Implementation of an Integrative Holistic Healthcare Model for People Living with Parkinson’s Disease

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Purpose: Research demonstrates that people with Parkinson’s disease (PD) benefit greatly from multidisciplinary medical care. Delaware does not have a Movement Disorder Center or a movement disorder specialist. To address this issue, the University of Delaware Nurse Managed Health Center (NMHC) developed a novel PD Telehealth Clinic serving individuals with PD and their caregivers throughout Delaware.

Design and Methods: The PD clinic is based on a collaborative framework that uses synchronous video conferencing telehealth technology to bring together out-of-state clinicians and scientists with expertise in PD to help deliver specialized care to PD patients and their caregivers. The team includes a movement disorder specialist, psychologists, nurse practitioners, researchers, physical and speech therapists, exercise physiologists, nutritionists, and graduate students. The PD Clinic delivery model seamlessly blends telehealth provider and onsite provider interactions, enabling the diagnosis, treatment, and ongoing management of PD.

Results: In the first 6 months of the Parkinson’s clinic opening, the nurse practitioners along with the movement disorder specialist evaluated 36 PD patients. Several patients have received recommendations to change their medication regimen by the movement disorder specialist. About 20 patients were referred to physical therapy, 7 to speech therapy, 9 to mental health services, 1 to occupational therapy, and 12 to local support groups. The location of the NMHC-PD clinic has reduced travel time and distance by as much as 1.5 hr or 80 miles, each way, and wait time for a new patient appointment is less than 3 months.

Implications: The NMHC – PD Telehealth Clinic provides access to specialized multidisciplinary and advanced care and was successfully implemented. This model can be replicated in other nurse managed health centers across the United States.

Key words: Parkinson’s disease, Integrative, Holistic, Telehealth, Telemedicine

Approximately 2,000 people living in the Delmarva Peninsula have Parkinson’s disease (PD). The Delmarva Peninsula includes all of Delaware, the Eastern Shore of Maryland, and, at its most southern tip, a small part of Virginia. It is located in the Mid-Atlantic region of the United States between the Chesapeake Bay, the Delaware Bay, and the Atlantic Ocean.
The Delmarva Peninsula is 180 miles long and at its widest is 60 miles with a land area of about 5.45 thousand square miles, see Figure 1. Access to and from the peninsula is via bridge or ferry or by driving to the northernmost part of Delaware.

Although there is currently no cure for PD, research demonstrates that PD patients benefit greatly from multidisciplinary medical care (van der Eijk, Faber, Al Shamma, Munneke, & Bloem, 2011). However, access to multidisciplinary medical care for people with PD is limited outside of large urban settings and cities. The average distance from the center of the Delmarva Peninsula to the closest city with a movement disorder specialist is 235 miles round trip. Oftentimes, due to the wait time and the required length of travel, patients elect not to make an appointment with a movement disorder specialist and a multidisciplinary team, leaving them vulnerable to care that does not comprehensively address the motor and nonmotor symptoms, and psychosocial aspects of PD.

People with PD who use a movement disorder center multidisciplinary team care benefit from early, accurate diagnosis, and appropriate treatment of PD motor and nonmotor symptoms (Carne et al., 2005). Typical primary motor symptoms include resting tremors, bradykinesia, rigidity, and postural instability (van der Marck et al., 2009). The majority of people with PD will also have one or more nonmotor symptoms. These nonmotor symptoms may not be visible, such as depression, but they can be significant (Breen & Drutyte, 2013; Chaudhuri, Healy, & Schapira, 2006; Schrag, 2006). Nonmotor symptoms might include sleep disturbances, constipation, bladder problems, sexual problems, excessive saliva, weight loss or gain, depression, and anxiety (Chaudhuri, Healy, & Schapira, 2006).

As the disease progresses, people with PD become increasingly dependent on family and friends who are often not prepared to deal with specific issues that may arise. For example, the side effects of some PD medications may include hallucinations or obsessive compulsive behaviors that can be frightening to families. Caregivers must be included in the education of how to recognize side effects of the drugs and when to access the healthcare team for assistance. Caregiver burden often increases as the disease progresses and PD symptoms become more complex (Pretzer-Aboff, Galik, & Resnick, 2009). A multidisciplinary team needs to provide comprehensive care and education for people with PD and their family caregivers. The treatment team should include professional members who are knowledgeable about the disease and who can devote time and resources to help support family and friends using a holistic healthcare model. Using this approach we can decrease stress on the patient and their family (van der Eijk, Faber, Al Shamma, Munneke, & Bloem, 2011).

Therefore, it is important to develop and examine an innovative healthcare model that removes barriers such as physical access to a multidisciplinary healthcare team of PD experts so that we can improve the care and quality of life of people living with this progressively debilitating disease.

### Building an Innovative Multidisciplinary Healthcare Team

The Parkinson’s Clinic is embedded in the Nurse Managed Health Center (NMHC) and shares the NMHC’s philosophy of providing patient-centered holistic healthcare. The framework of holistic healthcare that the NMHC uses is based on the ecological theory of human development (Bronfenbrenner, 1986). The ecological theory provides a model for understanding interactions between people, healthcare providers, and healthcare systems during a person’s lifespan that can influence a person’s behavior related to personal healthcare practices (Moen, Elder, Lüscher, & Bronfenbrenner, 1995). Thus, it was important for us to elicit the input from community stakeholders such as people living with PD and their caregivers, while we developed this model of care. Recognizing that the healthcare...
environment directly impacts people with PD, we needed a model that provided comprehensive education and support while allowing for individualized care.

Our novel healthcare model incorporates synchronous videoconferencing telehealth technology to import the expertise of a movement disorder specialist and a clinical psychologist with expertise in PD to our interdisciplinary patient-centered care model, Figure 2. Our model, Figure 2, illustrates the person with PD and their family as the central focus at all times. The patient and his or her family can access services as recommended by the healthcare team and desired. This is a dynamic model and can respond to the patients’ needs as those needs evolve over time due to disease progression. Early in the disease, patients may only wish to have consultation with the movement disorder specialist and nurse practitioner for medication management and disease education. Or, they may wish to participate in a structured therapy such as the Lee Silverman Voice Training “Loud” program (Fox, Morrison, Ramig, & Sapir, 2002). Patients and families using our center have easy access to ongoing information concerning other services and programs. A nurse coordinator knowledgeable about local and telehealth resources assists them in accessing additional services, educational support groups, and maintains an open communication channel with the PD patients and their families.

The Healthcare Team

Identifying key team members for each role identified in the model and having easy access to them was a critical step in the implementation of the model. The potential team members had to meet specific selection criteria before being considered for a required team member role. The first and most important criterion was that they had expertise in PD and or had a strong clinical background specifically in chronic disease management. The second was that they had experience working on a healthcare team as either an active member or in a leadership role. Third was that they needed be supportive of and willing to be engaged in research.

Using these criteria, we first sought a movement disorder specialist, one of the most important team members and integral to the medical management of the disease. Since there was not a single movement disorder specialist within the 5.45 thousand square miles of the Delmarva Peninsula, we needed creatively explore how to fill this void in local healthcare. By stepping outside the “clinical box” and using the professional network of connections developed by the NMHC Director of Research, the NMHC was able to identify a movement disorder specialist who met all our criteria approximately 100 miles away at Johns Hopkins Hospital. The next step was getting easy access to the movement disorder specialist. Telehealth has a long history in being used successfully to overcome patient barriers related to accessing healthcare (Rutledge, Haney, Bordelon, Renaud, & Fowler, 2014). Since it was not possible to have the movement disorder specialist physically present in the NMHC, we elected to use telehealth technology to virtually bring the movement disorder specialist to the NMHC. When the movement disorder specialist later relocated to University of Rochester approximately 330 miles away, the access to the movement disorder specialist did not change due to the use of telehealth technology.

Two common nonmotor problems that people with PD often have are depression and anxiety (Menza, Robertson-Hoffman, & Bonapace, 1993). Our telehealth model greatly helped fill the role of a mental health provider on the team to assist with the treatment of mental health issues specific to people with PD. Since the Delmarva Peninsula did not have a mental healthcare provider with expertise in PD, we reached out to a clinical psychologist in Rutgers University approximately 100 miles away. The clinical psychologist also had a strong interest in research opportunities, thus supporting the team in this important aspect of the Parkinson’s Clinic. Telehealth easily bridges the distance gap and provides the patients with easy access to a level of clinical expertise not available in the Delmarva Peninsula.

Access to other team members did not require the use of telehealth technology but did require creative use of clinical space and scheduling. The NMHC is fortunate to be located next to the University of Delaware Physical Therapy (PT) Department, which was ranked as the second best PT clinic in the United States by US News and World Report. The PT department has staff with expertise in treating PD. To provide speech therapy for patients at the NMHC, we partnered with a local hospital system and colocated a member of their speech department in the NMHC on a regularly scheduled service basis. The Healthcare Team

[Figure 2. Pretzer-Aboff and Prettyman’s Parkinson’s Model. An Integrative Holistic Healthcare Model for People with Parkinson’s.]
basis. The NMHC also hired a registered dietician to join the NMHC as an interdisciplinary team member.

Filling the role of the nurse practitioner in the model was straightforward, since the NMHC employs five nurse practitioners with experience in the management of chronic disease. Nurse practitioners have been shown to be strong leaders in interdisciplinary healthcare delivery models (Quinlan & Robertson, 2013). However, the nurse practitioners at the NMHC had limited experience in the treatment and management of people with PD. Overcoming this barrier required exploring educational opportunities. Through the generous support of the Edward J. Safra Foundation Visiting Nurse Faculty Program, an educational program for nursing faculty in schools of nursing, all five nurse practitioners completed a rigorous PD educational training program. In addition, the nurse practitioners developed a strong skill set in the use of telehealth technology.

The model of care delivery we developed is a hybrid model with a mix of telehealth and face-to-face interactions all taking place in one location. This is in congruence with a medical home model in which care is coordinated and structured around the needs of the patient in one location that is easy for patient access to healthcare (Houde, Melillo, & Holmes, 2012). The model is designed to be flexible enough to engage the patient over the course of their lifespan.

**Educational Overlay**

Interweaved among all the interaction of this dynamic model is education for patients, their caregivers, healthcare professionals, and students across all of the disciplines. For example, nurse practitioners are educating patients about their disease and how to identify problems and when to access the care team. People with PD are teaching students what it feels like to have a tremor, or how it makes them feel to lose their ability to walk smoothly across the room. The movement disorder specialist is educating nurse practitioners on the art of medication management. Scientists are sharing their research findings with all members of the team, including patients and caregivers of the benefits of different types of exercise, nonmedical treatment of gait disorders, medication adherence, and end of life care.

All of these interactions have created a sense of community. Educational support groups for people with PD and for caregivers have been initiated by community members. Educational lectures have increased in number. These interactions and educational opportunities across disciplines have increased awareness and expertise of PD across the state.

**Outline of an Initial Patient Visit—Model in Action**

The first visit for the PD patient is complex and involves a comprehensive look at each patient’s motor, nonmotor, and psychosocial symptoms.

1. At the time the patient schedules an appointment he or she is made aware that he or she will receive a packet of materials to be completed and returned prior to their appointment. The packet includes the following: welcome letter with instructions, a medical history form, a medication list form, and a number of standard validated Parkinson’s Questionnaires. The information is reviewed by the nurse practitioner and entered into the patient’s electronic medical record.

2. The appointment is scheduled for 3 hr and consists of three 1 hr long sessions.

3. The first hour is with the nurse practitioner and is designed to identify PD motor and nonmotor problems from both physical exam and the patients’ perspective.

4. The second hour is with the movement disorder specialist via LifeSize® video telehealth infrastructure and GlobalMED® telehealth hardware. The nurse practitioner stays with the patient during the session with the movement disorder specialist to help facilitate care and provide a consistent patient-provider relationship. At the end of the session, the nurse practitioner reviews the team’s recommendations and provides a written summary of the recommendations to the patient.

5. The patient then is introduced to the research team and is provided with information about research studies in which he or she might be interested in participating. The patient is given an opportunity to start the informed consent process for studies in which he or she would like to participate.

6. Follow-up visit schedules are individualized and are designed to address any motor and nonmotor problems with the appropriate PD team member.

7. The patient care coordinator contacts patients regarding their continuing plan of care as indicated several days after their appointment to answer questions and provide additional information as needed.

**Benefits of the Model for People with PD**

Our hybrid telehealth model provides a number of perceivable and palpable benefits for people with PD, including (a) Local access to a movement disorder specialist in the Delmarva Peninsula via telehealth technology, (b) early accurate diagnosis and appropriate treatment of PD motor and nonmotor symptoms, (c) decreased wait time for movement disorder specialist consultation, and (d) provide...
patients and caregivers local access to a multidisciplinary healthcare team of PD experts and scientists focused on improving the quality of life of the person living with PD.

In the first 6 months of the Parkinson’s clinic opening, the nurse practitioners along with the movement disorder specialist evaluated 36 PD patients. Several patients have received recommendations to change their medication regimen by the movement disorder specialist. About 20 patients were referred to physical therapy, 7 to speech therapy, 9 to mental health services, 1 to occupational therapy, and 12 to local support groups. Six patients with Geriatric Depression Scale scores indicating depression were referred to our clinical psychologist for evaluation via telemedicine technology. Over 20 patients and caregivers with identified knowledge deficit received educational booklets focusing on medication compliance and fitness. The location of the NMHC-PD clinic has reduced travel time and distance by as much as 1.5 hr or 80 miles, each way. Wait time for a new patient appointment is less than 3 months.

Benefits of the Model for Caregivers Supporting People with PD

Equally important to a successful holistic healthcare model is providing services that focus on the people who support the person with PD. Caregiver stress and burnout have been well-studied, and the literature indicates that this group of individuals requires comprehensive ongoing support (Dyck, 2009). Limited or lack of communication between the members of the care team with the primary support person can exacerbate the support person’s stress, leading to caregiver burnout (Hatano, Kubo, Shimo, Nishioka, & Hattori, 2009). To address this important issue, the Parkinson’s Clinic makes every effort to include the support person in all patient visits and sessions. The caregiver is invited to actively participate and provide feedback about the person he or she supports from his or her vantage point as a caregiver. This communication pattern between support person and the person with PD can be very dynamic and inform about the overall status of the person with PD from both a psychological and physical perspective. In addition to open and transparent communication com patterns, the multidisciplinary team develops services specifically for the support person. The support person can make a private appointment with a clinical psychologist who has expertise in caregiver issues and support. Social isolation and the negative consequences of the isolation are an issue for some caregivers (Roland, Jenkins, & Johnson, 2010). The Parkinson’s clinic is not only closely connected to the PD support groups for caregivers in the Delmarva Peninsula, but it also provides a meeting location for two of the local support groups. Parkinson’s Clinic healthcare professionals and researchers attend the meetings on a regular basis to provide information and actively listen to the concerns of the caregivers. The information from the support groups helps to shape the services and ongoing communication within the Parkinson’s Clinic.

Educational Benefits of the Model

The NMHC is committed to research excellence, academic leadership, and community service. Therefore, the NMHC strives to enhance opportunities for education, scholarship, and research for nursing faculty and students through studying and using best practices and innovative approaches to healthcare and service delivery. The Parkinson’s Clinic operates within the NMHC overall structure and was designed to fit the mission of the NMHC. To this end, the Parkinson’s Clinic engages both undergraduate and graduate nursing students in all aspects of the Parkinson’s Clinic. This includes but is not limited to helping with patient registration and data entry, assisting with patient care coordination, administration of physical and cognitive screening tests and tools, learning to use and operate telehealth systems, and helping with research studies (ranging from literature searches to data collection and data entry). This involvement helps students better understand PD and prepares them to be strong nursing advocates for people with PD in inpatient and outpatient settings. The literature shows that medications are not often managed correctly during a hospitalization for people with PD (Gerlach, Winogrodzka, & Weber, 2011). Nursing plays a critical role in averting potential medication mistakes and mismanagement. Having more nurses educated about PD in the community can lead to improved outcomes for people with PD. Nurse practitioners are providing more and more primary healthcare services in the community. It is incumbent upon the educational system to provide nurse practitioner students with knowledge about PD and experience treating PD so that the level of care within the Delmarva Peninsula for people with PD is the best individualized plan of care developed (Jarman, Hurwitz, Cook, Bajekal, & Lee, 2002).

Measuring Outcomes

A vital aspect of the Parkinson’s Clinic hybrid model is that it incorporates outcomes measurements as part of the ongoing comprehensive care of patients. The outcome assessment is designed to identify areas to improve clinical practice, which lead to improved patient care (Kleinpell, 2013). To this end, from the first day of the Parkinson’s Clinic we tracked the patients’ physical and psychosocial status as well as caregiver burden, mood, and quality of
life. When the data are analyzed, they will give clinicians, patients, and caregivers unprecedented information on the progression of disease and effectiveness of their treatment regimen. Specifically, we collect information using the following validated tools: the Montreal Cognitive Assessment (MoCA®; Nasreddine et al., 2005), designed as a rapid screening instrument for mild cognitive dysfunction; the Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986); the Parkinson's disease Questionnaire (PDQ-39; Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997), designed to address aspects of functioning and well-being for those affected by PD; and the Movement Disorder Society—Unified Parkinson Disease Rating Scale (MDS-UPDRS; Goetz et al., 2008) designed to monitor PD disability and impairment. In addition, information is collected regarding psychosis, depression, anxiety, sleep disorders, and a comprehensive medical history, including medications used and compliance with medications. Patient information, including satisfaction with the care received, is collected at every visit with the nurse practitioner, providing longitudinal data for comparison and tracking.

**Challenges**

While telehealth provides easy access to a movement disorder specialist, the movement disorder specialist still is only one medical specialist with multiple scheduling demands. Therefore, having access to and having enough time with the movement disorder specialist are two different issues. Having a solution to local access of a movement disorder specialist is a “double-edged sword.” On one side people with PD are excited to have local access to an movement disorder specialist and make appointments; on the other side, demand for the movement disorder specialist outstrips the time the movement disorder specialist has available in the Parkinson’s Clinic. Overcoming this issue will take creative partnerships and negotiations that continue to keep what is best for the people with PD and their support team as the primary goal. We are confident that with everyone working together we will overcome this issue.

Telehealth works to access the movement disorder specialist and the clinical psychologist in a seamless way that engages the patient without having technology interfere with the healthcare provider and patient relationship. Obtaining, installing, or using the technology is not the barrier, rather, it is the lack of a reimbursement process for telehealth visits in Delaware. Delaware is fortunate that Medicaid will reimburse for telehealth services. However, Medicaid is the only third-party health insurance provider in Delaware that supports a reimbursement structure for telehealth. Thus the majority of the patients seen in the Parkinson’s Clinic do not have insurance coverage for telehealth visits. The short term solution is that we have received grant funding to help cover the cost of the telehealth visits. However, this is not a sustainable model. Members of the Parkinson’s Clinic and members of the support groups are actively involved at the state level to resolve this issue at the legislative level.

The multidisciplinary team model is a powerful way to provide healthcare. When fully implemented is an effective way to meet the triple aim of healthcare of improving the patient experience of care, improving population health, and reducing the per capita cost of health care (Stiefel & Nolan, 2012). It is, however, a model that takes a great deal of team coordination and ongoing training. Team members have to learn to work together to use similar documentation tools, agree on data collection tools, how to use the information collected, and when to refer patients to other team members. In addition, it is important to not disrupt the relationships the people with PD already have with their existing healthcare team in the community. To address these issues requires time and excellent communication that is responsive and transparent to all members of the team. For our clinic, this is a dynamic process and continues to evolve over time. We have discovered that informally debriefing immediately after a Parkinson’s Clinic is a good way for all the members of the healthcare team (nurse practitioners, nurse coordinator, staff, and Directors) to identify both patient and system issues. These issues are documented and tracked and discussed at monthly team meetings.

**Next Steps**

The hybrid model we have adopted provides the person with PD access to a movement disorder specialist, nurse practitioner, physical therapist, speech therapist, clinical psychologist, registered dietitian, and a PD research team. The documentation is centralized into one electronic medical record. The next phase of development for the clinic is to begin care coordination that involves all the aforementioned healthcare providers to be at the table face-to-face (or virtually face-to-face via video conference) to discuss selected patient cases with the goal of improved patient care and outcomes.

The NMHC that houses the Parkinson’s Clinic is located in the northern portion of the 180 mile long Delmarva Peninsula. This means if a person with PD lives in the southern part of the Delmarva Peninsula, he or she still might have a round trip of over 300 miles to be seen in the Parkinson’s Clinic. To overcome this issue, the NMHC is exploring opening an office in the southern part of Delaware, which is near the middle of the Delmarva Peninsula. The Parkinson’s Clinic would operate in a very similar manner, using telehealth to access the resources that are not available in that part of the Delmarva Peninsula.
Conclusion

Delaware comprises 36% or 1,954 square miles of the Delmarva Peninsula and is the only state located entirely within the Delmarva Peninsula. Delaware has a population of 925,749, of which 15.9% (147,194) are 65 years or older, and this age group is growing rapidly. PD has a higher prevalence in older adults, so there will likely continue to be a steady increase in people with PD in Delaware who will require specialized healthcare. The NMHC–Parkinson’s Clinic was designed, developed, and implemented by nurses to improve access to specialized healthcare for people with PD and their support team. The model of care is based on a holistic healthcare model that brings together a multidisciplinary healthcare team of PD experts. The team consists of a movement disorder specialist, nurse practitioner, physical therapist, speech therapist, clinical psychologist, registered dietitian, and a PD research team. Due to the geographic location of the movement disorder specialist and the clinical psychologist, the Parkinson’s Clinic embraced the use and deployment of telehealth technology to provide access to these specialists. The NMHC successfully implemented providing seamless access to care a hybrid healthcare delivery model that blends traditional face-to-face office visits with telehealth visits on the same day. The hybrid model is patient-centered and designed to be flexible to meet the unique healthcare needs of people with PD motor and nonmotor symptoms. Recognizing that reimbursement for telehealth services is a barrier for people with PD to get healthcare the PD team engaged state healthcare policy leaders. This proactive approach for improved payment models for telehealth services lead to PD team leaders having a strong voice in state wide discussions that impact people with Parkinson’s access to telehealth services. Outcomes and clinical research are integrated in the model so that the model can be continuously evaluated and adapt as indicated in response to the data analysis. The clinic is currently collecting data and will begin data analysis and outcome reporting during the next phase of the Parkinson’s Clinic.

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References


