

Additional File 5: Subspecialty Disciplines and Models of Care for Parkinson's Disease (2005-2024)

Introduction

This supplementary file synthesizes information on subspecialty disciplines and models of care for Parkinson's disease (PD) that have developed over the past two decades. These developments reflect responses to the access barriers identified in our Critical Interpretive Synthesis and represent potential solutions to address inequitable access.

Subspecialty Disciplines in PD Care

Since 2005, PD care has evolved to incorporate a wider range of specialized healthcare professionals organized in interdisciplinary teams:

1. **Movement Disorders Specialists:** Neurologists with specialized training in PD have become central to complex care management, though geographic disparities in access persist [2].
2. **Parkinson's Nurses:** These specialists coordinate care, and provide patient education, serving as critical navigational resources for patients facing complex healthcare systems [1,2,3].
3. Physical therapists address mobility, balance, gait issues, fall risks, and chronic pain through task-specific training, amplitude-based movement strategies, and personalized exercise prescription, and dual-task training [1,2]
4. Occupational therapists enhance daily living activities, environmental modifications, hand dexterity therapy, and dual-task training [1,2]
5. Speech-language pathologists provide intensive voice treatments (e.g., Lee Silverman Voice Treatment [LSVT]), swallowing interventions, and cognitive-communication strategies [1,2,3,4]

These professionals, when trained in PD-specific approaches, provide more effective interventions.

6. Expanded Interdisciplinary Team Members:

- Neuropsychologists/Psychologists: Addressing cognitive and emotional challenges associated with PD [1,2]
- Social Workers: Supporting patients and caregivers with resources, care coordination, and emotional support [1,2]
- Dietitians: Providing nutritional guidance specific to PD needs [2]
- Recreation therapists: Supporting meaningful leisure activities [1]

- Vocational rehabilitation counselors: Assisting with employment challenges [1]
- 7. **Medical Specialists for Non-Motor Symptoms:** Including gastroenterologists, pulmonologists, neuro-ophthalmologists, urologists, psychiatrists, geriatricians, and palliative care specialists to address the complex non-motor manifestations of PD [1,2,4].

These specialized disciplines directly address provider knowledge barriers identified in Line-of-Argument 2 of our synthesis. However, their geographic concentration in urban centers and academic institutions has created uneven access patterns that can exacerbate existing disparities.

Evolving Models of Care

Several innovative care models have emerged to improve coordination and overcome geographic and socioeconomic access barriers:

1. **Integrated Multidisciplinary Care Models:** These models coordinate care across disciplines and settings (hospital, outpatient, community, home-based care). Case managers, including Parkinson's nurses, provide a coordinated point of access for persons living with Parkinson's disease, and organize linkages to subspecialty services [3]. Research shows modest improvements in health-related quality of life, particularly in outpatient settings [2]. Teams work collaboratively with regular meetings to synthesize goals and coordinate care [1,2].
2. **Network-Based Models:** ParkinsonNet, developed in the Netherlands, connects specially trained healthcare providers in regional networks. This model has demonstrated improved outcomes and cost reductions through evidence-based guidelines, continuous education, and interdisciplinary collaboration [1,2,3]. This approach directly addresses knowledge gaps in non-specialized providers.
3. **Care Models Based on Disease Stage:**
 - **Proactive Rehabilitation:** Early referral soon after diagnosis to address mild symptoms and focus on education and self-management [1]
 - **Restorative Rehabilitation:** Addressing functional impairments at any stage through targeted interventions [1]
 - **Skilled Maintenance Rehabilitation:** Long-term monitoring in advanced PD, focusing on preventing complications [1]
4. **Home-Hub-and-Spoke Models:** These combine care delivery at home (supported by technology), regional teams (spokes), and expert centers (hubs). This model specifically targets geographic barriers by bringing specialized care closer to patients [3].

5. Service Delivery Innovations:

- **One-Stop Clinics:** Multiple specialists provide comprehensive evaluations in a single visit, reducing transportation barriers [2]
 - **Home-Based Care Programs:** Teams visiting patients at home to provide tailored care for those with advanced disease [2]
 - **Day Clinics:** Hybrid models bridging inpatient and outpatient care for intensive treatment [1,2]
 - **Dental Model of Rehabilitation:** Regular re-assessments every 3–6 months to monitor and adjust care plans [1]
 - **Intensive Multidisciplinary Rehabilitation:** Concentrated therapy sessions (e.g., 2 hours/day for 6–7 days/week) [1]
6. **Telehealth Solutions:** Remote monitoring and consultations have expanded access to specialized care, particularly important during the COVID-19 pandemic. However, implementation barriers persist, including technological literacy challenges and infrastructure limitations that may disproportionately affect older adults and those of lower socioeconomic status [1,2,3,4].

7. Setting-Specific Models:

- **Emergency Department Pathways:** Redesigned processes to improve medication management for PD patients in emergency settings [2]
- **Hospital Care Initiatives:** Focused on reducing preventable harm during inpatient stays [4]
- **Community Partners in Care:** Specialized approaches for senior living communities and home care agencies [4]

These models directly address the geographic context barriers identified in Line-of-Argument 1 of our synthesis, particularly the complex interplay between regional factors and healthcare delivery systems.

Best Practices and Policy Implications

Several best practices have emerged that could inform policy interventions to address access inequities:

1. Person-Centered Care Approaches:

- Patient empowerment and self-management through education programs and shared decision-making tools [1,2,3]

- Helping patients identify personal goals, sources of motivation, and determinants of success [1]
- Lifestyle counseling and exercise prescription tailored to individual needs [1,3]
- Supporting patient autonomy and promoting active participation in care [1,2,4]

2. Proactive and Preventive Care:

- Early referral to rehabilitation services soon after diagnosis [1]
- Regular monitoring to detect and address complications before they escalate [1,3]
- Preventive approaches to avoid hospitalization and maintain function [1,2,3]
- This is particularly important for historically marginalized groups who often present at later disease stages

3. Team-Based Care Coordination:

- Regular team meetings to align treatment plans and monitor progress [1,2]
- Using dedicated care coordinators or Parkinson's nurses to streamline communication [2,4]
- Robust coordination across interprofessional healthcare teams [1,2,4]
- Clear role definition while maintaining flexible collaboration [1,2]

4. Specialized Training Programs:

- Disease-specific education for healthcare professionals across disciplines [1,2,3,4]
- Interprofessional education to improve team collaboration [1,3]
- Adherence to evidence-based guidelines adapted for PD care [1,2,3]
- These programs directly address knowledge gaps and biases that contribute to provider-level access barriers

5. Technology Integration with Equity Considerations:

- Digital tools for remote monitoring and timely interventions [1,2,3]
- Wearable sensors and mobile technologies to track symptoms [2,3]
- Implementation strategies that consider the "digital divide" affecting rural and socioeconomically disadvantaged populations [1,2,3]
- Support systems for patients with limited technological literacy [1,2]

6. Tailored Approaches Across the Disease Spectrum:

- Different care models for early, middle, and advanced disease stages [1,2]
- Palliative care principles integrated throughout the disease trajectory [2,4]
- Adaptive approaches as patient needs evolve [1,2,4]

These practices align with our theoretical framework by addressing multiple intersecting barriers simultaneously rather than through isolated interventions.

Implications for Addressing Intersectional Barriers

Our review identified how multiple marginalized identities create compound disadvantage in PD care access. Emerging care models show promise for addressing these intersectional barriers:

1. **For Rural/Remote Populations:** Telehealth, hub-and-spoke models, and specialized training for local providers can extend specialized care beyond urban centers [1,2,3]. The ParkinsonNet model specifically helps connect patients in underserved areas with properly trained specialists [1,3].
2. **For Racial/Ethnic Minorities:** Cultural competency training within network-based models and precision medicine approaches may help address provider biases and knowledge gaps regarding diverse disease presentations [2,3]. Person-centered care approaches that consider cultural background can improve engagement with services [1,4].
3. **For Older Adults with Mobility Limitations:** Home-based care, one-stop clinics, and telehealth can reduce transportation barriers, though implementation must consider technological literacy [1,2,4]. The "dental model" of regular scheduled reassessments can help maintain function and reduce crisis interventions [1].
4. **For Socioeconomically Disadvantaged Groups:** Integrated care models with social workers can help address social determinants of health that compound clinical challenges [2,4]. Evidence suggests that network-based models like ParkinsonNet can also reduce overall healthcare costs [1,3].
5. **For Patients with Advanced PD:** Specialized home-based care programs and skilled maintenance rehabilitation models can address the unique challenges of this population who face some of the greatest access barriers [1,2]. Integrated models also support timely access to services including nursing homes and facility-based care, and timely access to palliative care for pain and symptom management across the illness continuum and at the end of life [3].

Conclusion

The emergence of specialized disciplines and integrated care models represents potential solutions to the access barriers identified in our Critical Interpretive Synthesis. However, implementation has been uneven, often reinforcing existing geographic and socioeconomic disparities. Future development of PD care models should explicitly address intersectional barriers and evaluate their impact on historically marginalized populations. As Rafferty et al. [1] note, empirical testing of these models in pragmatic trials is needed to evaluate their impact on outcomes, quality of life, and integration with other disciplines, particularly for underserved populations.

References

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