

Yours, Mine, and Ours: A Qualitative Analysis of the Impact of Type 1 Diabetes Management in Older Adult Married Couples

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ABSTRACT

Objective. The purpose of this study was to understand perceptions of diabetes management responsibilities and the impact of diabetes on day-to-day activities in older adulthood for individuals with type 1 diabetes and their spouses.

Design and methods. This qualitative content analysis used a constant-compare approach to analyze individual interviews conducted with older adults and their spouses. People with type 1 diabetes (PWD) and their spouses were interviewed regarding how they coped or dealt with diabetes, what activities they carried out or avoided because of diabetes, and how they appraised diabetes as an individual or shared problem.

Results. Participants ($n = 52$) included 26 older adults with diabetes (mean age 69 years, SD 2.56 years; 38.5% female) and their spouses (mean age 68 years, SD 5.11 years; 61.5% female). Half of the PWD (50%) and the majority of spouses (76.9%) appraised diabetes as a shared issue. Five themes emerged from the interview data: 1) Perceptions of PWD of spouse involvement in diabetes care, 2) PWD underestimated the impact of diabetes on their spouse's daily lives, 3) gendered nature of spouses supporting diabetes management, 4) evolution of diabetes and the relationship across developmental time, and 5) differences in diabetes management among couples.

Conclusion. Older adults with type 1 diabetes and their spouses have different perspectives regarding diabetes support and responsibility and may not always realize what support is being provided or needed to optimize effective diabetes management. Advancing age with or without diabetes complications may necessitate that spouses provide diabetes support. Diabetes management training for spouses would likely be helpful.

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The incidence of type 1 diabetes is rising (1), as is the number of older adults (>65 years of age) who are living with type 1 diabetes (2). The life expectancy of individuals diagnosed with type 1 diabetes increased by 15 years between 1950–1964 and 1965–1980 (3). Type 1 diabetes is associated with a number of health complications, including myocardial infarction, cerebrovascular accidents, retinopathy, neuropathy, nephropathy (4), hypoglycemia and hypoglycemia unawareness (5),

and dementia—all of which are more common among older adults (3,6,7). Although individuals are now living longer with type 1 diabetes, they may experience significant functional and cognitive decline as a result of their illnesses. Older adults with type 1 diabetes are generally an understudied population.

Type 1 diabetes management in adulthood is most often examined at the individual level (8,9). Although couple relationships are the most important resource for supporting

people with type 1 diabetes (PWD) in adulthood, the understanding of spouses' experience is limited. In 2018, Whittemore et al. (10) conducted the first systematic review of the experiences of spouses of adult PWD. They found three themes reflected in spouses' experience of coping with type 1 diabetes. The first was the undercurrent of hypoglycemia. The continuous threat of hypoglycemia causes stress and fear for spouses (11,12). The second theme was spouses' involvement in diabetes care. Spouses are involved in a variety of ways such as providing instrumental, emotional, and moral support (13,14). The final theme was the impact on spouses' lives. That is, spouses experience sleep disturbances, diabetes-related stress, and varied emotional responses such as fear, worry, anxiety, and frustration to living with a person with diabetes (12,13,15,16). Additionally, some spouses reported that their relationship became closer due to diabetes, whereas others reported relationship conflicts due to diabetes management, unmet needs, and concerns about childbearing and childrearing (11,13). These studies lay a foundation for understanding spouses' experiences in dealing with type 1 diabetes. However, few studies included older adults (>65 years of age), and most studies used only spouses' data, leading to a limited understanding of the interdependent nature of couple relationships in older adulthood.

PWD, especially in older adulthood, may rely on a social network for increased assistance and care. For those who are married, the most likely person to be involved in diabetes is the spouse. In fact, couple relationships are one of the most critical and strongest resources for people facing major and minor stressful events in life. The coping processes of PWD may function both at the individual and dyadic levels (17). PWD and their spouses use individual coping strategies but also provide support to each other and cope with stressors

and other life events together (17–20). Married individuals live longer and enjoy better mental and physical health than unmarried individuals (21). Among adult PWD, living with a spouse is associated with better diabetes outcomes (22). Particularly for late-life married individuals, who perceive their future time as limited and want to spend time in more meaningful interactions, the interdependent nature and importance of a couple relationship increases (23).

Managing type 1 diabetes in older adulthood may put additional strain on relationships. Type 1 diabetes requires a myriad of self-management techniques that can directly and indirectly affect spouses (13). Older adult PWD face additional challenges that may further add to the burden or level of expected involvement from spouses. For example, older adult PWD are more prone to episodes of severe hypoglycemia due to impaired regulation of glucose and impaired awareness of hypoglycemia (6). As a result, they may come to rely on spouses for symptom identification and help with hypoglycemia treatment. The risks of diabetes-related complications such as kidney disease (24) and comorbid conditions increase with age, which may also require support from a spouse. The extent to which older PWD rely on spouses and the extent to which spousal involvement is generally helpful, harmful, or both for self-care in older adulthood is unknown.

The purpose of this qualitative study was to understand the perceptions that older adult PWD and their spouses have regarding diabetes management responsibilities and the impact of type 1 diabetes on day-to-day activities. We aimed to understand how PWD and their spouses view diabetes management and cope or “deal with” diabetes in daily life. We also aimed to understand whether there are meaningful qualitative differences between how

PWD and their spouses view the impact of diabetes on their lives.

Methods

The data presented in this article are from a subsample of a larger study of married couple dyads in which one individual is living with type 1 diabetes. This article focuses on a qualitative analysis of interviews conducted with older adults (≥ 65 years of age) and their spouses.

Recruitment

Participants were recruited from University-affiliated endocrinology clinics in two cities in the Mid-Atlantic and Southwestern regions of the United States for a study assessing collaborative coping in adult married couples in which one person had type 1 diabetes. The study procedures were approved by the institutional review boards at University of Utah and Carnegie Mellon University. Participants in the larger study were eligible to participate if they 1) were ≥ 25 years of age, 2) had been diagnosed with type 1 diabetes for at least 1 year, 3) spoke English as their primary language, 4) were free of any major impairments that might impede study completion (e.g., dementia), 5) in a romantic relationship and living with their spouse for at least 1 year, and 6) had a spouse who did not have diabetes who was also willing to participate in the study. The full sample included 199 couples. The current study focused on a subsample of 26 married couples in which the PWD were ≥ 65 years of age.

Interview

During a laboratory appointment, the PWD and their spouses were interviewed separately. Interviews were conducted by a trained research assistant. Individual interviews focused on how couples coped with diabetes. A semi-structured interview guide was developed by the research team (Table 1). All interviews were audio-recorded, transcribed verbatim, and verified for accuracy.

TABLE 1. Semi-Structured Interview Questions

1. How did (you tell your partner/your partner tell you) about (your/his or her) diabetes?
2. Tell me about the ways that you cope or deal with diabetes?
3. When problems arise with diabetes, how do you cope or handle them?
4. What things do you or your partner do specifically in relation to diabetes (like things you do on a daily basis in relation to diabetes)?
5. What things do you or your partner avoid doing in relation to diabetes?
6. What else can you tell me? Are there any other ways that you or your partner are coping or dealing with diabetes?
7. Which of the following phrases best describes how you think about diabetes? It is (my/my partner's) issue to deal with. It is (my/my partner's) issue, but I know that it affects (my partner/me). It is a shared issue. It is (my partner's/my) issue to deal with.

TABLE 2. Overall Demographic Characteristics

	Mean (SD)	Frequency, %
<i>Patients</i>		
Age, years	69.14 (2.56)	—
Female sex	—	38.5
White race	—	96.2
Hispanic ethnicity	—	3.8
A1C, %*	7.26 (.97)	—
Duration of diabetes (years)	32.12 (12.92)	—
Insulin pump use	—	53.8
Continuous glucose monitoring use	—	23.1
Comorbid conditions, <i>n</i>	3.30 (2.43)	—
<i>Partners</i>		
Age, years	67.55 (5.11)	—
Female sex	—	61.5
White race	—	100
Hispanic ethnicity	—	7.7
Comorbid conditions, <i>n</i>	2.50 (1.86)	—

*A1C was *n* = 25. One individual was removed because of an error with the laboratory A1C analyzer in the lab. This participant was otherwise retained in the sample.

Comorbidity

To more fully describe the sample, we included a description of comorbid illnesses and conditions using the Self-Administered Comorbidity Questionnaire (SCQ) (25). The SCQ is a short, self-report measure that assesses the presence of 12 common health problems (e.g., heart disease and hypertension) and allows partic-

ipants to list up to three additional health problems not otherwise listed.

Analysis

Using principles of qualitative description (26,27), the investigators analyzed the data using a constant-comparison approach (28) to examine similarities and differences in perceptions of diabetes management and coping among

couples (29). Qualitative analyses were conducted using NVivo version 11 (QSR International, Boston, Mass.) (30) to code the data. First, the authors coded eight PWD interviews as a team to develop the initial codebook. The remaining PWD interviews were coded by the authors in pairs or individually using the codebook. New codes were added on an ad hoc basis through an open coding approach (31). This process was then repeated for spouse interviews. Second, two separate teams compared PWD (authors M.L.L., E.L.T., and C.S.K.) and spouse (authors M.L.L., S.E.W., and N.A.A.) responses to identify group similarities or differences. Third, to understand how PWD and spouses responded differently or similarly within couples, a side-by-side comparison of PWD and spouse interviews was then conducted by a research team (authors M.L.L., S.E.W., and E.L.T.). At this time, couple response types (Table 1, question 7) were categorized, resulting in six types of couple responses: 1) PWD – it is my issue to deal with/spouse – it is my partner's issue but I know it affects me; 2) PWD – it is my issue to deal with/spouse – it is a shared issue; 3) PWD – it is my issue but I know it affects my partner/spouse – it is my partner's issue but I know it affects me; 4) PWD – it is my issue but I know it affects my partner/spouse – it is a shared issue; 5) PWD – it is a shared issue/spouse – it is my partner's issue but I know it affects me; and 6) PWD – it is a shared issue/spouse – it is a shared issue. Next, interviews were examined and compared across all couples to identify patterns in couple experiences. Finally, codes on the PWD level, spouse level, and couple level were compared, contrasted, and collapsed to develop corresponding themes that represented the couple (31,32).

Results

Our sample included 52 individuals in 26 couples. The average age of PWD was 69 years and of spouses was 68 years. All participants were mar-

ried, and the average length of relationship was 39 years (range 10–52). Remaining demographic information can be found in Table 2. There were no site differences in appraisal of how individuals thought about diabetes, based on question 7 in the interview (Table 3).

Sixteen PWD (66.7%) were diagnosed after establishing a relationship with their spouse; three PWD were diagnosed as adults and were initially misdiagnosed with type 2 diabetes. When including diabetes as a comorbid condition, PWD had significantly more comorbid conditions than spouses ($P < 0.003$). However, when diabetes was removed as a comorbid condition, there was no difference in the number of comorbid conditions between PWD and spouses ($P = 0.339$).

Five themes emerged from the independent PWD and spouse interviews: 1) PWD’s perceptions of spouse involvement in diabetes care, 2) PWD underestimated the impact of diabetes on their spouses’ daily lives, 3) gendered nature of spouses supporting diabetes management, 4) evolution of diabetes and the relationship across developmental time, and 5) differences in diabetes management among couples.

PWD’s Perceptions of Spouse Involvement in Diabetes Care

Diabetes care involved both PWD and spouses. However, PWD and spouses perceived the support spouses provided differently. PWD identified barriers to more spouse support, whereas spouses reported unrecognized support.

Differences in Perceived Spouse Support

Some PWD felt that their spouses were “there for them” to support their emotional and diabetes management needs. This support related to open communication, spouses’ willingness to integrate healthy behaviors into their own lives, and spouses’ willingness to support diabetes beyond the treatment of hypoglycemia. One person with diabetes stated, “She is

TABLE 3. Audio Responses and Comparison of Responses Between Sites

	Frequency, %
<i>Patients</i>	
My issue (A)	11.5
My issue but affects partner (B)	38.5
Shared issue (C)	50.0
My partner’s issue	0
<i>Partners</i>	
My partner’s issue (A)	0
My partner’s issue but affects me (B)	23.1
Shared issue (C)	76.9
My issue	0
<i>Between-site differences</i>	
A series of χ^2 tests revealed no statistical differences between sites on shared appraisal for patients ($\chi^2[2, n = 26] = 0.4.11, P = 0.13$) or partners ($\chi^2[1, n = 26] = 0.19, P = 0.66$).	

my rock, she cooks good meals and helps me with carb counting.” Both participants in this particular dyad shared supportive comments, including recognition that their behaviors influenced each other. Several PWD mentioned the importance of having their spouse listen to them when they were down. Moreover, PWD described how spouses’ help with meal planning made them feel supported and encouraged in their diabetes management.

PWD and spouses perceived the level of support that spouses provided differently. Some PWD overtly identified diabetes as their own issue, indicating little support from their spouse. Other PWD reported often feeling this way because they realized how their diabetes affected their spouse, but did not feel that the spouse was necessarily responsible for providing care or support. In contrast, spouses felt that they were providing support that the PWD failed to notice. For example, PWD noted that spouses helped them to treat hypoglycemia but did not see that spouses were engaged in other behaviors to prevent hypoglycemia, such as watching for warning signs, placing rapid-glucose options

in convenient locations, and offering reminders to eat.

Barriers to Spouse Support

PWD reported that diabetes-related burden, lack of knowledge, and lack of emotional support were barriers to spouse involvement in diabetes care. Some PWD expressed concerns about burdening their spouse at all and discussed their own independence in self-management. One person with diabetes reported, “I try to manage it literally all by myself. I don’t want to need some other person to help me. I think it’s easier for me to do it all myself rather than try to get my wife involved in it.” Some PWD wanted their spouse involved, but they felt their spouse’s limited diabetes knowledge prevented adequately supporting them except for treating hypoglycemia. For example, PWD did not feel that spouses understood the fluctuations of glucose, difficulties in keeping glucose in range, treatment of hyperglycemia, how to calculate insulin doses, or what to do in certain scenarios without the PWD guiding them. Concern about aggravating their spouse was also noted.

In some instances, PWD were concerned about whether their spouse could help them as they aged. One

person with diabetes noted, “[My spouse is] very concerned about it, he’s very good about listening to it, but he knows very little about it. He does not really still understand. I have thought about this a bit because, being 65, I’m not sure what I will do as I get older.” Some PWD relied on their spouse for reminders due to memory changes they were experiencing. These reminders were focused on glucose checking, taking insulin, and eating meals or snacks. PWD also noted that there was a lack of other supportive individuals beyond the spouse to help with diabetes-related reminders.

Unrecognized Spouse Support

Spouses provided various types of indirect and direct support, but this support was sometimes perceived differently by PWD and spouses. Spouses reported taking initiative in conducting their own diabetes research to become more informed, helping with carbohydrate counting, and offering reminders, but this was not always noticed or well received by PWD. In one couple, the spouse felt that he was being supportive by attending diabetes advocacy events, whereas the person with diabetes felt that the spouse was not supportive at all. Many spouses reported that they worried about the PWD, but PWD were not always aware of this. One spouse made sure his wife was awake before he left for work for his own peace of mind. Another spouse would have neighbors check on the person with diabetes when she was out of town, even though the person with diabetes thought this was “awkward.” One spouse noted, “I am a little bit worried if I would travel or something that if he would get low and not realize it, so that is a concern of mine.” Despite spouses’ clear involvement in diabetes, some spouses minimized the support they provided. In one case, the spouse was picking up diabetes supplies, making all of the medical appointments, and providing emotional support, but noted, “[the person with diabetes] does all of the work.”

PWD Underestimated the Impact of Diabetes on Their Spouse’s Daily Lives

Diabetes has an obvious impact on the daily lives of PWD, yet, some PWD tended to discuss the impact of diabetes on them as an individual rather than discussing the impact on their spouse and how it affected their daily lives as a couple.

Spouse Perceptions

Spouses reported that they were greatly affected by lifestyle changes related to their partner’s diabetes. Spouses discussed having to adjust activities, plans, and emotional responses to support the partner’s diabetes. Adjustments related to the timing of meals and exercise, sleep, travel, sex, and social activities. Sleep for spouses was affected by alarms from insulin pumps and continuous glucose monitors, as well as hypoglycemia symptoms PWD experience. These adjustments to their lifestyle affected their ability to be spontaneous. One spouse noted:

“We might be getting ready to go somewhere or do something, and she is hit with a high or a low that alters what we’re doing, whether its preparing for a night of sexual pleasure or going walking, eating, or conversing. It is something that comes out of the shadows and attacks. And so how do I deal with it? Sometimes pretty good, and sometimes not so good. I mean the big challenge is how to deal with it and adjust emotionally.”

Another spouse said:

“Dealing with diabetes . . . it is the ever-present elephant in the room. It never goes away. There’s almost nothing that you do that doesn’t have an impact on when are we going to eat next, when is he going to eat next, what’s his blood sugar? If he’s starting to fall asleep, does that mean he has a low blood sugar or is that part of the sleep apnea?”

PWD’s comorbid conditions also affected usual activities done together as a couple. In one case, the couple rode bikes regularly for exercise. However, when the person with diabetes experienced vision changes secondary to retinopathy, this activity ceased, and the couple had to permanently change their exercise routine. In another case, an annual lake vacation was cancelled due to the person with diabetes requiring surgery from a diabetes-related complication.

Some spouses reported positive lifestyle changes experienced as a result of their partner’s diabetes. For example, diabetes resulted in a general healthy lifestyle for the entire family, and some families took ownership of the diabetes. One spouse stated, “I considered it something that belonged to the whole family, and so we all treated it the same way. You learn how to eat over again, and you learn that you have to exercise, and that’s what we’ve been doing for many, many years now.”

Spouses who were experiencing their own comorbid health conditions often needed to watch their diet closely as well as exercise. Therefore, at times, spouse health needs coincided with those of PWD.

PWD Perceptions

PWD, in contrast, reported few limitations related to having diabetes and generally discussed the impact of diabetes in a more individualized manner. Although PWD did often recognize that spouses were helpful with hypoglycemia, few PWD recognized the emotional impact of diabetes on their spouse. Less often, PWD would hide their feelings from their spouse. As one person with diabetes explained, “I generally don’t share my concerns, and that helps me because I know she don’t understand it, and it helps me from getting irritated.”

In one contrasting instance, a person with diabetes stated, “I believe the harder part is on my partner in the sense that I could be unaware that I’m being short, that my disposition has

changed, so in that sense I feel that she has a harder time than I do.”

Gendered Nature of Spouses Supporting Diabetes Management

There were gender differences in how spouses supported PWD, although, in some instances, support was shared by both male and female spouses.

Female Spouse Support

Female spouses supported diabetes management in more ways than male spouses. Females were often involved in food preparation. In one case, a female spouse weighed food on a scale to support accurate insulin dosing. In another case, the female spouse adjusted the meal plans to keep insulin adjustments to a minimum. In general, female spouses prepared for potential diabetes problems by carrying treatment for hypoglycemia and packing snacks and other supplies needed for outings. Females often attended clinic visits with their spouse and recognized when the level of care needed to be increased. For example, one female spouse recommended that the person with diabetes see an endocrinologist instead of an internist. Some female spouses purposefully sought out information about diabetes, such as attending diabetes classes, researching substitute sugar options, and looking up other topics on the Internet as they arose. Female spouses sometimes picked up diabetes medications and supplies as well. Additionally, there was one case in which a female spouse used threats early in their relationship (i.e., divorce and taking away the kids) if the person with diabetes continued to neglect his diabetes management.

Male Spouse Support

Male spouses were more involved than female spouses with regard to diabetes technology support. Actions to support diabetes technology included insulin pump site and sensor changes, troubleshooting insulin pumps for infusion issues, and giving prompts to use the glucose meter. One male spouse monitored his wife, saying, “I

keep an eye on it . . . I can watch her [on her Dexcom, which can send glucose data to a caregiver] and see when she’s high and when she’s low. So, every so often, [I] check the button, just to check and see how she’s doing. Not to get after her or anything, it’s just to see how she’s doing, and if I need to do anything.” Although fewer males engaged in meal preparation than females, one male spouse was helping his wife count carbohydrates.

Shared Gender Support

Both female and male spouses attended to hypoglycemia prevention, identification, and treatment. They were constantly watching for hypoglycemia. One spouse stated, “You have to be mindful. I’m always mindful if there is a rapid change in mood. She ends up getting hungry and it can be a sign of high or low blood sugar. Sleepiness is another thing. And color.” Spouses sometimes recognized the PWD’s hypoglycemia unawareness and were able to bring it to the PWD’s attention. Both female and male spouses used gentle reminders to support diabetes management. These reminders were focused on self-management behaviors such as checking glucose, taking insulin, eating on a schedule, being prepared with medications and other supplies needed for outings, and noting behaviors that might indicate hypo- or hyperglycemia.

Evolution of Diabetes and the Relationship Across Developmental Time

Over time, couples changed the way they interacted with regard to diabetes management.

Changes in Interactions

Many PWD felt that their diabetes self-management had gone through different stages as they aged. In the early stages of diagnosis, some PWD noted that their self-management was not ideal but had improved in middle adulthood. As older adults, many PWD noted having great self-management, whereas others allowed for a slight relaxation of self-management behaviors.

Many couples had been together for decades. PWD and spouses noted a change in how they interacted with each other regarding diabetes over time. In the early stages of the relationship, some spouses did not want diabetes management to affect them. In one case, the spouse would sneak off to eat certain foods because she had become tired of following a monotonous healthy diet. Couples discussed feeling as though diabetes became more incorporated into their daily lives and said they viewed management as less of a nuisance or something to overcome as they aged. Couples discussed having learned to become more sensitive to each other—that is, having learned how each person might respond in a given situation based on previous experiences. This adaptation was not only in response to diabetes, but to the spouse’s unique circumstances, as well. One person with diabetes reported, “I would say the only thing probably that we’ve learned not to do is we’re probably both more sensitive to each other’s deals. He gets anxiety, and so I finally have figured out that’s not the best time to be pushing his buttons, you know. And he’s learned not to say, ‘Is there something you need?’” What one person might view as nagging, another might view as a helpful reminder.

Interdependence with Advancing Age

With the rise of chronic and comorbid conditions related to aging, both PWD and spouses were experiencing health concerns. For example, some PWD were already experiencing chronic wounds, nephropathy, retinopathy, cardiovascular disease, and stroke, whereas others worried about developing complications in the future. In response, health played a larger role in their lives, resulting in more interdependence. While both PWD and spouses relied on each other for various reasons, in general, PWD were more reliant on spouses. For example, PWD with memory issues relied more

heavily on their spouse for reminders, including reminders to take medications such as insulin or to check glucose levels. When PWD faced acute illness, the spouse role changed from “care spouse” to “caregiver.” One spouse stated, “After 6 days, they let her out of the hospital [and] I had to be the nurse and everything else.” In some instances, the roles of “care spouse” and “caregiver” were fluid. However, with advancing decline in the health status of PWD (i.e., due to stroke or cardiovascular disease), the role of “caregiver” became fixed and could become overwhelming as the spouse took over tasks. One participant noted, “We constantly check her weight, feet, open sores, change the sensor every 6 days, change the pump every 3 days . . . watch what you eat, you have to watch everything . . . It’s a constant battle.”

Spouses who had previously not attended to their own diet or exercise behaviors were now undergoing lifestyle changes due to new health circumstances (i.e., the development of chronic conditions such as heart disease and osteoarthritis). These new behaviors often matched the attention PWD gave to their own diabetes management.

Differences in Diabetes Management Among Couples

PWD and spouses appraised diabetes management differently within and across couples. The ways in which diabetes was approached resulted in collaborative and noncollaborative management strategies. In extreme cases, both PWD and spouses were emotionally burnt out due to diabetes management.

Collaborative Management Strategies

Some couples were in agreement in terms of diabetes management efforts. In a subset of couples, the PWD were very responsible and independent, necessitating low levels of support from their spouse. One person with diabetes stated, “I usually remember to get up and test, take the shots that I need,

have breakfast, and just go about my day. She’ll ask me when I think I’ll be ready to eat or what’s my glucose level at meal time. Then we’ll work out what time we’re gonna go to exercise.”

In a similar tone, the spouse stated:

“Sometimes I wonder if I should be doing more, but he is a very responsible human being. He always has been. So, I never have to say, you know, nag him to take his insulin or anything. That would be a nightmare. And so, I’m really lucky that way. If we’re going out to eat, I might remember to say, ‘Did you bring your insulin?’ and almost, like almost 100% of the time, he has already remembered it.”

Other couples had developed a joint process in which they would troubleshoot diabetes together. For example, some PWD would seek advice from their spouse about carbohydrate counting. One spouse stated, “Well, we pretty much work together. I mean she prepares the meals, and I mean she watches what I eat, and we watch the numbers together, I rely on her. I ask her, listen to what she tells me, and things seem to work out alright.”

Noncollaborative Management Strategies

Some couples were disjointed in their understanding of what diabetes-related support the other person needed. For example, there were couples in which PWD needed support, but the spouses seemed to be oblivious to this need or did not know how they could help. One person with diabetes stated, “It’s difficult because he doesn’t want to participate, and he’s not very encouraging.” Other times, spouses seemed to be struggling and focused on how diabetes affected them rather than on how to support the PWD. For example, one person with diabetes stated, “I think I do a pretty good job of managing my diabetes . . . I’m pretty organized. I’m kind of OCD really, and I stick to schedules,” while the spouse stated, “I don’t want to cope with it . . . I get a little frustrated. I’ll want to

not eat at a certain time. I’m just more spontaneous.”

Shared Emotional Burnout

In one case, both the person with diabetes and the spouse were in need of support due to acute health issues that changed the relationship dynamic. The person with diabetes was facing a new chronic condition and exacerbation of an existing chronic condition, while the spouse had to transition from being a spouse to being a full-time caregiver, in addition to his other responsibilities. The person with diabetes felt a sense of guilt, while the spouse felt a sense of resentment toward diabetes, but not toward the person with diabetes. This person with diabetes stated, “It’s just exhausting. I’m just so tired of being a diabetic,” while the spouse stated, “It’s a constant battle. You can’t just put her off in the corner somewhere and say, ‘Hey, take care of it, I got to go to work.’” Juggling the increasing health demands of the person with diabetes was overwhelming for both members of the couple.

Discussion

Our findings suggest that older adults with type 1 diabetes have varying perceptions about how their spouse is involved with diabetes care. Additionally, some PWD do not realize the direct and indirect support their spouse provides or how their spouse is affected by diabetes. Spouses tended to provide support in a gendered way with the exception of hypoglycemia prevention and treatment, in which all spouses were involved. We also found that PWD-level management evolves over time, as does the way couples respond to developmental changes. Finally, we identified differences in how couples do or do not collaborate with regard to diabetes management.

In general, many PWD and spouses perceived the spouse’s involvement in diabetes management differently, often with spouses viewing their involvement as greater than PWD perceived. The fact that many

efforts by spouses to assist PWD in diabetes management went unnoticed may reflect the invisible support that spouses may be providing that may be especially beneficial for well-being (33). However, such support may come at a cost to spouses. Spouses perceived that diabetes responsibilities and day-to-day activities affected their lives to a greater extent than did PWD. For example, spouses expressed limitations due to diabetes, such as travel, eating out, and spontaneity. Discrepancies between PWD and spouses' perceptions of involvement and the impact of that involvement may lead to conflict within couples and hamper the future availability of spouse support (34). Consequently, PWD and spouses did not appear to be on the same page with what type of spouse involvement would work for their relationship. We were not able to clearly identify what type of support PWD want or need, although it is likely based on individual circumstances.

Similar to research on type 2 diabetes (35), we identified that women may receive less support from their spouse for diabetes management than men. Consistent with other research (36), women were more likely than men to be responsible for food preparation. There was some suggestion that men may be more involved in aspects of diabetes management that involve technology, such as insulin pumps and continuous glucose monitoring. Whether such gender differences would be found in younger samples as they themselves age is an open question.

Hypoglycemia was a major concern of spouses. Many spouses also expressed concerns about leaving PWD for long periods of time without checking in to make sure they were okay, infringing on the independence of the PWD. Further, nearly all spouses identified ways in which they supported PWD during episodes of hypoglycemia, including a constant awareness of PWD's moods as a way of assessing possible hypo-

glycemia. The perceived responsibility spouses felt to watch over PWD was prevalent in our analysis. The acute concerns about hypoglycemia seemed to supersede the concerns related to hyperglycemia, as noted by others (10), even though hyperglycemia could contribute to complications.

An important component of the evolution of diabetes management across time involves the comorbid diabetes-related conditions that are common with longstanding type 1 diabetes (24). For example, older adults with diabetes have a twofold higher incidence of dementia than those without diabetes (37–39).

Couples in this study were not always adequately prepared for the changes and challenges a chronic condition brings to the relationship and how this may affect the independence of PWD in managing diabetes. Furthermore, spouses may not have the capacity to provide additional support, due to knowledge deficits or their own health status, and may need to decrease their level of support. Previous research indicates that individuals providing care to a spouse who are experiencing health problems themselves have less marital satisfaction and may be less able to provide the care for their spouse (40). In the event that their spouse is no longer able to provide support, PWD may need to identify other care partners, such as adult children or siblings, to help support their diabetes management. In some instances, a higher level of care, such as in-home care, home health services, or an assisted living facility, may be necessary, each of which has been helpful in supporting the use of diabetes technology in older adults (41).

These results point to the importance of the transition period during late adulthood. There is a dearth of information on the transition from middle adulthood to older adulthood, a time when PWD age differently, depending on their diabetes duration, presence of complications, and genetics. In addition, spouses may not be

in a position to provide the diabetes support they did in earlier adulthood due to their own declining health status. PWD who were independent in middle adulthood may require the support of others as they age.

Spouses are often assumed to be individuals who will step up to provide this care. However, we found that spouse education may be limited, which can hinder the provision of effective diabetes-related support. Limited knowledge about how to provide effective support may be especially detrimental for older adults who are also experiencing cognitive changes resulting from normal aging (i.e., slower processing or forgetfulness) or diabetes. Although spouses do understand how to support hypoglycemia and healthy diet and exercise recommendations, they may not understand the mechanics of diabetes management, such as checking glucose levels or managing medications (e.g., making micro-adjustments to insulin doses), which are activities that older PWD may need assistance with as they age.

Clinical Implications

The American Diabetes Association recommends that the level of social and family support be considered when making treatment recommendations. It is clear that more research is needed regarding how to provide that support so that it is beneficial for PWD. Congruently, spouses should be provided assistance to maintain the increasing support they may need to provide to PWD with advancing age (42). Open communication between couples is necessary to understand how each person in the relationship views diabetes and his or her role in supporting diabetes-management.

Consistent with other research (10), we found that diabetes affects the lives of spouses in many ways and perhaps in more ways than PWD realize. Harnessing spouses' desire to be supportive by providing routine education may improve PWD's capacity to adequately manage diabe-

tes, which may in turn improve health outcomes for older adults with type 1 diabetes. Furthermore, PWD-spouse couples reaching agreement on how the spouse can best support diabetes management could help improve expectations within these couples. Empowering spouses could also reduce the worry or other psychological factors that may be limiting their quality of life.

Clinicians should assess spouses' willingness and ability to increase support if PWD experience functional or cognitive declines. Furthermore, clinicians may want to encourage older adults with diabetes to bring their spouses to appointments to address the spouses' current involvement, diabetes knowledge, and willingness and ability to increase support, if necessary. Understanding spouses' current involvement, as perceived by both PWD and spouses, may resolve barriers to spouse involvement. Discussions should take place regarding PWD and spouse support expectations and how to optimize support from the spouse in a way that is acceptable to both PWD and spouses. Spouses' knowledge should be assessed to determine if they adequately understand diabetes management beyond meal preparation and treatment of hypoglycemia. In the event of discrepancies, referrals for diabetes education sessions that include spouses may be helpful.

Limitations

Our study provides an in-depth look at how couples in older adulthood think about their management of diabetes. However, there are limitations to consider. First, our sample included mostly non-Hispanic white and well-educated individuals in heterosexual relationships. Thus, our results may not generalize to ethnic minority couples, those of lower socioeconomic status, or those in same-sex relationships. We found a gendered nature to some diabetes management responsibilities, although our sample had more female spouses than males. Future research should seek to understand the

role of gender in older adult same-sex couples and future generations of older adults. Second, participants in this study were free of significant cognitive impairment as necessitated by the goals (i.e., cognitive testing) of the larger study. Although some of our participants experienced cognitive limitations, these were mild. PWD's and spouses' involvement in diabetes management and perspectives on coping with management may be very different for couples in which PWD have more significant cognitive impairment. Finally, the study used a structured interview style, which did not allow for additional prompts that may have led to greater depth of understanding about how PWD and spouses emotionally coped with diabetes. Although we specifically asked about coping with diabetes, nearly all PWD and spouses interpreted interview questions in terms of diabetes management. Future studies should investigate how coping relates to perceptions of diabetes management and its influence on PWD-spouse relationships. Because of our small sample size, it was beyond the scope of this analysis to examine how the number of comorbidities, complications, or drugs taken or how the use of insulin affected the type of support PWD receive from their spouses. However, these are important questions for future research.

Conclusion

Couples have different perspectives regarding diabetes support and responsibility. Older adults with type 1 diabetes and their spouses may not always realize what support is being provided or is needed to optimize effective diabetes management. Developmental changes in PWD due to age and diabetes complications may require additional support from spouses, yet spouses may not be adequately prepared to provide the level of care needed for successful management.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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Author Contributions

M.L.L., S.E.W., N.A.A., E.L.T., and C.S.K. analyzed the data and wrote the manuscript. V.S.H. collected the data and reviewed/edited the manuscript. C.A.B. collected the data and wrote the manuscript. M.L.L. 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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