Why we need an internationally shared rehabilitation definition for clinical research purposes for a step forward of the field

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Abstract

Purpose: Responding to a recent editorial arguing against defining rehabilitation, we discuss the reasons for developing a classification of rehabilitation for research purposes, its philosophical background and some of the possible risks.

Why define: Science requires the definition and classification of phenomena to allow replication of experiments and studies, and to allow interpretation and use of the findings. As understanding increases, the definitions can be refined. Defining rehabilitation does run the risk of excluding some interventions or practices that are either considered rehabilitation (perhaps wrongly) or are rehabilitation interventions; when identified, these errors in definition can be remedied. Defining rehabilitation for research purposes should not inhibit but could (possibly) orient research.

Risk of not: Without a definition, rehabilitation will remain in a permanent limbo. Experts will (apparently) know what it is, while others are left guessing or failing to comprehend or recognise it. This uncertainty may reassure some people, because all possible interventions are included, we argue that it downgrades the understanding of our field because interventions that are not rehabilitation are, nonetheless, called rehabilitation. In an era of international collaboration, and of undertaking systematic reviews with metanalysis, we need a shared definition.

Conclusion Terminology is often controversial, but definition enables progress in understanding such that terms themselves can evolve over time.

A recent, fascinating (as usual) editorial by Derick Wade (1) raised the issue of the impossible task of defining rehabilitation – a task that Cochrane Rehabilitation embarked on, with the ambition of achieving the first operational definition for research purposes (2). In this editorial, we discuss the reasons for this effort, some of the philosophical and scientific background, some limitations (and criticisms received), and how much previous experiences with debating the meaning of key terminology has already contributed to shaping the world of rehabilitation.

Several definitions and conceptual descriptions of rehabilitation exist (3). Some are popular among consumers (4), others among professionals (3) and researchers (5), who mainly refer to the most important international agencies, like the World Health Organization (WHO) (6). Some are synthetic and simple (4), others comprehensive but also complicated (1,3). However, they do not allow what research needs: classifying what is and what is not rehabilitation (2-5,7). For this reason, in 2019, Cochrane Rehabilitation launched its "rehabilitation definition for research purposes" project (2) that is now coming to an end.

Science is based on simplifications to understand fundamental phenomena that often become progressively more complicated as understanding grows. Science usually follows a process beginning with initial theories or hypotheses that have been developed from qualitative or explorative research or from ideas arising from clinical practice. These theories and hypotheses are then tested to generate evidence to support or refute them or provide further exploration avenues.

This is precisely the process that Cochrane Rehabilitation decided to follow to improve the current situation around the definition of rehabilitation. We began with some basic

research (3-5,7) followed by a qualitative consensus development process (1) to achieve the first version of a definition of rehabilitation for research purposes, which can now be taken forward for testing by scientists worldwide.

From a philosophical standpoint, we argue that we will not have any growth without a clear definition as a first attempt to understand what is and what is not rehabilitation. Koyré (8) discussed the progress from the medieval age (the "Closed World") to the modern, scientific world (the "Infinite Universe") through the "invention" of the watch. In the Middle Ages, time was a never-ending continuum, conceptually impossible to divide into discrete elements. Consequently, people imprecisely met at "dawn", or "sunset", or "when the sun is high in the sky".

The arbitrary decision to divide time into segments of a specific length gradually led to the current precision: today we meet at 2h05' pm sharp, and we know that the fastest man in the world runs 100 meters in 9"58. In this way, humans did not negate the never-ending continuum of time. Still, they developed some (always perfectible) instruments to understand it. Similarly, an operational definition of rehabilitation should provide an instrument for improving understanding without limiting further debate on the topic and, most of all, without pretending to be exhaustive or not perfectible.

We disagree that it is unfeasible to define rehabilitation because it is impossible to include all its parts in the definition. We could debate the mereological fallacy (9), which warns against inferring the meaning of a "whole" from a study of its part. Alternatively, we could take an ethnosemantic perspective (10), which encourages analysing the meaning of terms from its component parts.

There are centuries of philosophical debate on the meaning of words; we are interested in more practical problems. In our view, the concept of rehabilitation cannot be harmed by inclusion and exclusion criteria more than the never-ending continuum of time by a watch. We broke up the definition into single words/concepts (with relative meanings) to make it operational, to offer scientists clear elements to make decisions. Nevertheless, the definition is valid only if taken as a whole: any intervention respecting one or several parts, but not all of them, does not respect the definition.

Wade (1) proposes a solution in complex or high-stake cases using the judgement of a group of people. This process is precisely what Cochrane Rehabilitation proved failing (7,11). We found that solely having a system of people making judgements about what is and what is not rehabilitation resulted in increasingly arbitrary decisions that were difficult to track. This meant we need to create better criteria for making these decisions, and a definition is one way to start.

Providing a definition runs the risk of expelling some interventions or practices that are either considered rehabilitation (perhaps wrongly) or, even worse, that effectively are rehabilitation. One of these expulsions refers to single interventions provided by single rehabilitation professionals: this decision came to avoid the circular argument we previously used – "rehabilitation is what rehabilitation professionals do" (7,11).

This prior approach to defining rehabilitation was problematic for two reasons: 1) rehabilitation professionals can provide interventions that are not rehabilitation, and 2) rehabilitation includes interventions that rehabilitation professionals do not provide. While the second statement is widely accepted, stakeholders tend to reject the first for professional reasons. It was one of the most significant criticisms we received. Still, we

decided to use a conceptual line of argument not necessarily interwoven with professional interests.

Another criticism we received about the exclusion criteria is that they could inhibit research on specific interventions. We cannot disagree more. The current definition can only (possibly) orient research. During its development, we better understood that rehabilitation is a whole (process). In contrast, single, stand-alone interventions are not rehabilitation but can be part (or not) of a rehabilitation process. This interpretation will be submitted to research evaluation.

There will also be research on our definition and practices that could be (momentarily) considered "not rehabilitation" because of the definition. All this research will improve the overall understanding of rehabilitation and possibly drive to a new version of this definition.

Wade raised the argument that instances of misclassification, requiring systems for handling misclassification, are evidence that a definition is faulty or has failed to achieve its purpose (1). We argue that definitions of words are inevitably imperfect, while explorations of misclassifications provide opportunities to refine and improve shared understanding of a definition. Misclassifications describe the boundaries of definitions. They allow research, refinements, and debate to better understand the words and their meaning.

We recognise that this is a first effort with its consequent inherent limitations. Nevertheless, we affirm the importance of this attempt, without which clinical rehabilitation will remain in a permanent limbo for experts who know "the thing" while all the others are left guessing or fail to comprehend or recognising it. We argue that,

while this limbo can seem reassuring to some (we include everything that is rehabilitation, at the cost of not excluding interventions that are not rehabilitation), in the end, it downgrades the overall understanding of our field (not excluding what is not rehabilitation means being confused with it).

In addition, the more we turn to international collaboration, or we try to summarise and metanalyse the evidence for worldwide use, the more we need a shared understanding. Socio-cultural and historical conditions considerably drive our understanding of rehabilitation and make it local and particular (12). This confusion is the enemy of research and understanding, and ultimately of the growth called by all international agencies for rehabilitation (13). In the end, the current lack of a good definition limited our ability to define evidence-based practice in rehabilitation and, therefore, ultimately undermines quality service delivery for patients.

In the world of rehabilitation, we already experienced a cultural breakthrough when the WHO defined the words “impairments”, “disability” and “handicap” (14). We also experienced how their application increased understanding, leading 20 years later, together with society changes, to their upgrade within the overall framework of “functioning” (15), including the terms “capacity” and “performance”. We are not stating that this process was uncontroversial or that a complete international agreement on these concepts and terminology was ever fully achieved. Still, the fact is that these terms offer a reference framework that nobody can ignore, even when personally not accepting it. More than anything, applying these terms according to their established definition reduces the risk of ambiguity. Most of the rehabilitation students learn this terminology and its

respective definitions. They are part of our evolving world and will continue to evolve (with all the words in our dictionaries) through time and use.

We agree with Wade (1) that definitions of words can be (or perhaps are always) incomplete representations of the concept they refer to and that one word can have many different definitions depending on the context. However, in our view, missing a clear definition of the term for research purposes impairs rehabilitation internally (research and reciprocal understanding) and externally (inappropriate attribution of interventions, or use of inappropriate terms like “conservative”, “non-pharmacological”, “(re)enablement”, “resettlement”, “restorative care” etc). For these many reasons, Cochrane Rehabilitation is developing the first rehabilitation definition for research purposes.

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