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Using User-Feedback to Develop a Website: MyT1DHope, for Parents of Children with T1D

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ABSTRACT

Effectively caring for a child with type-1 diabetes (T1D) can be extremely demanding and stressful for the entire family. The difficulties of caring for a child with T1D impact the psychological and physical well-being of the parents. Interventions aimed at reducing stress and increasing coping may improve parental outcomes. This project sought to develop a resource to be used as a preliminary intervention step for these parents. This research was conducted in two parts. Part 1 includes three stages of formative evaluation, including a focus group, interviews, and a survey with parents to examine the current landscape of diabetes websites as a resource. Using data from Part 1, Part 2 of the study included the identification of a theory to guide the design of a website, the development of the website, and an 8-week pilot study of the website with parents with a child with T1D. Significant improvements were found in diabetes knowledge and caregivers' satisfaction of life. No changes were found in social support, self-efficacy, or quality of life. Overall, the data show that the parents were generally satisfied with the website. Through this work, researchers were able to develop a deeper understanding of the needs of parents caring for a child with T1D to develop the initial component of a larger intervention.

Effectively caring for a child with type-1 diabetes (T1D) can be extremely demanding and stressful for the entire family (Pierce, Kozikowski, Lee, & Wysocki, 2017). Management of T1D is complex and since the diagnosis often occurs in childhood it requires parents to take on the responsibility of managing the child's care (Downing et al., 2013). Proper T1D care typically includes monitoring blood glucose (i.e., blood sugar) and physical activity, calculating carbohydrate intake, and adjusting and administering insulin multiple times throughout the day and night (Downing et al., 2013; Herbert, Owen, Pascarella, & Streisand, 2013). Daily care creates a demanding situation for parents; for example, one common worry is nighttime care. Many parents report waking in the middle of the night to test nocturnal blood glucose levels (Monaghan, Hilliard, Cogen, & Streisand, 2009). Caregiving demands and worries often increase parental anxiety and stress (Streisand, Swift, Wickmark, Chen, & Holmes, 2005).

As a result of care demands, parents are at risk of experiencing depression, anxiety, marital strain, and feelings of loneliness, isolation, feelings of guilt, and loss of control (Brehaut et al., 2009; Cohen, 1999; Smith & Lazarus, 1993; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). Interventions aimed at reducing stress and worry, and increasing adaptive coping may improve these outcomes for parents (Streisand et al., 2005). Past literature has demonstrated improving diabetes knowledge, social support, and problem-solving skills help parents adjust to life with a child with T1D (Feldman et al., 2018). Information and communication technologies (ICTs) are one approach for parents to access these types of interventions (Mikal, Rice, Abeyta, & DeVilbiss, 2013).

Technologies provide a variety of affordances including the ability to connect with and support others regardless of time, geography, confidentiality, and vast amounts of information that is relatively easy to access (Ingersoll, Shannon, Berger, Pickard, & Holtz, 2017; Walther & Boyd, 2002). Although there are countless websites available to help parents with a child with T1D, it is unclear how many consider the enduser in its development. There have been a small number of studies that have used and described using a patient-centered approach to design a web resource (Neubeck et al., 2016; Revenäs et al., 2015; Stinson et al., 2014; Taylor, Bray, Staggers, & Olson, 2003; Winterling et al., 2016). These studies demonstrate that incorporating user feedback throughout the design and development process allows the website to have the most potential for effectiveness.

The objective of this research was to develop a website resource, as an initial step in a larger intervention, for parents with a child with T1D. We sought to create a site that aggregated credible and trusted information to help parents increase knowledge surrounding T1D, improve social support, perceptions of self-efficacy, and quality of life. This objective

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was addressed through two key steps. In Part 1, a formative evaluation of parents' caregiving needs was assessed to guide the design and development of a website intervention. In Part 2, a website, MyT1DHope, was developed, and an 8-week study with parents with a child with T1D was conducted to assess outcomes.

Part 1: Formative evaluation

Researchers conducted both qualitative and quantitative assessments with parents of children, 5–18 years old, with T1D. This formative evaluation was conducted to gather patient-centered feedback to build an effective and engaging website (Dabbs et al., 2009). Formative evaluation allows researchers to understand the context of the issues from the users' point-of-view and address significant needs of the user before the intervention has been developed, thereby improving effectiveness, usability, and engagement of the website (Hulscher, Laurant, & Grol, 2003; Peng, Yuan, & Holtz, 2016).

Information was gathered in three separate and iterative stages before website development. For the first stage, researchers conducted a focus group to gain a broader understanding of the current online landscape of resources available to help parents with a child with T1D. Based on those results, a semi-structured interview protocol was developed to be used in the second stage of assessment. This staged consisted of phone interviews with parents to gather more information for our website content and gather feedback for the website organization. Stages 1 and 2 allowed us to develop a survey to understand what topics are of interest to the users and should be added to the website. Each of the stages is described in more detail in subsequent sections. Table 1 provides information on the topics covered in the formative evaluations.

Sample

Participants for all stages were recruited through a partnership with JDRF (formerly the Juvenile Diabetes Research Foundation) of southeast Michigan's family network, as well as Facebook, Twitter, and an area parent email listserv. To be included, the participant had to be a parent of a child with T1D between the ages of 5–18 years old. The university's Institutional Review Board approved all portions of this study.

Stage 1 Data collection

A small focus group session was held with three parents of children with T1D. The focus group was originally scheduled for six parents; however, only three parents were able to attend due to weather conditions. We followed up with the three missing participants; see Stage 2 below for more information. Before the focus group, we asked parents to review four current websites (http://www.inputdiabetes.org.uk/; http://www.childrenwithdiabetesuk.org/; http://diabetes.org/; http://www.diabetesforecast.org/). At the focus group, participants completed informed consent to participate. The goal of the focus group was to provide context regarding the daily lives of families living with T1D, the current landscape of diabetes information online, and gather feedback on user preferences for online information. We additionally discussed

Table 1. Topics covered and percent interest.

				Percent
	Focus	Phone		(*Survey
Τορίς	Group	Interviews	Survey	only)
Web recourses (websites currently	v	v	v	0,
used	^	^	^	
Online support groups used	x	x	x	
Facebook usage	X	X	Л	
Sample websites: likes, dislikes,	x	X		
suggestions	~			
Information about how to	Х	Х	Х	86%
educate and communicate with				
secondary caregivers (e.g.				
schools, coaches, etc.), and				
resources about allowable				
school accommodations				
A private and moderated		Х	Х	
Facebook group for parents of				
children with T1D				
Current diabetes information,	Х			
including current research,				
trusted websites, and resources				
on treatment options	v			
Information on positive parent	Х			
communication and problem				
solving skills	v	v	v	0.00/
neurophicing non-verbal mental of	~	^	Λ	00%
Nutrition	Y	Y	Y	Q10 / ₆
Youth eating disorders	x	x	x	43%
Carbohydrate counting	x	x	X	64%
The many factors [aside from	Х	X	Х	86%
food] that effect blood sugar				
Alcohol	Х	Х	Х	68%
Driving	Х	Х	Х	69%
Having productive conversations	Х	Х	Х	87%
with your kid about T1D topics				
Organization of website by		Х	Х	
milestones and what				
milestones to include				
Research studies			X	95%
Addressing child's mental health			X	88%
Addressing parent's mental health			v	6904
noods			^	0870
Starting school or going to camp			x	50%
Interest in participating in			x	
a Michigan-only secret			~	
moderated Facebook group for				
parents of children with T1D				

*Percent interest includes participant responses of "somewhat interested" or "extremely interested" on the Stage 3 survey

the themes and concepts of a website design we were developing based on previous research (i.e., LeRouge & Wickramasinghe, 2013; Nicholas, Gutwin, & Paterson, 2013). This website was presented through bullet-points.

The session lasted just over 2 h. The results from the focus group aided in the refinement of our website concept and the development of the subsequent interview and survey questions. The focus group was audio-recorded, transcribed verbatim, and hand-coded. Using a thematic analysis, the data was organized by the complexity of parenting, the coping strategies of social support, and information-seeking (Nicholas et al., 2013). The team iteratively developed a set of themes that captured the focus group dialog (Smith, 2015). The codes were presented to the whole group for clarification and feedback. Then, two members of the team coded a random selection of the transcript to ensure inter-coder reliability of themes. Reliability was measured as percent agreement between the coders. Inter-coder reliability was established by obtaining agreement above 90%. Any disagreements were resolved through discussion.

Stage 1 Results

In the focus group, two parents had a 6-year-old child, and the third parent had a 14-year-old child (See Table 2). The session resulted in two main themes of interest: (1) Facebook as the main source of support; and (2) Need for valuable information across the child's developmental stages in one well-organized location. Throughout the focus group, the parents expressed how hard it is to cope with and manage their child's T1D.

The parents expressed their worry and feelings of guilt throughout the group. They also spoke of the barrage of

Table 2	. Respondents	demographic	characteristics.
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Variable	Focus	Phone	Survey (Online & In-
Variable	Group	Interview	Person)
N	3	3	90
Gender of Parent			
Male	1	0	-
Female	2	3	-
Age of Parent*			
18–24	-	-	0
25–34	-	-	11
35–44	-	-	34
45–54	-	-	19
55–64	-	-	5
≥65	-	-	0
Highest Degree Achieved*			
No Schooling	-	-	0
Nursery School to 8 th	-	-	0
Grade			
Some High School, No	-	-	1
Diploma			
High School Graduate or	-	-	8
Equivalent			
Some College, No Degree	_	_	11
Trade/Technical/	_	_	9
Vocational Training			
Associate Degree	_	_	6
Bachelor's Degree	_	_	15
Master's Degree	_	_	15
Professional Degree	_	_	2
Doctorate Degree	_	_	2
Ethnicity Origin (or Bace)*			-
White	_	_	66
Hispanic or Latino	_	_	4
Black or African American	_	_	0
Native American or	_	_	1
American Indian			
Asian/Pacific Islander	_	_	2
Asian/Facine Islander	_	_	0
Age of Child with T1D			0
	0	0	9
5_7	1	0	13
8-10	0	1	19
11_13	1	2	24
14–15	0	0	7
>16	õ	0	18
Child's age at diagnosis	Ū	Ū	10
	1	0	16
5_7	0	0	16
8_10	0	2	23
11_13	1	2	18
14_15	0	0	3
14-15 >16	0	0	7
≥10 Current treatment of	0	0	/
dishotor			
Injustions	0	1	41
Bump	U 2	ו ר	41 40
rump Continuous Glucoso	2	2	4Z 40
Monitor (CGM)	2	2	40

* = demographics assessed only for the online survey (N = 70)

information they encountered, along with the constant tasks of managing T1D. One parent said, "When we were diagnosed and in the hospital, at that point, it was strictly just survival mode... but once we got home, it was like bringing an infant home and then the parent guilt of 'did we do something wrong?"

These types of feelings left the parents looking for support, to know that they were not alone in this. Many of the parents turned to Facebook for this support. One of the participants said, "As far as support... I'm on a support group on Facebook, and... there's always somebody on because somebody's always awake." When asked about currently used websites, the participants focused on the lack of having all the needed information in one location. Specifically, one parent said:

I feel like I did have to go to quite a few different spots to try and connect it. But now, just, like, sustaining and daily living, it's more of the up-and-coming and to make sure that we can stay in the loop of where we are [with management]...

Next, participants viewed and discussed existing websites (four websites mentioned previously, sent via email before the focus group) that support families impacted by T1D. Parents thought the websites' designs were outdated or too busy. They felt the organization of the information was confusing and reiterated the need for information specific to T1D spanning children's developmental stages in one wellorganized location. One parent said:

You have different milestones, though. Like, the different things that come up. So, like... for our son, it was like when he started preschool. Okay, what do we need to do to prepare for preschool? What things do we need? So, I'm looking for information for that. Then, when he goes to kindergarten, looking for information for that and how you deal with it. When you're going to travel, looking for information about what's the best way to travel with someone with diabetes. So, different life events that happen.

Our initial concept and themes of the website, which would house trustworthy and reliable information and links for parents and caregivers, was well-received by the parent participants in the focus group. They particularly liked that the website would be branded by the university where the researchers were located, adding a level of credibility that many of the example websites did not have. They provided additional content topics to include and helped brainstorm ideas for organizing the large amount of information. Overall, this group helped refine content and design by suggesting that information is organized by "Milestones" and "Life Events" reflecting developmental stages.

Stage 2 Data collection

For stage two, separate phone interviews were conducted with the three parents of children with T1D that were unable to come to the focus group. The phone interviews followed a similar, but updated guide, as the focus group, covering the following topics: currently used resources, websites, and online social support for T1D related questions; perceptions of existing websites that support T1D families; thoughts on our updated website prototype design that included the milestones and life events concept; and topics to include on the website. Phone interviews lasted approximately 30 min each. All of the interviews were audio-recorded, transcribed verbatim, and hand-coded. The themes from the focus group were used as a starting point for analysis.

Stage 2 Results

The phone interviews were conducted with three parents: two parents each with an 11-year-old child and one parent with a 10year-old child. Four main themes emerged from the interviews, including: (1) current resources used for support and information; (2) perceptions of currently used resources; (3) frequency of use; and (4) feedback on the milestone idea suggested in Stage 1.

Similar to the focus group, multiple parents cited Facebook groups as one of the top places they seek out social support. However, there were some reservations about Facebook by one parent, stating:

So I've looked on various Facebook pages that have felt kind of overwhelming for just the first few months after diagnosis. So I've found that those are more for the people who are in the trenches and have dealt with this for a long time, and it gets a little scary when you're just new to it so I just get off those pages.

Additionally, parents liked *JDRF's website* (http://www.jdrf. org/), as well as *Project Blue November* (http://www.project bluenovember.com/) and *Beyond Type 1* (https://beyond type1.org/) websites. (Focus group participants in Stage 1 did mention JDRF, but did not mention the other two websites.) They were asked what they liked and disliked about these resources. A parent talked about her use of the different web resources, stating:

I've looked at [JDRF] to gain information about how to support research. I've looked at the ADA for like 504 plan ideas. I think I go to websites more for kind of the 'big picture,' long-term things and I go to the Facebook groups for more day-to-day because I can shoot something on there like 'hey, this just happened, this is what her CGM (Continuous Glucose Monitor) looks like, what do you think, what do you do?'

Overall, participants found information the most trustworthy and useful when it was provided by those who also have T1D, like the website *Beyond Type 1*. Parents also stated how important it was to them to have everything organized clearly in one location. "To have it [diabetes information] all in one spot, 'this is my go-to website to find all my information." This led to further support of our milestones idea that was suggested by parents during the focus group, where information would be organized based on the child's grade in school. This idea was well-received in the interviews. One parent said:

I think that's [the milestones] perfect. I mean, I think we kind of touched on that earlier where I don't want to go through the horror stories just to figure out how to put my one foot in front of the other on those early days, so I really like that.

Participants were also asked how often they used the resources. Typically, they reported reading Facebook group posts each day, but they did not post in them nearly as often. They went to the websites when they were seeking both specific (e.g., 504 Forms) and general information (i.e., general T1D information).

Lastly, the prototype themes (sent via email ahead of time) of the website were presented and feedback and suggestions were gathered. Their feedback included personalized printouts for secondary caregivers (e.g., babysitters, sport coaches), and reiterated the importance of the milestones.

Stage 3 Data collection

In addition to the focus group and phone interviews, inperson (n = 20) and online surveys (n = 70) were conducted in stage three with parents of children with T1D, to gather additional information on which topics would be most helpful to them to include on the website. The survey consisted of 18 items. These items were based on previous research, in combination with Stage 1 and 2 results, including topics found on the websites that were mentioned from the focus groups, were used to compile the possible topics of interest (Amillategui, Mora, Calle, & Giralt, 2009; Holtz, Murray, Hershey, Dunneback et al., 2017; Holtz, Murray, Hershey, Richman et al., 2017; Nicholas et al., 2013). The survey included demographic questions, challenges of diabetes care, and topics of interest. A list of challenges of care and topics were presented, and participants answered yes or no, see Table 1. Currently used resources, websites, and online social support for T1D was assessed using open-ended questions. The in-person survey was conducted at a JDRF information fair event and did not assess parent demographics due to time constraints (e.g., parents did not have much time as there were many booths to visit at the information fair). The online survey did assess demographic information of the parents. Researchers were particularly interested in learning which topics were most needed from the perspective of T1D parents, regardless of the child's age or length of diagnosis.

Stage 3 Results

Ninety-three parents participated in either the paper or online survey. Three responses were eliminated from the online survey as they were not parents of a child with type-1 diabetes, resulting in 90 total responses. See Table 2 for full demographic information.

The key objective of this stage was to understand what topics for the website are relevant for this population. More than 50% of participants were either somewhat interested or extremely interested in all of the topics, except information on the connection to youth eating disorders (43% of participants were somewhat or extremely interested). Table 1 provides the topics and percentage of parents who were interested. Parents were also asked about any other concerns about their children as they age. The most cited reason for concern (42%) was their child moving out on their own. Other issues of concern included health complications, insurance, and management burnout.

Part 2: Website design, development and pilot study

Design and development of the website

When analyzing the results of Part 1, we utilized the Transactional Model of Stress and Coping (TMSC) framework useful to organize our findings (Azar & Solomon, 2001; Folkman & Moskowitz, 2000; Lazarus & Cohen, 1977). The TMSC framework is used for evaluating the process of coping with stressful events, which can include daily

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management of T1D. Through this model, threatening experiences, like a child being diagnosed with T1D, are viewed as transactions between the person and their environment; the person's appraisals of the stressors, as well as the psychological, social and cultural resources that the person has, mediate the impact of the stressors on the person (Lazarus & Cohen, 1977). This framework has been used previously in examining the coping strategies of parents with a child with T1D (Azar & Solomon, 2001). Although TMSC has been considered in overall health transitions (like a diagnosis of a chronic condition) (Mikal et al., 2013), TMSC has not yet been used to develop interventions to aid in the coping process of a child with T1D. There are two types of appraisals, primary and secondary. In the case of our population, an example of a primary appraisal is how stressful the parent perceives T1D management, and the secondary appraisal is how much the parent feels in control, has access to coping, and their ability to cope with the demands of T1D management.

The focus group along with past research demonstrate that parents of children with T1D often perceive their situation as stressful and uncertain (Holtz, Murray, Hershey, Dunneback et al., 2017), and many feel guilty of their child's diagnosis (Bowes, Lowes, Warner, & Gregory, 2009). Based on this feedback, a social support network was included in our intervention to act as a potential coping resource for parents. Many parents already go to Facebook for social support (Holtz, Smock, & Reyes-Gastelum, 2015); therefore, our website provides a social support network through a closed Facebook group, specifically for parents within the state of Michigan.

Additionally, these perceptions of guilt and responsibility in caring for T1D can contribute to feelings of loss of control (Smith, Lazarus, & Pope, 1993). This decreases the likelihood that parents can successfully cope with T1D management (Folkman & Moskowitz, 2000; Lazarus & Folkman, 1984). Therefore, our website seeks to increase coping skills, social support, and T1D information to positively impact parents' quality of life, using both emotion- and problem-focused coping strategies. One example of emotional-focused strategies our website features are stories from similar parents (Gibson, 1988; Lazarus & Folkman, 1984). Upon completion of website development, a pilot study to evaluate changes in knowledge, social support, self-efficacy, quality of life, as well as usability and satisfaction was conducted.

Website development

MyT1DHope, a website for parents who have a child with T1D, was developed by a professional company using the feedback from the three formative stages of this study and was guided by the TMSC framework. The website acts as a warehouse of all information related to navigating the life events and milestones of a child's development, with the added complexity of T1D. This website provides links to many trustworthy and reliable websites, rather than trying to duplicate existing information already available on other websites. The key component of MyT1DHope is to provide reliable and trustworthy information that is organized in a useful way for parents. Additionally, a closed-Facebook group connected to the website for social support was provided.

Pilot study

Methods

Recruitment was conducted via JDRF listservs, social media, and the university Extension's listservs. Interested participants contacted researchers through email or phone call and all study instructions were sent via email. The overall survey ran over 12 weeks, July-October 2017. At baseline, participants were consented, asked to complete a baseline survey and then asked to view the website at least once every week for 8-weeks. Enrollment in the study occurred on a rolling basis. The baseline survey included questions regarding demographics, parenting (Frick, 1991), diabetes knowledge (Collins, Mughal, Barnett, Fitzgerald, & Lloyd, 2011) $(\alpha = .95)$, social support (Zimet, Dahlem, Zimet, & Farley, 1988) (α = .99), diabetes self-efficacy (Iannotti et al., 2006) $(\alpha = .98)$, and diabetes caretaker quality of life (Vandagriff, Marrero, Ingersoll, & Fineberg, 1992). Parenting style was also measured as a multi-component demographic variable with a 5-point Likert-scale was used to assess each dimension (1 = Never; 5 = Very Often), with higher scores on positive dimensions and lower scores on negative dimensions were equal to more effective parenting. Parenting was evaluated on six parenting dimensions, including involvement (α = .83), positive parenting (α = .86), poor monitoring $(\alpha = .83)$, inconsistent discipline $(\alpha = .84)$, corporal punishment (α = .60), and other discipline (α = .35) and are reported with demographic information. The diabetes caretaker quality of life measure includes three subscales that measure life satisfaction ($\alpha = .96$), impact of diabetes on life $(\alpha = .95)$, and worry specific to caring for a child with diabetes (α = .95). Researchers sent a weekly reminder via text message or email to remind participants to utilize the website. The post-test survey included all of the same scales, except demographics, and added a validated website satisfaction and usability questionnaire ($\alpha = .98$) (Lewis, 1995; Schreier, 2012). Google Analytics data was used to measure the number of visitors to the website each week. The website did not require a log-in and therefore usage was not gathered for individual users. Additionally, participants were asked three open-ended questions about their perceptions of the website to evaluate satisfaction. The open-ended questions included concerns not addressed by the website, what participants liked most about the website, and if there was anything else they wanted to share.

The surveys consisted mostly of Likert-scale items, knowledge was true/false. Descriptive statistics were conducted on the quantitative data. We then conducted pair-sample t-tests to measure mean differences from pre-to post-intervention using SPSS version 25 (IBM SPSS Statistics for Macintosh, Armonk, NY). The qualitative data were analyzed to identify major themes.

Results

A total of 50 parents were enrolled in the study after completing the consent process. Four parents were lost to follow-up, with 46 parents having completed the post-test questionnaire. The majority of parents were the child's biological mother (89%), white (85%) and were between the ages of 35–44 years old (56%). Most were married (91%) with an annual household income of \$75,000 or more (63%). The majority of parents were employed (67%). The majority of parents scored high on involvement (M = 4.26, SD = .44) and positive parenting (M = 4.39, SD = .52). Additionally, parents scored low on poor monitoring (M = 1.48, SD = .58), inconsistent discipline (M = 2.15, SD = .77), corporal punishment (M = 1.22, SD = .41), and other disciplines (M = 2.63, SD = .50).

Significant improvements from pre- to post-intervention were found in caregivers' diabetes knowledge and life satisfaction. With a medium effect size, caregivers' diabetes knowledge was significantly higher at the post- (M = 1.01, SD = .09) compared to the pre-test (M = .96, SD = .12; t(45) = -2.89, p = .006, d= .47). With a small effect size, the caregivers' life satisfaction was significantly higher at the post- (M = 3.57, SD = .62) compared to pre-test (M = 3.38, SD = .58; t(45) = -2.80, p = .007, d = .31). There were no significant differences found in the remaining measures: Social support (post: M = 5.58, SD = 1.43; pre: M = 5.66, SD = 1.14; t(45) = .32, p = .75), self-efficacy (post: M = 4.56, SD = .40; pre: M = 4.49, SD = .34; t (45) = -1.93, p = .06, quality of life (post: M = 2.66, SD = .57; pre: M = 2.70, SD = .44; t(45) = .47, p = .64), worry surrounding caring for a child with T1D (post: M = 2.98, SD = .79; pre: M = 2.98, SD = .88; t(45) = .02, p = .98). Additionally, regarding the usability scale (7-point, Likert-scale, 1 = Strongly agree; 7 = Strongly disagree), the mean parent report of the website usability was in satisfactory range (M = 2.03, SD = .95), see Table 3. Data from Google Analytics showed an average of 22 unique users per week, with 315 total page views within the time period of the study.

The open-ended responses also evaluated the participants' satisfaction with the website. The majority (82%) of responses were positive. The emerging themes within the positive feedback included: ease of use, informative, one site with all information needed, and social support. These themes are closely related to the formative evaluation results, which confirms that despite the small sample sizes from Stages 1 and 2,

Table 3. Usability and satisfaction questions.

Question Wording	Mean (SD)
Overall, I am satisfied with how easy it is to use the website	1.80 (.93)
It was simple to use the website	1.80 (.91)
I could effectively complete my tasks with the help of the website	2.19 (1.08)
I was able to complete the tasks quickly	2.08 (1.11)
I was able to efficiently complete the tasks	2.08 (1.09)
It was easy to learn how to use the website	1.80 (.86)
Whenever I made a mistake using the website, I could recover easily	2.13 (1.14)
The information (such as online help and on-screen messages)	2.19 (1.20)
provided with the website was clear	
It was easy to find the information I needed	2.19 (1.24)
The information provided was easy to understand	1.84 (.842)
The information was effective in helping me complete tasks	2.23 (1.19)
The organization of information was clear	2.04 (1.05)
The interface of the website was pleasant	1.95 (1.07)
I liked using the interface of this website	2.02 (1.10)
This website has all the functions and capabilities I expect it to have	2.23 (1.30)
Overall, I am satisfied with this website	1.95 (1.15)

* = 7-point Likert scale was used to assess each question: 1 = Strongly Agree; 7 = Strongly Disagree participant feedback provided adequate insight for developing an effective website for parents. Many parents stated that the website was easy to use, organized logically, and they liked that the information was from a reliable source. Parents enjoyed the social support components, including stories from other T1D families and the Facebook group. Participants also commented on concerns that they felt were not addressed by the website. The themes within the improvement feedback included: more information on current technology (e.g., artificial pancreas) and helping with interpreting blood sugar data, including specific, tailored help with interpreting their child's data in order to notice blood sugar trends.

Discussion

Caring for a child with T1D is complicated and can cause stress and worry for parents. This study sought to assess what information would be helpful on a website for parents with a child with T1D to help ease these negative feelings. The participants stated that the resources that are currently available are not well organized, are not specific to T1D (i.e., diabetes in general), and are not geographically local. Through our formative evaluation, we used the TMSC to better organize our findings and used it as a lens in the design of the website.

Considering both user perspectives and theory is imperative to achieving effective and engaging interventions (Hekler et al., 2016). This project used the TMSC framework, which offers one approach for developing interventions to increase coping for parents who have a child with T1D. Additionally, the formative research provided insight into the parents' appraisals of the complexities of T1D management, specifically their feelings of guilt and uncertainty. This understanding of their needs provides confidence in the developing effective interventions (e.g., Manojlovich, Squires, Davies, & Graham, 2015; C. M. Johnson, Johnson, & Zhang, 2005). We started this process through a formative phase and were able to apply their feedback and suggestions to the websites, and ultimately achieved high usability and satisfaction ratings from users.

While we found significant improvements on two of the measures, diabetes knowledge and satisfaction of life in caring for a child with T1D (a quality of life measure), effect sizes were medium and small, respectively, and thus should be considered with some reservation. There were no significant differences in social support, self-efficacy, and the other measures of quality of life. These null effects may be attributable to pre-test scores that were already high (i.e., ceiling effect), a short duration intervention (i.e., 8 weeks) with limited dose, and a small sample of parents (i.e., low power). Additionally, these ceiling effects may also be explained through the style of parenting these parents reported, because T1D is an all-encompassing fact for these parents who are very highly involved in their child's daily life.

While we found some positive results in this intervention, we believe this website may be more helpful for families who have a child that has been recently diagnosed with T1D. We hope to further explore who the website may be best suited for and the impacts of the website on these individuals in conjunction with a larger planned intervention.

Limitations

These focus groups, interviews, surveys, and the pilot test are not representative of all parents with children with T1D, reflected in small and homogeneous samples. However, despite these limitations, this work provides a framework for others seeking to develop user-centered technology-based health interventions.

Implications for health communication practitioners and scholars

Health communication practitioners and scholars should consider incorporating end-user feedback throughout the design and development of websites to effectively address user needs. The results of this study support that researchers and practitioners may not always understand the full context of the users needs without conducting formative evaluations. Furthermore, the use of a theoretical lens in combination with formative assessments can help improve the effectiveness of an intervention, reduce the costs, and save time in intervention development.

Conclusion

Many website resources exist with the purpose of providing information to those impacted by T1D. However, there is a lack of reliable, well-organized and trustworthy information for caregiving parents across their child's lifespan in one location. This paper reports on the multiple mixed research methods for developing a website or other ICT intervention for parents with children with T1D. Through this work, researchers we were able to develop have an increased awareness deeper understanding of the needs of parents caring for a child with T1D. This study has important implications for companies and researchers in designing websites that will be useful tools for groups or organizations that are seeking to support parents of children with T1D, including diabetes educators. Researchers suggest using a combination of methods when seeking to develop relevant and usable resources for target populations (Morse, 2010). Our findings are being used as a basis to integrate the website with a larger intervention, in which we will hope to improve the parents and children with T1D ability to cope, that will lead to improved overall health for the entire family.

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Disclosure of potential conflicts of interest

The authors have no conflicts of interest to declare.

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References

- Amillategui, B., Mora, E., Calle, J. R., & Giralt, P. (2009). Special needs of children with type 1 diabetes at primary school: Perceptions from parents, children, and teachers. *Pediatric Diabetes*, 10(1), 67–73. doi:10.1111/j.1399-5448.2008.00457.x
- Azar, R., & Solomon, C. R. (2001). Coping strategies of parents facing child diabetes mellitus. *Journal of Pediatric Nursing*, 16(6), 418–428. doi:10.1053/jpdn.2001.27878
- Bowes, S., Lowes, L., Warner, J., & Gregory, J. W. (2009). Chronic sorrow in parents of children with type 1 diabetes. *Journal of Advanced Nursing*, 65(5), 992–1000. doi:10.1111/jan.2009.65.issue-5
- Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., & Rosenbaum, P. L. (2009). Health among caregivers of children with health problems: Findings from a Canadian population-based study. *American Journal of Public Health*, 99(7), 1254–1262. doi:10.2105/AJPH.2007.129817
- Cohen, M. S. (1999). Families coping with childhood chronic illness: A research review. *Families, Systems, & Health, 17*(2), 149–164. doi:10.1037/h0089879
- Collins, G., Mughal, S., Barnett, A., Fitzgerald, J., & Lloyd, C. (2011). Modification and validation of the revised diabetes knowledge scale. *Diabetic Medicine*, 28(3), 306–310. doi:10.1111/j.1464-5491.2010.03190.x
- Dabbs, A. D. V., Myers, B. A., Mc Curry, K. R., Dunbar-Jacob, J., Hawkins, R. P., Begey, A., & Dew, M. A. (2009). User-centered design and interactive health technologies for patients. *Computers, Informatics, Nursing: CIN, 27*(3), 175. doi:10.1097/ NCN.0b013e31819f7c7c
- Downing, J., Gleeson, H. K., Clayton, P. E., Davis, J. R., Wales, J. K., & Callery, P. (2013). Transition in endocrinology: The challenge of maintaining continuity. *Clinical Endocrinology*, 78(1), 29–35. doi:10.1111/j.1365-2265.2012.04473.x
- Feldman, M. A., Anderson, L. M., Shapiro, J. B., Jedraszko, A. M., Evans, M., Weil, L. E., ... Weissberg-Benchell, J. (2018). Familybased interventions targeting improvements in health and family outcomes of children and adolescents with type 1 diabetes: A systematic review. *Current Diabetes Reports*, 18(3), 15. doi:10.1007/s11892-018-1107-0
- Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist*, 55(6), 647–654.
- Frick, P. (1991). The Alabama parenting questionnaire. Unpublished rating scale, University of Alabama.
- Gibson, C. (1988). Perspective in parental coping with a chronically ill child: The case of cystic fibrosis. *Issues in Comprehensive Pediatric Nursing*, 11(1), 33–41.
- Hekler, E. B., Michie, S., Pavel, M., Rivera, D. E., Collins, L. M., Jimison, H. B., ... Spruijt-Metz, D. (2016). Advancing models and theories for digital behavior change interventions. *American Journal of Preventive Medicine*, 51(5), 825–832. doi:10.1016/j.amepre.2016.06.013
- Herbert, L., Owen, V., Pascarella, L., & Streisand, R. (2013). Text message interventions for children and adolescents with type 1 diabetes: A systematic review. *Diabetes Technology & Therapeutics*, 15(5), 362–370. doi:10.1089/dia.2012.0291
- Holtz, B., Murray, K., & Park, T. (2018). Serious games for children with chronic diseases: A systematic review. *Games for Health Journal*, 7(5), 1–11. doi:10.1089/g4h.2018.0024

- Holtz, B., Smock, A., & Reyes-Gastelum, D. (2015). Connected motherhood: Social support for moms and moms-to-be on Facebook. *Telemedicine and e-Health*, 21(5), 415–421. doi:10.1089/tmj.2014.0118
- Holtz, B. E., Murray, K. M., Hershey, D. D., Dunneback, J. K., Cotten, S. R., Holmstrom, A. J., ... Wood, M. A. (2017). Developing a patient-centered mhealth app: A tool for adolescents with type 1 diabetes and their parents. *JMIR mHealth and uHealth*, 5(4), e53. doi:10.2196/mhealth.6654
- Holtz, B. E., Murray, K. M., Hershey, D. D., Richman, J., Dunneback, J. K., Vyas, A., & Wood, M. A. (2017). The design and development of MyT1DHero: A mobile app for adolescents with type 1 diabetes and their parents. *Journal of Telemedicine and Telecare*, (1357633X17745470). doi:10.1177/1357633X17745470
- Hulscher, M. E. J. L., Laurant, M. G. H., & Grol, R. P. T. M. (2003). Process evaluation on quality improvement interventions. *BMJ Quality & Safety*, 12(1), 40–46. doi:10.1136/qhc.12.1.40
- Iannotti, R. J., Schneider, S., Nansel, T. R., Haynie, D. L., Plotnick, L. P., Clark, L. M., ... Simons-Morton, B. (2006). Self-efficacy, outcome expectations, and diabetes self-management in adolescents with type 1 diabetes. *Journal of Developmental & Behavioral Pediatrics*, 27(2), 98–105. doi:10.1097/00004703-200604000-00003
- Ingersoll, B., Shannon, K., Berger, N., Pickard, K., & Holtz, B. (2017). Self-directed telehealth parent-mediated intervention for children with autism spectrum disorder: Examination of the potential reach and utilization in community settings. *Journal of Medical Internet Research*, 19(7), e248. doi:10.2196/jmir.7484
- Johnson, C. M., Johnson, T. R., & Zhang, J. (2005). A user-centered framework for redesigning health care interfaces. *Journal of Biomedical Informatics*, 38(1), 75–87. doi:10.1016/j.jbi.2004.11.005
- Lazarus, R. S., & Cohen, J. B. (1977). Environmental stress. In A. Irwin & J. F. Wohlwill (Eds.), *Human behavior and environment* (pp. 89–127). Boston, MA: Springer.
- Lazarus, R. S., & Folkman, S. (1984). Coping and adaptation. In W. D. Gentry (Ed.), *The handbook of behavioral medicine* (pp. 282–325). New York, NY: Guilford.
- LeRouge, C., & Wickramasinghe, N. (2013). A review of user-centered design for diabetes-related consumer health informatics technologies. *Journal of Diabetes Science and Technology*, 7(4), 1039–1056. doi:10.1177/193229681300700429
- Lewis, J. R. (1995). IBM computer usability satisfaction questionnaires: Psychometric evaluation and instructions for use. *International Journal of Human-Computer Interaction*, 7(1), 57–78. doi:10.1080/10447319509526110
- Manojlovich, M., Squires, J. E., Davies, B., & Graham, I. D. (2015). Hiding in plain sight: Communication theory in implementation science. *Implementation Science*, *10*(1), 58. doi:10.1186/s13012-015-0244-y
- Mikal, J. P., Rice, R. E., Abeyta, A., & DeVilbiss, J. (2013). Transition, stress and computer-mediated social support. *Computers in Human Behavior*, 29(5), A40–A53. doi:10.1016/j.chb.2012.12.012
- Monaghan, M. C., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2009). Nighttime caregiving behaviors among parents of young children with Type 1 diabetes: Associations with illness characteristics and parent functioning. *Families, Systems, & Health, 27*(1), 28. doi:10.1037/ a0014770
- Morse, J. M. (2010). Simultaneous and sequential qualitative mixed method designs. *Qualitative Inquiry*, 16(6), 483–491. doi:10.1177/ 1077800410364741
- Neubeck, L., Coorey, G., Peiris, D., Mulley, J., Heeley, E., Hersch, F., & Redfern, J. (2016). Development of an integrated e-health tool for people with, or at high risk of, cardiovascular disease: The Consumer Navigation of Electronic Cardiovascular Tools (CONNECT) web

application. International Journal of Medical Informatics, 96, 24-37. doi:10.1016/j.ijmedinf.2016.01.009

- Nicholas, D., Gutwin, C., & Paterson, B. (2013). Examining preference for website support to parent of adolescents with diabetes. Social Work in Health Care, 52(9), 862–879. doi:10.1080/00981389.2013.827144
- Peng, W., Yuan, S., & Holtz, B. (2016). Exploring the challenges and opportunities of health mobile apps for individuals with type 2 diabetes living in rural communities. *Telemedicine and e-Health*, 22(9), 1–6. doi:10.1089/tmj.2016.29000.crd
- Pierce, J. S., Kozikowski, C., Lee, J. M., & Wysocki, T. (2017). Type 1 diabetes in very young children: A model of parent and child influences on management and outcomes. *Pediatric Diabetes*, 18(1), 17–25. doi:10.1111/pedi.12351
- Revenäs, Å., Opava, C. H., Martin, C., Demmelmaier, I., Keller, C., & Åsenlöf, P. (2015). Development of a web-based and mobile app to support physical activity in individuals with rheumatoid arthritis: Results from the second step of a co-design process. *JMIR Research Protocols*, 4, 1. doi:10.2196/resprot.3795
- Schreier, M. (2012). *Qualitative content analysis in practice*. London, UK: Sage.
- Smith, C. A., & Lazarus, R. S. (1993). Appraisal components, core relational themes, and the emotions. *Cognition & Emotion*, 7(3–4), 233–269. doi:10.1080/02699939308409189
- Smith, H. K. N., Lazarus, R. S., & Pope, L. K. (1993). In search of the "hot" cognitions: Attributions, appraisals, and their relation to emotion. *Journal of Personality and Social Psychology*, 65(5), 916–929.
- Smith, J. A. (2015). Qualitative psychology: A practical guide to research methods (3rd ed.). London, UK: Sage.
- Stinson, J. N., Lalloo, C., Harris, L., Isaac, L., Campbell, F., Brown, S., ... Pink, L. R. (2014). iCanCope with Pain[™]: User-centred design of a web-and mobile-based self-management program for youth with chronic pain based on identified health care needs. *Pain Research* and Management, 19(5), 257–265.
- Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C. S. (2005). Pediatric parenting stress among parents of children with type 1 diabetes: The role of self-efficacy, responsibility, and fear. *Journal of Pediatric Psychology*, 30(6), 513–521. doi:10.1093/jpepsy/jsi076
- Sullivan-Bolyai, S., Deatrick, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with type 1 diabetes. *Journal of Pediatric Nursing*, 18(1), 21–29. doi:10.1053/jpdn.2003.4
- Taylor, D. P., Bray, B. E., Staggers, N., & Olson, R. J. (2003). Usercentered development of a Web-based preschool vision screening tool. In AMIA Annual Symposium Proceedings (Vol. 2003, pp. 654). Washington, DC: American Medical Informatics Association.
- Vandagriff, J. L., Marrero, D. G., Ingersoll, G. M., & Fineberg, N. S. (1992). Parents of children with diabetes: What are they worried about? *The Diabetes Educator*, 18(4), 299–302. doi:10.1177/ 014572179201800407
- Walther, J. B., & Boyd, S. (2002). Attraction to computer-mediated social support. In C. A. Lin & D. Atkin (Eds.), Communication technology and society: Audience adoption and uses (pp. 153–188).
- Winterling, J. W. M., Obol, C. M., Lampic, C., Eriksson, L. E., Pelters, B., & Wettergren, L. (2016). Development of a self-help web-based intervention targeting young cancer patients with sexual problems and fertility distress in collaboration with patient research partners. *JMIR Research Protocols*, 5(2). doi:10.2196/resprot.5499
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52(1), 30–41. doi:10.1207/s15327752jpa5201_2