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# Describing Support: A Qualitative Study of Couples Living with Diabetes

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Family and marital support have been shown to be associated with better treatment adherence, illness adaptation, and blood sugar control in studies of individuals with diabetes. However, the behaviors and attitudes that describe appropriate support have not been defined. This is a qualitative study which asked couples who live with diabetes to define support. Seventy-four individuals (patients and spouses) participated in semi-structured interviews. Transcripts of these interviews were rigorously coded and analyzed by a team of researchers. A sampling of quotes is provided. Helpful behavior was particularly evident in the areas of dietary control and regimen specific support, general relational support, and reminders. Nonhelpful

behaviors included nagging, problems with diet management, and poor communication. Descriptions of couple interactions highlighted issues related to independence and coping with hypoglycemia. These areas should be emphasized in interventions that are directed at helping spouses effectively support their partners who have diabetes.

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iabetes mellitus affects more than 16 million Americans (USDHHS, 2000), is the 7th leading cause of death, and has a cost of more than \$100 billion per year (USDHHS, 1998). Chronic high blood glucose (sugar) levels are associated with debilitating complications, including coronary artery disease, peripheral vascular disease, nerve damage, eye problems and blindness, kidney disease, and amputations. Studies convincingly demonstrate that complications can be minimized if patients maintain normal blood glucose levels (DCCT Research Group, 1993; UKPDS Study Group, 1998), but this requires adherence to a complicated regimen, including oral medications and/or insulin administration, blood glucose testing, dietary therapy, and exercise. Finding ways to help patients adhere to diabetes management regimen is a major goal.

A social systems perspective has emerged which expands the focus of clinical intervention from one which often

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addressed the patient only, to one which also incorporates the patient's interaction with his or her social environment (Fisher, Chesla, Bartz, et al., 1998). Better treatment adherence, illness adaptation, and blood glucose control have been related to greater family support and/or less family conflict (Cardenas, Vallbona, Baker, & Yusim, 1987; Garay-Sevilla, Nara, Malacara, et al., 1995; Primomo, Yates, & Woods, 1990; Schwartz, Coulson, Toovy, et al., 1991; Trief, Grant, Elbert, & Weinstock, 1998). Further, Trief, Himes, Orendorff, and Weinstock (2001), and Trief, Wade, Britton, and Weinstock (2002) also found positive relationships between marital adjustment, intimacy, and quality of life, and a borderline significant relationship between marital adjustment and blood glucose control. Additional research supports and calls for familybased interventions to treat diabetes and other chronic illnesses (Anderson, 2001; Guthrie, Sargent, Speelman, & Parks, 1990; Onnis, DiGennaro, Cespa, et al., 2001; Weihs, Fisher, & Baird, 2002; Wysocki, 1993).

The impact of marital support may be particularly strong in diabetes management, where the healthcare regimen, e.g., food purchase and preparation, medication administration, and exercise often involves spouses (Coyne & Smith, 1994). Studies have defined "support" as spouse participation in the diabetes-related intervention, and examined its effect on treatment efficacy. In an elderly group participating in a diabetes education program, Gilden, Hendryx, Casia, and Singh (1989) found that patients whose spouses participated showed greater improvement in knowledge, blood glucose control, and stress level. Similarly, Wing, Marcus, Epstein, and Jawad (1991) found that obese, diabetic women in a weight control program that included their obese spouses lost more weight than those who participated alone. However, Peyrot, McMurray, and Hedges (1988) pointed out that spouse involvement and knowledge may also lead to marital friction, and hamper rather than enhance adherence and control. Some literature supports this with evidence of negative effects of marital conflict on blood glucose control and regimen adherence (Katz, 1969) and spouse criticality (Klausner, Koenigsberg, Skolnick, et al., 1995). Thus, it appears that there can be both positive and negative impacts of relationships on diabetes care.

"Support" has been measured generally in terms of overall marital adjustment (Spanier, 1976) and specifically as the size of one's social network (Cohen, Doyle, Skoner, et al., 1997), the perceived availability of material aid, and having someone to talk to and do things with (Cohen, Mermelstein, Kamarck, & Hoberman, 1985). In several studies of children with type 1 diabetes, researchers have developed tools to assess diabetesspecific family environment variables. For example, Waller, Chipman, Hardy, et al., (1986) developed the Diabetes Specific Family Behavior Scale to measure guidance/ control and warmth/caring dimensions of the family dynamics. Similarly, Anderson, Auslander, Jung, et al. (1990) identified three factors on their Diabetes Family Responsibility Questionnaire to assess the dimension of sharing of diabetes-related responsibilities. For adults with diabetes, Schafer, McCaul, & Glasgow (1986) developed the Diabetes Family Support Questionnaire to assess family behaviors that support or interfere with four diabetes regimen behaviors, but internal consistency and reliability was low.

Thus, the literature provides little direction for the spouses of patients with diabetes who walk a fine line between trying to appropriately support their ill spouse, while trying to avoid fostering marital conflict. The purpose of this qualitative study was to learn, from couples who deal with diabetes daily, what is support? We chose a qualitative approach so that we

Table
Qualitative Interview Questions

Questions for Individuals with Diabetes and their Spouses

- Patient: How often do you discuss diabetes with your spouse? Spouse: (same)
  Patient: What does your spouse say or do to help you manage diabetes? Spouse: What do you say or do to help your spouse manage diabetes?
- 3) Patient: What have you found to be helpful? Not helpful? Spouse: (same)
- 4) Patient: What could your spouse do or say in the future that would be most helpful? (What could your spouse do differently?) Spouse: What could you do or say in the future that would be most helpful? (What could you do or say differently?)
- 5) Patient: How do you respond to your spouse's attempts to help? Spouse: How does your spouse respond to your attempts to help?
- 6) Patient: Do you feel you're working as a couple to manage the diabetes? If so, in what ways? If not, why not? Spouse: (same)

could learn about the daily experience of couples living with diabetes on a more personal and intimate level than is often offered by the more constrained methods of quantitative work (Patton, 2001).

# METHOD

# Procedure

Participants were recruited from the Joslin Diabetes Center at S.U.N.Y. Upstate Medical University, Syracuse, NY. Patients were identified as potential participants if they were between 18 and 65 years of age, had been diagnosed with diabetes for at least 1 year, and had been married for at least 1 year. Once permission was obtained from the patients' endocrinologists, letters explaining the purpose of the study and informed consents were mailed to potential participants. The letters invited participants and their spouses to return the informed consents if they were willing to be interviewed on the telephone regarding the role of spousal support in the management of diabetes. Of the 243 letters mailed, 80 responses were received (33%). A phone call was made to each of the respondents and, where possible, an interview time was scheduled. Eight individuals were unable

to be contacted, resulting in 72 completed interviews. The interviews were completed by graduate research assistants who had been trained and were supervised by the principal investigators.

Each of the 72 phone interviews followed a structured schedule (see Table), which served to focus the investigators' questions on separate, specific aspects of spousal support (Lofland & Lofland, 1995). Patients and spouses were each asked questions on the schedule and were interviewed separately to maintain privacy. The majority of the interviews lasted less than 30 minutes. This study was reviewed and approved by the Institutional Review Board for the Protection of Human Subjects.

# Participants

Forty individuals with diabetes, and 32 spouses participated. Twenty-nine were married couples. The predominantly Caucasian sample (96%) of patients was 58% female. The average age for both patients and spouses was 49 years. The majority of patients had type 2 diabetes (55%) and were being treated with insulin (88%); the average time since diagnosis was 19 years. Medical records revealed a

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mean hemoglobin A1c level of 7.7% and few complications caused by diabetes (mean of less than 1). Hemoglobin A1c is a measure of blood glucose control over the prior 3 months; the higher the reading the poorer the control. While percentages less than 6.4% are considered ideal, the HbA1c of many patients is much higher.

# Analysis

Because there is no theory relating spousal support to the management of diabetes, a grounded theory approach to qualitative research was selected for data analysis (Glaser & Strauss, 1967; Rafuls & Moon, 1996). "Grounded theory is a methodology based on theory development from data that are collected and analyzed systemically and recursively" (p. 65). This innovative method of scientific inquiry aims to develop new theory inductively, unlike traditional methods that are focused on deductively testing and verifying extant theory. The principal analytic tool in this study, like most grounded theory projects, was constant comparison across subjects where incidents and phenomena were compared for similarities and differences in properties, dimensions, and processes. The "naming" of similar phenomena or coding helped "to label, separate, compile, and organize data" (Charmaz, 1983, p. 111).

In the first phase of coding (open coding), conceptual labels were given to preliminary groupings of alike phenomena (Corbin & Strauss, 1990). In the second phase (axial coding) the researchers returned to the data to revise hypotheses and strengthen conceptual links. In the later stages of coding, often termed selective, categories were again refined and "unified around a 'core' categor[ies that] represent[ed] the central [findings] of the study" (p. 14).

A team of five researchers independently analyzed interview transcripts. Patient and spouse transcripts were initially analyzed by question. The team then met and discussed which quotes were relevant to the research question and should be included in the analysis. Once identified, the quotes were then placed into initial groups relating to specific types of support, responses to help given, and clearly identifiable, often repeated descriptions.

For example, the initial grouping of quotes regarding "helpful behaviors" yielded 27 different codes (e.g., food preparation, communication, low blood sugar). These initial codes were grouped and named, whenever possible, based upon the language used by the participants themselves. At this stage of coding, stringent efforts were made to honor and highlight the participants' language (Constas, 1992). Next, the team members identified possible exceptions to and redundancies in the initial coding criteria and collaboratively worked to re-group the original 27 codes into 14 more theoretically dense groupings. At this stage codes such as "diet, sweets, and food preparation," the participants' initial language, were combined to form a broader, more theoretical "dietary issues" grouping.

The names for these groupings were based more upon relevant literature in the field and the authors' own research and clinical experience that highlights key themes in diabetes management (Trief et al., 2001). This rendering of the data informed by previous analytical findings is often referred to as theoretical sampling of the data (Charmaz, 1983; Corbin & Strauss, 1990). As a result, the newly labeled codes provided a more complete or "thicker" description of the couples' interactions around dietary issues (Geertz, 1988). This process was repeated until no new redundancies or exceptions-often labeled theoretical saturation-were located that could add to the richness of the description. Using this process and criteria as a guide, the primary researcher then completed the analysis.

# Quality Control

Numerous qualitative researchers (Goetz & LeCompte, 1984; Lincoln & Guba, 1985;

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Seale, 1999) have stressed the need to highlight the trustworthiness and internal and external factors that contribute to traditionally described validity of qualitative findings. A number of trustworthiness safeguards were used in the present study. First, transcripts were independently analyzed by a five-member team to identify which quotes were relevant to the research project. The inclusion and initial grouping of codes proceeded in a collaborative manner, thus drawing upon multiple perspectives and requiring consensus. Second, two of the team members had conducted a majority of the interviews. Their participation allowed for the use of multiple data sources (transcripts, personal notes, personal recall), key to insuring trustworthiness (Denzin, 1978). Third, two of the authors who had not participated in the analysis reviewed the results to insure that links from quotes to codes and then from codes to categories were clear, logical, and representative of previous findings from a sample at the same clinic. This safeguard helped increase the likelihood that "another researcher would arrive at similar findings from the data" (Rafuls & Moon, 1996, p. 77).

# RESULTS

Because of similarities in responses, results will be presented in three broad topic areas. The first group of responses is comprised of perceptions of spousal behavior that is, or would be, *helpful* in the management of diabetes. The second group of responses highlights *nonhelpful* behavior. The third group of responses center on descriptions of *couple interaction* in relation to diabetes management. Because responses from patients and spouses were similar, data were combined. Selected quotes are presented in each area.

# Descriptions of Helpful Behavior

Dietary control and regimen specific support. When asked to describe what partners do to help manage diabetes, patients (33 statements) and spouses (43 statements) most frequently responded with answers relating to dietary control. Whether it was grocery shopping, food preparation, a shared diet plan, or strict adherence to dietary guidelines, many identified these efforts as helpful. Several examples highlight the efforts of spouses to plan and prepare appropriate meals.

Patient: "He buys my special foods that we need, like the Sweet'n Low, and the whole wheat breads and grains and the flours."

Patient: "He likes to cook a lot of meat. I will tell him, 'Don't fry it, that makes my blood sugar zoom up,' and he is fine with that. Then he will say 'okay, well I am just going to lightly sauté yours or broil it.' So he is very consolatory toward my dietary restrictions."

Spouse: "I've gone into the store and have turned over every package, every vegetable thing, seeing how many carbohydrates are in what he has to eat and that is what I try to do. So I know what popcorn to get and which vegetable to get that's got the lowest in it."

Other comments illustrate how adjustments to the timing and location of meals were also perceived as beneficial.

Spouse: "I've learned that he needs to eat within 30 minutes after the insulin, now that he is on that. So I am sure to give him some time just before supper so he knows when I am coming."

Patient: "When we go out to dinner or we go on trips or anything like that, he is even stricter than I am sometimes. He'll say, 'Well, [my wife] can't do that,' That helps me cope with the situation, and he is very happy to stay here at home where I can fix meals that I can eat."

In these cases, participants recognized that changes were required in eating patterns in order to manage diabetes properly.

Although most participants felt support relating to dietary control was important, some couples reported conflict and resistance. For example: Spouse: "I try to buy healthy foods. Unfortunately, my husband goes and buys other stuff that he likes to eat. I try to teach my kids how to eat healthy, how to live healthy. My husband is not very receptive. He is one of those people, 'Don't tell me what to eat because I am going to eat what I want.'"

Other commonly described helpful behaviors related to assisting with shots or medication (20 comments) and checking blood sugar levels (19). Comments comprising these codes ranged from encouragement and sticking to a routine to actually preparing and injecting insulin and filling/ dispensing other medication.

General relational support. The next most frequent group of responses (31 patients; 13 spouses) highlighted general "supportive" attitudes instead of specific deeds. Typical responses were:

Patient: "He would help me with anything I ever needed. He is very supportive."

Patient: "She is just a supportive person all around in every way, not just with diabetes."

Spouse: "I just think letting her talk to someone about it, or discuss it [is helpful]."

These comments reflected confidence that support is available and could be called upon as needed, regardless of the type of assistance required. Other comments revealed more specific indicators of support:

Patient: "She is very cooperative, she thinks of me, I can't ask for more than that."

Spouse: "A verbal-backing support is different than saying let's go out and go for a walk, we do that for both of us."

Spouse: "Talking nicely. Asking him how he feels, instead of telling him."

Couples also made observations (20) regarding helpful communication/ problem-solving exchanges. Participants made specific reference to the importance of "having a sounding board" and working together to remedy difficult problems.

Patient: "That discussion, that back and

forth to try and figure out something [blood sugar levels] that doesn't make sense right away and sometimes it still doesn't make it at the end. But sometimes there is a possible explanation or we'll discover a pattern. It is helpful having a sounding board."

## Reminders

Another frequently described helpful behavior was the act of reminding (14 patients; 12 spouses). Whether it was a quick reminder to check blood glucose levels, take medication, or pack extra snacks, both patients and spouses described this type of help as crucial.

Patient: "Well, I am really active and I ski and I bike and I am out alone a lot. He is always 'Do you have your candy with you. Did you bring your cell phone?"

Patient: "He will say something like 'When was the last time you ate?" [or] 'What was your last sugar?" "

# Descriptions of Nonhelpful Behavior

Participants provided focused, articulate examples of nonhelpful spousal behavior, although fewer in number.

*Nagging.* Both patients (5 statements) and spouses (7 statements) noted that "nagging/criticizing" was problematic.

Patient: "Yeah, I get the lecture every once in awhile—just when I don't need it."

Comments highlight the reactivity of patients to nagging behavior and the efforts of spouses to curb responses to avoid triggering their partner. Specifically, patients expressed contempt over "bugging" and "harping" behavior. Spouses noted that "critical," "constant," or "controlling" reminders often resulted in nonhelpful nagging. One patient highlighted her frustration with her spouse, stating:

Patient: "If I have taken my insulin and I don't feel like eating, he says 'You should eat, you gotta eat, and you know you have to have something in your stomach because the other pills that you have to take will eat your stomach up.' In other words he is not my mother!" One spouse articulately describes how she learned to distinguish between helpful and nonhelpful behaviors.

Spouse: "Yeah, nagging and being scared and nervous hasn't been helpful. I think if I am calm about things. If I see certain actions in him that I think he needs to check his blood sugar, and saying something nicely to him. That basically helps [and] still [makes] him feel like a person too."

Problems with diet management. A few partners recognized (5 patient; 3 spouse) that a spouse's eating behaviors could negatively impact the illness. Participants described difficulties ranging from preparing inappropriate food to modeling bad eating habits.

Spouse: "I guess the only problem that I do have is when he wants to have something that I think is really unhealthy to eat. He has cooked it, and I am there and I say 'I really wish you wouldn't do that.' So I feel obliged to eat something, I don't eat very much of it, but I eat some of it."

Spouse: "I have an eating problem myself; so if I want to eat, I know it triggers him to go eat other things, too."

*Poor communication.* Just as couples noted that good communication skills facilitate diabetes management, both patients (4) and spouses (3) responded that poor communication impedes it.

Patient: "He started out ignoring it completely and that didn't help either because I needed to talk about things. He just didn't talk about it in the beginning. I said that he should butt out so he tried not talking about it at all. It wasn't his fault, it was as much my fault as it was his fault."

Spouse: "What doesn't work is by not communicating and just thinking that you know what she wants. It takes effort to communicate, you have to stop and just try to do that. Things that do help are communicating and just taking time to listen, effective listening. Not listening and doing certain things that you assume you know [doesn't help]."

Other comments from patients described specific spousal emotions (anger, crankiness, or worry) that were perceived as not helpful. Spouses noted that conflict, even with issues not related to diabetes, could also serve as a barrier to management.

## Descriptions of Couple Interactions

Couples' responses to questions 5 and 6 (see Table) describe how patients generally respond to spouses' efforts to help, and if the couples feel they are working together to manage diabetes. The majority of comments for the 40 patients (61% of the total number of responses to questions 5 and 6) and 32 spouses (65% of statements) described positive/receptive reactions to spouse help and unified/supportive couple interaction. These comments revealed teamwork in the areas of diet (17 patient; 22 spouse), blood glucose testing, and other medical issues (7 patient; 18 spouse), as well as general involvement and support (10 patient; 6 spouse) and helpful communication exchanges (8 patient; 7 spouse). Comments comprising these codes were similar in tone and substance to descriptions of "helpful behavior." However, descriptions of negative responses to spouse help and non-unified couple interaction did provide unique insight into how couples see themselves.

Independence. One code emerging from answers to questions 5 and 6 was "independence/resistance." When asked about how they worked together as a couple, 12 patients and 11 spouses made comments (33 total) that, at times, they have preferred to, or been left to, manage certain aspects of the illness alone. In all but one of the comments, participants noted that the need to be independent, and the oft-accompanying resistance to help, resulted in tension and/or conflict. This was particularly true where spouses wanted and tried to be involved in the diabetes management, but were blocked by a partner who refused to share his or

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her burden. Reasons listed for this refusal ranged from a desire to protect a spouse from suffering to a lack of trust in a spouse's ability to truly provide needed help.

Patient: "I usually say, 'Don't worry about it, I know what I am doing, I know more about this than you because I live it every day.'"

Spouse: "Even when I try to help her again, she says 'You've had your chance once before.' So that is where we are not working together...when you try to help, she doesn't want it because of half-hearted attempts to assist in other times in the past."

Spouse: "He doesn't like talking about it...It's not like he ever asks for help, or even says he needs help or whatever. Now that I am aware of so much more, I watch all the time and I get very nervous when I feel like he is not doing what he should."

Interactions during low blood sugar—A distinct issue. Low blood sugar (hypo-glycemia) can arise when individuals with diabetes have injected too much insulin, eaten too little food, or have exercised without extra food, causing shakiness, weakness, nervousness, headache, hunger, and blurred vision. Hypoglycemic individuals often become confused, have difficulty thinking clearly, may have convulsions, or collapse. Therefore, a spouse may need to act quickly, while the partner may resist the help.

Partners spoke (patient 7; spouse 4) about problems giving help during hypoglycemic episodes.

Spouse: "I get very concerned about her having low sugar and I become very annoyed at the fact that it is going to go down or it is down. We had an incident this morning.

"I woke up, went in the shower and came out and I generally check her blood sugar for her before I come down and have breakfast. Well, she is laying there in a cold sweat and she has a 36 blood sugar. I get aggravated because I am on a tight schedule [and now]I've got to feed her something." Patient: "If I had a reaction while we were out or something he would get very angry and say 'This is why I don't take you out any place,' if the meal was late or something like that. Then I would cry and cry and cry."

They also spoke about how difficult it can be receiving help during these crises.

Patient: "Sometimes my anger is a character flaw. Sometimes it is a direct function of my sugar getting sufficiently low that it is affecting my mood and my thought process.

"There is at least one occasion that I still haven't found out exactly what happened that I more or less came to my senses sitting at the kitchen table and my wife was sitting on the couch at the other end of the house crying, because of something that I did. I still don't know what that was."

Spouse: "When he is having a low it is very difficult. You know they get agitated when they have a low...[it is] just mainly difficult when [he] is at that really low point, where no matter what you are saying to him, it is really not getting through because he is in that fog."

Although partners recognize spousal support during lows is crucial, many struggle with how best to manage a situation that can often end in frustration, anger, and conflict.

Patient: "If I am having a reaction, he just knows to stay away from me because I really will...lash out on him when he tries to tell me to eat something."

## DISCUSSION

The purpose of this qualitative study was to learn, from the perspective of those who live with diabetes, whether or not support from spouses is important to their ability to manage the disease, and to learn what "support" means to these individuals. We have learned several things.

We know successful dietary management is critical to diabetes control. From the interviews, we have learned that, for

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these couples, adherence to diet is also where spousal support is much needed. There are many ways supportive partners help. They purchase and plan appropriate meals; are sensitive to the importance of meal timing; and remind, motivate, and cajole to help patients exert necessary self-control. In addition, partners provide specific assistance relative to other aspects of the diabetes regimen, such as reminding the patient to perform blood glucose tests when necessary. It is readily apparent that these skills depend on the partner being well-educated about diabetes, its successful management, and potential pitfalls.

The participants also described the importance of feeling emotionally supported within the marriage. While this was more difficult for participants to put into words, it clearly hinges on open communication of feelings and ability to problem-solve when difficulties arise.

Our analysis suggests that high potential for conflict exists, as partners may cross the line from reminding to nagging, or struggle with how to respect their spouse's need for independence while dealing with their own fears about the consequences of poor disease management. Unique challenges associated with hypoglycemia were also highlighted.

The study has several strengths. It involved a broad sample of 72 individuals, provided reliable results by using multiple coding checks, and was analyzed by a collaborative team. However, the use of a semi-structured questionnaire may have limited the responses. Also, the sample was biased toward those willing to participate in a study about spouse involvement, and this may not be representative. Additional research is needed that can access and then describe deeper and more complete descriptions from couples regarding specific interactions relating to diabetes. This might involve fieldwork consisting of observations of couples interacting in their natural settings, or observed interactive dialogues, so that the phenomenon of interest, i.e., partner interactions around diabetes, might be directly observed, not merely reported. It would also be interesting to explore the different perspectives of patients and spouses, as well as possible gender differences.

# Clinical Implications

The results raise implications for clinical practice, both for family therapists, and other healthcare providers who may be working with a patient who has diabetes. The implications relate both to the patient with diabetes, and to the marital relationship.

From the perspective of improving diabetes management, the study highlights the importance of assessing both patients and spouses. Given the significant role that spouses often play in promoting or hindering effective diabetes management, their knowledge, beliefs, and attitudes should be understood and, where problematic, addressed directly. Diabetes educators can provide education and attitudinal exploration to insure that the spouse has a sound and accurate knowledge base, and is clear about his or her goals for the diabetic spouse. The involvement of family therapists may be appropriate when problematic communication styles and interactions interfere with good disease management. The spouses will be involved, and efforts should be directed to make that involvement helpful and supportive, which may involve the collaborative efforts of a multidisciplinary team.

The interview results also highlight the ways that diabetes can strain a marriage. Therefore, if physicians, nurses, and other healthcare professionals can provide an opportunity for patients and spouses to discuss these potential negative feelings, it may help couples navigate their relationship through the difficult times of diabetes. Referral to therapists who could provide training in effective marital communication may also be beneficial.

We believe we were able to hear the "voices" of diabetic patients and their spouses, learn how marital relationships affect diabetes management, and demonstrate how dealing with diabetes may affect marriage. Interventions to promote adherence should stress the importance of dietary issues, conjoint communication and problem-solving, diabetes education for the spouse, as well as ways to walk the tightrope between support and nagging/ criticism. Most partners already try to support spouses in dealing with this difficult disease. Interventions that help them do so effectively and appropriately will likely improve disease management as well as strengthen the marriage.

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