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ORIGINAL ARTICLE

Telemedicine at a brazilian Down syndrome outpatient clinic during the covid-19 pandemic

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Down syndrome, Telemedicine, Covid-19.

Abstract

Objective: This study aims to analyze the use of telemedicine during the Covid-19 pandemic (efficiency, effectiveness, positive and negative points as a modality of care) and educational and therapeutic parameters of the patient with Down syndrome during this period. **Metodology:** Data were collected remotely using an online form created by the authors and answered by patients or their caregivers from the Down Syndrome Outpatient Clinic of a university hospital in the South of Brazil. **Results:** 65 responses were received, with 44.6% of the participants residing in Curitiba, 32.3% in the metropolitan region, 12.3% in the interior of Paraná and 10.8% in other states. Twenty-eight (43.1%) receive the Continued Benefit of Social Assistance. As for education, 41.5% attended special schools, 26.2% regular education, 10.8% both regular education and special education, and 21.5% do not studied. During the pandemic, 81.3% had remote school activities, and 41.3% did not undergo therapy. Health needs were met with consultation through telemedicine in 96.7%. Strengths: not having to go to the clinic (59.4%), easy access to the consultation (71.9%), feeling comfortable with the telemedicine consultation (46.9%), feeling understood by doctors (42.2%), having their doubts and concerns answered (62.5%), not having to miss work (25%). Weakness: impossibility of carrying out the physical examination (100%), connection problems (18.6%), feeling uncomfortable with the telemedicine consultation (10%). **Conclusion:** Telemedicine was a viable option for patients with Down syndrome during the Covid-19 pandemic with many positive points. During the pandemic, 81.3% had remote school activities, and 41.3% didnt go to therapies.

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INTRODUCTION

The COVID-19 pandemic in just a few months has turned the world upside down. Personal distancing to prevent the increase in cases, in-person health consultations have become problematic. Therefore, the World Health Organization (WHO), the United States Center for Disease Control, the Federal Council of Medicine in Brazil and other countries have recommended the use of telemedicine during the current pandemic[1,2].

Initially, the cancellation of elective procedures in all services was indicated. Telemedicine was the option for monitoring patients at many outpatient clinic[1,2].

Down syndrome (DS) or trisomy 21 is the most common chromosomal abnormality[3,4], being the most recurrent aetiology of intellectual disability of genetic origin[5]. The Brazilian estimation is 45 million people with some physical or intellectual disability, and the population of people with DS corresponds to approximately 300 thousand people, with a life expectancy of about 60 years[6,7].

Down syndrome does not represent a disease, but it defines a permanent condition that cannot be changed[8]. The treatment aims to enable autonomy and overcome limitations, thus promoting the exercise of citizenship. There is a need for early intervention with the help of a multidisciplinary team in order to develop the full potential of DS. The family, school and multidisciplinary team must work cohesively for better results[9].

Created in 1997, the Down Syndrome Outpatient Clinic at Hospital de Clínicas of UFPR was the first centre in Latin America for specialized care for people with DS and their families with an interdisciplinary team. It currently has more than 4,500 registered patients and an average of 30 patients seen per week.

In the context of physical isolation determined by the coronavirus pandemic (SARS-CoV-2), Law 13,989 was approved[10]. The emergency use of telemedicine was allowed for the exercise of medicine mediated by technologies for assistance, research, prevention and health promotion.

The first described case of its use occurred in 1897 to enable the diagnosis of croup by employing a telephone call when listening to the cough pattern of a child[11].

The effectiveness and applicability of a telehealth approach vary by speciality, care environment, and patient preference[12]. Although recent in Brazil, they have shown satisfactory results[13,14].

Telemedicine was applied at the Down Syndrome Outpatient Clinic from April 2020 to July 2021. The justification for this is the need for continuous monitoring and the higher risk of complications and mortality in these patients[15].

The objective was to analyze the evaluations of telemedicine as a form of care at a Down Syndrome Outpatient Clinic through questionnaires applied to patients and their guardians, physicians and medical students.

METHODOLOGY

The Down Syndrome Outpatient Clinic started its activities in 1997 at a university hospital in the South of Brazil. It is a referral service for clinical follow-up and their families.

The research method is observational, transversal and descriptive. The data were obtained through a questionnaire with 24 questions to assess telemedicine care at the Down Syndrome Outpatient Clinic, created by the authors and answered by patients or their caregivers from the Down Syndrome Outpatient Clinic from Dezember 2020 to August 2021. Data were obtained remotely and sent by WhatsApp message to patients and team managers. The form allowed completion when the answer was to agree with the Confidentiality Term. The study approved by the Human Research Ethics Committee of the Health Sciences Sector of HC UFPR on November 23, 2020 (CAAE: 39750620.5.0000.0096).

RESULTS

Six hundred questionnaires were send to patients through Whatsapp. Only 65 (10.8%) retorned answered, 94.3% by the father or mother and the remaining 5.7% by a sibling. Age ranged between 0 and 48 years, with a higher prevalence in childhood. It was no difference in participation between the sexes. In Table 1, there are socioeconomic data collected and data on education and complementary therapies.

Table 2 contains data on satisfaction with telemedicine care.

The main positives and negatives of the telemedicine consultation reported by the participants are in Table 3.

DISCUSSION

The study was at a hospital with care fully funded by the government. There is no direct relationship between socioeconomic level and the incidence of DS. In our study, 43.1% receive the Benefit of Continued Social Assistance, whose one of the prerequisites is having gross family income divided by the number of family members less than one minimum wage room.

In other countries, there is this correlation. In Mexico, a survey at a specialized service for DS showed that 67% of the patients' families were among the poorest 40% in the country, and about a half need loans to pay medical expenses. A third had catastrophic health expenses[16].

In South Korea, about 13% of families of children with DS receive medical aid, compared to only 3% of families without children with DS receive this benefit. In addition, the average health expenditure of families with DS children is about ten times higher than that of families without children with DS[17]. Recipients of these aids have a much higher risk of having catastrophic health expenditures than the general population[18].

Table 1. Educational and therapeutic data of patients care at the Down syndrome outpatient clinic of CHC - UFPR by telemedicine during the covid-19 pandemic (2020-2021).

		N	%
Sex	Male	33	50,8
	Female	32	49,2
Age	0-10 years old	40	61,5
	10-20 years old	15	23,1
	20 or more years old	6	9,2
City where you live	Curitiba	29	44,6
	Metropolitan region	21	32,3
	Countryside	8	12,3
	Another State	7	10,8
Benefit of social assistance	Yes	28	43,1
	No	37	56,9
School	Special education	27	41,5
	Inclusive education	17	26,2
	Both	7	10,8
	None	14	21,5
Pandemic school activities	Yes	52	81,3
	No	12	18,8
	Face-to face	13	20,6
Therapies in the pandemic	Remote	21	33,3
	Both	3	4,8
	Not occurred	26	41,3

Table 2. Assessment of quality of care by telemedicine of patients of the Down syndrome outpatient clinic of CHC - UFPR (2020-2021).

Telemedicine consultation evaluation		n	%
How the consultation was conducted (WhatsApp)	Video call	60	92,3
	Audio call	5	7,7
The place where the consultation took place was adequate (Quiet, privacy, good connection, comfortable)	Yes	60	92,3
	No	5	7,7
Satisfaction with the remote consultation	extremely satisfied	44	67,7
	moderately satisfied	19	29,2
	Dissatisfied	2	3,1
Query quality	extremely superior	16	24,6
Evaluation of the telemedicine consultation	moderately superior	15	23,1
	slightly higher	2	3,1
	Equal	15	23,1
	little lower	13	20
	moderately inferior	1	1,5
	extremely inferior	3	4,6

Table 3. Strengths and weakness of telemedicine care for patients of the Down syndrome outpatient clinic of CHC - UFPR (2020-2021).

Evaluation of the telemedicine consultation	N	%
Strengths		
No need to go to the Down Syndrome clinic	38	59,4
Easy access to consultation	46	71,9
I felt comfortable using telemedicine	30	46,9
I felt understood by the doctor	27	42,2
Answered concerns	40	62,5
I didn't have to miss work.	16	25
Weakness		
Inability to perform a physical examination	65	100
Difficulty accessing consultation	0	0
Connection problem	11	18,6
I felt uncomfortable using telemedicine	6	10
I didn't feel understood by the doctor	2	3,4
Not answered concerns	1	1,7

Regarding access to care, 76.9% of patients lived in Curitiba or the Metropolitan Region. There are few specialized services in DS in Brazil. People with DS who live in the countryside or other states needed travel to access a specialized face-to-face care.

Twenty-six (41.3%) patients did not undergo therapies during the pandemic. It results harm to development and autonomy. The same trend occurred in other research when 75% of adolescents with DS had no therapeutic sessions for at least three months during the pandemic. The stimuli were performed only at home by some families[19].

Regarding the patients' educational profile, 78.5% were in schools. Fifty-two (81.3%) had remote school activities during the pandemic. Regarding the type of education, 41.5% still study exclusively in special education and 10.8% in regular and special education. It demonstrates that the Statute of Persons with Disabilities[20] has not yet fully implemented, as it provides that people with disabilities, including those with DS, must attend regular education. Paraná is a Brazilian state with special schools and special classes at "inclusive" schools. Buckley (2006)[21] observed that people with DS at inclusive education have much better linguistic and interpersonal development than those at special education.

Regardless of socioeconomic and educational levels, the predominantly positive assessments (96.7%) point to the feasibility of telemedicine for the longitudinal care of people with DS. The telemedicine weakness reported by the patients was the impossibility of performing the physical examination like in the face-to-face consultation. It could indicate a permanent demand for telemedicine consultations for specialized DS services.

The satisfaction of telemedicine consultations in other services is like the findings in this work that similar positive and negative points appearing[22,23]. It may be a useful tool for screening or to resolve minor problems that will not require examination, and which often refer the patient to an appointment.

Connection during consultations is dependent on the existence of adequate telecommunications infrastructure. For complete national integration with broadband or 5G networks by 2030, an investment in the construction and maintenance of structure, the administration and regulation of existing services[24]. The current internet connection had progressively increased its quality and general consumer satisfaction[24-26].

However, about 40 million Brazilians, mainly from the poorest social classes, still did not have internet access[7]. The use of telemedicine ends up being more appropriate in more developed urban regions and wealthier social classes. However, this was not an obstacle for most patients who participated in this study.

One possible limitation of this study was the low number of answered questionnaires what probably would not happen if our instrument had a smaller number of questions. We will remember to do in the future.

Conclusion: Building a good doctor-patient relationship is essential to instilling patient confidence that they are receiving the best possible care. It can be carried out in person or by telemedicine. User assessments via online questionnaires should contain few but consistent questions to motivate the public to respond.

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