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SYSTEMATIC REVIEW

Assessment of activities and participation of people by rehabilitation-focused clinical registries: a systematic scoping review

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ABSTRACT

INTRODUCTION: Rehabilitation is considered a key intervention in health care. Clinical registries, defined as an organized system that uses observational methods to collect information to assess specific outcomes in a defined population, can contribute to assessing the impact of the rehabilitation intervention. This review aims to identify and describe rehabilitation-specific registry systems with an emphasis on identifying outcomes that enable the assessment of vital areas and activities of daily living.

EVIDENCE ACQUISITION: A systematic scoping review was conducted. A systematic search was conducted up to August 2022 in MEDLINE/PubMed, Embase, Cochrane Library, Epistemonikos, and other search resources. Studies related to rehabilitation registries presented data on people with health problems that could limit their functioning were selected. The inclusion of studies/clinical registries was not limited by methodological design, year of publication, country, or language. The unit of analysis was rehabilitation registries. The measurement instruments used to assess the outcomes were explored to estimate the domain assessed from the vital areas related to functioning and disability as described by the International Classification of Functioning, Disability and Health (ICF). The vital areas were classified according to activities of daily living (ADLs).

EVIDENCE SYNTHESIS: Seventy-one registries in rehabilitation were identified. The registries included a median of 3 (IQR 2-5) assessment instruments designed to assess the impact of different rehabilitation programs. In total, 137 different assessment scales or instruments were identified. Each rehabilitation registry assessed 6 (IQR 2-8) domains of the ICF, and 15.4% of registries assessed all domains. The most assessed domain was "Mobility" (89.7%), and the least assessed was "General Tasks and Demands" (25.6%). In addition, 92.3% of rehabilitation registries assessed basic ADLs, 76.9% advanced ADLs, and 71.8% instrumental ADLs.

CONCLUSIONS: Although clinical registries do not claim to directly assess the impact of rehabilitation programs on people's functioning according to the ICF framework, it was identified that a low percentage of them assessed the nine vital areas through different outcome assessment instruments. However, most rehabilitation registries directly or indirectly assess some basic, instrumental, and advanced ADLs. The findings of this review highlight the need to improve the design of clinical registries focused on assessing the impact of rehabilitation programs to assess people in all areas of their lives.

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KEY WORDS: International Classification of Functioning, Disability and Health; Rehabilitation; Registries.

Introduction

Global trends in health and aging indicate the need for a major expansion of rehabilitation services in countries worldwide, especially in low- and middle-income countries.[1] While access to rehabilitation is highly variable in low- and middle-income countries, it tends to be low.[2] This may be partly due to the limited capacity of health services to absorb this demand and the disadvantageous ratio of rehabilitation professionals to the target population.[3]

The World Health Organization (WHO) has issued a call to action: Rehabilitation 2030 declares rehabilitation as the key health strategy for the 21st century, needed for the entire population. WHO calls on member states to "ensure all actions to improve access to rehabilitation services, incorporating them into universal health coverage, and urging countries to develop comprehensive service delivery models, multidisciplinary workforce development, expand financing mechanisms and improve health information systems."[3]

Rehabilitation is considered a critical intervention in health care, alongside prevention, promotion, treatment, and palliative care, and should therefore be seen as an essential component of integrated health services, the actions of which should be monitored and evaluated.[4, 5] Rehabilitation thus becomes an investment in human capital and resources that contribute to countries' economic and social development.

Although different countries have had different levels of achievement in the coverage and quality of rehabilitation care,[6] they recognize that there are still gaps to be filled.[7-10] New and challenging tasks arise, among them optimizing the information and registration systems to assess the impact of different rehabilitation interventions on people's functioning. This may enable the evaluation of different models of rehabilitation-based care and potential strategies for improvement,[11, 12] which could subsequently enhance research and evidence generation.[13]

Several tools can contribute to improving health information systems. One of these is clinical registries, an organized system that uses observational methods to collect information to assess specific outcomes in a defined population.[14] While the definition of "health observatories" is still unclear, clinical registries tend to be more specific and aim to provide information to assess the effect of health programs. In contrast, observatories tend to be used more in detecting information gaps and identifying and resolving health inequities.[15, 16]

Although a significant number of studies are based on clinical registries, a low percentage of them have evaluated the impact of registry implementation on health outcomes.[17] The implementation of lung and colon cancer registries has been associated with improved survival.[18, 19] However, this has not occurred when implemented in acute stroke care.[20] In terms of impact on the care process, some studies have shown improved impact in people with diabetes[21] and in a smoking cessation program.[22] However, none of the 17 studies identified by Hoque *et al.*'s review rigorously evaluated the impact of implementing clinical registries on healthcare costs.[17]

The clinical registries and databases at the local and global level focus on the prospective collection of information on general rehabilitation processes or those related to specific health conditions.[23, 24] Their characteristics and the results derived from their analyses are widely available in the literature, repositories, and governmental or scientific society sites. Depending on the objectives of these registries, the entities that develop them, the resources, and the health system in which they are inserted, they are likely to include different variables and critical data that directly or indirectly assess the functioning, performance, capacity and participation of individuals according to the International Classification of Functioning, Disability and Health (ICF).[25] Therefore, identifying, evaluating, and collecting information from existing rehabilitation registries could generate a relevant basis for developing registries and clinical databases in countries lacking such instruments,

allowing the evaluation of specific strategies for improving rehabilitation processes and broader health policies. This review aimed to identify and describe rehabilitation registry systems, emphasizing identifying outcomes that allow assessing people's functioning.

Evidence acquisition

A scoping review was conducted following the updated recommendations of the Joanna Briggs Institute (JBI).[26] A rapid review methodology was used.[27] The protocol for this review is registered on the International Platform of Registered Systematic Review and Meta-analysis Protocols (INPLASY) under number INPLASY202220006. The findings were reported following the extension for scoping reviews of the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA-ScR) statement.[28]

Search strategy

A systematic search was conducted up to August 2022 in MEDLINE/PubMed, Embase, Cochrane Library, and Epistemonikos. The strategy considered a sensitive approach and used controlled language (MeSH, EMTREE) and natural language (Supplementary Digital Material 1: Supplementary Table I). It was not limited by publication date, publication status, or the language of the studies.

In addition, a manual search was conducted in repositories of rehabilitation and disability registries such as the Center for Large Data Research and Data Sharing in Rehabilitation (CDLR) (https://www.utmb.edu/cldr/about-us/about-cldr), the Archive of Data on Disability to Enable Policy and research (ADDEP) (https://www.icpsr.umich.edu/web/pages/ADDEP/about.html), and the database of the International Network of Health Technology Assessment Agencies (INAHTA) (Supplementary Table I).

Eligibility criteria

Eligibility criteria for study selection were divided into participants or population included in the studies, the concept or phenomenon involved, and the context in which the studies were conducted (PCC framework):[26]

- participants: studies were included with adult or pediatric patients enrolled, with any condition or pathology that may lead to a limitation or restriction in functioning according to the ICF;[25]
- concept: studies were included if they presented data from a rehabilitation registry or database containing a minimum data set. To be considered a rehabilitation registry, these had to include some rehabilitation intervention aimed at improving the different vital areas assessed in the ICF framework.[25] These registries could include clinical and administrative information that can be used to improve the quality of care and monitor or answer research questions;
- context: studies conducted in the context of rehabilitation and functional assessment programs at any level of care were included. The programs must have directly or indirectly addressed aspects or variables that can account for functioning according to the ICF.[25]

The inclusion of studies/clinical registries was not limited by methodological design, year of publication, country, or language.

Selection of studies/registries

In the first stage, titles and abstracts were independently screened by two reviewers using the Rayyan® application.[29] Disagreements were solved by consensus or ultimately by a third reviewer.

Studies that proceeded to a second stage were read in full text to identify the names of the rehabilitation registries or databases. In the third stage, these identified registries were comprehensively assessed by reading the full text of the most informative publications available or by reviewing additional documentation on the registries' websites.

The same process was followed for registries identified in other sources (other than scientific publications), applying the eligibility criteria to information related to the openly available objectives and components of the registries.

Fulfillment of the eligibility criteria by the rehabilitation registries or databases (second to third stage) was checked by one reviewer and verified by a non-blinded second reviewer.

Information extraction

Considering that the unit of analysis was the rehabilitation registries, the data were extracted from each register's web pages, from repositories of rehabilitation or disability registries, or from different reports of published studies that have used these registries as a source of information.

The information extracted considered:

- general characteristics of the registry, such as name, country, target health condition or pathology, data collection methods, data collectors, and funding sources;
- variables and data collected at the user/person level;
- variables and data on the provider, facility, or health service characteristics;
- exposure variables and data included, such as inter-

ventions received, characteristics and timing of the intervention, specific rehabilitation program, professionals involved, and equipment;

- variables related to the use of resources;
- outcomes included and their measurement methods, such as questionnaires, scales, instruments, or specific assessment tests. We preferred to extract the method of assessment rather than the domain or construct assessed due to the feasibility of obtaining the information.

One reviewer extracted data from the registries using a standard form available on the REDCap® platform, which was validated by a non-blinded second reviewer.

Synthesis of information

The study and registry selection process is presented in a flowchart modified from that proposed by the updated version of the PRISMA statement.[30] This flowchart shows primary (*e.g.*, observational studies) and secondary (*e.g.*, systematic reviews) studies, followed by rehabilitation registries that met the eligibility criteria.

The information extracted from the identified rehabilitation registries was synthesized qualitatively using tables for presentation and quantitatively using median and interquartile range (IQR) or absolute values with their respective percentages.

The different tests or measurement instruments used to assess the outcomes were explored in detail by rehabilitation experts and clinicians to estimate the phenomenon or domain assessed from the vital areas (actions or tasks) described by the ICF aimed at assessing individuals' functioning, performance, and capacity.[25] For this purpose, the vital areas were classified according to activities of daily living (ADLs) (Figure 1).

In addition, a matrix was created that cross-referenced the registries and outcomes identified. The figures were designed to show the vital areas of the ICF related to functioning and disability with their respective components[25] and the type of ADLs assessed by the different registries.

Evidence synthesis

Registries selection

A total of 14,273 unique records were identified in the electronic database search, of which four systematic reviews[23, 24, 31, 32] and 2533 primary studies were screened to identify registries or databases. A total of 1341 registries or databases were identified, of which 65 were rehabilitation specific and were therefore included. In addition, a further six registries were included from searching other information sources, totaling 71 rehabilitation registries included in this systematic scoping review (Table I, Figure 2).

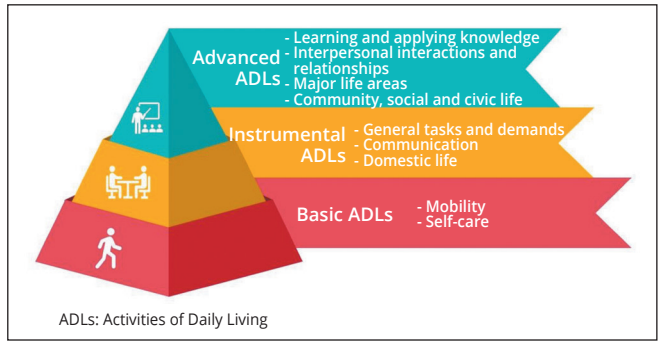

Figure 1.—Classification of the ICF's vital areas according to the ADLs.

Description of rehabilitation registries

The distribution of the 71 identified registries is mainly concentrated in North America, Europe, Oceania, and Southeast Asia. Ten are multinational (two or more countries), and most implemented in a single country were carried out in the USA (24.3%).

The availability of information varied for the different characteristics of the registries. Forty-five out of 57 rehabilitation registries (78.9%) considered exclusively the adult population. Sixty-four rehabilitation registries reported data about the clinical area; 23.4% were considered global, *i.e.*, they were applied to anyone who underwent a rehabilitation program without distinction of pathology, while 37.5% were implemented exclusively on people with neurological conditions, and 24.6% on cardiac diseases (Table I).

Of the 28 registries from which information on data collection methodology could be obtained, 64.3% reported that it was carried out longitudinally, 17.9% cross-sectionally, and the rest in a mixed manner. Furthermore, 30 registries reported information on the context in which the register was used; of these, 46.7% were applied in both outpatient and inpatient settings, and 26.7% were applied exclusively in outpatient or inpatient settings. Of the 31 registries for which information on the level of care could be ascertained, 83.9% were considered to have been implemented in specialized rehabilitation centers (Supplementary Digital Material 2: Supplementary Table II).

We were unable to access or identify the variables collected by 15 (21.1%) of the 71 rehabilitation registries included in this review. The different variables collected

TABLE I.—*Description of rehabilitation registries.*

Name of the registry	Acronym	Country	Users	Access
Global				
American Association of Cardiovascular and Pulmonary Rehabilitation Registry	AACVPR	USA	Mixed	https://www.aacvpr.org/
Australasian Rehabilitation Outcomes Centre	AROC	Multinational	Mixed	https://www.uow.edu.au/ahsri/aroc/
Boston Rehabilitative Impairment Study of the Elderly	Boston RISE	USA	Adult	DOI: 10.1016/j.apmr.2012.08.217
Cardiovascular & Pulmonary Health in Motion Cardiac Rehabilitation database	CPHM	Canada	Adult	https://www.nshealth.ca/content/cardiac-rehabilitation-program
Department of Veterans Affairs (VA) Medical Rehabilitation Records		USA	Adult	https://www.archives.gov/research/guide-fed-records/groups/015.html
Dutch Dataset Pain Rehabilitation	DDPR	Netherlands	Adult	DOI: 10.1002/ejp.937
Early Intervention Colorado	EI-CO	USA	Pediatric	https://coloradoofficeofearlychildhood.secure.force.com/eicolorado/EI_Home?lang=en
Japanese Association of Rehabilitation Medicine Patient Database		Japan		https://www.jarm.or.jp/english/introduction.html
Japan Rehabilitation Nutrition Database		Japan	Adult	DOI: 10.1111/jhn.12887
National Registry for Pain Rehabilitation	NRS	Sweden	Mixed	https://skr.se/en/kvalitetsregister/hittaregister/registerarkiv/smartrehabilitering.44556.html
Physical Therapy Outcomes Registry	APTA Registry	USA		https://www.ptoutcomes.com/
Polytrauma Rehabilitation Centers	VHA PRCs	USA	Adult	https://www.polytrauma.va.gov/system-of-care/care-facilities/polytrauma-rehabilitation-centers.asp
Rehabilitation Register by the Social Insurance Institution of Finland		Finland		https://www.etk.fi/en/services-for-experts/registers/
Swedish Quality Registry for Pain Rehabilitation	SWRP	Sweden	Adult	DOI: 10.2340/16501977-0631
WebRehab Sweden		Sweden	Adult	https://svereh.registercentrum.se/
Cardiac				
Canadian Cardiac Rehabilitation Registry	CCRR	Canada	Adult	DOI: 10.1155/2015/278979
Cardiac rehabilitation and secondary prevention registry of St. Joseph's Health Care London	CRSP	Canada	Adult	https://www.southwesthealthline.ca/displayservice.aspx?id=13529
Cardiac Rehabilitation Minimum Data Set in South Australia		Australia	Adult	DOI: 10.1016/j.hlc.2015.06.786
Danish Cardiac Rehabilitation Database	DHRD	Denmark	Adult	https://www.danishhealthdata.com/find-health-data/
European Cardiac Rehabilitation Database	EuroCaReD	Multinational	Adult	DOI: 10.2147/CLEP.S99502
International Cardiac Rehabilitation Registry	ICCR	Multinational	Adult	https://globalcardiacrehab.com/ICRR-Governance
Italian Survey on Cardiac Rehabilitation and Secondary Prevention after Cardiac Revascularization	ICAROS Study	Italy	Adult	DOI: 10.4081/monaldi.2008.417
Japanese Association of Cardiac Rehabilitation Registry	JACR	Japan	Adult	https://www.jacr.jp/en/
National Registry of Cardiac Rehabilitation Programs in Mexico II	RENAPREC II	Mexico	Mixed	DOI: 10.1016/j.acmx.2016.04.010
NSW Cardiac Rehabilitation Minimum dataset	CRMDS	Australia	Mixed	DOI: 10.1016/j.hlc.2016.06.771
Ontario Cardiac Rehabilitation Pilot Model		Canada	Adult	DOI: 10.2459/JCM.0b013e32835794c1
Rehab-North Register		Denmark	Adult	DOI: 10.1080/14017431.2017.1385838
Transparency Registry to Objectify Guideline-Oriented Risk Factor Management	TROL	Germany	Adult	DOI: 10.2147/VHRM.S28949
Victorian Cardiac Rehabilitation Registry	VCRR	Australia	Adult	https://vcor.org.au/
Wisconsin Cardiac Rehabilitation Outcomes Registry	WiCORE	USA	Adult	DOI: 10.1097/HCR.0000000000000017
Working Group Outpatient Cardiac Rehabilitation Registry	AGAKAR	Austria	Adult	DOI: 10.1007/s00508-014-0527-3
Musculoskeletal				
Anterior Cruciate Ligament Rehabilitation Outcome Registry	ACL Registry	Multinational	Mixed	https://www.aclstudygroup.com/acl-registries.php
European Research on Incapacitating Disease and Social Support Study	EURIDISS	Multinational	Adult	https://cordis.europa.eu/project/id/MR4*0344
Swedish Knee Arthroplasty Register		Sweden	Adult	https://www.myknee.se/en/
Uniform Data System for Medical Rehabilitation Database	UDSMR	USA	Adult	https://www.udsmr.org/
Neurological				
Asklepios Hamburg Multicenter Early Stroke Rehabilitation Registry		Germany	Adult	DOI: 10.1007/s00115-019-0740-4

(To be continued)

TABLE I.—*Description of rehabilitation registries (continues).*

Name of the registry	Acronym	Country	Users	Access
Cognitive Rehabilitation Research Group Stroke Registry in St. Louis	CRRGSR	Multinational	Adult	Doi: 10.1159/000502278
Collaborative Evaluation of Rehabilitation in Stroke across Europe	CERISE	Multinational	Adult	https://faber.kuleuven.be/onderzoek/dep3/neuro/cerise/mission_statement.htm
Coma Outcome of Early Rehabilitation Patients - Registry	KOPF-Register	Germany	Adult	DOI: 10.1016/j.apmr.2014.09.030
Federal Interagency Traumatic Brain Injury Research	FITBIR	Multinational	Adult	https://fitbir.nih.gov/
Ischemic Stroke in Neurologic Rehabilitation Registry	INSIGHT	Germany	Adult	DOI: 10.1111/j.1747-4949.2011.00752
Korean Brain Rehabilitation Registry	KBRR	South Korea	Adult	DOI: 10.3346/jkms.2012.27.6.691
Multiple Sclerosis Rehabilitation Repository	MSRehabrep	Multinational	Adult	DOI: 10.7224/1537-2073.2016-009
National Rehabilitation Reporting System	NRS	Canada	Adult	https://med2020.ca/products/abstracting/nrs/
National Spinal Cord Injury Statistical Center	NSCISC	USA	Mixed	https://www.nscisc.uab.edu/
Online Database System developed by the Korean Society of Neurorehabilitation		South Korea	Adult	DOI: 10.3346/jkms.2015.30.5.644
Post-Stroke Rehabilitation Outcomes Project Database	PSROP	USA	Adult	DOI: 10.1016/j.apmr.2005.09.015
Rehabilitation and Habilitation Trajectories, Intervention and Services for Preschool Children with Cerebral Palsy	CPHAB	Norway	Pediatric	https://www.med.uio.no/helsam/english/research/projects/cp-rehab-children/index.html
Retraining Walking Over Ground in a Powered Exoskeleton After Spinal Cord Injury		Canada	Adult	DOI: 10.1186/s12984-019-0585-x
Research Unit on Brain Injury Rehabilitation Copenhagen registry	RUBIC Registry	Denmark		DOI: 10.3389/fneur.2018.01180
Spinal Cord Injury Model System	SCIMS	USA	Adult	https://msktc.org/sci/model-system-centers
Spinal Cord Injury Rehabilitation	SCIRehab	USA	Mixed	https://datasetdirectory.disabilitystatistics.org/
Swedish National Quality Register for Stroke Care	Riks-Stroke	Sweden	Adult	https://www.riksstroke.org/method/
Thai Stroke Rehabilitation Registry	TSRR	Thailand	Adult	DOI: 10.1186/1471-2318-13-33
Traumatic Brain Injury Model Systems National Database	TBIMS	USA	Mixed	https://msktc.org/tbi/model-system-centers
UK Rehabilitation Outcomes Collaborative National Database	UKROC	United Kingdom		https://www.ukroc.org/
Veterans Affairs Polytrauma Rehabilitation Center TBI Model Systems	VA TBIMS	USA	Adult	https://www.polytrauma.va.gov/PolytraumaCenterDatabase/index.asp
Virtual International Stroke Trials Archive	VISTA-rehab	Multinational	Adult	https://www.virtualtrialsarchives.org/vista/
Zurich Observational Registry of Rehabilitation Outcomes	ZORRO	Germany		https://softpro.eu/project/open-access
Respiratory				
Clinical physiotherapy database for First Contact Physiotherapy	PhysDB-FCP	Denmark	Adult	DOI: 10.1136/bmjopen-2020-040207
North Carolina Pulmonary Rehabilitation Outcomes Registry		USA	Adult	https://nccraonline.org/category/articles/
Other				
Effect of Disease Level on Outcomes of Supervised Exercise in Intermittent Claudication Registry	ELECT Registry	Netherlands	Adult	DOI: 10.1097/SLA.0000000000004073
Inpatient Rehabilitation Facility Compare	IRF Compare	USA		https://www.medicare.gov/care-compare/?providerType=InpatientRehabilitation&redirect=true
National Information Service for Allied Health Care	LiPZ	Netherlands		DOI: 10.1186/1471-2474-14-128
Ongoing Patient Records	OPR	Netherlands	Mixed	DOI: 10.1080/09593980701209097
Outpatient Physiotherapy Department in Singapore		Singapore		https://www.sgh.com.sg/patient-care/specialties-services/physiotherapy-overview
Private Practice Management Program of The University of Queensland	PPMP	Australia		DOI: 10.1080/09593980701209097
Rehabilitation Research Center	REVAL	Netherlands		https://www.uhasselt.be/en/research/research-groups/detail/2231-rehabilitation-research-center
State Funded Physical Therapy Outcome System	SFPTOS	USA	Adult	DOI: 10.1080/09593980701209097
University Medical Centre Utrecht		Netherlands		DOI: 10.1080/09593980701209097

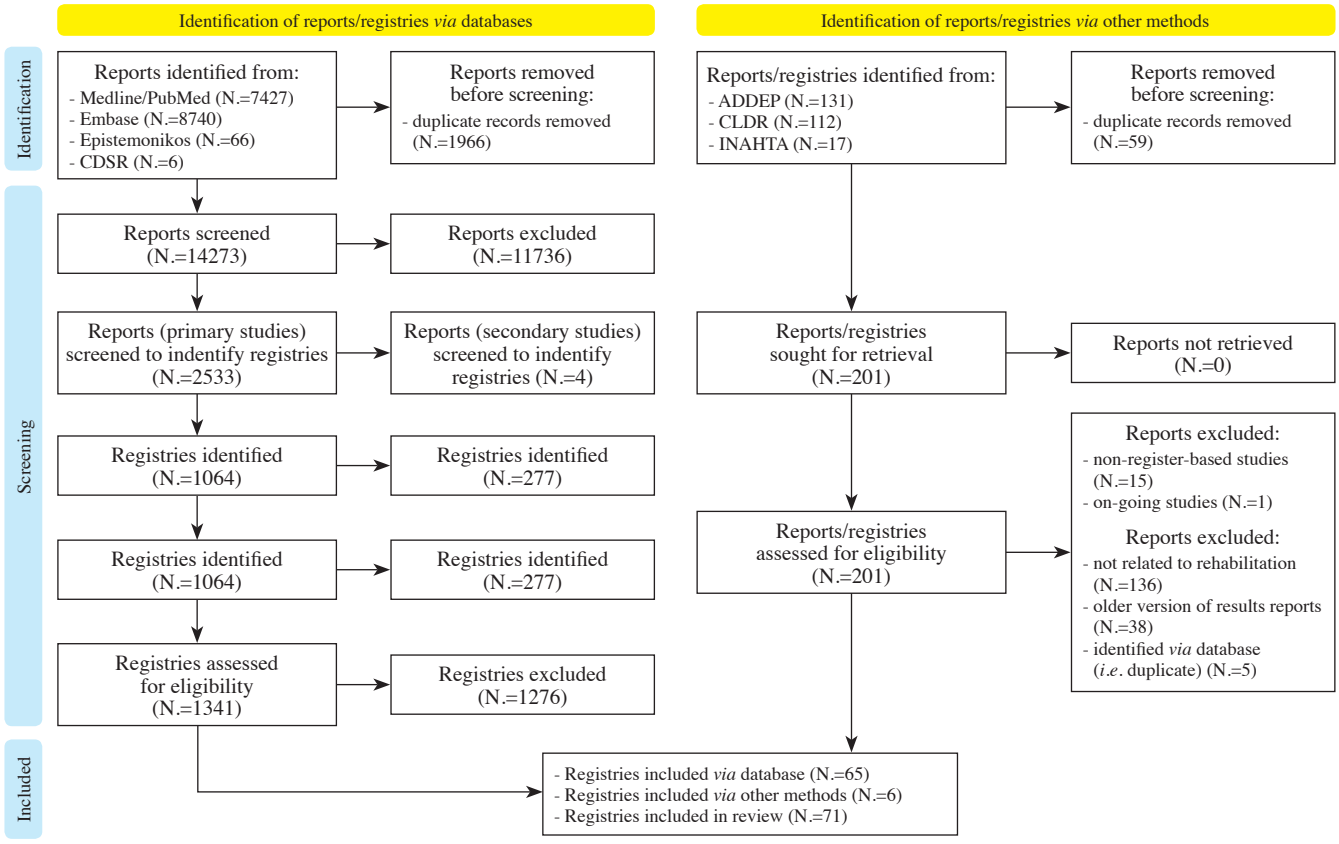

Figure 2.—Study selection flowchart.
ADDEP: Archive of Data on Disability to Enable Policy and Research; CDSR: Cochrane Database of Systematic Review; CLDR: Center for Large Data Research & Data Sharing in Rehabilitation; INAHTA: International Network of Agencies for Health Technology Assessment.

from the others 55 registries were extracted from their websites, feasibility and follow-up reports published as scientific studies, and evidence synthesis studies.[23, 24, 31, 32]

User/person-related variables

Variables collected to characterize the user/person were identified in 46 (83.6%) of the 55 available rehabilitation registries (Table II).

The registries included a median of 5 (IQR 3-6.5) types of variables to characterize the user/person included in the rehabilitation programs. Socio-demographic variables, such as age, gender, race/ethnicity, and marital status, among others, were the most collected by the registries (94.1%). By contrast, variables related to household income were the least considered (3.9%). Variables that can account for people's participation in society, such as employment status and level of physical activity, were collected by 29.4% and 11.8% of the registries, respectively (Supplementary Digital Material 3: Supplementary Table III).

Variables related to the provider of rehabilitation services

Variables collected to characterize the provider of rehabilitation services were identified in 9 (16.6%) of the 55 available rehabilitation registries (Table II).

The registries included a median of 1 (IQR 1-1) type of variable related to the characterization of the rehabilitation provider, of which 5 (55.6%) registries collected variables related to the identification of the health or rehabilitation facility, four (44.4%) registries collected variables related to the characteristics of the health or rehabilitation facility, and two (22.2%) registries collected variables related to the characterization of the professionals delivering the rehabilitation interventions.

Variables related to rehabilitation interventions

Variables collected to characterize the rehabilitation interventions performed were identified in 21 (38.2%) of the 55 available rehabilitation registries (Table II).

TABLE II.—*Variables reported by clinical registries.*

Name of the registry	Acronym	Variables				
		User/ person	Provider of services	Interventions	Resource utilization	Outcomes
Global						
American Association of Cardiovascular and Pulmonary Rehabilitation Registry	AACVPR	x		x		x
Australasian Rehabilitation Outcomes Centre	AROC	x				x
Boston Rehabilitative Impairment Study of the Elderly	Boston RISE	x				x
Cardiovascular & Pulmonary Health in Motion Cardiac Rehabilitation database	CPHM					
Department of Veterans Affairs (VA) Medical Rehabilitation Records				x		x
Dutch Dataset Pain Rehabilitation	DDPR	x			x	x
Early Intervention Colorado	EI-CO	x		x		x
Japanese Association of Rehabilitation Medicine Patient Database						
Japan Rehabilitation Nutrition Database		x				
National Registry for Pain Rehabilitation	NRS	x	x			
Physical Therapy Outcomes Registry	APTA Registry		x			x
Polytrauma Rehabilitation Centers	VHA PRCs					x
Rehabilitation Register by the Social Insurance Institution of Finland						
Swedish Quality Registry for Pain Rehabilitation	SWRP	x				x
WebRehab Sweden		x				x
Cardiac						
Canadian Cardiac Rehabilitation Registry	CCRR	x		x		x
Cardiac rehabilitation and secondary prevention registry of St. Joseph's Health Care London	CRSP					
Cardiac Rehabilitation Minimum Data Set in South Australia						
Danish Cardiac Rehabilitation Database	DHRD	x				
European Cardiac Rehabilitation Database	EuroCaReD	x		x		x
International Cardiac Rehabilitation Registry	ICCR	x	x			x
Italian Survey on Cardiac Rehabilitation and Secondary Prevention after Cardiac Revascularization	ICAROS Study	x	x	x		x
Japanese Association of Cardiac Rehabilitation Registry	JACR	x				
National Registry of Cardiac Rehabilitation Programs in Mexico II	RENAPREC II	x		x		
NSW Cardiac Rehabilitation Minimum dataset	CRMDS	x		x		
Ontario Cardiac Rehabilitation Pilot Model						
Rehab-North Register		x				
Transparency Registry to Objectify Guideline-Oriented Risk Factor Management	TROL	x				
Victorian Cardiac Rehabilitation Registry	VCRR	x	x	x		x
Wisconsin Cardiac Rehabilitation Outcomes Registry	WiCORE	x				x
Working Group Outpatient Cardiac Rehabilitation Registry	AGAKAR	x				x
Musculoskeletal						
Anterior Cruciate Ligament Rehabilitation Outcome Registry	ACL Registry	x				x
European Research on Incapacitating Disease and Social Support Study	EURIDISS	x				x
Swedish Knee Arthroplasty Register		x	x			
Uniform Data System for Medical Rehabilitation Database	UDSMR					x
Neurological						
Asklepios Hamburg Multicenter Early Stroke Rehabilitation Registry		x				x
Cognitive Rehabilitation Research Group Stroke Registry in St. Louis	CRRGSR					
Collaborative Evaluation of Rehabilitation in Stroke across Europe	CERISE					
Coma Outcome of Early Rehabilitation Patients - Registry	KOPF-Register					
Federal Interagency Traumatic Brain Injury Research	FITBIR	x				x
Ischemic Stroke in Neurologic Rehabilitation Registry	INSIGHT	x				x
Korean Brain Rehabilitation Registry	KBRR	x	x		x	x
Multiple Sclerosis Rehabilitation Repository	MSRehabrep					
National Rehabilitation Reporting System	NRS	x	x	x	x	x

(To be continued)

TABLE II.—*Variables reported by clinical registries (continues).*

Name of the registry	Acronym	Variables				
		User/ person	Provider of services	Interventions	Resource utilization	Outcomes
National Spinal Cord Injury Statistical Center	NSCISC	x		x	x	x
Online Database System developed by the Korean Society of Neurorehabilitation		x		x	x	x
Post-Stroke Rehabilitation Outcomes Project Database	PSROP			x		x
Rehabilitation and Habilitation Trajectories, Intervention and Services for Preschool Children with Cerebral Palsy	CPHAB					
Retraining Walking Over Ground in a Powered Exoskeleton After Spinal Cord Injury		x				x
Research Unit on Brain Injury Rehabilitation Copenhagen registry	RUBIC Registry					
Spinal Cord Injury Model System	SCIMS	x			x	x
Spinal Cord Injury Rehabilitation	SCIRehab	x		x		x
Swedish National Quality Register for Stroke Care	Riks-Stroke	x				
Thai Stroke Rehabilitation Registry	TSRR	x		x	x	x
Traumatic Brain Injury Model Systems National Database	TBIMS	x			x	x
UK Rehabilitation Outcomes Collaborative National Database	UKROC	x	x			x
Veterans Affairs Polytrauma Rehabilitation Center TBI Model Systems	VA TBIMS	x		x		
Virtual International Stroke Trials Archive	VISTA-rehab	x				x
Zurich Observational Registry of Rehabilitation Outcomes	ZORRO					
Respiratory						
Clinical physiotherapy database for First Contact Physiotherapy	PhysDB-FCP	x		x		x
North Carolina Pulmonary Rehabilitation Outcomes Registry						
Other						
Effect of Disease Level on Outcomes of Supervised Exercise in Intermittent Claudication Registry	ELECT Registry	x		x		x
Inpatient Rehabilitation Facility Compare	IRF Compare					
National Information Service for Allied Health Care	LiPZ	x		x	x	
Ongoing Patient Records	OPR	x		x		x
Outpatient Physiotherapy Department in Singapore						
Private Practice Management Program of The University of Queensland	PPMP					
Rehabilitation Research Center	REVAL					
State Funded Physical Therapy Outcome System	SFPTOS	x		x		x
University Medical Centre Utrecht						

The registries included a median of one (IQR 1-2) type of variables related to rehabilitation interventions, of which 18 (78.3%) registries collected variables related to the frequency or duration of interventions, nine (39.3%) registries collected variables related to the description of interventions delivered to users, five (21.7%) registries collected variables related to the context in which the interventions were carried out (individual, group, outpatient, inpatient, among others), and four (17.4%) registries collected the time delay between referral to the rehabilitation program and the start of the program.

Variables related to resource utilization

Variables collected to characterize resource utilization associated with rehabilitation programs were identified in nine (16.4%) of the 55 available rehabilitation registries (Table II).

The registries included a median of 1.5 (IQR 1-2) types of variables related to resource utilization, of which seven (70%) registries considered variables related to the length of hospital stay, five (50%) registries collected variables related to the system or payer of the rehabilitation service (health insurance), four (40%) registries considered variables related to the management and quality of services following discharge from the rehabilitation program, such as rehospitalization, need for specific drugs, or need to consult a health center.

Outcomes related to people's functioning

Data collected to assess outcomes derived from implementing rehabilitation programs were identified in 39 (70.9%) of the 55 available rehabilitation registries.

The registries included a median of 3 (IQR 2-5) assessment instruments designed to assess the impact of different rehabilitation programs. In total, 137 different assessment scales or instruments were identified. The most used

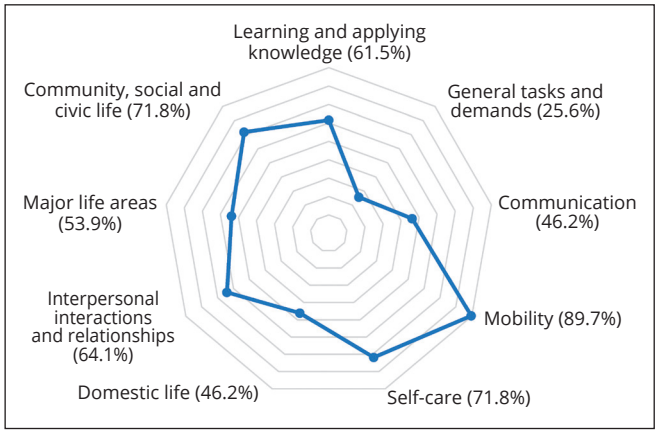

Figure 3.—Percentages of the rehabilitation registries that valued directly or indirectly the ICF's vital areas (tasks or actions).

were the Functional Independence Measure (FIM) scale (7.3%), 6-minute Walk Test (6MWT) (4.4%), Barthel Index (BI) scale (4.4%), Cardiopulmonary Exercise Test (2.9%) and the Disability Rating Scale (DRS) (2.9%). A single rehabilitation registry used 82.5% of the assessment instruments or scales (Supplementary Digital Material 4: Supplementary Figure 1).

Regarding the vital areas (tasks or actions) according to the ICF to assess people's performance and capacity, and considering all the assessment instruments included by each specific registry, each rehabilitation registry directly or indirectly assessed six domains (IQR 2-8), and only six (15.4%) registries assessed all domains, considering that 13 assessment instruments did not assess any of these domains. The most assessed domain was "Mobility" (89.7%), and the least assessed domain was "General Tasks and Demands" (25.6%) (Figure 3, with details in Supplementary Digital Material 5: Supplementary Table IV).

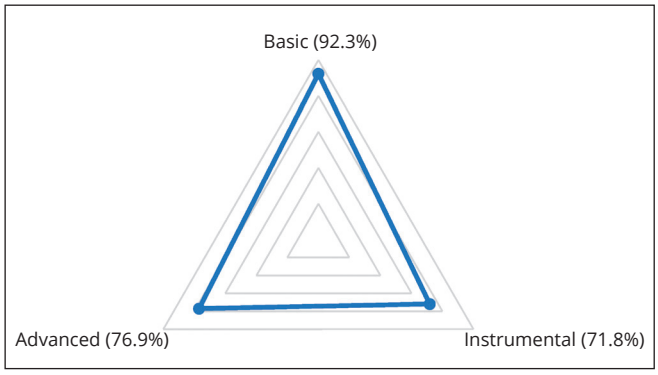

Figure 4.—Percentages of the rehabilitation registries that assessed directly or indirectly the activities of daily living.

Considering the proposed classification of basic, instrumental, and advanced ADLs, only one (2.6%) registry did not assess any type of ADL. Of the remaining 38 rehabilitation registries that assessed at least one type of ADL, 36 (92.3%) assessed basic ADLs, 30 (76.9%) assessed advanced ADLs, and 28 (71.8%) assessed instrumental ADLs (Figure 4, with details in Supplementary Digital Material 6: Supplementary Table V). Furthermore, considering the 137 different assessment instruments or tests, 77 (56.2%) assessed basic ADLs, 55 (40.1%) advanced ADLs, and 91 (66.4%) instrumental ADLs (Supplementary Digital Material 7: Supplementary Table VI).

Discussion

This systematic scoping review was conducted to systematize information from different registry systems implemented to collect information from rehabilitation programs developed in different parts of the world, emphasizing the variables, scales, instruments, or evaluation tests aimed at assessing the impact of such programs on persons. These variables could be identified in 39 of the 71 registries included. Most of the registries were implemented in the adult population and considered neurological or cardiac pathologies, or two or more health conditions simultaneously.

Fifty percent of the rehabilitation registries included 3 or more assessment instruments to evaluate the condition of individuals at the time of discharge from their programs. Despite this, a smaller proportion of registries directly or indirectly assessed all domains of life areas (tasks or actions) used to rate activities and participation in assessing people's functioning and disability according to the ICF framework.[25] Fifty percent of the registries assessed at most 6 of these domains, with mobility being the most rated life area. This phenomenon can be understood from the perspective that several of the assessment tools used by the different rehabilitation registries were developed several decades before the ICF framework was established,[25] and that a significant proportion of the registries identified by this review are pathology-specific. It is therefore logical that, for example, cardiac rehabilitation registries[31] use tests or assessment instruments that assess the level of physical activity and functional exercise capacity as outcome measures,[33, 34] variables that relate most closely to the "Mobility" domain of the ICF framework.[25] In contrast, rehabilitation registries specific to neurological pathologies have a more holistic approach, including assessment instruments that directly or indirectly assess domains related to life in society.

On the other hand, this scoping review showed that almost all rehabilitation registries assessed basic ADLs, with a low percentage not considering advanced and instrumental ADLs. This finding should be considered and replicated in new registries that may be in the planning phase. Furthermore, the evaluation of different health policies, including rehabilitation programs regardless of their objectives or scope, should consider evaluating their impact through direct variables and direct variables but also broaden their scope to assess people's functioning.[35] This should be linked to the creation of information systems or registries,[36] an essential part that would allow improvements at the clinical and management level, and their corresponding evaluation.[37, 38]

The findings of this review highlight the need to improve the design of clinical registries focused on assessing the impact of rehabilitation programs to assess people in all areas of their lives. One of the measures that could improve the representativeness of the vital areas considered by the ICF framework in clinical registries aimed at measuring the impact of rehabilitation programs is that all stakeholders, especially rehabilitation professionals, and the end-users themselves, are considered during their design.

These rehabilitation registry systems should be feasible to implement from the point of view of human and technological resources,[39, 40] and include a limited number of validated assessment instruments.[41, 42] The registries should consider the assessment not only of basic and instrumental ADLs,[43] but also advanced ADLs,[44] which would make it possible to account for all domains of the ICF, and thus comprehensively assess people's functioning, understanding them not as isolated beings but as social beings who need to interact with other people and with their environment.

Strengths and limitations of the study

This systematic scoping review had the strength of using a sensitive search strategy that was applied in the primary biomedical databases, which was not limited by the methodological design or publication date of the studies, and which was complemented by a search of grey literature. In addition, screening by title and abstract of the studies was performed independently and blinded by two reviewers.

One of the limitations of this review was the impossibility of identifying the variables included in all the rehabilitation registries because they were not accessible. However, the fact that we were able to extract information from approximately 80% of the identified registries could be considered a representative sample. On the other hand, it should be considered that the variables identified were extracted both from the registries' web pages and published reports in the form of periodical reports or scientific studies, so not necessarily all the data or variables collected by the registries were rescued. However, it is unlikely that the published reports do not report outcome variables, the focus of this review, since these are the ones that allow us to assess the impact of rehabilitation programs.

Something that could be identified as a limitation is the grouping of ADLs based on the ICF domains, since these domains can undoubtedly respond to more than one ADL; however, they were used in this way for practical purposes.

Future research

Considering the findings of this systematic scoping review as a starting point, different governmental organizations related to health care and rehabilitation could implement strategies and research studies to determine the minimum data set that assesses people's functioning or capacity according to each country's health model. It would be advisable for various actors to take part in this initiative, from health managers through rehabilitation-related clinical and administrative professionals to healthcare system users.

Conclusions

This systematic scoping review identified 71 rehabilitation registries implemented chiefly in the adult population with neurological and cardiac pathologies and without distinction by health condition. Although clinical registries do not claim to directly assess the impact of rehabilitation programs on people's functioning according to the ICF framework, it was identified that a low percentage of them assessed the nine vital areas through different outcome assessment instruments. In addition, most rehabilitation registries directly or indirectly assess some basic, instrumental, and advanced ADLs.

The findings of this review highlight the need to improve the design of clinical registries focused on assessing the impact of rehabilitation programs to assess people in all areas of their lives.

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Conflicts of interest
Ximena Neculhueque-Zapata, Raúl Valenzuela-Suazo, and Camilo Águila-Villanueva are workers of the Ministry of Health of Chile; however, they did not work directly in the selection of studies and data analysis. The remaining authors declare that the research was conducted without any commercial or financial relationships that could be construed as a potential conflict of interest.

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Authors' contributions
Ruvistay Gutierrez-Arias, Ximena Neculhueque-Zapata, Raúl Valenzuela-Suazo, Maria-José Oliveras and Pamela Seron have given substantial contributions to the conception or the design of the manuscript, Ruvistay Gutierrez-Arias, Camilo Morales, Luis Vásquez, Yorschua Jalil, Gabriel Nasri Marzuca-Nassr, Jacqueline Loreto Inostroza Quiroz, Rocío Fuentes-Aspe, Ricardo Solano, Gabriel Salgado-Maldonado, Raúl Aguilera-Eguía and Carolina Garcés-Burgos to acquisition, analysis and interpretation of the data. Ruvistay Gutierrez-Arias participated in drafting the manuscript, Ximena Neculhueque-Zapata, Raúl Valenzuela-Suazo, Maria-José Oliveros, and Pamela Seron revised it critically. All authors read and approved the final version of the manuscript.

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