

ABSTRACT

Title of Document: Formative research regarding social support programs and young adults living with type one diabetes

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Little research has been conducted regarding social support programs (SSPs) for young adults with Type 1 Diabetes Mellitus (T1DM). Formative research was conducted including: in-depth interviews with individuals who have organized or lead SSPs, a survey of young adults with T1DM, and forming a community advisory board to develop themes and discussion points for a SSP.

Eight interviews were conducted. The perceived benefits of and barriers to attending a SSP, the perceived barriers to managing a SSP, and topics important for young adults were described. 38 individuals completed the survey and were included in the analysis. The survey identified ever attended a SSP as significant in the perception of tangible and affectionate support. Two CAB meetings resulted in six themes and discussion points to be used as a framework for a proposed SSP.

This study suggests the benefit of SSPs for young adults and provides insight into the role of SSPs in managing T1DM.

**FORMATIVE RESEARCH REGARDING SOCIAL SUPPORT
PROGRAMS AND YOUNG ADULTS LIVING WITH TYPE ONE
DIABETES**

By

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LIST OF ABBREVIATIONS

SSP: Social support program

T1DM: Type one diabetes mellitus

T2DM: Type two diabetes mellitus

DM: Diabetes Mellitus (non-specific)

A1C: Hemoglobin A1C

ADA: American Diabetes Association

SMBG: Self-monitoring of blood glucose

MNT: Medical nutritional therapy

JDRF: Juvenile Diabetes Research Foundation

CBPR: Community based participatory research

CAB: Community advisory boards

CHAPTER 1: INTRODUCTION

Type one diabetes mellitus (T1DM) is a chronic autoimmune disease characterized by destruction of pancreatic beta cells and treated through daily insulin injections and lifestyle management. Although type two diabetes (T2DM) is more prevalent, the incidence of T1DM is on an upward trend and the per person cost of T1DM is higher. Much of the health care costs from T1DM related complications and suboptimal glycemic control partly explain higher rates and severity of complications. Because there is no cure for T1DM, effective diabetes self-management is essential to prevention of diabetes-related complications. There can be both clinical, treatment access and usage, and psychosocial reason for poor glycemic control [1-15]. Young adults are particularly vulnerable to poor glycemic control for a variety of reasons, such as competing life priorities and the transition from pediatric to adult care [16, 17]. The main concept of T1DM management is maintaining a lifestyle that will keep blood glucose levels near normal concentrations without risking extreme high or low levels [18]. A common method for controlling blood glucose levels is to calculate insulin doses from current blood glucose levels and the amount of carbohydrates consumed, determined through carbohydrate counting, exchange systems, or other methods. While being the major determinants of blood glucose levels, diet and insulin doses alone do not always account for the multiple factors that can affect blood glucose levels, such as stress, physical activity, or illness. Despite the widespread use of these methods, current diabetes management often does not result in adequate blood glucose control as defined by hemoglobin A1C levels [19, 20]. This may be due to the lack of focus on psychosocial aspect, such as social support, included in clinical care practices. The Diabetes Attitudes, Wishes and Needs second study (DAWN2) reported 44.6% of participants having

significant diabetes related distress, but only 23.7% stated that their health care team asked how diabetes impacted their life [21]. Because of this, research needs to address the most effective ways to address the psychosocial aspects of T1DM in order to better understand its role in long term glycemic control.

Increased social support has been shown to increase self-care activities, adherence to management, and other psychosocial variables [2-4]. Providing a social support program outside of the current clinical setting offered might be beneficial for individuals who do not reach desired A1C levels. Community-based social support structures have been extensively studied and implemented for type two diabetics, but insufficient work has been done studying the effectiveness of community-based programs exclusively for individuals living with T1DM [3].

The objectives of this study are to conduct formative research regarding social support programs for individuals living with T1DM and propose a community-based diabetes social support program led by a peer leader for young adults living with T1DM.

CHAPTER 2: LITERATURE REVIEW

2.1 Type 1 diabetes mellitus prevalence and impact in the U.S.

Type one diabetes mellitus (T1DM) is a chronic disease characterized by destruction of pancreatic beta cells and treated through exogenous insulin injection and lifestyle management. The number of people living in the US with T1DM is not clear. The CDC estimates that approximately one million individuals in the United States have T1DM, while the Juvenile Diabetes Research Foundation (JDRF) puts the estimate as high as three million [22]. The average individual health care costs for people with diabetes, T1DM and T2DM combined, was twice as high compared to people without diabetes [23]. The total cost of T1DM care in 2007 was 14.9 billion dollars, which accounts for a higher per person cost than type two diabetes [24]. Along with higher per person costs, the prevalence of T1DM is increasing. A study of diagnosed T1DM cases showed an increased incidence of 21.1% from 2001 to 2009 in all sex and race/ethnicity groups in the US youths aged 0 to 19 [25]. A projection of the future prevalence of T1DM in youth showed a possible 144% increase from 2010 to 2050, with the largest increase in racial/ethnic minority groups [26].

2.2 Diabetes related complications

Diabetes complications are more common in individuals living with T1DM compared to individuals living with T2DM, possibly due to longer disease duration and worse glycemic control. A study comparing complications prevalence in youth living with T1DM versus T2DM showed that 20% of individuals with T1DM already developed some form of retinopathy and 27% had developed peripheral neuropathy [27]. 67.1% of individuals screened in the Diabetes Control and Complications Trial developed retinopathy within 5 years after diagnosis [28]. Presence of diabetic neuropathy increased the incidence of coronary heart disease eight fold in a

pair matched longitudinal study of T1DM patients [29]. Diabetic nephropathy occurred in approximately 40% of patients with diabetes disease duration greater than 20 years in two studies, and development was strongly associated with other diabetes complications [30, 31]. Individuals living with either T1DM or T2DM are more likely to have strokes at younger ages, have higher risk of mortality due to strokes, and have longer recovery times due to having a stroke [32].

Improving A1C and improving the lipid profile decreases future complications involved with T1DM. Coronary heart disease risk is decreased with lowered cholesterol in diabetic patients [33]. Future complications such as neuropathy, nephropathy, and retinopathy were all reduced in an intensive insulin therapy group, who had lower A1C levels [34]. A 1% reduction in A1C levels was associated with a 37% reduction in risk of microvascular complications and 21% reduction for diabetes related deaths in individuals living with T2DM [35]. Improving glycemic control and blood lipid profile results in lowered risk of future diabetes related complications and lowers the cost of diabetes care.

2.3 Diet quality of individuals with T1DM

The majority of dietary analyses of individuals living with T1DM are in adolescent populations. A dietary assessment using 24 hour recalls of 50 adolescents with T1DM and 40 demographically matched peers showed those with T1DM have significantly lower scores on the USDA's Healthy Eating Index [36]. Another study of adolescents living with T1DM showed low adherence to dietary guidelines with intake of fruit, vegetables, and whole grains being less than half the recommended amount [37]. Overall dietary intake of many youth living with T1DM does not meet American Diabetes Association (ADA) recommendations, especially with respect to saturated fat intake. Only 6.5% of participants in the SEARCH for Diabetes in Youth Study, a

five year multicenter study of diabetes in youths across the United States, met the recommended amount of saturated fat intake as assessed by a food frequency questionnaire [38]. Additionally adults living with T1DM were reported to consume fat, including saturated fat, and protein at levels higher than recommended by the ADA [39, 40]. Individuals living with T1DM have also been shown to have LDL cholesterol levels above and HDL cholesterol levels below the ADA recommended values [40, 41]. Lower A1C levels also correlated with a lipid profile closer to the desired levels [42]. A diet high in both fat and protein and poor glycemic control can contribute to diabetes related complications such as cardiovascular disease and nephropathy. More frequent reminders of recommended intake and discussion of strategies to reduce fat intake could help individuals living with T1DM reach the recommended intake of all macronutrients.

2.4 Glycemic control status

A follow up to the landmark clinical study, The Diabetes Control and Compliance Trial (DCCT), showed that only 3.4% of young adults achieved A1C levels of <7% during an average 7.7 year follow up while following the intensive care regimen of the DCCT [19]. A more recent study looking at the T1D exchange clinical registry showed 17% of 18 to 26 year olds and 30% of 26 to 31 year olds living with T1DM reached an A1C goal of <7.0 and all groups had the majority of individuals with A1C levels between 7% and 9% [43]. A review of 10 studies comparing continuous versus self-monitoring of blood glucose levels in individuals living with T1DM reported mean A1C levels ranging from 7.6 to 9.4% for all groups [20]. While continuous blood glucose monitoring did significantly improve A1C levels, no group reached the desired level of 7% set by the ADA. Continuous blood glucose monitoring tracks blood glucose levels at all times through a monitor, while self monitoring of blood glucose levels uses blood glucose meters to test a blood sample a recommended 3 to 8 times per day [18]. Generally blood glucose

levels are checked before meals with additional checks recommended in between meals if blood glucose levels are high at the next meal check. Additionally individuals living with T1DM are recommended to check blood glucose levels during activities that may alter blood glucose levels such as when sick or after exercising. Even with technologies such as continuous glucose monitoring and insulin pump therapy, more intensive self-management programs, or programs designed to improve current self-management programs, are needed to reach the desired A1C levels.

2.4.1 Operation barriers to glycemic control

The frequency of self-monitoring of blood glucose (SMBG) and carbohydrate counting accuracy are both inadequate in many individuals living with T1DM and need to be addressed in diabetes education programs [6, 44]. SMBG has many barriers to adherence including sex, age, income, education level and belonging to an ethnic minority [7]. In individuals living with T1DM, male sex, Asian/Pacific islander ancestry, living in an impoverished neighborhood, taking fewer daily insulin injections, and smoking were independently associated with significantly increased odds of monitoring less than three times daily [7]. Additionally SMBG has been shown to be a mediator between higher A1C levels and depressive symptoms in adolescent living with T1DM [45]. Carbohydrate counting commonly does not result in long term improved blood glucose control because individuals living with T1DM often over or underestimated the carbohydrate content of their foods [6, 8, 46, 47]. Despite this, nutritional interventions focusing on carbohydrate counting often improve A1C levels, at least in the short term, suggesting the need for more intensive and/or more frequent nutrition education [48-50].

2.4.2 Psychosocial barriers to glycemic control

Psychosocial barriers to glycemic control include: limited diabetes knowledge, self-care activities, self-efficacy, adherence to management, social support and quality of life. Diabetes knowledge is the understanding the nature of the disease, treatment, and it's complications [9]. Self-care activities are those practices taken to manage the disease requirements, such as SMBG and insulin dosing, and is a subset of self-management activities which includes further lifestyle and disease management practices [51]. Self-efficacy is the belief that one can perform a given task [52]. Adherence to management is the extent to which an individual's behavior coincides with medical or health advice [10]. Quality of life is a construct that combines the perception physical, social, and emotional well-being into a single measureable outcome [11]. These factors, along with the later described feelings of social support, interact and influence each other to affect diabetes outcomes and glycemic control.

Limited diabetes knowledge and self-efficacy were shown to be a predictor of glycemic control [12, 13]. Self-management behaviors, including adherence to a self-care activity recommendations, and quality of life measures also correlated with A1C [14]. A program focused on empowering individuals living with diabetes to set achievable goals improved self-efficacy, diabetes related attitude measures, and glycemic control [53]. Self-efficacy has been shown to be a good predictor of self care activities and A1C in young adults living with T1DM [15]. Group based social support has been shown to improve diabetes control [3]. Current recommendations for diabetes self-management education include addressing psychosocial and emotional issues as they are related to improved diabetes management [54, 55]. Care recommendations developed specifically for young adults living with T1DM include increased attendance at diabetes education programs, providing opportunities to discuss diabetes related

stresses, and fostering peer-support networks [56]. While clinical practices can address many of these in some way, a community-based social support program may be better suited to address these issues in an effective manner.

2.4.3 Health care system barriers

One study 88.8% of individuals living with T1DM had some type of health insurance coverage in 1995 [57]. Another study from the same time frame saw that 13.0% lacked drug benefit coverage, which would be a significant barrier to obtaining blood glucose testing strips [7]. A 2012 study surveying young adults living with T1DM showed that 90% had private insurance coverage, 9% were covered under Medicaid, and 1% were uninsured [16]. A high percentage of insurance coverage is expected due to the numerous costs associated with diabetes care, but the lack of drug benefits coverage could be a significant barrier to the recommended amount of SMBG. Even with health insurance coverage, care is often lapsed in young adults living with T1DM when transitioning from pediatric to adult diabetes care [16]. Barriers most strongly associated with a successful transition to adult care include lack of referral names or contact information, competing life priorities, and insurance problems [16]. In addition to the psychosocial challenges, health provider, health system challenges, and developmental challenges were shown to contribute to lack of follow up during the transition from pediatric to adult T1DM care and this transition also caused a high degree of stressful life circumstances and poor care outcomes [17].

2.5 Current care practices

The main goal in teaching self-management techniques to individuals living with T1DM is to strive for A1C levels equal to or less than 7% [18]. Standard DM education and medical nutritional therapy teaches various methods, including carbohydrate counting, to identify the

amount of carbohydrates in a given meal, correct dietary intake, insulin dosing, and self-monitoring of blood glucose levels to reach this goal. These techniques are commonly used in controlling blood glucose levels, but often are not enough to reach the desired A1C levels. A possible reason for not reaching adequate levels of glycemic control may be due to clinical care not addressing the numerous psychosocial barriers to glycemic control stated in section 2.3.2. For those with A1C above 7%, current practices are not working well enough and additional strategies to improve care are needed. A large aspect of DM care that cannot directly be addressed clinically is social support, which has been shown to improve various measures of psychosocial well-being and clinical care outcomes [2-4].

Individuals living with T1DM generally receive care individually from health care professionals including endocrine, nutrition, and other health professionals focusing on standard DM self-management strategies. Group care has benefits that may be lacking in a traditional care regimen. In a randomized control trial of group vs. individual education in individuals living with T2DM, diabetes knowledge, quality of life, and A1C levels were improved or maintained with the group education [58]. Diabetes camps provide the most extensive data for group based education in individuals living with T1DM, specifically adolescents. Psychosocial benefits such as improved ability to cope with diabetes related emotional stress, quality of life, and diabetes knowledge have been seen in individuals who attend a camp [59, 60]. Little data is available on the role of group education specific to T1DM outside of the camp setting, and thus in adult populations.

Medical nutritional therapy (MNT) is an important part of a DM care routine and is recommended annually. MNT consists of a one on one session with a registered dietician who has experience in treating diabetes [54]. These treatments provide an analysis of dietary intake,

recommendations on eating habits, assessments of glycemic control, nutrition education, and diabetes education [61]. Little data is available on the frequency that individuals living with T1DM receive MNT or other nutrition education. Measures of dietary intake shows that most adults living with T1DM focus their diet on controlling carbohydrates and that this does not result in the desired level of blood glucose control or dietary intake [41]. In addition to the need for more information on the frequency of MNT, the role of social support groups and informal DM education needs to be explored in adherence to dietary intake, carbohydrate counting skills, and treatment recommendation adherence.

2.6 Social support systems

Social support is a blanket term for a variety of social functions and includes a persons social network, social embeddedness, and social climate and is commonly defined with the attributes of emotional, instrumental, informational, and appraisal support [62]. In the context of DM management, social support can be thought of as the assistance given by others in dealing with all aspects of diabetes care. This assistance can be seen from the perspective of family, friends, as well as through programs designed to foster social support among others affected by the disease, such as DM support groups.

Compliance with treatment recommendations and social support showed a significant relationship in individuals living with T1DM [1]. Adolescents living with T1DM rely on friends and family for social support and they are involved in dietary management and self care behaviors [2]. Social support plays a key role in T1DM management, possibly by influencing underlying psychosocial variables such as self-efficacy and quality of life. Internet based social support systems improved social support measures in individuals living with T2DM after 3 months [63]. A review of social support programs for individuals living with T2DM found that

classic social support structures such as family, spouse, and friends did not improve diabetes control, but proposes improved psychosocial functioning through DM social support groups [3]. Classic support structures such as family can offer practical help, such as reminders to check blood glucose levels, and aid in stress management, but lack insight that other individuals living with diabetes will have into disease burden and other aspects of daily living with diabetes [3, 4]. A study of a social support program for young adults living with T1DM ran through the Joslin diabetes clinic lead by a clinical psychologist showed decreased A1C and diabetes burden along with an increase in self-care activities [64]. This 5-month program with weekly meetings covered topics managing diabetes in day-to-day life, experiences and interactions with others who do not have diabetes and emotions related to diabetes [64].

Despite these findings, little research has been done looking at the effectiveness of community-based social support programs for T1DM and specifically in young adult populations. While the disease management is drastically different in T1DM and T2DM, social support is crucial in both and the use of community-based social support programs needs to be explored in T1DM treatment.

2.6.1 Community-based social support programs

Different models of DM social support programs have been extensively described and include in person group self-management programs, peer coaches, community health workers, telephone based, and internet based support programs [65]. In person self-management programs, especially with peer leaders also living with the chronic disease, were most successful when patients were sharing experiences and information rather than following a formalized education format [65]. These support programs often focus on individuals living with T2DM, and currently there is little research describing the current state of community-based social

support programs for individuals living with T1DM. While various organizations, such as the Juvenile Diabetes Research Foundation and American Diabetes Association and individual clinics, offer such programs, they do not describe their characteristics, use, or effectiveness. A study showed that online, peer led support communities are utilized by individuals living with T1DM and function in a similar manner to traditional in person social support programs [66]. While these online communities exist, there are few studies determining their effectiveness or comparing them to in person social support programs.

2.6.2 Community advisory boards in development of DM programs

A critical component of planning a health promotion program is developing materials that will be effective for individual behavior changes in members of the target population.

Community based participatory research (CBPR) is a viable approach to equitably involve members of the target population and researchers in developing materials [67]. By having all partners contribute their expertise and share responsibility and ownership this process enhances our understanding of a given phenomenon, the unique barriers encountered by young adults living with T1DM and how to address them through a social support group, and integrates the knowledge gained with a proposed intervention to improve the health and wellbeing of these young adults. To operationalize the CBPR approach, a community advisory board can be included in the development process of health promotion programs [68]. Community advisory boards (CABs) have been used to inform research protocols and other aspects of program design in order to best serve the target population [69, 70]. CABs have been used in a number programs designed for individuals living with T2DM, often focusing on prevention and diabetes self-management, but have not been used to develop programs for individuals living with T1DM [71-75].

2.6.3 Role of community health worker, lay health advisors, and peer leaders in DM management and care

The proposed program intends to use a peer leader based on a community health worker model. Community health workers (CHW) can offer a unique health care experience that is more focused on the patient's personal well-being and patient experience compared to the standard health outcomes encouraged in standard clinical care [65]. Currently, CHWs are mainly used in underserved, minority populations [76]. Their expertise's relies on the fact that they have encountered many of the same barriers as the target population and have unique insights into their experiences and barriers to healthy living [76]. The American Public Health Association defines CHWs as:

frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables CHWs to serve as a liaison ... between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. CHWs also build individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy.[77]

Having participants work with a CHW who provided DM education and regular home visits focusing on patient empowerment has been effective in improving glycemic control as part of programs for Latino and African American adult living with T2DM [78]. Another study using CHW in T2DM care in the Rio Grande Valley showed working with a CHW as the primary diabetes educators improved glycemic control, diabetes knowledge, self efficacy, and self management activities [79]. Despite this, CHWs have not been used in T1DM care, and there are no CHW training materials related to dealing with individuals living with T1DM and their distinctive needs. This may be due to the individual and more intensive care required by individuals living with T1DM and the larger impact of T2DM especially in minority

communities, but using peer leaders based on the CHW model could be effective in providing social support and building effective support structures.

2.7 Formative research

Formative research is one of the critical components determining the success of an intervention program because it provides a systematic foundation to identify clear objectives, and to guide effective intervention development. Formative research has been used to develop interventions focused on improving self-care activities among youth living with T1DM and T2DM prevention programs [80, 81]. Because the current literature regarding interventions for individuals living with T1DM is often focused on clinical and psychosocial outcomes as well as psychosocial predictors of clinical care, the attitudes and beliefs of individuals living with T1DM are less prevalent [3]. Additionally, little is known about current community-based social support programs for young adults living with T1DM. Formative research is often comprised of conducting needs assessments and understanding beliefs, perceptions, and attitudes of a target population in order to design and implement a successful intervention program. This paper seeks to describe the beliefs, perceptions, and attitudes of both young adults living with T1DM as well as individuals with experience organizing, managing, or running social support programs for individuals living with T1DM in order to propose a social support program for young adults living with T1DM.

CHAPTER 3: RESEARCH OBJECTIVES AND AIMS

The objective of the present study was to conduct formative research for the development of a community-based social support program. In particular, the benefits of and the barriers to attending a social support program, and key aspects of successful diabetes self-management for young adults living with T1DM will be explored.

The specific aims include the following:

Aim 1: To describe the current state of social support programs for individuals living with T1DM as well as explore the feasibility of a community-based social support program and to assess barriers and facilitators in conducting and sustaining community-based social support programs for individuals living with T1DM

Aim 2: To identify perception of social support programs, perceived barriers to attendance, perceived benefits of attendance for young adults living with T1DM, and significant factors involved in the perception of social support among young adults living with T1DM

Aim 3: To generate specific themes and topics that could be integrated for future community-based social support program for individuals living with T1DM using a community advisory board

The key strengths of the present study include: the identification of the current state of social support programs for individuals living with T1DM, the use of multiple qualitative research methods to identify the benefits of and barrier to attending a social support program, the inclusion of data from individuals who have attended, managed, and/or coordinated social support programs, and the use of a community advisory board in developing a framework for a social support program for young adults living with T1DM.

CHAPTER 4: METHODOLOGY

4.1 Community advisory board

The community advisory board was formed in order to develop themes and discussion topics to be used in a social support program for young adults living with T1DM. The CAB members were told each theme was intended to represent a major factor in living with T1DM and discussion points were intended to provoke discussion among a group of young adults regarding that theme. A CAB was used rather than an expert panel in order to get a representative view of the issues faced by young adults living with T1DM.

4.1.1 CAB recruitment

The members of the CAB were recruited through listserv messages to the University of Maryland- College Park faculty, staff, and students, posts to the Greater Chesapeake and Potomac chapter of the Juvenile Diabetes Research Foundation Facebook page, and personal messages from the first author to a registered dietician diagnosed with T1DM. Two listserv messages were sent out, three posts were made to the JDRF Facebook page, and the first author sent one personal message. Recruitment took place between April and July 2014. The recruitment messages described the project's goals, its' eligibility criteria, and program details, such how many meetings would be held and expectations for reviewing material. Eligible participants had a diagnosis of T1DM and either were in the age range of the future social support program's target population, 18 to 35 years, or were working in a T1DM related health profession, and were living in the Washington D.C., Maryland, and Virginia area. All interested parties who contacted the first were screened based on the eligibility criteria, and one was deemed ineligible based on a diagnosis of T2DM. A total of six individuals agreed to be community advisory board members including the first author who acted as group moderator.

Two members, who were the only respondents to the Facebook posts, dropped out of the study before the meetings began, leaving a total of four members living with T1DM participating in the CAB process. One member of the CAB holds a Registered Dietician, Licensed dietician/nutritionist designation and also works as an insulin pump trainer while the other three members were within the program's target population age range.

4.1.2 Data collection instrument

Data collection for the first meeting was the results of a discussion using nominal group process, a technique used to obtain consensus among a group, described below and resulted in themes representing one week in a future social support group for young adults living with T1DM [82]. The worksheet shown in appendix 1 shows the idea writing worksheet used as a data collection tool for the second meeting. This worksheet lists one of the topics developed in meeting one and asks for initial idea and comments to be recorded on which potential topics, hands on activities, or skills should be included in a discussion structured around the given theme.

4.1.3 Procedure

The CAB met twice on the University of Maryland-College Park campus in July 2014. Each meeting lasted approximately one hour. At the CAB meetings either nominal group process or the idea writing exercise described below was performed per meeting to develop either themes or discussion points for the planned social support program. Themes will represent the overarching topic for each planned social support program meeting, while the discussion points were thought to be particularly important subjects or ones that could provoke meaningful discussions among study participants for a given theme. Both meetings were audio-recorded for future review if needed. Three CAB members, each of whom was in the program's

target age range, were present at the CAB meetings. Following each meeting, all developed material was reviewed, commented on, and approved by these three members as well as the fourth CAB member who could not attend the in-person group meetings due to scheduling conflicts. This study was approved by the Institutional Review Board of the University of Maryland-College Park.

Table 4.1 Process use to obtain consensus among CAB group members

Step	Process
1	Individually brainstorming the major themes that should be covered in six meetings of a T1DM social support group for young adults
2	As a group, record ideas on whiteboard in a round robin type discussion
3	Discuss what themes were recorded and combine similar ideas that fall under the same theme
4	If necessary, vote to determine the 6 themes that should be covered in six meetings of a T1DM social support group for young adults
5	Record final results and confirm group consensus

Nominal group process to generate major themes

At the first CAB meeting, informed consent was obtained using the CAB informed consent form shown in appendix *, the intended social support program was introduced by the group moderator, and nominal group process was used to obtain consensus from CAB group members on what overall themes should be discussed in a social support group for young adults living with T1DM [82]. The steps of the nominal group process that the CAB followed are outlined in Table 4.3.1. Each group member individually brainstormed for twenty minutes to determine the major themes that would be discussed in a social support group for young adults living with T1DM. Afterwards, a round robin discussion ensued for each CAB member to share the themes. Each theme was written on a whiteboard and discussed among the group members.

Similar themes were combined. Because six themes emerged out of the resulting discussion, voting was not necessary. The group moderator then took the six themes and reworded them to make them appealing to potential members of the planned social support program. For example the theme “Nutrition” was changed to “Focus on food: Following nutrition recommendations for diabetes.” The group moderator also put the themes in order of the weeks they would be occurring during the planned social support program. These reworded themes were emailed to CAB group members on the day following the first meeting for approval.

Idea writing exercise to develop detailed discussion points

During the second meeting, the worksheet shown in appendix 1 was used to ask for potential discussion topics, comments, and ideas that would be helpful to social support group discussion topics and comments to be recorded for a particular theme. Six worksheets were made representing the six themes and were put into two groups. For each group of worksheets, each individual CAB member started with one sheet, spent 10 minutes recording his/her ideas and when finished passed the sheet to the next CAB member until they received their initial sheet which was reviewed a final time. This process occurred twice so all worksheets were completed by each group member. Following the second meeting, the group moderator collected the discussion points listed under the Initial Ideas column, reworded them based on the comments column to be concise and appealing in the context of a social support program to generate a list of discussion points for each theme. Discussion points listed in the Initial Idea column were removed from final list if appearing on two sheets or if was already adequately covered in a previous discussion point, or if a discussion point was more appropriate for another theme it was moved by the group moderator. The collected and revised discussion points were emailed to the CAB for revisions and final approval.

4.2 In depth interviews with social support group leaders

The interview were conducted in order to get the opinion of individuals who have organized, lead, or managed social support programs for individuals living with T1DM on the structure of current social support programs, the role of social support program, the topics and discussions that are most helpful in managing T1DM, and the major issues faced through living with T1DM. The interview covered four major topics: 1) the role of a social support group leader, 2) the needs and function of community based social support programs in T1DM management, 3) the perceived barriers and facilitators in managing a community based social support program, and 4) the health care systems role in T1DM care.

4.2.1 Interviewee recruitment

Individuals with experience in organizing, leading, or managing social support groups or programs for individuals living with T1DM who lived in Maryland, Washington D.C. and Virginia were contacted and asked to participate in the interviews between December 2014 and February 2015. Twenty-two individuals were contacted regarding the interview. Fifteen of these individual's contact information was listed as the on the Local Support Groups webpage of the Greater Chesapeake and Potomac chapter of the Juvenile Diabetes Research Foundations. Additionally, Delia Whitfield, the chapter's Senior Outreach Manager, made two referrals of individual who were not listed on the webpage but fit the inclusion criteria of the interview. One interview was scheduled based on a referral by an interviewee. Two interview requests were sent to individuals who had previously been contacted for other reasons. An interview request was also sent to the email listed for both the University of Maryland-College Park and Johns Hopkins University College Diabetes Network groups. Each individual or group was contacted through email or by telephone up to two times and had the project's goals and methods described to him

or her. If they were willing to participate, the program coordinator scheduled an interview date, time, and location that were most convenient to the interviewee. The research team was seeking to conduct approximately 20 interviews and a total of 8 social support program leaders participated in the interviews.

4.2.2 In depth interview procedure

At the scheduled time, the interviewer obtained informed consent using the In Depth Interview Consent Form shown in appendix 2. The interviewer gave a brief description of the purpose of this interview, to collect qualitative data on the use of social support groups for individuals living with T1DM, then proceeded in asking the questions on the in depth interview protocol in appendix 3. Each interviewee was told the interview would last approximately 1 hour, but if time was an issue that the interview could be shortened. This study was approved by the Institutional Review Board of the University of Maryland-College Park

4.2.3 Data collection

Throughout the interview, the interviewer will take field notes to summarize the interviewee's responses to the questions based upon the in depth interview protocol. Additionally, all discussions were audio recorded using an iPhone. The interview covered the four main topics mentioned above with three to five questions regarding each topic. In determining the role of social support group leader, the interviewee was asked their personal relationship with T1DM, their involvement in social support groups or programs, and how they organized and promoted their social support group or program. For the needs and functions of community-based social support programs, questions regarding the group that was managed as well as topics discussed, the role of the social support group in T1DM self-management, key aspects of managing T1DM, and the benefits of attending a social support program. To

determine the perceived barriers and facilitators in managing a social support programs, the interviewee was asked about the barriers and facilitators they had experienced through running a social support program, how they addressed the barriers, why groups are not attended by individuals who would benefit, how attendance could be improved, and any issues related T1DM management and care among young adults. Finally to determine the health care systems role in T1DM care, the interviewee asked about the current health care systems role, how easy it is to access the healthcare system for young adults in the transitional stage, if young adults take advantage of other health care professionals such as nutritionists, what the advantages of community based programs over clinical care, and if they had any suggestions to improve current social support programs for individuals living with T1DM.

4.2.4 Data analysis

The material was familiarized by listening to the audio recordings of each interview while reviewing the field notes taken. For the two interviews where audio recordings were not available the field notes were reviewed. The thematic framework for the interviews focused on whether the question asked was regarding the social support group or regarding factors related to diabetes self-management and whether the answers were 1) descriptive of the social support program 2) a barrier to managing and maintaining a social support program 3) a benefit of attending a social support program, or 4) a barrier to successful T1DM self-management. The interviewees' answer to each question was summarized and compiled into a spreadsheet based on the field notes as well as the audio recording taken from each interview and refined based on subsequent review of the field notes and audio recordings. Based on the thematic framework, codes were applied to both the questions and answers. In order to identify similar themes and factors throughout, thematic charts were generated. Based on these charts as well as referring

back to the field notes and audio recordings, common themes and key ideas were interpreted based on recurrence throughout the interviewees' answers and the importance interviewees stress on particular topics.

4.3 Online survey of young adults living with T1DM

The online survey was created to identify the perception of social support among young adults living with T1DM, identify which factors are significant in the perception of social support, identify major benefits of attending social support programs, and identify major barriers to attending social support programs. The survey inclusion criteria are aged 18-35 and diagnosed with T1DM for at least 1 year. This study was approved by the Institutional Review Board of the University of Maryland-College Park

4.3.1 Online survey distribution

The survey was distributed sending a link to the online survey to social support group leaders to distribute to their groups, to Delia Whitfield who is the outreach coordinator of JDRF Greater Chesapeake and Potomac chapter for distribution, as well as by posting the link to the Greater Chesapeake and Potomac JDRF chapter Facebook page along with a brief description and eligibility requirements in completing the survey. Informed consent was established on the front page of the survey.

4.3.2 Data collection tool

The survey can be found in appendix 4 and was generated using the Qualtrics survey tool software version 61472 [83]. The survey consists of an informed consent section, a demographics section i.e. age racial/ethnic group, diabetes information section i.e. insulin delivery method, years since diagnosis and, use of continuous glucose monitoring and a perception of social support section modeled after the RAND medical outcomes (RAND MOS)

social support survey [84]. The RAND MOS social support survey was developed to measure the perception of social support among chronically ill individuals and was previously validated with multitrait scaling analysis supporting the four dimensions of support as well as the overall support scale. These scales were distinct from structural measures of social support and related health measures, such as depression. The RAND MOS social support survey showed high reliability with all $\alpha > 0.91$.

The diabetes information section

This section of the survey was used to capture information on current self-management practices including the use and perception of social support programs. Example questions include “What was your last A1C reading”, “have you ever attended an in person, formal type one diabetes social support group or program, such as a JDRF affiliated support group”, “if yes, what areas of diabetes management have felt most improved due to attending a social support group or program”, and “do you use online sources of support regarding diabetes management, such as Facebook support groups”.

The RAND MOS social support survey section

This section of the survey measures the individuals perception of social support, consists of 19 questions, all of which were reproduced in a manner consistent with the original tool. The survey covers four dimensions of social support along with one additional item not belonging to a particular dimension: emotional and informational support with 8 items, tangible support with 4 items, affectionate support with 3 items, and positive social interaction with 3 items.

4.3.3 Data analysis

Qualitative results

The qualitative survey results, the answers to questions 16, 17, 20 and 21 which asked for benefits of attending social support programs and important topics to be typed out by the respondent as well as ranking reasons why a social support program was not attending and how different types of T1DM care were effective in improving self-management, were recorded to identify benefits of social support programs and barriers to attending social support programs reported by the individuals who had taken the survey.

Differences in perception of social support

The raw score of each dimension of the perception of social support section as well as the overall score of the perception of social support section were converted to a 100-point scale. Descriptive statistics were produced. Independent sample t-tests and one-way ANOVA tests were used to test differences in the overall perception of social support as well as differences in emotional and informational support, tangible support, affectionate support, and positive social interaction as given by the results of the perception of social support survey section of the online survey between sex, education level, employment status, income group, type of insurance coverage, A1C category, insulin delivery method, attendance of a social support group ever, attendance of a social support group in the last six months, membership of a diabetes club, and use of online social support. Significance was set at $P < 0.05$. All quantitative analyses were done using SPSS Version 22.0.

CHAPTER 5: RESULTS

The results of the in-depth interviews with social support group leaders were used to describe current social support programs for individuals living with T1DM, to describe the role of social support programs in T1DM self-management, to identify major benefits of and barriers to attending a social support program, and to identify issues particularly important for young adults living with T1DM. The online survey with young adults living with T1DM was conducted to identify factors important to the perception of social support. The CAB meetings resulted in a framework for a proposed six-week social support program for young adults living with T1DM that addresses major themes and provides discussion points for each theme.

5.1 Community Advisory Board

5.1.1 CAB demographics

The CAB was made up of 4 individuals. The CAB was half female and had a mean age of 28 ± 11.4 . All members of the CAB were diagnosed with T1DM for greater than 1 year, were Caucasian, had either some college education, or are a college graduate, and had household incomes between \$20,000 and \$100,000+ per year.

5.1.2 Themes and discussion topics developed by the CAB

Six themes emerged during the nominal group process conducted at the CAB meetings. These themes were decided on by the CAB members to be important factors in diabetes self-management and/or that could represent significant barriers to receiving adequate and effective care based on their own personal experiences. Each theme represents one meeting of a social support program for young adults living with T1DM. Below is each theme resulting from meeting one with the CAB's rationale, quotes from CAB members, as well as discussion points resulting from meeting two.

Week one: “Taking care of your diabetes: Self-care activities and how to manage them”

Self-care activities such as self-monitoring of blood glucose and insulin dosing are critical in successfully self-managing diabetes, and the group agreed that this theme would be relevant to young adults living with T1DM as well as a good starting point for the following social support program meetings. This discussion will be an opportunity for group members to share strategies, techniques, and frustrations related to self-care activities. When introducing the theme in the round robin discussion, one CAB member remarked, “The obvious stuff (self-care activities) is still important to talk about... why do you sometimes forget to check blood sugar?” When discussing managing self care activities and why it is an significant conversation to have, another CAB member said “What is your ideal range, what is your recommended range, and what do you think you can do to make those the same?” The discussion points for week one were the following: 1) self-monitoring of blood glucose, 2) blood glucose awareness, 3) insulin administration, 4) insulin pump use, 5) handling emergency situation, 6) use of other medications and 7) adhering to treatment recommendations in everyday living.

Week two: “Focus on food: Following nutrition recommendations for diabetes”

Nutrition and diet are extremely important for diabetes self-management. This discussion will allow for a discussion of general nutrition information, techniques and strategies to consume recommended amounts of each macronutrient, and how different foods affect blood glucose levels. When discussing questions encountered in their own experience living with T1DM one CAB members asked “How often should I eat?” while another stated, “How much carbs, fat, protein should I eat?” The discussion points for week two were the following: 1) macronutrient information and recommended intake, 2) how each macronutrient affects blood glucose levels, 3)

serving vs. portion sizes, 4) how often one should eat, 5) eating food not prepared at home, 6) “Cheat foods”, and 7) keeping a healthy relationship with food.

Week three: “Stress and diabetes: Physical and mental aspects”.

Diabetes can cause a high number of stressful life circumstances, and stressful circumstances can in turn have a large affect on blood glucose levels. Recognizing how stresses affect your blood glucose levels and having stress management techniques can relieve some of the burden of T1DM. When discussing why stress management is important for T1DM management, a CAB member commented, “ It’s important to avoid burnout (referring to disease burnout, or the lack of self-management activities due to high stress)”. Another CAB member posed “How does emotional stress affect your blood sugar, and how does your blood sugar affect your emotions” The discussion points for week three were the following: 1) general stress management, 2) physical activity and blood glucose levels, 3) illness, 4) emotional stress, 5) disease burnout, and 6) unhealthy habits used to cope with stress.

Week four: “Knowing your body: How self-care activities, nutrition, stress, and everything else affects your diabetes”

This discussion will expand the topics covered in the first three weeks discussions with a further emphasis on the personal affects activities have on blood glucose levels. When discussing various activities that young adults may encounter, one CAB member asked “How does working out, exercising, drinking alcohol, etc., affect my blood sugar?”. In a discussion of personal strategies used to recognize blood glucose levels, one CAB member recounted “When I started out I tried to guess my blood sugar before I checked it.... Just knowing the area is good, it’s helpful for times when you can’t check your blood sugar”. The discussion points for week four were the following: 1) recognizing how blood glucose levels react to changes in daily life, 2)

effects of sleep, 3) predicting situations where blood glucose levels may be affected, 4) and recognizing high and low patterns.

Week five: “Handling your relationships with diabetes: Personal, professional, social, and public”

This discussion will allow participants to discuss a variety of stresses associated with social situations encountered in living with T1DM and share techniques and strategies on handling these situations. When discussing general interactions in public, meeting new people, or in social situations where diabetes is brought up, a CAB member said “How do you react in public, are you open with it or do you try to hide it?”. When commenting on why being able to effectively communicate within personal relationships is important to young adults living with T1DM a CAB member said “Since this is going to be a young adult population...They will be replacing old people who supported them with newer people who may not know about diabetes”. During a discussion the perception of T1DM by the general public or in interactions with individuals not familiar with T1DM, one CAB member probed the group “What does the public know, how do they feel about it. What do you say about it?”. The discussion points for week five were the following: 1) managing diabetes in personal and professional relationships, 2) the public perception of diabetes, 3) handling social situations, and 4) the reliability and usefulness of online sources of support.

Week six: “Dealing with health care: Who you should see, how often, and things to talk about”

Young adults living with T1DM often encounters issues and frustrations regarding access and information to health care. This discussion can provide a forum to discuss these issues and provide strategies to have beneficial communication with health care professionals as well as give the opportunity for those satisfied with their care team to provide recommendations. When

discussing their personal experience with gaps in healthcare, one CAB member recalled “I’ve had a lot of problems with moving around, getting blood tests, I’ve gone long periods of time without seeing a doctor” During a discussion of seeing registered dietitians to supplement T1DM care, one CAB member said “I saw one (a registered dietitian) when I was first diagnosed and it was not helpful”. The discussion points for week six were the following: 1) what members of a diabetes care team should be seen, why, and how often, 2) finding a diabetes care team, 3) having successful interactions with health professionals, 4) new technologies such as continuous monitoring systems, 5) insurance resources and frustrations, and 6) feelings and frustrations experienced during diabetes health care appointments.

5.1.3 Overall structure of the social support program developed by the CAB

Figure 5.1 shows the overall flow of the social support program themes and discussion topics. The first four week’s discussion themes reflect many aspects of T1DM care given by the American Diabetes Association Standards of Medical Care for Diabetes [18]. The final two weeks’ discussion themes move away from diabetes self-management discussions and focus more on social and health care level aspects of living with T1DM. Week five’s discussion theme extends to interpersonal and community situations that occur with living with T1DM and how they impact T1DM self-management. Week six emphasizes the type of care young adults living with T1DM should be receiving, how often, and what should be discussed as well as other frustrations that come with navigating the health care system. The discussion points highlight issues of basic T1DM care as well as those that may be particularly important for young adults living with T1DM.

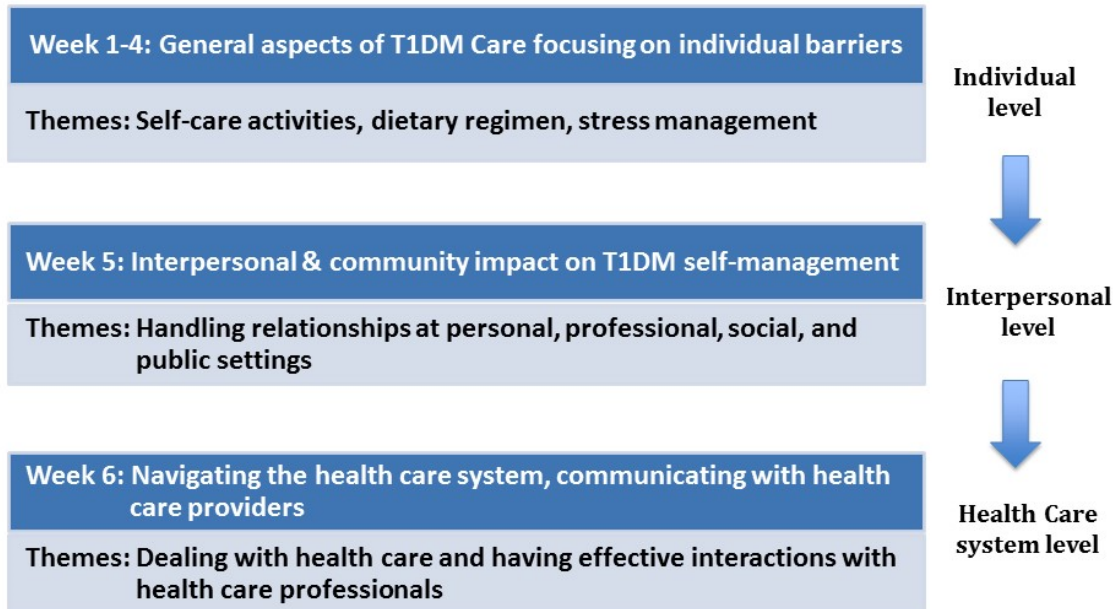


Figure 5.1: Overall flow of themes developed by the CAB

5.2 In depth interviews with social support group leaders

Out of the twenty two individuals contacted, a total of eight interviews were scheduled and conducted to determine the current state of social support programs, the barriers to running and maintaining a successful social support program, the perceived benefits of attending social support programs, and the perceived barriers to successful T1DM self-management in young adults. One individual who was contacted was not willing to meet for an interview and thirteen individuals did not reply after the first or second interview request. Interviews lasted between 24 minutes and 62 minutes with an average time of approximately 45 minutes. Two of the interviews were not audio-recorded; one due to technical errors and one due to the interview environment not being conducive to audio recording. The low number of interviews was due to low response rate to email requests, with only seven out of twenty one responses to email

requests, as well as the lack of social support group leaders located in a reasonable distance for an interview to be scheduled.

5.2.1 Interviewee description

Six interviewees were either current or former leaders and/or coordinators of formal social support programs for individuals with T1DM in either Maryland or Virginia. Of these six, one was living with T1DM, another was a certified diabetes educator working in a diabetes clinic, and the remaining four were parents of children living with T1DM. Two interviewees were founders of chapters of a social support organization for individuals with T1DM on college campuses. Both of these individuals were living with T1DM and were based in Maryland.

5.2.2 Types of social support programs and characteristics

Of the interviews conducted, two types of social support programs emerged. The first is formal social support groups, which met monthly at a community location, typically a church, clinic, library, and often consisted of alternating meeting style between unstructured discussions and invited speakers on relevant diabetes topics. The second type were social support programs based on college campuses and exclusively for students of that institution. All group leaders were highly motivated individuals who had a strong interest in T1DM management and the issues faced by individuals living with T1DM. One group member's quote summarized many of the group leaders attitude towards managing a group and their role in providing resources: "People don't know there are resources out there, and I am willing to go out and get those things, so if you're not like that I can share them with people to make life easier". A thematic chart describing the two types of social support programs is shown in Table 5.1.

Table 5.1: Description of types of social support programs of interview participants

Formal support groups					
Interview	Meeting venue	Approximate meeting per year	Main target audience	Recruitment	Definition of success
1	Church	9-10	Parents of children living with T1DM	Word of mouth Clinical connection, JDRF ¹	Members getting something out of it
2	Library	7-8	Parents of children living with T1DM	Word of mouth JDRF	Attendance
3	Community center	8	Parents of children living with T1DM	Word of mouth, clinical connection, JDRF	Attendance Support given
4	Clinic	12	Adult insulin pump users	Word of mouth, clinical connection, JDRF	Attendance Questions being asked
5	Clinic	12	Adult insulin pump users	Word of mouth, clinical connection, JDRF, advertisements	Repeat attendances Discussion Participant thanks
7	Library	7-8	Parents of children living with T1DM	Word of mouth, JDRF	Regular attendance Members getting something out of it
College based support groups					
Interview	Meeting venue	Approximate meeting per year	Target audience	Recruitment	Definition of success
6	On campus	No-set amount (informal meetings)	Undergraduate and graduate students	Word of mouth, limited advertising	Members getting something out of it
8	On campus	24	Undergraduate and graduate students	Word of mouth, clinical connection, advertising	Any benefit to members Increase in quality of life Having safety net

1. Juvenile diabetes research foundation

Formal support groups

The formal support groups met between seven and twelve times per year depending on the group. The formal support groups served two different populations but retained similarity in structure. Four of the groups were mostly attended by parents of children living with T1DM, even though all individuals affected by T1DM were welcome to attend. The other two groups consisted of adult insulin pump users between twenty and seventy years of age. All group leaders reported group members consisting mostly of women. Meetings for both types of formal support groups consisted of either a speaker or informal group discussions. Many interviewees stated that the informal group discussions were more effective for relieving diabetes related stress and were more popular among group members. Some examples of speakers and/or topics include: school nurses, pump vendors and other company representatives, registered dietitians, foot care, dental care, and stress management. Speakers regarding school were limited to the groups serving parents of children living with T1DM. Attendance was reported as a problem for all groups, including limited attendance at a particular meeting and irregular attendance by individuals. Group leaders did not actively recruit membership, but information about the group spread through word of mouth, by recommendations for newly diagnosed individuals/families from clinicians, posting advertisements in clinics, having contact information on JDRF's list of support groups, and maintaining email lists. Group leaders defined a successful group meeting based mainly upon the positive experience of those who attend being related to the leader and attendance, especially regularity. On what made a successful meeting, it was said "I felt as long as you were providing support, whether it was to one person or to ten, it was a success", "If they are talking and there's not a lot of quiet time I know they are getting something out of that" and, and that "they keep coming back"

College based support groups

The college based support groups were at different stages of development. The first group was formed less than 1 year ago and meets informally with no set meeting schedule to discuss issues regarding college and diabetes such as eating healthy on campus, alcohol and diabetes, and maintaining blood glucose control. The group has recruited lightly and most of its members have been found through word of mouth and group member recommendations to personal acquaintances living with T1DM. The second group has been established for over a year, and meets one to two times a month at scheduled events. This group has a connection to the student health center for referring new members as well as displays advertisements on campus. Topics discussed include alcohol and diabetes, anxiety and depression due to diabetes, and general “taboo topics” which individuals may not feel comfortable speaking to their endocrinologist about. Concerning these taboo topics it was said, “Our age group is vulnerable to anxiety and depression and that sort of thing. Having someone to talk to is great, and having someone to talk to you about stuff your doctor won’t”. The group leaders defined success as members getting any benefit from attendance often assessed by self-report to the group leader, regular attendance of members, and increases in quality of life, sharing resources, and having a support system if emergency situations occur. About success it was said “The fact that we have people return on a regular basis means some people are at least getting something out of it” and that “Giving any little benefit that’s going to improve your quality of life” were measures of their groups success. One group leader also related a story regarding a situation where a group member was without testing supplies and insulin due to a fire, but was able to contact other group members and receive enough supplies to maintain their self-management activities.

Social support group summary

Both these types of groups met between one to two times per month and seven out of eight regularly invited speakers on diabetes related issues. Many were either associated with a clinic, either formally or through referrals, or to JDRF. The major recruitment strategy for both types of group was word of mouth referrals, and both reported that advertisements either through flyers, online presence, and campus presence were less effective at finding new members. Recruitment of new members was not a major priority for all group leaders except the newly formed college based group, but instead maintaining the group and offering benefit to the current members was. Attendance and participant engagement, appreciation, and perceived benefits were the major indicators of success among interviewees. The focus of both types of group was similar; to provide a venue for individuals with similar experience to share experiences, both positive and negative, with a group who empathizes and provide comradery. The major difference between groups was the demographics of the members, and thus the resulting focus of discussions. The college based groups narrow age range allowed for issues common to young adults living with T1DM to be a major factor in discussions, such as alcohol use, while the formal groups often focused on either parenting a child with T1DM for the four groups consisting mainly of parents and sharing information on technology and techniques for the groups consisting of pump users. According to the group leaders, the main reason for not attending a social support program also differed by group type, with some overlap. The most common reason for not attending a formal support group was based on the logistics of attending the group meetings due to time constraints while the most common reason for college based support groups was based on denial of T1DM being a major factor in everyday living.

While the structure, demographics, and other factors may differ between groups, the goal of all leaders appeared to be the same: to provide a venue for individuals who often are different from the majority of the population an opportunity to be among their peers, share their emotions, and experience an empathetic community. Group leaders also stated that having a community of peers allows for more open, comfortable communication of issues faced through living with diabetes, many of which are not clinically related. Regarding this idea, one group member said “There isn’t much you can’t Google when it comes to diabetes care, or you can ask your endocrinologist, but you’re not going to get that positive viewpoint”

5.2.3 Perceived benefits of attending social support programs

The perceived benefits of attending social support programs reported by the group leaders were described and grouped into three aspects: group learning, emotional aspects, and building a peer network. There was a large overlap of the perceived benefits of attending a social support program between all social support program leaders, regardless of the type of support group or the demographics of the group served. The similar issues faced by all individuals living with T1DM can explain the consistency between group types. A thematic chart for the perceived benefits of attending a social support program is shown in Table 5.2.

Table 5.2. Benefits of attending a social support group or program reported in interviews of support group leaders

Interview	Group learning	Emotional Aspects	Personal Connection
1	Share techniques	Know you are not alone Vent frustrations	Establishing peer group
2	Share positive experiences	Know you are not alone Vent frustrations	Make connections
3	Share experience Share information Share ideas Learn new techniques	Only people living with T1DM can relate	Make connections
4	Share techniques Share experience with new technology	Know you are not alone	Face to face contact
5	Share experience Share problems	Engagement with disease	Develop bonds Make connection
6	Share positive viewpoint	Empowering Personal perception of diabetes Vent Frustrations	Spend time with other people living with T1DM
7	Share information Share Knowledge Provide resources	Know you are not alone Vent Frustrations Empathy Emotional well-being Personal perception of diabetes	Spend time with other people living with T1DM Comradery
8	Share experience Provide resources	Know you are not alone Personal perception of diabetes	Motivation from peers Spend time with other people living with T1DM

Group learning: practical skills and experiences

The sharing of ideas, experiences and techniques was mentioned purposely by 7 interviewees and the concept of learning from the group was present in all interviews. Many leaders mentioned that getting different perspectives and ideas was a major benefits, stating “sometimes you’ve been doing something for years and you think it’s the right thing, but it’s not,” and “I feel like I am well educated and involved in the diabetes community, but every time I went to a meeting I learned something new”. One group leader stated, “Some people aren’t so involved in the diabetes community, they don’t know about things like the Dexcom (a

continuous glucose monitor) or pumps”. Some examples of ideas and techniques that were shared included sharing experience with new technology such as insulin pumps and continuous glucose monitors, giving a bolus of insulin before changing infusion sites while using the Omnipod (a type of insulin pump), using the square bolus feature on insulin pumps when eating high fat meals, insulin dosing recommendations such as giving insulin 15 minutes before eating to reduce postprandial glucose rise, relating positive experiences with medical supply companies, and sharing positive experiences with diabetes, such as reaching a A1C goal.

Emotional aspects

A common comment was that attending social support programs let members “know they are not alone” in having T1DM with 5 interviewees using the exact phrase and the others echoing similar sentiments. On why knowing they are not alone is important, it was said “seeing people that are going through the same thing is helpful because diabetes isn’t like other chronic conditions, its constant care”. Related to this, making connections to other individuals living with T1DM was stated as a benefit of attending social support program.

In addition to sharing practical advice such as self-care recommendations, the social support group also provides a place to share emotions and vent frustrations, such as the public perception of T1DM being the same disease as T2DM, and being able to address the emotional side of diabetes with individuals who will understand the experience. One group leader said regarding invited speakers to her group “one of the most popular topics was having someone come in to talk about the emotional side of diabetes”. A major frustration among group members relayed through the interviews was the perception of the public as T1DM and T2DM being the same disease or having confusion between the two due to the much higher prevalence of T2DM and poor education about T1DM. A common emotion related during the interviews was that only

people who have experience with T1DM are able to truly empathize, making social support programs one of the few venues to receive this type of support.

Peer support network and personal connections

The role of the social support program was often suggested as being a place to find empathy for individuals living with T1DM. Attending a support group also builds comradery among individuals, which can lead to positive motivation to self-manage their diabetes. One group leader remarked “Being in the group motivates me to keep up” referring to self-management activities. Another said “If you are meeting on a regular basis, even just to talk, even just the idea of spending time around other people with diabetes, I think can be very empowering and very motivating”. The group leaders stated that the aspects most improved in T1DM self-management from attending social support programs were individual perception of T1DM, motivation and engagement in self-management and dealing with associated challenges, reinforcement of good behaviors, and accepting T1DM as a part of life. One interviewee repeatedly stated that a major benefit of social support programs was allowing for individuals with diabetes to recognize that while a major aspect of their life, T1DM does not define who they are as a person.

Group leaders also stated that the peer environment and of a social support program offered benefits. When discussing the benefits of attending a social support group compared to clinical care, one group leader mentioned that “Everyone (at the social support group) is a diabetic, most endocrinologists are not, having someone who is physically going through this, who are actual diabetic, can be really helpful”. It was also noted that individuals may not feel comfortable discussing certain topics, such as underage alcohol use or emotional problems, with endocrinologists and other members of a diabetes care team. Regarding this dynamic and why a

social support program may be more suited for discussing these issues it was said “They are very good at the diabetes part, but that are not very good at the social part and the other issues that can be caused by diabetes”.

5.2.4 Barriers to successful social support programs

Group leaders also stated many barriers to running a successful social support program and are grouped as perception of social support programs, practical issues, stigma regarding living with T1DM, and issues of avoidance of T1DM and are summarized in Table 5.3. These

Table 5.3: Barriers to successful social support programs reported in interviews of support group leaders

Interview	Perception of support groups	Practical issues	Stigma	Avoidance
1	“Weak” Feel like it wont help Distress due to social interaction	Finding membership	Don’t want to identify as living with T1DM	
2	Distress due to social interaction	Logistics Time commitment Funding for group		Diabetes Burnout
3	Feel like it won’t help	Logistics Time commitment	Don’t want T1DM to affect self perception	
4	Feel like it wont help	Logistics Finding membership	Don’t want to identify as living with T1DM	Denial of T1DM
5	Haven’t experienced support group: negative association	Logistics Finding membership		Denial of T1DM
6	Feel like it won’t help	Finding membership		Denial of T1DM Diabetes Burnout
7	Distress due to social interaction			Denial of T1DM Diabetes Burnout
8	Feel like it wont help	Logistics Finding membership	View of T1DM as disability	Denial of T1DM

Attendance was regularly brought up through the interviews. Group leaders stated difficulties in seeking membership due to many factors including: the perception of social support groups, practical issues, the stigma of diabetes, and avoidance of diabetes. It should also be noted that many group leaders expressed that social support programs are not suited for all individuals simply due to personality traits such as high social anxiety and not feeling comfortable in group situations, but they should be available to all individuals living with T1DM if wanted. The most identified barrier to attendance was logistical problems i.e. meeting time, date, length, and location for the formal groups and new member recruitment for the college-based groups, which could be caused by a variety of factors. Again there was a large overlap of the perceived barriers to attending a social support program between all social support program leaders, regardless of the type of support group or the demographics of the group served.

Perception of social support groups

The perception of attending support groups making one “weak” was stated as being a reason for not attending a social support program by one interviewee and this general perception of social support program attendees was stated as a potential barrier in many interviews. This notion was suggested as coming from the idea of support programs only being utilized by individuals who can not handle the stresses of their condition compared to the idea of support programs being an outlet for all individuals to share experiences regardless of their management status. This concept was often brought up in relation to the barrier to successful self-management due to low perceived susceptibility and general feelings of health and it was said “Young people even with diabetes feel like they are healthy individuals and do not need that assistance”. The perception attending a support group will not be beneficial was also mentioned. Regarding the

perception that attending support groups will not be beneficial it was said, “They think they have all the answers”. Because young adults are not yet affected by complications and may manage their diabetes well, they do not think that attendance will improve either their T1DM management or emotional state. This perception may also come from the fact that many groups are targeted towards specific populations such as parents of children living with T1DM or insulin pump users, and the topics and discussions in these groups would not be relevant to individuals outside these populations.

Practical issues

Despite attendance being an issue, most groups did not actively recruit new membership and relied on word of mouth referrals for seeking new participants. This was mainly due to the privacy issues associated with seeking out new members through clinics, lack of funding, as well as the time commitment of the group leaders themselves. Logistical issues were often mentioned as a reason for poor attendance. The lack of organization of group i.e. regular meeting time and location, can make it difficult for individuals looking for a social support group to plan and allot time in their schedule to attend. The time commitment of attending a meetings including travel time was also brought up often. Typical meeting times were approximately one hour, but accounting for travel time can make attending a social support program a much larger commitment. One interviewee stated that some members of her group had traveled approximately an hour and half to two hours each way to attend, bringing the total time to between four and five hours. This large travel time was due to a lack of a closer support program, which suggests a need for more localized support programs. Related to the time commitment, competing life priorities, i.e. school, work, or employment, was stated as being a barrier to attendance. Meeting times were generally in the evening on weekdays, so individuals with

schedule conflicts at these times would not be able to attend. Finally, having meeting topics that interest the group was mentioned as a significant barrier to attendance. Bringing in speakers alternating with unstructured group discussions reduced this barrier somewhat, but the limited number of speakers available and topics to be covered may lead to poor attendance. Related to this, poor attendance was reported to sometimes lead to further poor attendance due to unproductive meetings.

Stigma of diabetes

Interviewees suggested that one reason for not attending a social support program was the concern of being identified as a diabetic. This may be due to poor public knowledge of T1DM, privacy concerns, or a reluctance to accept T1DM as a major factor in one's life. Regarding the stigma associated with diabetes it was said "I think there's still a stigma as diabetes as a disability, maybe you're limited and can't do certain things, some people do not want to reveal they are diabetic because of that stigma" and "people don't like the association with type two, and the questions (that come along with that association)". Pertaining to the second quote, a common frustration was the public perception of and confusion between T1DM and T2DM. Attending a social support program for individuals living with T1DM identifies the individual as living with T1DM, information they may not want to make public.

Avoidance of diabetes

Avoidance of diabetes was stated as a major reason for not attending social support programs. The avoidance of diabetes is common among individuals living with T1DM and commonly is referred to as disease burnout, or the lack of self-management due to the stressful circumstances of disease management. One interviewee stated that "Young people aren't ready to talk about diabetes yet" referring to the fact that many young adults are not comfortable in

discussing topics related to living with T1DM and thus are unwilling to attend social support programs. As mentioned above, living with T1DM requires constant care, which can generate high amounts of stress. It was also said that not yet accepting diabetes as a major part of one's life was common among young adults. Avoidance of diabetes was also stated as a significant factor barrier to successful T1DM self-management among young adults in addition to being a barrier to support program attendance.

5.2.5 Barriers to successful T1DM self-management among young adults

Group leaders also stated issues in T1DM self-management among young adults which were grouped into being related to self-management activities, the perceived health status, as well as avoidance of diabetes and are summarized in Table 5.4.

Table 5.4 Barriers to successful T1DM self-management among young adults reported in interviews of support group leaders

Interview	Self-Management	Perceived Health status	Avoidance
1	Discipline Competing life priorities superseding self-management	Do not take advantage of health care professionals	
2		Feeling invincible	Unresolved anger towards T1DM Burnout
3	Competing life priorities superseding self-management	Do not take advantage of health care professionals	
4	Peer pressure in social situations Increased responsibility Competing life priorities superseding self-management	Do not take advantage of health care professionals	Denial of T1DM
5	Inconsistent management	Do not take advantage of health care professionals Feel healthy	Denial of T1DM
6	Discipline Peer pressure in social situations Increased responsibility	Do not take advantage of health care professionals Feel healthy	Denial of T1DM Burnout
7	Maintaining self-management	Do not take advantage of health care professionals	Denial of T1DM Burnout
8	Peer pressure in social	Do not take advantage of health care	Denial of T1DM

Self-management and increased Responsibilities

Consistency and discipline in self-management with the transition to independent management and increased responsibilities during young adulthood was mentioned by five of the interviewees and stressed as a major factor in maintaining glycemic control. Dependable SMBG, insulin dosing, and maintaining a healthy diet requires active engagement. One interviewee stated “It’s a lifestyle interference, so the blood glucose testing and insulin taking is inconsistent”. For many young adults, a portion of this burden was previously taken on by their parents and the shift towards adulthood necessitates further effort in order to retain sufficient self-management. On why young adults were particularly at risk for poor management and interviewee stated “it’s hard to manage diabetes with all the changes in life”. These issues were said to be more prevalent in individuals who were recently diagnosed compared to those who had been living with T1DM since childhood. All interviewees who were living with T1DM reported that avoiding peer pressure and making healthy choices in social settings, especially regarding alcohol use and dietary choices was a major issue and responsibility placed upon young adults living with T1DM.

Perceived health status

Low perceived susceptibility to complications and other health issues due to poor self-management was also stated as a reason for not maintaining recommended self-management activities. Young adults generally are in good health and are not yet affected by complications related to poor glycemic control, which can take years to develop. Group leaders also stated that young adults living with T1DM do not take advantage of health care professionals beyond their

primary care provider, such as nutritionists and certified diabetes educators, and this may be due to low perceived susceptibility to complications, feelings of good overall health and invincibility, competing life priorities and the fact that adult care is less regimented than pediatric care. The pediatric to adult care transition was reported and being potentially problematic depending on one's situation, relationship to their diabetes care team, and individual's responsibility with self-management.

Avoidance of diabetes

Denial of diabetes as being a major part of one's life and lack of acceptance of need to engage in self-care activities due to disease burnout was stated as both a barrier to successful self-management and a barrier to attending social support programs for young adults living with T1DM. While discussing why this is an issue, it was said "Some people don't like to realize they are diabetic" and that "it's hard to manage diabetes with all the changes in life". The avoidance combined with the low perceived susceptibility due to overall good health may cause individuals to not engage in self-management as meticulously as they should. Denial of the condition was especially noted to be important among newly diagnosed individuals, while disease burnout was stated as an issue for all young adults living with T1DM.

5.3 Online survey

5.3.1 Descriptive statistics

Seventy-five individuals initiated the survey tool and thirty-eight individuals completed the survey and were included in the analysis. Those who did not complete the survey either initiated the survey but did not answer any questions (nineteen individuals) or completed the demographics and diabetes information section but not the perception of social support section (eighteen individuals). The average age 25.8 ± 5.1 years with an average years since diagnosis of

T1DM of 14.3 ± 7.7 years. 73.7% of respondents were female. The respondents were highly educated with 50% having at least some graduate or professional education and of high socioeconomic status with 52.4% earning greater than \$60,000 per year. The majority of respondents were never married, 78.9%, White, non-Hispanic, 94.7%, and had private insurance provided by their employer, 84.2%. Respondents reported high levels of glycemic control with 84.2% reporting their last A1C reading being less than 8%. The majority of respondents were insulin pump users, 86.8%, and used continuous glucose monitors, 60.5%. 63.2% of respondents reported that they had ever attended a social support group or program, but only 34.2% reported attending a social support group or program in the past 6 months. 57.9% of respondents were members of diabetes clubs and 68.4% used online sources of support, such as diabetes support groups on Facebook.

The scores from the perception of social support section for each dimension as well as the overall scale shown in Table 5.5 were consistent with scores obtained in the validation study of the RAND MOS social support scale [84].

Table 5.5: Perception of social support in online survey participants.

Dimension/Scale	Average Score*
Emotional and Informational	70.7 ± 25.3
Tangible	67.7 ± 31.3
Affectionate	77.4 ± 26.9
Positive Social Interaction	77.7 ± 25.6
Overall	72.5 ± 23.2

* Average score reported as raw score converted to 100-point scale \pm standard deviation

Table 5.6: Demographics and diabetes information of online survey participants

Variable	Percentage
Female	73.7
Education Level	
High school or less	2.6
Some college	26.3
Completed college	21.1
Some graduate/Professional school	21.1
Completed Graduate/ Professional school	28.9
Employment Status	
Full time	71.1
Part time	18.4
Unemployed	10.5
Marital Status	
Never Married	78.9
Married	21.1
Income Level	
\$0-\$19,999	5.3
\$20k-\$39,999	10.5
\$40k-\$59,999	13.2
\$60k-\$79,999	18.4
\$100K+	34.2
No answer/ Don't Know	18.4
Racial Ethnic Group	
White, non-Hispanic	94.7
Hispanic	5.3
Variable	Percentage
Type of Insurance Coverage	
Private from Employer	84.2
Private Bought	13.2
Other	2.6
A1C Category	
Under 8%	84.2
Between 8% and 10%	15.8
Continuous Glucose Monitor Use	
Yes	60.5
Insulin Delivery Method	
Insulin Pen	13.2
Insulin Pump	86.8
Attend Social Support Program Ever	
Yes	63.2
Attend Social Support Program in Last 6 Months	
Yes	34.2
Member of Diabetes Club	

Yes	57.9
Use Online Support	
Yes	68.4

5.3.2 Result of independent sample T-tests and One-way ANOVA

This independent sample T-tests found that males had lower scores on the Emotional and Information dimension of the perception of social support section (55.8 ± 29.5) compared to females (75.9 ± 21.7) ($p=0.028$), insulin pen users had significantly lower scores on the Tangible Support dimension of the perception of social support section (40.0 ± 19.1) compared to insulin pump users (71.9 ± 27.6) ($p=0.032$), and individuals who had never attended a social support program had significantly lower scores on the Tangible Support and Affectionate Support dimensions (52.7 ± 37.8 and 62.5 ± 34.0 respectively) compared to individuals who had ever attended a social support program (76.4 ± 23.4 and 86.1 ± 17.3), ($p=0.022$ and $p=0.027$ respectively). Average scores and significance levels are summarized in Table 5.7.

Table 5.7: Perception of social support score on emotional/informational, tangible, and affectionate support by gender, insulin delivery method, and ever attending a social support group or program.

	Dimension of social support					
	Emotional& informational	p-value	Tangible	p-value	Affectionate	p-value
Gender						
Male	55.8 ± 29.5	0.028*	60.0 ± 29.9	NS	67.9 ± 32.3	NS
Female	75.9 ± 21.7		70.4 ± 31.8		81.4 ± 19.2	
Insulin delivery						
Pen users	$51.3 \pm 30.$	NS	40.0 ± 42.8	0.032*	63.3 ± 31.7	NS
Pump users	73.6 ± 23.5		71.9 ± 27.6		79.6 ± 26.0	
Attend SSG ever		NS				
Yes	76.8 ± 19.3		76.4 ± 23.4	0.022*	86.1 ± 17.3	0.027*
No	60.2 ± 30.9		52.7 ± 37.8		62.5 ± 34.0	

*Significant $p < 0.05$

There were no significant differences between average scores in any dimension or overall score on the perception of social support section of the survey based on marital status, racial/ethnic group, A1C category, attend a social support program in the last 6 months, being a member of a diabetes club, or use of online support. One-way ANOVA tests showed there were no significant difference between average scores in any dimension or overall score on the perception of social support section of the survey between groups for education level, employment status, and income level. The most significant results of this analysis were: the differences in perception of social support on the affectionate and tangible support dimensions based on ever attending a social support group, and the lack of a difference in perception of social support in any dimension or in the overall score for A1C category.

5.3.3 Results of qualitative analysis

The benefits given of attending social support programs by individuals who had ever attended a social support program include, general support, blood glucose testing, accountability, insulin dosing, ability to ask questions, mental strength, and tips and ticks to everyday life. Only six individuals answer this question compared to the twenty-four individuals who answered yes to the previous question. Reasons why a social support group or program was never attended were ranked in the following order: 1) No program or group available, 2) not enough time, 3) no interest, 4) don't feel it would help with diabetes management, 5) don't feel comfortable attending and 6) other reason (none listed). These ranking was based on the answers of eleven individuals out of fourteen who responded they had never attended a social support program. Ten individuals responded with beneficial topics for discussion in a social support group or problem include sharing personal experiences with self-management, insurance issues, what to do when sick, traveling or exercising, daily problems and solutions, healthy food options/diet/nutrition,

information about new technology, and stress management. The ability of each activity to improve diabetes self management were ranked by eleven individuals in the following order: 1) in person diabetes social support group or program, 2) doctors appointments with your primary diabetes caregivers, 3) additional diabetes education 4) online diabetes social support group or program, and 5) other.

CHAPTER 6: PROPOSED INTERVENTION

Based on the formative research conducted as well as previous literature reviewed, this chapter will propose a social support program for young adults living with T1DM that highlights the benefits of attending a social support program as well as attempt to address the perceived barriers to successfully implementing and running a social support program.

6.1 Conceptual framework

The conceptual framework of the proposed programs relates how the social support group meetings will provide individual and group resources to improve T1DM psychosocial functioning, specifically feelings of social support, self efficacy, and diabetes quality of life, T1DM self management activities, and ultimately glycemic control

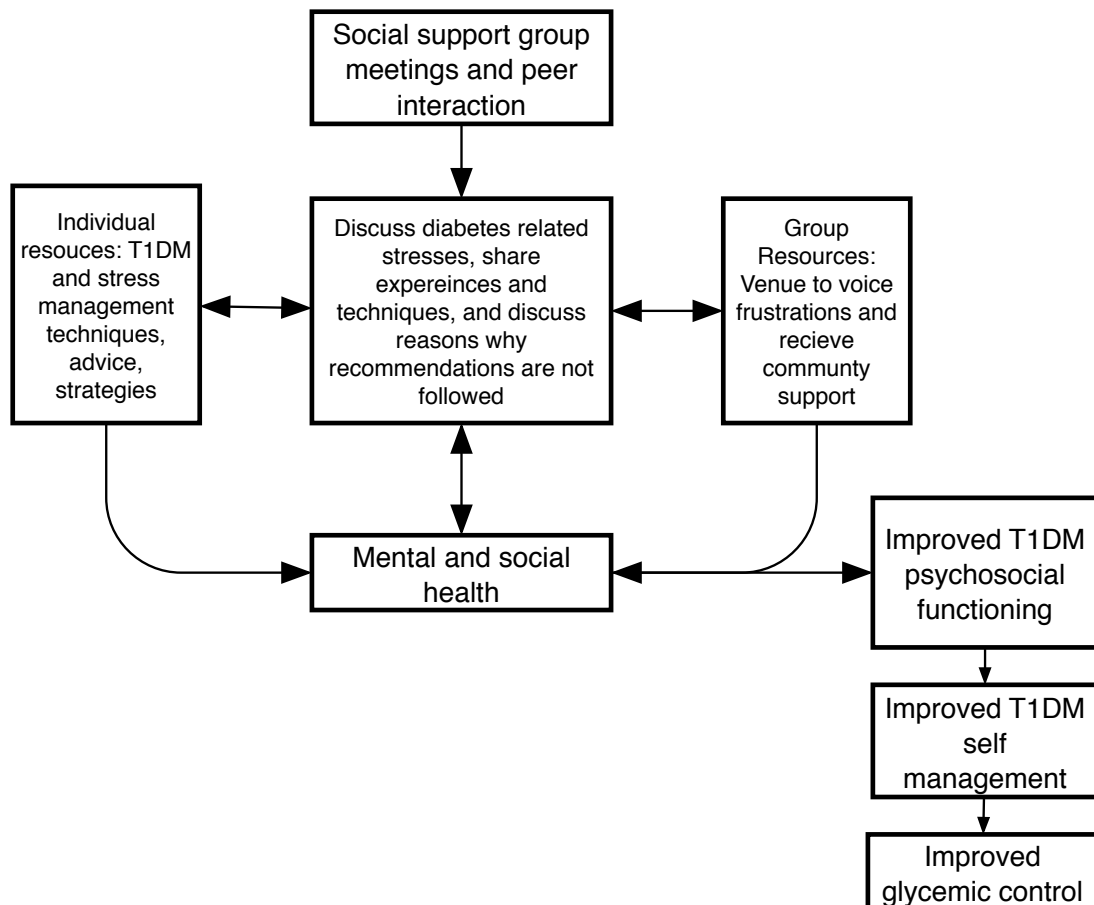


Figure 6.1: Conceptual framework of proposed program

6.2 Theoretical background

The proposed program will be informed by the Social Ecological Model (SEM) that states that levels of factors influence behaviors and that each level interacts with the others as well as social cognitive theory (SCT) [85-87]. The levels of the SEM are intrapersonal and interpersonal, which will be addressed using SCT, as well as community and policy levels. The social support group will offer an environment where positive reinforcement is given to proper self-management activities and participants can learn from the experience of other group members, as well as constant support network through the use of online social networks. Through group interactions and the sharing of T1DM management techniques, advice, and strategies, this program intends to improve the emotional coping response and behavioral capability of participants. This program aims to improve self-efficacy and diabetes related knowledge through setting attainable goals for meeting recommended self-care activities and general diabetes education provided by the peer leader if requested by the group members and not adequately answered by other group members respectively. Through this, participants will have increased perception of social support, increased self-efficacy, and increased diabetes quality of life. Since the most common reason listed on the online survey for not attending a social support program was no program or group available, community level factors will be addressed by developing and implementing a social support program for young adults living with T1DM targeting an area without a current support program available. Policy level factors will be acknowledged that the major focus of T1DM self-management is clinical care and that behavioral aspects of T1DM self-management need to be further explored. The program's conceptual framework focuses on the interpersonal and intrapersonal levels and will be used to

guide the proposed program along with the CAB framework. The proposed program does not have the scope to adequately address policy level factors beyond acknowledging their existence and pilot testing the social support program in order to encourage more widespread development and attendance of social support programs for young adults living with T1DM.

6.3 Intervention program

The intervention program will be offered to individuals who are between the ages of 18 and 35 and has been diagnosed with T1DM for at least one year. Any individuals with a A1C percentage higher than 10% will be advised to seek more intensive care through their clinical team, but there will be no lower limit based on A1C due to there being no difference in perception of social support based on A1C categories under 10% according to the online survey. Once 6 participants have matching availability, a group will be created and meetings will begin. The intervention will consist of two components.

- 1) Unstructured, group discussion session led by a peer leader in a community-based setting meeting weekly for 6 weeks: The discussion session will be given in six to ten person groups. Meeting themes and discussion points developed by the CAB will be used as a framework for the group discussions. As stated in the interviews, unstructured group discussions were often more beneficial to and popular with participants compared with having a planned speaker. Having an unstructured discussion informed by the CAB framework will allow for group participants to discuss many issues faced by young adults living with T1DM but not restricting them to a set curriculum. All information to be presented was reviewed by a registered dietician through the CAB as well as independently by Dr. Kristi Silver, an endocrinologist.

2) Web based social support structure using Facebook groups: As mentioned in multiple interviews, online support has become more common, but the survey has shown that there is no difference in perception of social support even with use of online support. While having an online support network may not be effective on its own, supplementing in person meetings with online support may allow for increased peer network building. Participants will be encouraged to post and comment on experiences of living with diabetes and share topics much like in group discussions. This will provide a constant area for social support outside of the group meetings and allow discussions to be further explored. Having peer leaders monitoring the discussion will also allow for appropriate suggestions to participant's requests for further information, health care options, or resources. The peer leader will use this tool to communicate and expand on issues brought up in the social support group meetings as well as posting relevant reminders about proper self-management activities. The addition of an online component will further increase feelings of social support

6.4 Peer leader role

The peer leader will be a young adult living with T1DM who has been diagnosed for at least one year and be knowledgeable in T1DM self-management strategies. The peer leader should be active in the T1DM community and motivated, resembling the characteristics of the group leaders but with further knowledge of recommended self-management activities and common issues encountered by young adults living with T1DM as identified by the interviews. Additionally, the peer leader will be instructed on what recommendations can be made in this type of program and when to instruct participants to consult their endocrinologist, nurse practitioner, nutritionist, or certified diabetes educator.

Because of the limited time frame of this program, the social support group meetings need to cover topics that are helpful to as many participants as possible. To ensure beneficial discussions are being held, the peer leader will keep discussions limited to that week's theme and apply strategies to foster beneficial discussion. If a participant brings up a topic that does not apply to that week's discussion, the peer leader will either: suggest that the group cover that issue in the appropriate week, discuss the issue briefly then suggest that the conversation continue in the online support group, and/or offer to discuss the issue individually or provide resources that will address that individual's question or issue. Based on the results of the interviews, the peer leader will encourage all individuals to share their personal strategies for managing their diabetes, any experiences with new technology that may be brought up in discussion, and provide insight into what works for them and what does not. To save time and allow for more complete discussions, the peer leader will encourage use of the online support group to expand on topics and provide further resources. To improve self-efficacy, the peer leader will also ask participants to set attainable goals for reaching the recommended level of self-care activities for SMBG, other diabetes self-care activities, and nutrient intake and encourage the group to share strategies to accomplish these goals, difficulties they are experiencing accomplishing these goals, and examples of how they accomplished these goals

6.5 Addressing barriers to support group utilization

The highest ranked reason for not attending a social support program in the online survey was the no group or program was available, so access to a program may be a major barrier not identified through the interviews of group leaders. The main reason stated in the interview process for not attending a social support program was logistical and time constraint issues as well as denial of T1DM being a major factor in ones life. To address these issues the proposed

intervention will be offered in an area where there is not an active social support program currently and at the most conducive time and place for the intended population. To do this, additional formative research should be completed to identify a suitable target area and then with the target population to identify locations, times, and days that would most likely to be attended before beginning recruitment for the intervention. Additionally, the recruitment materials should emphasize the six-week nature of the program as opposed to the typical open-ended support program more commonly encountered. In order to address the issue of denial, recruitment material will emphasize the importance of taking care of your diabetes and engaging in self-management activities.

Recruitment, while not a major focus of the support group leaders, was stated as an issue in the interviews, and a previous attempt to recruit for a social support study using online outreach to a Facebook group of 330 individuals with T1DM living in Baltimore, Washington D.C., and Northern Virginia as well as a recruitment letter contacting 184 individuals who attend the University of Maryland Medical Center Center for Diabetes and Endocrinology (UMMC CDE) resulted in 1 and 3 responses respectively. Of those 4 responses, one was deemed ineligible due to having A1C levels fewer than 8% and another for having multiple other chronic conditions. It is suspected that the low response rate may be due to: not having an established meeting location, time, and date when initially contacting potential participants, recruiting from a large geographic range, and outreach methods. The proposed program will take steps to address these issues by: having an established meeting location, time, and dates through previously conducted research, partnering with a clinic who serves individuals who live in a smaller geographic area compared to the UMMC CDE, and using a more complete recruitment outreach

strategy, replicating the online and letter writing strategies and adding telephone outreach as well as a larger in person presence at the actual clinic.

The proposed program will also emphasize the perceived benefits of attending a social support program using attractive flyers with catchphrases based on these perceived benefits such as “Come to share! Come to learn”, “Do you have Type 1 Diabetes, you are not alone! Make new type one friends” and “Want to vent, we are here for that!”. The flyer used in the previous recruitment did not emphasize the benefits of attending a social support program.

CHAPTER 7: DISCUSSION AND CONCLUSIONS

Through conducting this research, it became apparent at the beneficial role of social support programs for individuals living with T1DM. These programs provide a venue where both techniques and strategies for successful self-management can be shared, an outlet where the numerous stresses and frustrations can be vented to an empathetic peer group, and offers the ability to form a peer support network. The fact that only five percent of all diabetes cases are T1DM necessitates these groups, as there are few settings in which an individual living with T1DM has the opportunity to be among peers. It was also clear that young adulthood, and the life changes that come with it, create a potentially dangerous situation for individuals living with T1DM where self-management may lapse, and social support programs can act as a safety net to prevent this from occurring.

The major benefits of attending a social support program offered by the group leader during the interviews focus on increasing knowledge of everyday self-management strategies and techniques through group learning, improved emotional functioning through sharing of experiences, as well as building a support network. These benefits would not be attainable through clinical care due to the focus on glycemic control through medical treatment and oftentimes lack of communication regarding the emotional aspects of T1DM self-management. Individuals also may feel more comfortable sharing the negative experiences encountered through living with T1DM in a social support program among peers rather than with medical professionals who may or may not be diagnosed with T1DM. This may be due to not wanting to upset the medical professional, not feeling comfortable in the clinical environment, or unwillingness to discuss taboo topics with a medical profession, such as alcohol use. The peer environment allows for these issues to be discussed and solutions to be found. Through the

online survey, individuals who had ever attended a social support group had increased scores on both tangible and affectionate support dimensions versus those who had not, while there was no difference in scores between those who had attended a social support group in the last six months and those who have not. This suggests that individual relationships and personal connections formed in social support groups are retained and continue to function as a source of support even when the group is no longer attended. Because of this, short-term social support programs may be as effective at improving social support as open-ended support programs through building personal relationships among participants that last even after the program is complete. The study by Markowitz and Laffel, which lasted for 5 months, also suggests the effectiveness of shorter programs, at least in the short term [64]. While this study demonstrates the benefits of attending a social support program even a limited number of times and building these peer relationship, the support groups structure represented in the Markowitz and Laffel study does not resemble the majority of social support programs, which do not have resources such as a clinically trained psychologist with experience in T1DM management to lead the group.

Because social support programs aren't well attended, as supported by the group leader interviews as well as attempts to recruit for a social support study, new and innovative strategies for attracting participants are needed. In addition to this, different formats and combinations for social support programs for individuals living with T1DM should be explored. A key issue related to the attendance of social support programs is the logistical conflicts and time commitment of attending. In order to combat this issue, groups should be scheduled at an appropriate time and at a location convenient to the population it serves, but also the benefits of social support programs should be presented and reinforced in clinical care. By increasing the awareness of the benefits of attending a social support program, more individuals may be willing

to make the time commitment needed. Additionally, new formats such as a short-term program rather than the open-ended programs that meet monthly should be explored as alternatives that may be more appealing to some. While addressing the benefits of social support programs, attempts to combat the perception of social support programs and the stigma related to living with T1DM should also be spoken on. The perception of social support programs not being useful may be due to experiences with social support programs that were not relevant to that individual. Half of the groups leaders interviewed stated that the population served by their groups is parents of children living with T1DM, and discussion occurring between these individuals are likely not helpful for young adults. As apparent of the large online communities for individuals living with T1DM as well as the percentage of survey respondents who utilize online-based support, web based social support is becoming more widespread and should be integrated into current and future planned programs. While the large communities exist, they may not offer the same benefits of attending an in person social support program which may allow for more personal connections to be made. The addition of an online component can allow for more complete communication, better forming of personal connections, and retention of these personal connections if a short term social support program format is used, especially among groups such as young adults who utilize technology daily.

The issues faced by young adults living with T1DM were also covered and particularly important discussion topics were identified through the interviews as well as the CAB meetings. In particular, the denial of diabetes as a major factor in one's life and the lack of self-management activities that accompanies it are particularly problematic. In addition to the long-term damage done by increased blood glucose levels, the immediate dangers of diabetic ketoacidosis means that this issue needs to be effectively addressed. This becomes increasingly

concerning if the individual does not identify publicly as living with T1DM, which was stated as an issue for young adults. The public perception of T1DM, the stigma associated with diabetes, competing life priorities, and stressful circumstances due to living with T1DM can all contribute to this, and may more effectively be addressed by peers rather than in a clinical context. While addressing the need to improve self-management, having a peer group can also allow for individuals to be more comfortable in sharing their diagnosis with others. Additionally, learning techniques and strategies to cope with peer pressures in social situations and make healthy decisions was identified by all interviewees who were living with T1DM but not particularly stressed by those who were parents of children living with T1DM suggesting that this is an essential discussion that should be had among young adults living with T1DM.

While conducting this research, numerous barriers were encountered. Mainly, participation was lacking for each of the projects and hindered by the time frame for completing each project. Many interview requests were not responded to and one individual was not willing to meet in person for the interview. The time frame and geographic limits also limited the number of individuals who could be interviewed. In future studies, offering some form of compensation, increasing the geographic area, and increasing the overall time frame for the project could result in more interviews and more complete data. Additionally, six of the groups did not mainly serve young adults, but instead either adults of all ages or parents of children with diabetes. Future studies should attempt to contact more college-based groups as well as formal groups designed for young adults living with T1DM. Despite this, the issues raised by all group leaders were consistent independent of population served. Although contacting approximately 70 individuals with connections to the diabetes community to distribute the online survey, only 75 individuals initiated the survey and 38 completed the survey successfully. The respondents to the

survey also were fairly homogenous in regards to sex (73.7 % female), education level (97.4% had at least some college, and 50% had at least some graduate/professional school), racial/ethnic group (94.7 White, non-Hispanic), and A1C category (84.2% under 8%), suggesting that the results may not be externally applicable and these results should not be used to infer information about other populations not represented in the survey. In future studies to increase both initiation and completion of the survey compensation should be offered as well as building in distribution through existing online T1DM communities in order to reach a larger number and more diverse group of individuals living with T1DM. Finally, the CAB was limited both in recruitment with four individuals agreeing to participate, and in the demographics. First, participant recruitment challenges (e.g. limited scope and low interest) resulted in a low number of individuals participating with fairly homogenous backgrounds. This may not reflect a full view of issues faced by individuals living with T1DM from other demographics, such as racial or ethnic minorities or those from different socioeconomic groups. While the sample size and demographics of the CAB were limiting, many of the topics raised are universal to individuals with T1DM; such as monitoring blood glucose levels the recommended amount per day, but are often not addressed in the context of the changing life circumstances encountered by young adults. Also, the time frame for the overall project limited the number of meeting that could be held and the depth of material developed. In future studies, recruitment for the CAB should include more strategies and an extended time frame should be incorporated in order to allow for recruitment of a larger number of individuals as well as the ability to conduct more meetings to further develop the material. In all cases, increasing participation would strengthen the results described here and could be accomplished by extending the time frame for each project,

increasing and diversifying the recruitment strategies and venues used, and offering some form of compensation to participants.

This research also addressed a number of research gaps. First, there is very little information on the current format and strategies of functioning social support groups for individuals living with T1DM. Second, while psychosocial and treatment related benefits have been described of attending a social support program, the perceived benefits stated in the interviews and through the online survey display the tangible and emotional benefits as potential outcomes to be measured. These benefits, such as knowing you are not alone or being able to vent frustrations, can be extremely important to the mental health of the attendees. Identifying the perceived barriers to starting and maintaining a social support program also will allow for more effective development of social support programs.

A community-based social support program has the potential to address the three aims. Improving social support and related psychosocial measures may result in better glycemic control and lower rates of T1DM related complications, leading to better individual health as well as reduced costs. Participation in a community-based program has the potential to offer an expanded care option and receive supplemental DM self-management support. Additionally, offering a community-based program can provide a better care experience by offering diabetes related support and information outside of a clinical setting and among peers where individuals may feel more comfortable discussing issues not commonly covered in clinical practice and alleviating diabetes related stress. Community based programs are also important during transitional phases, such as the switch from pediatric to adult based care. Indeed, having community-based group support programs could help eliminate gaps in treatment through referrals to adult based diabetes care teams, offering social support in dealing with the transition,

and encourage treatment adherence and continued self-management during a time that may be lacking in traditional clinical care.

Social support programs can be an effective and significant means to address the aspects of T1DM self-management not adequately covered through clinical care. Their use should be further explored, and research should be conducted to determine which format, dose, and discussions are most efficient in building a peer network, improving diabetes related emotion functioning, and improving clinical care outcomes such as A1C levels. Additionally, further investigation into current community-based social support programs is warranted. Due to the changing life circumstances, young adults living with T1DM could benefit greatly to social support programs tailored to their needs and developed to address issues encountered by the particular population.

CHAPTER 8: SUMMARY AND FUTURE IMPLICATIONS

The formative research presented here identified the characteristics of a limited number of social support groups in Maryland and Northern Virginia, presented some major barriers to running and maintaining successful groups, identified perceived benefits of attending social support groups, described factors thought to be particularly important for young adults in diabetes self-management, described what individual factors had an impact on the perception of social support among this group, and provided a framework for a future social support program for young adults living with T1DM. Additionally, this study showed that among the survey sample ever attending a social support group or program resulted in higher levels of both tangible and affectionate support dimensions, suggesting that social support groups may have a function in improving the perception of tangible and affectionate support. Along with the framework developed by the CAB, the interview results show that participant sharing of experiences, techniques, ideas, and emotions as well as making personal connections to other group members through unstructured group discussions should be the main intervention component to be encouraged by a peer leader.

While there were limitations in each of the formative research projects, this program possesses a number of aspects that have the potential to improve care outcomes for T1DM treatment. The use of a community advisory board in the development in diabetes programs allows for program developers to acquire a framework that represents the views on which factors and barriers are most pertinent among their intended population. The interviews with social support group leaders described the current state of social support groups while also identifying

barriers to running and managing a successful group. Because there currently is no research regarding this topic, the information gleaned from these interviews can serve as a valuable resource for individuals looking to start their own social support program for individuals living with T1DM. The identification of the perceived benefits of attending a social support group can also be used in the recruitment and advertising of social support programs. Finally, the interviews identified factors particularly important for young adults living with T1DM, which, along with the CAB framework, can be used to inform discussion topics for social support programs targeted for this population. Based on this formative research, there are numerous benefits to attending social support programs for young adults living with T1DM and the use of social support programs and other strategies to address the psychosocial and behavioral side of diabetes self-management need to be further explored.

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IDEA WRITING

STEP ONE: INITIAL IDEAS (approximately 5 minutes)

- Leave plenty of room around and between ideas
- Write all ideas on the left hand side and number each idea

STEP TWO: WRITTEN INTERACTION (approximately 5 minutes)

- Pass each sheet to the person sitting on your left
- Read the ideas
- If you have a new initial idea, write it in the Initial Idea column
- Write down your reactions to each initial idea in the comments section
 - Which do you like or dislike?
 - What else can you add to each initial idea?
 - How could each idea be improved

STEP THREE: DISCUSSION (approximately 5 minutes)

- Read your initial ideas, added ideas, and comments
- Conduct a discussion of the principal ideas from all the sheets
- Record a summary of the ideas, activities, and skills developed

Question: What potential topic, hands on activities, or skills should be included in a discussion themed _____

Initial Ideas

Comments

Community Advisory Board Consent Form

Project Title	Development of a Type One Diabetes Group Social Support Using a Community Advisory Board
Purpose of the Study	<p><i>The purpose of this research project is to develop material for a community-based social support group program lead by a community health worker designed specifically for type one diabetics.</i></p> <p><i>This research is being conducted by Patrick Brady and Hee-Jung Song at the University of Maryland, College Park. We are inviting you to participate in this research project because you are interested in a developing a diabetes social support group specifically for type one diabetics and/or have health expertise that can be reflected in the program.</i></p>
Procedures	<p><i>The procedure involved two in person group meeting for 2 hours, which will be audio recorded, as well as online communications with the principle investigator to review any material and results of the meeting and to approve all materials developed. During the in person group meetings, the PI will initiate a discussion to develop themes and topics for support program and you will be asked to engage in the discussion. Your opinions, suggestions, and comments are valuable and will not be judged. A sample question is "What potential topics should be included in a discussion of nutrition in a type one diabetes mellitus (T1DM) specific support group?"</i></p> <p><i>All meetings will be held at the University of Maryland-College Park. The first meeting will consist of an introduction to the project being developed and then, using nominal group process, 6 topics will be selected for discussion themes for a social support group. In the second meeting, and idea writing will be used to develop potential discussion topics for each discussion theme. Following the second meeting, all materials developed will be emailed to study participants for review. After all reviews and revisions are complete, the final themes and potential discussion topics will be emailed out for approval.</i></p> <p><i>Do you consent to be audio recorded as part of the study procedure? Please initial Yes _____ No _____</i></p>
Potential Risks and Discomforts	<i>There are no risks associated with participation in this study</i>
Potential Benefits	<i>There is no direct benefit to you. We hope that, in the future, other people might benefit from this study through improved understanding of the role of community advisory boards in the development of T1DM management programs.</i>

<p>Confidentiality</p>	<p><i>We will not link our name with anything you say. The information you give us will be kept confidential. Only the people who work on this project will have access to the data we collect. Any potential loss of confidentiality will be minimized by storing all information and audio files on a password-protected computer and all paperwork will be stored in a locked office desk.</i></p> <p><i>Identifying information will be collected on the Participant Information Sheet and kept separate from all other material developed. After email addresses are added to an email list for communication purposes, all personally identifying information will be blacked out on the Participant Information Sheet.</i></p> <p><i>Only the study PI and research staff will have access to any personally identifying information. Because this is a group process, there is an inherent potential loss of confidentiality. All participants will be asked to not repeat any information stated at the meetings and encouraged to only share information they are comfortable with. During the meetings, please respect the privacy of other participants and please keep the information you hear in the meeting confidential.</i></p> <p>If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</p>
<p>Right to Withdraw and Questions</p>	<p>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</p> <p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p style="text-align: center;">Patrick Brady 3205A Marie Mount Hall, Department of Nutrition and food Science, College of Agriculture and Natural Resources, University of Maryland, College Park, MD 20742 Tel: 302-547-3176</p> <p style="text-align: center;">Or</p>

	<p style="text-align: center;">Hee-Jung Song 3301 Marie Mount Hall, Department of Nutrition and Food Science College of Agriculture and Natural Resources, University of Maryland, College Park, MD 20741 Tel: 301-405-8898</p>	
Participant Rights	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p style="text-align: center;">University of Maryland College Park Institutional Review Board Office 1204 Marie Mount Hall College Park, Maryland, 20742 E-mail: irb@umd.edu Telephone: 301-405-0678</p> <p>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</p>	
Statement of Consent	<p>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</p> <p>If you agree to participate, please sign your name below.</p>	
Signature and Date	NAME OF PARTICIPANT (Please Print)	
	SIGNATURE OF PARTICIPANT	
	DATE	

In depth Interview Consent Form

Project Title	Development of a Type One Diabetes Group Social Support Using a Community Advisory Board
Purpose of the Study	<p><i>The purpose of this research project is to develop material for a community-based social support group program lead by a peer leader designed specifically for type one diabetics and support the developed program.</i></p> <p><i>This research is being conducted by Patrick Brady and Hee-Jung Song at the University of Maryland, College Park. We are inviting you to participate in this research project because you are interested in a developing a diabetes social support group specifically for type one diabetics and/or have health expertise that can be reflected in the program.</i></p>
Procedures	<p><i>The procedure involves one on one interviews that will last approximately one hour, which will be audio recorded. After contacting participants, the PI will schedule an interview time. The interviewer will give a brief description of the purpose of this interview (to collect qualitative data on the use of social support groups for type one diabetics) then will proceed in asking the questions. All discussions will be audio recorded using an iPhone. Throughout the interview, the interviewer will take field notes in a notebook that will be stored in a locked desk.</i></p> <p><i>Do you consent to be audio recorded as part of the study procedure? Please initial Yes _____ No _____</i></p>
Potential Risks and Discomforts	<i>There are no risks associated with participation in this study</i>
Potential Benefits	<i>There is no direct benefit to you. We hope that, in the future, other people might benefit from this study through improved understanding of the role of community advisory boards in the development of T1DM management programs and the role of social support programs in T1DM management.</i>
Confidentiality	<p><i>We will not link our name with anything you say. The information you give us will be kept confidential. Only the people who work on this project will have access to the data we collect. Any potential loss of confidentiality will be minimized by storing all information and audio files on a password-protected computer and all paperwork will be stored in a locked office desk.</i></p> <p><i>Only the study PI and research staff will have access to any personally identifying information.</i></p>

	<p>If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</p>
<p>Right to Withdraw and Questions</p>	<p>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</p> <p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p style="text-align: center;">Patrick Brady 3205A Marie Mount Hall, Department of Nutrition and food Science, College of Agriculture and Natural Resources, University of Maryland, College Park, MD 20742 Tel: 302-547-3176</p> <p style="text-align: center;">Or</p> <p style="text-align: center;">Hee-Jung Song 3301 Marie Mount Hall, Department of Nutrition and Food Science College or Agriculture and Natural Resources, University of Maryland, College Park, MD 20741 Tel: 301-405-8898</p>
<p>Participant Rights</p>	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p style="text-align: center;">University of Maryland College Park Institutional Review Board Office 1204 Marie Mount Hall College Park, Maryland, 20742 E-mail: irb@umd.edu Telephone: 301-405-0678</p> <p>This research has been reviewed according to the University of</p>

	Maryland, College Park IRB procedures for research involving human subjects.	
Statement of Consent	<p>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</p> <p>If you agree to participate, please sign your name below.</p>	
Signature and Date	NAME OF PARTICIPANT (Please Print)	
	SIGNATURE OF PARTICIPANT	
	DATE	

Development of a Social Support Program for Young Adults with Type One Diabetes Mellitus

In depth interview protocol with community social support program leaders

Date:

Time:

Place:

Interviewee's name:

Participants

Individuals with experience in organizing, running, or attending social support groups or programs for type one diabetics will be contacted and asked to participate in the interviews. If they are willing to participate, the program coordinator will schedule and interview date, time, and location. The research team is seeking to conduct approximately 20 interviews.

Protocols

At the scheduled time, the interviewer will first obtain informed consent using the In Depth Interview Consent Form. The interviewer will give a brief description of the purpose of this interview (to collect qualitative data on the use of social support groups for type one diabetics) then will proceed in asking the questions listed below. All discussions will be audio recorded using an iPhone. Throughout the interview, the interviewer will take field notes.

Introduction

This interview is being conducted to get your opinion about type one diabetes management and the role of social support programs in it. I am especially interested in hearing about leading a social support group for type one diabetics for young adults, the role you see of social support groups in managing diabetes, and the topics and discussions you find most important

If it is okay with you, I will be taping recording our conversation. I assure you that all your comments will remain confidential. If you agree to this interview and the tape recording, please read over the consent form, ask any questions you may have about the consent process, and if willing, sign the consent form

Questions

Topic 1: Role of a social support group leader

1. How would you describe your relationship with type one diabetes?
2. Describe your involvement in social support groups or programs for type one diabetics.
-Probe: How do you keep up to date on type one diabetes information
3. Describe how you set up you social support program, how you got the word out about your program, and how you got individuals to attend group meetings
-Probe: describe the demographics of your social support group
-Probe: connections to clinics/other support group leaders

Topic 2: Needs, function of community based social support program for T1DM

1. Would you please describe your current, community based social support program.
 - Probe: can you give me some example of common topics or curriculum?
 - Probe: How do you determine if you group is successful? By participants' characteristics, meeting frequency, topics covered, improvements in DM management measured how, etc.
2. What are key aspects in managing type one diabetes, especially for young adults?
3. What do you see the role of social support groups or programs being in type one diabetes management?
4. What discussion topics do you believe are the most helpful in managing type one diabetes?
5. What do you think are the benefits of attending a social support group or program and what aspects of diabetes are most improved through attending social support groups or programs?

Topic 3; Perceived barriers and facilitators in managing community based social support program for T1DM

7. Describe your perception regarding both barriers and facilitators in managing type one diabetes program.
 - Probe: How do you address these barriers?
8. Why do you think social support groups or programs aren't attended by some people who would benefit?
9. How do you think attendance at social support groups or programs could be improved?
10. Are you aware of any problems specifically related to T1DM management and care among young adults with T1DM? what are these problems?

Topic 4: Health care system in T1DM care

11. How would you describe the current health care system's role in managing type one diabetes?
 - Probe: Is the system easy to access and utilize for young adults in transitional stage?
 - Probe: Do young adults take advantage of all health professionals they should (ex nutritionist)
12. What do you think are the advantages of community-based programs over classical clinical based care in the context of T1DM?
13. Is there anything else you would like to say regarding social support groups or programs?
 - Probe: any suggestion to improve current support program for type one diabetes

Online Survey Tool

3/9/2015

Qualtrics Survey Software

Block 3

Thank you for participating in the brief survey regarding social support, social support groups and programs, and diabetes management. This survey will take approximately 20 minutes.

All responses will be kept confidential, and no personally identifying information will be collected when completing this survey

This research is being conducted by Patrick Brady at the University of Maryland College Park. We are inviting you to participate in this study because you have type one diabetes and are between the ages of 18 and 35 years old. The purpose of this research project is to examine your experiences regarding social support programs and assess the your perception of social support.

The procedure involves taking part in a brief, online survey regarding your participation in social support programs as well as your perception of your current level of social support

There are no risks associated with participation in this research study

There are no direct benefits from participating in this research, however possible benefits include increasing the general knowledge regarding the experience type one diabetics have with social support programs

Any potential loss of confidentiality will be minimized by not including or linking any personal identifying to your responses.

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research you may stop participating at any time. You may also choose not to answer any questions you do not choose to. If you decide not to participate in this study or if you stop participating at any time you will not be penalized in any way.

If you decide to stop taking part in this study, or if you have questions, concerns, or complaints, or if you need to report an injury related to the research please contact the investigator:

Patrick Brady
3205A Marie Mount Hall, Department of Nutrition and Food Science
College of Agriculture and Natural Resources
University of Maryland College Park
College Park, MD 20742
302-547-3176/pjbrady2@gmail.com

If you have questions about your rights as a research participant or wish to report a research related injury, please contact:

University of Maryland College Park
Institutional Review Board Office
1204 Marie Mount Hall
College Park, Maryland, 20742
E-mail: irb@umd.edu
Telephone: 301-405-0678

This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human

subjects.

By beginning the survey, you acknowledge that you have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty

Default Question Block

What is your sex?

- Male
 Female

What is your age?

What is your education level

- None
 Some Elementary School
 Completed Elementary School
 Some High School
 Completed High School
 Some College
 Completed College
 Some Graduate/Professional School
 Completed Graduate/Professional School

Employment Status (Students put full time/part time depending on your enrollment if not also working)

- Working Full time
 Working Part time
 Retired
 Unemployed
 No answer or don't know

Marital Status

- Never Married
 Married
 Widowed
 Divorced
 No answer/ don't know

What is the annual income of your household including salary, interest, and supplementary income?

- 0-\$19,999
- \$20,000-\$39,999
- \$40,000-\$59,999
- \$60,000-\$79,999
- \$80,000-\$99,999
- Greater than \$100,000
- No answer or don't know

Racial/Ethnic Group

- White, Non-Hispanic
- Hispanic
- African American
- Asian American
- Other
- No answer or don't know

What type of insurance do you have?

- No insurance
- Medicaid
- Private insurance through employer (example Bluecross Blueshield)
- Private insurance bought personally (example BCBS)
- Other

How long have you had Diabetes in years?

What was your last A1C reading?

- under 8%
- 8% to 10%
- Over 10%
- No answer/Don't know

Primary insulin delivery method?

- Insulin injections
- Insulin pen
- Insulin pump
- Other

No answer or don't know

Do you use a continuous glucose monitor?

Yes

No

Have you ever attend an in person, formal type one diabetes social support group or program, such as a JDRF affiliated support group?

Yes

No

Have you attended an in person, formal type one diabetes social support group or program in the past 6 months

Yes

No

If you answered yes, what areas of diabetes management have felt most improved due to attending a social support group or program

If you answered no, rank the reasons why you do not attend a social support group or program?

- No program or group available

- Not enough time

- No interest

- Don't feel comfortable attending social support group or program

- Don't feel it would help with diabetes management

- Other

Do you belong to a diabetes club or group which offers support in a non formal social support group setting, such as a program run by the College Diabetes Network or other Diabetes related group?

Yes

No

Do you use online sources of support regarding diabetes management, such as a facebook support group?

Yes

No

What topics do you think would be most beneficial to discuss in a social support group or program?

How would you rank each item in being able to improve your diabetes self-management?

- In person diabetes social support group or program

- online diabetes social support group or program

- Doctors appointments with your primary diabetes caregiver

- Additional Diabetes education (ex Nutritionist or Certified Diabetes Educator appointment)

- Other

Block 2

How often do you feel like you have

	Someone you can count on to listen to you when you need to talk	Someone to give you information to help you understand a situation	Someone to give you good advice about a crisis	Someone to confide in or talk to about yourself or your problems
	Answer 1	Answer 2	Answer 3	Answer 4
None of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A little of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How often do you feel like you have

	Someone whose advice you really want	Someone to share your most private worries and fears with	Someone to turn to for suggestions about how to deal with a personal problem	Someone who understands your problems
	Answer 1	Answer 2	Answer 3	Answer 4
None of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A little of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How often do you feel like you have

	Someone to help you if you were confined to bed	Someone to take you to the doctor if you needed it	Someone to prepare your meals if you were unable to do it yourself	Someone to help with daily chores if you were sick
	Answer 1	Answer 2	Answer 3	Answer 4
None of				

3/9/2015

Qualtrics Survey Software

the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A little of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How often do you feel like you have

	Someone who shows you love and affection Answer 1	Someone to love and make you feel wanted Answer 2	Someone who hugs you Answer 3
None of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A little of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How often do you feel like you have

	Someone to have a good time with Answer 1	Someone to get together with for relaxation Answer 2	Someone to do something enjoyable with Answer 3	Someone to do things with to help you get your mind off things Answer 4
None of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A little of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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