Feasibility of telemedicine for patients with parkinsonism in the Brazilian public health system

# Viabilidade da telemedicina para pacientes com parkinsonismo no sistema público de saúde brasileiro

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Arq. Neuropsiquiatr. 2022;80(9):914-921.

Abstract	<ul> <li>Background Telemedicine for patients with parkinsonism is feasible, cost-effective and satisfactory. However, the feasibility of this modality of care for this subpopulation is not known in real-life scenarios of developing countries like Brazil.</li> <li>Objective To evaluate the feasibility of telemedicine for patients with parkinsonism in a developing country.</li> <li>Methods A cross-sectional study with patients with parkinsonism treated in the Brazilian public healthcare system. We included 130 patients, who were contacted by telephone; those who could be reached underwent a structured interview for data collection. The primary outcomes were the feasibility of teleconsultations and video consultations, but we also performed a logistic regression regarding the feasibility of a video consultation and associated factors.</li> </ul>
<ul> <li>Keywords</li> <li>Parkinsonian Disorders</li> <li>Parkinson Disease</li> <li>Telemedicine</li> <li>Remote Consultation</li> </ul>	<b>Results</b> Telemedicine was feasible and accepted by 69 (53.08%) patients regarding teleconsultations and by 50 (38.5%) patients regarding video consultations. Teleconsultations were feasible for 80.2%, and video consultations were feasible for 58.1% of the patients reachable through telephone calls. Having a higher family income was positively correlated with the feasibility for a video consultation while a negative association was observed regarding being married or in a stable union and having a low level of schooling.

received October 11, 2021 accepted December 13, 2021 DOI https://doi.org/ 10.1055/s-0042-1755323. ISSN 0004-282X.

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**Conclusions** A significant proportion of patients with parkinsonism in a developing country are unreachable, unwilling, or unable to participate in telemedicine. Among the reachable patients, feasibility is higher but still lower than what is reported in studies in developed countries. Family income, level of schooling, and marital status were associated with the feasibility of video consultations.

ResumoAntecedentesA telemedicina para pacientes com parkinsonismo é viável, econômica<br/>e satisfatória. No entanto, a viabilidade dessa modalidade de atendimento para essa<br/>subpopulação não é conhecida no cenário da vida real de países em desenvolvimento<br/>como o Brasil.

**Objetivo** Avaliar a viabilidade da telemedicina para pacientes com parkinsonismo em um país em desenvolvimento.

**Métodos** Estudo transversal com pacientes com parkinsonismo atendidos na rede pública de saúde brasileira. Foram incluídos 130 pacientes, que foram contatados por telefone; os que responderam foram submetidos a uma entrevista estruturada para coleta de dados. Os resultados primários foram a viabilidade para teleconsultas e videoconsultas, mas também foi realizada uma regressão logística entre a viabilidade de uma videoconsulta e fatores associados.

**Resultados** A participação em telemedicina era possível ou consentida por 69 (53,08%) dos pacientes com relação a teleconsultas, e por 50 (38,5%) com relação a videoconsultas. As teleconsultas e videoconsultas eram viáveis para 80,2% e 58,1% dos pacientes acessíveis por telefone, respectivamente. Uma maior renda familiar foi positivamente correlacionada com a viabilidade de uma videoconsulta, enquanto uma associação negativa foi observada com relação a ser casado ou estar em união estável e ter baixo grau de escolaridade.

- Palavras-chave
- Transtornos
   Parkinsonianos
- Doença de Parkinson
- Telemedicina
- Consulta Remota

**Conclusões** Uma proporção significativa de pacientes com parkinsonismo em um país em desenvolvimento é inacessível, não quer, ou não pode participar da telemedicina. Entre os pacientes contatáveis, a viabilidade é maior, mas ainda menor do que a relatada em estudos em países desenvolvidos. Renda familiar, escolaridade e estado civil foram associados à viabilidade das videoconsultas.

# INTRODUCTION

Parkinson's disease (PD) and other forms of atypical parkinsonism are chronic neurodegenerative disorders associated with a considerable healthcare burden and the need for frequent specialized medical consultations for symptomatic management.<sup>1,2</sup> Telemedicine for patients with parkinsonian syndromes is a topic of interest due to the unequal geographical distribution of healthcare providers, the limited supply of neurologists, and the fact that many patients do not reside close to a movement disorders clinic.<sup>3</sup> The recent coronavirus disease 2019 (COVID-19) pandemic hindered access to specialized care by these patients due to the need to reduce the risk of contamination through quarantine measures.<sup>4</sup> This scenario increased even more the demand for patient care to be delivered through telemedicine.<sup>5–7</sup>

Several studies have demonstrated the feasibility, cost reduction, satisfaction reported, and effectiveness of telemedicine for patients with PD.<sup>8–12</sup> However, most were conducted in developed countries, had strict inclusion and exclusion criteria, or were performed using protocols that would facilitate telemedicine through the provision of the technological means necessary for it and instructions on how to use them. It is unknown how feasible it is to locate patients with parkinsonian syndromes and perform teleconsultations for them in developing countries such as Brazil, where limited access to the technological means to undergo a teleconsultation or video consultation or a low level of schooling could hinder this modality of care. The present study aims to assess the feasibility of telemedicine in a Brazilian public healthcare center for patients with PD and parkinsonian syndromes.

# **METHODS**

#### Design

We conducted a cross-sectional study aimed to evaluate the feasibility of telephone and video consultations for patients with PD and other parkinsonian syndromes regularly followed up in a movement disorders clinic of the Brazilian public health system. The feasibility of a teleconsultation was defined as a patient being reachable through a telephone call and being able and willing to participate in telemedicine. The feasibility for video consultations was defined as a patient who is not only able to participate, but who also possesses the technological means, the knowledge on how to use them, and interest in participating. The present study was reviewed and approved by the Ethics Committee of Hospital de Clínicas de Porto Alegre, in Southern Brazil, and all the measures to protect the data and privacy of the patients were strictly followed. We also followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement.<sup>13</sup>

# Participants

The participants were patients currently in follow-up in a movement disorders clinic that provides care for patients with variable degrees of complexity, ranging from those with only mild symptoms to those who require deep brain stimulation. All patients had a diagnosis of PD as per the Movement Disorders Society diagnostic criteria<sup>14</sup> or of other parkinsonian syndromes. A convenience sample of 130 patients that had their visits impaired by the restrictions imposed by the COVID-19 pandemic between May and September 2020 was obtained, and all of them were included in the study.

## Data collection procedures and variables

Telephone calls using data from the clinic's registry were performed to locate the 130 patients. All telephone numbers were called at least twice in different days before considering a patient unreachable for telemedicine. After the patient and/or caretaker answered the call, we excluded the subjects who were not interested in participating in telemedicine, those who were no longer alive, and those who were living in nursing homes or were hospitalized. After the subjects agreed to participate, a structured interview to collect data was performed. Informed consent regarding data collection was obtained via verbal confirmation by telephone of the procedures, and a form to obtain written proof was sent electronically to the patients by the means chosen by them, such as a messaging applications or email. Data regarding the dementia status was obtained by consulting the patients' electronic medical records.

Data collection yielded the following sociodemographic and clinical data: rate of answers to the telephone calls, number of patients who failed to meet the to inclusion criteria, age, gender, presence of a caretaker, marital status, ethnicity, level of schooling, family income, clinical diagnosis, disease duration, a previous diagnosis of dementia, treatment with deep brain stimulation, and score on the Schwab and England Activities of Daily Living (ADL) scale.<sup>15</sup> Opinions regarding telemedicine were collected through questions on: the effectiveness of telemedicine for patients with parkinsonian syndrome, the possibility of worsened care if the patient only underwent evaluations through telemedicine, the time needed to travel to arrive at the clinic, and the possible benefits of teleconsultations in comparison to in-person visits (open-ended question). Lastly, the feasibility of video consultations was evaluated through the following variables: owning a telephone, tablet or a computer with adequate internet access, having the knowledge on how to use one of these devices to participate in a video consultation, which applications were preferred for a video consultation, being interested in participating, and, if the help of someone was required for the video consultation. The primary outcomes were: 1) being reachable to receive an invitation for a teleconsultation through telephone calls and not presenting any exclusion criteria; and 2) having the interest, technological means and knowledge in handling the technology required to undergo a video consultation.

## Statistical analysis

The numerical variables were expressed as means and standard deviations, and the categorical variables, as absolute and relative frequencies. The following variables were dichotomized for purposes of statistical analyses: marital status (married or stable union versus single, widowed or divorced), dependency status as per the proposed cut-off of 80% to consider a patient dependent in the Schwab and England ADL scale (sensitivity: 85%; specificity: 69%),<sup>15</sup> and low level of schooling (elementary school or lower versus higher levels of schooling). To evaluate the predictors of the feasibility of undergoing a video consultation, we performed a univariate analysis regarding the readiness for it (measured by the interest, the technological means, and the knowledge to use said means) and the variables of interest. Statistical significance was determined by values of  $p \leq 0.05$ , and the confidence interval (CI) used was of 95%. A backward stepwise multivariate logistic regression model was constructed with the variables exhibiting values of  $p \leq 0.2$  in the univariate analysis. All analyses were performed using Python, version 3.6.9, and the modules Pandas, version 1.2.5, SciPy, version 1.7.0, and Statsmodels, version 0.12.2.

# RESULTS

#### **Descriptive statistics**

The sociodemographic and clinical data are presented in **- Table 1**. The mean age of the sample was 64.68 years, and 67.8% were male, 56.5% were married or in a stable union, and 89.9% were white. The level of schooling was low, with 24.6% having concluded elementary school and only 17.4% with a bachelor degree or with a higher level of schooling. Family income showed an overall poor population; 21.7% and 46.4% earned 1 and 2 minimum wage per month respectively. The most prevalent disease (91.3%) was PD, and the mean duration of the disease was 1of 0.94 years. Most (81.2%) did not have dementia, and only a minority (17.4%) was undergoing treatment with deep brain stimulation. As per the Schwab and England ADL scale, 78.3% were dependent.

**- Table 2** contains the opinions regarding telemedicine and questions on the feasibility of video consultations. Most care-takers or patients (89.86%) considered teleconsultations effective, while almost half considered that care can be worsened if patients only had this modality of assistance. The mean time needed to travel to arrive at the clinic was of 91.30 minutes. The most reported benefits of teleconsultations were not needing to mobilize the patient for an in-person visit

**Table 1** Sociodemographic and clinical data (n = 69)

Variables				
Age, mean $\pm$ standard deviation	64.68 ± 11.10			
Gender, male	44	63.8%		
Marital status, married or stable union	39	56.5%		
Ethnicity, white	62	89.9%		
Degree of education				
Elementary school or lower	17	24.6%		
Middle school	14	20.3%		
High school	26	37.7%		
Bachelor degree or higher	12	17.4%		
Family income (monthly minimum wages)				
1	15	21.7%		
2	30	43.5%		
3	15	21.7%		
4 or more	9	13.0%		
Diagnosis, Parkinson's disease	63	91.3%		
Disease's duration, mean $\pm$ standard deviation	mean $\pm$ standard deviation 10.94 $\pm$ 6.71			
Absence of dementia	56	81.2%		
Treatment with deep brain stimulation	12	17.4%		
Schwab and England scale, dependen <sup>1</sup>	54	78.3%		

Data presented as n and %, unless otherwise specified.

<sup>1</sup>Score of 80% or lower in the scale.

(66.7%), safety during the COVID-19 pandemic (33.3%), and not needing to pay for travel costs (30.4%). Most patients or caretakers had a telephone, tablet or computer with internet access (85.5%) and knowledge on how to use these devices for video consultations (79.7%). They reported having the means and interest in attending a video consultation (72.5%), which, for most of the sample (88%), would be held using a smartphone and with the aid of someone else (74%).

# Feasibility of telemedicine

Out of the 130 patients included in the present study, being reachable and willing to undergo a teleconsultation was

**Table 2** Opinions regarding telemedicine for parkinsonism and questions regarding the feasibility of video consultations (n = 69)

		N	%
Teleconsultation is effective		62	89.9%
Worsened care if only by teleconsultation		29	42.0%
Travel time to the clinic (minutes): mean $\pm$ standard deviation		91.30±87.7	
Benefits of teleconsultations (open-ended)	No need to mobilize patient for in-person visit	46	66.7%
	Safety in the context of the COVID-19 pandemic	23	33.3%
	No need to pay for travel costs	21	30.4%
	No need to wait in a waiting room	1	1.5%
	Possibility of more consultations	2	2.9%
Has a telephone, tablet or computer with internet access		59	85.5%
Knows how to use technology for video consultations		55	79.7%
Has the interest and means to attend to a video consultation		50	72.5%*
Technology preferred for video consultations ( $n = 50$ ): smartphone		44	88.0%
Would receive aid from a caretaker in a video consultation ( $n = 50$ )			74.0%

Notes: Data presented as numbers and percentages, unless otherwise specified. \*In comparison to the total study population, the prevalence is of 38.5% (n = 130).

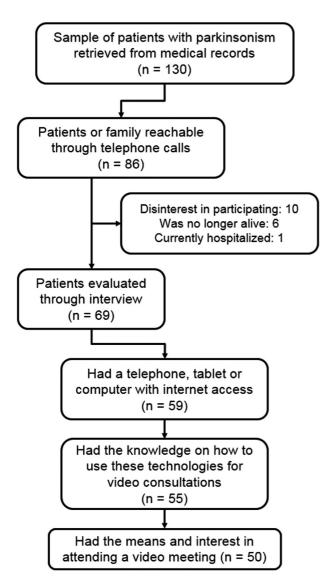


Figure 1 Patient evaluation during each stage of data collection.

feasible for 69 (53.1%) subjects, while a video consultation for the evaluation of motor parameters was feasible for 50 (38.5%) participants. Among the patients who were reachable through telephone calls (n = 86), teleconsultations were feasible for 80.2%, and video consultations were feasible for 58.1%. **- Figure 1** shows the number of patients who were evaluated in each step until the information on the feasibility of undergoing a teleconsultation or video consultation was obtained.

## Predictors of the feasibility of a video consultation

**– Table 3** describes the univariate logistic regression analyses, in which the feasibility of undergoing a video consultation was associated with family income, marital status and level of schooling, and was not correlated with age, gender, clinical diagnosis, disease duration, presence of dementia, and dependency status. In the final multivariate model, family income was positively correlated with the feasibility of undergoing a video consultation (odds ratio [OR]: 2.78; 95%CI: 1.16–6.67; p = 0.02), and being married or in a stable union and having a low level of schooling were associated

with a lower chance of being able to undergo a video consultation (OR: 0.19; 95%CI 0.05–0.76; p = 0.02; and OR: 0.22; 95%CI: 0.06–0.83; p = 0.02 respectively). These results are displayed in **- Table 4**.

# DISCUSSION

The present study aimed to evaluate the feasibility of telemedicine for patients with parkinsonism in a developing country such as Brazil. We observed that only 53.1% of patients included were reachable and able or willing to undergo a teleconsultation, while 38.5% ultimately had the technological means, the knowledge on how to use the devices for video consultation, and interest in undergoing one. Among the reachable patients, teleconsultations were feasible for 80.2% and video consultations, for 58.1%. To our knowledge, this is one of a few studies to address the feasibility of teleconsultations and video consultations for patients with parkinsonism in the real-life scenario of the public healthcare system of a developing country.

The only other study conducted in a developing country regarding the same topic was performed in Egypt, and the authors<sup>16</sup> reported a rate of telemedicine readiness higher than the one found in our study. In that study,<sup>16</sup> the authors were able to reach 39 out of 51 patients with PD (76.5%), and only 21 (41.2% of the total sample and 53.4% of the reachable patients) of them declared they were able to attend a virtual visit. Most had a low socioeconomic status (57.9%) and had levels of schooling ranging from illiterate to preparatory school (52.6%).<sup>16</sup> Most other studies on this topic were clinical trials<sup>8,10,11</sup> performed in the United States, and some were observational studies,<sup>9,12</sup> all with satisfactory adherence to telemedicine and virtual visits. Overall, the participants in those studies had a high level of schooling (67% to 73.2% had a bachelor's degree in some studies,<sup>8,11</sup> while others<sup>9,12</sup> reported that at least 98.8% had studied until high school or higher). Beck et. al.<sup>11</sup> identified that 97.9% of their participants had familiarity with internet use and 44.3% had already undergone virtual visits, while another study<sup>12</sup> reported that 98.8% of its participants had access to the internet. Socioeconomic status was often not reported, but, based on the aforementioned data, it can be assumed to be high. These observations indicate that, considering how public healthcare services are currently organized in developing countries like Brazil, telemedicine is not feasible for a considerable portion of patients.

The low rate of feasibility of telemedicine found in the present study and in the one conducted in Egypt<sup>16</sup> could be explained by a variety of reasons. Administrative limitations play an important role, since having outdated or incorrect contact data for the patients could lead to a high rate unreachable patients, which may partially be resolved as healthcare services adapt to the recent needs of telemedicine.<sup>6</sup> Moreover, cultural barriers could contribute to a low rate of feasibility, as patients who are not accustomed to telemedicine could refuse it for thinking it would be ineffective or even for not trusting an evaluation made through a telephone call by a stranger.<sup>17</sup> Finally, telemedicine in

	Had the means and interest in attending a video consultation $(n = 69)$		OR (95%CI)	<i>P</i> -value
	No (n = 19)	Yes (n = 50)		
Age (years)	-	-	1.02 (0.97–1.07)	0.36
Family income (monthly minimum wages)	-	-	2.21 (1.1–4.44)	0.03
Disease duration	-	-	1.04 (0.95–1.13)	0.42
Gender: male	14 (73.7%)	30 (60.0%)	0.54 (0.17–1.72)	0.29
Marital status: married or in a stable union*	15 (79%)	24 (48.0%)	0.25 (0.07–0.85)	0.03
Level of schooling: low**	9 (47.4%)	8 (16.0%)	0.21 (0.07–0.69)	0.01
Diagnosis of Parkinson disease	18 (94.7%)	45 (90.0%)	0.5 (0.05–4.58)	0.54
Absence of dementia	17 (89.5%)	39 (78.0%)	0.42 (0.08–2.09)	0.29
Treatment with deep brain stimulation: yes	1 (5.3%)	11 (22.0%)	5.08 (0.61-42.38)	0.13
Classification in the Schwab and England Activities of Daily Living scale: dependent***	14 (73.7%)	40 (80.0%)	1.43 (0.42–4.91)	0.57

Table 3 Univariate logistic regression regarding the feasibility of video consultations and clinico-demographic variables

Abbreviations: 95%CI, 95% confidence interval; OR, odds ratio.

Notes: The categorical variables are expressed as absolute and relative frequencies. \*Versus "single, widowed or divorced". \*\*Elementary school or lower. \*\*\*Score of 80% or lower on the scale.

Table 4 Multivariate logistic regression between feasibility of video consultations and clinico-demographic variables

Step 1: initial multivariate model	OR (95%CI)	p-value
Family income (monthly minimum wages)	2.63 (1.09–6.25)	0.03
Marital status: married or in a stable union*	0.2 (0.05–0.81)	0.02
Level of schooling: low**	0.16 (0.04–0.71)	0.02
Treatment with deep brain stimulation: yes	7.69 (0.78–100.0)	0.08
Step 2: final multivariate model	OR (95%CI)	p-value
Family income (monthly minimum wages)	2.78 (1.16–6.67)	0.02
Marital status: married or in a stable union*	0.19 (0.05–0.76)	0.02
Level of schooling low**	0.22 (0.06-0.83)	0.02

Abbreviations: 95%CI, 95% confidence interval; OR, odds ratio.

Notes: The categorical variables are expressed as absolute and relative frequencies. \*Versus "single, widowed or divorced". \*\*Elementary school or lower.

general (both for teleconsultations and video consultations) depends directly on the availability of the technological means to access it, internet connection, and the knowledge on how to use these devices, which is directly dependent on a person's income .

In the present study, most patients or caretakers considered teleconsultations effective, an observation also reported by studies on the same topic performed in developed<sup>10</sup> and developing countries.<sup>16</sup> The mean time needed to travel to arrive at the movement disorders clinic in the present study was high, especially in a vast country such as Brazil. This is probably associated with the main reported benefits of teleconsultations in comparison to in-person visits, which were not needing to mobilize the patient or to pay for travel costs. Smartphones were the preferred tool for video consultations, which indicates that this device is mostly available to patients despite their low family income.<sup>18</sup>

In the present study, the patients or caretakers had a low level of schooling, with only approximately 17.4% having a bachelor's degree or higher. As aforementioned, this finding is in contrast to those of studies conducted in developed countries,<sup>8-12</sup> in which most participants had at least a high school or bachelor's degree or a higher level of education. In support of these observations, we identified that low levels of schooling were associated with low rates of feasibility of undergoing a video consultation. In a previous study by Darrat el al.<sup>19</sup> on patient participation in telehealth during the COVID-19 pandemic, the authors did not identify an association between the level of schooling and video telehealth adherence, but most of the patients included had high levels of schooling. Family income was correlated with the feasibility of a virtual visit,<sup>19</sup> a finding also reported herein. In the present study, being married or in a stable union was associated with a lower chance of a patient undergoing a video consultation, which is in contrast to what was reported by Darrat et al.<sup>19</sup> One hypothesis is that our patient's companions could also be care-dependent and unable to help the patient undergo in a video consultation.

Despite the relatively small sample size, we were able to recruit more subjects compared with previous similar studies.<sup>12,16</sup> Other strengths of the present study are the evaluation of telemedicine feasibility in a real-life scenario and the collection of clinico-sociodemographic factors associated with video consultations. One limitation of the present study was that we did not collect data on physician satisfaction regarding the teleconsultation. Future studies on this topic with larger sample sizes in developing and low-income countries are needed to better understand and identify the obstacles found in providing telemedicine for patients with parkinsonism. Investigations of cost- and quality-related outcomes are also encouraged to better understand the benefits of this modality of care in this setting.

The results herein reported indicate that several measures are important to ascertain the feasibility of telemedicine in developing countries. First, having an adequate medical registry of telephone numbers and e-mail addresses of patients is pivotal. Moreover, cultural barriers to telemedicine should be addressed in in-person visits, as uncertainty regarding the participation in telemedicine may have been one of the reasons why patients did not agree to participate in the present study. Lastly, the technological and educational limitations inherent to a country's development stage are difficult and complex to overcome, for they are dependent on local socioeconomic conditions and policies. These and other barriers and possible directions for telemedicine for patients with PD are thoroughly discussed elsewhere.<sup>20</sup>

In conclusion, a significant proportion of patients currently in follow-up in a movement disorders clinic in a public healthcare setting of a developing country were unreachable, unwilling, or unable to participate in teleconsultations or video consultations. Even among reachable patients, the rate of feasibility of teleconsultations was lower than what is reported in studies conducted in developed countries, with video consultations feasibility also being low. General opinion of patients or caretakers regarding telemedicine was positive in the present study. Factors such as family income, level of schooling and marital status were associated with the feasibility of undergoing a video consultation. Having an adequate medical registry of telephone numbers and email addresses, educating patients on the usefulness of telemedicine to overcome cultural barriers, and overcoming technological and educational limitations are pivotal to better provide this modality of care to this subpopulation. Telemedicine is a proven cost-efficient and satisfactory modality of care in patients with parkinsonism, and its implementation needs to overcome many administrative, cultural, technical and sociodemographic limitations in developing countries like Brazil.

# Authors' Contributions

DTS: conceptualization, data curation, formal analysis, methodology, project administration, supervision, writing

of the original draft, and review and editing of the article; DMFC, MZS: conceptualization, data curation, investigation, and review and editing of the article; MTSS, PF, LWM: data curation, investigation, and review and editing of the article; AFSS: conceptualization, formal analysis, methodology, project administration, supervision, writing of the original draft, and review and editing of the article.

#### **Conflict of Interest**

The authors have no conflict of interests to declare.

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