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SPECIAL COMMUNICATION

Beneficiaries of Rehabilitation



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Abstract

Recent research and the actions of the World Health Organization (WHO) have clarified the nature and value of rehabilitation as a key health strategy of the 21st century. However, strengthening rehabilitation in national health systems around the world is a challenge, partly because there is not an evidence-based argument that rehabilitation is a good economic and social investment. This argument, in turn, depends on characterizing the current and potential beneficiaries of rehabilitation, namely the individuals who could benefit from rehabilitation services whether or not they currently receive these services. Although identifying current beneficiaries is essential for evaluating the current demand for rehabilitation in existing health systems, as well as for making the economic investment case for rehabilitation within national health systems, it is only by characterizing potential beneficiaries that we can identify unmet needs and the potential social effect of rehabilitation. The objective of this study is to take a preliminary step toward both tasks by offering an overview of intuitively plausible approaches to characterizing beneficiaries of rehabilitation and to highlight limitations and challenges with each approach. We rely on the WHO's definition of rehabilitation, particularly the aim of rehabilitation to "optimize functioning and reduce disability," as our starting point.

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Since the Declaration of Alma-Ata in 1978,¹ which was recently reaffirmed in The Declaration of Astana,² 5 health strategies have been identified to achieve the societal objective of a national health system to improve the health of its citizens. These are health promotion, disease prevention, cure, rehabilitation, and palliation. Health promotion and disease prevention arose during the 19th century and have remained the core of public health. The curative strategy came into its own in the 20th century with a wave of more effective means for curing and managing diseases and other health conditions. Palliation also came on the scene in the 20th century and focused on optimizing the quality of life at the end of life. Of the 5 health strategies, rehabilitation has been the least well understood, especially in terms of its contribution to individual well-being and societal welfare. Only recently has this changed.³

The World Health Organization (WHO) has defined rehabilitation as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment."^{4(p2)} In its call for action "Rehabilitation 2030," the WHO proclaimed rehabilitation as the

"health strategy of the 21st century,"^{4,5} in light of population aging (eg, arthritis, diabetes, dementia) and the epidemiologic challenge of noncommunicable diseases (eg, heart disease and diabetes), which contributed to 73.4% of the total deaths worldwide in 2017.⁶ Together, these trends entail a steady and dramatic increase in the number of individuals experiencing limitations in functioning and increased disability. It is this ever-increasing population health need that rehabilitation addresses.

The WHO's focus on "functioning," the key concept in its International Classification of Functioning, Disability and Health (ICF),⁷ helps to explain both the distinctiveness of rehabilitation as a health strategy and its current salience.⁸⁻¹⁰ In the ICF, "functioning" is the general term used for all body functions and structures, as well as all activities in which individuals engage, from the simplest (eg, watching and sitting) to the most complex (eg, work and participating in community activities). In the ICF, disability is a problem in functioning, from mild to severe. Rehabilitation specialists and researchers agree that rehabilitation does not prevent, reverse, or undo the damage caused by disease or injury but rather strives to restore and optimize functioning and reduces disability. Rehabilitation alleviates the effect of living with a health condition, especially a chronic condition, by means of interventions and techniques designed to improve the intrinsic capacity of body functions and structures and to support patients

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in the translation of this optimized intrinsic capacity into the actual performance of daily activities in interaction with the environment, thereby reducing disability.¹¹⁻¹⁵

Thanks in part to the WHO's "Rehabilitation 2030" Initiative,⁵ the nature of rehabilitation, its value, and social importance have been clarified. However, a characterization of who the potential beneficiaries of rehabilitation are is yet to be established. Being clear about who benefits from rehabilitation is essential to plan the future provision of rehabilitation services and realize the WHO's goal of strengthening rehabilitation in national health systems around the world, as well as to convince health system planners that rehabilitation is a good economic and social investment. There are, however, 2 distinct tasks here. The first is developing an approach, namely the tools and data required to identify current beneficiaries of rehabilitation. The second is to characterize potential beneficiaries of rehabilitation, those individuals who could benefit from rehabilitation services whether or not they currently receive these services. Although identifying current beneficiaries is essential for evaluating the current demand for rehabilitation in existing health systems and making the economic investment case for rehabilitation within national health systems, it is only by characterizing potential beneficiaries that we can address unmet needs to enhance the potential social effect of rehabilitation to meet the challenge of realizing the WHO's vision of "Rehabilitation 2030."¹⁶

Therefore, the objective of this study was to take a preliminary step toward both tasks by offering an overview of intuitively plausible, general approaches to characterizing the actual and potential beneficiaries of rehabilitation, and to highlight limitations and challenges with each approach. However, our aim is not entirely theoretical. If we can find the best approach to a conceptual description of the beneficiaries of rehabilitation, this would not only assist in planning for the future need for rehabilitation services within national health systems, but it would also address the urgent requirement of social justice that no potential group of beneficiaries is left behind.¹⁷ By establishing theoretical upper and lower limits of beneficiaries of rehabilitation, we can take the next step to describe a politically negotiated benchmark and added value of rehabilitation in terms of the values of individual well-being and societal welfare.¹⁸ We rely on the WHO's definition of rehabilitation, particularly the aim of rehabilitation to "optimize functioning and reduce disability," as our starting point.

The perspective of epidemiology

A beneficiary of rehabilitation is anyone who could benefit from rehabilitation services and, in light of WHO's definition, more specifically someone experiencing one or more health conditions (eg, disease, injury, or natural process such as aging) that limit his or her functioning in one or more domain. Following the ICF,¹² limitations in functioning include diminished or altered body

functions, structures in one or more organ system, and the associated limitations in the capacity to carry out actions, ranging from basic actions of seeing and hearing, moving, communicating, and other daily activities to more and more complex activities of life and areas of social participation, which, in interaction with the physical, interpersonal, and social environment produces disability. Unfortunately, this characterization borders on a tautology: anyone who could benefit from optimizing functioning is a beneficiary of rehabilitation, the aim of which is to optimize functioning in one or more domains. Like most tautologies, although true enough, this one is not very helpful.

This suggests that characterizing a beneficiary of rehabilitation directly from the WHO's definition (ie, anyone with a health condition with some degree of functioning limitation) at best establishes an upper theoretical boundary to potential beneficiaries of rehabilitation. This might be called the purely epidemiologic approach to defining beneficiaries. A more sophisticated version of this approach was presented at the Second WHO Rehabilitation 2030 meeting in Geneva in 2019 in which data from the Global Burden of Disease Study was used to show that approximately 2.4 billion people could potentially benefit from rehabilitation at some point in their lives.¹⁹ As this number was based on prevalence figures for the top 20 health conditions for which we have evidence that rehabilitation services are relevant, over the life course, this number represents, once again, a theoretical upper limit of the size of the beneficiary population.

It is important to be clear that this theoretical limit may include more rehabilitation needs than is meaningful, even theoretically. We know from the ICF that functioning is a continuous, not dichotomous notion; it is a matter of "more or less" rather than "yes or no." This creates the following dilemma: because having some level of reduced functioning (even if extremely minimal) in some domain of functioning is a universal feature of human existence, it follows that literally everyone is a potential beneficiary of rehabilitation. However, it would be absurd to insist that rehabilitation services and supports must be provided to everyone, however minimal the extent of functioning limitation or the most minimal disability. What we have here is a logical issue common to any continuous phenomena and for which the solution is obvious. We need to create cutoff points or minimal threshold levels on the functioning and disability continua. Where population norms for functioning domains exist, cutoffs might be referenced to these norms. In any event, negligible decrements in vision, hearing, mobility, muscle strength, respiration, and so on, do not qualify one to be a beneficiary of rehabilitation. Only those decrements that, as experienced in one's complex environment, fall beyond some agreed-upon threshold level of severity identify candidates as beneficiaries.

There is a direct parallel here with the phenomena of multimorbidity associated with aging. An individual may have health problems in several areas such as arthritis in the knees, vision and hearing problems, and memory or cognitive decline. Although none of these issues would qualify as more than mild or moderate in severity on its own, together they may profoundly affect an individual's life. The lesson here is that to construct a viable model of "functioning limitation" suitable to identify rehabilitation needs, we cannot merely add together the various functioning problems an individual may experience. What is required is a summary measure of health that could provide the basis for an emergent, overall limitation to which each specific limitation contributes. Like the more general problem of identifying and justifying a threshold severity level of functioning in specific

List of abbreviations:

- CRPD** Convention on the Rights of Persons with Disabilities
ICF International Classification of Functioning, Disability and Health
WHO World Health Organization

domains, constructing a general model usable across health conditions and applicable along the lifespan is a challenge, and the literature on attempts and their failures is substantial.²⁰ It may well be impossible. Yet, once again, even if this challenge is resolved, at best we could use it to construct a purely theoretical upper threshold of potential rehabilitation beneficiaries.

The perspective of human rights

A very different approach is provided by ethical norms, represented in part by internationally recognized human rights and other normative standards. Although the epidemiologic perspective sets theoretical upper limits to rehabilitation beneficiaries in terms of potential rehabilitation needs in epidemiologic terms, ethical norms establish the boundaries within this latter class in terms of "deserved needs" or equivalently, needs society has a prima facie obligation to address. Although not always viewed in this light, ethical norms function logically to set practical limitations on theoretical needs: ethical requirements are bound by the principle of "ought implies can" (most famously attributed to Immanuel Kant).²¹ The point is that no individual or social organization can, logically, have an obligation that cannot feasibly be met. No one can be ethically bound to do the impossible. Thus, even if an individual has rehabilitation needs in theory, on the human rights perspective, he or she is only a true beneficiary if those needs can be satisfied feasibly and practically. At the same time, future innovations in rehabilitation practice may make it feasible to provide rehabilitation benefits to individuals who are not true beneficiaries today. It is therefore important to acknowledge a set of possible beneficiaries who may benefit in the future. Of course, we cannot precisely specify who is in this set of possible beneficiaries as we cannot predict the future.

In one of the few references to the human right to rehabilitation, Article 26 of the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD)²² builds in this criterion of practical feasibility when it asserts that states must "take effective and appropriate measures" to "organize, strengthen and extend comprehensive habilitation and rehabilitation services and programs, particularly in the areas of health, employment, education and social services...".²³ Although there is no mention of which services countries must provide, the CRPD does indirectly specify the desired outcome of these services, namely "...to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life." The legal expression of the ethical "ought implies can" maxim is the doctrine of progressive realization in which states are only obliged to implement human rights to the degree that is socially, politically, and economically feasible, but must always seek to "progressively" extend implementation into the future. In short, the human rights approach identifies beneficiaries of rehabilitation as those who, contingent on practical societal limitations, will enjoy, or will be more likely to enjoy, the beneficial outcomes associated with rehabilitation.

This approach raises several problems. First, it is very unlikely that the beneficial outcomes of optimizing functioning and reducing disability will depend entirely on rehabilitation interventions. Therefore, defining a beneficiary in these terms would require an unimaginably complex analysis of the conditions under which any rehabilitation intervention would, in particular instances and all things considered, increase the likelihood of the recipient achieving these benefits. Secondly, we would normally

believe that a person benefits from rehabilitation even if these specific outcomes are not thereby achieved. Finally, and more generally, it is not possible to define rehabilitation beneficiaries in terms of benefits actually or potentially received from rehabilitation without circularity, that is, a rehabilitation beneficiary is someone who benefits from rehabilitation.

There is another fundamental issue raised by the CRPD: does a beneficiary of rehabilitation have to be an individual with disabilities? Of course, in one sense this is tautological: a person with disabilities is a person with suboptimal functioning in one or more functioning domains, so an intervention designed to optimize suboptimal functioning can only benefit a person with disabilities. Unfortunately, the problem is deeper than this.

Arguably, there are 2 senses of the phrase "person with disabilities."²⁴ The first sense is that just mentioned, namely anyone with suboptimal functioning in some domain. As this sense of the phrase applies to anyone with suboptimal functioning, it might be called the universal sense of the phrase. However, the far more common sense of "person with disabilities" is that of an individual who self-identifies or is socially identified as an individual with disabilities. In this sense, an individual with disabilities has a social identity and is a member of a social subpopulation, which is a recognized vulnerable or marginalized group. It is in this sense that the CRPD is operating. Individuals in this subpopulation are perceived as, and perceive themselves to be, a distinct minority group who have been historically disadvantaged in many ways, including diminished or limited access to rehabilitation services. The CRPD is a human rights document designed specifically to address that injustice.

It is an indisputable fact that individuals with disabilities constitute a minority identity who have historically been disadvantaged and discriminated against in many ways. That is not the issue. However, although there is a social obligation to remedy this and ensure that individuals with disabilities have access to rehabilitation services, at the same time rehabilitation is not a health strategy exclusively reserved for this group. Rather, a beneficiary of rehabilitation surely must include anyone who can benefit from a service the aim of which is to optimize functioning. In the end, although the human rights perspective may not be useful as a way of operationalizing the notion of a rehabilitation beneficiary, it does leave us with an important insight: rehabilitation is a health service for everyone, not some specific minority that is self-identified or otherwise. The human right to rehabilitation is, as it was intended to be, a universal human right.

The perspective of the health system: rehabilitation user groups

The discussion has been perhaps too abstract. If the task is to determine who is a beneficiary of rehabilitation, both potentially and in current practice, we need to turn to the health system itself and focus on actual service delivery. As a health care strategy, rehabilitation should be an integral part of the continuum of care and, although the extent of its usage and coverage varies across national health care systems, primarily as a function of the level of resources available for health care, but often too because of public perceptions about the added value of rehabilitation, we should be able to identify beneficiaries of rehabilitation more straightforwardly in terms of the rehabilitation services that are commonly provided. On this approach, the challenge is to create rehabilitation user groups in terms of benefits received and determine the number of beneficiaries in each group. The sum total of these

rehabilitation service users constitutes, for each country, that nation's set of rehabilitation beneficiaries.

Reimbursement user groups

The clearest example of this health systems approach to identify the benefits of rehabilitation is to rely on actual service categories used for reimbursement accounting systems. Private and public funders of health services, including rehabilitation services, rely on accounting typologies that create reimbursable categories of services. The most well-known and widely used of these is the Organization for Economic Co-operation and Development's System of Health Accounts.²⁵ The 2011 revision of the System of Health Accounts aligns its characterization of rehabilitation with the WHO's health care service typology and divides rehabilitation services in terms of 4 modes of provision: inpatient, day care, outpatient, and home-based. The document tackles some difficult "boundary" issues between rehabilitation and other health strategies such as curative and preventive, although it makes decisions that might be controversial from the perspective of rehabilitation (eg, it excludes all long-term care services from the sphere of rehabilitation). Nonetheless, the Organization for Economic Co-operation and Development system structures payment arrangements consistently and its framework of services and boundary decisions are made to reflect and rationalize existing payment regimes, whether public, private, or mixed.

Identifying beneficiaries of rehabilitation as recipients of rehabilitation services that are reimbursed in terms of an accounting system has the obvious benefit of aligning theory with practice. A system of health accounts equates "service provided" and "service funded," and then indirectly identifies beneficiaries as anyone who could benefit from the services that are actually provided. Realistically, only someone who can benefit from a service that is actually provided and reimbursed can truly be called a beneficiary of rehabilitation. That is the intuitive strength of this approach, but it is also its drawback. Using health accounts to identify the class of beneficiaries of rehabilitation restricts that class to those for whom received services have been reimbursed, which of course does not help us to identify those who could have benefited from rehabilitation but, for whatever reason, did not.

The reimbursement approach does address one of the 2 tasks stated previously, namely to identify actual rehabilitation service users in terms of a typology of user groups. Moreover, these data are readily available in most countries, so it is feasible to quantify actual rehabilitation beneficiaries and to compare this group with recipients of other health services. However, our major challenge is finding not just a theoretical upper bound (as with the epidemiologic approach), a tautological characterization (as with the human rights approach), or a concrete lower bound to the class of beneficiaries of rehabilitation. The challenge is to identify a realistic and measurable characterization of the set of potential beneficiaries of rehabilitation. For this, we need other ways of identifying rehabilitation service user groups.

Rehabilitation service provision user groups

At least 3 tactics for identifying beneficiaries of rehabilitation in terms of service provision are available. The first begins with a systematic categorization or typology of rehabilitation services of the sort that is used in rehabilitation clinical quality management initiatives carried out either by rehabilitation professional organizations²⁶ or by countries themselves.²⁷ Each rehabilitation service identifies a user group, and these user groups generate the overall population of rehabilitation beneficiaries. Alternatively,

one could cluster rehabilitation services by type in terms of their setting across the continuum of care, ranging from primary, acute, postacute, and community-based care.

The second tactic relies on the insight of the epidemiologic approach mentioned above, and identifies those health conditions for which, in practice, rehabilitation services are provided. By focusing on the health condition, it is possible to associate user groups with all of the relevant features of the progress and chronicity of the health condition, making use of some standard description of rehabilitation service requirements for each user group. The WHO's current work on creating essential "packages" of rehabilitation services for the implementation of universal health coverage for rehabilitation provides examples of this approach.²⁸ Implicitly, this approach resolves the problem of finding thresholds of the severity of functioning limitation by domain by relying on the defining features of each health condition and restricting the number of conditions to those that are the most burdensome as determined by the Global Burden of Disease studies, and by exploiting the linkage between the functioning properties listed in the 11th revision of the WHO's International Classification of Diseases.²⁹

The final strategy is similar but identifies rehabilitation services by the life course stage and age-indexed health conditions. Instead of the "silo" approach of using health conditions to define groups, user groups can be identified in terms of their common rehabilitation requirements associated with their life course stage and, where necessary, adding additional rehabilitation services required for health problems not linked to life course stage. In this way, common life course rehabilitation needs define the user group, and no distinction is made between, for example, a working-age adult requiring poststroke rehabilitation from someone requiring psychiatric rehabilitation for stress-related health problems. Using life course stage instead of disease group shows the value of relying on functioning as the underlying aim of rehabilitation interventions. Incidentally, this approach would make it possible to incorporate the fact that rehabilitation is offered in many sectors of the state and that the role of the non-health sectors is also determined by life course stage. This is possible because the priorities of rehabilitation planning change with the basic characteristics of the stage in life, across the life course. For example, in musculoskeletal conditions, children tend to manifest specific problems (eg, scoliosis) that affect the smooth transition from early life to school. For adults, common problems involve low back pain and the need to return to work, whereas for elderly adults, degenerative joint diseases raise the need for joint replacements designed to ensure independent living. The life course approach, in short, highlights the realities of different priorities in beneficiaries of rehabilitation given their stage in life.

Unresolved problems with the user group approach

There may be other approaches to defining rehabilitation user groups, but these are all sensible strategies commonly in use. However, each presumes the availability of data, particularly data about functioning limitations at the individual and population levels,⁹ which is simply not realistic in many instances. Moreover, as the aim is to characterize underserved populations of potential beneficiaries of rehabilitation, each tactic faces difficulties.

For obvious reasons, published attempts at developing rehabilitation service typologies are based on existing practice at country level. However, this means that novel rehabilitation services to address as yet unmet rehabilitation needs and underserved populations, such as rehabilitation to address a dramatic increase

in postintensive care syndrome associated with the coronavirus disease 2019 pandemic,³⁰ are simply left out.

Although creating user groups in terms of health conditions is intuitively attractive, it may not be possible in practice to predict comorbidities for each health condition and may be challenging to estimate the rehabilitation requirements of individuals with secondary health conditions or multimorbidity. The presence of a secondary health condition may also radically change the needs of a member of a defined user group. We are beginning to get a sense of the degree of complexity in treatment planning, and modalities generated by comorbidities in the case of noncommunicable diseases,^{31,32} especially in the case of aging, multimorbidity greatly complicates the provision of health care resources.^{33,34} Although these are real concerns, the framework provides a feasible approach that can be used at the country level for even low-resource countries.

The life course approach realistically focuses on the high-need episodes for rehabilitation linked to stages of life. The principal drawback to this way of characterizing user groups is that it ignores the enormous diversity of rehabilitation service requirements associated with differences in the underlying health conditions potentially experienced by individuals in the same age group.

Conclusion

Societal determination of beneficiaries of rehabilitation

We have reviewed candidate approaches to characterizing the actual and potential beneficiaries of rehabilitation. Although none are without either theoretical or practical challenges, several avenues are promising. The importance of starting with the WHO's definition of rehabilitation and focusing on the aim of rehabilitation to optimize functioning and reduce disability has guided the discussion. Not only is functioning the focus of rehabilitation services, but limitations in functioning form the foundation of all approaches to characterizing a beneficiary of rehabilitation, from the epidemiologic upper limit, the human rights characterization of rehabilitation needs, and the reimbursement-based lower limit to the variety of tactics to use health services as the basis for characterizing rehabilitation user groups. Functioning is the key to making sense of when, and under what conditions, an individual is an actual or potential beneficiary of rehabilitation.

Always keeping in mind society's substantial investment in health care generally, and the enormous population of individuals who, epidemiologically, could potentially benefit from rehabilitation services, society will inevitably have to decide who will be a beneficiary and who will not. This will require a decision about which of the approaches described above are best suited to identify current beneficiaries of rehabilitation. In addition, the decision of who should be included in this group in the future will require a political negotiation based on an economic evaluation of these services, determined either in terms of consumer preferences, satisfaction, or some measure of utility. We know of no national-level efforts currently underway to carry out this economic investment case for rehabilitation. Nonetheless, the language of functioning can guide us, as it links rehabilitation services directly to what matters to people about their health, namely the activities they can perform, the social roles available to them, and the goals and aspirations they can achieve. For this reason, it is essential for the provision of rehabilitation that relevant functioning measures,

including clinical performance tests, clinical observations, and self-report assessments, be used to assess the need for rehabilitation interventions and, subsequently, to evaluate the effectiveness of those treatments. Healthcare generally contributes, not merely to a longer life, but to an active and flourishing life of optimal functioning. Individual well-being, in other words, is the ultimate normative value of rehabilitation for an individual. Arguably, societal welfare is the value that society's investment in rehabilitation can help to achieve.²¹ The societal decision about the beneficiaries of rehabilitation should, we believe, be negotiated in light of these important values, as these are the true benefits that rehabilitation provides each of us and our society.

Keywords

Health services needs and demand; International classification of functioning, disability and health; Learning health system; Rehabilitation

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