

LETTER TO THE EDITOR

Reply to DeLisa's comment (J Rehabil Med 2007; 39: 736) on the Special Issue about the development of Human Functioning and Rehabilitation Research

The authors are grateful to Prof. DeLisa (1) for contributing to the discussion about the Special Issue of the *Journal of Rehabilitation Medicine* on "The ICF as a Unifying Model for the Conceptualization, Organization and Development of Human Functioning and Rehabilitation Research" edited by Grimby, Melvin and Stucki (2). Prof. DeLisa raises a number of important issues.

In our reply to Prof. DeLisa we focus on the operationalization of the concepts presented, the procedure applied for identifying the five distinct scientific fields, the communication between the distinct scientific fields, and the need for a "common umbrella" (1) of the fields. Finally, we comment on some minor issues.

ISSUE 1 - THE OPERATIONALIZATION OF THE PRESENTED IDEAS

Prof. DeLisa states that the papers of the Special Issue of the *Journal of Rehabilitation Medicine* (2) "do not sufficiently address the difficulties presented when operationalizing broad concepts." "...devising data standards such as the ICF appears easier than creating a comprehensive biopsychosocial model of 'human functioning, disability and health' that can span a variety of sciences, professions, and units of analysis (cells to society) to guide various research questions, agenda or domains." (1)

We agree with Prof. DeLisa that the operationalization of the presented concepts for the further development of Human Functioning and Rehabilitation Research (HFRR) is a complex issue that poses a number of challenges. The discussion of these difficulties, started by the *Journal of Rehabilitation Medicine*, can already be seen as a first step towards overcoming them.

Since every operationalization requires a theoretical concept or idea that is going to be operationalized, the theoretical conceptualization of an issue always precedes its operationalization. The papers presented in the Special Issue (2) are thus more conceptual than operational. The concrete operationalization of these concepts will take time and raise a number of new theoretical questions. It is conceivable that the operationalization of the presented ideas will be fostered through the development of specific examples. We have, for instance, presented how concepts such as the organization of HFRR into five distinct scientific fields can be operationalized when designing a research institution committed to the comprehensive study of human functioning in spinal cord injury (3).

ISSUE 2 - DISTINGUISHING THE FIVE DISTINCT SCIENTIFIC FIELDS

Prof. DeLisa sees a problem in the process we used to delineate the suggested five distinct scientific fields. In his opinion, "this

appears to be circular reasoning: first, distinctions are identified, then, structures are created based on the distinctions, and next, distinctions are defined based on the structures" (1).

Indeed, the description of our process may have led to misunderstandings. Our explanation of the process included the terms "distinctions" in the first step and "distinct" in the third. The use of the term "distinctions" vs. e.g. "delineations" or "demarcations" or "differences" in the context of "distinct" fields may appear circular. However, we recall the famous phrase of the anthropologist, psychologist and philosopher Gregory Bateson, which states that "information is a difference that makes a difference" (4). In order to truly make a difference, we would like to restate our process more clearly.

In the living world, distinct entities exist or have meaning only in so far as they can be distinguished from other entities. The identification of differences exists for every unique perception, thought, or communication: e.g. between night and day in the biblical creation of the world, between butyric acid and other smells in von Uexkuel's famous example of the tick, or between accepted and rejected papers in scientific journals.

Therefore, the identification of differences or distinctions always provides the basis for the description of contents, such as for different scientific fields that can then be called "distinct".

In the case under consideration, we use two identifying distinctions with which different aspects of HFRR can be ordered. One is the distinction between basic, applied and professional sciences. The other is the distinction between the comprehensive perspective and the perspective focused on the biomedical aspects of functioning. We then combine these two distinctions. This results in a two-dimensional structure that can be depicted in a coordinate system or contingency table. Within the therewith established theoretical space we construct the five distinct but related scientific fields as ideal types and hopefully can make a difference.

ISSUE 3 - THE COMMUNICATION OF KNOWLEDGE ALONG THE DISTINCT SCIENTIFIC FIELDS

Prof. DeLisa points to the need to better explain the bidirectional arrows in Fig. 1 of our paper on developing a comprehensive structure for HFRR from the cell to society (5) and the communication of scientific knowledge among the distinct scientific fields.

Actually, Prof. DeLisa himself provides an illustrative example: the well institutionalized Phase I to Phase IV clinical trials (1). A specific example would be the experimental treatment of spinal cord repair. Clinical trials of phases I to IV are now needed to show the safety and efficacy of these

treatments in humans. Since the ultimate proof of their benefit will be the demonstration of a positive change of functioning in the population, a comparison of data to a historical cohort may also be appropriate. This may provide public health or human functioning perspective to the results of the experimental studies. Obviously, good HFRR taps the full potential of experimental and observational studies that are appropriate for a certain research question.

In addition, there may be less institutionalized and planned communications among the distinct scientific fields that can lead to the establishment of common research agendas: e.g. applied researchers may read about the results of fundamental research in scientific journals and develop ideas as to how these results could be applied to rehabilitation practice. Conversely, applied researchers may discover correlations without understanding the underlying causal mechanisms that might bring problems to the agendas of fundamental researchers. Moreover, the findings of HFRR from the comprehensive perspective might motivate biomedical researchers to study, for example, the biological correlates of human-environment interactions. Conversely, the examination of the research and theories from the biomedical perspective may uncover gaps in our understanding of functioning that may be closed through research and theories from the comprehensive perspective. Also, the structure of theoretical models may be transferred from one field to another; e.g. general systems theory was developed in biology (6) and latter translated to social systems (7).

The communication between the distinct scientific fields in HFRR will probably be fostered through the establishment of institutional structures that put these communications on a regular basis. Examples include interdisciplinary research institutions that unite research in all or some of the distinct scientific fields (3), congresses that span the full range of HFRR, or interdisciplinary university centres (8). The more institutional structures available to facilitate this kind of exchange there are, the more coherent the area of HFRR will become.

ISSUES 4 - WHY NOT SIMPLY STRENGTHEN HUMAN FUNCTIONING AND REHABILITATION RESEARCH IN RELATED FIELDS?

Prof. DeLisa also points out that “one wonders if it is actually productive to blend the five sciences under a common integrated umbrella. Perhaps it is better to celebrate the sciences as they provide their own, unique complete answers to specific research questions that stem from issues, questions and concerns in applied rehabilitation” (1).

This is in fact an excellent point. Obviously, this approach should be taken anyway. The disciplinary approach to questions in human functioning and rehabilitation will stay relevant and necessary. It is also important that scientific questions are inspired by other questions and issues that are rooted in applied rehabilitation or, most importantly, in experiences of people with certain health conditions. An important means of assuring and institutionalizing this conjunction may be to

foster community-based participatory research (9) settings. However this ‘bottom-up-approach’ may be complemented by a more ‘top-down-approach’ that generates new scientific knowledge and questions by discussions between different scientific fields and disciplines within a particular research area such as HFRR and thus “under a common umbrella” (1), denominator, or theme (8). Why not strengthen the exchange of ideas among diverse research programs that share the topic of human functioning and rehabilitation? We do not think that the views of the related fields as “endoskeleton” and HFRR as an “exoskeleton” (1) are mutually exclusive. In contrary, it is conceivable that scientific rigor and innovativeness within the fields - a strong ‘endoskeleton’ so to say - will strengthen the whole area of HFRR, whilst the scientific exchange facilitated by the ‘exoskeleton’ ‘HFRR’ will foster the innovativeness and creativity within the fields; and may even lead to promising emerging fields such as bioinformatics in another research area (10).

Also, through the common denominator HFRR, the whole area and the distinct but related scientific fields will become more visible to the public and policy makers. This may lead to increases in funding streams for disciplinary as well as interdisciplinary research in functioning and disability. It may further a common identity of researchers that will in turn facilitate the scientific exchange across distinct fields in the area of HFRR.

We agree with Prof. DeLisa that the “effective ‘interaction’ among the scientists” from different disciplines is indispensable for the setting up of “a research agenda that can improve the ‘interaction’ between persons with disabilities and their surroundings” (1). The identification and conceptual description of an area such as HFRR comprising distinct scientific fields is surely only a starting point for strengthening the interaction among researchers from different disciplines and fields. In the end one needs the living exchange between particular researchers such as psychologists and anthropologists to take place within the physical space of concrete research organizations, conferences and networking meetings (11).

OTHER ISSUES

Prof. DeLisa questions the value of our statement that the Human Functioning Sciences (HFS) should develop instruments or measures for a variety of purposes ranging from clinical practice to international surveys. This suggestion was in the article on conceptual descriptions and domains for research in the five distinct scientific fields (12). Instead, he suggests that it is better to “promote and support the development of the instruments within the already well-established fields, rather than building a new field around the effort”.

This partly seems to be a misunderstanding of our use of the term “development”. In our understanding, the development of instruments in the HFS includes the comparison and critique of existing and new instruments in the already established fields. The ICF-linking (13), for instance, provides an excellent opportunity to compare the content of different instruments.

Also, the question ‘what to measure’ in clinical practice can be treated by the HFS. Actually, in the HFS the domain of classification and measurement is already quite well established as can be seen from the ongoing development and discussion of ICF Core Sets (14).

As far as our article on Journals, Societies and Conferences in HFRR (15) is concerned, Prof. DeLisa gives us the advice “better to encourage the societies to promote and engage in more research on disabilities, in particular those societies that do not have obvious connections to rehabilitation in their journal titles” (1). We hope that our review of the journals, societies and conferences with respect to their coverage of research in disability and rehabilitation may already be seen as part of that encouragement. A periodical update of such research may add to this objective.

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