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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

approach extends beyond traditional written and verbal responses to share the worldview of participants. It demonstrates how to work with patients to create opportunities to improve awareness and spark dialogue among those who play a role in supporting the self-management of chronic illness. The integration of creative arts and participatory methods can have a positive impact for those involved in research and can enhance public engagement with research.

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SATURDAY, 06 JUNE 2020

Campaigning

PARE0034

PUTTING A FACE TO RHEUMATISM: MULTICHANNEL AWARENESS CAMPAIGN FOR RHEUMATIC DISEASES

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Background: Although one in four Europeans are affected by rheumatism, the various disease patterns and the consequences for patients are still largely unknown to the general public. Furthermore, it is still widely believed that rheumatism affects only older people. Patients often cite the lack of comprehension of rheumatic diseases as a major hurdle in their daily private and professional lives (1). Therefore, it is imperative to find effective means for providing essential information to patients about the disease and improving their quality of life by raising awareness among the general public. One strategy for reaching this goal was implemented in 2018, when the Swiss League against Rheumatism (SLR) founded a patient council consisting of around ten members affected by rheumatic diseases. The council members advise the SLR on the specific needs and wishes of rheumatic patients. Most members are open to sharing their experiences with the disease with the interested public.

Objectives: The overall goal of our campaign is to raise awareness for rheumatic diseases among the general public. By showcasing patients and their struggles, rheumatism is made tangible to the general public and prejudices and barriers are reduced. The campaign focuses especially on the fact that rheumatism also affects young people. Additionally, the work carried out by the SLR and its services for patients are to be publicised among patients and in their environment. The campaign was aimed at the following target groups: patients' families, health professionals, multipliers and the general public.

Methods: In order to put a specific face to rheumatism and to show that anyone, even young people, can be affected by a rheumatic disease, the SLR asked the members of the patient council to share their story for a multichannel outreach campaign. By the end of 2019 portraits had been taken and, in close collaboration with each council member, concise statements had been chosen in order to illustrate what patients struggle. The main focus was to give patients a voice and to showcase their struggles both in mainstream media such as local newspapers and on social media channels. The combination of pictures of apparently healthy people with a quote about their struggle with rheumatism creates an unexpected discrepancy in the reader's mind. Starting in 2020 the ads were distributed in several formats to editorial offices (tabloid press, local newspapers, specialist media) across Switzerland, asking the editors to publish them for free (as filler ads, when ads cannot be sold). The campaign was launched simultaneously on our social media channels and linked with existing content on our website.

Results: The first ads have already been placed and the analysis of their impact is currently being evaluated. We are still in the process of distributing our ads to an even broader audience. We expect to see a rise in media coverage and the number of free ads as well as an increased number of visitors on our website and social media channels. At a qualitative level we have received very positive feedback from our patient council, patients, and health professionals as well as journalists.

Conclusion: Featuring authentic patients and telling their stories facilitates media activities and aids in removing the barriers surrounding rheumatism. It helps to dispel misconceptions surrounding the topic, especially the notion that only people aged 60 and over are affected by rheumatism.

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"My struggle is not just against pain and limitations, but also for acceptance." Sarah, 31 years old