

Caregivers' Perspectives on Travel Barriers for People with Spinal Cord Injury

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Objectives: Research indicates that people with disabilities travel less often than the general population. Various environmental barriers to participation in travel have been identified in the literature from the perspective of individuals living with SCI^{1,2}. The literature also documents that caregivers are a sensitive group of people who critically affect the quality of life of people living with SCI^{3,4}. Therefore, caregiver's perspectives on travel barriers will help us to develop a holistic understanding of the travel experiences of individuals living with SCI. The purpose of this presentation is to examine the environmental and psychological barriers to travel participation by individuals living with SCI from the perspectives of their caregivers.

Design/Method: Data used in this presentation are from a larger study that interviewed 39 people with SCI who are enrolled in the Rocky Mountain Regional Spinal Injury System. These participants then provided the contact information of their caregivers/family members for further interviews. A total of 24 in-depth interviews with caregivers were conducted over the telephone between May to September 2015, and the interviews ranged from 20 to 60 minutes. Caregivers interviewed had either traveled with the person with SCI or were knowledgeable about travel barriers for people with SCI.

Results: Caregivers confirmed the travel barriers identified by individuals living with SCI. Respondents identified that systemic ignorance towards people with disabilities in society (e.g., lack of knowledge about accessibility and disability rights, stereotypes/stigma, discrimination, and lack of understanding of Americans with Disabilities Act (ADA) on the part of travel service employees) constitutes the most important portion of the barrier that they encounter when they travel with their loved ones living with SCI. As a result, caregivers are concerned not only about the physical safety of their loved ones, but also their emotional health. Additionally, caregivers were found to be stronger advocates, such that they were more vocal than the individual living with SCI when they felt the disability rights were violated. As a result, some caregivers expressed that they felt exhausted and emotionally drained. They felt that they had to be "on guard" all the time.

Conclusion: Inaccessibility has been identified as a major barrier in prohibiting individuals with SCI and their families from traveling more often. Findings from the study show that physical barriers, however, are not sufficient in understanding the travel experiences of people with SCI. To ensure the family can sustain the quality of life as that before the injury, the emotional health of both the person with SCI and their caregiver should be taken into consideration.

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Reference:

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