

Personal and Relationship Challenges of Adults With Type 1 Diabetes

A qualitative focus group study

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OBJECTIVE—Little is known about the psychosocial challenges of adults living with type 1 diabetes or its impact on partner relationships. This qualitative study was undertaken to gain better understanding of these issues.

RESEARCH DESIGN AND METHODS—Four focus groups were held, two with adult type 1 diabetic patients ($n = 16$) and two with partners ($n = 14$). Two broad questions were posed: “What are the emotional and interpersonal challenges you have experienced because you have (your partner has) type 1 diabetes?” and “How does the fact that you have (your partner has) type 1 diabetes affect your relationship with your partner, positively and/or negatively?” Sessions were recorded and transcribed, and analyzed by a team of four researchers, using constant comparative methods to identify core domains and concepts.

RESULTS—Four main domains were identified: 1) impact of diabetes on the relationship, including level of partner involvement, emotional impact of diabetes on the relationship, and concerns about child-rearing; 2) understanding the impact of hypoglycemia; 3) stress of potential complications; and 4) benefits of technology. Themes suggest that, although partner involvement varies (very little to significant), there exists significant anxiety about hypoglycemia and future complications and sources of conflict that may increase relationship stress. Partner support is highly valued, and technology has a positive influence.

CONCLUSIONS—Adults with type 1 diabetes face unique emotional and interpersonal challenges. Future research should focus on gaining a better understanding of how they cope and the effect of psychosocial stressors and coping on adherence, quality of life, and glycemic control.

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Studies of people with type 1 diabetes have focused on children and young adults and describe many emotional and interpersonal challenges. Youth are at increased risk for psychiatric, eating, and substance abuse disorders, interpersonal problems, nonadherence, and poor quality of life (1,2). “Emerging” adults must address the responsibilities of intensive self-care (e.g., healthcare access) while managing normative challenges (e.g., jobs) (3,4).

Little is known about common psychosocial challenges of adults with type 1 diabetes. Type 1 diabetes is a challenging

disease. Those diagnosed as children live with the disease for most of their lives. All are vulnerable to complications that affect quality of life (5). Self-care is demanding, requiring frequent testing, insulin adjustment, and hypervigilance against hypoglycemia. Studies show the negative effects on quality of life of male sexual dysfunction (6) and of frequent or traumatic severe hypoglycemia episodes (7). The odds of depression are two times higher for adults with type 1 diabetes (8), and disordered eating and insulin omission are concerns (9). Effective coping skills are important; they relate to

better glycemic control (10,11) and regimen adherence (10,12). Personal models of type 1 diabetes that are more negative (e.g., less perceived control) relate to poorer coping and clinic attendance (13). Overall, the literature on psychosocial challenges and factors affecting the outcomes of adult type 1 diabetic patients is lacking.

One area studied is the effect of family support on outcomes. Greater family conflict for youth with type 1 diabetes, and less family support for adults, predicts poorer adherence (14,15). For adults with type 2 diabetes, greater marital satisfaction relates to lower risk of developing metabolic syndrome (16), better marital quality relates to better quality of life and adherence (17–19), and nonsupportive partner behaviors relate to poorer medication adherence (20). Also, partners of people with type 2 diabetes may experience as much, or more, distress as the patient (21).

One would expect similar significant effects on important relationships of adult type 1 diabetic patients. One study found that those who achieved improved glycemic control with continuous glucose monitoring also reported that their “significant other” encouraged and participated with them (22). One study of spouses of patients who had recently experienced severe hypoglycemia found greater distress and marital conflict than spouses whose partners had not, and even more fear of hypoglycemia than the patients (23). Generally, little is known about these intra- and interpersonal challenges.

We adopted a qualitative approach to better understand the unique psychosocial challenges of adults with type 1 diabetes, and patient/partner perspectives on how diabetes impacts their relationships (24). We chose focus groups, not individual interviews, because data are obtained from the communication between participants, as they share experiences and comment on different perspectives. Also, sometimes participants are more open when less inhibited members explore difficult topics, and more open in a group format (25).

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RESEARCH DESIGN AND METHODS

We held four focus groups. The inclusion criteria were as follows: ≥ 21 years of age, diagnosis of type 1 diabetes ≥ 2 years duration, married/partnered (≥ 1 year), and could speak/read English. We identified potential subjects through chart review. We invited prospective participants by letter, to help us “learn about how having type 1 diabetes affects adult relationships, especially the relationship with a spouse or partner, as well as about other personal challenges type 1 diabetic patients experience related to their diabetes.” Eligible respondents provided informed consent prior to the group. Participants completed demographic questionnaires.

Focus groups

Two patient groups ($n = 9$ and 7) and two partner groups ($n = 7$ and 7) were held at a healthcare facility in the evening where providers offer multidisciplinary diabetes care to patients from urban, suburban, and rural areas of New York state. Each group lasted 1.5–2 h, dinner was served, and participants were compensated (\$50 + mileage) for time. The first author facilitated each group. Participants were asked two broad questions: 1) “What are the emotional and interpersonal challenges you have experienced because you have (your partner has) type 1 diabetes?” and 2) “How does the fact that you have (your partner has) type 1 diabetes affect your relationship with your partner, positively and/or negatively?” Within these two framing questions, discussion was free-flowing. The facilitator encouraged interaction with open-ended questions and direct requests for participants to comment and share similar experiences. Sessions were recorded and transcribed for analysis.

Analysis

The principal analytic tool was constant comparison in which researchers compare incidents and phenomena across subjects for similarities and differences in properties, dimensions, and processes (26). The phenomena being compared were the transcribed comments and observations made by participants; examples are provided below as quotes. The “naming” of similar phenomena, or coding, allowed us “to label, separate, compile, and organize data” (27). Codes are the grouping and linking of comments that are alike, which form the framework that defines our findings. First, reviewers gave code labels to form preliminary

groupings of similar phenomena. Next, they returned to the data to strengthen conceptual links and generate hypotheses. Finally, groupings were refined to finalize core-coded categories.

The second author (professor and marriage and family therapist) provided training to a team of three researchers (marriage and family therapy graduate students). Team members independently reviewed transcripts to place comments in groups based on similarity. They provided written and in-person feedback to the lead researcher about the conceptualization of key concepts, and the lead researcher developed initial groupings that were fed back to the team for editing. Initially, comments were placed into loose groups relating to specific types of experiences based on identifiable, repeated descriptions of key issues. When possible, groupings were labeled using participant language. Codes were based upon relevant literature and the authors’ research and clinical experiences (17–19). Also, emerging codes were compared with previous analytical findings for consistency, a process often called theoretical sampling of the data (26,27). The newly labeled codes provided a more complete or “thicker” description of the couples’ perceptions (28). This process was repeated by the second author until no additional groupings, and no new relevant redundancies, were found. This theoretical saturation process adds to the richness of descriptions. Results were returned to the analysis team at each level for feedback and additions/corrections.

Quality control

Qualitative researchers stress the importance of trustworthiness (28,29), and safeguards were used. Transcripts were independently analyzed by a four-member team to identify relevant comments. The initial inclusion of comments and grouping into codes proceeded collaboratively, with multiple perspectives and consensus. The lead author conducted the focus groups, providing an external quality check as she did not participate in the analyses. Her participation, along with the written notes of team members, provided multiple data sources (transcripts, personal notes, and personal recall), also ensuring trustworthiness (29).

Participants

Of the 55 potential participants identified through chart review, 16 patients and

15 partners agreed to participate (1 partner was ill); thus, the final numbers were 16 patients and 14 partners. See Table 1 for demographic information. The mean age was 48.3 years (patients) and 45.6 years (partners). Eleven (68.8%) patients and five (35.7%) partners were women. Although nonmarried couples were eligible, 100% were married. This was a well-educated group (all patients and most partners had some college and many had graduate degrees). The mean recent A1C (self-report) was 7.6%. They reported the following complications: hypertension ($n = 6$), stomach problems ($n = 4$), retinopathy ($n = 3$), kidney disease ($n = 2$), and depression ($n = 2$), and only one reported heart disease, neuropathy, stroke, and/or memory problems.

RESULTS—Because results were grouped in similar domains, patient and partner inputs are presented for each domain. Four major domains were identified: impact of diabetes on the relationship, understanding the impact of hypoglycemia, stress of potential complications, and benefits of technology. For each concept, we provide quotes that capture the idea being presented. We have also provided sex, age ($>$ or < 40 years), and years married ($>$ or < 15 years). We chose not to provide specific ages or years married in order to protect the confidentiality of our participants.

Impact of diabetes on the relationship

This domain includes three subareas: level of partner involvement in patient self-care, emotional impact on the relationship, and concerns about child-rearing.

(A) Level of partner involvement in patient self-care

Because the facilitator directly queried about the impact of diabetes on relationships, the largest segment of comments related to spouse level of involvement. Participants described clearly how they and their partners manage an illness that influences daily routines so fully (eating, sleeping, and activities).

Patients described spouses as supportive, caring, and helpful. This supportive grouping is comprised of comments referring to spouses as “open and caring,” “very loving and compassionate,” and “so great and supportive.” A second group described an independent approach to self-care, reflecting a patient’s personal sense of responsibility to manage the illness, or the impression that

Table 1—Focus group data of adults with type 1 diabetes and partners

	Patient focus groups			Partner focus groups		
	Group 1 (n = 9)	Group 2 (n = 7)	Total (n = 16)	Group 1 (n = 7)	Group 2 (n = 7)	Total (n = 14)
Age (years, mean, SD)	55.0 (19.5)	46.6 (15.1)	51.3 (17.7)	50.7 (15.7)	40.4 (9.2)	45.6 (13.5)
Sex, female (n, %)	5 (55.6)	6 (85.7)	11 (68.8)	2 (28.6)	3 (42.9)	5 (35.7)
Education (n, %)						
High school/GED	0 (0)	0 (0)	0 (0)	1 (14.3)	1 (14.3)	2 (14.3)
Some college	3 (33.3)	1 (14.3)	4 (25.0)	1 (14.3)	0 (0)	1 (7.1)
College degree	3 (33.3)	0 (0)	3 (18.8)	2 (28.6)	2 (28.6)	4 (28.6)
Graduate degree	3 (33.3)	6 (85.8)	9 (56.3)	3 (42.9)	4 (57.2)	7 (50.0)
Married, yes (n, %)	9 (100)	7 (100)	16 (100)	7 (100)	7 (100)	14 (100)
No. years married (mean, SD)	22.0 (18.3)	15.9 (16.9)	19.3 (17.4)	14.4 (16.7)	13.8 (10.2)	14.1 (13.3)
Age at diagnosis (years, mean, SD)	27.9 (20.7)	24.6 (17.5)	26.4 (18.8)	N/A	N/A	N/A
Recent A1C (mean, SD)	7.7 (0.98)	7.4 (0.86)	7.6 (0.9)	N/A	N/A	N/A
Treatment (n, %)						
Multiple injections	2 (22.2)	2 (28.6)	4 (25)	N/A	N/A	N/A
Insulin pump	7 (77.8)	5 (71.4)	12 (75)	N/A	N/A	N/A
Insulin protocol (n, %)						
Fixed dose	0 (0)	0 (0)	0 (0)	N/A	N/A	N/A
Insulin-to-carb ratio	7 (77.8)	4 (57.1)	11 (68.8)	N/A	N/A	N/A
Scale from provider	2 (22.2)	3 (42.9)	5 (31.3)	N/A	N/A	N/A
Hospitalized for DKA in past 12 months (n, %)	0 (0)	0 (0)	0 (0)	N/A	N/A	N/A
Severe high blood glucose episode in past 12 months (n, %)	0 (0)	2 (28.6)	2 (12.5)	N/A	N/A	N/A

partners do not know how or want to help.

Patient: "I know what I have to do, I can deal with it, just let me go and I'm fine" (<40-year-old female, married <15 years).

Patient: "I think he counts on me taking care of it, which is fine with me because I also don't want to be a burden" (>40-year-old female, married >15 years).

Partner: "It's something he deals with, I'm there if he needs help, but he never really asks for it" (>40-year-old female, married >15 years).

The third group is described as "help when asked." These patients perceived their partners as helpful when called upon, but not heavily involved. These spouses claimed to be minimally involved; however, anecdotes suggest more illness-specific knowledge and involvement.

Patient: "He's very good about it and ... he will step in and help with care if I ask him to, but he won't go overboard and he won't preach at me" (>40-year-old female, married >15 years).

Partner: "I'm probably minimally involved, but involved, not overly so" (>40-year-old male, married >15 years).

Partners also reported a larger degree of involvement early, i.e., right after

diagnosis if diagnosed as an adult, but less involvement as time passed.

(B) Emotional impact on the relationship. Patients frequently spoke of a positive, or minimized a negative, influence on their relationship because of the great support of a spouse.

"My husband is so great and so supportive... when I got married... it just immediately became like 'our thing' and it was just really a great relief to have someone else to share the burdens" (>40-year-old female, married >15 years).

"My wife's pretty helpful and supportive ... she kind of makes it... [seem] like it's no big deal" (>40-year-old male, married >15 years).

Others stated that diabetes has not affected their marriage; for example, "diabetes has never really come into play in my marriage" (<40-year-old female, married <15 years). Overall, the majority of patients' comments spoke to how the spouse was involved in management, not to relationship dynamics.

A second smaller group spoke of the negative impact of diabetes on their relationship. These more detailed comments described increased emotional distance, sexual intimacy problems, difficult decisions about if and when to have children, caring for young children with the constant threat of hypoglycemia,

and a general increase in relationship stress.

"I think that we have grown farther apart in the 16 years we have been married.... I can't say it's all because of the diabetes, but it's a big issue. I'm not going to cry [laughs]. I did that years ago. I'm done with that" (>40-year-old female, married >15 years). Partners made more overt statements about the negative influence of diabetes on their relationships, e.g., "not good" and "hard." One comment captures the tone: "I would say there is no positive effect on the relationship at all, for any of us" (>40-year-old female, married >15 years).

Less frequent comments identified partners who believe the illness has brought them closer, with a united approach that has led to increased emotional connection: "We connect so much, it's like us against the world kind of thing" (>40-year-old male, married <15 years).

"I think if you get through that [the hard times] you share that history and it brings you closer" (>40-year-old male, married >15 years).

Lastly, a few comments defined acceptance, e.g., "I look at it as a disease you can live with" (>40-year-old female, married >15 years).

(C) Concerns about child-rearing. Another grouping relates to specific concerns

the partner has about the patient's ability to bear and actively raise children, and fear of passing it on.

"The point that we are at in our lives right now is whether or not to have a third child... for the first time really in my life I feel like, okay, the diabetes is playing a bigger role than I would like it to play... my doctor said, 'There is no guarantee that you... wouldn't have complications... in pregnancies, and you could have another great pregnancy, but do you want to take that risk?' I hate making that decision because of my diabetes. My husband... would love a third child, but he would rather have me than a third child. Still, that's been hard. I think harder for me than for him" (<40-year-old female, married <15 years).

The following comment captures this issue and the ever-present partner concern about hypoglycemia, this time in relationship to childcare:

"We've got a 2-year-old and one on the way... she's going to have two little infants to chase around and the doctor told her it takes from her body. I gotta worry about that and then if I'm at work all day and now she has these two guys.... Is she all right? Is she keeping an eye on her blood sugar? But... it's not really a founded concern. [I've] never gotten any phone call 'your wife's passed out in the mall and... your son's like gone' (<40-year-old male, married <15 years).

Understanding the impact of hypoglycemia

Patients. Patients described hypoglycemia as "the worst feeling" and "life and energy draining," with great fear of lows. They described a need to exercise constant vigilance to protect themselves and family from burdens related to lows. One statement captures the sentiment: "I do everything in my power to avoid the lows" (>40-year-old female, married >15 years).

Patients described efforts to avoid lows (e.g., identifying poor food choices) to feel "in control." They described ways to help loved ones react appropriately (e.g., glucose tablets in every room). And they described the benefits of technological advances (e.g., insulin pump), which have reduced their frequency and intensity.

A smaller group was more focused on acceptance, describing less worry and hypervigilance: "Neither my husband nor I worry so much about being hypoglycemic" (<40-year-old female, married <15 years).

"I am sorry... I accept... I don't worry" (>40-year-old female, married >15 years).

This is not a reckless abandon, but the acknowledgment that worry and vigilance may not be helpful. One participant said, "So, I don't worry about it anymore, about the complications. I know they're there, but it's more... let's go day by day, let's go hour by hour, let's keep the blood sugars where they're supposed to be" (>40-year-old female, married >15 years). However, the general tone was that hypoglycemic episodes, with their terrible physical sensations and cognitive impairment, leave them with feelings of little control and are a significant source of anxiety.

Partners. Partners also described significant worry, stress, and anxiety about hypoglycemia and frustration in trying to prevent or manage it, e.g., the need to carry snacks, to remind and check during lows, and prearrange for emergencies. Three examples capture the stress.

"If I'm out of town then it's just totally terrifying to know if that [a low blood glucose episode] happened in the middle of the night, [to] know he's there by himself" (<40-year-old female, married <15 years).

"I would [want my partner to] understand how scary it is to be the person watching, not the person going through it, because they don't know, the person who's giving the glucagon and thinks you are going to die" (>40-year-old female, married >15 years).

"We've had a lot of bad experiences... but a couple times I had to call 9-1-1. You know, that's a big deal for me... when she's low... if she goes to bed and it's low and it gets low at night, that's when it's bad... The last one was right after our son was born and she was breastfeeding and they told her that she was going to have to adjust everything... So I woke up and it was crazy. I'd never seen anything like it. She is making these horrible noises and I called 9-1-1 and... she wasn't coming out at all. So the paramedics got there and they had a hard time getting the I.V. in her... when she like started to come around, he's like 'Oh, I thought we were going to lose you there' and I just about lost it. So she stopped breastfeeding right after that" (<40-year-old male, married <15 years).

Another set described the conflict, moodiness, and irritability often associated with hyper- or hypoglycemia:

"Sometimes I get mad because he doesn't feel it and I notice it his feet are

going and he's twitching and I'll say, 'Why don't you go test your blood sugar?' 'Why? I don't need to do it.' I'll say, 'Would you please do it for me? Just go test your blood sugar.' Then he'll test and he's low. I can remember a couple of times I was giving him candy bars when he was low and he'd fling them across the room and I picked one up and I put it in his mouth and he bit my finger and I wanted to slug him. (Laugh) So I says, 'Okay, be that way. I'm not going to help you anymore.' So he finally picks up the candy bars and started to eat them. Yeah, they have their mood swings" (>40-year-old female, married >15 years).

Stress of potential complications

Patients. Patients spoke about the ever-looming threat of complications, the "horror stories" about severe complications (e.g., blindness and amputation) and their distress when others share these stories. Patients are keenly aware that they need to "save organs" through good management. They reported feeling frustrated when labeled "in poor control," "brittle," or a "bad diabetic," as they feel criticized, guilty, and ashamed.

"Even as a kid... the doctor would take my blood sugar and if it ran high it was 'You'll go blind. What do you think is going to happen?' I had one doctor... he told me to go make my next appointment at the funeral home" (<40-year-old female, married <15 years).

"I worked in a school district... the school nurse said to me, 'Well how long have you been diabetic?' I said, 'This is my tenth year.' She goes, 'The first ten years are a free ride, after that it's all downhill'" (>40-year-old female, married >15 years).

They are angry and hurt when others blame them yet they feel they are making sincere efforts. Overall, patients described being keenly aware of potential devastating complications and emphasized their need for supportive, nonblaming responses from others.

Partners. The partners also expressed pressing fears of complications. As one partner said, "it is like a ticking bomb." She described the intense concern partners can experience: "I still to this day wonder how much damage is going to show up later from all that bad out of control stuff for five or six years... we're like 50 and he was 20 then... and he has no kidney problems, no eye problems, but I still think about it often because I think he had a lot of damage... what he

did 25 years ago may be what we see in five years, not the good stuff he's done for the past 20 years. So we don't really discuss it because what's to discuss?" (>40-year-old female, married >15 years).

Partners also outlined specific challenges, such as exercise and weight control, wrestling with insurance companies, and patients' nearly complete dependence on them during hypoglycemic events. The cumulative toll of management may be more than the sum of individual stressors.

Benefits of technology

Patients and partners. Participants spoke frequently about changes due to technology (i.e., insulin pump and continuous glucose monitor). They spontaneously shared stories and advice and clearly appreciated the opportunity to share and learn from each other.

There were two main themes. First, life is more manageable with the new technologies. Although they expressed frustration (malfunctions, cost/insurance struggles, and interrupted sleep from alarms), the great majority of comments spoke to improved quality of life. One patient described the life-changing nature of technology: "I love my pump. My pump made me feel much more normal, nondiabetic" (>40-year-old female, married >15 years).

Others described increased freedom (e.g., to travel) and the decreased burden of no more daily injections. Partners also described less stress and responsibility with the pump as it promotes independence. Several said they were much less involved in patient self-care, with some not knowing how to program the pump or address problems.

CONCLUSIONS—Adults with type 1 diabetes are healthier, living longer, and benefiting from technological advances. They face behavioral, emotional, and interpersonal challenges. We know that adults with type 2 diabetes are at increased risk for depression (8,30) and diabetes distress (31), and that these outcomes negatively affect their adherence to self-care (32,33) and glycemic control (34,35), and present challenges for their partner relationships (36). But much less is known about adults with type 1 diabetes. They too report anxiety and depression, especially if they experience severe hypoglycemia (5,23). But because they are typically included with type 2 diabetic patients in quantitative

studies, we do not know about their unique contribution to the findings. Family support has a positive influence on self-management for adults with type 2 diabetes (19,20,37), and our data support its relevance for adults with type 1 diabetes.

This qualitative study was undertaken to gain a richer understanding of these issues for adults with type 1 diabetes. We listened to the voices of these patients and partners. The themes that emerged suggest that, although partner involvement may vary, the significant anxiety (especially about hypoglycemia) and fear (especially about future complications) weigh on them and their relationships. They lead us to several conclusions. First, relationships are unique, and one cannot assume that all patients want an actively involved partner, or that all are overwhelmed by diabetes-related distress. Second, relationships change, and needs at one time during the course of the relationship and the disease may be very different than at another point. Therefore, it is important to assess the individuals in the relationship to develop an intervention that is tailored to their unique needs. Third, one must know their specific concerns. For example, is child-bearing, or child-rearing, a major concern, or is their stress focused elsewhere? Fourth, many patients experience anxiety about their long-term health, and clinicians should recognize that emphasizing complications to motivate behavior change may merely raise that anxiety and increase their self-blame. Finally, although technology has many positive benefits, it may lead partners to withdraw, or be excluded, from care, which may decrease the level of perceived support.

Limitations

Although focus group methodology can promote openness, it may suggest more consensus than exists if participants are inhibited in expressing differing viewpoints. The groups were not diverse, and future qualitative research should explore these questions with couples of varied cultures and education. Groups of healthcare providers would also elicit unique perspectives. Finally, although we have drawn tentative conclusions from our data, this pilot work was primarily aimed at generating ideas and directions for future study that should explore these issues in more detail and depth with a more diverse group of individuals.

We believe that adults with type 1 diabetes deserve increased attention by researchers to better understand their emotions, coping mechanisms, and psychosocial outcomes, and the relationship of these factors to adherence and glycemic control. Also, their partners, and the effect that living with type 1 diabetes has on them and their relationships, should be assessed. Future interventions might be developed that engage the partner and evaluated to see if, and in what ways, this is beneficial. Our goal is to develop and test interventions that will help patients and partners cope with these challenges effectively and succeed in their self-management.

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P.M.T. contributed to the study design, researched data, and wrote the manuscript. J.G.S. contributed to the study design, performed the analyses, and wrote and edited the manuscript. J.A.D., P.J.F., and R.S.W. contributed to the study design and reviewed and edited the manuscript. P.M.T. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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