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PETS-D (Parents Education Through Simulation – Diabetes): Parents' Qualitative Results

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Abstract

Objective—Parents who have a child newly diagnosed with type 1 diabetes (T1D) must quickly learn daily diabetes self-management. An RCT was conducted using human patient simulation (HPS) to enhance parents learning diabetes self-management with children with new-onset T1D. The purpose of this study was to describe parents' perspectives of using HPS to augment diabetes education.

Methods—A qualitative descriptive design was used with open-ended in-depth interviews of parents (n=49) post-intervention. Qualitative directed content analysis was used.

Results—The majority of parents were positive about learning with HPS. Although a few parents said the HPS was “hokey” or “creepy,” most reported the visual and hands-on learning was realistic and very beneficial. Seeing a seizure increased their fear although they would have panicked if they had not had that learning experience, and it helped build their diabetes self-

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Contributors' Statement Page

Neesha Ramchandani: Ms. Ramchandani helped with the data analysis, grouped the data into themes, and tabulated the data, and performed the statistical analysis of the demographics. She also drafted the initial manuscript and edited subsequent manuscripts.

Laura L. Maguire: Dr. Maguire performed the majority of the parent interviews and initially coded and tabulated the data.

Kailyn Stern: Ms. Stern participated in the development of the paper and critically reviewed and edited the manuscript.

Jose B. Quintos: Dr. Quintos assisted in recruitment and retention of families and with the data analysis and critically reviewed and edited the manuscript.

Mary Lee: Dr. Lee assisted in recruitment and retention of families and critically reviewed and edited the manuscript.

Susan Sullivan-Bolyai: Dr. Sullivan-Bolyai conceptualized and designed the study, interviewed the initial set of parents completing the clinical trial, reviewed the transcripts and themes that emerged from the data, edited the initial and subsequent manuscripts, and approved the final manuscript as submitted.

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

management confidence. Recommendations included teaching others with the HPS (grandparents, siblings, babysitters, and school nurses).

Conclusion—HPS-enhanced education is an acceptable and viable option that was generally well-received by parents of children with new-onset T1D.

Practice Implications—The technique should be studied with parents of children with other chronic illnesses to see if the benefits found in this study are applicable to other settings.

Keywords

type 1 diabetes; parent education; simulation; HPS; vignette

1. Introduction

Parents who have a child newly diagnosed with type 1 diabetes (T1D) must quickly learn how to manage their care. Within a few days, they need to be able to be as proficient as health care providers in giving injections, checking blood glucose, treating and troubleshooting mild to severe hypoglycemia and hyperglycemia, and understanding when insulin dose adjustments need to be made [1-3]. Acquisition of these skills is essential for their child's well-being and even survival. Currently, parents learn diabetes self-management skills through education sessions with the pediatric diabetes team [1, 4-6] and practice hands-on techniques of blood glucose (BG) monitoring and insulin administration either on a stuffed animal or pillow, on themselves, or on their child. Some parents are nervous to practice on their child lest they do something wrong and hurt their child as a result [7-9].

Post hospital discharge, one of parents' biggest fears in diabetes self-management is about hypoglycemia [1]. If not treated in a timely manner, a mild low BG can quickly progress to unconsciousness and seizures. Parents whose children with T1D have had episodes of severe hypoglycemia become afraid of recurrence, and often maintain their child's blood glucose higher than the recommended target range [4, 8, 10, 11]. This can have long-term deleterious consequences to the child's health, as high blood glucose levels have been associated with the presence and progression of microvascular and macrovascular diabetes-related complications [12-14]. Since many episodes of severe hypoglycemia occur overnight, the majority of parents also stop sleeping through the night, which affects their own well-being and ability to function at full capacity [11]. If parents could experience what severe hypoglycemia was like in a practice setting before having to deal with it in real life, they may feel more prepared and less afraid if it should occur.

Human patient simulators (HPS) have been used to teach nursing and health professional students medical management and patient care techniques for almost 2 decades, with great success [6, 15-18]. It follows that HPS should be a useful tool to teach parents medical interventions that they may need to perform at home on a routine basis. However, prior to the PETS-D study by Sullivan-Bolyai and colleagues [19, 20] there have been no reports of using HPS to educate either adult patients about their chronic conditions or parents about medical management of their child's chronic illness.

HPS is a potentially beneficial way to teach diabetes self-management to parents whose children are newly diagnosed with T1D [6, 15]. It allows the parents to practice invasive skills such as checking blood glucose, giving insulin injections, and giving glucagon injections without worrying if they are hurting their child. They have the chance to learn proper disease self-management techniques without experiencing any adverse sequelae of having improper techniques. They can also practice as many times as they want on something that resembles their child, without worry.

A randomized controlled trial was conducted using HPS to enhance the teaching of diabetes-specific survival skills to parents with children newly diagnosed with T1D [19, 20]. Post-intervention interviews were conducted to gather feedback from parents on their experiences using this new technology to assist with diabetes education. The purpose of this paper is to present the qualitative findings of the parents' perspectives of using HPS as part of new-onset diabetes education.

2. Methods

This paper discusses the qualitative portion of a larger IRB-approved study, whose methods and quantitative results have been presented elsewhere [19, 20]. The larger study was a randomized controlled trial with three diabetes education sessions using novel methods given to parents over the first twelve weeks after their child was diagnosed with T1D. The focus of the three teaching sessions were hypoglycemia (session 1, done at time of diagnosis/study initiation), hyperglycemia (session 2, done at 1 month post-diagnosis), and BG pattern management (session 3, done at 3 months post-diagnosis). Final data collection was done at 14 weeks post-diagnosis. In addition to using the HPS for practice, education sessions included the use of scripted vignettes to ensure all aspects of each session topic were covered in a similar manner for all study participants. The control group received the same scripted vignette parent education sessions as the intervention group but without the use of the HPS.

An additional informed consent was obtained from all subjects prior to their participation in the qualitative portion of the study. A qualitative descriptive approach was used [21]. Both the PI and a doctoral student performed open-ended in-depth interviews of mothers and fathers who had used the HPS as a teaching tool following the three session, 14 week intervention. Individual 30 minute non-recorded phone interview appointments, conducted from the interviewer's private office, were scheduled for parent convenience. The interviewer verified quality acoustics, explained the interview purpose, asked structured interview questions (Table 1), and advised parents that occasional pauses may be taken to record their responses in writing. Meticulous notes were taken by the interviewer. At the conclusion, the interviewer asked parents whether they had comments to add and thanked them for their participation. All written notes were deidentified, and only the interviewers had access to the names of the individuals who had participated in the qualitative portion of the study. Interviews were analyzed using qualitative directed content analysis of the note-based data [21]. Rich descriptive summaries emerged from parent responses to the interview questions asked. The descriptions captured maximum variation of the learning experience. We also reached informational redundancy.

The HPS used in this study was a child-sized robot from Gaumard (Gaumard Scientific, Miami, Florida) who needed a cervical collar to keep his head in place, as the neck was very flexible. Hyperextension or flexion of the neck interrupted the software and caused functionality issues. The cervical collar minimized the incidence of such issues during the teaching sessions.

3. Results

Forty-nine parents of children with new-onset T1D from 32 families participated in this study (**31 mothers and 18 fathers**). Demographics of the parents and their children at time of diagnosis appear in Table 2.

3.1. HPS Teaching

HPS teaching was perceived as beneficial by the large majority (96%; **29 mothers and 18 fathers**) of parents who participated in the sessions. Parents said that the hands-on learning helped (27/49 parents), and that using the HPS was helpful and informative (23/49 parents): “It was more thorough/advanced/comprehensive compared to other trainings.” “Seeing it helped put it all together.” “I am more comfortable now because of HPS.” Parents liked that they did not have to experiment on their child (this was explicitly stated by 12 parents). They thought that the visual of having the robot physically in the education room helped (13 parents), and six parents likened it to a CPR/Resusci-Annie/crash test dummy. Two parents did not think that using the HPS for diabetes education was helpful, saying that it either did nothing for them (one parent) and that it was “hokey” and they were “not sure it added that much to the training” (one parent).

Parents reported having easy, straightforward, step-by-step instruction from the diabetes educator with the clinical vignettes and the HPS to augment their education led parents to feeling confident in both the knowledge and skills they must possess in order to keep their child healthy. Of the 49 parents interviewed, 7 participants reported being nervous/scared/overwhelmed at first. Along with the 3 vignettes on hypoglycemia, hyperglycemia/sick-day management and pattern recognition, in which the HPS played a key role in simulating the scenario, the HPS was used most often to teach parents how to draw up and administer glucagon in case of severe hypoglycemia (34/49 parents). It was also used to teach insulin administration, injection site selection, and blood glucose monitoring. Approximately half of the parents (21/49) reported that skills practice on the HPS helped them to feel competent in the diabetes self-management tasks they had practiced. “If we hadn't practiced with simulation and something ever happened....Without having that hands-on....Now that I went through it with the doll – I know what to do. That was very helpful.”

3.2. Vignettes with HPS Teaching

Providing diabetes education using vignettes was something that was being used for the first time in a randomized controlled trial. When used in conjunction with the HPS, parents generally found the vignette/HPS combination to be realistic, with the right amount of practice time and cueing by the diabetes educator (explicitly stated by 35/49 parents). Some parents specifically noted that the hypoglycemia vignette was helpful (20/49 parents), the

pattern management vignette was helpful (12/49 parents), and the hyperglycemia vignette was helpful (10/49 parents). The HPS component of this education was seen as being particularly beneficial: “With the hands-on, you go through it [skill practice] and you get comfortable and confident and you think I can do this – anyone could do this. That's how it makes you feel.” Three mothers and five fathers expressed wanting more time to review the vignettes.

3.3. Tremors and Hypoglycemia Practice

Parents most commonly found seeing the HPS have seizures/tremors during the hypoglycemia session scary, and it made them anxious knowing it could happen (19/49 parents; **17 mothers and 2 fathers**). But 37% of parents voiced that this was the most important of all the teaching: “It showed us that we would be anxious – that we would be scared and even shaking if it happens. It's good to see that beforehand.” Parents appreciated that they could learn what to do in a practice situation (17/49 parents). Not only did it make it real, it was helpful and made them aware of what to look for. Working with the HPS made it “sink in” or “stick” better, locked it in to the parents’ minds, and took the “pressure off.” After the training, one parent stated that they would not overreact if their child had a hypoglycemic seizure because they had already experienced it and knew how to intervene with the HPS. All but two parents found the hypoglycemic seizures session with the HPS to be helpful, either to have the hands-on experience with it (30/49 parents) or even just to see what it looked like (23/49 parents). Said one parent: “Being able to watch it helped me to plan how I would react to it, rather than panic.” One parent who did not find the HPS-enhanced scenario helpful said that what they observed on the HPS (change in breathing patterns) was redundant to what the diabetes nurse educator had already demonstrated. There were also a few mechanical issues reported (seizure and breathing component malfunctioning so there was minimal simulated activity) with the HPS that limited the observation and interactive activities which may have contributed to these comments.

Observation of tremors in the HPS was intended to be done during session 1, the teaching session on hypoglycemia, with other opportunities to practice during the other 2 sessions if warranted (parents requested or if the CDE determined they needed more booster sessions on management of severe hypoglycemia). However, presentation of this symptom and associated education was almost evenly distributed across sessions 1, 2, and 3 for the parents, or done over several teaching sessions. In retrospect, the majority of parents (28/49) thought that session 1 was the best session in which to teach about hypoglycemic seizures with tremor observation. Twenty-seven percent of parents preferred to have the tremors observation done in session 3 or over several sessions. Two parents were not sure what the best timing for this instruction would be.

3.4. Reactions to the HPS Itself

Parents’ perceptions of the HPS itself were mixed. Almost half of the parents had negative reactions to the HPS (24/49; **19 mothers and 5 fathers**). It was called creepy, strange, freaky, or disturbing by almost one-third of parents and scary by 10% of parents. However, the other half explicitly stated that the HPS was not scary (19/49). Yet some parents who thought the HPS was freaky also found it helpful: “Kinda freaky...scary...It was helpful – but

it was like a big doll and dolls creep me out – I think it's just me.” There was an equal number of parents who called the HPS creepy, strange, freaky, or disturbing, compared to those who called it interesting, amazing, cool, exciting, or neat (15/49). The HPS was perceived to be real-looking, real-feeling, and lifelike by 35% of parents, and even thought to be fun, funny, or comical by 16%. Said one parent: “I was really impressed. He had the cap on and was dressed really nicely. He had the Arizona shirt – and we like Arizona. I was amazed...He is impressive.”

3.5. Other Topics That Should be Addressed Using the Vignette/HPS Teaching Combination

When asked if the HPS teaching sessions should be used further, one parent responded: “Definitely! Every parent should be taught with one of those dolls, to do everything....It was very helpful. The class with the hands-on should be given to everyone....You don't normally have to give injections – so you don't want to practice on your child – now you can use the doll instead.” The majority of parents (71.4%) appreciated receiving the vignette/HPS teaching sessions. The sessions were reported to decrease fear and anxiety surrounding diabetes self-management because of the ability to practice skills on the robot. Parents suggested that the HPS be used further for a variety of different teaching sessions. The most frequent suggestion was to use the HPS for refresher sessions either every 6 months or at 1 and/or 2 years post-diagnosis (21/49). Other suggested teaching sessions included a review of severe hypoglycemia and/or glucagon use every few months, with insulin pump initiation, alongside carbohydrate counting/nutrition education, with lifestyle changes such as starting school or sleepovers, to inform parents what to expect over the long term, and for refresher sessions as needed.

Two parents (**both mothers**) did not find the system helpful and said it should not be tested further. One of them appreciated the teaching they received, but felt that the CDE did “fine” without the simulator and was “not so sure” if HPS should continue to be part of the initial diabetes education. This parent continued, “Just having a book wouldn't be good. If you were to keep the simulator it should talk more and be more realistic.” Four parents explicitly stated they were not interested in a refresher session with the HPS because they made sure they practiced the less commonly used diabetes self-management skills, such as glucagon use, regularly on their own. One parent did suggest that additional sessions may be warranted if new content (i.e. insulin pump training) was introduced.

3.6. Who should be taught using HPS

Parents generally thought that HPS teaching would be beneficial for all caregivers and all exposed to diabetes. The overwhelming top choices for receiving HPS instruction were grandparents (31 responses) and babysitters or any caregivers (30 responses). Others included all siblings (17 responses), teachers and school staff (11 responses), school nurses (10 responses), aunts and uncles, day care providers or nannies, specifically the older sibling, any other family member, the child with diabetes (6 responses), all hospital/doctor's office workers/nurses, any individual with diabetes, parents of the child's friends, specifically the younger sibling, having a family session, student nurses, other children without diabetes, the ex-spouse, and the boy scout leader. Only one parent reported that the

HPS teaching sessions would not be good for anyone else in their family, because there was no one else in his immediate family to help, and he did not believe his father (the child's grandfather) would remember any of the education provided.

3.7. Issues with HPS use

Negatives surrounding the HPS teaching sessions included several reports of mechanical problems and several reports of having a difficult time seeing the tremors/seizures on the HPS. The HPS needed a neck brace to stabilize the connection of the computer to the device; without it, the neck hyperextended and the controller became disconnected. When both parents attended the HPS-enhanced teaching session together, in one case the spouse took over the session because he was more technologically inclined. Despite these issues, HPS-enhanced diabetes education was still perceived by the majority of parents to be beneficial, and went beyond the acquisition of diabetes knowledge and self-management skills. Eight parents appreciated the HPS education sessions because they also reinforced team parenting.

4. Discussion and Conclusion

4.1. Discussion

As has been published about the benefits of training health professional students using HPS [6, 15-18], the HPS education sessions for parents of children with new-onset T1D helped build the parents' diabetes self-management confidence. It helped to allay the issues of nervousness surrounding diabetes knowledge acquisition and skills practice [7-9] and fear of severe hypoglycemia [1] that is commonly found in parents of children with new-onset T1D. The majority of parents in this study preferred learning with the robot over using their child as a guinea pig. They found the visual, hands-on learning opportunity very beneficial. The HPS was perceived as being realistic, especially the seizure experience. Overall, parents provided a balanced perspective of the enhancement of diabetes education with HPS. Data were not analyzed **in depth** by parent gender because the researchers were seeking overall parent perspectives of how best to utilize HPS as part of new-onset diabetes education. Although many parents vocalized it is scary knowing your child could have a seizure, no one refused to participate in the simulated tremor experience. Many parents described how the tremor simulation experience worked against the normal reaction of panic upon seeing and needing to respond to a child having a seizure. The simulation experience instead prepares them for action and control of the panic response. Future studies **will determine if there are any** gender-specific needs such as reactions to the HPS and processing the information received.

A severe hypoglycemic episode instills parents with such fear and anxiety of it happening again that they compensate by running their child's BG's higher than the recommended target range for weeks to months afterwards, which can be detrimental for the child in the long run [9, 10, 13, 14, 22-24]. While seeing a seizure increased the parents' fear, parents reported they would have panicked more during a real seizure if they had not had that experience. Additionally, since many severe hypoglycemic episodes occur overnight, the parents stop sleeping through the night, thus compromising their own well-being and ability

to function at full capacity [10, 11, 25]. Simulation training for emergent situations increases feelings of preparedness and comfort and decreases situational anxiety in health care professionals [26]. It remains to be seen whether having the hands-on training with HPS and being called into action during a simulated crisis instead of being given time to panic will change parents' long-term reactions to a real severe hypoglycemic episode if it should occur.

As beneficial as HPS teaching is, it is not without its problems. Mechanical problems with the robot were experienced in this study and have also been reported in the nursing education empirical literature [16, 17]. Attempts are underway to re-engineer the HPS used for diabetes teaching so that it has fewer mechanical problems and appears more life-like.

As the parents in this study expressed, anyone who is involved in the care of a child with T1D would ostensibly benefit from learning diabetes self-management skills using HPS. Indeed, two of this study's researchers recently explored the feasibility of using HPS to teach hypoglycemia management to grandparents of grandchildren with T1D. Quantitative study findings revealed that HPS-taught grandparents showed consistently larger improvement in T1D knowledge, confidence, and fear than non-HPS taught grandparents [27]. The HPS gives the individual the opportunity to learn about diabetes and practice necessary skills as much as necessary and at any time without causing undue harm to the child with T1D. Additionally, the trainer and the trainee do not have to wait for specific situations necessitating BG monitoring or insulin or glucagon administration to arise in order to get the training and practice they need [20].

The Diabetes Nurse Educators involved in this study took favorably to HPS- and vignette-enhanced diabetes education as well. A rich description of their experiences will be reported elsewhere. From a practice perspective though, they continue to use the HPS and the vignettes for teaching even now, long after the study has ended.

4.2. Conclusions

HPS to enhance teaching of diabetes self-management skills is an acceptable and viable option that was generally well-received by parents of children with new-onset T1D. The parents liked having the opportunity to practice diabetes self-management skills on something life-like other than themselves or their child. While a few parents did not find the HPS teaching helpful, positive reactions to HPS-enhanced education far outweighed the negatives. Parents' recommendations on timing and use of the HPS will be incorporated into future research studies. HPS use for education of other populations, including children with T1D and their other caregivers, will also be studied.

4.3. Practice Implications

HPS allows individuals to experience situations without having to wait for them to occur in real life. This enables them to learn skills in advance of having to use them or become more proficient in skills that are new to them but which they need to start using immediately. Additionally, when used to teach parents how to deal with emergent situations such as severe hypoglycemia, the HPS may remove the post-episode anxiety often seen in clinical practice by better preparing parents for what to expect and how to intervene. Future studies should be done to see if this indeed is the case.

This is the first paper to show that HPS can and should be used to teach parents of children with chronic illness medical management skills. The educators liked this teaching tool so much that they continued to use it after the study was over. The technique should be studied in groups of parents of children with chronic illnesses other than T1D to see if the benefits found in this study persist with other chronic illnesses.

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Abbreviations

BG	blood glucose
HPS	Human Patient Simulator
PETS-D	Parent Education Through Simulation – Diabetes
T1D	type 1 diabetes

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Highlights

- This is the first study to use HPS to provide education to parents of children with a chronic illness.
- HPS to enhance T1D teaching is an acceptable and viable option that was well-received by parents.
- Parents liked having the opportunity to practice diabetes skills on something life-like.
- Positive reactions to HPS-enhanced education far outweighed the negatives.
- Educators involved in this study liked HPS so much that they continue to use it after study completion.

Table 1

Interview Questions.

1.	Tell me what the (parent education) teaching experience was like for you compared to other teaching sessions you may have had (in the past) ?
2.	What was your reaction to using simulation?
3.	Tell me about the (hypoglycemia) vignette with the HPS before going home.
4.	Tell me about the skill practice (teaching experience – giving insulin injections, blood glucose monitoring, recognition of signs & symptoms of hypoglycemia, appropriate interventions for hypoglycemia, glucagon use, recognition of signs and symptoms of hyperglycemia, appropriate interventions for hyperglycemia, pattern management) .
5.	(Hypoglycemia-related) Tremors and practice response. Did you choose to observe and practice (hypoglycemia) tremors during the sessions? What was that like for you?
6.	Overall, is this supplemental (human patient simulator) learning experience something you think should be further tested and potentially used with other families who have children newly diagnosed (with type 1 diabetes) ?

Table 2

Demographics.

Characteristics:	PETS-D Interviews (N=49)
PARENT'S age, mean (SD)	38.7 (7.7)
Female gender, % (N)	63.3 (31)
White, % (N)	91.8 (45)
Educational level, % (N):	
<high school or missing	14.3 (7)
High school	24.5 (12)
Some college	22.4 (11)
College	20.4 (10)
Post-graduate	18.4 (9)
Marital status, % (N):	
Married	73.5 (36)
Significant other	12.2 (6)
Divorced / separated	12.2 (6)
Single	2.0 (1)
CHILD'S age at diagnosis, mean (SD)	8.2 (4.2)
Child aged <6 yrs old, % (N)	40 (16)
Child's gender, % (N)	73.5 (36) M / 26.5 (13) F
# of days child hospitalized, mean (SD)	2.3 (0.9)