

Assessing the Educational Needs of Canadians with Systemic Sclerosis

To the Editor:

Changes in appearance, significant morbidity, and the absence of disease-modifying therapies may lead to psychosocial issues in patients with systemic sclerosis (SSc)^{1,2,3,4}. Limited education may contribute to poor medication adherence⁵. Education of patients could potentially mediate some of these outcomes^{2,6} because patient education in rheumatic disease improves self-efficacy and self-management^{7,8}. An Educational Needs Assessment Tool (ENAT) was developed to assess the perceived educational needs of people with rheumatic disease⁹, and has been validated in patients with SSc¹⁰. We used the ENAT to survey a sample of Canadians with SSc to understand their educational need(s) to inform educational initiatives and future research. This project was not deemed to require ethics approval by the Hamilton Integrated Research Ethics Board, and thus written consent was not required.

The ENAT questionnaire was posted on the Scleroderma Society of Ontario and Scleroderma Society of Canada social media accounts in August 2017. Patients from 2 clinics were also provided with the online survey link. All data were self-reported. Participants were asked the dichotomous question, “Do you want education about anything to help you deal with your scleroderma?”, an open-ended question about desired educational needs, and were asked to describe the extent to which they want to know about their SSc (4-point Likert scale). Seven domains of perceived needs (4–7 questions each) were assessed. Responses were given on a 5-point Likert scale (0 = not at all important; 4 = extremely important). A total score was derived for each domain and overall (maximum 156 = high need). Scores were then converted into a percent of maximum score¹¹. Linear regression analyses determined the association between patient characteristics and ENAT scores. Stata for Mac (version 13.2) was used for data analysis.

Characteristics of the 49 patients are summarized in Table 1. The mean (SD) total ENAT score was 111 (34), representing 71.2% of the maximum score (Table 2). Highest needs were in the domains of information about SSc, self-help, and treatments. Desire for disease-related information was associated with total ENAT score ($\beta = 25.56$; $p < 0.001$). There was no association between total ENAT score and age, duration of disease, or age at school completion ($p > 0.05$). Open-ended responses identified needs related to organ involvement ($n = 10$), pain ($n = 8$), research and/or emerging treatments ($n = 8$), disease effect on mental health and daily function ($n = 6$), Raynaud phenomenon ($n = 4$), complementary and alternative management ($n = 3$), and enhancing interactions with specialist physicians ($n = 3$).

Our results demonstrate high overall educational needs, indicated by relatively high mean total ENAT score, with greatest needs in self-help, disease information, and treatment. As expected, those desiring more disease-related information had higher overall educational needs. Open-ended responses suggest a need for more information regarding research initiatives, alternative treatments, and the management of disease

Table 2. Education Needs Assessment Tool (ENAT) scores in each of the 7 domains ($n = 49$).

Domain	Mean (SD)	SD	Range	Mean (% of max)*
Managing pain (0–24)	15.7	5.8	2.7–24	65.4
Movement (0–20)	12.7	5.9	0–20	63.5
Feelings (0–16)	10.9	5.0	0–16	68.1
Scleroderma (0–28)	21.9	6.0	6.2–28	78.2
Treatments (0–28)	20.2	7.4	0–28	72.1
Self-help (0–24)	18.4	5.5	4.3–24	76.7
Support (0–16)	11.2	4.7	0–16	70.0
Total ENAT score (0–156)	111.0	34.3	15–156	71.2

* Greatest needs as determined by the maximum possible ENAT score¹¹.

sequela. Our data generally support results from previous studies^{6,11,12,13}, including the presence of significant psychosocial needs^{12,13}. Although not explored in detail here, addressing psychosocial needs should be prioritized in future initiatives.

We collected minimal patient characteristics data (Table 1), which did not allow us to adequately explore potential differences between those who did versus did not want information related to SSc. It is unclear whether those with low education needs have sufficient disease-related knowledge or whether they are different demographically (socioeconomic status, access to care, health literacy) from those with high needs. Personal health-related outcomes (i.e., disease activity) may also play a role in educational needs, as previously shown in other rheumatologic conditions¹⁴. Thus, an important next step would be to explore characteristics of patients who do not want disease-related education and whether perceived needs may be linked to disease outcomes and healthcare access.

Our data relied on self-report for diagnosis of SSc and were limited to a convenience sample of participants who had access to the Internet and social media. While we had 49 respondents, a larger sample compared to similar studies^{6,11,12}, we are unable to comment on the generalizability of our results. A study investigating Internet use among patients with SSc found widespread use and a preference for disease-related information over nonmedical information (e.g., lifestyle modification)¹⁵. Another study demonstrated patient interest in multidisciplinary services and information provided by rheumatologists¹³. Future research should explore the optimal medium for providing information to patients, needs of non-Internet users, and methods of optimizing the delivery of online education.

The variability of our patient population (Table 1) and their educational needs (Table 2) suggests that a multifactorial approach to addressing patient needs is required. To address a patient-directed agenda and the heterogeneity in patients and needs, partnerships between patients, patient groups, clinicians, and researchers should be fostered. Such partnerships would facilitate the development of informational materials and appropriate, effective, and accessible methods of information dissemination. In so doing, we would optimize information and delivery to meet the needs of patients in this study, and also those who are more difficult to reach or do not use the Internet.

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