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Association Between Perceived Health Care Provider Support and Satisfaction with Insulin Pumps in Children with Type 1 Diabetes Mellitus: Opportunities for Pharmacists

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Keywords: Insulin pumps, Parent perceptions, Perceived healthcare provider support

Abstract

Purpose: *The purpose of this pilot study was to describe parents' perceived healthcare provider support for integrating technology, satisfaction with insulin pump use in their child with T1DM, and the relationship between parents' perceived healthcare provider support and satisfaction with insulin pump use.*

Methods: *A cross-sectional, correlational design was used to collect data for the present study. The study was conducted through an Internet survey among Mid-South parents who have a child with T1DM, 18 years old or younger using an insulin pump and/or continuous glucose monitoring (CGM). Frequencies, descriptive statistics, and correlation coefficients were calculated.*

Results: *Most of the parents surveyed used an endocrinologist/pediatric endocrinologist as their primary diabetes healthcare provider and considered three to four healthcare professionals as part of the diabetes healthcare team who helped them utilize insulin pumps and advanced technologies. Parents (23.4%) indicated a pharmacist was part of the healthcare team who helped them utilize technology. Parents appeared to perceive support for using insulin pumps; however, there is room for improvement. The more perceived support for integrating technology, the more satisfied the parents were with using insulin pumps (r=0.431, p=0.005).*

Conclusions: *Results from this study suggest that parents and children need continued education, support and training to integrate insulin pumps into diabetes self-management. As more patients attempt to adopt insulin pumps and other advanced technologies, it will be important for pharmacists to support the adoption and integration of these technologies and be knowledgeable and helpful if asked about technology-related challenges.*

Purpose

Although continuous subcutaneous insulin infusion (CSII), more commonly known as insulin pump therapy, has been shown to improve blood glucose control, its use is not widely adopted.[1,2,3] Insulin pump therapy use is associated with high household incomes, having private healthcare insurance, a higher level of parental education, as well as being Caucasian.[4] Discontinuation rates are estimated to range from 0 - 64% in children and adults.[5] Reasons for discontinuation found in clinical studies include skin discomfort, infection at infusion site, anxiety about technology, body image concerns, cost/insurance issues, technical difficulties with pump, inconvenience, and dislike or difficultly with needle insertion.[5] Few studies have looked at child and parent experiences with insulin pumps in the real world.

Another newer diabetes technology to help improve glucose control is Continuous Glucose Monitoring (CGM).[6,7] Likewise,

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this technology is also not widely adopted in the pediatric population. The Juvenile Diabetes Research Foundation (JDRF) Continuous Glucose Monitoring Study Group stated that while studies suggest promise for CGM, "questions remain regarding the potential effects of its incorporation into diabetes management on psychosocial and patient-reported outcomes. The extent to which CGM exerts positive or negative psychosocial effects could influence patients' frequency and persistence of CGM use."[8]

As use of technology is associated with improved glucose control, clinicians will need to find ways to educate parents and children to overcome barriers and set realistic expectations to promote its use in children with Type 1 Diabetes Mellitus (T1DM). It has been suggested that increased provider support, education, and monitoring will be necessary to improve the adoption and utilization of insulin pumps and other technologies in diabetes self-management.[5] It is likely that relationships with healthcare providers can facilitate the integration of insulin pumps into diabetes self-management in juvenile patients with T1DM.[9] Thus, it is suggested that an important factor in the adoption and continued use of insulin pumps is perceived healthcare provider support for integrating technology. Perceived healthcare provider support is defined as the extent to which the parent perceives that the healthcare team acknowledges and supports the use of technology in the child's diabetes self-management. This definition is adapted from Ludman's (2002) work on perceived clinical support in the mental illnesses.[10] This concept of provider support is related to the more general construct of a therapeutic relationship, yet it focuses specifically on the perception of feeling supported by healthcare providers in using technology in diabetes self-management.

Studies have shown that community pharmacists can have a positive impact on patient outcomes in diabetes patients.[11] As insulin pump use increases, non-specialty practitioners will need to be knowledgeable of diabetes technology. The pharmacy is a point of access for diabetes medications and supplies, and thus the pharmacist will be key in educating patients and supporting the use of insulin pumps and CGM.[1] Potti and Haines (2009) state that pharmacists should be familiar with the newer technology and help patients troubleshoot problems with their use.[12]

Additional research is needed to better understand how healthcare providers, including pharmacists, can influence the use and satisfaction of insulin pumps in diabetes self-management in the real world. Thus, the purpose of this pilot study was to describe parents' perceived healthcare provider support for integrating technology, satisfaction with insulin pumps in the diabetes self-management of their child with T1DM, and the relationship between parents' perceived healthcare provider support and satisfaction with insulin pump use in their children. It is hypothesized that parents who perceive more support would be more satisfied with the insulin pump.

Methods

Study Design

A cross-sectional, correlational design was used to collect data for the present study. The study was approved by the Institutional Review Board (IRB) at a southeastern university under exempt status. This article presents the methods and results of one portion of a larger survey study.

Sample and Data Collection Procedures

Mid-South parents who have a child with T1DM, 18 years old or younger using an insulin pump or CGM were surveyed. The Northwestern Arkansas, West Tennessee, and Mississippi chapters of the JDRF sent an e-mail with the survey link to their membership. A follow-up reminder e-mail was sent one week later. The Nashville JDRF chapter placed a link to the survey on their Facebook page. Camp Hopewell, which offers a summer camp specifically for children with TIDM, also sent the survey to parents in their database who have children with T1DM. The invite e-mail provided information about the purpose of the study and that the study was voluntary and anonymous. To ensure the appropriate participants (i.e., parents who had a child with T1DM, 18 years old or younger) responded to the survey, several screening questions were included in the beginning of the survey.

Survey Instrument

The electronic survey was developed using Qualtrics®. Screening questions asked the potential participant if he/she had a child with T1DM who is currently 18 years old or younger and if their child was currently using an insulin pump and/or CGM.

The first part of the survey included demographic and health status variables about the parent respondent and their child with T1DM. The next part of the survey included questions about which members of the healthcare team helped integrate technology into the child's diabetes self-management and what information resources they used to learn about advanced technology. This section of the survey also included 9 items to measure perceived healthcare provider support for integrating technology into diabetes self-management. As previously stated, perceived healthcare provider support was defined as the extent to which the parent perceives that the healthcare team acknowledges and supports the use of technology in the child's diabetes self-

management. This measure was adapted from the Healthcare Climate Questionnaire, which is an instrument that measures provider support (i.e., the extent to which healthcare providers acknowledge and support patients' self-management of their chronic illness). This measure has been used in patients with mental health disorders and had a Cronbach's alpha of 0.95.[13]

Further, the survey included questions about the parent's and child's experiences with insulin pumps (e.g., number of years using the pump, number of pumps used, etc.) and insulin pump satisfaction. For this study, insulin pump satisfaction was defined as the parent's report of face-valid and salient aspects of the process and outcome of the insulin pump use.[2] It was measured using the Insulin Pump Therapy Satisfaction questionnaire.[2] This questionnaire is a standardized measure of satisfaction with insulin pumps that includes four items related to the process (satisfaction, preparedness, ease of use, and ease of use relative to expectations) and six additional items that assess the outcome (i.e., perceived effectiveness) of the use of the insulin pump. The first four items are rated on a 5-point Likert-type scale, with the end points reflecting the item (very unsatisfied to very satisfied, very unprepared to very prepared, not at all easy to very easy, and much harder to much easier). Higher numbers on the scale indicate greater satisfaction with insulin pumps. The six additional items are related to key areas of life change associated with using the pump. They are also rated on a 5-point Likert-type scale ranging from 1=much worse to 5=much better. In a previous study, these 10 items had acceptable reliability with a Cronbach's alpha of 0.69.[2] To assess the barriers to insulin pump use, a question with several barriers identified from the literature was included whereby parents selected the most common barriers to continued use.

The survey was professionally examined by three diabetes experts, and their comments were used to make revisions in the survey content. Further, the instrument was pre-tested by administering it to three parents at a diabetes clinic to determine the approximate time needed to complete the entire questionnaire, as well as for wording, and item clarity. Based on the feedback from the pre-test, the instrument was revised before administering it to participating parents.

Data Analysis

Once the survey was closed, data were transferred from Qualtrics® to SPSS 20.0 (Chicago, IL) for analysis. Data were reviewed for missing data and responses with missing data for more than 50% of the eligible items were deleted from the analysis file. Frequencies, descriptive statistics, and correlation coefficients were calculated.

Results

In this pilot study, 98 parents responded to the survey, of which 66 indicated that they had a child 18 years old or younger with TIDM. From the 66 responses, 48 parents indicated that their child currently uses advanced diabetes technology, while 18 parents indicated that their child does not. One parent of the 48 parent responses only provided demographic information in the survey and was therefore excluded. Thus, the survey produced 47 final responses from parents of children with TIDM who are currently utilizing an insulin pump and/or CGM device. The eighteen parents whose children did not use insulin pumps and/or CGM devices cited cost issues (33%) and the potential for interference with sports/outside play/other activities (22.2%) as the two most common reasons for not using advanced diabetes technology.

Forty-three of the 47 participants were white, 63.8% lived in an urban community, 76.6% had a college degree or higher and 96% had private insurance. Sixty-four percent of the respondents had a male child with diabetes. The child's mean age was 13.87 years (range 6-18 years), and the mean age when diagnosed with T1DM was 8.09 years. Sixty-two percent of respondents indicated that their child's A1C at last visit was < 8.0%, 23.4% indicated it was between 8.0 – 9.0%, while 14.9% of the parents responded that their child's A1C was above 9.0%. These sample characteristics are similar to what we have found in another study of children with Type 1 diabetes and to other studies in the literature based on this region of the country.

Participants most frequently considered their pediatric endocrinologist/endocrinologist (80.9%) and certified diabetes educator (CDE) (57.4%) to be part of their child's diabetes healthcare team who helped integrate diabetes technology into their child's diabetes self-management. Participants reported that on average they had 3.83 members on their healthcare team who helped them integrate technology into their child's diabetes self-management, including diabetes technology company representatives, other physicians, nurses, pharmacists, or dieticians (Table 1). When asked to select which information sources they used to get information about their insulin pumps or CGM, the top three sources were: endocrinologist (52.2%), support group (51.1%), and diabetes technology company representative (46.8%). Three participants indicated the pharmacist was a source of information about insulin pumps or CGM.

Perceived diabetes healthcare team support specifically pertaining to integrating technology into the child's diabetes self-management was measured using nine items (Table 2). Cronbach's alpha was calculated to be 0.98, similar to the

Perron et al. results.[13] The overall mean score for the nine items was 5.97 (range = 1.78 to 7.00, overall summated score = 53.71), indicating support with room for improvement.

Forty-two parents indicated that their child is currently using an insulin pump in their diabetes self-management. Of the 42 respondents, 62.8% have used their current insulin pump for more than two years, and 18.6% have used more than three different insulin pumps. The majority of respondents indicated that either the diabetes technology company representative (41.9%) or a CDE (39.5%) initially trained them on the use of the insulin pump technology.

Ten items were used to measure satisfaction with insulin pumps, where a higher number indicated a more positive response (Table 3). To assess reliability, Cronbach's alpha was calculated. The alpha value was 0.82, which is acceptable. When the results were scaled from one to five, the average satisfaction sum was 4.08. For the process items, parents indicated that it was not very easy to use and that it was more difficult to use compared to what was expected. For the outcome items, parents agreed that the insulin pump improved flexibility of meal and sleep schedule and food variety. When provided with a list of sixteen common barriers to using insulin pumps, study participants reported infusion site rotation issues (57.4%), cost and insurance issues related to insulin pump supplies (52.2%), infusion site being uncomfortable/painful (44.0%), and fear of device malfunction (40.4%) as the top four challenges they have experienced.

To explore if the perceived diabetes healthcare team support was related to satisfaction with insulin pump, a correlation coefficient was calculated and found significant (correlation coefficient r=0.431; p = 0.005). Therefore, the greater the perceived diabetes healthcare team support, the more satisfied the parent of a child with TIDM is with the insulin pump.

Discussion

Diabetes is a multi-faceted disease. For parents of a child with diabetes, healthcare provider support is essential in adopting, utilizing, and integrating new diabetes technology. The goal of diabetes technology integration is to improve a child's healthcare outcomes and give the parents more control of their child's diabetes management. It is essential to understand how healthcare providers can support the integration of advanced technology into diabetes self-management.

Due to the multitude of health effects that result from diabetes, the development of a healthcare team is essential to achieving diabetes goals. Survey participants had a variety of different individuals on their healthcare team, including pharmacists. Almost 25% indicated the pharmacist was a key member of the team for integrating technology; and it is possible that some of the CDEs could be pharmacists as well. Pharmacists have an important role to play in helping parents and children utilize insulin pumps and CGMs. There are opportunities for more community pharmacists to develop services to help diabetes patients use insulin pumps and other advanced technologies.

The participants appeared to perceive support for integrating technology; however, there is room for improvement. For example, parents rated the items related to technology training, awareness of what to expect from technology, and encouragement to ask questions about technology lower than some of the other items. Even these adopters of technology still perceive barriers to using the technology and dealing with some of the economic and psychosocial issues resulting from the use of technology. The use of an insulin pump did not alleviate worry related to diabetes and may have increased the social aspect of device usage. More support may be necessary to combat the psychosocial issues related to technology integration. By addressing some of the psychosocial aspects of technology integration, it may possible to increase satisfaction and adoption of technology in juvenile diabetes management.

As more patients attempt to adopt advanced technologies, it will be important for the entire diabetes healthcare team to support the adoption and integration of these technologies. Some healthcare professionals, including pharmacists or dieticians, may be underutilized with respect to integrating technology into diabetes self-management. The results emphasize the need for pharmacists to be trained and confident with insulin pumps and other advanced technologies. The participants did not utilize the pharmacist as an information source about technology. It is essential that pharmacists are not only educated about diabetes technology but also make their skills accessible to patients when and if questions and concerns arise.

More insulin pump education and training for pharmacists providing diabetes care may be needed.[12] There will be an increased need for pharmacists to develop niche services around diabetes technology and to become certified insulin pump trainers. These pharmacists will be important in training patients on how to use the technology, trouble-shooting when the technology malfunctions, and helping the patient adapt to the use of technology.

Results from this study suggest that parents and children need continued support and training to integrate technology into diabetes self-management. These parents were not participating in other clinical trials so these results reflect adopting technology in the real-world, particularly in the South. Further investigation is needed to better understand the clinical, economic, and psychosocial aspects of technology integration as well as methods to increase perceived support from pharmacists for adopting diabetes technology.

Certain limitations of this survey study need to be acknowledged. The study employed a convenience sampling technique in a geographically select area and thus the perceptions of parent respondents that participated in the study may not be representative of all parents of children with T1DM. Additionally, the limited sample size restricts the generalizability of the findings from this study. However, the study still highlights the importance of healthcare professionals, including pharmacists, in educating and facilitating the use of insulin pumps and other technologies.

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Tables

Table 1: Members of Healthcare Team Who Help Integrate Technology into Child's Diabetes Self-Management

Healthcare Team Members	Frequency of Healthcare Team Member Utilization N (%)
Pediatric Endocrinologist/Endocrinologist	38 (80.9%)
Certified Diabetes Educator (CDE)	27 (57.4%)
Diabetes Technology Company Representative	23 (48.9%)
Nurse/ Nurse Practitioner	19 (40.4%)
Pediatrician/Other Family Doctor	16 (34%)
Diabetic Supplier	11 (23.4%)
Pharmacist	11 (23.4%)
Dietician	9 (19.1%)
Board Certified – Advanced Diabetes Manager (BC-ADM)	4 (8.5%)

Table 2: Mean Item Scores for Perceived Diabetes Healthcare Team Support

Item	Mean Score*
My child's diabetes healthcare team conveys confidence in my ability to make change with advanced diabetes technology.	6.26
I feel understood by my child's diabetes healthcare team.	6.14
My child's diabetes healthcare team regularly reviews my child's progress while using advanced diabetes technology.	6.00
I feel that my child's diabetes healthcare team has provided me choices and options with advanced diabetes technology.	5.95
My child's diabetes healthcare team encourages me to ask questions about advanced diabetes technology.	5.93
My child's diabetes healthcare team makes sure we stay in regular contact.	5.88
My child's diabetes healthcare team made me aware of what to expect from using advanced diabetes technology.	5.88
My child's diabetes healthcare team tries to understand how I see things before suggesting a new way of doing things with advanced diabetes technology.	5.86
My child's diabetes healthcare team has provided training on advanced diabetes technology.	5.81
Overall Mean Score:	**5.97**
Overall Summated Score:	**53.71**

*7-point scale where 1 = Strongly disagree and 7 = Strongly agree

Table 3: Satisfaction with Insulin Pump	
Item	**Mean Score***
Preparedness for transition to insulin pump	4.05
Satisfaction with insulin pump	3.95
Ease of use of insulin pump	3.91
Difficulty of insulin pump use compared to expectation	3.51
Flexibility of meal schedule	4.60
Food variety	4.49
Flexibility of sleep schedule	4.47
Knowledge of diabetes	4.09
Level of your child's responsibility	3.88
Worry related to diabetes	3.81
Overall Mean Score:	4.08
Overall Summated Score:	40.76

*Higher scores indicate greater satisfaction on a 5 point Likerty-type scale