A new classification for outcomes in illness and injury

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Illness and injury can lead to complex problems for patients and clinicians. A new approach from the World Health Organization (WHO), the International Classification of Functioning, Disability and Health (ICF), may help manage such patients, and evaluate the success of the interventions used. The authors discuss the application of the ICF model.

Ongoing advances in health care have led to more people surviving even very severe injury and illness. While some people attain a good recovery, others go on to experience consequences that can be enduring and difficult for the person, his/her family and the health professionals managing the person's care. While it is not easy to understanding the complexity of individual experience, it is important to develop robust ways of considering and addressing such complexity so that the most appropriate interventions can be delivered (improved processes) and meaningful recovery promoted (improved outcomes).

This article presents an approach that is increasingly considered a useful framework in rehabilitation. While it does not provide all the answers, it has some important advantages over previous models, in describing the consequences of illness and injury. As such, it may have a role in promoting a rethink of how to work with patients in a formal rehabilitation setting and those promoting adaptation and recovery in a hospital or community setting.

This article provides some of the conceptual background for addressing such topics as outcome measurement and the effectiveness of inpatient rehabilitation, the topics covered by the other two articles in this symposium (Sinnott and Dean, 2005; Thomson and Taylor, 2005). This article addresses three aspects of rehabilitation models:

- The background to rehabilitation models and their uses in rehabilitation
- A summary and critique of the International Classification of Functioning, Disability and Health (ICF) (World Health Organization (WHO), 2001) in relation to other models
- Applications of the ICF in clinical practice.

BACKGROUND TO MODELS IN REHABILITATION

Most people would agree that descriptors such as 'recovery', 'cure' and 'survival' are insufficient for the outcomes many patients experience after illness or injury. A number of models or frameworks have been proposed to try to capture a wider range of outcomes and to provide a basis for measures addressing those outcomes. One of the most widely used of these frameworks has been the International Classification of Impairment, Disability and Handicaps (ICIDH) (WHO, 1980). This framework has been so influential that it has been called 'one of the greatest advances in rehabilitation in recent times' (Wade and Halligan, 2003). It provides a comprehensive approach to understanding the consequences of disabling conditions by proposing that pathology and impairment (anatomical and/or structural changes) remained important, but that disability (ability to function) and handicap (the person's roles in life) also needed to be considered.

The ICIDH has contributed greatly to guiding the management of chronic or disabling conditions and gave birth to thousands of outcome measures, some of which are still considered the gold standards in their fields. However, the ICIDH has also been criticized for:

- Containing stigmatizing language, e.g. the word 'handicap' was regarded as stigmatizing by many (Oliver, 1993; Pfeiffer, 1999)
- Being a normative concept, expressing what are essentially judgments from the societal point of view, rather than that of the individual (Badley, 1993, 1995; Peters, 1995, 1996; Pfeiffer, 1999)
- Focusing solely on the individual when external factors also impact on people's ability to function (Oliver, 1993; Rioux, 1997)

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- Implying a unidirectional causal flow from impairment to disability to handicap, when consequences of chronic health conditions are more complex and multidimensional (WHO, 2001; Hurst, 2003)
- Being based largely on a professional viewpoint rather than engaging with the views of people who experienced such conditions (Oliver, 1993)
- Being difficult to operationalize, i.e. realize into outcome measures. A case in point is handicap, where few measures have been developed and even fewer found to be robust (Cardol et al, 1999a).

As a result of ongoing work addressing these criticisms, the ICIDH has been superseded by the International Classification of Functioning, Disability and Health (ICF) endorsed by the World Health Assembly in May 2001 (WHO, 2001). It will be interesting to observe whether the ICF succeeds in addressing the above criticisms and provides a firmer basis on which to deliver interventions and develop more appropriate outcome measures.

A SUMMARY

The ICF presents human functioning as a multidimensional concept relating to:

- Body structures and body functions, including physiological and psychological function
- The activities that people do
- The life situation and social roles that people participate in.

Despite it's apparent similarity to the ICIDH, the language used is more positive (notice that 'handicap' has disappeared) and the definitions provided are clearer (*Table 1*).

This need for enhanced definitions is not peculiar to models such the ICIDH. For instance, quality of life (QoL), a framework with much common sense appeal in the field of rehabilitation and other areas of medicine, remains the focus of much debate with the concepts underpinning many QoL measures lacking clear definition (Taylor and McPherson, 1999; McPherson et al, 2004b). While it can be tempting to gloss over the need for conceptual clarity as being 'just about semantics', it is an important step in establishing the utility and validity of a model and resultant outcome tools. It is hard to address or measure something if it is not defined, and the ICF appears to have tightened definitions of its terminology significantly.

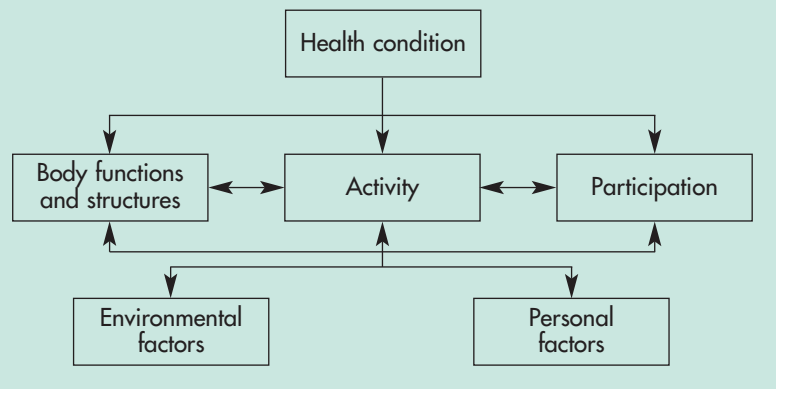
The ICF also addresses the next set of criticisms – that of being reductionist, unidirectional, and focused only on the individual as if removed from his/her circumstances. The ICF explicitly describes how functioning and disability can be influenced by environmental factors (such as the physical environment, physical aids and appliances, social policies or even other people's attitudes and beliefs). It also addresses personal factors which may impact on the person's experience of his/her condition, e.g. ethnicity, gender, and personality characteristics. In this way, the ICF extends the focus and language of disability and rehabilitation from being predominately biomedical to including psycho-socio-cultural dimensions. By making the interrelationships clear and explicit (*Figure 1*), the model both suggests new ways of thinking about the consequences of a condition, and also proposes a range of levels where intervention may be warranted.

This model in turn informs a hierarchical classification system extending from each of the elements described above. Like other familiar approaches, such as the International Statistical Classification of Disease and Related Health Problems (ICD-10), an alphanumeric system can be used to classify specific items relating to functioning and disability. For example, the code

TABLE 1.
Domains of the International Classification of Functioning, Disability and Health (ICF)

Domain	Definition	Example
Impairments	Problems in body function or structure such as a significant deviation or loss	Raised blood pressure Loss of a limb Pain Cognitive deficit
Activity limitation	Difficulties that an individual may have executing activities	Inability to walk Inability to dress oneself Inability to hang out washing
Participation restrictions	Problems that an individual may experience with involvement in life situations	Inability to return to work Inability to fulfil one's normal social roles in a family

Figure 1. Interrelationship between the components of the International Classification of Functioning, Disability and Health.



'd4103' classifies difficulties with getting into, and out of, a seated position from lying. Modifiers can also be added to indicate the extent or magnitude of disabilities. For instance, a severe (but not complete) activity limitation related to getting from lying to sitting is represented by d4103.3.

This brings us to the next criticism of previous models or frameworks, i.e. that they fail to incorporate patient perspectives. While arguments for considering the patient's perspective on illness and disability seem intuitive, the majority of models and resultant measures have been developed without input from people with the conditions themselves (McPherson et al, 2004a). During the development of the ICF, extensive consultation with international disability advocacy groups occurred, largely to the credit of the Disability Rights Movement rather than the WHO itself (Hurst, 2003). As a result, the ICF model can claim to be based, at least in part, on the experience of people with disabilities.

Despite these apparently positive steps, the ICF remains debated. For example, it has been argued that: by 'classifying' people with disabilities, the ICF is discriminatory in itself (Hammell, 2004); that the steps to inform the model or framework by people's experience has been too limited (Wade and Halligan, 2003); and that the failure to recognize other specific person-centred phenomena, including free will and quality of life, limits the ICF's applicability (Nordenfelt, 2003; Ueda and Okawa, 2003).

There is no doubt that the issue of 'classification' remains contentious. However, improved categorization of the condition (and not the person) could, and arguably should, benefit patients as limited resources are able to be directed more appropriately. While consultation during development was perhaps more limited than desired by all stakeholders, a number of studies are underway to evaluate whether the ICF is more responsive to people's needs than previous models. Such research includes the authors' recent work exploring 'what matters most' to people after stroke, with chronic pain, rheumatoid arthritis or terminal illness (McPherson et al, 2004b). Interviews with these people suggested that each domain of the ICF is considered important by people with complex conditions. However, as reported by others, e.g. Nordenfelt (2003) and Ueda and Okawa (2003), the authors found that a number of additional components absent from the ICF were also important. Perhaps no one model or framework can provide a 'complete' picture, and the practical response is to use the model which at any time point provides the best and most complete understanding with an expectation that continued work to expand physicians understanding is required.

The final important criticism of models and frameworks, including the ICF, concerns their operationalization. In other words, does the framework serve a purpose as far as enabling measurement and evaluation? There have been substantial efforts to develop 'rules' to link outcome measures to the ICF (Cieza et al, 2002; 2004a) and research has shown that various health-status measures cover different components of functioning and health as defined by the ICF (Stucki and Cieza, 2004). Such work helps illustrate which measures can be used in clinical practice, and where further measures are needed. Ongoing work by these and other researchers is attempting to identify and develop such measures of 'participation', the ICF domain where few measures are available. Potentially valuable examples the authors have used include the Subjective Index of Physical and Social Outcome (SIPSO) (Trigg and Wood, 2000) and the Impact on Participation and Autonomy (IPA) (Cardol et al, 1999b). Both consider patients' perspectives of rehabilitation outcomes and evaluate constructs that are proposed as important for participation in society.

APPLICATION

In addition to a model being the basis for exploring 'outcomes', ideally it should address 'processes' or interventions for patients. The authors outlined earlier how the ICF conceptual framework tackles a holistic perspective of health and disease by including psycho-sociocultural components and the interrelationships between these components. If it is accepted that such an interrelationship impacts on patients – and it is hard to deny given data on inequalities in health and outcome, e.g. Wilkinson and Marmot (2003), and Oliver and Exworthy (2003) – it makes sense to develop assessment processes, interventions and ways of working with patients that address these interrelationships. While a broadened approach may not be deemed necessary for all patients, most practitioners can think of a number of patients where such traditional approaches to management have failed.

The ICF seems particularly useful for conceptualizing and prioritizing treatment plans for people who have complex presentations, such as back pain, multiple injuries, permanent disabilities or challenging sociocultural backgrounds. Core sets of ICF data have been agreed by an international panel of experts (Stucki and

Grimby, 2004; Weigl et al, 2004), and these are now tested in many chronic conditions ranging from diabetes to backpain and stroke (Cieza et al, 2004b; Geyh et al, 2004; Ruof et al, 2004). The ICF is being increasingly used as a basis for interventions, such as goal-setting and as an aid to communication in interdisciplinary teams (George and Ronaldson, 2003; Reardon and Harmon, 2003; Rentsch et al, 2003). The ICF also provides an explicit basis for evaluation of environmental factors that can affect the impact an injury or disease process can have on an individual's life. These factors can then become a focus of intervention rather than limiting clinical work to treatment of pathology and impairments (Schneidert et al, 2003). Just one example of this application is found in a framework developed for standardizing seating assessment and prescription for children with cerebral palsy (McDonald et al, 2004).

Despite criticisms about the validity of a universal descriptive classification system (Wade and Halligan, 2003), others (Australian Institute of Health and Welfare, 2003) propose that the alphanumeric system of the ICF is useful for describing patient caseloads in a more comprehensive way than other systems. Steiner et al (2002) go as far as to propose that in addition to the obvious administrative use of such a system, the coding system can contribute clinically by ensuring interdisciplinary team members have a common language to discuss rehabilitation case scenarios. Along with Wade and Halligan (2003), the authors are cautious about the use of the numeric system for categorizing individuals for clinical reasons (any model or framework will have limits when applied to an individual's specific management). However, classification of some sort is probably here to stay for administrative purposes, and it is vital that the system is as equitable and informative as possible. In comparison with other universal approaches, e.g. ICD-9 and ICIDH-1, the ICF seems to more adequately reflect the range of consequences for people with disabling conditions.

In addition to application of the ICF at the local level of clinical services, the WHO has suggested that the ICF has a role to play in the development of health-care policies, compensation systems, clinical education, and heath informatics (WHO, 2001). Although these potential applications have yet to be fully explored, it appears that the ICF framework, with the broad perspective it provides on health and disability, may contribute to complex issues in hospital management, such as patient prioritization, casemix funding, and quality auditing.

CONCLUSIONS

Does the ICF address issues that other models do not? 'In part', has to be the answer for the meantime. It contains more precise definitions of terminology and seems to facilitate a more holistic assessment of patient needs. The ICF is currently being used successfully to inform interventions that are problematic and complex, such as goal setting and interdisciplinary team work. However, it is fair to say that research addressing whether the ICF is an improved basis for interventions is in its infancy (Bilbao et al, 2003; Cooey-O'Halloran et al, 2004; Goldstein et al, 2004), as is work on determining its adequacy as the basis of outcome measures (Wade and Halligan, 2003). Perhaps the main strength of the ICF is that it encourages a move away from treating problems towards treating people. For those who wish to deliver health services in such a way, it is undoubtedly a useful tool. HM

Conflict of interest: none

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KEY POINTS

- Improving the quality of care for people with complex injury or illness relies on improved understanding of its wide ranging consequences.
- The World Health Organization has developed a number of models attempting to promote this understanding, the latest of which is the International Classification of Functioning, Disability and Health (ICF).
- The ICF has been found to help practitioners deliver interventions that appear to be more responsive to the complex consequences of disabling conditions.
- The ICF can guide practitioners and researchers to address a broader range of indicators of 'successful outcome'.
- More research into the ICF is needed but it seems to offer a useful way ahead in rethinking individual management and evaluating services for people with complex conditions.

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