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Titolo tesi: Self-care in people with Motor Neuron Disease: a mixed method study

ABSTRACT

Background. Motor neuron diseases are a group of chronic, progressive disorders characterized by the gradual, progressive loss of neurons (Gao & Hong, 2008). These neurodegenerative diseases include disorders like Amyotrophic Lateral Sclerosis (Valadi, 2015) and Spinal Muscular Atrophy (Kolb, & Kissel, 2015). People with Motor Neuron Diseases live a progress condition in which dependence on other and on machine is elevated (Kolb, 2015; Valadi, 2015). Self-care is defined as a process of maintaining health through health promoting practices and managing illness (Riegel, Jaarsma, & Stromberg, 2012). Self-care is considered a patient centered outcome and the promotion of self-care is a key point of nursing care for patients with chronic illness (Riegel, Jaarsma, & Stromberg, 2012; Ko, Bratzke, & Roberts, 2018; Liu, 2014). The concept of self-care is poorly studied in people with MND, self-care behaviors were not identified in this population.

Objective. The objective of this doctoral program was (1) to explore the concept of self-care for people with MND in qualitative and quantitative studies, (2) to gain insight into the process used by people with SMA and ALS in performing self-care, and (3) to develop and psychometrically test the properties of the Self-care in Motor Neuron Disease Index.

Methods. In this dissertation program we conducted three studies, with three different designs, to correspond with each doctoral objective to aim. The 5-stage integrative review as described by Whittemore and Knalf was conducted in the first study (Whittemore, & Knafl, 2005). A qualitative study using grounded theory (GT) method based on in-depth interviews, simultaneous comparative analysis, codes, memos, and identification of categories was selected, and Charmaz's constructivist perspective was adopted for second aim (Charmaz, 2014). In third study, using qualitative and quantitative approaches, a disease-specific self-care index was developed and validated through three phases and five versions in an iterative process. The first phase involved health professionals and patient interviews, and literature reviews for items identification. Second phase evaluated content and face validity of the instrument. During the third phase we administered the instrument to a sample of people with MND and from data evaluated construct validity and reliability of the instrument.

Results. In the integrative review 15 articles met inclusion criteria. Seven discuss decision-making process and adherence to ventilation and nutritional therapy. Five discuss strategies used by people with MND to optimize living with this illness and depending on others. Four discuss care and monitoring behaviors performed and recommended to people with MND. No studies focused on self-care in people with MND were identified in the literature. In the second study twenty-one people with spinal muscular atrophy and amyotrophic lateral sclerosis were deeply interviewed. Data were analyzed according to grounded theory methodology: initial line-by-line coding, memo writing, focused coding, advanced memo writing, and category definition. Five categories were identified as grounded in the data. The process starts from ''being yourself in the care,'' and it develops thanks to ''growing and changing'' and with a ''thinking about the future'' approach. ''Family role'' and ''you and who helps you'' categories affect the process itself. The self- care in Motor Neuron Disease (SCMND) index was developed, based on middle range- theory of self-care of chronic illness, including 15 self-care behaviors, related to respiration, nutrition, mobility, medication, medical visits and complications management. CVR ranged from 0.78 to 1 and CVI was 0.94. Cronbach's α ranged from 0.71 to 0.84 and ICC test-retest ranged from 0.93 to 0.98. Increased self-care behaviors median values were associated with

mechanical ventilation, cough assistance and dysphagia. Domains differed significantly based on ER access (maintenance), hospital admissions (monitoring and management) and respiratory infection (management) (p<0.05).

Conclusion. This doctoral program has shown that the concept of self-care in people with MND has different features than other populations. Self-care is related to dependence on others and on machines. The process of self-care is based on the preservation of identity and it is not defined in a day-to-day perspective and self-care behaviors change with the progression of the disease. The decision-making and the control over the disease and care are a widespread need among this population. Family can help in the self- care process, but the most important contribution of families as perceived by patients is their closeness and their affection. The instrument we developed and psychometrically tested was based on the middle-range theory of self-care in chronic disease, we developed a tool and attempted to prove the content validity, the known group validity and reliability. The results of this study suggest that SCMND index is a valid and a reliable tool, useful in clinical practice to evaluate the self-care behaviors implemented by people with motor neuron diseases.

Key Words. Motor neuron disease, self-care, caregiver, dyad, review, grounded theory, instrument development, psychometrically test