Parental Self-Efficacy and Online Support Among Parents of Children Diagnosed With Type 1 Diabetes Mellitus

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Type 1 diabetes mellitus is a significant health care concern among youth and is currently the most prevalent childhood chronic illness (Marvicsin, 2008). More than 15,000 children in the United States are newly diagnosed with type 1 diabetes mellitus every year (Centers for Disease Control and Prevention [CDC], 2007). Parents may be devastated when learning their child has type 1 diabetes, initially having feelings of shock, anxiety, fear, grief, and isolation (Amer, 2008; Streisand, Swift, Wickmark, Chen, & Holmes, 2005; Whittimore, Urban, Tamborlane, & Grey, 2003). Lowes and Lyne (2000) discussed the presence of chronic sorrow or grief related to the significant loss of health in a child. This sorrow stems from feelings of lost freedom, diminished support systems, and inability to protect a child. This sorrow differs from feelings of shock, anxiety, fear, grief, and isolation (Amer, 2008; Streisand, Swift, Wickmark, Chen, & Holmes, 2005; Whittimore, Urban, Tamborlane, & Grey, 2003). Lowes and Lyne (2000) discussed the presence of chronic sorrow or grief related to the significant loss of health in a child. This sorrow stems from feelings of lost freedom, diminished support systems, and inability to protect a child from danger (Lowes & Lyne, 2000). Acclimating to the regimented health care needs of a child newly diagnosed with diabetes may be an overwhelming challenge. Parents quickly realize the harsh realities of diabetes and the worry regarding a child’s future health are never-ending concerns when dealing with a lifelong illness potentially riddled with serious complications (Amer, 2008; Ginsberg et al., 2005).

While learning the intricacies of caring for a child with type 1 diabetes, it is important that family members are able to develop healthy coping strategies (Wennick & Hallstrom, 2007; Whittimore et al., 2003). Use of social support for families is an essential component to the development of increased adaptation (McDougal, 2002). Such social support systems help parents and children share experiences with others who may understand the disease-related feelings of frustration, guilt, and uncertainty (McDougal, 2002). To help meet social support needs related to diabetes management, the use of the Internet as a potential source of health promotion has become an increasingly popular support alternative in the realm of chronic health conditions (Bull, Gaglio, McKay, & Glasgow, 2005; Heisler, 2007). Research has also found that enhancing the perceived self-efficacy of diabetes management for a child is an important goal of diabetes care (Anderson, Funnell, Fitzgerald, & Marrero, 2000; Sousa, Zauszniewski, Musil, Price Lea, & Davis, 2005; Streisand et al., 2005). The purpose of this EBP project focused on the implementation of a Web-based social support platform (Eisenberg, 2002). The pilot EPB study investigated the impact of the Web-based social support platform on enhancement of parental self-efficacy in relation to type 1 diabetes management and coping abilities.

Background and Significance

Although studies have found that the use of social support and the development of self-efficacy is essen-
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Several studies that focused on the use of social support in relation to type 1 diabetes management of children with type 1 diabetes were excluded (for example, those unassociated with the clinical problem, lack of self-efficacy focus, no use of social support). Studies pertaining to families and children with type 1 diabetes were considered most appropriate. Due to the scarcity of studies focused only on children, research involving adults with diabetes and other chronic illness were included to provide richer information on the underlying concepts of self-efficacy and social support. To present a thorough review of all perspectives, studies that found little or no statistical significance in the use of social support in relation to the development of self-efficacy were also considered to learn from the suggestions offered by these authors and to avoid pitfalls. Despite lack of statistical significance, these studies still identified social support as important to emotional well-being.

Measurement scales were also closely reviewed. Such scales varied widely but tended to focus on a) self-efficacy (Anderson et al., 2000; Johnston-Brooks, Lewis, & Garg, 2002; Marvicsin, 2008; Ott, Greening, Palardy, Holderby, & DeBell, 2000; Sousa et al., 2005; Streisand et al., 2005; Williams & Bond, 2002), b) confidence in diabetes self-care (Sousa et al., 2005; Van der Ven, Weiniger, Pouwer, Ader, & Snoek, 2003), c) self-esteem (Johnston-Brooks et al., 2002), d) self-care knowledge (Williams & Bond, 2002), e) social support (Williams & Bond, 2002), f) depression (Whittimore et al., 2008), g) satisfaction with life (Cheung, Cureton, & Canham, 2006), h) family functioning (Chisholm et al., 2007; Ott et al., 2000; Streisand et al., 2005; Whittimore et al., 2008), and i) adjustment profiles in either parents or children (Amer, 2008; Chisholm et al., 2007). Although diverse, most instruments were found to be internally consistent and were used multiple times in previous research.

The literature corroborated the use of social support for families and children in increasing self-efficacy, helping to manage stress, and/or diminishing feelings of isolation among family members (Cheung et al., 2006; Chisholm et al., 2007; Ginsburg et al., 2005; Streisand et al., 2005). The importance of self-efficacy was reiterated in multiple studies and suggested a positive impact on self-confidence and the perceived ability of patients and families to take on the task of diabetes management (Chisholm et al., 2007; Johnston-Brooks et al., 2002; Marvicsin, 2008; Sousa et al., 2005; Williams & Bond, 2002; Van Der Ven et al., 2003). Ott and colleagues (2000) reported self-efficacy “as a significant mediator for the relation between personal responsibility and adherence” (p. 56). Social support can be a contributing factor to supporting positive family interactions, developing optimism, improving confidence, promoting well-being, and preventing long-term complications related to type 1 diabetes (Ott et al., 2000).

The literature also supported the use of the Internet as a viable option for open communication with others who share in similar life experiences managing chronic illness (Rasmussen et al., 2007; Ravert et al., 2004). A systematic review by Murray, Burns, See Tai, Lai, and Nazareth (2009) included a meta-analysis to assess the effects of interactive health communication applications (IHCA) for people with chronic illnesses. IHCA are Internet-
based information packages for patients that combine health information as well as at least one type of social, decision, or behavioral support. The analysis found that in regard to the use of an Internet platform for social support, the ability to share experiences with people with the same illness was an important intervention (Murray et al., 2009). The availability and convenience of a 24-hour online discussion group was considered a positive aspect of electronic social support systems. Murray and colleagues (2009) described these findings as being congruent with other qualitative studies regarding Internet use. Recommendations were made for continued investment in IHCAs with social support components and ongoing evaluation of these interventions.

**Theoretical Underpinnings**

To guide the development of the type 1 diabetes Web-based social support platform, the middle-range theory of self-efficacy was used. Developed in the late 1970s and “derived from the social cognitive theory” (Resnick, 2004, p. 99), Bandura (1982) posited that self-efficacy plays a very substantial role in helping to determine the choices people make and the amount of effort they will expend when facing a challenge. Self-efficacy is addressed widely in the literature related to the management of chronic illness and is thought to be essential to effective disease management in that it provides a foundation for personal motivation, increased well-being, and a sense of personal accomplishment (Resnick, 2004). The amount of self-efficacy an individual possesses also has an impact on perseverance, self-confidence, and the amount of anxiety that a person brings into the situation (Resnick, 2004).

Self-efficacy theory provided a framework for understanding how individuals cope with chronic illness and how such coping has an impact on outcome expectations. Diabetes, cancer, chronic obstructive pulmonary disease, and arthritis are ex-
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Examples of diseases where self-efficacy theory has been used to guide the development of programs aimed at increasing health promotion and outcome expectations in disease management (Rubin, 2001). Studies have also specifically focused on self-management and self-care issues related to diabetes (Resnick, 2004). According to Bandura (1982), self-efficacy beliefs come from four main informational sources: mastery experiences, vicarious experiences, verbal persuasion, and affective states. These four informational sources were used to guide the development of the online social support platform used in this EBP project (see Figure 1).

Evidence-Based Practice Model

The use of an EBP model was necessary to facilitate the successful implementation of this intervention into nursing practice. To guide this project, Roger’s Diffusion of Innovation Theory (Dobbins, Ciliska, Estabrooks, & Hayward, 2005), an EBP framework, was used. The framework is based on five stages: 1) knowledge, 2) persuasion, 3) decision, 4) implementation, and 5) confirmation (Dobbins et al., 2005).

Careful analysis, planning, decision-making, and facilitation were essential considerations in the change process. Use of an EBP framework greatly assisted in guiding the process of this nursing practice change. Through literature review, analysis of the evidence, and assessment of utility, a recommendation for implementation of a practice change was apparent. The proposed online social support platform met an identified gap in the social needs of families with a child with type 1 diabetes.

Current practice within the regional clinic that serves children with type 1 diabetes lacked formal social support for parents. Nurses, physicians, and patient representatives in the pediatric community indicated that parents were requesting the development of a social support group. Stakeholders important to implementing a successful project were identified (such as nurses, nurse practitioners, pediatric endocrinologists, patient educators, parent advocates, and parents of children diagnosed with type 1 diabetes) and provided valuable feedback during project development. Institutional Review Board (IRB) approval for this project was obtained through the first author’s IRB.

Methods

Design

A single group pre-test/post-test descriptive design was used to compare self-reported parental self-efficacy scores pre- and post-Web site implementation. Although the use of true experimental design, randomization, and manipulation would greatly strengthen generalizability of the findings (Burns & Grove, 2009), such a research design is not conducive to EBP implementation wherein the goal is to translate existing evidence from the literature into the reality of an ever-changing practice setting, rather than imposing controls on the natural health care environment.

Measurement Methods/Tools

For the purposes of this project, the pre- and post-levels of self-reported parental self-efficacy in diabetes management were the primary outcome measurements. When considering the measurement of self-efficacy, one must also consider that self-efficacy is a situation-dependent and highly contextual phenomenon (Resnick, 2004). In this regard, Resnick (2004) stated that “no single standardized measure of self-efficacy will be appropriate for all studies” (p. 112). Therefore, researchers must often individualize an existing self-efficacy measurement based on the specific situation. Two instruments for measurements of parental self-efficacy were thoroughly reviewed and modified for purposes of this project. The Diabetes Empowerment Scale (DES) has been found to be adaptable and reliable in measuring self-efficacy in various studies, and was easily revised for application to family self-efficacy in type 1 diabetes management. Public access and use of the DES tool was granted through the Michigan Diabetes Research and Training Center (MDRTC) (2012). Additionally, the Self-Efficacy for Diabetes Scale (SED), originally developed for use with adolescents, was also used and adapted in previous studies for the use with parents in measuring “perceived ability to manage their child’s diabetes” (Streisand et al., 2005, p. 515). Approval for the use of the revised SED tool for the measurement of parental self-efficacy was secured (R. Streisand, personal communication, May 12, 2009). Both the DES and SED scales were determined to be flexible and reliable tools for outcome measurement.

Non-research evidence is also essential in determining usefulness of EBP projects (Goode, 2000). Secondary outcome measures included summative data collected in a post-test survey questionnaire. Written feedback from parents regarding usefulness of the Web site, and suggestions for improvement was invited.

The family-focused online social support platform was made accessible through an invitation process outlined on an informational brochure. To recruit parents, brochures regarding the online social support platform were made available at a regional clinic (where children with diabetes are seen routinely), a community YMCA, and county public health department. Parents wishing to access the online social support platform and/or participate were provided information in the brochure on how to contact the investigator via phone or e-mail. A packet, including cover letter, Web site utilization waiver, inclusion/exclusion criteria, implied consent, pretests, and additional survey data, were sent to interested parents.

To participate in the study, parents were required to be over 18 years of age, have a child diagnosed with type 1 diabetes, and have Internet access. The signed waiver released the researcher from all liability for site use, and parents agreed to not share medical advice or disclose private information to others outside the group. The site was available to parents regardless of participation in the corresponding study. Once completed surveys and waivers were returned, the researcher sent the parents an electronic link (via e-mail) to join the online social support platform, along with instructions on how to create their username and password. Parents were then able to log onto the site using a self-created username and password of their choice (their real name or a pseudonym).

Six weeks after initial invitation to join the site, post-test surveys, Web site utility/feedback questions, and pre-addressed/postage-paid envelope were sent to parents. The six-week time period between data collection was established to allow parents adequate time for platform utilization, while also minimizing the risk of attrition. Additionally, in a previous test-retest reliability study of the DES, suggestion of differing domains of self-efficacy were found at the beginning and end of a six-week period (Anderson et al., 2000).

Results

A single sample paired t-test was used to analyze pre- and post-imple-
mentation data comparison. Of 14 parent participants, a total of 9 parents completed the pre- and post-test surveys. Length of time since child’s diagnosis ranged from 3 months to 18 years, with 2 participants having a child diagnosed less than one year. Due to small sample size of this pilot study, it was not possible to provide meaningful analysis on a question-by-question basis or to provide a comparison of data between groups (such as seasoned versus novice parents). A future study with a larger sample is recommended so such comparisons can be presented and generalizations explored.

The overall aggregate scores of the SED and DES pre-test/post-test data were compared to determine statistical significance for both survey results. While the DES pre- and post-implementation scores revealed no significant change in scores ($p = 0.06$), a statistically significant increase ($p < 0.05$) occurred between the pre- and post-implementation scores on the SED survey (Table 1). Secondary outcome data supported the positive relationship of social support and self-efficacy in raising a child with type 1 diabetes (see Table 2). Additional suggestions for improvement and indication for continuing the online social support platform for other parents was indicated by participants’ narrative responses.

**Discussion**

Although the published research gathered for this project sufficiently confirmed the use of social support in relation to the development of self-efficacy, no known study to date specifically used a Web-based social support group for families dealing with childhood type 1 diabetes. However, as several studies focused on the use of Internet support for teens or adults with type 1 diabetes, it was hypothesized that parents of children with type 1 diabetes would benefit similarly from such an intervention.

Additional characteristics of the EBP innovation were considered in the implementation process. Organizational factors, environmental factors, and individuals played an essential role in whether a Web-based social support platform would be readily adopted by parents (Dobbins et al., 2005). No formal support group existed for families with children diagnosed type 1 diabetes in this community; therefore, the need for a social support group was promoted by key stakeholders (such as nurses, nurse practitioners, pediatric endocrinologists, patient educators, parent advocates, and parents of children diagnosed with type 1 diabetes).

Evidence further substantiated this initiative as a means of filling the existing gap in patient care related to the need for a social support group among these families. Patient encounters validated a desire for enhanced social networking between families for this priority population. Thus, the timing of this EBP project was ideal for successful innovation adoption. The use of online social support was feasible in that it was found to be cost-effective, and once developed, involved little upkeep. Initial cost of the online support platform included printing of informational brochures ($200) and technological development/support ($1,200). The site continues to serve as a resource for parents. As of June 2012 (24 months since the site went live), 30 parent members are using the platform. New members are added on a regular basis by a volunteer online support group moderator.

Benefits noted in this EBP project included participant confirmation that the online support group was a safe

**Table 1. Data Comparison of DES and SED Scales**

<table>
<thead>
<tr>
<th>Survey</th>
<th>Pre-Implementation Mean (SD)</th>
<th>Post-Implementation Mean (SD)</th>
<th>Paired t-Test ($\alpha = 0.05$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Empowerment Scale-Short Form-Parent Modified ($n = 9$)</td>
<td>4.25 (0.78)</td>
<td>4.41 (0.57)</td>
<td>1.65 ($p = 0.0689$)</td>
</tr>
<tr>
<td>Self-Efficacy for Diabetes Scale-Parent Modified ($n = 9$)</td>
<td>4.29 (0.88)</td>
<td>4.53 (0.68)</td>
<td>2.55 ($p = 0.0171^*$)</td>
</tr>
</tbody>
</table>

*Significant.

**Table 2. Web Site Utilization – Parent Feedback**

<table>
<thead>
<tr>
<th>Parental Feedback on Posttest Questionnaire ($N = 9$)</th>
</tr>
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<tbody>
<tr>
<td><strong>What was most useful on the Web site?</strong></td>
</tr>
<tr>
<td>· Discussions ($n = 7$), research information ($n = 3$)</td>
</tr>
<tr>
<td>· Diabetic events around the area/JDRF walk information</td>
</tr>
<tr>
<td>· Other parents with more experience</td>
</tr>
<tr>
<td>· Recognizing that each family has similar challenges ($n = 2$)</td>
</tr>
<tr>
<td>· Local family networking</td>
</tr>
<tr>
<td>· Hearing other members stories ($n = 3$)</td>
</tr>
<tr>
<td>· Comparing notes with other parents</td>
</tr>
<tr>
<td>· Getting ideas for school/daycare</td>
</tr>
<tr>
<td>· Finding out about diabetes camp experiences ($n = 4$)</td>
</tr>
<tr>
<td>· Recipes and healthy snack ideas ($n = 5$)</td>
</tr>
<tr>
<td>· “Inspirational to see how well older kids are doing.”</td>
</tr>
<tr>
<td>· “Knowing I’m not alone.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suggestions for improvement?</th>
<th>Would you recommend this Web site to other parents?</th>
</tr>
</thead>
<tbody>
<tr>
<td>· “Create areas for age specific groups (such as toddler/teens).”</td>
<td>· Yes ($n = 8$)</td>
</tr>
<tr>
<td>· “Keep getting more participants.”</td>
<td>· “Yes, especially for newly diagnosed.”</td>
</tr>
</tbody>
</table>
and secure environment for the sharing of life experiences related to the care of a child with type 1 diabetes. In relation to diabetes management and coping, improvement in parental self-efficacy score (SED) after participation in the online support group was documented. Certain limitations existed in the recruitment of participants. Follow-up time frame for the pilot study was short, resulting in a small sample size, and thereby, limiting analysis of results. Additionally, access to the Internet and e-mail required for parents to use an online support group may have discouraged participation by some who would otherwise have benefited from social support.

**Implications for Nursing**

The use of social support interventions has been widely researched and associated with the Theory of Self-Efficacy. Self-efficacy skills are identified as essential predictors of effective coping and overall management of chronic illnesses. Families learning to adjust to the everyday challenges of managing a child’s diabetic regimen can benefit from networking with other parents and children in similar circumstances. Roger’s Diffusion of Innovations Theory and the Theory of Self-Efficacy frameworks were easily adaptable and guided the strategic development and implementation of the online social support platform. Parents’ self-reported self-efficacy scores revealed a statistically significant increase in the pre- and post-implementation data on the SED tool ($p < 0.015$).

The results of this EBP project suggest that the use of a Web-based social support platform is a cost-effective and innovative means of providing a resource for networking and information sharing among families facing similar challenges in raising a child with type 1 diabetes. Research based on the use of Internet support group platforms is continually evolving, and the inherent need for further translational research on this topic is recommended (Murray et al., 2009; Rasmussen et al., 2007; Ravert et al., 2004). Nurses can champion innovations such as Web-based social support platforms within health care and community settings, promoting continual adaptation and eventual progression of normalcy in living life with diabetes or other chronic illnesses.

**References**


