

Care Experience of Parents of Children with Type 1 Diabetes Using Diabetes Treatment Technology: A Meta-Synthesis of Qualitative Studies

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ABSTRACT

The systematic integration of the qualitative research on the real experience of the parents of children with type 1 diabetes using the diabetes treatment technology, to provide a reference for the promotion of the clinical use of diabetes. A systematic review and meta-synthesis of qualitative studies. Qualitative studies reporting the use of diabetes treatment Technology A qualitative study on raising experience of children with type 1 diabetes were retrieved from electronic databases of PubMed, Web of Science, Medline, Ovid, The Cochrane Library, Embase, CINAHL, Sinomed, JBI Evidence-based Health Care International Cooperation Center Library and WANFANG data, CNKI and WEIPU data from inception to May 31, 2021. Eight study were included, 11 categories and 3 integration results were extracted, including using attitudes; perceive benefits; and facing difficulties and challenges. Diabetes treatment technology has many benefits in actual use, but there are also many obstacles. Clinical medical staff should take active measures against the obstacles in combination with the current situation to promote the clinical advancement of diabetes technology.

Keywords: diabetes treatment technology; children with type 1 diabetes; parents; real experience; qualitative research; meta-synthesis

INTRODUCTION

Type 1 diabetes mellitus (type 1 diabetes mellitus, T1DM) is one of the common chronic metabolic diseases in childhood, which seriously endangers the physical and mental health of children. By 2017, there were about 110 million children with T1DM worldwide, and it is estimated that 79000 new cases will be reported each year [1]. The main goal of the treatment of type 1 diabetes in children is to control blood sugar and reduce the incidence of complications. The International Pediatric and Adolescent Diabetes Association recommends that continuous blood glucose monitoring (CGM) and continuous subcutaneous insulin infusion (CSII) as the best treatment for childhood diabetes [2], which can reduce the number of punctures, reduce pain, keep blood sugar more stable, and improve the sleep quality of parents [3-4]. However, it can also cause parents to pay more attention to the treatment of children's diseases, frequently check blood sugar levels and equipment operation, and lead to negative emotions such as tension and anxiety. To some extent, parents also relaxed the supervision of their children's lifestyle, resulting in some caregivers and children with the misunderstanding that if they pay attention to adjust the dose of insulin, they can eat and exercise at will, thus aggravating the illness of their children. At present, there are more and more qualitative studies on the parental care experience of children with T1DM using CGM and CSII, but the results are controversial. Therefore, to better promote diabetes treatment technology in the field of childhood diabetes in China, promote parents to adapt to the role of care, and benefit more children.

This study uses Meta integration method [5] to explore the real experience of parents of children with T1DM who use CGM and CSII, to provide evidence-based basis for formulating health education plans for parents of children with T1DM.

DESIGN

This systematic review is a meta-synthesis of the qualitative existing literature, including a literature search, process of quality appraisal, themes synthesis and reciprocal translation.

Search criteria and procedures

Electronic search strategy

The formulation of inclusion and exclusion criteria was guided by the PICo-D inclusive model recommended by the Australian JBI evidence-based Health Care Center [6]. The PICo-D protocol was refined to four categories: ① P (population): Caregivers or parents of children with T1DM; ② PI (phenomenon of interest): parents' views on the CGM or CSII to manage type 1 diabetes in their children; ③ Co (context): home care; ④ D (design): qualitative research methods. An exhaustive list of terms for population, intervention and outcome was developed as detailed in Table 1.

The search was limited to peer-reviewed papers published in English or Chinese from the establishment of the database to August 31, 2021.

The following electronic databases were used to search: PubMed, Web of Science, Medline, Ovid, The Cochrane Library, Embase, CINAHL, Sinomed, JBI evidence-based Health Care International Cooperation Center, Wan fang, and CNKI.

In addition, all references included in the study were followed up to supplement the relevant literature. Figure 1.

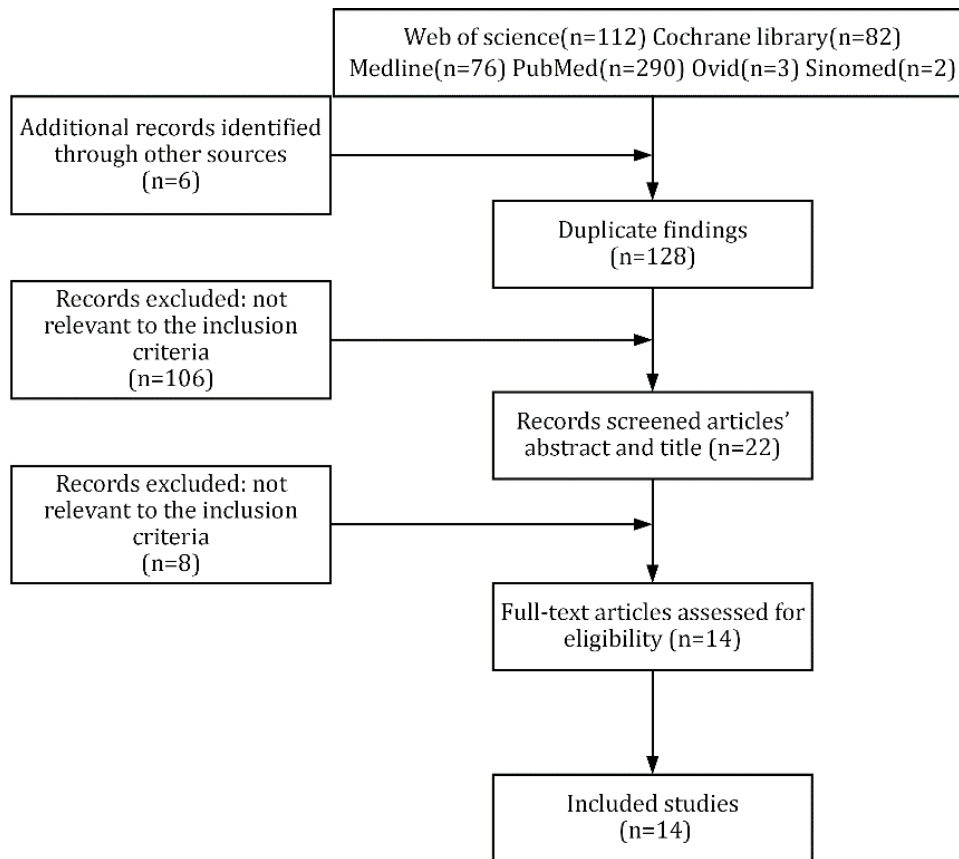


FIGURE 1: The flowchart of studies in qualitative meta-synthesis

TABLE 1: Search terma

Population: "children with type 1 diabetes" OR "insulin dependent diabetes mellitus" AND "parent*" OR "mother*" OR "father*" OR "caregiver"
Phenomenon of interest: Experience, opinion or views of caregivers or parents on the use of CGM and / or CSII to manage children's diseases
Context: home care
Design: "qualitative study" OR "qualitative research" OR "phenomenological research" OR "rooted theoretical research" OR "ethnographic research" OR "narrative research"

Assessment of methodological quality

The quality of the included literature was independently evaluated by two researchers trained in evidence-based methodology according to the 2016 Australian JBI evidence-based Health Care Center Qualitative Research Quality Evaluation Standard [7]. When the evaluation results conflict, the superior researchers will decide. There are 10 items in the evaluation, and each evaluation project is evaluated as "yes", "no", "unclear" and "not applicable". The quality evaluation is divided into A, B and C3 levels. Grade An is fully in line with the quality evaluation criteria, the possibility of bias is small; grade B is partially in line with the evaluation criteria, the possibility of bias is medium; grade C is completely not in line with the evaluation criteria, the possibility of bias is greater. This study finally included the literature with quality evaluation grade B or above. Results were compared and differences resolved through discussion and consensus.

Data extraction and analysis

In this study, Literature screening and data extraction were carried out independently by two researchers. First, duplicate documents were excluded by Note Express document management software. According to the inclusion and exclusion criteria, first read the title and abstract of the literature for preliminary screening, exclude the obviously irrelevant literature, and then read the full text to screen again and determine the final inclusion of the literature. After the screening results were obtained, the two researchers conducted a centralized discussion, and when there was a dispute between the two sides, they consulted the superior researchers to determine whether to include them or not. The extraction contents include author, country, research methods, research objects, phenomena of interest, and topics related to this study.

Using the method of collective integration, the researchers repeatedly read the original literature, understood, analyzed, and explained the results of each study, and further summarized and summarized according to its meaning to form a new category. Through the analysis of the internal and external relations among various categories, it is summarized as the result of integration, and a new interpretation of this phenomenon is obtained, which makes it more general, targeted and persuasive.

RESULTS

Table 3 summarized the key features of the articles including author, country, data collection, participants, character, phenomenon of interest, and themes. Among the 14 papers, 4 were grade A, and the remaining 10 were grade B. The quality evaluation results of the included literature are shown in Table 4.

TABLE 3: Key feature and characteristics of sixteen qualitative included studies

Author(s)	Country	Data collection	Population	phenomenon of interest	Themes
Hilliard et al [8]	USA	Semi-structured qualitative interview	55 parents of children aged 1 to < 8 years with T1DM duration ≥6 months	child currently or previously used CGM and their experiences with CGM.	Benefits: decreased worry about glucose excursions, improved sleep, increased their sense of safety when away from children. Challenges: painful insertions, wearing multiple devices on small bodies, disruptive alerts, data gaps due to lost signals, skin/ adhesive problems, and difficulty interpreting the amount of information generated by CGM
ELBALSHY et al [9]	New Zealand	semi structured interviews (in person or via video conference)	12 parents of children (aged ≤16 years) with type 1 diabetes using MM-CGM	experiences of families using MM-CGM including challenges faced and their advice to others who may choose to use the technology.	(1) Appropriate size of equipment; (2) website provides online resources for easy learning; (3) lack of professional guidance; (4) difficulties during software installation; (5) signal loss; (6) improved quality of life and sleep
Bomba et al [10]	Germany	interviewed	5 families (9 parents, 8 children and adolescents) who used the SAP technology for 6 months	explore the experiences of transition to sensor-augmented pump therapy (SAP) in families with 2 affected children	(1) fewer fingertip blood glucose measurements; (2) fewer consumables required; (3) difficulty finding a suitable time for calibration; (4) longer time to restart medical equipment; (5) changes in children’s personal development; (6) changes in peer and family relationships
Haslund-thomsen et al [11]	Denmark	interviewed	12 ethnic Danish families/parents of children with T1DM (12 mothers and 6 fathers)	To explore parents’ experience of having a child aged 4–9 years with type 1 diabetes mellitus (T1DM) using continuous glucose monitor (CGM)	(1) Living in the context of the unpredictability of diabetes; (2) Establishing a sense of control and security with the CGM; (3) Learning to use and trust the CGM and educating other caregivers.
Rankin et al [12]	England	in-depth interviews	19 parents of children (aged ≤12 years) with Type 1 diabetes who used an insulin pump.	to understand the impact on parents who care for young children using insulin pumps	(1) Reduced injection pain; (2) smooth blood sugar control; (3) reduced risk of hypoglycemia
Lawton et al [13]	England	semi structured qualitative interviews	55 parents of children aged 1 to < 8 years, with T1D duration ≥6 months	Benefits and Barriers of Continuous Glucose Monitoring in Young Children with Type 1 Diabetes	(1) View blood glucose values quickly and easily to predict and manage the future; (2) retrospective analysis of data to help parents understand the impact of lifestyle and insulin on blood sugar levels; (3) medical device malfunctions; (4) inappropriate alerts; data delay

Author(s)	Country	Data collection	Population	phenomenon of interest	Themes
Boucher et al [14]	New Zealand	semi-structured interviews	12 parents (9 mothers) and 3 fathers	to explore parental perspectives after flash glucose monitoring commencement in adolescents and young adults with type 1 diabetes	(1) Improve parental negative emotions and improve well-being; (2) reduce diabetes-specific conflict; (3) promote parent-caregiver role adaptation; (4) help parents make treatment decisions; (5) sensor signal loss and sensor failure; (6) medical equipment cost issues; (7) physician unfamiliarity with medical equipment
Rashotte et al [15]	Canada	in-depth interview	7 adolescents (13-17years) and 9 parents	explore adolescents' and parents' daily experience of living with SAPT.	(1) Have high expectations for medical equipment; (2) make psychological and life preparations for the use of CGM and CSII in advance; (3) cause trouble to the children's family; (4) learn to accept CGM and CSII
Barnard et al [16]	England	Semi structured interviews	15 adolescents (12-18years) and 13 parents	To explore the experiences of adolescents with type 1 diabetes mellitus (T1DM) and their parents	(1) Peace of mind, security; (2) gain confidence in managing diabetes; (3) improve diabetes control; (4) improve sleep quality; (5) alerts; (6) question device accuracy
Wysocki et al [17]	USA	Qualitative interviews	7 children with type 1 diabetes and 9 parents	Considerations for an insulin pump or continuous glucose monitor in adolescents with type 1 diabetes and their parents	(1) Alerts; (2) improve blood sugar control; (3) real-time continuous monitoring and reminders
Gildersleeve et al [18]	USA	focus group interview	15 parents of children aged 5-8 years with T1DM	Improving the safety and functionality of artificial pancreas systems for young children	(1) Set use passwords; preset early, intermediate, and advanced child use categories; (2) use its blood sugar correction function to help food selection; automatic exercise mode; (3) language information prompt function; (4) set emergency contacts; (5) remote monitoring of websites and apps; (6) gamification, such as rewards Diabetes-friendly behaviors; (7) comprehensive training for all cares involved with childhood diabetes
Lawton et al [19]	England	semi-structured interview	15 children, 9 parents	Experiences and Perspectives of Parents of Children Using Hybrid Closed-Loop Systems in Daily Life	(1) Adjust insulin infusion according to own blood sugar level; (2) reduce diabetes burden and make lifestyle more flexible and freer; (3) hope to optimize its effectiveness; (4) information support needs
Lawton et al [20]	England	In-depth interview	want-four parents adolescents who using a hybrid day-and-night closed-loop system and 3 months later,	To explore individuals' experiences of daytime use of a day-and-night hybrid closed-loop system	(1) Reduce diabetes burden; (2) doubt the reliability of information; (3) real-time continuous monitoring and reminders
Garza et al [21]	USA	Forty-eight semi structured focus groups and 89 individual interviews	283 Parents of children (12-20years) with type 1 diabetes	to examine how the automated insulin delivery system may impact family functioning and individual members	(1) Desire to reduce the concerns and burden of diabetes for patients and caregivers; (2) hope that this system can reduce daily stress; (3) improve family relationships

TABLE 4: Methodological qualitative evaluation results were included in this study

Studies	①	②	③	④	⑤	⑥	⑦	⑧	⑨	⑩	Grade
1	Y	Y	Y	Y	Y	N	Y	N	?	Y	B
2	Y	Y	Y	Y	Y	N	Y	N	Y	Y	B
3	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
4	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	A
5	Y	Y	Y	Y	Y	Y	N	N	Y	Y	B
6	Y	Y	Y	Y	Y	Y	N	N	Y	Y	B
7	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	A
8	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	B
9	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	A
10	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
11	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	A
12	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	B
13	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
14	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	B

Y: yes; N: no; unable to ascertain;

Note: ① whether the philosophical viewpoint expounded is consistent with the research method; ② Whether the research method is consistent with the research question or goal; ③ Whether the research method is consistent with the data collection method; ④ Whether the research method is consistent with data analysis and expression; ⑤ research Whether the method and result interpretation are consistent; ⑥ Whether to clarify the potential impact of researchers' concepts and values on research; ⑦ Whether to elaborate on the research The influence of the author on the research and the influence of the research on the researcher; ⑧ whether it fully represents the meaning stated by the participants; ⑨ Research conforms to current ethics Ethical standards and proof of research ethics approval recognized by academic institutions; ⑩ Whether research conclusions are derived from data analysis and interpretation.

Theme 1: Contradictory attitude

• *Approved treatment for CGM or CSII*

Most families prefer to buy directly from the manufacturer ("I prefer to buy directly from Medtronic (manufacturer name) [8]"), so that they can obtain after-sales service and online learning materials provided by the service provider. All parents agree that CGM and CSII are reliable technologies, powerful devices that can be customized for the special needs of children, and a new approach to disease management that offers families hope for treatment and eases caregiving fatigue ("This is a kind of The new experience gave me the confidence to take care of children[11]"). The use of CSII and CGM in the treatment of children's diseases, parents said they would continue to use it and recommend it to other families ("I would recommend it to my child's patients, and I will continue to use it [10]").

• *Dissatisfied with the alarm function*

Some parents complain that the alarm function sometimes doesn't work at all ("the alarm sound is too low to wake me or my child at night[13]"), but it is a burden ("if the alarm occurs at night, I have to get up and go frequently" Check[20]), especially at night when false alarms are a disturbance to sleep. In addition, some children choose to turn off their alarm clocks when they are in school, because the beeping of the alarm can be a distraction in the classroom, attracting attention, and they feel embarrassed ("The alarm sounded in class and the students were watching me [17]").

Theme 2: perceived benefit

• *Improve parental awareness of disease*

The CGM can dynamically display the blood sugar level of children, and realize real-time data sharing with the mobile phone ("You don't need to do a lot, just glance at the mobile phone [20]"), and it is convenient and quick to obtain the blood sugar value. The trend of blood sugar levels can tell how fast blood sugar levels rise or fall, helping parents understand and explain whether the child's abnormal behavior is caused by their own problem or disease ("He is always listless, I don't know if he is tired or low blood sugar. It helps parents to understand the impact of food and exercise on children's blood sugar, improve parents' cognition of the disease, and help children adjust short-term lifestyles in a timely manner, such as changing mealtimes, reducing exercise intensity, reducing the frequency of hypoglycemia and the ability of parents to adjust treatment strategies in a timely manner.

• *Alleviate hypoglycemia fear and improve quality of life*

After the use of CSII and CGM, children and their parents had more opportunities for social activities and their quality of life improved [9]. CGM monitors blood sugar changes in children in real time ("because we know if there is any problem, the alarm will beep and no longer worry about her hypoglycemia [11]"), parents do not need to be vigilant 24 hours a day, relieve their Negative emotions such as anxiety, tension, fear of hypoglycemia, and more peace of mind. Now that parents are refocusing on their child instead of worrying about blood sugar all the time, ("CGM helps me monitor my child's blood sugar changes, and I trust it (CGM) [13]"), they feel more at ease and safer the children also receive more love and care from their parents.

• *Alleviate negative emotions in children*

Subcutaneous insulin injections multiple times a day is a routine treatment for T1DM. The harsh treatment requirements cause pain and anger in children, and make parents feel nervous and panic. After switching to CSII and CGM, the child was less frequently stabbed, had a reduced risk of subcutaneous induration or lipoid hyperplasia, and the parents felt more at ease ("CSII made things easier because he hated injections so much" [19]). The child has fewer interruptions to play due to blood glucose monitoring ("the biggest advantage is that you don't have to prick your fingers all the time [9]"), is more adventurous in group activities, and gets along better with peers (he was always nervous before) Uneasy, now, he is clearly more relaxed [10]).

- *Changes in parent-child relationship*

The retrospective data provided by the CGM suggests that parents have problems in management ("When I look at the abnormal data, I think about what the child was eating and doing at that time [9]"), discuss with the child when blood sugar occurs. What happened when the abnormality occurred, and the children were more involved in the management of the disease, reducing the conflict between parents and children. Parents no longer need to constantly remind their children to perform self-management tasks, such as monitoring blood sugar, reducing the burden of parental care, and improving the relationship with their children. In addition, the child's technical advantages ("My child will give me some manipulation skills [14]"), provide guidance to parents, and help the child develop a supportive partnership with the parent. However, the combined use of CSII therapy and CGM also had some negative effects on family relationships. Overprotective and monitoring behaviors of parents ("I can look at his CGM records and ask him "what did he do", which makes him think CGM is monitoring him [17]"), and the loss of privacy of the child causes tension in the parent-child relationship, this can lead to family conflict.

Theme 3 : Difficulties and Challenges

- *Inconvenient to operate*

There are many functions of CGM and CSII, and the parameter settings are required to be precise. Parents have difficulties in operating medical equipment. Most people find it too difficult for them to install sensor software and upload data ("I asked my child's diabetes team for help and they don't understand" [19]), and some devices only work with iOS phone systems ("Mobile phones specially assigned to children" [11]). Some parents even need to seek technical help from professionals ("I asked my brother-in-law; he is an expert in IT" [9]).

- *Device problem*

Loss of signal and blockages are the most common problems. ("In school classrooms, false alarms sometimes appear" [8]). This not only disturbs the classroom order, but also embarrassing the children, causing them to feel inferior. The lowest basic rate at 0:006:00 at night can easily lead to blockage of the pipe, ("the alarm will be issued after the pipe is blocked, and I will get up to check what the problem is" [13]). This will disturb the sleep of parents and increase the burden of parental care. In addition, when the CGM shares data with the mobile phone, the data may not be updated in time, and the CGM signal will be lost.

- *Economic burden*

For most homes, CGM or CSII are prohibitively expensive. Compared to the cost of several test strips per day ("I would rather give up CGM" [14]), many families cannot afford the high cost of medical equipment. Not only that, but also need to bear the additional cost of medicines, pipelines, special adhesives, and other supplies. Some parents choose to quit their jobs to take better care of their children, which further increases the financial burden on the family. Parents hope government funding or health insurance to pay for medical equipment.

- *Cause distress to children*

The child's skin is delicate, and the tape holding the sensor irritates the skin, causing skin irritation, pain, or bleeding. Not only that, because the child needs to wear medical equipment for a long time and change it regularly, it is very difficult for parents to find a suitable and comfortable position for the child. When the child is exercising, it will also cause sudden and severe tingling or the sensor falls off due to the pulling of the pipeline, which not only causes the child's physical pain, but also generates additional costs.

Wearing medical equipment also has a negative effect on the child's appearance ("there is an extra (insulin pump) attached to the body, which can be seen in tight clothes" [15]), and they feel very uncomfortable when seen by others. Embarrassment, causing the child to feel unwelcome or different.

DISCUSSION

Meet the needs of parents' education and training, and promote the promotion and application of medical equipment

The results of this study show that parents can adjust their children's lifestyles based on CGM information and retrospective data to better control their children's blood sugar levels and improve their children's quality of life. This is consistent with the results of previous studies [20], but there are still some parents indicated that they were not familiar with the use of CSII. Studies have found [22, 23] that parents who get more information about the use of CSII in diabetes management strategies from medical staff can reduce their care burden. With the continuous advancement of technology, the performance and wearing comfort of medical equipment continue to improve [24], and it is very important to ensure that families of children receive the latest education about current diabetes medical equipment. Lawton et al. [25, 26] found that the need for training was stronger in families of children using both SCII and CGM. Therefore, it is particularly important to carry out continuous and progressive education and training for parents of children with T1DM, and actively promote the application of this technology in the field of treatment of children with T1DM to benefit more children.

"Integrating" with CGM or CSII is a long process

CGM or CGM is an emerging technology for disease management in children with T1DM, and research [15] shows that parents realize that they need to prepare mentally for the use of CGM in advance and consider other stressful factors in their lives. Therefore, when supporting families in learning to use devices, medical staff must be aware of the complexities of medical devices and their impact on the daily life of families, including how to communicate with each family, the potential stress and dilemmas of using treatment devices, and what to do. Preparation [11]. This can be achieved through teaching sessions, written materials, and video demonstrations of medical equipment, gradually allowing children and their caregivers to receive medical equipment, reducing barriers to use, promoting disease control, and improving children's lives quality.

Successful use of CGM and CSII requires overcoming obstacles

The use of medical devices can reduce the burden of diabetes management for children and their caregivers and improve the quality of life for families, but the use of new technologies presents many challenges. Current research shows that frequent alarms, high equipment costs, and wearing multiple devices negatively impact children with T1DM and their parents, whether using CSII, CGM, or a combination of the two. Among them, parents reported that the alarm would interfere with their own and their children's sleep quality. Young children can be so afraid of the alarm that they are afraid to sleep alone, which can increase parental concerns. So, personalize your alerts, keep your device safe and useful, provide truly useful alerts and reduce hassle. This can help children and their parents make treatment decisions and ease the anxiety of parents and school staff due to the alarm.

CONCLUSION

This study adopts the Meta integration method to summarize and explore parents' views and experience of using CGM and CSII for disease management, and systematically interpret parents' attitudes, perceived benefits, and obstacles and difficulties they face. This can provide adequate support for Chinese parents who are or will use CGM and CSII to manage their children with T1DM and can also help medical staff to provide personalized treatment plans for children with T1DM and their parents.

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