

BMJ Open Exploring disease-related and treatment-related issues and concerns experienced by adults with spondyloarthritis, inflammatory bowel disease and psoriasis to identify unmet needs: a qualitative clinical concept mapping study

Zara R Stisen ¹, Marie Skougaard,^{1,2} Katrine Risager Christensen,³ Mark Andrew Ainsworth,⁴ Rebekka Lund Hansen,¹ Simon Francis Thomsen,⁵ Mette Mogensen,⁵ Lene Dreyer,⁶ Lars Erik Kristensen,¹ Tanja Schjødt Jørgensen¹

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For numbered affiliations see end of article.

Correspondence to

Dr Zara R Stisen;
zara.rebecca.stisen.03@regionh.dk

ABSTRACT

Objectives Exploring patients' perspectives for significant factors of relevance in living with a chronic disease is important to discover unmet needs and challenges. The primary objective of this study was to explore disease-related and treatment-related issues and concerns experienced by adults with spondyloarthropathies (SpA) and associated diseases. As a secondary objective, we wanted to explore whether these factors were generic or disease dependent.

Design We used group concept mapping (GCM), a validated qualitative method, to identify disease-related and treatment-related issues and concerns. Participants generated statements in the GCM workshops and organised them into clusters to develop concepts. Furthermore, participants rated each statement for importance from 1: 'not important at all' to 5: 'of great importance'.

Setting Participants were recruited during routine care at the outpatient clinic at the hospitals in the period from May 2018 to July 2022.

Participants Eligible participants were adults ≥18 years and diagnosed with axial spondyloarthritis (AxSpA), psoriatic arthritis (PsA), psoriasis (PsO) or inflammatory bowel disease—split into Crohn's disease (CD) and ulcerative colitis (UC).

Results 52 patients participated in the 11 workshops divided into groups according to their diagnosis. They created a total of 1275 statements that generated 10 AxSpA concepts, 7 PsA concepts, 7 PsO concepts, 10 CD concepts and 11 UC concepts. The highest rated concepts within each disease group were: AxSpA, 'lack of understanding/to be heard and seen by healthcare professionals' (mean rating 4.0); PsA, 'medication (effects and side effects)' (mean rating 3.8); PsO, 'social and psychological problems, the shame' (mean rating 4.0); CD, 'positive attitudes' (mean rating 4.3) and UC, 'take responsibility and control over your life' (mean rating 4.0).

Conclusion People with SpA and associated diseases largely agree on which concepts describe their disease-related and treatment-related issues and concerns with a few of them being more disease-specific.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The identification of disease-related and treatment-related issues and concerns in this study, resembles the phenomenological approach where open questions, following the natural flow in the interview, allow the participants to be the experts without the limitations of predefined questions.
- ⇒ The study follows the group concept mapping method, which is a well-known and validated method to create a participant-authored visual map of ideas.
- ⇒ A large qualitative study across disciplines has, to our knowledge, never been done before limitations of the current study may have included selection bias, that is, because the workshops lasted approximately 4.5 hours; this could have led to the exclusion of people with full-time jobs or people with high disease activity might have opted out due to a lack of energy.
- ⇒ Other limitations are the relatively small group sizes and the fact that other comorbidities could also affect the patient's perception of disease.

INTRODUCTION

Each patient's way of living with and relating to their chronic disease is unique. However, patients with chronic diseases may have some mutual concerns and challenges. They must not only handle the disease itself, but also the consequences of the disease on their everyday and emotional lives. Most patients affected by chronic diseases depend on medical

treatment for suppressing or controlling the disease. Low disease activity is often used as a primary target in the treatment plan. But what if other targets are more urgent to the patient? Living with a chronic disease can have a profound impact on a person's quality of life and well-being due to pain, physical limitations, management of the condition and mental health issues. This can result in withdrawal from social, community and occupational activities. Healthcare professionals might underestimate the disease burden patients with chronic diseases experience, which could lead to a communication gap—a gap that challenges the process of defining individual treatment targets, in which it is necessary to consider the patient's values and preferences to identify and understand this patient's priorities.^{1–3} Spondyloarthropathies (SpA) refers to a family of seronegative inflammatory rheumatic diseases, such as axial spondyloarthritis (AxSpA) and psoriatic arthritis (PsA), which share certain clinical characteristics. The most prominent features of SpA are inflammation of the axial joints, asymmetric oligoarthritis, enthesitis and dactylitis—causing pain, stiffness and fatigue. The SpAs are further associated with psoriasis (PsO) and inflammatory bowel disease (IBD).^{4,5}

One way to explore patients' perspectives on life with a chronic disease is by using the validated group concept mapping (GCM) method.⁶ GCM has a mixed-methods approach: qualitative input and quantitative analyses. The method allows for multiple voices and perspectives to be perceived. It seeks insight and activates the engagement of individuals, organises variation in stakeholder knowledge and opinion, and produces a visual result of the sum of individuals' ideas and thoughts on the topic. The participants are involved in several steps of the research process, including generating ideas, structuring statements, interpreting the concept map and rating the importance of each statement.⁷

The vision of this current study is closely aligned with the healthcare sector's commitment to help patients live healthier and to ensure high-quality lives. We want to increase knowledge about which factors are essential when living with a chronic disease, seen from a patient perspective and increase awareness about the discrepancy there might be between doctor and patient experienced quality in care. We need to speak the same language in order to make shared decisions when it comes to treatment strategies. The aim of this study was to explore disease-related and treatment-related issues and concerns experienced by adult patients with AxSpA, PsA, PsO and IBD. As a secondary objective, we wanted to explore whether these factors were generic or disease dependent.

METHODS

Group concept mapping

In short, GCM is a formal group process using a structured approach to identify ideas on a topic of interest and organise them into domains based on a mixed-method participatory design that incorporates group processes and multivariate statistical analyses (multidimensional scaling and hierarchical cluster analysis).^{7,8} GCM is considered highly effective for developing outcome measures, for example, patient perceptions when investigating healthcare.^{6,9,10} Within GCM, participants are involved in several steps of the conceptual process and the final results are illustrated in maps where ideas developed during the process are organised thematically.¹¹ The GCM process includes the following phases: (1) preparation and generation of seeding question by the researchers, (2) generation of statements (individual brainstorming done by the participants), (3) structuring statements (sorting and rating of importance of statements done by the participants), (4) computational program performing GCM analysis (sorting results from step 3 serves as an input to the multidimensional scaling and to the creation of maps,¹⁰ (5) interpreting the result (validation done by the participants facilitated by the researchers) and (6) utilisation of the result.

Participants

The study was conducted at the outpatient clinics at the Department of Rheumatology and the Department of Dermatology at Bispebjerg and Frederiksberg Hospital, and the Department of Gastroenterology at Herlev and Gentofte Hospital, all in the Copenhagen area of Denmark. For AxSpA patients, we further recruited through the patient association. Eligible participants were identified in the period from May 2018 to July 2022. Patients diagnosed by their treating physician with either AxSpA, PsA, PsO or IBD—split into Crohn's disease (CD) and ulcerative colitis (UC), were invited to participate in the study. Inclusion criteria were age ≥18 years and signed informed consent. Exclusion criteria were patients who were unable to speak, write or understand Danish. Participants with all disease activity severities, from generally stable to high, were included.

The participants with IBD and their GCM workshops are also described by Christensen *et al.*¹²

GCM workshops

Eligible patients were invited to participate in a GCM workshop using the Concept System Groupwisdom software, designed to support each step in the GCM process, at the Parker Institute or the department of Gastroenterology at Herlev and Gentofte Hospital. Each workshop lasted 4.5 hours and was facilitated, from beginning to end, by TSJ and at least one experienced investigator. All patients were asked the same initial question: 'Thinking as broadly as you can—please list all your thoughts (experiences, issues, beliefs and concerns) that impacts your life with your disease'. Clustering analysis was performed based on

the participant statements based on the initial question using MDS (CS Global MAX; Concept Systems¹³). Any duplicate statements were removed.^{6 10 11 14}

To identify which statements were of most importance for the patients, they were asked to rate the importance of each statement on a 5-point scale, from 1 'not important at all', 2: 'a little important', 3: 'somewhat important', 4: 'very important' and 5: 'of great importance'. Mean and median ratings of importance assigned by the patients for each statement were calculated. How many workshops were held depended on when qualitative data saturation (defined as the presence of redundancy in emerging concepts) was achieved.

In addition, information regarding participants' demographic characteristics, such as age, disease duration, current medication, working status and the intensity of pain and fatigue using the VAS (Visual Analogue Scale 0–10 cm), was obtained at each workshop.

Statistics and analysis

Categorical variables are presented as numbers (n) and percentages (%) and continuous variables as mean and SD. If data are not following a normal distribution, they are presented as median and IQR.

Data were analysed by using the GS Groupwisdom software. After the GCM workshops, the individual disease groups' concept maps were consolidated by removing identical statements using standardised content analysis.¹⁴ The reduced statement pool was independently thematically analysed, preserving fine distinctions in the wording across statements. The exact wording of the statements and cluster labels from the participants was kept, and subclusters were given labels derived from specific statements. The mean and median rating of statement importance within each subcluster was calculated using Wilcoxon two-sample test.

Based on the sorting and rating, multidimensional scaling and cluster analyses were performed, in which

related statements were grouped into concepts.⁷ When all workshops were done the results from each disease type were merged. This was done by the researchers facilitating the workshops using thematic analyses, forming concepts from the clusters organised by themes by the patients in the workshop.

Patient and public involvement

To enable understanding of the patient perspective, the study included a patient representative as part of the research team. The patient was particularly involved in input to the study design and conception. The patient representative was recruited from the outpatient clinic at The Parker Institute, Frederiksberg Hospital.

RESULTS

Participants and GCM workshops

A total of 52 patients participated in 11 GCM workshops, stratified according to their disease: 9 AxSpA patients, 8 PsA patients, 9 PsO patients, 13 patients with CD and 13 patients with UC. Participant characteristics are shown in [table 1](#).

From the 11 GCM workshops, a total of 1275 statements emerged from the workshops. In AxSpA, 118 statements were generated resulting in 10 concepts, in PsA 160 statements were generated resulting in 7 concepts, in PsO 187 statements were generated resulting in 7 concepts, in CD 335 statements were generated resulting in 10 concepts and in UC 408 statements were generated resulting in 11 concepts.

Axial spondyloarthritis

The two highest rated AxSpA concepts were (1) 'lack of understanding/to be heard and seen by health professionals' (mean rating 4.0) and 2) 'consequences/Limitations in work-life' (mean rating 3.7). Examples of the

Table 1 Participant characteristics

	AxSpA	PsA	PsO	CD	UC
Participants, n (%)	9 (17)	8 (16)	9 (17)	13 (25)	13 (25)
Female, n (%)	2 (22)	6 (75)	3 (33)	8 (62)	9 (69)
Age, years	54 (47–65)	52 (39–60)	61 (51–66)	42 (39–51)	43 (36–49)
Disease duration, years	20 (8–30)	2 (1–13)	19 (5–35)	17 (12–20)	11 (5–15)
Working, n (%)	5 (56)	3 (38)	3 (33)	11 (85)	11 (85)
Treatment					
No current medicine, n (%)	4 (44)	1 (13)	2 (22)	0 (0)	0 (0)
Biologics, n (%)	5 (56)	5 (62)	5 (56)	12 (92)	12 (92)
Other, n (%)	0 (0)	2 (25)	2 (22)	1 (8)	1 (8)
VAS pain (0–10 cm)	3 (2–5)	7 (4–8)	2 (1–4)	2 (1–3)	2 (0–3)
VAS fatigue (0–10 cm)	4 (4–5)	7 (7–8)	2 (0–4)	5 (2–7)	4 (2–5)
All values are median (IQR) unless otherwise stated.					
AxSpA, axial spondyloarthritis; CD, Crohn's disease; PsA, psoriatic arthritis; PsO, psoriasis; UC, ulcerative colitis; VAS, Visual Analogue Scale.					

highest rated statements within these concepts were (1) 'in the time before my diagnosis, I have lost trust in the healthcare professionals' (mean rating 4.5) and 'I did not feel heard or seen until I was diagnosed' (mean rating 4.5) and 2) 'Can I work and be active in the future or will I have to live differently?' (mean rating 4.7). The lowest rated statements were 1. 'There is a lack of openness and recognition regarding alternative treatment options in the healthcare system' (mean rating 3.0) and 'I will always tell my employer about my disease' (mean rating 2.7).

The lowest rated AxSpA concept was 'surroundings'/relatives' understanding and 'good' advice' (mean rating 3.2). The highest rated statements within this concept were 'I experience a discrepancy between the understanding of pain vs fatigue' (mean rating 4.0) and 'I experience understanding for my disease when I talk about it' (mean rating 4.0) and the lowest was 'The good advice is probably well-intentioned' (mean rating 2.0).

Psoriatic arthritis

The two highest rated PsA concepts were (1) 'medication (effects and side effects)' (mean rating 3.8) and (2) 'consequences of pain and fatigue, what you are exposed to, the feelings around it' (mean rating 3.7). The highest rated statements within these concepts were (1) 'concerns about the medicine' (mean rating 4.8) and 2) 'worsening of pain' (mean rating 4.8). The lowest rated statements were (1) 'The medicine (MTX) and something else was stopped because my liver numbers increased very much' (mean rating 1.8) and (2) 'limitations regarding my grandchildren' (mean rating 1.8).

The lowest rated PsA concept was 'patientisation (not a person, but just someone in the system)' (mean rating 3.2). The highest rated statement within this concept was 'If I have to increase the dose, I tell him (the doctor)—I don't want to' (mean rating 4.3) and the lowest was 'I've been through tons of treatments that didn't work' (mean rating 1.8).

Psoriasis

The two highest rated PsO concepts were (1) 'social and psychological problems, the shame' (mean rating 4.0) and (2) 'at the doctor/the doctor knows my body' (mean rating 3.7). The highest rated statements within these concepts were (1) 'It scares me to show my disease to strangers' (mean rating 4.8) and 2). 'The doctors must hear what I say' (mean rating 4.6) and 'it is a matter of being taken seriously as a whole person' (mean rating 4.6). The lowest rated statements were (1) 'You close yourself in' (mean rating 2.5) and 2) 'Have been told that the disease reduces the length of life by 2 years' (mean rating 2.8).

The lowest rated PsO concept was 'consequence of the disease/the disease itself' (mean rating 3.2). The highest rated statement within this concept was 'I have jobs that I haven't got because of my disease (I was rejected by the Military—couldn't wear a helmet because I had psoriasis)' (mean rating 4.5) and the lowest was 'I can't just go

travelling for a long time on my boat, because I have to have treatment' (mean rating 1.8).

Crohn's disease

The two highest rated CD concepts were (1) 'positive attitudes' (mean rating 4.3) and (2) 'accept and recognition' (4.0). Examples of the highest rated statements within these concepts were (1) 'The future is bright and I will not let myself be ruled by my illness' (mean rating 5.0) and 'I'm a very positive human being' (mean rating 5.0) and (2) 'The better balance I have in my life, the better I feel about my illness' (mean rating 5.0) and 'A psychologist might be a good idea to have affiliated with the department' (mean rating 5.0). Examples of the lowest rated statements were (1) 'It's easier to get sick as a child because you do not think about things or take a stand' (mean rating 3.3) and 'I do not take into account what I eat at all even though I know the consequence. I take the consequence of what I eat/drink' (mean rating 3.3) and (2) 'Who are you talking to—it cannot be me who has got a chronic disease' (mean rating 2.3) and 'Has had a long course before final diagnosis' (mean rating 2.3).

The lowest rated CD concept was 'meeting the hospital' (mean rating 3.6). The highest rated statements within this concept were 'I miss the doctor who has followed me for 30 years and knows my medical history' (mean rating 5.0) and 'You sometimes feel that it is about economics' (mean rating 5.0) and the lowest was 'I have been asked if my parents had rheumatic diseases. So, something is in the genes. right?' (mean rating 1.7).

Ulcerative colitis

The two highest rated UC concepts were (1) 'take responsibility and control over your life' (mean rating 4.0) and 2) 'medication' (3.9). Examples of the highest rated statements within these concepts were (1) 'My focus is on a healthier, more balanced life. I am convinced that it has a positive effect on my life regardless of the effect of the medicine' (mean rating 5.0) and 'It is the disease that must live with me and not the other way around' (mean rating 5.0) and 2) 'I'm worried if the medicine stops working' (mean rating 5.0) and 'I hope I can get well again' (mean rating 5.0). Examples of the lowest rated statements were (1) 'I have become calmer after I got my disease' (mean rating 1.7) and 'I have become more thoughtful after I got my disease (the boulder bass is tamed)' (mean rating 1.7) and 2) 'I do not know how I can tell if my medicine is working or not' (mean rating 2.0) and 'Imurel increases time to healing. The physicians cannot answer whether it also prolongs recovery of other tissues (muscles/training). Persistent concerns' (mean rating 2.0).

The lowest rated UC concept was 'the influence and importance of diet' (mean rating 3.0). The highest rated statement within this concept was 'diet can affect the disease' (mean rating 4.3) and the lowest was 'When I take lactase pills. lactose is no problem' (mean rating 1.3).

Table 2 The highest and the lowest rated concepts for each disease group and related statements

	Highest/lowest rated concepts	Rating*	Statements (examples)
AxSpA	Lack of understanding/to be heard and seen by healthcare professionals	4.0	❖I did not feel heard or seen until I was diagnosed ❖I had the feeling that others thought it was something I was imagining
	Surroundings'/relatives' understanding and 'good' advice	3.2	❖You just have to... ❖I cannot stand other people's worries
PsA	Medication (effects and side effects)	3.8	❖I also get hair loss from the medicine ❖It's a vicious circle I've fallen into
	Patientisation (not a person, but just someone in the system)	3.2	❖I feel that the doctor has to 'check his ticks' - very bureaucratic ❖You can feel like an experimental animal
PsO	Social and psychological problems, the shame	4.0	❖Self-esteem disappears ❖Felt like a leper
	Consequence of the disease/the disease itself	3.2	❖People were very focused on my hands (due to the disease) in relation to my job (working with people) ❖Stress can trigger the symptoms
CD	Positive attitudes	4.3	❖The future is bright, and I will not let myself be ruled by my illness ❖I cannot change my disease
	Meeting the hospital	3.6	❖I wish some of the meetings could be done electronically ❖You sometimes feel that it is about economics
UC	Take responsibility and control over your life	4.0	❖My focus is on a healthier, more balanced life. I am convinced that it has a positive effect on my life regardless of the effect of the medicine ❖It is the disease that must live with me and not the other way around
	The influence and importance of diet	3.0	❖I think a lot about what I eat (what foods) ❖Confusion about diet. There is a lot of contradictory information

*Mean rating of each concept. (1) 'not important at all', (2) 'a little important', (3) 'somewhat important', (4) 'very important' and (5) 'of great importance'.

AxSpA, axial spondyloarthritis; CD, Crohn's disease; PsA, psoriatic arthritis; PsO, psoriasis; UC, ulcerative colitis.

Concepts and statements across disease groups

The highest-rated and lowest-rated concepts for each disease group are presented in table 2. For each concept, two representative statement examples for the concept are given. All statements for each concept from the AxSpA, PsA and PsO workshop are listed within online supplemental file 1. Statements from the IBD-workshops in online supplemental file 1 to Christensen *et al.*¹²

Figure 1 displays which concepts the participants agreed on independent of disease groups. The six concepts are: 'Concerns about the disease and the future/where will it lead?', 'Consequences of the disease/limits by social and work life', 'Medication and treatment/how do I know I am getting the best treatment?', 'At the doctor/not a human just a number in the system', 'Relationship with others/difficult for others to understand the consequences of my disease', and 'Acceptance of the disease/I take control of my life—not the disease'.

Figure 2 displays concepts and important statements that are more disease specific. For AxSpA: 'Many experiences a long process before they get their diagnosis' and 'There is an incredible amount of 'good advices', for PsA: 'You can feel like an experimental animal/I have received lots of treatments that did not work', 'Gruelling

battle with the system', for PsO: 'Ashamed about appearance/the imprint the disease leaves' and 'It itches all the time' and for IBD: 'The influence and importance of the diet' (UC) and 'Worry and thoughts for the present and future; can I expect more surgeries?' (CD).

Figure 3 displays some of the most prominent concepts and statements shared between only two of the disease groups. For PsA and AxSpA: 'Difficult to have an invisible disease/are not being taken seriously', and for PsA and PsO: 'Mental impact—the disease dampens my mood'.

DISCUSSION

The aim of this qualitative study was to explore disease-related and treatment-related issues and concerns experienced by adults living with AxSpA, PsA, PsO and IBD, and whether these factors were generic or disease dependent. The study exposed that people with SpA and associated diseases largely agreed on which concepts describe their disease-related and treatment-related issues and concerns. We identified six concepts that were present independent of disease group (figure 1). Notably, the individual disease groups each had only one concept (out of 7–11 concepts) that were disease specific (figures 2 and

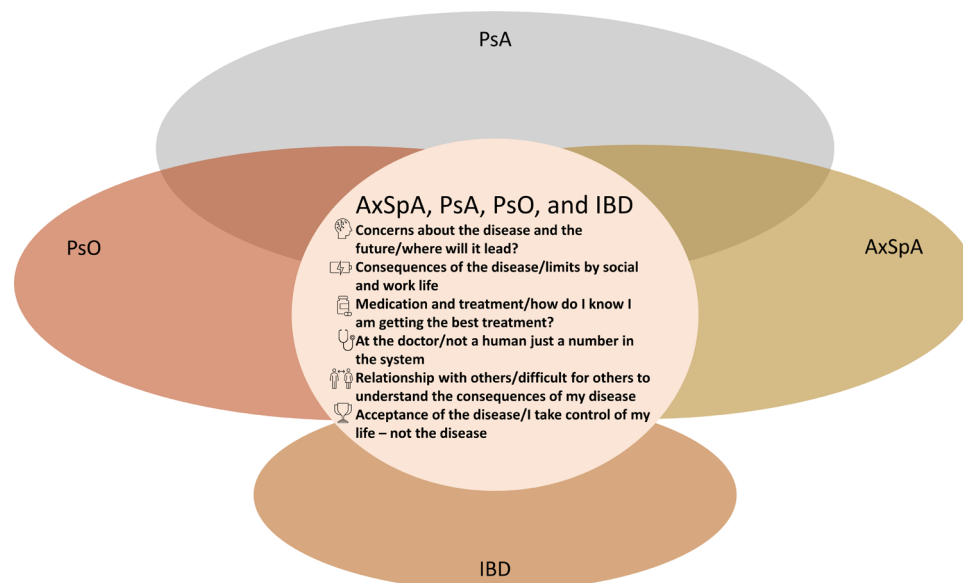


Figure 1 Generic concepts the participants agreed on independent of disease groups. AxSpA, axial spondyloarthritis; IBD, inflammatory bowel disease; PsA, psoriatic arthritis; PsO, psoriasis.

3). This suggests that the common determinant is not driven by the diagnosis itself, but by the person living with a chronic disease.

The disease-specific concepts in this study (figures 2 and 3) are overall consistent with what has been described in the literature^{15–18} for the past decades. Although these are still very important to consider, they should not exclude attention to the generic concepts; rather an add-on.

Not just a number in the system—is one of the concepts the participants agreed on across the investigated chronic diseases. The proportion of adults affected by at least one chronic disease is increasing. The implications of such diseases are substantial.^{2 19} Chronic diseases cause high individual, medical and societal costs, all of which should be considered in its

management. Based on the findings in this study, it is important to see individuals with chronic diseases as not ‘just’ patients. They are more than their disease. They have family, friends, work and social lives. When they are at the doctor, they often get the feeling that the doctor only sees their disease and not the whole person. We need to change that. The system must embrace the whole person and take responsibility for the overall treatment in shared decision-making with the patient. When we ask patients about their symptoms, we should further ask how these symptoms interfere with their function and impacts their quality of life.

Previous studies outline that SpA may result in life-long physical impairment and functional disability.

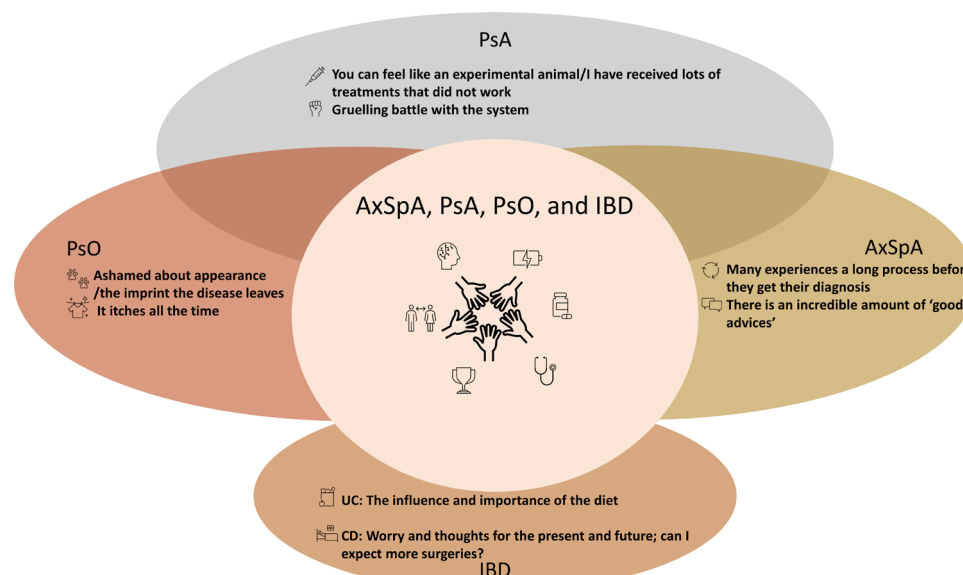


Figure 2 Concepts and important statements that are disease specific. AxSpA, axial spondyloarthritis; CD, Crohn’s disease; IBD, inflammatory bowel disease; PsA, psoriatic arthritis; PsO, psoriasis; UC, ulcerative colitis.

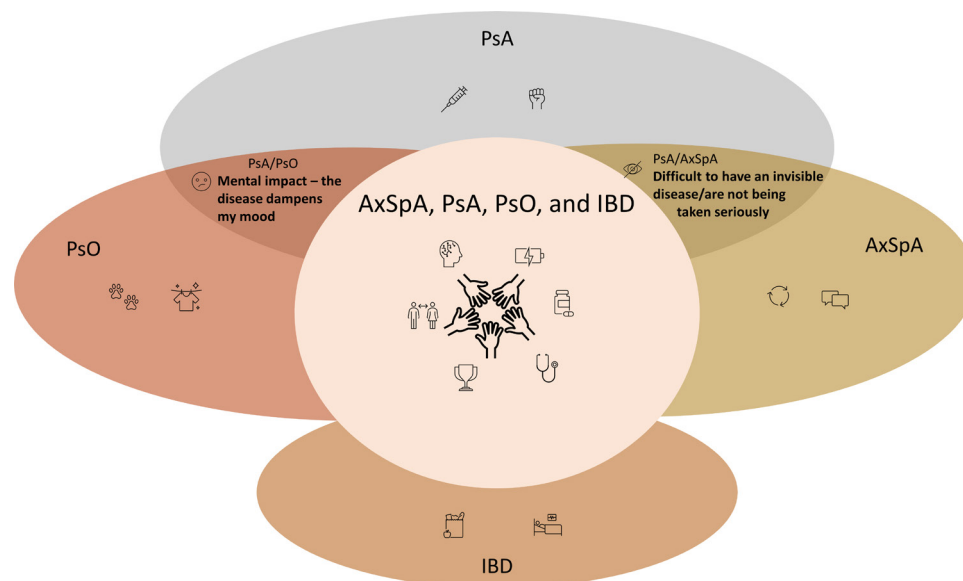


Figure 3 Concepts and important statements shared between only two of the disease groups. AxSpA, axial spondyloarthritis; IBD, inflammatory bowel disease; PsA, psoriatic arthritis; PsO, psoriasis.

Because of the chronic character and the extensive negative effect on patients' daily lives, patient-reported outcomes, such as fatigue, sleep, pain and quality of life, should also be a focus in management strategies in order to support these patients in the best possible way as a healthcare professional.^{20–22} Impact on work life was another recurring topic in this study across disease groups. The potential reduction in physical ability may additionally over time lead to work disability (WD). A study performed in an ankylosing spondylitis (AS) population exposed that WD occurred in 18.5%. Subjects with systemic diseases associated with AS (eg, IBD and PsO) had even higher rates of WD.²³

The strengths of the study were the use of GCM—a well-known and validated method to create a participant-authored visual map of ideas, and combine it with specific analysis and data interpretation methods.⁷ It creates a framework that is multi-purpose: from planning to implementation—through evaluation—using patients as the expert knowledge source on 'life with a chronic disease'. We did not decide on a fixed number of workshops in advance, rather we repeated workshops within each disease groups until qualitative data saturation was achieved. To our knowledge, a large multidisciplinary qualitative study like this has never been done before. Limitations include selection bias: the workshops lasted 4.5 hours, which might have excluded people working full time; people with high disease activity might have opted out due to lack of energy. Despite this, demographic characteristics, for example, age, sex and work status, are well distributed, and the participants are, to the best of our belief, representative of the group of patients they speak for.

Discovering unmet needs and challenges helps towards empowering patients. Patient empowerment is a process through which people gain greater control over decisions and actions affecting their health. Successful patient empowerment is crucial when aiming to ensure optimal disease management, to avoid functional disability, and for maintaining occupational availability, thereby increasing the value of healthcare for patients. The integration of the patients' subjective values and preferences with personalised medicine should facilitate a more comprehensive and personalised care of patients with chronic diseases. There is a need to change the traditional way of thinking in the process towards a more value-based healthcare system. Clinical remission is not always the type of remission the patient is satisfied with. To find out, we need to listen to the individual in front of us and ask: what is important to you? We may not be able to 'fix it', and we, as well as the patient, need to accept this. But we can recognise what fills up the patient's everyday life with their chronic disease in order to guide them to the best possible self-care and acceptance.

Results from this study illustrate that most issues regarding disease related patient concerns are shared across chronic inflammatory skin, gut and joint diseases. Concerns about the future, consequences of the disease and its limitations on social and work life, medication, meeting the hospital/healthcare professionals, relationship with others and the acceptance of the disease are all shared concepts across disease groups. Future research should focus on developing a core set of outcome measures that are of key relevance for the patients rather than disease entities, to be assessed and implemented in a real-life clinical setting ensuring patients perspectives on living a life with a chronic disease. Moreover, this study suggests

several unmet needs for cross-discipline shared care regarding the identified patient concerns with chronic inflammatory diseases.

Author affiliations

¹The Parker Institute, Bispebjerg and Frederiksberg Hospital, University of Copenhagen, Frederiksberg, Denmark

²Department of Clinical Immunology, Aarhus University Hospital, Aarhus, Denmark

³Department of Gastroenterology, Herlev and Gentofte Hospital, Herlev, Denmark

⁴Department of Gastroenterology and Hepatology, Odense University Hospital, Odense, Denmark

⁵Department of Dermatology, Bispebjerg and Frederiksberg Hospital, University of Copenhagen, Copenhagen, Denmark

⁶Center of Rheumatic Research Aalborg (CERRA), Department of Rheumatology, Aalborg University Hospital, Aalborg University, Aalborg, Denmark

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ORCID iD

Zara R Stisen <http://orcid.org/0000-0001-9740-4885>

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All statements divided in concepts from the AXIAL SPONDYLOARTHRITIS workshops

Statements	Frequency of rating*					Statement		Concept	
	1	2	3	4	5	Mean	Median	Mean	Median
Consequences/Limitations in work-life									
I use my energy wrong. I use it all on work.		1			2	4,0	5	3.7	4
I have felt compelled to tell colleagues that I have some limitations due to Bechterew's disease		1	1	1		3,0	3		
I had to tell and be very open about my disease at work			3			3,0	3		
Openness at work has been necessary to be understood			3	1		3,3	3		
I have to decline jobs because of my disease		1	1	1		3,0	3		
It limits me with regard to new work		1		1	1	3,7	4		
Is there anyone who wants to hire me, if they know about my disease?			2		1	3,7	3		
I never told I had Bechterew's disease at work. I want to be judged for my work and not my disease			3			3,0	3		
I will always tell my employer about my disease		1	2			2,7	3		
I arrange my work-life so that I can keep up with it and recharge			1	2		3,7	4		
I have worked part-time to prioritize my disease and family life in order to have enough energy		1			2	4,0	5		
I have reduced my work hours and thus my salary, so it costs money to be ill		1	1	1		3,0	3		
The options for pension and flexjob are very limited in relation to knowledge about disease in the public sector				2	1	4,3	4		
I have gone from 110 per cent to 90 per cent because of my disease			1	1	1	4,0	4		
All treatment and physiotherapy take place during the day, which then affects my workday			1	1	1	4,0	4		
I have made a conscious career change from “fast pace” in the private sector to a position in the public sector to take my disease into account		1			2	4,0	5		
Home working days due to covid have given increased flexibility in everyday life				2	1	4,3	4		
Can I work and be active in the future or will I have to live differently?				1	2	4,7	5		
I had to arrange my work-life so that I could rest		1			1	3,5	4		
Due to my disease, I retired earlier than expected		1			1	3,5	4		
The first three months of my early retirement were the longest of my life				1	1	4,5	5		
My work-life stopped very abruptly				1	1	4,5	5		
Worries now and in the future									
Worry about whether I can keep up with my work-life			1		2	4,3	5	3.6	4
Uncertainty about the future			3			3,0	3		
Will I be able to start a family?			1	1	1	4,0	4		
Uncertainty with the new unpredictability in my life		1		2		3,3	4		
I am worried about passing it on to my children		1	1		1	3,3	3		
I am worried about getting diseases related to Bechterew's disease			2	1		3,3	3		
What does the medicine do to my body in the long run?			1	1	1	4,0	4		
It is unpredictable who will have effect of the medicine and how long it works			3			3,0	3		
Worried that my back is growing together			2		1	3,7	3		
Concerned about the development of the disease over time				2	1	4,3	4		
Does fatigue increase over time?				2	1	4,3	4		
Do back and joint stiffness increase?				2	1	4,3	4		
I am worried whether I can continue my sport if the disease develops			2		1	3,7	3		
I am worried whether my daughter will inherit the disease	1			1	1	3,3	4		
I am worried that my stiff neck will result in me losing my driver's licens	1			1	1	3,3	4		
I am worried about the biological medicine stop working and I have a relapse		1			2	4,0	5		
Those who are close to me do not need to worry. I leave that to the healthcare professionals	2				1	2,3	1		
Take responsibility for your own situation									

Openness to family and friends about the disease			1		2	4,3	5	3.8	4	
You must take responsibility for your own situation and not sit back			1		2	3,7	4			
You can do something yourself					3	4,0	4			
Recreation and interests are very important so that the disease does not take up so much				2	1	4,3	4			
You have to get input, e.g., socially and culturally, so that the disease gets less space				1	2	4,7	5			
Mental health becomes charged with positive things				1	2	4,7	5			
Now that there is limited medical treatment available, positive distractions are even more important		1		1	1	3,7	4			
It is important to set goals including sub-goals		1		1	1	3,7	4			
I ride my bike a lot and I am really happy about that. I would be sad if I could not do that			1	1	1	4,0	4			
Being able to run every day makes me really happy. It gives me a boost in everyday life			1	1	1	4,0	4			
It is good to have a routine so that I get up and go out every morning	1				2	3,0	4			
It is important to be open to yourself, also in relation to alternative treatment			1	2		3,7	4			
Am I doing enough myself to manage my disease?			1	2		3,7	4			
Can I counteract the development of my disease myself?			1	2		3,7	4			
Quality of life and content are very important				1	2	4,7	5			
Should I be patient-ignorant or take responsibility and thus be an expert?	1		2			2,3	3			
It is an advantage to be prepared before the appointment at the hospital				2	1	4,3	4			
I solve the challenges I face with my disease		1	1			2,5	3			
Identity/recognition/accept										
I cannot do everything I would like to and have a hard time accepting that				1	2	4,7	5	3.2	3	
My disease does not matter much. Has become a part of my life			2	1		3,3	3			
The disease affects social life. Makes it awkward		1	1	1		3,0	3			
It has been a process to tell others I don't know, that I have a disease			1	2		3,7	4			
When you are not ill, you have the privilege of being normal		1	1		1	3,3	3			
When you are ill, you are both ill and have to put yourself in a vulnerable situation of having to tell colleagues about it			3			3,0	3			
I work full time so no one will say I am sick			1	2		3,7	4			
At times you can feel a little self-pity			1	1	1	4,0	4			
Why me?			1	2		3,7	4			
I have opted out of being part of patient associations in order not to be a patient	2		1			1,7	1			
My identity is not to be a patient, on the other hand, I am 100 per cent something else	1		1		1	3,0	3			
It has always been my trademark to be physically strong and the disease will not change that		1		1	1	3,7	4			
I have said no to paid physiotherapy because then I am not a patient and have chosen private physiotherapy instead	2		1			1,7	1			
I have learned more about myself - for better or for worse			2		1	3,7	3			
I have gained insight into what is important for me to be able to do and what matters				3		4,0	4			
My sister didn't want to take medicine because she then felt ill	2	1				1,3	1			
I have not felt a deprivation due to my disease because I do not know what I have missed out on		1	2			2,7	3			
My boyfriend got another package	1		1		1	3,0	3			
My boyfriend gets involved in the treatment by, for example, having to tape a shoulder and he should not have to	2				1	2,3	1			
I see my wife's concern as support more than a worry			1	1	1	4,0	4			
The heredity of the disease has played a role in having children, but not decisively	1			1	1	3,3	4			
Surrounding's/relatives understanding and "good" advice										
People find it difficult to accept my situation and its limitations		1	1		1	3,3	3	3.2	3	
People have considered me to be a hypochondriac			1	2		3,7	4			

I cannot stand other people's worries			2		1	3,7	3		
My wife does not worry, on the contrary, she paces me a little	2				1	2,3	1		
I experience understanding for my disease when I talk about it			2		1	3,7	3		
People find it difficult to accept my situation and its limitations			1	1	1	4,0	4		
People are not aware of and do not understand that I need, for example, to rest in the afternoon	1			1	1	3,3	4		
I experience a discrepancy between the understanding of pain versus fatigue			1	1	1	4,0	4		
Now stop that nonsense			1	1		3,5	4		
You just have to...			1	1		3,5	4		
There is an incredible amount of good advice		1		1		3,0	3		
The good advice is probably well-intentioned	1		1			2,0	2		
I think my boyfriend is overprotective of me		1	1			2,5	3		
I am made more vulnerable than I am		1	1			2,5	3		
My wife worries about me more than I do		1	1			2,5	3		
Diagnosis/medicine/treatment									
I am glad that I can tolerate my medicine				1	2	4,7	5	3.4	4
When I can no longer take NSAIDs, I will have to take Codipar, which is perhaps not appropriate for driving	2				1	2,3	1		
I wish there was a better alternative to painkillers that do not affect my driving	2				1	2,3	1		
When I experienced treatment failure, I learned why I take the medicine		1			2	4,0	5		
I stopped feeling ill after I stopped taking the medicine		1		1	1	3,7	4		
The disease is so significant if I do not get medicine so there is no alternative		1			2	4,0	5		
I do not worry about side effects to the medicine as the effect far exceeds the side effects		1			2	4,0	5		
I never felt like I needed medicine other than a little painkiller	1	1			1	2,7	2		
I think about whether the progression of my disease would have been different if I had received medicine earlier	1	1	1			2,0	2		
Many people experience a long process before they get their diagnosis	1		1		1	3,0	3		
The experience until you get the diagnosis is a bit random compared to whom you meet on your way		1	1		1	3,3	3		
I don't know if I could have benefited from medication via the hospital	1	1			1	2,7	2		
Before my diagnosis, the pain was the focus of my everyday life					2	5,0	5		
It was a relief to get the diagnosis				1	1	4,5	5		
I thought I was crazy before I got the diagnosis			1	1		3,5	4		
I was given hope that my pain would go away when I was diagnosed				1	1	4,5	5		
I had an expectation that something could be done when I received my diagnosis				1	1	4,5	5		
I am thinking about how long my body can take this medicine		1		1		3,0	3		
It is probably not completely harmless to take medicine for a long time		1		1		3,0	3		
Medicine is good for something and maybe not good for something else		1		1		3,0	3		
I go less to the hospital after I have switched to medication, I can take at home			1	1		3,5	4		
I am incredibly happy to go to the hospital to receive my medicine	1		1			2,0	2		
I find it scary how dependent I am on that medicine			1		1	4,0	4		
Five days before I have to get my medicine, I can feel my disease			1	1		3,5	4		
I have experienced worse treatment in outer Denmark		1		1		3,0	3		
Lack of understanding/to be heard and seen by healthcare professionals									
No one listened to me when my symptoms started			1	1	1	4,0	4	4.0	4
There is a lack of openness and recognition regarding alternative treatment options in the healthcare system		1	1	1		3,0	3		
In the time before my diagnosis, I have lost trust in the health care professionals				1	1	4,5	5		
I did not feel heard or seen until I was diagnosed				1	1	4,5	5		
I was asked to exercise more even though I was already exercising			1		1	4,0	4		

I did not feel I got help to solve my challenges			1	1	4,0	4		
You just need to take some painkillers (symptom treatment)			1	1	4,0	4		
I was not examined when I came with my pain				1	1	4,5	5	
I had the feeling that others thought it was something I was imagining		1			1	3,5	4	
Everyday life with Bechterew's disease								
There are many things I would like to do. And sometimes I push myself too much				3		4,0	4	
Wish I had more energy in my spare time				2	1	4,3	4	
Fatigue is paramount for me			1	2		3,7	4	
Træthed har været årsag til at jeg har skiftet job	1			1	1	3,3	4	
I have had to put myself aside		1	1	1		3,0	3	
I have to spend a lot of time on mobility exercises and physiotherapy that others don't have to		1	2			2,7	3	
I have to opt out because my disease takes time		1	1		1	3,3	3	
It is not fair that I have to spend time on e.g. exercises when others don't have to		1		2		3,3	4	
My spare time is filled with disease obligations instead of what I want to do		1		1	1	3,7	4	
If I don't exercise, I don't have the energy to do what I have to do. It is unfair		1	1	1		3,0	3	
I limit myself in terms of hard physical work in everyday life due to the disease		1	2			2,7	3	3.5
For me, cold means inactivity due to joint pain	1	1		1		2,3	2	4
If I am too active, it costs me energy the next day		1	1	1		3,0	3	
Definitely, a need to rest in the afternoon to function well					3	5,0	5	
I had to constantly balance the things I wanted to do with my pain		1			1	3,5	4	
What does it cost in terms of pain to do what I want to do?		1		1		3,0	3	
You only have a certain amount of energy to spend each day				1	1	4,5	5	
I cannot do housework				1	1	4,5	5	
It annoys me endlessly that I cannot do work at home				1	1	4,5	5	
Things in everyday life are challenging for me due to Bechterew's disease			1		1	4,0	4	
It annoys me that I am not so flexible in my body				1	1	4,5	5	
I am stiff in the body and that limits me in terms of swimming			1		1	4,0	4	
I do not worry about my disease		2				2,0	2	
Sometimes there is too much focus on my situation/Bechterew's disease		1	1			2,5	3	
I can no longer tolerate alcohol as a result of my disease		1		1		3,0	3	
Meeting the hospital/healthcare system								
You must not let yourself be taken over by the system			2	1		3,3	3	
Rheumatologists also considered me to be a hypochondriac			2		1	3,7	3	
There are unrealistic expectations of what the doctor thinks I can achieve in my everyday life in terms of exercise		1	2			2,7	3	
If you have Bechterew's disease, it is almost a guarantee that you will not get Crohn's disease	1		1	1		2,7	3	
Much focus is placed on pain in relation to the disease			3			3,0	3	
Lack of information about what the consequence of the medicine is			1	2		3,7	4	
I feel seen and heard by my doctor				2	1	4,3	4	
At the doctor's, it is a lot about medicine			1	2		3,7	4	
Danbio is a good tool in the meeting with the doctor				2	1	4,3	4	
Especially the nurses see and hear me			1	1	1	4,0	4	
Exchange of your regular doctor can be a challenge			1	2		3,7	4	
It is a good thing to be able to write directly to the doctor if in doubt				1	2	4,7	5	
I have generally felt really well taken care of and met by competent healthcare professionals			2		1	3,7	3	
My strategy is to let the doctor worry about the disease and not me		1	1		1	3,3	3	3.3
I have confidence in healthcare professionals in general regarding my disease			1	2		3,7	4	3
I have experienced a shift in confidence - felt alone with the disease	1	1			1	2,7	2	
I stopped at the physiotherapist as I did not feel he could do anything for me that I could not do myself	2		1			1,7	1	

I think it is reasonable after paying taxes for forty years, that I use the healthcare system	1		1		1	3,0	3		
I feel I am burdening the public sector because of a banality	2		1			1,7	1		
I cost the public sector a lot of money	1	1	1			2,0	2		
I feel that I inconvenience the public system unnecessarily	2		1			1,7	1		
I have great chemistry with my doctor and that makes me feel safe			1		1	4,0	4		
I feel my doctor sincerely listens and hears what I say				1	1	4,5	5		
It is important that my doctor continues		1			1	3,5	4		
My doctor made me aware of my rights			1		1	4,0	4		
It is important that you, as a patient, feel free to speak up against the system you have become a part of			1	1		3,5	4		
Life with Bechterew's disease									
Difficult to plan your life for the long term			3			3,0	3		
It gives me less confidence that the disease can suddenly overwhelm me			2	1		3,3	3		
The mind and the physical are connected			1		2	4,3	5		
The unpredictability can lead to worries which can lead to a depressive state		1			2	4,0	5		
Being ill offers the opportunity to seek financial compensation, but it costs energy			2	1		3,3	3		
I have joined the patient association to meet others with the disease		1		2		3,3	4		
Stress has a big impact on my disease			1	2		3,7	4		
*Rating - 1: 'Not important at all', 2: 'A little important', 3: 'Somewhat important', 4: 'Very important' and 5: 'Of great importance'.									

All statements divided in concepts from the PSORIATIC ARTHRITIS workshops

	Frequency of rating*					Statement		Concept	
Statements	1	2	3	4	5	Mean	Median	Mean	Median
Concerns in relation to my illness/unanswered questions									
What must I do? If I feel pain, must I stop what I'm doing?					3	3.0	3	3.7	4
What makes my condition worse or better?				1	2	4.7	5		
I have many unanswered questions.				2	1	4.3	4		
I would like more information as regards what I can do myself			2		2	4.0	4		
Is my illness at a standstill, - should I resign myself to where I am now?			1	3		3.8	4		
It's hard to know whether I should continue when it hurts		2		2		3.0	3		
Thinking about whether I can stay in my apartment because my knees were so sore				1	1	4.5	5		
What are my prospects				2	2	4.5	5		
The pain has not improved after I took my medication (MTX)				1	1	4.5	5		
Concerned for the future				3	1	4.3	4		
Worried about experiencing more pain				3	1	4.3	4		
It worries me that my mobility may be reduced				3	1	4.3	4		
If it becomes worse - I will feel like I'm in deep trouble				4		4.0	4		
How bad will it become - will I end up in a wheelchair?			1	2	1	4.0	4		
Worries about my physical condition in general			1	2	1	4.0	4		
What can it develop into	1			1	2	3.8	5		
I'm concerned about the limitations the illness forces on my everyday			2	1	1	3.8	4		
When I was diagnosed, I was afraid I would end up in a wheelchair	1	1		1	1	3.0	3		
Could not get a clear overview of the consequences the illness might possibly result in? Lose my apartment, be fired, etc?			1	1	1	3.0	4		
Worry about whether I can still be active with my kids, if I feel worse	2			1	1	2.8	3		
What worries me is not being able to interact with my children	2	1			1	2.3	2		
I'm concerned that I might need help getting out of bed for example	2		1	1		2.3	2		
The development of my illness - will it get worse?				1	3	4.8	5		
I could not return to the job I had before the illness				1	2	4.7	5		
What job opportunities are there if I do not have a job?			1	1	2	4.3	5		
Worry about whether my current job is too physically demanding	1			2		2.3	3		
Financial worries	1		1	1		2.0	2		
How long can I continue to work	1				2	2.8	3		
Consequences of pain and fatigue, what I will be subjected to, feelings about that									
Worsening of pain				1	3	4.8	5	3.7	4
Before I had biological medication, I could not get up from the floor				1	2	4.7	5		
Difficulty with cutting because of the pain				1	2	4.7	5		
Had a hard time getting up because of pain in fingers and wrist				2	2	4.5	5		
Wake up with severe pain at night				2	1	4.3	4		
Hurts a lot - dietary does not help	1		2		1	3.0	3		
My arthritis is very much influenced by the fluctuating Danish weather	1	1	1	1		2.5	3		
It's a vicious cycle I have fallen into				1	2	4.7	5		
It is stressful because they (the system) do not do anything to help me				2	2	4.5	5		
My husband is also affected by me receiving chemotherapy (MTX)				2	1	4.3	4		
My husband is anxious on my behalf because I am receiving chemotherapy (MTX)				2	1	4.3	4		
I hide my hands				2	1	4.3	4		
When I am in pain, I do not use my body as I would like, - affects me a lot				3	1	4.3	4		
I turn the anger inward so as not to upset anybody			1	2	1	4.0	4		
Mental impact - the illness dampens my mood			2	1	1	3.8	4		
The pain associated with psoriatic arthritis is great			1	3		3.8	4		
Feel guilty about not doing what I know I can to feel better			2	1	1	3.8	4		
Suffering from psoriatic arthritis is a full-time job		1	1	2		3.3	4		
Loss of vigour for periods	1		1	2		3.0	4		
Consequences of not being able to use my body - the basic level is deteriorating more and more			1	2	1	4.0	4		

My body is becoming more and more twisted (due to illness/inactivity)	1			2	1	3.5	4		
I have to sleep for a few hours when I get home from work	2	1			1	2.3	2		
I am very much affected by fatigue				1	2	4.7	5		
Increased fatigue				2	2	4.5	5		
I am very tired - use up all my energy at work	1	1	1		1	2.8	3		
My pain restricts my participation in Yoga etc. (physical activity)			2	1	1	3.8	4		
Lose things	1			2	1	3.5	4		
Constantly losing things, - very frustrating	1			2	1	3.5	4		
Difficulty performing work because of arthritis	1			1	1	3.3	3		
Many limitations as regards being with my children - need help from others	2		1		1	2.5	2		
Limitations as regards my grandchildren	3					1.0	1		
Have difficulty climbing stairs - no strength in my joints (hard)			1	1	1	4.0	4		
Medication (effects and adverse effects)									
Concerns about the medication					4	5.0	5	3.8	4
Does the medication work?			1		3	4.5	5		
Decreases the effect (of the medication) over time				2	2	4.5	5		
What impact does the medication have on me				3	1	4.3	4		
There are many adverse effects from all the medications I take because of my illness(es)				3	1	4.3	4		
You never hear any good stories about MTX - why should I take it?			1	1	1	4.0	4		
I worry a lot about whether the biological medication I receive can cause cancer		1		1	2	4.0	5		
If the medication does not work - will I be on a roundabout for the rest of my life	1			2	1	3.5	4		
Concerned about whether I can have children because of the medication	2				2	3.0	3		
The medication causes hair loss (Arava)				1	2	4.7	5		
The frequency of the arthritis attacks has increased markedly after I received MTX				1	1	4.5	5		
I am mentally affected by medication				2	2	4.5	5		
Hair loss (adverse effect)				2	2	4.5	5		
It's annoying that I have to howl all the time (adverse effect)				2	1	4.3	4		
I get angry over nothing - snarling all the time				2	1	4.3	4		
I don't want to read the leaflet about the adverse effects, as I'll just feel bad			1	1	2	4.3	5		
Get sore ankles and swollen toes (arthritis) from MTX			1	1	2	4.3	5		
Become more tired when I take the medication (MTX)			1	1	1	4.0	4		
After I started the MTX, I become very sad			1	2	1	4.0	4		
I think I get a fever from the MTX (adverse effect) - my bedclothes are dripping wet after I take it			1	1	1	4.0	4		
After I started taking MTX I feel that I suffer flu-like symptoms			1	2	1	4.0	4		
Adverse effects from the medication (MTX)			1	1	2	4.3	5		
I become aggressive for the first few days I take MTX (adverse effect)		1		2	1	3.8	4		
Adverse effects from the medication (MTX)	1			1	2	3.8	5		
I am emotionally affected by the medication			2	2		3.5	4		
The medication (MTX) and something else was stopped, as my liver countsincreased a lot	3				1	2.0	1		
If it gets worse I will stop taking MTX			1	2	1	4.0	4		
I have tried to stop taking the medication (but it did not go as well as I had hoped				4		4.0	4		
Has my condition improved while I took the medication..... could I possibly do without it?			2	2		3.5	4		
I tried to stop taking MTX, but I became very poorly	2			1	1	2.8	3		
I have thought about whether I could do without the medication				3	1	4.3	4		
I've finally received biological medication	2			1	1	2.8	3		
I have high expectations for my biological medication	1			1	2	3.8	5		
The medication works very differently on different people. Many also have great success stories	1		1	2		3.0	4		
Can I get the medication I want		1		2	1	4.0	5		

I have tested many of the biological preparations - but they had no effect or I could not tolerate them	2		1	1		2.3	2		
Frustrated about having to take MTX for a long time, without it having worked				2	2	4.5	5		
My own approach (I do something myself)									
I am not overly affected by the illness, such that I can tolerate it if it does not get worse				1	2	4.7	5	3.6	4
I have difficulty performing everyday objects at home - but I will find a solution		1		3		3.5	4		
One finds a way			2	1	1	3.8	4		
Everything is possible, a way is found			2	1	1	3.8	4		
I find a solution to the problems - so that they do not take over			1	3		3.8	4		
I refuse to spend my time worrying about myself - otherwise I couldn't do anything		1	1	2		3.3	4		
Exercise improves my mood		1		1	2	4.0	5		
I think a lot about my illness before I go to the doctor		1		1	2	4.0	5		
When I was diagnosed, I tried many alternative methods	1		1		2	3.5	4		
What can I do myself?			2	1	1	3.8	4		
I am amazed that there has been no focus on diet	1	1			2	3.3	4		
Heat helps my illness	1			1	2	3.8	5		
When I have been in the sun for 14 days, I can do things I otherwise cannot	1				3	4.0	5		
Dietary changes can help a person's general condition		1	2	1		3.0	3		
Did not have the patience to wait for the alternative methods to work	1		2	1		2.8	3		
Very dry heat helps my arthritis a lot	1			2	1	3.5	4		
I am not physically active - but I am active with many other things, which keeps me going				2	1	4.3	4		
The patient against the bureaucracy (Doctors' authority – they have the power)/ Patientization (not a person, but just someone in the system)/Powerless/Frustration									
Feel that the doctor must "dot the i's" - very bureaucratic		1		1	2	4.0	5	3.2	3
It seems odd (I feel stupid) that I must first go through several different drugs before I get the biological medication	1			2	1	3.5	4		
I do not like the fact that I have to try different medication before I get the biological one	1		1	1	1	3.3	4		
Very difficult to get biological medication	2				2	3.0	3		
They wear white coats, - so they must know what they are saying	1	1	2			2.3	3		
You can feel like an experimental animal	1	1	1	1		2.5	3		
Some doctors have a personal interest in issuing the medication they say you have to take	1	1	1	1		2.5	3		
I have received lots of treatments that did not work	1			2		3.0	4		
I've been lucky, doctors have believed in me				1	3	4.8	5		
If I have to increase the dosage, I tell him (the doctor) I will not				2	1	4.3	4		
If you are a strong patient (know what you want), you can get suggest some things - you are taken seriously		1		2	1	3.8	4		
I do not want MTX - even if they force me to take it - I will find another solution	1	2		1	1	3.0	3		
I wonder if they really can force me to take MTX or biological medication	2				2	3.0	3		
The doctor says that if I do not do as he says, he will not visit me	3				1	2.0	1		
Meeting with the system (municipality)									
No consideration is given to my situation as regards what I can do now, and which jobs are open to me				1	2	4.7	5	3.3	3
The municipality does not believe what I say			1		3	4.5	5		
The system (the municipality) does not believe what the doctors say is wrong with me				2	2	4.5	5		
The cash system has no understanding of my situation				2	1	4.3	4		
It cannot be right that you go and say you hurt everywhere (says the municipality)			1	1	2	4.3	5		

Trying to get help from the unemployment benefit system - but it is very hard				1	2	4.7	5		
It is scary that it is not the same for everyone - but hard to see how it could be different			2	1	1	3.8	4		
Very hard to get aids from Copenhagen municipality - depending on where you live	1		1	1	1	3.3	4		
I would like to be offered training (they do not want to be liable for me in the gym)		2		2		3.0	3		
Everything is about the economy	1		2	1		2.8	3		
Tried to get help for babies from the municipality, but I couldn't	2	1			1	2.3	2		
Difficult to get further training because of the economy	1		1		1	3.0	3		
Applying for a flexible job was a struggle	2				1	2.3	1		
Contact with the public system is gruelling	1			1	1	3.3	4		
You have to be mentally prepared to do battle with the system (the municipality)		1		1	1	3.7	4		
You are constantly confronted with the limitations of the illness in everyday life				3		4.0	4		
While applying for flexible jobs, I was constantly asked how sick I really am	2				1	2.3	1		
Difficult having an invisible disability									
I have a difficulty saying that I cannot do the same things as before				2	1	4.3	4	3.4	3
Hard to tell people that I have psoriatic arthritis			1	1	1	4.0	4		
Annoying that you have to give a long scientific report if you cannot drink a glass of wine		1	1	1	1	3.5	4		
People misunderstand the reason why you cannot drink alcohol		1	1		1	3.3	3		
People have trouble understanding that I cannot drink a beer or a glass of wine as before, due to the medication		1	2		1	3.3	3		
You have to justify why you cannot drink a glass of wine		1	2		1	3.3	3		
If you tell people that you are receiving chemotherapy (MTX), they become frightened		1	1	1	1	3.5	4		
Can feel that some people are reluctant to touch me because of my illness				2	1	4.3	4		
Get the feeling that people feel sorry for me		1	1	1	1	3.5	4		
Feel I am not being taken seriously	1	1	1	1		2.5	3		
People have difficulty understanding how sick I am, since you cannot see it				2	1	4.3	4		
Difficult having an invisible disability				2	1	4.3	4		
Hard to explain to people how much pain I'm in				1	2	4.7	5		
A lot of the arthritis pain is difficult to explain				2	1	4.3	4		
*Rating - 1: 'Not important at all', 2: 'A little important', 3: 'Somewhat important', 4: 'Very important' and 5: 'Of great importance'.									

All statements divided in concepts from the PSORIASIS workshops

	Frequency of rating*					Statement		Concept	
Statements	1	2	3	4	5	Mean	Median	Mean	Median
Social and psychological problems, the shame									
It scares me to show my illness to strangers				1	4	4.8	5	4.0	4
The shame of skin flaking			1		4	4.6	5		
Self-esteem disappears			2		3	4.2	5		
I was terrified to talk to girls (as a teenager)	2		1		2	3.0	3		
It goes beyond my vanity			2		3	4.2	5		
Do not want to display it in public			2	1	2	4.0	4		
Ashamed of the impression the illness makes (must shake the sheets after sleeping in the homes of others)		1			4	4.4	5		
It affected me socially			3		2	3.8	3		
My nails look like they've been hit with a hammer				1	4	4.8	5		
Do not show it to others (if, for example, I sleep in a hotel room with others)	1				4	4.2	5		
Hated physical education in school	1			2	2	3.8	4		
Socially hampered me greatly	1		2		2	3.4	3		
Build barriers to protect myself	2		1		2	3.0	3		
Life before biological treatment -> I would not wear t-shirts or shorts	1		2	2		3.0	3		
Felt like a leper	1	2			2	3.0	2		
Was very modest	1		4			2.6	3		
I have to prepare myself mentally for a few days beforehand if I have to show myself/my illness in public		2		1	2	3.6	4		
Do not wear t-shirts	1		2	2		3.0	3		
You shut yourself in	2		1		1	2.5	2		
Genes, pain, symptoms									
It itches all the time				1	3	4.8	5	3.7	4
Bleeding wounds - hurts			1		3	4.5	5		
The wounds are very painful			1		3	4.5	5		
Painful when wounds cracks			2		3	4.2	4		
Cannot help scratching			2		2	4.0	4		
The nails come loose (very fragile)				1	4	4.8	5		
Affects the nails - nails take on another shape				1	4	4.8	5		
Can be hard to sleep due to pain					5	5.0	5		
The cracks are very painful			3		1	3.4	3		
Wake up because you feel it all the time				2	3	4.6	5		
It's a kind of hell for us			2	1	2	4.0	4		
"don't scratch it" - it's really hard!		2		3		3.2	4		
I have become thin-skinned			2	1	1	3.8	4		
The skin cracks if I bend down, - very painful		1	1	1	1	3.5	4		
Often have difficulty walking and running (bottom of feet crack)					5	5.0	5		
Cutting nails f**king hurts	2			1	2	3.2	4		
Constantly in pain				3	2	4.4	4		
Constant inflammation in the elbows. I chose not to protect myself (due to my work)		1	2	1		3.0	3		
The clothes can be troublesome - feels painful			3	2		3.4	3		
Itching can become pain			4	1		3.2	3		
Burning and stinging underfoot, mostly at night - wake in the night			2	2	1	3.8	4		
Outbreaks make eyes sensitive to light	2		2	1		2.6	3		
I think it has been a serious disability	1	1			2	3.3	4		
At the doctor/the doctor knows my body									
The doctors must listen to what I say				3	2	4.4	4	3.7	4
It is a matter of being taken seriously as a person				3	2	4.4	4		
I know my body better than anyone else			2	1	2	4.0	4		

It is infinitely annoying that doctors focus on numbers and not on what the individual patient wishes			3		2	3.8	4		
There is no understanding that I know my body better - "try to investigate what I think the problem is"			1	2	2	4.2	4		
(the doctor) lacks understanding of the individual			3		2	3.8	4		
Seems annoying constantly having to tell the same story again and again			3		2	3.8	4		
Hard to relate to "numbers" the doctor uses...			3		2	3.8	4		
When I'm standing half naked in Bispebjerg - many people come in looking for/asking about something - it bothers me!		1	1	1	1	3.5	4		
Panicked about the fact that no one knew what was wrong with me				3	1	4.3	4		
It's tough fighting the system			3		2	3.8	4		
A year and six months passed before I was diagnosed - even though I had psoriasis all over me				2	2	4.5	5		
From the beginning, I was bounced around the system - they had no idea what was wrong		1	1	1	1	3.5	4		
My GP had no idea what was wrong with me and recommended I try all sorts of creams - to no effect!	1	1		1	1	3.0	3		
Long wait for treatment	1		1	1	1	3.3	4		
How do I know if I'm getting the best treatment?				2	3	4.6	5		
We are subjected to a lot of different things - how do I know that it is the best treatment			2	1	2	4.0	4		
I don't think that my treatment is good enough (apply cream, tar ointment, steroid creams + pellets)	2			2	1	3.0	4		
Felt that doctors were uncertain as to which treatment was best			1	3		3.8	4		
Doctors are sometimes searching in the dark			1	3		3.8	4		
I told my doctor that it doesn't seem good enough	2			1	2	3.2	4		
The doctor thinks we have to wait and see... and then maybe change treatment	2		2	1		2.4	3		
Continuing to try new medications - because the effect wears off		1	1	1	1	3.5	4		
Feel like the doctors are experimenting on me		1	1	2		3.3	4		
You have to hurry when you are in discussions with the doctor	1		2		1	3.0	3		
Was diagnosed... I thought what now... did not know much about the illness				2	2	4.5	5		
Not nice when the dermatologist does not say that the hormone cream enters the bloodstream	1				3	4.0	5		
I have read that inadequate treatments can lead to complications			2		3	4.2	5		
I don't know the reason behind the sudden flare up			4	1		3.2	3		
I thought of all the pictures I had seen and thought about it a lot			1	2	1	4.0	4		
I have not been told the adverse effects of biological medication (from the doctor/hospital)	1		1		2	3.5	4		
Worried about sequelae (e.g. arthritis)			4		1	3.4	3		
Spreading makes me uneasy (I've got it in more places than just on my hands and feet)		2	2		1	3.0	3		
I do not know the adverse effects of biological medication	1	1	1	1		2.5	3		
MTX → adverse effect - is said that you can die from it				2	3	4.6	5		
I was terrified when I was diagnosed, - had seen some terrible images		1	1	2		3.3	4		
I have no idea why I got the illness		2	3			2.6	3		
Have been told that the illness reduces length of life by 2 years			4	1		3.2	3		
Medication and treatment									
I noticed that all of my symptoms disappeared within 14 days (with biological medication)					5	5.0	5	3.5	4
Biological treatment is a miracle!				1	4	4.8	5		
What happens if the medication does not work any more - or if I do not get it any more				1	3	4.8	5		
Am I guaranteed to receive Humira forever				1	3	4.8	5		
Subsidies are continuously being cut - concerned about continuing to receive Humira				1	3	4.8	4		
May be concerned about money for biological treatment running out			2		3	4.2	5		
Will I get the illness again (major concern)				2	2	4.5	5		

I am a little cautious (medication) about what I put in my body				2	2	4.5	5		
I would not take MTX due to adverse effects - did not say in the leaflet what was good about MTX			3		2	3.6	8		
This is not the end (if this treatment does not work, then it's on to the next)	1		1		2	3.5	4		
Must take medication for the rest of my life		2		3		3.2	4		
I think the hospital I am affiliated to is great	1			1	2	3.8	5		
It flares up immediately if I miss a treatment (biological treatment)			1	2	2	4.2	4		
I do not think about it in my day to day life any more - my treatment works	2			1	1	2.8	3		
I am not in pain	4		1			1.4	1		
Do not like wasting my time on discussions with the doctor (feel good) - would rather the doctor spent time on those who need it		4				2.0	2		
I tolerate MTX			2		2	4.0	4		
Individually what the body can tolerate			4	1		3.2	3		
I put on weight after the MTX treatment - it is a side effect.	1			1	2	3.8	5		
Biological medication also affects the liver	1			1	2	3.8	5		
I could not tolerate MTX	1		1		2	3.5	4		
The skin peeled off my heels (received MTX)	1		1	1	1	3.3	4		
My skin has become thinner, because I have applied all sorts of creams		1	2		1	3.3	3		
I am bad all over (open sores), - do not know if it is an adverse effect	1		2	1		2.8	3		
Could not tolerate MTX	2			1	2	3.2	4		
Was quite mad about MTX	2			1	2	3.2	4		
Must be more aware of how I move (easily bruised)	1	2	1			2.1	2		
Suffered adverse effects from previous treatments (steroid cream) - bruising	2	1	1			1.8	2		
Nausea after MTX	3			1		1.8	1		
Relationship with partner/others								3.2	3
Lack of discussion with others in the same situation	2				3	3.4	5		
Would love to participate in network groups	2				3	3.4	5		
No one understands the illness			3		2	3.8	3		
Do not understand why there is no network groups (the psoriasis association)	2		2		1	2.6	3		
Feel all alone with the illness			4		1	3.4	3		
No one who knows the illness			3		2	3.8	3		
Intimate relationships - what do partners think?	1			1	2	3.8	5		
My own thoughts about myself as regards being intimate with others	1			1	2	3.8	5		
What do partners think - they think it's disgusting	1			1	2	3.8	5		
Affects my sex life (no fun if you have cream applied all over one's body)	1	2			2	3.0	2		
Enjoy less sex during treatment - also affects me mentally	2		2	1		2.4	3		
Concern when starting a new relationship	1		1	1	1	3.3	4		
What does my partner think about how I look ("my butt looks like a baboon's")	1		1	1	1	3.3	4		
There are days when you do not feel like sex		3	2			2.4	2		
Will I get a girlfriend/wife	1		2		1	3.0	3		
It's not contagious	1			2	1	3.5	4		
Others are afraid of touching me. They think it's contagious		2		1	1	3.3	3		
Feel that people seem scared	2		1		2	3.0	3		
Feel that people keep a distance	2		1		2	3.0	3		
Kept my distance from having a social life with others	3				2	2.6	1		
I've met people that would not shake my hand	2		2	1		2.4	3		
Are you contagious/non-contagious...	2		3			2.2	3		
Everyone stares	1	2			1	2.5	2		
Others are afraid that it is contagious		2	2			2.5	3		
People look at me funny	2	1			1	2.3	2		
When you go to work, you feel very dirty (hair made greasy by treatment/tar)		1		1	2	4.0	5		
Friends think it is helping, but it is not - it's f**king annoying when they comment on my flaky/oatmeal skin		2			2	3.5	4		

It looks ugly	1	1			2	3.3	4		
I think it is uncomfortable for others (girlfriend/wife) to hold my hand	2		2	1		2.4	3		
Confronted with my illness everyday	3				1	2.0	1		
Must always explain why you do not have a shot with your coffee		4	1			2.2	2		
Many offer me good advice - know-it-alls	2		3			2.2	3		
No understanding of the limitations caused by the illness (cannot drink a little schnapps)		4	1			2.2	2		
"It's not an illness that can kill you," but that does not alter the illness's impact on life	1	1	1	1		2.5	3		
Own attitude/personal perception									
The sooner you accept the illness the better			1	2	1	4.0	4		
The illness controlled my life more before I learned to accept it			2	1	2	4.0	4		
In my teenage years, I always had an answer ready if someone asked about the illness	2		3			2.2	3		
Will have to accept the illness	1			1	2	3.8	5		
Depends on the stage of your life when you are diagnosed (how old you are) as regards accepting the illness		1		2	1	3.8	4		
You must be careful that it does not take over your life	1		2	1		2.8	3		
I was dressed up in the summer - would not show myself due to the illness	1		2		1	3.0	3		
Will my children also suffer this illness?	1		1		2	3.5	4		
Decided early on that I would not bring children into the world - do not want them to experience the same thing			4		1	3.3	3		
When you reach the stage of daring to expose yourself, then you have won a battle			2	1	2	4.0	4		
I believe you have to be honest and speak about it			2	2		3.5	4		
I have decided that it is not my problem what others think	1			2	1	3.5	4	3.2	3
I don't want to hear about my "oatmeal"	1	1		1	1	3.0	3		
I don't want to hear that it is contagious or it's disgusting	1	1		1	1	3.0	3		
I told my friends that I do not want to constantly hear about the illness	2			1	1	2.8	3		
I won't cover myself up - if they want, they can just ask me	3				1	2.0	1		
It would be fine if my psoriasis remains stable - I can live with itching		2			3	3.8	5		
You learn to live with it		2	1		2	3.4	3		
Only learned to accept the illness at the age of 40			2	1	2	4.0	4		
Men are not as meticulous as women as regards appearance			3	1		3.3	3		
You cannot be cured of the illness		2		1	2	3.6	4		
"To be looked at and touched is very nice"	1		1	2		3.0	4		
I have to vacuum constantly (white flakes over everything)	2		2			2.0	2		
"Kids thought I had burned myself in a fire"	3				1	2.0	1		
I have never experienced itching	3		1			1.5	1		
Nivea cream can combat the worst dryness	1	4				1.8	2		
The impact of the illness/the illness itself									
There were jobs that I did not get because of my illness (was turned down by the Military - could not wear a helmet because I had psoriasis)			1		3	4.5	5		
People really focused on my hands (due to the illness) as regards my job (working with people)		1		1	2	4.0	5		
Jobs don't grow on trees (especially with illness)		2	1	2		3.0	3		
Absenteeism for treatment can be a problem		2	1	2		3.0	3		
My illness has prevented me from taking some jobs	1	1	1		1	2.8	3		
Psoriasis is triggered by stress			2		2	4.0	4		
I cannot tolerate alcohol - the illness flares up		2	2	1		2.8	3		
Stress can trigger the symptoms	2		1		2	3.0	3		
I think that psoriasis can be controlled through diet	1		3			2.5	3		
It is a lifelong treatment - it limits the joy when it works		2			3	3.8	5		
Due to large patches on my buttocks, it was hard to sit on the bus etc.				2	2	4.5	5		
Can I move to Aarhus and get my medication there?	1		1	1	1	3.3	4		
You must always take the medication	1	1	1		1	2.8	3		

When planning holidays, it must be taken into account when the medication must be taken etc.	1	1	1	1		2.5	3		
It is too difficult to bring the medication on vacation - we plan our vacation on that basis	1	1	1	1		2.5	3		
I would like to get a tattoo - but do not dare - imagine it caused the illness to come back	1		3			2.5	3		
I think about my illness, since it requires logistics (must be retrieved, brought along, etc.)	1	1	1	1		2.5	3		
I cannot just leave on my boat for long periods, because I must have the treatment	2		3			2.2	3		
*Rating - 1: 'Not important at all', 2: 'A little important', 3: 'Somewhat important', 4: 'Very important' and 5: 'Of great importance'.									