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WHO Family of International Classifications (FIC)

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Functional Capability List (FCL) insufficient for evaluating posttraumatic impairment, a plea for implementation of ICF

Permanent impairment caused by injury or disease can be financially compensated. Such compensation is needed for pecuniary damages and non pecuniary damages (pain suffering and loss of amenities).

Material damage is for the most part generated by loss of physical and/or psychological (cognitive) capabilities of the victim. The victim is unable to function at the same level as before. This can cause impairment in functioning regarding self care, housekeeping capacity, private and occupational activities.

To properly evaluate and compensate for the caused personal impairment, the hypothetical situation without the accident should be compared to the expected posttraumatic future. In The Netherlands a Functional Capability List (FCL, "Functionele Mogelijkheden Lijst") is used to determine such impairment. The FCL is a tool developed by and used by the Dutch Social Security System, particularly with regards to the Collective Social Inability Insurance. The FCL compares a person's remaining capacities to a (rather arbitrarily) adapted set of "average normal values of functioning" of the Dutch population, rather than comparing these remaining capacities to the individual's capabilities before the harmful incidents.

The Dutch social security and insurance system

The Functional Capability List was developed as an aid for the social security services.

In order to determine a set of "normal values of functioning in daily life", a group of physicians in the field of social security related healthcare agreed upon what should be considered to be normal levels of activities in "everyday lifestyle".

These levels were established after evaluating 120.000 records of incapacitated workers medical files. These workers had been medically evaluated for their remaining functional capability to function in (adapted and suitable) occupational work in 1998. In this way, a set of "normal values" was established. All of these workers, of all ages and background, had in common that they suffered from some form of impairment! We consider that such "an average normal functioning" is likely to be less than the normal functioning of the healthy working population.

From the viewpoint of the personal injury lawyer it is important to realize that, in extending the use of such an averaged FCL, for the purpose of liability evaluations, the reference points for "normal functioning" are not in accordance with the real individual capabilities which the victim enjoyed before the harmful incident. Therefore use of the FCL, and its particular set of definitions of "normal level of activities" as reference points, can have grave consequences, as it does not properly evaluate the real extend of loss of functional capabilities of the individual victim.

Editorial Board

Dr Marijke W. de Kleijn-de Vrankrijker
Drs Huib Ten Napel
Dr Willem M. Hirs

Realization and Design

A.C. Alta, Studio RIVM

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Address

WHO-FIC Collaborating Centre
Department for Public Health Forecasting
National Institute of Public Health and the Environment (RIVM), P.O.Box 1,
3720 BA Bilthoven, The Netherlands.
Telephone: 0031 30 274 2039/4276
Fax: 0031 30 274 4450
Website: www.rivm.nl/who-fic
E-mail secretariate: Lummy.Blomer@rivm.nl
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Contents

Functional Capability List ...	1
<i>Editorial</i>	2
International organisations	
WHO-FIC Network Meeting	2
ATC classification of medicines	3
Launch of ICF-CY in Venice	4
Harmonization of ISO 9999 & ICF	5
FIC around the World	
<i>Europe:</i>	
ICF: Quantitative Measurement of Capacity and Performance	5
<i>Nordic Countries:</i>	
Targeting Non-obvious Errors in Death Certificates	8
<i>The Netherlands:</i>	
Dutch ICF Train the trainers course	8
ICF References	8

In search of a proper alternative to the FCL, some basic questions should be answered first.

How to evaluate the capability of functioning of a human being?

Evaluation of functional capabilities using the biopsychosocial model, the previously used medical and social concepts are combined in The International Classification of Functioning, Disability and Health (ICF). By using the ICF, the functioning of an individual as a whole is described completely.

What are basic demands which aims to evaluate the functional capabilities before and after a harmful incident ?

An ideal evaluation system should be individually applicable, be as valid as possible, be understandable for all those concerned, as well as being reproducible.

Unfortunately such a standard does not exist.

Using an ICF based presentation of impairment some limitations will also remain to a certain extent. As a description of an individual functioning becomes more detailed, this will be better accessible to all those concerned and also do more justice to them.

As the description becomes more detailed, this will improve fairness for all those involved.

Conclusion

In our considered opinion, the use of the Functional Capability List (FCL) is insufficient to evaluate the personal capabilities of a victim prior to a harmful incident. The International Classification of Functioning, Disability and Health (ICF) is better suited to describe these individual normal capabilities as such and is also better validated.

Future development of evaluation instruments for loss of capabilities should be based on the ICF. A pilot study would be desirable to evaluate the possibilities and limitations of using such an ICF-based system with regards to liability claims.

For information:

R.I. Teulings, director of De Medicus Intermediair, a medicolegal advisory firm for personnel injury victims (after traffic accidents medical malpractice and occupational exposure) and editor of the personnel injury journal "Letse! en Schade" (Injury and Damage), and Marcel Herpers, medicolegal advisor and medical advisor for the Dutch Social Security Services and free-lance lecturer at the Netherlands School of Public and Occupational Health (NSPOH)
e-mail: info@medicusintermediair.nl

Editorial

The annual WHO-FIC network meeting last autumn in Trieste was an interesting phenomenon. The readers will see a lot of meeting impressions in this newsletter. See also the full list of papers, <https://crs.sanita.fvg.it/WHO>.

A new potential member being the International Classification for Nursing Practice was presented by Amy Coenen; see paper nr WHO-FIC 2007/D045 at the WHO website for the annual meeting 2007. The decision about acceptance as a related member of the WHO-FIC will be discussed during the mid-year meeting in April 2008 based on collected opinions and comments.

A major event was the official launch of the ICF-CY in Venice preceding the network meeting, see page 4. We are now involved in the Dutch translation and hope to have the full translation ready mid 2008. Several parties are interested in the implementation of the ICF-CY in The Netherlands, so we feel a lot of pressure to finalize the translation. We should like to hear the experiences concerning the ICF-CY in other parts of the world.

Further steps have been made concerning harmonization of ISO9999 and the external factors classification of the ICF, see page 5. Both being members of the family they can be more complementary to each other.

The MHADIE European conference Milan, Italy, 28-30 November 2007 included a lot of interesting presentations regarding the ICF, see www.mhadie.it. One of the

presentations has been summarized by the authors for this newsletter: ICF quantitative measurement of capacity and performance. We found this work very stimulating and hope to see how the results can be used for our work in practice.

Please enjoy reading this newsletter and let us know your news and experiences. Sharing information makes life easier!

International Organizations

WHOFIC Network Meeting

28 October - 3 November 2007



Information Power: Owning and Sharing

The 2007 Annual meeting of the WHO Network of Collaborating Centres for the Family of International Classifications in Trieste, Italy was co-organized by the Centre in Italy and the Measurements and Health Information Systems (MHI) Department of the World Health Organization.

168 international participants attended the meeting from 10 Centres, and representatives from Ministries of Health or National Statistical Bureaus from 27 countries.

In 2008, the WHO-FIC Network will meet from 26 October to 1 November 2008 in Delhi, India.

All documents are published on the website of the 2007 Annual Meeting of the WHO-FIC Network, see <https://crs.sanita.fvg.it/WHO/>. In this Newsletter we highlight new ICD-information from the meeting report summary, in addition to information given at the WHO FIC website, e.g. the production of ICD-11, <http://extranet.who.int/icdrevision/help/docs/ICDRevision.pdf>.

ICD Implementation

A WHO database for the implementation of ICD, and other members of the WHO-FIC is online available, see <http://www.who.int/classifications/icd/implementation/en/index.html>. Information was gathered through a questionnaire that was distributed to all applicants of translation rights, implementation support, and other key informants. A current morbidity use survey will further enhance the quality of information, and inform the ICD revision process, and existing information will inform the database.

Regional implementation networks of the WHO-FIC will address fostering information sharing, and implementation strategies. Procedures for regional networks will be based on experience, and the action plan for the Asia-Pacific Network. This Network was first convened in Tunis, October 2006, and had its second meeting in Kyoto, Japan, on 10, and 11 September 2007. It's three working groups will focus on a set of use cases: (1) Mortality, (2) Morbidity, disability, and functioning, and (3) Health information systems. This network also presented a pragmatic approach to (a) information sharing, (b) human resource development, and (c) academic activities. WHO-EURO will consider a European network in cooperation with the WHO-FIC Implementation Committee.

A small working group will develop a draft implementation toolkit at country level that includes details for rationale, steps, material needed, and possible stakeholders.

ICD-XM: National modifications of ICD are being combined in a common

framework that is based on LexGrid, and ClaML. Some modifications are already available in this format.

ICD Updates

125 proposals were reviewed by the Update, and Revision Committee in 2007. Special attention was given to new codes for dysplasia of prostate, HIV complicating pregnancy, childbirth and the puerperium, Chronic kidney disease redefining the stages, and terminology used to describe chronic kidney disease as opposed to chronic renal failure, and tumour lysis syndrome. All changes will be published on the WHO website. The next major update of ICD-10 is deferred to 2010.

For more information:

Dr Robert Jakob, Medical Officer
WHO, Geneva
Tel.: +41 22 791 5877 or + 41 22 791 2142
E-mail: jakobr@who.int

ATC classification of medicines

The WHO Collaborating Centre for Drug Statistics Methodology was established in 1982 as a European Centre linked to the WHO Regional Office for Europe in Copenhagen. In 1996, WHO recognised the need to develop use of the ATC/DDD system as an international standard for drug utilisation studies. The Centre was therefore linked directly to the WHO Headquarters in Geneva. According to the agreement between WHO and the Norwegian government, the Centre's main tasks are development and maintenance of the ATC/DDD system, including:

- Classifying drugs according to the Anatomical Therapeutic Chemical (ATC) system.
- Establishing Defined Daily Doses (DDDs) for drugs, which have been assigned an ATC code.
- Reviewing and revising as necessary the ATC classification system and DDDs.

- Stimulating and influencing the practical use of the ATC system by co-operating with researchers in the drug utilisation field.

Since 2002, the Centre has been located at the Norwegian Institute of Public Health, in the department of pharmacoepidemiology. Most of the scientific advisors and secretaries are working part time at the Centre and part time with the Norwegian Drug Utilization statistics and research. This is regarded as an optimal situation in the sense that the "caretakers" of the methodology are also users of the same methodology and therefore fully aware of the implications of the technical decisions on the practical use.

In 1996, when the decision on globalizing the ATC/DDD system was taken, the WHO Division of Drug Management and Policies in Geneva established the WHO International Working Group for Drug Statistics Methodology. The Centre works in close collaboration with this Working Group regarding the development and maintenance of the ATC/DDD system. The Working Group now consists of 12 WHO appointed experts in clinical pharmacology, drug utilisation, drug regulation, drug evaluation, statistics and medicine from the following countries: Australia, Japan, India, Sri Lanka, Pakistan, Morocco, Ghana, Zimbabwe, USA, Ecuador, The Netherlands and Denmark. The Working Group has two annual meeting and all decisions regarding ATC classifications (and DDDs) are taken in this group.

The Centre has recently conducted a survey regarding the international use of the ATC classification (and the DDD unit). The overall response rate of the survey was 40 %. Users of the ATC/DDD system in 110 countries were requested to fill in the questionnaire and users in 72 countries (65% of the countries) responded. The results indicated that 62 % of the responders used the ATC classification for drug utilization research, 36 % used it as a classification system in drug catalogues, 32 % used the classification in

connection with monitoring of adverse drug reactions, 27 % used it for reimbursement decisions (not recommended) and 22 % mentioned various other purposes. The results from the survey will be ready for presentation at the next meeting of the WHO Working Group for Drug Statistics Methodology in Oslo 24-25 October '08.

The Centre collaborates with the INN (International Non-proprietary Name) Programme, Quality Assurance & Safety at the WHO Geneva. The ATC codes are integrated in the INN database. The Centre and the SNOMED International Pharmacy Working group are also exploring the possibilities of linking the two systems.

For information:

Marit Rønning, Director
WHO Collaborating Centre for Drug
Statistics Methodology
e-mail: marit.ronning@flii.no

Report on the launch of the ICF-CY in Venice

On October 25 and 26 2007, just a few days before the annual meeting of the WHO-FIC Network, the Venetian Island of San Servolo was the scenic stage for the official launch of the new adaptation for children and youth of the ICF: ICF-CY. The ICF-CY was developed over a period of 5 year, by a dedicated international Work-Group following a WHO call for such endeavour and funded by the CDC/CCHP/NCBDDD, USA. The WHO meeting was hosted by the Veneto Region of Italy, and witnessed a packed audience of professionals from various backgrounds, all linked by the keen interest in this new classification. The meeting was opened by the Veneto Regional Minister for social affairs, and was articulated in a first day devoted to the presentation of the steps which led to the development of ICF-CY, the main issues faced during the work, the next steps ahead, and the likely areas of immediate implementation of the new tool. In the first section contributions by Bedirhan Üstün and Nenad Kostanjsek from the central offices of WHO focused on the

need for such an adaptation to ICF, and the link with assessment instruments that the classification already may offer. The address by the CDC/CCHP/NCBDDD director D. Trevathan focused on the reason leading to the CDC commitment and to the possible future fall-out in the public health sector. The members of the ICF-CY work group then presented the principles guiding the work of the group (Rune Simeonsson, ICF-CY WG chair), the structural and formal characteristics of the adaptation (Huib Ten Napel), the critical areas of changes monitored (Eva Björck-Åkesson), the experiences gathered around the world during the field trials (Matilde Leonardi, WG co-chair), and the open issues left for the work ahead (Andrea Martinuzzi). Don Lollar, the missing member of the WG was home recovering from heart surgery, but was present in spirit throughout the meeting.

The same group during the afternoon drafted the possible latitudes for implementation of ICF-CY in three key areas of children and youth functioning and disability: Health and public health, education and children's rights. The ways in which such implementation may find realization, or the settings in which ICF introduction may indeed make a difference were the themes for the second day of the meeting.

The second day was open for the contributions from various sites in Italy and from around the world (China, Argentina, South Africa, Thailand, USA, Japan, the EU). The contributions were clustered into three thematic workshops: Health, Education and Rights, and presented either the ongoing experiences in implementation of the new 'tool', or the issues in which its introduction may represent a positive response to a specific need. Areas of ICF use or possible application mapped in the Health sector were the rehabilitation process, the networking of territorial Health services, the monitoring of health services delivery, the functional profiling of rare or complex health conditions. The impact of ICF-CY on education was discussed in the

Education workshop, with contributions addressing the background in which, for example in OECD countries, ICF-CY use may be warranted, the possible introduction of ICF-CY as conceptual organizer of the functional diagnosis in children with special education needs, the ways in which ICF-CY may help in drawing the educational plan and its adaptation to the special needs of the child and the adolescent, and finally the possible impact that ICF-CY use in educational settings may produce towards the full realization of the Salamanca Statement.

In the workshop on the Rights issue ICF CY was projected on the issue of rights realization, in some way reading disability and functioning as a Human Right issue, which for children and youth is an even more delicate and intricate one. Therefore the intimate relationships between poverty and disability, advocacy and disability, equalization of opportunities were addressed and discussed.

The meeting was closed by a round table discussion in which the conclusions stemming from the workshops were the ground on which to launch an ambitious program: a global initiative for the monitoring of children health and disability. This goal was embraced by the Regional Minister for Social Affairs, warmly sustained by WHO and joined by other participants to the table, such as the deputy Health minister of Mozambique. The developing scheme would be a "me too" project structure, in which each participant will join in a common initiative and protocol and will search for financial coverage. 2008 may thus see the growing up of ICF-CY both in its daily practice and in a paradigm for research on disability in the developing age globally.

For information:

andrea.martinuzzi@cn.lnf.it

International Organization for Standardization

Harmonization of ISO 9999 & ICF

In March 2007 the fourth edition of the ISO 9999, one of the related classifications of the ICF, was published. In this fourth version the terminology used is harmonized with ICF-terminology. The title of the ISO 9999 has been changed from "Technical aids for persons with disabilities - Classification and terminology" to "Assistive products for persons with disability - Classification and terminology". The basis concepts of the ICF are included in the ISO 9999.

During the meeting in Stockholm in April 2006, ISO/TC173/SC2, responsible for the ISO 9999, has decided to launch the next revision process of the ISO 9999 by formulating a New Work Item Proposal in December 2007. It is the aim of the subcommittee and of WG11, the working group beyond this subcommittee, to take a major step in the harmonization of the ISO 9999 and the ICF during this new revision process, which will result in the fifth edition of the ISO 9999 in December 2010. The revision process of the ISO 9999 parallels, in time, the present update and revision process of the ICF.

Three members of WG11 – Petra Winkelmann from Germany and Theo Bougie and Yvonne Heerkens from the Netherlands - submitted a first proposal to FDRG Project 7 (Environmental factors). As experts of FDRG Project 7, Petra Winkelmann and Yvonne Heerkens participated in the WHO-meeting in Trieste in October 2007. During this meeting the proposal was presented and discussed both in a general meeting and in a meeting with the experts of FDRG Project 7.

The proposal contains two suggestions:

- 1) to match the definition of assistive devices in ICF and ISO 9999; and
- 2) to revise the current structure of the first chapter of the list of environ-

mental factors of the ICF and the first-level classification of ISO 9999.

The members of the FDRG project 7 welcomed the initiative of the WG11 representatives and understood its importance and benefits. The group endorsed the concept of harmonization within the timelines and constraints outlined for minor and major updates of the ICF. In preparation of the FDRG meeting of 2008, WG11 has been invited to propose an adapted structure of ISO 9999 and chapter 1 'products and technology' of ICF Environmental factors.

During the next meeting of WG11, in March 2008, this will be a major topic.

Some comments have been obtained on the document concerning the relationship between ISO 9999 subclasses or divisions and ICF classes (see Newsletter on the WHO-FIC, Volume 5, Number 1, 2007) which was distributed by the WHO-FIC Collaborating Centre in The Netherlands. A new version of this document will be ready in March.

For information:

Yvonne Heerkens, e-mail:
woittiez.heerkens@wxs.nl

FIC around the World

Europe

The International Classification of Functioning, Disability and Health (ICF): Quantitative Measurement of Capacity and Performance

Introduction

A considerable amount of data on disability is available at international level. However, the definition of disability and the instruments used to measure it vary substantially among health surveys and the results are not usually comparable. Therefore, agreement on the way that disability is conceptualized and the methods for assessing it are urgently needed(1).

The WHO's international classification of functioning, disability and health (ICF) was the result of nearly a decade of collaboration and field testing. It has been endorsed by all member states, and provides a complete conceptualisation of disability(2). In contrast with the old medical model perspective, the social model of disability incorporated into the ICF arises from the interaction between an individual's functional status and the environment. After presenting a set of functional limitations, the ICF incorporates the social model by including information on how an individual's functional capabilities are affected by their environment.

The ICF is a detailed classification, containing more than 1400 codes divided into three domains (Body function & structures, Activities & Participation, and Environmental factors). It clearly provides the most comprehensive systematic language to describe disability and other related factors(3). Developing a quantitative approach, as a complement to the current qualitative classification of disability with the information compiled by the ICF, would facilitate comparisons. However, to date there has been no attempt to obtain a

continuous measure of disability from the ICF codes. The aim of this study was to evaluate the underlying factor structure of the Activities and Participation domain and to define a scoring system.

Methods

Within the 'Measuring Health and Disability in Europe-MHADIE' EU project, a multi-centre cross-sectional study of patients (n=1019) with 8 different chronic conditions (musculoskeletal conditions, multiple sclerosis, Parkinson disease, migraine, stroke, depression, bipolar disorder, and traumatic brain injury) was conducted. Patients' evaluation was performed by trained health-professionals who completed the ICF-checklist as well as other questionnaires and assessments. The ICF checklist includes the 125 most representative ICF codes(4;5), 48 of which correspond to the Activities & Participation domain: Learning and applying knowledge (6 codes); General tasks and demands (2 codes); Communication (5 codes); Mobility (6 codes); Self-care (7 codes); Domestic life (4 codes); Interpersonal interactions and relationships (7 codes); Major life areas (6 codes); and Community, social and civic life (5 codes). Information on 'Capacity' and 'Performance' was recorded separately for each of these codes using a 5-point Likert scale: from 0 ('no impairment') to 4 ('complete impairment').

In order to examine the underlying factorial structure of the Activities and Participation domain, the sample was randomly divided (after stratifying by pathology and severity) into 2 sub-samples of n=501 and n=518, respectively. The first stage in the analysis involved an exploratory factor analysis (EFA) with promax rotation conducted with one half of the sample to identify significantly correlated factors; the second stage consisted of testing for the existence of a unidimensional construct on the other half of the sample, using confirmatory factor analysis (CFA) with a global second order factor. Goodness-of-fit for the CFA models was tested using the Confirmatory Fit Index (CFI) and

Tucker-Lewis Index (TLI). Values over 0.9 are recommended for these indices. As the variables analyzed were categorical, specific methods based on polychoric correlations, and the robust-weighted least squares estimator(6) were used for EFA and CFA. This analytical strategy was applied separately to the 'Capacity' and 'Performance' sub-domains, using the Mplus software(7).

Results

Twelve codes were excluded from the analysis, 8 due to missing data (>60% of patients) and 4 due to poor variance (>90% patients with value equal to 0). In the EFA, the model with the Root Mean Square Residuals (RMSR) nearest to 0.06 was selected. The EFA models identified four different factors for both the 'Capacity' and the 'Performance' subdomains (RMSR= 0.0617 and 0.0632, respectively). Goodness of fit indices of CFA were acceptable for 'Capacity', with CFI and TLI values above 0.9. CFA of 'Performance' showed TLI= 0.958 and CFI= 0.880. These CFA results confirm the presence of a global second order factor for each subdomain, indicating their unidimensionality, and supporting the development of 'Capacity' and 'Performance' scores. The scores created by Mplus through an iterative process showed positive skewness, reflecting the higher proportion of patients with low scores (better functional capacity). This pattern was more marked for 'Performance' scores.

Discussion

This is the first quantitative approach to summarizing ICF-checklist information on 'Capacity' and 'Performance' as continuous variables. Although ICF was created as a classification system, our findings have demonstrated that 'Capacity' and 'Performance' are two different unidimensional concepts with scalable properties, indicating that disability as assessed by the ICF checklist can be considered a measurable continuum. Scores of 'Capacity' and 'Performance' can therefore be created but should be considered complementary to the rich,

comprehensive descriptive information provided by the ICF. Scores could be particularly useful for clinical and epidemiological research by allowing comparisons of severity or developing thresholds to obtain comparable disability prevalence data. Adding the possibility of analysing 'Capacity' and 'Performance' information in terms of continuous scores increases the ICF's flexibility, making it suitable for a very wide range of applications.

One of the limitations of the study is that the scores obtained are sample dependent and not directly generalizable to other populations. Also, although some of the goodness-of-fit indices did not meet theoretical requirements, the CFA models fitted the data sufficiently well to support further research extending Factor Analysis methodology to other ICF domains or settings. Further research is required and is currently ongoing to test different confirmatory factor models.

Study supported by: EC (MHADIE_SP24-CT-2004-513708); ISCIII_FIS (PI 061579 and PI 051542); DURSI-GENCAT (2005-SGR-00491); and AGAUR (2007FIC 00544).

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Figure 1. Results of the confirmatory factor analysis with a global second order factor to test for the existence of a unidimensional construct on 'Capacity'.

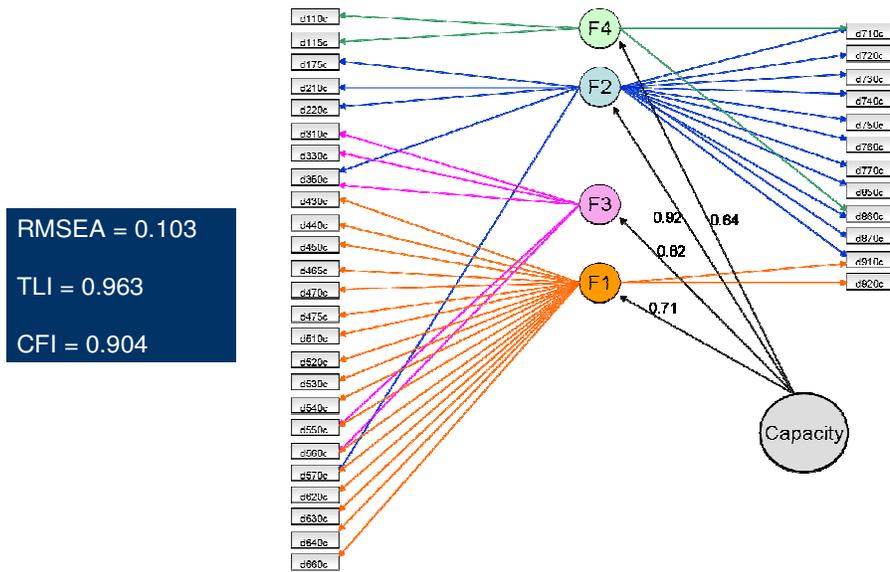
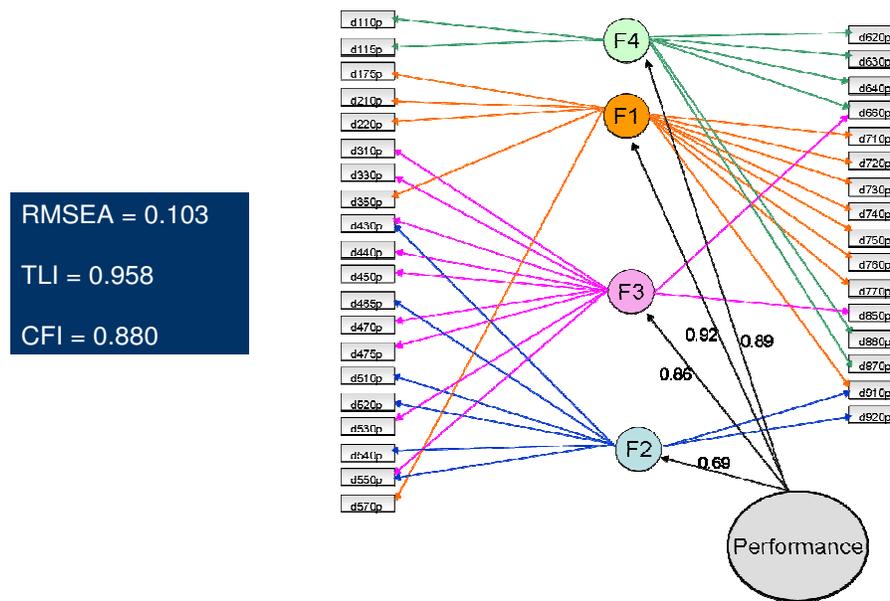


Figure 2. Results of the confirmatory factor analysis with a global second order factor to test for the existence of a unidimensional construct on 'Performance'.



For information:

Josue Almansa (1), Olatz Garin(1,2), Somnath Chatterjii(3), Gemma Vilagut(1,2), Ester Villalonga-Olives(1,2), Jordi Alonso(1,2), Jose Maria Valderas(2,4), Marta Nieto-Moreno(5), Jose Luis Ayuso(5), Alarcos Cieza(6), Matilde Leonardi(7), Alberto Raggi(7), Olga Svestkova(8), Helena Burger(9), Vittorio Racca(10), Carlo Francescutti(11), Eduard Vieta(12), Montse Ferrer(1,2)

1. Health Services Research Unit, IMIM-Hospital del Mar, Barcelona, Spain;
2. CIBER en Epidemiología y Salud Pública (CIBERESP), Spain;
3. Classification, Assessment, Surveys and Terminology, WHO, Geneva, Switzerland;
4. National Primary Care Research and Development Centre, University of Manchester, United Kingdom;
5. Psychiatry Medical School, Universidad Autonoma de Madrid, Spain;
6. Physical Medicine and Rehabilitation Ludwig-Maximilians-University, Munich, Germany;
7. Direzione Scientifica, Fondazione Istituto Neurologico Carlo Besta, Milano, Italy;
8. Department of Rehabilitation Medicine, First Medical Faculty, Charles University in Prague, Czech Republic;
9. Rehabilitation Institute or the Republic of Slovenia, Ljubljana, Slovenia;
10. Istituto S. Maria Nascente IRCCS, FONDAZIONE DON CARLO GNOCCHI ONLUS, Milano, Italy;
11. Agenzia Regionale di Sanità, Udine, Italy;
12. Hospital Clinic, University of Barcelona, IDIBAPS, CIBERSAM, Barcelona, Spain

Nordic Countries

Targeting Non-obvious Errors in Death Certificates

Under this title Lars Age Johansson wrote his doctoral thesis* that concluded that producers of official mortality statistics could reduce the number of non-obvious errors in the statistics by collecting additional information on incompatible deaths and on deaths in high-risk diagnostic groups. ICD conventions, not at least the concept of "underlying cause of death", contribute to the quality problem since they presuppose that all deaths are due to a single underlying cause. However, in an ageing population an increasing number of deaths are due to an accumulation of etiologically unrelated conditions.

This conclusion is underpinned as follows:

Producers of mortality statistics check for errors in death certification but current methods only capture obvious mistakes. My thesis investigates whether non-obvious errors can be found by linking death certificates to hospital discharge data.

Data: 69,818 deaths in Sweden 1995.

Paper I: Analysing differences between the underlying cause of death from the death certificate (UC) and the main discharge condition from the patient's last hospitalization (MDC). Paper II: Testing whether differences can be explained by ICD definitions of UC and MDC. Paper III: Surveying methods in 44 current studies on the accuracy of death certificates. Paper IV: Checking death certificates against case summaries for: i) 573 deaths where UC and MDC were the same or the difference could be explained; ii) 562 deaths where the difference could not be explained.

Results: In 54% of deaths the MDC differed from the UC. Almost two-thirds of the differences were medically compatible since the MDC might have developed as a complication of the UC. Of 44 recent evaluation studies, only 8 describe the methods in such detail that the study could be replicated. Incompatibility between MDC and UC indicates a

four-fold risk that the death certificate is inaccurate. For some diagnostic groups, however, death certificates are often inaccurate even when the UC and MDC are compatible.

*Johansson, Lars Age, Targeting Non-obvious Errors in Death Certificates, Uppsala University, 2008, 105 p, distributed by University Library, Box 510, 75120 Uppsala; see also <http://publications.uu.se/theses/abstract.xsq?dbid=8420>

For information:

Lars.Age.Johansson@socialstyrelsen.se

The Netherlands

ICF Train the trainers course

The Dutch Collaborating Centre receives many requests for presentations, workshops and training on the use of, or just to be informed about the state of art of developments concerning the ICF. A high number of these requests come from nursing profession educational institutes. In collaboration with the National Expertise centre of Nursing (LEV) the Centre has therefore developed a 'Train the trainer course' for nursing experts, policymakers, teachers, etc. The training is based on the ICF trainers course which is under development within the WHO-FIC Network. It has been adapted and elaborated for the Dutch situation. The course lasts four months, under guidance of ICF experts from the Centre. The aim of the course is to enable trainees to implement the ICF in their specific situation and to transfer knowledge on the ICF onto colleagues within their organization. A first (general) pilot training course was in February 2008, other training courses have been scheduled for March and October this year. The ICF training within the nursing profession will be coordinated by LEV. All other interested groups or persons are referred to the Dutch WHO-FIC Centre.

The ICF Trainers course has been developed in such a way that it can be used for general ICF training as well.

For information:

Huib.ten.napel@rivm.nl
Nursing: w.degraaf@levv.nl

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