



“Not having a minute of self-distancing during the social distancing is exhausting”: a qualitative study on the perspective of caregivers of youth with type 1 diabetes during the COVID-19 pandemic

Janine Alessi^{1,2} · Giovana B. de Oliveira³ · Isadora N. Erthal³ · Julia B. Teixeira³ · Milena S. Morello³ · Raquel J. E. Ribeiro³ · Taíse R. de Carvalho^{3,4} · Eduarda H. Jaeger³ · Beatriz D. Schaan^{1,5,6,7} · Gabriela H. Telo^{2,3,4}

Received: 26 April 2021 / Accepted: 29 May 2021
© Springer-Verlag Italia S.r.l., part of Springer Nature 2021

Abstract

Objective To investigate the impact of the COVID-19 pandemic on caregivers of youth with type 1 diabetes.

Methods We performed a qualitative research based on an open-ended questionnaire that was conducted through an online platform for primary caregivers of children and adolescents with type 1 diabetes. Participants were asked to describe the impact of the COVID-19 outbreak on their caring for youth with diabetes, as well as the emotional burden that it has brought to their personal lives. Interview responses were coded and stratified by youth age: ≤ 12 years (youth aged ≤ 12 years) and between 13 and 18 years (youth aged > 12 years). The connections between the responses were identified based on either positive or negative content of the reported experience. Data were analyzed in accordance with an inductive reasoning methodology.

Results A total of 318 participants (mean age of 40.3 ± 8.1 years old) were included, representing caregivers of youth aged 11.7 ± 4.3 -year-old with diabetes duration of 5.1 ± 3.8 years. The preponderance of negative feelings was noteworthy. Regarding diabetes care, more than 80% of participants reported concern and anxiety about the changes in habits that accompanied the pandemic. Also, more than half of caregivers regretted the isolation of their youth, factors that were associated with greater difficulty in achieving good glycemic control. Regarding the personal burden experienced, the negative impact of uncertainties and concerns about the COVID-19 were present in almost all participants.

Conclusion The period of pandemic may lead to exhaustion in caregivers of youths with type 1 diabetes, which reflects the need for mental health support strategies to help those families.

Keywords COVID-19 outbreak · Type 1 diabetes · Emotional burden · Mental health · Caregivers · Social distancing

Introduction

The diagnosis and management of youth with type 1 diabetes may have a negative emotional impact on parents and caregivers. Concern about hypoglycemia, fear of future complications, and guilt about glycemic control can result in excessive

Managed by Massimo Porta.

✉ Janine Alessi
janinealessi@gmail.com

¹ Graduate Program in Medical Science: Endocrinology, Universidade Federal Do Rio Grande Do Sul, Porto Alegre, Brazil

² Internal Medicine Department, Hospital São Lucas - Pontifícia Universidade Católica Do Rio Grande Do Sul, Porto Alegre, Brazil

³ School of Medicine, Pontifícia Universidade Católica Do Rio Grande Do Sul, Porto Alegre, Brazil

⁴ Graduate Program in Medicine and Health Sciences, Pontifícia Universidade Católica Do Rio Grande Do Sul, Porto Alegre, Brazil

⁵ School of Medicine, Universidade Federal Do Rio Grande Do Sul, Porto Alegre, Brazil

⁶ Endocrinology Division, Hospital de Clínicas de Porto Alegre, Porto Alegre, Brazil

⁷ Instituto de Avaliação de Tecnologia em Saúde (IATS), Porto Alegre, Brazil

worries, depressive symptoms, and anxiety disorders [1, 2]. A study carried out in a non-pandemic situation showed that caregivers of children play a fundamental role in controlling the disease and experience the responsibility for any short or long-term consequences related to diabetes [1]. Another study showed that parents suffer from constant concerns about the care for their children even when the child was with a secondary caregiver. It makes the role of caregivers a full-time job [3]. The emotional burden of caregivers might have consequences not only on the parents' psychological well-being, but may also have indirect effects on glycemic control of the youth [2, 4]. A better understanding of the negative feelings experienced by parents and caregivers is necessary for the development of supporting strategies that promote an improvement in family well-being [1].

The COVID-19 pandemic has the potential to cause a significant emotional burden on caregivers of youth with type 1 diabetes. In usual situations, these caregivers need regular support from health professionals to feel confident about the care of their youth's diabetes and to help in the management of emotional reactions and life changes that accompany the diagnosis [5]. The unavailability of medical appointments and the difficulty in obtaining specialized support during the pandemic may generate feelings of concern and insecurity in this group. Moreover, the fear of possible infection by the new coronavirus and the uncertainty regarding its severity in patients with diabetes makes the current pandemic even more alarming for caregivers [3, 6]. These circumstances reveal a greater vulnerability of those responsible for youth with diabetes to experience emotional distress during the outbreak.

The social distancing measures required by the COVID-19 pandemic may also become a challenge for caregivers of children and adolescents with diabetes, who are forced to face a new reality with their youth at home full time. Also, children and adolescents may be lonelier and more anxious than usual, which can make it even more difficult for parents to deal with this new personal distress [7]. Understanding how the pandemic is affecting these caregivers and knowing the psychological demands of these families is essential for the development of coping strategies for similar situations in future. A previous study evaluated the impact of the pandemic on the mental health of caregivers of youth with type 1 diabetes compared to caregivers of youth without diabetes. This study found a positive screening for mental health disorders during social distancing more often in caregivers of youth with type 1 diabetes (OR 2.43; 95% CI, 1.70–3.47), particularly in those aged under 12 years old [8]. However, there are no studies to date assessing caregivers' impressions about the changes that occurred during the pandemic, and the importance of caring for caregivers of youth with type 1 diabetes in this situation is still overlooked. This inductive reasoning study aims to explore the experiences and perceptions of how the current

pandemic is affecting these caregivers, generating important insights for future strategies and mental health support.

Methods

Study design and participants

This study uses web-based qualitative research to evaluate the emotional repercussions of the COVID-19 pandemic in caregivers of youth with type 1 diabetes. A non-directive approach using free-form comments was used throughout the study. Guidelines for web-based qualitative health research were used for the study design [9–11]. Adults of any age who were the primary caregivers of children and adolescents (aged less than or equal to 18 years old) with a previous diagnosis of type 1 diabetes were electronically recruited to participate in this study. Considering the limitations on interactions between the participants and the researchers during the pandemic, and aiming to preserve the safety of both, all study procedures were carried out remotely. The invitation to participate was issued through the social media of the Juvenile Diabetes Association, a society that integrates associations throughout Brazil intended for caregivers of children and adolescents with diabetes. Electronic invitations were sent between May 18 and June 9 of 2020, approximately two months after the beginning of the pandemic in Brazil. Inclusion criteria were being an adult over 18 years of age and being the parent or primary caregiver of children/adolescents aged less than or equal to 18 years old with type 1 diabetes. Caregivers of youth without type 1 diabetes were excluded from this study. During the evaluation, Brazil was considered one of the epicenters of the COVID-19 spread, justifying the suspension of school activities and non-emergency medical consultations. The manuscript description follows the consolidated criteria for reporting qualitative research (COREQ) guidelines [12].

Data collection

Free-form answers to non-directive questions were provided through the SurveyMonkey online platform (San Mateo, CA, U.S.A.; <http://www.surveymonkey.com>). There was no direct interaction between the researcher and the participant during the study. The choice of this model was based on its potential to acquire a subjective and deep understanding of the attitudes, feelings, and motivations of the participants, using open surveys and self-administered questionnaires in the form of free-form comments to examine the impact of the COVID-19 pandemic in caregivers. This format used reveals views and feelings normally inaccessible through direct questions and provides greater insight into attitudes and intentions than predefined questions, which are often directed or biased [9–11, 13]. Moreover, this model proved

to be appropriate for assessing a large amount of data during the pandemic, saving participants from exposure and unnecessary risks.

The assessment was performed in two steps. First, an objective questionnaire regarding sociodemographic and clinical information was sent to participants. Data referring to the latest glycosylated hemoglobin, the presence of complications of the disease, and other aspects related to diabetes were based on the caregivers' report. Second, a subjective assessment was performed to explore the experiences and perceptions of how the current pandemic is affecting these caregivers. For this evaluation, free-form spaces were left to the participant to openly discuss the emotional impact of the pandemic. This assessment was conducted using the following non-directive questions:

1. The burden of care: Describe, in your words, how the current COVID-19 pandemic has impacted your life related to the child or adolescent for whom you are responsible.
2. Personal emotional impact: Describe how you feel, in the context of social distancing, about the emotional burden that the COVID-19 pandemic has brought into your life.

Responses were automatically recorded on the online platform. As there was no direct contact with the researcher and the answers were free text, the information was not discussed until it was saturated, which is a limitation of the chosen web-based model. Furthermore, considering the emergency of the COVID-19 pandemic and the need for quick responses to provide important insights for the psychological support of these caregivers, there was no time to conduct a pilot study with the proposed survey strategy.

Questionnaires were applied for changes that occurred during the COVID-19 pandemic. This assessment included social distancing, maintenance of school activities, family income, and difficulty in medical assistance. It was considered "partial social distancing" for participants who went out for basic activities, such as market, pharmacy, and health care. Total social distancing refers to participants who followed the orientation of home quarantine. School activities were considered partially suspended if the youth maintained remote scholar activities during the pandemic, and totally suspended if no school activities were performed. The questionnaire included "yes" or "no" response options for the presence of difficulties related to family income and medical care assistance during the pandemic.

Research team and reflexivity

Researchers J.A (MD), B.D.S (MD Ph.D.), and G.H.T (MD Ph.D.), females, were responsible for preparing the proposed open-ended questionnaire. B.D.S and G.H.T have extensive experience in caring for children and adolescents with type 1

diabetes, and the researchers, J.A, G.B.O, B.D.S, and G.H.T, have carried out several studies evaluating the impact of the COVID-19 pandemic on patients with diabetes [8, 14]. The study participants had no previous relationship with the researchers. In the enrollment, the interests and motivations for conducting the proposed interview were explored in an introductory text.

Sampling

One advantage of the online survey interview format was the convenience for participants, who could answer the questions from their homes, increasing the response rates. Besides, the absence of an interviewer reduced the risk of the social-desirability bias. The initial protocol of this study was designed for a quantitative evaluation of the impact of the pandemic on caregivers of youth with type 1 diabetes. For this reason, the sample size included in this study was based on the calculation performed for the primary quantitative analyses. The results and detailed description of the quantitative evaluation were published previously [8]. The Krejcie and Morgan Sampling Formula was used to determine a sample size for a quantitative analysis using a 95% confidence level and a margin of error of 0.05 [15]. Considering the prevalence of youth with type 1 diabetes in Brazil in 2019, 380 responses in the diabetes group were determined to be necessary to obtain the adequate power necessary for the sampling [16]. Therefore, this sample size was extrapolated for the qualitative assessment.

Analysis

The data were transcribed from the online platform SurveyMonkey, (San Mateo, CA, U.S.A.) to Microsoft Excel® (2010). Data were analyzed in accordance with the methodology for web-based qualitative data using an inductive reasoning methodology [12, 17]. Interview responses were coded and stratified by the youth age group: ≤ 12 years (youth ≤ 12 years) and between 13 and 18 years (youth > 12 years). Each response was read and re-read, ensuring that new insights were generated, and the semantic content was fully explored. The main themes were previously defined, according to the questions in the online survey. The connections between the responses were identified based on the positive or negative content of the reported experience. Following this step, all responses were analyzed, and the patterns between them were investigated to describe the participants' shared experiences. Throughout the analysis, the topics were discussed between researchers (J.A, G.O.B, J.B.T, I.N.E, R.E, M.M.), which ensured uniformity and systematization of the analyses based on the participants' original responses. The coding tree is available in Supplementary Fig. 1.

Ethical aspects

The project was approved by the research ethics committee (n° 4.045.411) and all patients included in the study agreed to the informed consent form.

Results

Participants

A total of 485 responses to the online questionnaire were collected, of which 16 did not accept the consent form, 35 youths were over 18 years old and 54 did not answer the free-form questions. The enrollment ended when 380 eligible participants had completed 75% of the questionnaire. A total of 62 participants chose not to answer the free-form non-directive questions. Thus, interviews with 318 participants were included in the analysis, being 174 of caregivers of youth ≤ 12 years and 144 of caregivers of youth > 12 years.

The included participants had a mean age of 40.3 ± 8.1 years; 95.6% were female; 69.5% were white; 50.6% had medium or low family income. Regarding youths, the mean age was 11.7 ± 4.3 years, with a mean diabetes duration of 5.1 ± 3.8 years. Concerning the COVID-19 pandemic, 36.5% of participants were following the guidance of total social distancing, without leaving home for any activity, and 67.3% of the caregivers reported that their youths had had their school activities suspended during the pandemic. Those who had school activities maintained these online (see Table 1).

The burden of caring for type 1 diabetes in youth aged ≤ 12 years during an outbreak

A total of 141 (81.5%) of the 174 interviewees reported that the pandemic had affected them negatively, increasing their burden related to the care of children's diabetes. Concern about diabetes control was the main feeling mentioned. According to most caregivers, the glycemic control became worse and more difficult during the pandemic, which increased their distress about the care of these youth aged ≤ 12 years.

We are having problems with glycemic control because staying at home all the time has made my daughter angry. This stress alters her glucose control and worsens the anxiety, which makes her want to eat all the time and not always healthy things. It worries me and tires me a lot. (Mother, 32 years old, 12-year-old child).

Table 1 Sociodemographics and clinical characteristics of study participants

	Total (n=318)
Age (years)	40.3 \pm 8.1
Sex (% female)	304 (95.6)
Race/ethnicity (% white)	221 (69.5)
Lower-middle income*	161 (50.6)
Parentage (% mother)	290 (91.2)
<i>Youth with type 1 diabetes characteristics</i>	
Age of the youth (years)	11.7 \pm 4.3
Disease duration (years)	5.1 \pm 3.8
HbA1c (%)	7.9 \pm 1.4
HbA1c (mmol/mol)	63 \pm 15.6
<i>COVID-19 period assessment</i>	
Follows social distancing	
Totally	116 (36.5)
Partially	192 (60.4)
School activities	
Totally suspended	214 (67.3)
Partially suspended	79 (24.8)
Financial difficulty	122 (38.4)
Difficulty in medical assistance	139 (43.7)

Data are mean \pm standard deviation or n (%). *Lower-middle income: a family that receives a total of fewer than 2564 reais per month, as defined by the *Strategic Affairs Secretariat (SAS)* of Brazil in 2012, equivalent to 495.8 dollars or 430 euros. It was considered "partial social distancing" for participants who go out for basic activities: market, pharmacy, and health care. Total social distancing includes participants who follow the orientation of home quarantine. School activities were considered partially suspended if the youth maintained remote scholar activities during the pandemic, and totally suspended if no school activities were performed

In addition to the impact on diabetes care, the pandemic was accompanied by challenges regarding the isolation of these youth aged ≤ 12 years. Not being able to go to school, practice their usual daily activities, and maintain their normal routines were considered negative effects of social distancing measures, generating anxiety and concerns for children and caregivers. This reality brought even greater pressure to parents, who felt a duty to keep the children entertained during the day.

It is challenging occupying, to make children expend energy and not feel the impact of everything that is happening. It is a challenge not to have social interaction at my child's age, and this is having an impact on me."
(Mother, 37 years old, 5-year-old child).

The overuse of electronics by youth was mentioned by several caregivers, generating different feelings. Some considered the increase in screen time (video games, computers, and smartphones) a negative consequence of social distancing, which aggravated sedentary behaviors and worsened glycemic

control. This has become a serious concern for caregivers. However, some caregivers considered this technology a form of refuge and distraction for youth and supported its use.

He likes games, and, while playing, he doesn't pay much attention to the bad things that are happening. That's why I have let him play. (Mother, 42 years old, 11-year-old child).

The burden of caring for type 1 diabetes in youth aged > 12 years during an outbreak

Overall, 120 (83.9%) of the 144 interviewees responsible for youth aged > 12 years reported that the pandemic had affected them negatively. Similar to the caregivers of youth aged ≤ 12 years, most caregivers reported “distress” and “sadness” due to the isolation of youth, which is an even greater challenge in this age group. These parents associated confinement with changes in their youth's mood, such as irritability, lack of patience, and aggressiveness in speech.

There is a lot of frustration because she is very sensitive and does not accept the confinement. That makes me sad, without reaction. I often get lost when she doesn't want to eat or eats the wrong foods. (Mother, 52 years old, 18-year-old adolescent).

Also, many interviewees reported that changes in daily habits during the pandemic significantly impaired their youth's glycemic control. These changes, added to the suspension of medical appointments, were associated with increased “anxiety” and “distress” in the caregivers, resulting in a feeling of “helplessness” in the face of difficulties and uncertainties related to the youth's health. “Frustration” at inadequate glycemic control proved to be common among those caregivers.

She is just at home, unable to practice physical exercises. The routine of being alone inside the house ends up complicating the control of diabetes. Eating more, spending more time lying down watching TV; it's very difficult. (Mother, 40 years old, 18-year-old adolescent).

Many caregivers regretted their financial difficulties in ensuring nutritious food and supplies for their youth during the pandemic, resulting in “guilt” and “uncertainty” regarding the possibility of continuing treatment. Finally, during times of uncertainty and anxiety, some parents also reported that they were trying to transmit security to their youth, which can become a burden and, consequently, another exhausting factor.

A minority of caregivers expressed being “calmer” and “less exhausted” during the pandemic. Some caregivers said that the youth aged > 12 years autonomy on diabetes care has doubled.

I feel my son is more mature, more willing to take care of himself. I hope this pandemic was the key he needed. (Mother, 39 years old, 18-year-old adolescent).

Personal impact of the pandemic era on youth aged ≤ 12 years caregivers

Regarding the personal impact that caregivers of youth aged ≤ 12 years with type 1 diabetes reported during the pandemic, approximately 155 (89.6%) interviewees felt that the pandemic had affected them negatively. Fear of the COVID-19 infection was the most addressed sentiment. Many caregivers emphasized this feeling due to their child's disease and were fearful about a possible relationship between type 1 diabetes and serious outcomes if infected. The lack of information about the relationship between COVID-19 and type 1 diabetes was remembered as an aggravating factor for the fear presented. Furthermore, several other responsibilities triggered weariness and exhaustion in caregivers, such as the financial situation and the condition of health institutions during the pandemic.

I feel like my hands and feet are tied, because I can't get the supplies my son needs, while dealing with the lack of medical care at the center where he should be cared for. (Mother, 41 years old, 12-year-old child).

Feelings often reported were “tiredness,” “exhaustion,” and “overload,” present in about one-third of the responses. Caregivers' statements reflected the changes that had occurred since the beginning of the social distancing measures when they were forced to assume the dual role of family provider and full-time caregiver. The workplace, which for many became a home office, has been challenging considering the child's presence and interference throughout the day. Also, the child's increased time at home after the closing of schools increased the demand for attention from caregivers. Many of them indicated that it had been very difficult to conciliate the demands of work and the necessity of caring for the youth at home, which made them feel unable to succeed in either role, generating more distress and anguish. Moreover, the lack of privacy and time for themselves made these caregivers feel overwhelmed.

I am overloaded by having a triple journey: taking care of my son, the house and working, since all three tasks have an increased load. (Father, 44 years old, 4-year-old child).

I feel unhappy. Not having a minute of self-distancing during the social distancing and always being available to everyone is exhausting. (Mother, 30 years old, 4-year-old child).

Personal impact of the pandemic era on youth aged > 12 years caregivers

Concerning the emotional impact that caregivers of youth aged > 12 years with type 1 diabetes are experiencing, a total of 132 (92.3%) interviewees felt that the pandemic had affected them negatively. The first major source of worry was related to the COVID-19 infection and its consequences. This concern seemed to be expressed even more among youth aged > 12 years caregivers considering the youth's greater autonomy and desire for socialization. For those youth who followed social distancing measures, caregivers reported concern and guilt related to the possibility of contracting the virus, a situation that aggravated their distress.

I feel constantly worried and guilty in the rare moments when I work outside the home. (I am) fearful of being contaminated and bringing the virus to my son, who is in total isolation at home. I miss socializing with friends and family, but the responsibility for him is a priority. (Mother, 42 years old, 13-year-old adolescent).

Caregivers also suffered frustration with youth' expectations about their desires and routine. The lack of freedom to come and go, the desire to see friends and family, and the suboptimal diabetes control during the pandemic were some factors that resulted in disagreements and worsened family relationships. The conflictual relationship with the youth during this period of greatest vulnerability led to emotional exhaustion in caregivers.

I feel very scared for her. She's in her teens, so it's more complicated. She wants to go out, but my husband and I won't let her, so she gets mad. It is a delicate time for all of us, and I feel exhausted. (Mother, 34 years old, 15-year-old adolescent).

The feelings of "uncertainty" and "powerlessness" were also expressed by caregivers. Not having control over the spread of the coronavirus, not knowing when this pandemic will end, and not having confidence about an improvement in the family's income made caregivers feel as their "hands were tied." The reduction of work and unemployment were cited by some parents as important causes of suffering during the pandemic. Among with financial difficulties, caregivers dealt with the anguish of being unable to buy the necessary supplies to care for their youth's diabetes. This resulted in an unimaginable burden for these individuals.

(I have) uncertainty about what will become of my work, because I work on my own, and do not receive help from anyone. The SUS [public health system in Brazil] has already failed to supply the diabetes treatment several times, and, without that, I had to buy them. During the pandemic, the work decreased, and expenses increased.

How will I be able to maintain my child's treatment? (Mother, 49 years old, 13-year-old adolescent).

Discussion

Social distancing measures and the psychological burden of facing a pandemic have negatively sensitized most of the caregivers of children and adolescents with type 1 diabetes. Regarding the care of their youth, most participants reported concern and anxiety related to changes in habits that accompanied the social distancing, factors that were associated with worsening glycemic control in some cases. Additionally, feelings of anguish and guilt accompanied the financial difficulties that some families have faced during this period. The inability to provide quality food and supplies for diabetes may imply worse glycemic control, which was mentioned as a cause of emotional distress. Most of the participants also regretted the isolation of their youth. The perception of changes in mood and irritability in the youths brought even more anguish and sadness to their caregivers. Despite the uncertainties and concerns about the COVID-19 infection being spread to the participants, feelings of weariness and exhaustion were pervasive among caregivers, although their origins differed. Increased family discussions and the difficulties involved with keeping the youth at home were the main sources of emotional burden in youth aged > 12 years' caregivers. The greater demand for attention and care of the children who were at home full time was the main cause of overload among youth aged ≤ 12 years' caregivers.

In pandemic situations, caregivers play a fundamental role in ensuring family care, stability, and security, which ends up consuming their time and energy [18]. Our results show that caregivers for youth with type 1 diabetes felt an increased need to provide care and a greater responsibility during the COVID-19 pandemic. Whittemore et al., in a study conducted in a non-pandemic context, showed that parents of children with type 1 diabetes had a higher basal rate of stress and greater concern, given that diabetes care requires a lot of responsibility, time, work, and routine [19]. When we consider a pandemic scenario in which many caregivers report a change in youth habits, a worse glycemic control, and an increase in concerns related to the youth's health, the negative feelings are exacerbated.

Social distancing measures also negatively affected both the youth and caregivers. Youth aged ≤ 12 years' caregivers more often reported feelings of exhaustion and fatigue, which were mostly related to the increased demand for attention at home. Similar results were found in studies conducted with caregivers of children without diabetes during the COVID-19 pandemic [20, 21]. An Italian study evaluated exhaustion in parents during the lockdown by COVID-19 and showed

that the cancellation of children's classes and social activities makes it very difficult for caregivers to reconcile work with the needs for attention, play, and education demanded by children [22]. This demand is even greater for caregivers of children with diabetes, considering an additional concern about glycemic control, which can trigger a physical and psychological burden.

In addition, the consequences on the social and psychological development of children have been even more pronounced than in adults, with irritability, distraction, and anxiety being commonly expressed by this age group [23]. Social distancing measures may also affect the adolescent's mental health, as a result of losing interaction with peers and, consequently, affecting the child's interpersonal relationships [24]. In the present study, most caregivers regretted the isolation of their youth and associated this with feelings of frustration, boredom, and irritability for the youth. Another factor to consider is the youth's aged > 12 years perception of the pandemic. On one hand, it is common for adolescents to underestimate the danger of COVID-19, which causes concern for caregivers and may trigger confrontations [25]. On the other hand, teens are more attentive and have the ability to understand what is happening. These factors may directly impact the caregivers, who experience the consequences of such emotional upheaval.

The difficulties pointed out by the caregivers make us reflect on possible strategies that could be used to mitigate the psychological impact in similar situations. First, the concern of family members draws attention to the lack of information that they have received about the relationship between COVID-19 and type 1 diabetes. The provision of easily accessible channels with reliable information could be an important ally and reduce the feeling of incompetence in these families. Second, the concern about the lack of care and the preoccupation with glycemic control is evident. The creation of specialized and low-cost telehealth centers for patients with type 1 diabetes is one way to meet the demands of care during the pandemic and should be prioritized. Third, channels for listening to these caregivers and providing guidance on emotional self-care should be made available. These could be effective and prevent the sense of overload. Fourth, the provision of multidisciplinary channels, through social media or phone, which allows free and easily accessible information on physical and nutritional guidance and mental health care for youth with type 1 diabetes could be very useful in such situations. Fifth, the use of applications that encourage playful activities for children and keep them entertained without the need for full-time parental attention could alleviate parents' exhaustion. Finally, creating groups on social media that allow peer interaction could be beneficial in allowing these caregivers to share their perceptions and help each other.

Our study has some limitations. The nature of the interviews, which were conducted via a website and without interaction with the researchers, did not allow the discussion of the issues until they were saturated. In addition, it is possible that caregivers who were most concerned and impacted by the pandemic were also more interested in answering the proposed questionnaire. Given that this was an online survey, the results depend on the commitment of the participants and on the veracity of the information provided, which may constitute potential information bias. Finally, most participants were female caregivers, which may reduce the validity of the results for male representatives. This high prevalence is in line with other studies conducted in pediatric outpatient care in Brazil, in which the mother plays the role of primary caregiver in 91.0–93.7% of cases [8, 26, 27]. Still, the emotional and physical overload that caregivers of youth with type 1 diabetes are experiencing during the current COVID-19 pandemic is plausible and deserves attention.

Despite these limitations, our study shows a potential negative impact on parents of children or adolescents with type 1 diabetes during the COVID-19 pandemic and it should not be neglected. The results suggest that periods of pandemics may create an emotional overload and lead to exhaustion those responsible for the care of youth with diabetes. More than ever, the mental well-being of caregivers should be prioritized, and coping strategies should be encouraged. The ability of parents to care, assist and protect their families depends mainly on their emotional well-being and resilience in the face of adversity.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00592-021-01753-3>.

Acknowledgements JA is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity and accuracy of the data.

Authors' Contribution JA involved in conceptualization, methodology, data curation, and writing—original draft preparation. GOB, JBT, INE, RE, MM, and TC participated in methodology and writing—original draft preparation. EHJ involved in writing—reviewing and editing. BDS participated in supervision and writing—reviewing and editing. GHT involved in conceptualization, supervision, and writing—reviewing and editing.

Funding This work was conducted with support from Programa de Pós Graduação em Ciências Médicas em Endocrinologia da Universidade Federal do Rio Grande do Sul, Faculdade de Medicina da Pontifícia Universidade Católica do Rio Grande do Sul and Hospital São Lucas da Pontifícia Universidade Católica do Rio Grande do Sul.

Data availability The data collected for the study, including deidentified participant data, will be available for 1 year after publication of the article upon justified request to the e-mail address of the main researcher and with a signed data access agreement.

Declarations

Conflict of interest No potential conflict of interest was reported by the authors.

Ethical approval The study was approved by the Research Ethics Committee of Hospital São Lucas da Pontifícia Universidade Católica do Rio Grande do Sul (CEP), number 4.045.411.

Consent for publication All authors have reviewed the final version of the manuscript and agree with the publication of the results presented.

Consent to participate All participants agreed to the free and informed consent form.

References

- Harrington KR, Boyle CT, Miller KM, Hilliard ME, Anderson BJ, Van Name M et al (2017) Management and family burdens endorsed by parents of youth <7 years old with type 1 diabetes. *J Diabetes Sci Technol* 11(5):980–987
- Van Gampelaere C, Luyckx K, Van Ryckeghem DML, Van Der Straaten S, Laridaen J, Goethals ER et al (2019) Mindfulness, worries, and parenting in parents of children with type 1 diabetes. *J Pediatr Psychol* 44:499–508
- Commissariat PV, Harrington KR, Whitehouse AL, Miller KM, Hilliard ME, Van Name M et al (2020) “I’m essentially his pancreas”: parent perceptions of diabetes burden and opportunities to reduce burden in the care of children <8 years old with type 1 diabetes. *Pediatr Diabetes* 21(2):377–383
- Viaene AS, Van Daele T, Bleys D, Faust K, Massa GG (2017) Fear of hypoglycemia, parenting stress, and metabolic control for children with type 1 diabetes and their parents. *J Clin Psychol Med Settings* 24:74–81
- Iversen AS, Graue M, Haugstvedt A, Råheim M (2018) Being mothers and fathers of a child with type 1 diabetes aged 1 to 7 years: a phenomenological study of parents’ experiences. *Int J Qual Stud Health Well-being* 13:1487758
- Limbers CA, Teasdale A (2018) Parenting stress in fathers of children with type 1 diabetes. *Fam Community Health* 41:117–122
- Fegert JM, Vitiello B, Plener PL, Clemens V (2020) Challenges and burden of the Coronavirus 2019 (COVID-19) pandemic for child and adolescent mental health: a narrative review to highlight clinical and research needs in the acute phase and the long return to normality. *Child Adolesc Psychiatry Ment Health* 14:1–11
- Alessi J, de Oliveira GB, Feiden G, Schaan BD, Telo GH (2021) Caring for caregivers: the impact of the COVID-19 pandemic on those responsible for children and adolescents with type 1 diabetes. *Sci Rep [Internet]* 11(1):1–10. Available from: <https://doi.org/10.1038/s41598-021-85874-3>
- Wilkerson JM, Iantaffi A, Grey JA, Bocking WO, Rosser BRS (2014) Recommendations for internet-based qualitative health research with hard-to-reach populations. *Qual Health Res* 24:561–574
- Neville S, Adams J, Cook C (2016) Using internet-based approaches to collect qualitative data from vulnerable groups: reflections from the field. *Contemp Nurse* 52:657–668
- Daley EM, McDermott RJ, McCormack Brown KR, Kittleson MJ (2003) Conducting web-based survey research: a lesson in internet designs. *Am J Health Behav* 27:116–124
- Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 6:349–357
- Sutton J, Austin Z (2015) Qualitative research: data collection, analysis, and management. *Can J Hosp Pharm* 68:226
- Alessi J, De Oliveira GB, Franco DW, Brino Do Amaral B, Becker AS, Knijnik CP et al (2020) Mental health in the era of COVID-19: prevalence of psychiatric disorders in a cohort of patients with type 1 and type 2 diabetes during the social distancing. *Diabetol Metab Syndr* 12:1–10
- Krejcie RV, Morgan DW (1970) Determining sample size for research activities. *Educ Psychol Meas* 30:607–610
- Patterson CC, Karuranga S, Salpea P, Saeedi P, Dahlquist G, Soltesz G et al (2019) Worldwide estimates of incidence, prevalence and mortality of type 1 diabetes in children and adolescents: results from the international diabetes federation diabetes atlas, 9th edition. *Diabetes Res Clin Pract* 157:107842
- Romano NC, Donovan C, Chen H, Nunamaker JF (2003) A methodology for analyzing Web-based qualitative data. *J Manag Inf Syst* 19:216–246
- Fong VC, Iarocci G (2020) Child and family outcomes following pandemics: a systematic review and recommendations on COVID-19 policies. *J Pediatr Psychol* 45:1124–1143
- Whittemore R, Jaser S, Chao A, Jang M, Grey M (2012) Psychological experience of parents of children with type 1 diabetes: a systematic mixed-studies review. *Diabetes Educ* 38:562–579
- Davidson B, Schmidt E, Mallar C, Mahmoud F, Rothenberg W, Hernandez J et al (2020) Risk and resilience of well-being in caregivers of young children in response to the COVID-19 pandemic. *Transl Behav Med* 11:305–313
- Fitzpatrick O, Carson A, Weisz JR (2020) Using mixed methods to identify the primary mental health problems and needs of children, adolescents, and their caregivers during the coronavirus (COVID-19) pandemic. *Child Psychiatry Hum Dev*. <https://doi.org/10.1007/s10578-020-01089-z>
- Marchetti D, Fontanesi L, Mazza C, Di Giandomenico S, Roma P, Verrocchio MC (2020) Parenting-related exhaustion during the Italian COVID-19 lockdown. *J Pediatr Psychol* 45:1114–1123
- Singh S, Roy D, Sinha K, Parveen S, Sharma G, Joshi G (2020) Impact of COVID-19 and lockdown on mental health of children and adolescents: a narrative review with recommendations. *Psychiatry Res*: 1–12
- Imran N, Zeshan M, Pervaiz Z (2020) Mental health considerations for children & adolescents in covid-19 pandemic. *Pak J Med Sci* 36:S67
- Buzzi C, Tucci M, Ciprandi R, Brambilla I, Caimmi S, Ciprandi G et al (2020) The psycho-social effects of COVID-19 on Italian adolescents’ attitudes and behaviors. *Ital J Pediatr* 46:1–7
- Barreta C, de Oliveira MAM, Dias AM, Chesani FH (2016) Caracterização dos cuidadores das crianças e dos adolescentes atendidos pelo projeto de extensão de um hospital universitário infantil. *Rev Bras Tecnol Sociais* 3:10–15
- Bertini GS (2016) Sobrecarga dos cuidadores informais de pacientes de um serviço de atenção domiciliar—Ribeirão Preto. *Diss de Mestr* 1:22–101

Publisher’s Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.