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Published in:
Rheumatology and Therapy

DOI:
[10.1007/s40744-023-00585-7](https://doi.org/10.1007/s40744-023-00585-7)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2023

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

van der Kraan, Y. M., Paap, D., Lennips, N., Veenstra, E. C. A., Wink, F. R., Kieskamp, S. C., & Spoorenberg, A. (2023). Patients' Needs Concerning Patient Education in Axial Spondyloarthritis: A Qualitative Study. *Rheumatology and Therapy*, 10(5), 1349-1368. <https://doi.org/10.1007/s40744-023-00585-7>

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Patients' Needs Concerning Patient Education in Axial Spondyloarthritis: A Qualitative Study

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Received: May 15, 2023 / Accepted: July 12, 2023 / Published online: July 31, 2023
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ABSTRACT

Introduction: Within the EULAR recommendations, patient education (PE) is stated as the basis of the management of axial spondyloarthritis (axSpA). However, educational needs are scarcely qualitatively studied in axSpA.

This study was presented at the NVR najaarsdagen 2021 in Amersfoort, The Netherlands, online SpA conference 2021, FSV Fysiek conference 2022 in Groningen, the Netherlands, SPARTAN Annual Meeting 2023 in Cleveland, United States of America and has been published in the online Abstract Book of the European Congress of Rheumatology EULAR 2021 (AB0481) [46].

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s40744-023-00585-7>.

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Therefore, we aimed to explore experiences and needs of PE in patients with axSpA.

Methods: A phenomenological approach was used, with semi-structured in-depth interviews with patients with axSpA including broad variation in characteristics. Thematic analysis was applied. To enhance credibility, data saturation, research triangulation, peer debriefing, member checking, theoretical notes, and bracketing were performed.

Results: Three interrelated themes regarding PE were identified from 20 interviews: illness perception, content, and 'availability'. Illness perception affects how patients experience and process PE, which consequently influences coping strategies. Prognosis, treatment, and coaching to self-management were identified as the most important content of PE. Regarding 'availability', face-to-face PE is preferred for exploring needs, supplemented by self-education, which can be freely applied. Additionally, sufficient time and a comprehensible amount of information were important and participants emphasized the need for axSpA-tailored information for relatives and friends. Participants reported a trusting patient–healthcare provider (HCP) relationship, and multidisciplinary and interdisciplinary attunement between HCPs as prerequisites for effective PE.

Conclusions: This first qualitative study exploring patients' experiences and needs of PE in axSpA revealed that prognosis, treatment, and coaching to self-management are

important regarding content, and the combination of face-to-face contact and self-education the preferred modalities. It seems essential that patients' illness perceptions are taken into account for effective PE. These results add relevant insights for future PE guidelines in axSpA.

Keywords: Axial spondyloarthritis; Interviews; Illness perception; Patient education; Qualitative research

Key Summary Points

Educational needs were qualitatively studied in a bottom-up approach in patients with axial spondyloarthritis (axSpA).

For effective patient education (PE) it is essential that patients' illness perceptions are taken into account.

Patients with axSpA address prognosis, treatment, and coaching to self-management as the most important PE topics.

In patients with axSpA, a trusting patient–healthcare provider (HCP) relationship and multidisciplinary and interdisciplinary attunement between HCPs are prerequisites for effective PE.

INTRODUCTION

Axial spondyloarthritis (axSpA) is an immune-mediated chronic inflammatory rheumatic disease with heterogeneous manifestations generally developing before the age of 40. Primarily, the sacroiliac joint and spine are affected, but also peripheral manifestations such as arthritis, enthesitis, and dactylitis may occur. Additionally, patients may suffer from extra skeletal manifestations such as uveitis, psoriasis, and IBD. Pain, stiffness, and fatigue have a large impact on daily activities and health-related quality of life (QoL) [1]. These symptoms are the

most common motivational factors for seeking medical care and are therefore important drivers of healthcare costs [2, 3]. Patient education (PE) is an important aspect in the guidance of patients with axSpA aiming to maintain QoL. PE not only transfers knowledge but also provides patients with the means to make beneficial decisions, which enables them to play an active role in the management of their disease and improve coping strategies, which may reduce the demand for healthcare resources [4–7].

PE encompasses all educational activities meliorating patients' health status and self-management including aspects of therapeutic education, health education, and health promotion [6–8]. PE is defined as “the process by which healthcare providers (HCPs) and others impart information to patients that will alter their health behaviors or improve their health status” [9]. There are different modalities of PE available, including verbal communication, written brochures, videos, podcasts, lectures, discussions, digital applications, or a combination thereof [10]. Despite the availability of these modalities, there are barriers on both the HCP's and the patient's side that make it hard to deliver PE effectively. The HCP's attitude and competences, such as knowledge, communication skills, and the ability to assess the educational needs of patients, may influence the quality of PE [11, 12]. Also, the patient's social and cultural background and physiological factors may influence how PE is received [13]. In addition, the level of health literacy, which helps patients in accessing, understanding, appraising, and applying information about healthcare is of great importance [13, 14].

Within the EULAR recommendations PE is stated as the basis of axSpA management because it contributes to reaching treatment goals [6, 7]. However, educational needs are still scarcely studied in axSpA [6, 7]. A recent questionnaire-based study in patients with axSpA showed that there are individual needs regarding PE depending on gender and age [15]. Another mixed-method study revealed that there is a need for PE in the areas of self-management, feelings and disease process [16]. Nevertheless, patients with axSpA included in

these studies had long disease duration and were of older age. Therefore, the transferability of the current evidence and recommendations is limited.

To our knowledge, the experiences and needs of PE in patients with axSpA have not been explored bottom-up using a qualitative research design. Moreover, the World Health Organization advocates incorporation of qualitative research into the development of guidelines and recommendations [17] because it generates rich and detailed data providing explanations and understanding of the complexity of human behavior and decision-making [18, 19].

METHODS

We aimed to explore experiences and needs of PE in patients with axSpA using a qualitative research design. An interpretive phenomenological approach was applied to develop a deeper understanding of the perspectives of patients with axSpA regarding PE [20]. The study was conducted in accordance with the Declaration of Helsinki. Approval for this study was obtained from the local ethics committees of the University Medical Center Groningen (UMCG) and the Medical Center Leeuwarden (MCL), TPO365,604. All participants provided written informed consent. For reporting, the COREQ checklist was used [Supplementary Material].

Researcher Characteristics

At the time of this study, the interviewers (EV, NL and YK) were senior medical students trained by one of the senior researchers (DP), with expertise in performing qualitative studies and research on PE which was useful for the in-depth quality of the interviews and methods of the study. This senior researcher and the interviewers of the research team (DP, EV, NL and YK) were not involved in the hospital care of the participants and were not acquainted with the participants prior to the study. The other senior researcher of our research team (AS) is a rheumatologist with clinical and research

expertise in axSpA; which was useful for the interpretation of the interviews.

Participants

Between March 2020 and November 2022, participants from the Groningen Leeuwarden Axial Spondyloarthritis (GLAS) cohort were recruited from a secondary and tertiary referral center. The GLAS cohort is an ongoing prospective long-term cohort study in patients with axSpA [21, 22]. The purposeful recruitment of patients with a broad variation in characteristics receiving usual care was conducted by screening medical files, and consultation of the GLAS nurse practitioners aiming to include 5 to 25 patients, based on a recommendation for phenomenological studies [20] (Table 1). Selected patients received written and verbal information. Participation was requested and written informed consent was obtained.

Patient and public involvement: Patients or members of the public were not directly involved in the design or conduct of this study.

Data Collection

Data were collected by semi-structured in-depth interviews. Based on the theory of health literacy [14], a theoretical framework was created by the interviewers (EV, NL and YK). This theoretical framework was discussed and adapted within the research team (AS, DP, EV, NL and YK), and subsequently used to develop the interview guide [Supplementary Material]. The interview guide was tested in a pilot interview with the first participant. During the interviews, the conversation followed a narrative structure of the chronology of the participant's disease experiences. Open-ended questions concerning PE were used and probes were formulated to acquire more in-depth information. Each interview was conducted by one of the interviewers and planned for 60 min. Additionally, peer-debriefing was applied from the start of the interviews; the interviewers discussed their experiences, impressions, and findings between interviews with a clinically experienced researcher (DP), until saturation of information

Table 1 Characteristics of the patients with axial spondyloarthritis in this study

Interviewee	Gender	Age	Symptom years	Diagnosis years	ASDAS ^a	PASS ^b	Level of education ^c	Marital status
Interviewee 1	Male	39	18	15	0.5	Yes	ISCED 7	Single
Interviewee 2	Male	56	30	30	2.9	No	ISCED 3	Divorced
Interviewee 3	Male	24	10	9	0.9	Yes	ISCED 6	In a relationship
Interviewee 4	Male	32	20	13	1.0	Yes	ISCED 6	In a relationship
Interviewee 5	Male	66	24	23	1.3	Yes	ISCED 3	Married
Interviewee 6	Male	33	7	5	1.2	Yes	ISCED 7	Married
Interviewee 7	Male	56	9	6	2.7	–	ISCED 2	Married
Interviewee 8	Female	30	15	9	2.1	No	ISCED 3	Single
Interviewee 9	Female	36	14	12	1.2	Yes	ISCED 7	Married
Interviewee 10	Female	56	18	17	3.2	–	ISCED 2	Married
Interviewee 11	Female	33	10	5	1.7	Yes	ISCED 3	Divorced
Interviewee 12	Female	27	3	2	1.9	No	ISCED 7	In a relationship
Interviewee 13	Female	31	2	2	1.7	Yes	ISCED 6	Single
Interviewee 14	Male	23	7	7	0.6	Yes	ISCED 3	Single
Interviewee 15	Female	38	10	7	3.0	Yes	ISCED 7	Married
Interviewee 16	Female	20	3	2	3.2	No	ISCED 6	Single
Interviewee 17	Female	66	6	6	3.1	Yes	ISCED 6	Married
Interviewee 18	Female	46	25	5	1.8	–	ISCED 7	Divorced
Interviewee 19	Male	33	2	1	2.5	Yes	ISCED 3	Single
Interviewee 20	Female	62	2	2	2.6	No	ISCED 2	Married

The age, ASDAS, PASS, symptom and disease duration data are taken from the Groningen Leeuwarden Axial Spondyloarthritis (GLAS) cohort documentation (PASS was not completed by interviewee 7, 10, and 18)

^aASDAS ankylosing spondylitis disease activity score [23]

^bPASS patient acceptable symptom-state questionnaire

^cISCED 2011 International Standard Classification of Education 2011 [24]

was agreed to be reached [25]. Data saturation was defined as the point at which no additional themes and subthemes emerged from the data [26].

Data Analysis

The data collection and analysis were conducted in an iterative manner. All interviews were audio recorded and transcribed verbatim. Subsequently, the transcripts were analyzed in Atlas-ti 7.5.7 [27], applying a thematic analysis to translate statements into themes [28]. All interviewers independently coded each transcript. The transcripts were coded in an inductive (data-driven) and deductive (theory-driven) manner [29]. Preliminary analyses and consensus meetings took place after three, eight, 12, 15, and 20 interviews in order to review the codes created so far. Codes were rephrased, merged, and deleted until consensus about the codebook was reached. Corresponding codes with a similar implication were categorized into themes and subthemes to provide an overview of participants' perspectives on PE. The quotes of the participants have been translated from Dutch to English by the researchers for this manuscript.

Trustworthiness

Multiple strategies were used to enhance credibility [30, 31]. First, the interviewers familiarized themselves with the data and documented the theoretical and reflective thoughts on the subject by designing a theoretical framework. The interviewers discussed their own views on PE regarding axSpA to enhance awareness of feelings and prejudices. Data of the pilot interview were included and used for bracketing and reflexivity. After each interview, the interview guide was discussed with the intention of improving it by including important findings that were further explored in subsequent interviews. Each research team meeting and peer debriefing was documented. Researcher triangulation was conducted. To verify the results and interpretations, member checking was conducted in which the interview transcript

and a summary of the results were discussed with the participants. Throughout the study, theoretical notes were kept to ensure continuous reflexivity on the theoretical framework, interview guide, and data analysis.

RESULTS

All 20 approached patients participated in the study (Table 1). Five participants were interviewed at the UMCG, three participants at the MCL, eight participants at home, one participant at work, and the three interviews took place by videocall due to COVID-19-related restrictions. No non-participants were present at the interview. After 15 interviews, data saturation was reached and five more interviews were conducted to verify that no new information emerged.

Theme 1: Illness Perception

Participants emphasized the importance of understanding the origins of their symptoms (*illness perception*) (Table 2; theme 1). For example, before diagnosis, a participant experienced symptoms of leg and back pain (*illness stimuli*), which she thought was fibromyalgia. This illustrates a *cognitive illness representation*. Participants indicated that discussing and seeking confirmation of their illness perceptions or experiences which they believe are related to their disease during PE provides them comfort and knowledge. They also mentioned that it helps them to readjust their illness perceptions and put it into perspective. However, participants also mentioned feeling restraint in addressing the need to discuss their illness perceptions, experiencing the clinical setting as uninviting. They felt that the HCPs are often under time pressure, are preoccupied with administration tasks, and do not pay sufficient attention to illness perception.

Furthermore, participants mentioned various *emotional illness representations*. For example, a participant reported experiencing overwhelming emotions after a significant life event (*illness stimulus*). This emotional state influenced the participant's perception of his illness

Table 2 Table of themes, subthemes, and supporting quotes

Themes	Description theme	Subthemes	Supporting quotes
Theme 1 Illness perception	The personal understanding and beliefs of the participant about a medical condition or disease. Illness perception follows the processing of illness stimuli. The illness perception is guiding the development of a coping strategy. This process is dynamic and constantly evaluated	Illness stimuli Cognitive illness representation	[The participant talks about the period before diagnosis] [Interviewee 16]: “It was a difficult time, because I knew something was wrong with my body. At home they did not believe me, even the general practitioner did not believe me. At that moment, I even began to doubt myself. Even though I know my body the best.” [The participant talks about the period before diagnosis] [Interviewee 12]: “During that time I also went to a party. I comb my hair, I put on make-up and then you see people who have not seen you for a while. They said: ‘oh, you look good!’, but in the meantime I tried my best not to cry.” [Interviewee 3]: “Last year I was able to run 10 km. Now that is no longer possible because of the pain in my groin. I did not think the pain was due to the disease, so I kept running with the pain.” [Interviewee 8]: “Scary thoughts crossed my mind. I thought that after five years, I would end up in a wheelchair... fully stiffened.”

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
		Emotional illness representation	<p>[The participant describes his emotional state after being declared incapacitated for his job]</p> <p>[Interviewee 5]: “It was very difficult for me because I liked my job. I was suddenly no longer allowed to do my job. I have done that all my life and I could not do that anymore, it was very hard for me.”</p> <p>[Interviewee 7]: “I was in a rut. I felt like I was nothing anymore. Let me put it this way: I did not feel like doing anything anymore. [...] At one moment I got everything at once. I did not want to tell you... I have had two TIAs (transient ischemic attacks) around the same time when I was told I had axial spondyloarthritis (axSpA). I was rejected from work. That all came within a time frame of two years.”</p> <p>[...] “I thought, leave me here, it is fine... I am not doing anything anymore.”</p>
		Coping strategy	<p>[Interviewee 2]: “I have made adjustments to my house. I built this house so it is suitable for me to move through when I am in a wheelchair. Because the expectations were, you could end up in a wheelchair. [...] That is what I was told back then.”</p> <p>[Interviewee 17]: “My father identified himself as his disease, ‘I am so sick!’. However, my youngest uncle kept on living, he kept being active. In my opinion, he [uncle] was better off. So, I do what I can. Maybe it takes a little bit more time, but I will keep trying and will not give up</p>

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
Theme 2. Participants’ needs regarding content	The most important topics of patient education (PE) in patients with axSpA according to the participants	Topics of PE Prognosis of the disease	<p>[Interviewee 18]: “ I think the problem with PE topics is that it is always general information. I think every situation is very specific. You can have a 100 people with the same diagnosis who have very different symptoms and on who the disease has a very different impact on their lives. It just depends on how you want to shape your life and the extent the disease affects you.”</p> <p>[Interviewee 8]: “I have had very scary scenarios in my head that in five years I would be numb [...]. It would be nice to have a conversation about this with someone who knows a little more about it. That it can be nuanced a little.”</p> <p>[Interviewee 10]: “[...] of course you can never say as a doctor: ‘you will look like this in twenty years.’ You cannot know what the future looks like, but they have to give you some examples about how it could be. There are a lot of people who do very well with medication, but there are also people who may end up in a wheelchair.”</p>

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
		Treatment of the disease	<p>[Interviewee 5]: “[...] I did not get Enbrel (type of biological) right away. I have been using that for a long time now, for 15 years. It has not been on the market for very long, so I wonder: what is the long-term effect on your body? That is still a bit of a gray area.”</p> <p>[The participant is talking about shared decision-making concerning medication options]</p> <p>[Interviewee 12]: “The healthcare provider (HCP) left the decision about medication largely to me and I thought: How should I know?! If you are 90 years old and you have to choose to be admitted to the hospital or not, then you really make a decision between two clear options. In this case I found it very difficult. I did not really feel the need for influence in the decision at that moment. Based on what should I make a decision? [...] I do not understand it anyway, I do not have the knowledge and I don’t feel like studying it.”</p>

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
		Coaching to self-management	<p>[Interviewee 17]: “I miss some guidance in things you can do yourself regarding the disease. I made an appointment at the dietitian myself. Little is said about what all your options are outside of the hospital.”</p> <p>[Interviewee 14]: “I would find it very interesting if a HCP would give me more information about the influence of nutrition on the disease.”</p> <p>[The interviewer asks the participant about the experience of the rehabilitation trajectory and the associated difficulties.]</p> <p>[Interviewee 1]: “That was quite an intensive process, but I was still studying at the time. So it was not so difficult then to find free time. I think you had to be there half a day per week. I thought that was quite a lot. [...] It was not that it was bad there and luckily I had enough time. But if I had worked, I would have thought: what am I doing here.”</p> <p>[The participant talks about finding a rest-activity balance]</p> <p>[Interviewee 17]: “I find it very difficult to not do everything myself, so they [HCPs] recommended me to take it more slowly and to take more rests in between tasks. I find it very difficult to take it more slowly...”</p>

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
Theme 3 'Availability' of PE	The experiences and preferences of the participants regarding the different modalities and moments of the received PE, the amount of time that was given to process the PE and axSpA tailored information for relatives and friends	The different modalities of PE	<p>[Interviewee 9]: “[...] you pass on the message, you give flyers and then you say: ‘In two weeks we will have telephone contact and if you still have questions you can ask them.’ [...] Instead of having to wait another year before you can ask questions again, because then you keep thinking: how about this... and then this...”</p> <p>[Interviewee 20]: “I prefer receiving information from the HCP, but I also like to read everything again when I come home. Normally I search on the internet for information, but a flyer is also useful, in which all the important things are stated.”</p> <p>[The participant talks about the telephone call in which she received her diagnosis. She is still very emotional about what happened years ago]</p> <p>[Interviewee 12]: “I had a lecture when the rheumatologist called, so I did not answer the telephone. A little later she called back and well. That was the moment I was told my diagnosis, standing outside the lecture hall somewhere [emotions are heard in her voice]. It still came as a really big blow.”</p> <p>[Interviewee 13]: “I always received a flyer with only 1 situation, the old retired person who could finally work in his garden again. Alright, but what about young people such as myself?”</p>

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
		The different moments in which PE is important	<p>[Interviewee 2]: “Last year I had a lot of symptoms of the disease. If you are doing badly, you will also delve into the disease a little more. When you are doing well, you think, ‘oh, great!’. The degree of symptoms therefore determines to what extent you want to delve into the disease.”</p> <p>[Interviewee 3]: “When you are emotional, it is nice to go deeper into certain matters. Then it is also nice if you get more information about what concerns you.”</p>
		Sufficient amount of time to process the PE	<p>[The participant talks about how the diagnosis was communicated to her]</p> <p>[Interviewee 12]: “I believe it was a very short conversation; this is the diagnosis and good luck with it. [...] I think that is something that could be improved because you need time to process it.”</p> <p>[Interviewee 16]: “I felt like I was missing a lot of information. The last 3 years went by so quickly and so much has happened. At consultations we talk about medication and we discuss how to move forward. For other topics is no time. [...] I would like a conversation in which we discuss the information that I have gotten the past years. I have not had such a conversation in 3 years... that is quite a long time.”</p>

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
Patient-HCP relationship; a prerequisite for effective PE	Prerequisites mentioned by the participants that affect the quality of PE that they receive	AxSpA tailored information for relatives and friends A trusting participant-HCP relationship	<p>[Interviewee 15]: “In addition to the patient, there is often a family with a partner and children and I miss PE directed to them. The disease has not only impact on the patient himself, but also on the environment. So maybe you could create something for them in terms of information provision.”</p> <p>[Interviewee 12]: “I came back from Russia in January and had an appointment with my HCP. She asked very specifically, not only about my health in Russia, but also how the trip had been. That personal contact with your HCP is very pleasant.”</p> <p>[Interviewee 6]: “What I do notice, maybe that is another thing I want to pass on to you, is that the trust you have as a patient in your HCP is essential to everything else.” [...] “that does something to the image of how professional someone actually is and that also does something to the image of how knowledgeable someone is in their profession. That is why I sometimes think: I get the answer to my question but do I trust that the answer is correct, that it is complete... that I have the right person in front of me. Then you notice that the moment you do not have trust in your HCP, a lot of doubt is created. Do we get complete information?”</p>

Table 2 continued

Themes	Description theme	Subthemes	Supporting quotes
		Multidisciplinary and interdisciplinary attunement between HCPs	<p>[Interviewee 1]: “A sport doctor only pays attention to his specialities, as does an orthopaedist. I find it strange that an orthopaedist does not think: ‘oh, maybe this could be something rheumatic!’. It is frustrating...”</p> <p>[Interviewee 5]: “What I noticed is that during my diagnostic process, nobody actually looks at the bigger picture. Physical therapist always see an explanation for your symptoms in the muscles. The orthopaedist said the position of my back was not good. [...] In the end they all separately found something to explain my symptoms, but no one saw the interrelated aspects.”</p>

HCPs healthcare providers, *AxSpA* axial spondyloarthritis

(axSpA), with the *emotional illness representation* (feeling sick, defeated, and down) taking precedence. The participant emphasized that he was not yet ready to receive PE, due to feeling overwhelmed with emotions. Another participant mentioned receiving information from a HCP suggesting the possibility of eventually ending up in a wheelchair. It seems that the information given by the HCP (*illness stimulus*) shaped the illness perception of the participant for the future. This was followed by preparing adjustments to his house (*coping strategy*) for potential wheelchair use (*cognitive illness representation*), showing that coping, as a result of an illness perception, may have a major impact on patients' lives. The illness perception process is constantly influenced by new illness stimuli, and is therefore dynamic and changes over time.

Theme 2: Participants' Needs Regarding Content

Many participants emphasized different needs regarding relevant topics for PE. The topics, *prognosis*, *treatment*, and *coaching to self-management* were mentioned as important in PE for patients with axSpA (Table 2; theme 2).

After a generally long, uncertain period preceding the diagnosis of axSpA, most of the participants underlined that they are in need of a clearer vision of what to expect in the short and long term. Participants reported that the *prognosis* of the disease can be very diverse and they balance between hope for improvement and fear of deterioration. Most participants related that by creating more clarity about their personal prognosis, they are better able to reduce uncertainty and anxiety.

Participants highly valued information on *treatment*. In their experience, treatment is

focused on pharmacological therapy. Some participants reported that they would like to participate more in making decisions about medication. On the other hand, other participants explained not feeling empowered enough to make an informed decision or to engage in discussion. For example, they reported that the information given is too much to process all at once to be effectively involved in the decision-making process.

Participants emphasized the need for *coaching to self-management*. They reported that not much information was given by the HCPs about lifestyle aspects other than physical activity. Participants are particularly interested in PE about possible disease-modifying nutrition, influence of bodyweight, and how to cope with fatigue. In respect of physical activity, participants mentioned that through PE they are made aware of its importance. Nonetheless, they are still in need of more practical guidance, such as how to incorporate physical activity into their daily lives and examples of exercises and/or recommendations on where to go for exercise support. However, simply providing more information about lifestyle seems not enough to integrate this into their lives since participants also reported beliefs and barriers concerning physical activity that prevents them from exercising, which could be addressed in PE to assist in their behavioral change. For instance, some participants believed that they need more motivation and support to expand the amount of physical activity. Three participants who received physical therapy in an axSpA exercise group emphasize that contact with other patients provides extra motivation to increase physical exercise and emotional support in sharing experiences. However, there were also some participants who reported not preferring group therapy/education because they do not want to socialize with other patients with axSpA. Participants also experienced barriers which discourage or prevent them from physical exercise, such as the time-consuming nature and intensity of rehabilitation programs.

Furthermore, in respect to *coaching to self-management*, participants mentioned that they experience difficulties in maintaining a balance

between physical load, mental load, and taking rest. Moreover, they mention struggling to cope with fatigue. Participants had to find a new balance in their energy level and consequently had to prioritize daily activities.

Besides the three topics described above, participants also expressed the need for information on symptoms, axSpA-related diseases, disease influence on daily life, and developments in research.

Theme 3: 'Availability' of PE

Participants reported receiving PE through various *modalities* at different *moments* in time. They stressed the need for balance in the *amount of information* given in order to process and understand PE, and highlighted the need for axSpA tailored information for relatives and friends (Table 2; theme 3). They received PE according to the following *modalities*: face-to-face, telephone call, flyer, symposia, website, online patient portal, and video. Most participants emphasized preferring face-to-face PE, due to the interaction with the HCP in which the focus is on personal needs. Participants felt that time is needed to process and understand the given information, which may lead to new questions. They expressed the need for information on self-education to explore these arising new questions. Another advantage of self-education mentioned by participants is flexibility and easy accessibility.

Participants also mentioned the importance of the right information at the right *moment*. The way in which the diagnosis is communicated has great influence on the emotional state of the patient. For instance, two participants mentioned receiving the diagnosis during a brief telephone call without proper follow-up. The participants were left with many unanswered questions and lacked coaching to meet their needs. Participants also emphasized that their educational needs during PE depend on interpatient variation in disease severity and understanding (part of health literacy). When participants felt uncertain about experienced symptoms, they had a greater need for PE. Furthermore, they expressed the need for HCPs to

check whether the PE met their individual needs, and whether it was understood and sufficient.

Also, participants emphasized the importance of taking into account the *amount of information* delivered, which depends on health literacy and the emotional state of the patient. For instance, some participants expressed a feeling of relief after their diagnosis because their symptoms finally had a cause. Others expressed a feeling of shock, as suddenly they have a chronic disease of which they know nothing about, influencing their daily lives. The participants emphasized that providing PE in manageable pieces, for example first focusing on the participant's emotional processing and understanding of the diagnosis, improves the quality of PE.

Lastly, participants expressed the need for axSpA-tailored *information for their relatives (including children) and friends*. They mentioned finding it difficult to properly explain their disease situation to their relatives and friends, especially to children. Having axSpA not only influences the patient but also the people close to them.

Prerequisites for Effective PE

In addition to the three themes, participants stressed that a *trusting patient-HCP relationship* and *multidisciplinary and interdisciplinary attunement between HCPs* is essential to secure the effectivity of PE (Table 2; prerequisites PE).

Participants indicated that the *relationship* with their HCP plays a major role in PE. They stressed the need for trust in the competences of the HCP. Participants reported that the level of trust they experience determines the extent to which they are willing to open up and express their cognitive and emotional needs to the HCP. Participants emphasized that they find it essential that the HCP shows a personal interest, which benefits the patient-HCP relationship. For example, a participant mentioned a positive effect on this relationship after the HCP expressed a personal interest in a for the patient important trip abroad.

Furthermore, participants stressed the importance of *multidisciplinary and interdisciplinary attunement between HCPs* about diagnostics, treatment, and PE. Especially during the diagnostic process it was mentioned that they have experienced that different HCPs explained symptoms differently, often restricted to their own expertise, which was sometimes conflicting with other HCPs' explanations. Participants perceived this as confusing and sometimes even frustrating. Therefore, to allow proper multidisciplinary and interdisciplinary attunement, participants advocated for a more patient-tailored holistic approach.

DISCUSSION

In this qualitative study we explored experiences and needs of PE in patients with axSpA. To our knowledge, this is the first bottom-up qualitative study evaluating PE in axSpA. Three interrelated themes were identified as important from patients' perspectives: illness perception, needs regarding content, and 'availability'. Beside these themes, participants reported a trusting patient-HCP relationship and multidisciplinary and interdisciplinary attunement between HCPs as prerequisites for effective PE.

Our theme "Illness perception" fits Leventhal's Common Sense Model, including our subthemes: illness stimuli, illness representations, and coping strategies [31]. Illness perception is important because it influences how individual patients experience and process PE. Previous research in axSpA has already shown that negative illness perceptions and evasive coping strategies are associated with worse QoL [32]. Overall, evasive and reappraisal coping strategies are predominant in patients with axSpA [33]. Interestingly, it has also been shown that without specific intervention, illness perceptions and coping strategies remain stable during the first years after axSpA diagnosis [34]. From our findings, it seems that illness stimuli from PE (including unintended stimuli) could influence coping strategies and therefore may have important consequences for the patient's wellbeing and QoL. This is in line with previous research that shows that coping

strategies are associated with patient-reported outcomes [32, 35]. Additionally, patients may have difficulties recording or processing information given (health literacy). Therefore, in clinical practice, the HCP's awareness of the patient's illness perception and health literacy is important, and helps to uncover the patient's individual needs in PE. If necessary, the illness perception can be readjusted into a more positive direction. Consequently, HCP's awareness of illness perception promotes more patient-tailored PE. Previous research showed that patient-tailored PE has positive effects on self-perceived health and global wellbeing [6, 7, 36, 37]. Also, the second overarching principle of the EULAR recommendations for the generic core competences of HCPs in rheumatology states that patient-tailored care and patient advocacy are fundamental in the care delivered by HCPs [12]. Previous studies in patients with axSpA showed no results on illness perception regarding PE [15, 16]. However, one study found the need for addressing feelings [16].

Regarding the content of PE, we found similar preferences in information about self-management, disease process, treatment, and prognosis [15, 16]. Compared to our study, mean disease duration and the age of participants were higher in these studies [15, 16]. Our qualitative study additionally showed that developments in research is an important aspect of PE.

Concerning the 'availability' of PE, participants prefer face-to-face PE, providing a situation in which HCP can offer information and coaching based on the participant's personal needs. A prerequisite for this modality is a trusting patient–HCP relationship to open up and express their needs [38, 39]. On the other hand, participants may benefit from more problem-based learning. In this active form of PE, patients are individually challenged to apply the information into their daily lives [40]. Our study shows that after face-to-face PE, there is a need for self-education. Literature shows that using a combination of learning strategies leads to more effective PE [10].

Interestingly, most participants perceived their current treatment predominantly as

pharmacological therapy, rather than treatment aiming on resilience and/or the ability to cope with chronic symptoms [41, 42]. Therefore, patients' attitudes towards ownership of their health seems important in how patients perceive PE and to what extent they are able to incorporate PE. Motivational interviewing may help the HCP to attain a more active attitude by the patient [43, 44]. If an active attitude could be established, it also may increase the effectiveness of PE [8, 43, 44].

The results from our study strengthen and provide new insights complementing the 2022 EULAR/ASAS recommendations on PE in axSpA [6]. A strength of our study was that patients were purposefully recruited. In contrast to earlier studies [15, 16], we had a larger number of patients and larger variation in patient age, resulting in a more representative heterogeneous axSpA study population. Furthermore, participants were recruited from a secondary and tertiary referral center, which contributes to the transferability of our study findings. Moreover, due to the methodology of this qualitative study trustworthiness of data was increased by addressing the thematic analysis methodological quality aspects from Nowell et al. [30], ensuring transparency. Data quality was strengthened through research triangulation.

There are a few limitations to consider in our study. Firstly, participants in our study did not receive group education apart from physical therapy in an axSpA-exercise group and none of the participants in our study were affiliated with the Dutch patient association. Therefore, we lack information on PE from these sources. Furthermore, the transferability of the study findings may partly depend on the socio-cultural background [45]. Therefore, patients with axSpA in countries with a different socio-cultural background than the Netherlands, may have different experiences and needs concerning PE.

CONCLUSIONS

Our bottom-up qualitative study in patients with axSpA shows that illness perception, specific content topics, and 'availability' are

important aspects of PE. PE should be patient-tailored and a trusting patient–HCP relationship, and multidisciplinary and interdisciplinary attunement between HCPs will support effective PE. However, our study shows that the implementation of effective patient-tailored education in axSpA patients is still challenging. Therefore, future research should focus on the evaluation of PE strategies incorporating the different aspects revealed from qualitative research with axSpA patients, preferably in collaboration with axSpA patient associations and HCP involved in the care of these patients.

ACKNOWLEDGEMENTS

The authors would like to thank all patients who participated in the GLAS cohort and acknowledge Mrs. S. Katerbarg, Mrs. B. Toonder, Mrs. A.A.H. van der Veen-Hebels, Mrs. M. Middelkoop-Boon, and Mrs. E. Markenstein for their help in recruiting participants for the study.

Funding. No funding or sponsorship was received for this study or publication of this article. The Rapid Service Fee was funded by the authors.

Author Contributions. Yvonne van der Kraan, Niels Lennips, Else Veenstra, Davy Paap and Anneke Spoorenberg designed the study. Yvonne van der Kraan, Niels Lennips and Else Veenstra conducted the interviews. Initial analysis was carried out by Yvonne van der Kraan, Niels Lennips and Else Veenstra. Yvonne van der Kraan and Davy Paap conducted the main analyses in consultation with Stan Kieskamp and Anneke Spoorenberg. Yvonne van der Kraan wrote the main manuscript text in consultation with Freke Wink, Davy Paap and Anneke Spoorenberg. All authors discussed the results and commented on the manuscript.

Disclosures. Yvonne van der Kraan, Davy Paap, Niels Lennips, Else Veenstra, Freke Wink, Stan Kieskamp and Anneke Spoorenberg have nothing to disclose.

Compliance with Ethics Guidelines. Approval for this study was obtained from the local ethics committees of the University Medical Center Groningen (UMCG) and the Medical Center Leeuwarden (MCL), TPO365,604. The study was conducted in accordance with the Declaration of Helsinki. All participants provided written informed consent. Consent for publication was obtained.

Data Availability. The interviews underlying this article cannot be shared publicly due to the privacy of individuals that participated in the study. The data will be shared on reasonable request to the corresponding author.

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