

# Patient Education in Spondyloarthritis Should be Guiding, Reliable and Available – A Qualitative Study

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## Conclusion:

This study highlights the importance of obtaining a guiding, reliable and available patient education for management of patients with SpA. Health care professionals need to consider the importance of presenting varied formats of education based on patients' experiences, expectations and evidence.



## Background:

The treatment cornerstones for patients with axial spondyloarthritis (SpA) are a combination of pharmacological and non-pharmacological treatment including patient education focusing on disease management. Health professionals are familiar with providing patient education but the knowledge is scarce concerning how patients perceive this education.

## Objective:

The aim of this study was to describe patients' experiences of education in SpA management.

## Method:

This study has a descriptive design. The qualitative content analysis was based on 11 interviews in patients with SpA. Strategic sampling was conducted with regard to sex (7 men, 4 women), age (38-66 years), subdiagnoses (5 patients with AS, 6 with USpA), quality of life (EQ5D 0.29-1.0), disease activity (BASDAI 1-6), physical function (BASFI 0-5), and global health (BASG 0-7).

The data was collected through an open interview guide (Table) and custom follow-up queries. The analysis was performed in seven steps and was aimed to describe and preserve contextual meanings. After coding and subgrouping, meaningful parts of the text were merged into categories.

**Table.** Open interview guide.

### Phrases

Describe your experiences of the received disease related education

What is of importances to better manage consequences of the disease on your everyday life?

How do you prefer to receive education?

## Results:

Three categories representing patients' experiences of education in disease management emerged; guiding education, reliable education and available education.

### Guiding education

**Guiding education (GE)** concerned SpA management including disease knowledge or lack of it. For example knowledge concerning symptoms, prognosis, treatment, self-management, climate impact, heredity, assisting devices and through self-perceived experience. The patients also describe GE to change over time.

*"It is something one also have learned over the years such as this with shoes. You have to make sure that you have proper shoes. It's just stupid to think otherwise. Soft shoes, that do not pinch, then you can handle it".*

### Reliable education

**Reliable education (RE)** How and by whom the education was communicated. Education was considered reliable if it was based on science and communicated by specialists. They experienced difficulties in assessing the large amount of educational knowledge. Reliability was increased if the education was individually tailored.

*"Advice and information should come from people who work with it. People who know what they're talking about. I have confidence in them and assume that they know what they're talking about and give me as good advice as possible."*

### Available education

**Available education (AE)** Education should be presented in varied formats, both orally and written. AE should be personally tailored and individual contacts with healthcare professionals when needed were of importance. Newer media like Skype, video and chat forums were requested.

*"I like to search and find the information myself. I often find it well thought out and useful with nice pictures and helpful written information. Then I think it's good to be able to take in the education when you need it, and have time for it. At that time you are more receptive to the information given"*

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