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LETTER

Addressing the unmet need for self-management strategies in idiopathic inflammatory myositis

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INTRODUCTION

The idiopathic inflammatory myopathies (IIM) are rare, where the rapidly evolving landscape with emergent literature makes chronic care even more challenging. In the evolving era of digital rheumatology, patients are more aware and involved in their clinical management than ever before.[1]

The first step in the direction of patient empowerment is to develop effective recommendations for devising universally accepted and feasible patient self-management strategies. The EULAR recently published guidance for self-management targeting individuals living with inflammatory arthritis.[2] The development of guidance for disease-specific interventions represents an unmet need, with an important limitation being the lack of literature supporting the value of such interventions.

Physician–patient collaboration

Aware and informed patients often resort to online information for disease management. The availability of telemedicine has made possible remote and borderless care, and greater physician–patient collaboration. Patient support groups are also involved in spreading awareness and fostering research.[3] The recent success of the MyPACER,[4] an entirely patient initiated registry for myositis reiterates that sustainable digital research is the solution.

The diagnosis label of IIM is in itself a challenge, and it is imperative to take into consideration the volume of information available online and offer adequate guidance to patients about the same. The acute phase of IIM may be marked by significant impaired mobility and inability to self-care. It is suggested that a multidisciplinary task force with physicians of different specialities be involved in patient care in addition to the caregivers, in order to cater to individual needs of such patients.

Exercise and physical therapy

The role of exercise in management is particularly indispensable in myositis and determines strength, endurance and disability in the long term. We envision that developing online, ready to assimilate tools for education with methods and instructions for exercise in different phases for patient with IIM would be appealing to patients. These could foster greater compliance, pending further investigation. Involvement of patient research partners can provide valuable insights into the challenges of such approaches and potential avenues for involving patients in self-care.

Comorbidity management

While initiating immunosuppressant treatment has always been challenging, the COVID-19 pandemic has brought new challenges to the fore. Digital checklists can be a powerful tool to remind patients of various facets of management and keep up to date with information on the fronts that need attention.

Digital rheumatology

The availability of several digital tools to track symptoms, monitor progress and record disease parameters also calls for a discussion around defining the appropriateness and acceptable extent of using Telemedicine approaches for managing myositis. Digital rheumatology networks involving partnerships between physicians, patients and technologists have led initiatives to test digital solutions in specific rheumatic disease groups.[5]

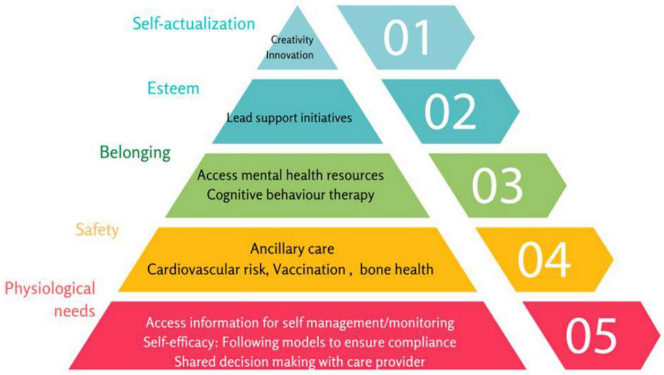

Figure 1 The figure depicts the Maslow's pyramid in the context of myositis to assert the unmet need for the development of self-management recommendations in IIM. IIM, idiopathic inflammatory myopathies.

Psychosocial interventions

A diagnosis of IIM often entails significant disability early in the disease course. A team-based effort with the kin, caregiver, physician and counsellors may go a long way in providing patients with the required emotional support and motivation for implementation, especially, for patients with poor health-related or functional literacy.

Sociocultural health beliefs and health literacy may play an instrumental role in engagement with self-care and other important aspects of disease management such as treatment adherence. Addressing these concerns would enhance, to our opinion, patient care. The figure depicts the Maslow's pyramid[6] (figure 1) in the context of myositis to assert the unmet need for the development of self-management recommendations in IIM.

CONCLUSION

In conclusion, we advocate the urgent need to investigate and develop self-management strategies in IIM in collaboration with healthcare professionals to promote patient empowerment with a vision to ensure patient care with non-pharmacological means complementary to medical treatment.

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