Background: Fatigue is difficult to manage. In addition to pain, fatigue is the symptom reported to have the most negative impact on performance of daily activities by people living with rheumatoid arthritis (RA). At Haukeland University Hospital in Bergen, Norway, an occupational therapy group is therefore offered as part of the rehabilitation program for people with inflammatory rheumatic diseases, to help them cope with fatigue in their everyday life.

Objectives: To explore patients experiences with the group and if there are unmet needs that should be addressed by health professionals.

Methods: Four to six months after attending rehabilitation, semi-structured interviews were conducted with two men and eight women of working age. Participants had a variety of inflammatory rheumatic diseases. The interviews were recorded and transcribed verbatim. Thematic analyses will be conducted.

Results: Preliminary findings indicate that persons living with rheumatic disease and fatigue have several needs to enhance their coping of everyday life, which can be described in three themes: (1) A need for increased understanding of fatigue and recognition by health professionals: Several informants reported feeling concerned, insecure and worried because they were unable to understand why they experienced overwhelming tiredness. Consequently, they wanted more knowledge concerning to which degree their fatigue was caused by their inflammatory rheumatic disease, or if it was caused by something else. They also wanted the rheumatologists to pay more attention to fatigue in persons with rheumatic diseases. (2) A need for information sharing with peers: Such sharing enhanced their understanding of fatigue, motivated them to consider trying out new strategies to manage their fatigue, and seemed to be the most important outcome of the activity paced group. (3) A need for practicing specific self-management strategies: The informants valued that an occupational therapist led the group. They further described that the focus on activity balance and how to manage daily activities increased their awareness of what to do to manage their everyday life. Planning and prioritizing meaningful activities were the most frequently reported strategy. Despite gaining more knowledge, several of the informants seemed to struggle with changing their behavior and, thus, continued to exceed their energy reserves. Therefore, a few informants clearly expressed a need for follow-up over time and for practicing specific strategies, to be able to change their behavior.

Conclusion: The participants described seem to need information to increase their understanding of fatigue and how to manage their everyday life with fatigue. They also need rheumatologists to recognize fatigue experienced by persons with inflammatory rheumatic diseases. However, knowledge and increased awareness of self-management strategies alone do not seem to enable the participants to change their behavior. Therefore, there seems to be a need for follow-up allowing the participants to practice and evaluate goal-setting and the use of activity pacing strategies in their daily life.

REFERENCE

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