Journal of Pediatric Nursing xxx (xxxx)

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Adapting to compromised routines: Parental perspectives on physical activity and health for children and adolescents with type 1 diabetes in the UK during COVID-19 lockdown

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ARTICLE INFO

Article history:
Received 14 December 2023
Revised 10 April 2024
Accepted 10 April 2024
Available online xxxx

Keywords:
Diabetes mellitus type 1
Exercise
COVID-19
Children
Physical activity

ABSTRACT

Purpose: To determine how COVID-19 lockdown impacted physical activity (PA) levels, wellbeing, and diabetes management in children (aged 0–17 years) with type 1 diabetes (T1D), from the perspectives of their parent/guardian.
Design and methods: This qualitative descriptive study is part of a larger, parallel mixed-methods design study, which incorporated a cross-sectional survey and semi-structured one-to-one interviews. Interviewees were recruited from the survey, which was distributed to parents of children/adolescents with T1D in the UK. Interviews explored diabetes management, mental and physical wellbeing, changes in PA levels, sleep quality before/during lockdown, and the effects of lockdown on the individual and their family. The interviews were transcribed and the data were analysed thematically.
Results: 14 interviews were conducted with parents. Thematic analysis generated a central theme of routine disruption, with four further themes on diabetes management routines, harnessing the opportunities of lockdown, weighing up risk, and variable impact on wellbeing.
Conclusions: Maintaining or increasing PA during COVID-19 lockdown was associated with better diabetes management, sleep, and wellbeing for children/adolescents with T1D, despite significant disruption to established routines. Use of technology during the pandemic contributed positively to wellbeing.
Practice implications: It is crucial to emphasize the significance of maintaining a well-structured routine when treating patients with type 1 diabetes. A consistent routine, incorporating regular physical exercise and good sleep hygiene, will help with managing overall diabetes control.

Introduction

The novel coronavirus 'COVID-19' pandemic was declared on 11th March 2020 by the World Health Organisation (Cucinotta & Vanelli, 2020). Since then, COVID-19 has significantly affected life worldwide. In the UK, those with type 1 diabetes (T1D) were placed in the clinically vulnerable group, meaning they were advised to socially distance and stay indoors other than for exercise (Herrick, 2023). The impact on the capacity of the UK National Health Service (NHS) to deliver routine care was substantial. For those living with T1D, many diabetes specialist clinics were moved online, necessitating remote consultations, and rendering routine blood testing for diabetes-related markers unavailable for several months (Khunti et al., 2022). Specialist clinics also suffered understaffing issues, as clinicians were re-deployed into COVID-19-related roles (Seidu et al., 2022). Internationally, those with T1D who live in low- and middle-income countries have had the additional challenge of dealing with insulin shortages and reduced access to blood testing strips (Odeh et al., 2020; Pal et al., 2021; Verma et al., 2020). It has since emerged that a third of individuals who died with COVID-19 between March 1st 2020 – May 11th 2020 had a form of diabetes (Barron et al., 2020). This caused significant concern for many

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https://doi.org/10.1016/j.pedn.2024.04.035

living or caring for those with T1D, increasing anxiety and fear levels further during a period of uncertainty (Monzon et al., 2021; Wargny et al., 2020). However, age, rather than T1D itself, is primarily associated with COVID-19-related mortality amongst those with T1D (Dessie & Zewotir, 2021).

In addition to significant well-being challenges, children and adolescents with T1D and their parents have needed to manage the impact of lockdown-related changes in physical activity (PA) levels on diabetes management. For this group, PA is recommended as it has positive impacts on HbA1c (MacMillan et al., 2014), and metabolic and psychological health (Absil et al., 2019; MacMillan et al., 2014), and any changes to PA routines can affect diabetes management. Lockdown restrictions necessitated significant changes to the amount and type of PA undertaken by many individuals (Bu et al., 2021; Paterson et al., 2021), and evidence indicates that those with T1D significantly reduced their PA levels during lockdown. (Assaloni et al., 2020; Calcaterra et al., 2021; Ceconi et al., 2020; Pal et al., 2021; Predieri et al., 2020).

Whilst the literature is sparse, early work indicates that many parents of children with T1D have experienced stress over perceived COVID-19 risk and lockdown in relation to their child; in particular, the impact of significant changes to their child's day-to-day routines (Şahinol & Başkavak, 2021; Vyas et al., 2022), and feelings of isolation (Alessi et al., 2021; Monzon et al., 2021). These findings mirror those from adults with T1D (Joensen et al., 2020), many of whom have also experienced furlough and redundancy in their working lives, further impacting their childcare routines.

The reduction in physical activity during lockdown meant an increase in sedentary behaviour (Stockwell et al., 2021). For individuals with T1D, this shift in behaviour led to a rapid rise in insulin sensitivity and increased glucose levels. This can increase the risk of both macrovascular diabetic complications such as strokes and myocardial infarctions, and microvascular diabetic-related complications, such as diabetic retinopathy, neuropathy and nephropathy (Tilden et al., 2023). Research indicates that individuals with T1D were less likely to achieve the international physical activity guidelines of engaging in 60 min of moderate-to-vigorous physical activity per day. This was observed both before and during the pandemic, with a higher percentage of people failing to meet this recommended benchmark during the pandemic (Huerta-Uribe et al., 2023). A reduction in physical activity reduces muscle strength and efficiency, meaning that an individual's baseline fitness will be lowered, which can be demotivating and further reduce physical activity rates (Bowden Davies et al., 2019). The reduction in PA levels also leads to lower levels of cardiorespiratory fitness. This, in combination with increased sedentary behaviour, predispose individuals to weight gain and a host of physical comorbidities such as hypertension and cardiovascular disease (Liese et al., 2013) which can occur in adulthood. It is known that those with T1D can have a reduced life expectancy of up to 20 years, and such comorbidities can significantly contribute to this.

This study aimed to determine how COVID-19 lockdown impacted physical activity (PA) levels, wellbeing, and diabetes management in children (aged 0–17 years) with type 1 diabetes (T1D), from the perspective of their parent/guardian.

Material and methods

Study design

This qualitative study was part of a larger, mixed-methods project on the topic. The larger study involved an online survey, which was circulated to parents and carers of children aged 0–17 years with T1D. The quantitative data of the larger study have not yet been published. At the end of the survey, respondents were asked to enter their contact information if they were interested in being contacted for a qualitative interview. Semi-structured interviews were then conducted with respondents remotely due to lockdown constraints during the pandemic, either over the phone or using the online platform, Zoom.

This study employed a qualitative descriptive approach, aligned with an epistemological position of constructionism. Constructionism posits that knowledge is not a reflection of an objective reality but is constructed by humans, largely through social interactions (Galbin, 2014). This perspective was adopted in our study to acknowledge the unique realities of each participant, shaped by their societal roles, interactions, living environments, and cultural values. Consequently, the significance and interpretation of experiences vary amongst individuals, contingent on their relevance and impact on personal fulfilment. Employing interviews facilitated an in-depth understanding of experiences previously unknown to the researchers or external observers, by capturing the essence of these experiences from the standpoint of the participants themselves.

Recruitment and data collection

Inclusion criteria were that participants are a parent/guardian of a child with T1D, aged 0–17 years old, living in the UK during the COVID-19 pandemic. No specific exclusion criteria were employed. Due to strict time restrictions, staff availability during the lockdown and the long ethical processes involved in recruiting under 18 s to research, the study team elected to focus exclusively on the parent/guardian perspective. We anticipated that parents/guardians would carry out most diabetes management for younger children who would otherwise be unable to contribute; additionally, we felt that parents would be best placed to describe pandemic-related impact on their family unit.

Recruitment took place online, with study advertisements placed on Twitter, diabetes groups on Facebook, and circulated to mailing lists for the Diabetes UK and Juvenile Diabetes Research Foundation charities using a purposive sampling strategy. Advertisements commenced on 7th August 2020; responses were received between 7th August 2020 and 3rd February 2021. During this period lockdown measures varied between UK devolved nations, with the UK Government introducing local or national lockdowns from 23rd March 2020 and with subsequent relaxing and re-enforcing of lockdown rules.

An information sheet and consent form were sent via email to those who indicated on the survey that they were interested in an interview. Participants provided simple electronic signatures to confirm their consent. Interviewees were given the option of being interviewed via the telephone or via secure video calling.

An interview topic guide was produced by the study team, which allowed participants to expand their answers and explore their experiences in more depth. The topic guide was piloted within the study team and with one adult with type 1 diabetes to test the general flow and structure of the interview. This approach was deemed valid as it provided insights into the kinds of questions and responses that might arise during the actual interviews with parents.

Questions in the interviews related to: parental understanding of the COVID-19 virus and its potential impact on their child; how the pandemic and associated lockdown has affected their child in terms of their PA level and type; diabetes management, insulin regimen and blood glucose levels; impact on family life including individual and family wellbeing; and information and guidance about the COVID-19 pandemic received and the quality and sufficiency of that information.

Interviews were audio recorded and transcribed verbatim by a university-approved transcription service.

Respondents were reviewed and sampled to ensure a range of child ages. Semi-structured interviews took place between 2nd September 2020 and 28 January 2021, and were carried out by RS (female research associate, with a doctorate in health services research and experienced in qualitative research in T1D). Interviews lasted 30–90 min.

Data analysis

RS and DW carried out an analysis of the qualitative dataset. Interview transcripts were transferred into NVivo 12 analysis software, which was used primarily to organise data. Reflexive thematic analysis was employed, using the six-phase framework set out by Braun and Clarke (Braun & Clarke, 2006). An inductive, data-driven approach was taken to analysis, meaning that the themes generated through our analysis were identified from the data itself, rather than via the use of a pre-existing coding frame (Braun & Clarke, 2019). An interpretative exploration was important to gain nuanced insights into the lived experiences of the participants. Interview transcripts were read in full (phase 1–familiarisation with data), then independently coded by RS (full dataset) and DW (20% of the dataset) (phase 2–generating codes). Codes were then merged and blended into themes, using the constant comparative technique (Braun & Clarke, 2019) (phase 3–search for themes). Candidate themes were discussed between RS and DW and then with the wider study team (phase 4—reviewing themes) and linked together (phase 5—defining themes) to form a finalised theme set. Themes were then aligned to the original research questions that we set out to explore (phase 6–writing up analysis).

Data analysis started once the first interview was conducted, and continued iteratively, throughout the data collection period and beyond. The absence of a predetermined sample size underscored the flexible and iterative nature of the recruitment and interview process. Recruitment to the study persisted until saturation was identified, whereby the research team responsible for the qualitative analysis (RS and DW) discussed both inductive thematic saturation (during data analysis) and data saturation (during data collection) (Saunders et al., 2018). The participant sample in this study is a representative cross-section of the broader demographic of young individuals with T1D. The average age of the young people stood at 12.6 years. T1D is more prevalent in Caucasian ethnicities and this was represented in our sample (Yanfang et al., 2020). T1D is slightly more prevalent in males than females (Tatti & Pavandeep, 2022), however our sample size includes more females.

Reflexivity and trustworthiness

The study utilised several techniques to enhance the trustworthiness of analysis.

Triangulation was used for the data collection and in the methodology, to aid with credibility. Multiple data sources were used to gather information, with recruitment for the survey taking place via various social media outlets, as well as diabetes-related mailing lists, demonstrating data and method triangulation. For the analysis, RS independently coded the transcripts, then identification of concepts, interpretation, and generation of themes was carried out by RS and DW then also discussed within the wider research team.

Data collection through interviews allowed thick descriptions to be provided, which gave a greater context to parents' thoughts, feelings and attitudes towards their child's diabetes management, PA levels and wellbeing during the lockdown. The semi-structured interview format allowed these to be explored further which helps the reader obtain a better understanding of the context and significance of actions and statements. Field notes were taken by RS during data collection which were then used within the analytical process to assist in theme development. Attention was paid to negative cases which helped to ensure validity.

Ethics approval and consent to participate

Ethical approval for this study was obtained from the North East-Newcastle and North Tyneside 2 Research Ethics Committee. The REC reference is 20/NE/0178. All methods were carried out in accordance with relevant guidelines and regulations. No experimental protocols were carried out. Informed consent was obtained from all participants and/or their legal guardian(s). Interview transcripts were anonymised, with participants being given pseudonyms to protect their identity. These pseudonyms, rather than real names, are used below to report results.

Results

Participant characteristics

Semi-structured interviews were conducted with 14 parents of children with T1D, consisting of 10 female parents and 4 male parents of 9 male children and 5 female children. The children's ages ranged from 7 to 16 years old, with the mean age for males being 12.8 years old, and for females, 11.6 years old.

Thematic analysis

Through thematic analysis, a central theme of routine disruption was identified. This overarching theme underpinned four further themes; 1) Lockdown impact on established diabetes routine; 2) Harnessing the opportunity to focus; 3) Weighing up risks and making decisions; 4) Impact on wellbeing. The finalised thematic map is depicted in Fig. 1, with the dotted lines showing the links between sub-themes.

Fig. 1 illustrates the complex interplay of themes and sub-themes that articulate the disruption of routines for individuals managing diabetes during lockdown. The central theme of routine disruption is the core from which four principal themes are identified. Firstly, the 'Lockdown impact on established diabetes routine' theme encapsulates the complex pandemic-related disruption in the daily management of diabetes, highlighting altered eating and insulin dosing regimens, and the need to adjust to treatment and healthcare monitoring changes. Secondly, the theme 'Harnessing the opportunity to focus' reveals an unanticipated silver lining of lockdown, where increased parental monitoring and the ability to test and tweak diabetes management became possible. The third theme, 'Weighing up risks and managing decisions,' underscores the balancing act between staying out of hospitals, limiting exposure to others, and navigating the consequences of inconsistent and unclear advice, which in turn impacts school-based education. Finally, 'Impact on wellbeing' encompasses the psychological and social facets of lockdown, where the disruption amplifies existing issues, yet also posits technology as a pivotal social lifeline and fosters a sense of increased ownership of time. The dotted lines connecting the sub-themes signify the dynamic and reciprocal relationships that define the lived experiences of those adjusting to the new norms of diabetes care amidst a pandemic.

Theme 1. Lockdown impact on established diabetes routine

Sub-theme: **Dealing with structured routine changes.** National COVID-19 lockdowns significantly disrupted daily life for children living with diabetes and their families. Many parents highlighted the need to maintain a diabetes management routine, including blood glucose testing and associated eating and dosing regimens. These long-standing management routines were directly impacted by changes to their child's schooling, PA, and COVID-19-related anxiety.

School, and the associated physical, mental, and dietary routine associated with attending a school, was discussed by nearly all respondents. Day-to-day diabetes management routines, such as mealtimes, glucose testing, and dosing, were strongly associated with going to school. These routines were severely compromised with lockdown and associated school closures. Whilst parents anticipated the impact of removing physical education school lessons on their child's blood glucose management, many highlighted the important influence of removing incidental PA routines at school, such as walking to/from school, between classrooms and so on.

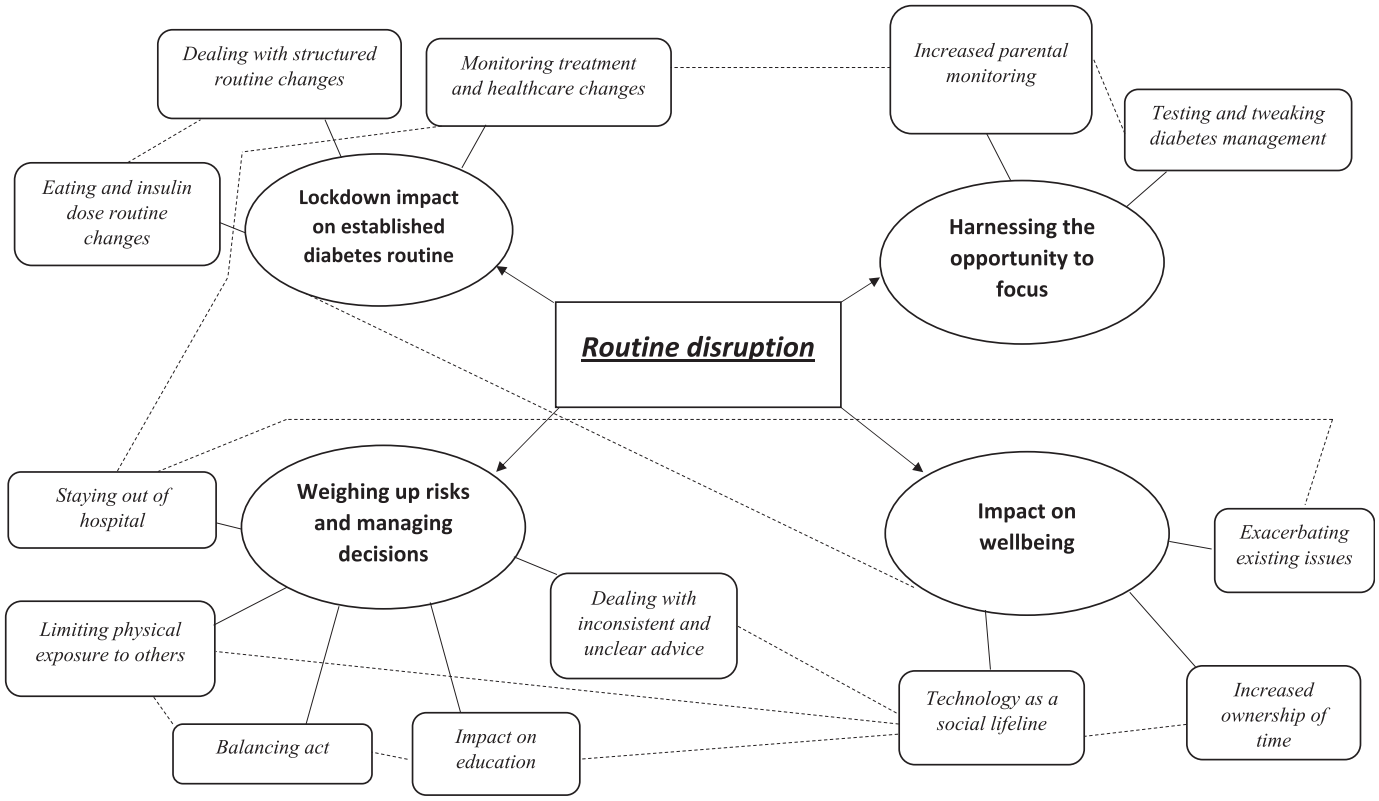

Fig. 1. Thematic map.

If you weren't a child who was particularly sporty, you might walk to school, you might walk from your classrooms, you're buzzing, and you're off doing things. Whereas it was a really sedentary time for the school days [during lockdown]. (Amy, mother of girl aged 14).

Changes in school meal routine and associated dosing were less impactful, as respondents simply reverted to meals and dosing strategies for weekends and school holidays. Some children took part in non-school related sporting activities, such as gymnastics and football, which were also stopped during lockdown. Coping with the discontinuation of extracurricular sports and its impact on diabetes was comparatively more manageable due to its predictable nature and established management routines, whereas adapting to the challenges of home-schooling presented a more complex adjustment process. A minority of children took up an alternative exercise such as running.

I think [recent disruption in child's blood glucose levels] is exacerbated by the fact that she is not getting her normal routine. Normally she would have been swimming for an hour at a time, twice or three times a week. So, to go from that kind of level of activity to more or less nothing has had an impact on her glycaemic control. (Chris, father of girl aged 16).

I noticed she was massively insulin resistant […] suddenly all her activities, she goes climbing, she does ballet, she walks to school, she cycles with friends, all of those. We do stuff at the weekend. Suddenly that stopped and the insulin requirement was massively hiked. (Amy, mother of girl aged 12).

Sub-theme: **Eating and insulin dose routine changes.** At the start of lockdown, changes in school routine and the impact on diabetes management had not been fully anticipated by parents, with many reflecting on a chaotic diabetes period.

The fact that he has not done as much activity [over lockdown] has meant that we've had to change some of his diet to account for the lack of burning off the energy really. We have had quite a dramatic impact on [child's] sugar level. So, we've adjusted the ratio and luckily now we seem to have got a bit more of a balance. (Katherine, mother of boy aged 10).

We've had to increase her basal rates twice since lockdown and reduce the food ratio meaning that she has more insulin for the same amount and then we've also had to be doing more corrections because she's been running high we've had to add more insulin on top of all of that to try and bring it down. (Chris, father of girl aged 16).

Sub-theme: **Monitoring treatment and healthcare changes.** Prior to the pandemic, patients would have in-person appointments to monitor their child's diabetes management, however during the pandemic these appointments became virtual. This meant that the element of physical examination was lost, and measuring HbA1c levels, an important measure of diabetes control, could not happen.

We've had virtual clinic appointments, I think they're trying to alternate them, so we have them every three months normally but through lockdown we've been [at clinic] about four times, I think… but if they do it over the phone they can't measure their HbA1c and stuff like that so my preference would be to go in and have it closely monitored (Laura, mother of boy aged 10).

As a result of the changes in healthcare delivery, some parents took more ownership of managing their child's diabetes by making additional decisions and using learning materials to further educate themselves about it.

Virtual clinics have been shorter than the actual clinics that we do have so I'm like right I need to be a bit bolder and take some decisions on things like his basals, his long acting insulin (Emma, mother of boy aged 7).

Theme 2. Harnessing the opportunity to focus

Sub-theme: **Testing and tweaking diabetes management.** Whilst the disruption to diabetes routines was almost universal, a proportion of respondents highlighted one positive aspect of lockdown: an opportunity to concentrate on their child's diabetes management and adjust diet and insulin dosing.

I actually felt a little bit more in control of [child's] blood glucose during lockdown, because we could give him more interventions in the day… we had some good times in range, and that was nice to see, the fruits of our labour I suppose. (Emma, mother of boy aged 7).

Sub-theme: **Increased parental monitoring.** As children were spending most of their time at home, many parents felt that they could test out adjustments in a safe space, rather than risking hypo/hyperglycaemia at school where treatment might be delayed or more difficult. This was more common for parents of younger children who were more responsible for their child's diabetes management.

The fact that he was in the house every day was a big advantage, he's in our care so if there was needing adjustments we would react to it immediately whereas if he's at school sometimes you'd have to send them a text message and it takes a while to read it and respond (James, father of boy aged 14).

Obviously normally [child] would be at school and stuff where her control of her blood sugar levels is much more difficult to manage. We're at home with her all of the time and then we can monitor her much more closely and can either give her more or less insulin – so in fact her HbA1c and stuff has been really good since lockdown. (Charlotte, mother of boy aged 16).

Some parents even took the opportunity to set their child up on DIY closed loop systems and carry out the associated fasted-state basal rate and insulin sensitivity/insulin-to-carbohydrate ratio testing, which they knew would not be compromised by school-based PA – organised or incidental.

We were in the same house, so I was able to monitor very closely what was happening. I use Nightscout so I was able – I always had the graphs up, like at the work laptop monitoring his blood sugar continuously. Whereas if I'm at work and he's at school you don't have that opportunity. (James, father of boy aged 14).

Theme 3. Weighing up risks, and making decisions

Sub-theme: **Balancing act.** Parents of older children were less likely to make any changes to their child's diabetes management, instead describing a balancing act between monitoring their child's diabetes and health more generally and allowing their child more autonomy over managing their condition. They also had to weigh up the extra precautions regarding lockdown measures versus maintaining their child's wellbeing and lifestyle.

He is growing up; he doesn't want me asking him every five minutes about everything to do with Type 1, but we do sit down and have a weekly review of his blood sugars. Now in saying that, when he's scanning his Libre, it comes to my phone, and I see it. It's really getting a balance so that I don't start to affect his mental health by over-managing it. (Michael, father of boy aged 15).

If your control is good, it's the weighing up between having a fulsome life versus limiting your life for an unknown variable so we're just trying to give him as a fulsome life as sensibly as possible. (Lucy, mother of boy aged 13).

Sub-theme: **Impact on education.** Several parents were worried about the risk of their children contracting the virus at school. Some decided to withdraw their child from school before the government closed them, and to stop/limit their contact with others. However, this was challenging for some as there were other factors they had to consider, such as how the child would be affected by not going to school from a wellbeing and physical activity perspective, and also from a diabetes-related perspective.

I'm having to weigh up the balance between making sure that his education is there and also making sure that his special needs are met and then obviously diabetes. (Katherine, mother of boy aged 10).

I work in a primary school and I was getting a bit twitchy at work and my husband was watching the news and he was getting very twitchy so we actually pulled him out of school before they were closed. (Helena, mother of boy aged 16).

The biggest potential source of any of us getting COVID has been [child] and her sister going to school. (Joanne, mother of girl aged 10).

Sub-theme: **Staying out of hospital.** Whilst the direct physical impact of COVID-19 infection was a worry, parents were particularly anxious about any resulting admission to hospital. This was because they were unsure if they would be allowed onto the wards due to COVID-19 restrictions, therefore being forced to rely on hospital staff to manage their child's diabetes. This could also impact the child's wellbeing, as they would be unwell in hospital without the support of their families, exacerbating what is already an unpleasant experience.

I think there was just sort of this massive worry about what would happen if he got [COVID-19], and obviously at the time he was still classed as a child, so if he went into hospital a parent would usually go with him - but would parents be able to go into children's wards? We had a lot of concerns about things like that. (Charlotte, mother of boy aged 16).

Hospital-based diabetes management was often viewed as poor even before the pandemic, and parents felt that hospital admission would risk poor glycaemic levels and ultimately diabetic ketoacidosis. There was an increased workload due to the number of COVID-19 related admissions, meaning staff were further stretched and may not have the time to appropriately manage diabetes.

Hospitals are overwhelmed anyway aren't they, and in my previous dealings with them, I really noticed how diabetes just wasn't managed in hospital. The staff are just too busy. And I felt like the stress of having [child] in hospital for any reason would be pretty unbearable because I'd be so worried about diabetes not being addressed in hospital quite frankly. (Helena, mother of boy aged 16).

Sub-theme: **Limiting physical exposure to others**. Some parents also started working from home before government guidance mandated it, to limit the risk of bringing the virus home from their workplace.

Kids – they can't social-distance. We know they can't and they touch everything including us so I am very concerned but I'll just get on with it and I have followed that thing about you come home, you wash your clothes, you go in the shower straight away. (Helena, mother of boy aged 16).

When children were allowed to go back to schools, additional measures were in place to limit interactions. This had an impact on their social connections and wellbeing, as they could only see a certain group on a regular basis, and the freedom to mix was taken away.

At recess time typically all third grade would go outside and they could all play together, well not any more so they are kind of set up in different parts of those school property and they're kept separate so they're only allowed to see the kids in their classroom. They can't see the kids from the other two classrooms and I know that really bums her out because she has friends in the other classes and she can't socialise or mingle with them. (Kerry, mother of girl aged 10).

Sub-theme: **Dealing with inconsistent and unclear advice**. At the start of lockdown parents were particularly concerned about the impact that COVID-19 infection might have on their child. Diabetes and COVID-19 related information to help make these decisions was described as inconsistent and lacking, causing anxiety for parents.

The information was a bit confusing. Partly of course because it was lumped in with Type 2 diabetes. It was lumped in with obesity. [Child] was picking up on it and the misinformation did make him concerned… It sounds like there has been Type 1 deaths, but it's all mixed up. (Lucy, mother of boy aged 13).

Some sought information from their child's diabetes clinic, which they found reassuring, particularly because clinicians could not give specific advice at the time. Others sought out research evidence on the internet, including on social media (Odeh et al., 2020). Peer support blogs and forums allowed parents to share their experiences and connect with other parents of children with type 1 diabetes. This helped them to support each other and learn about ways to help manage their own child's condition.

We haven't had any letters from GPs or contact or communication with anybody that say we have to do anything different. (Katherine, mother of boy aged 10).

The clinics sent stuff out to us and also following people like [Partha Kar] on Twitter who is the national coordinator for diabetes, he linked to various resources so between those two things felt we had enough information. (Chris, father of girl aged 16).

Theme 4. Impact on wellbeing

Sub-theme: **Exacerbating existing issues.** Lockdown had a particularly varied impact on the wellbeing of respondent's children. Children who were struggling with their mental health prior to the pandemic experienced exacerbations of their issues, including anxiety and agoraphobia (Meade, 2021). In turn, stress-related blood glucose variability made diabetes management more challenging. Poor mental health also led to additional physical health challenges such as self-harming, increased sedentary behaviours, and increased screen-time, the latter as a result of virtual schooling and social media usage to maintain connections with others.

During lockdown she's become more anxious I'd say, and she did do some self-harming at one point… [Child] has done no physical exercise during lockdown, because her anxiety has meant she doesn't like leaving the house. My concern mainly is that this anxiety of not leaving the house may turn into full blown agoraphobia, but you know, all we can do is support her. (Paul, father of girl aged 12).

Lockdown has been beyond ridiculously hard. [Child] has had bouts of depression. He already suffered with anxiety […] when the anxiety kicks in his bloods are just massively affected with the diabetes. He runs sky high; he doesn't want to eat properly; he then starts actually to neglect actually taking care of himself and we have a very difficult situation where [child] is actually quite dangerous and I can't leave him unsupervised. (Katherine, mother of boy aged 10).

Sub-theme: **Stress and worry.** The negative statistics such as COVID-19 death rates and hospital admissions dominated media outlets and children were constantly exposed to these. This meant some children tried to ignore their diabetes or became increasingly reliant on parental assistance in managing their condition.

[Child] just kept seeing the death rates on the television so it did have a massive impact on him. [int: how did it affect his diabetes management as well?] He just shuts down with that. He doesn't think to actually manage the diabetes, and he chooses to block it out. We've always had this as a problem, but [lockdown] has exacerbated it and pushed it to the extreme. (Katherine, mother of boy aged 10).

Sub-theme: **Increased ownership of time.** However, other children (and parents) enjoyed lockdown. Those who did highlighted that once they had got used to lockdown, it was an opportunity to relax, spend time together, and free themselves from the everyday busy-ness of normal life. This meant that parents had more time to order diabetes equipment and organise their supplies.

You don't order it on one order, you have to contact Dexcom, you have to contact Omnipod, you have to contact the pharmacy if you run out, they won't give you more than one month's worth so if he drops his strips and he knocks 50 strips on the floor we're then down for the month so I've got to phone – do you know what I mean? All of that when you're at home full time is bloody easy! (Lucy, mother of boy aged 13).

Families felt that because their children were at home, they felt more relaxed with regards to diabetes management, as they could closely monitor and intervene early if required, rather than waiting for the child to deteriorate and then someone with perhaps less understanding and experience e.g. at school or extra-curricular activities, would take care of them.

I feel as a parent more relaxed because she's so close. If she were to dip a little lower or a little higher, I'm right here to take care of it. It's not like she's at school that often or I'm in a waiting room during an activity and she's further away from me and I can't see her. The fact that she's nearby so much it has made me relax a lot more I'd say as far as the diabetes portion goes. (Kerry, mother of girl aged 10).

Sub-theme: **Technology as a social lifeline.** Online gaming and social media facilitated children's social connections, with some parents describing it as a lifeline for their child, allowing them to maintain friendships outside of school. Once restrictions were lifted, children would meet up in person, thanks to their continued connections via the internet. Despite this enjoyment, parents highlighted that their child would never be able to have the care-free childhood that their peers might, due to the stress of living with and managing their diabetes.

We bought [child] the gaming computer and I think his use of it has been, over the lockdown, appalling in terms of hours. However, I think it's kind of been necessary. Sometimes he's been on his own but he largely games with friends online and you can hear them chatting and stuff, and it's in our front room so we know what's going on. Yeah, I think that's been quite a lifeline. (Helena, other of boy aged 16).

They realised that they could keep in contact with each other through Xbox really well. They really enjoyed that and that's what precipitated them then meeting up a couple of weeks ago. It was literally the Xbox lot that met up but he's only done that once in the whole of lockdown and would not have done it before lockdown so that was quite significant. (Lucy, mother of girl aged 13).

During lockdown children could use social media as an effective way to communicate with others, both by sending messages and by having conversations or sending videos of themselves speaking to others. The element of human connection is crucial for mental wellbeing, and using social media to facilitate feelings of connectedness was important.

> *She's retreated into her electronic devices which in some ways –… [Child] goes onto Snapchat, whatever it is and talks to her friends so she's constantly talking to her friends because it's a little lifeline to normality. (Paul, father of girl aged 12).*

Discussion

COVID-19 lockdown in the UK had a mixed impact on children living with type 1 diabetes. PA levels decreased significantly during lockdown, with parents highlighting the loss of routine PA opportunities related to schooling. As a result of lockdown, parents felt that they could monitor their child's diabetes more closely than if they were away and reliant on others managing the condition. This was particularly important, as lockdown forced significant change in routine and behaviours, which impacted PA levels and therefore insulin requirements. Parents could make adjustments based on the change in routine and had the opportunity to focus on management and make instant adjustments. Wellbeing was relatively unaffected if the child/adolescent did not have pre-existing issues with their wellbeing, with technology and social media enabling them to maintain social connections during the pandemic. However, if they had experienced issues with mental health and wellbeing pre-lockdown, they were likely to be exacerbated by the pandemic and its impact on daily life, such as PA and socialising. This is in addition to lockdown being a period of significant uncertainty, which increased stress and anxiety levels.

This study highlights the significant influence of COVID-19 lockdown on children with T1D living in the UK. It also adds to the small body of literature (Gregory et al., 2022) on this topic, by elucidating some of the reasons underpinning the mixed picture of lockdown impact on this vulnerable patient group. At the beginning of the pandemic, parents had to weigh the risks versus the benefits of allowing their children to attend school, as there was no clear advice from schools or the government at the time. They also had to decide what extra-precautions they would take, such as shielding. The children described in our study by their parents had a previously established daily routine of attending school, with associated diabetes management strategies set up by their families, such as glucose testing, set mealtimes, and planned extracurricular activities. The lockdown severely disrupted these routines, and the resulting changes in insulin requirements were not anticipated by many parents at first, reflecting previous studies (Gregory et al., 2022; Şahinol & Başkavak, 2021). Incidental PA levels, such as walking around school, were part of an undercurrent of influences on blood glucose which were not always accounted for in existing diabetes management strategies, until they were removed as part of lockdown school closures.

Despite the majority of participants reporting a decrease in PA levels, changes in PA had some interesting associations in our sample. Children who had reduced their physical activity during the lockdown would initially be consuming the same quantity of food and receiving the same insulin, resulting in occasional instances of their blood glucose levels being outside the optimal range. This reflects other literature demonstrating a link between decreased PA and poorer blood glucose levels during lockdown (Ceconi et al., 2020; Predieri et al., 2020), highlighting the importance of maintaining PA and diabetes routines in children with type 1 diabetes (Ferguson et al., 2022). It also supports evidence linking lower levels of PA with poorer mental health amongst children during lockdown (Paterson et al., 2021). It is possible that parents who were more anxious about COVID-19 were less encouraging of their child's PA during lockdown, especially in situations (such as group activity) where it may increase risk of transmission. Other work has described this link (McCormack et al., 2020), as well as associations between lower PA levels and lower mood during lockdown (Ingram et al., 2020).

There were many positive outcomes resulting from the use of social media and technology, such as children being able to maintain communication with their friends, and online gaming being an 'escape' from the reality of the pandemic (Rimel et al., 2023). However, there are known negative effects that can result from an increased use of social media and technology that were not mentioned in the interviews. Negative effects include cyberbullying, depression, low self-esteem and an increase in risky behaviours online, relating to sexual behaviour, violence and substance abuse (Richards et al., 2015). Parents perceived the potential positive outcomes as more significant than any negative effects on their children, likely leading them to emphasize the positive aspects when discussing the topic. Although these particular negative social media effects were not mentioned during interviews, it is crucial to acknowledge and address them.

This study also demonstrates the importance of parents having access to reliable information sources on COVID-19 (and any other significant health risk factor) and being supported in making risk judgements which take into account their child's personal health situation and needs. From the interviews, parents felt that they were given too little information about the virus and its potential impact on their child. Sources of information often used 'diabetes' as an umbrella term, without differentiating between type 1 and type 2 which caused confusion and anxiety. A considerable number of parents sought information from clinical research, either through direct means or by relying on prominent figures within the NHS diabetes system who shared information considered reliable and well-founded. This underscores the significance of successful and transparent communication of scientific knowledge.

Strengths and Limitations

To our knowledge, this is the first in depth analysis of qualitative data on the experiences of children with type 1 diabetes and their families during lockdown due to COVID-19 in the UK. The data in this particular area addresses an identified research gap of physical activity and health from a parental perspective (Paterson et al., 2021), and allows generalisations of the findings to physical activity and diabetes management. However, interviews focused on the perspectives of parents rather than children directly, which may limit generalisability and may not fully represent their child's view on their own physical activity and wellbeing, the latter highlighted in recent parent/child quality of life rating studies (Eiser & Morse, 2001; Janse et al., 2008).

All the participants were based in the UK, and there may be differences if this study was expanded across Europe and other continents. This is especially true when comparing lockdown policies of individual countries. This would also increase the ethnic diversity, which could result in varying perspectives. This study focused on young people with T1D, however, there are other forms of diabetes that young people can have, such as maturity onset diabetes of the young, and now, increasingly, type 2 diabetes (He et al., 2022; Schober et al., 2009). These conditions were not accounted for in this study, but could be in the future.

Implications to practice

We recommend that future paediatric nursing practices include providing families with comprehensive information and guidance about COVID-19 or any similar virus. This knowledge will empower families to take effective protective action and adapt diabetes management strategies. When interacting with patients and their carers, it is also important to highlight how having an active lifestyle is a key part of T1DM management as it helps to regulate blood glucose levels. Additionally, PA is known to boost emotional and physical well-being, and therefore

reduces the risk of developing certain comorbidities such as hypertension and heart disease. PA also helps to improve sleep quality, which also has an impact on wellbeing. Engaging in nurse-led discussions that underscore the comprehensive benefits of a structured routine, encompassing physical activity and sleep, with patients and caregivers, can elevate awareness. This approach supports improved diabetes management and bolsters overall physical and mental health.

Conclusion

This study unpicks some of the mixed picture of the impact of COVID-19 lockdown for children and adolescents living with T1D in the UK. Maintaining routines during lockdown was extremely important for diabetes management and wellbeing, particularly routines related to PA. Maintaining or adding to an established PA routine during lockdown helped with sleep quality, wellbeing and the maintenance of normal insulin requirements. The majority of parents experienced a challenging period of adjustment to a novel routine, accompanied by unforeseen alterations in insulin needs. There was a period of 'trial and error', as children were generally less active during lockdown due to remote schooling and government restrictions limiting the type and amount of PA, yet their food intake generally remained the same or increased. As a result their insulin requirements changed, but a combination of a lack of awareness and lack of guidance and information from healthcare providers meant that this was a challenge for families. This transition was made more difficult by poor sleep and poor wellbeing, especially for children who were already struggling with these pre-pandemic, where these problems were exacerbated during the pandemic. These impacts may have a lasting effect on children/adolescents living with T1D in the years to come.

Ethics approval and consent to participate

Ethical approval for this study was obtained from the North East-Newcastle and North Tyneside 2 Research Ethics Committee. The REC reference is 20/NE/0178. All methods were carried out in accordance with relevant guidelines and regulations. No experimental protocols were carried out. Informed consent was obtained from all subjects and/or their legal guardian(s).

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Funding

RS and DW were funded to carry out this work with a grant from the Newcastle University COVID-19 Research Fund.

CRediT authorship contribution statement

Rachel Stocker: Conceptualization, Writing – review & editing. **Alisha Gupta:** Writing – review & editing, Conceptualization. **Guy S. Taylor:** Writing – original draft, Conceptualization. **James A. Shaw:** Writing – original draft. **Daniel J. West:** Writing – original draft.

Declaration of competing interest

The authors declare that they have no competing interests.

Acknowledgments

We thank our participants, who gave up their time to tell us about their lockdown experiences. We also thank Megan Driscoll who supported data collection.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pedn.2024.04.035.

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