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Title: Use and Perceptions of Nutrition Information Resources Among People with Systemic Sclerosis from the Scleroderma Patient-centered Intervention Network (SPIN) Cohort

Objective(s): The evidence base for nutritional and dietary strategies for people with systemic sclerosis (scleroderma, SSc) is limited, despite gastrointestinal manifestations being some of the most commonly experienced complications of the disease. Dietary guidelines for symptom management for SSc have therefore not been established in clinical practice, which may result in individuals seeking information from alternative sources. We previously conducted a study where we identified 27 sources within four categories (healthcare providers, print material, websites and other media platforms, events) from which people with SSc obtain information and advice on nutrition and diet to support healthy nutrition and manage gastrointestinal issues. The objectives of the present study were to (1) identify how commonly each of these sources of information is used by people with SSc and (2) assess perceived trustworthiness, accessibility, ease of comprehension, and individualization of each information resource.

Method(s): Participants in the international Scleroderma Patient-centered Intervention Network (SPIN) Cohort were invited to complete a separate survey on nutrition. They rated each of 27 types of resources (scale 0-10) for trustworthiness, accessibility, ease of comprehension, and individualization of information and indicated whether they had used the type of resource before.

Result(s): Among 1568 eligible SPIN Cohort participants, 727 (46%) completed the survey. Nearly all respondents (94%) had used at least one nutrition information resource. Among healthcare providers, all nine provider types received median ratings ≥ 8 on trustworthiness, degree of individualized information and ease of comprehension by participants who had used the resource, while accessibility scores were lower. All resources in the events category received median scores of ≥ 8 on ease of comprehension and trustworthiness, but scored lower on degree of individualized information and accessibility. Web-based resources received moderate-to-high ratings on accessibility (median: ≥ 8) and ease of comprehension (median: ≥ 7), and lower ratings on degree of individualized information, while trustworthiness scores were more variable. Ratings within the print materials category were highly resource-dependent, but consistently low on degree of individualized information. Information disseminated by patient organizations and conventional healthcare practitioners were consistently rated more favorably compared to other resources.

Conclusion(s): Demand for scleroderma and patient-specific nutrition and dietary information is high, and more can be done to provide this patient group with reliable and accessible information resources. Scleroderma patient organizations and healthcare providers play important roles in disseminating information given their wide reach and high trust among the SSc patient population