Human and social values that support the daily task of caregivers of children with severe disabilities: A qualitative explorative study

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Objective: To describe human and social values, and the motivations which support the daily task of caregivers of children with severe disabilities; and to explore what deprivations they have experienced as a result of taking over this task.

Method: A qualitative, phenomenological, and exploratory study was used, with an intended sample of four caregivers of children with cerebral palsy. Semi-structured interviews and a focus group were conducted with the caregivers. A written questionnaire was completed by Santiago’s Institute’s Psychosocial Department Chief Social Worker, to triangulate the information and increase the credibility and validity of this study. A conventional content analysis technique based on transcription and interpretation of the information gathered was used.

Results: All four caregivers were blood relatives to the children and ranged from 3 to 16 years of permanently dedicated care to their physical and daily needs, without remuneration. The defenselessness of the child’s disability at birth was a common motivation for caregivers to take on this task. An agreement was observed on an experienced decrease in social activities, recreation and couple relationships. The reaffirmation of human and social values through time became a life and joy motive for all caregivers.

Conclusion: Identified values were: love, responsibility, patience, life commitment, gratitude, perseverance, advice, courage, self-improvement and vocation to serve. Family provides the support to take care of children with a disability.

Key words: Human values, social values, caregiver, disability, child, cerebral palsy.