Rehabilitation information systems: What we know and what we want

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Abstract---Per the definition of the World Health Organization, rehabilitation is a set of interventions designed to optimize performance and reduce disability in people with a varying range of health-related disorders in interacting with their environment. Like many other fields of the health-care realm, the application and integration of valid and reliable research are perceivably highly
primitive. It is not possible to accurately measure or predict the need for rehabilitation services in general, and it is certainly difficult to do so for specific demographic or geographic classes. Service providers lack the tools to make objective policy and financial decision-making at the systemic level without accurate and reliable information management practices. To gain the capacity to transform the current guidelines of the ministry and make financial changes in the entire rehabilitation process, the rehabilitation sector needs a strong voice and a solid political base to guide the rehabilitation process therefrom. The current narrative review focuses on our knowledge of rehabilitation information systems and what we know and what we want.

**Keywords**—Rehabilitation, registration system, information system, rehabilitation registry.

**Introduction**

Health care is one of the most important social and economic challenges that every country face. Recently, healthcare managers, physicians, researchers, and other health professionals are facing increasing pressure due to the growing expectations of the public and private sectors. While increasing medical care costs have a major impact on people’s quality of life, continued population growth and aging affect health and every healthcare-related process [1,2]. In this regard, information and communication technology is increasingly used to advance management and policy goals in health matters [3,4].

In recent decades, following the upward trend of aging and the increase of various diseases, the high volume of health care data, the need to analyze data in the direction of correct decisions and policies is an essential principle [3]; In the field of health, the life and death of people depend on the quality of data, because the basis of decision-making for preventive, diagnostic, therapeutic and follow-up interventions is strongly dependent on data, and therefore any defect in the quality of data directly affects the quality of health [5,6].

Therefore, the need to follow up and continue the patient's care flow, and review the evidence to find the best care programs and disease control shows the need for extensive planning; This importance can only be fulfilled with the help of registry systems [7,8]. The registry system is an organized system for collecting, storing, retrieving, and analyzing to accurately describe the health care process, assessment, diagnosis, and documentation. which helps managers and policymakers to determine the situation, identify priorities and manage data resources. In addition, the creation and development of registry systems help to accurately identify the prevalence, incidence, and burden of disease, as well as understand specific health conditions and evaluate the effectiveness of interventions [7]. By collecting and integrating various clinical data, registry systems provide a single view of a single disease or outcome, which provides a comprehensive source for storing and retrieving the required clinical information [6].
Rehabilitation is a set of interventions when a person experiences limitations in daily physical, mental and social functioning due to aging or health conditions, including chronic diseases or disorders, injuries, or traumas. Like many other fields of the health-care realm, the application and integration of valid and reliable research are perceivably highly primitive. It is not possible to accurately measure or predict the need for rehabilitation services in general, and it is certainly difficult to do so for specific demographic or geographic classes [9,10]. Service providers lack the tools to make objective policy and financial decision-making at the systemic level without accurate and reliable information management practices. To gain the capacity to transform the current guidelines of the ministry and make financial changes in the entire rehabilitation process, the rehabilitation sector needs a strong voice and a solid political base to guide the rehabilitation process therefrom. The current narrative review focuses on our knowledge of rehabilitation information systems and what we know and what we want.

Methods

A systematic literature review was conducted to retrieve related articles. The search was performed by searching a string of keywords in the title, abstract, and keywords in PubMed, Embase, Scopus, and Web of Science databases. Also, by searching in Google search engine, websites of rehabilitation information systems were retrieved (the first 10 pages were examined). The search was conducted on November 14, 2021, without a time limit. To formulate a search strategy and determine keywords, articles related to the field of the minimum dataset, registry and rehabilitation were examined, as well as MeSH and Emtree keywords and phrases under the supervision of specialists in optometry, speech therapy, audiology, physiotherapy, health information management and medical informatics for Searching the databases used. The following two categories were used to search the databases:

1. ("Rehabilitation")

2. ("Minimum Data Set" or "Minimal Data Set" or "Core Data Set" or "Dataset" or "Common Data Elements" or "Datasets as Topic" or "Registries" or "Registry" or "form")

The search strategy in each database was included in Appendix 1.

The process of identifying and selecting the studies based on the PRISMA diagram is shown in Figure 1. In total, 62,273 documents were initially retrieved through scientific database and Google search engine searching, 37,161 of which were duplicates. Among the retrieved articles, 24,999 documents were excluded after the title and abstract screening. Finally, 59 eligible studies were found through this review.
What Is Rehabilitation?

Per the definition of the World Health Organization, rehabilitation is a set of interventions designed to optimize performance and reduce disability in people with a varying range of health-related disorders in interacting with their environment [10]. Rehabilitation, in essence, is a set of interventions aimed at individuals experiencing limitations in daily physical, mental, and social functioning owing to aging or health conditions, such as chronic diseases or disorders, injuries, or traumas. Rehabilitation may be required by anyone with a health condition such as impaired mobility, vision or cognition. As such, it is perceived to have a wide scope, and people with various health conditions or underlying disorders may need rehabilitation at some stages of their illness [12,13].

Prevalence and Epidemiology of Rehabilitation

In recent decades, given the growth of the aging population and the alarming rise of chronic diseases, the need for rehabilitation-based services has increased globally, the effects of which are more pronounced in low- and middle-income countries [12,14–20]. The World Health Organization estimated in 2019 that 2.41 billion people need rehabilitation services. That is, one out of every three people in the world needs rehabilitation services during his/her period of illness or injury [12].

In 2019, more than 1.6 billion adults aged 15–64 had conditions with potential rehabilitation benefits. Musculoskeletal disorders account for the largest share of...
rehabilitation services with approximately 1.71 billion people, the most important cause of which is low back pain, with a prevalence of 568 million people worldwide. The second largest avenue of need for rehabilitation-based services is sensory disorders with 677 million people; the most important causes can be visual impairment with 329 million people and hearing loss with 403 million people involved. The third largest need for rehabilitation services pertains to neurological disorders, with a prevalence of 255 million people worldwide. Here, strokes call for the most share of rehabilitation, with a prevalence of 86 million people around the world [12]. Sajjadi et al. (2015) employed the data from the 2006 census to determine the prevalence of disability in Iran, which revealed that about 1.4 percent or 14.4 per thousand people are plagued with some disability [21].

Moreover, statistics from 2011 indicate that more than 600 million people in the world are disabled from various physical, mental and social causes, 80% of which live in third world countries, and one-third of them are children. Statistics further suggest that one out of every 10 children born worldwide is either born disabled or becomes disabled from an incident. Statistics published by the United Nations show that about ten percent of the world’s youth population, i.e., 200 million people, have disabilities that can be categorized into six groups: physical, motor, mental, visual, hearing, speech and mental. These disabilities are due to many reasons, ranging from work-related incidents and car or motorcycle accidents to violence, war, poverty or congenital causes [13]. Observations also reveal that the disabled are not the only ones who may need rehabilitation services, as every person may need rehabilitation at some stage of his/her life due to injury, surgery, illness, malaise, or a decrease in their performance with age [20]. Moreover, national censuses in the past years indicate that disabled people constitute about 1 to 4 percent of the general population in Iran [21,22]. The University of Welfare and Rehabilitation Sciences president stated in 2020 that about 24 million people in the country need physical, mental and social rehabilitation services, with the highest priority for back pain [23].

Currently, the need for rehabilitation remains largely unanswered. In some low- and middle-income countries, more than 50% of people do not receive the required rehabilitation services. Moreover, existing rehabilitation services in 60-70% of countries have been disrupted by the COVID-19 pandemic [24,25]. Rehabilitation is an important part of health care and is necessary to achieve universal health coverage. Rehabilitation needs are increasing along with the increasing prevalence of non-communicable diseases and the aging population. National-wide measures should reinforce health systems to provide rehabilitation and make it available to all levels of health care [24]. An extensive range of evidence suggests that many people with COVID-19, regardless of the severity of the disease or the length of hospitalization after the acute phase, suffer long-term complications, further fueling the global demand for rehabilitation services increases globally [12, 15, 24-26].

**Existing Gap**

Rehabilitation services are rightfully perceived as beneficial to individuals and communities, as access to rehabilitation services enables people with health
disorders to live, learn and make incomes at their best. Additionally, they help prevent or shorten costly hospitalizations and prevent readmissions as a cost-benefit investment for individuals and communities. However, evidence points to high levels of unmet needs for rehabilitation globally, while the need for rehabilitation is expected to continue to increase. Countries should be prepared to provide rehabilitation well integrated into the health system and presented equitably [12,24,25-28]. As a result, given that resources are limited, and the need for rehabilitation is high, health system activists need relevant evidence to help prioritize and make decisions while allocating resources for rehabilitation-related practices in various countries. Rehabilitation services are currently not prioritized in many countries in the health-care system, partly due to competing demands for scarce health resources [23, 27]. Like many other fields of the health-care realm, the application and integration of valid and reliable research is perceivably highly primitive. It is not possible to accurately measure or predict the need for rehabilitation services in general, and it is certainly difficult to do so for specific demographic or geographic classes. Service providers lack the tools to make objective policy and financial decision-making at the systemic level without accurate and reliable information management practices.

Rehabilitation Information System

To implement profound changes within the current guidelines of the ministry and to force financial changes in the entire rehabilitation process, the rehabilitation sector needs a strong voice and a solid political base to guide the rehabilitation process therefrom [29]. This can be achieved only through the registries [30,31]. The registry is an organized system for collecting, storing, retrieving, and analyzing data and information for the subsequent accurate description of health care processes, evaluation, diagnosis, and documentation that helps managers and policy-makers to make light of the status quo, recognize priorities, and to manage data resources. Furthermore, the development of registries can enhance the accuracy of detecting disease prevalence, incidence, and costs, while helping understand specific health conditions and evaluate interventions' effectiveness [31]. The development and implementation of the Minimum Data Set (MDS) is the first and most important step in developing registries, which is associated with collecting accurate, standardized and comparable data at regional, national and international levels that can be used to collect data in a specific area [32, 33]. The minimum data set is a set of essential data elements that should be employed in collecting and reporting data in the registry [34, 35]. In any sub.realm of health care, MDS includes many data elements related to demographic characteristics, health status, therapeutic procedures, financial data, and discharge status [36]. It is shown to improve the accuracy and comprehensiveness of data, care plans, and quality of care and increase the quality of life of people in the community. The development of the minimum data set can help to standardize data and thus make it applicable for decision-making and policy-making purposes. Also, it provides the ability to compare data at national and international levels [37,38]. However, national hospital information registries often do not adequately integrate rehabilitation information. This complicates decision-making at all levels and is deemed a major obstacle to strengthening rehabilitation services worldwide. In response to the urgent need to improve rehabilitation services worldwide, the World Health Organization has issued a call to action for 2030 to
promote global rehabilitation. This call has identified 10 areas for coordinated attention to reduce unmet needs for rehabilitation [23]. A key measure publicized in the WHO Rehabilitation 2030 is the call to action for collecting rehabilitation-related information to improve health information systems and rehabilitation data hence being no exception [26,27]. Although this call seems extremely demanding in the flux of measures it requires, one of the most important and fundamental steps is to recommend strengthening hospital information systems by including rehabilitation information using the International Classification of Functioning, Disability and Health (ICF). The ICF is standard health management, epidemiology, and clinical purposes developed by the WHO that includes information on body functions and structures, activities, and contributions. The ICF also includes environmental factors that may influence performance. Performance-related information is of utmost significance for rehabilitation-related decision-making at all health system levels, as rehabilitation aims to optimize performance in light of impairments, disabilities, and acute or chronic illnesses [39,40]. In addition, the ICF for children and youth (ICF-CY) is a version of the ICF that is tailored for the characteristics of children and youth. It contains more detailed information on the use of the ICF when documenting the characteristics of individuals under 18 years of age [41].

Future Work

In recent years, many studies have been conducted in Iran on MDS registries. Most of these studies have also provided a native model for developing MDS for a disease, injury, or group of patients [42-53]. Nevertheless, none have sought to address the design of MDS or rehabilitation registry. However, some studies have proposed MDS for particular rehabilitation fields, such as audiology [45], physiotherapy [43], orthopedics [44], occupational therapy [54] and speech therapy [55]. Given the wide scope of rehabilitation and the needs of supporting organizations involved in Iran, such as the Ministry of Health, these data sets are perceived to lack the required inclusiveness.

Moreover, the proposed dataset for disability in Iran is only aimed at managing the data of the disabled people and hence cannot support other large groups that need rehabilitation services [38]. In contrast, other countries have developed a rehabilitation information system independent of the health information system [56-65]. Therefore, a national specialized minimum data set and subsequently a rehabilitation registry at a nationwide level is of paramount significance, as the rehabilitation registry is the very basis for founding other evidence-based rehabilitation information systems and the main cornerstone for measuring and improving the quality of rehabilitation services [66-73].

Ethical Considerations

Compliance with Ethical Guidelines

This study was approved by the ethical committee of Mashhad University of Medical Sciences (approval number IR.MUMS.REC.1400.296).
Conflict of interest

The authors declared no conflicts of interest.

References


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Uniform Data System for Medical Rehabilitation (UDSMR) [Available from: https://www.udsmr.org/about-us.]


Bakhshayeh S, Sarbaz M, Kimiafar K, Vakilian F, Eslami S. Barriers to participation in center-based cardiac rehabilitation programs and patients’ attitude toward home-based cardiac rehabilitation programs. Physiotherapy


Appendix 1

Search strategy for each database

**Embase**

Date: Saturday, November 14, 2021

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