ICF-BASED COMPARISON OF DISEASE-SPECIFIC INSTRUMENTS MEASURING PHYSICAL FUNCTIONAL ABILITY FOR ANKYLOSING SPONDYLITIS

Extended report

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Abstract

Objectives: The objectives were to link validated and widely used instruments measuring physical functional ability in ankylosing spondylitis (AS) to the International Classification of Functioning, Disability and Health (ICF) and to compare their contents based on the results of the linking process.

Methods: The Bath Ankylosing Spondylitis Functional Index (BASFI), Dougados Functional Index (DFI), Health Assessment Questionnaire modified for the spondylarthropathies (HAQ-S) and the Revised Leeds Disability Questionnaire (RLDQ) were linked to the ICF separately by two trained health professionals according to ten linkage rules.

Results: All concepts contained in the items of the selected instruments could be successfully linked to the ICF except for “illness” included in the HAQ-S. Altogether 55 different ICF-categories have been linked. 7 categories belong to „body functions“, 43 to „activities and participation“ and 5 to „environmental factors“. The component “body structure” is not contained in any of the four instruments. There are only 2 ICF-categories common to all selected questionnaires, whereas a high level of concordance concerning the concepts represented in them could be revealed. However, especially in terms of “activities and participation”, the emphasized aspects differ.

Conclusions: The ICF provides an excellent common framework for the comparison of disease-specific instruments for AS. For a future revision of the ICF the specification of major limitations in patients with AS is suggested.
Key Words:

ICF, Bath Ankylosing Spondylitis Functional Index (BASFI), Dougados Functional Index (DFI), Revised Leeds Disability Questionnaire (RLDQ), Health Assessment Questionnaire modified for the spondylarthropathies (HAQ-S)
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Introduction

Ankylosing spondylitis (AS) is thought to be the most common and typical form of spondylarthropathy. Pain and spinal stiffness, often gradually leading to severe impairments in physical functioning and quality of life, are regarded as the most important complaints as well as therapeutic challenges in AS [1, 2, 3].

In 1998, during the OMERACT (Outcome Measures in Rheumatology Clinical Trials) Conference, the members of the ASAS (Assessment in Ankylosing Spondylitis) Working Group selected “core sets” of outcome instruments to be applied in different kinds of trials in AS [4].

Three core sets for three different settings were proposed. In all these core sets the ASAS recommended the obligatory use of the domains physical function, pain, spinal mobility, spinal stiffness and patient global assessment [5].

Physical functional ability is assessed using self-administered instruments.

The Bath Ankylosing Functional Index (BASFI) [6], the Dougados Functional Index (DFI) [7,8], the Health Assessment Questionnaire modified for the spondylarthropathies (HAQ-S) [9] and the Revised Leeds Disability Questionnaire (RLDQ) [10] are among the most widely used, well established and internationally recommended instruments measuring physical functional ability in AS [11, 12, 13].

All these instruments have, however, both strengths and weaknesses.
When selecting or comparing instruments measuring physical functional ability for research or clinical settings, truth, feasibility and discrimination are to be considered [14].

However due to the different spectrum of items covered by the instruments a comparison between them is difficult.

The newly available ICF (International Classification of Functioning, Disability and Health, former ICIDH-2) [15] offers a possible solution for this dilemma. The ICF belongs to the family of classifications of the World Health Organization and represents a comprehensive common framework for describing functioning and health. Using established linkage rules [16] items included in physical functional ability measures can be linked to the best corresponding ICF-categories.

Accordingly, the objectives of our study were to link the BASFI, the DFI, the HAQ-S and the RLDQ to the ICF-classification and to compare the contents of these four instruments.

Methods

Measures

The BASFI is a self-administered, disease-specific instrument for AS, designed by a multiprofessional expert team of rheumatologists, physiotherapists and research-associates with major input from patients. The final version, first published in 1994, consists of ten questions altogether. Eight items concern activities referring to the functional anatomy of the patients, and two additional questions assess the patients’ ability to cope with everyday life [6].
The DFI is a self-administered, disease-specific instrument for AS designed by rheumatologists with special interest in AS and originally applied as an interview. The revised self-administered questionnaire contains 20 items corresponding to activities of daily living [7,8].

The Health Assessment Questionnaire (HAQ) modified for the spondylarthropathies (HAQ-S) is a self-administered, disease-specific instrument for AS. It was built on the standard HAQ designed for Rheumatoid Arthritis (RA) by adding five questions relating to neck and back functioning. Those were identified in a 1985 mailed survey of 300 British patients with AS (Karen Peer, Loughborough University, Nottingham, England, personal communication, 1985). The HAQ-S consists of 25 items [9].

The Revised Leeds Disability Questionnaire (RLDQ) is a self-administered, disease-specific instrument for AS. During the revision process of the questionnaire a group of 12 patients with AS was interviewed, all of whom were attending a 3-week inpatient rehabilitation course. The RLDQ includes 16 items grouped into four areas: ‘Mobility’, ‘bending down’, ‘reaching up and neck mobility’ and ‘posture’ [10].

The International Classification of Functioning, Disability and Health (ICF) [15] was designed to record and organize a wide range of information about health and health-related states in a standardized, common language. The ICF consists of two major parts, each containing two separate components. Part 1 covers FUNCTIONING and DISABILITY and includes the components:

1. Body Functions (b) and Structure (s) and
2. Activities and Participation (d).

Part 2 covers CONTEXTUAL FACTORS and includes the components:

1. Environmental Factors (e) and
2. Personal Factors (have not yet been classified by the ICF and are therefore not taken into account for the linking).

In the ICF-classification, the letters b, s, d, and e, which refer to the components of the classification, are followed by a numeric code starting with the chapter number (one digit), followed by the second level (two digits) and the third and fourth levels (one digit each). The component letter with the suffix of two, three, or four digits corresponds to the code of the so-called categories. Categories are the units of the ICF classification. Within each chapter, there are individual two-, three- or four-level categories. An example selected from the component *Body Functions* is presented in the following:

b2 Sensory functions and pain (chapter level or first level)
b280 Sensation of pain (second level)
b2801 Pain in body part (third level)
b28013 Pain in back (fourth level).

Within each component, the categories are arranged in a stem/branch/leaf scheme. Consequently, a lower level category shares the attributes of the higher-level categories to which it belongs, i.e. the use of a lower level (more detailed level) category automatically implies that the higher level category is applicable but not the other way round.

At the end of each embedded set of third or fourth level categories as well as at the end of each chapter, there are “other specified” categories (uniquely identified by the final code 8). These categories allow the coding of aspects not included in any other specific categories [15].

*Linkage of items to the ICF*

Tables showing the linkage process for the BASFI, the DFI, the HAQ-S and
the RLDQ can be requested from the corresponding author.

All four selected instruments were linked to the ICF separately by two trained health professionals according to ten linking rules [16].

The linking rules are guidelines, which enable concepts contained in health-status measures to be linked to the ICF in a standardized manner [16]. According to these rules, experts trained in the ICF are advised to link concepts contained in a health-status measure to the ICF-category representing this concept most precisely. The most important linking rules are summarized below.

If one item encompasses different constructs, the information in each construct should be linked. For example, in item 1 of the BASFI “Putting on your socks or tights without help or aids (e.g. sock aids)” the concepts “putting on your socks or tights”, “help” and “aids (e.g. sock aids)” have been linked to the ICF separately (see table 1).

If the content of an item is not explicitly included in the corresponding ICF category, i.e. the questionnaire provides more detailed information, “the other specified” option at the third or fourth coding level of the classification has to be applied [16]. This can be illustrated by the fourth item of the DFI ("4, Can you get into a bathtub") which was assigned to “d498”, i.e. “mobility, other specified.” The additional information has to be documented as well as the selected ICF-code.

If the content of an item is more general than the corresponding ICF-category the code of the higher level is linked. This can be illustrated by “5a, Getting up off the floor without help from lying on your back” of the BASFI which has been linked to the chapter “e3” of the classification (“support and relationships, defined as “(…) people or animals that provide physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities” [15].
The abbreviation hc is used for items concerning a health condition, e.g. the concept “illness” included in the HAQ-S (“How much stiffness have you had because of your illness in the past week?”).

To decide which ICF-category should be linked to each item in the four questionnaires consensus between the two health professionals was required. In case of disagreement concerning the selected categories a third independent assessor with expertise in the concept and taxonomy of the ICF and the linking rules was consulted to finally decide on the most suitable code.

The percentage of cases in which the third independent assessor was consulted for a final decision on the most precise ICF-category was calculated.

In addition, the degree of agreement between the two health professionals concerning the component, 1st, 2nd, and 3rd ICF-levels was calculated by means of the Kappa statistic [17] and the corresponding bootstrapped confidence intervals [18].

The data analysis was performed with SAS for Windows V8.

Results

Linkage process

All the 124 concepts contained in the items of the BASFI, DFI, HAQ-S and RLDQ could be successfully linked to the ICF-except for “illness” contained in the HAQ-S.

The third independent assessor was consulted for 26 out of the 124 concepts (21.0%). The results of the Kappa statistic, as well as the bootstrapped confidence intervals for the component, 1st, 2nd, and 3rd ICF-levels are presented in Table 1.

The estimated Kappa coefficients ranged from 0.78 at the component ICF-level to 0.98 at the 1st and 3rd ICF-level, respectively.
The width of the 95% bootstrapped confidence interval, which indicates the precision of the estimated Kappa coefficient was narrowest at the 3rd level and widest at the component ICF-level.

Altogether 55 different ICF-categories have been linked. 7 categories belong to the component „body functions“, 43 to „activities and participation“ and 5 to „environmental factors“. The component “body structure” is not contained in any of the 4 selected instruments.

Throughout the linkage process we identified 2 ICF-categories common to all 4 questionnaires.

**Linkage results**

The results of the linking process of the four selected instruments are presented in table 2.

All questionnaires covered the ICF-components “body function” and “activities and participation”, whereas “environmental factors” were only represented in the BASFI and the HAQ-S.

The HAQ-S is the instrument among those selected which could be linked to the majority of ICF-categories (20) not contained in the others. 16 of them refer to activities and participation, 2 to body functions and 2 to environmental factors.

Further specific analyses of the structure and the contents of the questionnaires enlightened during the linking process show that the DFI represents more items concerning „body functions“ (3) than the other selected instruments.

As revealed by the linking process, the questionnaires show a high level of concordance in terms of the domains of functioning and health they cover, whereas each of them includes different aspects. This especially applies for the component “activities and participation” of the classification.
All four instruments focus on the chapter “d4” (mobility) reflecting in 23 different ICF-categories but each of them includes specific constructs.

The DFI and the BASFI cover items which could be linked to the category “d410” (changing basic body position) and “d415” (maintaining a body position), whereas the HAQ-S focuses on mobility of the upper extremity which shows in the attributable concepts “lifting and carrying objects” (d430), “manipulating” (d4402) and “turning and twisting the hands or arms” (d4453). The DFI, the BASFI and the HAQ-S represent “picking up” (d4400), whereas the BASFI, the RLDQ and the HAQ-S include “reaching” (d4452). The DFI, the BASFI and the HAQ-S could be linked to “d4551” (climbing), one item of the RLDQ was assigned to “mobility, unspecified” (d499).

The ICF-concept “d 5 self-care” is represented in all four instruments. Items of each of them could be linked to the category “putting on footwear” (d5402). However apart from this common aspect their different accents are clearly separated. Items of the HAQ-S could be related to 8 different ICF-codes referring to d5 “self-care” with the chapter as a whole, the aspect of “washing oneself” (d510) as well as “eating” (d550) included. The latter two are not incorporated in the other three selected instruments.

The RLDQ could be linked to 4 ICF-categories referring to “self-care” which are not applicable for the other measures. Those are “toileting” (d530), “caring for toenails” (d5204), “taking off footwear” (d5403) as well as “drinking” (d560).

The DFI covers “putting on clothes” (d5400), the BASFI could be linked to “looking after one’s health, unspecified” (d5709).

The BASFI and the DFI both incorporate “remunerative employment” (d850), whereas the BASFI and the HAQ-S cover “caring for household objects, unspecified”
The RLDQ could not be linked to aspects concerning “work and employment”.

“Recreation and leisure, unspecified” (d6209) is only represented in the BASFI.

The BASFI covers three ICF-categories and the HAQ-S covers five ICF-categories relating to environmental factors. Three of them are identical (e1151 assistive products and technology for personal use in daily living, e1201 assistive products and technology for personal indoor and outdoor mobility and transportation and e3 support and relationships).

Additionally, the HAQ-S includes one item which could be linked to the e-component at a more general and comprehensive level than the BASFI (e135 products and technology for employment) as well as one further item linkable to the third level category “general products and technology for personal use in daily living” (e1150).

**Discussion**

The ICF is highly useful when comparing the contents of disease-specific instruments for AS. The linkage of all concepts except for “illness” (HAQ-S) of the most commonly used, self-administered questionnaires for AS to the classification has been possible based on acknowledged linking rules [16].

The degree of agreement between the two health professionals who performed the linking procedure was high according to the Kappa coefficient. However, estimation of the reliability of the linking process could be strengthened by increasing the number of raters in future studies.
By means of linking all four questionnaires to the ICF it could be proved that the classification is a very precise tool apart from very few exceptions. This underscores the findings of Weigl et al. [19].

The preciseness of the ICF can be illustrated e.g. by the items “19, to cough or sneeze” of the DFI and “coughing and sneezing” of the RLDQ, which could be transferred one to one to the ICF-code “additional respiratory function” (b450) as they are included exactly in its definition.

The linking procedure revealed that the DFI contains more items concerning “body functions” than the other three selected questionnaires. A possible explanation may be that the DFI was designed only by physicians [7,8] as opposed to the other three selected measures which have been conceptualized with major input from patients (HAQ-S, RLDQ) or by a multiprofessional team of including physiotherapists and patients (BASFI) [6].

The linking process also showed that only the HAQ-S includes “stiffness”, and none of the selected instruments represents “pain in back”, which are regarded as some of the clinically most relevant features in patients with ankylosing spondylitis [2]. This may be due to the fact that the selected instruments were explicitly designed to assess patients’ perception of their activities of daily living and not disease activity [6, 7, 8, 12].

During the linking procedure another striking difference between the selected instruments measuring physical functional ability in AS becomes obvious.

Whereas the BASFI and the HAQ-S include items and concepts referring to “environmental factors” of the classification, like “handrail or walking aid” (e1151 “assistive products and technology for personal use in daily living”), none of them is represented in the DFI and the RLDQ. A possible explanation for this finding could be
the fusion of the expertise of a multiprofessional team and the experience of patients with AS in the questions of the BASFI and HAQ-S respectively.

The e-component is not represented in the RLDQ. This may be due to the fact that patients’ advice was incorporated later on during the revision process of the questionnaire and not included in its first drafts [10].

Although the linking procedure revealed a high level of concordance in the ICF-concepts represented in the four selected measures, especially those concerning “activities and participation”, the emphasized aspects differ.

The difference between the contents of the HAQ-S and those of the DFI, BASFI and RLDQ becomes obvious in the ICF-categories referring to mobility of the upper extremity and self-care which are only applicable to the HAQ-S.

A possible explanation for this finding may be that the HAQ was originally designed as a disease-specific instrument for patients with RA and modified for AS later on by adding five items to the RA-version. In AS peripheral arthritis leading to disability of the upper extremity and especially impaired hand and arm use is rather unusual as compared to patients with RA. This may illustrate why fewer ICF-categories referring to mobility of the upper extremity are applicable to the other instruments.

Presumably for the same reason, aspects of self-care at a general level (d5) and especially the specific concept of “washing oneself” (d510) are represented in the HAQ-S, but not in the other selected instruments.

This possible explanation is reflected in the fact that none of the five AS-specific items of the HAQ-S could be linked to the chapter d5 of the ICF (see table 4).

Although questionnaires assessing physical functional ability in patients with ankylosing spondylitis like the BASFI, the DFI, the HAQ-S and the RLDQ can be successfully linked to the ICF, the classification should not be regarded as a
substitute for these instruments. In the future, it can serve as a common reference for all outcome measures.

Some results of the linking procedure, however, may provide helpful arguments for a future revision process of the ICF.

E.g. currently the item “Looking over your shoulder without turning your body” of the BASFI and the concept “Are you able to look in the rear view mirror?” as well as “Are you able to turn your head to drive in reverse?” of the HAQ-S had to be assigned to the more general parent category “d498” (mobility, other specified”). As affection of the cervical spine leading to impaired neck rotation can be regarded as one of the most important limitations in patients with AS [9] categories exactly representing this concept could be added to one of the next versions of the classification. The latter also holds for the item “How much stiffness have you had because of your illness” of the HAQ-S. Spinal stiffness- one of the major complaints in AS- had to be linked to the ICF-category 7800 (“sensation of muscle stiffness”) as the current version of the ICF does not include any other category closer to the sense of spinal stiffness.

The ICF-based comparison provides information about the contents addressed in the different measures. Therefore, it can be a useful tool when selecting specific measures for a study. The first question when selecting measures is to decide what should be measured in consideration of the study endpoints, the population studied and the planned intervention. The second question is to decide which measure to use. If one considers the contents covered in different measures a selection based on the question “What should be measured?” can be performed. Moreover, using the ICF as a reference framework allows a researcher or a recommending body to see which domains are covered in a specific instrument and, therefore, whether it is necessary to complement the study with further measures.
When compared to other types of qualitative review, the most important advantage of the content comparison of measures based on the ICF is the use of an external and independent reference to which all the instruments can be linked and by which all the instruments can be compared.

Measures vary both in the breadth of the dimensions measured as well as in the thoroughness and depth with which these different dimensions are measured [20, 21] Thus, the comparison of instruments often represents a cumbersome exercise. This could explain why many studies compare the psychometric properties of instruments, but content comparisons are scarcely represented in the literature. Since comparison based on the ICF is performed at the level of concepts, this difficulty is overcome. Comparison based on the ICF provides insight into both the bandwidth of the different generic instruments, i.e., the breadth of health dimensions measured, as well as the precision of the instruments, i.e., the thoroughness and depth of measurement.

In conclusion, the ICF provides an excellent common framework when comparing the contents of disease-specific instruments for patients with AS. The linking process is a very valuable tool to critically analyze physical functional ability instruments in all detail as it clearly shows which health domains are covered by them. For a future revision of the ICF, the specification of major limitations in patients with AS could provide a reference framework to define exactly what should be measured and which measures or items should be selected in detail to provide the most comprehensive picture of patients with AS. The ICF could then serve as a guideline for the design of innovative disease-specific instruments for AS.
References


Table 1: Estimated Kappa coefficient and the bootstrapped confidence intervals for the component, 1st, 2nd, and 3rd ICF-levels

<table>
<thead>
<tr>
<th>Component</th>
<th>Estimated Kappa Coefficient</th>
<th>95% Bootstrapped Confidence Intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Component</td>
<td>0.78</td>
<td>(0.65, 0.91)</td>
</tr>
<tr>
<td>1(^{st}) Level</td>
<td>0.98</td>
<td>(0.95, 1.00)</td>
</tr>
<tr>
<td>2(^{nd}) Level</td>
<td>0.97</td>
<td>(0.91, 1.00)</td>
</tr>
<tr>
<td>3(^{rd}) Level</td>
<td>0.98</td>
<td>(0.98, 1.00)</td>
</tr>
</tbody>
</table>
Table 2: Items of the DFI, the BASFI, the RLDQ and the HAQ-S and the corresponding ICF- categories

<table>
<thead>
<tr>
<th>ICF-Domains</th>
<th>DFI</th>
<th>BASFI</th>
<th>RLDQ</th>
<th>HAQ-S</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BODY FUNCTIONS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b134 Sleep functions</td>
<td>X</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b280 Sensation of pain</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>b289 Sensation of pain, other specified and unspecified</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>b4402 Depth of respiration</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b450 Additional respiratory functions</td>
<td>X</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>b7603 Supportive functions of arm or leg</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>b7800 Sensation of muscle stiffness</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>ACTIVITIES &amp; PARTICIPATION</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>d410 Changing basic body position</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d4100 Lying down</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
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<tr>
<td>d4101 Squatting</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>d4103 Sitting</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>d4104 Standing</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d4105 Bending</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>d4109 Changing basic body position, unspecified</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d4150 Maintaining a lying position</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d4153 Maintaining a sitting position</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d4154 Maintaining a standing position</td>
<td>X</td>
<td>x</td>
<td></td>
<td></td>
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<tr>
<td>d4201 Transferring oneself while lying</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d430 Lifting and carrying objects</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d4300 Lifting</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d4400 Picking up</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
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<tr>
<td>d4402 Manipulating</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d4452 Reaching</td>
<td>X</td>
<td>x</td>
<td>x</td>
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<tr>
<td>d4453 Turning or twisting the hands or arms</td>
<td></td>
<td></td>
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<td>x</td>
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<tr>
<td>d450 Walking</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
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<tr>
<td>d4551 Climbing</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td></td>
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<tr>
<td>d4552 Running</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d4751 Driving motorized vehicles</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d498 Mobility, other specified</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<tr>
<td>d499 Mobility, unspecified</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>d5 SELF-CARE</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d510 Washing oneself</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d5100 Washing body parts</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d5101 Washing whole body</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>d5102 Drying oneself</td>
<td></td>
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* X means that the ICF-domain was represented in the items or concepts of the questionnaire one or more times*
ICF-based comparison of disease-specific instruments measuring physical functional ability for ankylosing spondylitis

Tanja Sigl, Alarcos Cieza, Désirée van der Heijde and Gerold Stucki

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