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

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To cite: Stisen ZR, Skougaard M, Christensen KR, *et al*. 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. *BMJ Open* 2023;**13**:e071586. doi:10.1136/bmjopen-2023-071586

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2023-071586).

Received 03 January 2023
Accepted 28 September 2023

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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 preforming 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 Systems[13]). 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 ()	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

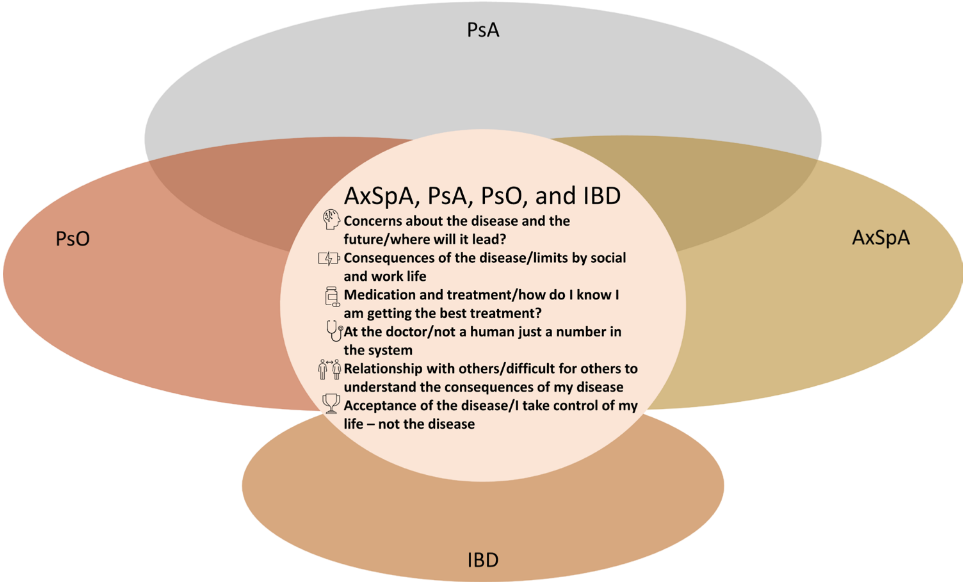

Figure 1 Generic concepts the participants agreed on independent of disease groups. AxSpA, axial spondyloarthritis; IBD, inflammatory bowel disease; PsA, psoriatic arthritis; PsO, psoriasis.

3). This suggests that the common determinator 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 lifelong physical impairment and functional disability.

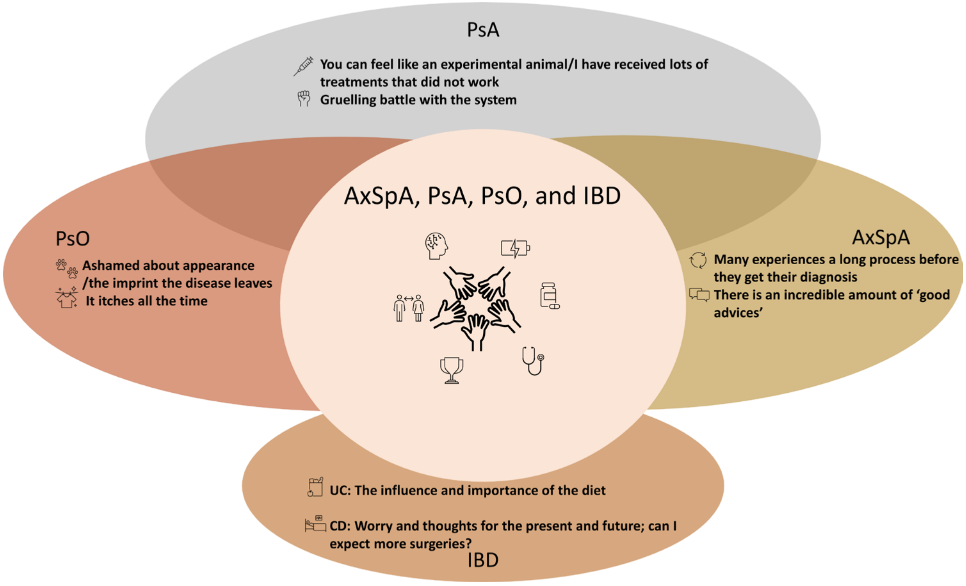

Figure 2 Concepts and important statements that are disease specific. AxSpA, axial spondyloarthritis; CD, Crohn's disease; IBD, inflammatory bowel disease; PsA, psoriatic arthritis; PsO, psoriasis; UC, ulcerative colitis.

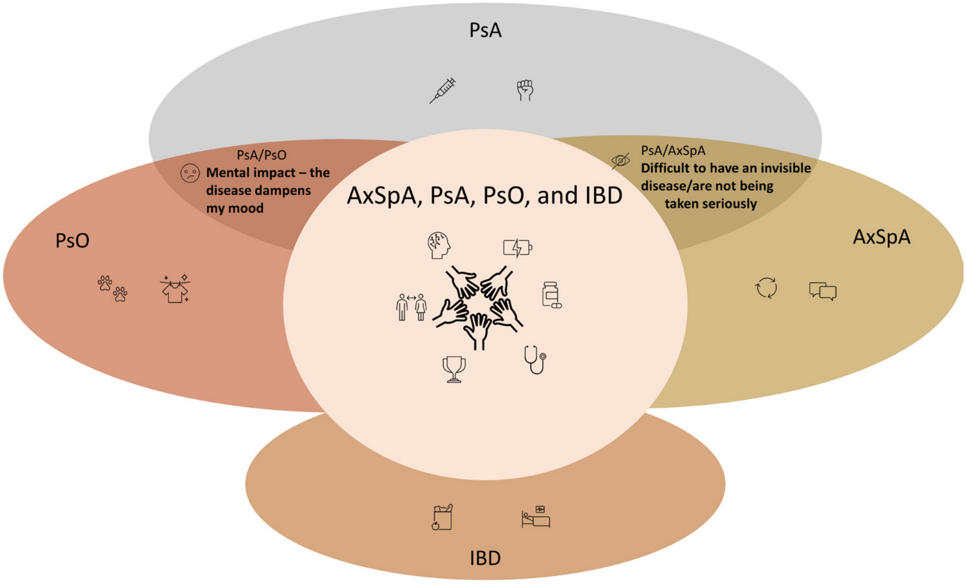

Figure 3 Concepts and important statements shared between only two of the disease groups. AxSpA, axial spondyloarthritis; IBD, inflammatory bowel disease; PsA, psoriatic arthritis; PsO, psoriasis.

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 multipurpose: 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.

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Acknowledgements We wish to acknowledge all participants in the study dedicating time and valuable knowledge on living a life with a chronic disease.

Contributors Conceptualisation: ZRS, MS, KRC, MAA, RLH, SFT, MM, LD, LEK and TSJ. Methodology: ZRS, MS, KRC, MAA, RLH, SFT, MM, LD, LEK and TSJ. Formal analysis: TSJ, MS, KRC and ZRS. Investigation: TSJ, MS, KRC and ZRS. Data curation: TSJ, MS, KRC, RLH and ZRS. Writing–original draft: TSJ and ZRS. Writing–review and editing: ZRS, MS, KRC, MAA, RLH, SFT, MM, LD, LEK and TSJ. Supervision: TSJ and LEK. Project administration: TSJ and ZRS. Funding acquisition: TSJ, LEK and ZRS. Guarantor: ZRS

Funding The Danish Rheumatism Association (award/grant no: R197-A7060), Danish Psoriasis Association (award/grant no: NA), Minister Erna Hamiltons Legat for videnskab og kunst (Award/Grant no: NA) and Oak Foundation (award/grant no: OCAY-18-774-OFIL).

Competing interests ZRS: none to declare. MS: has received research funding from Pfizer and Lilly. KRC: has served as speaker for Janssen and Pfizer and received funding from Pfizer and Gilead Nordic. MAA: Consultancy for Janssen and AbbVie. RLH: None to declare. SFT: Speaker or advisor for Sanofi, AbbVie, LEO Pharma, Pfizer, Eli Lilly, Novartis, UCB Pharma, Almirall and Janssen Pharmaceuticals, and received research support from Sanofi, AbbVie, LEO Pharma, Novartis, UCB Pharma, and Janssen Pharmaceuticals, outside the submitted work. MM: None to declare. LD: support for attending conferences from Janssen, UCB and Boehringer Ingelheim. Research grant from BMS, outside the submitted work. LEK: has served as a speaker and consultant for Pfizer, AbbVie, Amgen, UCB, Gilead, Biogen, BMS, MSD, Novartis, Eli Lilly, and Janssen and received research grants from Pfizer, AbbVie, UCB, Biogen, Novartis, Eli Lilly, and Janssen, outside the submitted work. TSJ: has served as a speaker and consultant for AbbVie, Pfizer, Roche, Novartis, UCB, Biogen, Gilead and Eli Lilly, outside the submitted work.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and informed consent from the participants was obtained before participation in the workshops. The project has been assessed by the Scientific Ethics Committees for the Capital Region of Denmark, who concluded, that it was not a health science research project as it is exclusively focus group interviews. The project was, therefore, not subject to notification, and we were permitted to perform it without permission from the Scientific Ethics Committees. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as online supplemental information.

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