Developing a service-user informed occupational therapy intervention to facilitate meaningful occupation for people with primary Sjögren’s syndrome in the NHS

Key findings

- Fatigue, sleep disturbances and pain/discomfort affect occupational performance in patients with primary Sjögren’s syndrome. These symptoms can also affect relationships with others and impact mood.

- Patients require support to self-manage these symptoms and would be accepting of therapy interventions which were proposed to them. These interventions include techniques such as cognitive behavioural therapy for insomnia (e.g. stimulus control and sleep restriction), activity management for fatigue (activity stabilisation and graded exercise therapy), mindfulness and acceptance and commitment therapy for pain management. However, occupational therapists and other health professionals need to provide a rationale for their interventions.

- One-size therapy interventions do not fit all and patients require access to personalised support.

- Different intensities of symptom management support are needed: Low intensity interventions would include access to written materials and access to peer support. Medium intensity interventions would offer specific symptom management support in groups or via a digital interface. Some people require high intensity, one-to-one therapy to help them self-manage their most troublesome symptoms.

Project aims

To develop an intervention model to improve function and participation in the autoimmune disease primary Sjögren’s syndrome (PSS). By exploring:

- The experience of fatigue, sleep disturbances and pain/discomfort in this patient group and to discuss the potential acceptability and feasibility of intervention components, which occupational therapists could deliver in the future

- The potential of interventions to address these symptoms (fatigue, sleep disturbances and pain/discomfort).

- A future model of delivering interventions to support patients to manage their symptoms

Background

PSS is an autoimmune disease, where the body attacks its own secretory glands causing dryness. In addition to the dryness, patients experience a range of other symptoms including fatigue, sleep disturbances and pain/discomfort. Many patients experience difficulty carrying out their daily activities due to the impact of their symptoms.

Patients believe that in order to participate better in their daily activities, they need to be empowered to manage these symptoms themselves.

Doctors in rheumatology clinics currently address the dryness features, whereas the other symptoms are rarely addressed with patients. Therefore, fatigue, sleep disturbances and pain/discomfort are needs, which remain largely unmet for many people with this disease.
Methodology

Focus groups with open-ended questions were used to collect qualitative data from ten patients with PSS and three partners of patients. Three focus groups covered six topics using a topic guide. Discussion topics included the symptoms of fatigue, sleep disturbances, pain, low mood, anxiety and potential modes of delivering interventions. As well as exploring these ideas, a range of symptom management therapy components (which had previously been proposed by specialist therapists and sourced from the literature) were presented to participants and discussed to ascertain their acceptability.

The data was transcribed and recorded verbatim and analysed using thematic analysis (Braun and Clarke, 2006). Following the thematic analysis, a summary of these findings were discussed in a focus group of NHS staff, which included occupational therapists (n=3), physiotherapists (n=2) and a psychologist.

Recommendations

Patients need individual care and a model of care incorporating three levels of increasing intensity is proposed:

a) Written information on PSS and advice on how to self-manage fatigue, sleep disturbances and pain/discomfort to be made available to all patients, particularly at diagnosis. Patients should be able to access peer support.

b) Symptom management support for fatigue, sleep disturbances and pain/discomfort, delivered in groups by a therapist with an experienced patient, or via a menu of symptom management digital modules, where patients can choose the module(s) they wish to work through.

c) One-to-one symptom management support for patients who require a high intensity intervention.

Further research is recommended, to carry out a feasibility pilot study of the digital intervention, followed by a multi-centred randomised controlled trial. Additional research is recommended to determine which PSS patients would benefit most from higher and lower intensity interventions for the management of fatigue, sleep disturbances and pain/discomfort.

Publications


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References