
Participation is a central concept in rehabilitation, and by addressing it in science and practice, rehabilitation professionals and scientists provide a link between biomedical science and care and population health. This lecture traces the history of the development of participation and proposes language that includes, but expands, the International Classification of Functioning, Disability and Health language to foster communication of rehabilitation scientists. It also presents a model of rehabilitation service that focuses on participation that can be developed from evidence generated by rehabilitation scientists.

Key Words: Rehabilitation; Terminology as topic.

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I AM GRATIFIED TO BE with you today to deliver the John Stanley Coulter Lecture. For me, this is an unexpected but most welcomed honor. We owe Dr. Coulter much gratitude for his selfless work over 3 decades to establish rehabilitation as a specialty of medicine. He had a vision of what rehabilitation should be, he profoundly influenced what it is becoming, and he provided an important foundation for what rehabilitation will be in the future.

It was more than 20 years ago that I was appointed to serve on the first NCMRR Advisory Committee. Serving on the committee enriched my life by bringing me together with leaders in the rehabilitation field who shared a vision for how we could improve the lives of individuals with illnesses and injuries by providing an infrastructure within the Institutes of Health to support scientists’ work. It was at the committee meetings that I had the good fortune to meet Dr. Henry Betts, Dr. Ted Cole, Judy Human, Dr. Kate Seelman, Peter Axelson, and Dr. David Gray, among others. For their guidance and inspiration, I am grateful. I also would like to acknowledge and thank several of my collaborators at Washington University: Drs. Alex Dromerick, Dorothy Edwards, Lisa Connor, and again, David Gray. I am also grateful to the rehabilitation scientists who recently invited me to become a member of their teams: Drs. Allen Heinemann, Anne Deutsch, Elliot Roth, and Joy Hammel. Finally, I offer my appreciation to Dr. Wayne Gordon and his committee for selecting me for this award. One is blessed when one’s work is informed by and allowed to be part of an interdisciplinary process that supports collective efforts aimed at improving the everyday lives of people. It is gratifying to me to have been afforded the opportunity to work with extraordinary colleagues and be recognized by them for doing what I love.

I am an occupational therapist who has spent 45 years in a profession that contributes to the field of rehabilitation in its science and services. The consumers on the NCMRR Advisory Committee taught me a humbling lesson: disability is not a problem originating within a person; rather, it exists when there is a poor person-environment fit. Since that time, I have been committed to a paradigm not focused on disability, but instead, on enablement and participation.

The general theme of my address today is to challenge us to think of rehabilitation as a continuum that is central to filling the gap between biomedical and population science and the gap between the biomedical system, in which people receive medical care, and the broader sociocultural system, in which people live. A focus on participation makes it possible to fill this gap in both our research and practice. For some individuals, the concept of participation is relatively new or simply a concept that other scientists and practitioners address. As a result, the individuals may not believe that participation is applicable to their work. My colleague, David Gray, and I put together table 1 to track the concept of participation in rehabilitation. I want to take a few moments to share that history with you because it is central to the points I will be making in this address.

Over the past 20 years, we have seen the evolution of rehabilitation science and a shift in the focus of clinical rehabilitation. Nagi first proposed a rehabilitation classification that helped foster the development of the science of rehabilitation. Using Nagi’s taxonomy, scientists from many related disciplines began to see how their work could contribute to a better understanding of health, because at that time, the definition of health was the absence of disease. The weaknesses of the early Nagi model and the early World Health Organization models were that they located disability within the person (ie, the person had an impairment that resulted in a disability). It was not until 6 consumers participated in the development of the NCMRR model that the focus began to change. The classification that emerged from this model made it possible for rehabilitation professionals and consumers to find a common language for communicating with one another. The NCMRR recognized that the science of rehabilitation spanned the biomedical, behavioral, and environmental sciences.

The 1997 IOM Committee took it a step further by describing the critical role of the environment in minimizing a disability. By 2001, the World Health Organization in the ICF had added the concept of activity and participation, but had deleted the concept of functional limitations. They had also
made explicit what was meant by environment. These were very important changes that should be understood by all persons who perceive their primary area of science or practice to be rehabilitation.

Since 1993, it has become necessary to develop rehabilitation science to increase the understanding of the concepts of activity, participation, environment, and quality of life. It has also become necessary to recognize the interaction of these concepts with the underlying biomedical systems and mechanisms that result in limitations experienced by people with injuries, chronic diseases, and developmental disorders.

The rehabilitation community had defined functional limitation as a restriction or lack of ability to perform an action or activity in the manner consistent with the purpose of an organ or organ system. The ICF did not include functional limitations; instead, they added activity, which was defined as the execution of a task or an action by an individual. This addition created a language problem for some rehabilitation scientists because actions are required for tasks and the 2 are not thought of as synonymous. It is further complicated by the fact that an activity limitation, as defined by ICF, is the difficulties a person may have in executing activities. In the term activity, we see action, task, and activities classified together. When these terms are operationalized in research studies, the 3 levels—action, task, and activity—are required for measurement. For example, in the activity of walking there is the action, which could be operationalized by the mechanics of the knee; the task, which could be operationalized as the swing phase of gait; and walking, which could be operationalized as a series of steps including step length and step rate, whereas, another scientist might be looking at walking as the means to get somewhere.

Participation is defined by the ICF as involvement in a life situation. There continues to be a debate about language because some associated with the ICF believe that activity and participation are 1 domain. From the example of walking, one can understand why having action, task, activity, and participation as 1 construct could be problematic. Jette et al documented distinct concepts in activity and participation in the area of physical functioning. Participation, according to how it is described in the ICF, is complex to measure as it is related to quality of life, autonomy, and performance with others; participation is dependent on environmental influences. An argument has also been made that participation is subjectively determined because it reports a person’s perceptions of fulfillment of personal and societal goals. The ICF definition of participation has also been criticized as not adequately capturing the subjective dimensions, including the meaning attributed to participation.

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It is certain that we will not fully understand these possibilities unless we study participation across levels of our science. Rehabilitation as a field has had its challenges. For a long period of time, we were not in the mainstream of medicine. Actually, Dr. Coulter’s work to have rehabilitation recognized as a specialty of medicine was a critical step that led to change. As society is further challenged by the growing need to manage chronic conditions, an aging population, and the increase in the number of children living with developmental disabilities, rehabilitation is coming to the forefront. We have always been oriented to improving people’s lives. But only in the last 20 years with many advances in our science, has there been greater understanding of the mechanisms of recovery and the approaches that foster adaptation. Rehabilitation scientists and practitioners have become major players in health care as they continue to make significant contributions that are enhancing the health of the people we serve.

To put this concept in current policy terminology, rehabilitation is the bridge between biomedical care and population health, the overall health of individuals comprising a population (fig 1). Health reform is adopting the concept of rehabilitation and habilitation as core services, and rehabilitation providers will have to describe and implement our efforts for both services.

Rehabilitation science contributes the knowledge to employ rehabilitation and habilitation approaches in our interactions with individuals whose lives are compromised by impairments or potentially disabling conditions, or who are at risk of disability. If we look at the overall, collective effort of the rehabilitation team, we are using knowledge and skills to target interventions to help people communicate, move, and perform the tasks that support self-sufficiency and are central to family, work, and community life. We provide people with the support to gain the necessary skills to manage their health and maintain their roles. The more that individuals do, the better off they are and the more likely they are to have stronger physiologic and psychologic health. The importance of reframing rehabilitation to include habilitation is critical at this time. Actually, I think many of us chose our professional careers so that we could use our knowledge to maximize a person’s independence. What we really strive for is to enable people to be autonomous, make choices, and live without restrictions. Our efforts to implement habilitation approaches will require that we educate our clinical and management teams about the concepts. We must also be sure that our science is being translated to affect clinical practices and policy development.

Underpinning the future of rehabilitation is our science. We are about to enter a period in time during which quality indicators will be central to care delivery and reimbursement. We are going to need scientists who are not only prepared to address biomedical and sociocultural aspects of care, but who are also able to answer questions that address the health service indicators (eg, cost, cost benefit, frequency, dose, and outcomes). Rehabilitation science embraces scientists from diverse fields to answer the questions to inform the interventions that can be applied to support recovery and adaptation. What is exciting about the field of rehabilitation is that it offers scientists many opportunities. The National Institutes of Health, Centers for Disease Control and Prevention, National Institute on Disability and Rehabilitation Research, Agency for Healthcare Research and Quality, and research funding agencies around the world have begun to call for projects that are targeted at improving the health and participation of people at the community level. For example, the Senate Appropriations Bill (July 30, 2009) asked the National Institutes of Health director to integrate NCMRR activities into all the Institutes to fund studies that will prevent the onset and progression of chronic health and disabling conditions.12 Science is needed at many levels because interventions can occur at many levels.

Advances in rehabilitation science are shaping new rehabilitation interventions. No matter what the intervention is, a multimodal approach is required, and all approaches require some degree of learning because a loss has created a novel situation for the patient. While some of the new interventions occur during the acute episode and are designed to foster recovery, others are organized to support adaptation. All interventions are central to participation and well-being; examples of new interventions are presented to highlight the importance of linking the intervention with participation. Pharmaceuticals focus on neuromodulatory and neurotransmitters. There seems to be this belief that one fixes the chemistry and, therefore, fixes the problem. We need to know how to integrate drugs into rehabilitation so that we can maximize arousal, plasticity, and recovery to understand how they are enhancing participation. Stimulation approaches are emerging. Nerve transfers (eg, the use of brachial plexus nerves to support elbow extension, wrist flexion, and thumb opposition) supply muscles that no longer are innervated. Do they foster participation? Do they improve quality of life? Cognitive and learning theories need to be applied and tested in behavioral interventions. Additional research is needed in massed versus blocked practice and retrieval in the context of reconsolidation; the decades of research in context, generalization, and transfer need to be applied to determine how they improve participation. Brain/machine and person/machine interfaces are environmental interventions that must be studied at the participation level so that sophisticated technology considers the needs of the user. For example, as robotic devices are used to replace a nonfunctional muscle, limited movement is augmented, and participation and quality of life may be enhanced.

At the environmental level, new partnerships are being formed with the fitness industry to acquire exercise equipment that is universally designed. Still, questions regarding whether or not people use the equipment and whether or not the equipment improves their participation and quality of life remain unanswered. Self-management strategies have long been used with people with chronic conditions. Evidence supports the efficacy of these approaches in improving the health of individuals with diabetes and arthritis, in particular. We need to use self-management approaches with the populations that receive rehabilitation; this approach will be the major strategy for maintaining health in habilitation. We need to answer the
question: how do self-management approaches improve participation and quality of life in persons with disabilities?

We now face a challenge. Scientists trained in many different disciplines—rehabilitation science, neuroscience, engineering, law, and the social sciences—are contributing knowledge to support recovery and adaptation, but each discipline has its own language. Further, individuals have been trained to do their work without being trained to work in an interdisciplinary context. Rehabilitation is an interdisciplinary field. Thus, in order to eliminate unnecessary barriers for individuals with disabling conditions, we need a language for rehabilitation science that supports cross-discipline and cross-science communication. As I was creating table 2 to represent the language of rehabilitation science, it became clear to me that the science of rehabilitation needs a different, but complementary language to the ICF, with the goal of making greater efforts to facilitate cross-disciplinary communication in our science.

This language table is not meant to be comprehensive; however, I do hope that all of you can see some of the terminology that you use in your scientific discipline (see table 2). I am not trying to challenge the ICF; the ICF serves as an important international classification for intervention, analysis, and policy. However, it does not describe all the levels of language necessary for rehabilitation science. Rehabilitation science needs language at 7 levels to link our science and scientists. Scientists whose work is oriented to support recovery will be reflected at the molecular and cellular mechanisms level. In the table, you will see words like plasticity, neurogenesis, and the action of neurotrophic factors, to name a few. Recovery is also reflected in the mechanisms of attentional control, in the integrity of anatomical and functional connectivity, in the ability of vascular systems to provide fuel and oxygen for the energetic support of cerebral activations, and in motor control. Another level requiring its own language is the biomechanical level. Many mechanical configurations are possible with different body function and structure. The language table (see table 2) should remind us that science must be developed at all levels if we are to have knowledge to translate findings that will inform the interventions to improve participation, health, and well-being. At this point, there is science at the molecular and cellular level that is being translated to the mechanism level. Work at the mechanism level is being translated to the functional limitation level. Work at the environmental level is being translated to the activity and participation levels. There is, however, little work devoted to translating from participation to mechanisms and from cellular and mechanism to participation. We are in danger of creating 2 cultures of rehabilitation science. If we do, we will not answer the questions that will guide interventions to improve the lives of the people whom rehabilitation can serve, and we will not have the knowledge to employ effective strategies that can be translated into policy.

It is not enough for interventions to have their desired effect (eg, to increase the number of neuronal connections after a spinal cord injury). What matters is not the number of connections but whether or not they work! How do we define work? Do we mean releasing neurotransmitters, firing action potentials, causing muscle twitches, or even causing muscle contractions? Or must the final arbiter of usefulness be that the muscle contraction must be able to contribute to a person’s meaningful action? Having the intermediate measures is critical for us to continue to improve, test, and review our work. But the final measure should be that the person is able to participate in activities that will provide quality to his or her life.

Why has participation not been studied consistently in translational research? Perhaps because the topics of education, school, work, recreation, leisure, religious participation, child-care, and social relationships do not at first blush seem to lend themselves to biomedical scientific investigation. Engagement in life is individualized and is a very complex construct. It can, however, be measured with constructs like time, frequency, effort, difficulty, support, satisfaction, meaning, choice, control, importance, and expectations. Participation can be measured objectively with global positioning systems and actigraph technology. Participation can be measured subjectively with persons reporting what they do, how important it is for them to do it, and what meaning it brings to them. Participation can be studied indirectly by reporting how much difficulty people experience in carrying out their activities, it can report level of assistance required, and it can be measured by understanding the barriers that limit their participation in home, work, and community life. Thus, to fulfill our potential to help people achieve the best outcomes from our rehabilitative services, it is critical that rehabilitation scientists include measures of participation to guide interventions and policy. By including participation, we will be able to answer questions of effectiveness.

Rehabilitation must build the knowledge and organize the collective efforts of its professionals in order to deliver services that will enable the people we serve to either recover or adapt...
to their conditions to achieve good health and the means to live quality lives. This requires that all of us—practitioners, scientists, and educators—focus on participation and make a major contribution to the national research agenda because we will contribute knowledge that will improve the human condition.

Some might think that what I have just suggested is impossible. It is certainly not my intent for every study to work across all levels, but some studies must. I would not suggest something that I did not know was possible. To work across levels requires interdisciplinary colleagues and the terms from each level to be studied and operationalized, with measures identified.

I want to share some work that has emerged from an interdisciplinary team of scientists at Washington University School of Medicine. In 1996, a team of neuroscientists, rehabilitation scientists, psychologists, and physician scientists responded to a request from the James S. McDonnell Foundation to develop a system that would allow emerging knowledge from cognitive neuroscience to improve the lives of people with cognitive loss. It was fortuitous that Dr. Alex Dromerick had just joined the faculty and was working with colleagues in occupational therapy, physical therapy, and speech therapy to develop an acute stroke data collection system, and he was willing to work to develop the Cognitive Rehabilitation Research Group. In the early phases of the work, Dr. Dromerick and I were coinvestigators in working to extend the data to build a patient registry, a lesion registry, and a database that included clinical, behavioral, performance and participation, and quality of life data on patients who had been admitted to Barnes Jewish Hospital after a stroke. We have published many findings from the study that included over 9000 patients, as of December 2009. I want to give you a little context on our sample: 50% had a mild stroke, as classified by a National Institutes of Health Stroke Scale of 0 to 5 (with a moderate stroke indicated by a score of 6–15 and a severe stroke indicated by a score >16). It was surprising to us to find that 46% of our population was under the age of 65. This finding raised our awareness of the rehabilitation needs of patients who had children at home and needed to be able to drive, work, and manage family and community roles. These data have guided the development of a wider range of restorative and compensatory strategies to provide adaptations for our patients to support their participation. We also became aware that many people who could benefit from rehabilitation and habilitation strategies had not even been referred for rehabilitation services.

We have comprehensive follow-up data on over 400 people in our sample. The Stroke Impact Scale, which was administered at 6 months, gives us a picture of the impact that a stroke has on people’s lives (fig 2).

What has been very interesting to us is how stroke severity, as measured by the National Institute of Health Stroke Scale, does not relate to outcomes. By looking at this visual display of data, we see that there are people with mild stroke who report good recovery, but there are also people with mild stroke who report problems with memory, emotion, communication, participation, and even the physical domain. If we look specifically at perceived recovery, there are people with mild stroke who report poor recovery scores, and there are people with more moderate or severe stroke who report good recovery scores. These data actually pose more questions than the data answer. What constitutes recovery to persons with stroke? What environmental supports are contributing to their perception of recovery? For persons with outcomes that are not perceived to be adequate, what programs could our rehabilitation centers offer to help them achieve their goals? And what factors are contributing to their perception of a poor outcome?

We have a young rehabilitation scientist at Washington University, Tim Wolf, who is particularly interested in the issues associated with participation in work after a stroke. Nearly one third of the people who have had strokes were working at the time of their stroke. Only one third of those people go back to work and of those who go back to work, only half are working at 6 months poststroke. I would like to share some data that highlight the issues faced by persons in the working-age group who were working before their stroke.

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**Fig 2. NIHSS vs Aspects of the Stroke Impact Scale. Abbreviation: NIHSS, National Institute of Health Stroke Scale.**
In a sample of 33 individuals (including 23 whites and 10 blacks) who were working before they incurred a mild stroke, the average age at the time of stroke was only 56-years-old (range, 32–69y). An approximately equal number of men (n=17) and women (n=16) were reported, and a large number were married (n=19) as compared to those who were either widowed (n=5) or not married (n=9). The average education (12.73y) reported by the participants was just slightly higher than high-school level. This is a population not unlike us; we mostly fit this age range. Perhaps we are more highly educated, but these people were working, involved in families, and participating in life activities to fulfill roles. They, however, had a mild stroke, and their lives changed.

Thirteen went home with no services, 12 received some outpatient services, 1 received home health services, only 6 went to inpatient rehabilitation, and 1 went to day treatment. The question is, were those services oriented to help them return to work, family, and community activities?

The following are the participation outcomes reported 6 months after their stroke. Fifteen of 33 participants reported that they were limited in their work, and 16 were limited in social activities. Eight experienced limitations in their quiet recreation, and 18 were limited in active recreation. Work and recreation, both of which are essential issues to promote health and well-being, are compromised. For 9 of the participants, their roles in their families and their participation in spiritual and religious activities changed. Twelve of the participants reported that they no longer had control over their lives, and 13 reported that they had trouble helping others. A very revealing response found that only 5 participants perceived that they had a 100% recovery. Nineteen people indicated that their recovery had been 90% or better, while 14 reported less than 90%, and some reported a recovery of only 20% to 80%.

What can we do to change this trajectory? Or what can we do to correct expectations? First, we can direct our science to learn about the impact stroke is having on people as they live their lives and as they participate in their roles, responsibilities, and work. Second, we can design and implement programs that focus on fostering participation. Such programs can be rehabilitative and habilitative because people who require rehabilitation services also need the knowledge and skills to integrate healthy behaviors into their daily lives.

We must put the focus of our rehabilitation programs on participation. It is through participation that rehabilitation and habilitation meet, and it is through a focus on fostering participation that people will be able to access the resources that rehabilitation professionals have to offer. Figure 3 represents the overall goal of rehabilitation: to foster participation and return people to family, work, and community life.

All rehabilitation professionals—physicians, occupational therapists, physical therapists, speech therapists, psychologists, and nurses—can see their contributions in this model. What is different about this model is that rather than placing the focus on specific services, it asks rehabilitation professionals to place their focus on building programs that will support participation. In order to take advantage of the knowledge being generated from rehabilitation science, we need to build programmatic models that bridge medical services and community life. Such services include opportunities for using mass training, virtual training strategies, assistive technology, driving assessments and training, training in supportive communication, home assessments and modifications, learning strategies, family training, new models of return to work, and contemporary mobility strategies to support community life and postrehabilitation fitness. There must be links with independent living centers and vocational rehabilitation; an emphasis must be placed on self-management strategies to not only manage primary and secondary health conditions, but also to help people acquire and use strategies to manage home, work, and community life.

By focusing on services that will enable participation, we can support recovery and adaptation. We will also fulfill the promise that our science and our professions offer: we will be known for our efforts to help people participate in their daily lives.

Thank you, and thank you Dr. Coulter for your efforts to establish rehabilitation as a field that is contributing scientific knowledge to improve the human condition.
References


