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Relationship between Educational Needs and Health Problems in People with Systemic Sclerosis: A Cross-Sectional Study

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Background

Systemic sclerosis (SSc) affects patients' functioning, quality of life and diminishes their life expectancy. More importantly the chronic progressive nature of the disease threatens the patients' life. In planning patient education in people with SSc and their families, it is extremely important to identify their health problems as these may determine their educational needs.

Objectives

(1) To identify health problems and the educational needs in people with SSc. (2) To determine the relationship between the health problems and their educational needs.

Methods

This was a multicentre cross-sectional study conducted at the Department of Rheumatology and Internal Diseases, in Medical University of Białystok, and in six other rheumatology centres in Poland. The inclusion criterion was diagnosis of SSc (based on the ACR/EULAR 2013 criteria) and a minimum age of 18 years.

Health problems were defined as disability (HAQ-DI), pain (Pain-VAS), fatigue (Fatigue-VAS), morning stiffness (Min) and the following self-reported problems measured using 0-100mm VAS: intestinal problems, breathing problems, Raynaud's phenomenon, finger ulceration and overall disease severity. The educational needs were measured using the Polish version of the Educational Needs Assessment Tool (Pol-ENAT). We used Pearson's correlation coefficient (r) to report the effect sizes, 0.10, 0.20 and 0.50 representing small, medium and large effects respectively.

Results

The sample comprised 140 patients, women being the majority (n=125; 89.3%). They had a mean \pm SD age of 54 years \pm 14.23 and disease duration of 11 \pm 10.27 years. Reported health problems were particularly severe in patients over 60 years.

The largest influence on daily activity in the whole study group was pain (r=0.294, p<0.001), morning joints stiffness (r=0.280, p<0.001) and fatigue (r=0.273, p=0.001). While the average value of HAQ was 1.11 \pm 0.70, patients with over 60 years had a mean HAQ=1.35 (p=0.001). In general, respondents were interested in patient education. Their reported overall educational needs were high.

There was a positive linear relationship between educational needs and disability (r=0.290, p<0.001). Similarly, educational needs were correlated with reported health problems such as pain (r=0.343, p<0.0001), morning stiffness (r=0.269, p=0.001), disease severity (r=0.259, p=0.002), fatigue (r=0.254, p=0.002), Raynaud's symptom (r=0.248, p=0.003) and ulceration of fingers (r=0.199, p=0.018).

Conclusions

All patients affirmed the need for education, the level of need increasing with age and disease duration. Educational needs were mainly related to arthritis process, managing pain and self-help measures. Interest in education was correlated to the subjective assessment of the disease and the reported sense of discomfort.

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