

Section on Person-centered Health Domains

Defining disability, functioning, autonomy and dependency in person-centered medicine and integrated care

Luis Salvador-Carulla, MD, PhD, Professor of Psychiatry, University of Cadiz, Head Section Psychiatry of Intellectual Disability World Psychiatric Association, Cadiz, Spain

Vladimir I. Gasca, MD, Assistant Professor of Psychiatry, Mount Sinai School of Medicine at Elmhurst Hospital Center, New York, USA

Correspondence to: Luis Salvador-Carulla, E-mail: luis.salvador@telefonica.net

Introduction

According to the integrative or holistic approach to health, medicine should not only be focused in disease and illness, but also on the consequences of disease and its contextual factors, as well as the positive aspects of health, such as adaptive functioning, protective factors, quality of life and the links of all these domains to care policy and planning [1].

Functioning and disability (D&F) are two related domains of a single health construct key to understand the relationship between the individual and the disease, where social support plays an effect modifier role [2]. Therefore, D&F is regarded as a key domain in the recent models of diagnosis (i.e. person-centered medicine) [3] and intervention (i.e. Integrated Care as a complex adaptive system) [4] within the holistic paradigm.

Despite the radical evolution of the area of disability since the 1950s, this concept is still regarded as 'elusive' in medicine [5] and there is a lack of international consensus on the definition of related concepts, such as functioning, autonomy or dependency. The complex relationship between the constructs of disability/functioning and autonomy/dependency has not been properly addressed by current international glossaries and classification systems; in spite of their relevance for care policy and planning.

As a matter of fact, the construct 'Disability and Functioning' (D&F) has been used with two different meanings in the health sector. These meanings correspond to separate models which use different approaches and tools to evaluate D&F. In this review, we describe the evolution and current concepts of D&F and other related terms, such as autonomy and dependency.

The 'Activities of Daily Living' approach to disability

The 'Activities of Daily Living' (ADL) model was originated in the US right after World War II to measure functioning in cancer patients and in physical rehabilitation [6]. In essence, ADLs are elementary tasks that allow getting around with minimum autonomy and independence, including any daily activity we perform for self-care, work, homemaking, and leisure. In the 1960s Katz et al. [7] and Lawton and Brody [8] distinguished two major groups of ADL: 'basic' activities related to self-care, such as bathing, dressing, eating, voluntary control of sphincters, grooming and walking; and 'instrumental' activities, such as light housework, preparing meals, taking medications, shopping for groceries or clothes, using the telephone and managing money.

This model was used to develop the Katz ADL index [9] and the Barthel index [10], which is still a standard rating scale to measure disability in geriatrics and other medical disciplines as well as the standard comparator to assess the psychometrics of related instruments [11]. In spite of its inconsistencies, the distinction between BADL and IADL

is still deeply grounded in the medical assessment of disability [12]. Whilst this approach may provide accurate assessment in a number of physical conditions, its content validity is unclear in complex illnesses where the social context play a significant role and where symptoms may directly produce a significant impairment of the daily functioning which is not mediated through ADLs (i.e. suicidal thoughts or non-adherence related to lack of insight which require intensive surveillance by family carers). Hence, the disability related to complex health conditions, such as severe mental illness, intellectual disability, autism, or early stages of dementia may not be adequately assessed using ADLs, as high social support may be needed even when there is hardly any impairment in 'basic' daily life activities.

The concept of 'dependency' derived from the ADL model in the early 1990s and it has provided an international framework for evaluation and care to frail population across the lifespan. In 1998, the European Council made a recommendation to EU member states to develop care for dependent population (persons with severe disability and need of support from a third person) based on the ADL approach. It defined 'dependency' as a condition related to the loss of autonomy and the need of support by a third person related to an impairment of activities of daily living, specially self-care, linking 'autonomy' and 'dependency' to a single construct. The analysis and monitoring of the dependent population in Europe was started [13] and Spain and other European member states which had not yet developed a care system for dependent population enacted a dependency law and planned a dependency care system. However, international comparability and the assessment criteria showed problems for a broad group of dependent population which include severe mental illness and other complex conditions. As a consequence, the Spanish Parliament approved a recommendation to adapt the official assessment procedure and tool based on ADLs to the model developed by the International Classification of Functioning last March 26th, 2009.

The WHO 'environmental' approach to 'functional disability'

This approach is based on a broader concept of functioning. It originated at the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980, which gave forward to the current International Classification of Functioning, Disability and Health (ICF) [14]. ICIDH shifted the relationship of health and functioning from the consequences of a disease or condition to the result of complex interactions among the individual, the environment and the disease or condition. The new ICF was designed taking into consideration this biopsychosocial/ integrative approach [15]. This system is comprised of three main components: body functions and structures, activities and participation, and contextual factors (environmental and personal factors).

The concept of 'environment' and 'environmental factors' in the ICF model

The 'environmental factors' make up the physical, social and attitudinal environment in which people live and conduct their lives. They are external to persons and can have a positive or negative influence on the individual's performance. These factors are organized in the classification to focus on two different levels:

- (a) Individual—physical and material features of the environment that an individual comes face to face with in his immediate environment, including settings, such as home, workplace and school, as well as direct contact with others, such as family, acquaintances, peers and strangers.
- (b) Societal—formal and informal social structures, services and overarching approaches or systems in the community or society that have an impact on individuals (organizations and services related to the work environment, community activities, government agencies, communication and transportation services, and informal social networks).

The concept of 'personal factors' in the ICF model

At the ICF model "personal factors are the particular background of an individual's life and living" [14]. They comprise features of the individual that are not part of a health condition, such as social and demographic factors (gender, race, age, education, profession) and individual psychological characteristics, such as lifestyle, habits, upbringing, coping styles, overall behaviour pattern and character style. Hence, the individual functioning is influenced by personal contextual factors that are different from the environmental factors and that have not been classified at the current version of the ICF due to problems in their standard categorisation.

In ICF 'functioning' is defined as a "generic term which includes body functions and structures, activities and participation. It indicates the positive aspects of the interaction between the individual (with a health condition) and its context factors (personal and environmental factors)" whilst 'disability' serves as an umbrella term for impairments, activity limitations or participation restrictions [14]. Here, disability is linked to global functioning in ICF while in the ADL model it is associated to impairment in a reduced set of activities. D&F may be initially regarded as a unidimensional bipolar construct with a positive pole (functioning) and a negative one (disability) at ICF. However, there is a clear asymmetry between the two poles, as positive functioning involves many more alternatives than negative functioning. On the other hand, the analysis of the hierarchical structure and the conceptual relationship between the terms 'functioning' and 'disability' at the WHO family of classifications and related documents indicate that 'disability' is actually a subcategory of 'functioning', as 'disease' is a subcategory of 'health condition', and 'quality of life' is a subcategory of 'well-being' [14]. The current definition of 'functioning' at ICF should be restricted to 'positive functioning' in future editions of the classification.

In any case the ICF provides a comprehensive conceptual background which is linked to the WHO family of classifications and related WHO documents. This enables the further development of key concepts, operational definitions and related assessment instruments.

As an example, the definitions of 'functioning' and 'disability' were not operationalised at the ICF and several research groups have provided operational alternatives using the ICF framework. The MHADIE (Measuring Health and Disability in Europe) group has defined 'disability' as a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors' [5]. Following the logic of WHO terminology, the DEFDEP (DEFinition of DEpendency in Mental Illness) consensus group defined "health-related environmental functioning" as "the capacity of an individual to live independently in the community with little or no help from others"; while 'health-related disability' may be defined as "a persistent impairment of environmental functioning" [16]. In 2006, the DEFDEP group was commissioned by the Catalan Agency of Dependency (PRODEP) to develop an ICF-based operational definition of 'functional dependency' in mental illness as an alternative to the official ADL-based definition used by the Spanish social care system. To begin with, the concept of 'dependency' used at the European Council recommendation is not at ICF or at the WHO glossaries [17, 18]. The word 'autonomy' has completely different meaning at the WHO glossaries and at the 1998 European Council recommendation. WHO defines 'autonomy' as "the perceived capacity to control, cope and take personal decisions on how a person lives his/her daily life, following his own norms and preferences" [18]. This definition of 'personal autonomy' is equivalent to self-direction, competence and self-empowerment, but it could not be included in the same construct than 'dependency'.

In spite of these problems, the ICF model can effectively provide an operational definition of dependency. 'Independence' is defined as the "ability to perform an activity with no or little help from others, including having control over any assistance required rather than the physical capacity to do everything oneself" [18]. This WHO concept was used by the DEFDEP group to produce a consensus definition of 'environmental functional dependency'. It was defined as "a state derived from a permanent or long-term health condition which limits and restricts daily life to the extent that the person needs support from another person or special aids to reach minimal functions of daily living" [16].

Discussion

The concept of health is dynamic, complex and closely linked to functioning. Many environmental and personal factors influence health and functioning. To date, there has been very little debate on the differences between the ADL and the ICF approaches to health-related functioning and disability; given their consequences in the assessment and care policy and planning for complex conditions, such as severe mental illnesses.

Health-related disabilities may be conceptualised by two different systems: ADL disability (based on ADL approach) and functional or contextual disability (based on the WHO approach). Functional disability may be further divided into 'environmental disability' and 'personal disability', although only functional environmental disability is classified and coded at the ICF. The conceptual background of the WHO-ICF approach has a broader perspective and it allows a better description of the functional impairment related to complex disorders, as well as new definitions of related concepts relevant for care policy and planning, such as care 'dependency'. Within this context 'functional environmental dependency' may be regarded as a transversal domain related to the interaction between disability, needs and support. This domain may not be linked to the WHO concept of 'personal autonomy' but to the WHO concept of 'independence' which in turn could be regarded as a synonym of function-related environmental autonomy.

In order to fully incorporate D&F into person-centered medicine and integrated care it is necessary to provide operational definitions of these terms and other closely related concepts, such as autonomy and dependency. The person-centered approach provides a clean framework that could be linked to ICF as it differentiates the domain disability (ill-being) and functioning (well-being) from a series of ICF-personal factors which may be incorporated into other domains of this model (risks/protective factors or experience of illness and health). In any case, the ontology of the domains provided by the person-centered model and the ICF model deserve further analysis. As an example, the term 'person' in the person-centered model is equivalent to the term 'individual' at the ICF. The ICF 'personal factors' (as said not yet defined) are dealt with in other domains of the person-centered model, where 'person' is an holistic concept whereas at the ICF it is limited to the psychological characteristics within a biopsychosocial approach. Therefore, a 'health-related environmental functioning' and a 'health-related environmental disability' should be assessed in the person-centered model which incorporates ability and fulfilment and other personal characteristics in other domains.

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References

1. Singer B, Ryff C. *New horizons in health: an integrative approach*. Washington, D.C.: National Academy Press; 2001.
2. Prince M, Patel V, Saxena S, Maj M, Maselko J, Phillips MR, Rahman A. No health without mental health. *Lancet* 2007 Sep 8;370(9590):859–77.
3. Mezzich JE. Psychiatry for the person: articulating medicine's science and humanism. *World Psychiatry* 2007 Jun; 6(2):65–7.
4. Edgren L. The meaning of integrated care: a systems approach. *International Journal of Integrated Care* [serial online] 2008 Oct 23;8. Available from: <http://www.ijic.org/>.
5. Leonardi M, Bickenbach J, Ustun TB, Kostanjsek N, Chatterji S, MHADIE Consortium. The definition of disability: what is in a name? *Lancet* 2006 Oct 7;368(9543):1219–21.
6. Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents. In: MacLeod CM, editors. *Evaluation of chemotherapeutic agents*. New York: Columbia University Press; 1949. p. 196.
7. Katz S, Ford A, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *Journal of the American Medical Association* 1963;185(12):914–919.
8. Lawton MP, Brody EM. The functional assessment in rehabilitation of elderly people: self maintaining and instrumental activities of daily living. *Gerontologist* 1969;9:179–86.
9. Katz S. Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living. *Journal of the American Geriatric Society* 1983 Dec;31(12):721–7.
10. Barthel DW, Mahoney FI. Functional evaluation: the Barthel index. *Maryland State Medical Journal* 1965;14:61–5.
11. Dijkstra A, Tiesinga LJ, Plantinga L, Veltman G, Dassen TWN. Diagnostic accuracy of the care dependency scale. *Journal of Advanced Nursing* 2005 May;50(4):410–6.
12. Freedman VA, Martin LG, Schoeni RF, Cornman JC. Declines in late-life disability: the role of early- and mid-life factors. *Social Science and Medicine* 2008 Apr;66(7):1588–602.
13. European Commission. *Feasibility study—comparable statistics in the area of care of dependent adults in the European Union*. Luxembourg: Office for Official Publications of the European Communities; 2003.
14. World Health Organisation. *International Classification of Functioning, Disability and Health (CIF)*. Geneva: WHO; 2001.
15. Stucki C, Cieza A. The International Classification of Functioning, Disability and Health (ICF). Core sets for rheumatoid arthritis: a way to specify functioning. *Annals of the Rheumatic Diseases* 2004 Nov;63(Suppl 2):ii40–ii45.
16. Salvador-Carulla L, editor. *Estudi DEFDEP: Definició operativa de dependència en persones amb discapacitat psíquica [DEFDEP Study: Operational definition of dependency in persons with psychological disability]*. Programa ProdeP de la Generalitat de Catalunya, 2006. [cited 2009 April 14]. Available from: <http://www.gencat.cat/>.
17. World Health Organisation. Division of Health Promotion, Education and Communications (HPR) (WHO/HPR/HEP/98.1). *Health promotion glossary*. Geneva: WHO; 1998.
18. World Health Organisation. *A glossary of terms for community health care and services for older persons*. Kobe (Japan): WHO; 2004. [cited 2009 April 14]. Available from: http://whqlibdoc.who.int/wkc/2004/WHO_WKC_Tech.Ser._04.2.pdf (Technical Report Vol. 5 WHO Centre for Health Development Ageing and Health. WHO/WKC/Tech.Ser./04.2).