

COMMENTARY

THE ICF AND FLORENCE NIGHTINGALE – BRINGING DATA TO STATISTICAL PROOF

In 1860 when Florence Nightingale urgently recommended the use of a classification of diseases for hospital morbidity statistics, she pointed out that this “would enable the value of particular methods of treatment and of special operations to be brought to statistical proof” (1). The coding and classification of disease has indeed found entrance into hospital and practitioners’ charts. The outcome of disease is increasingly not just a matter of life or death; the survival of patients faced with a medical emergency or crisis, such as severe acute illness or injury, has increased significantly in recent years. Surviving patients are at risk of experiencing significant loss of functioning even after discharge from acute hospital care. Consequently, the number of those with congenital or acquired disability is increasing.

Since its introduction, the International Classification of Functioning, Disability and Health (ICF) (2) has been praised as a breakthrough in rehabilitation practice and research. This classification reconciles the traditional biomedical model, centred on disease, signs and symptoms, with a patient-centred socio-psychological model, thus attracting notice on participation and context factors. The classification and model of the ICF make it clear that dealing with disability is not merely a question of amending and correcting body function and structure, but of inclusion and “full and effective participation in society on an equal basis with others” (3). The ICF acknowledges that a single disease may have more than one consequence and that individuals may present with symptoms, impairment of function or restriction of activity unexplained by the underlying pathology. Since the ICF model encourages healthcare professionals and policymakers to consider modifiable external factors, such as housing and social context and to respect patients’ preferences, it is suggested as a real benefit for both healthcare system and patient (4). Thus, the ICF model has found its way into national social legislation. Ten years after its introduction, however, the prospect is more sobering. Several practical obstacles are repeatedly evident when the implementation of the ICF classification is discussed.

First of all, it is not clear what is meant by the term “implementation.” If it were to be used like the International Classification of Diseases (ICD), health professionals would have to code absence or presence of disability, possibly aided by sufficiently efficient software. In practice this is limited by a lack of straightforward definition and operationalization. For example, benign paroxysmal vertigo in ICD-10 would be coded as H81.1. Thus, the pathology is coded uniquely. One of the consequences of vertigo can be restrictions in mobility, more precisely in ICF, d4500 Walking short distances, d4501 Walking long distances, d4502 Walking on different surfaces, d4551 Climbing, and d4552 Running. The ICF provides classifiers with which the extent of impairment or restriction can

be specified. However, how much a restriction, e.g. in running, is perceived as disabling, might differ between a sedentary octogenarian and a long-distance runner, i.e. depending on a person’s preferences and characteristics. The classification holds over 1,400 categories, which makes it impractical for daily clinical use. Also, hospitals and rehabilitation facilities already have their established documentation systems; introducing the ICF is frequently seen as an additional burden of documentation. Health professionals routinely use validated scales measuring a specific range of functioning. Reimbursement plans are also based on existing measures. There are no easy responses to this list of obstacles, which is by no means complete.

Although many feel that the comprehensiveness of the ICF is an asset, not a burden, the need to tailor ICF to the demands of particular contexts has been recognized. This was the primary motivation behind the idea of creating ICF Core Sets, selections of ICF categories from the entire classification which are relevant to specific health conditions or care situations. ICF Core Sets define common standards for what should properly be measured and reported. The methods to develop and validate ICF Core Sets were frequently described and include a whole series of methods and studies. This process has been discussed in the literature quite openly and frequently and is regarded as valid and reasonable (5, 6). Linking patient-reported goals to ICF categories is one of the methods to inform experts on the salient aspects of functioning relevant to a specific health condition or patient group or group of health professionals or to validate an existing set (7–9). Many authors have started to use subsets of the ICF or even subsets of the ICF Core Sets according to their specific needs. To give an example, colleagues from Switzerland used ICF Core Sets to code physiotherapeutic treatment goals and to monitor treatment success (10). The central issue, however, is always that the resulting set should reflect patients’ perspective and experience. Coming back to the coding problem mentioned above, the answer given here is that operationalizations for single categories might have to be defined according to the setting and patient population for which they are employed.

Preston et al. (11) propose an alternative method for the construction of ICF subsets that are relevant to children with cerebral palsy. They conducted a retrospective chart review extracting treatment goals and outcomes. Those goals and outcomes were then coded in terms of ICF-CY (the children and youth version of the ICF) components and categories by a single health professional. The authors state, “This approach may be more practical than those acknowledged in terms of time and human resources, as this method involved a single research physiotherapist who collated and organized the data in approximately 100 days.” This is certainly true, but there

are reasons for the huge effort which was employed when developing and validating ICF Core Sets. The major point is that a mapping of existing hospital records will only reflect current clinical assessment practice. This is more or less acknowledged by the authors, when they note that there are few categories from Environmental Factors. This appears to be the case, since clinicians tend to overemphasize Body Functions and underrate Participation and Context Factors. This is why, in general, the ICF Core Set development process uses a much broader approach. The perspective of the affected persons is acknowledged by both mapping patients' actual impairments and restrictions, i.e. first conducting a representative empirical survey and using a large set of ICF categories as an assessment tool, but also by asking them (in terms of qualitative interviews) about their experience of functioning and health besides standard clinical routine. In addition, linking of text data, such as patient records, to the ICF should be a straightforward and standardized process. However, this process is subjected to individual interpretations based on former experiences, whether those are clinical expertise or methodological knowledge. The incorporation of such individual interpretations is not a shortcoming but a main advantage of the linking methodology. Nevertheless, a second rater is recommended to increase reliability and external validity of these interpretations. To give an example from Preston et al. (11), "Improved social confidence" might be more of a participation issue; in other words, the main goal pertains to interpersonal interactions rather than to the mental function "confidence". Also, "cosmetic improvement" might not be a question of the mental representation of self, body image and time (which is impaired in conditions such as anorexia), but also of self-esteem (which is a personal factor). Although there are validity and methodological issues still to be discussed, the strength of this approach is that health professionals involved in daily clinical practice have started to use the ICF to code and standardize their records in the way the ICD has been used for over 100 years. Florence Nightingale's "bringing data to statistical proof" has to involve not only the correct classification of disease, but also of the consequences of disease, patients' goals and preferences, barriers and facilitators as important factors influencing treatment. It is hoped that this will improve outcomes.

REFERENCES

1. Nightingale F. Hospital statistics (abstract), and Appendix: Proposal for a uniform plan of hospital statistics. In: Fourth Session of the International Statistical Congress; 1860. London: Her Majesty's Stationary Office; 1860, p. 63–71.
2. World Health Organization (WHO). International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.
3. United Nations. Convention on the Rights of Persons with Disabilities. [cited 2011 Aug 11]. Available from: <http://www.un.org/disabilities/convention/conventionfull.shtml>.
4. Wade DT, Halligan PW. Do biomedical models of illness make for good healthcare systems? *BMJ* 2004; 329: 1398–1401.
5. Grill E, Ewert T, Chatterji S, Kostanjsek N, Stucki G. ICF Core Sets development for the acute hospital and early post-acute rehabilitation facilities. *Disabil Rehabil* 2005; 27: 361–366.
6. Grill E, Stucki G. Criteria for validating comprehensive ICF Core Sets and developing brief ICF Core Set versions. *J Rehabil Med* 2011; 43: 87–91.
7. Kus S, Muller M, Strobl R, Grill E. Patient goals in post-acute geriatric rehabilitation – goal attainment is an indicator for improved functioning. *J Rehabil Med* 2011; 43: 156–161.
8. Lohmann S, Decker J, Muller M, Strobl R, Grill E. The ICF forms a useful framework for classifying individual patient goals in post-acute rehabilitation. *J Rehabil Med* 2011; 43: 151–155.
9. Muller M, Strobl R, Grill E. Goals of patients with rehabilitation needs in acute hospitals: goal achievement is an indicator for improved functioning. *J Rehabil Med* 2011; 43: 145–150.
10. Huber EO, Tobler A, Gloor-Juzi T, Grill E, Gubler-Gut B. The ICF as a way to specify goals and to assess the outcome of physiotherapeutic interventions in the acute hospital. *J Rehabil Med* 2011; 43: 174–177.
11. Preston N, Clarke M, Bhakta B. Development of a framework to define the functional goals and outcomes of botulinum toxin A spasticity treatment relevant to the child and family living with cerebral palsy using the International Classification of Functioning, Disability and Health for Children and Youth. *J Rehabil Med* 2011; 43: 1010–1015.

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