





ORIGINAL ARTICLE

Development of a patient-reported experience measure for chronic inflammatory skin diseases

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Abstract

Background Patient involvement and high-quality patient-provider interactions are critical factors for quality of care in chronic inflammatory skin diseases. Also, assessing the patient's perspective contributes to optimizing care delivery and patient's experience. Until today, no user-friendly tools to measure patient experiences exist within immunodermatology.

Objectives The aim of this study was to identify the relevant items for patient's experience in immunodermatology and develop a concise questionnaire to assess patient's experience in routine clinical care.

Methods Potential relevant items for measuring patient's perspective of immunodermatology care were identified by a literature search. From this longlist, a shortlist from patient's perspective was distilled by semi-structured interviews with a diverse patient group. This list was reduced to final items using a modified Delphi method in a multi-stakeholder focus group. For each item, one question was formulated to generate the Patient-Reported Experience Measure (PREM) questionnaire. A first internal validation was achieved by an email round.

Results Forty longlist items were categorized into five domains (access to care, patient centeredness, access to information, care process and satisfaction). During interview rounds, 19 shortlist items were selected if mentioned by $\geq 40\%$ of interviewees. Via the focus group, the most important items were chosen by participant consensus. For each item, a question was formulated. The final PREM covers 11 items (plus 2 in case of a first consult). The first internal validation showed that the tool is clear, understandable and has an ideal length.

Conclusion This short user-friendly PREM can be used in scientific and routine settings to improve care for patients who suffer from chronic inflammatory skin diseases.

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Conflicts of interest

None.

Funding source

None.

Introduction

Inflammatory skin diseases comprise several complex chronic conditions (immunodermatoses), which are elicited by autoimmune- (e.g. psoriasis and bullous pemphigoid), autoinflammatory- (e.g. hidradenitis suppurativa) or allergic mechanisms (e.g. atopic dermatitis).¹ These conditions have a detrimental impact on physical, psychological, social functioning and severely impair patient's quality of life.² Recently, therapeutic options for these skin diseases have dramatically expanded and improved by the consequent use of immunosuppressants and the development of novel biologicals (e.g. anti-TNF-alpha-

or anti-IL-4/13 antibodies). Moreover, small molecules that regulate intracellular signalling processes (e.g. JAK-inhibitors) have become treatment options. These new modalities revolutionized the treatment of immunodermatoses. However, besides better disease control, targeting the immune systems harbours increased risks for side effects, such as renal damage and lethal sepsis. These treatment-associated risks require strict patient adherence to clinical and laboratory-based follow-up.^{3–5}

In this context, patients suffering from immunodermatoses require long-term high-quality medical care. This implies reliable patient adherence to diagnostic procedures and therapy,

which is crucial for medical outcomes. Patient involvement in their care and a good doctor-patient interaction were identified as basis for patient adherence. Thus, patient experiences strongly influence adherence and in consequence medical outcomes.⁶⁻⁸ Patient-reported experience measures (PREMs) are relatively new instruments that capture patient's perceptions of their experience with care delivery. PREMs differ from satisfaction questionnaires, which are rather general and subjective. PREMs measure specific aspects of the care process, which are highly valued by the patients, such as access to care, timeliness, quality of communication, behaviour of care providers and involvement in decision making.^{9,10} Acting on the findings from PREMs allows to improve (i) individual patient care, (ii) identify improvement areas and (iii) public information on the perceived quality of care.¹¹ In this context, the focus on the care delivery process can contribute to the optimization of patient's subjective well-being and to improve measurable medical outcomes, both of which are important to overall achievement of optimal high qualitative care.^{6,11} PREMs are not to be confused with patient-reported outcome measures (PROMs), which capture the patient's perception of their health status. PROMs measure outcomes of care like symptom burden (e.g. anxiety and depression). This aim of measuring can for example be clinical effectiveness and or safety.¹²

Although it is assumed that the majority of patients receive adequate care with substantial satisfaction, patient complaints occur regularly. Therefore, it is important to assess input from the patient's perspective to be able to identify relevant opportunities for improvement of the dermatological care delivery. This underlines the need of structured and systematic measurement of patient experiences as one of the qualitative pillars in order to ensure constant optimal care for patients with immunodermatoses. Currently, no user-friendly tools to measure patient experience of 'Immunodermatology consultations' exist. In Belgium, patient experiences were extensively measured hospital wide in 44 hospitals, which showed a modest increase in patient satisfaction over a period of 6 years. However, only weak associations between survey results and improvements were identified, which lead to the recommendation to develop more targeted approaches.¹³ This Flemish Patient Survey was used mainly for hospital-wide interventions and did not allow disease or care pathway-specific analysis of patient experience. Similarly, in the Netherlands, a 'Consumer Quality Index Chronic Skin disease' (CQI-CSD) was developed to measure quality of care from the patient's perspective. This 65-questions' CQI-CSD allows scientific analysis of patient experiences, but is too time consuming for patients to routinely provide feedback in a busy outpatient clinic.²

Goal of this study was to develop a patient-reported experience measure that allows routine measurement of patient experiences, especially in patient care and the management process in immunodermatology consultations. This PREM should be valid

to serve as proxy for patient-perceived quality of care and provide a basis for constant improvement of care delivery. The final PREM survey should be easy to understand for the patient and for which filling-in does not take long of the patient's time. Nevertheless, the PREM needs to comprise the most important items. Moreover, we aimed to achieve a first internal validation of this PREM within the participating patients and care providers.

Patients and methods

Study design

In order to gather the most relevant topics regarding immunodermatology consultations, a qualitative study was conducted by (i) a literature review, (ii) the use of semi-structured interviews, (iii) a focus group and (iv) mailing rounds. The study design was based on the Dutch guide for development of patient experience for measuring quality of care.¹¹

As a result of the literature review, a longlist of potential items for the PREM was elaborated using PubMed searches to identify existing tools and their characteristics. As search terms were used: 'patient reported experience', 'patient experience', 'patient perspective', 'inflammatory', 'chronic', 'skin', 'quality' and 'delivery of care' were used combined with either 'or' and 'and'. Based on the title, potentially relevant abstracts were analysed for content. Abstracts that revealed articles with relation to experience of care delivery for chronic diseases were retrieved in full text. Exclusion criteria were settings of acute care. Finally, 15 articles were defined as relevant. After analysis, structuring and discussion, a pool of items was rated as potentially relevant and categorized by consensus in 5 longlist domains: (i) access to care, (ii) access to information, (iii) patient centeredness, (iv) care process and (v) patient satisfaction.

The importance and adequacy of these items and possible missing relevant items were identified via patient interviews until saturation was reached ($n = 10$).

As the next step, an items' shortlist was generated by analysis and synthesis of the feedback from the interviews via a focus group with an expert panel (patients, nurses and dermatologists). In this step, consensus was reached over the most relevant items for the PREM among these stakeholders.

Finally, one relevant question was formulated for each shortlist item. Mailing rounds were used for the first internal validation to assess whether the drafted questions were judged as comprehensible and valid among the expert panel. The result of the mailing rounds serves as the final result of the PREM questions.

Selection of participants

To achieve a holistic view of the patient's vision, adult participants were recruited from the immunodermatology consultation at the UZ Brussel selected based on condition, disease duration

(acute, <6 months and chronic, >1-year disease duration), sex and age. Frequent diseases like atopic dermatitis and rare diseases like pemphigus vulgaris were included. Healthcare providers (HCPs; nurses, dermatologists and dermatology trainees) were selected based on experience with inflammatory skin diseases. Participants were recruited by personal contact, collaborated on a voluntary basis and signed the informed consent. Physicians were board-certified dermatologist from second- and third-line hospitals, as well as private practice-based and dermatology residents.

Data collection, processing and analysis

Ten patients were interviewed (semi-structured) by one researcher (EVDS) until data saturation was reached. Patients received the longlist with 49 items prior to the interview and were asked to rank the five most important, five very important and five important items. Patients could suggest additional relevant items not present in the longlist. The most frequently selected items by the patients formed the shortlist, which was further reduced by the focus group. For this process, 12 persons from different perspectives (patients and HCPs) were invited, ensuring an in-depth discussion from multiple perspectives.¹⁴ Consensus was reached following a modified Delphi method.¹⁵

Due to the restrictions imposed during the COVID-pandemic, face-to-face meetings were not possible, and therefore, both the interviews and the focus group took place per tele- or videoconference (Zoom Video Communications, Inc., San Jose, CA, USA). All conversations were audio-recorded and transcribed by one researcher (EVDS). Analysis and synthesis were conducted with NVIVO software, using thematic content analysis to identify new topics emerging from the data regarding patient's experiences.

As a form of triangulation, the transcripts were reviewed and independently coded by a second researcher. Disagreements in coding and categorization were discussed, and the coding framework refined as necessary using a constant comparison approach within the project team.¹⁶

Ethical considerations

The study followed the principles of the Declaration of Helsinki and obtained approval from the institutional ethics committee of the University Hospital UZ Brussel (ref. 2020/046).

Results

Description participants

In order to ensure a diverse patient population, 10 patients were selected for the interviews based on (Table 1): Four patients had frequent diseases (atopic dermatitis and psoriasis), and six patients suffered from rare diseases. Two patients were recently diagnosed, whereas eight patients lived already longer with their immunodermatological diagnosis. One of the patients acted also

as a patient representative of a patient organization. Six patients were male, and four were female; their average age was 58 years.

As care providers, two nurses from the UZ Brussel Dermatology department participated and eight dermatologists with different professional backgrounds were invited to take part in the focus group:

- Three senior dermatologists from two different university hospitals (UZ Leuven and UZ Brussel).
- Two dermatology residents.
- Three dermatologists worked in second-line hospitals or private office.

Topics and domains

The literature study identified 49 items, which formed the initial longlist (Table 2). These items could be categorized in five domains: (i) access to care, (ii) patient centeredness, (iii) access to information, (iv) care process and (v) patient satisfaction.

The highest share of the items fell into the domain of patient centeredness (29%) and access to care (27%), followed by access to care (18%), care process (16%) and patient satisfaction (10%; Fig. 1).

During interviews, patients had to indicate their preferred order of importance of longlist items and whether items were missing. Indeed, an extra item 'feeling comfortable with undressing during the physical examination' was identified during patient interviews.

Table 3 shows the shortlist with the 19 most recurring items, defined as important by at least 40% of the interviewed patients. In this ranking, the portions of the frequency of items between the five domains changed (Fig. 2). The domain patient centeredness covered the majority of items (53% instead of 29% in the longlist) and also items covering the care process ranked more frequently in the shortlist than in the longlist (21% instead of

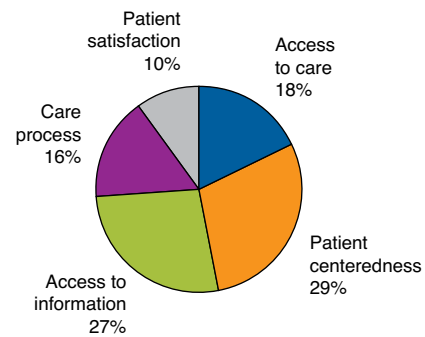
Table 1 Patient demographics

	Frequent disease:	Number <i>n</i> = 10
Diagnosis	Atopic dermatitis	2
	Psoriasis	2
	Rare skin disease:	
	Bullous pemphigus	2
	Granuloma annulare	1
	Dermatomyositis	1
	Pemphigus vulgaris	1
	Systemic sclerosis	1
Sex	M: 6 F: 4	
Age	Av. 58 years	
Time since diagnosis	<6 months: 2	
	>1 year: 8	

Table 2 Initial longlist domains and items

Domain	49 Longlist items
1. Access to care	<ol style="list-style-type: none"> 1. Time between making appointment and appointment itself 2. Unexpected cancellations 3. Time waiting room 4. Care access during office hours 5. Duration of the appointment (time spent with provider) 6. Mobility 7. Preferred care provider 8. Emergency contacts 9. Access to care between consultations
2. Patient centeredness	<ol style="list-style-type: none"> 1. Patient empowerment 2. Personal preferences taken into account 3. Emotional support 4. Opportunity to address questions 5. Care provider listens 6. Care provider takes enough time 7. Care provider shows respect 8. Shared decision making 9. Involvement family or partner 10. Who is who in your care team (clear roles and responsibility) 11. Providing understandable information and clear explanations 12. Giving clear answers to your questions 13. Providing understandable and clear explanations of treatment and medication 14. Providing understandable and clear explanations of disease and diagnosis
3. Access to information	<ol style="list-style-type: none"> 1. Administrative information 2. Information on other services, organizations 3. Sufficient information 4. Timing of providing information 5. Use of clinical record 6. Information source 7. Explanation disease 8. Explanation treatment 9. Explanation treatment plan 10. Explanation of possible flare of disease 11. Information about impact on daily life 12. Information on coping with your condition 13. Information on non-pharmacological care
4. Care process	<ol style="list-style-type: none"> 1. Effects of treatment 2. Care organization and coordination 3. Collaboration of care providers 4. Care of the general practitioner (GP) 5. Safety of care 6. Cleanliness healthcare facility 7. Privacy respected by healthcare facility 8. Confidence and trust in delivery of care
5. Patient satisfaction	<ol style="list-style-type: none"> 1. Satisfaction in general 2. Satisfaction about access to care 3. Satisfaction about delivered care 4. Satisfaction about care facility 5. Satisfaction about care providers

Translation from Dutch into English not linguistically validated.

**Figure 1** Domain and items longlist.**Table 3** Domains and items after analysis and synthesis interviews (shortlist)

Domain	Top items
Access to care	<ul style="list-style-type: none"> Emergency contacts Time between making appointment and appointment itself Time waiting room
Patient centeredness	<ul style="list-style-type: none"> Care provider listens Providing understandable information and clear explanations Opportunity to address questions Care provider takes enough time Emotional support Care provider shows respect Who is who in your care team (clear roles and responsibility) Personal preferences taken into account Providing understandable and clear explanations of treatment and medication Shared decision making
Access to information	<ul style="list-style-type: none"> Explanation disease Information on coping with your condition
Care process	<ul style="list-style-type: none"> Safety of care Confidence and trust in delivery of care Care organization and coordination Collaboration of care providers

Translation from Dutch into English not linguistically validated.

16%). The importance of access to care was almost unchanged in the shortlist (16% instead of 18%). Access to information was reduced in the shortlist (11% instead of 27%). Items covering patient satisfaction were not ranked sufficiently high to be incorporated in the shortlist.

The item 'feeling comfortable with undressing during the physical examination' that was brought up during interviews was only twice mentioned by patients and therefore was not taken up in the short list (cut-off 4 times rated as important).

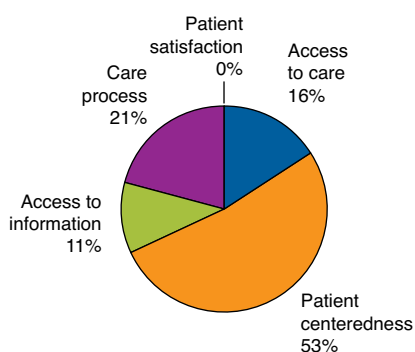


Figure 2 Domain and items shortlist.

The patients emphasized in the interviews that clear and understandable information is of high importance to them:

.. laymen’s language. . . well, medical language is ok, but it has to be understandable. They (the doctors) have to see whether the patient understands.

Other important quotes emphasize the importance of trust in the patient-physician relation and that taking the whole human and not only physical symptoms into account:

. . . the patient has to have a high confidence and believe in his treating medical specialist. . .

. . . the patient is more than the symptoms he has at the moment of consultation. He has to deal with it, he has to go working with it, run a family. . .

Chronic inflammatory skin conditions have a multifactorial disease burden, affecting not physical well-being, but greatly impact on social, sexual, professional or leisure activities. These individual dimensions are affected differently between patients, which led to the following statement:

. . . the doctor needs to know what is going on with the patient. . . Two patients can have the same disease, but each of them can experience it differently. . .The doctor should listen to the individual situation.

In the next step, a focus group with two patients and six dermatologists, two dermatology residents and two nurses was held to discuss, which shortlisted items should be used for the final PREM. Based on the 19-item shortlist, a consensus was reached in order to create a user-friendly questionnaire. The focus group decided upon 10 items. Two extra items were selected for an extended PREM in case of first-time consultation (Table 4A). Here, a further shift towards patient centeredness was observed, now covering 69% of the items (Fig. 3). However, two items referring to whether a patient has received understandable information can be attributed to the domain of ‘access to information’ as well as to the domain of ‘patient centeredness’.

Questions and internal validation

Based on the shortlist that was developed by the focus group, for each item, a question was formulated (10 + 2 questions in case of first-time consultation; Table 4B). The questions need to be answered using a fully labelled 5-point Likert scale (This scale is rather used when respondents are general public^{17,18}).

Table 4 Final domains and items of the PREM with drafted questions

Domain	Items (A)	Draft formulated questions and statements (B)
Patient centeredness	Possible combination or keeping split: ‘Care provider listens’ and ‘Opportunity to address questions’?	There is a good communication with the care provider
Patient centeredness	Shared decision making	I am actively involved in decisions about my treatment
Patient centeredness and access to information	Understandable, clear information on disease/diagnosis	I receive understandable information about my disease and prognoses
Patient centeredness and access to information	Understandable, clear information on treatment	I receive understandable information about the treatment and medication
Patient centeredness	Care provider takes enough time	The care provider takes enough time for me
Patient centeredness	Emotional support	The care provider shows empathy
Patient centeredness	Respect	The care provider treats me with respect
Patient centeredness	Personal preferences taken into account	My personal situation and preferences are taken into account
Care process	Confidence and trust in delivery of care	I have trust and confidence in the delivered care
Access to care	Time in waiting room	The waiting time in the waiting room before my appointment is acceptable
Extra question in case of the first consultation		
Access to information	Administrative information	The administrative aspects of care are clear
Access to care	Time between making appointment and appointment itself	Time between making appointment and appointment itself is acceptable

Translation from Dutch into English not linguistically validated.

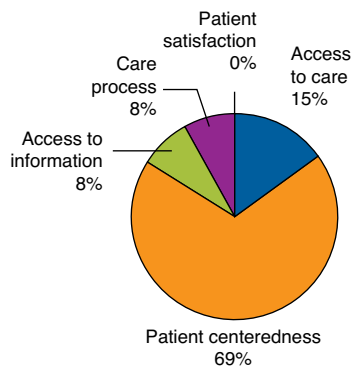


Figure 3 Domain and items final PREM.

In order to achieve internal validation, both the questionnaire and its instructions were distributed by email for evaluation to the interviewed patients and the HCP-group who participated in the focus group ($n = 20$). Table 5 shows the structured

Table 5 Evaluation questions on the draft PREM questionnaire by mailing round

<p>Should question 1 about 'good communication with the care provider' be split up in 1A and 1B?</p> <p>1A: 'The care provider listens to me' 1B: 'I have the opportunity to ask questions' Split up? Yes/No</p>
<p>Is the number of questions acceptable?</p> <p>Yes/No If no, why?</p>
<p>Are the instructions of the questionnaire clear?</p> <p>Yes/No If no: too long or too short?</p>
<p>Are there questions you like to add to the questionnaire?</p> <p>Yes/No If yes, which one?</p>
<p>Are there questions which can be deleted without changing the completeness of the questionnaire?</p> <p>Yes/No If yes, which one?</p>
<p>Is the content of the questions clear?</p> <p>Yes/No If no, why?</p>
<p>Do the questions cover the items?</p> <p>Yes/No If no, why?</p>

Translation from Dutch into English not linguistically validated.

questions used for the evaluation. This evaluation per email served as credibility check of the questionnaire.

Table 6 shows the result of this evaluation. One participant did not provide feedback. For question nr.1, whether the item 'good communication' should be split up into two questions 'the provider listens' and 'you have the opportunity to ask questions' 58% answered in favour for splitting up. Sixteen out of 19 participants rated the number of questions acceptable. The instructions of the questionnaire were clear to 16 of the 19 participants, while three participants raised comments concerning layout, use of some terms and wording. Additional questions were unnecessary according to

Table 6 Result of the evaluation on the questionnaire

Evaluation question	Yes	No	No feedback	Comments
1. Split up 'good communication' in 'listening' and opportunity to ask'?	11	8	1	• 'the two questions overlap'
2. Number of questions acceptable?	16	3	1	
3. Clear instructions?	16	3	1	• 'please shorten, so it fits on one page' • 'globally ok, only the term 'inflammatory skin disease' might not be very known by the patients, they use also rather eczema instead of atopic dermatitis' • 'word confidential is used twice; use please only once' • 'please mention that only the last consultation has to be considered'
4. Extra questions needed?	1	17	2	• 'adjust ranking of the questions: 3 as 2; 4 as 3 and 2 as 4'
5. Unnecessary questions?	2	17	1	• 'maybe question 5 is too much if question 1 is split up' • 'overlap between 2 and 8?' • 'involvement to strong? Rather only professional involvement'
6. Clear content?	18	1	1	• 'question 2: providing option for patients not wanting to be involved in decisions'
7. Questions covers items?	19	0	1	

$N = 20$.

Translation from Dutch into English not linguistically validated.

How do you agree with the following statement?	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. The provider listens to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I have the opportunity to ask questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I receive understandable information about my disease and prognoses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I receive understandable information about the treatment and medication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I am actively involved in decisions about my treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. The care provider takes enough time for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. The care provider shows empathy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The care provider treats me with respect.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My personal situation and preferences are taken into account.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I have trust and confidence in the delivered care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The waiting time in the waiting room before my appointment is acceptable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In case of the first consultation:					
12. The administrative aspects of care are clear.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Time between making appointment and appointment itself is acceptable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 4 Final PREM tool for immunodermatoses.

17 of 19 participants (one participant did not answer) and one proposed a different ranking of the questions. Seventeen of 19 participants did not identify unnecessary questions, although two participants might see an overlap. The content of the questions was considered to be clear by 18 of 19 participants. One participant recommended to foresee also a possible option for patients to not be actively involved in their medical decisions. The questions were unanimously approved to adequately assess the items.

The feedback on the questionnaire was discussed by the research group, and it was decided by voting whether to adjust the PREM in the following aspects:

- Splitting question 1 into two questions that separately address 'listening' and 'ability to ask questions' rather than asking only about 'good communication'.
- Changing the term 'atopic dermatitis' to 'atopic eczema'.
- Mentioning that only the last consultation has to be considered for filling-in the questionnaire.
- Switching the sequence of questions, number 2 (shared decision making) moves to place 4.
- Removing the words 'and anonymous' from the introduction to the PREM under the subject 'participation'.

Figure 4 shows the final PREM for chronic inflammatory skin diseases (translated from the original PREM in Dutch, not linguistically validated) with 11 plus 2 questions.

Discussion

We developed a concise questionnaire to measure patient experiences in order to ensure quality of care in routine clinical settings for immunodermatoses.

Different aspects of patient experience of care vary in importance by type of care, with a variation between items by type of hospitalization: on one hand between medical and surgical hospitalization and on the other hand by condition. He described aspects such as 'nurse communication', 'clean and quiet', 'staff responsiveness', 'doctor communication', 'pain control', 'communication about medication' and 'discharge information'. Thus, in order to be able to improve quality of care, it is relevant to target the aspects of care delivery that matter most for each type of care.¹⁹

To delineate what is important for an outpatient population suffering from immunodermatoses, it was important to start with a broad bottom-up approach, including providers from second- and third-line organizations. Patient sampling reflected the population consisting of multiple conditions with relevant

variables that affect patient's needs (sex, age, disease duration, rare vs. frequent diseases and newly diagnosed vs. chronic disease). Our patient sample was considerably smaller than the >1160 patients who participated in the development of the Dutch CQI-CSD.² Notably, the recruitment to our study was restricted due to the COVID-19 pandemic, but the recurrence of items judged as highly important reached saturation levels for developing a pilot-PREM for immunodermatoses.

The literature study delivered a broad range of 49 items that were identified from a diverse set of chronic inflammatory conditions, including the skin (systemic sclerosis), joints (rheumatic arthritis), lung (COPD, pulmonary hypertension) and chronic diseases in general.^{2,20–25} These items were classified into five domains of experience in order to provide insight on patient's needs in chronic care from a higher perspective. This approach is not consistently followed by other authors who sometimes include also some PROM-questions.²²

During the process of distilling items of the highest importance to patients from the 49-item longlist to the 19-item shortlist, a shift was observed from a rather equal distribution of topics within the domains, with two large clusters in the longlist patient centeredness 29% and access to information 27% vs. patient satisfaction, access to care and care process each ranging from 10 to 18%. Unexpectedly, patient satisfaction was not present in the shortlist anymore and items were dominated by patient centeredness (53%) and a cluster of three smaller domains (care process, access to care and access to information, accounting for 21%, 16% and 11% respectively). This trend was even stronger for the final PREM, in which 69% of items cover patient centeredness and access to care ranking second (15% of items). Items targeting mobility, cleanliness, use of medical record, other information resources, privacy, and satisfaction were not regarded as most important items. Although a very granular data set as obtained by the CQI-CSD2 might be useful to providers and provider organizations, the ideal length of survey has shown to be 11–15 questions, which take <8 min to answer.²⁶ Otherwise, the abandon rate and numbers of incomplete questionnaires rise.²⁶ This recommendation was confirmed by our own patients during interviews who agreed that a survey between 10 and 15 questions is acceptable, as validated by the mail round.

The focus on patient centeredness items identified in our study as highly valued by the patients with immunodermatoses is similar to other PREMS of chronic diseases. Dimensions of patients' experience of health care often focus on communication by treatment staff, interaction with the physician, confidence and trust.²³ However, a lot of variation exist between different PREMS for chronic diseases, such as using a mix of patient-reported experience and outcome questions.²² Others use more detailed disease-specific questions (e.g. about receiving information on smoking cessation, dietary guidance and assessment of depression development) or refer to care in another

clinical setting like primary care.^{27,28} Also, the experience of living with a certain disease instead of experience with healthcare providers is subject of existing questionnaires.²⁴ Moreover, PREMs are affected by culture, healthcare systems and languages used.²⁹

In conclusion, patient centeredness is of utmost importance and most highly valued by patients suffering from immunodermatoses. When developing a PREM, it is important to have a clear-cut aim in mind, such as comparing patients experience across individual providers, hospitals or identification of opportunities for improvement on a specific level. In our case, we aimed a concise and user-friendly questionnaire, with a maximum of 10 to 15 clear questions. This PREM will now be used for monitoring the quality of care in a routine immunodermatology clinic.

Data Availability Statement

Data will be made available upon request.

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