



## **Patients' Perspectives About Dietary Maintenance In Type 2 Diabetes**

By: **Melissa Gutschall, PhD, RD**, Lisa L. Onega, PhD, RN, and Wanda K. Wright, MSN

### **Abstract**

This investigation used a qualitative, open-ended semistructured interview guide to understand the perspectives of individuals with type 2 diabetes ( $n = 23$ ) concerning factors necessary to maintain dietary changes. Five categories related to maintenance of diagnosis-related dietary changes emerged: self-discipline; understanding emotions; supportive relationships with family, friends, and health care providers; need for education; and strategies to maintain a healthy diet. While the small sample limits applicability of findings to all people with diabetes, dietitians can develop a repertoire of strategies within each category to facilitate mastery over daily challenges and maintenance of healthy dietary behaviors.

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This investigation used a qualitative, open-ended semistructured interview guide to understand the perspectives of individuals with type 2 diabetes ( $n = 23$ ) concerning factors necessary to maintain dietary changes. Five categories related to maintenance of diagnosis-related dietary changes emerged: self-discipline; understanding emotions; supportive relationships with family, friends, and health care providers; need for education; and strategies to maintain a healthy diet. While the small sample limits applicability of findings to all people with diabetes, dietitians can develop a repertoire of strategies within each category to facilitate mastery over daily challenges and maintenance of healthy dietary behaviors. **Key words:** *behavior change, dietary maintenance, patient perspective, type 2 diabetes*

**D**IABETES affects nearly 10% of the US population.<sup>1</sup> The prevalence of diabetes is rising<sup>1,2</sup> and, globally, is expected to double by the year 2030.<sup>2</sup> Diabetes costs \$132 billion yearly,<sup>3</sup> and approximately 25% of the total Medicare budget is related to poor glycemic control.<sup>4</sup> Lifestyle changes decrease the risk of developing type 2 diabetes, as well as the risk of developing complications.<sup>3,5,6</sup>

Metabolic outcomes significantly improved in controlled clinical trials following di-

etary changes.<sup>5,6,7-9</sup> However, diet is one of the most difficult areas of diabetes to manage.<sup>10</sup> Consequently, changes often are not maintained.<sup>11</sup> While behavioral changes are important to nutrition therapy, maintenance of those changes is critical in achieving positive outcomes in diabetes.

Diabetes is a self-managed disease with individuals making daily choices that affect the success or failure of disease management. Health care professionals may have varying levels of training about the diet required to maintain control of diabetes. Additionally, a gap in the literature is found with regard to what patients believe they need to maintain dietary changes over the long term.<sup>12-15</sup> Thus, even in those individuals receiving dietary education for diabetes, therapies provided may not effectively match what patients identify as important to managing the disease successfully for a lifetime. This project aimed to understand patients' perspectives regarding maintenance of the dietary regimen and to inform dietetic practitioners about factors that may extend educational efforts beyond the short term.

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**Author Affiliations:** *Department of Nutrition and Healthcare Management, Appalachian State University, Boone, North Carolina (Dr Gutschall); School of Nursing, Radford University, Radford, Virginia (Dr Onega); and Bristol Regional Health Center, Bristol, Tennessee (Ms Wright).*

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**Correspondence:** *Melissa Gutschall, PhD, RD, Department of Nutrition and Healthcare Management, Appalachian State University, Box 32168, Boone, NC 28608 (gutschallmd@appstate.edu).*

## PROCEDURES

The project used a qualitative, open-ended interview guide designed to identify factors that individuals with type 2 diabetes perceived as necessary for successful dietary maintenance.

Participants ( $n = 23$ ) had been diagnosed with type 2 diabetes for at least 1 year and were between the ages of 21 and 70 years. Children and older adults were excluded because they may have unique developmental perspectives that could complicate comprehension of factors necessary for successful dietary maintenance. Being diagnosed for at least 1 year enabled participants to have some experience with the disease and the effects of various dietary choices.

Participants were recruited through advertisements at local physicians' offices, community centers, support group meetings, and campus locations. Telephone screening was conducted to determine eligibility, explain the interview process, and schedule a time for individual interviews. Of the 29 people screened, 5 did not meet the age criterion, and 1 had been diagnosed for less than a year.

This research was approved by the institutional review board at the sponsoring institution. Participants provided written informed consent. Participants volunteered to donate their time to the study and did not receive incentives. Most of them stated that the time was beneficial to exploring their own feelings about diabetes management.

Two of the 3 authors were skilled in qualitative research methods, and all authors worked together as a team in formulating the procedures for this project. The 3 authors collaborated in developing the interview guide, discussing procedures for interviewing, and conducting the interviews. After giving consent to participate in study procedures, volunteers completed a demographic and diabetes management questionnaire. Questions included information about HbA<sub>1c</sub> values, previous diabetes education experiences, and self-monitoring patterns. Semistructured interviews, lasting between 60 and 90 minutes,

were conducted in a quiet, comfortable, and private setting, such as a conference room at a community center. A list of open-ended questions served as an interview guide (see Table 1). Follow-up questions and remarks, such as "What did you do then?" and "Tell me more," enabled the researchers to elicit clarification and elaboration of participants' comments. Interviews were audiotaped and subsequently transcribed. Interviewing and transcription occurred simultaneously to facilitate ongoing comparison among the data, and interviews were completed once data saturation was reached.<sup>16</sup>

## DATA ANALYSIS

Descriptive statistics were used to analyze demographic and diabetes management questionnaires. Transcribed interviews were reviewed to ensure accuracy and coded on the basis of changes in ideas. Ideas were grouped according to similarities and differences and then categorized into themes. Researchers compared coding, grouping, and thematic analysis of the transcripts to gain analytic and interpretive consensus.

## FINDINGS

Approximately 75% of participants received a formal hospital-based series of diabetes education classes at initial diagnosis. While classes were in compliance with national standards and included nutrition education, participants agreed that the programs were neither individualized nor focused on what to do following goal attainment. All participants ( $n = 23$ ) believed that dietary maintenance should last a lifetime, and all concurred that periods of relapse were common (see Table 2). *Maintenance* was defined as "being able to get [blood glucose] at the right place and being able to keep it there," "eating things that will keep me from having any extremes to where I become unhealthy," and "keeping track of carbohydrate intake."

**Table 1. Interview Guide**

<p><b>The first questions I will ask you are about what it means to you to successfully manage your diet.</b></p> <ol style="list-style-type: none"><li>1. Tell me about a situation when you made a long-lasting dietary change as a result of having diabetes.</li><li>2. Tell me about a situation when you were not able to successfully make a long-lasting dietary change as a result of having diabetes.</li><li>3. Please tell me about how you have managed your diabetes since your diagnosis.</li><li>4. Regarding diabetes care, what do you feel you know well?</li><li>5. What do you feel you do not know about your diabetes and diet?</li><li>6. Do you feel you are maintaining your diet? Why or why not?</li><li>7. What does maintaining your diet mean to you?</li><li>8. How would you measure dietary maintenance of your diabetes?</li><li>9. Have the dietary changes that you made lasted?</li><li>10. Does dietary maintenance affect the diet as a whole or only specific foods? Please explain.</li><li>12. How often do you think about diet and controlling your blood sugar?</li><li>13. What motivates you with regard to dietary management of diabetes?</li></ol> <p><b>Now we will talk about what you think helps you successfully manage your diet.</b></p> <ol style="list-style-type: none"><li>1. Tell me about a time when you used specific strategies to make lasting dietary changes as a result of your diabetes.</li><li>2. Tell me about a time when you tried to make dietary changes to help your diabetes but were unsuccessful. Why was the change unsuccessful? What might have made it more permanent?</li><li>3. How do you make dietary changes?</li><li>4. Describe how you manage your diabetes with diet.</li><li>5. What do you do when you feel you have gotten off track with you diet?</li><li>6. What helps you regain control?</li><li>7. How do you know when you are doing well with dietary intake?</li><li>8. What would help you increase your confidence in your ability to manage your diabetic diet?</li><li>9. What helps you control blood sugar levels?</li><li>10. What are challenges to controlling blood sugar levels?<ol style="list-style-type: none"><li>a) What do you feel you are doing well?</li><li>b) What would help you?</li></ol></li><li>11. In terms of diet, what brings your blood sugar to a more normal level? What does not?</li><li>12. What helps you choose to do those things that are successful in achieving a better blood sugar level?</li></ol> <p><b>Next, we will talk about what type of contact with healthcare providers you would find most helpful in assisting you to initiate and maintain dietary changes.</b></p> <ol style="list-style-type: none"><li>1. Tell me about a time when you had a good experience with a health care professional related to diet and diabetes.</li><li>2. Tell me about a time when you had a bad experience with a health care professional related to diet and diabetes.</li><li>3. Who supports you in managing your diabetes? What do they do that helps you?</li><li>4. How often is that support necessary?</li><li>5. What type of health care practice or practitioner would help you manage the diet aspect of your diabetes, i.e., nurse, doctor, dietician?</li><li>6. Describe your past experiences with dietary education for diabetes.</li><li>7. How often would you like to receive dietary education related to diabetes, 1 time, ongoing?</li><li>8. What type of interaction is best for you to learn (eg, group, individual, phone-call, and Internet?)</li><li>9. How could educators/practitioners better help you with your diet?</li><li>10. How well do you feel that healthcare practitioners relate to your situation and what it is like to manage your diet with diabetes?</li><li>11. What are they doing well?</li><li>12. What could they do better?</li></ol> <p>Please share with me anything that you feel would help me understand issues related to diabetes and diet.</p>
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**Table 2.** Description of Participants (n = 23)

Characteristic	Participants' Description
Gender	Female = 15 (65.2%); male = 8 (34.8%)
Age	Mean = 56.6 years; SD = 8.8 years
Ethnicity	Caucasian = 21 (91.3%); African American = 2 (4.3%)
Marital status	Married = 16 (69.6%); not married = 7 (30.4%)
Employment status	Employed = 10 (43.5%); not employed = 13 (56.5%)
Education	College degree or higher = 18 (78.3%); no college degree = 5 (21.3%)
Years with diabetes	Mean = 7.2 years; SD = 7.8 years
Hemoglobin A <sub>1c</sub>	Mean = 7.1g/dL; SD = 1.6
Received diabetes education	Yes = 17 (73.9%); no = 6 (26.1%)

Five factors that individuals with type 2 diabetes perceived as necessary for successful dietary maintenance emerged: self-discipline; understanding emotions; supportive relationships with family, friends, and health care providers; need for education; and strategies to maintain a healthy diet.

### SELF-DISCIPLINE

Participants believed that healthy dietary habits contributed to the control of their blood glucose and A<sub>1c</sub> levels, yet varying degrees of self-discipline were reported. On a scale of 0 to 10, participants rated the importance of maintaining blood glucose levels as 8.4, while confidence for doing so was rated as 6.7.

Those with a strong sense of self-discipline planned ahead, making decisions before they were faced with difficult situations. Participants reported challenges to self-discipline, including stress, family and work schedules, eating out, and social engagements involving food. A commonly expressed idea was the ability to incorporate “problem” foods in limited amounts and settings to feel in control. If a food was eaten in greater amounts than recommended or not planned into the daily routine, the individual’s sense of control was lost.

Participants varied in their self-discipline related to problem foods. They used avoidance, decreased portion sizes, and found suitable alternatives. Some could easily eliminate

problem foods, while others were concerned that denial would make the food more desirable and lead to an episode of overconsumption. One participant described avoiding bagels completely, but she ate pizza in small portions. Another gave up dessert but ate 2 rolls with dinner. The criteria used to rationalize the inclusion of some foods, while omitting others, seemed to be related to a risk versus benefit (guilt vs pleasure) analysis. Regardless of how much self-discipline individuals displayed, they identified that self-control was necessary for successful dietary maintenance (see Table 3).

### UNDERSTANDING EMOTIONS

A variety of emotions were associated with dietary maintenance, including fear, anger, guilt, stress, and depression. Some participants expressed resentment toward having the disease, questioning, “Why me?” Dietary changes impacted their sense of self-worth and quality of life, with one participant stating that she “deliberately abused” her body by eating the wrong foods.

Life stress and depression were common among participants, both those who felt they were successful with dietary maintenance and those who did not. The ability to understand emotions, cope well, and keep diet a priority in the face of challenges made the difference.

Fear was common among those who had experienced a physical consequence of poor

**Table 3.** Factors Contributing to Dietary Maintenance

<p><b>Self-discipline</b></p> <p>“In the end, it’s not up to the education, it’s up to me doing it.”</p> <p>“I set my mind to the fact I had to change what I eat. Once I decided to do it, I have never had any problems with making that decision . . . .”</p> <p>“I know what I’m supposed to do, I just don’t do it.”</p> <p><b>Emotions</b></p> <p>“If I’m depressed, I’ll just eat whatever I can find.”</p> <p>“When I’m stressed, I eat things I shouldn’t.”</p> <p>“I deliberately abused my body because of anger.”</p> <p><b>Relationships</b></p> <p>“My wife does understand it [diabetes] . . . . She has supper cooked most nights; if not, she plans to have the right foods available.”</p> <p>“I got a lot of inspiration from ——. When she cooks and brings some stuff to church, when they have some dinner, she says now I got this salad over here, you can eat that.”</p> <p>“Having a physician that understands the situation and will talk with you.”</p> <p><b>Education</b></p> <p>“How can I live with this? What do I need to do? What might not get me off to the right start?”</p> <p>“I want information about diabetes—what causes it, how the body works. I think classes would have been very helpful.”</p> <p>“Someone who could [say] what this food does . . . how to prepare this food to where it will not be hard on you. What is a diabetic diet?”</p> <p><b>Strategies</b></p> <p>“You try to make better choices, like okay don’t go for the pastry, try to go for the lesser of the two evils. Okay, which is the lesser of the two evils, a white biscuit or a croissant? Okay, half a croissant would be better than eating the biscuit I think . . . .”</p> <p>“Yes, I’ll bring the healthy thing or cook a few things healthy that I know I can eat.”</p> <p>“If I cheat, I see what happens. If I eat something I shouldn’t eat, and I test it and it’s high, I’m like, okay, can’t do that!</p> <p>“If you know your numbers, you know what you can and cannot do.”</p>
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glycemic control, such as a temporary loss of eyesight, or had seen such a complication in a family member. Fear of taking medications or insulin was mentioned multiple times. Anger was almost always mentioned as a factor related to the initial diagnosis of the disease, while guilt predominated as a frequent emotion related to dietary choices. Those who identified and understood their emotions were more successful with dietary maintenance than those who did not (see Table 3).

### **SUPPORTIVE RELATIONSHIP WITH FAMILY, FRIENDS, AND HEALTH CARE PROVIDERS**

Relationships emerged as having both positive and negative influences on dietary main-

tenance, depending on the level of care, education, and support that was available and desired. Participants who received support from spouses, friends, and health care providers were able to manage their diet more successfully. Positive relationships provided a strong support network through effective communication about disease management.

When positive support was given at home, participants were able to make decisions that allowed better disease maintenance. For example, one participant’s wife had healthy food available even when there was no time to cook. This helped the individual manage his diabetes on a more consistent basis.

Participants who received little support from families and friends found it harder to maintain their diet. For example, one participant’s husband brought home Moon Pies even

though she believed he knew that these represented an unhealthy dietary choice, and found them difficult to resist. In addition, social gatherings were challenging for those individuals when low-carbohydrate choices were not available.

The idea of peer support was mentioned several times when participants were queried about what else would help them manage their disease more effectively. The majority felt that a support person, or “diabetes coach,” should be another individual with diabetes because this person would be able to relate to the specific requirements for disease management. Participants believed that they could obtain support from a coach and gain satisfaction and confidence from helping that individual in return.

Support from health care providers encouraged participants to maintain their diet. A nurse from one participant’s insurance company called every 2 to 3 months to allow him to ask questions and provide information. On the contrary, some participants felt that their physician did not listen to what they were saying. They wanted guidance in the management of diabetes, having a desire to control their blood glucose (see Table 3).

### **NEED FOR EDUCATION**

While most participants (75%) had completed an accredited diabetes self-management education program, all wanted more information and were overwhelmed when diagnosed initially. They needed answers to their questions about diet and blood glucose patterns along with time to practice and reinforce that information. In addition to more detailed meal planning and preparation, they wanted information about diabetes and its consequences. Information about how foods affect blood glucose levels was of major importance to all participants.

Participants felt that they needed contact with someone else to maintain accountability for disease management. The desired frequency of this contact varied from one time per week to one time per month, but all

agreed that “knowing someone is available” for them to assist in problem solving was comforting. The key was regular communication, no matter what the modality was. As for formal learning, the majority of participants would like to see refresher classes 1 to 2 times per year, individualized education, and the setting of realistic goals (see Table 3).

### **STRATEGIES TO MAINTAIN A HEALTHY DIET**

Participants who maintained their diet performed frequent blood glucose monitoring and displayed a positive preoccupation with dietary planning. A visible outcome and an understanding of the relationship between food and blood glucose helped individuals solve problems effectively. Self-monitoring reinforced meal choices, taught participants about the relationship between foods and blood glucose, and provided accountability for their actions. One participant described self-monitoring as “that’s your lifeline . . .” Participants had strategies for incorporating favorite foods and used a trial-and-error process to learn about their compatibility with particular foods. They articulated specific strategies for making trade-offs, following a routine that is flexible and adaptable, and using compensatory tactics immediately following a relapse.

While relapses were inevitable for most, those who were successful with dietary maintenance decreased the length of the relapse, building confidence and promoting long-term maintenance. They did not perceive a relapse as a major failure because they were able to get back on track. Compensations for indulgences were made at the next meal or planned for ahead of time when a situation was expected, such as a social gathering. Terms such as “on guard,” “defensive eating,” or “conscious awareness” were used by those who felt that they were maintaining their diet and felt that negative physical feelings, such as sluggishness, outweighed the pleasure of indulging.

On the contrary, others were in denial. They reported seeing a high blood glucose value but did nothing to compensate and they had no plan of action. They did not test blood glucose after meals. In fact, some rarely tested blood sugars out of fear of seeing a negative result or remaining ambivalent and unready to face change.

Participants who did not perceive themselves as successful at dietary maintenance were not able to articulate specific strategies to help them to move forward. They used general terms such as “healthy diet” and “right foods” rather than amounts of carbohydrates or particular food choices when describing what they thought they should be eating. They expressed a lack of routine meal planning, which was also a barrier for successful maintenance when routines were broken by situations such as vacations or altered work schedules (see Table 3). Suggested applications for each identified category to practice are provided in Table 4.

## DISCUSSION

The goal of this project was to explore the perceptions of individuals with type 2 diabetes regarding the maintenance of dietary changes to manage their disease. The following 5 categories emerged as factors that contributed to dietary maintenance: self-discipline; understanding emotions involved with the diagnosis of diabetes; supportive relationships with family, friends, and health care providers; the desire for more education; and strategies used to maintain dietary changes.

Individuals who perceived themselves as successful with dietary maintenance possessed self-discipline for practicing self-monitoring and problem-solving skills. The relationship between self-care and reduced comorbidities is well documented,<sup>4,12,17</sup> and problem-solving ability has been an independent predictor for diabetes self-care at 6-month follow-ups.<sup>18</sup> Self-monitoring increases problem-solving skills by allowing patients to correlate the relationship between food and

blood glucose, maintain accountability for the result, and make appropriate adaptations to their diet. In fact, self-monitoring is 1 of 3 general behavior patterns (along with decreased fat intake and physical activity) that have been consistently related to maintaining dietary behavior change.<sup>17,19,20</sup> Patients should be encouraged to self-monitor more frequently following various meals as a learning tool for improving their self-care capabilities.

Participants identified fear, anger, guilt, stress, and depression as common emotions during disease diagnosis and management. Those who perceived themselves as maintaining the diet articulated specific coping strategies. Those who did not spoke in vague terms and could not describe what they needed to move forward. A lack of coping skills when faced with the disease and other life stresses creates a prime opportunity for relapse.<sup>21</sup> In fact, 42% of dietary lapses have been related to intrapersonal problems such as physical states or moods.<sup>22</sup> Those who relapse are more likely to use avoidance strategies when faced with a difficult situation.<sup>23</sup> Thus, emotions, as triggers to relapse of behavior, can be one step in a downward spiral of decreasing self-management and increasing behavioral lapses until old habits eventually take precedence over newly adopted behaviors. Interactions during the behavioral change process would assist individuals with diabetes to understand the normalcy of their emotions and help them separate eating from emotions.

Continued support is a way to manage the array of emotions experienced with a chronic disease. While many participants in this study could not name a specific support person for diabetes, those who perceived themselves as successful with dietary maintenance took advantage of support programs. When asked about an ideal support situation, several participants mentioned peer support. They felt that someone else with diabetes would be the best person to confide in regarding disease management strategies. Peer support may enhance maintenance most effectively by providing continued contact after initial education, rather than during education.<sup>24</sup>

**Table 4.** Application of the 5 Identified Factors in Practice

**Self-discipline**

Address problem foods with a risk-benefit (or pleasure vs guilt) approach and help patients identify acceptable alternatives.

Include self-control as part of your conversations to identify what may help the patient increase control.

Practice problem-solving scenarios regularly through patient discussions of their own experiences or constructed examples.

**Emotions**

Help patient identify the relationship between particular emotions and food intake.

Develop coping strategies to handle emotions, which will ultimately affect dietary management.

Reinforce that a range of emotions is typical and okay. Patients should seek help if those emotions begin to affect daily management.

**Relationships with family, friends, and health care providers**

Inquire about sources of support. Encourage support group participation and identification of a support person with diabetes.

Improve listening skills and supportive behaviors in yourself and follow-up with patients as possible.

Help patients develop ways to openly communicate with others about disease needs.

**Education**

Allow more time for practice with the information during education and between educational sessions so that patient questions are developed and guided feedback can be provided.

Consider follow-up “refresher” courses once or twice per year if possible, or facilitate connections among participants for continued support and learning.

Include relapse information as part of education; address management following goal attainment.

Make yourself available to patients for questions that arise following education.

**Strategies**

Encourage regular self-monitoring, especially after meals as a learning tool. Consider more frequent monitoring in early stages of the disease to identify food and blood glucose relationships, and during times of relapse to increase accountability.

Develop a specific plan for trade-offs when faced with problematic foods or a compensatory plan to get back on track.

Set specific and measurable goals that are behavior oriented, especially in those with ambivalence.

Provide a menu of strategies that each patient can choose from to individualize acceptability and promote success.

Exposing all the facets of support is difficult, but the potential for this construct to facilitate the maintenance process is significant. The lack of support mentioned by participants in this study indicates the need for increased support systems to achieve successfully dietary maintenance when faced with a chronic disease.

Participants did not feel that education was individualized, nor did it focus on what to do following goal attainment. They did not have a clear understanding of how to use blood glucose values to make subsequent food choices or enough understanding of carbohydrate

counting to be successful with dietary maintenance. Participants expressed a desire for more follow-up education, as reflected by comments about refresher courses, constant reminders, and having someone available for questions at their convenience. Experience-based education may promote greater satisfaction with diabetes-related knowledge and has been related to decreased H<sub>b</sub>A<sub>1c</sub> levels 2 years following intervention.<sup>25</sup> Allowing time for guided practice with meal planning, application of problem-solving strategies to individual situations, and detailed feedback within the education process would help foster the

acquisition of greater knowledge and experience with disease management. Perhaps interdisciplinary provision of this education, with greater interactions between dietitians and other health care providers, would also increase successful management for the individual with diabetes.

Within the education process, the long-term goals of better health, lower risk of complications, and feeling better should be stressed to a greater degree when clinicians discuss disease severity. A common focus on weight loss as a primary outcome, rather than dietary changes, may contribute to individuals having misplaced goals. Establishing specific goals may allow the person to focus on dietary changes that will elicit both improved blood glucose control and weight loss.<sup>22</sup> Setting frequent and specific goals has been related to a greater number of behavioral strategies used for dietary change.<sup>26</sup> In turn, using more behavioral strategies during the process of change may lead to greater success with maintaining the diet.<sup>20,27</sup> Making targeted changes may not be as overwhelming as the all or none approach that was apparent in those who did not perceive themselves as being successful with maintenance.

While all participants in this study knew that dietary changes were important, some could not articulate a plan for making those changes and were overwhelmed with the number of dietary decisions to be made each

day. Offering options for handling challenging situations and assessing the acceptability, success, or failure of strategies could help tailor these tactics to each individual. Allowing the patient to choose the preferred method to make lifestyle changes may be one approach to long-term dietary maintenance.<sup>28</sup> In this study, participants who perceived that they were maintaining the diet possessed the confidence and skills necessary to adapt to new routines and not slip back to old habits completely. Maintenance may actually be a state of constant change, where adaptability and flexibility with physical, social, and environmental conditions are critical to prolonging the desired change.<sup>29</sup>

### Implications for Practice

This project identified 5 categories that individuals described as important to them for maintaining dietary changes in diabetes management. Practitioners may select applicable strategies from this qualitative approach based upon the needs of each patient. Using information from patients with type 2 diabetes may help frame dietary intervention and education and encourage follow-up that matches what practitioners know to what patients feel they need. Dietitians should plan for maintenance as part of the education process by incorporating relapse prevention information and facilitating opportunities for peer and professional support.

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