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Study protocol for a multi-center, prospective Parkinson's disease registry in Iran

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Movement Disorders; Parkinson Disease; Registration; Methods; Clinical Protocols

Abstract

Background: Parkinson's disease (PD) is a globally prevalent neurodegenerative condition that requires accurate diagnosis and tailored treatments. Despite the rising prevalence of PD in Iran, there has historically been a lack of standardized, multi-center data infrastructure to comprehensively record disease features, progression, and treatment results in this population. To address this gap, we present the Shahid Beheshti Medical University Parkinson's Disease Registry (SBMU-PDR).

Methods: The SBMU-PDR is a multi-center, prospective, observational registry established in 2020, with enrollment ongoing through 2026. The registry is designed to collect and analyze comprehensive data from patients with PD. Standardized forms were used to gather information on demographics, medication history, comorbidities, and the severity of motor and non-motor symptoms at baseline and during six-year follow-up visits. Data integrity and ethical compliance are maintained through specialized committees.

Results: The SBMU-PDR's well-defined protocol ensures consistent data collection, thereby minimizing errors, enhancing data reliability, and facilitating comparison across different registries. With a focus on inclusivity, SBMU-PDR aims to elucidate PD risk factors, demographic characteristics, and clinical profiles among a substantial patient cohort, facilitate early detection, and contribute to improved patient outcomes.

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Measurable outcomes include disease progression, frequency and types of treatment, and cohort-level demographic and risk-factor distributions. The registry's extensive data pool serves as a valuable resource for advancing research initiatives, refining patient care, and contributing to the understanding of PD's intricate nature.

Conclusion: The SBMU-PDR project signifies a paradigm shift in PD registry methodologies, offering a valuable tool for advancing scientific understanding in the realm of movement disorders.

Introduction

Parkinson's disease (PD), a progressively advancing neurodegenerative condition, affects millions globally, emphasizing the crucial need for accurate diagnosis and treatment.[1] The escalating number of patients with PD underscores the significance of tailored approaches to address specific symptoms and disease stages. To meet this need, PD registries have been established worldwide.[2] Such registries facilitate early disease detection, which is a pivotal factor in slowing disease progression and enhancing patient quality of life (QoL) through timely interventions.[3] Beyond providing researchers and scientists with access to a substantial dataset, patient registries contribute to a deeper understanding of the disease, potentially leading to effective treatments. Additionally, these registries empower healthcare providers and policymakers by offering insights into disease prevalence and impact, aiding in strategic planning and resource allocation for improved patient services.[4]

Even with the global expansion of PD registries, there are still large gaps that need to be addressed. Established registries across many European national cohorts have been a valuable source of data on patients with PD; however, most remain centered in high-income nations, leaving low- and middle-income regions significantly underrepresented.[5] This disparity is especially significant because research suggests that the Middle East and North Africa (MENA) have the highest rates of PD and disability worldwide.[6] Furthermore, the ability to pool data or generalize findings of patients with different genetic backgrounds, environmental exposures, and healthcare access patterns is limited by heterogeneity in data collection protocols, inclusion variables, and inconsistent use of validated outcome measures.[7] Iran has a large number of PD cases and an aging population, but it lacks a multi-center, standardized registry system for patients with PD to fill these methodological and geographical deficiencies. To bridge this void, the Shahid Beheshti Medical University Parkinson's Disease Registry (SBMU-PDR) was established. The SBMU-PDR employs a standardized, prospective, multi-center protocol to capture both motor and non-motor symptoms within a population that is ethnically and environmentally distinct.

Established in 2020, SBMU-PDR is dedicated to the systematic collection and analysis of data from individuals diagnosed with PD, as well as their caregivers and families. The registry aims to enhance the understanding of the disease and its impact on patients' lives. To account for the chronic nature of PD and the necessity for long-term monitoring, the SBMU-PDR utilizes a well-defined protocol which ensures consistent data collection, providing insights into disease progression and treatment outcomes over time.[8] This systematic approach aids in identifying changes in the disease and refining treatment strategies accordingly.[4] Standardized protocols across registries minimize errors and enhance data reliability and accuracy, ensuring the registry serves as a central repository for researchers and healthcare professionals.[2] Moreover, standardized protocols enable the comparative analysis of data across different registries, helping researchers identify trends, patterns, and potential risk factors associated with PD.[2] This approach also highlights any gaps or inconsistencies in the data, promoting continuous improvement in registry quality. Standardized and ethical data collection in PD registries benefits the researchers, healthcare professionals, and patients. Patients can trust that their data contribute to improved care and outcomes and address unmet needs or care gaps.[9] This emphasis on a well-defined protocol ultimately leads to enhanced patient outcomes and better care for the PD community.[9]

Establishing protocols is essential for providing researchers with access to a substantial, consistent, and reliable data pool. Such data serve as a cornerstone for studying disease, innovating new treatments, and assessing the effectiveness of existing ones.

The primary objective of this paper is to outline the SBMU-PDR registry's architecture, methodology, and data collection procedures. The registry's specific objectives are to: 1) describe the clinical, demographic, and risk-factor profile of a

sizable, prospectively enrolled Iranian PD cohort; 2) use standardized, validated assessment tools to record the natural history of both motor and non-motor symptoms; 3) assess treatment patterns and their relationship to the progression of symptoms; and 4) establish an infrastructure to facilitate future analytical and interventional research.

Materials and Methods

Study design: The SBMU-PDR is a comprehensive, nationwide, multi-center, prospective, longitudinal, observational, record-based registry designed to recruit and monitor patients with PD over a six-year period starting in 2020. As this is a registry study rather than a hypothesis-testing clinical trial, no formal a priori sample size or power calculation was carried out; instead, enrollment follows a feasibility-based strategy, aiming to include all eligible patients presenting to participating centers during the study period.

The SBMU-PDR utilizes data from multiple centers nationwide to ensure a geographically and demographically varied patient cohort. The registry is positioned to capture previously undocumented regional variability in disease presentation, healthcare access, and treatment patterns by enrolling patients from both high-prevalence metropolitan areas and resource-limited, remote regions. Recruitment is a continuous process; rather than utilizing a fixed enrollment window, the registry operates as an open, rolling-enrollment cohort, with new eligible patients added at each clinical visit to participating centers. In order to support adequate enrollment across geographically dispersed and resource-variable centers, the registry offers standardized training and ongoing supervision to all site-specific data collection personnel. This approach minimizes logistical barriers to participation, especially for patients with mobility limitations or those living in more remote provinces. Rather than a single recruitment drive, enrollment is conducted incrementally throughout the six-year study period (2020–2026). By the conclusion of this period, the registry is expected to include approximately 5000 patients, corresponding to an average annual accrual of roughly 830 participants across the centers. This figure represents approximately 80% of the annual number of patients with PD routinely seen at these centers, supporting the feasibility of the projected cohort size. In keeping with the registry's feasibility-based, open, rolling-enrollment design, this number serves as a pragmatic projection of the expected cohort size rather than a formal sample-size target or a power-based requirement. Enrollment, therefore, remains continuous throughout the study period, with all eligible patients approached for participation upon clinical presentation.

Diagnosis is confirmed by movement disorder specialists. Unless a clinical re-evaluation raises suspicions of a different diagnosis, in which case the patient's diagnostic classification is updated and recorded in the registry record, diagnostic status is not re-adjudicated at each follow-up visit.

Definition and objectives of the registry: The SBMU-PDR is meticulously designed with a structured network of clinicians and researchers. Its primary objective is to elucidate disparities in PD risk, demographic characteristics, and clinical profiles among a substantial cohort of patients with PD. Primary outcomes include disease progression, measured through change in motor severity from baseline to each annual follow-up, and non-motor symptom burden, measured via non-motor aspects of daily living at the same time points. Initially conceptualized as a pilot study, the registry commenced its operations in collaboration with three prominent university hospitals of Shahid Beheshti University of Medical Sciences, Tehran, Iran: Shohada-e-Tajrish, Loghman, and Imam Hossein. Shohada-e-Tajrish Hospital, a prominent referral center for PD and movement disorders, is the main center of the SBMU-PDR, where the registry is based. Upon successful completion of this pilot phase, the initiative underwent a significant expansion, integrating 10 additional private and academic institutions across Iran. Specifically, participating neurologists are currently located in Tehran, Isfahan, Kerman, Ardebil, Semnan, Izeh, Ilam, Rafsanjan, and Zabol cities.

Concurrently, the registry aims to monitor patient progression, assess treatment outcomes, and attract specialized medical professionals to the center. A pivotal aspect of the initiative involves facilitating patient participation in innovative clinical research. Complementing its primary objectives, the SBMU-PDR pursues secondary aims focused on enhancing patient care and advancing scientific understanding. These aims include evaluating treatment efficacy, assessing its impact on patients' QoL, formulating novel treatment protocols, augmenting knowledge regarding preventive strategies, and rigorously analyzing data for quality enhancement and

control. Therefore, secondary outcomes include treatment patterns and motor complications, baseline demographic and risk-factor distributions, and patient risk profiles, while also assessing the feasibility of future embedded studies. Moreover, changes in prescribed regimens are captured longitudinally at each visit, allowing observational tracking of real-world treatment modification over time.

Furthermore, the SBMU-PDR is committed to promoting equitable and superior care for individuals with PD. In alignment with this commitment, the initiative aims to contribute substantively to the formulation of innovative healthcare policies tailored to the unique needs and challenges faced by the PD population.

Structure of the registry: The registry is organized into distinct committees, each with specific roles. The Strategic Committee oversees data registration, confirms PD diagnoses, and supervises all registration steps, including research and educational activities. Monthly meetings with the data registration lead ensure qualitative and quantitative evaluation of registered information. Additionally, this committee reviews and approves or disapproves requests to use registry data for research.

The Scientific Committee, led by the Research Assistant, monitors participating physicians and plays a pivotal role in developing the initial registration protocol and designing questionnaires based on international standards.

To ensure data validity, completeness, and longitudinal consistency, personnel undergo a structured training program comprising both initial instruction and continuous professional supervision—a requirement further intensified by the implementation of the electronic data registration system.

The Executive Committee, comprising physicians, registrars, data collectors, and data entry operators, is responsible for data collection, entry, analysis, and the management of data access requests. Together, these committees uphold the registry's commitment to maintaining data quality and ethical use in research and medical decision-making.

Ethical considerations: The registry operates under an approved consent form sanctioned by the Ministry of Health and Medical Education, with additional approval granted by the Health Research Ethics Committee of Shahid Beheshti University of Medical Sciences in December 2019. Informed verbal consent is systematically obtained from all participants, following a thorough explanation of the registry's purpose, procedures, benefits, and risks, alongside comprehensive information about patient rights and responsibilities. Additionally, volunteers have the option to request and review a copy of the consent form before in-person visit. Only staff members with a personalized, authorized security code who have first identified possibly eligible patients are permitted to approach participants; no patient information is disclosed to unapproved parties. In order to ensure that the recruiting process itself poses no more privacy risk than standard clinical care, all identifying information is coded and stored separately from clinical/research data after enrolment.

Vulnerable population: Patients in advanced stages of PD may present with cognitive impairment, dementia, or communication difficulties, potentially affecting their capacity to provide informed consent. However, their inclusion is scientifically essential to capture the full clinical spectrum of the disease; excluding them would skew the registry toward milder disease and compromise its representative nature. To mitigate risks to this population, a number of precautions are taken. First, verbal consent is obtained from a legally authorized agent following a thorough explanation of the registry in cases where the patient lacks the capacity to give autonomous consent. Second, there is no experimental intervention, randomization, or departure from routine clinical care involved in participation; data collection is restricted to structured interviews and the evaluation of pre-existing clinical data, limiting the participants' physical or psychological stress. Third, rather than requiring in-person attendance, which could be difficult for patients with significant motor disabilities, data collection techniques are made to accommodate patients with motor or communicative impairments. Fourth, before being used in research, all patient data are de-identified and coded, as previously mentioned. Lastly, registry membership is kept completely distinct from a patient's access to treatment because participants and their representatives are free to decline participation or withdraw at any time without affecting their continued clinical care at participating centers.

Population: The registry targets patients diagnosed with PD based on clinical features and

the International Parkinson and Movement Disorder Society (MDS) criteria.[10] Participants are recruited from the neurology clinics affiliated with Shahid Beheshti University of Medical Sciences, as well as from participating partner centres. Additionally, the registry includes individuals receiving Levodopa medication as per national pharmaceutical data.

We included patients who visited movement disorder clinics for routine clinical encounters in order to ensure that all potential cases were recruited. Moreover, patients who had visited participating clinics prior to the registry's launch and for whom valid contact information was available were recruited retrospectively. This allowed for the inclusion of an existing patient base rather than limiting the cohort to new presentations, which accelerated early enrollment during the pilot phase.

Patients with atypical parkinsonian syndromes (e.g., progressive supranuclear palsy, multiple system atrophy) or parkinsonism attributable to secondary causes (e.g., drug-induced parkinsonism, vascular parkinsonism) that did not meet MDS clinical diagnostic criteria for idiopathic PD were excluded from the registry, as well as those who were unable or unwilling to give consent (directly or through a legally designated representative).

Patient recruitment and enrollment workflow for the SBMU-PDR registry is shown in figure 1.

Data collection: The registry process encompasses phone or in-person interviews or an internet-based registration platform. Patient information is recorded by trained personnel across participating clinics using standardized questionnaires developed by the Scientific Committee. To ensure measurement validity, the data collection instruments were designed in accordance with established diagnostic criteria and internationally validated assessment tools.

At the beginning of the project, the PD registration program utilized paper-based questionnaires for data collection. In November 2021, following the design of the PD registration system—a subset of the integrated disease registration system at Shahid Beheshti University of Medical Sciences—the process of registering PD data was transitioned to a digital format. This platform operates on the RABBIT registry system, and data are captured through structured electronic report forms (Supplementary File 1).

The web-based system used in the SBMU-PDR registry protocol ensures efficient and secure data collection, storage, and retrieval. This system allows for real-time monitoring of data entry and remote data entry, reducing the need for in-person visits and increasing the efficiency of the registry. Besides, via a web-based system, all data collected are encrypted and stored on secure servers maintained by Shahid Beheshti University of Medical Sciences, further protecting patient privacy. Additionally, the system enforces consistent coding of mandatory variables across all 13 centers and reduces free-text variability.

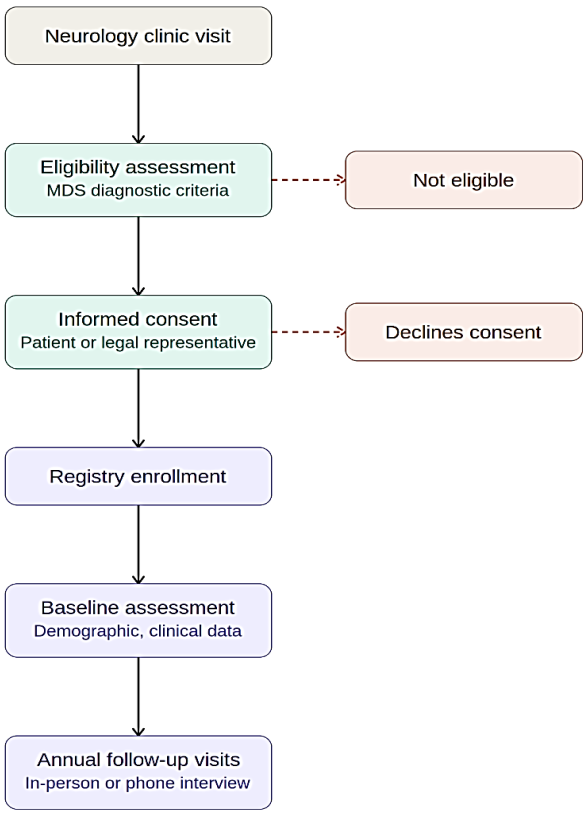


Figure 1. Patient recruitment and enrollment workflow of the Shahid Beheshti Medical University Parkinson's Disease Registry (SBMU-PDR)

Patients who present to participating neurology clinics are evaluated for eligibility based on International Parkinson and Movement Disorder Society (MDS) diagnostic criteria; those who are eligible undergo informed consent (obtained directly or through a legally authorized representative) prior to registry enrollment, baseline assessment, and subsequent annual follow-up.

The web-based system used in the SBMU-PDR registry allows for multiple levels of access, regulated by unique security codes. Accordingly, different levels of access to data are given to people according to the specific roles and responsibilities of each user. By defining a special security code for each person who is responsible for data entry, it is

assured that they can only access and update their own registered data, and therefore, the system streamlines the process and reduces the risk of errors, allowing for efficient and accurate management of the data.

To ensure a comprehensive view of the patient's background and disease progression, the SBMU-PDR registry collects a wide range of information through both mandatory and optional fields. Demographic information includes mandatory variables such as name, date of birth, sex, national ID, ethnicity, occupation, and duration of PD, with optional fields for marital status, educational attainment, contact information, and city of residence. Clinical assessments encompass mandatory medical history (e.g., dominant hand, initial presentation of PD, and the first affected extremity) and optional anthropometric data (weight and height). Habitual history includes mandatory reporting of smoking and coffee consumption, while alcohol and non-cigarette smoking are optional. Furthermore, the registry records detailed medical history, including past neurological and non-neurological diseases, drug history, PD treatment protocols (e.g., exact names of the drugs and advanced therapies including deep brain stimulation (DBS) and apomorphine pump therapy), and history of protective factors and risk factors. Finally, the protocol mandates the recording of PD-specific details, including age of onset, initial symptoms, involved organs, and family history of neurological disease. Furthermore, to evaluate disease state, mandatory assessments include the Hoehn and Yahr staging system, the Unified Parkinson's Disease Rating Scale (UPDRS), and evaluations of motor fluctuations and dyskinesia, with optional inclusion of neuroimaging findings [e.g., magnetic resonance imaging (MRI)]. All of the included variables are summarized in table 1.

Primary outcome variables include disease progression indicators and motor complications. Predictor variables consist of demographic characteristics, disease-related factors, and treatment-related variables. Potential confounders—comprising non-neurological comorbidities, habitual factors, and educational level—are collected at baseline because they may independently influence symptom severity or reporting and can be adjusted for in future analyses. Effect modifiers of particular interest include sex and age of onset, both previously shown in the PD literature to differentially influence symptom profile and disease trajectory, allowing planned subgroup or interaction analyses in downstream studies.

Table 1. Variables collected in the Shahid Beheshti Medical University Parkinson's Disease Registry (SBMU-PDR)

Domain	Variable
Demographics	Age
	Sex
	Education
	Occupation
	Ethnicity
Disease characteristics	Age at onset
	Disease duration
	Initial symptoms
	Disease subtype
Motor assessments	MDS-UPDRS
	Hoehn and Yahr stage
	Dyskinesia assessment
	Motor fluctuations
Imaging data	Brain MRI findings
Treatment data	Pharmacological therapies
	Deep brain stimulation
	Apomorphine pump therapy
Outcome measures	Disease progression
	Mortality

The table summarizes the domains and variables collected at baseline and during annual follow-up. Mandatory variables are those required for registry enrollment or follow-up, whereas optional variables are collected when available.
MDS: International Parkinson and Movement Disorder Society; MRI: Magnetic resonance imaging; UPDRS: Unified Parkinson's Disease Rating Scale

To facilitate longitudinal follow-up, contact information of legally authorized representatives is collected when necessary. After the initial registration, patients undergo annual assessments via interview or telephone to monitor disease progression, with all findings documented in standardized follow-up questionnaires.

The personnel responsible for data entry are granted access to the system using unique security code assigned during initial registration. This ensures that they can only access and update the data that they are responsible for, further protecting patient privacy and the integrity of the data. Moreover, all data collectors and registrars receive standardized initial training in questionnaire administration and diagnostic criteria application.

To ensure data quality, questionnaires are reviewed weekly by supervisors to find missing or inconsistent entries, and monthly reports are submitted to the main director and Scientific

Committee. Every three months, meetings involve registration executives, project partners, and data collection personnel. An annual progress report is submitted to the Disease Registration Committee, and data quality assurance is routinely reviewed by the Scientific Committee, ensuring the integrity of the registration processes and software systems.

Formal inter-rater reliability testing, including appropriate agreement statistics, will be incorporated into future protocol updates to quantitatively evaluate agreement among assessors across participating centers.

Given the long-term, prospective nature of the registry, specific procedures have been developed to handle participant dropout, missed follow-up visits, and protocol deviations. Patients who cannot be reached at a planned annual follow-up are contacted by phone up to two times, using the alternative contact information of legally authorized representatives when available. If contact cannot be established after these attempts, the patient is recorded as "lost to follow-up" in the registry database, with the reason for discontinuation (e.g., death, relocation, withdrawal of consent, or inability to contact) rather than being deleted, protecting the integrity of baseline data for cross-sectional and survival analyses. Consent may be withdrawn at any moment by participants or their representatives; in such circumstances, previously obtained data are kept in de-identified form unless the participant specifically requests removal, in compliance with the registry's ethical clearance. Deviations from protocol, such as missing required fields or discrepancies found during the Scientific Committee's quality assessment, are noted and resolved by contacting the data collector again. Deviations that are persistent or unresolved are reported to the Strategic Committee. This framework guarantees the detection and correction of protocol violations.

In order to prevent the same patient from being registered more than once across participating facilities, the registry system verifies incoming records against the patient's national ID, which is used as a unique identification at the moment of registration.

Anonymity and confidentiality of subjects: Comprehensive guidelines governing the release of information and protocols and ensuring data security and confidentiality have been established for academics and researchers. All patient-related information is securely stored in locked cabinets and protected computer files, with access strictly limited to authorized personnel within specified centres. Each person responsible for data entry has individualized access to the system regulated by the Scientific and Strategic Committees and can only access and update their registered data.

Different pre-defined levels of access, regulated by unique security codes, are granted to physicians and registrars. To safeguard patient privacy for research purposes, all data are collected and coded anonymously. Patient names are excluded from any research data or registry reports, replaced by a unique registry code number in data extract files.

Throughout the registry's implementation, data access is governed by a management flowchart and the confidentiality principles established by the Scientific and Strategic Committees. Requests for registered data—including those for theses and research projects—undergo rigorous scrutiny. Upon submission of a proposal and approval by the Committee, individuals receive only de-identified, coded data limited to the variables required for the approved study. Furthermore, they are bound by a Data Use Agreement prohibiting re-identification attempts or further redistribution, ensuring compliance with the specific needs of the intended study.

The ethical principles of patient information registration, encompassing confidentiality, accessibility, and consent for SBMU-PDR, are conducted in accordance with the guidelines established by the Ethics Committee of Shahid Beheshti University of Medical Sciences.

The Strategic and Scientific Committees of the registry oversee the approval process for all requests to access the SBMU-PDR dataset. There are no limitations on data ownership, access, or sharing imposed by funding sources or collaborating centers; Shahid Beheshti University of Medical Sciences is the only owner of the dataset. Access to registry data is presently unrestricted by contractual agreements with other parties or businesses.

Data will be kept in coded form for long-term epidemiological research throughout the lifetime of the registry's operation. In accordance with the security infrastructure, all data storage is limited to certain research workers at each participating site.

Statistical analyses will be performed using SPSS (version 27, IBM Corporation, Armonk, NY, USA). The registry cohort's baseline clinical, demographic, and risk-factor characteristics will be summarized using descriptive statistics.

Continuous variables will be presented as means and standard deviations (SDs) or medians and interquartile ranges (IQRs), depending on normality of their distribution, while categorical variables will be reported as frequencies and percentages. Time (or disease duration) will be modeled as the primary predictor of interest for longitudinal outcomes (disease progression, non-motor symptom burden). To account for repeated annual measurements and within-subject correlations, mixed-effects models or generalized estimating equations (GEE) will be employed. Patients lost to follow-up will be kept in the analysis dataset using their available baseline and interim data rather than being excluded; missing data will be evaluated using multiple imputation for important analytic variables. Since there are no formal power estimates for these comparisons, subgroup analyses will be pre-specified wherever feasible and considered as exploratory. Given the descriptive nature of the registry, multivariable correction for age and sex will be used to address confounding and lower the risk of overfitting. Those without enough baseline information to verify diagnosis or eligibility will not be included in the analytic population.

Results

The methodology employed in the medical data collection process for PD is comprehensive and systematic. It entails the compilation of information pertaining to both initial and current symptoms, encompassing motor and non-motor manifestations. Additionally, a meticulous record is maintained of medication regimens, potential drug-induced complications, the patient's history of DBS, and familial predisposition to the disease.

Furthermore, patients undergo thorough inquiry regarding their willingness to participate in diverse research studies, ranging from drug trials to genetic research, environmental exposure studies, biomarker investigations, and psychophysical studies. Patient data are extracted from the neurology clinic records at Shahid Beheshti University Hospitals, capturing information on disease progression, response to treatment, and both motor and non-motor features. The records also include research-specific parameters and comprehensive tracking of morbidity and mortality during follow-up.

Data are securely stored within an online system, with access restricted to authorized individuals. This repository of information serves as a valuable resource, facilitating various analyses and contributing to the overarching objectives of enhancing patient care and refining the healthcare system.

Discussion

The SBMU-PDR addresses an important gap in the international PD registry landscape by providing a prospective, multicenter infrastructure in an Iranian population that remains underrepresented in global registry research. Its principal contribution is to identify risk factors, characterize patient cohorts with high precision,[11] serve as a foundation for large-scale research initiatives and epidemiological evaluations, and advance our understanding of this intricate disease.[12] This infrastructure provides an opportunity to generate longitudinal evidence from a population with distinct demographic, environmental, and healthcare characteristics and to facilitate future comparisons with established international registries.

Existing registries demonstrate the value of standardized longitudinal data for studying PD epidemiology, environmental and genetic risk factors, treatment patterns, and disease progression. For example, registry initiatives in France[13] and Thailand[14] have demonstrated the feasibility of large-scale clinical data collection in different healthcare settings, while population-based registries in other countries have supported investigation of genetic susceptibility, environmental exposures, medication use, and clinical outcomes.[2,14-17] However, these experiences cannot necessarily be extrapolated directly to Iran because healthcare infrastructure, demographic characteristics, environmental exposures, and treatment practices differ substantially across regions.

Moreover, regional studies have provided important evidence regarding PD, but their methodological and geographical scope has often limited their ability to provide longitudinal, nationally representative clinical data. In Iran, a large-scale, community-based study of 19500 individuals in Tehran City provided important estimates of probable parkinsonism, but it was primarily designed as a prevalence study based on population screening.[18] Similarly, a community-based study in Assiut, Egypt, provided valuable prevalence and clinical-profile data; however, it was restricted to a single governorate.[19]

In Northern Jordan, a hospital-based research across three major hospitals identified 102 patients and provided useful prevalence and clinical characteristics, but was geographically restricted to one region and had a relatively small cohort size.[20]Furthermore, at the regional level, Global Burden of Disease (GBD) analyses have helped quantify the substantial burden of PD across the MENA;[6] however, these analyses have also highlighted the limited availability of high-quality primary epidemiological data from several countries and the resulting reliance on modeling assumptions.

More recently, the Consortium for Global Diversity in Parkinson ’s Disease (CDG-PD) established a multicenter database involving 20 institutes across nine Middle East, North Africa, and South Asia (MENASA) countries.[21] This represents an important advance toward region-specific PD research. However, its center-based participation and predominantly cross-sectional structure leave opportunities for further development of longitudinal and more broadly representative clinical data. In this regional context, the SBMU-PDR provides a complementary national infrastructure with prospective longitudinal follow-up across geographically diverse centers within Iran. Its standardized collection of demographic characteristics, disease history, motor and non-motor manifestations, treatment exposure, advanced therapies, and annual follow-up outcomes enables questions that cannot be adequately addressed by prevalence surveys, geographically restricted cohorts, or cross-sectional databases alone. The registry, therefore, provides an opportunity to examine disease trajectories over time, while also creating a platform for future research relevant to Iran and potentially other countries with similar healthcare contexts.

The geographic breadth and standardized structure of the SBMU-PDR may improve the diversity of clinical presentations captured by the registry. In addition, the availability of flexible interview and follow-up modalities may facilitate continued participation among patients with substantial motor or communicative limitations. Together, these features may help reduce selective loss of patients with more advanced disease and improve the comprehensiveness of the clinical spectrum represented in longitudinal follow-up.

In the future, the registry's growing longitudinal dataset is anticipated to facilitate cross-registry comparisons, embedded sub-studies on treatment response, and the characterization of motor complication trajectories. Moreover, the SBMU-PDR can be used for computational and predictive modeling approaches to disease progression. The registry would be further positioned as a platform for translational and biomarker-driven PD research with planned protocol expansions.

Limitations: Several limitations of the SBMU-PDR registry should be acknowledged. First, the consistency of clinical evaluations among the participating neurologists in the registry has not been experimentally measured, as formal inter-rater reliability or duplicate-assessment processes have not yet been implemented. Future protocol updates will address this by including formal inter-rater agreement testing [e.g., intraclass correlation coefficients (ICCs) or weighted kappa statistics, as appropriate] for the primary clinical instruments (UPDRS, Hoehn and Yahr staging system) and recurring calibration sessions for evaluating neurologists at participating centers. Second, the registry does not yet include several outcome measures that are pertinent to long-term PD morbidity, such as falls, hospitalizations, and institutionalization, which limits its usefulness for research on these particular outcomes. Third, blinded or quantitative reassessment of imaging changes over time is not possible because MRI data in the registry are restricted to the treating neurologist's clinical interpretation at the time of review rather than stored Digital Imaging and Communications in Medicine (DICOM) images or standardized radiology reports. Future protocol amendments may address this by incorporating archived, de-identified imaging data to enable more methodical longitudinal comparison. Last but not least, the registry does not yet gather laboratory data, which restricts the capacity to connect clinical findings with objective biochemical or biomarker measurements; this is a possible area for future protocol extension.

Conclusion

PD registries represent a crucial cornerstone in our efforts to unravel the ambiguities of this intricate neurodegenerative disorder. The unification of genetic and environmental factors in PD etiology necessitates comprehensive data collection methods, and the evolution from traditional registration approaches to sophisticated computer-based methods signifies a paradigm shift in this domain. As we look to the future, the SBMU-PDR project is a valuable tool for advancing both patient

care and the scientific understanding in the field of movement disorders.

Conflict of Interests

The authors declare no conflict of interest in this study.

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