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Incorporating a Caregiver Support Group for Parents of Children Diagnosed with Type 1 Diabetes Mellitus (T1DM)

by

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Dedication

For my daughter, Nora.

You are unique, determined, independent and so loved. You can do anything you set your mind to and will always have my full support. This is for you, my girl.

Love, Mama

Acknowledgments

I would like to thank my project chair, Dr. Lynette Galloway, for her professional and personal ideas, wisdom, and support. Thank you for helping me stay on the long path to graduation and for your help with the finalization of this project, even when I wanted to quit a thousand times. Thank you to Dr. Luz Huntington-Moskos for her unique and helpful perspective, and her assistance in the finalization of my project (and all those statistics!). You are so good with words and have been very encouraging to me for the last year.

I want to thank Paula Struck, for being my main contact and support person through the Novak Center for Children's Health. I could not have completed this research without your leadership and constant support. You are a phenomenal social worker, and the Wendy Novak Diabetes Center and the parents are so lucky to have you. A huge thank you to Dr. Paul Hiers too, for reading my proposal, helping me with edits, and trusting my ideas and research. I want to thank Jaime Walker, for being the best cheerleader and for sparking my interest in this support group. You have been there for me every step of the way, even though you are the busiest person I know, and you are always so encouraging. Thank you for connecting me to these parents and Paula, and for just being wonderful.

I would like to thank my mom and dad, Colleen and Dave Murdock. You both have been my supporters from the very beginning, pushing me to go back to school and encouraging me every step of the way. Thank you to my in-laws, especially Brooke and Ron Weber, Jennifer and Joe Recktenwald, Allie Recktenwald, and Hannah Miles. Thank you for being Nora's babysitters, supplying me with endless chocolates and treats, and being some of my biggest supporters. The last three years were made possible because of you all.

Finally, my husband, best friend, confidante, and my number one fan, Rudy. Thank you for being my shoulder to cry on (daily) and the person that convinced me to keep going when I was ready to quit (also daily). Thank you for reading and editing every single paper, listening to my presentations, printing out hundreds of pages of notes, and supplying me with endless amounts of milkshakes, candy, and caffeine to keep me going. I love you more than I could ever put into words, here’s to making your lifelong dream of being a stay-at-home dad a reality.

Contents

Abstract

Background: Learning to live with a chronic illness can be one of the most stressful times for a child and family. A new diagnosis of Type 1 Diabetes Mellitus (T1DM) consists of overwhelming amounts of education, and at the time of a new diagnosis, caregivers can experience extreme emotions, including depression and anxiety. Parent support groups have been shown to validate and alleviate parents' emotions surrounding the diagnosis.

Purpose: The purpose of this project was to initiate a support group for parents and caregivers of children diagnosed with new-onset T1DM that can be maintained and expanded in the future to increase parental perceived social support.

Methods: Parents and caregivers of children with new-onset T1DM were recruited through the Wendy Novak Diabetes Center to attend a virtual support group. Participants completed the Social Support Index (SSI) tool before and after each session attended. An optional open-ended questionnaire was available to complete for quality improvement purposes. Results from the SSI were recorded and analyzed using IBM SPSS Statistics 27.

Results: The Wilcoxon Signed Rank Test revealed a Z-value of -1.289 ($p > .05$) with a large effect size ($r=.52$). Mean total scores also decreased from the pre-group ($M=46.83$, $Sd=5.115$) to the post-group ($M=44.33$, $Sd=5.820$). Responses from the open-ended questionnaires were also recorded.

Discussion: Although quantitative data did not show statistical significance, responses from the open-ended questionnaires were overwhelmingly positive, and supported the support group intervention. For future research, a qualitative study may provide greater insight and context related to barriers and facilitators for participation.

Background

One of the most common endocrine diseases of childhood is Type 1 Diabetes Mellitus (T1DM). As of January 2020, more than 200,000 children under the age of 20 years old are living with T1DM in the United States (JDRF International, 2020). The number of adolescents with this diagnosis is expected to continue to rise in the next thirty years and will cost the healthcare system more than $16 billion (JDRF International, 2020). Learning to live with a chronic illness can be one of the most stressful times for the child and family. A new diagnosis of T1DM consists of overwhelming amounts of education surrounding new medications, diet and activity restrictions, blood sugar monitoring, and learning to give insulin injections. At the time of a new diagnosis, caregivers can experience extreme emotions and a lack of confidence in caring for the child. Parents have reported feelings of isolation, abandonment, and mental health problems, such as anxiety and depression (Balkhi et al., 2013; Pate et al., 2015; Rankin et al., 2016; Sassmann et al., 2012; Sullivan-Bolyai et al., 2010). As parents and caregivers strive to support and advocate for their child, become the connection between the family and the diabetes care team, and adjust to the diagnoses themselves, anxiety and depression are just two side effects that should be considered (Pate et al., 2015).

One way to support the caregivers of children diagnosed with T1DM is a parent or caregiver support group. Parent support groups are shown to be an effective way to validate fears about care, disease complications, and to help to improve confidence in caring for the child (Boman, A., 2018; Channon et al., 2016; Konradsdottir et al., 2011; Monaghan et al., 2011; Pate, et al., 2015; Rankin et al., 2016; Sassmann et al., 2012; Tully et al., 2017; Wysocki et al., 2007). At the time of diagnosis and while adjusting to a new lifestyle, the needs of caregivers must be addressed to help them to feel valued as a parent. By establishing a safe space for parents to express chronic illness questions, frustrations, and even grief, parents can better adapt to a new life of caring for a child with a chronic disease and provide a higher quality of life for the child.

The target population for this project was parents and caregivers of children with newly diagnosed T1DM. External research shows that this is a vulnerable population with many educational and emotional needs to be addressed (Boman, 2017; Channon et al., 2016; Christie et al., 2008; Konradsdottir & Svavarsdottir, 2011; Monaghan et al., 2012; Pate et al., 2015; Rankin et al., 2016; Sassmann et al., 2012; Sullivan-Bolyai et al., 2010). Outcomes of parent and caregiver support groups are often positive, such as decreased fear related to caring for a child with T1DM, decreased feelings of depression and anxiety for parents, and increased feelings of perceived peer support. For this reason, parents and caregivers of children diagnosed with T1DM within the past six months were recruited to participate in the support group sessions. Caregivers, meaning grandparents, extended family members, and foster parents were included in the target population because many children are not being raised by biological parents at this time, or the diabetic responsibilities fall onto multiple members of the family. Parents and caregivers of children ages one to eighteen years were deemed eligible to participate. Diagnoses of Type 2 Diabetes Mellitus (T2DM) were excluded at this time.

Rationale

A needs assessment was performed through multiple virtual meetings with key stakeholders, including social workers, nurse managers, and endocrinology staff from the Wendy Novak Diabetes Center. Because the Wendy Novak Diabetes Center already provides education-based workshops, a discussion-based, open-ended parent support group was deemed necessary, and the development of curriculum and basic topics was planned.

The feasibility of this support group was determined by completed surveys and results from open-ended questions. Data from pre-session Social Support Index (SSI) surveys and post-session SSI surveys were compared for each participant to see if total scores improved after participation in the support group. Feasibility will continue to be established by the number of returning participants and the sustainability of the group.

Each virtual group session included valuable resources for parents, including emotional validation and how to manage T1DM in the summertime. These topics will help with the sustainability of the support group. Feedback from participants for discussion topics will assist in maintaining attendance for future groups. Sustainability will also be established by continuing contact with participants via email, inviting them to join the Wendy Novak Diabetes Center private Facebook page, “The Type 1 Club”, and recruiting new parents and caregivers for the support group throughout the year.

Purpose

External evidence suggests that parents of children diagnosed with T1DM benefit emotionally and psychologically by participating in a support group. Support groups are shown to be an effective way to help parents feel validated in their fears regarding diabetes care, less anxious about complications such as hyper- or hypo-glycemia and improve confidence in caring for the child. Support groups are also a way to improve community outreach and help parents and caregivers foster relationships outside of the home (Boman, A., 2018; Channon et al., 2016; Christie et al., 2008; Konradsdottir et al. 2011; Monaghan et al., 2011; Pate, et al., 2015; Rankin et al., 2016; Sassmann et al., 2012; Sullivan-Bolyai et al., 2010; Tully et al., 2017; Wysocki et al., 2007). The purpose of this project was to successfully implement a sustainable support group to improve feelings of perceived support for parents and caregivers at the time of the child's new diagnosis of T1DM and to retain and grow the support group.

Setting

The project intervention was conducted through the Wendy Novak Diabetes Center, an outpatient diabetes clinic within the Novak Center for Children's Health. An affiliate of Norton Healthcare since March 2020, the Novak Center for Children's Health houses outpatient clinics for pediatric specialties, including endocrinology, and provides diagnostic and therapeutic services to children. The endocrinology wing has two departments: 1) endocrine disorders, including growth disorders, sexual development and maturation, thyroid disorders, pituitary, and adrenal disorders, and 2) Diabetes Mellitus. The Wendy Novak Diabetes Center sees more than 4,500 patients in one year and more than 1,500 of those patients have a diagnosis of diabetes. The support group sessions were led virtually via Zoom technology by the graduate student researcher, with assistance from a staff licensed clinical social worker (LCSW) and a staff nurse certified in diabetes education.

Ethical Statement

This project proposal was submitted to the University of Louisville Institutional Review Board for review and received approval in January 2021. This project also received approval from the Wendy Novak Diabetes Center, the director of patient care services at Norton Healthcare Learning and Development Institute of Nursing, and the CNO of the Novak Center for Children's Health. Permission was obtained to use the Social Support Index (SSI) from Laurie McCubbin, PhD, associate professor at the University of Louisville, Jason A. Sievers, PhD, coordinator at the University of Louisville and Hamilton I. McCubbin, PhD, professor and director at the University of Hawaii at Manoa. All participant responses were kept anonymous and only the graduate student had access to the completed surveys and questionnaires.

Conceptual Framework

The Iowa Model is the framework that guided this evidence-based project intervention. The Iowa Model was developed to assist nursing staff in researching, developing, and implementing a practice change for quality improvement. This framework provides a step-by-step pathway to identify ways to improve patient care (Buckwalter et al., 2017). The Iowa Model was most recently updated in 2017. Changes to the model include making the framework more "linear" so it is easier to follow and separating different parts of the pathway, including making "conducting research" a separate step (Buckwalter et al., 2017). The first step in the Iowa model is to identify a "trigger", or an area of practice that warrants a change. The trigger in this project was high caregiver emotions and feelings of isolation related to a new diagnosis of T1DM in a child. Creating a support group for this situation was a priority for the Wendy Novak Diabetes Center, so a small team of key stakeholders was formed to start creating the support group, per the second step. These stakeholders included a Licensed Clinical Social Worker (LCSW), a staff endocrinologist, the nursing support staff supervisor, Norton Healthcare and The Novak Center for Children's Health administration personnel, and the graduate student researcher. The third step included reviewing research and synthesizing evidence related to parent support groups and T1DM in children. The evidence supported implementing a support group for this population. The final steps of the Iowa Model helped to guide the intervention and included the recruitment of participants, collection of data before and after the session, implementing the virtual group sessions, and evaluating and maintaining the support group.

Intervention

This project involved marketing the virtual support groups to parents and caregivers through the Wendy Novak Diabetes Center. Staff endocrinologists, diabetes educators, and social workers advertised the support group in person and on the private Facebook page, with assistance from the graduate student researcher. Marketing tactics were limited and had to be pre-approved by the marketing department at the Novak Center for Children's Health. The private Facebook page (Type 1 Club) has two-hundred and twenty-one members. The post advertising the virtual support group sessions was viewed by fifty people. Eligible participants registered for the free sessions through a link provided to them and attendance was capped at fifteen people. The participants were sent the Zoom link at the time of registration. Before the first session, registered participants received a welcome email from the graduate student researcher that explained the support group, the evidence-based practice project, and the research being conducted. A link was provided for the online Social Support Index (SSI) survey in the email and participants were encouraged to complete this before attending the group session. The participants were also provided the link for the survey during the session and were asked to complete the survey twice, once before or during the support group session and once after. To help encourage participants to attend the group session and complete the surveys, there was a drawing for two gift cards worth $50 each that participants were eligible for once they completed the post-group survey. Because of time constraints, SSI data was only collected throughout two sessions of the virtual support group. Literature shows that short-term support groups can have a significant impact on adaptation and coping skills for parent participants, in as little as five meetings over twelve months (Konradsdottir & Svavarsdottir, 2011; Tully et al., 2017). SSI surveys were collected, and the responses were recorded and organized after each session by the graduate student researcher.

External evidence agrees that support groups are beneficial for parents of children with newly diagnosed T1DM. A review of the literature shows an increase in perceived social support regardless of the type of support group (Balkhi et al., 2014; Boman, 2018; Channon et al., 2016; Merkel & Wright, 2014; Monaghan et al., 2012; Sullivan-Bolyai et al., 2010). Peer support is increasingly valuable according to the World Health Organization (WHO), and parent mentors are becoming a common component of support groups (WHO, 2007). The Parents Listen Understand Support study (PLUS) and the Social Support to Empower Parents study (STEP) both utilized parent mentors. In these support groups, experienced parents, or parents of children diagnosed with T1DM for at least one year, were assigned to parents of children with new-onset T1DM, also known as project parents (Sullivan-Bolyai et al., 2010; Channon et al., 2016). The STEP study shows that parent mentors were consistently utilized for advice and affirmation by project parents (Sullivan-Bolyai et al., 2010). The PLUS study, which was based on the STEP program, concluded that parent-to-parent support was more valuable than support received from healthcare professionals (Channon et al., 2016). Retention and engagement of participants were successful in both studies due to consistent follow up by the “experienced parents” and showed promise for implementing the program in a larger setting (Sullivan-Bolyai et al., 2010; Channon et al., 2016). A third study shows that peer support does not have to be face-to-face to be effective. Monaghan et al. (2012) show that telephone conversations can be just as beneficial. A group of parents receiving support via a total of five individual telephone conversations had significantly decreased scores for parental stress and perceived social support when compared to a group not receiving any type of support (Monaghan et al., 2012).

Another emerging trend that has shown positive results is online support forums. A study by Balkhi et al. (2014) sought to assess the impact that online forums have on parental stress and motivation in caring for a child diagnosed with T1DM. The study shows that the need for social support and the desire for increased knowledge related to diabetes care are the main reasons for visiting an online group (Balkhi et al., 2014). The outcomes of this study (increased social support, knowledge accumulation, and level of trust) are consistent with many in-person support groups (Balkhi et al., 2014). Merkel & Wright (2012) also studied the effects of an online support group. In the evidence-based practice (EBP) project, an online support group was implemented to study parental self-efficacy in caring for a child with diabetes and to increase social support. Engagement varied, as participants were able to utilize the web-based group in whichever way they saw fit. The EBP project finds that participants desired an enhanced social network and utilizing a web-based approach was cost-effective and feasible to continue (Merkel & Wright, 2012). The online support forum is still currently being used by parents.

Psychological and educational support groups also consistently show positive outcomes for parent participants. Konradsdottir & Svavarsdottir (2011) and Pate et al. (2015) addressed coping patterns and parental adaptation to the child's diagnosis of T1DM. Objectives of these studies include empowering parents as a caregiver and improving coping and adjustment with a chronic illness. Both studies found that the use of coping strategies increases confidence in caregiving abilities, reduces anxiety, and improves adaptation to a new way of life (Konradsdottir & Svavarsdottir, 2011; Pate et al., 2015). Sassmann et al. (2012) also implemented an educational support group. Parents of children with T1DM were randomly assigned to a control group or participated in six training and education sessions led by a psychologist. The sessions included information on goal setting and communication skills, working on relationships, handling conflicts related to diabetes, and individual problems related to having a child with a chronic illness. For those that completed all training sessions, parental distress (defined as anxiety and depression) decreased significantly, strengths improved slightly, and metabolic control was deemed stable in the child (Sassmann et al., 2012).

Important aspects of a successful support group include experienced parents as a resource and mentor, following up with parents after the initial diagnosis, and providing a venue where caregivers feel comfortable and encouraged. Outcomes of parent support groups include decreased parental distress (Konradsdottir & Svavarsdottir, 2011; Pate et al., 2015; Sassman et al., 2012), increased perceived social support (Balkhi et al., 2014; Merkel & Wright, 2012; Monaghan et al., 2012) and improved confidence in caring for the child (Channon et al., 2016; Sassmann et al., 2012; Sullivan-Bolyai et al., 2010).

Methods

Participants included caregivers and parents of children of any age diagnosed with T1DM. Parents and caregivers of children diagnosed with T2DM were not recruited to participate at this time. Due to the COVID-19 pandemic and to protect the health and safety of participants, the support group sessions were held virtually via Zoom technology, which was made available by the Novak Center for Children's Health. Potential participants were recruited through the Wendy Novak Diabetes Center and were asked to register for each group session. Upon registration, the Zoom link for the meeting was sent. Before the first group session, participants were sent an email by the graduate student researcher that included information about the group, the EBP project, and a link to the SSI survey. The link for the survey was also provided during the group session so participants could complete the survey twice. The parents were instructed to fill out the Likert-style SSI survey using a unique numeric ID, such as a fourdigit birth date. This ID was used each time the survey was completed, to help with data organization and ensured anonymity for each participant. The SSI was made available through a survey builder website (www.freeonlinesurveys.com), and the responses were time-stamped to assist with matching pre- and post-group surveys. At the end of the session, all participant names were entered into a drawing and two participants were chosen for a $50 gift card of their choice.

A study by Rankin et al. (2016) finds that parents desire reassurance and emotional support at the time of diagnosis, in addition to diabetes information and education. The same study also describes parental ambivalence in asking for support or help from the diabetes care team (Rankin et al., 2016). A second study by Boman (2018) states that interaction between parents is a necessary complement to traditional diabetes education. The Type 1 Club, a private Facebook group with two-hundred and twenty-one members, is managed by the Wendy Novak Diabetes Center and currently provides educational sessions that parents can attend to learn more about T1DM and have questions answered by endocrinologists and other support staff. Due to these current educational sessions and considering the wealth of information parents receive at the time of a new diagnosis, the curriculum for these support group sessions was kept more open-ended encourage conversation and discussion between participants. According to Tully et al. (2017), open discussion forums produce positive outcomes, and parents report decreased daily stress and appreciation for the feeling of "common ground". In the same study, 89% of parents thought that peer discussion was important in helping to manage emotions and coping skills (Tully et al., 2017).

The first session was to be held in February 2021, but due to limited time to advertise and a short registration window, there were no participants. The registration and marketing for the March session were more successful and there was a total of seven participants. The first session centered around introductions for the participants and included a conversation starter ("describe the funniest or most ridiculous myths you have heard about T1DM") to help facilitate engagement. Parents were able to talk freely about their child's diagnosis, how they are coping today, and what they wished to take away from this support group. Parents were asked at the end of the session if there were specific topics that they would be interested in discussing at the next session and this information was recorded for planning purposed by the graduate student. From this feedback, the main topics for the second session was developed.

For the second session, parents wished to discuss summer plans, and how these plans would be different with a diagnosis of T1DM. A certified diabetes educator was able to attend as well, to answer questions that arose from these parent-led discussions, including how to swim with an insulin pump, how to store supplies in the heat, and how to properly treat low blood sugars during the summer months. There were also demonstration supplies made available that the graduate student researcher was able to assist with.

After these sessions, parent participants were reminded to register for the next month's session and were asked to fill out the post-session SSI survey and an open-ended questionnaire. The link for these surveys was provided during the group session and sent in an email by the graduate student researcher the following day. The open-ended questionnaire was developed for quality improvement and sustainability of the support group and included:

1. What did you enjoy the most about the virtual group tonight?
2. What can be improved for the next virtual group?
3. What topics are most valuable to you for discussion?
4. How likely are you to continue to participate in these group sessions?

Once surveys were completed, data from the pre- and post-group SSI surveys and responses to each open-ended question were organized and cleaned. There were six pairs of surveys included in the data analysis. Any surveys that were not completed, or surveys that did not have a match (i.e., a pre-survey was completed but a post-survey was not) were discarded. Responses to the SSI surveys were entered into an excel spreadsheet and SPSS was used to analyze and run statistical tests.

Zoom Pro was provided as the medium for the virtual support group. This technology would typically cost $149.90 per year and was provided by the Novak Center for Children's Health. The SSI tool was free to use with permission from the creators. The website (www.freeonlinesurves.com) that was used to build the SSI surveys and the open-ended questionnaires was $35.88, paid for by the graduate student researcher. The presentation topics for the virtual sessions was researched and developed by the graduate student researcher at no cost. Marketing and recruitment for the support group was carried out by the Novak Center for Children's Health marketing department. An incentive for participants to complete two SSI surveys was provided in the form of a drawing for two $50 gift cards, purchased by the graduate student researcher. The staff from the Wendy Novak Diabetes Center, including the Licensed Clinical Social Worker (LCSW), endocrinologist, and the nurse supervisor involved in the planning of the group donated their time for the EBP project and were not compensated.

Measures

The instrument that was used as a pre-test/post-test measure is the Social Support Index (SSI). First developed in 1982, the goal of the SSI is to record the degree to which families find social support within their community (McCubbin et al., 1982). The developers of the SSI tool determined that social support is a very important aspect of family resiliency and can be used as an intermediary against family crisis, recovery, and distress (McCubbin et al., 1982).

The SSI tool consists of 17 items on a 5-point Likert scale. The Likert scale ranges from "Strongly Disagree" to "Strongly Agree". Questions are meant to determine the extent to which families feel support from their communities. Each answer correlates with a score from "0" to "4", for example, "Strongly Disagree" would be scored a "0", while "Strongly Agree" would be scored as a "4". Six of the items are scored the opposite ("Strongly Disagree" is scored a 4, etc.) to ensure that all items are score in a positive direction for interpretation purposes. The total score for each SSI completed is obtained by summing each number circled by the participant, with the highest score possible being 68 (McCubbin et al., 1982). A higher score is correlated with higher perceived social support by the respondent.

Each complete SSI survey had a unique numeric ID attached to assist with accurate data collection, and no personal identifying information was used in any capacity. A Wilcoxon Signed Rank test was run to compare pre-test and post-test SSI data from the sessions. Responses to the open-ended questions were reviewed, recorded, and shared with staff from the Wendy Novak Diabetes Center for planning, improvement, and quality assurance purposes.

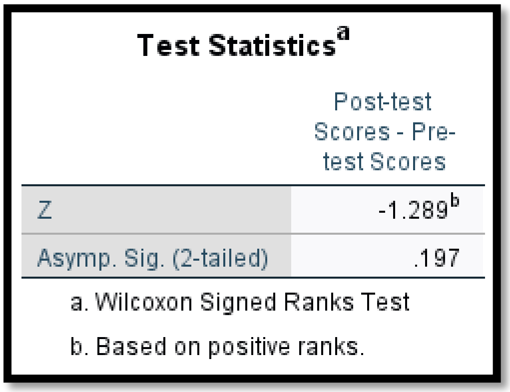
Data Analysis

IBM SPSS Statistics 27 software was utilized to evaluate the significance of the virtual support group. A Wilcoxon Signed Rank Test was used to compare pre-group SSI surveys and post-group SSI surveys. This test was used as a non-parametric alternative to a paired t-test because of the small sample size (n=6). SPSS 27 was also used to run descriptive statistics (mean, standard deviation, and frequencies) of each SSI survey question. The open-ended questionnaires were used for qualitative data purposes only, for improvement of the support group. The four questions were completed at the end of each support group session and responses were recorded by the graduate student researcher. Feedback via email was also recorded. Quantitative and qualitative data were kept anonymous by using a unique ID for each participant and removing names and identifying information from emails. All data analyses were shared with the Wendy Novak Diabetes Center.

Results

The Wilcoxon Signed Rank Test revealed a Z-value of -1.289 ($p > .05$) with a large effect size ($r=.52$) (see table 1). Mean total scores decreased from the pre-group (M=46.83, Sd=5.115) to the post-group (M=44.33, Sd=5.820) (see table 3). Three participants had post-survey total scores less than pre-survey total scores and two participants had equal pre-survey and post-survey total scores (see table 2). There was one participant that attended both virtual sessions. That participant's total scores improved from the pre-survey to the post-survey after the second session.

Table 1
Wilcoxon Signed Ranks Test



Test Statistics[a]

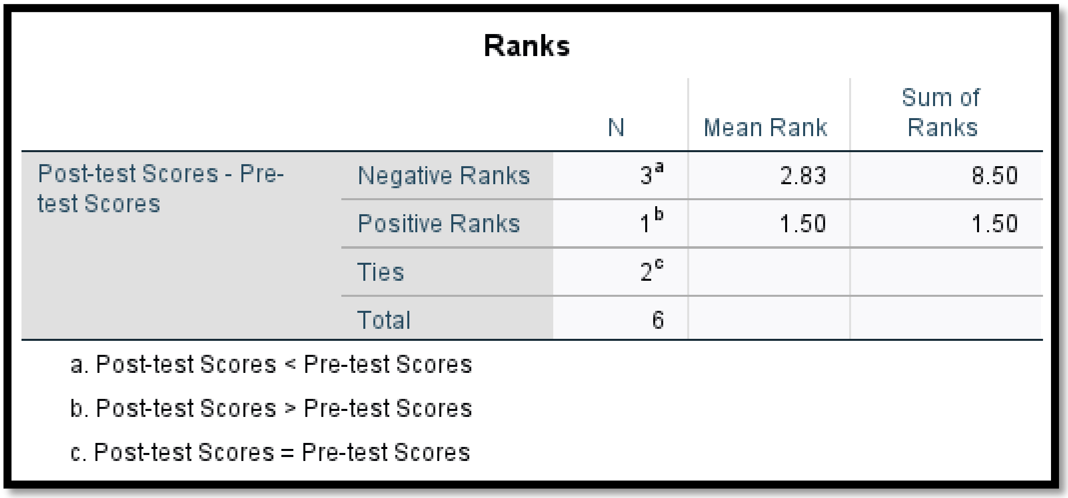
	Post-test Scores - Pre-test Scores
Z	-1.289[b]
Asymp. Sig. (2-tailed)	.197

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.

Table 2

Pre-test/Post-test Mean Ranks



Ranks

		N	Mean Rank	Sum of Ranks
Post-test Scores - Pre-test Scores	Negative Ranks	3[a]	2.83	8.50
	Positive Ranks	1[b]	1.50	1.50
	Ties	2[c]		
	Total	6		

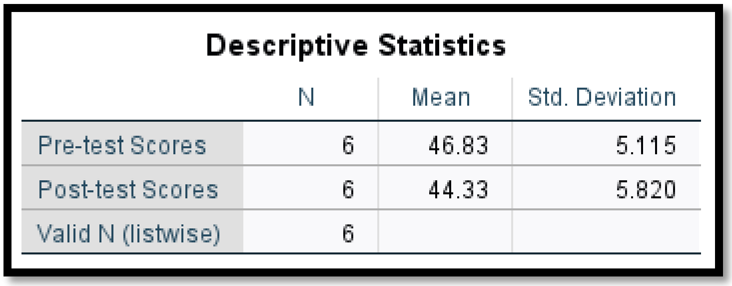
a. Post-test Scores < Pre-test Scores

b. Post-test Scores > Pre-test Scores

c. Post-test Scores = Pre-test Scores

Table 3

Pre-test/Post-test Mean Total Scores with Standard Deviation



Descriptive Statistics

	N	Mean	Std. Deviation
Pre-test Scores	6	46.83	5.115
Post-test Scores	6	44.33	5.820
Valid N (listwise)	6		

The responses for the open-ended questionnaire and emails were grouped into four different categories, based on the four questions. The first category was the value of the support group to the participants. The question asked, “what did you enjoy most about the support group”. The second category was the improvement of the support group and asked, “what can be improved for the next virtual group”. The third category included the question “what topics are most valuable to you for discussion” and was based on planning. The final category was based on continuity, and asked, “How likely are you to continue to participate in these group sessions” (see table 4).

For the first session, responses to the value category included “chatting with others in the same situation”, “making connections” and “meeting others”. Responses for the improvement category included “more structure”, “technology”, and “nothing”. Responses for the planning category included “any and everything to help me navigate through this”, “everything”, and “connection and community”. Finally, responses in the continuity category included “very”, “highly likely”, and “will continue” (see table 5).

For the second session, responses to the value category included “meeting with other T1D parents” “I really enjoyed getting to see local people from our community”, “no judgment with feeling overwhelmed”, and “everything was inviting, I appreciate it very much”. For the improvement category, responses included “nothing, it’s going great”, and “nothing, I really enjoyed it”. For the planning category, responses included “treating the kids normally”, the emotional drain of T1DM”, “how to function like a normal child/family”, and “education and management”. For the final continuity category after session two, responses included “very likely” (see table 4).

Table 4
Open-ended Questionnaire Responses

Category	**Response**
Value: What did you enjoy most about the support group?	• “Meeting others” • “Connecting with others” • “Chatting with others in the same situation” • “Personal communication” • “Meeting with other parents” • “Seeing local people from our community” • “No question seemed too silly to ask” • “No judgment with feeling overwhelmed” • “Everything was very inviting”
Improvement: What can be improved for the next virtual group?	• “Nothing, it’s going great” • “More structure” • “Technology”

Planning: What topics are most valuable to you for discussion?	• "Connection and community" • "Anything and everything to help me navigate through this" • "Treating the kids 'normally'" • "How to function like normal child/family"
Continuity: How likely are you to continue to participate in these group sessions?	• "Very likely" • "Will continue" • "Highly likely"

Discussion

A diagnosis such as T1DM can be completely devastating for families. Anxiety and depression stem from the stress of learning about this chronic life-long disease (Pate et al., 2015). Parents require support to successfully adjust to their child's new lifestyle (Rankin et al., 2016). The hypothesis at the beginning of this quality improvement project was that attending the virtual support group would increase perceived social support, and total scores from the SSI surveys would increase. The Wilcoxon Signed Rank test did not show statistical significance (z=-1.289, p >.05), and mean scores decreased from the pre-group SSI surveys to the post-group SSI surveys.

The decrease in scores could be attributed to multiple variables from the study. The planning, intervention, and data analysis took place between late 2020 and early 2021, in the middle of the COVID-19 pandemic. The support group had to be changed from face-to-face meetings to a virtual format for the health and safety of all participants. Although technology was helpful to implementing the support group during a pandemic it was also a barrier. The older generation of participants did have trouble with registration and with the Zoom style format. There was a total of thirteen participants registered for the first session, and only six attended. The pre-test/post-test approach could have also been a limitation. The SSI survey, a Likert-style questionnaire was relatively long (seventeen items), and six of the questions were asked negatively (i.e., “this is not a very good community to bring children up in”) and had to be scored in a positive direction, opposite of the eleven other questions. This could have been confusing for participants since the majority of the questions are worded positively (i.e., “people can depend on each other in this community”). For the first session, there were a total of six attendees while the second session only had two participants. This could have been due to the gift card drawing after the first session attracting more participants. For future studies, incentives could encourage participation. There was only one participant that attended both sessions of the virtual support group. That individual’s total SSI score improved from the pre- and post-surveys of the first session (pre-survey total score=46, post-survey total score=45), to the pre- and post-surveys of the second session (pre-survey total score=47, post-survey total score=50). This improvement in scores after attending more than one session is promising for future research and should be considered in future studies.

Although quantitative data showed no statistical significance for the improvement of total SSI scores, qualitative data from the open-ended questionnaires was overwhelmingly positive. The questionnaire was optional, but all participants completed it. Multiple private emails were also received, with positive feedback, such as “thank you for having the discussion group available”, “thank you for taking this terrible disease so seriously and not just looking at the numbers”, and “I look forward to joining the next meeting”. The most valuable question from the improvement category (“what topics are most valuable to you for discussion”) assisted in planning for future session topics and helped narrow down what was most important for parents. For example, multiple parents asked for tips on babysitters and childcare for children with T1DM, so a future session is being dedicated to assisting with these challenges. Future studies with this particular population might have more significant results if a more qualitative approach to intervention is taken.

The participation goal for each support group session was ten to fifteen attendees, with participants returning for each consecutive session. The first planned session had zero attendees. This session was supposed to be held in February 2021, during an ice and snowstorm where multiple civilians in Louisville lost power. The marketing for the first session could have also contributed to participation. The registration window was only open for a total of forty-eight hours the weekend before the scheduled Zoom session. Once the registration window was closed, it was unable to be opened again for potential participants. Finding a time to hold group sessions was also a challenge. This population has young children with a chronic disease, and therefore no date or time would fit every family. After the first session with attendance, the time of the support group was pushed back one hour at the request of the participants. Although this adjustment did not improve attendance for the following session, future research studies need to take into account the busy schedules of the families.

Registration was carried out by the Novak Center for Children's Health marketing department since the support group was a new event. The graduate student researcher and an LCSW advertised via the Type 1 Club private Facebook group, and physicians were sent information about the support group to share with patients and families. Participants registered for the free sessions before attending, and participation was capped at fifteen. The sessions were planned for specific days and times and extra sessions could not be added, which could have contributed to low participation. The actual registration page could have also been confusing for parents because it required participants to select how many people would be attending and appeared as though payment was needed. The sessions were free of charge, and once the number of attendees was selected, the next registration page detailed this. For future research, a more open participation approach or the removal of registration for each session might be helpful. Text messages or phone calls for those that do not have email addresses or those that don't regularly check their email would also be beneficial in future study and would be more inclusive.

Adapting to a life-changing diagnosis in a child can be very difficult for caregivers. Fear, anxiety, and depression are common emotions surrounding the care of a child with new-onset T1DM (Balkhi et al., 2013; Pate et al., 2015; Rankin et al., 2016; Sassmann et al., 2012; Sullivan-Bolyai et al., 2010). Caregivers have expressed the need for reassurance psychologically and emotionally after a complex diagnosis, but many parents feel that healthcare professionals are unable to provide them with empathetic support (Rankin et al., 2016). Support groups can provide an environment where emotional, affirmational, and practical support is shared between parents (Tully et al., 2017). Qualitative data from this study supported that sharing "lived experiences" can ultimately help promote confidence in care for parents and caregivers (Tully et al., 2017). Because the number of children diagnosed with T1DM is only expected to grow, future research with parents of these children will be important to help with adjustment to their new lifestyle.

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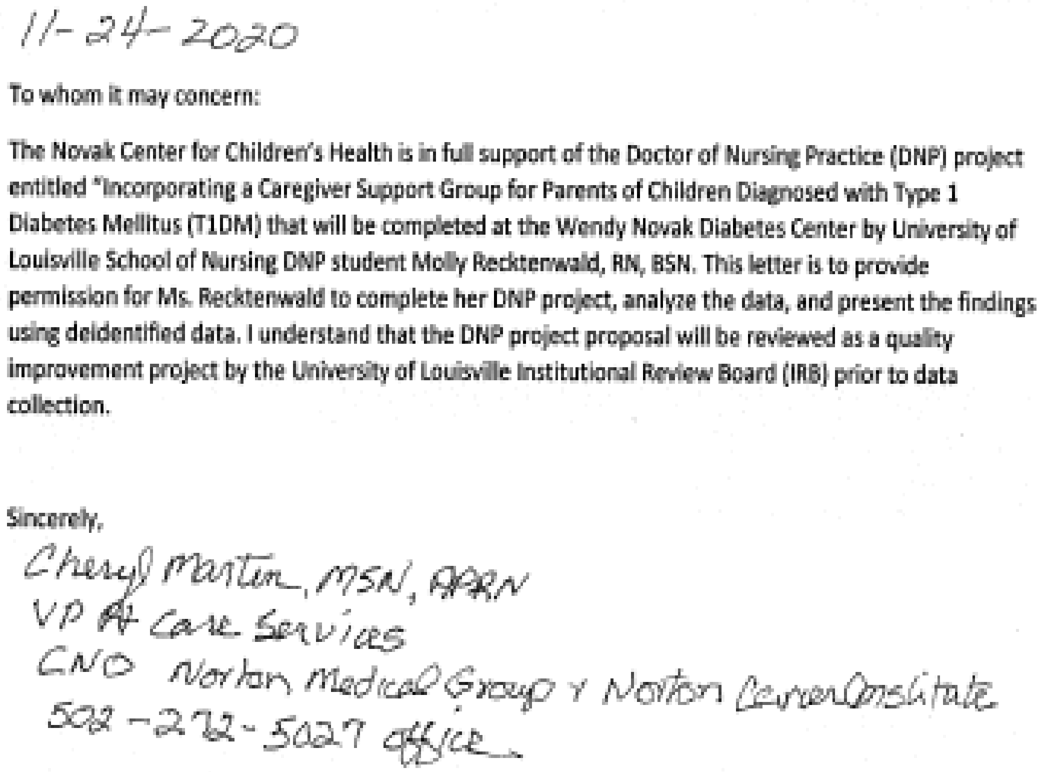
Appendix A: Letter of Support



11-24-2020

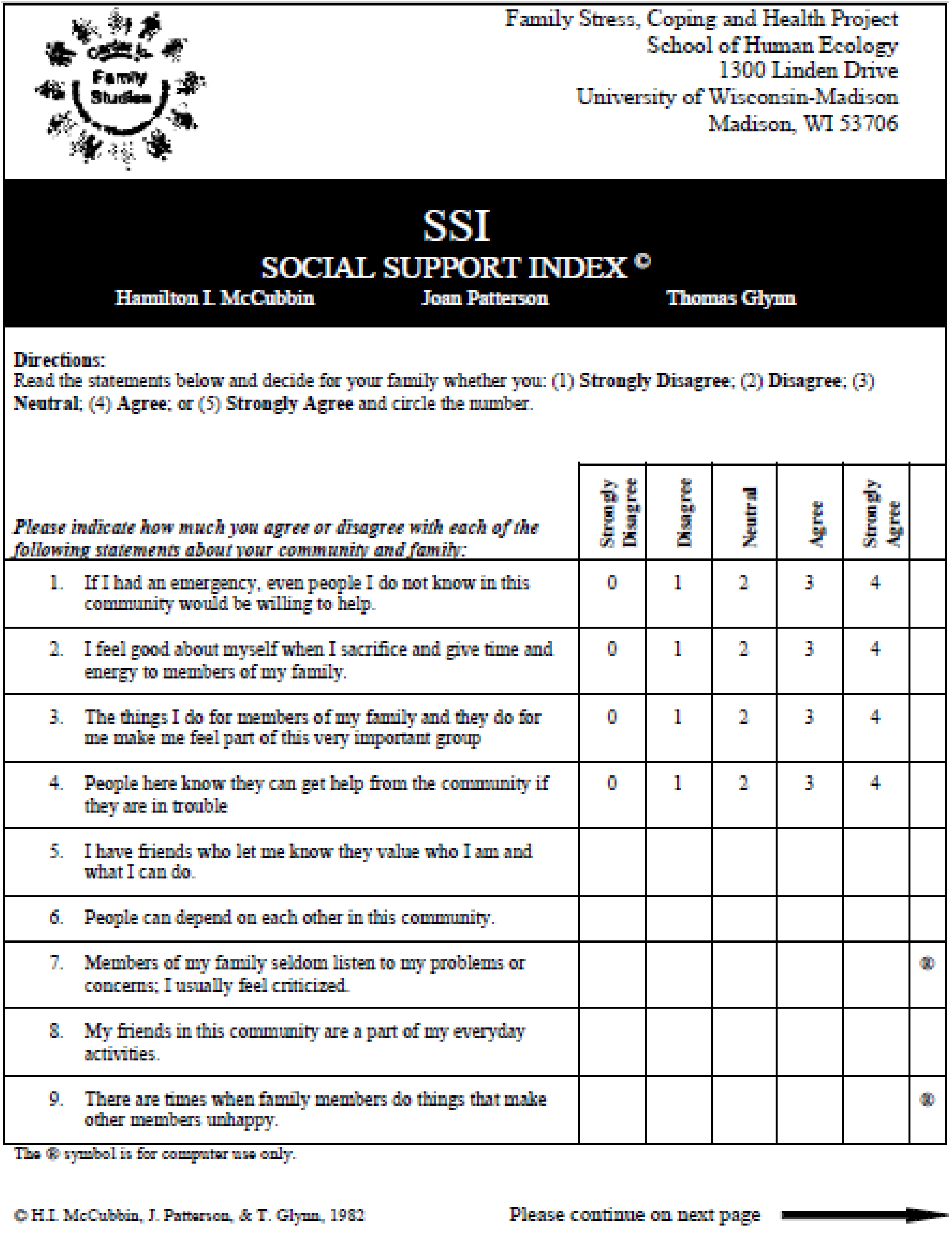
To whom it may concern:

The Novak Center for Children's Health is in full support of the Doctor of Nursing Practice (DNP) project entitled "Incorporating a Caregiver Support Group for Parents of Children Diagnosed with Type 1 Diabetes Mellitus (T1DM) that will be completed at the Wendy Novak Diabetes Center by University of Louisville School of Nursing DNP student Molly Recktenwald, RN, BSN. This letter is to provide permission for Ms. Recktenwald to complete her DNP project, analyze the data, and present the findings using deidentified data. I understand that the DNP project proposal will be reviewed as a quality improvement project by the University of Louisville Institutional Review Board (IRB) prior to data collection.

Sincerely,

Cheryl Martin, MSN, APRN
VP Pt Care Services
CNO Norton Medical Group + Norton Cancer Institute
502-272-5027 office

Appendix B: Social Support Index



Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

SSI

SOCIAL SUPPORT INDEX ©

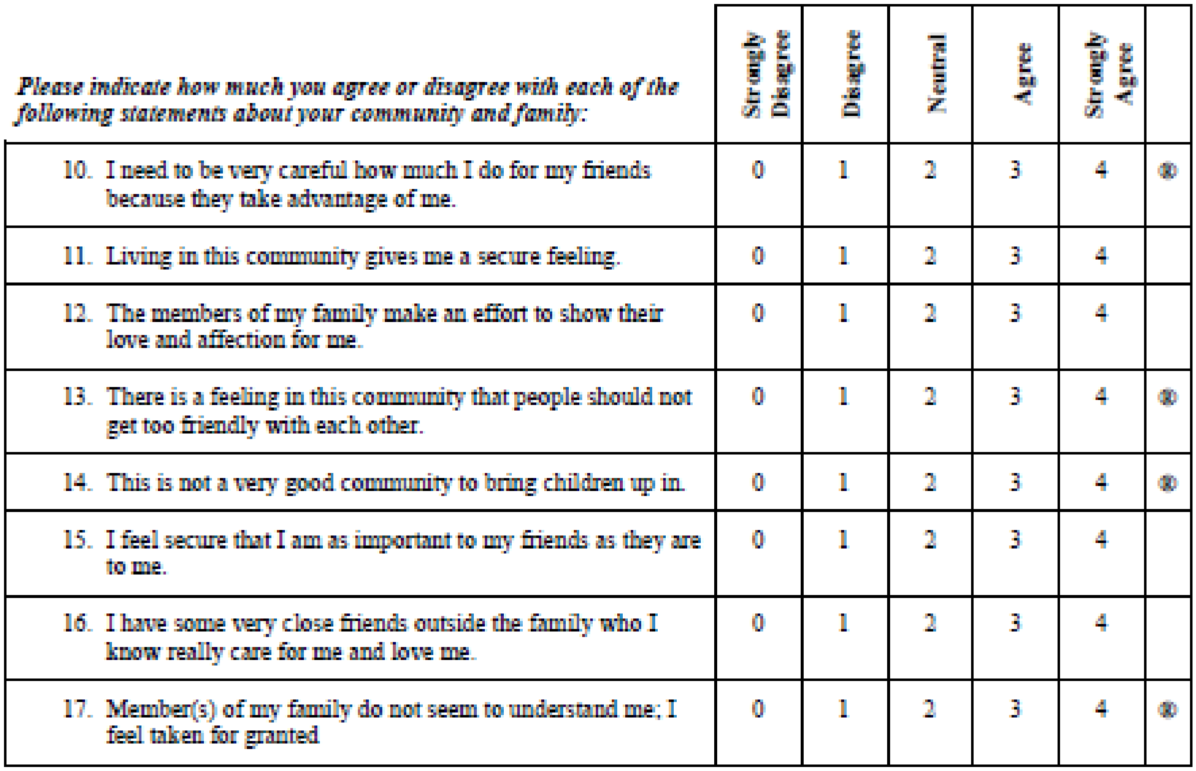
Hamilton I. McCubbin **Joan Patterson** **Thomas Glynn**

Directions:
Read the statements below and decide for your family whether you: (1) **Strongly Disagree**; (2) **Disagree**; (3) **Neutral**; (4) **Agree**; or (5) **Strongly Agree** and circle the number.

Please indicate how much you agree or disagree with each of the following statements about your community and family:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	
1. If I had an emergency, even people I do not know in this community would be willing to help.	0	1	2	3	4	
2. I feel good about myself when I sacrifice and give time and energy to members of my family.	0	1	2	3	4	
3. The things I do for members of my family and they do for me make me feel part of this very important group	0	1	2	3	4	
4. People here know they can get help from the community if they are in trouble	0	1	2	3	4	
5. I have friends who let me know they value who I am and what I can do.						
6. People can depend on each other in this community.						
7. Members of my family seldom listen to my problems or concerns; I usually feel criticized.						®
8. My friends in this community are a part of my everyday activities.						
9. There are times when family members do things that make other members unhappy.						®

The ® symbol is for computer use only.

Please continue on next page →

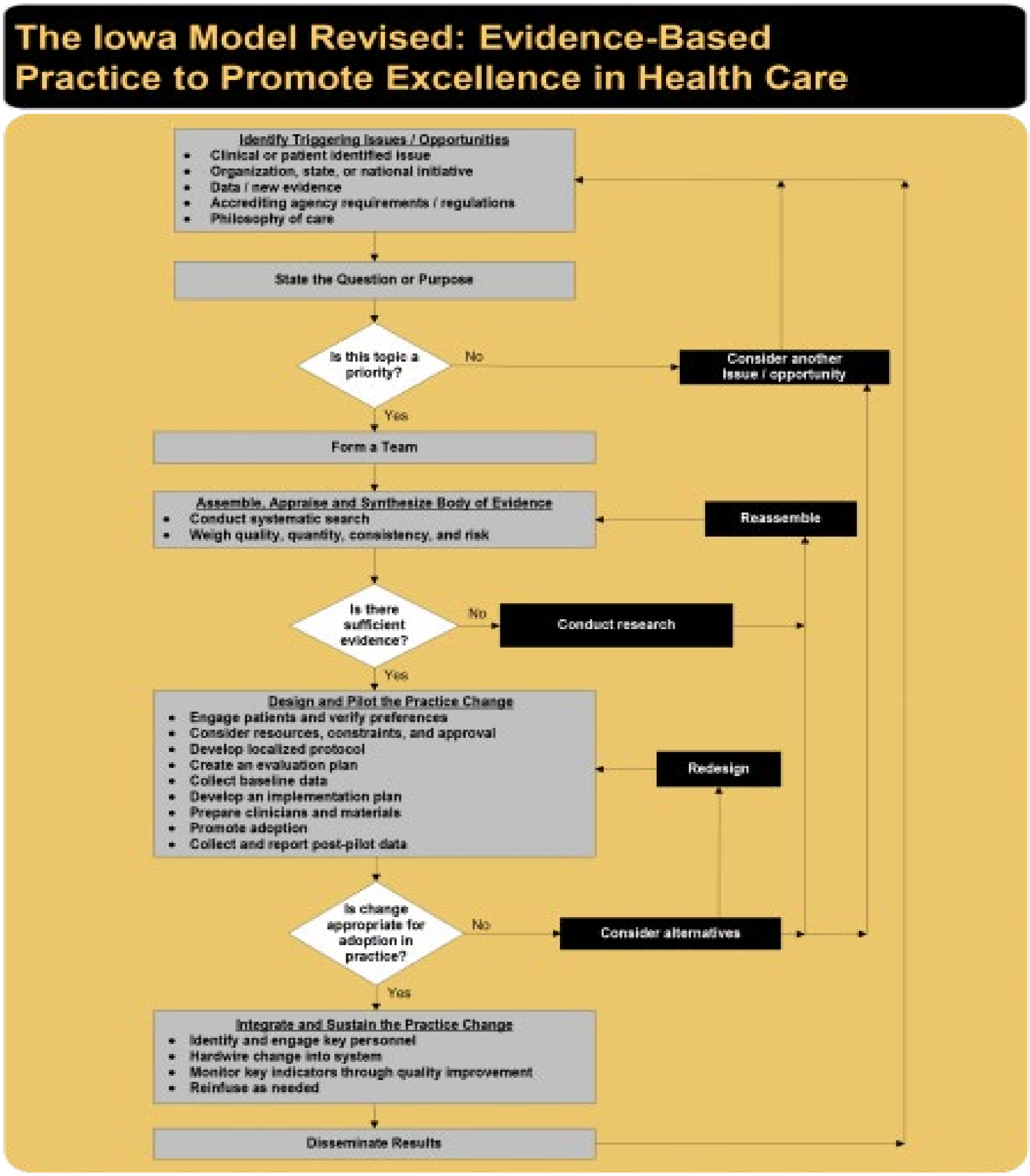


Please indicate how much you agree or disagree with each of the following statements about your community and family:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	
10. I need to be very careful how much I do for my friends because they take advantage of me.	0	1	2	3	4	®
11. Living in this community gives me a secure feeling.	0	1	2	3	4	
12. The members of my family make an effort to show their love and affection for me.	0	1	2	3	4	
13. There is a feeling in this community that people should not get too friendly with each other.	0	1	2	3	4	®
14. This is not a very good community to bring children up in.	0	1	2	3	4	®
15. I feel secure that I am as important to my friends as they are to me.	0	1	2	3	4	
16. I have some very close friends outside the family who I know really care for me and love me.	0	1	2	3	4	
17. Member(s) of my family do not seem to understand me; I feel taken for granted	0	1	2	3	4	®

Appendix C: Open-Ended Questions

1. What did you enjoy the most about the virtual group tonight?
2. What can be improved for the next virtual group?
3. What topics are most valuable to you for discussion?
4. How likely are you to continue to participate in these group sessions?

Appendix D: The Iowa Model



Appendix E: Support Group Curriculum Outline

Virtual Session #1
March 17, 2021, 6:00-7:00 PM

1. Introductions
    a. Paula Struck (LCSW-Wendy Novak Diabetes Center)
    b. Molly Recktenwald (Graduate Student Researcher)
2. Explanation of support group
    a. Goals
    b. Format of group
    c. Expectation of participants
3. Explanation of EBP Project (Molly Recktenwald)
    a. SSI Survey
    b. Open-Ended Response Questions
    c. Dissemination Information
    d. Privacy Statement
    e. Gift Card Drawing
4. Participant Meet and Greet
    a. Introductions of parents and caregivers
5. Ice Breaker Question
    a. What is the most ridiculous or funniest myth you have heard about T1DM?
        I. "Kids will outgrow it"
        II. "Did they eat too much sugar?"
        III. "Using an insulin pump cures them"
        IV. "Vitamins/probiotic/essential oils/etc. will make diabetes go away"
        V. "Diabetes can be reversed with diet and exercise"
6. Conclusion
    a. Questions/comments/concerns from participants
    b. Reminders: Email with survey/open-ended questions
    c. Announcement of next virtual session: Date and time

Virtual Session #2
April 21, 2021, 6:30-7:30PM

1. Welcome
    a. New/returning participant introductions
    b. Paula/Molly introductions
    c. Group expectations/explanation
    d. Follow-up from the first meeting
    e. Pre-survey link
2. Ice Breaker Question (2 options, can be used at any point during the meeting)
    a. What was the first thing that went through your mind when you heard that your child was diagnosed with diabetes?
    b. What is something positive that has happened for you or your family (diabetes-related or not) so far this year?
3. Summer-Time Diabetes Tips (Interactive and Informative)

   a. Hypoglycemia kits – what to include, how to store, first aid tips, medical ID (demonstration supplies)
   b. Pool tips for pumps – 1 hour at a time, how to clip/unclip, frequent breaks, skin prep (demonstration supplies)
   c. Traveling with a T1 child – what to bring
   d. Summer camps/activities – what are your plans?
4. Resources
   a. Handouts (links can be emailed)
5. Conclusion
   a. Questions/comments/concerns from participants
   b. Topics for future sessions
   c. Post-survey link
   d. Information about next session and registration: May 19th