Development of ICF Core Sets for Multiple Sclerosis

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Für ZHAW, Dept. Gesundheit,
Institut Ergotherapie, 2010

International Classification of Functioning, Disability and Health
ICF
www.who.int/classifications/icf
Approved by the World Health Assembly in May 2001

ICF is WHO’s framework for measuring health and disability at both individual and population levels

While the International Classification of Diseases ICD classifies diseases as causes of death, the ICF classifies health

Dr. Gro Harlem Brundtland
Former Director General, WHO
Bio-medical model of disease

Health Condition (disease, trauma)

Evaluation of the disease consequences

Integrative model of functioning and disability

Health Condition (disease, trauma)

Functioning/ Disability

Environmental Factors

Personal Factors

Contextual Factors

The biopsychosocial model of functioning and disability

ICF provides an international common language and universal conceptual framework for describing functioning, disability and health
ICF Classification

List of

– mutually exclusive and
– cumulative exhaustive
categories which allows to unambiguously classify, describe and communicate about functioning

The list is, at least in principle, finite

How many categories do we need to comprehensively describe, classify and communicate the human experience of functioning and disability?

ICF

1454 categories

ICF categories

Health Condition
(disease, trauma)

493 Body Functions
310 Body Structures

384 Activities & Participation

253 Environmental Factors

Personal Factors

Contextual Factors
"To be useful, practical ICF based tools need to be tailored to the need of the users without forgoing the information needed for health statistics and health reporting"


"Tools" for practical use of ICF

- ICF Checklist
- ICF Core Sets
- ICF Intervention Categories

The ICF is the full dictionary of functioning

ICF Core Sets are fractions of the ICF relevant for specific health conditions and / or a specific context
ICF Core Sets

Brief ICF Core Sets: 10-15
- Research standard and statistics
- Encounter single professional

Comprehensive ICF Core Sets: 70-200
- Multi-disciplinary team
- As few as possible, as many as necessary

Selection depends on health condition/ specific context

ICF Core Sets serve as international standards regarding
- what to measure
- what to report
ICF Core Sets

- link the ICF to
  - health conditions
  - the world of measurement instruments

Development of ICF Core Sets
Institute for Health and Rehabilitation Sciences
ICF Research Branch, WHO CC FIC Germany
Ludwig-Maximilian University
Munich, Germany

WHO
CAS Team - Classification, Assessment and Standards
Partner-Organisations
Current developments

- Scleroderma – Vienna - EUSTAR, EULAR
- SLE – Vienna - EULAR, OMERACT
- Psoriasis Arthritis – Wellington - EULAR, OMERACT
- Sleep – Helsinki - WASM
- Multiple Sclerosis – Valens - MSIF
- Traumatic Brain Injury – Barcelona - WFNR
- Bipolar disorders – Munich - ISPRM
- Vision – Milan - ISPRM
- Migraine/Headache – Paris - ISPRM
- Manual Medicine – Zurich - SAMM
- Oral functioning – Switzerland (SUVA)
- Work reintegration

Development of ICF Core Sets for MS

World Health Organization (CAS Team)
Valens Rehabilitation Centre, Switzerland
ICF Research Branch, WHO FIC CC, Germany
Ludwig Maximilian University, Germany
Multiple Sclerosis International Federation (MSIF)
International Society of Physical and Rehabilitation Medicine (ISPRM)

Preparatory Phase
- Clinical perspective
- Researcher perspective
- Patient perspective
- Expert perspective
- Systematic review
- Qualitative study
- Expert survey

Phase I
- International ICF Consensus Conference

Phase II
- Implementation and Validation of 1st Version of ICF Core Sets

Timeline
- 2007/2008
- 2008
Publikation über gesamtes Projekt

Study aim
To describe functioning as well as environmental factors of individuals with MS from the clinical perspective

Methods
• Multicenter cross-sectional study with 4 study centres in Switzerland and Germany
• Interview, documentation, questionnaires
• Data collection once by one health professional

Participants

<table>
<thead>
<tr>
<th>N</th>
<th>205 participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>148 female (72%); 57 male (28%)</td>
</tr>
<tr>
<td>Age</td>
<td>19 - 76 years; mean 44.7 years</td>
</tr>
</tbody>
</table>
| MS form      | RR MS = 112 (55%); male 23 (11%)
               | PP MS = 33 (16%); male 13 (6%)
               | SP MS = 60 (29%); male 21 (10%)
| EDSS         | EDSS 1 – 7.5; mean 3.7
               | EDSS 1 - 3.5 = 111 (54%)
               | EDSS 4 - 6.5 = 78 (38%)
               | EDSS 7 – 10 = 16 ( 8%) |
Publikation Ergebnisse

L. Holper, M. Coenen, A. Weise et al.

Identified ICF categories

| Body Functions (b)          | 40 |
| Body Structures (s)         | 10 |
| Activities & Participation (d) | 57 |
| Environmental Factors (e)   | 32 |

Total 139

Preparatory Phase

- Clinical perspective
  - Empirical study
- Researcher perspective
  - Systematic review
- Patient perspective
  - Qualitative study
- Expert perspective
  - Expert survey

Phase I

- International ICF Consensus Conference

Phase II

- Implementation and Validation of 1st Version of ICF Core Sets
Study aim
To identify the areas of functioning, disability and health reported in published studies on patients with Multiple Sclerosis (research perspective)

Methods
- MEDLINE, EMBASE, PSYCINFO, CINAHL, CENTRAL
- Published in 2002-2007 in English
- Search terms

Results
- 5,310 studies
- 1st Eligibility check on abstracts: 1,998 studies
- 2nd Eligibility check on full texts: 354 studies

→ 269 studies fulfilled the eligibility criteria for further analyses
Parameters extracted: 4,744

Data analysis
- Part 1: Translation
- Frequency analysis
- List of parameters
**Identified ICF categories**

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body functions (b)</td>
<td>66</td>
</tr>
<tr>
<td>Body structures (s)</td>
<td>14</td>
</tr>
<tr>
<td>Activities &amp; Participation (d)</td>
<td>70</td>
</tr>
<tr>
<td>Environmental Factors (e)</td>
<td>31</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>181</strong></td>
</tr>
</tbody>
</table>

**Candidate ICF categories** (2nd level)

- Systematic review
- International ICF Consensus Conference
- 1st Version of ICF Core Sets

**Preparatory Phase**

- Researcher perspective
  - Systematic review
  - Qualitative study
- Patient perspective
  - Qualitative study
- Expert perspective
  - Expert survey

**Phase I**

- International ICF Consensus Conference

**Phase II**

- Implementation and Validation of 1st Version of ICF Core Sets

**Study aim**

To identify relevant aspects of functioning as well as environmental factors from the patient perspective

**Methods**

- Focus groups with individuals with MS
- 6 open-ended questions according to ICF components
### Data analysis

**Part 1**
Identification of meaningful concepts

**Part 2**
Linking of meaningful concepts to the ICF

**Identification of saturation**

### Participants

<table>
<thead>
<tr>
<th>N</th>
<th>27 participants / 6 focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>19 female; 8 male</td>
</tr>
<tr>
<td>Age</td>
<td>Median 50 years (28 – 73)</td>
</tr>
<tr>
<td>MS form</td>
<td>RR MS n=7</td>
</tr>
<tr>
<td></td>
<td>PP MS n=6</td>
</tr>
<tr>
<td></td>
<td>SP MS n=14</td>
</tr>
<tr>
<td>EDS5</td>
<td>Median 6.5 (2.5 – 8)</td>
</tr>
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</table>

### Identified ICF categories

<table>
<thead>
<tr>
<th>Body Functions</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Str</td>
<td>--</td>
</tr>
<tr>
<td>Candidate ICF categories (2nd level)</td>
<td>31</td>
</tr>
<tr>
<td>Activities</td>
<td>31</td>
</tr>
<tr>
<td>Environmental Factors</td>
<td>38</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>104</strong></td>
</tr>
</tbody>
</table>
Study aim
To identify relevant aspects of functioning as well as environmental factors from the perspective of health professionals treating patients with MS

Methods
- International internet survey
- Health professionals from different WHO world regions experienced in the treatment of MS

Participants
46 countries
n=65
n=15
n=52
n=11
n=30
Participants

<table>
<thead>
<tr>
<th>N</th>
<th>173 health professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>113 female (65%); 60 male (35%)</td>
</tr>
<tr>
<td>Age</td>
<td>Mean 44.9 years (27 – 83)</td>
</tr>
<tr>
<td>Years of experience</td>
<td>Mean 13.4 years (5.0; 50.0)</td>
</tr>
</tbody>
</table>

Expert survey

- Physicians: n=49
- Physiotherapists: n=28
- Social workers: n=11
- Speech & Language therapists: n=15
- Psychologists: n=25
- Nurses: n=25
- Occupational therapists: n=20

7756 statements

Data analysis

- Part 1: Translation to the ICF
- Frequency analysis
- Linking
Identified ICF categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Functions</td>
<td>51</td>
</tr>
<tr>
<td>Body Structures</td>
<td>21</td>
</tr>
<tr>
<td>Environmental Factors (e)</td>
<td>47</td>
</tr>
<tr>
<td>Activities &amp; Participation (d)</td>
<td>57</td>
</tr>
<tr>
<td>Body Functions</td>
<td>51</td>
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<tr>
<td>Environmental Factors (e)</td>
<td>47</td>
</tr>
<tr>
<td>Total</td>
<td>176</td>
</tr>
</tbody>
</table>

Preparatory studies

- Clinical perspective
  - Empirical study
- Researcher perspective
  - Systematic review
- Patient perspective
  - Qualitative study
- Expert perspective
  - Expert survey

199 2nd level ICF categories

Preparatory Phase

- International ICF Consensus Conference

Consensus Conference

- Implementation and Validation of 1st Version of ICF Core Sets
During the conference …
a decision-making and consensus process takes place to decide on

- ICF Core Sets for MS
- Comprehensive ICF Core Set
- Brief ICF Core Set

Decision-making and consensus process

- Plenary sessions
- Working group sessions
  - WG leader
  - WG assistant
### Working groups

**WG room**
- B351
  - F. Khan
  - A. Hassan
  - E. Måsson L.
  - M. Renom G.
  - A. Stuifbergen
  - S. Sungkarat
  - C. Vaney
  - S. Kus

**WG leader**
- J. Freeman
  - B. Anderseck
  - F. Cáceres
  - M. Govaerts
  - J. Hinrichs
  - C. Stevens
  - A. Vogt
  - L. Holper

**WG members**
- D. Miller
- S. Chitnis
- B. Anderseck
- P. Flachenecker
- P. Hoang
- J. Jansa
- L. Vahter
- E. Willoughby
- C. Sabariego

**WG assistant**
- L. Holper

### Results

**Prel. Comprehensive ICF Core Set for MS**
- 138 ICF categories

**Preliminary Brief ICF Core Set for MS**
- 37 candidate ICF categories
**Implementation & Validation**

- Manual
- Empirical study (Fary Khan/Australia?)
- Australian qualitative study
- Delphi studies with
  - physicians
  - occupational therapists (Stephanie Berno)
  - physiotherapists (Andrea Wiedenmann)
  - psychologists (Michaela Coenen)
  - nurses (Andreas Leib)
  - speech & language therapists (Marta Renom Guiteras)

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**Preliminary Comprehensive ICF Core Set for MS: 138 categories**

<table>
<thead>
<tr>
<th>Category</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body functions</td>
<td>40 (29.0%)</td>
</tr>
<tr>
<td>Body structures</td>
<td>7 (5.1%)</td>
</tr>
<tr>
<td>Activities &amp; Participation</td>
<td>53 (38.4%)</td>
</tr>
<tr>
<td>Environmental factors</td>
<td>38 (27.5%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>138</td>
</tr>
</tbody>
</table>

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**Activities & Participation: 53 categories**
Environmental Factors: 38 categories

Preliminary Brief
ICF Core Set for MS: 37 categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body functions</td>
<td>14 (38.0%)</td>
</tr>
<tr>
<td>Body structures</td>
<td>3 (8.0%)</td>
</tr>
<tr>
<td>Activities &amp; Participation</td>
<td>12 (32.0%)</td>
</tr>
<tr>
<td>Environmental factors</td>
<td>8 (22.0%)</td>
</tr>
<tr>
<td>Total</td>
<td>37</td>
</tr>
</tbody>
</table>

ICF Core Sets

serve as international standards regarding
- what to measure
- what to report
Brief ICF Core Set for MS  
(37 categories)  
can serve as a worldwide agreed-upon:  
- Research standard: minimum data will be collected and reported about with regard to this diagnosis  
- Clinical standard: minimum data will be collected and reported during encounter with a single professional  

Comprehensive ICF Core Set for MS  
(138 categories)  
can serve as a worldwide agreed-upon:  
- Checklist for observation & questioning  
- Guideline for choosing relevant measurements/ observation tools  
- Guideline for developing missing measurements  
- Guideline for reporting & documenting in a multi-disciplinary setting  
- Checklist for dividing tasks in a multi-disciplinary setting  
- Guideline for structure of saving clinical data that is comparable for research worldwide  
- …  

THANK YOU!  
Andrea Weise  
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