



## Short communication

## Telemedicine in Parkinson's disease: A patient perspective at a tertiary care centre

Judy K. Qiang<sup>a</sup>, Connie Marras<sup>b,\*</sup><sup>a</sup> Faculty of Medicine, University of Toronto, 1 King's College Circle, Toronto, ON M5S 1A8, Canada<sup>b</sup> Morton and Gloria Shulman Movement Disorders Centre and the Edmond J. Safra Program in Parkinson's Research, Division of Neurology, University of Toronto, 399 Bathurst St., Toronto, ON M5T 2S8, Canada

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## ABSTRACT

**Introduction:** To overcome travel distance and lack of local expertise, telemedicine programs have been implemented and are still pilot programs in many jurisdictions. Patient perspectives remain poorly understood. In the largest study to date, we examined user satisfaction and predictors of patient choice to use telemedicine among Parkinson's Disease (PD) patients in the context of a well-developed telemedicine system. These data can help to optimize healthcare delivery by telemedicine.

**Methods:** A patient satisfaction questionnaire was administered to current or previous users via telephone. Patients' cost savings were determined. The proportion of non-users interested in using telemedicine was quantified. Demographic and clinical characteristics of those who expressed interest in the program vs. those who did not were compared.

**Results:** A total of 34 users and 103 non-users were recruited. Users reported an average cost reduction of \$200 and 209 minutes of reduction in commute time ( $p < 0.01$ ). While a majority (29/34 users) reported interest in continuing with telemedicine, inexperience of some telehealth nurses was a major source of patient dissatisfaction. Patients preferred a combination of telehealth and in-person visits. A majority of non-users (55/103, 53%) declared interest in telemedicine, but it had not been offered to them. A lower Hoehn and Yahr stage and a longer commute time were associated with patient interest in telemedicine.

**Conclusions:** Training of nurses is an important determinant of patient satisfaction. Clinicians should consider offering telehealth to all patients for whom it is medically appropriate, especially those who experience long travel times.

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## 1. Introduction

The progressive nature of both motor and cognitive dysfunction seen in Parkinson's Disease (PD) creates a significant burden not only for the affected individual, but also for their caretakers and society at large. The growing disability, coupled with travel distance and lack of available expertise limit access to care and increase healthcare costs. To overcome these barriers in PD and other diseases, telemedicine programs have been implemented and remain in pilot stages in many jurisdictions [1].

The Ontario Telemedicine Network (OTN) is a well-developed service that has been in use for more than a decade [2]. It offers patients the option of attending clinical appointments via video conferencing at one of the telehealth centres (either a community clinic or hospital) close to patients' homes. In some areas, patients may be able to connect with their physicians using telemedicine from home.

Several studies have shown that assessment of motor impairment in PD via telehealth is feasible, valid, and reliable [3,4]. Randomized clinical trials (RCTs) have shown that telemedicine programs for PD care could be feasible, cost-effective, and provide clinical benefit equivalent to that of traditional in-person care [5,6]. A case report found both motor and cognitive improvements in a PD patient at the end of an eight-month trial of telemedicine [7]. Furthermore, RCTs have shown that compared with in-person care, those randomized to telehealth had significant improvements in quality of life [8].

\* Corresponding author. Division of Neurology, University of Toronto, Movement Disorders Centre, 7MCL, 399 Bathurst St. Toronto, ON M5T 2S8, Canada. Tel.: +1 416 603 6422.

E-mail addresses: [j.qiang@mail.utoronto.ca](mailto:j.qiang@mail.utoronto.ca) (J.K. Qiang), [connie.marras@uhnresearch.ca](mailto:connie.marras@uhnresearch.ca), [cmarras@uhnresearch.ca](mailto:cmarras@uhnresearch.ca) (C. Marras).

These results suggest that an important aspect of optimizing care for PD patients in the future will be to understand how to optimize the application and the uptake of telemedicine. A recent case series of 35 patients in the U.S. reported that patient satisfaction with telehealth visits exceeded 90% [9]. Although encouraging, it is important to know if these results are generalizable to other telemedicine systems and to understand reasons for dissatisfaction.

In this study, we built upon previous studies by measuring satisfaction with telehealth services, rates of patient retention, as well as reasons for discontinuing telemedicine. We also measured the proportion of patients interested in telemedicine in a large cohort at an academic centre, and identified predictors of patient interest in telemedicine. The perspectives of non-users of telehealth have not been studied to our knowledge. Understanding these perspectives can help to optimize the uptake of telemedicine services.

## 2. Methods

### 2.1. Participants

All PD patients who have used telehealth at some point since 2009 at Toronto Western Hospital were invited to participate in the study. Adult PD patients not using telehealth, seen at our clinic during October and November 2013, were also invited to participate. Telephone interviews were completed either by patients themselves or by proxy in cases where patients had difficulty participating in the study due to communication barriers and/or cognitive impairment. This study was approved by the University Health Network Research Ethics Board.

### 2.2. Procedures

Users and non-users of telehealth at Toronto Western Hospital, Movement Disorders clinic completed a structured telephone interview. Users were asked to report cost of travelling and travel times to our clinic vs. cost of travelling and travel times to the nearest telehealth centre. All of our patients had received telemedicine services at the most conveniently located centre. This minimized the amount of travelling, but did not completely eliminate the need for commute to their appointments. They were also asked whether they would continue using telehealth, and to provide a reason if discontinuing telemedicine. A patient satisfaction questionnaire with each question answered using a six point Likert scale (Supplementary Table 1) was administered.

Non-users were asked whether they would be interested in using telehealth services. The description of telehealth for non-users can be found in Supplementary Methods. Demographic and clinical characteristics of those who declined telehealth vs. those who chose telehealth vs. those who were unsure about telehealth were compared. Non-users were also asked to provide reasons for and against telemedicine. Clinical data, including most recent United Parkinson's Disease Rating Scale (UPDRS) motor score and Hoehn and Yahr (H&Y) stage was obtained by chart review.

### 2.3. Statistical analysis

Demographic and clinical characteristics of non-users were summarized and compared in groups according to their interest in telemedicine services. Continuous variables were compared using Analysis of Variance (ANOVA). Categorical variables were compared using the chi-square test.

Mean reduction in travel time, distance, and associated costs were quantified with significant reductions determined by *t* tests. Level of satisfaction with telehealth was compared between patients who continued and patients who discontinued using it by *t* test. Statistical significance was set as a two-tailed  $p \leq 0.05$ .

## 3. Results

### 3.1. Experience of support staff is an important source of dissatisfaction

Of the 76 PD patients who currently use or previously used telehealth, we were able to contact 51. 34 users chose to participate in the study. Demographic and clinical characteristics of these patients are shown (Table 1). Users reported an average of \$200 in cost reduction ( $p < 0.01$ ), an average of 209 minutes in travel time reduction ( $p < 0.01$ ), and an average reduction of 160 km in distance travelled to clinical appointments ( $p < 0.01$ ) per clinical visit.

**Table 1**

Clinical characteristics of telehealth users and non-users.

| Variable                           | Users               | Non-users          |
|------------------------------------|---------------------|--------------------|
| Total number                       | 34                  | 103                |
| Average age at survey (SD)         | 65.8 yrs (11.5 yrs) | 67.6 yrs (9.1 yrs) |
| Average disease duration (SD)      | 14.5 yrs (6.7 yrs)  | 10.7 yrs (5.9 yrs) |
| Gender                             |                     |                    |
| Male (%)                           | 27 (79%)            | 66 (64%)           |
| Female (%)                         | 7 (21%)             | 37 (36%)           |
| First language                     |                     |                    |
| English speakers (%)               | 27 (79%)            | 85 (83%)           |
| Non-English speakers (%)           | 7 (21%)             | 17 (17%)           |
| Employment                         |                     |                    |
| Retired (%)                        | 22 (65%)            | 69 (67%)           |
| Working (%)                        | 9 (26%)             | 18 (17%)           |
| Disability (%)                     | 1 (3%)              | 14 (14%)           |
| Education level                    |                     |                    |
| University degrees or higher (%)   | 12 (35%)            | 56 (54%)           |
| High school or college degrees (%) | 20 (59%)            | 44 (43%)           |
| Average UPDRS III score            | 24.2                | 20.7               |
| (most recent F/U)                  |                     |                    |
| Missing (n)                        | 9                   | 15                 |
| H&Y (most recent F/U)              |                     |                    |
| <2                                 | 2                   | 10                 |
| 2–3                                | 13                  | 48                 |
| ≥3                                 | 10                  | 30                 |
| Missing (n)                        | 9                   | 15                 |

Most users (29/34, 85%) chose to continue with telehealth. All five patients who discontinued telehealth were treated with Deep Brain Stimulation (DBS), and required the assistance of a trained technician or nurse during the telehealth visit. The inexperience of these personnel, as compared to those at the Movement Disorders centre was cited as a major reason for discontinuing telehealth. One patient terminated the use of telemedicine due to relocation to another major city and preference for a local Movement Disorders specialist.

Close to 90% of users reported feeling either highly satisfied or satisfied with the technical aspects of using telehealth. Additionally, users in our study reported a rate of close to or over 80% satisfaction with the various aspects of quality of care (Fig. 1). There was no difference in satisfaction scores between individuals of H&Y stage 2 or less compared with those of H&Y stage 3 or higher.

Not surprisingly, those who discontinued telemedicine were significantly less satisfied with the program than those who chose to continue with telehealth ( $p < 0.01$  for technical aspects and quality of care).

While 29/34 patients chose to continue with telehealth, 22/34 patients desired a combination of in-person and telehealth visits. Only 11/34 patients actually preferred telehealth to in-person visits, despite the fact that 30/34 patients felt it was easier to attend their appointments via telehealth.

### 3.2. Non-users are interested in using telehealth

Of the 253 PD patients who were seen at our centre during October and November 2013, we were able to contact 172 patients. 103 patients ultimately decided to participate in our study. Patient characteristics are shown (Table 1).

A majority of non-users (55/103, 53%) were interested in using telehealth, either partially or completely replacing their in-person visits. These patients have never used telehealth either because they did not know about the program and/or because they were never invited to use telehealth by their physicians. 41/103 (40%) of patients were not interested in telemedicine services; 7/103 or 7% of subjects were unsure about using telehealth.

Those who were interested in telehealth felt that use of telemedicine would result in significant cost savings. Others felt their

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