ICF: Representing the Patient beyond a Medical Classification of Diagnoses

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Abstract

The International Classification of Functioning, Disability and Health (ICF) is a component essential to ensuring the collection of accurate and complete healthcare data that correctly reflect the care provided to individuals. In fact, many countries outside of the United States have found uses for ICF. While research continues in the United States on the potential value of implementing ICF, deliberations are establishing the need to implement ICF to develop knowledge about the physical, mental, and social functioning of patients. In the course of these deliberations, issues related to current data collection activities, the use of ICF in an electronic health record (EHR) system, training requirements, and terminology maps are beginning to emerge.

Introduction

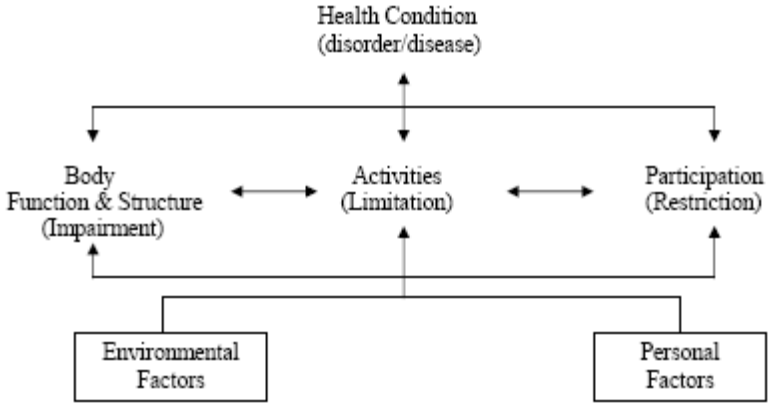
The International Classification of Functioning, Disability and Health (ICF) is one of the World Health Organization's Family of International Classifications (WHO-FIC).[1] The purpose of WHO-FIC is to promote the appropriate selection of classifications in the range of settings in the healthcare field around the world. Since a single classification system cannot encompass all types of healthcare information or provide the level of detail desired for various uses of healthcare data, multiple classifications have been developed to meet specific user requirements. WHO-FIC provides a framework to code a wide range of information about health (for example, diagnosis, functioning, disability, and reasons for contact with health services) and uses standardized language, permitting communication about health and healthcare around the world and among various disciplines and sciences.

The World Health Organization (WHO) family contains two core, or reference, classifications: the International Classification of Diseases (ICD) and ICF. A third classification, the International Classification of Health Interventions (ICHI), is under development. The core WHO classifications cover the main parameters of the health system and are a product of national agreements. They have achieved broad acceptance and official agreement for use and are approved and recommended as guidelines for international reporting on health.

ICD, which is now in its 10th revision, known as ICD-10, is used to classify diseases and other related health problems. ICF is used to classify functioning, disability, and health. It is a system of health and health-related domains that describe body functions, body structures, activities, and participation. It is useful for understanding and measuring health outcomes.

Figure 1 illustrates ICF by showing the overall organization of the classification.

Figure 1



Organization of the International Classification of Functioning, Disability and Health (ICF). Source: National Institute for Disability and Rehabilitation Research. "Notice of Proposed Long-Range Plan for Fiscal Years 2005–2009." *Federal Register*, July 27, 2005, available at http://www.ed.gov/legislation/FedRegister/other/2005-3/072705d.html.

Looking beyond Mortality and Disease

The WHO's *ICF Beginners Guide* indicates that studies have demonstrated the limits of having information on only the diagnosis of a patient.[2] These limits include the inability to predict such things as service needs or work performance. Without additional data on levels of functioning and disability, health planning and management are more difficult.

Because of its flexibility, ICF can offer various applications for use. The WHO lists the following examples of uses of ICF.[3]

At the individual level

- For the assessment of individuals
- For individual treatment planning
- For the evaluation of treatment and other interventions
- For communication among physicians, nurses, physiotherapists, occupational therapists, other health workers, social service workers, and community agencies
- For self-evaluation by consumers

At the institutional level

- For educational and training purposes
- For resource planning and development
- For quality improvement
- For management and outcome evaluation
- For managed care models of healthcare delivery

At the social level

- For eligibility criteria for state entitlements such as social security benefits, disability pensions, workers' compensation, and insurance
- For social policy development, including legislative review, model legislation, regulations and guidelines, and definitions for antidiscrimination legislation
- For needs assessments
- For environmental assessment for universal design, implementation of mandated accessibility, identification of environmental facilitators and barriers, and changes to social policy

ICF complements ICD-10 and looks beyond mortality and disease (see the section below for examples of applying ICF codes to case studies). The information on diseases and other health conditions provided by ICD-10 is enriched by the additional

information on functional status provided by ICF. ICD and ICF together offer a more complete picture by identifying both an individual's health condition and how the individual functions in society with that condition. Together, information on diagnosis plus functioning provides a broader and more meaningful picture of the health of people or populations.[4] ICF was originally developed to provide this broader picture of the health of populations by gathering data in a consistent way around the world to allow for data comparability.

Examples of Applying ICF Codes to Case Studies

The following scenarios provided by the WHO Assessment Classification and Epidemiology Group 2000 give examples of the application of ICF codes.[5] These examples do not generally contain enough information to code the severity of impairment, but codes are included to illustrate aspects of the text.

Example 1

Mr. B has a high-level spinal cord injury, as a result of a severe neck injury, and cannot perform the basic movements required to drive a standard car. However, with a suitably modified vehicle, he can drive safely. Unfortunately, there is a law in his state that prohibits him from driving. The following codes might be used to describe Mr. B.

b730.3 Muscle power functions—severe impairment
a475.1 Driving—mild difficulty (in performance of activity in modified vehicle)
e120+4 Products for personal mobility and transportation—complete facilitator
e540-4 Transportation services, systems, and policies—complete barrier

Example 2

A couple have been married for several years and have always wanted to have children. They both have intellectual impairment. There are no medical reasons why they cannot have children, and they believe that they will not have any problems in the day-to-day care of a child. Yet they have decided not to have a child because they believe that people will think they are unsuitable parents and their child will be shunned by other children and made fun of. The following codes might be used to describe the main aspects relating to this couple's life and current situation.

b117.1 Intellectual functions—mild impairment
b660.0 Procreation functions—no impairment
a660.08 Assisting others—no difficulty with performance (capacity not specified)
p760.38 Family relationships—severe difficulty with performance (capacity not specified)
e460+3 Societal attitudes and beliefs—severe barrier

Example 3

Mr. C has cerebral palsy. He cannot speak clearly, but his speech has improved with the help of a speech therapist. Around friends or close colleagues at work he has no difficulty with conversations. However, most strangers do not take the time to listen carefully to understand him. So Mr. C does not always get what he wants in shops and restaurants. The following codes might be applied in describing Mr. C.

b320.2 Articulation functions—moderate impairment
d330.1 Producing spoken messages—mild difficulty
d350.0 Conversation—no difficulty
d355.0 Discussion—no difficulty
d620.1 Acquisition of goods and services—mild difficulty
d730.1 Relating with strangers—mild difficulty
d750.0 Informal social relationships—no difficulty
e580+3 Health services, systems and policies—'severe' (strong) facilitator
e345-1 Strangers—mild barrier

Combination of ICF and ICD

Information on mortality provided by ICD-10 and information on health outcomes provided by ICF may be combined in summary measures of population health, which can be used for monitoring population health and observing its distribution patterns, and also for assessing the contributions of different causes of mortality and morbidity. Table 1 shows an example of the use of ICD and ICF together. In the example, a mother with three young children begins feeling tired, apathetic, and impatient. Everyday activities and responsibilities have become a burden. The diagnosis is endogenous depression (ICD code 296.2).

Table 1: Example of the Use of ICD and ICF Together for Endogenous Depression (ICD Code 296.2)

Body Function/Structure	Activity and Participation	Environment
b130.1 energy and drive	a2400.2 handling stress and other psychological demands-responsibilities	e310.2 support and relationships of immediate family
b152.1 emotional functions	a6300.2 preparing simple meals	
	p855.1 participation in non-remunerative employment	
	a5702.2 looking after one's health-maintaining one's health	

Source: Australian Institute of Health and Welfare

ICF and Data Collection

The ICF classification systematically groups different health and health-related domains for a given health condition; that is, it classifies what people can do when they have a disease or disorder. The body component of the classification system covers functions and structures of the body system. The activity and participation component of the classification system covers a range of life domains that people engage in (for example, learning, self-care, moving around, and work). Also listed are environmental factors that interact with all of these domains. Thus, ICF encompasses health and health-related outcomes, including nonfatal health outcomes.

In general, the need to collect data is often determined by international, national, or state requirements. A key aspect of data collection is the development of data dictionaries and standardized data sets. A data dictionary is a descriptive list of data elements to be collected in an information system or database. A data set is a list of recommended data elements with uniform definitions. Data sets and their data dictionaries are important for ensuring consistent data collection and reporting of data for internal and external uses.

For example, Australia has developed two national data dictionaries, the *National Community Services Data Dictionary* and the *National Health Data Dictionary*, to improve comparability of data and make data collection activities more efficient and effective by reducing duplication in data development and ensuring that information is appropriate to its purpose.[6] Included in the *National Community Services Data Dictionary* is a set of disability data items based on ICF. According to Fortune, one application of these data items has been to collect data on client support needs and, in doing so, to provide a profile of client support needs for different service types.[7] Collecting the data items also allows an assessment of trends over time to inform policy on service planning, provisions, and funding.

Functional status was one of the core health data elements previously recommended by the National Committee on Vital and Health Statistics (NCVHS) for enrollment and encounter records. According to the NCVHS report "Classifying and Reporting Functional Status," there are a number of ways in which functional status assessment may be done, including professional observation, testing, and self-reporting by the patient or a proxy. In addition, the instruments used to collect this data range from generic to disease specific or practice specific. The report notes the need for a standardized way to include functional status data in administrative records and related data sets.[8] The use of ICF would standardize the reporting of functional status.

In the United States, two areas where clinical data related to the ICF domains are currently collected are the long-term care minimum data set known as Minimum Data Set for Nursing Facility Resident Assessment and Care Screening (MDS), and the Outcomes and Assessment Information Set (OASIS), which is a core group of data elements that represent items of a comprehensive assessment for an adult home care patient. Other areas where clinical data related to ICF domains are

included are the Functional Independence Measure (FIM) for rehabilitation, the Residual Functional Capacity Form (RFC), the National Health Interview Survey, and the National Health and Nutrition Examination Survey.

MDS contains items that reflect the acuity level of the nursing facility resident, including diagnoses, treatments, and an evaluation of the resident's functional status. MDS is used to monitor the quality of care provided to nursing facility residents. Providers use the data to assist them in their ongoing quality improvement activities. In addition, state surveyors find the data helpful in identifying potential problem areas that should be addressed during the survey process. Finally, the Centers for Medicare & Medicaid Services (CMS) utilize the data for long-term quality monitoring and program planning.

OASIS forms the basis for measuring patient outcomes for the purpose of outcome-based quality improvement. OASIS contains items that encompass sociodemographic, environmental, support system, health, and functional status attributes of adult (nonmaternity) patients.

Since functional status information is commonly used in nursing home care and home care, both MDS and OASIS provide an initial opportunity to integrate ICF information into health records and related data sets, thereby standardizing data collection activities.

ICF and the Electronic Health Record System

There are numerous ongoing projects related to the implementation of the electronic health record (EHR) system. These include creating a maximum data set, establishing data content and standards across the core data sets, and outlining the benefits of reducing the number of core data sets in the healthcare industry by streamlining data collection and reporting. One of these projects is the Consolidated Health Informatics (CHI) initiative. CHI includes the Department of Health and Human Services, the Department of Defense, and the Veterans Administration. Under this initiative, the agencies adopt standards for health information domains for use in federal health data systems, enabling all federal agencies in the health enterprise to "speak the same language."

CHI formed a disability workgroup and performed a content coverage analysis. Although they did not recommend ICF as the standard for disability content for the federal government, neither did they recommend SNOMED CT®. SNOMED CT is a clinical terminology that provides a common language that facilitates consistency in capturing, sharing, storing, retrieving, and aggregating health data across specialties and sites of care.[9] They did note that even if SNOMED CT were modified to support disability terms, concepts, and phrases needed by the federal government, maps to the classification systems would be needed. The workgroup noted: "A terminology itself would also not be sufficient to provide a conceptual framework for understanding functioning and disability (i.e., a strength of the ICF)."[10]

The potential of ICF in an EHR system appears great. ICF while itself is a tool for classifying disability data, a practical tool, i.e., ICF checklist, has been developed. This multidimensional tool may be used to evaluate an individual's functioning (that is, in activities of daily living) and disability, which can be used across settings and different patient populations. A common use of ICF and the tool to evaluate functioning is in disability benefit determination. These tools could be integrated in the clinical application of an EHR system to capture and report data in a consistent manner. The ICF concept identifiers are linked to the responses on the evaluation tool. ICF concept identifiers coupled with ICD-10 diagnosis codes provide better information on service needs, length of stay, and functional outcomes than just information on diagnosis alone. Thus, ICF provides better data, needed to meet the demands of an increasingly global and electronic healthcare environment. In addition, ICF provides a significant opportunity to improve the capture of information about the increasingly complex delivery of healthcare.

For example, the Australian Institute of Health and Welfare is considering establishing a common functional outcome module, essentially a minimum data set on functioning. According to Fortune, functional outcome modules may provide a vehicle for including a standard set of key information on functioning in electronic health records.[11]

Training Requirements

Providing a convincing argument for capturing functional status using ICF will result in advancing the adoption and use of a standard to describe the disability domain. A standard results in efficiencies in payment, surveys, public quality reports, external quality monitoring, internal quality monitoring, eligibility determinations, and policy development.

Countries outside of the United States that have established ICF as the standard for communicating functional status and disability have incorporated training in ICF into academic institutions for therapists, nurses, and social workers.
Other stakeholders who will require education and training include

- Physicians, and, in particular, specialists in physical medicine, geriatrics, rheumatology, and pediatrics, on the potential use of functional status information in clinical care
- Therapists, on the advantages of functional status information in guiding therapy in areas such as hearing, speech, vision, cognition, and mobility
- Nurses, on the advantages of functional status information in developing interventions to restore or maintain function or prevent or minimize its decline
- Social workers, on the advantages of functional status information in determining an individual's needs
- Public health practitioners, on the benefits of tracking changes, following people across settings, and monitoring quality and outcomes
- Payers of healthcare claims, on the potential economic benefits of functional status information

ICF and Maps

Organizations using clinical terminologies in their own electronic health record systems have come to the conclusion that true "enter once, use many times" functionality will depend upon the reliability, validity, and usability of maps. At its simplest, mapping is linking content from one terminology or classification scheme to another. It requires deciding how the terminologies or classification schemes match or, in some instances, deciding how they are similar or that they don't match at all. Mapping considers the different purposes, levels of detail, and coding guidelines of the terminologies or classification schemes. The mapping process employs a standard method by which the terminology context or classification description principles are interpreted between systems. Automated maps create efficiency by minimizing duplicative data entry and allowing patient data integration across a wide variety of computer applications.

According to the report *Patient Safety: Achieving a New Standard for Care*, to meet the needs for the national information infrastructure and the EHR, systems are needed that automate the process of mapping from a clinical terminology such as SNOMED CT and other terminologies in the core group to supplemental terminologies.[12] NCVHS also recommended that mapping occur to important related terminologies.[13] The core represent a group of terminologies that have met the NCVHS criteria for inclusion in the patient medical record information (PMRI) terminology standards and important related terminologies are those while not meeting the criteria are used in essential administrative and clinical processes.[14]

In particular, mapping from SNOMED-CT to ICF will improve the value of clinical data, as it will

1. facilitate retrieval of coded data at the desired level of detail depending on the purposes for which the data are being used, such as to evaluate healthcare quality or to target interventions, and
2. allow for better statistical data not possible with SNOMED-CT alone. For example, aggregated data can be used for policy development, monitoring of population health, economic analyses, research, and intervention studies.

Recent Research Developments

A proposed long-range plan prepared by the federal government's key agency for disability and rehabilitation research, the National Institute on Disability and Rehabilitation Research (NIDDR), was released on July 27, 2005. NIDDR is an organization within the Office of Special Education and Rehabilitative Services of the U.S. Department of Education. The NIDDR plan embraced ICF, recognizing that data must be grounded in an appropriate organizational framework such as ICF to be helpful for policy, research, programs, and services. The plan further states, "To evaluate the potential uses of the ICF, a variety of measurement tools and data systems must be examined in addition to further evaluation of the implications of the classification for U.S. populations."[15]

Conclusion

Health is not merely the absence of disease. In order to fully represent the health of the U.S. population, more knowledge about the physical, mental, and social functioning of the population is required. It is clear from the published research that ICF has found a place in the international community. While further research on the potential uses of ICF and the value of

implementing it is needed, ICF should be used to begin developing this knowledge. In the interim, it is crucial that standard-setting organizations hold a place open for this element.

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Notes

1. World Health Organization Web site. www.who.int/classifications/en/.
2. World Health Organization. *Towards a Common Language for Functioning, Disability and Health: ICF. Geneva 2002*. Available at http://www3.who.int/icf/beginners/bg.pdf
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