PARTNER PERSPECTIVES ON LIFE WITH A PERSON WITH TYPE 1 DIABETES

ABSTRACT

Type 1 diabetes affects all aspects of life for both the person with the disease and their loved ones. For partners, negotiating the caregiving role can be challenging.

Objective: Partners of people with type 1 diabetes are positioned to provide crucial support for their significant other, but they may struggle with the caregiving role. The purpose of this study was to determine the challenges and needs of these partners.

Research Design and Methods: In this qualitative study, in-depth interviews were conducted with 19 partners of people with type 1 diabetes. A semi-structured interview guide was used during the interviews. Thematic analysis was conducted using qualitative data management and analysis software.

Results: The analysis of the interviews revealed that partners face numerous challenges in the caregiving of their partner. Partners reported struggling with: (1) emotional strain from fear and distress over diabetes symptoms and complications that result in caregiver burden; (2) determining how to avoid relationship conflict; and (3) knowing how to provide life sustaining care during diabetes medical emergencies.

Conclusions: Partners of people with diabetes would benefit from diabetes education targeting emergency care and the psychosocial impacts of diabetes. This additional education could potentially ease the emotional strains of caregiving.
INTRODUCTION

Living with a disease like type 1 diabetes (T1D) can be challenging. Diabetes is a chronic, life threatening condition in which individuals experience impaired pancreatic functioning. Type 1 diabetes is generally diagnosed in childhood or adolescence, but it can also develop during adulthood. It is estimated that approximately 3 million people have type 1 diabetes in the United States with adults comprising 85% of this population [1]. Daily life with type 1 diabetes necessitates the use of insulin administration, blood glucose monitoring, dietary modifications, and exercise to manage blood glucose levels and avoid short-term and long-term complications. The goal of diabetes management is to artificially maintain blood glucose levels within normal ranges, and prevent or decrease the occurrence of complications such as neuropathy and nephropathy from hyperglycemia, mental confusion, shakiness, seizure, or unconsciousness from hypoglycemia [2]. Given the unending nature of diabetes self-care, family members are often prime caregivers in daily life.

The impact of diabetes and other chronic conditions on family systems is a growing area of interest [3]. At present the caregiving role of parents as caregivers of children with T1D and partners of adults with type 2 diabetes has received more attention than partners of adults with type 1 diabetes [4]. Given that T1D is often diagnosed in childhood or adolescence, research has been instrumental in understanding how diabetes affects family functioning, parental distress, and quality of life among families living with diabetes [5]. As the primary caregivers of children, parents often struggle with the demands of diabetes management, and they experience significant fear and distress [6, 7]. The intensity and challenges of the parental caregiver role can be compared in many ways with the experiences of partners of those with diabetes.

Research investigating the impact of type 2 diabetes on romantic relationships indicates partners are in a pivotal position to influence success with diet and self-care regimes; however, these partners’ attempts may result in resistance and increased interpersonal conflict [8]. Exerting social control, or influencing a significant other’s behavior, exerts a cost for the partner in the form of increased stress [9, 10]. August and colleagues [11] found among couples living with type 2 diabetes, increased stress was associated with monitoring the significant other’s health, and engagement in his/her diabetes self-care behaviors produced increased caregiver burden. However, this burden was mitigated by the partner’s confidence in the diabetes management of their significant other and the response to their social support efforts.

August and colleagues [12] also reported a distinction between social control and social support that is useful for understanding the role of caregivers. Social control is the attempt to influence behavior directly, while social support is indicated by indirect behavior such as preparing healthy meals or purchasing medications for a loved one. In this study, exerting social control when attempting to influence dietary choices of a partner resulted in increased stress and conflict.

The chronic nature of diabetes care can produce chronic stressors for partners that shape their assessment of daily life and the overall relationship. Iida and colleagues [13] report that daily diabetes distress is associated with increased conflict, and as symptoms progress, partners reported less enjoyment in the relationship. Trief and colleagues [14, 15] found that marital quality and intimacy are associated with blood glucose control; therefore, helping couples cope with interpersonal conflict may improve diabetes control and relationship quality.

The evidence from research shows that intimate relationships have a direct effect on health outcomes [16]; therefore, it is necessary that the patient’s individual health behaviors be considered in the context of his/her social systems. In this social ecological view of diabetes, family relationships become a natural starting place to improve health and well-being. The purpose of our exploratory research is to gain feedback from partners of adults with type 1 diabetes on the challenges and needs they face in life with diabetes.

METHOD

We conducted a qualitative study using interviews with partners of people with type 1 diabetes. Individual face-to-face and telephone interviews were used for both in-depth discussions of personal experiences and to allow for broad geographical recruitment. Recruitment advertisements were posted on diabetes social media sites and distributed to members of diabetes organizations and local clinical centers. Eligibility for the study included being at least 18 years of age and being in a committed relationship for at least one year with a person diagnosed with type 1
diabetes. Participants were recruited for face-to-face interviews with the option of participating in a telephone interview if unable to attend in person due to geographic distance. Participants were screened for inclusion by the researchers prior to obtaining consent for participation. All participants were compensated for their time with a $20 gift card, and the study procedures were approved by University of South Florida Institutional Review Board.

Interviews were held in a private office and lasted 60-90 minutes between late 2012 - early 2013. The interviews were conducted by the co-investigators using a semi-structured interview guide. Questions centered on the challenges partners face in living with a person with diabetes, how partners show support, how diabetes impacts their lives together, and how partners cope. For example, we asked, “What are some of the greatest challenges you face in helping your loved one manage diabetes?” and “How do you think diabetes will impact the future of your relationship?”

Interviews were audio recorded with participant consent and transcribed verbatim within one week of each session. De-identified transcripts and interviewer notes were analyzed for content and coded using Atlas.ti v.6 (GmbH, Germany), a qualitative data management and analysis software. The authors followed a systematic analysis process based on a grounded theory approach. Analysis began with an initial reading, the assignment of open codes, and the development of a codebook that was modified continuously to include more specific sub-codes [17]. The coding process and modification of the codebook were performed with an accompanying audit trail as more data was collected and analyzed. The co-investigators repeated this process with each additional interview transcript. The systematic process of analysis included the identification of overarching themes based on the codes and sub-codes. Once all transcripts were coded, themes were identified and compared to see how interacting factors affected partners’ perceptions and experiences. Transcripts were independently coded by the co-investigators and discrepancies in coding were refined until 100% inter-coder agreement was reached to increase reliability [18]. Targeted recruitment continued until preliminary assessment of the data indicated saturation. At the point no new codes were produced from additional interviews, recruitment ceased.

Nineteen individuals participated in interviews (11 males, 8 females). The participants’ mean age was 35 years.

![Methodological Process](image-url)
(range of 19-61 years old). The mean age of the partners with T1D was 34 years. The couples’ relationship duration ranged from 1-27 years with a mean of 9.4 years. Four of the participants were not married, but were engaged or co-habitating. For simplification, we refer to all participants in this study as “partner” regardless of marital status. All participants resided in the United States with the exception of one participant who lived in the United Kingdom. The disease duration of the participants’ loved ones ranged from 7-41 years with a mean of 17.9 years. Twenty-six percent (5/19) of the participants reported that their significant other was diagnosed as an adult during their relationship. None of the participants were diagnosed with diabetes.

RESULTS

The results of the study provided insight into the emotional and practical implications of diabetes in romantic relationships. Our analysis resulted in three overarching themes: 1) factors that affect the caregiving role of the partner; 2) the emotional strain partners feel; and 3) the ways partners cope with life with diabetes.

Emotional strain of loving a person with diabetes

For participants, living with a partner’s diabetes needs often caused emotional strain. Partners faced conflicts and stress in their relationship that ultimately impacted their well-being and indirectly impacted their significant other’s diabetes management. For partners, the emotional challenges of diabetes revolved around the fear of emergency low blood sugar episodes, worry about long-term complications, and distress over a perceived shortened life expectancy for their mate. The combination of short-term and long-term fears increased their sense of burden. For example, one twenty-eight year-old female stated:

I guess what worries me most is if he’d have an emergency situation and I wasn’t there. In the long term I worry about long term complications and things that might shorten his life. I’ve expressed that fear, “I’m not going to be with you if you’re not taking care of yourself. If you don’t care, how do you expect me to care?”

Fears about diabetes complications often placed partners in a position of feeling helpless and worried for their loved ones. A twenty-one year-old man described his emotional concern for his girlfriend:

Protection is a big instinct for me and [diabetes] is a huge, dangerous area that I have zero influence in. I can do absolutely nothing to help protect her. That is a bad feeling for a boyfriend. That is the one area where I feel literally helpless.

Feelings of helplessness were exacerbated during emergency low blood sugar episodes. In this sample, 90% of participants had provided life-sustaining care for their partner during a low blood glucose emergency, yet only 26% had received formal education on diabetes care. Respondents expressed doubts about their knowledge regarding the signs of diabetes emergencies and how to react quickly and appropriately. Emergency health episodes were described as traumatic for partners. During severe low blood sugar episodes loved ones with diabetes can become unresponsive. In the midst of one such event, a forty-eight year-old wife struggled to elevate her husband’s blood sugar while on vacation. Being in a rural area, she feared that he would die before medical assistance could arrive. She relayed that the event continued to affect her years later. For partners, emergency episodes highlight the life-altering aspects of diabetes.

Participants described grieving for the loss of a “normal” life. Many of the partners assume that diabetes complications will limit their life choices or their partner’s health in the future. A twenty-year-old man stated that he and his partner “talk about the future a lot. That is one of the things I think about the most, because I have no idea. . . . I don’t know how to be prepared for whatever is coming.” All participants revealed that the risk of diabetes complications influenced the couple’s major life decisions, such as the decision to have children or employment decisions.

Many partners in this study described feeling less equipped to handle the emotional adjustments to diabetes than supporting their partner’s physical diabetes management. One thirty-seven year-old woman who received diabetes education at the time of her husband’s diagnosis stated that, “They taught me the logistics of the disease like how to give a shot and how to test his blood sugar. Nobody told us about the emotional stresses of the disease.” At times partners struggled to cope with how the symptoms of diabetes affect their significant other’s behavior. Some partners also struggled to handle their partner’s depression and diabetes burnout, which led to poor diabetes management, more symptoms and increased conflict between couples.
Managing the caregiver role

In this study sample, the caregiving role varied depending on the partner’s level of experience with diabetes, but overall, partners attempted to provide non-obtrusive support. Most described providing small acts of instrumental support such as offering food or drink during low blood sugar episodes, making healthier meal choices as a family, carrying glucose tabs when away from home, or asking if the partner needed to check blood sugar levels. These tasks occurred while monitoring their partner for signs of low or high blood sugars. Partners described learning the signs of low and high blood glucose through past experience and discreetly watching for these warning signs. One twenty-five year-old male participant described his caregiving role as being a “diabetes detective.” Deciphering whether diabetes was the cause of a behavior, and therefore needed to be addressed, was a challenge. A thirty-six year-old woman stated:

*I think the big thing for the companion of a Type 1 is to be able to read what things are diabetes-related, and what is just normal human behavior. Is this behavior due to low-blood sugar or are you just fussy?*

Being aware of the signs of fluctuating blood glucose allowed the partner to intervene if needed. Partners explained that this high level of alert often increased their stress and resulted in more direct questioning of their partner’s blood glucose numbers or providing unsolicited advice on how to manage diabetes. Their partners objected to this “nagging,” thus increasing conflict within the relationship. One thirty-four year-old man stated that he struggled to not overstep his role as a caregiver when his girlfriend struggled to manage her diabetes. He compared the experience to “backseat driving.” He said, “You don’t think they’re managing their diabetes as well as they should be. I still feel that sometimes, but I’m trying to find that balance. I don’t want to be the nag that I was.” As his comments highlight, monitoring the partner while still respecting the partner’s ability to manage their diabetes requires a delicate balance. Maintaining a supportive caregiving role when faced with conflict was a challenge for many in this sample. Fear of symptoms and complications prompted partners to become more directly involved in diabetes care, which was often interpreted as nagging by partners and resulted in increased inter-personal conflict. Partners voiced a desire to respect their significant other’s autonomy and independence, and struggled to avoid an overbearing, controlling caregiving role.

It also was reported that poor management, depression, diabetes burnout, or illness associated with a health crisis or hospitalization prompted partners to become more involved in daily diabetes care. When partners believed their significant other needed more direct support, they increasingly asked about blood glucose numbers, attended clinical appointments, and helped with dietary choices. The shift from watchful monitoring of behavioral cues to being more direct with requests about diabetes care and providing more hands-on caregiving was described by several participants. A thirty-nine year-old wife related that she had minimal involvement in her husband’s diabetes until his management suffered and it impacted their family’s safety. She realized that he was struggling with depression and diabetes burn-out after he suffered a severe hypoglycemic episode, which caused him to drive recklessly with their family in the car. This crisis prompted a shift toward a more active caregiving role on her part.

The caregiving role was also impacted by the partner’s level of experience with diabetes, which was reflected through the age of diagnosis. Most participants’ partners (74%) were diagnosed as children or adolescents prior to the current relationship, while only five were diagnosed as adults during their relationship. When the diagnosis was determined prior to the relationship, the significant other with diabetes was described as independent, and thus, the partner took a “hands-off approach” to caregiving. These partners were also less likely to have received diabetes education from a health care provider. Partners whose significant other developed diabetes later in life and experienced the diagnosis during the relationship reported receiving formal diabetes education from health care providers during the initial health care contacts and afterward. They were also more likely to attend diabetes clinical appointments with their spouse, and these appointments gave them an opportunity to ask questions directly to the health care provider.

When partners were asked how they received information about diabetes, all participants reported that their loved one was the primary source of information. Some participants (37%) reported actively seeking diabetes information via the Internet or medical professionals. Participants stated that they wanted to know more about the disease in order to better assist their partner on a daily basis or during emergencies. Participants felt that knowing more about diabetes would help them feel more confident in the caregiving role, and better understand their significant other’s diabetes experiences.
Coping strategies

Participants in this study shared strategies that assist them in coping with the stress of diabetes caregiving. Universally, coping with diabetes and negotiating the caregiver role was best handled with clear communication between partners and determining boundaries. As a thirty-six year-old female participant explained:

> It's about communication and the Type 1 telling you what they need. Checking their blood glucose numbers is a good example. He told me not to ask and now I don't ask. It is a back and forth about what the other one needs in order to best help that person in the way they want to be helped.

These types of compromises facilitated trust and respect. For participants, respect is an extension of trust. As one thirty-two year-old husband stated:

> I have a lot of sympathy for what she's going through. I cannot say that I have empathy, in that I don't understand what it's like to live with diabetes even though I'm right next to it. I think respect is crucial.

Coping with diabetes resulted in positive outcomes for many of the couples. These outcomes included an appreciation for time together, encouragement to live healthier lives, improved communication, and increased respect for each other. Partners recognized the work their loved one performed to protect his or her health, and they voiced a sense of pride in their loved one's efforts. Some partners also made the effort to improve their own diets and communication skills because of diabetes.

DISCUSSION

This qualitative study explores the perspectives of partners of individuals with type 1 diabetes. Partners are positioned to be valuable resources in diabetes management [19]; however, the effectiveness of the role is impacted by a lack of adequate diabetes education and support to cope with the emotional aspects of caregiving. Partners take on a variety of caregiving tasks that include providing verbal encouragement and helping their loved one perform self-care tasks [20]. In this study, partners expressed a desire to be helpful in appropriate ways in order to decrease conflict in the relationship and support the health and well-being of their significant other. Nevertheless, negotiating the caregiver role posed challenges. These results reiterate the findings that monitoring one's partner takes a toll [11]. Identifying ways to support partners as caregivers is important for improving diabetes management. Partners struggle with the effects of fear, loss, and stress [21]. These emotions coupled with the daily needs of diabetes management result in chronic stress and caregiver burden that is largely unaddressed [11].

Maintaining a balance between appropriate caregiving and exerting social control out of frustration was a challenge for participants. Determining when and how to increase their involvement was a challenge due in part to the possibility of rapidly changing blood glucose levels. This is especially relevant for individuals with T1D who may need direct assistance during hypoglycemic episodes [22] but relatively little direct care at other times. Partners responded to their significant other's changing diabetes needs by vigilantly monitoring behavior; however, partners routinely stated that they did not want to be like the parents of their significant other. As partners recognized severe diabetes symptoms or impaired functioning, they became more involved in caregiving by using direct care and social control tactics instead of verbal support. Although the intent is to help improve the partner's health, the recipients of this attention may at times resent the interference.

Participants who reported more relationship satisfaction and felt comfortable negotiating their caregiving role revealed adaptive strategies that helped them form a successful partnership. These partners had received more education about diabetes from health care providers, and they had confidence in their partner's abilities to care for themselves. The couples also established productive communication strategies about diabetes, and they determined boundaries for appropriate support together and renegotiated them over time. Partners reported the positive benefit of active and ongoing communication about the needs of each person around diabetes. This communication was described as instrumental for decreasing stress and increasing the partner's confidence. Unfortunately, most of the partners were often excluded from health care interactions and opportunities for formal diabetes education until health crises occurred.
CONCLUSION

The results of this study indicate that partners of people with diabetes have unmet needs, and the caregiving role of spouses often varies over the life course of the relationship. Partners would benefit from formal education on the etiology and management of diabetes provided by health care professionals [23]. Education should include training in emergency medical response, information on depression, and diabetes burn-out. Partners and their loved ones may also benefit from family therapy or training focused on improving communication skills. When appropriate, partners could be included in health care interactions to provide them with an opportunity to learn more about diabetes and how to appropriately provide support in the relationship.

The study contributes to our understanding of caregiver burden among partners of people with diabetes. Future research should expand the scope of this study to address generalizability across this population and to better understand the potential differences in disease and life experiences that would affect the caregiving role. It is important to better understand the cumulative effects of chronic stress on the caregiver and relationships over time. Partners are potential resources for diabetes management. When the needs of these caregivers are met, they have the potential to provide support for better diabetes and psychosocial outcomes.

LIMITATIONS

Although saturation was determined to be met, the small sample size of 19 can be considered a limitation. The sample is also limited in its lack of ethnic diversity. Future studies should explore how culture may affect care-giving behaviors. Future studies should also include a quantitative element to further validate findings. This study concentrated on qualitative methodology, which is rich in context but would be strengthened by the support of quantitative data.

REFERENCES


