

# Patient journey pain points in spondyloarthritis and psoriasis: The case of Greece

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## ABSTRACT

For the diseases spondyloarthritis (SpA) and psoriasis, the patient's journey commences when the first symptoms present themselves. However, many patients ignore the initial symptoms, until the moment they become unbearable. Additionally, due to GPs/family physicians and primary healthcare providers' lack of knowledge, both SpA and psoriasis remain underdiagnosed, and patients need to undertake multiple visits and health examinations to get correctly diagnosed. With regard to appropriate treatment, a combination of pharmacotherapy, counselling and education

is useful to improve the patient's quality of life, with healthcare professionals ensuring the patient's adherence to the therapy. In Greece, the lack of health protocols and health technology assessment procedures create a burden in the screening, diagnosis and treatment of patients with SpA and psoriasis. Based on the aforementioned, the existence of a comprehensive, patient-centred and integrated healthcare system is of crucial importance so that patients with chronic conditions can have quality healthcare, better prognosis and reduced cost of care.

## COMMENTARY

Despite the fact that skin disorders lead to chronicity, usually, people consider them less important than other diseases, as they are not life-threatening. Evidence of the peculiarities of seronegative spondyloarthropathies (SpA) and psoriasis (including psoriatic arthritis) has increased worldwide, as indicated by the large number of recent publications on this topic<sup>1</sup>.

SpA is a heterogeneous group of chronic inflammatory rheumatic diseases present as inflammatory back pain, asymmetric peripheral arthritis, enthesitis, dactylitis, and tenosynovitis. SpA can even cause structural complications to spine and sacroiliac joints. Genetic issues, microbial triggers, inflammation of bone marrow and enthesial structures are critical determinants of the disease<sup>2,3</sup>. Prevalence of SpA varies among populations and geographical areas. Worldwide prevalence is estimated to be from 0.5% to 1.9%<sup>4</sup>. According to the ESORDIG study, Greece has a lower prevalence of SpA compared to other countries (0.49%)<sup>5</sup>. However, up-to-date data are lacking, yet needed in public policy planning.

Psoriasis is an autoimmune chronic inflammatory

disorder of the skin. Plaque psoriasis is the most common manifestation of the disease (85% frequency). Frequency of occurrence is from 2 to 4% worldwide, with around 125 million people living with psoriasis<sup>6</sup>. Psoriatic arthritis (also known as inflammatory arthritis) affects 4% to 30% of individuals with psoriasis<sup>7</sup>. Prevalence of non-mandatory registration ranges from 0.09% to 11.4%. The disease onset can be at any age but with two peaks in the age groups 16–22 and 57–60 years<sup>8</sup>. In general, new cases of psoriasis and psoriatic arthritis are higher in Europe and USA and lower in Latin America<sup>9</sup>. In Greece, epidemiological evidence of the parameters of this disease and its most frequent symptoms and target points have been examined<sup>10</sup>. In 2013, a retrospective study demonstrated that among 278 patients with psoriasis, 86% were diagnosed with plaque psoriasis, 5% guttate, 2% palms and soles, 2% inverse, 1% pustular and 4% with psoriasis of more than one type<sup>11</sup>.

Both SpA and psoriasis are severe health problems and are related to a lower quality of life. Additionally, they are closely connected with low physical and emotional status (stress, depression, anxiety, and sometimes even suicidal

ideation)<sup>8,12</sup>. Except for the aforementioned problems, the diseases are linked to impaired productivity<sup>8,13,14</sup>.

Based on all the above, the aim of this brief policy article is to depict SpA and psoriasis patients' journey within a healthcare system and the steps needed to improve this journey.

### Patient journey

For both diseases, the patient's journey commences when the first symptoms are presented. The first contact point for patients with SpA is the general practitioner while for the psoriasis patients a general practitioner or dermatologist (Contact Point 1). However, in both cases first contact with the healthcare system takes place when the signs and symptoms deteriorate, with discomfort and pain being unbearable leading to difficulties in performing daily tasks. This delay in the first contact is a result of many factors such as misconception of the seriousness of the disease and familial experience of the disease etc. All previously mentioned points could be defined as pre-contact pain points (Pain Point 1).

The core aim of health policy-makers and healthcare system must be the modification of these barriers with patient engagement and population awareness being at the centre of this reform. Within this context the Greek public healthcare (PHC) system has been under reform in the last years<sup>15</sup>, by mainly shifting the role of the GPs/family physicians as the system gatekeeper. Despite the political will for this reform, GPs/family physicians may not have sufficient training and education as well as the appropriate tools for disease diagnosis<sup>5</sup>. Due to the lack of knowledge and competencies, GPs/family physicians may ignore the severity of the symptoms and misdiagnose the disease or refer the patient to the appropriate specialist.

Unfortunately, in Greece patients may directly visit a rheumatologist without initially visiting a GP or family doctor (or another primary health care practitioner). Most of the times, the specialist is the first contact point for these patients. A direct visit to a specialist leads to an important gap in the time frame in which SpA patients seek advice. Due to the visit delay, in most of the cases, the disease has already progressed. Psoriasis symptoms are usually ameliorated with some lifestyle changes such as less stress, healthy diet, smoking cessation, and reduced alcohol consumption<sup>16</sup>. Subsequently, all the delays mentioned above for both SpA and psoriasis are significant for a disease progress and could be characterized as Pain Point 2.

It is well-known that many patients do not pay attention to the numerous initial symptoms, until they become unbearable. In most cases, other healthcare specialists (in gastroenterology, dermatology, orthopaedics, and ophthalmology) are not familiar with screening modalities, and this can lead to perception inconsistencies and problematic diagnosis and management<sup>8</sup>. Lack of adequate training<sup>17</sup> for psoriasis leads to lack of awareness resulting

in under-diagnosis, inappropriate therapy and unfulfillment of patient needs (Pain Point 2a). Except for misdiagnosing the disease, delayed diagnosis (Pain Point 2b) is another important aspect. Results from the ESORDING study show that SpA patients who visit a rheumatologist have a 91.3% chance of correct diagnosis compared to only 11.6% for patients that visit other specialists ( $p < 0.005$ ). This demonstrates the importance of a correct diagnosis by the physician<sup>18</sup>.

When the disease is finally diagnosed well and appropriate treatment is provided by healthcare personnel, the patient's quality of life improves<sup>19,20</sup>. The combination of pharmacotherapy, counselling and education is an effective measure to improve a patient's quality of life. It is of paramount significance that PHC providers operating in primary healthcare be aware of psoriasis and SpA, their management and co-morbidities. After receiving the appropriate treatment and the disease starts to regress, patient satisfaction and physician-patient interaction are improved and the total outcome for both sides is positive (Pain Point a). At this point for both diseases, it is of high importance to provide the most efficient and appropriate treatment. Health protocols have a crucial role (and in Greece authorities are working in this direction) together with the implementation of health technology assessment procedures<sup>21-23</sup> (Pain Point 3).

Clinicians need to ensure that patient adherence to the proposed therapeutical scheme is followed accordingly (Pain Point 4). Moreover, there should be a transition of the course of treatment (Pain Point 4a), through either a change in the treatment setting or a change in the actual healthcare provider to ensure the continuity of care and the (re-) alignment with appropriate treatment to ensure adherence to pharmacotherapy (Pain Point 4b). In order to increase patient adherence, improved communication with patient and family, simplifying instructions, imparting knowledge, modifying patient beliefs, tailoring education according patient sociodemographic status, are essential<sup>24</sup>. In general, treatment regimens should be offered based on the patient's health status, co-morbidities, impact on quality of life, and response to previous therapies etc.

### CONCLUSION

In order to facilitate the patient's journey, collaboration and synergies between different actors (government, healthcare personnel, patient organizations) are necessary. They should work to provide comprehensive, patient-centred and integrated healthcare services for patients with chronic conditions. This will improve quality of care and access to care, as well as patient outcomes and patient experiences with healthcare systems, while at the same time, the cost of care will be reduced. It is essential that health policymakers in collaboration with healthcare personnel develop guidelines and protocols for disease diagnosis and management. Additionally, healthcare providers' training

would increase efficiency and improve patient experiences and health status. Finally, patient organizations should continue advocating their rights and provide support to people suffering from psoriasis and SpA.

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