

Telemedicine in the monitoring of patients with dementia: a Brazilians caregivers's perspective

Bruna Moreira-Constantin, Giovanna Carpen-Padovani, Ana V. Cordeiro-Gaede, Amanda Chamma-Coelho, Ricardo K. Martinez-Souza, Renato Nishihara

Introduction. The SARS-CoV-2 (COVID-19) pandemic warranted expanded care via telemedicine across a breath of medical specialties. The aim of the study is to analyze the preferences of caregivers of patients with dementia on the use of telemedicine in monitoring these patients.

Subjects and methods. Caregivers and family members responsible for patients with dementia completed an online self-applicable questionnaire, which was distributed in Facebook and WhatsApp groups between April and October 2020.

Results. 130 responses were obtained; most caregivers were women (83.8%), of whom 60% were daughters of patients. Most patients were also women (75.3%). Alzheimer's disease caused dementia in 73% of cases. The Internet was accessible to 98% of respondents, yet less than half (33.8%) had used telemedicine at least once. Although 66.9% of caregivers would be willing to use telemedicine if the doctor offered it, 63% believed that the cost of video consultations should be lower than those face-to-face. During the COVID-19 pandemic, 85.3% of caregivers needed to contact the physician: just over half of these consultations were face-to-face (52.2%), but telemedicine was preferred (62.3%) if possible.

Conclusion. Caregivers accepted and were interested in telemedicine as a tool for monitoring patients with dementia, especially those with walking difficulties.

Key words. Caregivers. COVID-19. Dementia. Patient care. Remote consultation. Telemedicine.

Introduction

The medical field has widely accepted information technology as a way to enable medical practice, research, and education without the burden of geographical barriers [1]. Telemedicine (TM) is defined by the Federal Council of Medicine resolution number 1,643/2002 as the practice of medicine using active methodologies of communication and data, with the aim of assistance, education, and health research [2]. The COVID-19 pandemic prompted the Federal Council of Medicine to expand TM to pre-clinical care, medical appointments, monitoring, and diagnosis [3].

TM remains difficult to culturally implement despite emergency orders and widespread adoption. The Brazilian Federal Board of Medicine, doctors, and patients consider presential consultation irreplaceable [4]. Culture influences doctor-patient relationship/interactions, and Brazilians tend to be very affective. The patient views the doctor as someone who is familiar and reliable [5]. The pri-

mary goal of TM is to accommodate patients in remote locations. However, the growth of TM also allows easier access to healthcare services for those with small children and mobility restrictions [6].

Dementia is one of the main causes of incapacity in the elderly, demanding continuous care and culminating in total dependence of the patient [7]. The progression of its symptoms varies from person to person, and each patient experiences dementia in a unique way: those affected often share symptoms, but their degree varies [8]. Neurological patients, especially those with dementia, will benefit from TM because this public health problem affects more than 47 million people worldwide, demanding an organized, comprehensive approach to mitigate the physical, emotional, and economic burdens of this devastating disease [9]. This is possible by coordinating and helping caregivers and relatives to assist these patients. The aim of this study is to evaluate the perspectives of family members and caregivers on the use of TM to monitor patients with dementia.

Department of Medicine.
Universidade Positivo. Curitiba,
Paraná, Brazil.

Correspondence:

Prof. Renato Nishihara.
Departamento de Medicina.
Universidade Positivo. Rua Prof.
Pedro Viriato, 5300. Código
postal: 81280-330 Curitiba,
Paraná, Brasil.

E-mail:

renatonishihara@up.edu.br

ORCID:

<https://orcid.org/0000-0003-1637-0201> (B.M.C.).
<https://orcid.org/0000-0003-1337-0898> (G.C.P.).
<https://orcid.org/0000-0002-6527-8156> (A.V.C.G.).
<https://orcid.org/0000-0001-6299-5179> (A.C.C.).
<https://orcid.org/0000-0003-2161-2666> (R.K.M.S.).
<https://orcid.org/0000-0002-1234-8093> (R.N.).

Ethics approval:

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the Committee of Ethics in Research from Universidade Positivo under protocol number 4.076.046 from June 8th, 2020.

Consent to participate:

All participants signed an informed consent.

Transparency declaration:

The authors affirm that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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Table I. Demographic data of caregivers studied ($n = 130$).

	<i>n</i>	%
Sex		
Female	109	83.8
Male	21	16.1
Age/ Years		
20-40	26	20
41-50	35	26.9
51-60	41	31.5
61-70	13	10
71-90	15	11.5
Schooling		
Basic education	8	6.2
High School	27	20.9
University Education	85	65.9
Master's/doctorate degree	10	7.6
Marital status		
Single	27	20.7
Married	87	66.9
Divorced	12	9.2
Widowed	4	3
City of residence		
Country Town	68	52.3
Capital	62	47.6
Family relations with the patient		
Daughter	78	60
Spouse	25	19.4
Son	11	8.4
Others	16	12.3
Is the main caregiver	97	74.6
Has assistance to take care of the patient (yes answers)	86	66.1
Number of patient's caregivers		
One	57	43.8
Two	40	30.7
Three or more	33	25.3
Lives in the same residence of the patient	90	69.2
Time allocated to patient's care		
6 or more hours a day	95	73
2 hours a day	21	16.1
4 hours a day	14	10.7

Subjects and methods

This cross-sectional and descriptive study was approved by the Ethic Committee of the Positivo University. A self-applicable 30-question questionnaire was distributed online in Facebook and WhatsApp groups, whose members included caregivers and family members of patients with dementia, as well

as those financially responsible for such patients, between April and October of 2020.

The survey was divided into three sections:

- *Section 1.* The first part of the questionnaire included questions about the patient and the caregiver, including age, sex, level of education, location, how long the patient had been diagnosed with dementia, and if there were other concomitant comorbidities.
- *Section 2.* The second part of the questionnaire asked about the patient's caregiver (if there are caregivers and, if so, how many), logistical details on access and transportation of the patient with dementia to the health team that monitors them, and whether the respondents were already familiar with TM.
- *Section 3.* The final part of the questionnaire presented practical situations in the form of clinical cases to which TM could be applied to patient care. The answers could be used to evaluate whether the respondents viewed TM favorably and in which situations they considered its use appropriate.

Statistical analysis

The data were aggregated in Microsoft Excel. Only completed questionnaires with the following features were included: the patient had a confirmed diagnosis of dementia and was followed up for this condition, the patient and caregiver lived in Brazil, and the consenting respondent was a caregiver, family member, or financial guardian of the patient diagnosed with dementia.

Statistical analyses were performed using Graph-Pad Prism 5.0. Continuous variables were expressed as mean \pm standard deviation and compared using the t- and Mann-Whitney tests. Categorical variables were expressed as percentages and compared using the chi-square test or Fisher's exact test, as appropriate. p -values < 0.05 were considered statistically significant.

Results

Table I shows the sociodemographic data of the family member or financial guardian of the studied patient. 83.8% were women, of whom 60% were daughters of the patients. The average age was 52.3 ± 11.45 years. Most (65%) of caregivers had higher education, 66.9% were married, and 73% spent six or more hours per day caring for the patient.

Table II shows the patient's sociodemographic

data. Women constituted 75.3% of cases, and 36.1% were in the 81-90 age groups. Nearly half (45%) were widowers. Most (52.7%) patients had primary education, 53% lived in country towns, and 66.1% had health insurance. The major causes of dementia among these patients were Alzheimer's (73%), followed by stroke (13%) and psychiatric disorders (4.6%). Among them, 51.5% had preserved walking capacity, and 53% were diagnosed with dementia less than five years ago.

Table III shows the use of TM and preference of caregivers regarding the use of this tool. Nearly all (98%) participants could access the Internet at home, and 72.3% were familiar with TM; however, only 33.8% have used the tool. 66.9% would use the tool if the doctor offered the service, but only 26.9% would pay the same amount as a face-to-face consultation. In addition, 39.2% believe that TM will replace face-to-face consultation in the future. Among caregivers, 46.9% believed that the lack of human contact does not diminish the doctor-patient relationship, and the majority (67.6%) believed that a TM consultation has the same validity as presential consultation.

Table IV shows the opinions of users on TM. This method was widely accepted for consultations to return and evaluate medical exams: 92.3% would do so by TM. If it was necessary to contact a doctor during the coronavirus pandemic, 62.3% preferred teleconsultation over video.

Discussion

This study evaluated the opinions of family caregivers of patients with dementia on telemedicine (TM) in Brazil. TM was widely accepted to monitor these patients, and the COVID-19 pandemic changed the way TM is used.

Most caregivers were female and the daughters of patients; similar data in other studies can be attributed to the historical divide between genders, in which women take care of the home and family [10]. Two-thirds of caregivers were married, spent six hours or more per day caring for the patient, and lived in the same place as the patient; other studies also found that family caregivers dedicate more time daily to patient care [11]. Two-thirds of caregivers had entered higher education, suggesting a limitation of this study's design; people with greater access to and knowledge of technologies more readily answer such questionnaires. In addition, more than half had health insurance and possibly easier access to online services.

Table II. Demographic data of patients studied ($n = 130$).

	<i>n</i>	%
Sex		
Female	98	75.3
Male	32	24.6
Age Years		
50-60	8	6.1
61-70	27	20.7
71-80	40	30.7
81-90	47	36.1
91-100	8	6.1
Schooling		
No education	11	8.4
Basic education	68	52.7
High school	23	17.8
University education	28	20.9
Marital status		
Single	2	1.5
Married	51	39.2
Divorced	18	13.8
Widowed	59	45.3
City of residence		
Country Town	69	53
Capital	61	46.9
Health insurance		
	86	66.1
The main cause of the patient's dementia		
Alzheimer's disease	95	73
Stroke	17	13
Frontotemporal dementia	5	3.8
Parkinson's Disease	4	3
Lewy body disease	4	3
Others	12	9.2
Comorbidities		
High blood pressure	46	35.4
Diabetes	24	18.4
Dyslipidemia	6	4.6
Thyroidopathy	6	4.6
Heart disease	6	4.6
Arthropathy	5	3.8
Others	64	42.3
Walking ability		
Uses no walking aid	67	51.5
Does not walk	42	32.3
Walks with aid (walking stick or walking aid)	21	16.1
How long ago was the dementia diagnosed		
Five years ago	69	53
Ten years ago	40	30.8
Fifteen years ago	12	9.2
Twenty years or more	3	2.3
Non declared	6	4.6

Table II. Demographic data of patients studied ($n = 130$) (cont.).

	<i>n</i>	%
Among patients with transport difficulty ($n = 58/130$). the major problem is		
Place the patient in the vehicle	45	77.5
Bedridden patient	3	5
Difficulty in having proper means of transport	6	10.3
Others	6	10.3
Average time to the health service		
30 minutes	86	66.1
1 hour	21	16
More than 1 hour	23	17.6

Most patients were women, which were expected because they live on average eight years longer than men [12]. Dementia is more prevalent in the eighth decade of life, which is in line with this study [13]. Just over half of the patients completed elementary school, and most were widowers and residents of inner cities. Yi et al [14] found that 91% of the caregivers in another study preferred to see a specialist via TM rather than in-person, which agrees with our study [14].

The most common cause of dementia was Alzheimer's disease, and the main comorbidity was systemic arterial hypertension, which other authors have also observed [12,15]. Two-thirds were diagnosed less than five years ago. Patient care during early stages of dementia is mainly provided by family members, who suffer from worse physical and mental health outcomes when compared to formal caregivers. TM reduces the burden on family members by providing care facilities, which may explain its wide acceptance [16]. Half of the patients were able to walk without assistance, yet TM is preferable to avoid driving for their care due to time spent on the road, the difficulty of placing the patient in the vehicle, and patient stress [14].

Nearly all respondents had Internet access and were familiar with technology. This only partially reflects the Brazilian population: although 3/4 of the country is connected to the network, it was not until 2020 that the Internet reliably reached more than 50% of countryside residents, who have difficulty accessing health teams [4,17].

Respondents to this survey were aware of TM as a medical tool, and one-third had used it at least once. This may not have been the case if this research was conducted before the COVID-19 pandemic. Previously, TM was used in Brazil only for

Table III. Data about the use of Telemedicine (TM).

	<i>n</i>	%
How familiar are you with the use of technology in your daily life?		
Very familiar	77/130	59.2
Average familiar	38/130	29.2
Unfamiliar	15/130	11.5
Have internet access at home		
Yes/Answers	128/130	98.5
Have you ever known about TM until this questionnaire application?		
Yes/Answers	94/130	72.3
Have you previously used TM?		
Yes/Answers	44/130	33.8
Do you know someone who uses TM?		
Yes	63/130	48.4
If your doctor offers you consultation by TM. would you do it?		
Never	1/130	0.7
Maybe	42/130	32.3
Yes	87/130	66.9
Medical consultation by TM has the same utility as face-to-face appointment?		
Yes/Answers	88/130	67.6
Do you believe the TM negatively affects the relationship between doctor and patient?		
Yes	46/130	35.3
No	61/130	46.9
Indifferent	23/130	17.6
TM appointment value (\$); when compared with face-to-face consultation. should be:		
The same	35/130	26.9
Lower	82/130	63
Should not be charged	13/130	10
Do you believe your doctor is prepared to use TM?		
Yes	100/130	76.9
Do you believe TM will replace face-to-face consultation?		
Yes	51/130	39.2

educational and health research purposes [2]. The onset of the pandemic warranted health services that respected social distancing, especially for the elderly, to simultaneously reduce the risk of infection and allow access to a doctor [14,18]. TM

gained space and notoriety among physicians and patients, who began to see this resource as a solution for services that do not require face-to-face care, such as monitoring chronic conditions without harm, renewal of prescriptions, return and evaluation of laboratory tests, as well as preventing patients with limited mobility or advanced dementia from having to travel for long periods of time or distances for a routine appointment. Two-thirds of the participants believed that an appointment via TM has the same validity as a face-to-face appointment, and about half believed that the lack of human contact does not negatively affect the appointment or the doctor-patient relationship. This finding is noteworthy, as the Brazilian population is warm in family relationships and friendships, extending this behavior to the doctor-patient relationship [5]. This may explain why a minority of respondents believed that TM will replace face-to-face consultation. Teleconsultation has several technical and legal barriers: the impossibility of performing a physical examination, unstable Internet connections, and the legitimacy of its use outside the context of the pandemic [3,4,14].

Only 1/4 of the respondents believed that teleconsultation has the same monetary value as a face-to-face consultation. Yet the advance of TM has already prompted healthcare providers to reorganize the system by directing care, strengthening primary care, and reducing the direct search for specialists [18]. Ultimately, TM should complement care for patients with dementia and not replace the face-to-face consultation, which is essential in many cases.

During the pandemic, 85% of caregivers reported having contacted their doctor due to their family member's dementia, and just over half did so in-person. Of those who did not need medical help, most preferred video teleconsultation, indicating general acceptance of this tool. In this scenario, caregivers can adjust the home environment for TM by instructing the patient before the appointment, establishing realistic expectations, and reducing the novelty of the situation [14].

The COVID-19 pandemic has increased TM consultations and prescriptions [19]. However, it is difficult to evaluate the success of TM, as there are many barriers to its implementation [19]. TM is expected to be widely adopted by physicians, caregivers, and patients as a resource for care [19]. Physicians have the opportunity to learn their patients' preferences and to better communicate with other health professionals, while caregivers can learn more about the usefulness of this tool as a way to

Table IV. Opinions and preferences of caregivers regarding the consultation model.

	<i>n</i>	%
Would you use telemedicine for consultation only with return of exams? Yes	120	92.3
If there is a sudden change in the patient's condition, would you prefer to contact the doctor's office and make an online appointment or call the emergency service?		
Asks for an online evaluation	114	87.6
Goes to the hospital	16	12.3
What do you think is the best for monitoring the patient's condition?		
Take notes and show them to the doctor personally	17	13
Collect and send information to the doctor in real time via Internet	113	86.9
Would you contact a doctor from a different city where you live, by telemedicine, for a second opinion? Yes	125	96.1
During the period of the coronavirus pandemic (COVID-19) was there a need to contact a doctor? Yes	111	85.3
If so, how was the consultation?		
Contact by message	23	20.7
Presential	58	52.2
Video teleconsultation	30	27
It was not necessary to contact the doctor during the coronavirus pandemic, but if it were necessary, what would be your preference?		
Presential appointment	30	23
Video teleconsultation	81	62.3
Contact by message	13	10
Others	6	4.6

reduce costs of patient transport. Improving overall satisfaction with health services is possible through better resource allocation and healthcare organization. TM should be regulated so that it does not confuse doctors and patients, especially those with dementia [4].

Conclusion

Most caregivers and patients have Internet access at home and understand how to use technology in their daily lives. They generally accepted and were interested in telemedicine as a tool for monitoring patients with dementia, especially those with walking difficulties.

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Telemedicina en la monitorización de pacientes con demencia: una perspectiva de cuidadores brasileños

Introducción. La pandemia de SARS-CoV-2 (COVID-19) requirió una atención ampliada a través de la telemedicina en una variedad de especialidades médicas. El objetivo del estudio es analizar las preferencias de los cuidadores de pacientes con demencia sobre el uso de la telemedicina en el seguimiento de estos pacientes.

Sujetos y métodos. Los cuidadores y familiares a cargo de pacientes con demencia completaron un cuestionario autoaplicable en línea, que se distribuyó en grupos de Facebook y WhatsApp entre abril y octubre de 2020.

Resultados. Se obtuvieron 130 respuestas; la mayoría de los cuidadores eran mujeres (83,8%), de las cuales el 60% eran hijas de pacientes. La mayoría de los pacientes también eran mujeres (75,3%). La enfermedad de Alzheimer causó demencia en el 73% de los casos. Internet era accesible para el 98% de los encuestados, pero menos de la mitad (33,8%) había utilizado la telemedicina al menos una vez. Aunque el 66,9% de los cuidadores estaría dispuesto a utilizar la telemedicina si el médico se la ofreciera, el 63% cree que el coste de las videoconsultas debería ser inferior al de las presenciales. Durante la pandemia de COVID-19, el 85,3% de los cuidadores necesitó contactar con el médico: poco más de la mitad de estas consultas fueron presenciales (52,2%), pero se prefirió la telemedicina (62,3%) si era posible.

Conclusión. Los cuidadores aceptaron y se interesaron por la telemedicina como herramienta para el seguimiento de los pacientes con demencia, especialmente los que tenían dificultad para caminar.

Palabras clave. Atención al paciente. Consulta remota. COVID-19. Cuidadores. Demencia. Telemedicina.