


Managing type 1 diabetes during the COVID-19 pandemic is a team effort: a qualitative study of the experiences of young people and their parents

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ABSTRACT

Objective To explore the experiences of young people with type 1 diabetes mellitus (T1DM) and their parents in accessing integrated family-centred care in the Australian Capital Territory during the COVID-19 pandemic.

Methods and analysis This is a pragmatic, qualitative descriptive study for which we conducted semistructured interviews with 11 young people with T1DM aged 12–16 years and 10 of their parents who attended an outpatient diabetes service in Canberra, Australia. Thematic analysis was conducted in accordance with the methods outlined by Braun and Clarke.

Results Three themes were identified: feeling vulnerable, new ways of accessing care and trust in the interdisciplinary diabetes healthcare team. Participants believed having T1DM made them more vulnerable to poor outcomes if they contracted COVID-19, resulting in avoidance of face-to-face care. Telephone consultations offered a convenient and contact-free way to undertake 3-monthly reviews. The greatest difference between telephone and face-to-face consultations was not having access to the whole interdisciplinary diabetes support team at one appointment, physical examination and haemoglobin A1c testing during telehealth consultations. Participants trusted that clinicians would arrange face-to-face meetings if required. Some felt a video option might be better than telephone, reflecting in part the need for more training in communication skills for remote consultations.

Conclusion Young people with T1DM and their parents require collaborative care and contact with multiple healthcare professionals to facilitate self-management and glycaemic control. While telephone consultations offered convenient, safe, contact-free access to healthcare professionals during the COVID-19 pandemic, the added value of video consultations and facilitating access to the whole interdisciplinary diabetes support team need to be considered in future clinical implementation of telehealth.

INTRODUCTION

The COVID-19 pandemic has placed great strain on healthcare services globally. In epidemics, pandemics and natural disasters,

Key messages

What is already known about this subject?

- ▶ Young people with type 1 diabetes mellitus (T1DM) require collaborative care and contact with healthcare professionals to facilitate self-management and glycaemic control.

What does this study add?

- ▶ The need for reduced social contact to minimise virus spread has fast-tracked telehealth.
- ▶ Young people with T1DM continue to collaborate with their healthcare professionals through telephone consultations and struggle sometimes to understand clinical messages without visual cues.
- ▶ Trust in an interdisciplinary diabetes healthcare team mitigates some concerns about diabetes management during the COVID-19 pandemic.

How might this impact on clinical practice or future developments?

- ▶ The added value of video consultations, skills development for healthcare professionals and facilitating access to the whole interdisciplinary diabetes support team need to be considered in future clinical implementation of telehealth.

prioritising emergency responses can lead to neglect or deferment of ‘usual care’, resulting in increased all-cause morbidity and mortality.^{1–4} Early evidence suggests that people with diabetes may also be at increased risk of poor outcomes if they contract COVID-19, although it is not yet known whether children with type 1 diabetes mellitus (T1DM) are at greater risk of contracting COVID-19 or whether they are at risk of poorer outcomes.⁵ In a snapshot survey of paediatricians in Ireland and the UK, one-third in emergency department settings reported seeing delays in presentation for serious illnesses, with diabetes (new presentations and diabetic



ketoacidosis) being the most common delayed presentation.⁶ This has not been the general experience in Australia.⁷ However, any reduction in healthcare access can impact the health of children, and those with chronic conditions such as T1DM are at higher risk of severe illness from doing so compared with healthy children.⁸ One of the greatest challenges presented by the COVID-19 pandemic is how best to provide care for those who might be too worried to seek it.⁹

Australia's health system response to COVID-19 has sought to address these concerns through protecting vulnerable populations and supporting continued provision of usual care to the whole community.^{10–12} Response has included rapid implementation of telehealth, via telephone and video, publicly funded through Australia's universal public healthcare scheme, Medicare and the related Medicare Benefits Schedule (MBS).¹³ Telehealth has enabled access to healthcare to people with a wide range of health conditions, protecting vulnerable patients and clinicians and mitigating COVID-19 transmission in healthcare settings.¹² MBS telehealth items have been expanded to cover consultations with general practitioners and allied health professionals, including credentialled diabetes educators, as well as most endocrinology/diabetes services, including for paediatric endocrinology, to ensure continued outpatient care provided through the public hospital system.¹¹

Integrated family-centred care that addresses physical, psychological and social care is key to managing the needs of children and young people with chronic and complex health conditions.^{14–16} In the Australian Capital Territory (ACT), the Paediatric Endocrine and Diabetes Service (PEDS) based at the Centenary Hospital for Women, Youth and Children provides an integrated outpatient care service that offers access to an interdisciplinary team, with members working collaboratively in the best interest of patients and their families. It includes two paediatric endocrinologists, an endocrine registrar, three credentialled diabetes educators, a diabetes dietitian, a diabetes social worker and a registered nurse, and offers referral to the hospital's psychology services. Following the onset of COVID-19, from 26 March 2020 the ACT PEDS clinic has offered telehealth consultations. All participants were transitioned to telephone consultations with their endocrinologist in place of usual face-to-face 3-monthly check-ins with the interdisciplinary diabetes team. We explored the experiences of young people and their parents in accessing integrated family-centred care at the ACT PEDS clinic during the COVID-19 pandemic.

METHODS

We used a pragmatic, qualitative descriptive approach¹⁷ to elucidate participants' experiences using semistructured interview guides based on expert knowledge (informed by young people with T1DM and parents) and an inductive thematic analysis following Braun and Clarke's six-step method.¹⁸

Patient and public involvement

Our research team included four young people with T1DM, two parents of a young person with T1DM, a diabetes educator, four endocrinologists and four health service researchers. All contributed to the study design, including interview protocol development, data analysis and drafting the paper. Research team members were not included as interview participants.

Participants and recruitment

We recruited from a pool of young people and their parents who either had participated in previous research with our group or had registered an expression of interest for involvement in research about T1DM as part of Our Health in Our Hands programme of research, a multidisciplinary project aiming to advance the rapid digitalisation and personalisation of healthcare, with a focus on improving the diagnosis and management of T1DM.¹⁹ All potential participants attended the PEDS clinic at the Centenary Hospital for Women, Youth and Children. All participants were provided information about the study and gave informed written consent prior to interviews.

Data collection

Due to COVID-19 restrictions in place, all interviews were contactless and conducted either online (via Zoom) or by telephone between June and July 2020 by two researchers (AP, NB-S). Interviews were recorded and transcribed and of 20–40 min duration. Participants were asked which providers they had consulted with during the pandemic, the modality used, whether they felt that their (or their child's) diabetes had been managed well and any concerns they had about the pandemic, especially related to accessing care. For exemplar questions from the guide, see [box 1](#). After nine interviews we felt data saturation was reached. A further two interviews were conducted for

Box 1 Exemplar questions from the interview guide

- ▶ Which doctors or other healthcare professionals do you/your child usually see to help manage your health and how often you see them?
- ▶ Can you tell me about any health problems you/your child have had since mid-March 2020 when the telehealth consultations were introduced and which healthcare professionals you/your child have seen since telehealth consultations were introduced?
- ▶ Can you tell me about any video or phone consultations you/your child have had since mid-March 2020? Which ones were good/not so good and why?
- ▶ Have any of your/your child's regular healthcare appointments been cancelled or postponed since mid-March when telehealth consultations were introduced? Which ones and why? How did you feel about that?
- ▶ Are you worried about COVID-19 and if so what sorts of things are you concerned about? Have you made any changes to your life?
- ▶ Thinking about all that has happened since mid-March 2020, do you feel your/your child's diabetes has been managed as well as it could have been during this period? Why?

confirmation. Haemoglobin A1c (HbA1c) records were unavailable for participants.

Data analysis

We followed Braun and Clarke's six-step process, five of which underpinned our inductive analysis of the data—data familiarisation, generation of codes, collation of themes, thematic review and definition of themes—followed by writing the paper as the final step.¹⁸ Two researchers (AP, NB-S) read the transcripts multiple times to ensure data familiarity, following which they discussed the data and agreed on a coding framework. They then collated three preliminary themes, each of which was reflective and descriptive of several codes. Discussions were then held with a further two team members (JD, SHD), during which themes were reviewed and refined. These themes were discussed and finalised at a subsequent meeting with all team members prior to writing the paper. NVivo V.12 analysis software was used to support data coding and analysis.²⁰

RESULTS

Eleven young people aged 12–16 years with a clinical diagnosis of T1DM took part in the interviews. Parents were invited to attend and contribute to the conversation. Interview questions were directed at both parents and young people. Nine young people were accompanied by one parent, one was accompanied by both parents and the eldest chose to attend alone. Participants reported receiving the initial diagnosis of T1DM at 0.5–13 years and had been living with the T1DM diagnosis for 1–14.5 years. They used a range of different devices for managing their diabetes, with most self-reporting good control of their blood glucose. Participant characteristics are presented in [table 1](#).

Participants shared their experiences of managing diabetes during the COVID-19 pandemic and how the

pandemic affected self-management. Three themes emerged: feeling vulnerable, new ways of accessing care and trust in the interdisciplinary diabetes healthcare team.

Theme 1: feeling vulnerable

Overall, participants were relieved at the low levels of COVID-19 in the ACT and surrounding areas compared with other areas in Australia and the world, and recognised that this mitigated some of their concerns about contracting and/or transmitting COVID-19. Young people and parents who were more concerned reported that they believed that while T1DM may not increase the risk of contracting COVID-19, having T1DM made them more vulnerable to poor outcomes should they contract it. Some had discussed this with their endocrinologist from the paediatric diabetes service.

We had a good chat with the endocrinologist about it, because I think COVID was a conversation to have... [S]he did say he had no more likelihood of getting COVID, but it just means unfortunately if he does get it he'll get a bit sicker. (Parent of participant 1)

All participants reported that they followed the recommended practices for social distancing and hand hygiene, regardless of the low level of transmission in the ACT region.

[B]ecause I feel like we're pretty good in Canberra. But it's still a bit worrying. (Young person, participant 8)

Some were more concerned about other household members being vulnerable.

I'm not worried for myself, I'm worried for my... [g]randad [who] is elderly, and he lives with us... and has cancer. (Young person, participant 9)

Table 1 Participant characteristics

Identification number	Age of young person with T1DM	Parent present	Age at diagnosis (years)	Years with T1DM	Gender	Insulin pump user	Continuous glucose monitor user	Flash glucose monitor user
1	≥15	Y	≥10	≤5	M	Y	Y	N
2	≥15	Y	≤5	≥10	F	Y	Y	N
3	10–14	Y	6–9	6–9	F	Y	Y	N
4	10–14	Y	≤5	≥10	M	Y	Y	N
5	10–14	Y	≥10	≤5	F	Y	Y	N
6	≥15	Y	≤5	≥10	M	Y	Y	N
7	≥15	Y	6–9	6–9	M	Y	N	Y
8	≥15	N	≥10	≤5	M	Y	Y	Y
9	10–14	Y	≥10	≤5	F	N	Y	N
10	≥15	Y	≤5	≥10	M	Y	Y	N
11	10–14	Y	6–9	≤5	F	N	Y	N

F, female; M, male; N, no; T1DM, type 1 diabetes mellitus; Y, yes.

Participants' concerns translated to some changed behaviours, such as avoiding public transport, reducing social activities and ensuring they had extra medication and sensor supplies. Some had discussed ongoing availability with their pharmacist and planned accordingly, recognising their vulnerability if supply became problematic. Some parents found it difficult to assess levels of additional risk for young people and to determine when they should return to school.

I think the biggest thing for me was when they suddenly said... [t]he kids were going back to school... [Being] worried that we were doing the right thing. (Parent of participant 1)

Some parents chose to postpone usual care appointments due to concerns about the young person's vulnerability.

I haven't booked anything. So, there is some tests that my children probably should go and have, but I just haven't booked them. Just to keep our family well and safe. (Parent of participant 6)

Theme 2: new ways of accessing care

The paediatric diabetes service pivoted to delivering contact-free services in March 2020 in response to the pandemic. All participants had their regular face-to-face 3-monthly check-in with the interdisciplinary diabetes team transitioned to a telephone consultation with their endocrinologist. While none of the participants had experienced telehealth previously, they reported that telephone consultations provided a convenient and contact-free alternative to face-to-face appointments, especially when the young person was managing well and blood glucose levels were 'staying within range'.

[I]t actually worked really well for us, because it was an 8:30 am appointment, and we did it from home, then I had him back to school pretty much on time... [U]sually, when we go to the hospital, we have to wait around. (Parent of participant 4)

In general, participants had positive experiences with telehealth. A notable change described was the inability to have a point-of-care HbA1c test, which they had become accustomed to having while attending their 3-monthly consultation and being able to discuss their results with the broader interdisciplinary diabetes team, including the diabetes educator. This was central to their usual routine and an important aspect of participants' confidence about their self-management practice. It provided an opportunity for them to plan any adjustments needed for the following 3 months.

[W]e weren't allowed to do, like, the normal thing... we couldn't get that [HbA1c] done, we couldn't really go face-to-face...we didn't get that done. (Young person, participant 9)

[R]eally my main goal for those visits is that HbA1c, because that really does help me guide what adjustments and what things we do personally and just, you know, relying on the doctors to make those decisions or to guide us. (Parent of participant 6)

Instead, most participants uploaded data from their continuous glucose monitor (CGM) and insulin pumps or shared data using an app prior to telehealth consultations. While the CGM provided an estimation of HbA1c over the previous 3 months, some participants did not find it as satisfactory.

[N]ormally they do the HbA1c, they couldn't do that. But with [Name]'s CGM, they are able to see a sort of digital prediction of what they think it will be. I think for one quarter, that's fine. But I think that's not a long-term solution. (Parent of participant 1)

One parent chose to decline the consultation as no point-of-care HbA1c test could be conducted and the young person was managing well; they knew they could contact the team if they had any issues.

[H]e was tracking quite well with his levels, so I felt that we were quite comfortable in managing for the next three months without having that clinic conference. (Parent of participant 6)

While some young people preferred the speed and efficiency of a telephone consultation, most participants (both young people and parents) highlighted that they missed the opportunity to be able to speak with the broader interdisciplinary diabetes team face-to-face.

When you're there, face-to-face, you have the opportunity to...well, you see the nurse, then the diabetes educator, then the endocrinologist, and then occasionally the dietitian. So, you have that flexibility if you're there physically. (Parent of participant 7)

Another issue raised by participants about telephone consultations was the lack of a physical examination which could enable early detection of potential health issues.

But there are also benefits of going...to the face-to-face consultation, too, because they check your heart rate and, you know, where you're doing your CGM, if there are any lumps or anything. That can only be done by physically touching you. So there's a few things that they have to look after. (Parent of participant 11)

While no participants experienced a video consultation, several felt this might enable better communication compared with the telephone.

We can't see the doctor [on the telephone] as in his body language... [Video's] more like face-to-face... [Y]ou're not only just hearing sound, you can actually see the person you're talking to. (Parent of participant 9; young person, participant 9 agreed)

It's just a little bit hard [on the phone] to, like, understand what he was meaning. (Young person, participant 8)

Others were left feeling their telehealth consultation was less thorough, less personal and more 'transactional' compared with their usual experience of engaging with the interdisciplinary support team.

[I]t was all a bit quicker and a bit stinted. It didn't feel like the usual sort of "wrap-around" service..... It's normally as much about your wellbeing and emotionally, physically and everything else as much as the diabetes. (Parent of participant 1)

Both young people and their parents felt the value of telehealth was to act as an interim measure that offered a contact-free consultation. Looking to the future, they felt telehealth could have a place in their health regimen for some, but not all, consultations if the young person is managing their diabetes well. There was a clear consensus that a face-to-face consultation that enables a physical examination, if necessary, was considered the gold standard of care.

Theme 3: trust in the interdisciplinary diabetes healthcare team

Management of T1DM for a young person, and their parents, is constant, complex and changeable. Devices such as insulin pumps and CGMs require user training, adjustment over time and regular calibration. Insulin doses must be adjusted in response to growth, changes in activity levels and diet. Some participants found changes in exercise levels due to COVID-19 restrictions impacted on insulin needs. They struggled with calculating correct basal rates but were able to contact a member of the interdisciplinary diabetes team for assistance.

Participants described their trust in the interdisciplinary diabetes team whose 'wrap-around' support mitigated against the uncertainties they felt during COVID-19.

[W]e can call them, like, at any time of the day. It's normally really good, because, like, if we just had a couple of questions we can just call them up. (Young person, participant 8)

Providing patients with a central email contact point for the team enabled coordination of care to continue. While most participants preferred face-to-face consultations, knowing they could access their team to request assistance and advice underpinned their willingness to use telehealth consultations.

[O]ur educators and endocrinologists are really easy to access. Whenever I'm sending them an e-mail, they're really good and call us back and help us immediately...[T]hat's a real relief for us. (Parent of participant 11)

Participants trusted the interdisciplinary diabetes team to act in a safe and responsible manner and organise face-to-face consultations when needed.

[W]e're going in for this new pump, and because they're fitting a new medical device, we're going into the hospital. So COVID or no COVID, we're going in for that. (Parent of participant 1; young person, participant 1 agreed)

DISCUSSION

Young persons' and parents' experiences accessing healthcare for T1DM during the COVID-19 pandemic centred on maintaining usual care and routines established prior to the pandemic. Decision making was informed by their experiences of living with T1DM and the knowledge that they could rely on the interdisciplinary diabetes team for support. Telephone consultations provided an opportunity for continuity of usual healthcare, which is critical for diabetes management.

Prior to COVID-19, telehealth was known to aid management of adult and paediatric diabetes,^{21–25} especially when supplemented by data from insulin pumps, sensors and glucose monitors, providing clinicians with an in-depth overview of patients' self-management.^{22–26} The key benefits of telehealth identified by participants in our study align with the literature and are broadly catalogued as improved accessibility, convenience and reduced travel time,^{21–27–28} and contact-free consultations to reduce exposure to COVID-19.²⁹ However, participants also recognised inherent shortcomings such as the inability for physical examination and lack of point-of-care HbA1c testing, which was perceived as an important aspect of their previous regular 3-monthly consultations. Discussion around the HbA1c test underpinned management plans, allowing reflection on previous successes and anticipated changes. A study of four rural Australian clinics found paediatric patients with T1DM responded well to video consultations with their endocrinologist when this was in addition to a nurse at the clinic setting up the call and conducting a physical examination and an HbA1c test.²⁸

With the onset of COVID-19 telehealth use has been promoted and expanded in many countries, including Australia, England, France, Italy, the Netherlands, Canada and the USA.³⁰ At the time of this study, most telehealth in Australia was conducted by telephone, reflecting the rapid roll-out of telehealth ahead of the platform video technologies.³¹ Participants found telephone consultations challenging as they were unable to read their clinician's body language to clarify meaning, which speaks to the need for clearer communication strategies for telephone consultations and an added strength of video consultations. General practitioners conducting teleconsultations during COVID-19 have also reported difficulties with telephone consultations, including missing non-verbal cues and an inability to understand patients'



needs.³² Participants suggested video consultations might better enable communication and some studies have found higher levels of satisfaction among patients and staff using video links.³³ However, there is also evidence that telephone consultations are effective, require less technology and that video options should supplement rather than replace them.³³ The difficulties experienced by both clinicians and participants might be early-user effects, which may improve with training and more experience in new modes of consulting. The long-term sustainability of telehealth will require a workforce that is skilled and competent in using telehealth.³⁴

Young people with T1DM require regular and ongoing support from a range of healthcare professionals to manage complex and changing healthcare needs as they transition to adulthood. Diabetes distress in young people is common and closely related to blood glucose maintenance.³⁵ Participants described blood glucose management as central to their everyday life and becoming anxious if it was 'out of range'. In a survey of paediatric diabetes healthcare professionals during the COVID-19 pandemic, anxiety and stress were the most commonly reported psychological symptoms of parents of young people with T1DM.³⁶ Addressing psychosocial issues during stressful times is important for young people and their families as it can greatly impact diabetes control. Having access to an interdisciplinary diabetes team that includes endocrinologists, dietitians, diabetes educators, psychologists, allied health professionals and social workers to provide both clinical and emotional support is recognised as beneficial for both the patients and the parents.³⁷ All participants identified the importance of their interdisciplinary healthcare team and a strong sense of trust and reliance on being able to contact them for information and support. While uncomfortable that they could not engage with the team as a whole during telephone consultations with their endocrinologist, participants did not report any perceptions of care fragmentation, which was probably due to their capacity to readily access support from team members via email and telephone as needed.

Strengths and limitations

While the prevalence of COVID-19 infection in this community was low at the time of this study, the need to engage with telehealth existed, providing an excellent opportunity to examine patients' perspectives of this in relation to a large interdisciplinary team. The rigour and relevance of our study were strengthened through the involvement of young people with T1DM and their parents in our research team,^{38 39} who contributed to the development of the interview guide, data analysis and drafting the paper. While having access to a pool of young people and parents interested in research aided recruitment, a potential limitation is that participants likely reflect a highly engaged group. Also, our focus on a single healthcare service is not representative of the broader Australian population. Having a parent present

at interviews may also have limited young people's voices. As most participants were managing blood glucose well, further research about young people with unstable diabetes, those without access to technology to support teleconsultations and those unable to access integrated services such as the PEDS clinic would provide a broader perspective.

CONCLUSION

Young people with T1DM and their parents require collaborative care and contact with multiple health professionals to facilitate self-management and glycaemic control. Telephone consultations offer convenient, safe and contact-free access to healthcare professionals for management of chronic conditions such as T1DM, a role highlighted by the COVID-19 pandemic. Clinicians and patients alike have adapted to using telehealth, especially telephone consultations, at a time when face-to-face consultations harbour some risk of contracting COVID-19. The value of video consultations and simultaneous access to the whole interdisciplinary diabetes support team need to be considered in future clinical implementation of telehealth for young people with T1DM. When the COVID-19 situation resolves it is unlikely that patients and providers will choose to return to a solely inperson model, preferring the option for 'virtual' clinics in some form as appropriate.¹⁶ A flexible hybrid model that offers the convenience of telehealth for some appointments interspersed with more personal face-to-face appointments in which physical examination and point-of-care HbA1c testing are also possible may offer a way forward.

Contributors AP, NB-S, SHD, CN, AL, RS, EB, KB, HE, EP, KW, CP and JD contributed to the study design. Interviews were conducted by AP and NB-S. Initial analysis was conducted by AP and NB-S and further refined in discussions with JD and SHD. Analysis and themes were finalised with the entire team (AP, NB-S, SHD, CN, AL, RS, EB, KB, HE, EP, KW, CP and JD). AP and NB-S prepared the initial draft of the manuscript. SHD, CN, AL, RS, EB, KB, HE, EP, KW, CP and JD contributed to all later drafts of the manuscript. AP is the guarantor of the article.

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Competing interests None declared.

Patient consent for publication Not required.

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Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available. Data are not available due to privacy and requirements of the ethics approval that was granted.

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REFERENCES

- Runkle JD, Brock-Martin A, Karmaus W, et al. Secondary surge capacity: a framework for understanding long-term access to primary care for medically vulnerable populations in disaster recovery. *Am J Public Health* 2012;102:e24–32.
- Hartmann-Boyce J, Morris E, Goyder C, et al. Diabetes and COVID-19: risks, management, and Learnings from other national disasters. *Diabetes Care* 2020;43:1695–703.
- Kishore N, Marqués D, Mahmud A, et al. Mortality in Puerto Rico after Hurricane Maria. *N Engl J Med Overseas Ed* 2018;379:162–70.
- Mokdad AH, Mensah GA, Posner SF, et al. When chronic conditions become acute: prevention and control of chronic diseases and adverse health outcomes during natural disasters. *Prev Chronic Dis* 2005;2 Spec no:A04.
- DiMeglio LA, Albanese-O'Neill A, Muñoz CE, et al. COVID-19 and children with Diabetes-Updates, unknowns, and next steps: first, do no extrapolation. *Diabetes Care* 2020;43:2631–4.
- Lynn RM, Avis JL, Lenton S, et al. Delayed access to care and late presentations in children during the COVID-19 pandemic: a snapshot survey of 4075 paediatricians in the UK and Ireland. *Arch Dis Child* 2021;106:e8.
- Atlas G, Rodrigues F, Moshage Y, et al. Presentation of paediatric type 1 diabetes in Melbourne, Australia during the initial stages of the COVID-19 pandemic. *J Paediatr Child Health* 2020;56:1654–5.
- Lazzerini M, Barbi E, Apicella A, et al. Delayed access or provision of care in Italy resulting from fear of COVID-19. *Lancet Child Adolesc Health* 2020;4:e10–11.
- Rosenbaum L. The Untold Toll — The Pandemic's Effects on Patients without Covid-19. *N Engl J Med Overseas Ed* 2020;382:2368–71.
- Kidd M. Australia's primary care COVID-19 response. *Aust J Gen Pract* 2020;49.
- Andrikopoulos S, Johnson G. The Australian response to the COVID-19 pandemic and diabetes - Lessons learned. *Diabetes Res Clin Pract* 2020;165:108246.
- Desborough J, Hall Dykgraaf S, de Toca L, et al. Australia's national COVID-19 primary care response. *Med J Aust* 2020;213:104–6.
- Australian Government Department of Health. The Australian health system, 2019. Available: <https://www.health.gov.au/about-us/the-australian-health-system> [Accessed 3 Mar 2021].
- Nooteboom LA, Kuiper CHZ, Mulder EA, et al. What do parents expect in the 21st century? A qualitative analysis of integrated youth care. *Int J Integr Care* 2020;20:8.
- Johnson H, Simons M, Newcomb D, et al. Understanding young people and their care providers' perceptions and experiences of integrated care within a tertiary paediatric hospital setting, using interpretive phenomenological analysis. *Int J Integr Care* 2020;20:7.
- Danne T, Limbert C. COVID-19, type 1 diabetes, and technology: why paediatric patients are leading the way. *The Lancet Diabetes & Endocrinology* 2020;8:465–7.
- Neergaard MA, Olesen F, Andersen RS, et al. Qualitative description - the poor cousin of health research? *BMC Med Res Methodol* 2009;9:52.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
- Our health in our hands (OHIOH): transforming healthcare, 2020. Available: <https://www.anu.edu.au/research/research-initiatives/our-health-in-our-hands> [Accessed 17 Nov 2020].
- NVivo. Qualitative Data Analysis Software [computer program]. Version 12, 2020. Available: <https://www.qsrinternational.com/nvivo/nvivo-products/nvivo-12-plus> [Accessed 15 Jun 2020].
- Haynes SC, Marcin JP, Dayal P, et al. Impact of telemedicine on visit attendance for paediatric patients receiving endocrinology specialty care. *J Telemed Telecare* 2020;1357633X:20972911.
- De Guzman KR, Snoswell CL, Taylor ML, et al. A systematic review of pediatric Telediabetes service models. *Diabetes Technol Ther* 2020;22:623–38.
- Wood CL, Clements SA, McFann K, et al. Use of telemedicine to improve adherence to American diabetes association standards in pediatric type 1 diabetes. *Diabetes Technol Ther* 2016;18:7–14.
- Tchero H, Kangambega P, Briatte C, et al. Clinical effectiveness of telemedicine in diabetes mellitus: a meta-analysis of 42 randomized controlled trials. *Telemed J E Health* 2019;25:569–83.
- Wu C, Wu Z, Yang L, et al. Evaluation of the clinical outcomes of telehealth for managing diabetes: a PRISMA-compliant meta-analysis. *Medicine* 2018;97:e12962.
- Rodriguez T. Telemedicine for diabetes management during the COVID-19 pandemic and beyond, 2020. Available: <https://www.endocrinologyadvisor.com/home/topics/diabetes/telemedicine-for-diabetes-management-update-and-interviews/> [Accessed 10 Sep 2020].
- O'Cathail M, Sivanandan MA, Diver C, et al. The use of Patient-Facing Teleconsultations in the National health service: Scoping review. *JMIR Med Inform* 2020;8:e15380.
- Williams M. Using telehealth for rural paediatric diabetics: does it deliver good care? *J Paediatr Child Health* 2021;57:109–13.
- Monaghesh E, Hajizadeh A. The role of telehealth during COVID-19 outbreak: a systematic review based on current evidence. *BMC Public Health* 2020;20:1193.
- The Commonwealth Fund. International health news brief: COVID-19 special edition, 2020. Available: <https://www.commonwealthfund.org/publications/newsletter-article/2020/may/international-health-news-brief-covid-19-special-edition> [Accessed 11 Sep 2020].
- Snowsell C, Hobson G. Telehealth and coronavirus: Medicare benefits schedule (Mbs) activity in Australia, 2020. Available: <https://coh.centre.uq.edu.au/telehealth-and-coronavirus-medicare-benefits-schedule-mbs-activity-australia> [Accessed 1 Mar 2021].
- Verhoeven V, Tsakitzidis G, Philips H, et al. Impact of the COVID-19 pandemic on the core functions of primary care: will the cure be worse than the disease? A qualitative interview study in Flemish GPs. *BMJ Open* 2020;10:e039674.
- Greenhalgh T, Wherton J, Shaw S, et al. Video consultations for covid-19. *BMJ* 2020;368:m998.
- Thomas EE, Haydon HM, Mehrotra A, et al. Building on the momentum: sustaining telehealth beyond COVID-19. *J Telemed Telecare* 2020;1357633X:20960638.
- Hagger V, Hendrieckx C, Cameron F, et al. Diabetes distress is more strongly associated with HbA1c than depressive symptoms in adolescents with type 1 diabetes: results from diabetes miles Youth-Australia. *Pediatr Diabetes* 2018;19:840–7.
- Elbarbary NS, Dos Santos TJ, de Beaufort C, et al. COVID-19 outbreak and pediatric diabetes: perceptions of health care professionals worldwide. *Pediatr Diabetes* 2020;21:1083–92.
- Husband A. The role of the paediatric interdisciplinary diabetes team in the care of children and adolescents with diabetes. *Paediatr Child Health* 2005;10:17.
- Brew-Sam N, Chhabra M, Parkinson A, et al. Experiences of young people and their caregivers of using technology to manage type 1 diabetes mellitus: systematic literature review and narrative synthesis. *JMIR Diabetes* 2021;6:e20973.
- Wale JL, Thomas S, Hamerlijnck D, et al. Patients and public are important stakeholders in health technology assessment but the level of involvement is low - a call to action. *Res Involv Engagem* 2021;7:1.