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CHALLENGES IN PARKINSON'S DISEASE MANAGEMENT IN PRIMARY CARE IN INDONESIA: A NARRATIVE REVIEW

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ABSTRAK

Parkinson's disease (PD) is a rapidly growing neurological disorder with significant health implications, especially in low- and middle-income countries (LMICs) like Indonesia. This review analyzed the challenges and opportunities for managing PD in Indonesian primary care. The prevalence of PD in Indonesia has surged by 143% since 1990, reaching 89.91 per 100,000 people in 2019, which is likely underestimated owing to healthcare system limitations. Primary care is critical for early PD detection, although diagnostic accuracy is a concern. Enhancing the primary care capacity for early identification is essential through specialized training, telemedicine, and PD-specific assessment tools. Continuous monitoring of medication adherence, treatment efficacy, and symptom progression is vital for its effective management. Integrating palliative care principles and supporting caregivers is crucial for providing comprehensive care. This review recommends a structured approach to PD management in Indonesia, incorporating it into chronic disease programs, improving diagnostic tools, and developing caregiver support systems to address the growing PD burden and optimize patient outcomes in resource-limited settings.

Keywords: Parkinson's Disease, Primary Care, Diagnostic Accuracy, Caregiver Support

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INTRODUCTION

Parkinson's disease (PD) is a progressive neurodegenerative disorder affecting movement, balance, and coordination. This condition is defined by the degeneration of dopaminergic neurons in a particular region of the brain known as the substantia nigra

(Kulcsarova et al., 2024). PD is characterized by four cardinal symptoms: tremors, muscular rigidity, bradykinesia (reduced movement speed), and impaired postural stability (Hallett & Hess, 2017). As the condition advances, patients may experience a range of non-motor symptoms including cognitive impairment, mood disorders, disrupted sleep patterns, and autonomic nervous system dysfunction (Carroll et al., 2021). Although PD is mainly a neurological disorder, it can lead to complications affecting other organ systems such as the cardiovascular, gastrointestinal, musculoskeletal, respiratory, and metabolic systems (Armstrong & Okun, 2020). These complications considerably affect the overall health and quality of life of patients with the disease.

PD, a significant global health issue, is the fastest-growing neurological disorder worldwide, accounting for 5.8 million DALYs and 329,000 deaths in 2019, with an 81% increase in DALYs and a doubled mortality rate since 2000 (Schiess et al., 2022). The burden of PD varies among LMICs (Pereira et al., 2024), with a higher prevalence than the global average (Yang et al., 2024). Indonesia lacks comprehensive PD documentation, but 2020 estimates suggest a 0.1-0.2% prevalence, reflecting trends in other LMICs, particularly in Asia (Zhong & Zhu, 2022). PD substantially increases the economic burden on patients and caregivers, with the U.S. burden reaching 51.9 billion USD in 2017 and projected to exceed 79 billion USD by 2037 (Yang et al., 2020). The economic burden in LMICs and Indonesia is under documented, but studies indicate that significant costs increase with rising PD prevalence (Lindvall et al., 2024).

The increasing global disease and economic burden of PD, particularly in LMICs such as Indonesia, poses significant challenges for PD management. The growing economic burden of Parkinson's disease (PD) highlights the urgent need for cost-effective management strategies, particularly in low- and middle-income countries (LMICs) such as Indonesia (Schiess et al., 2022). The complexity of PD management, access to disease-related healthcare, and the evolving nature of the disease may cause pressure on healthcare systems in these regions and increase strain on their resources and infrastructure (Bhidayasiri et al., 2020). Addressing this challenge requires a multifaceted approach, including improved early detection methods, enhanced access to specialized care, and the development of innovative, affordable treatment options tailored to the specific needs of LMIC populations (Makanjuola et al., 2021).

Managing Parkinson's disease (PD) in resource-limited settings requires examining the vital role of primary care in improving patient outcomes. The effectiveness of primary care lies in its accessibility and affordability, which are crucial for long-term conditions, such as PD (Murtagh et al., 2021). It aids PD management through early recognition, referral, treatment monitoring, non-motor symptom management, multidisciplinary care coordination, caregiver support, and palliative care (Sousa et al., 2021). This article reviews PD management challenges in Indonesian primary care, assesses PD's growing burden in Indonesia, explores the role of primary care in PD management, identifies barriers and opportunities for enhancing PD care at the primary level, discusses strategies to improve primary care providers' PD management capacity, and evaluates primary care's potential for cost-effective and accessible PD management in Indonesia.

METHODS

A narrative review was conducted to examine Parkinson's disease (PD) management challenges in Indonesian primary care, leveraging its ability to synthesize

diverse literature. A systematic search using several AI search engines such as R Discovery, Elicit, Sciscpace, and Consensus was conducted using a prompt covering the prevalence of PD in Indonesia and LMICs, primary care's role in early detection, referral, treatment monitoring, care coordination, caregiver support, and palliative care for PD. The search included English and Indonesian articles from to 2014-2024, encompassing original research, systematic reviews, meta-analyses, and pertinent policy documents on PD management in primary care in Indonesia or similar LMICs. Articles focusing solely on advanced hospital care and those irrelevant to Indonesia were excluded.

The articles included in the analysis were carefully assessed, and relevant data were extracted and synthesized. These include information on the prevalence, management strategies, challenges in primary care, and proposed solutions. The data were synthesized to identify common themes, trends, and knowledge gaps. The synthesized data were analyzed to discern the challenges and opportunities in PD management in Indonesian primary care, with a focus on context-specific issues and improvement strategies. This narrative review enables a thorough examination of the complex relationship between PD management and primary care in Indonesia, offering valuable insights for healthcare providers, policymakers, and researchers.

RESULTS

A systematic search on the prevalence of PD in LMICs shows that the prevalence of PD varies greatly among regions, ranging from 49 per 100,000 population in Sub-Saharan to 1081 per 100,000 population in Latin America and the Caribbean. The overall prevalence of PD in LMICs is 516 per 100,000 people. The prevalence of PD increases with age, but there are no sex-based differences. The prevalence of PD increases with GDP per capita and life expectancy (Pereira et al., 2024). In Indonesia, the estimated prevalence of PD was 89.91 per 100,000 population in 2019, which indicated a 143% increase in the prevalence compared to the prevalence in 1990 (Ou et al., 2021).

Findings from the literature search indicate that primary care plays a crucial role in the early detection of PD, as it often serves as the initial point of contact with healthcare systems for the general population, particularly in LMICs (Li & Zheng, 2022). However, the diagnostic accuracy of primary care physicians remains a significant concern, and there is substantial disparity in the diagnostic capabilities of primary care practitioners (Khan et al., 2023). To our knowledge, no study has identified the role of primary care in early PD detection in Indonesia. The management of PD remains under the supervision of secondary care specialists. Patients are mostly referred to secondary care at advanced stages, showing the limited contribution of primary care in PD management (Raisa et al., 2023). The lack of a systematic PD management approach in Indonesia's healthcare system highlights policymakers' perceptions of the importance of PD in relation to other health issues (Kusuma et al., 2019).

Enhancing primary care's ability to identify PD early is a significant breakthrough, especially for LMICs, through the development of PD-specific assessment tools, advanced technologies, and unique biological indicators (Postuma & Berg, 2016). Screening questionnaires such as The CDEPA have shown promising accuracy and feasibility, particularly in resource-limited settings (Martinez-Martin et al., 2018). Technological tools, including wearable sensors, mobile apps, and AI can improve the early detection of PD (Oung et al., 2014). However, ensuring that these technologies are accessible to diverse populations remains challenging. Preliminary findings suggest that biomarkers such as benzoic, palmitic, and oleic acids show promise for PD screening, although further validation is required (Konjevod et al., 2022).

While the management of PD has become the primary responsibility of neurologists in secondary care, continuous monitoring of medication adherence, treatment efficacy, adverse effects, and symptom prognosis is essential to achieve the therapeutic objectives of PD management (Kanellos et al., 2023). Therefore, the role of primary care physicians is fundamental. Various strategies have been developed to enhance the quality of ongoing PD treatment monitoring, with a primary focus on in-home monitoring systems. This emphasis on home-based monitoring has been recognized as a crucial element in the effective management of PD (Orban & Şipoş, 2021). A multidisciplinary healthcare team dedicated to daily patient monitoring has demonstrated efficacy in improving various outcomes of Parkinson's disease (PD) treatment using a chronic care model (Connor et al., 2019). Recently, a technological approach utilizing wearable inertial sensors was implemented to enhance PD management monitoring while minimizing the requirement for the extensive involvement of healthcare personnel (Sica et al., 2021).

Palliative care enhances the quality of life of those facing life-threatening conditions by addressing various issues and extends beyond end-of-life care to manage chronic illnesses such as PD from early stages (Senderovich & Jimenez Lopez, 2021). Integrating palliative care principles enables healthcare providers to offer comprehensive support throughout chronic disease progression and to improve patients' overall quality of life (Tarolli & Holloway, 2020). Primary care, with its close patient relationships, can be the main provider of palliative care for PD through a multidisciplinary team addressing motor and non-motor symptoms to optimize patient quality of life (Kluger et al., 2020). Supporting caregivers is crucial, and primary care providers can establish caregiver support groups and offer necessary services to enhance the quality of PD treatment for both patients and caregivers (Garon et al., 2023). Moreover, end-of-life care, particularly for advanced PD symptoms, such as dementia, should be accessible through primary care to ensure high-quality management (Katz, 2020).

DISCUSSIONS

This review found that the prevalence of PD in LMICs varies significantly among regions. Latin America and the Caribbean had the highest prevalence compared to other regions. The prevalence of PD in Indonesia has increased significantly during the last three decades but is still below the average global prevalence. Primary care plays a crucial role in early PD detection; however, its diagnostic accuracy remains a concern. Enhancing the ability of primary care to identify PD early is essential, especially in resource-limited settings. Strategies include the development of PD-specific assessment tools, advanced technologies, and biomarkers. Continuous monitoring of medication adherence, treatment efficacy, and symptom progression is vital for effective management of PD. Integrating palliative care principles and supporting caregivers is crucial for comprehensive PD care in primary healthcare settings.

The prevalence of PD in LMICs varies considerably among regions. Indonesia has experienced a substantial increase in the prevalence of PD over the past three decades, although the prevalence remains below the global average. Multiple factors, including genetic and environmental factors, influence the prevalence of PD (Ascherio & Schwarzschild, 2016). However, a significant determinant in estimating PD prevalence is the capacity of the national healthcare system to diagnose PD at the earliest possible stage and document findings in the national health information system (Ou et al., 2021). The

prevalence of PD in Indonesia is likely underestimated, considering the lack of capacity of the Indonesian healthcare system currently in PD management (Schröders et al., 2017). Simultaneously, Indonesia also undergoes demographic, epidemiological, and economic transition, which has been associated with the increased prevalence of PD in other countries with better healthcare systems (Ben-Shlomo et al., 2024). The increasing burden of PD poses a significant challenge that should prompt policymakers to establish a more structural approach, as the future burden of PD may place considerable strain on Indonesia's health care infrastructure.

The diagnostic accuracy of PD in primary care remains a major obstacle to the larger contribution of primary care to the management of PD in LMICs and Indonesia. This problem is particularly related to the capacity of health personnel in primary healthcare facilities, which is inadequate for identifying PD at an early stage (Hustad et al., 2018). To address this issue, a specialized training curriculum for primary care physicians can be developed, focusing on recognizing early Parkinson's disease (PD) symptoms and diagnostic criteria, especially in high-risk patients (Plouvier et al., 2016). Implementing telemedicine solutions for real-time consultation may enhance PD diagnostic accuracy in primary care settings. However, establishing a well-organized network of primary and secondary care facilities is crucial for effective implementation (Dröschel et al., 2017). Ongoing medical education and professional development are vital to ensure that primary care providers comply with the latest PD guidelines (Cohen et al., 2023).

Accurate diagnostic tools are crucial for early detection (PD) detection in Indonesia's resource-limited primary care settings. A PD-specific questionnaire is more feasible for large-scale implementation in Indonesia than are wearable sensors or biomarkers. Adopting internationally standardized PD screening questionnaires, such as the PDSQ and PDQ-39, is crucial, as they have been validated in multiple languages and settings in LMICs, suggesting their potential suitability for Indonesia (Nelson et al., 2020). Collaborative studies between neurologist associations and primary care stakeholders are necessary to validate and assess the practicality of these tools (Shalash et al., 2020). To enhance diagnostic accuracy, both conventional and digital platforms, such as mobile or web-based applications, should be made available (Prashanth & Dutta Roy, 2018). This approach should be complemented by integrated information systems to improve the accuracy of the PD-related data in Indonesia.

Continuous monitoring of PD in primary care is essential for the optimal management of PD; however, it is impeded by the inadequacies of infrastructure in Indonesia, particularly regarding the availability of pharmacological treatment and adverse drug effect monitoring at the primary care level (Werdhani, 2019). Modifications to the care model are necessary to enhance continuous monitoring of PD during primary care (Bloem et al., 2020). Policymakers should establish a specific line of care for PD, such as the incorporation of PD into chronic disease programs such as PROLANIS, which would support PD management at the primary level with requisite resources, including regulation, medication, laboratory examination, and referral pathways to secondary and tertiary levels.

Caregiver support, an integral component of Parkinson's disease (PD) management, has received insufficient attention in Indonesia. The assessment of caregiver burden should be incorporated into continuous monitoring of patients at the primary care level (Boone et al., 2021). Access to essential medical services such as mental health support is necessary to alleviate the psychological burden on caregivers (Sturm et al., 2019). The establishment of community-based support groups for PD caregivers, coordinated through primary care, can provide sustainable assistance to caregivers, considering the chronic and progressive nature of PD (Boersma et al., 2017). A more formalized community-based effort to support

PD caregivers, such as the establishment of a patient organization or foundation, can serve as a strategic initiative for long-term advocacy to optimize PD management in Indonesia.

In conclusion, this review highlights the variability in Parkinson's disease (PD) prevalence across low- and middle-income countries, with Indonesia experiencing a notable increase. It emphasizes the role of primary care in early detection and recommends strategies such as specialized training, telemedicine, and PD-specific assessment tools. Continuous monitoring, palliative care integration, and caregiver support are crucial. To improve PD management in Indonesia, policymakers should establish a structured approach that incorporates PD into chronic disease programs, enhances diagnostic tools, and develops community-based support systems.

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