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Examining Preferences for Website Support to Parents of Adolescents With Diabetes

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Diabetes can be stressful as parents seek optimal outcomes for their adolescent with type 1 diabetes. This study examined parents' interest and perspectives related to online diabetes resources. Based on a qualitative description approach, 14 qualitative group interviews were conducted with (i) parents of adolescents with diabetes (n = 29), and (ii) pediatric health care providers (n = 31). Participants were recruited, through a purposive sampling approach, at pediatric centers in three Canadian cities. Qualitative data were subjected to thematic analysis comprising data coding, categorization, and ultimate theme generation. Participants described parental care for adolescents with diabetes as complex and reflective of difficult and nuanced tasks. They recommended the development of a comprehensive parent-based information and support website, and identified crucial elements of the website. Overarching themes comprised the following: complex parenting

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processes in diabetes care, parents' need for information and support, challenges and benefits of online support, key elements of an online resource, and caution regarding online resources. Based on these findings, website information and support emerged as a viable and desired resource for augmenting pediatric care within clinical settings. Caution was also offered in addressing potential challenges inherent in online support. Findings offer guidance for online support to parents.

KEYWORDS Type 1 diabetes, online resources, parents, pediatrics, information and support

INTRODUCTION

Type 1 diabetes is a complex condition that presents health monitoring and care challenges that can be particularly difficult during adolescence. For parents of youth with diabetes, a unique form of parenting appears to emerge whereby typical elements of parental care may not readily fit (Paterson & Brewer, 2009; Whittemore, Jaser, Chao, Jang, & Grey, 2012). In this article, we examine online support for parents of adolescents with type 1 diabetes. Study findings ultimately were used to guide the development and evaluation of an information and support website for parents of adolescents with diabetes. This article builds on an earlier description of this phase of the project (Holtslander, Kornder, Letourneau, Turner, & Paterson, 2012) by illuminating core elements as well as benefits and challenges of online support, based on parent and health care provider perspectives.

BACKGROUND

Parents of adolescents with diabetes face many condition-related challenges such as the management of meals, exercise, insulin adjustment, and their child's development of independence and self-identity. At a vulnerable developmental stage, adolescents are at risk for poor illness management and adjustment difficulties. Teens with diabetes reportedly experience lower life satisfaction and poorer perceptions of their health than their peers (Faulkner, 2003). They worry about and/or express upset related to their diabetes, and report that the management of their diabetes is difficult (Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998). Diabetes-related family conflict has been shown to decrease youth self-reported quality of life (Laffel et al., 2003).

In caring for their children, parents may struggle, particularly if the youth's diabetes management is poor. One study found that parents of adolescents reported significantly lower life satisfaction than parents of

school-aged children, and also found that metabolic control affected parental life satisfaction (Faulkner and Clark, 1998). In a systematic review of the literature, Whittlemore et al. (2012) found about a third of parents of children with type 1 diabetes reported distress at the time of diagnosis, with nearly a fifth of parents reporting distress at 1 to 4 years after diagnosis. Such distress also impacts their children, with Whittlemore et al. (2012) reporting that parental distress was associated with higher self-reported stress and depression in children, poorer child behavior, worse diabetes management, and lower self-reported quality of life in children. Streisand, Swift, Wickmark, Chen, and Holmes (2005) found that parents' stress was largely related to parental beliefs about their own ability in caring for diabetes, level of responsibility, and fear of hyperglycemia.

A study by Haugstvedt, Wentzel-Larsen, Rokne, and Graue (2011) contrasted mothers' and fathers' stress levels and found that both groups reported long-term health concerns to be the most stressful, with mothers experiencing significantly more stress related to medical treatment and emotional distress. Additionally, Streisand et al. (2005) found that certain demographic features were associated with higher levels of stress, including being a non-Caucasian parent of a younger child, having lower socioeconomic status, being a single parent, and having a child on conventional insulin injection therapy. Additionally, a study by Haugstvedt, Wentzel-Larsen, Graue, Søvik, & Rokne (2010) found that fears and worries of parents may negatively affect glycemic control, with higher levels of child responsibility over care resulting in increased parental fear of hyperglycemia and higher parental stress.

For youth as well as their parents and families, the challenges that are associated with diabetes are complex and multifaceted. For example, changes in blood-glucose levels in adolescents with diabetes can result in greater shifts in mood relative to non-diabetic peers. This may heighten intra-family conflict and ultimately increased difficulties managing diabetes (Kyngas & Rissanen, 2001). Stigma related to their illness may also arise. Schur and colleagues reported that, "(p)articipants expressed a pervasive fear of stigma, a fear of being discovered as different and of being judged by others as less acceptable than the norm (either on account of diabetes or the associations others might make with diabetes), despite little or no experience of enacted stigma" (Schur, Gamsu, & Barley, 1999, p. 231). Depression and low socioeconomic status were associated with poorer glycemic control in young people (Hassan, Loar, Anderson, & Heptulla, 2006).

With regards to metabolic control, one study of young adults recently transferred from pediatric to adult care found that the young people estimated their metabolic control to be higher than it actually was (Busse et al., 2007). Additionally, body image and weight gain were cited as concerns, especially among adolescent females, and such concerns may lead to a lack of adherence with diabetes care management strategies (Jack,

2003). Jack (2003) also outlined a number of other possible factors that may lead to issues in metabolic control: stress, depression, intentional health-compromising behaviors (i.e., substance use), eating disorders, and peer pressure. Furthermore, the transition to more self-responsibility in adolescence can impact metabolic control. Cameron (2006) also identified puberty as a period in which issues can arise due to biological changes that may cause issues with metabolic control, such as insulin resistance.

Sexuality and reproductive health was noted to be of further concern, for instance, as it relates to hypoglycaemia (Cameron, 2006). Frey, Ellis, Naar-King, and Greger (2004) studied 31 mother–child dyads and found that 16% of the sample reported not taking insulin every day, a further 16% did not take the right amount of insulin every day, and 26% were not always careful when measuring and administering insulin. Nearly 65% of the mothers in this study reported supervising insulin administration, and 55% of adolescents reported their mothers supervising their insulin administration.

As adolescents mature they take on more responsibility in the management of their diabetes, and when done effectively, they develop a sense of ownership in their self-management (Wysocki et al., 1996). For parents, this transition may be stressful as they relinquish control and decision-making roles in their adolescent's life (Paterson & Brewer, 2009). Parental anxiety may result, which can in turn establish barriers to a young person's transition to further independence (Fleming, Carter, & Gillibrand, 2002), and parents may be viewed as overprotective (Cadario et al., 2009). Feelings of grief are also associated with the transition to adulthood, with Bowes and colleagues (2009) noting that the, "(t)ransition from pediatric to adult services was a particularly difficult time for parents, whose children were now young adults. They experienced a sense of loss when their child moved from the familiarity of the pediatric team, and felt sidelined concerning their child's diabetes care" (Bowes, Lowes, Warner, & Gregory, 2009, p. 998).

Given these multiple pressures and difficulties associated with diabetes, parents are reported to experience a periodic sense of aloneness for which informational and social support are desired (Paterson & Brewer, 2009). As an example from adult-based care, a systematic review identified several forms of social support used with people who have diabetes including: in-person peer group support with a physician, telephone group support, organized online group support, spousal support by participating in diabetes education, peer support after diabetes education, and family and friend support in diabetes education (van Dam et al., 2005). The review further reported that each of these forms of support was able to positively influence self-care and diabetes management.

However, there were drawbacks associated with these various methods. Spousal participation in weight loss education groups negatively affected outcomes for obese men with type 2 diabetes, more social support than

desired resulted in negative health impacts, and more instrumental support than necessary led to feelings of dependency and loss of control (van Dam et al., 2005). To this end, it appears that if social and informational support is effectively developed, an online resource may be a helpful tool as parents often use the internet to seek information about their child's condition, and find it useful as a supplement to clinic visits (Tuffrey & Finlay, 2002).

ROLE OF THE INTERNET AS A SOURCE OF SUPPORT

The Internet increasingly has become central in daily life for the majority of Canadians. Statistics Canada (2011) reports that 79% of Canadian households have Internet access, with over half of these connected households having multiple devices with which to access the Internet. More than half of Canadians have used the Internet to search for health information (Middleton & Leith, 2007), and this number will likely continue to increase. As a result, online modalities may provide parents with access to information and support resources, and have the potential to do so in a timely and an accessible and effective way. This is particularly important for those living in rural or remote regions who may be unable to easily access in-person social support or information (Scharer, 2005). Further benefits of Internet access include the ability to connect with more people than would be possible in an in-person forum, participant convenience, unlimited geographic reach, accessibility to persons who are socially isolated, potential for anonymity, interventional flexibility (e.g., synchronous vs. asynchronous), ability to manage large amounts of information, and access to broadband and video transmission. Several studies demonstrate the effectiveness of online resources in terms of improved health behaviors and increased social support (Glasgow, McKay, Feil, & Barrera, 2003; Gottlieb, 2000; Nicholas, 2003; Nicholas et al., 2009).

Although interactive technology may be helpful to provide support and information, many websites do not integrate peer support interactivity or include real-time feedback to improve access to care (Bull, Gaglio, McKay, & Glasgow, 2005). Websites that offer targeted support to parents are rare. In addition, service providers tend to design online health interventions (Burrows, Nettleton, Pleace, Loader, & Muncer, 2000; Paterson & Hopwood, 2010); hence, the opinions of users are often not incorporated in website design process, potentially risking failure to reflect user needs (Nikolova-Houston, 2005). As a result of these gaps, this study elicited parents' and health care providers' perceptions of website resource preferences and considerations in the ultimate aim of developing an online parent support resource for parents of adolescents with type 1 diabetes. This article addresses parents' needs for information and support as well as potential benefits, cautions and key elements of online support for parents.

METHODS

This study comprised an initial component of a larger multiphase study that entailed the development and mixed-method evaluation of an interactive website for parents of adolescents with type 1 diabetes. Results of this broader study are forthcoming. This initial data gathering component of the project was specifically guided by *qualitative description*, a relatively recent addition to the qualitative research methodology literature (Padgett, 2008). Qualitative description is an approach that is ideal for effectively identifying observations and constructs emerging from narrative-based data. It examines the “surface of words and events” rather than offering in-depth analysis from a specifically defined lens or theoretical approach to data interpretation (Sandelowski, 2000). This approach can be applied when expected findings are relatively straightforward; hence, not laden with theoretical underpinnings or the need for extensive interpretive contextual analysis. Unlike other approaches such as grounded theory that is focused at the level of processes and relationships of variables or phenomenology that elicits deep meanings or essential qualities of phenomena (Creswell, 1998), qualitative description tends to be broad-based in its overview and description of perspectives, and thus is not deeply entrenched in a particular theoretical genre.

Consistent with qualitative description, purposive sampling for variation was sought. This included recruitment of both parents (mothers and fathers) and health care providers as well as diversity in home region, family constellation, and age of represented adolescent with diabetes. Among health care provider participants, inter-disciplinarity was sought across relevant professions working with diabetic adolescents and their families. To augment parent perceptions, health care providers who were immersed in serving multiple families affected by adolescent-based diabetes also participated in group interviews. It was hoped that this would additionally yield a broader expanse of participants who work with a wide range of parents whose adolescent has diabetes. This approach reflected an attempt to achieve sampling comprehensiveness and efficiency in rapidly representing a wide range of families, and thereby a breadth of parent and family demographic profiles. A total of fourteen group interviews were held in the Canadian cities of Fredericton, New Brunswick; Edmonton, Alberta; and Saskatoon, Saskatchewan. These cities reflect distinct demographic and regional profiles including diverse health care systems and resources for parents of adolescents with diabetes.

Of the 14 group interviews, 8 groups included only parents. These participants had at least one adolescent with Type 1 diabetes. A total of 29 parents (21 mothers and 8 fathers, including 5 couples) were interviewed. Participants' children, ranging in age from 13 to 21 years, had been diagnosed with diabetes one to 20 years prior to the study. Two families had

two adolescents with diabetes, and one parent herself also had diabetes. Six of the 14 group interviews consisted of health care providers ($n = 31$; 24 females, 7 males). These participants comprised 9 physicians, 14 nurses, 2 social workers, 2 psychologists, and 4 nurse or dietician diabetes educators. All interviewed health care professionals provided adolescent diabetes care and education.

Group interviews comprised an initial welcome and joining “ice breakers” with participants. The aims of the study were reviewed, and participants had opportunity to raise any questions or comments about the anticipated research process. They were invited to discuss online support needs and preferences relative to adolescents with diabetes. Interviews comprised a series of salient open-ended questions that were used consistently in both individual and group interviews, and across regional data collection sites. Questions elicited perceptions of parent experience, education and support needs, as well as specific preferences, if any, related to online-based resources. The interview schedule, with open-ended questions and probes, was initially developed following literature review and pilot feedback from clinicians and researchers in the field. The interviews lasted 60 to 90 minutes, were facilitated by experienced Bachelor and Master-level trained qualitative research interviewers with extensive training and supervision by PhD-level supervisors (research team members) who each brought an extensive qualitative interviewing background. Interviews occurred in the diabetes clinic or another convenient location for participants. If distance from the interview site was prohibitive, participants were interviewed by telephone; however, the process and interview guide were consistent across modalities. Interviews were digitally recorded and transcribed verbatim.

Analysis of the transcribed interviews consisted of code identification, category saturation, and theme generation, assisted by NVivo qualitative data management software (QSR International, 2007). This analysis, conducted by a trained research assistant under the close supervision of the core research team who brought extensive data analysis experience, was methodologically guided by a constant comparative approach that comprised: (i) line-by-line review for codes, (ii) categorization or grouping of codes both within and across transcripts, and (iii) based on a process of continual review and verification with the data, generation of themes. Telephone and face-to-face data were analysed independently and then grouped for subsequent analysis. Differences in telephone and face-to-face data were not noted; hence, the pools of data were integrated. Similarly, individual and group data were analysed separately and then grouped, with no content difference noted according to individual versus group modality of data collection.

Trustworthiness, as a means of verifying qualitative rigor in mitigating and articulating potential researcher bias (Lincoln & Guba, 1985), included several established methods. These methods included *negative case analysis* in which disconfirming instances of emerging codes, categories and themes

were sought in the data, *referential adequacy*, which was demonstrated by the inclusion of verbatim quotes from transcripts, and *thick description* as indicated by sample and contextual description. *Prolonged engagement* was achieved through multiple, lengthy interviews with a range of stakeholders, and *peer debriefing* was facilitated through extensive review of findings among team members involved in diabetes support and eHealth. *Authenticity* and *fairness*, emerging quality criteria in qualitative research (Erlandson, Harris, Skipper, & Allen, 1993), were reflected in tangible benefits of the research for participants, as demonstrated by the subsequent development of a website designed according to their guidance and preference (which was accessible to participants).

Confidentiality of data was upheld, and ethics approval from host institutions was received prior to study commencement. All participants provided informed and written consent for study participation.

RESULTS

Parents and health care providers supplied commentary that addressed the following themes: complex parenting in adolescent diabetes, parents' need for information and support, opportunities offered by online support, and cautions regarding an online support resource. These themes, along with associated sub-themes, were largely consistent across parent and health care provider participant groups. Each theme is discussed below.

Complex Parenting in Adolescent Diabetes

Parents noted that adolescents, although increasingly involved in their care, varied in their level of diabetes management and decision-making maturity. Less responsible levels of self-care were a source of anxiety for many parents and, at times, precipitated conflict with their adolescent. One mother, for instance, described taking control over her daughter's care because of this adolescent's non-compliance. Speaking about this caregiving role, this mother stated in frustration and veiled humor, "When she gets mad at me, I remind her that I am her pancreas."

In terms of caregiving complexities, participants described type 1 diabetes as a multilayered disease, given its pervasive impact on physiology, complicated demands regarding food intake, and complex interplay of self-monitoring, functioning and social relationships. Parents conveyed adolescence as, "the hardest time in life to control blood sugars," with one mother specifying that, "blood sugars and driving scare me."

Participants described few existing opportunities for parents to talk with fellow parents of adolescents with diabetes, and little opportunity for social support. They generally suggested that clinic staff seek to be helpful, but

often lack understanding about the depth of concern and anxiety that parents experience. Of this unique parental experience, a parent participant stated, “health care providers are good, but they don’t live with it (diabetes). I don’t go to bed the same way as [health care professionals] go to bed. I know I will not sleep at night.”

Parents’ Need for Information and Support

Participants commonly described parents’ need for support in fostering increased adolescent responsibility for diabetes self-care. Managing diabetes was described to be complex and confusing, with parents commonly identifying the need for more information and support than they were receiving. To that end, participants generally felt that online parent-to-parent support offered, “a different and stronger kind of understanding with another parent,” based on shared experiences and concerns for the well-being of their respective children. Participants identified the need for support in educating school personnel, as teachers and administrators were reported to often not recognize the severity of diabetes. Parents consistently stated that schools could, “make things easier or tougher”; hence information to, and advocacy with, schools were seen as necessary to, “keep [the diabetic adolescent] safe” at school.

Overall, health care providers and parents were largely consistent in identifying key concerns, with health care providers concurring with parents about the need for parental support due to the complex and nuanced care that diabetes requires. Health care providers particularly thought that it would be beneficial for parents to have the opportunity to normalize their experiences by connecting and ultimately sharing with others who are dealing with similar concerns. This was deemed to be especially true for parents of newly diagnosed adolescents who were thought of as more anxious about managing their child’s diabetes. As an example, a health care provider stated, “The newly diagnosed [parents] are so anxious that to talk to other people who survived that initial diagnosis [would help to] connect . . . them because we’ve got to keep them moving on.”

Participants felt that online support would be particularly helpful for parents in rural and/or remote communities and for those from other cultures seeking information and support. Having an opportunity to read and re-read about health information and resources was viewed as instructive and reinforcing. A parent stated:

Because there is so much information to learn and to go over—treating highs, treating lows, . . . testing. All that stuff . . . should be up there [online] as at a glance you can click and check off and make sure you are doing all of these things. . . . You are reassured that you are doing everything.

Overall, parents described multiple advantages of online information and support. In particular, they valued the accessibility within their home and the availability of key information.

Opportunities Offered by Online Support

Generally favoring online resources for augmenting clinical services, participants described potential benefits associated with this online support. Gaps and needs that reportedly could be addressed were described as: insufficient opportunity for parent-to-parent support; a lack of focused, accessible, credible, and timely information about type 1 diabetes or local resources; the need for reassurance to parents in terms of their management of care and support to their teen with type 1 diabetes; and insufficient information and support targeted to siblings and other family members.

Participants highlighted the importance of an online resource that gathers and distributes relevant and current information, offers support, and generates connection among families experiencing type 1 diabetes. In particular, parents desired credible advice about how to deal with their adolescent's diabetes and other parenting challenges. Parents stated that the resource should be easy to navigate, comprise simple language, and be updated frequently. Health care providers had similar responses as did parents, but focused more on the need for up-to-date information and parents' need for ongoing education. One health care professional stated that online applications uniquely afford parents the opportunity, "to go back and quietly review diabetes-related information in their home." Parents also acknowledged that, "we forget, and need reminders about [topics such as] carbs and insulin dosages." Recommendations included information sessions or modules for parents and families.

Both parents and health care professionals noted the importance of professional involvement in an online resource. Parents recommended an expert moderator and an "ask an expert" feature. They requested relevant community stakeholders to answer specific questions (e.g., police officers, paramedics, or teachers). Parents wanted information on: nutrition, insulin dosing, dealing with illness, emergency management, new treatments and products, research, and links to other sites. It was important to parents that the site was endorsed by their health care providers, which thereby rendered it as "credible." One parent stated, as an example, "I always try and go to good sites, I don't go to . . . random stupid sites. I have to get reputable sites."

Participants (both parents and health care providers) identified a wide range of required elements in an online support network. They desired support in dealing with teen-specific issues such as managing diabetes at school, sexuality, birth control, and alcohol use. They recommended stories from families, and a listing of local resources. Parents sought networks of discussion related to grappling with behavioral challenges of their

adolescent. As an example, a parent desired peer support from other parents who were, “dealing with a hormonal teenager who does not want to eat.” Health care professionals recognized the need and desire of parents who are, “so anxious to talk with other parents who have survived the initial diagnosis.” They identified a priority for parents to, “see that all [parents] are fighting the same battle.” Health care providers suggested that parents with similar concerns could be connected within virtual small groups.

Parents suggested a variety of interactive features including videos addressing educational topics (e.g., glucagon injection), frequently asked questions, parent profiles (e.g., a “Facebook” format), live chat, a question feature that could be addressed to experts or other parents, surveys, checklists about diabetes, and a search engine. The opportunity for an *interactive* website was strongly endorsed by participants. For example, the inclusion of checklists was suggested so that parents could gauge where their adolescent is at, relative to expected developmental and transitional milestones. Parenting resources were also recommended, as was interactive learning via quizzes, checklists, video clips and webcasts.

Cautions Regarding an Online Support Resource

When asked what should be avoided in an online resource, participants identified concerns about proprietary advertising and sometimes excessive information. They did not want a site where primarily negative stories or vignettes were conveyed or where clinical program complaints were listed. Existing sites reportedly contain information from other countries, rendering these sites largely irrelevant and inaccurate in the local context (e.g., different dietary measuring systems/metrics, regionally distinct resources). They suggested that it is important to have content that is specific to one’s region including the health care system where the target group is located. As a Canadian, one parent stated,

My problem is with the American sites. For Canadian provinces there aren’t very many . . . ; having that Canadian content is important. They have people from all over the world on that site and they talk about things that we can’t even get in Canada. . . . I prefer having a mostly Canadian site for that reason.

Participants raised concerns about the safety and accuracy of an online resource. For example, they suggested that information from other parents should be labeled as opinion only. Parents were also concerned about who would access the site and how posts would be regulated and monitored. They suggested that a moderator could remove information that may be unreliable (e.g., erroneous natural “cures” for diabetes). Health care providers suggested the use of passwords and screening information.

Additionally, health care providers felt that live support would impose time demands that may be overly onerous on professionals' time. Consequently, they suggested using asynchronous support along with a listing of answers to common questions.

DISCUSSION

Parents of adolescents with diabetes face substantial challenges for which information and support are needed. Parents and health care providers generally express desire for an online support resource, which may reflect the current lack of accessible sources of information and support within existing systems of care (Holtslander et al., 2012). In addition, parents often lack immediate access to key information in times of crisis or anxiety, and current systems (e.g., health, education, community services) often do not offer integrated, coordinated models of care. To address this gap, participants suggested that it is important to develop online resources that bridge traditional barriers and sectors of care, provide information, address concerns, and offer parent-to-parent support. These findings corroborate existing research in other populations demonstrating the relative effectiveness of online supports in fostering information and support (Glasgow et al., 2003; Gottlieb, 2000; Nicholas, 2003; Nicholas et al., 2009). Furthermore, Faulkner (2003) found that repeatedly telling people that their child had diabetes and explaining what this meant negatively impacted parents' quality of life; to this end, online support with peers who have a similar background and understanding potentially can ease these challenges.

An emerging issue yet priority for website development, reflects the inclusion of information targeted to specific needs and "real-life" concerns, with practical ideas and strategies for moving forward. Beyond targeted information in dealing with diabetes care, participants wanted the resource to be positive and growth-oriented, which may relate to Bowes and colleagues' (2009) findings that parents (both mothers and fathers) experienced "chronic sorrow" related to their child's type 1 diabetes. The current study adds to this literature by advocating for a resource that not only addresses diabetes as a health care and lifestyle issue, but also offers hopeful messaging and feasible strategies that help parents and their families navigate daily care. As such, participants desired both accuracy and positive messaging. Explicitly crafting website tenor and nuance appears to be a relatively novel yet important consideration within the pediatric diabetes care literature.

Parents suggested that a support resource that addresses needs will inherently support the complexity of firstly, parenting an adolescent and secondly, parenting an adolescent with diabetes. Accordingly, the online resource was felt to require attention to everyday activities as well as emergent challenges or crises encountered by youth and parents in type

1 diabetes, all within an accessible forum. This finding addresses parents' concerns also found in Bowes et al.'s (2009) study that, "although they felt supported by the clinical team in relation to the practicalities of diabetes management, there was an overwhelming belief that ongoing emotional support should have been available as and when needed" (p. 998).

Health care professionals suggested password entry into the website; however, there also appeared to be a relatively strong alternative perspective, largely from parents, favoring unrestricted website access. Balancing ease of access with the risk of unscrupulous activity was seen to merit carefully weighed adjudication. Considerations include the personal and family risks of unsecured network use versus the potential limitations of inconvenience and impediments to entering the website, with parents generally favoring access ease and some parents further expressing concern over forgotten passwords.

For specialized needs and individualized problems, parents suggested an "ask an expert" feature or live online support that would be staffed and/or monitored by professionals. Health care providers, however, were concerned that they lack the time and resources to provide such a feature. To ensure this degree of professional monitoring and interactivity and to ensure currency of information, the infusion of sufficient resources appears warranted. Given budgetary constraints in the Canadian and other health care systems, it may be initially difficult to secure funding and/or staffing for a professionally mediated parent website. Yet a deeper look from a fiscal and service quality perspective may reveal that online resources potentially offer savings by proactively distributing a needed intervention and thereby possibly decreasing alternative information/support and/or an emergent intervention. This may have a bearing on direct patient care and education costs, care safety, and family quality of life. To this end, further evaluation studies are needed, as is consideration of ways to leverage costs. For instance, "frequently asked questions" may be a less expensive alternative to health care providers individually responding to questions of parents. In this endeavor, ascertaining common concerns and questions of parents is important, and ultimately supports the aim of accessible, targeted support and information for parents and their families.

Without sufficient resources for inputting, updating and sustaining website content, this potentially helpful resource risks obsolescence due to failing to acquire or maintain up to date information, hence diminishing impact. If this occurs, parents will continue to struggle without the flexibility and accessibility of resources that are technologically available. Conversely, if an online resource is to be useful to parents, Web developers must accommodate the needs and design considerations specific to this group of resource users. In considering priorities and needs, these findings corroborate with the literature in calling for dynamic online information and support in which interactivity can be facilitated among online members (Nicholas, 2009; Nicholas et al., 2003).

TABLE 1 Parent and Family Needs, Online Resources, and Potential Challenges Associated With Online Applications

Identified need	How need can be addressed through social support	How online applications can bolster social support outcomes	Potential challenges with online applications
Parent isolation and lack of support	Enhanced coping is fostered through informational, emotional, and tangible support	Ease of access to online support; Ability to readily find a quorum of peers to forge connection; Ideal for increased support access for rural and remote communities or other potentially isolated groups	For some parents, online support may not be preferred or accessible; Risk of insufficient personalization, breach of confidentiality and/or impeded depth or opportunity for relationship formation
Lack of knowledge about diabetes and/or insufficient resources within the community	Information and a repository of resources can be provided and continually updated	Accessibility of resource listings that can be located in a centralized virtual location; Ability to print as needed; Classification of resources can be organized by topic or other logical categorization scheme	As in offline resource databases, resources and associated links require periodic updating
Periodic need for parental reassurance and affirmation	Professional and peer support can offer guidance and parental reinforcement; Parents can review constructive ideas, and talk with parent peers about similar caregiving experiences	Online support can be accessible when and where needed and desired; Online networking permits constructively grappling with issues in a non-stigmatizing or identifying environment	Given the propensity for blunted communication periodically presented online, critique conveyed toward a parent within online communication may appear overstated, risking parent intimidation or upset; Explicit rules about online etiquette and ongoing monitoring may be needed
Lack of support for healthy siblings	Targeted information and support can enhance sibling well-being	Ease of accessibility as siblings and their families can obtain information when and where desired	Parents likely will need to facilitate access for siblings and/or inform siblings of this resource
Need to discern complex and possibly non evidence-based information; Difficulty knowing which sources of information to trust	Credible information can be encouraged through health care provider endorsement	Local health care authority could periodically review website content	Need to periodically check and communicate that information is updated; Requires on-going investment in review for informational currency including relevance and accuracy

In conclusion, participating parents and health care providers felt that Web-based information and support can augment clinical care for adolescents with type 1 diabetes and their families. Such infusion of augmentative online information and support was viewed as potentially helpful in guiding, nurturing and supporting parents as they provide daily diabetes care, encourage youth engagement in self-care, and deal with other day-to-day parenting challenges. Table 1 identifies diabetes-related parent and family needs, means by which online support mediates these needs, and potential challenges with this form of support. Reflecting on these findings, both benefits and challenges were associated with online support.

Study Limitations

Inherent to its design, this study was limited by a relatively homogeneous sample of Canadian parents and their health care providers, as noted by Holtzlander et al. (2012). To mitigate this concern, we sampled for diversity by recruiting from three distinct geographic regions and health systems. Beyond parent participants, the additional inclusion of health care providers who provide diabetes care to a broad range of families, offered vicarious access to an extensive array, hence a wide range of family experiences and circumstances. However, it is acknowledged that this approach, although efficient and comprehensive in scope, invariably also infused the views of health care providers, which additionally introduced a layer of alternative perspectives. From this exploratory work, a larger study representing a wide range of parent and family experiences is recommended.

CONCLUSION

Website resources appear to increase caregiver resources by offering helpful information and support, hence offering promise for improving the wellbeing of parents and youth with type 1 diabetes. Considerations for a website's aim, navigation, accessibility, and currency must be carefully weighed and ultimately integrated in design, development, maintenance, and evaluation. To that end, listening to parents and health care professionals who provide support to families living with diabetes constitutes important steps toward user-friendly Web-based parent education and support.

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