

Background:

Systemic sclerosis (SSc) is a rare, chronic and heterogenous disease with many possible outcomes and an uncertain horizon which presents difficulties not only for patients, but also for caregivers.

Objectives:

To gain more insight in the experiences and unmet needs of caregivers for people with SSc in the Netherlands.

Methods:

The study had a qualitative design. Participants were recruited by the Dutch patient organization (NVLE) using social media. One focus group and two individual interviews with a semi structured approach were held. Participants were asked to note down their associations with the disease, which lead on to a group conversation moderated by two researchers (MRS, CHE). The focus group was audiotaped and transcribed. Individual telephone interviews were summarized. All participants verified and approved the reports afterwards.

Results:

Eight caregivers (4 males, 4 females: 4 partners, 2 widowers, 1 parent and 1 friend) of patients with SSc participated. Six attended the focus group session, two were interviewed over the phone. Several challenges were reported by the participants. The first challenge is coping with the chronic disease course, unawareness of treatment options and lack of information about limitations in treatment modalities. Furthermore, the witness of patients' ailing, changing bodies, decreasing mobility and poor energy levels without being able to provide a cure, was experienced as a huge burden by caregivers. Alongside this distress, caregivers personal lives are also affected; future opportunities are cut off, such as starting a family or continuing an active life style.

Caregivers addressed invalidation and the decrease in support from others due to misjudgment and misconceptions about severity, duration and impact of the illness. Over time, this resulted in a dwindling network of social and emotional support, affecting family-life, relationships and mental health of both patient and caregiver.

Another strain was the complex mutual process of coping and the lack of frank communication about the condition between the partners, towards their social network and the medical staff. This is partly due to the indolent course of the disease, but also due to fear of what the future would hold and lack of insight in prognosis.

Caregivers reported that care provided at the hospital did not actively involve caregivers, nor provided them with the much-needed information with regard to prognosis, long-term treatment plans or daily care.

Conclusion:

SSc has a major impact on the lives of caregivers, however, current care does not actively inform, include or support them to relieve some of this burden. Further research should focus on the modalities in which caregivers can be involved in the care and which information and support is required.

References:

Figure 1. Word cloud/associations by participants, as part of the method used in focus group discussion.

