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Titolo tesi: Influence of Cultural Values in Informal Caregiving of People with Heart Failure

ABSTRACT

Background: Heart failure (HF) is a clinical syndrome, defined as a condition characterised by an abnormality of cardiac structure and/or function. It has been defined as a global pandemic, with 64.3 million people estimated to suffer from HF worldwide. This number is expected to increase due to the ageing population and increased life expectancy. Moreover, because of the COVID-19 pandemic, there has been an increase in HF cases attributed to the cardiac damage that can occur with COVID-19 infections. Currently, the incidence of HF in Europe is about 3/1000 person-years (all age groups) or about 5/1000 person-years in adults. The prevalence of HF appears to be 1_2% of adults. Numerous studies in the literature demonstrating that self-care in HF improves important clinical outcomes such as mortality, quality of life, and re-hospitalization. However, although self-care is so important in patients with HF, several studies show that it is inadequate in many populations, especially in those who are older, with cognitive impairment, and depressed. In these cases, help from an informal caregiver is fundamental to support HF patient self-care. Informal caregivers are defined as those family members or persons outside the family, who provide most of the informal care to a person in with chronic diseases or disabilities without receiving salary or monetary compensation. Informal caregiver support to HF patient self-care has been conceptualised as 'Caregiver contribution to self-care', defined as that process in which the (informal) caregiver recommends to the patient the performance of those behaviours that help maintain stable HF and encourages adherence to evidence-based therapy (caregiver contribution to self-care maintenance), facilitate monitoring and perception of signs and symptoms (caregiver contribution to symptom monitoring and perception), and recognise a change in condition has occurred and respond to signs and symptoms of flare-ups with treatment implementation (caregiver contribution to self-care management). Contributors to HF self-care, caregiver confidence, the process of caregiver contribution to HF self-care and the outcomes are influenced by caregiver cultural values.

Aim: The general aim of this doctoral research program is to improve the knowledge about caregivers' unmet needs and how they are influenced by culture and how to inquire about cultural values in cross-cultural studies proposing a new coding technique.

Method: In the first study, a convergent mixed methods design (QUAL + QUAN) was used. A semi-structured interview guide was developed for the interviews. A qualitative content analysis was conducted following the seven-step process of Mayring (2014). The quantitative variables resilience, burden, anxiety and depression were measured using valid and reliable data collection instruments: Connor–Davidson Resilience Scale (CD-RISC), Caregiver Burden Inventory (CBI) and Hospital Anxiety and Depression Scale (HADS). In the second qualitative study, data were collected through individual

semi-structured face-to-face interviews. In the third study, we proposed a new coding technique, namely Contextual coding, for generating codes about the underlying context and implied cultural and social meaning of participants' words, statements, and phrases.

Results: In the first study, the mixed analysis demonstrated that the main factors affecting caregiver resilience were depression, psychological outlook, physical weariness, affective state, community connection and self-comforting activities of the caregivers. Both the qualitative and quantitative results supported these factors. The qualitative results provided an additional understanding of the factors that could not have been achieved through quantitative results alone. The quality of informal caregiving is affected by the resilience of caregivers. Cultural values influenced personal coping strategies, perceived social support and sense of community belongingness. From the second study, 33 codes was extracted. We summarised them into eight categories and identified four main themes: (1) *Time for yourself*, (2) *House management*, (3) *Time for the patient* (dedicated to directing care), and (4) *Time for own socialisation*. Finally in the third study, we proposed the contextual coding approach that can improve the comprehension and coherence of the coding process as it guides the researchers in coding data from different native languages and sociocultural contexts and sub-contexts.

Conclusion: The results mentioned about the studies performed are partially comprehensive of the complexity of caregiving phenomenon in HF. Although the studies proposed during this doctoral program can be considered the final results of the larger HF2CARE project, they propose a thick description of the problems identified by caregivers but they are lacking in results on how to solve them. The daily challenges to which caregivers were subjected were reported by participants as exhausting and influencing the quality of life leading them to experience burden. In order to assume a conscious role-taking without affecting the health of the caregivers themselves, interventions on them should be designed according to their needs and problems contextual to their cultural values. In addition to the main problems reported by caregivers, they complained of the impossibility of getting away from the home shared with the cared loved one because of his/her functional limitations due to HF. The pandemic, in addition to, probably increased the difficulties perceived by caregivers. Furthermore the COVID-19 event weighed down an important challenge that is already present in lives of caregivers daily. The impossibility of being able to move from home was in fact widely reported in the study proposed in chapter 3. New possible solutions for caregivers unable to leave home because of the functional limitations of their loved one's should be consider. New technologies such as virtual reality (VR) or platforms accessible via smartphones could be interesting solutions at low cost and wide usability. Caregivers also reported uncertainty about the future as a major source of stress. Solutions such as podcasts containing information about the disease and its management could be useful to caregivers in appeasing their insecurities. It is well known that heart failure affects the quality of life of the people affected. The quality of life and well-being not only of the person with heart failure but of the dyad or the family that takes care of it must become the focus of future research.