

# Conférence laurentienne de rhumatologie

## Laurentian Conference of Rheumatology

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Abstract #: 4

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### Caregiving intensity and perceived burden among informal caregivers of persons with systemic sclerosis compared to other chronic medical conditions

**Objective(s):** Informal caregivers are persons who provide assistance to a friend or family member with a health condition, typically without receiving financial compensation or formal training. Systemic sclerosis (SSc), or scleroderma, is a rare autoimmune connective tissue disease characterized by vascular injury, immune dysfunction and an abnormal fibrotic process that can affect multiple organ systems including the skin, lungs, gastrointestinal tract and cardiovascular system. People living with SSc often rely on informal caregivers to assist with a variety of daily tasks. The objective of the present study is to compare caregiving intensity and perceived burden of informal caregivers of people living with SSc to informal caregivers of patients with other chronic medical conditions.

**Method(s):** An online survey was completed by informal caregivers of people with SSc from December 2016 to June 2017. The survey included measures of caregiver intensity (Level of Care Index) and perceived burden (Zarit Burden Interview [ZBI]). In addition, a systematic search of Cochrane Central, CINAHL, EMBASE, MEDLINE, and PsycINFO databases was conducted from inception through October 11, 2017 to identify original studies that included the Level of Care Index or the ZBI among caregivers for people with chronic diseases, excluding cancer and diseases primarily characterized by cognitive or mental impairment.

**Result(s):** 202 informal caregivers of people with SSc completed the survey. The Level of Care Index was categorized as low burden in 55%, medium burden in 14%, and high burden in 31% of SSc caregivers. The mean ZBI score among caregivers was 13.5. Results are pending for the systematic review. From the database search, 2701 unique title/abstracts were identified. Of these title/abstracts, 2393 citations were excluded, and 308 full-texts were reviewed for eligibility. A total of 75 eligible articles that included the Level of Care Index or ZBI were included. Caregiver intensity and perceived burden of informal caregivers will be extracted and compared to results from our survey of caregivers of people diagnosed with SSc.

**Conclusion(s):** No previous studies have examined caregiving intensity and caregiver burden among informal caregivers of people with SSc. This study will document caregiving intensity and burden in comparison to more common diseases with more extensive research evidence.

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