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A data set for the design and implementation of the upper limb disability registry

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Abstract:

BACKGROUND: If the data elements needed for patient registries are not identified, designing and implementing them can be very challenging. Identifying and introducing a Data Set (DS) can help solve this challenge. The aim of this study was to identify and present a DS for the design and implementation of the upper limb disability registry.

MATERIALS AND METHODS: This cross-sectional study was conducted in two phases. In the first phase, to identify the administrative and clinical data elements required for registry, a comprehensive study was conducted in PubMed, Web of Science, and Scopus databases. Then, the necessary data elements were extracted from the studies and a questionnaire was designed based on them. In the second phase, in order to confirm the DS, the questionnaire was distributed to 20 orthopedic, physical medicine and rehabilitation physicians and physiotherapists during a two-round Delphi. In order to analyze the data, the frequency and mean score of each data element were calculated. Data elements that received an agreement more than 75% in the first or two-round Delphi were considered for the final DS.

RESULTS: A total of 81 data elements in five categories of "demographic data", "clinical presentation", "past medical history", "psychological issues", and "pharmacological and non-pharmacological treatments" were extracted from the studies. Finally, 78 data elements were approved by experts as essential data elements for designing a patient registry for upper limb disabilities.

CONCLUSION: In this study, the data elements necessary for the design and implementation of the upper limb disability registry were suggested. This DS can help registry designers and health data administrators know what data needs to be included in the registry system in order to have a successful design and implementation. Moreover, this standardized DS can be effective for integrating and improving the information management of people with upper limb disabilities and used to accurately gather the upper limb disabilities data for research and policymaking purposes.

Keywords:

Data set, disabilities, registries, upper extremity

Introduction

Upper limb conditions are very common in the general population and are often associated with disability and pain. Upper limb disabilities have a greater impact on disability and limitations in normal activities than other parts of the body.[1] Also, people with upper limb disabilities can experience challenges such as paralysis, loss of sensation, pain, and spasticity in the hands, arms, and shoulders. Therefore, treatment of these patients is a basic need.[2] One way to help better treat patients with upper limb disabilities is for therapists to have access to their data and information.[3]

Registries can be described as a longitudinal, systematic, and accurate collection of

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real-world data that describes health status and medical interventions in a given population of individuals. Registries allow the collection of real-world data on the clinical course of diseases and their impact on patients and healthcare providers.[4] Bae *et al*.,[5] by examining the registry of congenital malformations and disorders of the upper extremities, showed that the data recorded in these registries help to further investigate the impact of congenital malformations of the upper extremities on society. In another study, Bae *et al*.,[6] noted that through continuous recording and longitudinal follow-up, registries can increase understanding of upper limb functions and the psychosocial aspects of children's health. Also, these powerful tools can be used to understand variations in treatment and outcomes, study the course of the disease, understand changes in treatment and outcomes, examine factors affecting prognosis and quality of life, and describe care patterns including: care appropriateness and inequalities in providing medical services, evaluating effectiveness, monitoring safety and injury, and assessing the quality of care.[7]

Properly designed and executed disease registries can provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness.[7] In order for us to successfully design a registry to collect accurate data, we must first identify its Data Set (DS). Using DS as a standard tool for collecting integrated, accurate, and standard data is very helpful.[8] DS is used in a disease registry to access reliable and comparable information about the number of patients, treatment methods and outcomes of the provided health services relating to a specific disease.[9] DSs can also be used as a tool to record the most relevant and up-to-date health facts and provide timely decision-making for administrators by supplying a minimum level of variables related to the health condition of the individual including clinical, demographic, financial data.[10] While there is a growing interest in different countries to adopt a DS, no research has been undertaken so far in order to identify a DS for the design and implementation of the upper limb disability registry. To our knowledge, this study is the first study in which a DS for the design and implementation of the upper limb disability registry has been identified and presented. Only two studies by Bae *et al*.[5,6] were related to upper limb disability registries. These two studies also used registries to examine the effect of using Oberg-Manske-Tonkin (OMT) on recording congenital upper limb differences and assessing the functional, emotional, and social effects of congenital hand differences in children, respectively; however, no DSs were introduced and presented in these two studies. Therefore, the purpose of this study was to provide a DS for the design and implementation of an upper limb disability registry.

Materials and Methods

Study design and setting

This cross-sectional study was conducted in the two phases: Identify the data elements needed to design an upper limb disability registry and final approval of data elements using a Delphi study. These two phases are described in Figure 1.

Phase 1: Identify the data elements needed to design an upper limb disability registry

Search strategy

At this phase, we first reviewed the literature to identify the necessary data elements related to upper limb disability and registries on November 11, 2020, from three databases: PubMed, Web of Science, and Scopus. To retrieve related articles, we searched title and abstract of articles using following keywords and search strategy: ((upper extremity disability OR upper limb disability) AND (registries OR registry OR clinical registry OR patient registry OR disease registry population OR Register OR Minimum Data Set OR MDS OR data Set OR database)).

Inclusion and exclusion criteria

Inclusion criteria included publication of the article in English, access to the full text of the articles, mention of data elements and clinical and managerial parameters related to the upper limb disabilities in the articles.

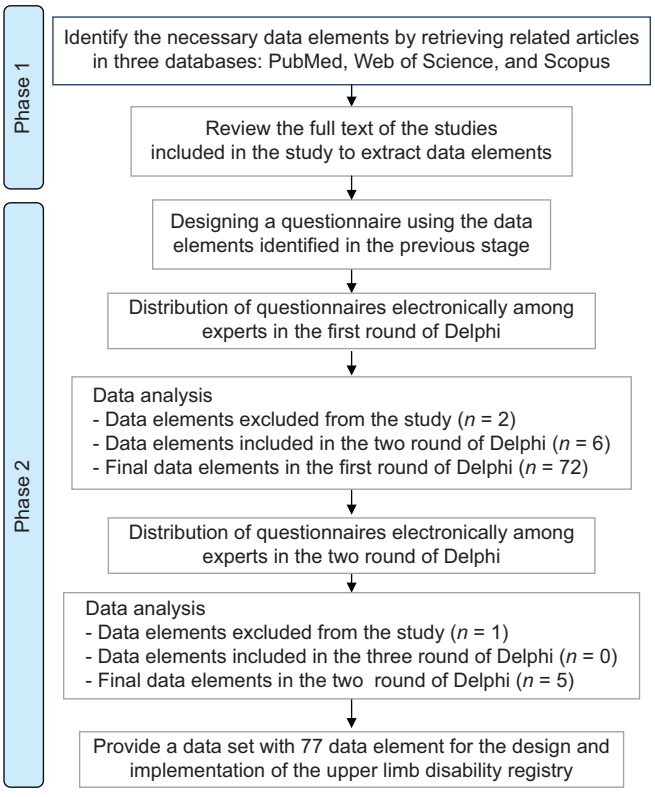

Figure 1: Study diagram

Exclusion criteria also included articles addressing other aspects of upper limb disabilities and failure to provide clear information on the clinical and managerial parameters of upper limb disabilities. Books and book chapters, letters to the editor, and abstracts of the conferences were excluded.

Selection and classification of articles

A total of 779 articles were extracted from the three databases. After removing duplicate articles (n = 174), the title and abstract of the articles were studied by one of the researchers (KhM and KB). Then, according to the inclusion and exclusion criteria, articles were included in the study. The articles included in the study were reviewed and approved by three researchers (KB, MSH, and ASh). Then, to extract the required data elements, the full text of these articles were studied (KhM and ASh). Finally, the extracted data elements were reviewed and finalized by three other researchers (ASh, KB, and AAH). At this stage, data collection was done with a data extraction form. This form included fields such as data element and reference.

Phase 2: Final approval of data elements using a Delphi study

Study participants and sampling

The study population included Orthopedists and physical medicine and rehabilitation specialists and Physiotherapists working in educational and medical centers affiliated to Kerman University of Medical Sciences (KUMS). Since in most Delphi studies the number of experts has been usually 15 to 20, 20 specialists and subspecialists in physical medicine and rehabilitation, orthopedists and physiotherapists were selected to participate in the study.[11] The following inclusion criteria were used to select participants:

- Employment of participants in educational and medical centers affiliated to KUMS
- Have a history of activity in the treatment or rehabilitation of upper limb disabilities for more than five years.

Data collection tool and technique

At this phase, the data collection tool was a questionnaire. This questionnaire was designed using the data elements identified in the previous stage. The designed questionnaire consisted of two parts: the first part included demographic information of experts and the second part included 98 questions related to data elements necessary to design the DS. These data elements were divided into five main categories: "demographic data", "clinical presentation", "past medical history", "psychological issues" and "pharmacological and non-pharmacological treatments". Also, to identify other data elements that were not listed in the questionnaire, an open-ended question was added at the end of the questionnaire.

A number between one and five was considered for scoring each data element. The face and content validity of the questionnaire was confirmed according to the opinions of medical informatics experts (two people), physical medicine and rehabilitation (one person), physiotherapist (one person), and a health information management expert. Based on the comments received, some synonymous and unrelated data elements were removed from the questionnaire and finally 80 data elements were approved for the questionnaire (18 data elements were removed).

The questionnaire was designed electronically. In the first round of Delphi, a questionnaire link was sent to the experts on October 10, 2021. By October 30, all questionnaires were completed. After collecting the questionnaires, the data were entered in SPSS 23.0, and then the frequency and mean score of each data element were calculated and analyzed. In order to decide on each data element in the first round of Delphi, an agreement level was considered. Data elements with an agreement of less than 50% (mean less than 2.5) were excluded, data elements with an agreement of 50 to 75% (mean 2.5 to 3.75) were re-assessed in the second round of Delphi, and data elements with an agreement of more than 75% (mean more than 3.75) (no need to re-measure in the second round of Delphi) were considered as the final data elements.[12,13] The second round Delphi questionnaire included data elements with an agreement of 50 to 75% (mean 2.5 to 3.75). One month after the first round of Delphi, that is, on November 10, 2021 the link to this questionnaire was sent to the same first-round Delphi participants. In the second round, after analyzing the data elements, only data elements that scored more than 75% (mean more than 3.75) were considered as data elements needed to design the registry of upper limb disabilities, data elements with an agreement below 50 were excluded, and data elements with an agreement of 50 to 75% were included into three-round Delphi. The process of including data elements into different Delphi rounds was repeated until all data elements agreement less than 50% or more than 75%.[12]

Ethical considerations

The protocol of this study was approved by research ethical committee of Kerman University of Medical Sciences (IR.KMU.REC.1400.606). The physiotherapists and physician's participation in the first and second round of Delphi was also completely voluntarily, and they had the chance to leave the study at any time without any consequences.

Results

Phase 1: To identify the data elements needed to design an upper limb disability registry

In accordance with the inclusion and exclusion criteria and after reviewing the articles, finally 64 articles were included in the study.[14-76] Eighty-two data elements extracted from these articles.

Phase 2: Final approval of data elements using a Delphi study

The frequency of men (80%) was higher than women. Most participants (45%) were between 35 and 44 years old. Most of these participants had between 5 and 15 years of service [Table 1].

The 82 data elements were divided into five categories: demographic data, past medical history, current history, psychological issues, and pharmacological and non-pharmacological treatments [Table 2]. Of the 81 data elements identified, 78 data elements were finally validated by experts as essential data elements for designing and presenting the upper limb disability registry DS in two Delphi rounds. In the first round of Delphi, the two data elements "father's name" and "income" were excluded from the study (agreement of less than 50%). Also, in the second round of Delphi, the "phone number" data element was removed.

As shown in Table 2, out of five categories, four categories of past medical history, clinical presentation, psychological issues, and pharmacological and non-pharmacological treatments, all their data elements were approved in the first round of Delphi.

Table 1: Participants' demographics

Variables	Frequency (%)
Sex	
Male	16 (80)
Female	4 (20)
Age	
25-34	7 (35)
35-44	9 (45)
45-54	3 (15.0)
>54	1 (5)
Education level	
Bachelor	3 (15)
Master	4 (20)
PhD	3 (15)
Specialists	8 (40)
Subspecialists	2 (10)
Type of medical specialties	
Physiotherapists	10 (50)
Orthopedists	6 (30)
Physical medicine and rehabilitation	4 (20)
Years of service (Year)	
5-15	9 (45)
16-25	7 (35)
>25	4 (20)

Six data elements: "date of birth" (3.45 (±1.27)), "marital status" (3.20 (±1.24)), "education level" (3.60 (1.04)), "place of residence" (3.30 (±0.92)), "phone number" (3.60 (±1.23)) and "body mass index" (3.70 (±1.12)) included the second round of Delphi with an agreement of 50 to 75. All accepted or rejected data elements in the first and second rounds of Delphi with standard deviation and mean score are shown in Tables 3 and 4.

As shown in Table 4, five data elements: "date of birth" (4.25 (±0.91)), "marital status" (4.02 (±1.03)), "literacy level" (4.05 (±1.05)), "occupation" (3.95 (±0.88)) and "Body mass index (BMI)" (4.45 (±0.68)) were confirmed in the second round. "Phone number" (2.20 (±1.11)) was excluded during this round.

Discussion

In this study, a DS was designed for a patient registry of upper limb disabilities. 82 data elements were identified in five categories: demographic data, past medical history, clinical presentation, psychological issues, and pharmacological and non-pharmacological treatments. Of the 82 data elements identified, 77 data elements were eventually approved by experts as the final upper limb disability registry DS.

Record number, national code, first name, last name, year of birth, gender, age, marital status, literacy level, occupation, place of residence, and BMI were data elements confirmed in our study in the category of demographic data. Also in the category of past medical history are data elements such as history of surgery on the upper limb and its anatomical location, upper limb spasticity, contraction of the upper limb joints, cause of upper limb disability, duration of the disability or defect, abnormalities or deformities in the upper limbs, spasticity, and amputation were approved. Biering-Sørensen *et al*.[77] designed a dataset for the International Spinal Cord Injury (SCI) upper limb. Their DS includes data elements such as time since the initial spinal cord lesion, hand-upper limb function, shoulder function classification, SCI-related complications affecting upper limb function like pain, use of assistive devices, spasms, contractures and edema, performed upper limb/hand reconstructive surgery, upper limb/hand reconstructive surgery. Their DS also includes data elements such as date of birth, duration of the injury, gender, the cause of SCI, and neurological status. Biering-Sørensen *et al*.[77] stated that this international upper extremity SCI DS facilitates the collection of standard data and the continuous reporting

Table 2: Clinical and administrative data primary groups for a minimum data set for UP

Category	The number of data elements	First round of Delphi			Second round of Delphi			The final number of data elements
		<50%	50-75%	≥75%	<50%	50-75%	≥75%	
Demographic information	15	2	6	7	1	0	5	12
Past medical history	35	0	0	34	0	0	0	35
Clinical presentation	19	0	0	19	0	0	0	19
Psychological issues	5	0	0	5	0	0	0	5
Pharmacological and non-pharmacological treatments	7	0	0	7	0	0	0	7

of upper extremity outcomes, enables comparison of outcomes, and facilitates SCI research.

"International Spinal Cord Injury Upper Extremity Basic Data Set"[77] and "International Spinal Cord Injury Core Data Set",[78] also emphasize demographic data elements such as date of birth, age, and gender. Studies have shown that demographic data are needed to obtain various information about health outcomes and vital events such as fertility, morbidity, mortality, and migration, and these data elements need to be considered in the design of registries.[79] For example, information about the age of study participants is very important for interpretation of results and comparing results across studies. Gathering date of birth information is the most accurate way to gather and store this information, as it allows easy calculation of age at injury as well as age at any future point in time when data might be collected.[78] Also, since the gender of a study population is important and most of the health consequences relate to it, this data element should always be considered in registries.[78] Richesson *et al*.[80] noted that important data that should be included in the registries for rare diseases and disabilities include genetic factors to establish genotype-phenotype correlations, family history, concomitant medications, and medical or surgical interventions. Lucyk *et al*.,[81] also believed that administrative data is used to monitor population, geographical change, population health, and healthcare planning.

But the clinical data collected by clinical staff relies on diagnosis and treatment and is used to help conduct research, health planning and policymaking.[82] These data are also essential for providing quality healthcare, improving healthcare management, reducing healthcare costs, population health management, conducting quality clinical research, and meeting the needs of funders and healthcare managers.[83,84] Considering the clinical data elements related to the patient's medical history such as surgeries, etiology of injury, associated injuries, signs and symptoms, date and place of discharge can accurately record patients' information and thus improve treatment processes for them.[78] For example, information on whether there is a spinal fracture and/or dislocation associated with SCI is important because treatment methods, length of stay, and treatment outcomes are usually related to the presence or absence of a spinal cord injury.[78]

DeVivo *et al*.,[78] also designed and presented an international DS for international spinal cord injury. This dataset contains data elements such as demographic features, dates of admission and discharge from first acute and rehabilitation care, reason of injury, place of discharge, existence of vertebral injuries and associated injuries, occurrence of spinal surgery, and measurements of neurological and was ventilator state.[78] Hughes *et al*.[85] reported the agreement reached on assessment protocols and outcome measures for evaluation of the upper limb in neuro-rehabilitation using technology. In this study, data elements (technology-generated data (e.g., kinematic, kinetic and activity measurements), movement quality, EMG, neuro-physiological measures and neuropsychological measurements and other non-motor areas such as attention, neglect, conflict and reaction time and pain agreement was obtained.

In another study,[86] an international spinal cord injury musculoskeletal basic DS was designed.

In the "International Spinal Cord Injury Pain Basic Data Set", there are data elements such as: any pain during the last seven days, number of various pain problems, description of the three worst pain difficulties, location of pain, mean pain intensity in the last week, types of pain, date of onset, number of days with pain in the last 7, time period of pain, and pain interference.[87] Widerström-Noga *et al*.[87] believed that the pain affects physical, social, and emotional functioning and even sleep, and that considering this data element in the DS is an essential data element. Therefore, it is necessary to include the parameters of pain intensity grading, pain classification and time pattern questions for each specific pain in the DS.[87] None of the datasets examined in these studies[77,78,85-87] focused specifically on the upper extremities. Also, what we observed in these studies, unlike the present study, is that none of these studies focused on psychological issues and patients' pharmacological and non-pharmacological treatments. However, it is important to pay attention to the type of treatment and psychological issues among people with upper limb disabilities, especially when the upper limb

Table 3: Accepted or rejected data elements in the first round of Delphi

Category	Data elements	Mean (SD)	Decision
Demographic data	Record number	4.20 (0.83)	√
	National code	4.30 (0.86)	√
	First name	4.05 (1.05)	√
	Last name	4.05 (1.05)	√
	Date of birth	3.45 (1.27)	*
	Father name	2.00 (1.07)	×
	Gender	3.85 (0.93)	√
	Age	4.25 (0.91)	√
	Income	2.35 (1.04)	×
	Marital status (Single, married, widowed, divorced)	3.20 (1.24)	*
	Literacy level (Illiterate, elementary, cycle, diploma, master diploma, bachelor, master, PhD)	3.60 (1.04)	*
	Occupation (Unemployed, housewife, freelancer, retiree, government employee)	3.79 (1.07)	√
	Place of residence (City, village)	3.30 (0.92)	*
	Phone number	3.60 (1.23)	*
	Body mass index (BMI)	3.70 (1.12)	*
Past medical history	History of underlying diseases (Heart disease, stroke, hypertension, MS, Parkinson's, etc.)	4.30 (0.97)	√
	Consumption of drugs, cigarettes and alcohol	4.00 (0.97)	√
	Hospitalization history	3.95 (0.79)	√
	Duration of hospital stay	3.94 (0.78)	√
	History of surgery on the upper limb	4.45 (0.66)	√
	Anatomical location of the surgery	4.45 (0.68)	√
	Laterality of hand surgery (Left, right hand, or both)	4.55 (0.60)	√
	Cause of upper limb disability (Illness, birth defects, accident, burn, etc.)	4.45 (0.68)	√
	Hand with a disability (Right or left hand or both)	4.25 (0.71)	√
	Upper limb defect level (Shoulder disarticulation, below the elbow, above the elbow, below the wrist, above the wrist)	4.50 (0.51)	√
	Duration of disability and/or upper limb defect	4.15 (0.87)	√
	Abnormalities or deformities in the upper limbs (Polydactyly, syndactyly, reduction defects, clubhand malformations, and syndromes with upper limb anomalies)	4.55 (0.60)	√
	Existence of a mass in the upper limb and its anatomical location	4.15 (0.81)	√
	Motor deficits history	4.35 (0.48)	√
	Amputation in the upper limb	4.35 (0.58)	√
	Amputation level (One finger or more, unilateral, Bilateral, other parts of upper limbs)	4.40 (0.50)	√
	History of hemiparesis	4.20 (0.76)	√
	Hand involved in hemiparesis (Right or left hand or both)	4.25 (0.85)	√
	History of hemiplegia	4.45 (0.60)	√
	Hand involved in hemiplegia (Right or left hand or both)	4.65 (0.48)	√
	History of Shoulder arthroplasty	4.20 (0.89)	√
	Shoulder arthroplasty (Right or left hand, both hands)	4.20 (0.89)	√
	Rotator cuff syndrome	4.10 (0.96)	√
	Hand involved in rotator cuff syndrome (Right or left hand or both)	3.80 (0.89)	√
	Carpal tunnel syndrome (CTS)	4.00 (0.64)	√
	Hand involved in carpal tunnel syndrome (Right or left hand or both)	3.85 (0.74)	√
	History of muscular and neurological diseases (such as Decoron's disease, Epicondilytis, ulnar nerve compression, etc)	4.15 (0.81)	√
	Osteoarthritis of the upper limbs (joints, elbows, wrists and fingers, etc.)	4.40 (0.82)	√
	Upper limb spasticity	4.30 (0.92)	√
	Degenerative arthritis/decreased joint range of motion	4.30 (0.73)	√
	Obstetric brachial plexus	4.40 (0.75)	√
	Upper limb arterial injury	4.35 (0.74)	√
	List of medications (such as analgesics, anticoagulants with vitamin K antagonists, etc.)	3.95 (0.88)	√
	Dominant hand (Right/left/ambidextrous)	3.85 (0.98)	√

Contd...

Table 3: Contd...

Category	Data elements	Mean (SD)	Decision
Clinical presentation	Existence of closed wounds in the upper limb	4.10 (0.64)	√
	Existence of open wounds in the upper limb	4.20 (0.52)	√
	Musculoskeletal pain (Sudden, intermittent, chronic, at rest, at night, in moving, during the care process, etc.)	4.25 (0.85)	√
	Intensity of musculoskeletal pain (Painless, mild pain, moderate pain, severe pain) based on VAS scale	4.25 (0.63)	√
	Anatomical location of pain (Shoulder, shoulder, wrist, elbow, etc.) and number of pain points	4.10 (0.91)	√
	Duration of pain	4.15 (0.81)	√
	Numbness and tingling in the upper limb along with its anatomical location	4.10 (0.64)	√
	Muscle stiffness	4.30 (0.57)	√
	Hand and finger strength (based on Dynamometry scale)	4.15 (0.48)	√
	Inflammation and swelling of the joints	4.15 (0.58)	√
	Tendinosis/impingement	4.30 (0.65)	√
	Vibration in the upper limb	4.10 (1.07)	√
	Contraction of the upper limb joints	4.10 (0.78)	√
	Extent of independence in daily activities (Complete dependence on others, severe dependence on others, moderate dependence, mild and independent dependence or no need for help)	4.30 (0.73)	√
	Range of motion of different parts of the upper limb (based on MMT/ROM)	4.25 (0.78)	√
	Bending of the fingers, elbows and other parts of the upper limbs	4.300.65)	√
	Existence of infection in the upper limb and soft tissue necrosis	4.30 (0.73)	√
	Injuries due to fractures, dislocations, sprains/strains, tears, contusions, nerve damage, joint disorders, tendon injuries, flexors in the upper limb	4.30 (0.65)	√
	Weakness in the upper limb (based on Dynamometry scale)	4.35 (0.58)	√
Psychological issues	Depression related to upper limb disability	3.85 (0.67)	√
	Anxiety and distress related to upper limb disability	3.80 (0.69)	√
	Need for social support	3.90 (0.85)	√
	History of suicide attempt due to a defect in the limb	3.95 (0.88)	√
	Social support at work	3.90 (0.91)	√
Pharmacological and non-pharmacological treatments	Brunnstrom Movement Therapy	3.80 (1.28)	√
	Stage and number of rehabilitation sessions performed	3.85 (1.2)	√
	Upper limb orthosis	3.90 (1.16)	√
	Prescribing of Medication (name of medications, medication ID, type of medications, value, dose, and type of prescription)	3.80 (0.69)	√
	Prescribe therapeutic or rehabilitation exercises	4.10 (718)	√
	Botulinum toxin prescription	3.85 (988)	√
	Prescribe muscle function measurement with EMG	3.95 (1.05)	√

*Note: Assessment in second-round Delphi, ×: Final exclusion and √: Final Acceptance

Table 4: Data elements examined in the second round of Delphi

Category	Data elements	Mean (SD)	Decision
Demographic data	Date of birth	4.25 (0.91)	√
	Marital status (Single, married, widowed, divorced)	4.02 (1.03)	√
	Literacy level (Illiterate, elementary, cycle, diploma, master diploma, bachelor, master, PhD)	4.05 (1.05)	√
	Occupation (Unemployed, housewife, freelancer, retiree, government employee)	3.95 (0.88)	√
	Phone number	2.20 (1.11)	×
	Body mass index (BMI)	4.45 (0.68)	√

*Note: ×: Final exclusion and √: Final Acceptance[13]

is disabled or amputated. Davidson *et al*.[88] described disability and amputation as a catastrophe for adults and their families, which can be associated with low self-esteem, anxiety and depression, impaired quality of life, and limited participation in society. Therefore, considering these types of data elements for registration can help to understand changes in treatment, upper limb function, psychosocial aspects of patients' health, and management decisions.[6,7]

According to the findings of this study and other studies and pharmacological and non-pharmacological

treatments such as rehabilitation[89] and the need for Brunnstrom therapy,[90] upper limb orthotics,[91,92] medication,[93,94] botulinum toxin treatment[95,96] and muscle function measurement with EMG[97] are the basic needs of these patients and should be included in the registry DS. Stewart *et al*.[98] argued that non-pharmacological approaches to treating post-stroke disabilities such as upper extremity disabilities should always be considered, especially for older patients. Because non-pharmacological interventions, such as rehabilitation and occupational therapy techniques, improve the activities of daily living among stroke survivors, they should be considered as essential data elements in the design of registry systems and information about them should be recorded in these systems.[98] In addition to non-pharmacological treatments, data elements related to pharmacological treatments should also be considered in the minimum data set.[99] In our study, these data elements were also included. By considering these data elements in a registry DS, we can increase the effectiveness and quality of care programs, provide an approach to improve the quality of care, and help managers and policymakers make timely and correct decisions.

Limitation and recommendation

This study had some limitations. To our knowledge, no DS has been provided for patients with upper extremity disabilities. Therefore, other studies related to upper limb disabilities were used to gain basic knowledge about DS presented in this study. It is suggested that similar studies be performed in accordance with the clinical needs and facilities of each country. We also used the opinions of experts in a city (Kerman) to confirm the data elements, it is suggested that future studies be conducted on a larger scale. In this study, we also did not use this DS in practice and in the real world. It is suggested that an upper limb registry be designed and implemented based on this DS to evaluate its applicability.

Conclusion

In this study, a DS was designed and presented to design and implement a registry for upper limb disabilities. Using this DS, it is possible to help registry designers and health data managers to know what information needs to be included in the system when designing these systems in order to have a successful design and implementation. Therefore, after creating a registry based on a DS, a reliable source of information can be provided for more detailed research and management decisions.

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Conflicts of interest

There are no conflicts of interest.

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