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ONLINE SPREAD AND PATIENT CONTRIBUTION TO THE IMPROVEMENT OF A SYSTEMIC SCLEROSIS PATIENT EDUCATION HANDOUT DURING THE PANDEMIC OF COVID-19

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BACKGROUND

Systemic sclerosis (SSc) is a rare autoimmune disease of the connective tissue, mainly characterized by excessive deposition of collagen in the skin and multiple internal organs. The hands are frequently compromised, mainly by Raynaud's phenomenon and scleroderma. To prevent and minimize these changes, drug treatment, rehabilitation, and patient education (PE) are essential, including guidance on the nature of SSc and hand care techniques. In this sense, the production and distribution of educational materials, such as patient education handouts, serve as adjuncts to PE.

MATERIALS AND METHODS

Based on the university hospital patients' doubts regarding self-care in SSc, a search of the scientific literature was carried out and a patient education handout was elaborated, explaining definitions of medical terms regarding SSc, such as scleroderma, Raynaud's phenomenon, and calcinosis, as well as addressing hand care techniques to prevent functional loss and complications. With social distancing imposed by the COVID-19 pandemic, an online version of the handout was released on the university website and social networks. Evaluation of the handout by 33 SSc patients, addressing the understanding of the text and illustrations, and a score (0-10) for the aesthetics, relevance, and explicitness was undertaken.

RESULTS

The online release of the handout increased its scope since it reached around 5,700 people. Of 33 patients evaluating the digital handout, none reported difficulties with the text and 87.9% reported no difficulties with the illustrations. They suggested the addition of new issues and the improvement of some illustrations. The scores given by the respondents to the patient education handout were very satisfactory, with an average of 9.21 (SD $\pm$ 0.80) for aesthetics; 9.30 (SD $\pm$ 0.85) for relevance and 9.57 (SD $\pm$ 0.63) for explicitness. After examining the responses, the handout was modified and a new version (Figs. 1-6) was developed and published on social networks. Patients addressing the new version of the handout commented on its improvement.

Figure 1. Cover of the patient education handout.

Figure 2. Page 2 of the patient education handout.

Figure 3. Page 3 of the patient education handout.

Figure 4. Page 4 of the patient education handout.

Figure 5. Page 5 of the patient education handout.

Figure 6. Back cover of the patient education handout.

CONCLUSION

The development of educational materials for patients with SSc is relevant, since they provide reliable information about this disease and hand care techniques, solving doubts, and preventing functional losses. The participation of patients in the development of educational materials may improve their understanding. With social distancing, the online distribution of the handout is expanding its scope. Given the good acceptance of patients, we believe that the objectives of this educational material have been achieved.

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