

Telehealth Management in Movement Disorder: A Retrospective Study

Angela Roberts-South, Linda Hall, Mandar S. Jog

ABSTRACT: Background: Management of chronic diseases such as movement disorders can be challenging. Nurse-administered telephone follow-up programs have demonstrated clinical and cost efficacy in a variety of health care models. However, their efficacy in movement disorders has not been sufficiently addressed. This observational study fills a knowledge gap by reporting the nature of individuals utilizing a nurse-administered telephone service and the reasons for and the outcomes of calls. **Method:** Consecutive calls received by the clinic for a 12-month duration were recorded. A sample of 312 calls from 132 patient charts was analyzed. Variables for analysis and coding schema were determined a-priori and included demographic information as well as information around the reasons for and outcomes of calls. The narratives of documented calls were reviewed retrospectively and responses coded for analysis by a separate researcher. Data was analyzed using descriptive statistical methods. **Result:** Patients made the majority of calls (49%). 27% of calls related to worsening symptoms and another 35% of calls related to medication issues or renewals. The mean call duration was 15.93 minutes. The majority of calls were received mid-way between clinic visits ($M = 89.24$ days). The nurse resolved 84% of calls independently. The mean number of calls per patient was 2.93. Issues reported by patients were resolved (approximately 90%) without need for follow-up emergency, family, or subspecialty clinic visits. **Conclusion:** The results underscore the complexity of medical issues in a movement disorders population. The current study provides support for a nurse-administered telephone follow-up program in movement disorders.

RÉSUMÉ: La télésanté dans le traitement des troubles du mouvement : étude rétrospective. Contexte : Le traitement des maladies chroniques telles les troubles du mouvement sont un défi. Les programmes de suivi téléphonique assurés par des infirmières ont démontré leur efficacité au point de vue clinique et financier dans différents modèles de soins de santé. Cependant leur efficacité dans les troubles du mouvement n'a pas été étudiée suffisamment. Cette étude d'observation a pour objectif de remédier à cette situation en rapportant les caractéristiques des individus qui ont recours au service téléphonique assuré par des infirmières et les raisons et les résultats des appels. **Méthode :** Les appels consécutifs reçus à la clinique au cours d'une période de 12 mois ont été enregistrés. Un échantillon de 312 appels consignés aux dossiers de 132 patients ont été analysés. Les variables choisies pour l'analyse et le mode de codage ont été déterminés a priori et incluaient de l'information démographique ainsi que de l'information concernant les raisons des appels et les résultats. Le compte rendu des appels documentés a été révisé rétrospectivement et les réponses ont été codées pour fin d'analyse par un autre chercheur. Les données ont été analysées au moyen de méthodes statistiques descriptives. **Résultats :** La majorité des appels provenait de patients (49%). Une aggravation des symptômes était le motif de 27% des appels et 35% des appels concernaient la médication ou son renouvellement. La durée moyenne des appels était de 15,93 minutes. La majorité des appels a eu lieu à mi-chemin entre les visites à la clinique ($M = 89,24$ jours). L'infirmière a résolu de façon indépendante le motif de 84% des appels. Le nombre moyen d'appels par patient était de 2,93. Les questions rapportées par les patients ont été résolues (environ 90%) sans nécessiter de visite de suivi d'urgence, de visite de la famille à la clinique ou de référence en sous-spécialité. **Conclusion :** Les résultats soulignent la complexité des questions médicales chez une population de patients atteints de troubles du mouvement. Cette étude démontre l'utilité d'un programme de suivi téléphonique assuré par une infirmière dans les troubles du mouvement.

Can J Neurol Sci. 2013; 40: 230-234

The management of chronic diseases such as Parkinson disease (PD) and other movement disorders (MD) is complex and benefits from a collaborative approach among patients, caregivers, community providers and clinic staff^{1,2}. Managing the myriad of issues in these conditions exclusively during clinic visits is difficult. Changes made in clinic may require monitoring. Staff may ask patients and care partners to monitor a management change and report back to the clinic. Additionally, patients and care partners may have questions and clinical issues that arise between clinic appointments. The clinical nurse is a critical member of the management team both during and between clinic visits.

A nurse-administered telephone follow-up program (NTF) is one method of managing clinical issues arising between visits

and facilitating collaboration among the patient, family, community, and clinic. Studies have reported the clinical benefit of such programs in a variety of areas including improving discharge outcomes for elderly patients, diabetes management, cardiac risk reduction, and malignant glioma management³⁻⁶.

From the University of Western Ontario (ARS, MSJ); London Health Sciences Centre (LH, MSJ); National Parkinson Foundation Centre of Excellence (ARS, LH, MSJ), London, Ontario, Canada.

RECEIVED NOVEMBER 7, 2011. FINAL REVISIONS SUBMITTED OCTOBER 31, 2012.

Correspondence to: Angela Roberts-South, 339 Windermere Road, A10-026, London, Ontario, N6A 5A5, Canada. Email: asouth4@uwo.ca

Beyond clinical benefit, multiple studies have reported the cost-benefit of NTF's⁷⁻¹⁰.

Presently NTF is a valuable but under-recognized and unreimbursed aspect of care for individuals with MD¹¹. A review of the literature found only two studies reporting the efficacy of such programs in MD. Adam, et al¹² reported on the nature of and outcome of between-clinic calls managed only by MD fellows and neurologists at a tertiary care centre. Liu, et al¹¹ focused on the characteristics of PD patients (anxiety, motor severity, medications) resulting in increased frequency of clinic telephone calls. However, they only reported data for PD. The objective of the present study is to fill a critical knowledge "gap" by reporting the demographics of individuals utilizing the telephone to access the clinic and the nature of issues reported and resolved via a nurse administered telephone follow-up program.

METHOD

Call Data

The study employed a retrospective design. The Human Subjects Research Ethics Board of the University of Western Ontario approved the study protocol and informed consent for calls was obtained per approved protocol. Data were collected from records of patients of a single tertiary care MD centre.

A single MD specialized nurse documented consecutive calls received over a 12-month period (July 2009 – June 2010). As part of routine protocol, the clinic nurse records calls made to the clinic in narrative form in the patient record. For the study, the clinic nurse continued this same process but expanding the data recorded for the purposes of the study. For the study duration, a log was created that documented every call made to the clinic in order to track the number of calls received. A total of 955 patients made calls during the study duration. The clinic services

approximately 4100 patients. A sample of 415 patient charts was randomly selected representing 10% of clinic patients and 43% of patients making calls annually.

All data were extracted from charts retrospectively. For the study, the following data were recorded for each call: caller relationship to patient (e.g. patient, family caregiver, pharmacist, physician office, etc.), reason for call as stated by caller, reason for call as determined by clinical nurse, call duration, staff resolving call issue (nurse vs. physician), duration from time call received to issue resolution, and call outcome (e.g. family physician visit, etc.). Call duration was defined as: direct time spent on phone with caller, time required to retrieve medical chart and determine issue/solution, and time required to document call. Demographic data also were collected from the clinic chart including: age, gender, movement disorder diagnosis, duration of disease, distance living from clinic, number of issues reported/call, number of calls/issue, and duration between call and most recent clinic visit.

To reduce bias, a separate researcher extracted data from the charts for analysis. The primary data sources were the chart entries documenting phone calls. Clinic visit dictations and patient information sheets served as sources of demographic data. The variables for data collection and coding schemas were determined *a priori*. An expert examiner (MJ) independently reviewed all narratives documenting phone calls and coded responses using *a priori* determined descriptors. However, as data were extracted, additional codes were created to accommodate information that did not fit into the *a priori* coding schema.

Statistical Analyses

A descriptive statistical methodology was employed. For categorical data variables, percentage and frequency counts were reported. For continuous data variables, means, standard deviations, and 95% confidence intervals were reported. Statistica software package was used for all analyses.

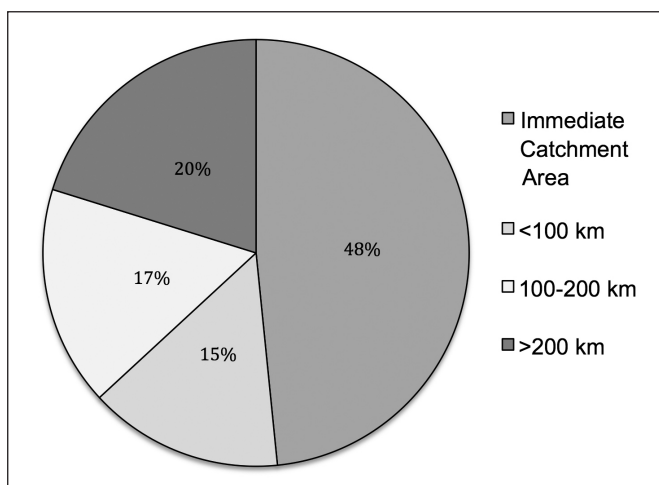


Figure 1: Driving Distance from Clinic Calls Made to Movement Disorder Centre. Data expressed as percentage of total calls (N = 312). Immediate Catchment Area = Calls made from individuals serviced within immediate geographical vicinity (London-Middlesex); < 100 km = Calls made from individuals serviced living < 100 km from clinic but outside of the immediate catchment area.

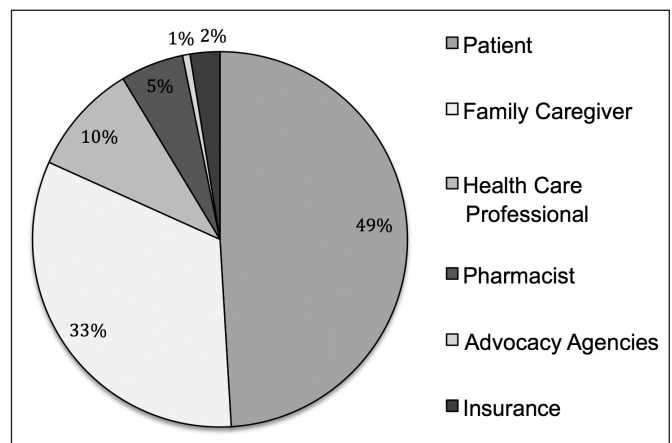


Figure 2: Distribution of Sources of Calls Made to Movement Disorders Centre. Data expressed as percentage of total calls (N = 312). Health Care Professional = physician office, allied health care, community care, etc. Advocacy Agencies = support services such as Parkinson Society Canada.

RESULTS

Demographics of Calls

132/415 sampled patient charts had sufficient documentation for use in the analyses. 312 calls from 132 charts were analyzed. The sample consisted of 35.58% women and 64.42% men. Mean age was 67.94 years (SD = 9.82), 95% CI [66.85, 69.03]. Mean disease duration was 9.79 years (SD = 6.03), 95% CI [9.12, 10.47]. The distribution of diagnoses across calls was: PD (82%), autonomic failure (3.8%), multiple system atrophy (3.2%), tremor (3.2%), Huntington disease (3.2%), Lewy body dementia (1.3%), dystonia (1.3%), restless leg syndrome (.6%), ataxia (.6%), and Tourette's syndrome (.6%). While the age of onset and gender distribution varies across MD, our sample was biased toward PD (82.0%). As such, our mean age, gender, and duration of disease is representative of the population sampled in the study¹³. As a tertiary care centre, the clinic services a large geographical area, which is reflected in the data (Figure 1). Patients and family caregivers (e.g. spouse, child) made the majority of calls; however, calls were received from a variety of individuals involved in the care of patients serviced by the clinic (Figure 2).

Table 1: Issues Reported In Calls Made To Movement Disorders Centre

	% Total
Top 10 Issues Reported by Callers	Calls
Worsening Symptoms (Motor)	27.0
Medication Issues (Non-renewal)	22.4
Renewal	12.4
DBS-PD Symptoms	3.7
Hallucinations	3.3
Insurance	2.5
Psychiatric	2.5
Non-Motor	2.5
Cognition	2.1
Speech and Swallowing	2.1

Calls were analyzed based on reasons stated by callers. Other issues reported in calls not in table above (frequency of occurrence < 2%; Range = 1.7% to .41%) presented in descending order of occurrence: diagnosis questions, motor fluctuations, pain, driving, general treatment questions, dizziness, long term care placement, chorea, urinary dysfunction, GI dysfunction, sleep dysfunction, dyskinesia, balance and falls.

Duration and Nature of Calls

The mean duration of calls was 15.93 minutes (SD = 7.34), 95% CI [15.11, 16.75]. Callers reported approximately one concern per call (M = 1.17, SD = .42, 95% CI [1.08, 1.18]). The mean number of calls per patient was 2.37 (SD = 1.85, 95% CI [2.05, 2.69]). The reasons for calls were diverse but the most common reasons were worsening symptoms and medications (Table 1).

Callers accessed the clinic mid-way between clinic visits (M = 89.24 days, SD = 70.66, 95% CI [81.33, 97.15]). Only 31% percent of calls were related to a concern expressed in a previous call suggesting most caller issues were novel requiring modification to an existing or development of a new management plan. Analysis of the repeat issue calls indicated that the majority of these calls were planned (call-back requested by the nurse) and related to monitoring a management change implemented during a prior phone call. The mean duration between calls was 8.95 days (SD = 23.37), 95% CI [6.33, 11.57].

Resolution of Calls

Data from the current study suggests that a trained MD nurse was able to resolve the majority of calls received by the clinic without physician consultation (83.65% of calls). Additionally, despite a busy clinical practice, calls were returned in an efficient manner (M = .89 days, SD = 1.68, 95% CI [.70, 1.08]). The majority of calls were resolved over the telephone with few issues requiring emergency department visits (2.56%), family physician visits (2.88%), or clinic visits (5.77%). The data of call outcomes suggest that medication changes unrelated to renewals were the primary outcomes of calls (Table 2). However, a substantial number of calls required counseling and teaching.

Table 2: Resolution of Calls Made to Movement Disorders Center

Outcome	% Total
	Calls
Medication Change – Movement Disorder Related Medications	24.68
Counseling/Teaching	17.31
Prescription Renewed (No Change)	13.46
Physician Visit	11.11
Medication Change – Non Movement Disorder Medications	10.26
Issue Resolved Without Intervention	9.30
No Changes to Treatment – No Call Back	7.37
No Changes to Treatment - Call Back	2.88
Form Completed	1.92
Changes to Treatment - Call Back	1.60

DISCUSSION

While the clinical benefit of nurses specializing in MD is known^{2,14}, the present study is the first to report specifically the benefit of a NTF in a specialized MD clinic. The data presented suggest that such a program may have a valuable role in the care of chronic movement disorders. Although these data were sampled from a tertiary care MD center in Canada, it may have applicability across a variety of chronic disease and clinic models.

Consistent with Adam, et al¹² and Liu, et al¹¹ calls were made by multiple individuals in the health care collaboration (patient, family care providers, health care practitioners, etc.). Patients made 49% of calls in the present study. This is consistent with Adam, et al¹² who reported that 48% of the calls in their study were generated by patients. While the utility of telephone follow-up may seem intuitive, Bostrom, et al¹⁵ reported that patients post hospital discharge, while having education needs, did not access medical resources by telephone. Our findings contrast with Bostrom, et al¹⁵ and suggest that a NTF in a MD population is a valuable education and clinical tool.

The results of the present study are consistent with findings from Adam, et al in a similar patient/clinic program where primary reasons for calls to the clinic were either disease (35.1%) or treatment (21.3%) related¹². Although the reasons for calls in the present study are more diverse than those reported previously^{11,12}, the majority of calls were related to worsening symptoms or pharmaceutical treatment issues. Collectively the present study and previous studies^{11,12} suggest that individuals with MD call for a breadth of reasons that represent the care complexity in chronic diseases including psychiatric, non-motor, and cognitive concerns. Despite the fact that the population sampled in this study was largely PD (82%), the diversity and distribution of reasons for calls is largely consistent with the literature on after-hours office calls from other medical practices such as headache¹⁶, internal medicine¹⁷, psychiatry¹⁸, and family medicine¹⁹.

In the present study, the primary outcomes of phone calls, as in the reasons for calls, were medication interventions: changes to PD meds (24.68%), renewals (13.46%), and changes to non-PD meds (10.26%). This is consistent with Adam, et al who reported similar outcomes with 42.5% interventions related to prescription issues¹². This suggests that telephone interventions for a similar population are consistent between a specialized nurse and neurologists. To further support this model, a previous study by Fincher, et al reported that nurse-based telehealth is an effective tool for educating/managing complicated medication routines in PD²⁰.

Aside from medication related issues the time spent in counseling/teaching in both the Adam et al¹² paper (21%) and the current paper (17.3%) are substantial. The critical role of teaching and counseling provided by telephone outside of direct physician visits has been previously reported²¹. Although methodological differences prevent direct comparisons, these similar outcomes, along with a low percentage of family or emergency physician visits suggests the nurse model in the current study had similar efficacy to the physician model in Adam, et al¹². Further, the findings of this study may suggest that nurses spend more time with callers with longer call durations as demonstrated in the present study ($M = 15.93$ minutes) in

contrast to a mean of 6.6 minutes spent by fellows in the Adam, et al study¹². However, methodological differences in calculating this variable between the two studies may also account for the discrepancy.

An important finding from this study is the timing of calls relative to clinic visits. Most subspecialty clinics, including the one in this study, follow patients at six month intervals. In the current study, the mean timing of calls was three months. Sardell, et al in a study of a nurse-led telephone clinic for patients with malignant glioma suggested that the availability of such a telephone service may prevent an otherwise subspecialty clinic visit⁶. The findings of the current study are consistent with Sardell, et al and suggest that a NTF program may allow access to the clinic in order to meet needs that otherwise would be met suboptimally between clinic visits. For example, patients and care partners may have counseling/teaching needs that cannot be deferred to the next scheduled clinic visit. Having access to the clinic may ensure that the information patients and care partners receive is reliable and accurate vs. seeking information from less reliable sources. Additionally, the NTF program may facilitate optimized medication management allowing medication changes to be made by the MD clinic. Cheng et al (2007) reported that four areas of care in PD significantly benefit from being managed by movement disorders specialty vs. by non-neurologists including medication wearing off, falls, depression, and hallucinations²². As such an NTF service delivery model may add substantial value to the care experienced by individuals with PD.

Nurse-administered telephone follow-up programs also may facilitate increased efficiency resulting in a cost benefit to the healthcare system. Previous studies have questioned the cost efficacy of nurse specialists in MD, specifically Parkinson disease^{14,23}. However these studies did not account for time spent in telephone related activities only direct clinic time. In the present study, the nurse was able to independently manage clinical issues 84% of the time suggesting a "complementary" role to the physician-run clinic for telephone follow-up.

A limitation of the study is that the data was collected retrospectively. While the sample was biased toward a PD population, the generalizability of the present study is strengthened by its consistencies with previous studies performed in other countries and other clinical populations/models. Our sample size, while substantial, is smaller than that reported in other comparative studies¹², which may be a limitation. Although cases analyzed were selected randomly, the study design did not specifically consider language or ethnicity, which may bias the sample in this study. It is possible that the utilization of NTF's and the issues raised by telephone may be affected by a variety of social and economic factors.

This study suggests that there is substantial value of a nurse managed telephone follow-up program as a complement to the MD neurologist clinical practice. Future directions should focus on differences among cultural and socioeconomic divisions and how these parameters affect access to and utilization of such programs. As well, this work would benefit from understanding the patient and care partner perceived benefit from such services.

ACKNOWLEDGEMENT

The authors thank Parkinson Society Canada for their financial support for this project.

CONFLICTS OF INTEREST NOTIFICATION

Ms. South is a PhD candidate at the University of Western Ontario and receives support from graduate student awards from Parkinson Society Canada and the University of Western Ontario.

Dr. Jog is a neurologist and sees patients with Parkinson's disease in his clinical practice. He serves on scientific advisory boards for Allergan (Chair 2008, 2009); Novartis (participant 2008-2011); Biovail (participant 2009-2011); Teva (Chair/participant 2008-2010). Travel grants for conference proceedings Teva 2008-11 and Novartis 2009-11, Allergan 2009-11. He has served as the Associate Editor for the Canadian Journal of Neurological Sciences 2008-current. He has received honoraria from Novartis, Allergan, Biovail Pharma, Teva Neuroscience, Merz Pharmaceutical, Boehringer Ingelheim, Prestwick Pharmaceuticals, and GlaxoSmithKline. Dr. Jog is a current co-investigator of two pilot study grants received from Parkinson's Society Canada and is also the recipient of previous and current grants from the Canadian Institutes of Health Research in the role of Primary Investigator and Co-investigator. He has also received funding from the National Research Council of Canada and from Parkinson Society Canada and the Academic Medical Organization of Southern Ontario. He sits on the board of Parkinson Society Canada (1998-present).

Ms. Hall is a clinic nurse specialist at the Centre of Excellence at London Health Sciences Centre. She receives partial financial support for her position from a grant from Parkinson Society Canada.

REFERENCES

- van der Marck MA, Kalf JG, Sturkenboom IHWM, Nijkrake MJ, Munneke M, Bloem BR. Multidisciplinary care for patients with Parkinson's disease. *Parkinsonism Relat Disord.* 2009;15(Suppl 3):S219-23.
- MacMahon DG, Thomas S. Practical approach to quality of life in Parkinson's disease: the nurse's role. *J Neurol.* 1988;245: S19-22.
- Naylor M, Brooten D, Campbell R, et al. Comprehensive discharge planning and home follow-up of hospitalized elders. A randomized clinical trial. *JAMA.* 1999;281(7):613-20.
- Nesari M, Zakerimoghadam M, Rajab A, Bassampour S, Faghizadeh S. Effect of telephone follow-up on adherence to a diabetes therapeutic regimen. *Jpn J Nurs Sci.* 2010;7(2):121-8.
- Mittag O, China C, Hoberg E, et al. Outcomes of cardiac rehabilitation with versus without a follow-up intervention rendered by telephone (Luebeck follow-up trial): overall and gender-specific effects. *Int J Rehab Res.* 2006;29(4):295-302.
- Sardell S, Sharpe G, Ashley S, Guerrero D, Brada M. Evaluation of a nurse-led telephone clinic in the follow-up of patients with malignant glioma. *J Clin Oncol.* 2000; 12(1):36-41.
- Botsis T, Hartvigsen G. Current and future perspectives in telecare for elderly people suffering from chronic diseases. *J Telemed Telecare.* 2008;14:195-203.
- Bertera E, Bertera R. The cost-effectiveness of telephone vs. clinic counseling for hypertensive patients: a pilot study. *Am J Public Health.* 1981;71(6):626-9.
- Lattimer V, Sassi F, George S, et al. Cost analysis of nurse telephone consultation in out of hours primary care: evidence from a randomized controlled trial. *BMJ.* 2000;320:1053-7.
- Riegel B, Carlson B, Kopp Z, LePetri B, Glaser D, Unger A. Effect of a standardized nurse case-management telephone intervention on resource use inpatients with chronic heart failure. *Arch Intern Med.* 2002;162:705-12.
- Liu AA, Boxhorn CE, Klufas MA, et al. Clinical predictors of frequent patient telephone calls in Parkinson's disease. *Parkinsonism Relat Disord.* 2011;17(2): 95-9.
- Adam OR, Ferrara JM, Aquilar Tabora LG, Nashatizadeh M, Negoita M, Jankovic J. Education research: patient telephone calls in a movement disorders centre: lessons in physician-trainee education. *Neurol.* 2009;73(10):e50-2.
- Van Den Eeden SK, Tanner CM, Bernstein AL, et al. Incidence of Parkinson's disease: variation by age, gender, and race/ethnicity. *Am J of Epidemiol.* 2003;157(11):1015-22.
- Jarman B, Hurwitz B, Cook A, Bajekal M, Lee A. Effects of community based nurses specializing in Parkinson's disease on health outcome and costs: randomized controlled trial. *BMJ.* 2002;324(7345):1072-9.
- Bostrom J, Caldwell J, McGuire K, Everson D. Telephone follow-up after discharge from the hospital: does it make a difference. *App Nurs Res.* 1996;9(2):47-52.
- Loder E, Geweke L. Volume and nature of telephone calls in a specialty headache practice. *Headache* 2002;42:883-7.
- Johnson B, Johnson C. Telephone medicine: a general internal medicine experience. *J Gen Intern Med.* 1990;5:234-9.
- Maritz J, Holroyd S. Characteristics of telephone calls in a psychiatric outpatient practice. *J Psychiatr Pract.* 2006;12:195-9.
- Morrison R, Arheart K, Rimmer W. Telephone medicine in a southern university private practice. *Am J Med Sci.* 1993;306(3): 157-9.
- Fincher L, Ward C, Dawkins V, Magee V, Willson P. Using telehealth to educate Parkinson's disease patients about complicated medication regimens. *J Gerontol Nurs.* 2009;35(2): 16-24.
- Closson BL, Mattingly LJ, Finne KM, Larson JA. Telephone follow-up program evaluation: application of Orem's self-care model. *Rehabil Nurs.* 1994;19(5):287-92.
- Cheng M, Swartztrauber K, Siderowf A, et al. Association of specialist involvement and quality of care for Parkinson's disease. *Mov Dis.* 2007;22(4):515-22.
- Reynolds H, Wilson-Barnett J, Richardson G. Evaluation of the role of the Parkinson's disease nurse specialist. *Int J Nurs Stud.* 2000; 37:337-49.