Received: 15 October 2020 | Revised: 15 December 2020 | Accepted: 21 December 2020

DOI: 10.1111/pedi.13180

CLINICAL CARE AND TECHNOLOGY

ISPAD International Society for Pediatric and Adolescent Diabetes WILEY

Changes to care delivery at nine international pediatric diabetes clinics in response to the COVID-19 global pandemic

Angelica Cristello Sarteau[1†] | Katherine Janine Souris[1†] | Jessica Wang[1] | Amira A. Ramadan[2] | Ananta Addala[3] | Deborah Bowlby[4] | Sarah Corathers[5,6] | Gun Forsander[7,8] | Bruce King[9,10] | Jennifer R. Law[2] | Wei Liu[11] | Faisal Malik[12] | Catherine Pihoker[12] | Michael Seid[13,6] | Carmel Smart[9,10] | Frida Sundberg[7,8] | Nikhil Tandon[14] | Michael Yao[15] | Terry Headley[4] | Elizabeth Mayer-Davis[1,16]

[1]Department of Nutrition, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

[2]Department of Pediatric Endocrinology, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

[3]Department of Pediatric Endocrinology, Stanford University, Stanford, California, USA

[4]Division of Pediatric Endocrinology, Medical University of South Carolina, Charleston, South Carolina, USA

[5]Department of Endocrinology, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA

[6]College of Medicine, University of Cincinnati, Cincinnati, Ohio, USA

[7]Department of Pediatrics, The Queen Silvia Children's Hospital Sahlgrenska University Hospital, Gothenburg, Sweden

[8]Institute of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

[9]Department of Pediatric Endocrinology, John Hunter Children's Hospital, New Lambton Heights, Australia

[10]Hunter Medical Research Institute, The University of Newcastle, Callaghan, Australia

[11]Department of Endocrinology, Peking University People's Hospital, Beijing, China

[12]Department of Pediatrics, Division of Endocrinology and Diabetes, University of Washington, Seattle, Washington, USA

[13]Department of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA

[14]Department of Endocrinology and Metabolism, All India Institute of Medical Sciences, Delhi, India

[15]Department of Pediatrics, University of New Mexico, Albuquerque, New Mexico, USA

[16]Department of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

Correspondence
Angelica Cristello Sarteau, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, 245 Rosenau Hall, Campus Box 7461, Chapel Hil, NC 27599, USA.
Email: angcri@live.unc.edu

Abstract

Background: Pediatric diabetes clinics around the world rapidly adapted care in response to COVID-19. We explored provider perceptions of care delivery adaptations and challenges for providers and patients across nine international pediatric diabetes clinics.

Methods: Providers in a quality improvement collaborative completed a questionnaire about clinic adaptations, including roles, care delivery methods, and provider and patient concerns and challenges. We employed a rapid analysis to identify main themes.

Results: Providers described adaptations within multiple domains of care delivery, including provider roles and workload, clinical encounter and team meeting format,

[†]Angelica Cristello Sarteau and Katherine Janine Souris contributed equally to this study.

care delivery platforms, self-management technology education, and patient-provider data sharing. Providers reported concerns about potential negative impacts on patients from COVID-19 and the clinical adaptations it required, including fears related to telemedicine efficacy, blood glucose and insulin pump/pen data sharing, and delayed care-seeking. Particular concern was expressed about already vulnerable patients. Simultaneously, providers reported 'silver linings' of adaptations that they perceived as having potential to inform care and self-management recommendations going forward, including time-saving clinic processes, telemedicine, lifestyle changes compelled by COVID-19, and improvements to family and clinic staff literacy around data sharing.

Conclusions: Providers across diverse clinical settings reported care delivery adaptations in response to COVID-19—particularly telemedicine processes—created challenges and opportunities to improve care quality and patient health. To develop quality care during COVID-19, providers emphasized the importance of generating evidence about which in-person or telemedicine processes were most beneficial for specific care scenarios, and incorporating the unique care needs of the most vulnerable patients.

KEYWORDS
COVID-19, Pediatrics, Quality Improvement, Qualitative Research, Type 1 Diabetes

1 | INTRODUCTION

Like other health care centers, pediatric diabetes clinics around the world have rapidly shifted operations in response to COVID-19 in an effort to minimize deleterious patient health consequences caused by disruption in essential ongoing care.[1] We, an existing international quality improvement collaborative of researchers and clinicians from nine pediatric diabetes clinics, developed a questionnaire to (a) ascertain changes to clinical responsibilities, care delivery, team communication, and attempts to minimize patient visits from diabetes complications; (b) document patient and provider concerns during the early months of COVID-19. Our main aim was to describe adaptations across centers and the perceived impacts of these changes on patients and providers.

2 | METHODS

The study was led by the University of North Carolina at Chapel Hill (UNC-CH) and conducted across collaborators: Stanford Diabetes Research Center, Stanford, CA; Seattle Children's Hospital, Seattle, WA; Medical University of South Carolina, Charleston, SC; Cincinnati Children's Hospital Medical Center, Cincinnati, OH; UNC Children's Hospital Pediatric Diabetes Clinic, Chapel Hill, NC; John Hunter Children's Hospital, Newcastle, Australia; Queen Silvia Children's Hospital, Gothenburg, Sweden; Peking University People's Hospital, Beijing, China; All India Institute of Medical Sciences, Delhi, India. Between May and August 2020, collaborators developed and completed a Qualtrics survey with quantitative and free response questions in four domains: 'Clinic Roles,' 'Care Delivery,' 'Data Collection and Administrative Platforms,' and 'Provider and Patient Concerns and Challenges.' UNC-CH institutional review board designated the study non-human subjects research.

To expediently understand care delivery adaptations in the rapidly evolving context of COVID-19, while also ensuring a systematic, comprehensive analysis, we used a rapid qualitative analysis approach designed to deliver findings with methodological rigor in time and resource constrained contexts. This method has yielded results consistent (i.e., no significant information differences) with those of in-depth analyses.[2-5] Table 1 describes the method.

3 | RESULTS

When providers were queried, all clinics were complying with local social distancing orders. Features of in-person care included sitting 1.5 m apart, face masks, daily temperature checks of staff and visitors, and limited waiting room occupancy.

Key themes that emerged included adaptive changes in care delivery due to COVID-19 (see Table 2), and their associated challenges and unanticipated 'silver linings.'

3.1 | Challenges of COVID-related adaptations

3.1.1 | Telemedicine concerns

Most clinics reported a sub-group of patients who lacked the internet connection required for video telemedicine format. Another primary drawback cited by providers was that certain features of in-person encounters could not be replicated virtually, including physical

TABLE 1 Rapid analysis using the matrix method

Step 1: Deductively coding free response answers by clinic and refining codebook	• Creation of a standard summary table ("matrix") for each clinic to aggregate free response data (i.e., questions and corresponding answers were placed in adjacent columns) • Independent review of summary tables for all clinics ("immersion") by each analyst (Angelica Cristello Sarteau, Katherine Janine Souris, Jessica Wang) • To calibrate theme identification, all analysts independently coded responses from one randomly selected clinic using deductive codes developed a priori from themes anticipated based on the survey aims and questions. These codes included: changes in clinical care delivery methods that were adopted in response to the pandemic, challenges in delivering diabetes care during the pandemic, opportunities (i.e., unanticipated positives), major concerns of clinicians, patients, and families, provider perceptions of the effect of the pandemic on health outcomes, and perceived sustainability of clinic adaptations • Working session to discuss discrepancies in coding, to ensure consensus regarding code definitions and consistency in code application, and to revise, collapse, and add codes • Calibration and working session process repeated, after which analysts randomly distributed the summary tables among themselves to apply the revised codebook and identify salient quotations from survey responses
Step 2: Aggregating quotes and themes by question and developing summary responses	• Consolidation of the quotes and codes from the clinic-specific summary tables developed in step 1 into a new set of question-specific summary tables (i.e., one table per survey question in which the quotes and codes in the responses across clinics could be examined simultaneously). This step facilitated comparison across clinic responses to each question and theme identification • To ensure consistent methodology, all analysts independently examined the same table and listed the most relevant codes, highlighted illustrative quotes, and produced a short 2-3 sentence summary of the main insights • Working session to discuss any discrepancies in their individual coding and achieved consensus on themes and quotes • Calibration and working session process repeated twice before the matrices were randomly assigned and the analysts independently coded the data in the remaining tables
Step 3: Consolidating summaries, key themes and quotes from each question into one matrix	• Transfer of response summaries, key codes, and illustrative themes from each matrix completed in step 2 into individual rows in the final matrix. Synthesizing the qualitative findings into one matrix facilitated examining this information together with the quantitative findings (i.e. continuous change in % of remote visits pre- and post-outbreak) which were aggregated in a separate table • Simultaneous comparison of the quantitative and qualitative matrices • Working session to create a written summary of study results organized by the most salient themes

examinations (i.e., check injection sites), routine tests (i.e., HbA1c), and complication screenings. A related challenge included shortened visit time as compared to in-person visits due to unstable internet connectivity, difficulty establishing rapport over teleconference, and technological barriers to sharing blood glucose or insulin pump/pen data electronically. Clinics reported insufficient information technology support and logistical difficulties related to teleconferencing platforms, which made preparing for virtual visits time consuming. Two clinics reported that integrating an interpreter into the visit posed a substantial challenge. Some clinics expressed uncertainty about the value of virtual diabetes education and about the sustainability of telemedicine in ensuring quality, health-promoting care.

3.1.2 | Data sharing–a steep learning curve

Providers described remote sharing of diabetes-related data between providers and patients as a steep learning curve for both parties that required extra time investments from the entire care team. Providers reported difficulties coaching families to share data remotely and challenges retrieving information from data management platforms, as they were accustomed to reviewing data in printed form. As with telemedicine, unstable or no internet connectivity and lack of electronic devices in patient homes presented a barrier to data sharing.

3.1.3 | Provider concern about diabetic ketoacidosis frequency and severity

Most centers were reluctant to make claims about increases in frequency or severity of diabetic ketoacidosis (DKA) in new-onset or established patients; however, a few centers perceived that DKA presentation in new-onset patients was more severe, with one speculating that there was an increase in later presentation due to, "*fear on the part of families or discouragement on*

TABLE 2 Summary of clinical care delivery adaptations

Domain of adaptation	Description
Provider roles and workload	• Providers shifted work hours, particularly research responsibilities, to evening hours to accommodate childcare needs • Increased non-physician (i.e., CDE, nurse, social worker) hours to provide logistical telemedicine support and manage new COVID-related responsibilities (i.e., staffing COVID screening checkpoints)
Provider meeting format	• Shifted to teleconference, however almost all clinics maintained the frequency of team meetings
Clinical encounter format	• 90–100% of visits occurred remotely post-outbreak (vs. a reported 0–5% before COVID-19). Most visits occurred via videoconference, with phone visits for a subset without videoconference capabilities • All clinics described parents and patients attending remote visits together • In-person visits limited to "urgent patients," newly diagnosed patients, patients with "more complex social situations," patients needing an interpreter, or patients without necessary technology for remote visits • Two clinics described developing a mitigation approach to keep patients out of the emergency department, which involved intensifying communication with families via phone (e.g., disseminating contact numbers of multiple providers) or social media platforms (e.g. managing a Facebook page with self-management tips and reminders)
Care delivery platforms	• Doximity and existing proprietary platforms built for the clinic pre-COVID were most frequently reported, although Skype, WhatsApp, Zoom, Jabber, and Cisco were also being utilized
Starting patients on self-management technology	• All clinics that were starting patients on continuous glucose monitors (CGMs) before COVID-19 reported starting patients on CGM via videoconference after the outbreak; in contrast, of clinics that started patients on insulin pumps before COVID-19, approximately half were starting patients on pumps remotely • Most patients began their pump or CGM education via telehealth, either with a clinic provider or a company representative, followed by a subsequent telehealth or in-person visit with the provider team for more advanced skill building • In-person visits for CGM and/or insulin pump starts were arranged if preferred by some clinics
Patient-provider sharing of self-management data	• A minority of clinics reported patients sending reports from their own uploads or providers obtaining remote downloads • Providers described using remote downloads more frequently (Clarity, Medtronic, Diasend, Glooko, T-connect, Carelink), patients holding logbooks up to the videoconference screen, and sending pictures of logs over WhatsApp/text

the part of health care professionals." Most clinics did not perceive an increase in frequency or severity of DKA in established patients. A few clinics described mitigation responses to prevent DKA in established patients and to proactively care for patients whose fear of seeking health care during the pandemic may have delayed care, such as increasing frequency of phone calls and number of care team members checking in with families.

3.1.4 | Provider concern about widening disparities

Providers in settings without universal health care expressed greatest concern over patients with challenging home lives, food insecurity, and other social and economic difficulties who would be least likely to receive appropriate care in the context of COVID-19. They reported observing widening disparities in care within their clinics during COVID-19, which they attributed to differential access to internet and, in turn, health support. Other factors potentially exacerbating disparities included shifts in clinical responsibilities that prevented social workers from following up with hard-to-reach patients and the loss of supervision from school staff that had previously ensured at least minimal consistency in insulin dosing for the most poorly managed children.

3.2 | Unanticipated silver linings

3.2.1 | Telemedicine as a "new best practice"

Just as providers expressed concerns over the efficacy and sustainability of telemedicine, they also described the pandemic as an opportunity to refine telemedicine processes, and most described it as a tool that may prove valuable and effective for ongoing care for certain families and clinical care needs.

3.2.2 | Improved data sharing literacy

Providers perceived the opportunity to better educate families on accessing, analyzing, and sharing diabetes-related data as a positive result of adaptations. Across the board, providers and families were described as becoming markedly more familiar accessing or sending diabetes related data remotely, a fundamental step towards improving families' ability to use that data to inform self-management.

3.2.3 | Increased efficiency

Providers devised new strategies to reduce physical contact with patients, which were described as having the added benefit of making

endocrinologist visits more efficient. Strategies included administering HbA1c tests, weight, and height measurements with minimal contact, and adding check-ins with a nurse 30 minprior to the endocrinologist encounter.

3.2.4 | Improved adherence to routine care

A few clinics remarked that family adherence to routine visits had increased, potentially due to elimination of travel time and a simpler life schedule. One clinic noted that insulin requirements had decreased and posited this to be due to parents' supervising more care throughout the day, including bolusing and limiting snacking, due to increased time at home.

4 | DISCUSSION

Providers at the nine clinics included in our study expressed concerns about negative health impacts resulting from the care adaptations at their clinic and the COVID-19 pandemic more broadly. Studies have substantiated their concerns that delayed care-seeking might increase rate and severity of DKA.[6-8] While providers in our study were concerned about negative impacts of telemedicine, the existing literature, while scarce, presents a divergent viewpoint. One study found satisfaction and training efficacy were comparable or improved for patients trained on insulin pump usage virtually during COVID-19 compared to patients trained in-person before COVID-19.[7] Additionally, although providers in our study expressed concerns about patient glycemic control, other studies suggest benefit of increased time at home. Studies of adolescents and adults have shown improvements in HbA1c and time in range.[9] As suggested by some providers in our study, other researchers attributed improvements in glycemic control during COVID-19 to more parental presence, meals at home, and a more consistent eating pattern.[9-11]

Providers in our study noted that adaptations were more likely to negatively impact patients who were already 'high-risk' due to poor glycemic control and family contexts burdened by economic, social, and behavioral obstacles to diabetes management. These patients are also most likely to be missing from studies examining effects of adaptions on patient health.[12] Factors like low socioeconomic status, health literacy, language proficiency, and access to reliable internet and cellular service are barriers to telemedicine accessibility for some families.[13] Patients with cognitive and sensory impairments face additional barriers to effective virtual communication.[14] Thus escalation in telemedicine usage during the COVID-19 pandemic may exacerbate disparities among vulnerable patients who already face increased health risks compared to the general population.[12]

5 | CONCLUSIONS

Our study highlights that clinic adaptations during COVID-19 created both challenges and opportunities for improvements to clinical processes. Providers perceived telemedicine as both insufficient to completely replace in-person clinical care and a potential long-term strategy to increase efficiency for certain clinical situations and improve adherence for certain patients. Evidence-based telemedicine should be developed as a clinical care tool given its potential to lower barriers to care that impact patient outcomes. A fundamental step to improving telemedicine involves understanding its unique purposes from in-person care. Awareness of patient privacy concerns and compatibility with regulations like the European Union General Data Protection Regulation—which may vary state to state and country to country—are also foundational.[15] Investigating in what circumstances and for which patients telemedicine may be comparable or superior to in-person care is an important topic for future quality improvement research, especially for chronic conditions and for the most complex patients, both of which are most readily neglected during periods of instability.

DATA AVAILABILITY STATEMENT

Data available on request from authors.

ORCID

Angelica Cristello Sarteau https://orcid.org/0000-0002-7303-4311
Ananta Addala https://orcid.org/0000-0002-0508-4309
Gun Forsander https://orcid.org/0000-0002-0266-9651
Faisal Malik https://orcid.org/0000-0002-2543-4214
Catherine Pihoker https://orcid.org/0000-0001-9074-7770
Frida Sundberg https://orcid.org/0000-0002-3681-7173
Nikhil Tandon https://orcid.org/0000-0003-4604-1986
Elizabeth Mayer-Davis https://orcid.org/0000-0003-3858-0517

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How to cite this article: Sarteau AC, Souris KJ, Wang J, et al. Changes to care delivery at nine international pediatric diabetes clinics in response to the COVID-19 global pandemic. *Pediatr Diabetes*. 2021;22:463–468. https://doi.org/10.1111/pedi.13180