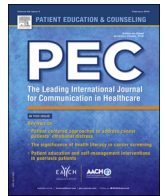




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PETS-D (parents education through simulation-diabetes): Parents' qualitative results[☆]

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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-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.

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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 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

Abbreviations: BG, blood glucose; HPS, human patient simulator; PETS-D, parent education through simulation-diabetes; T1D, type 1 diabetes.

[☆] We 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.

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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, provided at time of diagnosis/study initiation), hyperglycemia (session 2, provided at 1 month post-diagnosis), and BG pattern management (session 3, provided 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/

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)?

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