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LETTER TO THE EDITOR

Freedom from disease in plaque psoriasis: Comparing the perceived importance of voting round 2 statements from a Delphi consensus of patients, physicians and nurses

Dear Editor,

Psoriasis is a chronic disease that can have a profound effect on quality of life (QoL). Therefore, to ensure meaningful outcomes and appropriate target-setting in psoriasis treatment, it is important to consider patients' perspectives. To support this, we previously conducted a Delphi consensus on the definition of freedom from disease in psoriasis that included psoriasis patients, physicians and nurses.[1] The consensus highlighted that freedom from disease is multifaceted, comprising five key domains. Here, we report comparisons between the perceived importance of these five domains, and specific statements between patients, physicians and nurses; patients of different genders; and patients affected by different degrees of self-reported psoriasis severity. Identifying differences between these populations may aid conversations between people with psoriasis and healthcare professionals (HCPs) and facilitate the development of improved personalized treatment plans.

Overall, there was a high level of consensus between all analysed groups, although some differences in the perceived importance of various aspects of freedom from disease were observed. Physicians placed greater importance on the 'management of clinical symptoms' and 'well-being and QoL' domains relative to other groups, particularly for statements concerning skin clearance. Nurses rated the 'healthcare team support' domain as more important, and patients placed more importance on the cost of treatments than other groups (Figure 1).

Patients with milder psoriasis placed greater importance on 'psychosocial elements' and 'healthcare team support' relative to psoriasis patients with more severe disease. Having hope for the future and being able to focus on things other than their skin were particularly important to patients with milder psoriasis. Patients with moderate psoriasis placed numerically less importance on the management of clinical symptoms relative to patients who rated their disease as either 'mild' or 'severe'. They were less worried about lesions in non-visible areas and their skin being painful. Patients with severe psoriasis were less concerned with the cost of treatment relative to patients with milder forms of psoriasis (Figure 2).

Relative to males, females placed greater importance on 'psychosocial elements', particularly on feeling like they must cover up or consider psoriasis when choosing clothes or hairstyles and worrying about other people's reactions to their skin.

These differences provide an avenue for improving the connection between HCPs and patients in clinical practice. Our results further support the idea that people with psoriasis are more concerned with the cost of a treatment than physicians, with physicians prioritizing the management of clinical symptoms.[2] Physicians might, therefore, favour certain treatment options that have both high efficacy and cost, such as biologics, when an alternative treatment could more readily address a patient's concerns. In some populations, however, studies have shown that patients place less importance on cost,[3] and there can be variation across the population. For instance, patients already receiving biologics may view costs as a lower priority than those not receiving biologics.[4] This emphasizes that selecting the most patient-appropriate treatment requires a shared decision-making process to satisfy patient needs.

This research has limitations to bear in mind; some groups may not be representative due to heterogeneity among constituents. For instance, the patient population was enriched for those with mild disease. This may explain discrepancies in opinion between HCPs and patients, as the perspectives of HCPs may be more heavily influenced by interactions with more severely affected patients. The patient population was also enriched for people over 40 years of age, and age has been demonstrated to be a significant predictor of treatment preference.[5,6]

Nonetheless, this research highlights the importance of refining treatments for the individual while also providing insight into the preferences of certain groups of psoriasis stakeholders.

FUNDING INFORMATION

Janssen Pharmaceuticals.

CONFLICT OF INTEREST STATEMENT

I. van Ee: No conflicts of interest to declare. **E. Deprez:** Received consulting fees from Janssen. **A. Egeberg:** Received research funding from AbbVie, Boehringer Ingelheim, Bristol-Myers Squibb, Danish National Psoriasis Foundation, Eli Lilly, Janssen Pharmaceuticals, Kgl Hofbundtmager Aage Bang Foundation,

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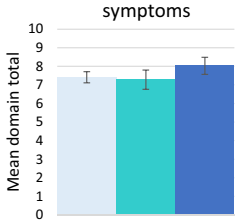
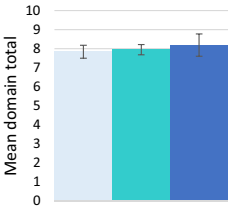
(a)



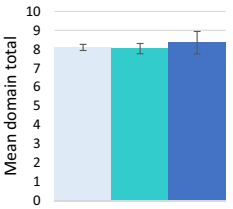
Individual domain statements	Patient	Nurse	Physician
I feel that I can keep my symptoms under control	7.92 (n=91)	7.92 (n=13)	8.52 (n=21)
I feel good in my skin	7.47 (n=91)	7.38 (n=13)	7.90 (n=21)
My skin is not itchy at all	7.32 (n=91)	7.23 (n=13)	7.90 (n=21)
My skin is not painful or sore	7.14 (n=91)	6.69 (n=13)	7.33 (n=21)
I am clear of all visible lesions on locations important to me (face, scalp, hands, etc.)	7.53 (n=91)	7.77 (n=13) Δ≥1	8.57 (n=21)
I am clear of lesions on my non-visible areas (knees, lower back, intimate areas, etc.) or those in difficult locations	7.10 (n=91)	6.69 (n=13)	7.95 (n=21) Δ≥1

(b)



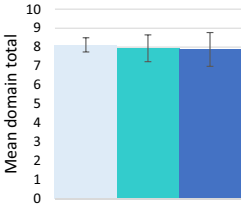
Individual domain statements	Patient	Nurse	Physician
My psoriasis does not define who I am	8.01 (n=80)	8.25 (n=12)	8.35 (n=20)
I can focus on things other than my skin	8.16 (n=80)	7.64 (n=11)	8.20 (n=20)
I am able to live a normal life and enjoy all the things that other people take for granted	8.09 (n=81)	7.67 (n=12)	9.05 (n=21) Δ≥1
I have hope for my future	8.16 (n=79) Δ≥1	8.17 (n=12) Δ≥1	6.95 (n=21)
I do not worry about peoples' reactions to my skin	7.45 (n=78)	8.08 (n=12)	8.19 (n=21)
I do not have to cover up or consider psoriasis when choosing clothes or my hairstyle	7.66 (n=77)	7.75 (n=12)	8.45 (n=20)
I am confident enough to pursue new relationships	7.28 (n=76)	8.25 (n=12)	8.19 (n=21)
My psoriasis does not affect my mood	7.86 (n=79)	7.75 (n=12)	8.10 (n=21)

(c)



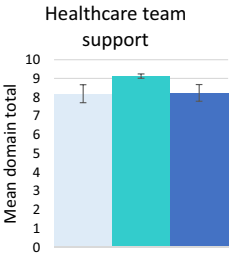
Individual domain statements	Patient	Nurse	Physician
My psoriasis does not disrupt my daily routine (work, housework, sleep, etc.)	7.95 (n=73)	8.50 (n=12)	8.65 (n=20)
My quality of life is independent of my psoriasis	8.23 (n=73)	7.83 (n=12)	8.38 (n=21)
I am comfortable being intimate with my partner	8.20 (n=74)	8.08 (n=12)	8.43 (n=21)
My psoriasis does not affect my social life	8.21 (n=71)	8.17 (n=12)	8.57 (n=21)
My psoriasis does not affect my relationships	8.16 (n=73)	7.83 (n=12)	8.90 (n=20) Δ≥1
I am not a burden to my family and friends because of my psoriasis	7.85 (n=73)	7.83 (n=12)	7.20 (n=20)

(d)



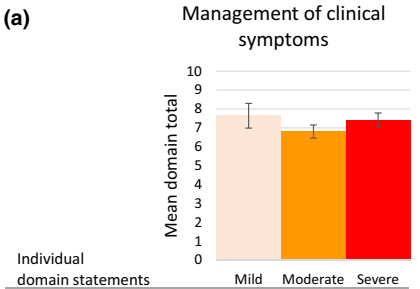
Individual domain statements	Patient	Nurse	Physician
I have access to all treatments that I need to manage my symptoms	8.42 (n=73)	8.75 (n=12)	8.90 (n=20)
My treatment helps me feel in control of my disease	8.07 (n=73)	8.42 (n=12)	8.90 (n=20)
My treatment has a long-lasting effect	8.42 (n=71)	8.42 (n=12)	8.45 (n=20)
I have broken the cycle of hope and disappointment	7.89 (n=72)	7.25 (n=12)	7.35 (n=20)
I do not worry about the side effects of my skin treatment	7.94 (n=72)	7.67 (n=12)	7.80 (n=20)
I do not worry about the cost of my skin treatment	7.53 (n=73)	6.83 (n=12)	6.65 (n=20)
I understand my psoriasis and know what treatments are available	8.58 (n=72) Δ≥1	8.25 (n=12) Δ≥1	7.10 (n=20)

(e)

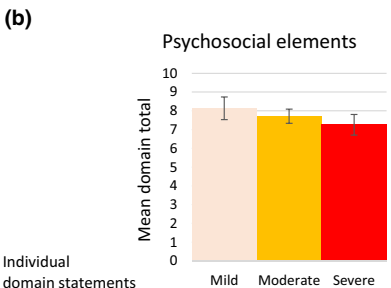


Individual domain statements	Patient	Nurse	Physician
I have access to the clinical support that I need to manage my symptoms and their consequences	8.06 (n=71) Δ≥1	9.08 (n=12)	8.30 (n=20)
My doctor/nurse understands how I feel and what I need from my treatment	8.04 (n=71) Δ≥1	9.17 (n=12)	8.45 (n=20)
I understand what my doctor/nurse tells me about my psoriasis and treatment	8.86 (n=71)	9.00 (n=12)	8.30 (n=20)
My doctor/nurse and I trust and acknowledge each other's expertise, and we work together to come to a mutually agreed plan for me	8.34 (n=71)	9.25 (n=12)	8.60 (n=20)
I trust the information that my healthcare team provide me with more than internet search results	8.56 (n=71)	8.92 (n=12)	8.55 (n=20)
I have a good relationship with my healthcare team so that I can talk about health problems associated with psoriasis	8.27 (n=70)	9.25 (n=12)	8.30 (n=20)
I can work with my healthcare team on decisions about treatment and lifestyle habits	8.15 (n=71) Δ≥1	9.17 (n=12) Δ≥1	8.15 (n=20)
My doctor/nurse takes cares of me, not just my psoriasis	7.23 (n=71) Δ≥1	9.17 (n=12) Δ≥1	7.20 (n=20)

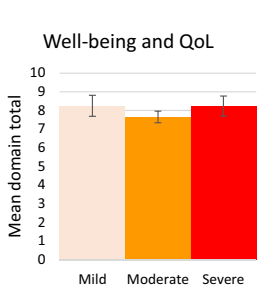
FIGURE 1 Average domain and individual statement scores between patients, nurses and physicians for each domain: (a) management of clinical symptoms, (b) psychosocial elements, (c) well-being and QoL, (d) treatment and (e) healthcare team support. Error bars denote the standard deviation. Lines highlight numerical differences of ≥1; note that the data are descriptive only and lines do not denote any statistical significance. Respondent type was not disclosed by five respondents. The n numbers have been included for the individual statements. The mean domain totals were calculated by averaging the scores for each statement. QoL, quality of life.



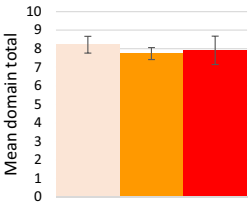
Individual domain statements	Mild	Moderate	Severe
I feel that I can keep my symptoms under control	8.67 (n=21)	7.43 (n=37)	7.50 (n=22)
I feel good in my skin	8.19 (n=21)	6.92 (n=37)	7.09 (n=22)
My skin is not itchy at all	7.48 (n=21)	6.65 (n=37)	7.41 (n=22)
My skin is not painful or sore	7.38 (n=21)	6.49 (n=37)	7.05 (n=22)
I am clear of all visible lesions on locations important to me (face, scalp, hands, etc.)	7.19 (n=21)	6.84 (n=37)	8.09 (n=22)
I am clear of lesions on my non-visible areas (knees, lower back, intimate areas, etc.) or those in difficult locations	6.95 (n=21)	6.51 (n=37)	7.36 (n=22)



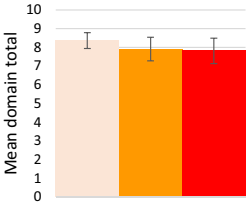
Individual domain statements	Mild	Moderate	Severe
My psoriasis does not define who I am	7.80 (n=20)	8.37 (n=30)	7.25 (n=20)
I can focus on things other than my skin	8.70 (n=20)	7.63 (n=30)	7.75 (n=20)
I am able to live a normal life and enjoy all the things that other people take for granted	8.45 (n=20)	7.87 (n=31)	7.45 (n=20)
I have hope for my future	9.20 (n=20)	7.70 (n=30)	7.37 (n=19)
I do not worry about peoples' reactions to my skin	7.80 (n=20)	7.24 (n=29)	7.11 (n=19)
I do not have to cover up or consider psoriasis when choosing clothes or my hairstyle	8.00 (n=20)	7.68 (n=28)	6.89 (n=19)
I am confident enough to pursue new relationships	7.75 (n=20)	7.22 (n=27)	6.21 (n=19)
My psoriasis does not affect my mood	7.35 (n=20)	8.00 (n=30)	8.00 (n=19)



Individual domain statements	Mild	Moderate	Severe
My psoriasis does not disrupt my daily routine (work, housework, sleep, etc.)	7.17 (n=18)	7.56 (n=27)	8.78 (n=18)
My quality of life is independent of my psoriasis	8.61 (n=18)	7.44 (n=27)	8.56 (n=18)
I am comfortable being intimate with my partner	8.22 (n=18)	8.25 (n=28)	7.83 (n=18)
My psoriasis does not affect my social life	8.71 (n=17)	7.70 (n=27)	8.17 (n=18)
My psoriasis does not affect my relationships	8.28 (n=18)	7.43 (n=28)	8.67 (n=18)
I am not a burden to my family and friends because of my psoriasis	8.50 (n=18)	7.50 (n=28)	7.39 (n=18)



Individual domain statements	Mild	Moderate	Severe
I have access to all treatments that I need to manage my symptoms	8.78 (n=18)	7.69 (n=29)	8.63 (n=16)
My treatment helps me feel in control of my disease	8.61 (n=18)	7.29 (n=28)	7.88 (n=17)
My treatment has a long-lasting effect	8.28 (n=18)	8.08 (n=26)	8.35 (n=17)
I have broken the cycle of hope and disappointment	7.83 (n=18)	7.56 (n=27)	7.47 (n=17)
I do not worry about the side effects of my skin treatment	7.94 (n=17)	7.61 (n=28)	8.12 (n=17)
I do not worry about the cost of my skin treatment	7.56 (n=18)	7.68 (n=28)	6.41 (n=17)
I understand my psoriasis and know what treatments are available	8.50 (n=18)	8.25 (n=28)	8.50 (n=16)



Individual domain statements	Mild	Moderate	Severe
I have access to the clinical support that I need to manage my symptoms and their consequences	8.00 (n=17)	7.81 (n=27)	7.65 (n=17)
My doctor/nurse understands how I feel and what I need from my treatment	8.00 (n=17)	7.93 (n=27)	7.53 (n=17)
I understand what my doctor/nurse tells me about my psoriasis and treatment	8.76 (n=17)	8.67 (n=27)	8.76 (n=17)
My doctor/nurse and I trust and acknowledge each other's expertise, and we work together to come to a mutually agreed plan for me	8.29 (n=17)	8.07 (n=27)	8.18 (n=17)
I trust the information that my healthcare team provide me with more than internet search results	9.06 (n=17)	8.04 (n=27)	8.59 (n=17)
I have a good relationship with my healthcare team so that I can talk about health problems associated with psoriasis	8.59 (n=17)	8.11 (n=27)	7.82 (n=17)
I can work with my healthcare team on decisions about treatment and lifestyle habits	8.35 (n=17)	8.15 (n=27)	7.18 (n=17)
My doctor/nurse takes cares of me, not just my psoriasis	7.82 (n=17)	6.48 (n=27)	6.76 (n=17)

FIGURE 2 Average domain and individual statement scores between people with mild, moderate or severe psoriasis for each domain: (a) management of clinical symptoms, (b) psychosocial elements, (c) well-being and QoL, (d) treatment and (e) healthcare team support. Error bars denote the standard deviation. Lines highlight numerical differences of ≥1; note that the data are descriptive only and lines do not denote any statistical significance. Self-reported psoriasis severity was not disclosed by 11 patients. The n numbers have been included for the individual statements. The mean domain totals were calculated by averaging the scores for each statement. QoL, quality of life.

Novartis, Pfizer, Simon Spies Foundation; received honoraria as consultant and/or speaker from AbbVie, Almirall, Boehringer Ingelheim, Bristol-Myers Squibb, Dermavant, Eli Lilly and Company, Galápagos NV, Galderma, Horizon Therapeutics, Janssen Pharmaceuticals, Leo Pharma, McNeil Consumer Healthcare, Mylan, Novartis, Pfizer, Samsung Bioepis Co., Ltd., Sun Pharmaceuticals, UCB, Union Therapeutics, Zuellig Pharma Ltd.; received honoraria for participation in advisory boards from AbbVie, Almirall, Boehringer Ingelheim, Bristol-Myers Squibb, Dermavant, Eli Lilly and Company, Galápagos NV, Janssen Pharmaceuticals, Leo Pharma, Mylan, Novartis, Pfizer, Samsung Bioepis Co., Ltd., UCB, Union Therapeutics. **C. Conrad:** Received research funding for AbbVie, Actelion, Amgen, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Eli Lilly, Galderma, Janssen, LEO Pharma, Novartis, Pfizer; received honoraria for consultancy, speaking, and/or participation in an advisory board from AbbVie, Amgen, Actelion, Amgen, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene, Eli Lilly, Galderma, Incyte, Janssen, LEO Pharma, MSD, Novartis, Pfizer, Samsung, UCB; received payment for expert testimony from; served in a fiduciary leadership role for SSDV, ESDR. **V. Corazza:** No conflicts of interest to declare. **L. Donati:** No conflicts of interest to declare. **J. Lambert:** Received unrestricted grants from AbbVie, Almirall, Celgene, Eli Lilly, Janssen-Cilag, LEO Pharma, Novartis, UCB; served as a speaker for AbbVie, Almirall, Bristol-Myers Squibb, Janssen-Cilag, Pfizer, UCB; served as a consultant for AbbVie, Bristol-Myers Squibb, Celgene, Eli Lilly, Janssen-Cilag, LEO Pharma, Novartis, UCB. **R. Lăpădatu:** Received consulting fees from GlaxoSmithKline. **A. Meyer:** No conflicts of interest to declare. **C. Paul:** Received research grants from AbbVie, Boehringer Ingelheim, Celgene, Eli Lilly, Janssen, Pierre Fabre, Sanofi, UCB; received honoraria for consultancy from AbbVie, Almirall, Amgen, Boehringer Ingelheim, Celgene, Eli Lilly, Janssen, LEO Pharma, Merck, Pierre Fabre, Pfizer, Regeneron, Sanofi, UCB. **R. Penzer-Hick:** Received consultancy fees from AbbVie, Amgen, Recordati. **K. Stephen:** Received consultancy fees and travel support from AbbVie, Almirall, Janssen, LEO Pharma, Novartis, UCB; received speaking fees from AbbVie, Almirall, Janssen, LEO Pharma, Novartis. **J. van der Zon:** No conflicts of interest to declare. **A. Bewley:** Received ad hoc honoraria or travel grants from AbbVie, Almirall, Eli Lilly, Galderma, Janssen, LEO Pharma, Novartis, Sanofi, UCB. Medical writing and editorial support were provided by Lumanity and funded by Janssen.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from Lumanity upon request (commsme-janssendermatology@lumanity.com).

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