

Fatigue in rheumatoid arthritis; an issue that is not discussed



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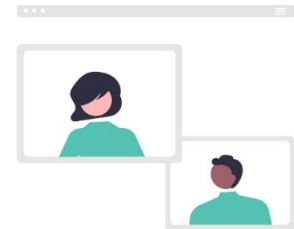


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Rheumatoid arthritis is a chronic disorder frequently causing pain, swelling and stiffness. In addition, up to 90% of people experience fatigue to a greater or lesser degree. Conversations between researchers and people with rheumatoid arthritis revealed that little attention seems to be paid to fatigue in discussions with healthcare providers. To better understand the experiences and needs of people with rheumatoid arthritis when discussing fatigue in a consultation, 10 interviews were conducted with people with rheumatoid arthritis.

Interviews

In May 2022, 10 online interviews were conducted with people with rheumatoid arthritis. They came from different parts of the Netherlands and are treated by different hospitals. Topics that were discussed in the interviews included what the participants' main complaints are due to arthritis, how their care is currently organised, whether they experience fatigue and how they deal with it. Other topics were whether and how fatigue is discussed in conversations with health care providers and how, ideally, they envisage this happening.



Outcomes

Several important themes emerged from the conversations

Fatigue is common and complex

When people with arthritis were asked about the symptoms they experienced, the emphasis was on pain and stiffness. Fatigue was hardly ever mentioned. Only when asked specifically it was mentioned that fatigue plays or had played a major role in the daily lives of a majority of the participants. The reason for not mentioning the fatigue was often that people did not want to come across as someone who complains, and that fatigue is never discussed in the same way as physical complaints by doctors, so they do not mention it directly themselves.

Little attention for fatigue in contacts with healthcare providers

During a consultation with a rheumatologist, fatigue is rarely, if ever, discussed. The doctor does not ask about it explicitly. Patients themselves are also reluctant to mention fatigue, although there is generally room to discuss it. The reason that people with arthritis give is that fatigue was mentioned at one time, but that the doctor did not do or say much about it. They also mention that other symptoms are sometimes more prominent, such as pain. They then choose to pay attention to those symptoms only. Doctors do acknowledge that fatigue is a symptom experienced by many people with arthritis. In general they do not offer concrete solutions or possible ways to better deal with the fatigue.

Finding solutions themselves

The people with arthritis indicated that they therefore try to find their own way of dealing with the fatigue. Different solutions were mentioned such as lifestyle (a low-carb diet, vegetarian diet, regular exercise), adapting the daily routine and clear planning (with or without support from an occupational therapist), mindfulness or a visit to a spa. Information about these was mostly found through a variety of digital sources.



Desires regarding discussing fatigue

People with arthritis indicated that it makes sense that in their contacts with healthcare providers, there is ample attention for physical complaints and the use of medication. They would prefer more attention for matters that affect their daily lives, such as fatigue. According to the participants, it would be a good idea for the rheumatologist to have insight into the extent to which people experience fatigue and how this develops over time. This is already recorded for pain, but not yet for fatigue. For people in the early stages of the disease, it is desired that it will be made clear immediately that fatigue is a common symptom. For people who experience significant fatigue, support in finding a possible solution from the healthcare provider would be welcome. This solution may be different for each person, since fatigue is complex and each person also has different needs. However, people with arthritis indicate that it is considered pleasant when healthcare providers can provide support in the search for a suitable solution. Whether this support comes from a rheumatologist or a (rheumatology) nurse is considered less important, as long as the support is easily accessible.

Conclusion and future



This study clearly showed that fatigue is common among people with rheumatoid arthritis. Fatigue is hardly discussed with healthcare providers, even though people with rheumatoid arthritis do feel the need for this. The participants appreciate the fact that their fatigue is acknowledged, yet would prefer that the healthcare provider thinks along with them about ways to relieve the fatigue and/or to cope better with it in daily life. In the coming period, we will discuss with people with arthritis, how this study might be followed up.

For more information or participation in future research you can contact us via r.wolkorte@utwente.nl.