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PARE0032

STRENGTHENING SELF-MANAGEMENT TO IMPROVE THE QUALITY OF LIFE AND HEALTH STATUS OF PATIENTS WITH INFLAMMATORY ARTHRITIS AND OSTEOPOROSIS IN SWITZERLAND

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Background: Previous UK studies suggest that people with arthritis taking part in self-management programmes feel more confident in their ability to manage and control their symptoms. These patients may also visit the doctor less frequently and have shown improved physical and clinical outcomes (1, 2). Based on this evidence, self-management has become an essential component of care for patients with arthritis, or generally with chronic diseases. However, there is still a huge gap regarding such self-management services and support programmes in rheumatology in Switzerland.

In the Swiss National Strategy "Musculoskeletal Diseases" 2017–2022, strengthening patients' empowerment is one of the main strategic pillars. Considering that approximately 500,000 people are suffering in Switzerland from inflammatory arthritis (IA) and osteoporosis (OP) alone, there is huge potential to strengthen patients' self-management capacity and thus improve their quality of life (3).

Therefore, the SLR has developed a self-management programme for IA and OP patients. In this programme medical assistants in outpatient rheumatology clinics are trained to consult patients in self-management. This programme is part of a two-year pilot project (2019–2020) that is supported by a consortium of important stakeholders in rheumatology in Switzerland.

Objectives: The ultimate objective is to increase the quality of life and the health status of people with IA and OP in Switzerland by enhancing their capacity for self-management. Furthermore, this pilot project aims at closing an important gap in the Swiss healthcare system by creating an innovative model that can potentially be replicated for other chronic diseases.

Methods: To measure the quality of life, the health status as well as the change in behaviour in patients, the study design includes both qualitative and quantitative methods. Patients enrolled in the programme are asked to answer a questionnaire at three points in time; at enrolment, after the last session and two months after completing the programme. It is expected that at least 45 patients will be enrolled. For a qualitative assessment, in-depth interviews will be conducted with rheumatologists and their medical assistants as well as some of the programme participants.

The training material for the medical assistants was developed by the SLR and will be evaluated by the programme participants. All patients will also evaluate the quality of the consulting provided by the medical assistant, answering a questionnaire after the last session.

Results: Within the first year of implementation, ten outpatient clinics, with twenty-four rheumatologists and twelve medical assistants, were enrolled in the pilot project. Four medical assistants were trained in 2019 and eight are in the process of receiving training in spring 2020. Only after the completion of training will patients be enrolled in the self-management programme. Therefore, outcome-related results cannot be expected until the beginning of 2021.

Conclusion: This pilot project provides an innovative approach to closing an important gap in the Swiss healthcare system and to providing a missing component of care for patients with IA and OP. However, it has been challenging to enrol enough clinics in the pilot project. The way the programme is embedded in the current healthcare system, it demands a cultural change within outpatient clinics, allowing medical assistants to step into a new role as consultant.

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SATURDAY, 06 JUNE 2020

Psychosocial support

PARE0033

I'M HERE BUT I'M NOT: A PHOTOVOICE STUDY OF THE LIVED EXPERIENCE OF SELF-MANAGING RHEUMATOID ARTHRITIS

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Background: Rheumatoid arthritis (RA) is a widespread chronic disease affecting about 1% of the population in the West. It is characterised by pain, fatigue and inflammation that can flare-up without warning. This makes the condition difficult to predict and manage. Bury (1982) introduced the concept of chronic illness as a disruptive experience to one's self-identity. This is often an invisible part of managing the illness and taken for granted by others, such as family members, friends and health care professionals. Thus, there is a need to raise awareness of the patients' lived experiences of self-managing this long-term chronic illness.

Objectives: We aimed to collaborate with people with RA to (i) record and reflect the community's strengths and concerns; (ii) raise awareness of the lived experience of self-managing RA (iii) spark a dialogue among key stakeholders around the self-management of RA.

Methods: A purposeful sample of people with RA (n=12) was recruited. An innovative qualitative methodology, Photovoice, was used (Wang & Burris, 1997). A series of small group workshops took place. Participants were provided with cameras and appropriate training. They were asked to take photographs of the "challenges and solutions to living with RA" over approximately two weeks. Semi-structured interviews were conducted incorporating photo elicitation. As a group, the participants, a visual artist and researcher co-created a photo exhibition for the public.

Results: Participants selected 32 photographs for the exhibition. They carried out a thematic analysis of the photos identifying four themes:

• *I'm Here but I'm Not* – this theme reflected feelings of alienation and social isolation.

• *Medicine in all its forms* – this theme captured attitudes towards medication and devices, as well as the creative ways people coped with RA.

• *Visible illness* – this concerned the recognition of RA. It captures the experience of RA as a "contested illness" and the challenge of gaining medical and cultural legitimacy.

• *Mind yourself* – this theme highlighted the value of self-care, often closely connected with the natural world and engagement with social activities. Exhibitions were held at a community arts centre and a large central hospital in Dublin city. A plain language report was also collaboratively produced.

Conclusion: This study shows how participatory methods can be used to explore the hidden experience of living with an invisible illness. This research design enabled participants to use photographs to reflect on their experiences and the meaning they intended to convey, thereby increasing trustworthiness of the findings through individual and group member checking. This