

Background:

Sjögren's syndrome (SS) is an autoimmune rheumatic disease with diverse symptoms including mental and physical fatigue, dryness, pain and sleep disturbances. These symptoms are interconnected and rarely occur in isolation. Improving symptoms and quality of life requires people with SS to navigate multiple interventions and engage in self-management. Smartphone applications (apps) can deliver multiple cognitive and behaviour-based interventions in users' everyday daily lives and are readily accessible. However, delivering several therapeutic interventions together within a single coherent self-management app requires systematic and evidence-based selection of intervention components, and an understanding of existing self-management approaches and their associated challenges for those living with SS.

Objectives:

To identify theory-based intervention components for inclusion in a SS self-management app. To understand the self-management approaches and challenges of those living with SS to inform in-app component delivery.

Methods:

First, to identify intervention components within the app, existing interventions that target each symptom of fatigue, dryness, pain, sleep disturbance were identified through a literature search. Their content was coded by the research team using behaviour change techniques and the Theoretical Domains Framework¹. The content was grouped to form five intervention components which target multiple symptoms.

Second, to understand SS self-management approaches and challenges, 13 people living with SS took part in a series of qualitative focus groups (n=6) and design workshops (n=7). Focus groups involved participants discussing their own self-management experiences and approaches (e.g. when and how they employed a variety of techniques). In design workshops participants sketched metaphors to explain these experiences and used craft materials to create "Magic Machines"² addressing their self-management challenges. Focus groups and design workshops were audio-recorded, transcribed, thematically analysed as a single data set, and findings mapped to the self-determination theory³ dimensions of capability, autonomy, and relatedness.

Results:

Intervention components identified were: i) SS psychoeducation, ii) relaxation techniques, iii) activity pacing and goal setting, iv) assertiveness and communication skills, and v) sleep and dryness tips. Participants tackled complex symptom patterns (i.e. symptom interrelatedness and flares) using different self-management approaches; reactively (focusing on the most severe symptom) or systematically (one symptom at a time). Knowing which intervention techniques to choose was felt to be challenging; however the availability of multiple interventions techniques provided a sense of optimism and motivation. Participants were enthusiastic about accessing several intervention techniques via an app, but warned that smartphones and technology can exacerbate mental fatigue and eye dryness. The invisible nature of symptoms, and highly visible nature of management techniques (e.g. applying eye drops), presented further self-management challenges relating to their interactions with other people.

Conclusion:

Promising components to include in an SS app were identified but should be tested in an optimisation trial. The in-app delivery of component modules should be designed to support diverse self-management approaches, choice and autonomy, yet provide module recommendations and guidance when needed, and be simple to use to reduce mental fatigue and dry eye symptoms. A self-management app should also be designed to enable users to share information about SS with other people.

References:

- ¹ Cane J, et al. (2012) *Implementation science*, 7(1), 37.
- ² Andersen K, & Wakkary R. (2019) *CHI Conference on Human Factors in Computing Systems* (p. 1-13).
- ³ Deci E, & Ryan R (2008) *Canadian psychology*, 49(3), 182.

