#### SPECIAL REPORT

# TOWARDS A CONCEPTUAL DESCRIPTION OF REHABILITATION AS A HEALTH STRATEGY

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Objective: A proposal for a conceptual description of rehabilitation was made in 2007 based on the International Classification of Functioning, Disability and Health. This conceptual description should foster the development of a common understanding of rehabilitation and its professions. The present paper aims to report on the development and current state of the discussions about this conceptual description and to provide the current version, which has been adopted by different European professional and scientific organizations.

Methods: First, the history of the development of the conceptual description of rehabilitation is reported. Secondly, suggestions for modifications or amendments are introduced, and the resulting phrases and terms are presented and discussed.

Discussion and conclusion: One major change to the conceptual description of rehabilitation is the explicit integration of the perspective of the disabled person. The relationship between person and provider is characterized as a partnership. However, it is argued that quality of life should not be introduced as a primary goal of rehabilitation. This conceptual description can foster a common understanding of the rehabilitation professions and provide a point of departure for clarifying the role of different professions and services within the broad field of rehabilitation. It can also serve to position rehabilitation as a major health strategy and to sharpen the perception of rehabilitation among external stakeholders.

Key words: rehabilitation; definition; healthcare.

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#### INTRODUCTION

Definitions and conceptual descriptions are tools in rehabilitation that influence the perception of problems by different stakeholders (1). They foster common understanding of problems or concepts and are a prerequisite of integrated action. Diverse perspectives contribute to difficulty in the understanding of terms or concepts. This is especially true for international activities, but it also holds true for different cultures or systems within nations, e.g. different healthcare sectors, professions or even disciplines within a profession. Shared definitions or conceptual descriptions are instrumental in achieving important health-related policy goals, such as those outlined in the United Nations Convention on the Rights of Persons with Disabilities (2) and the World Health Assembly resolution on disability and rehabilitation (3). In rehabilitation they can also serve as a means to develop a common understanding of rehabilitation, the rehabilitation professions and the professional discipline of physical and rehabilitation medicine (4).

Rehabilitation has a long history and there have been many attempts to define it (5–7). However, a widely shared and accepted definition has not emerged. It could be argued that it is too ambitious to reach a common definition of rehabilitation suitable for all purposes, perspectives or stakeholders. A legal definition of rehabilitation, for example, has to take into account respective wordings of relevant national laws and regulations. A medical definition of rehabilitation should be able to pinpoint rehabilitation as a health strategy within the care process. Patient advocacy groups might phrase a definition of rehabilitation from the users' perspective. Still, in order to provide a common general understanding of rehabilitation, it is useful to develop a conceptual description of rehabilitation that can serve as a reference for rehabilitation definitions from different perspectives or instrumental to different purposes.

The prospect of developing a shared conceptual description of rehabilitation has become much more promising with the development and adoption of the International Classification of Functioning, Disability and Health (ICF) (8). The ICF offers a new foundation for the conceptual description of rehabilitation because it provides a widely acknowledged and accepted conceptual model and classification of human functioning. Therefore, it should serve as the main reference for a conceptual description of rehabilitation. Starting in 2006, proposals have been made for an ICF-based conceptual description of rehabilitation as a health strategy (9, 10). The aim of the present paper is to report on the

development and current state of the discussions and to provide the current version of the conceptual description of rehabilitation that has been adopted by different professional organizations.

# DEVELOPMENT OF A CONCEPTUAL DESCRIPTION OF REHABILITATION

Based on a first draft of an ICF-based definition of rehabilitation in the White Book of Physical and Rehabilitative Medicine in Europe (9, 10), Stucki et al. (11) proposed a "conceptual description of rehabilitation" in a discussion paper in 2007 including an invitation to comment. In this paper, rehabilitation is understood from a public health perspective as one of 4 general health strategies, i.e. preventive, curative, rehabilitative and supportive strategies. The primary goal of rehabilitation as a health strategy is functioning, which relates directly to the model of functioning of the ICF. The original proposal of the conceptual description is found in Table I. An elaborate introduction into the conceptual background and word choice has been provided by the authors of the original drafted conceptual description (11). This conceptual description of rehabilitation has also been presented as one item of a proposed policy agenda for the International Society for Physical and Rehabilitation Medicine (ISPRM) (12).

This conceptual description of rehabilitation was sent to the delegates of the Section of Physical and Rehabilitation Medicine of the Union Européenne des Médecins Spécialistes (UEMS-PRM section), a panel of delegated experts from all European countries who were asked to comment. Also, members of the European Academy of Rehabilitation Medicine (EARM) were invited to comment. Comments were given primarily during meetings of the above-mentioned European professional or scientific bodies, or meetings not solely in European countries

Table I. Original conceptual description of rehabilitation based on the International Classification of Functioning, Disability and Health (ICF)

Rehabilitation is the health strategy which:

- based on WHO's integrative model of human functioning and disability
- applies and integrates biomedical and engineering approaches to optimize a person's capacity
  - approaches which build on and strengthen the resources of the **person** approaches which provide a **facilitating environment** and approaches which develop a **person's performance** in the interaction with the **environment**
- · over the course of a health condition
- along and across the continuum of care ranging from the acute hospital the rehabilitation facilities and the community
- and across sectors including health, education, labor and social affairs
- with the goal to enable people with health conditions experiencing or likely to experience disability to achieve and maintain optimal functioning in interaction with the environment

WHO: World Health Organization.

ICF terms are marked in bold. An additional paragraph about professions in rehabilitation has been omitted.

set up for different purposes, to members of the working group. This process, as well as the publications by Stucki et al. (12), led to a number of suggestions for modifications or amendments. These suggestions were collected and discussed by members of our working group involving the authors of this paper. On the basis of these discussions, the authors provide here a modified version of the conceptual description of rehabilitation.

In the remaining part of the paper we discuss these suggestions and present a modified version of the conceptual description of rehabilitation, which has been adopted by the UEMS-PRM section in March 2010, by the executive committee of the European Society of Physical and Rehabilitation Medicine (ESPRM) in March 2010, and by the European Academy of Rehabilitation Medicine in December 2010. The present conceptual description of rehabilitation is the result of a longer discussion process and might therefore be regarded not as the best solution, but merely as an optimal and best achievable one. We introduce the suggestions for modifications or amendments, and elaborate on their pros and cons and their meaning. We contrast the new version with the original version of the conceptual description of rehabilitation and describe and discuss the changes that were made.

# CURRENT CONCEPTUAL DESCRIPTION OF REHABILITATION

"Rehabilitation is the health strategy which, (...)"

This phrase was part of the original version of the conceptual description. It relates to the delineation of different health strategies that are related to the healthcare system, comprising prevention, cure, rehabilitation and support (11). A comparable delineation has been developed at the Organisation for Economic Co-operation and Development (OECD) system of health accounts (13). There they distinguish prevention, services of curative care, rehabilitative care, and long-term nursing care. By referring to rehabilitation as a health strategy it is acknowledged that the health sector should be the "reference", "root" or "anchor" sector of rehabilitation (11).

# "based on WHO's integrative model of functioning, disability and health"

This phrase does not suggest that the ICF is a necessary prerequisite for rehabilitation; rehabilitation has been provided for decades without the presence of the ICF. However, this phrase introduces the ICF as the anchor point or reference of the present conceptual description. In order to make the fundamental role of the ICF more explicit this phrase has been changed to refer directly to the title of the ICF, i.e. the International Classification of "Functioning, Disability and Health". The term "integrative" aims to account for the ICF model purpose of integrating two paradigms, i.e. the so-called (bio-) medical model and the social model of disability and functioning. It also serves to integrate an individual perspective, including somatic, psychological and psychosocial aspects of functioning with aspects of the immediate as well as the wider environment. The adjective "human" has been dropped, since it is self-evident that the model is related to functioning of humans.

"applies and integrates

## ⇒ approaches to assess functioning in light of health conditions"

It has been noted that the specific diagnostic task in rehabilitation, the assessment of functioning in individuals with a health condition, had been omitted. The term functioning makes clear that this assessment should be based on grounds of the ICF. In medical rehabilitation, a health condition as classified by means of the International Classification of Diseases (ICD) should be provided, but is not thought of as an essential task of the rehabilitation strategy itself. The ICF is not perfectly consistent as to whether it relates to health conditions or health per se. Here, an explicit reference to the more restrictive health condition term has been made. It could have been added that the assessment of human functioning should be made not only in light of health conditions, but also of contextual factors. However, since in the ICF the term functioning is conceptually related both to the health condition and to contextual factors they do not have to be added explicitly. The term "assess" is preferred to the term "diagnose" because the application of the ICF does not result in a diagnosis, but should provide the basis of a multidimensional assessment. This term has also been applied in the introduction of an ICF-based rehabilitation approach ("rehabilitation cycle") to characterize 1 out of 4 processes in rehabilitation: assessment, assignment (i.e. the process of assigning specific interventions to the person based on the results of the assessment phase in consideration of the personal goals of the disabled person), intervention and evaluation (14).

### ⇒ "approaches to optimize a person's capacity"

Contrary to the original version, the explicit reference to biomedical and engineering or technological approaches has been dropped. There are a number of different approaches from different professional fields that could be made explicit in this paragraph, all of which aim to optimize capacity or have similar purposes, such as occupational or exercise therapy. Since this conceptual description of rehabilitation was not set up to predetermine which professions should be integrated in rehabilitation, it was decided to discard the explicit reference to specific approaches.

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  ⇒ approaches that build on and strengthen the resources of the person
- ⇒ approaches that provide a facilitating environment
- ⇒ approaches that develop a **person's performance**"

These phrases have been left unchanged, except for substituting *that* for *which* for grammatical reasons. It should be noted that the term person is preferred to the term "people". It stresses that rehabilitation relates to persons that are different and do not represent a homogeneous group. This use of word is also in reference to the United Nations' Convention on the Rights of Persons with Disabilities<sup>1</sup>.

"

⇒ approaches that enhance a person's health-related quality of life in partnership between person and provider and in appreciation of the person's perception of his or her position in life"

These phrases are the result of the most substantial amendment that has been made. It has been argued that "quality of life" should be added as a "goal" of rehabilitation. Also, there should be a stronger emphasis on the person with health conditions experiencing or likely to experience disability to be "in the driver's seat". Both suggestions are strongly related to each other, namely by the notion of integrating the person's perspective into rehabilitation decision making.

On the one hand there is the emerging model of "shared decision making" that has even been called a model for physician—patient relationship in the 21<sup>st</sup> century (15). It is clear that the specific goals of rehabilitation cannot be set by the provider alone and, at the same time, not solely by the disabled person. In a more general sense, rehabilitation should be characterized by a "partnership" attitude between person and provider.

However, there are good arguments to refrain from including "quality of life" as another primary goal of rehabilitation next to functioning. The pros and cons for this suggestion have to be weighed. A clear advantage would be to emphasize the perspective of the person with a health condition experiencing or likely to experience disability. Still, quality of life cannot be added to the principal goal of functioning without some substantial trade-offs. First, quality of life is not a clearly defined term as is functioning. "Functioning" is not a colloquial, but an artificial word that has been specified in the ICF based on an integrative bio-psycho-social model of health as an umbrella term for body functions and structures, activities and participation of a person in interaction with the environment. Quality of life, on the contrary, has found a place in common language, although scientifically it is best characterized as a field of interest (16) rather than a specified scientific construct. This is due to the many connotations associated with the term "quality of life", including those that capture non-medical aspects of healthcare outcomes, subjective perspectives of the patients, representations of functional aspects of a person's life, references to objective living situations (standard of living) of a person, and so on. (17).

There have been attempts to link the ideas of quality of life to the concept of functioning as specified in the ICF (18, 19). This link is based on the notion of well-being as a general term "encompassing the total universe of human life domains, including physical, mental and social aspects, that make up what can be called a 'good life'" (8, p. 211). Quality of life could be understood as the subjective part of this well-being ("subjective well-being") and encompassing all relevant life domains. Quality of life in this sense has been argued to be a key outcome in *supportive* health strategies (11) with a special focus on individual aspects of quality of life as the primary care goals of palliation (e.g. 20). *Health-related* QoL, then, might be understood as the subjective perspective on functioning and disability.

Any health strategy, whether preventive, curative, rehabilitative or supportive, should take general aspects of a person's subjective well-being into account. However, rehabilitation

<sup>&</sup>lt;sup>1</sup>Article one of the UN convention reads: "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

cannot be about fulfilling individual's wishes per se, whatever they may be, but about goals related to functioning. Therefore, quality of life should not be the principal and specific goal of rehabilitation. That would run the risk of blurring the specificity of rehabilitation in terms of its orientation towards human functioning. Rehabilitation should, however, take into account non-health related aspects of QoL of a person. This is expressed in the phrase "in appreciation of the person's perception of his or her position in life", which relates directly to the WHO definition of quality of life. An earlier suggested phrase read "approaches that enhance a person's quality of life in light of health conditions". However, for reasons of clarity and current terminology it was changed to "approaches that enhance a person's health-related quality of life".

"over the course of a **health condition** and in all age groups; along and across the continuum of care, including hospitals, rehabilitation facilities and the community, and across sectors, including health, education, labor and social affairs;"

Here, an explicit reference has been added to ensure that persons of any age should be entitled to rehabilitation services. A key message of this phrase is the need for the integration of rehabilitation into the continuum of care. Rehabilitation cannot be thought of as something taking place solely in a specific institution, but rather as a health strategy applicable across the range of healthcare sectors (10). In this vein, we have not restricted rehabilitation to community services, but to community as a whole, including non-professional voluntary work. This is in line with the community-based rehabilitation (CBR) approach promoted by the International Labour Office (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the World Health Organization (WHO) (22, 23). In CBR two groups are meant to be involved in service delivery: non-professional community CBR workers and the professionals who provide specialized services.

"with the goal

to enable persons with **health conditions** experiencing or likely to experience **disability** to achieve and maintain optimal **functioning**"

We have replaced "people" by "persons" for the reasons stated above. It had been suggested to replace "enable" by the more forceful and active term "empower". However, empowerment is more a person-centred approach and does not necessarily include the interaction of person and environment that should be a prerequisite of the rehabilitation strategy as it is an integral part of the term "functioning". Also, the UN refer to their programme on the rights and dignity of persons with disabilities by the term *enable* ("UN enable"). Therefore, to sustain these references "enable" is retained.

The reference to the different professions that apply the

"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (21).

rehabilitation strategy that had been added in the original version in a separate paragraph has been dropped from the conceptual description for the sake of parsimony. It is taken up in the conceptual description of physical and rehabilitation medicine that has been developed and adopted in parallel with the conceptual description of rehabilitation (24).

Table II shows the complete modified conceptual description of rehabilitation

#### DISCUSSION

The present paper represents another step towards a shared and internationally accepted conceptual description of rehabilitation. The conceptual description of rehabilitation set out here has recently been adopted by European organizations in physical and rehabilitation medicine (UEMS-PRM, ESPRM, and EARM). It will be presented for adoption to the ISPRM, where it has been one item of a proposed policy agenda (13). However, we are aware of the European perspective that has served as a point of departure for this conceptual description. A similar discussion in different healthcare systems in other parts of the world may lead to different perspectives on the role or weighting of goals of rehabilitation, such as "quality of life" or "functional change", depending especially on cultural values, laws and regulations, governmental or funding agenicies' policies or health systems' incentives. The starting point of this conceptual description is the ICF, which is the widely accepted international framework to describe functioning as a goal of rehabilitation. Therefore, this starting point goes well beyond the European perspective. However, in other regions perspectives on ICF and its importance in day to day service delivery vary. Still, the ICF is the most commonly accepted

Table II. International Classification of Functioning, Disability and Health (ICF)-based conceptual description of rehabilitation strategy, modified version (ICF terms are marked in bold)

Rehabilitation is the health strategy which,

based on WHO's integrative model of functioning, disability and health  $\,$ 

applies and integrates

- ⇒ approaches to assess functioning in light of health conditions
- ⇒ approaches to optimize a person's capacity
- $\Rightarrow$  approaches that build on and strengthen the resources of the  $\boldsymbol{person}$
- ⇒ approaches that provide a **facilitating environment**
- ⇒ approaches that develop a **person's performance**
- $\Rightarrow$  approaches that enhance a person's health-related quality of life in partnership between person and provider
- and in appreciation of the person's perception of his or her position in life

over the course of a **health condition** and in all age groups; along and across the continuum of care, including hospitals, rehabilitation facilities and the community,

and across sectors, including health, education, labor and social affairs;

with the goal

to enable persons with **health conditions** experiencing or likely to experience **disability** to achieve and maintain optimal **functioning** 

conceptual background for rehabilitation and is able to integrate different conceptual perspectives.

It appears quite ambitious to try to develop a common understanding of rehabilitation or even a single conceptual description in a world characterized by profound cultural diversity. This paper may challenge rehabilitation providers in other world regions to take the opportunity to use this paper and its methodology to promote the discussion.

It has become clear that this paper does not intend to provide a "fixed" definition of rehabilitation, but as a conceptual description it should serve as a valuable frame of reference for the thinking in the field of rehabilitation, to foster a common understanding of the rehabilitation professions, and as a point of departure for clarifying the role of different professions and services within the broad field of rehabilitation. It is noteworthy that the recent World Report on Disability by the WHO and World Bank (25) provides a definition of rehabilitation; "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (p. 96), which conveys similar ideas to the conceptual description that we have presented here. This conceptual description may also serve to position rehabilitation as a major health strategy and to sharpen the perception of rehabilitation by stakeholders outside of rehabilitation. Therefore, it could foster the achievement of important policy goals to which rehabilitation can contribute substantially.

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