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Original article

Development of an environmental contextual factor item set relevant to global functioning and health in patients with axial spondyloarthritis

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Abstract

Objective. To describe the development of an Environmental contextual factors (EF) Item Set (EFIS) accompanying the disease specific Assessment of SpondyloArthritis international Society Health Index (ASAS HI).

Method. First, a candidate item pool was developed by linking items from existing questionnaires to 13 EF previously selected for the International Classification of Functioning, Disability and Health (ICF) /ASAS Core Set. Second, using data from two international surveys, which contained the EF item pool as well as the items from the ASAS HI, the number of EF items was reduced based on the correlation between the item and the ASAS HI sum score combined with expert opinion. Third, the final English EFIS was translated into 15 languages and cross-culturally validated.

Results. The initial item pool contained 53 EF addressing four ICF EF chapters: products and technology (e1), support and relationship (e3), attitudes (e4) and health services (e5). Based on 1754 responses of axial spondyloarthritis patients in an international survey, 44 of 53 initial items were removed based on low correlations to the

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ASAS HI or redundancy combined with expert opinion. Nine items of the initial item pool (range correlation 0.21–0.49) form the final EFIS. The EFIS was translated into 15 languages and field tested in 24 countries.

Conclusions. An EFIS is available complementing the ASAS HI and helps to interpret the ASAS HI results by gaining an understanding of the interaction between a health condition and contextual factors. The EFIS emphasizes the importance of support and relationships, as well as attitudes of the patient and health services in relation to self-reported health.

Key words: spondyloarthritis, contextual factors, outcome research

Rheumatology key messages

- Environmental context has impact on how an individual will remain active and participate in society.
- This new environmental factor item set (EFIS) helps in identifying environmental contextual factors relevant to axSpA patients.
- Health professionals can use EFIS to identify available resources to support patients in daily life.

Introduction

Patients with axial spondyloarthritis (axSpA) suffer from a wide range of axial and peripheral symptoms (i.e. pain, stiffness, sleep impairment, fatigue) [1]. AxSpA patients may be limited in daily activities and social participation [2]. However, axSpA's impact on a person's life can be explained only partially by direct health effects such as disease activity, physical function or comorbidities. Thus, interaction of individuals with their particular environmental context might decisively impact these individuals' remaining activity and societal participation [3]. The International Classification of Functioning, Disability and Health (ICF) emphasizes health results from complex interactions of impairments, limitations and restrictions caused by the disease and various contextual factors. One major ICF innovation is the identification and classification of these factors, distinguishing environmental and personal factors (Fig. 1) [4, 5]. Environmental factors (EF) are defined as the physical, social and attitudinal environment in which people live and conduct their lives [6]. Although personal contextual factors are relevant for functioning and health, a classification and definitions of personal contextual factors are still lacking [7]. Contextual factors can positively or negatively affect global functioning in daily life and thus act as either barriers or facilitators of a person's functioning. In general, EFs frequently act as both facilitators and barriers.

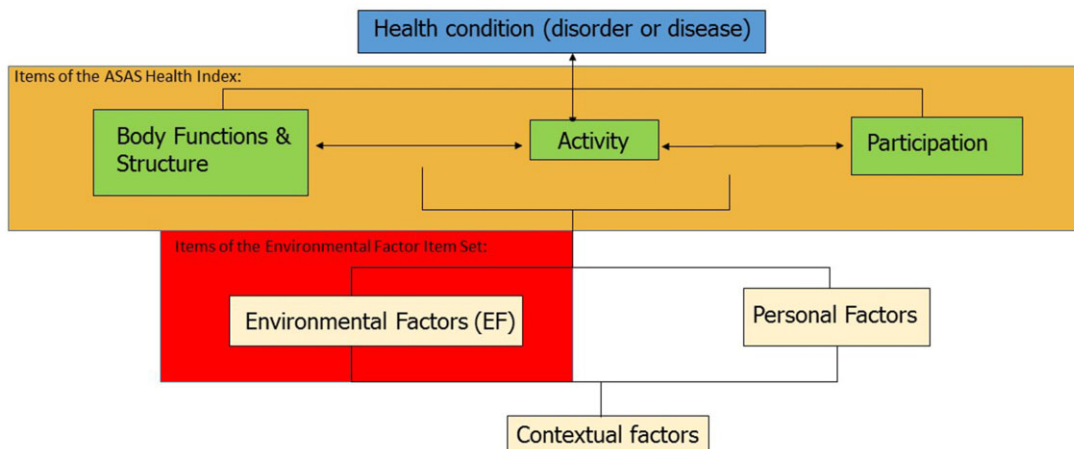
A set of EF categories defined in the Assessment of SpondyloArthritis international Society (ASAS)/WHO ICF Core Set for patients with ankylosing spondylitis (AS) comprises 13 EF categories in the Comprehensive Core Set [8]. Research on functioning and health in axSpA patients mainly focuses on the relationship between different health components of function and disability, while contextual factors are rarely considered. The OMERACT Contextual Factor Working Group developed guidance addressing

contextual factors in clinical trials and explicitly based identification of candidate contextual factors on the ICF [4]. Evidence relating contextual factors and outcomes of patients remains sparse. Impairment variables (disease activity and pain) explain only 33% of activity and participation restrictions, prompting further examination of contextual factors [2]. Contextual factors explained 37% and 47% of the variance in assessment tools like EuroQol five-dimension scale (EQ-5D) and Ankylosing Spondylitis Quality of Life Scale (ASQoL), respectively, with helplessness and employment being the most important contextual factors [3]. Lately, studies explored the effect of personal factors (i.e. age, gender, current employment, marital status, education, coping strategies), but few investigated the effect of environmental context (i.e. support and attitudes) for axSpA patients [9–11]. However, given the complexity of interfactorial interaction, contextual factors not only influence functioning but also functioning may affect the environment. To assess systematically the overall impact of SpA on functioning and health, ASAS developed a health index accompanied by a set of EFs aiming to facilitate interpretation of functioning and health. The ASAS Health Index (ASAS HI), based on the ASAS/WHO ICF Core Set for AS, contains 17 items addressing problems in body functions, activities and participation [12, 13]. The study's objective is to develop the accompanying EF Item Set (EFIS) by identifying characteristics, potentially influencing important aspects of self-reported functioning in axSpA patients.

Methods

The EFIS development paralleled the ASAS HI development, following the same six phases as of the ASAS HI in accordance with the study protocol (Table 1) [12, 13]. The 13 categories of the component 'EF' included in the Comprehensive ICF Core Set for AS served as the

Fig. 1 Structure of the International Classification of Functioning, Disability and Health (ICF)



Contextual factors [both the Personal Factors and the Environmental factors (EF)] influence the biopsychosocial domains body functions, activity and participation which are covered by the already published Assessment of SpondyloArthritis international Society (ASAS) Health Index.

TABLE 1 Phases of development for the Environmental Factors Item Set (EFIS)

	Phase	Aims	Methods
I	Preparatory	Development of candidate EF items representing the EF categories of the Comprehensive ICF Core Set for AS	Linkage of items from various assessment tools for functioning and health to 13 EF-categories covering 4 domains
II	1st international cross-sectional survey	Data collection and analyses for item reduction (within and across EF)	Correlation of each individual EFIS with sum score of ASAS HI was used to inform selection process
III	Expert consultation (Steering Committee)	Agreement on item reduction	Nominal Consensus Process based on level of correlation, redundancy and representation of ICF domains
IV	2nd international cross-sectional survey	Data collection and analyses for validation of the draft version and further item reduction	Correlation of each individual EF item to the sum score of the ASAS HI was used to inform consensus
V	Consensus Meeting (Steering Committee)	Agreement on a final version	Nominal Consensus Process based on level of correlation, redundancy and representation of ICF domains
VI	Translation and field test	Provision of a country-specific language version for each participating country	Forward-backward translation and cognitive debriefing according to Beaton <i>et al.</i> [14] resulting in some minor adaptations when needed by country PI

ASAS HI: Assessment of Spondyloarthritis International Society Health Index; EF: environmental factor; PI: principal investigator.

starting point [15] and covered four ICF chapters (subsequently called domains): products and technology (e1), support and relationships (e3), attitudes (e4) and services, systems and policies (e5) (summary of the descriptors in [Supplementary Data S1](#), available at *Rheumatology* online) [15]. The main difference of the

ASAS HI development was that in phase I patients did not weigh the importance of items representing the environmental contextual factors. All subsequent phases were conducted in parallel and in the same countries of the ASAS HI development throughout the whole process. A committee consisting of U.K., A.B., D.vdH.,

A.C., J.B. and one AS patient steered the process methodologically and select appropriate items based on the results of the cross-sectional surveys.

Patient and public involvement

Patients participated actively in all study phases, in the evaluation of the item pool as well as in the selection process of the final item set [12]. Patients also recommended ways to facilitate study participation while minimizing the burden of study visits.

Study phases

Preparatory phase

Candidate EF items were collected in 2008 by linking items from existing questionnaires to the 13 EF categories of the comprehensive ICF Core Set for AS. The items' origin and category linkage resulted either from existing questionnaires currently available in the AS field (identified by a systematic literature search) or from additional, but in AS uncommonly used instruments, which were already linked to the ICF (data from ICF Research Branch Munich). For eligibility, items had to be short, comprehensible and address a single concept. Similar to the item selection for the ASAS HI, items representing EF were quoted directly from the original instrument with some rewording to guarantee a consistent item structure (e.g. use of first person and present tense). The response option was dichotomized to 'I agree' and 'I do not agree'. Linkage was performed following the formal linking rules by two trained investigators (U.K. and A.B.) [16]. Finally, a face-to-face meeting was conducted with 13 AS patients from six countries (Canada, Germany, the Netherlands, Turkey, UK and USA) to evaluate relevance and understandability of items. Patients could propose new items if a concept was not adequately addressed in the item pool. Items and conversation were in English.

First international cross-sectional survey

A cross-sectional international web-based survey with axSpA patients from seven English-speaking countries, invited by national patient organizations and diagnosed by a physician, tested the item pool for the EFIS. Due to the item pool size, the questionnaires were split into five subsets sharing a common set of four EF items. These common EF items were chosen based on content validity, i.e. reflecting basic disease aspects (i.e. emotional support from family, medication side effects). Patients provided information on sociodemographic (age, symptom, disease duration) and disease characteristics [Bath AS Disease Activity Index (BASDAI), Bath AS Functional Index (BASFI), nocturnal and total back pain and Bath AS-patient Global Score (BAS-G) last week and over the last 6 months] all on a 0–10 numerical rating scale [17, 18].

Expert consultation

After presenting the results of the first web-based survey, the committee reduced the item pool by deleting items by a nominal consensus process [19]. This

process was informed by the correlation level between each individual EF item and sum score of the ASAS HI but requiring all four ICF chapters for EF to remain represented in the final selection. These proceedings should maintain relevant factors while avoiding redundancy within the EFIS. The committee assigned a descriptor for being either a facilitator or a barrier to each remaining item based on wording of the items. For example, the item 'I modify my living environment' was considered a change to the environment that should facilitate functioning, while the item 'My friends expect too much of me' was considered an attitude that would be a barrier for functioning.

Second international cross-sectional survey

A second international cross-sectional survey was undertaken among axSpA patients in six English-speaking countries.

Consensus

Selection of final EF items was informed by the correlation level between each EF item and sum score of the ASAS HI and optimal coverage of items to the variety of ICF domains/categories of the Comprehensive ICF Core Set for AS. Agreement was achieved by a nominal consensus process.

Translation

The final English EFIS was subsequently translated together with the ASAS-HI into 15 languages by using forward-backward translation [14, 20]. Availability of an ASAS member as country investigator to supervise translation/cultural validation and representation of the main languages worldwide were the main reasons to choose languages or translation of the ASAS HI. Translations and the original English version were field tested for content validity (including comprehension), applicability (cultural relevance) and feasibility using cognitive debriefing. Interviewees completed the EFIS questionnaire, and the response pattern of each single EF item was calculated. When needed, wording of the items was adapted based on the feedback of the patients.

The study complies with the Declaration of Helsinki and the locally appointed ethics committee of each international participating site approved the research protocol. Participants gave written informed consent prior to inclusion in the study.

Statistics

Respondents' characteristics in the sample are presented as mean (s.d.) for continuous variables or as absolute frequencies and percentages for categorical variables. Correlation between individual items of EFIS and ASAS HI total sum were calculated to inform the selection during the process of item reduction (Pearson). The selection process of EFIS items was informed by extent of correlation without application of a specific threshold. Final selection of EFIS items took extent of correlation coefficient, representation of the four relevant ICF chapters, and avoidance

of redundancy into account. The items with the lowest correlation (no specific cut off) were removed first.

Results

Analysis of the six phases is as follows.

Preparatory phase

Fifty-three items related to one of the EF categories of the WHO/ASAS Core Set for AS were found in 24 different questionnaires, none of them commonly used in patients with SpA. These items could be linked to 7 of the 13 EF categories of the ICF Core Set for SpA: drugs (e1101), products and technology for personal use in daily living (e115), products and technology for personal indoor and outdoor mobility and transportation (e120), design, construction and building products and technology of buildings for private use (e155), support and relationship (e3), attitudes (e4), and health care services, systems and policies (e580). Importantly, all four EF domains remained covered. The six ICF categories not represented by an available item comprise: products and technology for employment, design, construction and building products (e135), technology of buildings for public use (e150), transportation services, systems and policies (e540), social security services, systems and policies (e570), general social support services, systems and policies (e575) and labour and employment services, systems and policies (e590). All categories were rated by the patients either as partially represented by another EF item (e.g. category e155 represents also content of e135 or e150) or as covered by other ICF categories of the ASAS HI (e.g. category d870 represents also content of e590). During the patient meeting, five new items were proposed covering aspects of support

given by friends and relatives (e3), attitudes of friends (e4) and receipt of best possible treatment (e5). Items were quoted directly from the original instruments except for eight items in which transformation into first person and present tense was needed to guarantee a consistent item structure.

First international cross-sectional survey

A total of 1915 patients accessed the web-survey; 161 patients were excluded because of incomplete data. The characteristics of the remaining 1754 patients are shown in Table 2. Correlation coefficients between individual EF and ASAS HI sum score varied between -0.25 and 0.46 and were sorted in ascending order subsequently (Supplementary Table S1, available at *Rheumatology* online). Eight items were excluded because of the lowest correlation while ensuring that all four ICF chapters remained represented.

Expert consultation

After discussing the results of the first web-based survey, the committee selected the four items for each ICF domain, which correlated mostly to the ASAS HI sum score. Thus, 37 items were further deleted because of lower correlations. Of the remaining 16 items, eight items were assigned to act as a facilitator and eight items as a barrier based on theoretical considerations of the committee.

Second international cross-sectional survey

Six hundred and eighty-two patients accessed the second web-based survey and complete data sets of 622 patients were available for analysis. Correlation coefficients between individual items of EFIS and ASAS HI total sum varied between 0.09 and 0.49 (Table 3). Of note, 4 out of 8 (50%)

TABLE 2 Demographic and disease characteristics of participants for both surveys and the cognitive debriefing study

Variables	First web-based survey ^{a,b} (n = 1754)	Second web-based survey ^{a,c} (n = 622)	Cognitive debriefing study ^d (n = 214)
Male, n (%)	929 (53.0)	372 (59.8)	142 (66.3)
Age, mean (s.d.), years	48.3 (13.4)	48.3 (14.1)	40.5 (14.8)
Duration of symptoms, mean (s.d.), years	22.8 (14.0)	20.4 (13.8)	11.9 (11.6)
BASDAI, mean (s.d.)	5.5 (2.4)	5.4 (2.4)	4.3 (5.1)
BASFI, mean (s.d.)	4.6 (2.6)	4.5 (2.6)	NA
Total back pain (NRS 0–10), mean (s.d.)	6.0 (2.8)	4.7 (2.8)	NA

Table partly published in Kiltz *et al.* [12]. ^aAnalysis based on complete data set regarding demographic questionnaires. ^bPatients from seven English speaking countries [Australia (n = 24), Canada (n = 255), Ireland (n = 91), New Zealand (n = 36), Singapore (n = 40), UK (n = 706) and USA (n = 602)] represented four continents (Europe, America, Asia, Australia/New Zealand). ^cPatients from Canada (n = 94), Ireland (n = 81), New Zealand (n = 39), Singapore (n = 35), the UK (n = 190) and the USA (n = 183). ^dPatients from Australia, Austria, Canada, Colombia, Croatia, Egypt, France, Germany, Greece, Hungary, South Korea, Mexico, the Netherlands, Portugal, Russia, Switzerland, Thailand, Turkey and the USA (each country with 10 participants) as well as Belgium (n = 9), China (n = 2), Italy (n = 5) and Spain (n = 7). NA: not assessed; NRS: numerical rating scale.

TABLE 3 Environmental factors item set with results of second web-based survey and rating of consensus meeting

ICF chapter and category of ICF	Items linked to the ICF category	Facilitator ^a	Barrier ^b	Agreement with item of EFIS, <i>n</i> (%) ^c (<i>n</i> = 622) ^c	Correlation between item and ASAS HI sum score	Selection for EFIS
e1	Products and technologies					
e155	I modify my living environments	×		327 (52.6)	0.49	Included (item 4), wording adapted
e115	I might need some assistance during an attack		×	411 (66.1)	0.39	Excluded
e120	I need help to walk about outside (e.g. a walking aid or someone to support me)		×	78 (12.5)	0.37	Excluded
e1101	I take tablets to help me sleep	×		239 (38.4)	0.36	Excluded
e3	Support and relationship					
e3	As a result of my AS ^d , the children take more responsibility for household tasks	×		119 (44.1) ^e	0.48	Included (item 1), wording adapted
e3	I usually feel as if my family is pushing me	×		123 (19.8)	0.40	Excluded
e3	I don't like the way my friends act around me		×	62 (10)	0.30	Included (item 2)
e3	I can't count on my relatives to help me with my problems		×	186 (29.9)	0.21	Included (item 3)
e4	Attitudes					
e4	My friends expect too much of me		×	109 (17.5)	0.39	Included (item 7)
e4	No one pays much attention to me at home		×	101 (16.2)	0.24	Included (item 8)
e4	My friends understand me	×		413 (66.4)	-0.25	Included (item 9)
e4	My family usually considers my feelings	×		477 (76.7)	-0.09	Excluded
e5	Health care services, systems and policies					
e580	I have difficulties getting relapses acknowledged by a health care professional		×	169 (27.2)	0.32	Included (item 5), wording adapted
e580	Treatment of AS is taking up time		×	322 (51.7)	0.27	Included (item 6), wording adapted
e580	The therapy I received helped me functionally	×		420 (67.5)	-0.17	Excluded
e580	I am getting the best possible treatment for my condition	×		392 (63)	-0.17	Excluded

^aAssignment done before conducting the survey based on theoretical considerations. ^bAssignment done before conducting the survey based on theoretical considerations. ^cNumber of participants is based on the total cohort of 628 patients. Number of participants per item is <628 because of split pool. ^dDisease axSpA was historically called ankylosing spondylitis (AS) in the items of the initial item pool. ^e*n* = 270, as this item was not applicable for the remaining 352. ASAS HI: ASAS HI: Assessment of Spondyloarthritis International Society Health Index; EFIS: Environmental contextual factors Item Set; ICF: International Classification of Functioning, Disability and Health.

facilitators had a positive correlation with the ASAS HI instead of the theoretically expected negative correlation.

Consensus meeting

Nine items were included in the EFIS upon committee decision, based on the extent of the correlation coefficient between each individual EF item and the sum score of the ASAS HI considering avoidance of redundancy because of high correlation coefficient individual items of EFIS and ASAS HI total sum and coverage of representative domains of the Comprehensive ICF Core Set for AS (final EFIS in [Supplementary Data S2](#), available at *Rheumatology* online). Of the final nine items of the EFIS, three items were described as being a facilitator and six items were described as being a barrier ([Table 3](#)). The EFIS covers four ICF domains of EF: e1 ($n = 1$), e3 ($n = 3$), e4 ($n = 3$) and e5 ($n = 2$).

Translation

The nine items were translated into 15 languages (available at <https://www.asas-group.org/clinical-instruments/asas-health-index/>). Cognitive debriefing was performed in 24 countries with 214 patients interviewed ([Table 2](#)). Results of cognitive debriefing of the EFIS were partly published together with the results of the cognitive debriefing of the ASAS HI [[12](#), [20](#)]. Wording of two items was adapted based on the feedback during the qualitative interviews. For EFIS item 1, patients proposed changing the initial wording of 'ankylosing spondylitis' to 'my rheumatic disease' to harmonize nomenclature of patients with axial SpA worldwide and to support a global understanding for different patients' groups. In the same item, patients also proposed changing the wording of 'children' to 'my family/relatives' because it applies to a wider patient group. For EFIS item 4, patients proposed changing the initial wording of 'living environments' to 'home and work environments' because this term specifies the content of this item. For EFIS item 5, patients proposed changing the initial wording of 'relapsing' to 'worsening' because the word relapse is not commonly used for axSpA patients. All suggestions were implemented in the final EFIS version ([Supplementary Data S2](#), available at *Rheumatology* online).

Consensus on the final Item Set version

The final set of nine EF items complement the ASAS HI and was endorsed by ASAS members at their annual meeting in January 2013 (38 positive votes, 1 negative vote, 3 abstentions from voting).

Scoring of the EF Item Set

Each of the final nine statements can be answered with an agreement or disagreement. Due to its multidimensional approach, no sum score is available for the nine items of the final EFIS. The response pattern allows identification of areas of patients experience limitation where they may thus need individual support.

Discussion

This work portrays the successful EFIS development accompanying the ASAS HI, thus providing a comprehensive standardized framework to collect environmental contextual factors in axSpA patients. The EFIS represents environmental factors, identified by patients and experts (clinicians and researchers), relevant for functioning and health, moderately correlating with the ASAS HI. Factors addressing support/relationship, attitudes of the patient and health care services are brought together in one item set. For the first time in axSpA research, an item set assesses environmental contextual factors, developed in parallel to a health index utilizing the same classification system and methodology. The EFIS will help in interpreting the ASAS HI results, mediating the understanding of the interaction between a health condition and contextual factors. The availability of the EFIS will support interpretation of the scores on the ASAS HI and improve the general understanding of disability. The importance of contextual factors for appropriate patient-specific care is widely acknowledged. This factor pool enables health professionals to recognize barriers to functioning or to identify available supporting resources for daily life. Researchers should explore the magnitude of confounding or effect modification of contextual factors in the setting of observational studies or trials. However, a main limitation is that the classification and definition of personal factors to be included in the ICF are still lacking, leading to the fact that important information cannot be studied.

In a qualitative nominal group trial, the OMERACT Contextual Factor Working Group identified 28 generic variables characterizing the context of the individual person- and physical and social environment that are potentially relevant in all clinical studies in rheumatology [[4](#), [21](#)]. Our disease-specific set of environmental factors based on qualitative as well as quantitative evidence is relevant when functioning and health are the outcome domains. Compared with OMERACT's work, the EFIS did not specify personal factors. After defining these EF, additional knowledge supports understanding statistical consequences of these contextual factors, as they might directly influence the outcome or modify effects of interventions or disease activity on overall functioning and health [[8](#)].

Previous work reported the relevance of personal factors in experiencing health [[3](#), [22](#)]: personal factors (i.e. helplessness, employment status and education) impact health-related quality of life and health outcome [[3](#), [22](#)]. A recent review investigated the relationship of contextual factors and various work outcomes (i.e. employment status, sick leave, presenteeism) [[23](#)]. Environmental factors like absence of work accommodation, workplace support by colleagues or regulations of the social security system influenced work outcomes.

Item 4 of the current EFIS (I modified my work environment) addressed workplace adaptation and our assignment to the descriptor 'facilitator' based on theoretical considerations. However, correlation analysis indeed showed the positive association with functioning. It is likely that 'modifications at home or at work' (item 4) were made

since severe disease (confounding by indication) and impact on functioning would even be worse if such modifications were not made.

Similarly, item 1, 'As a result of my rheumatic disease, my family takes more responsibility for household tasks', paradoxically indicates interpretation challenges of the scores on the ASAS HI regarding the results of the environmental contextual factors. Being theoretically a facilitator, the 'reverse' correlation indicates functioning would be worse without modification or support from family—adjusting the ASAS HI score, similarly as for the HAQ, adjusted if persons use aids for physical activities, could solve the paradox. Even more relevant, additional research facilitates understanding the interaction between health condition and contextual factors in (non-pharmacological) interventions.

EFIS response patterns may also serve as a starting point for factor modification to improve functioning and health. Although EFIS is not validated for use in clinical practice, EFIS may give insights into individual impairments of environmental contextual factors and may help to address individual needs. The EFIS identifies environmental factors such as support and relationships based on the ASAS/WHO ICF Core Set for patients with AS, allowing to identify the environmental factor as a potential confounder and/or an effect modifier [4, 15]. Nevertheless, awareness increases that health experience in a particular environment results from complex relations between a health condition and a series of individual contextual factors [5]. Therefore, this set of disease-specific items based on a universal classification system was developed, describing potential interactions in axSpA patients.

The ASAS HI is the first instrument with an environmental contextual factor item set defined alongside its development. As an underlying concept, the ICF provided a list of environmental factors, comprehensive in their coverage of the external features of the physical, social and attitudinal world in which people conduct their lives. Using this approach clarifies different experiences of disability and helps in understanding feelings of discrimination and disadvantage. This difference explains the differing need for minimal or no environmental interventions to retain or develop full functioning while others not only face many environmental accommodations, but also face stigmatizing attitudes of others.

The EFIS was developed based on a disease-specific core set and thus enables researchers to investigate the interaction in axSpA patients. However, since the EFIS addresses superordinate categories of environmental contextual factors (such as attitudes and support), it can be discussed to what extent the factors could be applied in generic context. There are a numerous issues to consider in understanding the person–environment relationship. EF may often affect functioning not as a single category but as a complex array of multiple EFs.

The applied interactive approach recognized the multi-dimensional phenomenon, but requires further research to enlarge the understanding of the influence of EF on the health status of axSpA patients. Particularly, three issues should be considered: (i) EF influence on

health states might depend on the underlying disease, (ii) EF influence on health states might operate differently in the life span, and (iii) interaction between personal and environmental factors as well as interaction between contextual factors and psychological profile of the individual patients. Moreover, cultural and/or geographical differences were not addressed in this study but require further investigation since these factors might influence occurrence and expression of contextual factors [24, 25]. Additionally, the interaction between different EF as well as the integrative approach of the ICF require additional investigation. Knowledge about this integrative approach is crucial for a broader understanding of disability as well as for focusing on interventions to improve influence of contextual factors on health outcomes—especially from a global perspective.

To conclude, the suggested EFIS provides the scientific community with focal points and supports the comprehensive and systematic understanding of functioning, thus serving as guidance to identify relevant environmental contextual factors for axSpA patients. Importantly, patients' attitudes and health services regarding perceived health can be systematically understood and collected. Since knowledge about the influence of contextual factors on health outcomes is evolving, the use of the EFIS will for now be restricted to research settings. Further work will aim to explore when and how to utilize the EFIS in clinical practice.

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No additional data are available.

Supplementary data

Supplementary data are available at *Rheumatology* online.

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