

Conceptualizing a Rehabilitation ‘Model of Care’ for Improving the Quality of Life of People with Parkinson’s in India

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Abstract

Given the rise in the elderly population and predicted increase in age-related diseases like Parkinson’s disease, as well as the treatment gaps in Low-and-Middle-Income Countries (LMICs), there is an urgent need to develop a culturally and socioeconomically viable Parkinson’s model of care that would be multidisciplinary, replicable, affordable, and accessible to those who need it the most. We present here an outline of a rehabilitation model of care, which incorporates a standardized group therapy format, community-based Parkinson’s Support Centers, collaboration with local stakeholders to ensure sustainability, and active engagement of People with Parkinson’s (PwPs) and caregivers (CGs) in rehabilitation programs. This model of care incorporates a unique 16-session multi-disciplinary community rehabilitation module for PwPs and CGs which is evidence-based, easily deliverable by non-medical facilitators, relevant to PwPs and CGs, adaptable to different groups, practical and beneficial, and effective in a group – format. This rehabilitation model of care, encompassing the multidisciplinary rehabilitation module, holds promise for implementation in LMICs due to its dynamic nature, cost-effectiveness, community-based approach and easy adaptability to telehealth platforms. We share our experience of developing the model and outline implications for practice and insights about community rehabilitation work in LMICs.

Keywords: Community rehabilitation, neurorehabilitation, Parkinson’s disease

INTRODUCTION

Parkinson’s Disease (PD) is a common neurodegenerative disease affecting an estimated 10 million people worldwide.^[1] In India, a few area-specific population-based surveys have been conducted showing crude prevalence rates (CPR) of Parkinson’s varying between 6 to 53/10⁵^[2-4] excluding the small and ethnically different Parsi community where CPR was 328/10⁵.^[5] There are specific challenges in health care for the elderly in India, given that eighty percent of elderly Indians live in rural areas, 73% have not received formal education, and 60% live below the poverty line.^[3] PD may be more prevalent in rural (41/10⁵) as compared to urban (14/10⁵) areas.^[4] The lack of awareness about PD amongst the Indian population and the paucity of good screening systems in rural areas indicates a large cohort of the population remains undiagnosed. Thus, the exact incidence and prevalence of PD in India is still undetermined.^[1,6]

Parkinson’s disease is a complex condition requiring the expertise of a multidisciplinary team with the time and resources to educate, comprehensively treat and support not only the People with Parkinson’s (PwPs) but also their caregivers (CGs) and families.^[7] Studies on outpatient multidisciplinary programs have shown improvements in motor function, gait parameters, speech, depression, and health-related quality of life (QoL).^[8] Several evidence-based care models for Parkinson’s have emerged,^[9] however, these have originated primarily from developed, high-income countries, and there is limited guidance on how these models can be implemented in Low-and-Middle-Income Countries (LMICs). In most LMICs,

national policies and funding are largely directed toward infectious diseases, maternal and child health, malnutrition and the likes, and neurological disorders especially those associated with the elderly, like Parkinson’s, are consistently neglected.^[10,11] Government expenditure on health is inadequate in most developing countries, with PwPs relying heavily on out-of-pocket expenses even for basic healthcare.^[12] Most people in LMICs have no access to multidisciplinary services firstly due to their limited availability and secondly due to the high cost of the limited available services; this is even more pronounced in small towns, rural and tribal areas where, in addition to this, there is very little health-related awareness.^[13]

India is a challenging country for widescale health programs owing to its large population, diverse cultures, low literacy levels, poor access, and affordability of healthcare especially in smaller

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Submitted: 27-Apr-2023 **Revised:** 31-May-2023 **Accepted:** 17-Jun-2023

Published: 28-Jul-2023

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DOI: 10.4103/aian.aian_366_23

towns, rural and tribal areas. Thus, there is an urgent need in India to develop a culturally and socio-economically viable Parkinson's rehabilitation model of care that would be multidisciplinary, replicable, affordable, and accessible to those who need it the most.

What would a model of care look like?/Conceptualizing the model of care

Our conceptualization of the model of care originated from our experience working in a Parkinson's Support Center (PSC) in a suburb in Mumbai, a large urban city in India. The focus of the model was to meet the unmet needs of PwP and their CGs. Through informal engagement and focus group meetings with stakeholders, some key challenges emerged

1. A lack of information about PD which was accessible and easy to understand.
2. Lack of awareness about PD among the general public leading to fear of stigma and a delay in PwP seeking support.
3. Lack of professionals specialized in the management of PD.
4. Lack of affordable and accessible therapy for PD.
5. Lack of a health guide to support PwP and their families during their journey with PD.
6. A feeling of being "alone" due to a diagnosis of PD.
7. Lack of motivation and the skills to manage PD.

Thus, a model of care was developed that focused on overcoming these challenges. The key elements of this model are-

- Health education as a driving force for rehabilitation and therapy.
- Awareness and sensitization programs in communities, schools, colleges, and the corporate sector.
- Capacity building to upskill health professionals and to overcome paucity of specialists in PD care.
- Provision of free multidisciplinary therapy and rehabilitation through a standardized group therapy format, making it efficient and cost-effective for a country with a large population and limited resources. Figure 1 depicts the free-of-charge services provided to PwPs and CGs under this model of care.
- Access to specialist Allied health therapists to discuss changes in their clinical picture during their PD journey and be guided toward the appropriate health professional.
- Ensuring active engagement of the PwPs in their own treatment and developing the CG as a care integrator through education and training.

Provision of free-of-charge services is facilitated by the availability of funding; this was initially through private donors and charitable organizations, but in the past few years, funding from multinational companies as part of their corporate social responsibility has also sustained some projects. The model is focused not only on the needs of PwP and their families living in the community but also in engaging the entire community to participate, support, and sustain a PSC. This can be achieved through collaborations with local NGOs,

government organizations, local funding agencies, and other local healthcare facilities for both human and infrastructure resources as well as funding.

How can we design rehabilitation modules that help to overcome the health services gap?/Developing a multidisciplinary rehabilitation manual

The focus of our model is to provide psychoeducation, multidisciplinary therapy, and support to PwP and their CGs. Given the lack of healthcare professionals and access to rehabilitation services in multiple locations of the country, we attempted to undertake a project to develop and standardize a "community-based multidisciplinary rehabilitation manual" for the rehabilitation of PwP's in India, which could be implemented by non-medical facilitators and could be delivered in a group format.

This project was carried out in two phases:

- Phase 1- Development of the multidisciplinary rehabilitation manual for PwP's
- Phase 2- A pilot research study to evaluate the effectiveness of the multidisciplinary modules.

In Phase 1, a need analysis and consultation with rehabilitation experts in the field indicated that the content for the manual should include education and a multidisciplinary therapy approach to rehabilitation using unstructured interviews. A team of experts in the fields of neurology, physical therapy, occupational therapy, speech-language therapy, diet and nutrition, psychology, and creative therapies provided input from their respective fields. A multidisciplinary team formulated the input into a series of 16 modules [Table 1]. Each module consisted of an initial brief psychoeducation section followed by a therapy section to be delivered by the facilitator and an accompanying patient leaflet with information, exercises, and activities pertaining to the module conducted. Each session lasted for 2 hours and each group has to go through all 16 sessions in order. It was also accompanied by specific instructions for the facilitator along with additional reading references, teaching aids, and materials for activities. It was then piloted in a community group therapy set up, and modified based on feedback from PwPs, CGs, and health professionals.

In phase 2, we evaluated the feasibility and effectiveness of the multidisciplinary modules when delivered to a group of PwPs and CGs by non-medical facilitators with no prior knowledge of the condition. The modules were conducted by psychology students with no prior training in PD and in conducting group therapy. They were provided in-person training by staff and were also provided a booklet of instructions for facilitators. The efficacy of each module was evaluated by two independent research consultants who were senior mental health professionals and subject matter experts, who attended and observed each session and rated it, followed by conducting feedback interviews. A group of 15 PwPs and 12 CGs who were not previously exposed to multidisciplinary therapies for PD participated in this pilot. The three scales used were—The

Services provided free of cost by PDMDS

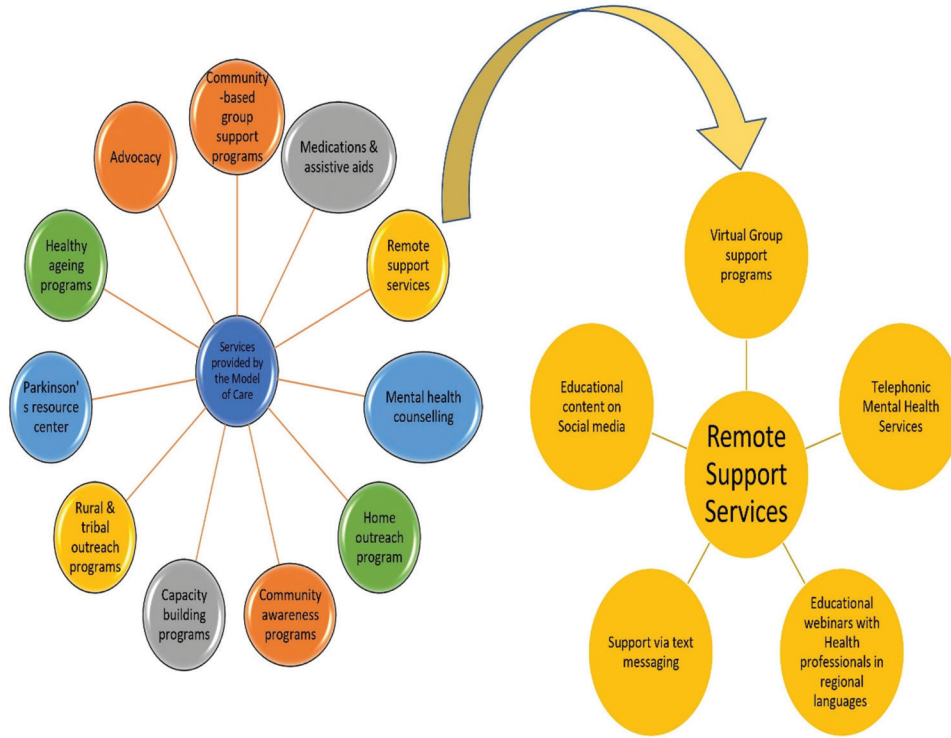


Figure 1: Services provided under the model of care

Parkinson's Disease Questionnaire – 39 (PDQ-39)^[14] and Unified Parkinson's Disease Rating Scale – Activities of Daily Living (UPDRS-ADL)^[15] used to assess PD-related parameters, and the Zarit Burden Interview (ZBI)^[16] for assessing caregiver burden. The scales were administered by the facilitators at intake just before session 1 and in a meeting just after the final session. In addition, different stakeholders provided feedback on the module's effectiveness, concept, design, mode of delivery, relevance, acceptability, and applicability.

Findings of data analyzes related to the three scales are reported in Figure 2. Improvements were seen in PDQ-39 scores post the module and in UPDRS-ADL scores. However, caregivers showed a slight increase in ZBI scores at the end of the study; reasons for the same could not be inferred but need to be explored. Inferential statistics were not conducted, given the limitations of the sample size. Qualitative analysis revealed positive trends in QoL, mobility, regained independence in ADL and skilled tasks, higher self-efficacy, improvement in emotional well-being and social support, and informed decision-making for both the PwPs and the CGs. Details about this pilot study including the evaluative process have also been presented elsewhere.^[17] The modules were then compiled into a final single manual consisting of all the material, tools, and skills required by a non-medical facilitator to deliver the modules. The manual was rated by the external evaluators as clear and novel in content, easily deliverable by non-medical facilitators, comprehensible and relevant to PwPs and CG, adaptable to different groups, interest generating, logical in

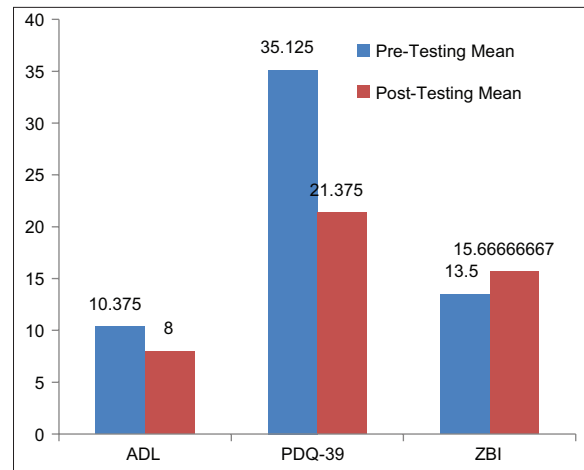


Figure 2: Pre and post-intervention results for multidisciplinary module pilot

flow and sequencing of sessions, practical and beneficial, and effective in a group format.

How can this model be replicated in low-resource settings?/Adapting our model of care to a small town, rural and tribal regions

After the initial pilot conducted in two locations in Mumbai, we used the same manual to train local community workers to replicate the model in multiple PSCs. Currently, the model of care consists of a network of PSCs spread all over India which may have members of varied age groups,

Table 1: Session framework of the Multidisciplinary Module

Session	Psychoeducation	Intervention
1	Introduction ✓ PDMDS; ✓ An Introduction to Parkinson's Disease and its symptoms	Physiotherapy 1 • Benefits of exercise • Precautions to be taken while exercising • General warm-up • Strategy instructions for posture correction, tremors, gait training, turning, and freezing
2	Diagnosis and Treatment ✓ Diagnosis and Course of PD ✓ Multidisciplinary Management of PD	Dance and Movement Therapy • Introduction to dance in therapy • General warm-up • Dance activity 1- self-expression • Dance activity 2- mirroring activity • Dance activity 3- group dance sequence • Cool down and debriefing
3	Problems of Everyday Living & Occupational Therapy Education about kinds of difficulties in Activities of Daily Living, and strategies from OT for- • Writing • Dressing • Eating • Bathing and toileting • Others- using a phone, bed mobility, walking toward a bed, movement in the house, getting into a four wheeler	
4	Motor Symptoms ✓ Motor Symptoms of PD On/Off Period	Physiotherapy 2 • General warm-up • Leg strengthening exercises • Balance exercises • Fall prevention strategies
5	Speech Difficulties ✓ Types of speech difficulties ✓ Causes of speech difficulties	Speech Therapy • An Introduction to Speech Therapy • Importance of posture and breathing in speech and related exercises • Improving the Volume of Voice • Importance of Expression of Voice and Related Exercises • Improving Clarity of Speech • Facial Exercises for Improved Communication
6	Cognitive Problems in PD ✓ Introduction to Cognition ✓ Overview of Cognitive Difficulties in PD ✓ Parkinson's Disease Dementia (PDD)- signs and tips for caregivers	Cognitive Intervention 1 • Categorization – Shopping List Activity • Visualization • Organization – Organizing Living Space
7	Medical and Surgical Treatments for PD ✓ Medicines and Drugs prescribed for PD ✓ Medication Diary ✓ Surgical Treatment Options in PD – Deep Brain Stimulation ✓ Medical PD Treatment in the Future: Stem Cell Therapy Research	Physiotherapy 3 • General Warm-up • Exercises for Trunk • Stretches for Improving Muscle Flexibility • Facial Exercises
8	Importance of Family Awareness about PD	Counselling Intervention for Caregivers • Introductory Session • Activity 1 (Understanding the spectrum of feelings and emotions) • Caregiver Burden- information and tips for coping • Activity 2 (Sharing what we love to love) Art Therapy for PwPs • Benefits of Art Activities • Activity 1 (Copy Drawing) • Activity 2 (My Favorite Things) • Activity 3 (Caregiver Card)
9	Constipation and Urinary Troubles in PD and Diet Intervention • Introduction to Diet and Nutrition • Food groups and the 'Eat Well Plate' • Special Diet Considerations for a Person with Parkinson's Disease • Food – Medicine Interaction	

Contd...

Table 1: Contd...

Session	Psychoeducation	Intervention
	<ul style="list-style-type: none"> • Osteoporosis • Constipation • Managing Weight • Exhaustion, Lack of Appetite, Nausea, Depression • Urinary Troubles • Dehydration • Healthy Eating Habit Tips 	
10	Affective Troubles, Sexual Dysfunction and Counselling Intervention for PwPs <ul style="list-style-type: none"> • Day to day affective/emotional concerns • Management of concerns using strategies from Cognitive Behavioral Interventions • Introspection exercise • Psychoeducation about clinical depression and strategies to cope • Activity- My terrific Timeline (reframing illness narrative) • Psychoeducation about anxiety and strategies to cope • Psychoeducation about impulse control issues and strategies to cope 	
11	Pain and Fatigue in PD <ul style="list-style-type: none"> ➤ Pain: Manifestations, Causes, Types, Dystonias ➤ Muscle Cramps ➤ Fatigue ➤ Morning Stiffness 	Physiotherapy 4 <ul style="list-style-type: none"> • Cognitive Movement Strategies (turning in bed, getting up from bed, sitting in a chair, standing up from the floor after a fall) • Bed exercises
12	Daytime Activities for the Elderly- daily planning	Cognitive Intervention 2 <ul style="list-style-type: none"> • Compensatory strategies for- • Attention and concentration • Problem-solving, planning, and decision-making • Visuo-spatial difficulties • General strategies and devices • Revision and application activity
13	Sleep and Perceptual Disturbances <ul style="list-style-type: none"> ➤ Sleep education ➤ Hallucinations and delusions- psychoeducation and strategies for caregiver 	Sleep Intervention <ul style="list-style-type: none"> • Sleep hygiene • Sleep intervention for specific sleep problems- Initial insomnia, middle insomnia, daytime sleepiness, restlessness or stiffness, breathing difficulties, nightmares, REM sleep behavior disorder • Breathing exercise • Sleep diary
14	Provisions for PwPs <ul style="list-style-type: none"> ➤ Disability certificate and its application ➤ Government benefits and provisions 	Oral Difficulties and Interventions <ul style="list-style-type: none"> • Swallowing difficulties and solutions • Drooling and its management • Dryness of mouth and its management • Music Therapy • Warm-up singing activity • My favorite song
15	Communication <ul style="list-style-type: none"> ➤ Importance of communication ➤ How to improve communication 	Speech Therapy Recap <ul style="list-style-type: none"> • Importance of posture and breathing in speech and related exercises • Improving the volume of voice • Importance of expression of voice and related exercises • Improving clarity of speech • Facial exercises for improved communication
16	Living with PD <ul style="list-style-type: none"> ➤ Personal stigma about PD and how to navigate and challenge it ➤ Misconceptions about PD ➤ How to create awareness about PD 	Physiotherapy Recap Helping you move better-recap of everyday symptom management; prevention, correction, and management strategies

socioeconomic backgrounds, and stages of Parkinson's. A PSC conducts multidisciplinary group therapy sessions for PwP and CGs in the regional language along with the provision of medical aids and assistive devices. The meetings encourage interaction, social engagement, and exchange of information

while also promoting physical, cognitive, recreational, and creative activities. The multidisciplinary rehabilitation manual being utilized in these PSCs enables us to provide a structured program which is evidence-based and delivered in a standardized format.

The expansion to rural and tribal areas, was challenged primarily by poor health awareness, lack of neurologists for diagnosis and medical management, and lack of healthcare professionals for the delivery of the model. The response of the community-based multidisciplinary rehabilitation model of care provided the impetus to expand services even in such low-resource areas. The dynamic and flexible nature of the model has enabled growth through a solutions-based approach and has enabled replication in rural and tribal parts of India.

In order to establish a PSC in these areas, we had to use the following processes:

1. Area mapping to identify accessible locations to conduct the group therapy program.
2. Collaboration with local NGOs, government organizations, village panchayats, and other local healthcare facilities for both human and infrastructure resources as well as funding.
3. Identification of existing healthcare workforce and building capacity to overcome paucity of health workers in the identified area.
4. Training of community health workers to carry out local door-to-door surveys to identify people living with Neurological symptoms in the identified area.
5. Medical camps with Neurologists to diagnose Parkinson's in the cohort of patients identified to have neurological symptoms and provide appropriate medical management.
6. Public awareness strategies and sensitization programs.

Figure 3 describes the steps in building PSCs. Our learnings from this process are that more time and resources are needed when selecting, educating, and training non-medical facilitators in rural and tribal areas. Training is required not only on the delivery of the multidisciplinary modules but also on the administrative aspect of setting up and sustaining a PSC. The actual processes chosen for each PSC and the duration from initial community contact to full running center varies from area to area and depends on factors such as initial receptivity of the community, availability and quality of local

resources, and availability of local funding. Currently, we have around 70 PSCs across the country along with some in South Africa and Kenya.

What could be ways to monitor and evaluate such community-based programs?

To maintain the quality of care at all the PSCs, regular monitoring and evaluation processes need to be in place. The PSC coordinators regularly document patient attendance, session feedback, and awareness and networking activities. These e-documents are available to the liaison officer and the core team members. Feedback sessions and evaluation meetings are conducted monthly for each center, which enables identification of problems at an early stage and serves as a record of challenges, solutions, and successes.

In addition to this, monitoring visits are conducted once or twice a year by senior organizational staff. For this purpose, the organization utilizes an assessment form created in-house, which takes into consideration the observations, complaints, and suggestions of the evaluator, the PSC coordinators, PwPs, and their caregivers. Focus areas are enrollment of new PwPs and engagement parameters, therapy environment, delivery of the module, and PwP needs and satisfaction. Subsequently, modification of the program may be required based on analyzes of the data to ensure the needs of participants are met.

Can such a model of care be adapted to telehealth?/ Adapting to a Hybrid model of care

The emergence of COVID-19, which affected health services and programs all over the world, gave an impetus to modify and adapt the multidisciplinary rehabilitation modules to enable them to be delivered effectively through various virtual communication platforms. This was well received by PwPs and their CGs, who were affected by the isolation from their doctors, therapists, family, and friends brought on by the lockdown. A switch to telehealth, although challenging, has also enabled the organization to reach out to those individuals

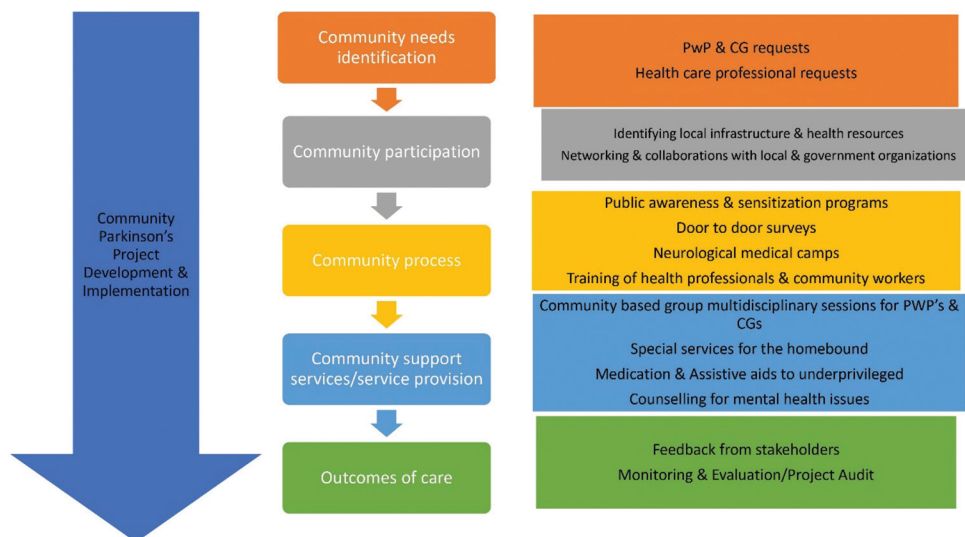


Figure 3: Steps in developing PSCs in the model of care

who were unable to access the services either due to mobility restrictions as a consequence of their disability or due to the lack of a PSC in their area of residence. Prior to COVID-19, the organization has been utilizing various communication platforms to interact with and provide regular training for the various PSC coordinators. This method is cost-effective especially with limited funding.

Currently, the organization offers a hybrid model of care with in-person support programs and services as well as virtual support programs and services. This has enabled it to significantly increase the number of PwPs and CGs it supports in India as well as those living in other countries in areas that have limited access to information and support.

What could be potential barriers and challenges in implementation?

Parkinson's care in India has to compete with a multitude of infectious and non-infectious diseases, all vying for the limited available resources. Financial resources are a key issue in most LMICs. To expand services to different parts of the country, funding is required not only to initiate newer PSCs but also to sustain existing centers. It becomes imperative to move to a phase of building a corpus that will ensure sustainability as well as allow for better planning and strategizing. Identification of local funders to support and promote their community-based PSC is a challenge but also a possible sustainable strategy.

Awareness of Parkinson's in India is low and, in rural and tribal areas is non-existent. As a result, a large proportion of the population continues to remain undiagnosed and underserved. In addition to this, dealing with health beliefs in these areas can be challenging and require a deeper understanding of cultures and practices in order to encourage people to seek help and utilize the available health services and resources. India also has a poor neurologist-population ratio with approximately 1 neurologist available for every 200,000 population with a majority (70–80%) practicing in urban areas.^[3] This poses a challenge for diagnosis and ongoing medical management.

Finally, the presence of 23 official languages and diverse cultures is a challenge for resource development and implementing rehabilitation programs. Educational information and resources need to be translated into the regional language and adapted to suit the culture and educational level of a particular region. This requires additional human and financial resources.

What could be potential implications of our model of care?

The preliminary promise of the Parkinson's rehabilitation model of care as seen by the presence of 70 PSCs in India and its continuing expansion into underserved areas, is due to its potential for replicability in varied socioeconomic settings and its reliance on local collaborations and locally generated funding for sustaining its centers.

Highlights of the Model of Care:

1. Implementation of such a program is possible even in parts of the country where there are limited to no multidisciplinary resources.

2. Group therapy design not only provides participants with a larger source of support but is also cost-effective.
3. The dynamic nature of the model allows it to be adapted, modified, expanded, and updated without changing the core values of education and rehabilitation to improve QoL.
4. The design of the module and the detailed capacity training manual makes it possible to set up these centers remotely and use virtual communication tools for training and monitoring.

CONCLUSION

Our experience has demonstrated to us the utility of community care models in building access to treatment and increasing awareness.^[18] We strongly believe that it is important for local governments and funding agencies to support community initiatives like these to aid early diagnosis and treatment and improve QoL of its population.

Acknowledgments

The authors would like to thank Cathryn Pinto, Shibani Devare, Deborah Herbert, Devika Mehta, Komal Parikh, Jagruti Wandrekar, Anjali Sivaramkrishnan, Navaz Irani, Neha Shah, Meghana Srinivasan, Nishaat Mukadam, Dr. Roshan Vania, Dr. Odette Gomes, Dr. Anjali Kant, and Dr. Salome Benjamin, for their contributions toward creating the multidisciplinary module, study implementation, and data processing. They would also like to thank the research consultants Dr. Anuradha Sovani and Dr. Shubha Thatte for their invaluable evaluative feedback of the module.

Financial support and sponsorship

The study was funded by the Narotam Seksharia Foundation and by the Parkinson's Disease and Movement Disorder Society.

Conflicts of interest

There are no conflicts of interest.

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