

# Practice Implications of What Couples Tell Us About Type 2 Diabetes Management

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## Abstract

Diabetes is a significant and growing chronic health problem in the United States. Substantial research has documented the consistently strong link between social relationships and health. With respect to diabetes, social relationships, and particularly marriage or cohabitation, have been shown to mediate lifestyle and medical surveillance behaviors, glycemic control, and other health outcomes. Further exploration of the marital or cohabiting relationship may be especially relevant to clinicians and educators because the self-care regimen often involves spouses or sig-

nificant others. With this in mind, the purpose of this study was to listen to and draw conclusions from what couples tell us about managing daily life with type 2 diabetes. Analyses revealed four core themes: educate yourselves, talk about the disease, work together, and be your own advocate. This qualitative study provided a unique perspective on couples' needs for care, which have important implications for the health community in acknowledging the spousal or cohabiting relationship in the management of diabetes.

Diabetes and its related complications represent one of the most significant and growing chronic health problems in the United States.<sup>1</sup> Roughly 20% of all adults  $\geq 60$  years of age (~ 10 million) have diabetes, and the vast majority have type 2 diabetes.<sup>2</sup> With the aging population, it is not surprising that adults in this age-group comprise the largest proportion of people with diabetes. Considering the rapidly increasing number of adults with diabetes and the enormous public health burden of the disease, the development and implementation of appropriate interventions is a crucial need.

Type 2 diabetes requires adults to assume responsibility for multiple lifestyle and medical surveillance self-care behaviors to achieve and sustain optimal glycemic control.<sup>2</sup> Lifestyle behaviors include adhering to a healthful diet and physical activity regimen, and medical surveillance behaviors include taking needed medications and maintaining

proper foot care, among other tasks. The importance of behavioral adherence has been emphasized in the medical literature; yet, fewer than one in eight adults > 20 years of age who are living with diabetes follow the guidelines for optimal management.<sup>3,4</sup> Adults also need to accept diabetes on an emotional level. Dealing with diabetes on a daily basis can be a psychological burden; adults may have negative experiences with insulin injections, needle sticks, physician visits, and anxiety caused by self-monitoring of blood glucose. Thus, understanding more fully how adults with diabetes live with and attempt to manage diabetes is crucial for developing appropriate behavioral interventions.

Given the behavioral and psychological demands of diabetes, a deeper exploration of the psychosocial factors is relevant to all aspects of diabetes management. A recent review of the literature called for research that focuses on the identification of specific psychosocial fac-

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tors that influence regimen adherence and glycemic control in adults with diabetes.<sup>5</sup> Recognizing the importance of the social context in helping adults improve self-care behaviors and glycemic control and thus reduce their risk of health complications is essential to developing more effective interventions for adults living with diabetes.<sup>6,7</sup> Exploring the marital or cohabiting relationship may be particularly helpful to health educators because the behavior regimen (e.g., food shopping, meal preparation, and exercise) often involves spouses or significant others.<sup>8</sup> Couples research has shown that spousal or partner support may mediate diabetes-related lifestyle and medical surveillance behaviors, glycemic control, and other health outcomes.<sup>9–16</sup>

Despite the growing body of literature on spousal or partner support and diabetes management, little is known about the psychosocial context of living with diabetes, and specifically the context of marriage or cohabitation. Therefore, to provide the highest quality of care for couples living with diabetes, we must first understand the psychosocial needs of this subpopulation. Toward this goal, the purpose of this study was to listen to and draw conclusions from what couples tell us about managing daily life with type 2 diabetes. The following sections describe the methods used, the findings, and the implications of those findings for adults with diabetes who are married or in a cohabiting relationship.

## METHODOLOGY

### Design

Focus group methods were used to explore the psychosocial needs of couples striving to manage type 2 diabetes. The group dynamic was structured to stimulate participants with diabetes and their spouses or partners to examine the influence of their relationships on needs for care with others who were in similar situations. The groups were segmented into people with diabetes (PWD) and spouses or partners of people with diabetes (SPWD). This allowed researchers to use the

shared experiences as a springboard for deeper examination and discussion of related issues, thus promoting greater depth in understanding without the potential influence or constraint exerted by their spouse or partner's presence. The research protocol was approved by the Pennsylvania State University Institutional Review Board before initiation of the study.

To maximize the phenomenon of interest, intensity sampling (a form of purposive sampling) was used to identify and select couples living with diabetes. Potential participants were screened by telephone for eligibility and other sociodemographic information (e.g., birth date, age, sex, race/ethnicity, years married or partnered, parental education, participant education, occupation, and year of diabetes diagnosis). Couple eligibility was determined on the basis of three criteria: couple participants were married or cohabiting, couple participants were  $\geq 50$  years of age, and at least one member of the couple had received a physician diagnosis of type 2 diabetes at least 1 year previously. Participants were excluded if they had any difficulties with bathing, dressing, personal hygiene, or walking or if they were diagnosed with a stroke, cancer, or Alzheimer's disease in the past year. Recruitment efforts were focused on the Pennsylvania State University Diabetes Registry, as well as through advertisements in newspapers, diabetes support group meetings, public service announcements, and flyers in community buildings. Responding couples were mailed a cover letter describing the study's purpose and procedures, along with two informed consent forms, which were completed and returned to researchers in provided pre-addressed, pre-paid envelopes.

In qualitative studies, the size of the sample is determined by the quality of data. Recruitment, data collection, and analysis are reiterative, occurring simultaneously. Two criteria are used to evaluate sampling: adequacy and appropriateness.<sup>17</sup> Adequacy addresses the volume of the data, or, in other words, there are adequate data to support

the emergent insights. Appropriateness refers to the quality of that data, which means the data provide the descriptive and interpretive depth required to clearly delineate the theoretical derivation. Using these criteria, data are collected until saturation is reached, which means when no new information is generated from the participants and the derived theoretical scheme accounts for the reported experiences or insights.

In this study, recruitment efforts were suspended when 30 couples (60 adults) were successfully enrolled. Of these, 23 couples included one person with diabetes and one who did not have diabetes. In the seven remaining couples, both adults had diabetes; however, one was diagnosed with diabetes within the previous year and did not meet the eligibility criteria for participation as a person with diabetes. For the latter couples, researchers assigned individuals who had been diagnosed with diabetes for the shorter period of time to the SPWD group and individuals with longer-standing diagnoses to the PWD group. Group members varied by age ( $\geq 50$  years of age), sex, race/ethnicity, and occupation; however, all group members lived in central Pennsylvania and shared the experience of living with type 2 diabetes themselves or of being the spouse or partner of someone with type 2 diabetes.

### Procedure

Twelve 90-minute focus groups, each with 5–10 participants, were conducted at the General Clinical Research Center in University Park, Pa., and at the Hershey Medical Center in Hershey, Pa. A structured discussion guide was devised, field-tested for flow and clarity of the discussion questions, and then used by trained moderators and co-moderators to promote consistency across the groups. Moderators were instructed in the use of directive probes to elicit additional information and clarify ambiguous comments; co-moderators wrote field notes to capture key points in and observations about the discussion. All focus groups were audio-recorded and transcribed verbatim. All names and identifiers were

**Table 1. Sociodemographic Characteristics of Participants With Diabetes and Their Spouses/Partners**

	PWD Mean (Range)	SPWD Mean (Range)
Age (years)	66.7 (51.0–81.0)	63.3 (50.0–76.0)
Median education	College	College
BMI (kg/m <sup>2</sup> )	32.2 (20.0–45.6)	27.4 (19.6–44.3)
Comorbid condition(s) (%)	97.3	82.6
Length of marriage (years)	38.7 (12.0–54.0)	38.7 (12.0–54.0)
First marriage (%)	82.8	82.8
Male (%)	70.0	30.0
Years with diabetes	10.1 (1.0–46.0)	
Takes recommended medicine(s) (%)	75.7	
Takes recommended insulin injection(s) (%)	24.3	
Takes recommended oral hypoglycemic medication(s) (%)	62.2	

Note: The items BMI, takes recommended medicine(s), takes recommended insulin injection(s), and takes recommended oral hypoglycemic medication(s) are based on self-reported measures of adherence.

removed from the text to protect participant confidentiality (e.g., “Dr. Smith from Hershey” would be replaced by Dr. [Endocrinologist] from [medical center]). These clean transcripts (i.e., transcripts purged of identifiers) were used in analysis.

#### Data Analysis

Qualitative data were analyzed using techniques described by Morgan<sup>18</sup> and Krueger.<sup>19</sup> Specifically, the discussion was summarized immediately after each of the sessions; codes were developed for relevant themes, using the research questions as guides; and the codes of new transcripts were compared to existing codes after each session to more fully develop the properties of the overarching categories. This process continued until saturation was reached, that is, until no new codes or categories emerged, and the research team, consisting of a registered dietitian, a gerontologist, and a graduate research assistant, reached consensus that coding additional transcripts would only repeat themes.

Credibility of the data was supported in three ways: 1) one investigator and the research assistant independently coded the data to check for inter-rater agreement; 2) other

investigators reviewed the independent coding sheets to resolve discrepancies in retaining and combining transcript data; and 3) common themes were independently summarized by the first investigator and research assistant, and discrepancies were reviewed and resolved by the other investigators. Dependability of the data interpretations was supported with an audit trail to track the decision-making process.

#### RESULTS

Table 1 provides general demographic and health characteristics of the 30 couples ( $n = 60$ ) who participated in the focus groups, based on the data obtained during eligibility screening. As shown, the mean age of participants overall was 65 years, and the mean length of marriage or cohabiting relationship was 38 years, with the overwhelming majority in their first marriage. The average PWD (61.7% of participants) was a college-educated man who had lived with diabetes for 10 years, had a BMI within the obese range, took oral medications rather than insulin, and had at least one comorbid illness. The SPWDs were, on average, college-educated, younger,

somewhat healthier, and had a lower BMI.

#### Defining Themes

Participants discussed a variety of health care needs and preferences for type 2 diabetes management. Although being in charge of one's own diabetes was the predominant mode, these couples worked toward a guiding principle of teamwork to maintain their diabetes care. Four core themes emerged from the discussions: *educate yourselves, talk about the disease, work together, and be your own advocate*. In the following sections, we describe each of these core themes. Table 2 presents the four major themes, along with additional quotations and potential intervention strategies.

#### Educate yourselves.

The constant influx of new and occasionally contradictory diet, exercise, and medication recommendations made self-care management challenging to participants in all 12 focus groups. A man with diabetes shared what he believed to be the most significant barrier in diabetes management: “As a society, we have not done a very good job of teaching people what is a healthy diet. The

**Table 2. Themes, Representative Quotations, and Intervention Strategies for Self-Management Among Couples Living With Diabetes**

Themes	Representative Quotations	Intervention Strategies
Educate yourselves.	<p>“We need something where we go once in a while to refresh ourselves on what is new and what is happening that they [referring to health care providers] recognize as being important. Someplace to share our concerns and see where we are—sort of benchmark ourselves and ask: How am I doing?”</p> <p>“It would be nice if when we check in [referring to physician visits] if we had some workshops or reviews periodically—just like you have to go to the doctor so many times a year for your A1C test and for the other checkups. It would be nice if we had it more or less available to go to these programs once or twice a year and have it covered by insurance.”</p> <p>“I think one of the frustrating things is that there is so much literature out there and there are so many different diets. Everything keeps changing from the food pyramid to carbs and I want to say, “Wait a minute.” I think we have to take three steps back and say what is the healthy part of this and what is the healthy part of that. Then we can make up our own diet.”</p>	Devote more attention to accurate and sensitive education in daily management strategies.
Talk about the disease.	<p>“I go to a diabetes support group . . . I have a place where I can go and talk. But I am concerned he has nobody to talk to except me and he is not coming to me with his fears. So I think support groups for couples or for spouses are good.”</p> <p>“I signed up for this [referring to the study] for one reason and that was because I wanted to get together with somebody who was in the same boat that I am in. I have not talked to anybody. Nobody cares if you have diabetes. I mean you just cannot sit down with your friends and your neighbors and talk about your diabetes. I mean that is just not done.”</p>	<p>Promote open communication among family members, clinicians, educators, and interventionists regarding the biopsychosocial care needs of people living with diabetes.</p> <p>Provide problem-solving skills to identify high-risk situations and minimize barriers to diabetes management.</p>
Work together.	<p>“Our daughter is a marriage and family therapist. When a couple would come across a health issue, she would meet with the couple together because she felt very firmly that you are in this together and you need each other.”</p> <p>“I cannot force her to follow her regimen. I have to understand that it is really hard. I need to support her and understand it. That is how you do it—you need to radically change your thoughts . . . Even though it is her responsibility, I can support her whenever it is possible.”</p>	<p>Illuminate the role of spousal or cohabiting relationships in diabetes management to develop and test interventions that provide more effective supports for adults living with diabetes.</p> <p>Assist with goal-setting to enable couples to focus attention and effort to achieve meaningful change.</p>
Be your own advocate.	<p>“I think the more patients become aware of how to take care of their disease rather than relying on the doctors, the more insight they will have. I think the more information doctors can give to people with diabetes the better. We need more education.”</p> <p>“Be careful of what you eat and be sure and check your blood sugar levels. Be sure to go to the doctor and have your eyes checked. Check your feet every day—wash them and make sure you do not have any tingling. And get some exercise.”</p> <p>“Try to be positive about how you approach diabetes. You can still make wonderful meals. You can still live life to the fullest.”</p>	Encourage active participation by both members of the couple in diabetes management.

lesson has not been learned by many people. We need education for the entire family.”

For most couples, the lack of available diabetes-related education programs was the most significant obstacle in their management. Couples conveyed a need for educational programs to become a regular component of their diabetes management to provide PWDs and SPWDs with the most up-to-date information. As one participant indicated when describing the need for diabetes education, “If you could have an educational program like two years later after you have settled into your routine, so you know what is expected . . . that would be very helpful.” Additionally, couples expressed dissatisfaction with existing insurance practices that did not cover multiple diabetes education classes.

All in all, couples recognized that diabetes education was a lifelong process that would continue to be needed as lifestyles changed and new information was made available.

#### **Talk about the disease.**

The inability to openly communicate on the subject of diabetes fueled significant negative emotions, including feelings of frustration, anger, and hopelessness, in many of the PWDs and SPWDs. The lack of communication within the community was attributed to the public not having enough accurate information about the disease. A PWD conveyed his sense of frustration with the health care community’s inability to talk to him about his diabetes management: “Teach me how to live with it on a daily basis because it is chronic—it is not going anywhere!” Both PWDs and SPWDs expressed a desire for health care practitioners, as well as friends and family members, to be more willing to talk about all aspects of the disease and offer practical suggestions for successful management.

Couples maintained that talking about diabetes was a necessary first step in learning how to cope with the complexities of daily life. As one SPWD remarked, “I think the important thing is to have somebody that you can ask questions to.” Thus, opportunities to talk with other couples about diabetes provided a nec-

essary means of support, which was evidenced in the following statement: “I am finally in a place (referring to the focus group) where we can sit here, and we can share ideas. I think this is what we really need.” Overall, couples wanted more opportunities to discuss their diabetes management on a daily basis, in both formal and informal settings. SPWDs also expressed a need for an open forum in which they could talk about effective ways to support their spouses or partners diagnosed with diabetes.

#### **Work together.**

Teamwork was a prominent theme throughout all 12 focus group discussions. Both PWDs and SPWDs echoed the importance of support with regard to self-care behaviors, emotional well-being, and overall quality of life. This sentiment was articulated best by the husband of a PWD: “I know that my wife taking care of her diabetes is her responsibility, but I can support it wherever I can.” Despite the acknowledged benefits of a supportive relationship, not all participants willingly put forth a joint effort. In cases where SPWDs played key roles in the day-to-day management of diabetes, PWDs reported greater collective control and satisfaction with their diabetes self-care, as noted by an older man with diabetes: “Good Lord, if it was not for my wife, I do not know where I would be. She takes care of me. She does it routinely with no problem. No nagging. No hassling.” In cases where SPWDs did not assume a supportive role, PWDs voiced greater confusion and frustration with their management. A woman with diabetes described a general dissatisfaction with her husband’s lack of support by saying, “When it comes to managing diabetes, what I would like to be different is for us to work together with my diabetes management.”

By and large, couples felt it was crucial to approach diabetes management as a team, with both the PWD and SPWD learning how to better support each other when meeting the daily demands of type 2 diabetes. As the number of adults with diabetes continues to grow, having the support of others will

become increasingly important. Spousal/partner support is a vital component in the management of type 2 diabetes.

#### **Be your own advocate.**

The partnership of care described by these couples extended beyond the health care system. All of the participants agreed that their diabetes management was not the sole responsibility of the health care provider, but rather was the shared responsibility of family members, physicians, and the greater health community. In addition, successful management depended on a couple’s willingness to take the lead in management and to voice their concerns regarding medications, complications, and the difficulties of adhering to lifestyle changes (particularly diet and exercise recommendations). A wife stressed the importance of asking for help: “I am going to try saying my husband is a diabetic and I need your support here.”

PWDs learned to assert their specific needs while simultaneously controlling the challenges they faced in day-to-day management. One participant captured this sentiment precisely: “Really, you have to be your own advocate.” Similarly, SPWDs emphasized the importance of taking an active role in the PWD’s management decisions. A husband explained his sense of responsibility to his wife’s diabetes management: “She has the disease, but it affects everything we do. I had to realize that this was something that affected both of us, and I have come to appreciate that.”

#### **CONCLUSIONS**

Diabetes represents a substantial health problem to society and, in particular, to those individuals living with diabetes. This research represents one of the first evaluations of the psychosocial needs of older married or cohabiting adults living with diabetes. Comments provided by the participants reveal important practice implications for diabetes care during midlife and older age. This study’s focus on couples living with type 2 diabetes and their collective experiences with managing the disease is unique. Its results pro-

vide further insights regarding the social challenges that make diabetes management difficult for couples. The results also provide insights into what couples need from the health care community and offers strategies to best support these couples. The difficulty associated with available education programs should prompt clinicians and educators to more aggressively address the social needs of couples living with diabetes. Creative strategies are needed to educate couples about effective ways to support the spouse or partner diagnosed with diabetes. Finally, the more the community knows about diabetes, the better prepared individuals and couples will be to talk about it, manage it, and, ultimately, take responsibility for their diabetes care.

This focus group study may be limited by the small sample size, recruited largely by convenience. Thus, its findings may have limited generalizability to the population at large. Cultural and social variations regarding marital roles, diabetes beliefs, and management among varied ethnocultural groups have not been addressed and warrant further study. Finally, the study's cross-sectional design limits an ability to discern causality. Notwithstanding these limitations, this study found that education, communication, support, and advocacy are of great importance in successful diabetes management.

#### IMPLICATIONS

The diabetes health care team is important in individualized goal-setting for older adults, but spouses, partners, other family members, and friends play an equally important role in meeting the needs for diabetes care. To improve care, the diabetes health care team should ideally target spousal/partner and associated support networks (e.g., family interventions). Older adults often have had a lifetime of experiences with diabetes, health care, and significant others that are powerful determinants of their management goals. Addressing these social influences may help the diabetes care team provide guidance for prioritizing medical treatment and preventive care while acknowledging the

individual's needs and preferences for health care.

The four themes presented in this article represent four points of intervention for couples living with diabetes. Each theme addresses a component of diabetes care in the social context of couples managing diabetes. Specific implications for interventions based on each theme are suggested below.

#### Educate yourselves.

Education about type 2 diabetes is not something PWDs and SPWDs do once at the time of diagnosis. Maintaining knowledge, skills, and tools in diabetes management helps PWDs and SPWDs stay up-to-date and avoid many of the complications associated with the disease. By learning on their own, couples are able to plan a diabetes management program that meets their needs and is based on their work schedules, family demands, leisure/recreational activities, lifestyle behaviors, and other health problems. Moreover, the diabetes health care team should strive to devote more attention to providing accurate and sensitive education throughout the course of a couple's diabetes care.

#### Talk about the disease.

The insights offered by these couples suggest that support-focused interventions should incorporate communication strategies adapted to diabetes-specific education. Diabetes management, as well as social relationships, depend heavily on communication; thus, improved communication could significantly enhance quality of life for couples living with diabetes while also potentially encouraging open communication about diabetes within the community. Additionally, diabetes management requires skills in problem solving to effectively identify high-risk situations for relapse and to minimize barriers to self-care. Together, PWDs and SPWDs can decide to either avoid high-risk situations or generate potential solutions before such situations arise. Collaborative decision making regarding effective solutions to high-risk situations can improve coping with a complex disease.

#### Work together.

To assist couples with the day-to-day management of diabetes, future interventions should maximize interactions with couples. The diagnosis of type 2 diabetes requires significant lifestyle modifications for PWDs and SPWDs. The participants demonstrated that managing type 2 diabetes collectively is achievable, but sustaining one's management may be difficult without constant support. Both PWDs and SPWDs may need to make changes in their diet, dietary patterns, and dietary schedules and begin or sustain an exercise program. Both PWDs and SPWDs would benefit from education about diabetes and the administration of medications. Each component of self-care, such as eating a healthy diet and engaging in regular physical activity, means setting a specific, achievable goal to be successful. Goal setting is a component of the problem-solving process. Once a potentially effective solution to a problem has been identified, the setting of a goal enables one to focus attention and effort to achieve meaningful change.

#### Be your own advocate.

There is so much going on in a PWD's diabetes care plan that it is easy to let health professionals (e.g., nurses, dietitians, pharmacists, doctors, exercise physiologists, podiatrists, and social workers) worry about the management decisions. But doing so will not result in adequate diabetes control. PWDs need to realize that living with type 2 diabetes can be overwhelming for any one person; having the support of one's spouse or partner is necessary to maximize successful management and, ultimately, improve quality of life for both partners. Together, couples can talk to their health care providers on a regular basis. Whether couples work with one health care provider or a team of providers, knowing their providers will enhance their ability to communicate with them. In addition, couples can take advantage of opportunities in their community and help facilitate community-based programs for the management of diabetes.

All in all, opportunities abound for meaningful interactions between PWDs and SPWDs to bolster successful management of type 2 diabetes. Such interactions enable PWDs to meet their individual and social needs by encouraging them to select and initiate self-care behaviors to achieve and sustain optimal glycemic control. Couples can learn to work together to identify and engage in behaviors that can serve to buffer the effects of diabetes on health and overall quality of life.

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