

# Mapping the Effect of Psoriatic Arthritis Using the International Classification of Functioning, Disability and Health

Tania Gudu, Uta Kiltz, Maarten de Wit, Tore Kristian Kvien, and Laure Gossec

**ABSTRACT. Objective.** The effect of a disease can be categorized by a standardized reference system: the International Classification of Functioning, Disability and Health (ICF). The objective was to map the effect of psoriatic arthritis (PsA) from the patient's perspective to the ICF.

**Methods.** A systematic literature review was performed. Qualitative publications reporting domains of impact important for patients with PsA were identified using the following terms: ("psoriatic arthritis") AND ("quality of life" OR "impact"). Meaningful concepts were extracted from the publications, grouped into domains and linked to the ICF categories. The number of concepts linked to each ICF category and to each ICF level was calculated. The number of concepts not linkable was also calculated.

**Results.** Eleven studies (13 articles) were included in the analysis. Twenty-five domains of impact were cited, of which the ability to work/volunteer and social participation were the most cited (both by 10 studies). In total, 258 concepts were identified, of which 217 could be linked to 136 different ICF categories; 41 concepts, mostly personal factors, could not be precisely linked. The most represented ICF component was activities and participation (42.6%) rather than body structures (10.3%) or body functions (29.4%). Ten studies (90.9%) reported impairments in the ability to work/volunteer and social participation, and 7 (63.6%) reported leisure activities, family and intimacy, pain, skin problems, and body image.

**Conclusion.** PsA widely affects all aspects of patients' lives, in particular aspects related to activities and participation. The ICF is a useful approach for the classification of disease effect. (J Rheumatol First Release December 15 2016; doi:10.3899/jrheum.160180)

## Key Indexing Words:

PSORIATIC ARTHRITIS

PATIENT PERSPECTIVE

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

QUALITY OF LIFE

SOCIETAL BURDEN

EMOTIONAL FUNCTIONS

From the Sorbonne Universités, UPMC Univ Paris 06, Institut Pierre Louis d'Epidémiologie et de Santé Publique, GRC-UPMC 08 (EEMOIS); AP-HP, Pitié Salpêtrière Hospital, Department of Rheumatology, Paris, France; Research Center of Rheumatic Diseases, Sf. Maria Hospital, University of Medicine and Pharmacy Carol Davila, Bucharest, Romania; Rheumazentrum Ruhrgebiet, Herne and Ruhr-University Bochum, Herne, Germany; Patient Research Partner, People with Arthritis/Rheumatism in Europe (EULAR PARE), Zurich, Switzerland; Department of Rheumatology, Diakonhjemmet Hospital, Oslo, Norway.

T. Gudu, MD, Sorbonne Universités, UPMC Univ Paris 06, Institut Pierre Louis d'Epidémiologie et de Santé Publique, GRC-UPMC 08 (EEMOIS), and AP-HP, Pitié Salpêtrière Hospital, Department of Rheumatology, and Research Center of Rheumatic Diseases, Sf. Maria Hospital, University of Medicine and Pharmacy Carol Davila; U. Kiltz, MD, Rheumazentrum Ruhrgebiet, Herne and Ruhr-University Bochum; M. de Wit, PhD, Patient Research Partner, EULAR PARE; T.K. Kvien, MD, PhD, Professor of Rheumatology, Department of Rheumatology, Diakonhjemmet Hospital; L. Gossec, MD, PhD, Professor of Rheumatology, Sorbonne Universités, UPMC Univ Paris 06, Institut Pierre Louis d'Epidémiologie et de Santé Publique, GRC-UPMC 08 (EEMOIS), and AP-HP, Pitié Salpêtrière Hospital, Department of Rheumatology.

Address correspondence to Prof. L. Gossec, Hôpital Pitié-Salpêtrière, Service de Rhumatologie, 47-83, Boulevard de l'Hôpital, 75013 Paris, France. E-mail: laure.gossec@aphp.fr

Accepted for publication November 11, 2016.

Psoriatic arthritis (PsA) is a heterogeneous disease with a major effect on patients' lives<sup>1,2,3,4</sup>. In PsA, the range of problems experienced by patients is broad and involves basic day-to-day activities, work and leisure activities, and community participation roles<sup>5</sup>. The effect of a disease can be better assessed from the patient's perspective by qualitative studies because they can identify patients' experiences<sup>6</sup>. There are several studies to assess the patient's perspective regarding the effect of PsA<sup>7,8,9,10</sup>. Although some aspects such as pain, skin, or functional disability are frequently cited, others such as fatigue are more rarely cited<sup>11</sup>. Overall, it is difficult to obtain an overview of the effect of PsA. Therefore, it would be of particular interest to categorize this effect by relating it to a universally accepted, standardized reference system.

The International Classification of Functioning, Disability and Health (ICF) has been developed and endorsed by the World Health Organization as the standard language and classification system for functioning and disability<sup>12</sup>. In the ICF, functioning and disability are multidimensional

concepts. Both are umbrella terms for body function, body structures, and activities and participation. They denote the positive or neutral aspects (for functioning) or negative aspects (for disability) of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors)<sup>12</sup>.

The ICF can be used as a reference framework, allowing a researcher or a group of experts assigned to develop a set of recommendations to see which domains of functioning/disability are covered by a specific set of domains of impact and vice versa<sup>13</sup>. Linking rules are available to standardize the process of connecting outcome measures to the ICF classification<sup>14,15</sup>. Linking domains of impact in PsA to the ICF would allow us to structure and categorize the effect of PsA and to compare it with other diseases. Further, this linking may reveal limitations of the ICF, i.e., domains that are important for patients but are not covered by the ICF<sup>14,16,17,18</sup>. A study assessed the effect of PsA in patients with PsA according to the ICF categories, but the sample size was small (94 patients) and did not reflect the overall effect that can be assessed through a systematic literature review<sup>19</sup>.

The objective of our work was to assess the patient-perceived effect of PsA through a systematic literature review and to map this effect to the ICF.

## MATERIALS AND METHODS

*Identification of publications with domains of impact important for patients with PsA.* A systematic literature review was conducted by 1 person (TG) in the PubMed/Medline and Embase databases on March 6, 2015. Publications were identified through a search that used the following terms: ("psoriatic arthritis") AND ("quality of life" OR "impact"), with a limitation to "Humans," "all adults: 19+ years," and "English," but with no limitation of time. Articles were also searched among any available unpublished work from recent congresses and among references of included articles. Only studies related to the effect of PsA from the patient's perspective were included, i.e., studies with a qualitative design or a qualitative component. The detailed methodology is presented in Supplementary Table 1 (available with the online version of this article).

The quality of the included studies was assessed according to the Critical Appraisal Skills Program checklist<sup>20</sup> for qualitative studies and the National Heart, Lung and Blood Institute checklist<sup>21</sup> for quantitative studies.

*Identifying domains of impact important for patients with PsA and extracting corresponding concepts.* Domains of impact were identified by 2 people (TG, LG) in the studies included in the systematic literature review. A domain was defined according to the Outcome Measures in Rheumatology recommendations as referring to relevant areas of outcome in rheumatology outcome studies<sup>22,23</sup>. To avoid confusion related to terminology, because second-level ICF categories are also called "domains of health," it was decided to name the domains identified in the studies as "domains of impact" and the units of the ICF only as "components" and "categories". Concepts were also generated from these sources. A concept was defined as 1 separate meaningful entity, such as a body structure, a body function, an activity, or a contextual factor<sup>7</sup>. An example of how this step was performed can be found in Supplementary Table 1 (available with the online version of this article).

*Linking concepts to the ICF.* The ICF part 1 covers functioning and disability and includes the components body functions, body structures, and activities and participation. Part 2 covers contextual factors and includes the components environmental factors and personal factors. The ICF consists of

multiple categories in each of these sections<sup>12</sup>. The detailed structure of the ICF is described in the Supplementary Table 1 (available with the online version of this article).

The identified concepts were linked to the ICF categories. The linking process was performed separately (blinded) by 2 independent raters (TG, UK) and a third rater for adjudication (LG) according to the updated linking rules<sup>15</sup> (Supplementary Table 1, available with the online version of this article). Some concepts that cannot be precisely linked are considered as not linkable by the ICF<sup>15</sup>. Concepts that were linked to the ICF domain personal factors could not be linked to categories because personal factors are not yet classified in the ICF<sup>13,15</sup>.

## RESULTS

*Systematic literature review.* In all, 643 publications were identified by the systematic literature review: 239 in PubMed/Medline and 404 in Embase. After removing duplicates, 460 publications were retained and screened, and 2 articles were added by hand search: 1 from the references of included articles and 1 from the professional meetings. Twelve articles and 1 congress abstract were included in our final analysis (Figure 1)<sup>10,24,25</sup>.

Of these 13 publications, 8 were exclusively on PsA<sup>7,9,10,24,25,26,27,28</sup> whereas the other 5<sup>29,30,31,32,33</sup> included patients with PsA and also patients with psoriasis (PsO) without arthritis (Table 1)<sup>7,9,10,24,25,26,27,28</sup>. Only 5 studies were qualitative *per se*; the other studies used qualitative work in the development of questionnaires and some of them did not precisely define the population involved in their qualitative phases, so the evaluation in these cases was difficult (Table 1).

*Domains of impact important for patients with PsA and extracting corresponding concepts.* Ten studies (90.9%) reported on the ability to work/volunteer and social participation, and 7 (63.6%) reported on leisure activities, family and intimacy, and other domains such as pain, skin problems, and body image. Joint problems were reported in almost half of the studies (45.5%).

*Linking concepts to the ICF.* In total, 258 concepts were extracted, of which 217 (84.1%) could be linked to the ICF categories. The agreement between raters was high (87.2%).

The 217 concepts were linked to 136 distinct ICF categories, of which 14 (10.3%) were part of body structures, 40 (29.4%) body functions, 58 (42.6%) activities and participation, and 24 (17.6%) environmental factors (Figure 2).

There were some differences regarding the number of the ICF categories and components when comparing by the type of study. In purely qualitative studies, concepts were linked to 92 ICF categories, the most represented ICF component being activities and participation (39.1%), followed by body functions (29.3%), environmental factors (20.7%), and body structures (10.9%). In studies with both quantitative and qualitative phases, concepts could be linked to 84 ICF categories, and activities and participation was also the most represented component (44.1%). Body functions represented 34.5%, environmental factors 14.3%, and body structures 7.1%.

Table 1. Studies included in the systematic literature review.

Studies	Methodology	Patients Involved in the Validation Phase of a Questionnaire	Patients Involved in the Qualitative Phase of Developing a Questionnaire /in a Qualitative Study	Study Quality Assessment*
Studies exclusively on PsA				
Gossec, <i>et al</i> <sup>9</sup>	Qualitative and quantitative	474 patients with PsA; 49.8% males; age: 50.4 (12.6); disease duration: 9.6 (9.4) yrs	12 patients with PsA from 12 European countries	Quantitative phase 8/9; qualitative phase 3/10
Torre-Alonso, <i>et al</i> <sup>26</sup>	Qualitative and quantitative	323 patients with PsA; age: 48.7 (11.8)	66 patients with PsA (7 focus groups)	Quantitative phase 8/9; qualitative phase 4/10
Wink, <i>et al</i> <sup>24</sup>	Qualitative and quantitative	211 patients with PsA; 54% males; mean age: 51.9; disease duration: median 6.6 yrs	10 patients with PsA (5 males); age: 39–79	Quantitative phase 5/9; qualitative phase 3/10
Szentpetery, <i>et al</i> <sup>27</sup> Palominos, <i>et al</i>	Qualitative	NA	6 patients with PsA; 3 males; age: 57.5 (10.9); disease duration: 20.3 (11.6) yrs	9/10
Hu, <i>et al</i> <sup>28</sup>	Qualitative and quantitative	60 patients with PsA; 70% were > 45 yrs	ND	Quantitative phase 6/9; qualitative phase ND
Billing, <i>et al</i> <sup>25</sup>	Qualitative and quantitative	123 patients with PsA; 46.7% males; age: 51.2 (14.8); disease duration: 5 (3.9) yrs	11 patients with PsA	Quantitative phase 5/9; qualitative phase 3/10
Stamm, <i>et al</i> <sup>7</sup>	Qualitative	NA	31 patients with PsA; age: 52.7 (11.1)	9/10
McKenna, <i>et al</i> <sup>10</sup>	Qualitative and quantitative	286 patients with PsA; 32.5% males; age: 50.6 (12.6); disease duration: 12.5 (10.2) yrs	48 patients with PsA; 66.6% males; age: 46.9 (13.4); disease duration: 12.1 (1–40) yrs	Quantitative phase 6/9; qualitative phase 6/10
Studies including also patients with psoriasis without arthritis				
Leino, <i>et al</i> <sup>29</sup>	Qualitative	NA	262 patients with psoriasis; 34 (12.7%) had PsA; 55% males; mean age: 58.4	6/10
Augustin, <i>et al</i> <sup>30</sup>	Qualitative and quantitative	203 patients with nail psoriasis; 30.3% had PsA; age: 49.3 (13.3)	120 patients with nail psoriasis: 100 from Germany, 20 from the United States	Quantitative phase 5/9; qualitative phase 5/10
Meyer, <i>et al</i> <sup>31</sup>	Qualitative and quantitative	590 patients with psoriasis; 34.6% had PsA; 48.7% males; mean age: 55.8 (18–88)	ND	Quantitative phase 7/9; qualitative phase ND
Globe, <i>et al</i> <sup>32</sup>	Qualitative	NA	39 patients with psoriasis; 3% had PsA; 43.6% males; age: 45 (22–26) for the severe psoriasis group, 36 (20–74) for the mild psoriasis group	8/10
Uttjek, <i>et al</i> <sup>33</sup>	Qualitative	NA	18 patients with psoriasis; 38.9% had PsA; 50% males; age: 58 (37–74)	10/10

\*Evaluation of the studies' quality was depicted as the number of fulfilled criteria out of the total applicable criteria for each type of study, either qualitative<sup>20</sup> or quantitative<sup>21</sup>. PsA: psoriatic arthritis; NA: not applicable; ND: not defined.

There were also some differences when comparing studies by the type of patients involved. In the studies including patients with PsA and also patients with PsO without arthritis, 56 ICF categories were linked, while in the studies involving patients with only PsA, 117 ICF categories were linked. Activities and participation was the most represented ICF component in the studies involving patients with PsO with or without arthritis (48.2%), followed by body functions (30.3%), body structures, and environmental factors (3.6% each). On the other hand, in the studies exclusively on PsA, the proportion of ICF categories in activities and participation

and body functions was not as different: 37.6% and 30.7%, respectively. Environmental factors represented 19.7% and body structures 12%.

*Frequency of ICF categories.* In total, 344 second-level ICF categories were identified among all included studies. The most frequent second-level ICF categories for each ICF component and their corresponding linked concepts are depicted in Table 2. The most frequent second-level category was b152: emotional functions (reported 45 times, i.e., 13% of 344), followed by d920: recreation and leisure (23 times, i.e., 6.7%). Also cited frequently were b134: sleep functions,

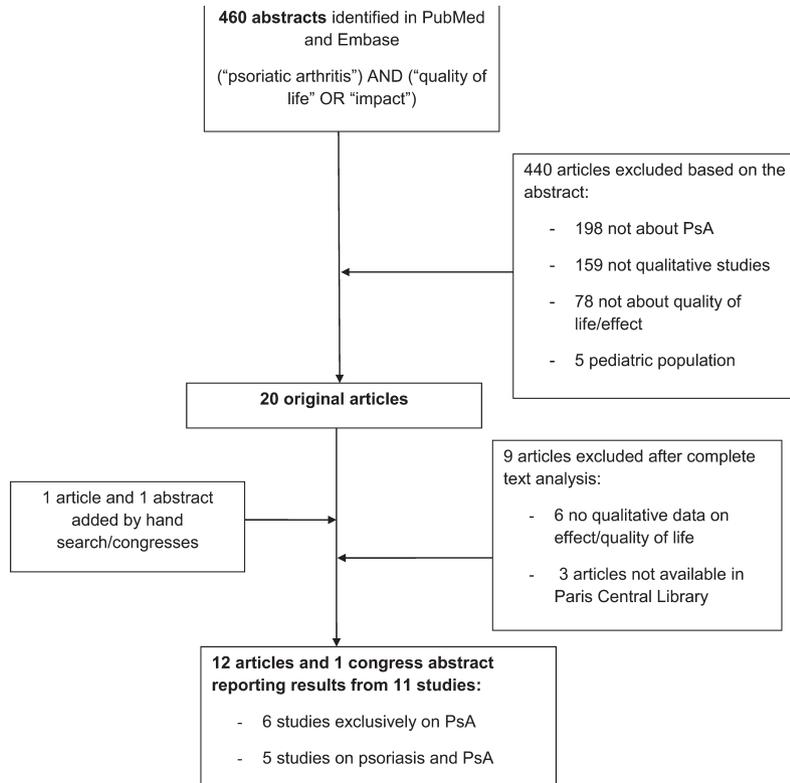


Figure 1. Flowchart showing the selection of publications that assessed the effect or quality of life in PsA. Three articles<sup>10,24,25</sup> were on the same study, the development and cross-cultural validation of the Psoriatic Arthritis Quality of Life, and brought no additional information regarding the domains of health important for patients with PsA. PsA: psoriatic arthritis.

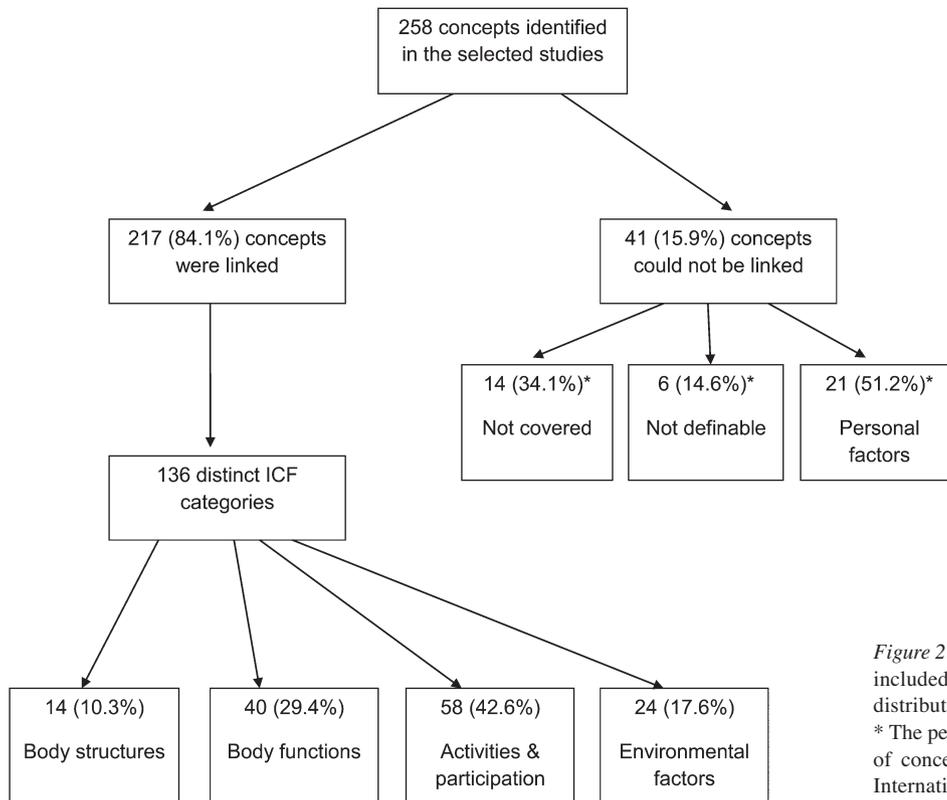


Figure 2. Number of concepts identified in the 11 studies included in the systematic literature review and their distribution across the major components of the ICF. \* The percentage was calculated out of the total number of concepts that could not be linked (n = 41). ICF: International Classification of Functioning, Disability and Health.

Table 2. Most frequent second-level ICF categories for each ICF component (of 344 second-level ICF categories total). Cumulative frequency of each ICF category is the number that expresses how many times an ICF category was linked to 1 or more concepts among all included studies.

ICF Component	Second Level ICF Category	Concepts Linked to the Second Level ICF Category, Examples	Cumulative Frequency, n (% of 344)	
Body structures	s770: Additional musculoskeletal structures related to movement	“joints,” “structure and functions of movement-related muscles,” “structure, stability, and mobility of the peripheral joints”	4 (1.2)	
	s730: Structure of upper extremity	“wrist,” “fingers”	3 (0.9)	
	s750: Structure of lower extremity	“ankle,” “knee”	2 (0.6)	
	s760: Structure of trunk	“spine”	2 (0.6)	
Body functions	b152: Emotional functions	“anxiety/feeling anxious,” “fear” (“of loneliness,” “of living with the disease,” “of pain,” “of being dependent on third parties,” “of not finding a job,” “of losing one’s job”), “feeling sad,” “feeling sorrowful,” “feeling depressed,” “feeling anger,” “feeling frustrated,” “feeling nervous,” “getting angry with oneself,” “mood affected by the pain,” “feeling there is no enjoyment in life,” “being irritated by people”	45 (13)	
	b134: Sleep functions	“sleep quality,” “sleep interruptions,” “falling asleep,” “feeling rested after waking,” “sleeping less,” “to rest or refresh yourself through rest,” “difficulty in waking up”	14 (4)	
	b455: Exercise tolerance functions	“fatigue,” “physically tired,” “exhaustion,” “needing to stop doing an activity to rest,” “diminished physical strength,” “taking a long time to recover from any physical effort”	14 (4)	
	b280: Sensation of pain	“pain in joints,” “pain in spine,” “pain during the night,” “pain not allowing to rest”	12 (3.5)	
	b840: Sensation related to the skin	“pain in skin,” “sensation related to the skin,” “itching related to the skin,” “burning/flare related to the skin”	12 (3.5)	
	b130: Energy and drive functions	“fatigue,” “mental fatigue,” “lack of energy,” “lack of drive to do things”	10 (2.9)	
	b180: Experience of self and time functions	“body image/appearance,” “self-esteem,” “feeling marked by visibility,” “having the feeling that the nails look ugly”	9 (2.6)	
	Activities and participation	d920: Recreation and leisure	“do leisure activities,” “intellectual or mental activities,” “activities requiring manual dexterity,” “muscle exercise/body building,” “swimming/diving,” “dancing,” “cycling,” “ballgames,” “gymnastics,” “play sports,” “attending/refusing invitations to social events,” “avoiding meeting people,” “patients not completely enjoying the occasion at social events”	23 (6.7)
		d440: Fine hand use	“grabbing something,” “cutting your meal,” “open previously opened jars,” “raising a 5-lb object above your head,” “open a car door,” “fine motor skills of the hand,” “handling of gadgets”	10 (2.9)
		d640: Doing housework	“ability to manage the home/do housework,” “doing laundry,” “cleaning the house,” “vacuum,” “replacing clothes and linens”	9 (2.6)
d410: Changing basic body position		“standing up from a chair,” “arising from the bed,” “bending down to pick up clothing from the floor,” “getting in and out of a transportation means”	8 (2.3)	
d850: Remunerative employment		“ability to work outside of the home at a job,” “professional life”	8 (2.3)	
d230: Carrying out daily routine		“ability to do activities that take up a major part of the day,” “capacity to perform daily physical activities,” “needing to limit everyday activities,” “learning to do things in new ways or change activities”	8 (2.3)	
Environmental factors		e110: Products or substances for personal consumption	“treatment and side effects,” “food”	6 (1.7)
		e580: Health services, systems, and policies	“access to a psychiatrist/psychologist,” “institutions of healthcare system,” “policies of health insurance companies”	4 (1.2)
	e575: General social support services, systems, and policies	“external assistance,” “physical assistance for daily tasks,” “health insurance”	3 (0.9)	

ICF: International Classification of Functioning, Disability and Health.

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2016. All rights reserved.

and b455: exercise tolerance functions, each with a cumulative frequency of 14 (4%).

Fatigue was also cited frequently. However, it was difficult to link the concept of fatigue to the ICF because there is no ICF category that reflects its entire meaning as seen from the perspective of patients with PsA. Thus, fatigue was linked to both b130: energy and drive functions and b455: exercise tolerance functions, reflecting both physical and psychological aspects of fatigue.

*Levels of linking.* Almost half of the concepts were linked to second-level ICF categories (67 out of 136, 49.2%). The ICF component that had the most specific categories (higher level) was body structures, with 57.2% of the concepts being linked to third- and fourth-level categories — mainly related to joint problems.

On the contrary, activities and participation had no fourth-level categories; however, half of them were third-level and covered a broad spectrum of domains of impact important for patients with PsA.

The majority of the ICF categories from body functions were second-level categories (52.5%). However, this might reflect limits of the ICF, because many of the concepts were named by patients at a higher level of specification, but with no appropriate match in the ICF. For example, various concepts related to skin problems, such as “itching related to skin,” “burning/flare related to skin,” “tightness of the skin,” and “pulling or stinging in your skin,” were all linked to the same second-level ICF category, namely b840: sensation related to skin.

*Concepts that could not be precisely linked to the ICF.* In all, 41 concepts (15.9%) could not be precisely linked to ICF categories. Most of these non-linkable concepts were personal factors (21 concepts, 51.2% of 41) and were mainly related to coping with the disease, e.g., “talking about the disease” and “hiding nails because of appearance”. Patients reported various ways of managing the disease: accepting and learning to live with the disease, turning coping into a daily routine, talking about the disease, hiding symptoms or avoiding certain situations and activities, and adjusting to the disease<sup>9,27,33</sup>. Finding positive aspects of the disease were also reported: changing priorities in life, opportunity to reflect, discover creative activities, or doing sports<sup>27,33</sup>.

Other concepts that could not be specifically linked were either “not definable” (6 concepts; e.g., “joint discomfort,” “not being able to keep people’s pace”) or “not covered” (14 concepts; e.g., “choices of a life of their own,” “feeling older than one’s age,” “taking a sick leave”).

## DISCUSSION

Our study allows us to obtain an overview of the effect of PsA from the patient’s perspective and to map this effect to the ICF. The effect of PsA is widely spread across aspects of quality of life, thus modifying not only physical aspects of

life but also psychological and social aspects<sup>34</sup>. Social aspects appear of particular importance to patients: the most frequently reported domains of impact were the ability to work and social participation. Further, activity and participation was the most represented ICF component in PsA (42.6%) and was much more frequent than body structures (10.3%), body functions (29.4%), and environmental factors (17.6%). In terms of cumulative frequency, the most frequently cited ICF categories were b152: emotional functions and d920: recreation and leisure. Sleep, fatigue, pain, and skin problems were also frequently reported. Linking was a higher level (more precise) for body structures. Although linking to the ICF allowed a more precise assessment of the disease effect, it is noteworthy that almost 16% of concepts could not be specifically linked to any of the ICF categories.

The identified concepts could be linked to all components of the ICF, confirming that the effect of PsA is wide-reaching and is spread across all aspects of life. To our knowledge, there is no similar attempt in the published literature to link all qualitative-based work assessing the effect of other rheumatic diseases, i.e., rheumatoid arthritis (RA) or ankylosing spondylitis (AS), to the ICF. Therefore, no direct disease comparison is possible. However, results from the ICF Core Sets for RA<sup>16</sup> and AS<sup>35</sup> showed that the most affected components were body structures and body functions: 44.9% in RA and 52.5% in AS.

Similar results in PsA were reported in a study of 94 patients from 5 countries<sup>19</sup>: more than half of the affected categories were classified into the activity and participation component compared with only a third in a methodologically similar study of patients with RA<sup>36</sup> and 45% in AS<sup>37</sup>. These results may reflect a higher societal effect of PsA, probably due to the additional burden of the skin disease and its consequences, knowing that PsO skin disease is socially disabling<sup>38,39,40</sup>.

Activities and participation was found to be well represented, irrespective of study type. However, in qualitative studies, body structures as well as environmental factors had a higher proportion than in the studies with both quantitative and qualitative methodology. This might be because in the latter, the qualitative work preceding the development of the questionnaires was presented in a lesser extent compared with exclusively qualitative studies. Detailed results from qualitative studies are important in assessing disease effect because they can better identify patients’ perspective. Additionally, in studies exclusively on PsA, the difference in proportion of ICF categories was not that significant for body functions and activities and participation as for studies involving patients with PsO with or without arthritis. Moreover, body structures were far more represented in studies with patients with only PsA, probably due to the additional burden of musculoskeletal involvement. This also strengthens the idea that the wide effect of PsA comes from

its having both skin and articular components. PsA was found to lead to significant psychological consequences.

The second-level ICF category “emotional functions” was frequently reported and it was linked to a very wide range of concepts: anxiety, fear, uncertainty, sadness, depression, lack of motivation, irritation, frustration, anger, etc. This reflects the high psychological burden of PsA, which may be partly explained by the impairment in social participation and relationships. Difficulties in linking psychological concepts reflect limitations of the ICF in discriminating categories of feelings. Highly specific information that is important for patients with PsA might be lost and reduced to only 1 emotional dimension, which is a major limit of the ICF and was also observed in RA<sup>16,41</sup>.

A number of concepts (41, 15.9%) could not be precisely linked to the ICF categories, similar to other studies<sup>18,42</sup>, indicating the limitations of the ICF. Most of the non-linkable concepts were personal factors, namely coping with the disease. This underlines the underestimated importance of coping strategies in patients with PsA.

It was difficult to compare the linking process to other studies, i.e., to bring information about discrepancies and similarities of concepts previously linked to the ICF because previous studies used different methodologies<sup>17,18</sup> or provided information from qualitative work<sup>43</sup>. There was only 1 situation where the same linked ICF categories were “re-used,”<sup>7</sup> and some difficulties in linking were common, i.e., concepts such as “fatigue,” different aspect of “emotional problems,” or various personal factors were difficult to link.

Our current study is subject to several limitations. Studies exclusively assessing the effect of PsO alone were not included in the systematic literature review, leading to a potential loss of information, considering that, because of the additional burden of the arthritis, the effect of PsA is different from the effect of PsO solely. Nevertheless, to be more inclusive on domains of impact, studies on PsA with or without some patients with only PsO were taken into consideration. Another weakness of our current analysis is the lack of more detailed information regarding the qualitative work preceding the development of the questionnaires assessing the effect of PsA compared with the qualitative studies where the patient’s perspective was extensively presented. This lack of information also hindered the assessment of quality and the risk of bias of the included studies. However, because data on the effect of PsA from the patient’s perspective are few, adding results from the qualitative phase of questionnaire development brings a wider perspective on the effect of PsA as reflected from the patient’s point of view. Additionally, not all the studies included in the systematic literature review assessed the whole effect of PsA. Some of the studies were focused on specific aspects of effect, such as nail involvement<sup>30</sup> or leisure<sup>29</sup>. This might explain the high cumulative frequency of the second-level ICF category d920: recreation and leisure. Nevertheless, this domain was cited

in 63.6% of the studies included in our analysis, demonstrating its importance attributed by the patients.

Another limitation is the lack of assessment of the association between specific disease characteristics and patient-reported effect. However, this is a limitation of qualitative studies in general.

These limits have already been pointed out in previous studies<sup>7,14,15,18,41</sup>: those due to the linking process, i.e., concepts that cannot be precisely linked to the ICF, personal factors that are not classified, the impossibility of differentiating between activities and participation, and the difficulty of linking concepts such as fatigue or various emotional feelings. Despite its flaws, the ICF has the advantage of being a standardized reference system, allowing the structuring/categorizing of effect and comparison across diseases<sup>13</sup>.

PsA widely affects all aspects of patients’ lives, in particular regarding activities and participation, reflecting the functional limitations and societal burden of PsA. These results will be of interest for the assessment of patients living with PsA.

## ACKNOWLEDGMENT

We thank Penelope Palominos (Porto Alegre, Brazil) for comments and suggestions that improved the manuscript.

## ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

## REFERENCES

1. Strand V, Sharp V, Koenig AS, Park G, Shi Y, Wang B, et al. Comparison of health-related quality of life in rheumatoid arthritis, psoriatic arthritis and psoriasis and effects of etanercept treatment. *Ann Rheum Dis* 2012;71:1143-50.
2. Borman P, Toy GG, Babaoğlu S, Bodur H, Ciliz D, Alli N. A comparative evaluation of quality of life and life satisfaction in patients with psoriatic and rheumatoid arthritis. *Clin Rheumatol* 2007;26:330-4.
3. Husted JA, Gladman DD, Farewell VT, Cook RJ. Health-related quality of life of patients with psoriatic arthritis: a comparison with rheumatoid arthritis. *Arthritis Rheum* 2001;45:151-8.
4. Husted JA, Gladman DD, Farewell VT, Long JA, Cook RJ. Validating the SF-36 health survey questionnaire in patients with psoriatic arthritis. *J Rheumatol* 1997;24:511-7.
5. Taylor WJ. Impact of psoriatic arthritis on the patient: through the lens of the WHO International Classification of Functioning, Health, and Disability. *Curr Rheumatol Rep* 2012;14:369-74.
6. Gossec L, Berenbaum F, Chauvin P, Lamiraud K, Russo-Marie F, Joubert JM, et al. Reporting of patient-perceived impact of rheumatoid arthritis and axial spondyloarthritis over 10 years: a systematic literature review. *Rheumatology* 2014;53:1274-81.
7. Stamm TA, Nell V, Mathis M, Coenen M, Aletaha D, Cieza A, et al. Concepts important to patients with psoriatic arthritis are not adequately covered by standard measures of functioning. *Arthritis Rheum* 2007;57:487-94.
8. Tillett W, Adebajo A, Brooke M, Campbell W, Coates LC, FitzGerald O, et al. Patient involvement in outcome measures for psoriatic arthritis. *Curr Rheumatol Rep* 2014;16:418.
9. Gossec L, de Wit M, Kiltz U, Braun J, Kalyoncu U, Scivo R, et al; EULAR PsAID Taskforce. A patient-derived and patient-reported outcome measure for assessing psoriatic arthritis: elaboration and preliminary validation of the Psoriatic Arthritis Impact of Disease

- (PsAID) questionnaire, a 13-country EULAR initiative. *Ann Rheum Dis* 2014;73:1012-9.
10. McKenna SP, Doward LC, Whalley D, Tennant A, Emery P, Veale DJ. Development of the PsAQoL: a quality of life instrument specific to psoriatic arthritis. *Ann Rheum Dis* 2004;63:162-9.
  11. Palominos PE, Gaujoux-Viala C, Fautrel B, Dougados M, Gossec L. Clinical outcomes in psoriatic arthritis: a systematic literature review. *Arthritis Care Res* 2012;64:397-406.
  12. World Health Organization. International classification of functioning, disability and health (ICF). [Internet. Accessed November 21, 2016.] Available from: [www.who.int/classifications/icf/en/](http://www.who.int/classifications/icf/en/)
  13. Kostanjsek N. Use of the International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Public Health* 2011;11 Suppl 4:S3.
  14. Cieza A, Brockow T, Ewert T, Amman E, Kollerits B, Chatterji S. Linking health-status measurements to the international classification of functioning, disability and health. *J Rehabil Med* 2002;34:205-10.
  15. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustün B, Stucki G. ICF linking rules: an update based on lessons learned. *J Rehabil Med* 2005;37:212-8.
  16. Stucki G, Cieza A, Geyh S, Battistella L, Lloyd J, Symmons D, et al. ICF Core Sets for rheumatoid arthritis. *J Rehabil Med* 2004;44 Suppl:87-93.
  17. Cieza A, Stucki G. Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). *Qual Life Res* 2005;14:1225-37.
  18. Geyh S, Cieza A, Kollerits B, Grimby G, Stucki G. Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review. *Qual Life Res* 2007; 16:833-51.
  19. Taylor WJ, Mease PJ, Adebajo A, Nash PJ, Feletar M, Gladman DD. Effect of psoriatic arthritis according to the affected categories of the international classification of functioning, disability and health. *J Rheumatol* 2010;37:1885-91.
  20. Critical Appraisal Skills Programme (CASP). CASP checklists. [Internet. Accessed November 14, 2016.] Available from: [www.casp-uk.net/#!casp-tools-checklists/c18f8](http://www.casp-uk.net/#!casp-tools-checklists/c18f8)
  21. National Heart, Lung, and Blood Institute. Quality assessment tool for observational cohort and cross-sectional studies. [Internet. Accessed November 14, 2016.] Available from: [www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort](http://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort)
  22. Fried BJ, Boers M, Baker PR. A method for achieving consensus on rheumatoid arthritis outcome measures: the OMERACT conference process. *J Rheumatol* 1993;20:548-51.
  23. Escorpizo R, Boers M, Stucki G, Boonen A. Examining the similarities and differences of OMERACT core sets using the ICF: first step towards an improved domain specification and development of an item pool to measure functioning and health. *J Rheumatol* 2011;38:1739-44.
  24. Wink F, Arends S, McKenna SP, Houtman PM, Brouwer E, Spoorenberg A. Validity and reliability of the Dutch adaptation of the Psoriatic Arthritis Quality of Life (PsAQoL) Questionnaire. *PLoS One* 2013;8:e55912.
  25. Billing E, McKenna SP, Staun M, Lindqvist U. Adaptation of the Psoriatic Arthritis Quality of Life (PsAQoL) instrument for Sweden. *Scand J Rheumatol* 2010;39:223-8.
  26. Torre-Alonso JC, Gratacós J, Rey-Rey JS, Valdazo de Diego JP, Urriticoechea-Arana A, Daudén E, et al. Development and validation of a new instrument to measure health-related quality of life in patients with psoriatic arthritis: the VITACORA-19. *J Rheumatol* 2014;41:2008-17.
  27. Szentpetery A, Johnson MA, Ritchlin CT. GRAPPA Trainees Symposium 2013: a report from the GRAPPA 2013 annual meeting. *J Rheumatol* 2014;41:1200-5.
  28. Hu SW, Holt EW, Husni ME, Qureshi AA. Willingness-to-pay stated preferences for 8 health-related quality-of-life domains in psoriatic arthritis: a pilot study. *Semin Arthritis Rheum* 2010;39:384-97.
  29. Leino M, Mustonen A, Mattila K, Koulu L, Tuominen R. Perceived impact of psoriasis on leisure-time activities. *Eur J Dermatol* 2014;24:224-8.
  30. Augustin M, Blome C, Costanzo A, Dauden E, Ferrandiz C, Girolomoni G, et al. Nail Assessment in Psoriasis and Psoriatic Arthritis (NAPPA): development and validation of a tool for assessment of nail psoriasis outcomes. *Br J Dermatol* 2014; 170:591-8.
  31. Meyer N, Paul C, Feneron D, Bardoulat I, Thiriet C, Camara C, et al. Psoriasis: an epidemiological evaluation of disease burden in 590 patients. *J Eur Acad Dermatol Venereol* 2010;24:1075-82.
  32. Globe D, Bayliss MS, Harrison DJ. The impact of itch symptoms in psoriasis: results from physician interviews and patient focus groups. *Health Qual Life Outcomes* 2009;7:62.
  33. Uttjek M, Nygren L, Stenberg B, Dufåker M. Marked by visibility of psoriasis in everyday life. *Qual Health Res* 2007;17:364-72.
  34. Gossec L, Smolen JS, Ramiro S, de Wit M, Cutolo M, Dougados M, et al. European League Against Rheumatism (EULAR) recommendations for the management of psoriatic arthritis with pharmacological therapies: 2015 update. *Ann Rheum Dis* 2016;75:499-510.
  35. Boonen A, Braun J, van der Horst Bruinsma IE, Huang F, Maksymowych W, Kostanjsek N, et al. ASAS/WHO ICF Core Sets for ankylosing spondylitis (AS): how to classify the impact of AS on functioning and health. *Ann Rheum Dis* 2010;69:102-7.
  36. Ewert T, Fuessl M, Cieza A, Andersen C, Chatterji S, Kostanjsek N, et al. Identification of the most common patient problems in patients with chronic conditions using the ICF checklist. *J Rehabil Med* 2004;44 Suppl:22-9.
  37. van Echteld I, Cieza A, Boonen A, Stucki G, Zochling J, Braun J, et al. Identification of the most common problems by patients with ankylosing spondylitis using the international classification of functioning, disability and health. *J Rheumatol* 2006;33:2475-83.
  38. Pariser D, Schenkel B, Carter C, Farahi K, Brown TM, Ellis CN; Psoriasis Patient Interview Study Group. A multicenter, non-interventional study to evaluate patient-reported experiences of living with psoriasis. *J Dermatolog Treat* 2016;27:19-26.
  39. Feldman SR, Malakouti M, Koo JY. Social impact of the burden of psoriasis: effects on patients and practice. *Dermatol Online J* 2014;20(8).
  40. Baker CS, Foley PA, Braue A. Psoriasis uncovered--measuring burden of disease impact in a survey of Australians with psoriasis. *Australas J Dermatol* 2013;54 Suppl 1:1-6.
  41. Stucki G, Cieza A. The International Classification of Functioning, Disability and Health (ICF) Core Sets for rheumatoid arthritis: a way to specify functioning. *Ann Rheum Dis* 2004;63 Suppl 2:ii40-ii45.
  42. Brockow T, Cieza A, Kuhlow H, Sigl T, Franke T, Harder M, et al. Identifying the concepts contained in outcome measures of clinical trials on musculoskeletal disorders and chronic widespread pain using the International Classification of Functioning, Disability and Health as a reference. *J Rehabil Med* 2004;44 Suppl:30-6.
  43. Stamm TA, Cieza A, Coenen M, Machold KP, Nell VP, Smolen JS, et al. Validating the International Classification of Functioning, Disability and Health Comprehensive Core Set for Rheumatoid Arthritis from the patient perspective: a qualitative study. *Arthritis Rheum* 2005;53:431-9.