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Continuity of care for children and adolescents with Type 1 Diabetes Mellitus during the COVID-19 pandemic

Continuidade do cuidado a crianças e adolescentes com Diabetes Mellitus Tipo 1 na pandemia de COVID-19

Continuidad de la atención a niños y adolescentes con Diabetes Mellitus tipo 1 durante la pandemia de COVID-19

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ABSTRACT

Objective: to analyze continuity of care for children and adolescents with Type 1 Diabetes Mellitus during the COVID-19 pandemic from the perspective of family caregivers and healthcare professionals. **Method:** a descriptive and exploratory study with a qualitative approach, guided by the concept of continuity of care from the World Health Organization. It was conducted at a pediatric endocrinology outpatient clinic in the countryside of São Paulo state, involving family caregivers and professionals (physician, nutritionist, and nurse). Data collection was carried out through the application of a sociodemographic characterization tool and a semi-structured interview. The interviews were fully transcribed and analyzed through the process of inductive thematic content analysis. **Results:** twenty-one caregivers and three healthcare professionals participated. The interview results were organized around two topics: (1) Interpersonal and longitudinal (dis)continuity, resulting in feelings of insecurity and lack of glycemic control; and (2) Management dis(continuity), with an emphasis on the lack of supplies during the pandemic period. **Final considerations and implication for practice:** during the pandemic, the bond between children/adolescents, families, and professionals was weakened, and care demands were not always met in a timely manner, negatively impacting continuity of care.

Keywords: Adolescent; Caregivers; Type 1 Diabetes Mellitus; Child; COVID-19 Pandemic.

RESUMO

Objetivo: analisar a continuidade do cuidado a crianças e adolescentes com Diabetes Mellitus Tipo 1 durante a pandemia de COVID-19 na perspectiva de familiares cuidadores e profissionais de saúde. **Método:** estudo qualitativo, descritivo e exploratório, que adotou como quadro teórico o conceito de continuidade do cuidado em saúde da Organização Mundial da Saúde. Foi realizado em um ambulatório de endocrinologia pediátrica do interior do estado de São Paulo junto a familiares cuidadores e profissionais (médico, nutricionista e enfermeiro). A coleta de dados se deu mediante aplicação de instrumento de caracterização sociodemográfica e entrevista semiestruturada. As entrevistas foram analisadas segundo o processo de análise de conteúdo do tipo temática indutiva. **Resultados:** participaram 21 familiares cuidadores e três profissionais de saúde. Os resultados das entrevistas foram organizados ao redor de dois temas: (1) Des(continuidade) interpessoal e longitudinal, repercutindo no sentimento de insegurança e no descontrole glicêmico; e (2) Des(continuidade) gerencial, com ênfase na falta de insumos durante o período pandêmico. **Considerações finais e implicação para a prática:** durante a pandemia, o vínculo entre crianças/adolescentes, familiares e profissionais foi fragilizado, e as demandas de cuidado nem sempre foram atendidas em tempo oportuno, impactando negativamente a continuidade do cuidado.

Palavras-chave: Adolescente; Cuidadores; Diabetes Mellitus Tipo 1; Criança; Pandemia de COVID-19.

RESUMEN

Objetivo: analizar la continuidad del cuidado de niños y adolescentes con Diabetes Mellitus Tipo 1 durante la pandemia de COVID-19 desde la perspectiva de familiares cuidadores y profesionales de la salud. **Método:** estudio descriptivo y exploratorio de enfoque cualitativo, guiado por el concepto de continuidad del cuidado de la Organización Mundial de la Salud. Se realizó en una clínica ambulatoria de endocrinología pediátrica en el interior del estado de São Paulo con familiares y profesionales de dicha clínica (médico, nutricionista y enfermero). La recolección de datos se realizó mediante la aplicación de un instrumento de caracterización sociodemográfica y una entrevista semiestructurada. Las entrevistas fueron transcritas íntegramente y analizadas según el proceso de análisis de contenido de tipo temático inductivo. **Resultados:** participaron 21 cuidadores y tres profesionales de la salud. Los resultados de las entrevistas se organizaron en torno a dos temas: (1) Dis(continuidad) interpersonal y longitudinal, que da lugar a sentimientos de inseguridad y falta de control glucémico; y (2) Dis(continuidad) gerencial - con énfasis en la falta de insumos durante el período de pandemia. **Consideraciones finales e implicaciones para la práctica:** durante la pandemia, el vínculo entre niños/adolescentes, familiares y profesionales se vio debilitado, y las demandas de atención no siempre fueron satisfechas de manera oportuna, lo que afectó negativamente la continuidad del cuidado.

Palabras clave: Adolescente; Cuidadores; Diabetes Mellitus Tipo 1; Niño; Pandemia de COVID-19.

INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is an autoimmune metabolic disease that belongs to the group of serious chronic pathologies. In this condition, the body's immune system does not recognize the pancreatic beta cells that participate in insulin production, and attacks and destroys them, thus becoming incapable of producing this hormone and regulating blood glucose levels.[1] The occurrence of this disease increases progressively each year among children and adolescents, and its clinical prognosis is directly associated with adequate metabolic control.[1]

T1DM requires changes in the daily lives of children/adolescents and their family caregivers, especially related to behaviors involving nutrition, physical activity, capillary blood glucose monitoring, application of multiple insulin injections and observation of signs and symptoms of hypoglycemia.[2]

Prior to the pandemic, the literature already indicated weaknesses in continuity of care for children and adolescents with chronic diseases, such as T1DM, with fragmented and specific actions not sufficient to ensure the needs of this clientele, increasing the lack of control of the clinical condition and, at times, unnecessary hospitalizations.[3] In this connection, another investigation supports this fact by showing that access of children with special health needs to the health network requires greater integration between primary care services, the community, the hospital and specialized services, in order to guarantee continuity of care for this clientele.[4]

The advent of the COVID-19 pandemic has raised new concerns for family members and healthcare professionals involved in the care of children and adolescents with T1DM, particularly because statistical data indicate a relationship between greater clinical severity and comorbidities such as diabetes.[5] With the lockdown, physical and leisure activities were temporarily suspended and there was an increase in the consumption of high-calorie foods, which had an impact on glycemic control and an increase in acute events related to diabetes.[6] In general, in-person appointments have been replaced by telephone or video appointments.[7] Furthermore, professionals stated that they suffered from a shortage of supplies and insulin.

According to the World Health Organization, continuity of care refers to the degree to which a series of health events are experienced by people as coherent and interconnected over time, consistent with their health needs and preferences. It mainly concerns patients' perspective on access to healthcare services and the support received in order to provide continuity of care.[8] It is common to find in the literature the use of the term "care coordination" as a synonym for continuity of care; however, although closely related, they are distinct terminologies because continuity of care is the expected outcome of effective coordination.[9]

Continuity of care can be understood through four interrelated perspectives: interpersonal continuity; longitudinal continuity; information continuity; and management continuity.[8] Interpersonal continuity deals with the relationships of trust established between professionals, patients and caregivers. Longitudinal continuity reflects the monitoring over time between the different levels of care. Informational continuity concerns the efficient exchange of data between healthcare professionals, ensuring that information relevant to patients' clinical history is transmitted in an accurate and timely manner. Management continuity corresponds to the ability to offer different types of care that complement each other in a timely manner and without duplication.[8]

Considering the above, we sought to answer the following research questions: what is the perception of healthcare professionals regarding the measures implemented in the care of children and adolescents with T1DM during the pandemic period? What is the perception of family caregivers regarding continuity of care for children and adolescents with T1DM during the COVID-19 pandemic? Therefore, this study aimed to analyze continuity of care for children and adolescents with T1DM during the COVID-19 pandemic from the perspective of family caregivers and healthcare professionals.

METHOD

This is a descriptive and exploratory study with a qualitative approach that adopted the World Health Organization's concept of continuity of healthcare as its theoretical framework.[8] The methodological design followed the recommendations for developing qualitative research from the COnsolidated criteria for REporting Qualitative research.[10]

The study was conducted in a municipality located in the countryside of the state of São Paulo with an estimated population of 254,857 inhabitants. However, recruitment of potential participants was triggered by appointments at the pediatric endocrinology outpatient clinic of a university hospital in the municipality.

Family caregivers of children and adolescents with T1DM treated at the aforementioned outpatient clinic during the pandemic period who were over 18 years of age were considered eligible. No exclusion criteria were applied to family caregivers. It is worth mentioning that family caregivers were defined as people who were responsible for the direct care of children or adolescents with T1DM, as well as those who maintained an intimate and affective relationship with children and adolescents, as in other studies.[6,11] Professionals from the multidisciplinary team who worked in the respective outpatient clinic during the pandemic period were also eligible. Professionals who remained away for more than six months during this period, whether due to medical leave, reassignment to other sectors or any other reason, were excluded, based on the principle that they might have difficulty reporting their perceptions.

After a favorable opinion from the hospital's teaching and research management and approval by the Research Ethics Committee, data collection began, which took place between July and October 2023. First, outpatient professionals were contacted and, upon expression of interest, a date and time were scheduled for data collection via the Google Meet® platform. During the virtual meeting, an online form was made available to professionals, initially consisting of the and Informed Consent Form (ICF). After reading the ICF and recording their agreement, professionals answered a sociodemographic characterization

instrument with the following questions: date of birth; function performed in the service; length of professional experience; and academic qualification. Subsequently, a semi-structured interview was conducted guided by the following guiding questions: when considering the care provided to children and adolescents with T1DM during the pandemic, what were the positive and negative aspects? It is worth mentioning that all eligible healthcare professionals agreed to participate in the research, excluding a nurse who remained away for more than six months during the pandemic and a newly hired doctor.

To collect data from family caregivers, it was first necessary to identify which children and adolescents with T1DM were treated at the respective outpatient clinic during the pandemic period. To this end, the hospital's IT department was asked to provide a list of care provided between March 2020 and May 2023. The list included 243 children/adolescents with different endocrinology-related diagnoses such as obesity, congenital hypothyroidism, diabetes, and precocious puberty. In order to specify those with T1DM, all clinical records were analyzed, and 43 children/adolescents with T1DM were identified.

The first contact with potentially eligible family caregivers took place in the waiting room of the outpatient clinic, and 22 family members were approached and invited to participate in the study, of which 21 accepted and one refused. Since this was a qualitative study, theoretical saturation was adopted as the criterion for completing data collection, i.e., the inclusion of new participants was suspended when the data began to present, in the researcher's assessment, a certain degree of redundancy or repetition.[12] Such saturation was found in the 18th interview, however, it was decided to include three other family members who expressed interest in participating. After that, the active search for potential participants was interrupted.

For those family caregivers who expressed interest in participating in the research, a date and time that best suited them was scheduled. Data collection took place through home visits or via a digital platform, according to participants' choice. Initially, they received the ICF to read and discuss with the researcher. Subsequently, a sociodemographic characterization instrument was applied to family caregivers, consisting of the following questions: date of birth; marital status; occupation; and degree of kinship with children/adolescents with T1DM. Afterwards, sociodemographic and clinical characterization data of children/adolescents with T1DM were collected, such as date of birth and time of experience with the disease.

Immediately afterwards, a semi-structured, audio-recorded interview was conducted, guided by the following guiding question: in your opinion, how was continuity of care for children/adolescents with T1DM provided during the pandemic? Despite a single guiding question, the researcher had essential topics in hand that needed to be addressed, such as access to appointments and tests, distribution of supplies, and positive and negative aspects of the pandemic. The interviews lasted approximately 25 minutes and were conducted by the first author, a graduate nurse duly trained to conduct semi-structured interviews.

The interviews with healthcare professionals and family caregivers were transcribed in full, constituting a single text *corpus* analyzed according to the inductive thematic content analysis process[13], without using any computer program for data processing and analysis. This method is divided into six stages: (1) familiarization with the data: consists of transcribing, reading and rereading the interviews, aiming to identify, analyze and report patterns from the data collected; (2) initial code generation: consists of identifying and creating systematically codes; (3) topic generation: consists of reviewing the initial codes, grouping them with the purpose of constructing the topics; (4) topic review: consists of reviewing and refining the codes extracted for each topic, and the data must be consistent with the defined topic; (5) topic definition and naming: consists of analyzing the topics again, in order to define and improve the naming of thematic cores according to the essence and specificity of each topic; and (6) report production: consists of preparing the final report with the analysis and interpretation of the thematic cores in light of the theoretical framework.

Chart 1 presents a summary of how the analytical process to construct the topics took place.

Taking into account the involvement of human beings in the research, the study was submitted to the Research Ethics Committee in compliance with Resolution 510/2016 of the Brazilian National Research Ethics Commission of the Brazilian National Health Council, and was approved in June 2023 under Opinion 5,991,226. To preserve anonymity, it was decided to identify participants through alphanumeric coding according to the chronological order of interviews as follows: FC1, FC2 and so on, for family caregivers, and P1 and P2, for healthcare professionals.

RESULTS

A doctor, a nurse and a nutritionist participated in the study. One participant had eight years of training, the others had over 15 years of professional experience. Regarding academic qualifications, one had a *lato sensu* specialization degree and two had a *stricto sensu* graduate degree.

Regarding the characterization of family caregivers and their respective children and adolescents with T1DM, 17 mothers, three grandmothers and one father participated with an average age of 44 years, with a minimum of 28 and a maximum of 71 years. Of the total, three family caregivers stated that they did not have a partner and were the sole caregivers of children or adolescents with T1DM. Concerning occupation, 15 reported having a paid job, five were housepersons and one was unemployed. As for children and adolescents with T1DM, the average age was 11.57 years, with a minimum of 4 and a maximum of 17 years. The average time since diagnosis was 4.76 years, with eight children/adolescents being diagnosed during the pandemic and the others having already experienced the disease previously.

The results of interviews were organized around two topics: (1) Interpersonal and longitudinal dis(continuity); and (2) Management dis(continuity).

Chart 1 – Summary of the analytical process and construction of topics. São Carlos, São Paulo, Brazil, 2023.

Initial codes	Intermediate codes	Topics
We had no access to doctors at all. Before, I had contact with her doctors. It was very difficult to schedule an appointment. The doctor became pregnant and could no longer see her.	Difficulty accessing appointments	Interpersonal and longitudinal dis(continuity)
A partnership that appears to have been dissolved. Breakdown of the doctor-patient relationship. We lost track of the case due to the pandemic. Great loss of connection with us.	Breaking the bond	
Newly diagnosed, you feel completely lost. No number to talk to. No teaching. I searched a lot on Google®. You panic, not knowing what to do.	No information	
During the pandemic, Glargine was lacking. This problem dates back to before the pandemic.	Shortage of insulin and supplies	Management (dis)continuity
I did a TV interview because I could not find insulin at the clinic. I spoke to people at the city hall, the councilman, on the radio, everything within my reach. I even worked for a year to buy these things.	Strategies to ensure child care	

Source: research data, 2023.

Interpersonal and longitudinal dis(continuity)

When asked about how continuity of care for children/adolescents with T1DM was maintained during the pandemic, family caregivers revealed experiences marked by interpersonal dis(continuity). According to reports from some participants, the pandemic had an impact on the bond between patients and healthcare professionals for different reasons.

From this perspective, one of the participants recalls that during the pandemic she was laid off from her job and consequently lost access to her health insurance. This situation caused the relationship of trust established between the child, family and the endocrinologist of the health insurance to be abruptly broken and, as a consequence, the loss of glycemic control.

> *As soon as the pandemic started, I became unemployed and we had to cancel our health insurance. We had no access to doctors at all. There was no follow-up care; everything was done at home. During the pandemic, her diabetes was skyrocketing; I was asking for help because I was afraid my daughter would die. It was between 400 and 500, and it seemed like her insulin never went down, because she was on old dosages, because she had already grown and gained weight. So, before the pandemic, I was in frequent contact with her doctors. We were even maintaining a reasonable clinical condition, always doing tests, prescribing different procedures to improve it.* (FC1)

Interpersonal (dis)continuity was experienced by other caregivers of children and/or adolescents with T1DM. According to the reports below, the reason for the interruption of care was the medical professional's absence due to being pregnant and constituting a risk group for COVID-19.

> *The doctor he was seeing stopped seeing her because she was pregnant, so she moved on to another doctor. They were supposed to call, but they didn't because her schedule was full. Every time I called them, they said there was no way, always like that, you know, going there and there being no doctor at all.* (FC2)

> *Then the pandemic hit, the doctor got pregnant and couldn't see her anymore. She simply stopped the appointments and said, "I'm not seeing her anymore". About 6 months went by.* (FC3)

> *When I discovered he had diabetes, I started seeing him at CEME, but there was a doctor who was pregnant and left.* (FC19)

The perception of interpersonal dis(continuity) was also described in healthcare professionals' reports:

> *There was no team during the pandemic. Everyone stopped working, there was no opening for new cases, but outpatient patients would be seen as needed, always with the idea of staying at home. Patients with diabetes are at risk; they shouldn't expose themselves. Well, I think I felt a breakdown in the doctor-patient relationship. I think they perhaps felt alone and had to be more autonomous. There are children whose follow-up we lost forever because of the pandemic; they never came back.* (P1)

> *Also, because they didn't have access to treatment, so, thinking about public health issues, this was horrible. They didn't have access and diabetics are patients that we need to keep an eye on. They had a big loss of bond with us. The children gained weight, had significant glycemic changes. Adolescents too. Adolescents are the worst, because then they lost control completely. So, it's clear that the pandemic brought big problems, and we are trying to reinsert/restore that bond with them again.* (P2)

Although less common, it is important to exemplify with a report that did not identify changes in care and relationships.

> *For me, nothing has changed. Thank God, he hasn't been sick during that time. The doctor ordered all the tests, took him to see her, and then he went to the ophthalmologist and the nutritionist. For me, nothing has changed.* (FC16)

In situations where T1DM diagnosis occurred during the pandemic period, longitudinal dis(continuity) was also perceived, especially due to the delay in obtaining access and professional guidance after hospital discharge, a period particularly marked by many doubts and fears regarding the situation management.

> *One day, I started noticing a lot of ants in my house. In the early hours of the morning, he would drink 2 to 3 liters of water. He went to a medical appointment with his health insurance company and was sent straight to the CCU; he had ketoacidosis. He spent the whole day and night in the CCU. When he was discharged, they told us to schedule an appointment with a pediatric endocrinologist. So, I scheduled one and the receptionist said we would be put on the waiting list. What do you mean by waiting list?* (FC3)

> *It was very difficult to get a bed. We were hospitalized for a period of time, I think it was ten days, if I'm not mistaken. The good thing is that she was already referred to a doctor and a nutritionist, but it was going to take a long time. I think it was a month after the diagnosis. And when you're newly diagnosed, you're completely lost.* (FC18)

The challenges in accessing healthcare professionals during the pandemic meant that efficient and accurate communication between healthcare professionals and family members, in general, was not ensured.

> *There was no number so we could talk, or to direct us to somewhere, you know? No teaching. It was only after the pandemic that the people at BHU explained some things.* (FC1)

Faced with this scenario, family caregivers turned to the internet to resolve their doubts.

> *I have Facebook®, so there's a diabetes page there that I always follow, I'm always asking for guidance.* (FC12)

> *I participated in a group on Instagram® and there were children who made video calls, so they participated during the pandemic.* (FC10)

In addition to social media, some participants used guidance received for controlling Type 2 Diabetes Mellitus from a close family member.

> *Thank God, I already had a little bit of information because of my father. I looked for a lot of information. Even so, I felt lost, you panic and don't know what to do.* (FC18)

> *I searched a lot on Google®, but I also have a base because I have a father who has diabetes, a grandmother who has diabetes, so I already have an idea.* (FC15)

On the other hand, this search for information "outside the technical environment" was problematized by one of the professionals:

> *There is a lot of information in the media about diabetes, especially type 2, not type 1... and then they follow a pattern for type 2, wanting it to solve type 1. So, we noticed this a lot. These wrong messages, Facebook® groups that I think, on the one hand, help, but on the other, they hinder a lot, because each individual is different, so we can't follow a general treatment for everyone.* (P2)

Finally, P1 reveals her perception of the repercussions of interpersonal and longitudinal (dis)continuity during the pandemic.

> *There was a greater return on combinations. Nowadays, we make combinations that they don't understand. Sometimes, they're not even willing to combine. It seems that our role has become more of a prescriber to provide access to medication, much more than a person who can help them and participate more in a participatory and combined way, as I thought there was before. There was a partnership that seems to have been undone.* (P1)

Management dis(continuity)

In general, reports from family caregivers indicated a perception of management discontinuity during the pandemic, i.e., they observed weaknesses in healthcare services in providing children/adolescents with T1DM with the care they required in a timely manner. In this regard, when asked about the use of any remote strategy to ensure continuity of care, outpatient professionals stated that they did not invest in this modality, as exemplified below:

> *I confess that this online service was very difficult, because our patients are SUS patients and they are patients with a very low level of understanding. So, it is already a problem for us to explain in person, imagine online. Like a mother, she couldn't turn on the button; she had a lot of difficulties.* (P2)

In the case of P18, her daughter was diagnosed with T1DM during the most critical period of the pandemic. Thus, management dis(continuity) was perceived when she traveled with the child to different services, especially given the overcrowding of emergency services and hospital admissions.

> *Her diagnosis was quite complicated, because it was right at that time when everything was full. So, it was like this: I went to the health center with a pediatrician. He measured my blood sugar and asked for an urgent referral to Santa Casa. So, I went to Santa Casa, they turned me down, I didn't go in and she was almost out of strength; her blood sugar was at 600 and a bit. So, I went to an ECU. It was full, there was no way to wait. I went to another ECU and from there they referred me to the teaching hospital.* (FC18)

The supply of insulin was also portrayed as lacking, another characteristic of management discontinuity.

> *We went there to get insulin, and the types of insulin offered by the government were constantly changing, and during the pandemic, it was absolutely horrible, from my point of view.* (FC1)
>
> *If I'm not mistaken, during the pandemic, there was a shortage of Glargine, which she applies once a day, but it was really out of stock; several people were unable to get it.* (FC10)

However, the challenges regarding the supply of insulin and supplies are not a particularity of the pandemic period.

> *Before the pandemic, there was also a time when there was a shortage of insulin, and during the pandemic, there was a shortage again. Now, there is also a shortage of the strip.* (FC8)
>
> *Since we discovered my daughter's disease, the problems have been the same: lack of supplies, lack of guidance, appointments that take too long. If you miss it, it takes too long to fit you in for an appointment. Many times, you go to get insulin, they have one and they don't have the other and you end up having to buy it. We find a way and buy it, but I keep imagining families who can't afford to buy it. We get busy and buy it, each one costs 120-150 reais. He's using 3 per month, imagine a family that can't afford to spend 450 per month on just one insulin, you know? This problem has been going on since before the pandemic, but now it's even worse; there's a shortage more than before, but even before the pandemic, there was this shortage problem.* (FC1)
>
> *He measures his diabetes 5 times a day and now they are giving him a little box of strips, so it's not even enough for 15 days, it's desperate, because before I would get three boxes, so we could do it, but now they are not providing all of that, just one.* (FC15)

In this context permeated by challenges, family caregivers described several strategies to ensure continuity of care for their child.

> *I even did an interview with EPTV because I couldn't find insulin at the clinic. I also managed to get it through donations from people who had some left over. I ended up asking for it from a girl because I was desperate. She couldn't do without it, so I ended up asking for it at the grocery store.* (FC15)
>
> *Because just one box of strips costs 100 reais, that's a lot. Insulin in the morning also costs 100 reais. So, for me, it's hard. I had to run around; I asked someone in my family if they could help me with money.* (FC12)
>
> *I even worked abroad for a year to be able to buy these things* [referring to the supplies]. (FC2)
>
> *It was a struggle to get this appointment at the teaching hospital. It was very difficult, I spoke to people from the city hall, the councilman, the radio, everything within my reach, until I got the appointment. Her life and ours are a constant struggle, it's a struggle every day.* (FC1).

DISCUSSION

The results revealed a breakdown in the bond between healthcare professionals and patients during the pandemic, revealing experiences of interpersonal discontinuity in family caregivers' perception. This disruption was highlighted by situations such as the loss of access to health insurance due to unemployment. This finding is in line with a previous study that points to a significant increase in unemployment rates during the pandemic, resulting in losses in healthcare for the population.

According to the authors, more than 30 million jobs were lost in the first months of the pandemic and access to preventive and chronic healthcare was suspended or postponed for many, resulting in increased health disparities.[14]

Another aspect identified in this research concerns the absence of healthcare professionals due to belonging to risk groups, specifically, due to being pregnant. Thus, the evidence in the literature clearly indicates that healthy pregnant women were more susceptible to developing COVID-19 due to their immune response that predisposes them to developing the disease.[15]

According to reports, during the pandemic, there was a reduction in the number of appointments for new cases, directly affecting continuity of care for those diagnosed during this period. In this regard, the pediatric population that developed new diseases unrelated to COVID-19 during the pandemic was exposed to a greater risk of worsening or death due to compromised access to hospital care.[16] Furthermore, according to a study carried out with 303 professionals working in care centers for people with T1DM in 75 different countries around the world, during the most critical phase of the pandemic, only 16.7% of professionals maintained the routine of in-person appointments, this percentage was higher (38%) when it came to patients with a recent diagnosis.[5]

In the same vein, according to an Italian study, children continued to fall ill during the pandemic with occasional infections and complications or with the acute onset of chronic conditions, such as cancer and diabetes.[17] However, there have been substantial reductions in access to pediatric care in Italy and children with chronic conditions have been exposed to a higher risk of severe illness due to lack of access to healthcare than their healthy peers.

Family caregivers and healthcare professionals who participated in this study perceived the negative impact of discontinuity of care on the glycemic control of children and adolescents. According to a systematic review that sought to identify the impact of the COVID-19 pandemic on clinical outcomes in people with diabetes, the studies did not suggest any difference in the frequency or severity of diabetic ketoacidosis among adults; however, among children and adolescents, most studies showed a significant increase in cases of ketoacidosis, including an increase in diabetes-related hospitalizations in pediatric intensive care units.[18] Furthermore, research carried out in Portugal that assessed the impact of confinement on glycemic control, weight and insulin requirements among children and adolescents with T1DM revealed an increase in the Body Mass Index of all patients (p=0.009) and worsening of metabolic control in the age group of 10–13 years (p=0.03), with a 0.4% increase in glycated hemoglobin.[19]

However, in contexts with greater access to health technologies, the repercussions were less evident. The first lockdown resulting from the pandemic did not harm the metabolic control of most children with diabetes, possibly due to glucose sensor and hybrid closed-loop pump technology, allowing data download and the practice of telemedicine.[20] Positive results were also mentioned in another investigation on the subject, indicating cases of children who exhibited good glycemic control during confinement, especially among those with adequate parental involvement and access to telemedicine.[6] However, these are realities far removed from those experienced by children and adolescents supported by Brazilian public services. In fact, in the present study, according to one professional, the remote modality was disregarded due to the limitations of family caregivers in handling electronic devices and in understanding the information.

The pandemic has also impacted other groups of children and adolescents with chronic conditions. An English study, using a qualitative approach, conducted with 20 parents of children with various chronic conditions, portrayed problems similar to those reported by participants in the current study, especially regarding long waiting times and deficiencies in telemedicine.[21] Furthermore, participants described feeling "lost" as contact with the multidisciplinary team was interrupted, resulting in, in some situations, inappropriate care.[21] These findings corroborate the narratives of this investigation, which portray searches for information in unofficial media such as groups on social networks in order to mitigate doubts regarding diabetes management.

Management discontinuity, highlighted by the shortage of insulin and other supplies necessary for adequate glycemic control, supports the literature, which also pointed out that ensuring basic supplies for diabetes such as glucose test strips and insulin was a challenge during the confinement period. As a result, many patients had to bear the costs.[5,22]

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

It was concluded that the results presented met the proposed objective and answered the research questions. In general, family and professional caregivers perceived a discontinuity in interpersonal relationships, exacerbating feelings of insecurity and culminating in glycemic loss of control. The lack of supplies was also characterized as an aspect that impacted continuity of care.

Regarding contributions and innovations for teaching, research and assistance in nursing and health, this research substantiates the existing literature by analyzing this topic based on the theoretical concept of continuity of care of the World Health Organization. Furthermore, it points out directions to mitigate the challenges experienced by children and adolescents with T1DM and their families in future health crises.

Finally, although data collection through a digital platform was foreseen in the methodological design, the impossibility of observing the home context and carrying out in-person interactions constituted a possible limitation of this study.

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DATA AVAILABILITY RESEARCH

The contents underlying the research text are included in the article.

CONFLICT OF INTEREST

None.

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