

Disability Research from the Perspective of Rehabilitation Medicine; Using ICF as a Multi-Scientific Model and a Basic Structure

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Disability Research

While historically, death and disease were the outcomes of interest to physicians, increasing importance is now also given to disability and quality of life as well as well-being. Disability, in particular, has received a great deal of attention as an important health outcome and social policy. The World Health Organization (WHO), in its International Classification of Function (ICF) [1] describes human functioning and disability both as an experience in relation to the health conditions and impairments, and as a result of interaction with the environment. The global diffusion of the ICF has also been noted in a study conducted by Wiegand et al. [2].

The burden of disability on the person as well as the society and the need for rehabilitation is stressed by the World Bank and WHO [3]. The leading cause for disability in the world by 2020 is expected to be non-communicable long-term diseases and, in Europe, the largest somatic group is expected to be due to neurological disorders or conditions. The most common cause of neurological disability is stroke. Many of the persons with stroke have multiple impairments and complex needs. Recent estimates indicate that stroke-related disability-adjusted life years (DALYs), a measure of overall disease burden, accounted worldwide for 38 million disease-related years of life lost and years lived with disability in 1990, which is expected to increase to 61 million disease-related years in 2020.

There are different conceptualizations of disability (medical and social models, bio psychosocial, charity, and human rights approaches). The medical model of disability “views disability as a problem of person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals” (medical care is central activity to be monitored and enhanced). The social model of disability, developed as a response to the medical model, clearly differentiates between impairment and disability and considers the latter a “socially created problem” that “is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by social environment” [4]. These models are also described in the social sciences discourse [5]. The “charity” approach – people with disabilities are viewed as victims of impairments and beneficiaries of charity (low decision-making capacity) [4]. WHO relied on an integrated model of disability – which merges both the medical and the social model – called bio-psychosocial model [6]. According to this model disability is the umbrella term for impairments, activity limitations, and participation restrictions referring to the negative aspects of interaction between an individual and that individual’s contextual factors [7,8].

This means that disability is not a condition that is permanent but an experience [9] that involves some or all the different parts of the ICF; impairment at the body level, limitations in activities, and restrictions in participation [3]. In a population study from Switzerland [10], it has been shown that there are no clear relationships between impairment and limitation in activity and participation, but via a cluster of contextual factors. Similarly, impairment and perceived health are not directly related. In the World Report on Disability [3], it is stated

that for some persons with disability, rehabilitation is essential for enabling participation. In Article 26, Habilitation and Rehabilitation, in the United Nations “Convention on the Rights of Persons with Disabilities” calls for: “appropriate measures, including peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life...” Rehabilitation has been defined as “the use of all means aimed at reducing impact of disabling and handicapping conditions and enabling people with disabilities to achieve optimal social integration” or as “a process of active change by which person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social functioning” [11]. The overall aim of rehabilitation is to enable people with disabilities to lead the life that they would wish [11], thus, rehabilitation encompasses a heterogeneous group of interventions, applied by different health care and health-related professionals, using disparate methodologies, at various stages in the patient’s journey such as after a stroke [12]. However, the bio psychosocial approach is the basis of rehabilitation [11] and in this way rehabilitation can be seen as a strategy to enable persons with different conditions that are experiencing disability to achieve and maintain the best possible functioning in their situation (environment). Rehabilitation goals can shift from initial input intended to minimize impairment, to more complex interventions that are designed to encourage active participation [12].

Patient and Person

Patient-centered healthcare has received notable attention recently [13,14]. The World Health Organization (WHO) has designated patient-centered care as 1 of 5 core competencies that clinicians must develop to deliver satisfactory healthcare in the twenty-first century [13]. The word patient originally meant “one who suffers”. The question is if you are a patient the whole time you are living with a diagnosis, or only when you are in contact with the health-care but a person the whole time. In our view, the latter is the case. Person-centered care addresses the holistic experience of illness from a patient’s perspective [15] and uses essential components of rehabilitative success, such as effective goal assessment and communication with stakeholders [16].

Therefore, there is also a need to discuss the definition of a person.

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Ricoeur and Kristensson Uggla [17] presents four dimensions of what a person is, and this is someone who is speaking, telling, acting, and responsible. Ricoeur's definition can give an increased understanding of how our perceptions of us as persons can be altered if we lose some of these four capacities. The individual must also deal with memory, history, and eventual oblivion [17]. With a brain injury, these capacities can be diminished or lost. These changes might alter the person's opinion of him/herself but also influence how the staff views the person. Therefore, persons with brain injuries are more vulnerable, have complex needs, and require more awareness and skill from the staff that are engaged in the rehabilitation process.

Patient and Relation

Another major challenge in the disability and rehabilitation context is to gain more knowledge about how healthcare providers (e.g. physician's) relationship to the patient can be improved in areas such as how a patient is experiencing vulnerable living conditions and/or the use of assistive devices. Patients with visual impairments and blindness, for example, made [18] the conscious choice not to use aids (white cane) even though they had both testing means and undergone basic rehabilitation and have not told the medical doctor or the hospital social worker about their apparent vulnerability because of guilt and shame [18]. One consequence of this has in turn contributed to the increasingly higher risk associated with the transport and movement in traffic. This example shows that there is potential to strengthen the relationship between caregiver and patient early in the rehabilitation phase. A prerequisite for such a relationship to arise and be maintained is that there is a reciprocal relationship [19]. One of the challenges to create a better relationship between caregiver and patient is improving communication. This could be achieved through educational excellence. Such educational excellence in the rehabilitation field could be developed among medical doctors, hospital social workers, and disability researchers concerning the task of bringing out messages and information, both completed and ongoing research. Such a mindset would agree well with the recommendations of the World Bank and what WHO writes about in the World Report on Disability [20].

Personal Factors

ICF explains personal factors as: "particular background of an individual's life and living, and comprise features of [an] individual that are not part of the health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level" [1].

Personal factors represent the differences that will always exist between people [21]. Each has his or her personal preferences and responses to disability [20]. As mentioned above, personal factors in the framework of ICF are part of contextual factors, which focus on features beyond the individual's health condition and are proposed to mediate how illness and disability are experienced and produced [22].

Disability and Rehabilitation Research

The bio-psychosocial of the ICF [1] is the foundation for disability research in the field of rehabilitation. This means that the focus can be on some or all the different parts of the ICF; the body level, activities, participation - but considering the effects on the person's functioning [23]. This means that often different methods for research

are used; both quantitative and qualitative but including the opinion of the person that is being researched. This can be done in a research group where professionals of different background/training cooperate since they all bring their skills and views into the research. The training of professionals has a focus on different parts of the biopsychosocial model; physicians as undergraduates have the focus on health condition/disease and body function and structure, whereas the social worker has more of a focus on the environmental factors and participation, and the physical therapist on body function and activity while the occupational therapist focuses on activities and participation. There is also a need to involve the user organizations in the research process so the experiences are being researched and not just those areas that we as researchers think are interesting. This was stressed by the Council of Europe in 2009 (www.coe.int/t/ngo) [24,25].

There is a strong need to understand functioning of persons with different health conditions as well as the experience of disability. The first part is to acknowledge the human need of functioning that is integrated in all of us. The second part is needed to understand what causes the experience of disability, which is the fundament in order to change this. This can be done by training or compensation on the level of body function, training or having different strategies on the level of activities. On the level of participation, the changes needed are often on the societal level but also sometimes the person might need information in order to enhance his/her chances to participate. This can be the case of a person with brain damage where the impairment might lead to a difficulty in "reading" the unspoken message and where information about this impairment and training of strategies might improve the situation of the person as well as those close to that person.

The World Report on Disability [20] calls for more research in rehabilitation. This lack of reliable research is a hindrance for development and implementation of effective rehabilitation policies and programs. One limitation (apart from lack of funding) is the lack of co-operation across relevant disciplines and with organizations representing persons with disability. In recent years it has also been suggested that the disability movement should be involved in terms of research activity [25]. Another positive effect of having disability organizations participate in the research field is that the results can be more efficient and that the disability area can become more accessible in the society. It is important that such involvement is monitored and that there is examination of the effects of increased participation of disabled persons.

In our multidisciplinary research group, there is a consciousness of these problems and an effort to create an environment of inclusion. A research environment where there is a mix of persons with different professional training, from different countries, has a higher possibility of creating good disability research. The development of disability research will be implemented also by a new generation of disabled researchers. The younger generation is more influenced by globalization in society in general and will have an impact on social development and research in the field. A new generation of European disability researchers has been trained in the field of ICF [26]. This educational background can provide a solid basis for the further development of the ICF.

To conclude, disability research that will make a difference should be based on the ICF. The model could include different interesting challenges for more researchers. The common language that ICF could offer also creates favorable conditions for disability research in the future. The ICF-instrument provides both challenges and opportunities for various interesting research and analyses in several disciplines.

Future disability researchers could also develop new knowledge in the field of rehabilitation medicine. Comparative studies of living conditions, social policy regulations, and applications of classification systems such as the ICF, should in future become more interesting and important to analyze.

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