

ABSTRACT

Caregiving experience of mothers of young people with traumatic tetraplegia. A qualitative phenomenological study

Introduction: Spinal cord injury (SCI) is defined as damage to the spine that results in a temporary or permanent change in its normal motor, sensory or autonomic function, with irreversible consequences. It is classified as paraplegia and tetraplegia, the latter makes the person highly dependent on care, requiring permanent help from another person to perform daily activities. **Objective:** To describe the experience of caregivers who are mothers of young people with traumatic tetraplegia, and who are patients of Instituto Teletón Santiago. **Methodology:** Qualitative study with descriptive phenomenological analysis. Data was gathered by means of semi-structured interviews, which were studied through qualitative content analysis with deductive categories. The overall sample was intentional, including the participation of five mothers who were primary caregivers of their children with tetraplegia, from Instituto Teletón Santiago. **Results:** The categories found were self-description, impact of the accident, care relationship, impact on the family and other significant factors, relation with the health care network, coping measures, beliefs and learning. The highlights of this type of dependent care included work overload, self-neglect, and deteriorated health. Significant situations from the moment of the accident reflect the experience as a whole. In these circumstances, love emerged as a pop-up topic and became known as the main value. The emotional burden of this experience has been contained and compensated by a positive approach to life, based on cultural and religious beliefs. **Conclusion:** Mothers become expert caregivers, providing holistic care that must be considered in the interventions of the rehabilitation team, to contribute to the reconstruction and resignification of this relationship of maternal/filial care.

Key words: Experience, mothers, care, tetraplegia, qualitative study