

Abstract

Burden and Self-Care Needs Among Informal Caregivers of Patients With Transthyretin Cardiac Amyloidosis (ATTR-CA): A Qualitative Analysis

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Introduction. Transthyretin cardiac amyloidosis (ATTR-CA) is a progressive infiltrative cardiomyopathy increasingly recognized as a cause of heart failure, particularly among older men. Its chronic trajectory necessitates substantial involvement of informal caregivers, with potential consequences for their psychological and physical well-being. Despite the increasing prevalence of ATTR-CA, evidence on caregiving experiences and caregivers' self-care needs remains scarce. AIM: To explore the caregiving experience of informal caregivers of patients with ATTR-CA, with a specific focus on self-care needs and the impact of caregiving demands on caregiver burden.

Methods. A qualitative analysis was conducted within a mixed-methods study, using individual semi-structured interviews conducted to caregivers of patients with ATTR-CA receiving disease-modifying therapies.

Results. Preliminary analysis of n = 17 interviews identified multiple dimensions of the caregiving experience, including emotional, physical, and personal life impacts. The findings also highlighted the role of support networks and caregivers' coping strategies in modulating perceived burden.

Discussion. Caregiving for patients with ATTR-CA is associated with a multidimensional burden. These findings emphasize the need for early identification of caregiver burden and the implementation of targeted interventions to support caregivers and their families, alongside the promotion of self-care strategies.

Keywords: Caregiver Burden, Self-Care, Transthyretin Amyloidosis, Qualitative Research

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