Impact of Nurse Navigation on Parkinson Disease Community Wellness

Stephanie De Santiago[a, b] *and Diane Nuñez*[a]

[a]College of Nursing and Health Innovation, Arizona State University, Phoenix, AZ, USA

565 N. 3rd St, Phoenix, AZ 85004, United States

[b]Banner Neuro Wellness, Banner University Medical Center-Phoenix, Phoenix, AZ, USA

1111 E. McDowell Rd, Phoenix, AZ 85006, United States

ABSTRACT

Background: There is a great need to provide people with Parkinson disease (PD) not only quality medical care, but social support and disease-related resources. Nurses have the training and interpersonal relationship skills to make a tremendous difference in the lives of people living with PD. **Objective:** This quality improvement project evaluated the effect of a nurse navigation program on self-efficacy among people living with PD. **Methods:** Twenty-four members of a PD specific wellness center in the United States were recruited to participate in a nurse navigation program for a 12-week period. The intervention period included an initial needs assessment, ten individual 45-minute sessions focused on specific aspects of PD wellness, and a concluding visit. **Results:** There was a significant decline in quality of life based on average PDQ-39 scores for the participants in January 2019 (M =24.44, SD=16.66) compared to January 2018 (M=20.11, SD =12.78) where higher scores signify worse quality of life; t(23)-4.329 p=0.025. Average self-efficacy for managing chronic disease pre-intervention scores (M=6.58, SD=1.70) verses post-intervention scores (M=7.44, SD=1.48) showed a significant increase in self-efficacy with a medium effect size; t(23)-0.854 p=0.016, d=0.54. Additionally, unique satisfaction surveys showed high satisfaction with nurse navigation throughout the participant sample and wellness center staff members. **Conclusions:** A nurse navigation program focusing on specific aspects of PD management can help improve participant's confidence in self-management of PD despite disease progression. Additionally, nurse navigation for people with PD was associated with high satisfaction among participants and staff members of a PD wellness center.
Keywords: Patient Navigation, Self-Efficacy, Quality of Life, Patient-Centered Care, Neuroscience Nursing, Community Health Services, Self-Management

INTRODUCTION

Parkinson's disease (PD) is a chronic progressive neurodegenerative disease that affects about one million Americans and over 10 million people worldwide. This disease is characterized by symptom manifestation including various motor and non-motor symptoms. As the second most common neurodegenerative disease, there is a great need to provide people with PD quality medical care, social support and disease management resources [1]. Research shows that PD specialist nurses provide practical skills, experience, and knowledge about PD that is a crucial component of personalized care and support for this patient population. Registered nurses specializing in PD can improve patient's sense of wellbeing while mitigating increased healthcare cost. Nurse-led PD services can also improve patient satisfaction, disease self-management, and overall patient care [2, 3, 4, 5, 6]. Registered nurses with a special interest and training in PD have played an active role in patient care in the United Kingdom since 1992 [2]. While other countries seem to be effectively utilizing nursing roles to provide PD related support and guidance, the United States has room for improvement [2,3].

Currently, areas where registered nurses in the United States are commonly providing disease management and guidance in a navigation role are oncology care and diabetes management. Oncology nurse navigators assist patients, families, and caregivers by helping them gain access to quality healthcare while overcoming barriers. This unique nursing role has been shown to improve patient and staff satisfaction related to oncology care while removing barriers in order to improve access to quality care [7, 8]. Additionally, nurse navigation can be useful for diabetes care in the community by providing patients with customized self-management programs and care coordination [9]. Positions similar to the nurse navigator position are also being used in other areas of healthcare such as emergency departments, hospitals, home health care, palliative care, and generalized care of older adults with chronic conditions. These nurses

focus on aspects of care such as medication management, chronic disease self-management, education, and fostering provider-patient communication [10, 11, 12, 13, 14].

High-quality nursing professionals knowledgeable about the disease and its unique characteristics are essential to the successful management of people with PD in the community wellness setting and aspects of the nurse navigator roles throughout other medical disciplines can be molded to better serve people with PD. Nurses play an important role in fostering a multifaceted interdisciplinary approach to community wellness for people with chronic conditions such as PD. A nurse navigator can conduct patient assessments, give supportive care, manage complex health conditions, and assist with integration and communication between clinicians. The nurse can act as a liaison between the patient and providers to ensure that the patient's problems are addressed, and the plan of care is clearly communicated and agreed upon [4, 15, 16]. Additionally, nurse navigation can target different care domains crucial to improving self-management of PD such as patient education and problem solving [17]. The purpose of this quality improvement project is to develop a nurse navigation program at an established Parkinson-specific community wellness center and evaluate its effect on self-efficacy for managing chronic disease among people living with PD.

MATERIALS AND METHODS

This project was conducted in a comprehensive Parkinson's-specific community wellness center that is part of a large not-for-profit health system in the Southwestern United States. The wellness center offers various group exercise classes, one-on-one mobility training, support groups, educational sessions, and social activities to active members with PD and their caregivers for a flat monthly fee. A nurse navigation program was initiated at the wellness center and was open to all paying members at no additional cost. The nurse navigation program was

designed with key aspects of self-management in mind and by taking into consideration the unique needs of people diagnosed with PD [17].

Ethical Considerations

This project was submitted to the Arizona State University (ASU) Institutional Review Board (IRB) as a quality improvement project and gained expedited IRB approval for one year. This quality improvement project provided participants with a consent letter summarizing project specifics and participant expectations during the initial nurse navigation visit. Completion of the demographics sheet and Self-Efficacy for Managing Chronic Disease 6-item Scale located in the initial participant packet following the consent letter was considered implied consent to participate in the project. Additionally, a HIPAA form was signed by participants granting the project team access to their exercise file at the wellness center and permission for the nurse navigator to discuss necessary medical information with his or her neurologist. No compensation was provided for participation other than a nominal gift of a pill box.

Recruitment

After obtaining IRB approval, 24 people with a clinical diagnosis of PD were recruited to participate in the 12-week nurse navigation program at the wellness center. Participants were recruited by invitational flyers posted in several different areas of the wellness center along with a recruitment presentation during a support group meeting about the new nurse navigation program that provided project specifics. Inclusion criteria for the sample included over the age of 18 years old, English speaking, able to read and write, diagnosed with PD by a neurologist, and currently paying for and participating in classes offered at the Parkinson's specific community wellness center. Exclusion criteria was less than 18 years of age, non-English speaking, no diagnosis of PD and not a current paying member of the wellness center.

Participant Sample

The average age of the subjects was 69 (*SD*=5.44) years and the ages ranged from 57 to 78 years. The sample consisted of 14 (58.3%) males and 10 (41.7%) females and all participants were Caucasian. The average number of years diagnosed with PD for the sample was 7.84 (*SD*=6.16) years. The sample had an average of 3.88 (*SD*=9.28) falls in the past year and an average of 0.08 hospitalizations (*SD*=0.28) in the past year. Additionally, we looked at participant's home support and found that 17 (70.8%) participants reported having help in the home and one participant (4.2%) reported having paid help.

Intervention

The nurse navigation program spanned a 12-week period with weekly 45-minute individual sessions conducted by the nurse navigator either in person or via telephone for each participant and visit attendance was tracked using a computerized weekly encounter log. Spouse caregivers were also welcomed to join participants during each session, of which 9 (37.5%) caregivers consistently participated in their partner's sessions. The registered nurse providing the intervention had specialty certification in neuroscience along with previous experience working with and managing people diagnosed with PD. Each session consisted of a pertinent topic related to PD management with the first and last week being initial and concluding visits. Table 1 describes in further detail all PD topics that were addressed by the nurse navigator, the order in which they were addressed, and the details of each session. Participants were also able to voice additional questions or concerns they had about their health or PD management during each session.

Measures

Outcome variables for this project included self-efficacy for managing chronic disease and participant and staff perceived value of the nurse navigation program. Quality of life data was also gathered to provide additional information on impact of PD on daily life of participants

for better interpretation of project outcome variables. Quality of life was measured over one year using retrospective data from January 2018 wellness center files compared to data collected in January 2019 at the wellness center using the PDQ-39. The PDQ-39 demonstrates satisfactory internal consistency (α = 0.51 to 0.96) and is proved to be reproducible (0.86 to 0.96). Subscales of the PDQ-39 showed convergence with similar subscales of the 36-Item Short Form Health Survey (SF-36) and is able to distinguish between levels of symptom progression [18]. The maximum score of this PD specific measurement tool is 100 with higher scores indicating poorer quality of life.

The Self-efficacy for Managing Chronic Disease 6-item Scale was administered pre and post-intervention to measure self-efficacy. This Likert scale measures an individual's confidence in self-management of PD by assessing topics such as symptom control, role function, emotional function and communication with physicians. The Self-efficacy for Managing Chronic Disease 6-item scale is a valid and reliable measure of self-efficacy for managing disease and shows good external validity with the German General Self Efficacy Scale (r_s= 0.578, p<0.001) and high internal consistency reliability (0.91 to 0.93) [19, 20]. This is a 6-item Likert scale with 1 being not at all confident and 10 being fully confident and total scores indicate the average of all 6 questions with a maximum score of 10. Due to limited measurement tools related to nurse navigation satisfaction, staff and participant satisfaction were obtained using originally created self-report surveys that included ordinal quantitative data along with qualitative data. These are non-standardized measures that have not been researched for validity or reliability and were used solely to gain a better understanding of overall participant perceptions of nurse navigation.

Data analysis

Our primary analysis assessed the change in overall self-efficacy scores pre and post-intervention along with evaluating participant's satisfaction with nurse navigation services.

Secondarily, we assessed quality of life over one year to obtain a better understanding of quality of life changes related to disease progression in the participant sample. All statistical data was stored and analyzed using SPSS and descriptive statistics were used to describe the sample and outcome variable. A two-tailed paired samples *t*-test was used to analyze the data of the outcome variables of interest.

RESULTS

Statistical analysis was conducted to analyze data related to quality of life, self-efficacy, and program satisfaction. We used an alpha level of 0.05 for all statistical tests. A paired samples *t*-test was conducted to compare quality of life in 2018 verses 2019 in the participant sample. There was a significant increase in total PDQ-39 scores from January 2018 (*M*=20.11, *SD*=12.78) verses January 2019 (*M*=24.44, *SD*=16.66) signifying an overall decline in quality of life; *t*(23)-4.329 p=0.025 (Figure 1). The PDQ-39 covers 8 dimensions that are assumed to impact quality of life and are used to compute the total quality of life scores reported above. PDQ-39 dimensions include mobility (*t*(23)-1.766 p=0.091), activities of daily living (*t*(23)-1.446 p=0.162), emotional well-being (*t*(23)-.827 p=0.417), stigma (*t*(23)-2.114 p=0.046), social support (*t*(23)-2.181 p=0.040), cognition (*t*(23)-1.550 p=0.135), communication (*t*(23)-2.095 p=0.047), and bodily discomfort (*t*(23)0.424 p=0.676).

A paired samples *t*-test was also conducted to compare the average self-efficacy pre and post-test scores. Significant improvement in the self-efficacy for managing chronic disease 6-item scale scores were noted when comparing before (*M*=6.58, *SD*=1.70) verses after (*M*=7.44, *SD*=1.48) participation in the nurse navigation program for the participant sample, *t*(23)-0.854, p=0.016 (Figure 2). A medium effect size was observed for the participant sample (*d*=0.54). A unique satisfaction survey was created to evaluate participant satisfaction with a max score of 70. Results suggest an overall high participant satisfaction with the various aspects of the nurse

navigation program targeted by the survey (M=62.208, SD=8.37). An additional satisfaction survey was created to evaluate wellness center staff satisfaction with nurse navigation services that were offered to their patients. This survey included three questions with a scale of 1 being disappointing and 5 being exceptional with a max score of 15. Results suggest that all staff members were highly satisfied with the implementation of the nurse navigation program at their place of work (M=15, SD=0).

DISCUSSION

People diagnosed with PD must have effective self-management skills in order to delay the expected decline in health and progression of disease. Programs to target self-management are crucial in this population and include education, problem solving, and goal setting [17]. Self-efficacy is the confidence a person has in their ability to complete an activity and is a way of measuring confidence in self-management of chronic disease [21, 22]. The findings from this quality improvement project suggest that nurse navigation can provide a systematic approach to improving self-efficacy for managing PD and can play a role in refining self-management skills. Nurse navigation imparted these skills in participants using these key components of self-management during individual navigation sessions to support participants, help them address barriers, and create goals related to their specific disease process.

Results showed that as expected, after one year of PD progression, quality of life significantly decreased in the 24-participant sample. Average PDQ-39 scores in both 2018 and 2019 for the participant sample (20.11 and 24.44 respectively) reflected better scores than the quality of life of the 124-participant sample described in a previous study using the same tool (M=30.0). This could be due to consistent participation in wellness center exercise classes and social support activities in this subject group along with advanced medical therapies developed since the previous study was conducted [23]. The PDQ-39 dimensions of stigma, social support,

and communication showed a statistically significant decline over one year. Interestingly, of all the dimensions assessed by the PDQ-39, the only dimension that did not worsen from 2018 to 2019 was bodily discomfort, again, possibly due to consistent participation in wellness center activities. However, this improvement was not statistically significant.

These findings are similar to a recent study conducted by Wagner and colleagues [24] that found while nurse navigation for oncology patients did not improve quality of life, these services did improve patient experience. We also found quality of life was not improved but satisfaction survey results for participants of the nurse navigation program showed participants as well as wellness center staff members were highly satisfied with nurse navigation program. Other previous research established results similar to the current findings relating to high satisfaction and sense of wellbeing in participants of a nurse navigation program for oncology patients as well as for people diagnosed with PD [4, 5, 7, 25].

Limitations

Limitations of this project include the use of self-report surveys to quantify quality of life and self-efficacy, absence of a control group to measure differences between people who attend the wellness center and those who do not, and lack of randomization of participants. Additionally, the program was open to all wellness center participants and participants were not matched for disease progression using a standardized form of progression measurement such as the Hoehn and Yahr scale or the Unified Parkinson's Disease Rating Scale (UPDRS).

Future Implications

Further studies with larger, more representative cohorts are needed to build the evidence to support nurse navigation as a self-management intervention for people with PD. It would also be beneficial to conduct more longitudinal studies to identify if improvements in self-efficacy due to nurse navigation are sustainable over time. Future research should also include

examination of nurse navigation at a multitude of PD community wellness centers, influence on caregivers, and the application of nurse navigation to patients newly diagnosed with PD who may not be as familiar with the disease as the participants in this study who had a longer duration of diagnosis.

Conclusion

In summary, results show that after a year of PD progression resulting in an overall expected decline in quality of life for participants, nurse navigation was able to improve self-efficacy for managing PD. Additionally, results of a satisfaction survey for participants and healthcare workers at the wellness center showed both groups demonstrated high satisfaction with nurse navigation services overall. Effectively delivering self-management support at a community wellness center specifically designed for people with PD may help meet the diverse needs of people with PD who could benefit from better access to self-management support and guidance.

CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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Table 1

Summary of Nurse Navigation Program

	Topic	Description
Week One	Initial Needs Assessment	Explanation of program, pre-intervention SEMCD-6 completion, medical history review, establish goals of care
Week Two	Medication Review	Review/creation of medication list, medication education (uses, side effects, interactions), pill box distribution
Week Three	Motor Symptom Education	Education and management guidance related to individual predominant motor symptoms
Week Four	Depression and Sleep	Completion of GDS and Epworth sleepiness scale, discussion of findings and approaches to improving depression and sleep
Week Five	Cognition	Completion of MoCA, education related to PD cognitive changes and ways to improve/maintain cognition
Week Six	Medication Review	Review of medication changes, education on and discussion of appropriate management of medications
Week Seven	ADL Assessment	Discussion of functional status and various medical devices and resources available to assist with ADLs and home life
Week Eight	Transportation Assessment	Completion of trail-making-test to assess executive function and discussion of driving safety and alternative transportation options
Week Nine	Advanced Directives	Completion/review of medical power of attorney and living will documents, confirmation that end of life planning is understood and decisions are in place and clearly communicated
Week Ten	Hospital Preparedness	Provided an "Aware in Care" kit from PD foundation, helped with filling kit with personalized information, education of necessary tools and resources pertinent to ensure safe hospitalization with PD
Week Eleven	Medication Review	Education of medication affordability and new medications for PD coming to the market soon
Week Twelve	Closure Assessment	Review goal achievement, discuss areas that still need assistance, post-intervention SEMCD-6

Notes. PD, Parkinson's disease; SEMCD-6, Self-efficacy for Managing Chronic Disease 6-item scale; MoCA, Montreal Cognitive Assessment; GDS, Geriatric Depression Scale; ADLs, Activities of Daily Living.
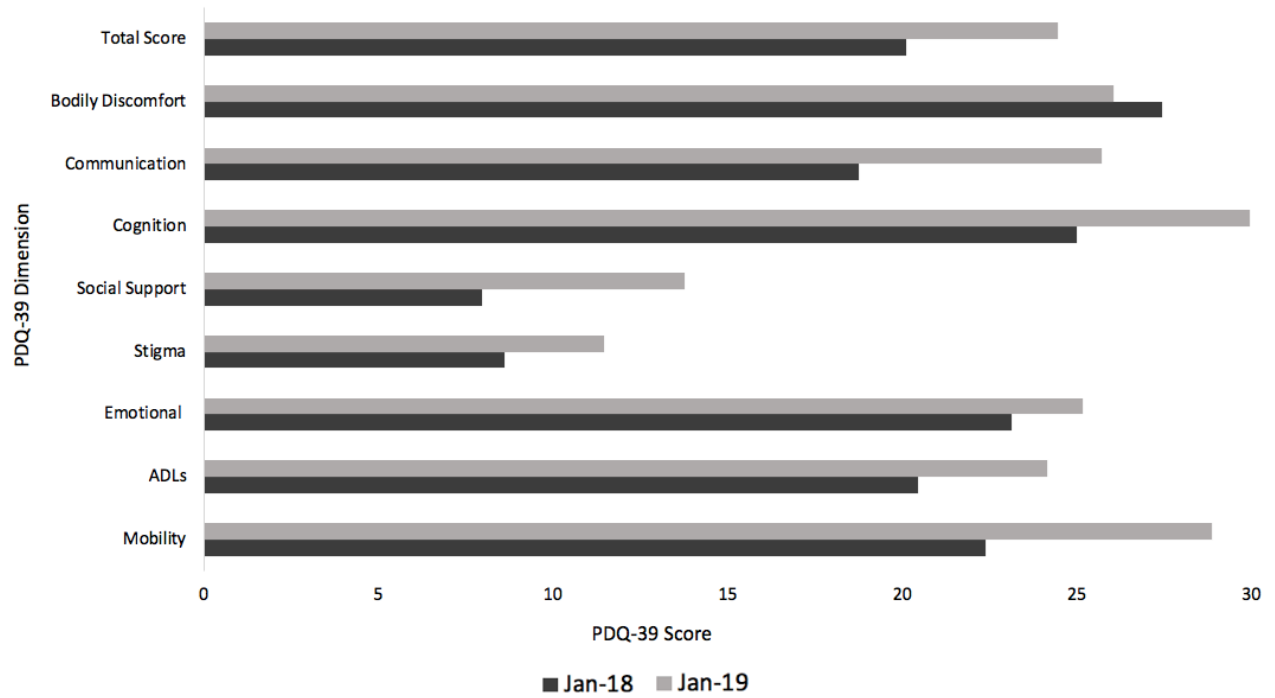
Figure 1 Mean Quality of Life Scores

Figure 1. PDQ-39 scores are reported as a percentage of 100 for participants in 2018 compared to 2019 with inclusion of all 8 individual dimensions assessed by the PDQ-39. Lower numbers indicate better quality of life.

Figure 2

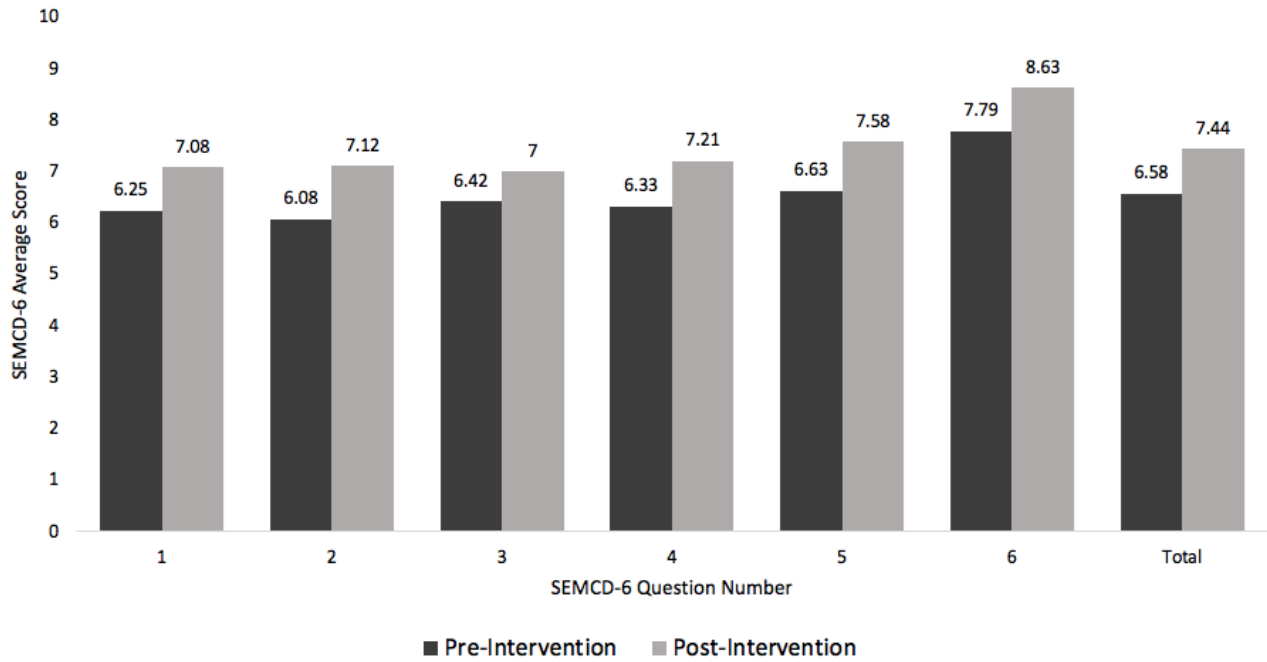*Mean Self-efficacy for Managing Chronic Disease 6-Item Scale scores*

Figure 2. Summary of mean SEMCD-6 scores for each question pre-intervention vs. post-intervention. Scores of this scale are reported on a 1-10 scale with 10 indicating high self-efficacy and 1 indicating low self-efficacy.