Original Article

Establishing a minimum data set for Parkinson's (PMDS) in Iran

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Abstract:

BACKGROUND: The minimum data set (MDS) is one of the important steps in the development of health care information systems. According to the Ministry of Health in Iran, a central and national registry along with Parkinson's MDS (PMDS) has not yet existed. So, this research was conducted to establish a PMDS in Iran.

MATERIAL AND METHODS: This study was a descriptive–comparative method, which was done in 2019–2021 in four phases: (1) determining data elements related to Parkinson's disease in Iran and selected countries; (2) extracting and categorizing the data elements; (3) making a PMDS draft; (4) evaluating a draft by Delphi technique. The research population was the MDS in Australia, Canada, the United States of America, and Iran. After extracting the data elements of Parkinson's disease from various resources, the primary draft PMDS was developed. Then, the research group divided it into two categories (administrative and clinical). After that, it was sent to 50 healthcare professionals for validation by the Delphi method.

RESULTS: Following the results of the two rounds of Delphi technique, Finally, PMDS was established including a total of 223 data elements in two categories: administrative and clinical with 72 and 151, respectively. Every category included 10 and 14 subcategories.

CONCLUSION: The first and the most important step for standardization of data collection nationally is creating MDS. Due to the necessity of the existence of PMDS, a complete list of PMDS was established for collecting data on Parkinson's patients.

Keywords:
Information systems, minimum data set, Parkinson, registry

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Introduction

Regarding the change in the population group and its tendency toward aging, It should be planned for appropriate actions to encounter the challenges of this age group in the population.[1] So, planning and making policies is essential to formulate a comprehensive health service for the elderly.[2] One of the most common diseases in the elderly is the Parkinson's disease which the health information system should manage and control through processing, analyzing, and managing. This disease is one of the most commonly destroyed central nervous systems.[3] In 2017, the prevalence of Parkinson's disease in the general population of Iran was 2,000, which increases in people >61 years of age to two per thousand.[4] Accordingly, including the population of 751,496,669 million people in Iran in 2011, it was predicted between 150 and 160,000 patients with Parkinson's.[5] Diseases registration systems are organized systems for collecting, storage, retrieval, analysis, and distribution of information that has a specific condition or condition.[6] Managers and policymakers need comprehensive, adequate, correct, and updated data for planning. Undoubtedly, the minimum data set (MDS) is the first step toward the establishment of a registration and database system to control the disease and identify its root causes.[7] The development of MDS creates a standard method for developing and extracting key

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data to make it easy to understand and allow them to compare.[8,9] This dataset can facilitate the timely possible communication between providers and decision-makers by providing the health status map of the individuals including; demographic, clinical, and administrative. Concerning the aging of the Iranian population, one of the untreated diseases of the elderly is Parkinson's disease, so shortly; we can see the growing trend of Parkinson's disease and its consequences in the country. At present, there are no accurate statistics on the prevalence and incidence of Parkinson's disease, which can be the lack of an information management system that has not been registered and collected. Therefore, due to the necessity of the existence of PMDS, a completed list of PMDS was established for collecting data on Parkinson's patients.

Materials and Methods

Study design and setting
This research project was an applied descriptive–comparative method, which was done in 2019–2021 in four phases:
1. Determining data elements related to Parkinson's in Iran and selected countries,
2. Extracting and categorizing data elements,
3. Making a PMDS pattern draft,
4. Evaluating a draft by the Delphi technique.

Study participants and sampling
The research population was the PMDS in Australia, Canada, the United States of America, and Iran. The source of data was divided into two groups; inside and outside of Iran. The United States, Canada, and Australia as the English-speaking countries with the most clinical, laboratory, and reviewed studies, as well as clinical guidelines for Parkinson's disease in comparison with other countries, were selected.[10] Outside of Iran resources includes: Identifying websites, databases, and Parkinson's registry, whose language was in English, whose information was available, open, or after requesting was provided. Inside Iran resources include neurological clinics, hospitals, and nervous and psychological research centers the country that accept and treat patients with Parkinson's and had the willingness to cooperate and provide information. After extracting data elements of Parkinson's from various resources, the primary draft PMDS was developed. Then, the research group divided it into two categories (administrative and clinical) and made a PMDS draft. The criterion for choosing the classification was to meet the research goal of the Parkinson's registry system. The reliability was confirmed by repeating the same circumstances and conditions in a previous research project.[11-13] The face validity was confirmed by the research group.

Data collection tool and technique
A combination of a questionnaire and a checklist that contains "Informed Consent" was provided. The respondents' sample with specific characters in two groups – clinical and administrative – was selected by snowball sampling. In snowball sampling, first, the research group introduced some respondents, and then respondents were introduced to refer other specialists that were working in these fields. The sampling went on until reaching saturation. The respondents had characteristics as follows; (a) Neurologists who have >5 years of experience in Parkinson's, in hospitals, and clinics. (b) Health Information Management Professionals and Medical Informatics who had >3 years of experience in research. The sum of respondents was 50 specialists, which included; "Health Information Management (# = 28), "Neurology" (# = 12), "Physiotherapy" (# = 7), and "Psychiatry" (# = 3) through the E-poll port online. They filled out the PMDS draft questions by themselves through the Delphi method in two-round. The cut-off-point benchmark for accepting and eliminating the data elements in the PMDS was ≥75%. The benchmark of the cut-off-point for accepting with edit was ≥25%. The benchmark of the cut-off-point for adding new data elements was ≥50%. The final pattern was established by using the Delphi method. To analyze data the Statistical Package for the Social Sciences (SPSS) 17 software was used

Ethical consideration
The data collection was based on "Informed Consent" and "the willingness to cooperate and provide information".

Results

The results of this study regarding participants in the validation stage were as follows: The average age of respondents was 39.8 years (age 27–53) and the average of their work experience was 15.9 years (3–30 years of work experience).

The results showed that in each of the three selected countries, Parkinson's medical records are maintained both manually and electronically. The cumulative number of Parkinson's patients' data elements accordingly administrative and clinical in selected countries and Iran are shown in Table 1. According to the results of this study, the data elements of Parkinson's patients are divided into two categories including administrative and clinical information in the health centers of the United States and Australia. In the health centers, a set of administrative data elements is included in Service provider, demographic information, patient admission number in the institute, patient demographic and husband/wife, patient psychology, counseling, diagnosis and patient procedures, treatment, and

discharge. The clinical data element set includes; symptoms and symptoms observed in the patient, history of illness and treatment, medical history, and patient assessment, history of patient addiction, family history, clinical examinations, patient imaging per month, patient experiments each month, and patient treatment information. Demographic data will be completed before the start of care and for the first time that the person goes to a center, and, of course, if some of the information is changed, the necessary edit will be made in subsequent forms. In the present study, national demographic data with the data in the forms of selected countries have lots of similarities. But in the MDS of these patients in the United States and Australia, in the demographic information section, the place of birth, the province of residence, the location address, postal code, and email are also included. In the forms of Canada, fewer elements in the demographic sector of the patient were remarkable than in other countries. According to resources, the Institute's information section was similar in all studied countries. The only difference is the existence of the Fax # of the institute in the United States of America. Other information is similar in the United States, Australia, and Canada, but in Iran forms, only name of the center is recorded.

In the second round of the Delphi, 21 from 93 administrative elements and 65 from 216 clinical elements were removed due to <75% of the agreement [Tables 2 and 3].

The primary draft of PMDS was evaluated by the four field specialists in neurologist, physiotherapist, psychologist, and health information management [Figure 1].

Discussion

Ojo *et al.* (2020),[14] aimed to study the Nigeria Parkinson's Disease Registry: Process, Profile, and Prospects of a Collaborative Project. Of the 29 of 36 states with the majority of the southern half of sub-Saharan Africa reviewed the National Register of Parkinson's Disease have participated. The purpose of this project was to attract 2000 with Parkinsonism from a total country in Nigeria by 2022, which recorded 578 patients in June 2019. In our presented pattern, Parkinson's disease registration is collected and analyzed patient information from the provinces in Iran at the national level in accordance with MDS Parkinson's, such as in Nigeria.

Kim *et al.* (2018)[15] in their study entitled "Diagnostic Validation for Participants in the Washington State Parkinson Disease Registry" recorded Parkinson's disease considered as an efficient tool for Parkinson's disease research projects in the northwest Pacific. The Washington State Parkinson Disease Registry (WPDR) was created to facilitate recruiting for Parkinson's disease (PD) research studies conducted in the Pacific Northwest. A diagnosis was considered "validated" if the individual met UK Parkinson's Disease Society Brain Bank (UKBB) clinical diagnostic criteria for PD. Our goal was to assess diagnostic accuracy within the WPDR cohort. We randomly selected and attempted to contact 168 of the 1,278 actively enrolled WPDR participants. Data were categorically collected from 106 participants. The diagnostic accuracy was 93.4%, which supports Parkinson's disease registry in Washington as a valid Parkinson's disease tool in the Northwest Pacific region. The MDS feeds registry systems. So, the results of this study can also be used to support and facilitate the duties of the Parkinson's registry in Iran.

Daneault *et al.* (2021),[16] aimed at analyzing the Levodopa Response for Parkinson's patients, the level of motor symptoms in patients with Parkinson's disease was investigated through wearable sensors. Participants were 31 patients with Parkinson's disease, which were selected for a four-day study using a lumbar and wrist sensor to examine waist and wrist movements. Real-time data from the sensors were attached to the Pebble smartwatch and the smartphone were transmitted to a cloud platform through a custom-designed smartphone application. The sensor data could be visualized in real-time by the research staff. After completion of the protocol, the Gene Active data was manually uploaded to the cloud platform. The combined data could then be accessed by researchers to perform analyses to be shared with the research team. A MDS is a tool for finding data from Parkinson's patients.
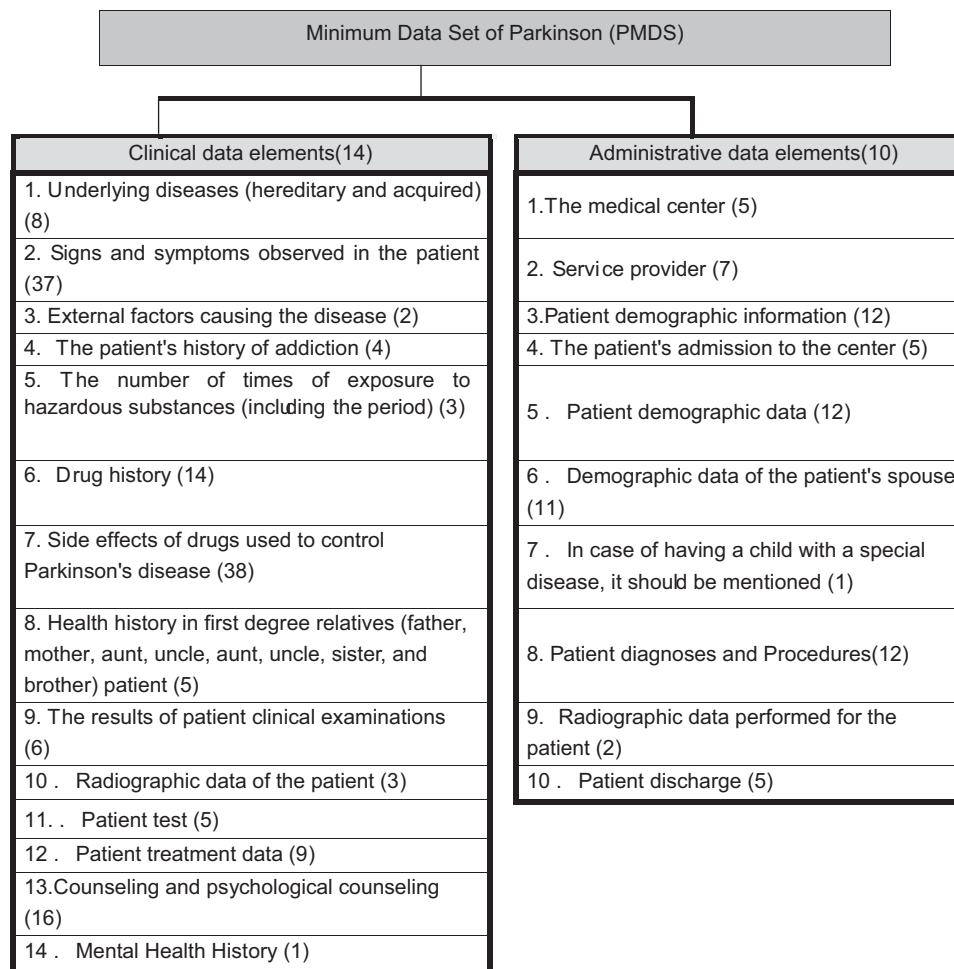
Table 1: Frequency of data elements in cumulative stage, according to countries and categories

Type/country	The United States of America	Australia	Canada	Iran
Administrative	86	71	55	51
Clinical	187	156	135	19
Total data elements	273	227	190	70

Table 2: Frequency and percentage of data elements according to different opinions in Delphi Rounds

Data elements	Accept		Reject		Add		Edit	
	R (1)	R (2)	R (1)	R (2)	R (1)	R (2)	R (1)	R (2)
Administrative	55 (59.14)	72 (93.50)	20 (21.50)	1 (1.29)	6 (6.45)	0	12 (12.90)	0
Clinical	122 (56.48)	151 (92.07)	44 (20.37)	7 (4.26)	12 (5.55)	0	24 (11.11)	0
Total	177 (57.28)	223 (92.53)	64 (20.71)	8 (3.31)	18 (5.82)	0	36 (8.41)	0

Figure 1: Pattern of the Parkinson's MDS (PMDS) for Iran (*The numbers in parenthesis were indicated in the number of a data set)

Table 3: Frequency of data elements in the first and second Delphi rounds

Data elements	Cumulative stage	Round one of the Delphi technique	Round two of the Delphi technique
Administrative	93	73	72
Clinical	216	158	151
Total	309	231	223

Limitation and recommendation

The innovation of this study was the use of online ports to collect data, and the main restriction was the participants' unwillingness to answer the questions due to the Coronavirus crisis.

Conclusion

According to the growing advances in the field of medical sciences and technology, the existence of integrated and comprehensive healthcare information in every local, country, and region is essential. Therefore, establishing valid, correct, and reliable data elements is fundamental to improving the quality of the information in the registry centers. In Iran, many problems such as the lack of comprehensive and integrated registration information of Parkinson's patients have led to consequent incomplete analysis. Implementation of the MDS of these patients can play an important role in improving the health indicators of the community and in creating access to the integrated health record. When an aggregated primary draft was evaluated through the Delphi method, it showed there are some data elements in the PMDS of selected countries that were not required and some need to be added. So, the complete list of the MDS was established after approving the reliability and validity of the content of the data set.

Authors' contribution

Ahmad Chitsaz contributed significantly to the conception and design of the study, and participated in reviewing, revising, and approving the manuscript.

Sima Ajami contributed significantly to the conception and design of the study, conducted the literature review, and participated in drafting, reviewing, revising, and approving the manuscript.

Maryam Varnaseri contributed significantly to the conception and design of the study, conducted the

literature review, and participated in drafting, revising, and approving the manuscript.

All authors approved the final manuscript.

Declaration of patient consent
The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Conflicts of interest
There are no conflicts of interest.

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