**Title of Project**: Reducing Smoking Among People Living with Mental Illnesses

**Principal Investigator and Team Members**: Sue Abderholden, MPH, Executive Director; Jessica DeWolfe, MPH

**Organization:** NAMI Minnesota (National Alliance on Mental Illness)

**Inclusive Dates of Project**: May 1, 2015 – April 30, 2016

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**Grant Award Number**: 16872475

**Purpose:** The goal of this project is to reduce tobacco use among individuals living with mental illnesses, through increasing provider awareness and engagement, and increasing available resources for quitting.

**Scope:** We aimed to train 300 providers and 200 people living with mental illnesses on smoking cessation across Minnesota, and establish two support groups in the Twin Cities metro.

**Methods:** We developed two one-hour workshops- one for providers on smoking cessation best practices and how to incorporate smoking cessation into their practice, and one for people living with mental illnesses on how to quit tobacco. We presented these workshops at mental health centers, clubhouses, public housing, and other community organizations across the state. We also partnered with local community organizations to host support groups, and used the *Learning About Healthy Living: Tobacco and You* curriculum (Williams, 2012).

**Results:** We trained 210 providers in 13 workshops and 187 people living with mental illnesses in 20 workshops. We established 3 support groups, one each at a clubhouse, a supported employment organization, and a day treatment center. We had 45 unique individuals attend one of the support groups, with 7 quit attempts during support groups, but no quit attempt lasted longer than 3 months.

Key Words: mental illness, smoking cessation, support group, provider training

**Purpose**

The overall goal of this project is to reduce the rate of tobacco use among individuals living with mental illnesses. This goal aligns with the aim of the grant to support projects that focus on improving the competence of healthcare professionals and the performance of healthcare systems so that all smokers can be helped to quit.

Our primary objectives are to 1) Increase awareness and engagement among mental health providers on the importance of smoking cessation; 2) Increase awareness of the benefits and cessation tools among people living with mental illnesses and their families, 3) Institute smoking cessation supports such as facilitating weekly wellness and smoking cessation groups; and 4) track cessation attempts, reductions and cessation longer than three months.

**Scope**

Individuals with mental illnesses are disproportionately affected by tobacco use and are not receiving adequate information and cessation services. Individuals with mental illnesses and substance abuse disorders are nicotine dependent at rates that are two to three times higher than the general population.

The statistics are alarming. According to a report released by the Centers for Disease Control and Prevention (CDC) in collaboration with the Substance Abuse and Mental Health Services Administration (SAMHSA), 39 percent of adults with a mental illness are cigarette smokers, compared with only 19 percent of adults who do not have a mental illness. In addition, adults with mental illnesses who do smoke are heavy smokers. Over 200,000 of the 443,000 annual deaths from smoking in the U.S. occur among people with mental illnesses and/or substance use disorders. The prevalence of smoking by diagnosis is as follows: major depression 36-80%; bipolar disorder 51-70%; schizophrenia 62-90%; anxiety disorders 32-60%; post-traumatic stress disorder 45-60%; attention deficit/hyperactivity disorder 38-42%; alcohol abuse 34-93%; other drug abuse 49-98%. Because individuals with mental illness have a higher rate of tobacco use, they are at greater risk to smoking-related illnesses and higher morbidity.

According to a needs assessment report prepared for the State Tobacco Education and Prevention Partnership (STEPP), Colorado Department of Public Health and Environment, individuals with mental illnesses want to quit smoking and want information on cessation services and resources. Individuals with mental illnesses deserve accurate information regarding tobacco use and options for quitting. There are real and perceived barriers to providing smoking cessation options in mental health and substance abuse settings. Many clinicians do not view tobacco cessation as a part of their scope of practice, feel tobacco cessation could be detrimental to the treatment plan, believe that tobacco use is not a treatment priority, and think that tobacco cessation strategies would be too time consuming. Lastly, many of the traditional smoking cessation programs are not as effective for persons with a serious mental illness.

NAMI Minnesota received a yearlong grant from the Medica Foundation in 2013/2014 to address the disproportionate rate of tobacco use among individuals living with mental illnesses and increase mental health providers' awareness of tobacco use as a problem. NAMI developed an hour-long curriculum that addressed tobacco use statistics, assessment tools and planning for interventions, cessation treatment options, and relapse prevention strategies. These workshops were delivered to over 300 mental health providers throughout Minnesota. NAMI also worked with mental health facilities on making organizational change that supports tobacco reduction utilizing the Colorado smoking cessation model. NAMI also included cessation information in all of NAMI's support groups and classes.

Building upon our experiences and lessons learned from this pilot project, the current project was designed to build on NAMI's previous efforts to increase education and awareness. Rather than just educating providers, its focus was also on educating the individuals who are affected by smoking and interested in quitting, and providing the support and tools that are needed for those with mental illnesses to remain quit.

**Methods**

*Intervention*

We conducted outreach to community providers and organizations to solicit "buy-in" to the importance of smoking cessation, and obtained commitment to train staff and offer smoking cessation tools. We aimed to provide the smoking cessation workshop 10 times to 300 people who work in mental health treatment and support settings. Our goal was to provide the workshop for people living with mental illnesses 20 times to 200 people. We also provided outreach to community organizations that serve people living with mental illnesses, such as drop-in centers and clubhouses, in order to find at least two organizations willing to host a weekly support group for smoking cessation. To further increase awareness and engagement on this issue we published articles in our newsletters, included smoking cessation information in all of NAMI's other educational workshops, support groups, the website, and through social media. These activities address the need to continue to raise awareness and engage mental health providers as to why smoking cessation is important and why they must be involved. It also addresses the issue that the subject of smoking cessation has not been broached with people with mental illnesses. NAMI wants to provide them with this information along with the tools and support needed. This includes educating family members on how to be supportive of smoking reduction and cessation.

*Workshop Development*

We developed two one-hour workshops, one for providers and one for people living with mental illnesses. The workshop for providers addressed tobacco use statistics, assessment tools, cessation treatment options, motivational interviewing, and relapse prevention strategies. The workshop outlined the reasons why the rate of smoking is so high among

individuals with mental illnesses, how smoking can affect mental illnesses, and how providers can work with their clients on quitting smoking. It describes the "5 A's" model, motivational interviewing techniques, medications to help their clients quit, as well as resources for referral. We also emphasized the importance of organizational change, putting the "5 A's" into practice, and communication strategies for making these changes.

The workshop for people living with mental illnesses covers the effects of smoking on the body, components of cigarette smoke, what makes tobacco addictive, medications and smoking, myths related to smoking and mental illness, as well as medications to quit, quit plans, triggers, relapse, asking for support, and coping strategies. Both workshops also surveyed local quitting resources, such as our state quit line, community clinic tobacco treatment programs, and nicotine anonymous meetings. The workshop was developed with principles of adult learning in mind, and was meant to be interactive to enhance learning. To accomplish this, we used the same "quit plan" handout used in the support groups. Workshop attendees were encouraged to fill out their quit plan as information was presented and they identified their own reasons to quit, triggers, steps they wanted to take towards quitting, medications they were interested in, and coping skills they will try. During the workshop participants were also asked to offer their own experiences with quitting and being addicted to smoking, to enhance discussion and reflection.

*Support Group Curriculum*

We chose to use a curriculum already developed and shown to be effective in the literature among people living with mental illnesses: *Learning About Healthy Living: Tobacco and You* (Williams, 2012). This curriculum was developed by the Robert Wood Johnson Medical School Division of Addiction Psychiatry, in collaboration with the New Jersey Division of Mental Health Services. It is a drop-in format over 20 weeks for people not yet ready to quit smoking, with each week addressing a different topic of smoking cessation and wellness. Some examples of weekly topics include: the chemicals in cigarette smoke, why cigarettes are addictive, and how to better manage stress. We also had a carbon monoxide monitor available for individual readings throughout the sessions. Another activity we incorporated into the support groups was helping the participants fill out a "change" or quit plan. It is a one page handout with spaces to write their quit date, reason to quit, triggers, coping strategies, and 5 detailed steps they'll take to support or get ready to quit, medications they'll use to help them quit, and their reward for quitting. For individuals who wanted to fill out the quit plan, the support group facilitator discussed each of the topics with them while filling it out together, providing education, motivational interviewing, and support.

We scheduled the support groups either during or after lunch, and on the organizations' most visited day, to try to increase attendance to the group. Snacks and water were provided during the group, as well.

*Data Collection*

There is a paucity of research on the reasons why people with mental illnesses decide to attempt to quit smoking or the methods that are most effective. The best way to learn how to help people with mental illnesses quit is to work directly with them and learn from them. To collect more information on smoking and the quit behavior of people living with mental illnesses NAMI developed baseline, weekly, and follow-up surveys for support group attendees (See appendix A and B for baseline and follow-up surveys). The surveys were adapted from both the Fagerstrom test for nicotine dependence (Heatherston, 1991) and the CDC's National Adult Tobacco Use Questionnaire (Office on Smoking and Health, CDC, 2009-2010). The baseline survey included questions on when they started using tobacco, how much they use, if they have made previous quit attempts, if a provider has ever offered them cessation services, and why they are interested in learning about smoking cessation. Weekly surveys collected data on current level of tobacco use, most recent quit attempt, including methods used to quit and how long the quit attempt lasted. The baseline survey measured current tobacco use, methods used to quit, and biggest barriers they experienced to quitting.

**Results**

*Workshops*

We trained 210 providers through 13 workshops across the state. We also provided the workshop for people living with mental illnesses 20 times, reaching 187 people. Some of the organizations we presented the workshops to were community mental health clinics, day treatment centers, clubhouses, public housing residents, veteran's homes, public health departments, and drug treatment centers. We also presented the workshop for providers at three professional conferences in the state.

*Support Groups*

We were able to establish three weekly support groups in the Twin Cities, one at a clubhouse, a supported employment organization, and a drop-in center. The workshops ran for 30, 18, and 22 weeks. The average attendance for the groups was 1.2, 1.4, and .89 people, and the mode for attendance was 0, 1, and 0, respectively. Across the three groups we had 44 unique individuals attend a group, with 10 individuals attending at least 8 sessions. We collected 32 baseline surveys on tobacco use, 15 weekly surveys from 10 individuals, and 7 follow-up surveys. Two of the support groups have ended, while one is ongoing as long as there is adequate attendance.

*Baseline Tobacco Use*

Participants reported using tobacco an average of 30.4 years, and 30 out of 32 participants currently smoked, while only 2 reported using smokeless tobacco. Smokers reported currently

smoking 6.4 days per week, and smoking 19.3 cigarettes on days they smoke. Using the measure from the Fagerstrom's Test for Nicotine Dependence on time from waking in the morning to first cigarette, 87.5% met the definition for moderate to severe tobacco dependence. All participants reported trying to quit in the past, with 31.2% reported having used any medication in the past to help them quit smoking. Money (81.3%), Health (71.8%), and Family (68.8%) were the most common reasons for wanting to quit tobacco. The majority of respondents reported that a doctor or provider had offered them help to quit smoking, with 96.9% reporting a doctor or provider had ever offered them any help to quit (Graph 1). Medication was the most frequently offered service by providers, with 91.6% of participants reporting ever been offered medication to quit smoking. While 46.9% reported being referred to a quitline, 12.5% were referred to another counselor or program, and 12.5% were offered cessation counseling by their provider.

*Quit Attempts*

There were 13 quit attempts among 11 support group participants; however, all participants relapsed before 3 months and were currently smoking at follow-up. Among the 13 quit attempts, abstinence from smoking lasted an average of 9.8 days before relapsing. The most common methods used to quit among the 11 participants who tried quitting were tapering down the number of cigarettes (11), changing habits (8), and cold turkey (7) (Graph 2). Since there was high loss to follow-up (only 7 follow-up surveys out of 44), we did not compare changes from baseline to follow-up. However, among participants who completed the follow-up survey, 71.4% reported having cut back on the number of cigarettes smoked by at least 5 cigarettes.

**Discussion**

*Principle Findings*

Participants reported a high level of smoking and nicotine dependence at baseline, with several previous quit attempts. Periods of absence from smoking ranged from a few months to several years before relapsing, indicating that they have the potential to be successful at quitting. Success at past quit attempts can help inform the current quit attempt, though participants should also know that the nicotine in cigarettes, as well as other changes, have made cigarettes more addictive over the past decade. Thus, their experience of quitting is likely to be different. Although the majority of participants reported having ever been offered help to quit smoking, this question may have been too broad to be meaningful, since it only captured any help ever offered. What's more interesting is that almost all of the participants were offered medication, while only around half were referred to a quit line or quit program, and only 12.5% were offered smoking cessation counseling by their provider. Although medication is an important intervention for quitting smoking, and doubles your chance of being successful, comprehensive

smoking cessation services include both medication and psychosocial support. In fact, adding counseling or coaching increases your chance of successfully quitting by 1/3, on top of medication benefits. This finding shows that providers need more education on how to coach clients to quit smoking, or how to refer them to services using a model like Ask-Advise-Refer. Despite a high loss to follow-up among support group participants, there were 13 quit attempts during the project. However, none of the quit attempts we captured lasted more than three months. One explanation for this may be the most common methods used to quit, which include tapering, cold turkey, and changing habits. Only 4 out of 11 individuals who attempted to quit used medications. Both the workshop and the support groups addressed tapering and cold turkey methods for quitting, and presented evidence that these methods make you more likely to relapse. It is surprising then that these were the most commonly used methods for quitting. When asked why they chose those methods, participants said they were reluctant to use the medications, they wanted to try it "on their own" first and then use medication, or they wanted to reduce instead of quitting outright because they enjoy smoking. A majority of participants also expressed a lack of confidence in meeting with their doctors to ask for the medications. One of the topics we covered during the quit plan was advocating for yourself and how to raise smoking cessation medications with your doctor. However, many clients had concerns about even calling their doctor to ask for an appointment, or told me that their doctor didn't prescribe medications for smoking cessation. This was a concerning finding, since every doctor can and should be prescribing smoking cessation medications. It is also concerning that these people living with a mental illness, who've been receiving services through the mental health system for months or years, don't have the skills to advocate for themselves to their doctor, especially since many doctors still hold false beliefs around smoking and mental illness. Future interventions among people living with mental illnesses should help increase medical advocacy skills, while doctors should receive more training in smoking cessation.

*Challenges*

Overall, support group and workshop attendance was low, which affected our ability to meet our objectives for the number of individuals reached. One of the problems with scheduling the workshops was that organizations wanted just one one-hour workshop to cover information for both staff and clients. So instead of scheduling both for different days they would only schedule the workshop for individuals, and have their staff come to that workshop. Another problem we faced was just low attendance, for both the workshops. For providers, some reasons given for low attendance were that we didn't offer CEU's, providers couldn't find the time that day, their manager wouldn't let them go, and there was a lack of support in the organization. Attendance at the support groups was also low, with a mode attendance of 0 or 1 in all three groups. Initially we tried to schedule groups during or after lunch on the organization's busiest day to retain participants. When we still experienced low attendance the support group facilitator met

with staff to brainstorm additional strategies, trained all staff about the group and the importance of smoking cessation for people living with mental illnesses, visited the organization to interact with residents outside the group hour for more visibility and awareness of the group, and then finally switched the group format to a "health educator" format- where the smoking cessation specialist was available for the same hour for anyone to come ask questions, get information, or fill out a change plan, without the group format. We also attempted to relaunch two of the support groups after New Year's 2016 to try to capitalize on New Year's resolutions. These changes didn't improve attendance, and two of the support groups ended, after 18 and 22 weeks. The third support group is ongoing and has had an average attendance of 3 participants over the last six weeks. From this experience, we've concluded that incorporating some kind of incentive for participation or quitting will likely increase attendance and quit attempts. Additionally, it is important to not only get "buy-in" from the organization- but have them champion the project. Although the organizations and staff we worked with supported the project, smoking cessation wasn't a part of their mission or culture, and it was unclear how often smoking cessation was addressed among clients outside the support group. The one hour a week support group is unlikely to have a profound effect unless it is supported by an organizational culture focused on encouraging clients to quit tobacco. If smoking cessation is ignored the rest of the time the client is at the organization, it sends a mixed message about the importance of quitting smoking. Although we tried working with the organizations on policy changes to support smoking cessation, the organizations were not interested in making a change at this time.

*Conclusions*

Despite the challenges we faced in scheduling and attendance of our programs, we were able to train a significant number of providers and people living with mental illnesses on how to quit smoking. Future interventions should focus on gaining full organizational support for advocating tobacco cessation, including possibly identifying and training a champion to push for organizational policy change or programs integrated throughout the organization. This would help support the message of the support groups, and hopefully increase attendance. Incentives, such as quit kits or gift cards, may also be needed to entice this population to quit. Finally, there needs to be more buy-in from top level management. Part of the reason there was low attendance at the provider workshops was that they were mostly optional for staff to attend and not promoted heavily within the organization. When there was a person at the organization championing smoking cessation, and telling other staff that it's important, there was higher attendance at the workshop. However, finding or creating a champion at each organization is not always feasible. There are a lot of efforts right now to engage providers and management around smoking cessation, and hopefully we will see an increase in interest for training on how to deliver smoking cessation services.

Appendix A. Baseline Tobacco Use Questionnaire.

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## Tobacco Use Questionnaire- Baseline

1. **About how long have you used tobacco? _____ year(s) and _____ month(s).**

2. **What age were you when you first started using tobacco _____**

3. **What kind of tobacco products do you CURRENTLY use? (Please check all that apply)**
   - ☐ Cigarettes
   - ☐ E-cigarettes or electronic cigarettes
   - ☐ Smokeless tobacco (chew or snuff)
   - ☐ Pipe, cigars, or cigarillos
   - ☐ Other: _____

4. **What kind of tobacco products have you used in the past but NO LONGER use? (Please check all that apply)**
   - ☐ Cigarettes
   - ☐ E-cigarettes or electronic cigarettes
   - ☐ Smokeless tobacco (chew or snuff)
   - ☐ Pipe, cigars, or cigarillos
   - ☐ Other: _____

5. **How many days a week do you smoke or use tobacco? _____**

6. **How many cigarettes do you usually have on days you smoke (1 pack = 20 cigarettes)? _____**

7. **How soon after you wake up do you first use tobacco?**
   - ☐ Within 30 minutes
   - ☐ After 30 minutes

8. **Do you sometimes wake up at night to have a cigarette or use tobacco?**

   ☐ Yes

   ☐ No

9. **How many people in your household use tobacco? _____**

10. **Do you smoke indoors at home?**

    ☐ Yes

    ☐ No

11. **How many times have you tried to quit tobacco in the past? _____ times.**

12. **What is the longest time you have gone without tobacco?**

_____ year (s) _____ week(s )_____ day(s) _____hour(s)

13. **Have you ever used medications to help you try to quit smoking cigarettes (For example, the nicotine patch, nicotine gum, Zyban or buproprion, nicotine lozenges, nicotine nasal spray, nicotine inhaler, or varenicline (Chantix)?**

    ☐ Yes

    ☐ No

14. **Do you want to quit tobacco?**

    ☐ Yes

    ☐ No

    ☐ Unsure

15. **How important is it to you to stop using tobacco? (Please circle one number)**

| **Not at all Important** | | | | **Average Importance** | | | | | **Extremely Important** |
|---|---|---|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

16. **How motivated are you today to quit tobacco?**

☐ Not motivated at all

☐ Somewhat motivated

☐ Extremely motivated

17. **What is the <u>most important</u> reason you want to quit tobacco? (Please only check 1)**

☐ Health

☐ Family

☐ Money

☐ Work

☐ To fit in

☐ Other: _____

18. **Please indicate which statement best describes your desire to quit tobacco use:**

☐ I currently smoke/ use tobacco and I do not want to quit in the next 6 months.

☐ I am seriously considering quitting in the next 6 months, but not in the next 30 days.

☐ I am interested in reducing the number of cigarettes I smoke, but not in quitting.

☐ I am interested in quitting smoking/tobacco use in the next 30 days.

19. **Has a doctor, mental health provider, or other service provider ever: (Please check all that apply).**

☐ Referred you to a telephone quit smoking helpline or quitline

☐ Referred you to another quit smoking program or counselor

☐ Provided any help to stop smoking/ tobacco use

☐ Offered you smoking cessation counseling

☐ Offered you medications or nicotine replacement therapy to help you stop smoking

**20. How confident are you that you will succeed in stopping tobacco use now? (Please check 1)**

☐ I am extremely doubtful I'll be able to quit

☐ I am slightly doubtful I'll be able to quit

☐ I am unsure if I'll be able to quit

☐ I am slightly confident I'll be able to quit

☐ I am extremely confident I'll be able to quit

**NAMI Minnesota is collecting information about what populations we are reaching so we can make sure everyone has access to our services. This information will be kept confidential and private.**

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**21. What is the highest grade of school that you have completed? (Please choose 1)**

☐ Eighth grade or less ☐ Some high school ☐ Finished high school or GED

☐ Some college ☐ Associate's Degree ☐ Bachelor's Degree

☐ Advanced College Degree (e.g., Masters, Doctorate, Medical, Law, etc.)

**20. What is your age?**

☐ 0-17 ☐ 18-24 ☐ 25-34 ☐ 35-44 ☐45-54 ☐ 55-64 ☐ 65-74 ☐ 75-84 ☐ 85+

**21. What is your gender?**

☐ Female ☐ Male ☐ Other_____

**22. What is your race?**

☐ African American or Black ☐ Alaska Native or American Indian ☐ Asian

☐ Two or more races ☐ Native Hawaiian or other Pacific Islander ☐ Caucasian/White

☐ Another race (please specify)_____

**24. What is your ethnicity?**

☐ Not Hispanic or Latino ☐ Hispanic or Latino

**25. What ZIP CODE do you live in?** _____

Appendix B. Follow-Up Tobacco Questionnaire

## Tobacco Use Questionnaire- Follow-up

1. **Are you currently using tobacco?**

   ☐ Yes

   ☐ No (**If no**, skip to question **8**)

2. **What kind of tobacco products do you CURRENTLY use? (Please check all that apply)**

   ☐ Cigarettes

   ☐ E-cigarettes or electronic cigarettes

   ☐ Smokeless tobacco (chew or snuff)

   ☐ Pipe, cigars, or cigarillos

   ☐ Other: _____

3. **How many days a week do you smoke or use tobacco? _____**

4. **How many cigarettes do you usually have on days you smoke (1 pack = 20 cigarettes)? _____**

5. **Have you recently reduced the number of cigarettes you smoke in a day by at least 5?**

   ☐ Yes

   ☐ No

6. **How soon after you wake up do you first use tobacco?**

   ☐ Within 30 minutes

   ☐ After 30 minutes

7. **Do you sometimes wake up at night to have a cigarette or use tobacco?**

   ☐ Yes

   ☐ No

8. **Do you smoke indoors at home?**

   ☐ Yes

   ☐ No

9. **What kind of tobacco products have you used in the past but NO LONGER use? (Please check all that apply)**

   ☐ Cigarettes

   ☐ E-cigarettes or electronic cigarettes

   ☐ Smokeless tobacco (chew or snuff)

   ☐ Pipe, cigars, or cigarillos

   ☐ Other: _____

10. **How long has it been since you last used tobacco?**

    _____ week(s )_____ day(s) _____hour(s)

11. **When was your last quit attempt?** _____

12. **During your most recent quit attempt, how long were you able to keep from using tobacco?**

    _____ week(s )_____ day(s) _____hour(s)

13. **Since starting the group sessions, what methods did you use/ are you using to quit? (Please check all that apply)**

    ☐ Nicotine patch

    ☐ Nicotine gum

    ☐ Nicotine lozenge

    ☐ Nicotine inhaler or nasal spray

    ☐ Slowly reducing number of cigarettes smoked (tapering cigarette use)

□ Medication like Chantix, Zyban, or Wellbutrin

□ Quit line (phone-based)

□ Quit website

□ "Cold Turkey"

□ Exercise

□ Changed habits

□ Other_____

**14. What factors were the most difficult when quitting or trying to quit? (Please check all that apply)**

□ Insomnia

□ Weight gain

□ Stress

□ Didn't know how to cope

□ Low or depressed mood

□ Anxiety/nervousness

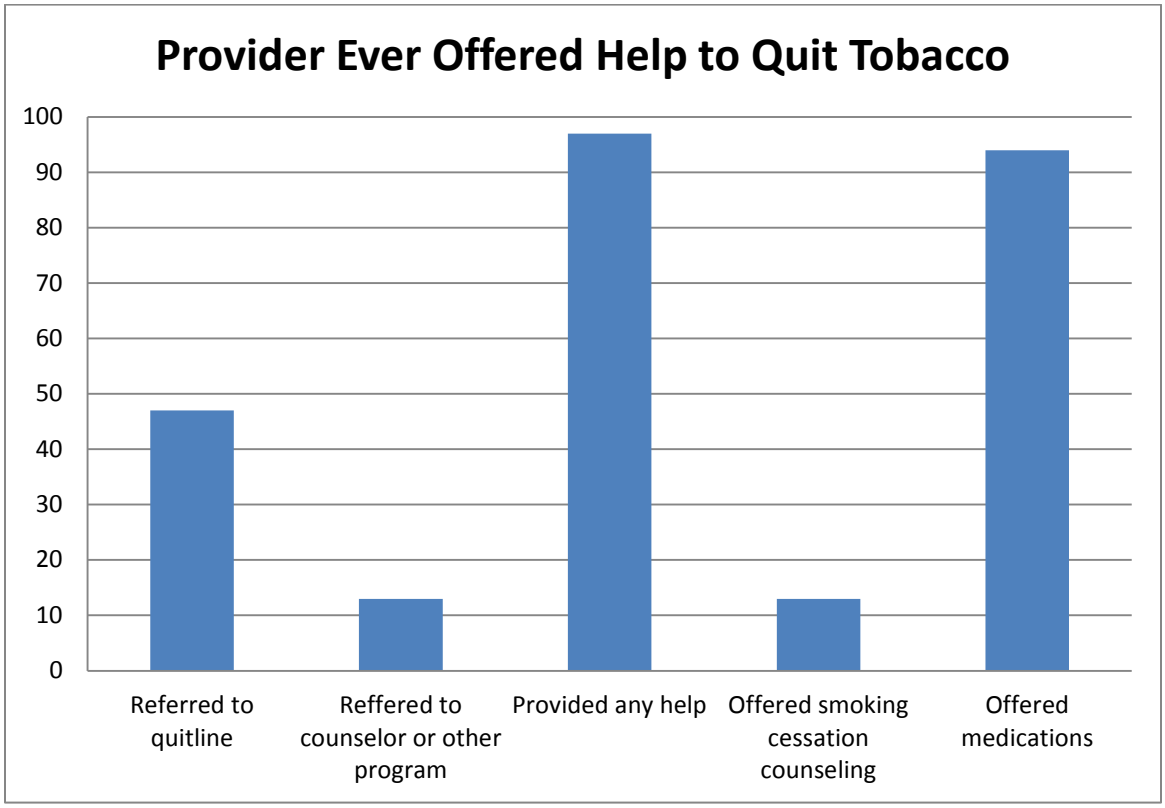
□ Social situations

□ Cost of medications or nicotine replacement therapy

□ Physical withdrawal from nicotine

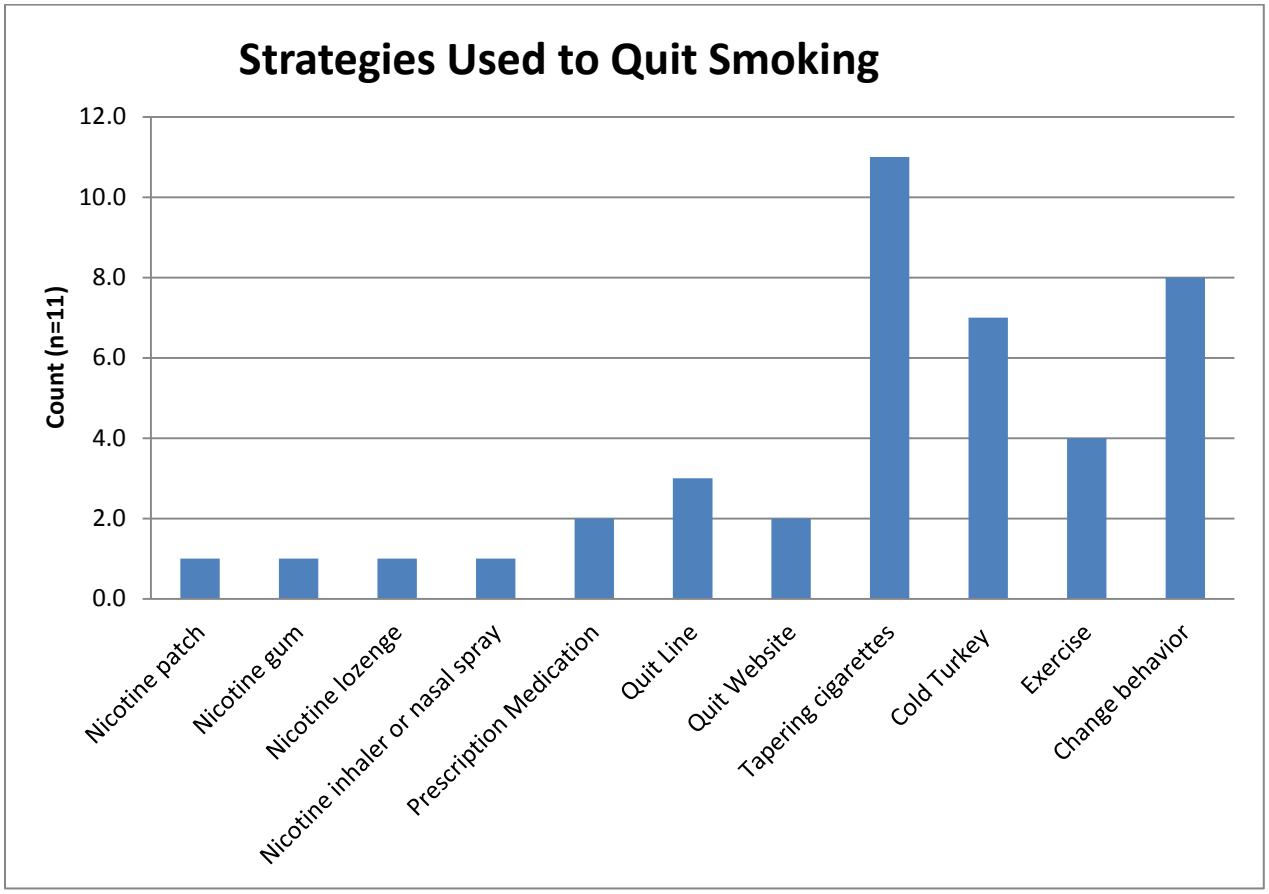
□ Other_____

Graph 1. Types of Help Provider Has Ever Offered to Quit Tobacco




Percent of participants (n=32) that ever had a provider or doctor offer each type of help to quit smoking. Participants could choose all that applied.

Graph 2. Strategies Used to Quit Smoking Among Support Group Attendees




Strategies used by participants (n=11) to quit smoking. Participants could endorse all the strategies they used.