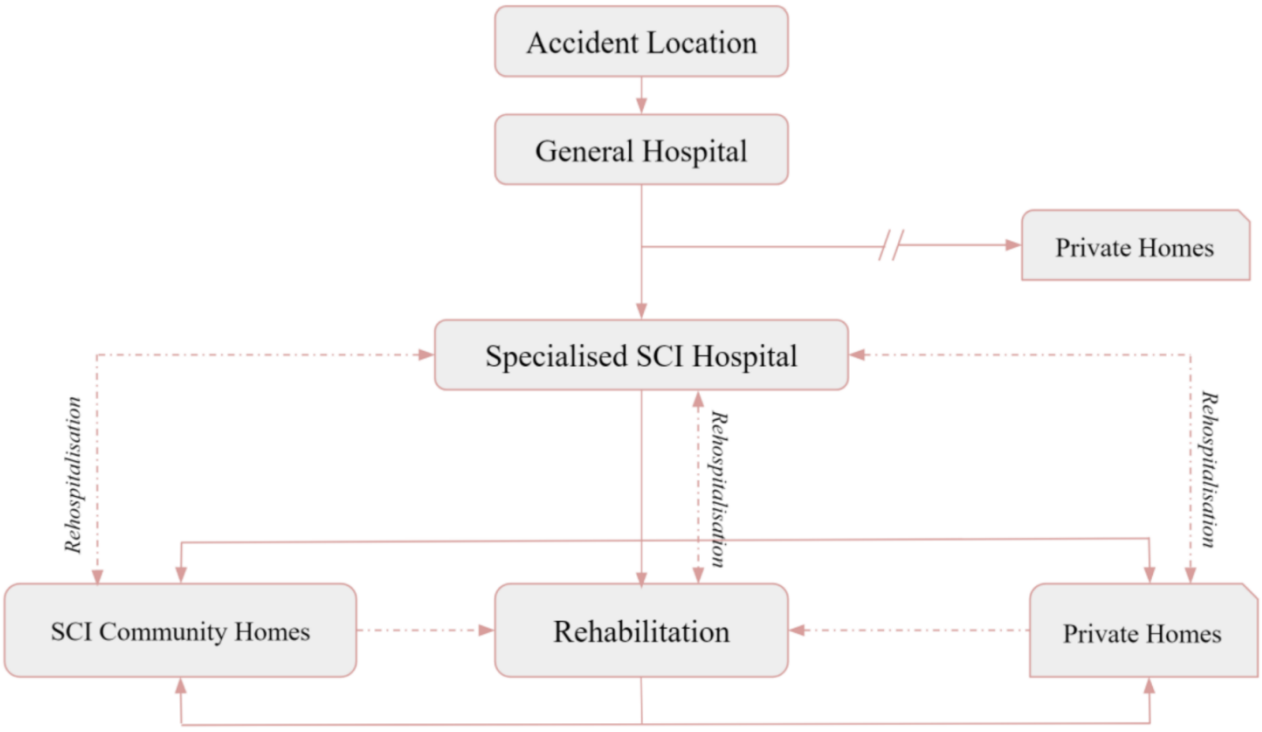


***Figure 1: Format of the flow of SCI individuals within the SCI ecosystem***

**The post-SCI journey can be divided into three kinds of settings the SCI individuals interact with, based on the SCI individual flow diagram (figure 1). The earliest stage is the *initial care setting*, next is the *rehabilitation centre setting*, and the latest is the *post-rehabilitation community homes/private residence setting*. Subsequent subsections provide an insight into the status quo and functioning of the three settings.**

## I. Initial Care Setting

**Initial Care setting is the time right after an individual suffers an SCI till the time they are in the care of the first medical facility (general or specialised hospital) they reach. Our research revealed that the initial contact point for most of the participants is a general hospital for this setting. Most of these hospitals were reported not to have**

**SCI specialists. Here, the SCI individuals are operated for their injury. In some cases (15%), SCI individuals were sent back to their homes right after, instead of a rehabilitation centre. 9% of the patients and families prefered to go home rather than joining a rehabilitation centre due to a lack of information or understanding of the significance of rehabilitation. Most of the rest were simply directed to the rehabilitation centres without informing them of the concept and the need for rehabilitation. This mostly led to the patients and caregivers believing that rehabilitation was meant for completely regaining their pre-injury body functionality.**

**Also, an Indian study reported that 63% of patients reached an SCI specialised institute only after 2-3 transfers to non-specialised facilities (Chhabra, Sharma, & Arora, 2018), leading to loss of crucial rehabilitation time. Further, no data is informing how many patients never reach an SCI specialised facility.**

**In our study, rehabilitation was completely absent in 12% of the participants. These participants were contacted at their private residences. These participants reported that they were not informed about the significance of rehabilitation or did not join rehabilitation due to financial constraints. Out of the participants who did reach a specialised SCI hospital, they were usually recommended to go to rehabilitation centres for further rehabilitation and adaptation to their altered lives after the injury. However, the participants reported that they were not informed about the concept and significance of rehabilitation.**

**In a nutshell, a lot of friction and information gaps were observed in the SCI individuals reaching the SCI rehabilitation centres. These**

**information gaps were seen to either completely prohibit SCI individuals from availing rehabilitation, or for the many who reached, precious early rehabilitation time was lost. Secondly, the individuals who were recommended to seek rehabilitation centres, were ill-informed about the concept of rehabilitation, raising false impressions and hopes.**

**Here, the significance of connecting general hospitals with specialised SCI hospitals and rehabilitation centres was realised. Further, the importance of dissemination of information to the patients about the concept and significance of rehabilitation at the early stages of their injury became apparent.**

## II. Rehabilitation Centres

**This setting is the time spent by SCI individuals in the rehabilitation centre after initial care and before entering the final living setting.**

**Chhabra and colleagues say that rehabilitation care centres should include services like physiotherapy, occupational therapy, psychological management, sexuality and fertility management, assistive technology, wheelchair clinic, peer counselling, educational classes, vocational placements, pre-discharge home visit, and follow-up home care services (Chhabra, Sharma, & Arora, 2018).**

**Such comprehensive services were found missing in most rehabilitation centres during this study, also reported by another study (Chhabra & Arora, 2013). It was observed that the service structure, quality and expenses of the services at various rehabilitation centres vary due to many factors like its type, i.e., defence or civilian, duration of stay, range of services, equipment and specialisation of the rehabilitation team. Further, no**

**standardised rehabilitation structure or informational ecosystem was observed in these centres. Lastly, understaffing at the rehabilitation centres was also noted as a significant issue causing incomplete rehabilitation. All these factors were seen to affect SCI individuals' readiness for their lives post-rehabilitation in the final living setting.**

## III. Post-Rehabilitation Community

**This setting comprises the Community Homes and Private Residences of the SCI individuals. Considering the needs of SCI individuals post-rehabilitation, Indian Central Government has developed community homes for defence veterans, including essential medical care, infrastructure support, assistance for daily activities, and vocational training, to provide quality life to these veterans. They have a choice to go to their private residences or remain at community homes established by the government. In addition, married veterans have a choice to live with their families in the family quarters inside the community campus. In our study, veterans from weaker financial backgrounds were observed to prefer remaining in community homes.**

**On the other hand, civilians go back to their private residences or civilian community homes after completing the rehabilitation program. However, most of the families of the SCI individuals from underprivileged backgrounds often cannot modify their private residences or cannot support the needs of the people with SCI. Hence, such SCI individuals end up transferring to the civilian SCI community homes wherever possible, which are mostly free of cost and are entirely run on funding through charitable donations, which could be quite erratic.**

**The civilian community homes that participated in this study were found quite lacking in the quality of their services and infrastructure and only supported male individuals. They were observed to have minimal staff. The only staff member with medical training was the Nurse; however, the Ward boys with no medical education were also seen to be responsible for medically demanding tasks. Since such community homes depend entirely on charity, many times, they can not provide even essential support.**

**Although after rehabilitation, the SCI individuals transfer to community homes or private residences, they visit rehabilitation centres or specialised SCI hospitals to get medical support if needed, such as for a secondary complication like Pressure Injury and Urinary Tract Infection.**

**Civilians were observed to have a tougher time adjusting to life post-rehabilitation due tothe lack of infrastructural, financial, familial and emotional support. Hence, post-rehabilitation settings for civilians emerges as a potential action space for researchers and designers.**

## Concluding Thoughts:

**Many pain points were uncovered in the three settings that SCI individuals interact within their post-SCI journeys.**

**In the conversation around redesigning rehabilitation in India, it is essential to recognise the need to develop a robust informational ecosystem that not only informs the SCI individuals and caregivers about rehabilitation tasks and processes but also about the intentions, expected outcomes and significance of these tasks. This contextualisation and dissemination of information should happen not only within the rehabilitation setting, but should begin in the**

**initial care setting and continue into the post-rehabilitation community setting.**

**Secondly, the general and specialised hospitals within the initial care settings must be connected to one another to enable quick transfer of patients as and when required.**

**Thirdly, it must be realised that not all SCI individuals return to their private residences post-rehabilitation, primarily due to the weak financial backgrounds and the feeling of being a burden on the family. Reimagined rehabilitation should cater for the needs of such SCI individuals and prepare them for a tougher life at sub-par civilian community homes.**

**Fourthly, a need is identified to reimagine the post-rehabilitation community homes, especially for civilian SCI individuals from financially challenged communities, to improve their current post-rehabilitation experience.**

**Lastly, the patient flow diagram is intended to give a holistic picture of the interaction of SCI individuals with the SCI ecosystem. It can be utilised as a map to identify the gaps in Indian SCI rehabilitation at various levels.**

**The researchers hope that this user research sheds light on some of the human issues within the current SCI ecosystem in the country and proves helpful for further investigations.**

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