



**BRIEF REPORT**

# Sources and Valence of Information Impacting Parents' Decisions to Use Diabetes Technologies in Young Children <8 Years Old with Type 1 Diabetes

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## Abstract

There are multiple information sources available to assist families in learning about rapidly advancing diabetes technologies as care options for their children. This study explored where and from whom families of young children with type 1 diabetes get information about diabetes technologies and the valence (positive vs. negative) of that information. Semi-structured interviews were conducted with parents (86% mothers) of 79 youth <8 years old with type 1 diabetes for  $\geq 6$  months, ([mean  $\pm$  standard deviation] age  $5.2 \pm 1.5$  years, diabetes duration  $2.4 \pm 1.3$  years, 77% white, A1c  $63 \pm 10$  mmol/mol [ $7.9 \pm 0.9\%$ ], 66% pump-treated, 58% using continuous glucose monitors [CGMs]). Interviews were transcribed and underwent content analysis to derive central themes. Most parents reported learning about new technologies from three direct sources: diabetes care providers, people with diabetes, and caregivers of children with diabetes. Parents also cited three indirect sources of information: online forums, publications, and diabetes-specific conferences. Parents reported hearing primarily positive things about technologies. Families not using pump and/or CGM noted reluctance to use technology due to family-specific concerns (e.g., cost, child's unwillingness to wear device) rather than information from outside sources. In this subset of parents, many still expressed willingness to initiate use once family-specific concerns were resolved. Parents of young children received largely positive information about diabetes technologies, primarily from health care providers and others familiar with using devices personally or for their children. To maximize diabetes technology use in young children, it is incumbent upon providers to ensure families receive balanced realistic information about benefits and barriers.

**Keywords:** Child, Diabetes mellitus, Type 1, Parents, Perception, Insulin pump, Continuous glucose monitor.

## Background

**M**ANAGEMENT OF TYPE 1 diabetes in very young children poses unique challenges for families. Children's physical growth, inconsistent activity, changing food preferences and eating patterns, immature language and cognition, and

behavioral or emotional outbursts can affect families' abilities to effectively manage diabetes.<sup>1</sup> Use of advanced diabetes technologies can help relieve some of these challenges. Recent guidelines from the American Diabetes Association and International Society for Pediatric and Adolescent Diabetes suggest that pump use may be the preferred method of

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insulin administration in young children, and a continuous glucose monitor (CGM) with alarms should be considered for all youth with type 1 diabetes.<sup>2,3</sup> CGM data-sharing functions can relieve substantial burden for some parents.<sup>4</sup> Data from the T1D Exchange (T1DX) Registry show that insulin pump use in young children is associated with better glycemic control compared with injection-based treatment.<sup>5</sup> Similarly, CGM users <6 years old were significantly more likely to achieve glycemic targets in an analysis of the T1DX and Diabetes Patienten Verlaufsdocumentation (DPV) registries.<sup>6</sup>

Despite evidence of the benefits of advanced diabetes technologies in young children, universal uptake remains elusive. In 2016–2018, the T1DX registry revealed that 60% of children <6 years old used pump therapy, whereas 51% used CGM therapy,<sup>7</sup> suggesting that there may be potential barriers to device uptake. Parents have suggested many concerns about devices, such as a pump physically interfering with their child's activities, worries about the pump's therapeutic effectiveness,<sup>8</sup> concerns about CGM insertions, minimal body "real estate" for device placement, and feeling overwhelmed by the amount of data generated by CGM.<sup>9</sup>

There is a wealth of information about diabetes technologies available to families, and parents' decisions to adopt technology for their young children may be influenced by the advice and opinions of others. The international Diabetes Attitudes, Wishes, and Needs (DAWN) study found that diabetes care teams were the most common source of information for young adults and parents.<sup>10</sup> Others have suggested websites, social networking platforms, and parents of children with type 1 diabetes are also important sources of information and peer support.<sup>10–15</sup> However, there have been few studies of how families access or perceive information about devices from these varied sources. The purpose of this study was to explore parent-reported information sources for diabetes technologies, valence information received (positive vs. negative), and how valence related to adoption of diabetes technologies in young children.

## Methods

Semi-structured interviews were conducted with 79 parents of children <8 years old with type 1 diabetes for  $\geq 6$  months duration at four major U.S. diabetes centers (Indiana University, Joslin Diabetes Center, Texas Children's Hospital, and Yale School of Medicine). Eligibility included A1c  $\leq 10.5\%$ , no profound developmental delays in children, and English-speaking parents. Parents completed demographic questionnaires, and the most recent hemoglobin A1c was taken from the child's medical record. Interview questions, created by a multidisciplinary team, broadly explored the benefits and challenges of various diabetes technologies.

Interviews were audio-recorded, transcribed by a Health Insurance Portability and Accountability Act (HIPAA)-compliant service (Landmark Associates, Inc.), and analyzed by three coders using an inductive process of thematic analysis to derive central themes using NVivo qualitative analysis software.<sup>16</sup> Detailed information on the qualitative analysis process has been previously published.<sup>9,17</sup>

## Results

Parent participants were mainly mothers (86%). Children were predominantly non-Hispanic white (77%), with a mean

age of  $5.2 \pm 1.5$  years and diabetes duration of  $2.4 \pm 1.3$  years. Youth had a mean A1c of  $63 \pm 10$  mmol/mol ( $7.9 \pm 0.9\%$ ); 66% used an insulin pump and 61% used CGM.

Qualitative analyses explored three areas related to information-gathering about diabetes technologies: (1) where parents received information, (2) valence of information received (positive vs. negative), and (3) how valence impacted their decision to use diabetes technologies.

### Sources of information

All parents knew of the major advanced technology options available for diabetes management: insulin pumps and CGM. Most reported receiving information about these technologies from direct interaction with others. Parents cited three main direct sources of information: (1) their child's diabetes care providers, (2) other people with type 1 diabetes, and (3) caregivers of children with type 1 diabetes.

[The CGM] was suggested by his doctors. They suggest it for their younger population, for the younger kids. (Mother of 5yo boy A)

I've talked to people that have it [type 1 diabetes], and they've said, "Oh, it's so much better to have the pumps now and the CGMs," and so I'm really grateful to have all that technology to make it a lot easier than it was before. (Mother of 5yo girl A)

When she first got diagnosed, we had a few family friends that have type 1 diabetic kids. The first thing they said is, "Get her on the pump. It'll help." (Mother of a 4yo girl)

Fewer parents reported learning about diabetes technologies from indirect sources, such as online searches and research/presentations geared toward the diabetes community.

### Valence of information

The majority of parents reported hearing only positive information about diabetes technologies, regardless of the source and whether the family utilized diabetes technologies.

I hear really wonderful things [about insulin pumps]. Honestly, I'd say 90 percent of it is really wonderful—people say really great things about it. Then there are people that say in the beginning, it's actually really difficult until you get used to it. Once you're used to it, it's great, and you're gonna regret you didn't do it sooner. (Mother of a 4yo boy)

### Decision to adopt technology

In families not using a pump and/or CGM, reluctance to adopt diabetes technologies was due to family-specific concerns. Many parents reported wanting to wait until their child was ready and willing to wear the device, whereas some expressed concern about costs.

[My child] hasn't shown a lot of interest in it [insulin pump] yet. We're waiting until it's something she wants to do. (Mother of 5yo girl B)

Everybody's raving about the pump. It may not be for everyone. It's affordability. That's the major factor into how we can manage. [...] Supplies cost a lot. (Mother of 5yo boy B)

Many still expressed a willingness to initiate technology use in the future. Very few parents reported not foreseeing any added benefit of devices in their daily lives.

We are certainly not opposed to it [CGM]. We just haven't really been pushed into it or really seen the need for it. I see a small need for it, but I think I would need just a little bit more info or personal experience from somebody else to kind of fill in those gaps and really get us on board with it. (Father of a 6yo girl)

## Discussion

This study demonstrates the spectrum of sources and primarily positive valence of information provided to parents of very young children with type 1 diabetes, and how such information can impact parents' decision to adopt diabetes technologies for their children. Parents' knowledge about diabetes technologies comes primarily from person-to-person sources, specifically providers and others using technologies (either personally or caring for someone who uses diabetes devices). In the current era of online resources, information sources can be face-to-face through video or through written communications. Parents in this study also utilized forums and online search tools as sources of information. Previous research has suggested ~60% of parents use the internet, both through social media and professional/personal informational websites, in seeking health information for their child with type 1 diabetes.<sup>11,12</sup>

It is noteworthy that the majority of parents in this study reported that nearly all information received regarding diabetes technologies was positive, regardless of their decision to use diabetes technologies for their children. In families not using technologies, parents noted their decision to abstain from devices was based on family-specific factors rather than negative outside information.

Some limitations may exist in our study. First, interviews reflect the perceptions parents whose children received care at large tertiary care diabetes clinics with substantial involvement in diabetes technology research. It is possible that devices are more often discussed and prescribed by providers in these clinics. It is also possible that parents who elected to participate in this study concerning diabetes technologies already had a positive attitude regarding such devices, particularly if previously discussed with their providers. Meanwhile, parents who receive care at less technology-savvy centers may not have the same exposure to diabetes technologies through their providers and thus utilize online sources more often. However, this concern was mitigated in our sample, which included parents of young children with a range of diabetes management approaches, technology use, and glycemic control, as well as families representing wide geographic and socioeconomic variation.

As families can be sources of information for others, dissemination of comprehensive information by health care providers is imperative. Previous research suggests that nearly 75% of parents found it important to be able talk to other parents of children with diabetes, but only 41% of health care providers endorsed consistently providing information about parent-to-parent networks.<sup>10</sup> Although parents in this study endorsed online sources less frequently, it is possible that online sources can influence some families' decisions regarding technology uptake. Therefore, it is important for health care providers to direct families to trusted accurate networking platforms

and online sources. In addition, it is incumbent upon health care providers to offer impartial and balanced education regarding benefits and challenges of diabetes technologies to each family, as providers serve as a primary information source for most families. As they make personal and informed decisions about technology use in their young children with T1D, families benefit from realistic expectations of the potential impact of diabetes technologies on their child's glycemic control and parent and child quality of life.

## Author Disclosure Statement

No competing financial interests exist.

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