SPECIAL COMMUNICATION

Issues in the Conceptualization and Measurement of Participation: An Overview

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While participation is increasingly defined as the key outcome of rehabilitation, disagreements on and shortcomings in the definition, operationalization, and measurement of this concept abound and interfere with the progress of clinical services and research. This article explores a number of the major issues related to the quantification of participation and makes suggestions for new directions, using the following orienting questions: What is the definition of participation? Where is the border between Participation and Activity? Is there more to participation than performance? What domains should be included in a participation measure? What are the appropriate metrics in quantifying participation? How do we define adequate participation? How should participation be operationalized? What is the proper measurement model for participation instruments? How should we collect data on participation? How do we evaluate the quality of a participation instrument?

Key Words: Data collection; Environment; Interpersonal relations; Quality of life; Questionnaires; Rehabilitation; Reproducibility of results; Role; Social adjustment; Social environment; Social isolation; Social support; Validation studies as topic.

> ". . . the ultimate aim of rehabilitation is to maximize a person's participation in society."[1(p970)]

PARTICIPATION IS A KEY outcome of rehabilitation and of other medical and social service programs supporting persons who, because of impairments resulting from injury, birth defect, disorder, or aging, are involved in family, household, community, and society to a lesser degree than they, their service providers, or society may desire. Everyone involved as a clinician or researcher in medical rehabilitation (and other professionals such as those employed in psychiatric rehabilitation, substance abuse rehabilitation, geriatrics, and developmental disabilities services and research) has some idea what participation is: it is the domain of functioning that is beyond impairment and performance of activities. It is more or less what we mean with instrumental ADLs (also called advanced/extended ADLs), community re-entry or participation, social or role or social role participation, social or societal integration, community living or (re)integration, independent living, normalization, psychosocial functioning or integration, handicap, social health or inclusion or adjustment or disability or disablement, social role valorization, and a number of other terms, varying by professional domain and by whether we want to emphasize a process of normalizing or the resulting status.[2,3]

Unfortunately, we do not have a standard definition of participation or of any of these other partly overlapping concepts. That is no problem in itself—there probably is limited consensus on many other concepts that are commonly used in rehabilitation. However, the problem is more significant with respect to participation than in relation to other terms that are key to rehabilitation. In addition, participation appears to be a part of the social model of disability, not the medical model, and issues such as the proper relationship of individual to society, biological and social standards for normality, and so forth, play a role in defining and operationalizing the concept.

Participation at first blush appears to be a simple concept to measure, but each attempt to construct an instrument needs to address issues in conceptualization and operationalization that get at the core of science epistemology and methodology (eg, value-free measurement) and of metrologic theory and practice (eg, CTT vs clinimetrics). Because of the norming of participation by social roles and cultural values, the potential for developing a single measure that is appropriate across age groups, sexes, socioeconomic classes, and cultures is debatable. The purpose of this article, which is introductory to a special issue devoted to the conceptualization, operationalization, and measurement of participation, is to lay out the major issues involved with these 3 steps leading to quantification of participation. A number of articles published in recent years have pointed out various predicaments in these areas and made

List of Abbreviations

ADLs	activities of daily living
CHART	Craig Hospital Assessment and Reporting Technique
CIQ	Community Integration Questionnaire
CTT	classical test theory
DCP	Disability Creation Process
EMA	ecological momentary assessment
ICF	*International Classification of Functioning, Disability and Health*
IRT	item response theory
NA	not applicable
PDA	personal digital assistant
SCI	spinal cord injury
WHO	World Health Organization

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suggestions for getting us out of them.[2,4-8] A few articles focused on systematically reviewing participation measures also have useful suggestions for improved measurement.[9-14] This article aims to show that the problems at various stages of the process of measurement are connected and offers some suggestions for improved measurement of participation. However, its primary objective is to point out where questions exist and where existing answers should be questioned.

Most measures and examples used in the following reflect the issues encountered in conceptualizing and operationalizing the participation of adults; however, these problems all are equally applicable to the case of children. In measuring the participation of children, some additional issues come into play, which are discussed by others.[7,12,15] Also, the current review focuses largely on issues in conceptualization and measurement as a topic in medical (physical) rehabilitation. Flynn and Aubry[3] offer an informative review of "Integration of persons with developmental or psychiatric disabilities: conceptualization and measurement" that is up to date with developments in those 2 areas of scholarship through 1999. Within medical rehabilitation, and in other fields, the definition and taxonomy of participation of the WHO's ICF[16] are increasingly used in the development of participation measures. Where in the following sections Participation (Participation Restrictions) and Activity (Activity Limitations) are capitalized, the concepts as defined and operationalized in the ICF are referred to. Where participation and activity are used without capitalization, other or broader conceptualizations or descriptions are denoted.

WHAT IS THE DEFINITION OF PARTICIPATION?

"Participation" has its roots in the Latin "pars" and "capere"—"part" and "to take." The meanings of the word in English dictionaries often include the following: partaking in something, association with others in a relationship, taking part with others in an activity, and social interaction in a group. However, nowadays most researchers who are interested in measuring participation go straight to the ICF and read its definition of Participation: "involvement in a life situation."[16(p10)] This is not a very useful definition: being born, and dying, and everything we do in between involve being in a life situation.[9,12] The obverse of Participation that the WHO offers, Participation Restrictions, has its own definition: "problems an individual may experience in involvement in life situations," which also does not help constrain the scope of Participation.[16(p10)] If a store clerk is not attentive, or FedEx does not show up in time to pick up my latest grant application, I experience a problem in a life situation, but these situations hardly seem to be issues resulting from the intersection of health problems and the environment—a key claim in both the ICF and the DCP[17] about the emergence of Participation Restrictions.

The explanations in the ICF manual[16(p15,p213)] are not helpful. For instance, in specifying that the qualifier "performance" can be applied to the concepts Participation and Activity in order to operationalize them, it is noted that performance can also be understood as "the lived experience" of people in the actual context in which they live.[16(p15)] For those who perform qualitative research, "lived experience" has a meaning that is diametrically opposed to what the ICF intends: not a system of categories to classify aspects of an objectively existing reality, but the subjective experience of people who are going through a particular life event or process such as relearning self-care lost as a result of injury or illness[18] or (not) being excluded from activities with nondisabled peers.[19]

The concept of Participation as delineated in the ICF gains more clarity when considered next to the ICF concept of Activity and its definition. However, concepts deserve their own definition and should not be defined by default.[5] Consequently, the field is still in need of a consensus definition of participation. Even with the ex cathedra definition of Participation by WHO, there still is no consensus on the definition of participation, or community integration, the term used most popularly.[20] Appendix 1 provides a sample of definitions, collected from various sources. The collection may serve as a starting point for discussion, clarification of the concept, and possible consensus. (It should be noted that these definitions are largely limited to participation quantifiable as performance, as discussed in the section "Is there more to participation than performance?")

The definitions in appendix 1 were developed by researchers or other professionals. Another approach is to use focus groups or other qualitative research methodologies to get lay people's definition of participation.[28,33,34] This may lead to surprises. For instance, Mars et al[35] suggest that in the eyes of older adults with a chronic physical illness, only positive experiences count as social participation. McColl et al[20] found differences in the definitions offered by respondents with positive versus those with negative self-evaluations. One concern with these approaches to conceptualization is that frequently respondents do not know how to describe participation.[34,35] If the interviewer needs to give examples or descriptions, there is reason to doubt that delegation of authority is a fruitful approach to the definition of scientific constructs.

WHERE IS THE BORDER BETWEEN PARTICIPATION AND ACTIVITY—OR DO WE NOT NEED ONE?

While the ICF's definition of Participation is fuzzy at best, the ICF definitions of Activity (and its obverse, Activity Limitation) are much clearer and in line with previous theory and research.[36] Activity is defined as "the execution of a task or action by an individual" and Activity Limitations as "difficulties an individual may have in executing activities."[16(p14)] The decision to define Activity (Limitations) and Participation (Restrictions) as separate constructs, but to offer only a single taxonomy that does not differentiate the 2, has resulted in confusion in spite of the fact that an appendix to the ICF offers 3 options to separate Activities from Participation in the taxonomic listing.

Distinguishing between concrete, person-level, immediately observable Activities and more abstract, community-society–level Participation is an old tradition in rehabilitation and has been the basis of fruitful research and efficient administration of services. The refusal of WHO to make a split in the taxonomy parallel to the one in the ICF conceptual framework creates problems, at least for those who insist that the taxonomy should follow the ICF's theory. Pragmatists may be happy to select one of the ICF appendix options for distinguishing Activity and Participation and go to work.

An alternative to basing a distinction on theoretical grounds is to use empirical, data-driven techniques to draw a dividing line. One study found evidence that items in a functional assessment instrument could be sorted into groups that paralleled the Activity-Participation distinction.[37] However, in a second study, the same authors found evidence that led them to reverse their position.[38] Post et al[39] too, in a factor analysis of either IMPACT-S items or subscores, found no separation between Activities and Participations, but instead factors that cut across the divide, in spite of different answer stems in items