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Tried and True: Self-Regulation Theory as a Guiding Framework for Teaching Parents Diabetes Education Using Human Patient Simulation

Susan Sullivan-Bolyai, DNSc, CNS, RN, FAAN*, Kimberly Johnson, BSN, CDE, RN, Karen Cullen, BSN, CDE, RN, Terry Hamm, BSN, CDE, RN, Jean Bisordi, BSN, CDE, RN, Kathleen Blaney, MPH, RN, Laura Maguire, MS, RN, and Gail Melkus, EdD, RN, FAAN

Abstract

Parents become emotionally upset when learning their child has Type 1 Diabetes, yet they are expected to quickly learn functional diabetes management. The purpose of this article is to describe the application of Self-Regulation theory to guide a family-focused education intervention using human patient simulation to enhance the initial education of parents in diabetes management. A brief description is provided of the intervention framed by Self-Regulation theory. Based on the literature, we describe the educational vignettes used based on Self-Regulation in the randomized controlled trial entitled Parent Education Through Simulation-Diabetes. Examples of theory-in-practice will be illustrated by parental learning responses to this alternative educational innovation.

Keywords

Self-Regulation Theory; Parent education; Type 1 Diabetes; human patient simulation

After a child is diagnosed with Type 1 Diabetes (T1D) parents have described experiencing a steep learning curve (1) juxtaposed with a heavy emotional response. Parents have described at first only being able to digest the necessary survival skills to manage the child's diabetes when home. Within three months they described starting to put the big picture together conceptually (the juggling of the child's nutritional intake and carbohydrate counting, glucose monitoring, developmental and activity level, balanced with the insulin required). For some parents, this more complex conceptual stage may not happen depending on their cognitive and health literacy abilities. However, at time of diagnosis all parents report receiving reams of written materials without consideration for their individual learning styles, health literacy, reading, synthesis and application of knowledge abilities. At the same time, their emotional responses to the diagnosis may interfere with assimilation of this material and expectation to functionally respond to the diabetes management.

*Corresponding Author Susan Sullivan-Bolyai DNSc, CNS, RN, FAAN Associate Professor NYU College of Nursing ssb7@nyu.edu.

¹Pediatric HAL by Gaumard Inc. (referred to in this study as Simkid) is a high-fidelity simulator for training health care providers in critical life events and to teach emergency skills and decision making.

Typically, pediatric nurses who are certified diabetes educators (CDEs) are the primary teachers of the parent (s). They frequently use inanimate objects like dolls, or draw pictures of the steps of diabetes management. In the situation of learning to give injections, they may use the classic ‘orange’ or on occasion, practice the technical skills on a family member. However, what is lacking with the standard education process is the reciprocity of responses that occurs in real life between the child and parent who is providing the management, and parental decision making, based on how the child responds to the treatment.

The parent education process in the hospital when children are newly diagnosed with T1D is very short (typically 1–2 day length of stay) driven by the child’s medical stability. Diabetes management education consists of complex information at a time when parents are still emotionally dealing with the shock of the diagnosis. Discharge may occur before the parents feel adequately prepared to take over the day-to-day diabetes management.(2) In some cases the parent education is initially conducted in the outpatient setting. (3)

This dilemma led us to test an innovative technology teaching intervention (PETS-D: Parent Education Through Simulation-Diabetes) to make the learning more interactive and hopefully easier to assimilate. Therefore, the purpose of this article is to describe the application of Self-Regulation (S-R, as interpreted by Jean Johnson) (4) to guide this family-focused intervention using a child size human patient simulator (HPS, high fidelity computer operated robotic education technology) to enhance the initial education of parents in the day-to-day management of T1D. We will describe the theoretical framework that guides the intervention and the literature that lead to the development of the 3 teaching vignettes used in the parent education intervention. We will also provide theory- in-practice examples from the parents to illustrate its link to S-R theory.

Brief Overview of PETS-D

The 2001 Institute of Medicine report included a patient/family centered aim to engage patients, families and communities in the mission to improve quality of care (5). In support of those recommendations, focus group and pilot two-group studies informed the development of a randomized controlled trial education intervention. We set out to test the use of action-oriented reciprocal HPS education to augment the parent learning experience after their child was diagnosed with T1D including the focus, the timing, and presentation of the educational vignettes (1). Both the experimental and control group received a total of 3 teaching sessions over the first 12 weeks after diagnosis. We are currently analyzing the study results with reports to follow.

THEORETICAL FRAMEWORK

Leventhal’s(6) S-R theory as interpreted, tested and applied by Johnson(4), guided this intervention study (see Figure 1). S-R theory was developed during the 1960s and 1970s in a cyclical fashion, with changes and modification of concepts and propositions based on empirical data (both laboratory and human intervention studies). In the 1970s nursing played an important role in developing this framework through informational teaching during pre-operative interventions. The early studies reported that providing patients with pre-operative concrete, written information about a procedure (descriptions of physical sensations and

their causes, the surgical environment, and temporal conditions such as timing of procedure) actually decreased anxiety, improved patient confidence, and decreased hospital stays.(7) These studies started a practice revolution regarding patient education that has become standard of care. In the adult literature there have been numerous studies using self-regulation theory to craft educational interventions to decrease stress and anxiety and afford patients better coping strategies to rely on while undergoing a variety of medical screening procedures (colonoscopy, endoscopy, pelvic examination), during self-assessment for health-related issues such as self-breast examination or acute myocardial infarction, during invasive treatments such as chemotherapy and radiation, and for preparation for pre and post-operative surgical care.(4)

In pediatric nursing, S-R theory was first used to test pre-procedural education for children. Johnson et al.'s cornerstone cast removal intervention study investigated providing young children with information, sounds, and visualization of what the cast removal experience would be like prior to the procedure.(8) It resulted in less stress and anxiety for those children receiving the intervention prior to cast removal. This study set the stage for pre-procedural and pre-surgical play education across the country.

Parent education is another area that fits well with S-R theory. For instance, partially based on the S-R theory, Melnyk et al. developed an in-hospital educational-behavioral intervention for mothers whose children were critically ill.(9) Mothers who received the intervention reported significantly less stress, negative mood, and depression, and were more active in their children's hospital care compared to the control mothers.

According to Johnson,(4) there are four assumptions guiding self-regulation that are linked to information processing theory which are used to control our responses and behaviors when presented with a traumatic event or information. First, how we perceive and interpret traumatic or stressful experiences, such as a parent first learning about their child's chronic illness, inform responses and behaviors.

Second, we take the experience information and develop a cognitive picture, visualization, or scheme (similar to reality) that will guide us for real life experiences as to what signs or sensations to look for, what actions to take, and what we might expect to see from our actions. This process also helps us develop confidence in our abilities to handle the experience if and when it occurs.

Third, the information schema is organized from very concrete levels to abstract ones. It is hierarchical with, for example, lower level concrete tasks forming the groundwork for the higher level abstract concepts. For instance, learning how to administer insulin is a lower level task, while understanding how to adjust insulin dose contingent on carbohydrate intake and exercise is a higher level abstract task. Finally, knowing what to expect, how to respond to the intended experience (through knowledge and technical skill competence gained) and taking action, decreases any discrepancy of the expected event and reality, thus increasing parental confidence and decreasing associated fear and stress.

S-R recognizes the uniqueness of each situation and each person's response to an experience, with each individual determining how to respond, what action to take, and how

satisfied one will be with the outcome. Thus, S-R refers to the phenomenon that each individual responds differently depending on how their cognitive scheme was developed and experienced. Nurses especially play an important role in how schema are developed and used.

Johnson(4) described two parallel and dynamic coping pathways that occur with S-R. The first pathway focuses on regulating what is referred to as functional responses and goals. The pathway includes concrete objective features of the event. In the case of a parent whose child has T1D, attention focuses on out-of-the-normal behavioral responses in their child which could be interpreted as signs of hypoglycemia (eg. lethargy, paleness, clamminess), thinking about why this may have occurred, such as the child was just outside actively playing with friends; linking all of these pieces of information to previously taught information to 'what to do next.' In other words, test the child's blood glucose level, and if below normal parameters, treat as instructed, and continue to observe and evaluate for back-to-normal child behavior.

The second pathway focuses on emotional responses and goals and proceeds in the same manner as described in the functional pathway, but from a subjective and emotional level.(4) The emotional responses are unique and individual, from anger to sadness. Research findings supported that if individuals focused predominantly on the second pathway, they were more emotionally labile. Thus, keeping emotions in check through the functional pathway resulted in patients having better emotional outcomes. Both of these pathways come into play when an individual experiences a traumatic event or experience. The individual attempts to deal with and understand the event or experience to limit the associated emotional discomfort.

The nurse plays an important role through educational and behavioral interventions to assist patients and/or family members in forming cognitive schema. For example, by educating parents in the day-to-day management of their child newly diagnosed with T1D, they will be able to confidently observe, identify, problem-solve and competently treat their child, thus minimizing their concern, fear, and stress. Thus, along with written and verbal information presented to parents about T1D, it is proposed that visual and tactile simulation experiences may enhance the parent learning process. Formation of schema via the functional response pathway may improve their knowledge and skill base competence, strengthening their confidence level, as well as having an effect on the emotional pathway, by decreasing parental fear, stress and concern. We propose that by providing parents PETS-D that consists of standard diabetes education and HPS experiences, parents will better develop 1) visual cognitive schemata for the necessary care they must provide the child, 2) knowledge and problem-solving skill competence regarding the disease and its management, 3) confidence in believing they can provide the care effectively, and 4) less fear and stress/anxiety. In addition, positive child health and parent management outcomes may emerge quicker with this type of visual and hand-on experiential education.(10, 11) The theory-driven intervention may be very useful for families with limited education and those with only one parent caring for the child with limited time for learning.

Review of the Literature

Typically, parent education covers the basic T1D pathophysiology knowledge, blood glucose monitoring, recognition and management of hypoglycemia (parents' number one fear), hyperglycemia, administration of insulin, glucagon, and 'sick day' (ie. flu or gastrointestinal illness) management.(12) This complex knowledge and skill development is like (stated by a father) "being given the NYC phonebook and told to memorize it in two days!" In addition, Ginsberg et al. (13) conducted a mixed methods study with parents to determine factors that affect successful diabetes management and found parents ranked diabetes-related skills and knowledge as 4 of the 9 top items of importance, underscoring the necessary focus on parent education. Thus, it is important to explore education intervention models such as using S-R and HPS that focus on the transition of care to the parents, especially during the early months after diagnosis, when parents are the most stressed.(14, 15) Potentially, this type of education strategy will augment the nurse's discharge teaching role as well. (16–18)

To date, an exhaustive search of the English literature found no empirical studies in which HPS had been used with parent teaching for children with chronic conditions or illnesses, or specifically, with those newly diagnosed with T1D. We hypothesize that this type of teaching strategy may strengthen diabetes parental knowledge and skill competence, such as psychomotor skills (glucose monitoring, insulin or glucagon injections) and affective skills (recognizing physical changes that may signify hypoglycemia or hyperglycemia).

Nurses use primarily six strategies when teaching patients and/or caregivers: providing a plan of what information or skills need to be learned and evaluated, asking questions to assess the individual's knowledge level, providing information, giving explanations or clarification, instructing, and correcting through demonstration to correct performance(19). Parents of children newly diagnosed with T1D need to have opportunities to visualize and think about what might happen and how to respond in a variety of situations (referred to as the 'what ifs'). HPS offers hands-on opportunities to practice the skills that could enhance S-R schema formation. This type of emergency preparedness is essential for families living with someone with a chronic illness or condition.(20)

HPS may also provide a better way of practicing and applying the proactive 'what if' situations that some parents, even after years of managing their child's illness, have difficulty, such as prevention of hypoglycemia and hyperglycemia. Wysocki et al (21) reported that children with T1D whose parents had deficient diabetes problem-solving skills may be at risk for poor glycemic control. Enhanced simulated learning opportunities in a safe teaching environment may help form the visual schemata that parents can then transfer to real-life situations.

HPS as an Innovative Parent Education Strategy

HPS has been used in medical education for almost four decades (22) but only in the past fifteen years has nursing employed this educational strategy to enhance student nurse education.(23) In particular, the ability to improve critical thinking, decision making and clinical skills makes it potentially a viable teaching strategy to help parents of children

newly diagnosed with a medical condition such as T1D more quickly learn and become confident in managing the illness.

Since the turn of the 21st century, HPS has increasingly been used to teach nursing students the nuances of patient care (17, 24–27) (such as psychomotor and decision-making skills) and has been reported to enhance the learning process. It is also a safe way (before working with patients) to learn how to manage rare and infrequent events.(28, 29) Internal consistency using HPS was reported in teaching medical students such psychomotor tasks as a difficult intubation, and managing critical events including anaphylactic reaction or postoperative hypotension.(28–30) Similarly, these are skills parents of newly diagnosed children with T1D must become proficient in for day-to-day management. HPS provides a safe environment to learn health care tasks and responsibilities that mirror real world clinical situations.

Only one study (RCT) used an infant human simulator to educate (with a competency-based curriculum framework) high school students in an effort to decrease teen pregnancy by exposing them to the complexities of parenting. The authors randomized 236 adolescent male and females and educated them in infant care.(31) Post-test two group responses differed significantly for three attitude scales, (pragmatic, $F(1, 234)=10.08$ $p<0.002$; social, $F(1, 234)=13.266$, $p<0.001$; and responsible, $F(1, 234)=13.27$, $p<0.001$). The infant simulator was an effective tool for teaching childcare skills.

Presently, parents have access to web-based software simulation programs such as AIDA (An educational simulator for Insulin Dosage and Dietary Aadjustment in diabetes) (32) to practice the effects of diet and insulin on blood glucose. One needs basic knowledge of pathophysiology related to diabetes management to use this computer software program. This type of computer simulation is often too sophisticated for parents of children newly diagnosed as they are reported to be overwhelmed with the complexity of diabetes management. Nor does it provide opportunities to practice the psychomotor skills and build emotional readiness of getting comfortable and competent with injections and glucose monitoring. Thus, based on S-R theory using HPS for building functional knowledge and skill competence could also potentially enhance parent confidence, prior to “practicing” the skills on their child (e.g. insulin injections), as well as decreasing some of the emotional stress associated with the family transitioning home after diagnosis.

Description of the Teaching Vignettes

Following is a detailed description of each of the 3 vignettes we use to educate the parents about diabetes management based on the principles Johnson used in her seminal cast removal study. Table 1 summarizes the content for each vignette for both the experimental and control arms of the study illustrating the key ingredients of S-R theory. The functional and emotional response concepts are highlighted in both the table and the vignette descriptions.

Vignette 1, Session 1 (after diagnosis)—Parents in both experimental and control groups discuss and review with the CDE (the functional response) what is T1D, signs, symptoms, and treatment of hypoglycemia, hyperglycemia, sick day management, blood

glucose monitoring, insulin administration over the course of the 2 day admission.(33, 34) The same information is covered sequentially with parents receiving the education on an outpatient basis.

The amount of time spent (typically between 60–90 minutes per session) is recorded on a *CDE Teaching Evaluation and Documentation* form. We have a formal intervention fidelity framework whereby we have observed and collected data for the past 4 years on both sites, both experimental and control groups to maintain the validity of the functional and emotional response goals and have found no statistical difference for time spent teaching or information covered by group.

The teaching content for each vignette and allotted time was determined through discussions and consensus of an expert group of pediatric CDEs and parent focus groups (1). It also accounts for the flexibility in time needed to meet different parental learning styles and emotional responses. The only difference in material covered is that the experimental group has the HPS experience, which visually illustrates the vignette application/practice and S-R reciprocity between the ‘child HPS’ and parents, allowing for variation in potential emotional responses. In fact, in the pilot work the CDEs stated using HPS was natural and really enhanced the teaching method. It takes no more time, but shows concrete illustrations that normally are just discussed and explained to the parents. For example, to explain what a tremor looks like, in the control group, the nurse typically ‘demonstrates’ a tremor, what to do next, how to draw up and administer glucagon. With the experimental group, HPS illustrates a tremor (mild and more potent), followed by the nurse cueing the parents: ‘Now what do you do?’ The educator also has the parents use a simulated glucagon kit, allowing for practice of mixing, drawing up, and injecting the child simulator, followed by practice of follow-up treatment.

After each of the educational sessions a review and summary occurs in both study arms. In addition, with HPS the review and summary is referred to as ‘debriefing,’ where the visual experience is linked with the information covered to enhance S-R principles especially the emotional response to the learning and practice process. This added benefit deals with the fear parents may have observing tremors and/or administering invasive procedures such as finger sticks and injections.

Vignette 2, Session 2 (1 month after diagnosis)—Session 2 (60–90 minutes) builds on teaching in session 1. Parents in both the control and experimental group review with the CDE their understanding of diabetes management to date, focusing much more on the nutritional food issues and activity aspects of day-to-day management as part of the functional response. Again, the amount of time spent is carefully recorded. For the experimental group, HPS is used to visually enhance the ‘what if’ situations that may occur in real life, such as the child acting out (strategies for checking glucose level while using behavior management techniques if necessary). For instance, we can program the child HPS to say ‘NO!’ when the parent attempts to give the child juice to treat a low blood glucose. The nurse then says “so how are you going to handle this?” and they discuss strategies for dealing with the behavior (such as distraction or other developmentally appropriate behavior management options). The parent would then practice the problem-solving options with the

nurse programming the child HPS to respond. As in session 1, a review/summary occurs for the control arm; debriefing for the experimental arm to address the emotional response to the education experience.

Vignette 3, Session 3 (3 months after diagnosis)—Session 3 (60–90 minutes) builds on teaching in session 2. Parents in both control and experimental groups review with the CDE any issues that occurred during the past six weeks (since last teaching session) that they want to review or practice. The parents will be asked what specifically they want to review regarding day-to-day diabetes management (individualizing the functional response). This strategy allows for differences in parental understanding of diabetes management, issues they are struggling with, and varying parent learning styles. HPS is used to help address individualized family issues and situations that may arise with day-to-day management. For instance, functional behavioral response issues that the CDEs commonly get questions about from parents may be shared and illustrated (role modeling and role play) with simulation. For instance, struggling with giving insulin injections and having the parent(s) role play with the child HPS, having the robot verbally respond (“I don’t want to!!”) can be simulated and practiced to help build parental confidence in handling the situation using S-R principles. The parental emotional response can be underscored with the HPS scenarios to provide opportunities to practice how to respond to the child in a controlled environment. If this same issue arose with the control group, the CDE covers the information but may use role play (educator taking on role of child and having parent respond). A review/summary again occurs for the control arm; debriefing for the experimental arm where the emotional response is again revisited. At the end of the trial for each parent we also (within the intervention fidelity plan) query them (Likert scale, treatment receipt questionnaire) as to the level of knowledge or skillset gained over the 12-week trial to ensure the same information has been covered over the course of the 3 vignette sessions and confidence in providing the care.

Examples of theory-in-practice

To illustrate how theory comes to life we will share some of the comments made by parents who participated in the study and received the HPS intervention. Overwhelmingly, the post intervention qualitative interviews have been positive and provide strong illustrations of how S-R theory guides the parent education experience. Although we do not share with the parents the theory driving the study, parents repeatedly said without prompting (especially those who self-identified as visual learners): “I am a visual learner so this is great!” They verbalized forming visual pictures of the management they practiced during the teaching vignette sessions. They also shared that in situations where they noticed their child ‘going low’ they were able to refer back to the visual schemata and react appropriately to their child’s needs (‘the care comes alive’). The physical “hands-on” practice and reciprocity among the parents, CDE and HPS allowed for individualized teaching dependent on the parent’s responses as well.

Seeing a seizure/tremor and how to respond was described by many as giving them the confidence necessary that they could handle the situation if it occurred in real life. They especially reported liking the glucagon practice with HPS. The drawing up of the saline and

transferring it into the glucagon vial was described as helpful in preparation for those ‘what ifs’ situations by experiencing and then remembering back to the visual learning that occurred. One parent expressed “seeing what could happen and how to respond has calmed me down but prepared me to know what to do too.”

Discussion

To our knowledge, this study is the first RCT to use S-R theory to examine the use of HPS to instruct and prepare parents to manage their children’s diabetes management needs when they are newly diagnosed. We have used an innovative way to teach parents in a safe, action-oriented activity guided by the principles of S-R theory. When families are bombarded with the emotional shock of a chronic illness concurrently with the demands of functionally having to quickly learn diabetes management, education technology strategies that focus on easier assimilation of knowledge and skillset are warranted, but need to be tested. The principles of S-R theory naturally flow with the hands-on practice, reciprocity among the parents, educator and HPS. This type of experiential learning is also in a safe environment where practice makes perfect. To quote Aristotle: *"For the things we have to learn before we can do them, we learn by doing them"*.

HPS is expensive but most medical centers now have acquired this technology to train and reinforce skills for both nurses and physicians. Future work using S-R theory and HPS can also evaluate if the principles apply with group learning sessions. Perhaps not only being more efficient, the group learning process may enhance both functional knowledge assimilation and emotional responses through social support. In addition, it will be important to consider exploring cultural learning differences when using S-R theory and HPS to teach families their children’s special health care needs. It is essential for improving clinical outcomes that we find ways to better educate parents in functional diabetes management knowledge while addressing ways to support their emotional responses. S-R theory with HPS may be one of those strategies.

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Figure 1.
 Model of Information Processing in Self-Regulation Theory
 (Written permission to reproduce model received from Oncology Nursing Society, Oct. 2007)

Table 1

Content included in the 3 teaching vignette sessions for control and experimental groups.

Session	Time	Topic: Control group	Topic: Experimental group with simulation visual illustration
1	After diagnosis 60–90 minutes	Survival skills: what is diabetes, blood glucose monitoring, injections, recognizing & treating hypoglycemia, introduction to tremors & management Summary & review	<u>Functional Response</u> : Survival skills: what is diabetes, glucose checks, injections, recognizing & treating hypoglycemia, introduction to tremors (seeing one) and management Practicing technical skills <u>Emotional Response</u> : Summary, review, and simulation debriefing
2	1 month post diagnosis 60–90 minutes	Sick day management, hyperglycemia, nutritional food issues and activity aspects of day-to-day management; discuss and practice the 'what ifs' Summary & review	<u>Functional Response</u> : Sick day management, hyperglycemia, nutritional food issues and activity aspects of day-to-day management; discuss and practice with HPS the 'what ifs' <u>Emotional Response</u> : Summary, review, and simulation debriefing
3	3 months post 60–90 minutes	Day-to-day management issues including glucose number patterns; Putting it all together Summary & review	<u>Functional Response</u> : Day-to-day management issues including glucose number patterns; Putting it all together; Discuss and practice with HPS <u>Emotional Response</u> : Summary, review, and simulation debriefing