Barriers and Facilitators to Enrollment and Retention in the National Diabetes Prevention Program: Perspectives of Women and Clinicians Within a Health System

Katherine Jane Williams Baucom,1 Mandy L. Pershing,2 Kaitlyn M. Dwenger,2 Michelle Karasawa,2 Jessica N. Cohan,2,3 and Elissa M. Ozanne2,*,3

Abstract

Background: More than 10% of US adults are living with type 2 diabetes. The Centers for Disease Control and Prevention established the National Diabetes Prevention Program (National DPP) in 2010 in an effort to delay or prevent this disease among individuals at high risk. Unfortunately, enrollment and retention rates are low. This qualitative study aims to understand barriers and facilitators to enrolling and completing the National DPP among women, and to provide recommendations for improvement.

Methods: Semistructured interviews were conducted with the following: (1) women who were eligible for the National DPP, but declined to enroll (n = 11); (2) women who enrolled in the National DPP, but did not complete the program (n = 12); and (3) clinicians who treat women eligible for the National DPP (n = 12). Transcripts of the interviews were coded using content analysis.

Results: The 35 interviews (23 patients and 12 clinicians) provided further insight into known barriers, such as the cost of the program, the time that it takes, and inconvenient locations. The study also identified previously undiscovered barriers, including the program not meeting participants’ expectations and facilitating referrals. Furthermore, improved communication between clinicians, patients, and National DPP staff could ensure that both clinicians and National DPP staff are aware of patients’ goals and their individual barriers to success.

Conclusions: Enrollment and retention in the National DPP may be improved with additional communication, more training for National DPP staff to work more closely with participants, adding better incentives to participation, and making the program more accessible through flexibility in time and/or locations.

Keywords: barriers; diabetes prevention; prediabetes; recruitment; retention

Introduction

Diabetes is one of the most common diseases in the United States, with an estimated 13% of the adult population—over 34 million people—living with diabetes.1 Over 90% of people with diabetes have type 2 diabetes (T2D), a largely preventable disease.2 In addition to those living with T2D, many adults in the United States are at heightened risk for T2D. For example, in 2018, an estimated 88 million US adults had prediabetes, with blood glucose levels above normal, but not yet diagnostic of T2D.1

The National Diabetes Prevention Program (National DPP) was developed in 2010 by the Centers for Disease...
Control and Prevention (CDC) for individuals at heightened risk for T2D, with the goal of slowing disease progression and reducing the incidence of T2D through weight loss.\(^3\) Participants in the program meet as a group between two and four times a month to work with program facilitators to lose 5%–7% of their body weight through eating healthier and being more physically active.\(^3\) In the original clinical efficacy study of the Diabetes Prevention Program, the lifestyle intervention was associated with a 58% risk reduction in diabetes and an average 12.3-pound weight loss over a follow-up of 2.8 years.\(^4\) Furthermore, these benefits persisted 10\(^5\) and 15 years after program completion.\(^6\)

However, enrolling and retaining participants in the National DPP are particularly challenging, with just 10% of participants who begin the National DPP in community or health care settings completing the full year-long program.\(^7\)

Some of the commonly reported factors associated with lack of enrollment in diabetes prevention programs include being younger,\(^8\) not fluent in English,\(^8\) program cost,\(^9,10\) location of the program and transportation,\(^8,10\) being busy with work,\(^8\) and a long wait period before enrollment.\(^11,12\) Some cultural/community barriers to enrollment have also been reported, including poor communication and coordination between the public health sector and providers, lack of knowledge by community members, and poor integration of interests/skills of community members.\(^13\)

Compared with those who stay in diabetes prevention programs, those who enroll, but do not complete programs are more likely to be younger, male, and have a lower income.\(^14\) Participants who did not complete programs have cited stressors or unstable life circumstances, transportation difficulties, needing childcare, having family obligations, lack of family support, and chronic pain.\(^11,14\)

Just one known study of the National DPP, focused on women of childbearing age, includes in-depth interviews with patients from within a health system.\(^15\) Given women’s higher engagement with the National DPP to date,\(^16\) there is substantial opportunity for qualitative study in this group. This study extends the research with a qualitative analysis of barriers and facilitators to enrollment and retention within a health system from the perspectives of (1) women referred to the National DPP and (2) referring clinicians. Greater knowledge in this area has the potential to inform future implementation of the National DPP and increase its reach.

### Materials and Methods

#### Study design

Semistructured interviews were conducted with 35 participants in the following three groups: (1) women who are eligible for the National DPP, but declined to enroll (i.e., nonenrollees; \(n = 11\)); (2) women who enrolled in the National DPP and completed at least one session, but did not complete the 16-session “core curriculum” of the program delivered over the first 6 months (i.e., noncompleters; \(n = 12\)); and (3) clinicians who treat women eligible for the National DPP (\(n = 12\)).

#### Participants

Patient participants for this study were women who were overweight and considered to be at high risk for T2D, and thus met CDC National DPP eligibility criteria. The University of Utah (UofU) National DPP program office provided names of individuals who met study inclusion criteria for either the nonenrollee or noncompleter group. The UofU National DPP has been fully recognized by the CDC since 2018 and is offered to patients, employees, and their families, and several community groups. At the time of recruitment for this study, the out-of-pocket cost of the program was $50. Participants in this study needed to be able to converse in English. Women included in the nonenrollee group were offered an opportunity to enroll in the UofU National DPP, but chose not to enroll. Noncompleters were women who enrolled in the UofU National DPP and completed at least one session, but did not complete the core curriculum (i.e., did not complete the first 6 months of the year-long program). Recruitment of patients took place from December 2017 to June 2018 with interviews being conducted either at the UofU or over the phone.

Clinicians who were part of the care pathway of women at risk for diabetes were considered eligible for this study. This included primary care physicians and clinicians involved in diabetes prevention efforts, breast cancer prevention, wellness, and/or diabetes. Recruitment of clinicians took place from July 2018 to December 2018 with interviews being conducted in person or over the phone. Informed consent was obtained from all individual participants included in this study.

#### Procedures

All study procedures were reviewed and approved by the University of Utah IRB. After women were determined to be eligible for the study by the UofU National
DPP, emails were sent to invite participation in the study. If potential participants did not have an email on record, letters were mailed to them. After this initial contact, members of the study team followed up by phone three to five times. Women who enrolled in the study were provided an informed consent cover letter and were scheduled for an in-person or phone interview. After the completion of the interview, participants received a $50 gift card.

Eligible clinicians were those who were in a position to refer patients to the National DPP and were identified through departmental lists and referrals from other clinicians. Potential participants were informed of the study by email and then were contacted by phone for enrollment. If a clinician agreed to participate, they were provided an informed consent cover letter and were scheduled for an in-person or phone interview. Clinicians were not compensated for participating.

**Interviews and data analysis**

The semistructured interviews focused on issues related to barriers and facilitators to enrollment and participation in the National DPP. Topics were tailored to the type of participant (nonenrollee, noncompleter, or clinician). The patient topics included were as follows: (1) knowledge about and interest in the National DPP; (2) barriers to enrolling in and/or completing the National DPP; (3) motivating factors for enrolling and/or participating in the National DPP; (4) social or cultural influences; and (5) opportunities for improving enrollment and retention in the National DPP. Clinician interviews focused on five main questions, which were as follows: (1) number/percent of patients seen who are pre-diabetic or at risk for developing diabetes; (2) approach taken with these patients; (3) thoughts about the National DPP and related programs; (4) the motivation for patients to join the National DPP; and (5) opportunities for increasing participation in lifestyle interventions.

Two study team members (E.M.O. and M.K.) conducted the interviews and coded the transcripts using a content analysis method with an inductive approach in qualitative analysis software. Interviews were first open coded for meaning units and given headings. These headings were then grouped into categories. Three interview transcripts (one from each group) were reviewed and discussed by the coders to reach consensus. The coding was iteratively updated through periodic discussion between the two coders.

**Results**

A total of 35 participants were interviewed (11 nonenrollees, 12 noncompleters, and 12 clinicians). Interviews lasted an average of 31 minutes for patients (range: 20–45 minutes) and 26 minutes for clinicians (range: 15–60 minutes). Patient participants who did not enroll in the National DPP were more racially/ethnically diverse than those who enrolled in the National DPP, but did not complete the program (Table 1). Of the 12 clinician participants, 8 (75%) were women. The clinicians included family medicine (n = 7) and internal medicine (n = 3) physicians, a nurse practitioner, and a wellness specialist. Emergent categories of barriers, facilitators, and opportunities for improvement are presented below, separated by patient and clinician perspectives. Differences discovered based on the two types of patient participants (nonenrollees vs. noncompleters) are described. Representative quotes (Q) are highlighted throughout the results section and detailed in Tables 2–4.

**Barriers to enrollment and retention in the National DPP**

**Patient perspective.** The location (n = 4 of 23), cost (n = 3 of 23), and timing (n = 15 of 23) of the class were all mentioned as barriers to National DPP enrollment or completion. Location was only described as a barrier by the nonenrollees, and cost was only described as a barrier by noncompleters. However, for two of the noncompleters, the cost ($50 USD) was described as being too low. If the cost was higher, they expressed that they would have had higher expectations for the program and been more motivated to complete the program. One noncompleter mentioned

| Table 1. Patient Demographics |
|-----------------------------|
|                           | Nonenrollees | Noncompleters |
| Age                        | 51 (14.0)    | 52 (14.5)     |
| White (non-Hispanic)       | 4 (36%)      | 11 (92%)      |
| Hispanic/White             | 2 (18%)      | 0 (0%)        |
| Asian                      | 2 (18%)      | 0 (0%)        |
| African American           | 1 (9%)       | 0 (0%)        |
| Native Hawaiian            | 0 (0%)       | 1 (8%)        |
| Unknown                    | 2 (18%)      | 0 (0%)        |
| Employment status          |              |               |
| UofU employee              | 2 (18%)      | 4 (33%)       |
| Non-UofU employee          | 1 (9%)       | 8 (67%)       |
| Unknown                    | 8 (73%)      | 0 (0%)        |

SD, standard deviation; UofU, University of Utah.
that the cost was too high, but that did not stop her from making it work. The cost of the National DPP was not mentioned by the nonenrollees as a barrier to enrollment. Timing of the National DPP class was described as a barrier by both nonenrollees and non-completers. Classes conflicted with work schedules, school classes, or other life obligations.

In addition to replicating the above previously identified barriers, nonenrollees identified their current health status (n = 3 of 11) as another barrier to joining the National DPP. When asked reasons for not joining, patients described various health conditions as barriers to enrollment (Table 2: Q1–Q3).

Among noncompleters, a major barrier identified by all was the class not meeting their expectations (n = 12), including a discrepancy between the information women hoped to learn and the program content (n = 8), concerns about the class leaders (n = 4), and dissatisfaction with the class setup (n = 6). Before coming to the first class, they had an idea of what information they wanted to learn from the class and were disappointed when those topics were not covered in class (Table 2: Q4, Q5).

In addition to expectations they held about the class, some women also felt that their primary individual goals for the program were not consistent with the participant goals the National DPP requires. Out of 19 women who were asked what their definition of success would be or what they thought should be viewed as achieving success in the program, 6 mentioned that attendance would be important and 14 women mentioned that meeting their primary individual goals would be a success for them (e.g., developing or maintaining a healthy diet, maintaining weight, lowering A1c levels, or generally increasing physical activity) even if they did not meet the specific goals of the National DPP (Table 2: Q6–Q8).

Clinician perspective. All clinicians (n = 12) were asked their thoughts about these programs in general and whether or not they feel there are any barriers to referral, enrollment, or participation for the National DPP or comparable programs. Consistent with patient interviews and results of previous studies, costs of the program (n = 8), location (n = 9), and time (n = 7) were noted as top factors affecting enrollment and retention rates for the National DPP by clinicians. In addition, several clinicians (n = 3) described their lack of knowledge or a lack of information about the National DPP as a barrier to their referral and women’s enrollment in the program (Table 3: Q1–Q3). Clinicians (n = 3) also described the referral and follow-up process within the health system as a potential barrier. For example, clinicians expressed a desire to know the outcomes of internal National DPP referrals they placed, noting this would lead to more referrals (Table 3: Q4–Q9).
Q4. Other system-level processes noted by clinicians as barriers to referral and enrollment included the responsibility being placed on the clinician rather than the patient, the clinician wanting to establish rapport before a referral, or the National DPP not referring patients to other programs when there is no availability (Table 3: Q5–Q7).

| Categories | Representative quotes |
|------------|------------------------|
| Barriers of referring program: lack of clinician knowledge about the National DPP | Q1: “It’s really easy if I’m super confident about location and time I can tell them. I know really well when my dietician is seeing patients and where’s she’s at and exactly what they’ll experience. I have a pretty good idea of what they’ll experience in the Diabetes Prevention Program but I don’t exactly know where the location is and what the times are. Are they in the evening, in the morning? It’s kind of a little bit of a black box.”—Record 27 |
| Barriers of referring program: systematic problems or preferences | Q2: “I think you should kind of more advertise this program because we truly don’t know about it. I know about this because I was doing the diabetes project here at the office; why don’t you come in and talk to us about this and tell us, ‘This is what it is, blah, blah, blah, this is for your patients. I think you should do more advertising for your program.’”—Record 9 |
| Barriers of referring program: referral puts the responsibility on the clinician rather than the patient | Q3: “I think just feeling knowledgeable about it too, like where are the classes? How much money are they going to cost? Cause I think that’s sort of, if the patient starts asking a lot of questions or God forbid they go to the program and they’re like, ‘I didn’t know it was going to be $500’… I feel like that can be another barrier to referring to programs—it’s not that providers don’t know how to do it because [all] you have to do is type in an order, like refer to DPP, but maybe not knowing exactly what’s going to happen after their patients get referred. I have I think probably more knowledge of it than the average PCP, but I think that can be a barrier too sometimes.”—Record 1 |
| Barriers of referring program: lack of clinician knowledge about the National DPP | Q4: “Yeah, we don’t have access to that [other programs], but I do think—so Intermountain [Hospital] has this three-pronged approached and it’s institutional. And it’s like, at least according to what they told me, all our patients get screened and if they have pre-diabetes they are referred. Regardless. They are referred either to Way to Health, which is their DPP, individual nutrition counseling, or Diabetes 101 (which is a one-hour class). Every patient, with pre-diabetes by A1C or glucose tests, gets one of those options. In our system [a different hospital], that is not true. Now is that because we don’t have a streamlined system or is that because our providers don’t want to be told what to do? I don’t know! … I think if we had a systematic way to do that [choices for referrals], there would be more referrals.”—Record 6 |
| Barriers of referring program: systematic problems or preferences | Q5: “I’m saying, ‘We (the health system) are taking this on and we are going to reach out for you and we are going to help you.’ And so if the health system drops the ball on that ‘we’, then instead of the patient going to be like, ‘Well that didn’t work,’ they come back to me and are like, ‘That didn’t work.’ … So when the ball gets dropped it goes back to the primary care doc who referred. And so, whereas with the other stuff you’ve sort of been like, ‘Here are your choices. Take responsibility and go forward.’ With the DPP, we’re saying we’re going to take responsibility for making this work for you and when we (the global we) don’t take responsibility for making it work, it goes back to the PCP.”—Record 4 |
| Barriers of referring program: referral puts the responsibility on the patient | Q6: “I think, and this is my opinion (I don’t know that it’s necessarily based in ‘pure science’), my opinion is that if you build rapport with the patient and sort of understand what their individual motivations, barriers, etc. are, then referral can sometimes be better received than just like, ‘you have an abnormal BMI, here’s a list of things you need to do. You should go to this program.’ Like, patients are just going to be like, ‘what’ … That’s probably for me and my current practice the biggest barrier.”—Record 1 |
| Facilitators to enrollment and retention in the National DPP, and opportunities for improvement | Q7: “I think that if I hand off to DPP, and then they’re not able to accommodate but they hand off to something else (whether it’s Weight Watchers or something at the Y or something wherever), that’s fine; but it feels really hard like if I’ve gotten them to the point that they’re engaged and the answer is, ‘We don’t have anything for you,’ then it’s like they’re just back in my court.”—Record 4 |

We viewed these as facilitators to enrollment and retention in the National DPP, and opportunities for improvement.

Patient perspective
All patients (n = 23) were asked if knowing that weight loss and physical activity (primary goals of the National DPP) could help with the prevention of other diseases would motivate them to participate in the National DPP; only three participants said that knowledge of disease prevention would not make any difference in their participation in the National DPP. Many patients identified diseases that would be most important to prevent besides diabetes, given their own or their family members’ experiences with the disease. Heart disease (n = 7) and hypertension (n = 6) were the most
important to patients to prevent. Patients also mentioned arthritis (n = 3), cancer (general) (n = 2), anxiety (n = 2), depression (n = 2), heart attack (n = 2), mental health problems broadly (n = 1), stroke (n = 1), asthma (n = 1), and breast cancer (n = 1) specifically. Many women reported that preventing all diseases were important (n = 6), while some reported that specifically breast cancer prevention was important to them (n = 3).

The National DPP providing additional support from the program leaders (i.e., lifestyle coaches) to improve enrollment and retention was positively received (n = 16). The main perceived benefits were that lifestyle coaches could individualize the program in ways that may not be feasible during class (n = 6), help participants stay on track and complete the program (n = 6), and provide additional follow-up in terms of reminders and accountability (n = 3). Examples of how lifestyle coaches could individualize the program included the follows: helping with tailoring diets and meal planning, facilitating personalized goals, and assisting with life circumstances that may influence their participation in the program (Table 4: Q1–Q3). Almost all women (n = 22) were in support of additional incentives to National DPP participation and completion, such as raffles for gift cards, gym memberships, healthy snacks, or employer incentives (e.g., insurance discounts, wellness program points, etc.).

Patients viewed increasing the accessibility of National DPP classes as an opportunity for improvement. They liked the idea of having the National DPP offered closer to work or home locations (n = 9). Providing the option for online classes (n = 8) or a hybrid classes with a combination of in-person and online meetings (n = 12) was liked by patients. Some patients (n = 8) thought that making the possible times for the program more accessible was an option for improvement, and others (n = 4) were in support of a lower cost or free option for the program, or it being covered by insurance.

Clinician perspective. The 12 clinicians interviewed also identified several factors that could increase enrollment and retention in the National DPP. All clinicians were asked their thoughts on the use of multiple health concerns that are risk motivating to encourage participation in the National DPP or similar programs. Half of the clinicians (n = 6) were in support of describing the additional health benefits beyond diabetes that result from the National DPP, such as cancer. However, two of these clinicians who expressed that it would be motivating for patients thought it would be hard for patients to make those connections between the diseases. For the clinicians who did not believe it would be helpful to describe risk reduction for other disease as a result of the National DPP (n = 3), their reasoning was that disease risk is very individual and there is only so much time in a National DPP meeting to talk about additional topics. Two clinicians thought that combining the motivation to prevent other diseases with the
National DPP would only be beneficial if targeting certain cultural populations; for example, one clinician expressed that it would not make a difference to combine breast cancer prevention with diabetes prevention unless it was focused on specific groups that had a higher risk of breast cancer, including individuals from Asian, Polynesian, Native American, or Native Alaskan groups. One clinician had no opinion on this topic.

Nine clinicians suggested specific diseases that would be more motivating than diabetes to join a lifestyle change program. All cancers (n = 4), including breast cancer (n = 2), were viewed as the most motivating, followed by cardiovascular disease (n = 3), hypertension (n = 3), pregnancy complications or infertility (n = 2), arthritis (n = 2), mental health (n = 1), obesity (n = 1), stroke (n = 1), and muscular skeletal disease (n = 1).

Clinicians were asked what opportunities they see for increasing participation in lifestyle interventions. They echoed patient-expressed improvements, with the biggest opportunity being to increase accessibility for the patients in regard to location, time, and cost of the National DPP and similar programs (n = 5). The creation and use of an incentive program for participants (n = 2) were also mentioned; however, this was noted as not a sustainable option.

In terms of the enrollment process, clinicians believed increasing care team and/or clinician involvement (n = 5) would increase enrollment. Incorporating multiple members of a patient’s care team in the referral and follow-up process was an important related suggestion (n = 3) (Table 4: Q4–Q6). Another clinician expressed the importance of referring clinicians following up with the patient after the initial referral. Finally, the need for continued follow-up contact with the patient in terms of long-term outreach was expressed as helpful for getting patients to join in lifestyle intervention programs.

Discussion

Our study has identified barriers that have not yet been addressed in the literature, from the perspective of both clinicians and participants, including issues with the program not meeting participants’ expectations and focusing on goals different than those of the patients. Previously identified barriers were also identified in this study; namely, cost of the program, time that it takes, and inconvenient locations—indicating the continued importance of addressing these barriers when implementing these programs.

While patients and clinicians had differing views of barriers, there was some overlap between these two groups in terms of facilitators and recommendations. One major overlap addressed the nature of the National DPP staff. Participants felt that the staff were not involved closely enough with participants’ progress and did not accommodate diverse individual goals that might differ from the base National DPP program goals. Many clinicians wanted more communication with the National DPP in terms of making sure that their patients were reaching adequate services when they were referred to the National DPP. Much of the concern stemmed from the fact that clinicians do not tend to know what happens when a patient is referred to the National DPP. Information that was expressed as missing includes the cost, process, or support of the program. In addition, in cases where the patient returns to the clinician for some reason (i.e., lack of program availability, no follow-up contact by the National DPP after the referral was made), there is no clear next step. These barriers may prevent referrals to the National DPP. Some clinicians suggested that there needs to be more adequate advertisement about the nature of the program so that they can make more educated referrals for their patients. Finally, unique to our study was the suggestion that improved communication between clinician, patient, and National DPP staff could ensure that both clinicians and the National DPP staff are aware of patients’ individual goals as well as their barriers to success.

Several other studies have also examined factors related to enrollment and retention in the National DPP. One of these studies compared population estimates of eligibility to actual enrollment and found that adults who were eligible, but did not enroll in the National DPP during the first 5 years of its nationwide implementation were more likely to be younger or older (relative to middle aged), Hispanic (relative to non-Hispanic), and male (relative to female). Over this same time frame, individuals who enrolled in—but did not complete—the National DPP were more likely to be younger and racial/ethnic minority participants. Qualitative studies have identified barriers to enrollment and retention, including childcare, transportation, and scheduling, length of the year-long program, and discomfort with the group modality. Identified facilitators to enrollment and retention include intrinsic motivation (e.g., wanting to meet the National DPP challenges), as well as extrinsic factors such as connection with Lifestyle Coach and other participants.

Next, to address the above-mentioned barriers discovered in our study, we suggest some program modifications. Better advertisement for the National DPP
would address some known barriers, as well as new, and would address concerns from both patients and clinicians.

Advertisement for clinicians could include more detailed information regarding program function and flow. Advertisement for potential patients could include more information addressing how the program prevents other diseases, in addition to diabetes. Another main barrier was a lack of trust and support from the National DPP staff. These issues suggest that the National DPP needs to provide better training for their staff members to be more successful at developing rapport with patients and better address patients’ specific goals that expand from the National DPP base goals. Another modification suggested by participants was better incentives for meetings goals within the program, such as raffles for gift cards, gym memberships, or employer incentives (e.g., insurance discounts and wellness program points). Most importantly, accessibility to the program needs to be expanded to have a better online presence. By addressing these modifications, there could be a potential increase in the enrollment and retention in the National DPP.

Study limitations
The primary limitation to this study is that the participants may not be representative of the broader population of potential clinicians and National DPP participants, as this study was conducted at just one of the many health systems delivering the program. The barriers and facilitators identified may not be representative of barriers and facilitators in other systems. Generalizability of these findings is also limited by the lack of diversity in the study sample. Although we contacted all women patients who were eligible for the study, racial diversity differed greatly, with more racial diversity in the nonenrollee group compared with the noncompleter group (Table 1). Despite these limitations, findings from this study add to the broader literature in this area.

Conclusions
Although increasing participation in the National DPP has implications for millions of US adults at risk for T2D, there are many known barriers to participating in this program. Our qualitative study identified a number of important and actionable barriers, including additional advertisement, more training for National DPP staff to work more closely with participants, adding better incentives to participation, and making the program more accessible to people through flexibility in time and/or locations to increase enrollment and retention within the National DPP and help prevent disease in many more people across the country.

Ethical Standards
All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Disclaimer
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