

Struggling to Stay on Track

Participants share benefits and barriers to completing the National Diabetes Prevention Program

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ABSTRACT

The National Diabetes Prevention Program (NDPP) is a Centers for Disease Control and Prevention (CDC) recognized lifestyle change program aimed at preventing or delaying the onset of type 2 diabetes in high risk individuals. While research on the NDPP has demonstrated effectiveness, participant attendance and retention within the NDPP remains a concern, with more information regarding engagement being a continuing need. To help address these issues, we conducted interviews with NDPP participants in New York State who dropped out of the program, examining individual, social, environmental, and programmatic factors contributing to their discontinued participation.

We conducted interviews with 26 individuals from 11 different programs, representing rural, suburban and urban communities, and a variety of organizational settings. Among those interviewed, the reasons for dropping out of the NDPP can be grouped into three broad categories: (1) conflicting needs and obligations; (2) personal priorities and motivation; and (3) dissatisfaction with the program. Several who stopped their participation due to conflicting responsibilities, including competing health issues, reported benefits and expressed regret in not being able to complete the program.

Our results suggest that participants who drop out of NDPPs do so for both programmatic and personal reasons, but that many found the program valuable regardless. In order to benefit a greater number of participants, interviewees recommended that NDPP providers be prepared to offer concrete resources (e.g., cookbooks, skill-building activities) for veterans of weight loss programs and be proactive (e.g., promoting make-up sessions) in case of scheduling conflicts and/or reduced motivation.

BACKGROUND

The National Diabetes Prevention Program (NDPP) is a Centers for Disease Control and Prevention (CDC) recognized lifestyle change program aimed at preventing or delaying the onset of type 2 diabetes in high risk individuals. The NDPP is a year-long program facilitated by a trained lifestyle coach and consists of 16 weekly “core” sessions followed by monthly “post-core” sessions.¹ Research has shown that people with prediabetes who participate and lose weight in this lifestyle program can reduce their risk of developing type 2 diabetes by 58%.²

Based on promising results from many community based settings,^{3,4} the NDPP is being widely implemented by health care providers, health departments, faith institutions, employers, and community organizations across the country. However, participant attendance and retention within the NDPP is a major concern. For example, results from an evaluation of the New York State YMCA Diabetes Prevention Program found that 38% of participants attended less than half of the 16 sessions.⁵ Research suggests that attendance matters: a meta-analysis of 28 real-world NDPP studies found that with each additional lifestyle session attended, weight loss increased by 0.26 percentage points.⁶ These findings suggest a need for improved understanding of factors that may promote optimal engagement among NDPP participants.

In an effort to partially address this need, we conducted interviews with NDPP participants in New York State who dropped out of the program, examining individual, social, environmental, and programmatic factors contributing to their discontinued participation.

Study Population

We interviewed 26 individuals from 11 different programs, representing rural, suburban and urban communities, and a variety of organizational settings (see Figure 1). On average, interviewees attended 5.5 sessions (range 2–8). Of the 26 participants, the mean age was 55 years (range 24–76) and 88 % were female. The large proportion of female participants in this study mirrors NDPP participant characteristics nationally, where engagement among men has been significantly lower than women.⁷ Approximately 35 % were African American, 12 % Latino, and 46 % white. Fifty-eight percent were working full-time and 77 % had attended some college or had a college degree. (See Table 1)

FIGURE 1. PARTICIPATING NDPP SITES AND NUMBER OF PARTICIPANTS INTERVIEWED PER SITE

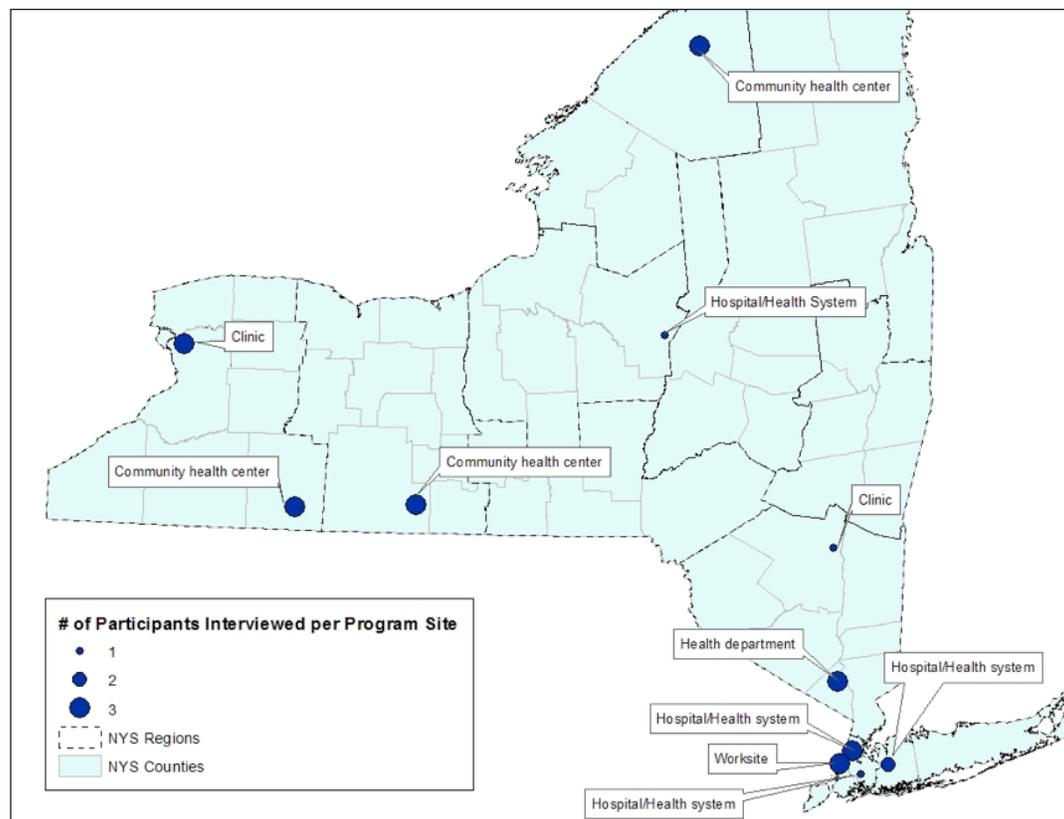


TABLE 1. PARTICIPANT DEMOGRAPHICS

| DEMOGRAPHICS | N | % |
|--------------------------------|----------|----------|
| RACE/ETHNICITY | | |
| Black or African American | 9 | 34.6% |
| Hispanic/Latino | 3 | 11.5% |
| White/Caucasian | 12 | 46.2% |
| Other | 1 | 3.8% |
| Prefer not to answer | 1 | 3.8% |
| EDUCATION | | |
| Less than high school graduate | 1 | 3.8% |
| High school graduate or GED | 5 | 19.2% |
| Some college but no degree | 10 | 38.5% |
| College degree or higher | 10 | 38.5% |
| EMPLOYMENT | | |
| Employed full-time | 15 | 57.7% |
| Employed part-time | 2 | 7.7% |
| Retired | 4 | 15.4% |
| Unable to work | 4 | 15.4% |
| Unemployed | 1 | 3.8% |

FINDINGS

Despite having dropped out of the program, many of those interviewed expressed a good understanding of the risks of developing diabetes, commonly referencing friends or family members with diabetes and describing the impact diabetes had on the lives of those individuals. Many recognized the significance of family history for their own risk of developing diabetes. For example, a participant whose mother and father both had diabetes, noted that it was like “*two bullets coming out of the gun.*” They were also aware that even with a family history, their own weight loss and behavior change could reduce their risk. Perceptions of their own efficacy in this regard varied, as the quotes below demonstrate.

[Getting diabetes is] pretty likely, if I don't watch what I eat. It's definitely in my family, so I should make sure that I take preventative measures so I don't end up getting it.

-30 YEAR OLD FEMALE

I don't wanna be pre-diabetic. I don't—I don't! Don't wanna go down the same path that my mom's going down. I know what being a diabetic entails. My mother doesn't take insulin, but she does take the pills. I know about it.

- 40 YEAR OLD FEMALE

Reasons for discontinued participation in the NDPP

Among those interviewed, the reasons for dropping out of the NDPP can be grouped into three broad categories: (1) conflicting needs and obligations; (2) personal priorities and motivation; and (3) dissatisfaction with the program.

Conflicting needs and obligations

Approximately half of the interviewed participants referenced issues with conflicting obligations, including travel plans and—for those in worksite programs—job responsibilities. There were also logistical issues related to timing, such as discomfort with driving at night or in the winter, particularly among older adults and individuals with disabilities.

I work certain hours. That's why later on I had to leave, because the time and the hours. I think it was between 12:30 to 1:30, so my job kept calling me and everything. So it was kind of interfering with the job.

- 39 YEAR OLD FEMALE

Several participants referenced a chronic or acute health issue that prevented them from continuing the class or made it difficult for them to follow the program recommendations. A portion indicated that they were essentially homebound, either temporarily or permanently, due to an illness or condition, as the quotes below reflect.

I have a really bad sciatic nerve problem, so right now at this moment, it's like really kind of hard for me to even walk around ... I mean, I push myself but it's really exhausting just to go to the doctors and come home. By the time I get back home, I'm exhausted because I'm pushing myself to keep moving and stay mobile.

- 43 YEAR OLD FEMALE

I think I went maybe three times, four times. I didn't go a lot because I was ill and then I was out for four months ... I wasn't at work. I was on disability so I wasn't coming in to the city or anything.

- 55 YEAR OLD FEMALE

Personal priorities and motivation

A number of participants spoke of emotional burdens or other stresses in their lives that made it difficult to prioritize attendance at NDPP sessions. In some instances, participants alluded to a sense of guilt that they had when they put their own needs (i.e., attending the NDPP on a regular basis) over the needs of others. Although the specific issues they described differed, several mentioned that once they missed two or three sessions, they found it difficult to motivate themselves to return to the program.

I suffered with losing two to three people from deaths, and that happened back to back. It caused me to miss the appointments, missing out on the meetings that we were supposed to attend. And once I missed three meetings, I just told the doctor that I would have to try to go through the program once they start the program again. Because at this point in time, it just, you know, I just couldn't see myself being able to catch up or stay with the class, when I had so much going on as far as my personal life goes.

- 47 YEAR OLD FEMALE

[I had] a self-brought perceived guilt trip that, "Okay, well, my son can't make this practice. My daughter is gonna miss work this day. No one's making dinner for the family. My mom has to get the medicine for my father but she can't right now. She can't drive. Maybe I can do it." So I allowed again the external factors to take hold and again, my self-perceived guilt trip started to kick in where I said, "You know what? I need to take care of this right now. I'll be okay. I'll be okay."

- 52 YEAR OLD MALE

I'm a widow. It's gonna be five years next year. I'm relatively young to be going through that. I think I just—it started to be the changing seasons and I remember it clearly, it was the anniversary my dad had passed away and I just was really struggling to—once you missed a class it was way easier to miss another class. Then it just was like ... I just was like, "I'm not at a point where I'm committed," and I just had resigned myself from going. More of an emotional thing on my end, certainly nothing to do with the class that was being offered.

– 43 YEAR OLD FEMALE

Among those who dropped out for personal reasons or declining motivation, there was a notable sense of regret, since many were still concerned about developing diabetes and saw the NDPP as an opportunity to reduce their risk.

I regret my decision of leaving the class not once, but twice, and it plays on me whenever I pick up an article, a book that might be talking about someone who struggled with diabetes or what have you. So there's that guilt that's been kicking in.

– 52 YEAR OLD MALE

I truly regret that I had to stop. You know, because while I was in the program ... they offered like the Zumba class and stuff like that, and whenever I was able to attend during the hours that I was off work, I tried to attend that. Now all I am back to is work and home, and I'm not really active when I get home. So I really regret the fact that I had to leave the program, because the program made me aware, and it had me accountable for the things that I had done within that week's time from one class to the next class.

– 47 YEAR OLD FEMALE

Dissatisfaction with the program

Several participants reported that dissatisfaction with the program led—or contributed—to their decision to stop attending. Complaints focused on interpersonal issues related to program implementation and the curriculum,^a which was considered by some to be:

- Too simple and/or general to be useful for those who had participated in diet programs or tried to lose weight previously, as it lacked specific tools (e.g., menus) and updated dietary information (e.g., insufficient information on sugar);
- A poor fit with respect to individual preferences;
- Cumbersome, specifically with respect to dietary tracking. Tracking was particularly challenging for those who cooked from scratch, rather than purchasing packaged foods that are labeled with dietary information.

I think I just do better, just on my own, without any attention being brought to me, or people having to focus on that all the time ... It's a huge motivator for some, but I'm not one of those people.

– 64 YEAR OLD FEMALE

Frankly, it was not doing any good. It was an awful, awful lot of record keeping, which I admit the value of, but it just seemed that there had to be a simpler way to do it ... I mean it would be every time that you sat down to eat something, you were looking up how much fat was in it, how much sodium, and I know all that's important, but I just—I couldn't get my—and it's probably my failure and not the programs failure ... I just want to have a tuna-fish sandwich. I don't want to, you know, count the flakes of tuna.

– 76 YEAR OLD FEMALE

^a All participants were enrolled in NDPP's that used the 2012 curriculum.

Okay, the reasons I stopped. Everything I was learning, I had already known. I could write my own diet book, I have been on so many of them, and I did not like counting the calories and figuring out every little fat detail, or gram of fat.

- 65 YEAR OLD FEMALE

Perceived effectiveness and impact of the program

Despite having not finished the program, participants described benefits and valuable knowledge gained, particularly as related to healthy eating (e.g., portion control, healthy and unhealthy fats, tips for eating out, etc.). Even some of those who reported knowing the material prior to joining the program, mentioned the information provided was a good refresher and reminded them of common sense guidelines.

So my coach, she was very good at helping me, knowing that it's going to take me a while to start cooking. So helping me navigate restaurants and things like that. If this is what I'm going to have to do, then I'm going to have to learn to eat healthy within that parameter of eating out and things like that."

- 62 YEAR OLD FEMALE

It felt like a lot of it was familiar to me, like things that you know but just don't do, if that makes sense. I know there was—I think that the section on how much fat, where she would actually bring in and if you cook with fat and sugar and showing the percentages. That was really gross. That was super impactful.

- 43 YEAR OLD FEMALE

Some participants also reported weight loss and positive behavioral changes resulting from their experiences with the NDPP. However, several described difficulties with maintaining weight loss over time or falling back into poor habits, as referenced by the quote below.

Lately because I've stopped going, I kind of converted back to my old ways and I'm trying to get myself back on track now but [when] I was going, you know, I even went and purchased the watch [the Fitbit] so I could track my activity and things like that, logging things. But like I said, I converted back into my old ways. I've gone back to eating fast foods versus me trying to eat nutritional foods. I mean, it's just a fight that I have to continue to fight with until I get a control over it. ... Yes, I did lose weight and I've gained the weight back plus a few pounds.

– 47 YEAR OLD FEMALE

Participant recommendations

Participants made a number of recommendations for program implementation changes they felt might have motivated them to engage with the NDPP longer. Those who lost momentum after missing a few sessions recommended increased outreach from coaches, which would emphasize the acceptability and importance of returning to the group, despite the missed sessions. Logistical recommendations centered on greater sensitivity to timing, specifically for worksite programs (adjusting the length to fit within a lunch hour) and for those programs that necessitated participant travel (avoiding night time travel in the winter). Curricular recommendations focused on increased concrete tools and additional information, such as menus and recipes, more comprehensive information on nutrition, and more information on diabetes and its effects on health.

You know the smartest—the most wonderful thing they could've done, is if they could've come up with a booklet that said ...“What to make when you haven't got the slightest idea of what to make.” Recipes for us to do, because if you have worked, or tried to lose weight and tried to lose weight, you've tried all kinds of recipes, and you get so you don't know what food you should eat and what food you shouldn't eat.

– 76 YEAR OLD FEMALE

I would like to have seen where the class maybe delved into more of the ramifications, the complications that come from the disease itself, because I think I minimized the effects of diabetes, how it can control your life and shorten your life and limit your life ... I think I need to know a little bit more about it, and then I think I would have made it more of a priority.

– 62 YEAR OLD FEMALE

CONCLUSIONS

Discontinued participation is a common concern in NDPP implementation across the United States, and in the implementation of other multi-session evidence-based health programming. Although the 26 individuals interviewed for this study had differing perceptions of the program and a variety of reasons for dropping out, a number of themes were identified that may inform relatively simple adaptations that more consistently engage participants.

For those who dropped out due to dissatisfaction with the curriculum, adjustments and/or supplemental materials may be helpful. Specific recommendations from the interviews included menus and recipes, as well as more information on diabetes and its consequences, so as to emphasize the severity of the disease. Some of these changes may have already been incorporated into the CDC's new diabetes prevention curriculum, Prevent T2, which places a greater focus on eating a balanced diet versus counting fat grams, provides healthy shopping and cooking tips, and includes more information on the health effects of sugar and sugary drinks.

With the understanding that life changes and conflicting obligations will inevitably arise for some participants, NDPP coordinators may need to think creatively about how to retain these individuals. This may require individualized responses, such as referrals to programs offered at other times, persistent outreach from the coach, or encouragement to reengage in a later session. It is important to note that several of those interviewed expressed regret over their decision to stop, suggesting an opportunity to leverage those feelings in order to re-engage participants.

In sum, participants interviewed for this study, all of whom discontinued their participation in the NDPP prior to completing nine of the sixteen core sessions, described a variety of factors and reasons impacting their engagement in the program. Assuming they are, on the whole, typical of others who have dropped out, simple and feasible adaptations may have a notable effect on retention in future implementations of the program.

METHODOLOGY

We conducted open-ended telephone interviews with individuals across New York State who dropped out of the NDPP; which we defined as completion of at least two, but no more than eight sessions. Interviews lasted about 30 minutes and utilized a semi-structured guide.

To engage participants, we contacted organizations that had implemented the NDPP within the last two years (2014–2016), asking them to identify individuals who met the study criteria and to facilitate outreach regarding study participation. Eleven organizations agreed to collaborate in the study, representing a diverse mix of locations and setting type (e.g., community based organization, health department, large hospital system, community health center network, labor union). To ensure diversity in participants and program experience, we interviewed no more than three individuals from each collaborating organization. To the greatest extent possible, we worked with collaborating organizations to recruit men and racial and ethnic minorities, but were limited in our ability to successfully meet this goal due to a limited pool of potential participants. The study protocol was approved by The New York Academy of Medicine Institutional Review Board and participants received an honoraria of \$25.

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