The Journey from Rehab to Home and Community

AN EXPERIENCE MAP CO-DESIGNED WITH PEOPLE LIVING WITH SPINAL CORD INJURIES

Time

The time in months following the transition from rehab into community and home.

Feelings

The range of emotions participants felt during these phases of transition. These feelings range between more negatively associated emotions to more positively associated emotions, and demonstrate the spectrum of emotions at any given phase.

Goals and Activities

The major goals and activities participants were trying to achieve during different phases of their transition. These activities reflect themes found across different participant goals and activities.

Pain Points, Gaps and Barriers

The pain points, gaps and barriers in the lives of participants that made their experiences difficult. These points reflect themes found across different participant pain points.

Ideas for Improving Experience

The ideas generated by participants that would have made a positive impact on their experiences.

Early (0–3 months)

I feel vulnerable and scared

Fear and vulnerability coming out of rehab and experiencing fewer supports, fear of falling, and of the wheelchair or getting injured, and being intimidated by the world outside home.

I feel disconnected from myself and others

Feeling disconnected from wheelchair and other standard equipment, social supports like friends and family, feeling dehumanized by insurance and medical system processes.

I feel frustrated and stressed

Stress around reconnecting with friends, frustrations adapting home and routines after rehab, frustrations with inaccessibility during travel, experiencing barriers in the community and being excluded from usual routines and activities.

I feel accomplished leaving rehab

Accomplishment around new milestones and overcoming obstacles, such as navigating travel for the first time and getting back to work.

Focusing on physical health and safety

Attending to the needs of my physical body to feel safe as I continue to recover and gain my strength.

Establishing new routines and independence at home

Creating and planning new ways of doing everyday activities setting up my home to be more accessible, managing time to leave my home, and learning how to be mobile, etc.

Re-adapting to old routines and activities

Coming back to activities that were part of my life before my injury and understanding my limits-learning what it would mean to get back to work, recreation and sports, and community events.

Reconnecting with friends

Re-establishing friendships and learning what my friendships mean as I continue to transition back into my home and community settings.

Preparing to and travelling in community and beyond

Learning what I need to do in order to travel safely, and researching the accessibility of places in the community and beyond.

Accessibility barriers and challenges at home

Not having a home that works for my new needs or a person to help me navigate these challenges.

Delays and challenges accessing care and equipment

Long processes to get equipment like personalized wheelchairs, and to access care like outreach therapy and home care workers.

Lack of mental health and social support

Not having the resources to help me with my feelings and emotions, and not having the guidance to help me navigate the changes in my personal and community relationships.

Challenges with accessibility during travel and transit

Physical spaces not being accessible to my mobility needs and lack of understanding from service providers on accessibility standards.

Losing aspects of identity

Challenges in coming to terms with how my injury has affected important aspects of my life that have been shaped by my lifestyle before my injury.

Lack of peer support and information

Not having connections with other people who live with SCIs to learn from them, and not having health care providers with first hand experience of SCIs.

Challenges adapting to wheelchair and equipment

Difficulty in adapting to my mobility equipment as it damages my body, and the places I use it in.

Middle (4–6 months)

I feel broken

Emotional impacts of adapting to mobility, continued frustration and challenges navigating the built environment, anxiety that restrict activities, frustration around access to equipment and physiotherapy.

I feel curious

Curiosity in approaching aspects of self and life that need to be redefined. For example, curiosity in the wardrobe and in hearing recommendations from others with lived experience.

I feel happy returning to normalcy

Finding joy in returning to activities and errands that feel "normal," like grocery shopping, parenting activities, driving, sports, and hobbies.

I feel a sense of liberation

Feeling more comfortable and confident leaving home and navigating public spaces like transit and airports, and feeling more independence and a sense of freedom, particularly from starting to drive again.

Preparing to drive

Learning the requirements for driving with my abilities, getting hand controls and practising driving in a new way.

Adapting to the accessibility of places

Learning and managing the physical barriers of the different places like restaurants, public spaces, and hotel rooms.

Re-adapting to old routines and activities

Continuing the process of returning to activities that were part of my life before my injury like parenting, getting back to work, and household chores.

Exploring mobility supports and sporting equipment

Learning about the types of mobility and sporting equipment that is financially accessible to me and that would help me in the future.

Navigating interpersonal relationships

Learning how to manage my relationships with family, friends, and neighbours, and how to manage romantic relationships.

Managing physical safety and accidents

Continuing to focus on the recovery of my physical well-being and handling new accidents that happen.

Figuring out my clothing and wardrobe

Figuring out what I can wear that will work for me and help me feel like me.

Challenges in my relationships with family members

Difficulty in managing my needs in my journey and my role in relationships with family-as a child, as a parent or as a sibling.

Lack of peer support and information

Not having connections with other people who have had SCIs to learn from them, and not having health care providers with first hand experience of SCIs.

Lack of support for family caregiver

Family caregivers not having access to resources to help them learn about the role of caregiving, or mental and emotional supports to help them meet their unique needs as caregivers.

Delays and challenges accessing care and equipment

Financial barriers and long processes prevent access to equipment that would help me in my journey.

Inaccessible public and private spaces

Lack of accessibility to public and private spaces-no alternatives to stairs, broken door buttons, cramped spaces, etc.

Disruption from COVID-19

Disruption in services like physiotherapy due to COVID-19.

Challenges with outdoors and seasonal activities

Difficulty in adapting to the changing seasons and the activities it necessitates-new ways of travelling and mobility and household chores like yard maintenance.

Challenges in my relationship with my body and how I care for it

Difficulty in managing how I care for my body when challenges unexpectedly affect me-ranging from gastrointestinal issues to new emotional triggers around my clothing.

Over-reactive strangers

Social reactions and stigma when encountering people in public-lack of awareness about accessibility, over-reaction from strangers to my needs, and ignorant and harmful comments, etc.

Late (7–18+ months)

I am still struggling

Continued challenges in physically navigating spaces, rebuilding daily life, managing emotionally and accepting that my life has changed because of my injury.

I feel nostalgic

Nostalgia around habits, routines, and passions from before injury, missing homes and other spaces that are not currently accessible.

I feel agile

Experimenting with different physical activities and sports, gaining confidence with these activities, and finding routines to stay active and physically fit.

I feel hopeful

Anticipation of new milestones, like getting back to a home, starting to drive again, or getting back to work. Focusing on optimism as a way to stay hopeful and motivated day-to-day.

I feel proud

Pride in participating in sports and other rewarding activities, sometimes enabled by new adaptive equipment, and pride in using specialized equipment or overcome barriers. Being able to take risks and have fun.

Exploring capabilities and limits

Testing my boundaries with longer travel and day trips, participation in research projects, and experimentation with different mobility equipment as I increase my strength.

Gaining new independence through activities and responsibilities

Increasing the level of independence I can manage with activities like staying at home with my kids, gaining more responsibility at work, and/or driving on my own.

Living and adapting to routines

Continuing to live out the established routines and patterns I created during the transition process.

Managing through accidents with mobility device

Challenges in maintaining and repairing equipment after an accident has occurred.

Lack of access to and knowledge of resources

Not knowing how to find resources, or who to go to for that information as I continue my journey.

Ideas for Improving Experience

- Provide support through a centralized care navigator or coordinator
- Support holistic wellbeing with access to a broad range of specialists, care providers, and support organizations
- Peer support during and after rehab on broad range of topics
- Provide support materials in easily accessible formats and channels
- Provide a focus during rehab on reconnecting with support networks (partner, family, friends, community)
- Connect people to centralized resources before leaving rehab
- Provide training and health supports for caregivers
- Create accessible public infrastructure and transit
- Strengthen peer support and networks
- Create access to clear and known resources that accomodate accessibility need
- Provide personalized training for individual needs (like navigating personal homes, etc)
- Create a central repository of resources to support across the lifespan of an individual with an SCI
- Connect with social and mental health supports

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