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SPECIAL REPORT

A EUROPEAN ACADEMY OF REHABILITATION MEDICINE ACADEMIC DEBATE: DESCRIBING EXPERIENCED HEALTH ON THE BASIS OF THE WHO'S MODEL OF FUNCTIONING (ICF) OR ON THE THEORY OF SOCIAL PRODUCTIVITY

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The first Academic Debate was held within the European Academy of Rehabilitation Medicine (EARM) in Budapest in 2016. The question debated was: is it possible to provide a theory neutral framework to describe the lived experience of health or is there an appropriate theory to understand what constitute the most relevant factors in health (and well-being). First the link between the International Classification of Functioning, Disability and Health (ICF) and rehabilitation as a key health strategy was explained. It was then argued that supplementing the ICF by theory-based approaches (e.g. a theory of social productivity) may advance explanations with regard to participation and links with health and well-being. Thirdly, it was recalled that one of the strengths of the ICF is exactly being "theory neutral". There was no doubt that there is a need for scientific theories to describe functioning and health. The theory of social productivity seems to be an important contribution towards this goal. However, the definition of well-being in relation to the operationalization of functioning and health needs to be further developed. The conclusion cannot be an "either-or" (classification vs theory). Projects should be set up both to further develop the ICF and to refine (or develop new) theories.

Key words: rehabilitation; International Classification of Functioning, Disability and Health; well-being; social productivity.

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LAY ABSTRACT

In the European Academy of Rehabilitation Medicine a debate was held on whether it is possible to describe the lived experience of health in a neutral way, or if we need theories to understand what the most relevant factors of health (and well-being) are. This was illustrated with the case of creating better social relationships by being productive, for example through work. The International Classification of Functioning, Disability and Health (ICF) provides a framework and classification to describe health and functioning and is "theory neutral" over cultures. However, ICF should be further developed and scientific theories are needed to be able to better measure, describe and explain health, functioning and well-being. The debate raised important questions that require more study and discussions.

Academic Debates within the European Academy of Rehabilitation Medicine (EARM) are structured discussions between 2 experts taking a different position with regard to a single relevant topic in the field of Rehabilitation Medicine (1). Based on an initiative by Bengt H. Sjölund and Gerold Stucki in the Foresight Committee and a decision of the General Assembly in 2015, the first Academic Debate was held within the European Academy of Rehabilitation Medicine (EARM) in Budapest on 1 September 2016. The topic of the debate was the description of health using the conceptual framework of the International Classification of Functioning, Disability and Health (ICF) and the theory of social productivity. It was based on the article entitled "Olle Höök Lectureship 2015: The World Health Organization's paradigm shift and implementation of the International Classification of Functioning, Disability and Health in Rehabilitation" by Gerold Stucki (2), the paper entitled "Fair opportunities, social productivity and well-being in disability: towards a theoretical foundation" by Johannes Siegrist & Christine Fekete (3), and the commentary "Reply to 'fair opportunities, social productivity and well-being in disability: towards a theoretical foundation'" by Jerome Bickenbach (4).

All academicians could contribute to the debate. In addition, Johannes Siegrist and Jerome Bickenbach were invited. Carlotte Kiekens volunteered to prepare a report (together with Christoph Gutenbrunner). All members of the Academy were asked to send further comments after the debate (Stefano Negrini responded to this call).

AN ESSAY, A THEORY AND A COMMENTARY

The debate was introduced by Gerold Stucki summarizing the essay based on the Olle Höök lecture he

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gave in Riga on 16 September 2015 (2). He described rehabilitation as a health strategy aiming at optimal functioning and setting active health goals. The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains (5). As the functioning and disability of an individual occurs in a context, ICF also includes a list of environmental factors. ICF is the World Health Organization (WHO) framework for describing health and disability at both individual and population levels. ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21) and is now the international standard for describing and monitoring functioning. The ICF is closely linked to the emergence of rehabilitation as a key health strategy of the 21st century, as it is a conceptual framework describing function and the lived experience of health; however, it cannot explain functioning. It is also questioned whether theory-based approaches may relate to the ICF.

Johannes Siegrist was invited to explore how the theory of social productivity could explain the links between participation and well-being (3). He hypothesized that full participation in social life, including being socially productive by means of paid or voluntary work significantly contributes to well-being. In his view being socially productive may offer a dual utility, being personal needs satisfaction increasing well-being, as well as providing societal benefits. According to Siegrist & Fekete (3), supplementing the ICF by theory-based approaches may advance explanations with regard to the notion of participation. Siegrist stated that the ICF lacks accuracy to describe core notions/terms, such as activity and participation, and expressed the need to disentangle these concepts, extending participation beyond the current simple description as it assumes involvement of other people. He added 4 key aspects related to participation:

1. subjective meaning;
2. autonomy;
3. belongingness; and
4. opportunity of engagement through participation.

Siegrist concluded by highlighting the restriction of the ICF as a descriptive taxonomy and the lack to explain observed variations. He stressed that the benefit of social productivity could explain links between participation and health and well-being.

Jerome Bickenbach, one of the developers of the ICF, refuted this idea in his commentary. He recalled that 1 of the important strengths of the ICF is exactly being "theory neutral". The ICF is primarily a classification and an international standard language for collating comparable data about disability. Whereas the ICIDH was a normative setting out of a theory of what a good life should be, the ICF provides a framework to collect neutral data on the lived experience of people. Adding explanatory theories specifying the contours of the relationship between biomedical and environmental determinants of disability may, according to Bickenbach, undermine the classification function.

However, an explanation of the relationship between environmental factors and levels of social productivity may enrich the ICF. He pointed out that well-being, the outcome referred to by Siegrist & Fekete, is clearly not an ICF component, although it is a plausible long-term outcome, and may be linked to a person's functioning. When developing the ICF, the WHO insisted on remaining within objective aspects of biomedical phenomena. The term well-being can be characterized in many ways and agreement on how to do so or assess and measure is lacking.

Furthermore, Bickenbach did not agree with Siegrist's proposal to make a distinction between activity and participation, as, for him, there is no robust way of distinguishing these constructs. The ultimate outcome is well-being, but this cannot be normative without being paternalistic. Normativity is in conflict with current models of patient-centred care where a rather eudaimonistic model is advanced, emphasizing self-efficacy, autonomy, sense of purpose and meaning in life.

THREE COMMENTS AND DISCUSSION

Jean-Pierre Didier commented on the ICF and mentioned that the acceptability of the ICF is sometimes critically discussed by people with disabilities and their associates. Moreover, he underlines that the ICF is still not widely used and gave 4 possible explanations for this:

1. The tool is constructed within a complex (probably too complex) structure.
2. The tool appears as a classification, too far from clinical practice.
3. The tension between the medical and social model of disability persists despite the ICF.
4. ICF tries to satisfy people who are too different and needs of too different fields.

Christoph Gutenbrunner focussed on the point that the ICF has been described as "theory-neutral", "appropriate to describe" the lived situation of persons with disability and "not normative", and raised a number of questions:

- Has the ICF really been developed without an (*implicit*) theory behind it? In sociology theories about the interaction of persons with the environment have been existent previously.

- If there is no theory behind the ICF, don't we need to develop theories, in particular on the interaction of the ICF domains (*e.g. interaction between participation and environmental factors*)?
- The ICF is not normative; however, some problems still exist. One problem is that, with the use of the ICF from the background of human rights, a highly normative aspect comes in. And, secondly, how to solve the problem of the absence of the classification of the personal factors? They have not been classified because this would have questioned the neutrality of the classifications on the background of societal norms. As personal factors do exist, a debate on the dilemma of societal norms and personal factors needs to be held.

According to Gutenbrunner it seems that a lot of work is still needed on the theoretical foundation of the ICF (*or, at least, of its understanding and use*). The model or theory of "social productivity" (3) has been described as being able to explain important factors of the interaction of an individual with society. Here too, some questions remain unanswered:

- The theory of social productivity has been (*mainly*) developed and proven in industrialized countries. The questions arise as to whether it is universal and applicable to other societies, and what are the cultural factors influencing productivity and its perception.
- It must be acknowledged that different theories concerning social integration and well-being exist. Is there an approach to integrate different theories?
- The model of social productivity uses a number of assumptions, e.g. using terms such as well-being, including relevant factors of influence and an action-reaction model. How much clarity (and consensus) do we have with regard to these assumptions?

In summary, to Gutenbrunner the theory of social productivity is an important approach to better understand "functioning as an interaction of persons with health conditions and the environment". However, many questions remain unanswered and need both a theoretical approach and a proof of concept by collecting data.

Antti Malmivaara commented from a health economics point of view using 2 perspectives: the healthcare perspective and the social perspective. The healthcare perspective focuses on advancement of health among individuals and within populations, and on resource use and respective costs within the healthcare system. The societal perspective also includes indirect costs: the most important arising from sick leave and disability pensions. The healthcare perspective concords with the perspective of an individual as a recipient of healthcare. For an individual, perceived well-being is of great importance, and as well as the functioning and participation operationalized by the ICF. In the healthcare perspective cost-effectiveness and cost-utility analyses are restricted to the benefits and costs within the healthcare system. However, the ability to work, whether paid or voluntary, may be an important part of well-being and functioning. In the societal perspective, all benefits and costs due to the healthcare system are included, but, in addition, also the changes in productivity due to sickness. Also, voluntary work may have incremental monetary value to society, and should be considered in the societal perspective. Malmivaara concluded that the EARM Academic Debate provided points, which may also be utilized in health economic thinking.

The open plenary discussion was started by Henk Stam, who questioned the effect of productive activity, such as work in a cultural context across different regions in the world. Mauro Zampolini added that the underlying mechanism to well-being induced by productivity is mostly the reward, which, in fact, can also be caused by other satisfying activities. Anne Chamberlain stressed that there are huge individual variations in how "the reward" is obtained, for example in artists who may have to wait years before they are successful (and rewarded). Finally, Diane Playford referred to "caring" as a specific activity, citing the 20th century philosopher Milton Mayeroff (6). Thus, caring too could be considered as a "rewarding" activity that could be linked to well-being.

In summary, there was no conclusion on whether theory-based approaches may use or relate to the ICF at this point. Whereas the ICF was meant to be theory neutral, implementing it for data collection remains a difficult task. The ICF, as a framework, could be a basis for theory development. Siegrist argued with findings from empirical research, that a theory of social productivity can explain links between participation and well-being. However, during the debate with the academy members a consensus could not be obtained. Quality of life remains difficult to measure and there may be theories that could assist in gaining insights. More reflection and research seem necessary to further develop and study these concepts.

After the debate, an additional comment was written by Stefano Negrini, who agreed that the ICF cannot be normative or, at least, should try not to be. To Negrini, preserving the ICF as such would anyhow be a mistake: instead we must make it evolve. Classifications are like languages, since they allow all of us to use the same terms to describe the same health condition.

According to Negrini, participation topics are at the stage probably the least well represented in the ICF, and refinement in that area should probably be higher than in others. In relation to the debate, the problem

is not whether consumptive and productive activities can be approached without being normative. The question is whether they should be considered important for the human being, and consequently introduced in the ICF as central issues of participation. If this is true, the approach to them should not be normative as correctly proposed. Jerome Bickenbach indicated that he does not see a difference between activity and participation, which for him is a continuum. We probably need more clarity on this matter. In fact, one could argue that a difference clearly comes from the most important point he raised, i.e. that we must not be normative in the ICF. As physicians, the absence of norms can be considered true only for participation (better or worse mobility should be judged only by the patient themself), while we absolutely need to be normative in activities, measuring and defining what is the "normal" activity for a human being as a reference to judge the presence or not of an activity limitation. In this sense, for physicians there is a clear distinction between activity and participation, and this should be maintained. For Negrini this also explains why the PRM specialty is clearly primarily focused on activities and impairments, while participation is ultimately the goal, but not one of our main fields of competence.

CONCLUSION

All in all, the first structured academic debate within the EARM focussed on a very relevant topic: is it possible to provide a theory neutral framework to describe the lived experience of health, or is there an appropriate theory to understand what constitute the most relevant factors of health (and well-being) (*and how they can be operationalized*).

The ICF provides a framework to operationalize health and functioning and is supposed to be "theory neutral". The emerging questions from the debate relate to 2 main issues:

- The independence of the ICF model from any theory must be further elucidated both in reviewing the process of its development including comparisons with already existing theories on health and participation, and in demonstrating its feasibility to be used in different theories on health and participation as well as in different settings and cultures.
- With regard to the feasibility of the use of the ICF, it seems that the efforts to make the classification more user-friendly should continue. In addition, some questions about the ICF remain open, e.g. whether it can be understood across cultures. Last, but not least, the debate showed some issues of the classification itself, e.g. the problem of not classifying personal factors and to not distinguish between activities and participation.
- There was no doubt that there is a need for scientific theories to describe functioning and health. The theory of social productivity seems to be an important contribution towards this goal. However, here some major questions have been raised:
- The definition of well-being (*and quality of life*) in relation to the operationalization of functioning and health needs to be further developed. The theory of social productivity provides one approach, but other approaches seem to be necessary.
- The theory of social productivity addresses one important factor to operationalize functioning; however, the questions remains unanswered as to whether other (*additional*) approaches are needed and whether this theory is applicable across cultures.

Last, but not least, the conclusion cannot be an "either-or" (*classification vs theory*). More work should be invested and projects should be set up both to further develop the ICF and refine (*or develop new*) theories. Further debates, scientific projects and symposia around these topics should be organized.

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