



Living with systemic sclerosis: exploring its impact on caregivers

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LETTER TO THE EDITOR

Living with systemic sclerosis: exploring its impact on caregivers

We read with great interest the article of Millette and colleagues, which provides valuable insights in the interaction between patients with systemic sclerosis (SSc) and close relatives, from a patient's perspective [1]. Millette et al. observed that it is paramount for patients with SSc to receive emotional, informational, and instrumental support from their social environment, which is in line with results from earlier studies [2]. Furthermore, Millette et al. reported that communication styles and relational factors influenced the way patients were supported. The authors therefore concluded that rehabilitation programs should pay attention to interventions aiming to improve coping with SSc in a collective way.

In addition – and close relation to their conclusions – our study group would like to emphasize the importance of acknowledging the major role close relatives play in daily care for patients with SSc. Moreover, SSc as a rare, chronic and heterogenous disease with an uncertain horizon presents difficulties not only for patients, but also for their social relationships. Therefore, we would like to extend the attention to caregivers and close relatives of patients with SSc. Their experiences were investigated in a qualitative study in the Netherlands last year (2018), which is, to our knowledge, the first time this perspective was explored in SSc.

We conducted interviews in order to gain more insight in the experiences and unmet needs of caregivers for people with SSc. The interviews were audiotaped and transcribed. The participants

verified and approved the reports afterwards. Eight caregivers of patients with SSc (four males, four partners, two widowers, one parent and one friend) participated. Six attended a focus group session, two were interviewed over the phone. Participants reported they faced several challenges in daily life living with or caring for a person with SSc. An overview of the themes and related issues brought forward in our study is provided in Table 1.

First, coping with the heterogeneous character of SSc and consequently the uncertainties of the prognosis was mentioned as a huge emotional burden. Secondly, the lack of information about treatment options and limitations in treatment modalities worsened the troubled prospective.

Furthermore, the witness of patients' ailing, changing bodies and poor energy levels without being able to provide a cure, was experienced as a huge burden for all participants. Alongside this distress, the personal lives of partners were also affected; future opportunities were cut off, such as starting a family or continuing an active life style and holidays. With regard to providing of support, caregivers experienced large emotional and sometimes physical demands. They became the main support for the patient. Caregivers addressed invalidation and the decrease in support from others due to misjudgment and misconceptions about severity, duration and impact of the illness. They experienced that over time, this lack of understanding and acknowledgment, resulted in a dwindling network of social and emotional support, affecting

Table 1. Themes and subthemes with quotes.

Themes	Subthemes	Issues	Quotes
Knowledge	Lack of information	Uncertainties due to heterogeneous character of SSc Uncertainties due to unknown prognosis Limited information about treatment options Misunderstanding	"There is just so little information about SSc available." "We were told that there was no treatment available." "If you have cancer, it is at least clear what you can expect."
Effect of SSc on personal life of caregivers	Providing support	Emotional demands Physical demands	"I have to balance to join social activities, she is confronted with the condition so often already."
	Less future opportunities Decline of social network	Adjust work and other activities/leisure Unwanted childlessness Decrease in support from others due to misjudgment Complex condition to explain to others Taboo	"I was afraid she would outlive me, who would have taken care of her?" "Friends stayed away." "People lose interest: she is still alive so it was not that bad" "People feel uncomfortable with bad news."
Changing relationship	Behavioral changes	Protecting the partner Being the main caregiver	"My wife did not want to be patronized, although I sometimes do." "I am taking care of her 24/7."
	Physical changes and disabilities Communication	Poor energy levels Changing bodies Avoidance of communication Differences in process of coping between caregivers and patients	"Looking back at the pictures, you can see the changes in her face" "He does not understand how hard it has been on me in the past year. I experience stress about his poor health." "She wants me to accept her condition, yet she has not accepted it herself." "For ten years, I was not allowed to tell anyone about her condition. I did it, though, I had to talk about it to empty my own head."
Support for caregivers	Involvement of caregivers in health care	Few interaction between physician and caregivers Lack of education or involvement in decision making	"There is no attention for the continuous adjustments, limitations, grieving process we have to go through." "One simple question that could be helpful, would be: how do you feel, what is going on in your head."
	Support for caregiver	No attention for caregivers in health care Support provided by social contacts for caregiver	"I hoped that I was asked how I felt, how we feel." "We have a very kind family who ask about me too."

family-life, relationships and mental health of both patient and caregiver.

In line with the findings reported by Milette et al, caregivers mentioned to struggle with the complex mutual process of coping with and the lack of frank communication about the condition between the partners, towards their social network and the medical staff. Partly, due to the indolent course of the disease, which made it seldomly an explicit part of the conversation, but also, due to fear of what the future would hold and lack of insight in prognosis. Consistent with reports from patients, caregivers as well reported that care provided at the hospital did not actively involve caregivers, nor provided them with the much-needed references or information with regard to prognosis, long-term treatment plans or daily care.

In conclusion, our study illustrates the huge impact of SSc on the lives of caregivers and social relations of patients and challenges they face towards supporting their loved-ones. Caregivers should be more involved in the care of patients with SSc. This supports Milette's et al implication that we should not only support people with SSc by encouraging them to seek support from their close social relationships, but also by providing these close relations with accessible information sources and supportive services.

Disclosure statement

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