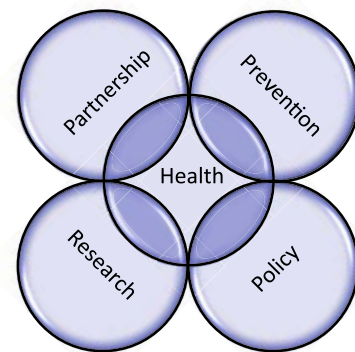


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THE J. MCDONALD
WILLIAMS INSTITUTE



Center for

COMMUNITY HEALTH

at UNTHSC

The Dallas Family Access Network Performance Improvement Process:

Enhancing Care for HIV-Positive Women

This research was supported by the
UT Southwestern Medical Center.

UT SOUTHWESTERN
MEDICAL CENTER

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Research Brief

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INTRODUCTION

The Dallas Family Access Network (DFAN) provides access to medical and social services for HIV-positive women, youth, children, and infants and their affected family members under Part D of the United States Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Treatment Modernization Act. They serve the Dallas Eligible Metropolitan Area (EMA), which includes Collin, Dallas, Denton, Ellis, Henderson, Hunt, Kaufman, and Rockwall Counties. Their services are especially critical to the well-being of citizens of Dallas County, as Dallas has the highest HIV/AIDS incidence and prevalence rates in the state of Texas (Texas Department of State Health Services, 2006; US Census Bureau, 2006).

However, persons living with HIV/AIDS (PLWHAs) in the Dallas EMA often choose not to seek care. According to the Ryan White Planning Council of the Dallas Area/Ryan White Consortium of North Texas' (RWPC/C) 2005 Comprehensive Needs Assessment, there are over 5,000 people in the Dallas area who are aware of their HIV/AIDS status but are not receiving primary medical care. This makes up almost 50% of PLWHAs in the area, and it does not include those who have HIV/AIDS but are unaware of their status. The most common barriers to care reported in the RWPC/C needs assessment were substance abuse and not believing that they needed care because they did not feel sick. Other important barriers to care included a lack of financial resources and transportation, not wanting to be stigmatized, and not knowing about the services in the area. Female respondents also commonly cited a lack of child care as a major reason for missing appointments.

This study, conducted in 2007, seeks to expand on the knowledge gained from the RWPC/C Comprehensive Needs Assessment to provide essential information to enhance DFAN's ability to retain HIV positive women in care. It aims to identify social, psychosocial, and structural barriers, particularly those specific to DFAN, that discourage the DFAN target population of women from seeking care and/or that encourage them to drop out of care. Results from this study will be used to improve DFAN's family centered model of care.

BACKGROUND

DFAN was established in 1989 and has since served HIV/AIDS clients without interruption through the department of Pediatrics at UT Southwestern Medical Center in Dallas. At its inception, the founders of DFAN chose not to create an independent agency but to design a collaborative network, which built on the strengths of existing community agencies. Through its family-centered network model, DFAN strives to provide seamless, comprehensive, high-quality health care and social services to HIV+ women, infants, children, youth, and their affected families.

The vision of DFAN is to improve the health and well-being of HIV+ women, children, youth and their affected family members through a family-centered network of medical and social service providers that share and maximize resources to identify and eliminate barriers to care. Its mission is to increase access to healthcare and social services for HIV impacted families through coordinated efforts within our family-centered model.

METHODS

This study, conducted in 2007, involved three primary activities: (1) face-to-face surveys with women who access services through DFAN; (2) a focus group with HIV+ women; and (3) surveys with DFAN social service and health care providers. Due to the sensitive nature of some of the questions asked, data collection did not include identifying information for participants. Participants in the face-to-face surveys and focus group received a \$15 Wal-Mart gift card to compensate them for their time. The study was approved by the University of Texas Southwestern Medical Center Institutional Review Board.

FACE-TO-FACE SURVEYS

Using convenience sampling, we conducted face-to-face surveys with 103 women who accessed medical and/or social services through DFAN during the study period. The survey aimed to identify any unmet needs, physical, psychological, or social, that hindered them from accessing HIV care. The time required to take each survey ranged from 45 to 120 minutes. Participants for the survey were recruited from the five DFAN medical sites listed in Table 1.

Table 1. DFAN health care sites included in the proposed study

Site	Address
AIDS Arms	
Peabody Health Center	1906 Peabody Avenue Dallas, TX 75215
Parkland Health and Hospital System	
Amelia Court Clinic	1936 Amelia Court Dallas, TX 75235
Bluitt Flowers Health Center	303 Overton Road Dallas, TX 75216
Parkland OB/GYN Clinic	5201 Harry Hines, 3rd floor Dallas, TX 75235
Southeast Dallas Health Center	9202 Elam Road Dallas, TX 75217

Women were considered eligible to take the survey if they met the following eligibility criteria:

- HIV-positive;
- Receiving HIV care from a DFAN health care site (see Table 1);
- 18 years of age or older; and
- Spoke English or Spanish

Women of all races/ethnicities were eligible for participation. Pregnant women were also eligible for participation as they represent one of DFAN's critical target subpopulations. Data

regarding women's pregnancy status were not collected, however, so we do not know how many, if any, pregnant women took the survey.

Trained research assistants (RAs), two of whom spoke Spanish, recruited eligible women for the face-to-face survey from DFAN's medical sites (as listed in Table 1). Eligible women visiting one of the study clinics during the study period were informed by clinic staff before, during, or after their appointment about the study. If the client was willing to hear more about the study, staff referred her to the RA in a private room in the clinic who provided her with information about the study, the time required to complete the survey, and the potential risks and benefits of participation. If the client seemed willing to enroll in the study, the RA asked for verbal consent to participate and then conducted the survey. For Spanish speaking participants, a Spanish language version of the survey was administered. The time for survey administration ranged from about 45 to 120 minutes, with an average of about 60 minutes.

FOCUS GROUPS

Investigators also held one focus group with a sample of HIV-positive women who were currently accessing HIV care through DFAN. The focus group was conducted in order to provide investigators with qualitative data regarding the unmet needs and barriers to accessing HIV care through DFAN. Women were considered eligible for the focus group if they met the following eligibility criteria:

- HIV-positive;
- Receiving HIV care from a DFAN health care site (see Table 1);
- 18 years of age or older; and
- Spoke English

As with the face-to-face surveys, pregnant women and women from all races/ethnicities were eligible to participate in the focus group.

DFAN case managers worked with investigators to recruit women into the focus groups. The case managers identified eligible clients who they believed were likely to attend the focus group from their case lists. They then contacted these clients, either during a regularly scheduled visit or with a phone call, to inform them of the study. Interested clients were given the time, date, and place of the focus group and asked to attend to receive more information.

The focus group took place at Parkland Health and Hospital System's Amelia Court Clinic. A total of 10 women were scheduled to participate, and 9 women actually participated in the focus group. As each client arrived, investigators provided information about the study, the time involved in the focus group, and the potential risks and benefits of participation. If the client seemed willing to enroll in the study, the investigator asked for verbal consent to

participate. When each of the interested women had arrived and provided verbal consent, the moderator began the focus group.

Participants were asked 8 questions that required them to reflect on their experiences, identify the challenges they have faced, and illuminate the ways in which organizations could eliminate some of the barriers to HIV/AIDS care. Questions included the following:

1. What specifically do you want from a health care facility? (Moderator probe: types of services they would like to see). How does this differ from what you are actually receiving?
2. Can you identify the barriers to maintaining health care appointments? Which one is the largest barrier? How might service providers reduce these barriers?
3. In your mind, what motivates you to keep your health care appointments? What is the most powerful motivator?
4. What types of children's services do you currently need? If support services for your child(ren) were available, would you use them? (Moderator probe: Why or why not?)
5. What is your biggest fear or concern related to being positive? Have you discussed this with anyone? What are the other aspects of your illness or general health that you have not discussed with anyone? (Moderator probe: Why haven't you discussed them?)
6. If you could change one thing to improve your experience of receiving care what would it be? If you could change one thing about your provider what would it be? Would these changes increase your level of adherence to care?
7. What role do you think you play in your health care? (Moderator probe: Would you describe your role as a partner, a client, or something else?). How has your role in your own health care changed over time?
8. What is your opinion of the function of a peer advocate? What have they contributed to your experience in care?

The focus group was recorded, allowing the moderator and the note taker to ensure that the focus group went smoothly and that notes on non-verbal aspects of the conversation were available to use in the analysis. No information that directly/personally identified the participants was recorded. First names only were used in the focus groups, and these were changed to pseudonyms during audio transcription and data analysis to ensure confidentiality.

The investigators also attempted to conduct a second focus group with women who had dropped out of care so that we could get input from women who had experienced significant barriers to care. For this focus group, case managers attempted to recruit women lost to care despite their high no-show rate (i.e. not attending scheduled HIV medical appointments). Case managers from both Amelia Court and AIDS Arms identified women who had dropped out of care (i.e. had not had an HIV medical appointment in over 6 months) from their client lists and attempted to call these women. After three weeks of recruiting, only one of the women who had been contacted had agreed to attend to the focus group, and the focus group had to be canceled.

PROVIDER SURVEY

Investigators distributed a brief survey to providers from each of DFAN's partner agencies, in order to obtain the providers' perspectives on barriers to care for their clients. DFAN's partner agencies include those listed in Table 2. These surveys were anonymous; no identifying information was requested of participants. Directors from each DFAN site identified eligible participants. The director received the provider surveys from a research assistant and distributed the surveys in person or through interoffice mail/email to all persons who directly provide social services or health care services to HIV+ women through DFAN. Once completed, participants could email their responses to an investigator or return surveys to a secured location at their agency from which a research assistant would collect them. If participants chose to email the survey to an investigator, identifying personal or agency information (such as the participants' email address) was deleted from the document, the document was printed, and the email deleted so that participants could not be identified. All social service and health care providers employed by the DFAN partner agencies who were 18 years of age or older and who were able to read and write English were eligible for participation. In total, 12 provider surveys were returned to investigators and examined for this report.

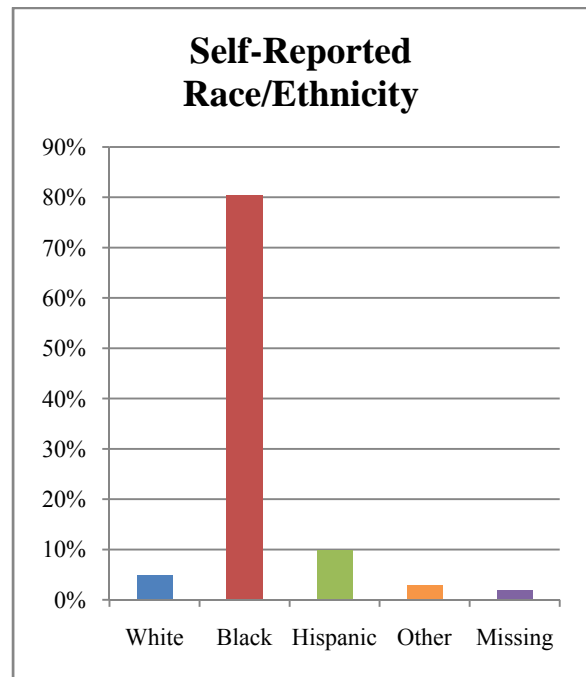
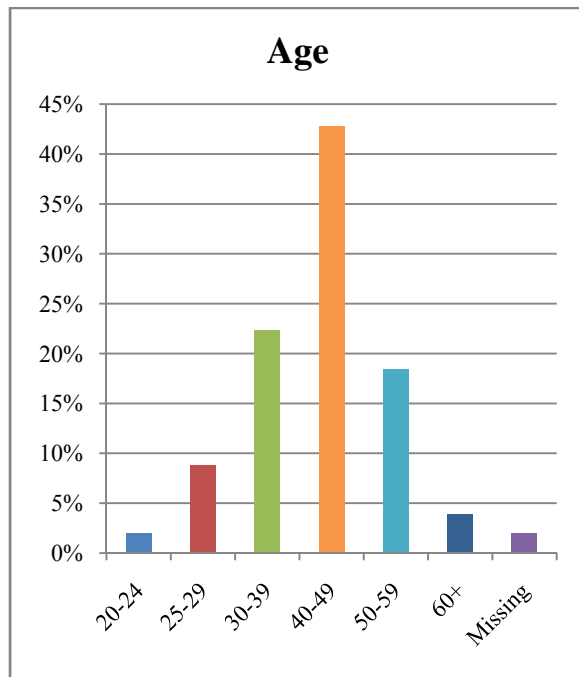
Table 2. DFAN partner agency sites for provider survey

Site	Address
AIDS Arms, Inc.	219 Sunset Avenue Dallas, TX 75208
AIDS Interfaith Network, Inc.	501 N. Stemmons Freeway Dallas, TX 75207
Bryan's House	P.O. Box 35868 Dallas, TX 75235
Children's Medical Center of Dallas	1935 Motor Street Dallas, TX 75235
Parkland Health and Hospital System	5201 Harry Hines Blvd. Dallas, TX 75235
UT Southwestern- OB/GYN Department	5323 Harry Hines Blvd. Dallas, TX 75390
Welcome House, Inc.	4202 S. Lancaster Road Dallas, TX 75216

FACE-TO-FACE SURVEY AND FOCUS GROUP RESULTS

DEMOGRAPHICS OF PARTICIPANTS

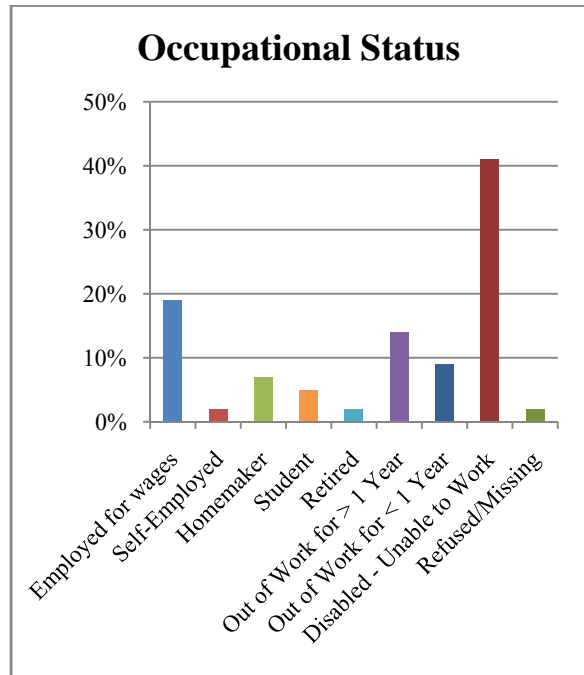
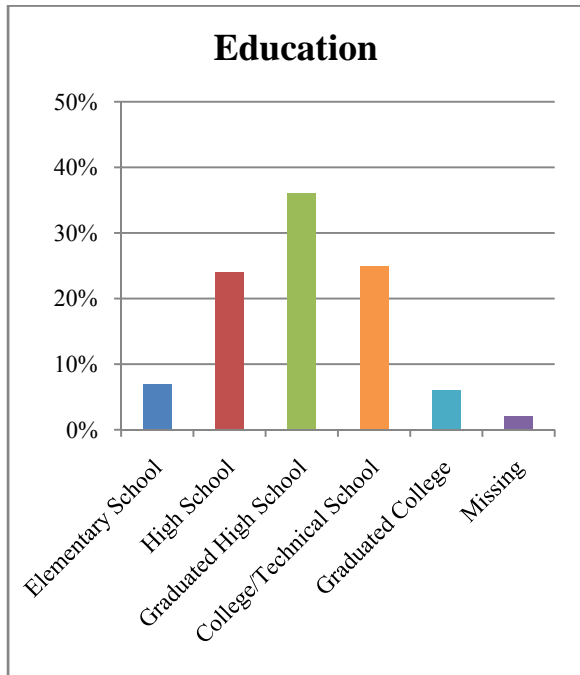
The majority of women taking the DFAN survey were African American women (80%), followed by Hispanic women (10%), and White women (5%). The women ranged in age from 23 to 63 years, with the majority of women (43%) being between 40 and 49 years old. This reflects the overall trend of the disease in Dallas. African American women are one of the fastest growing groups affected by HIV/AIDS nationwide, with heterosexual contact being the primary mode of exposure.¹ Furthermore, people living with HIV/AIDS (PLWHAs) are living longer and the face of HIV/AIDS continues to age.²⁻³



SOCIOECONOMIC STATUS

Most of the women who took the survey were fairly well educated, with about 70% having at least a high school diploma. However, only about 20% of the women were employed for wages or self-employed. Almost 65% of these women were out of work or unable to work due to disability, and an additional 15% were retired, students, or homemakers. Thus, nearly 80% of participants were without a regular income of their own. These data, along with comments from women in the focus groups, suggest that a lack of employment may be a significant barrier to care. Research shows that PLWHAs who work report a higher quality of life and functional status compared to those who do not,⁴ but that a lack of employment opportunities for PLWHAs is a major concern for PLWHAs in many communities.⁵ Many women in the focus group reported a desire to work, but felt that they could not, either because

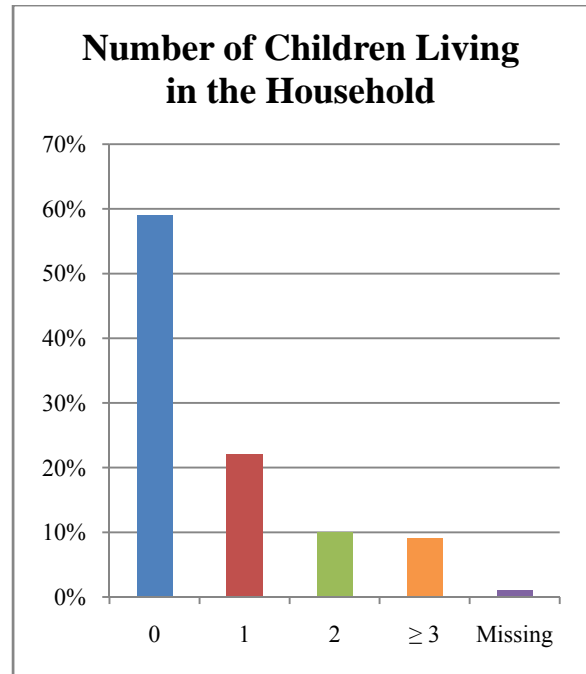
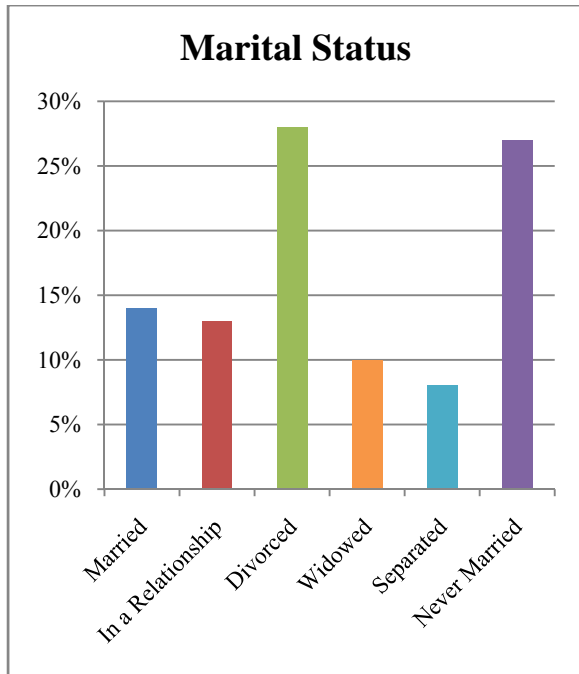
they lacked transportation or because attending doctor’s appointments caused them to miss too much work. In the scientific literature, other PLWHAs have also reported fear of losing government benefits, excessive stress/fatigue, a lack of knowledge of their rights as disabled persons, and physical limitations (often due to side effects from HIV medications) as barriers to returning to work.⁶



HOUSEHOLD/FAMILY STRUCTURE

Almost 75% of survey participants were single women, divorced, widowed, separated, or never married. About 14% were married and an additional 13% of participants were in a relationship. Research suggests that in some populations, single HIV-positive women experience less anxiety, have slightly less limited daily functioning, and are more likely to use condoms during sexual intercourse compared to non-single HIV-positive women.⁷⁻⁸ Other research, however, shows that single women in Dallas, especially single mothers, are more likely to live in poverty, which affects their ability to access health care, transportation, quality childcare, healthy foods, fit housing, and many other necessities.⁹

More than half of the women in the survey (59%) did not have children living in their homes. This may reflect the older age distribution of survey participants.



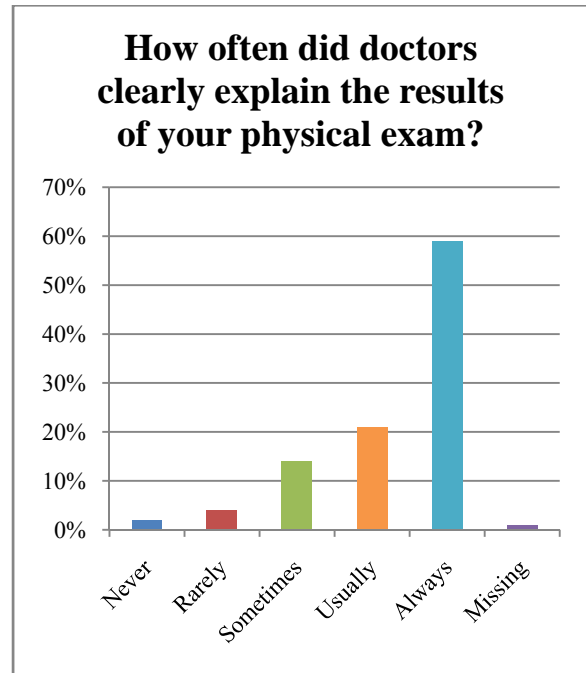
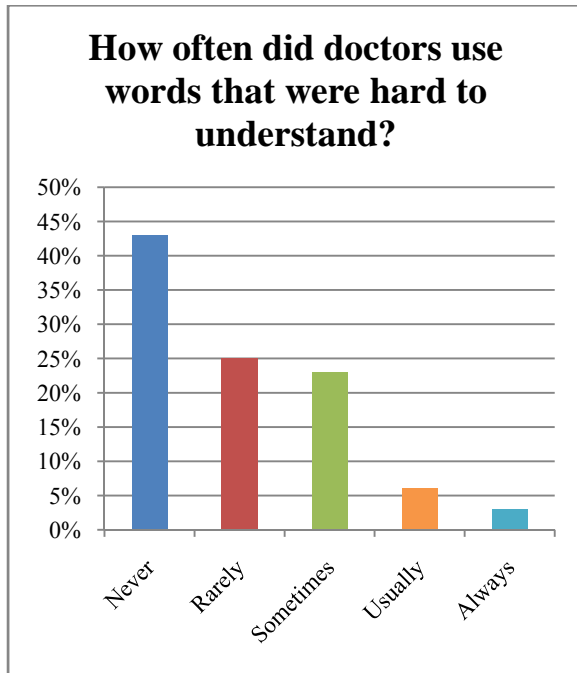
Fewer than 25% of women taking the survey owned their own homes, either outright or with a mortgage. In comparison, 67% of women rented their homes and 11% occupied a home without payment, usually meaning they lived with a friend or relative. These data suggest that housing may be a significant barrier to care among women in DFAN. As noted in the National Minority AIDS Council report, *African Americans, Health Disparities and HIV/AIDS*,¹⁰ families that rent their home often spend too much of their income on housing and cannot afford to access health care services. Even when the health care services are free or the cost greatly reduced, taking time off work to wait for services may be cost-prohibitive to those women who work. Furthermore, rented homes and those occupied without payment are also generally less stable than owned homes. Thus, women living in these homes are more likely to move frequently, making it difficult for case managers to contact them if they miss appointments or fail to follow-up with their referrals.

Many women (40%) also reported having no automobiles available for use by people in their household. Another 40% of women reported having only one car available for their household. These data suggest that a lack of readily accessible transportation may be a barrier to care for some women in DFAN.

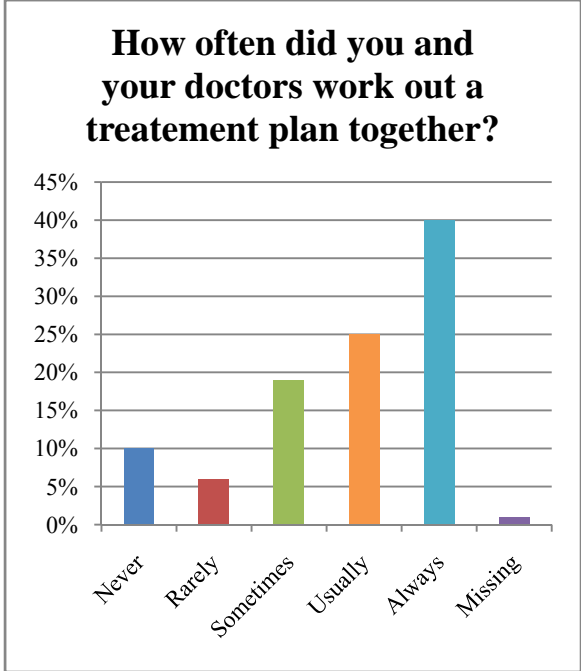
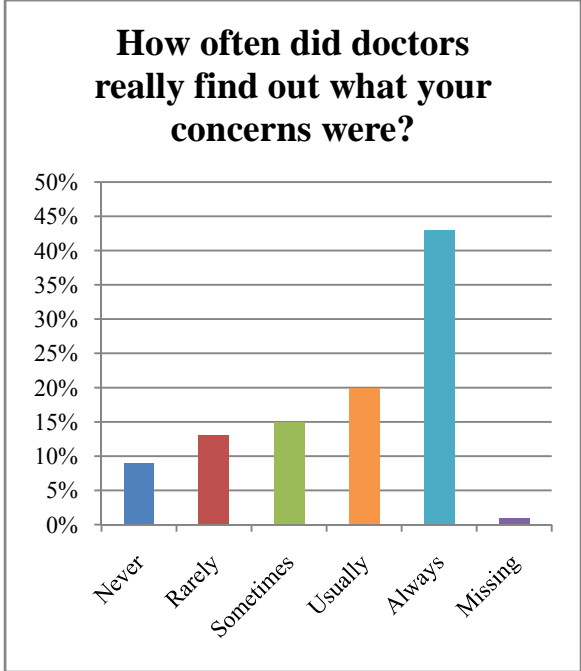
HEALTH CARE & SERVICES

PHYSICIAN-PATIENT RELATIONSHIPS

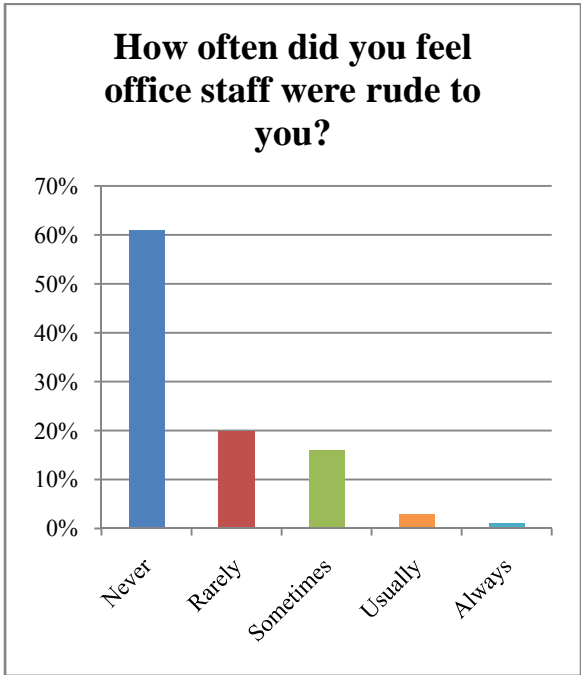
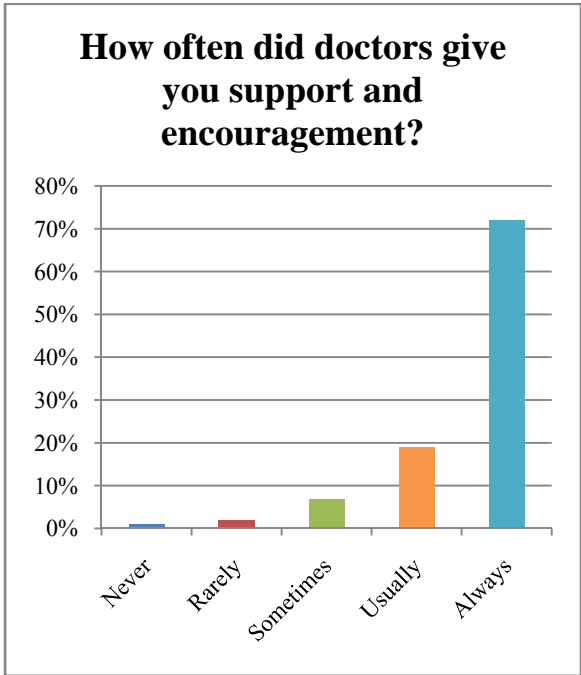
Overall, participants seemed pleased with their interactions with their physicians and the clinic staff. The women generally reported that their doctors communicated well with them. Most women (68%) reported that doctors never or rarely used language that was hard to understand, and 80% of women reported that their doctor usually or always explained the results of their physical exams clearly.



Women also seemed to feel that their physicians listened to their needs well. Over 60% of women said that their doctors usually or always found out what their concerns were, and 65% of women reported that they usually or always worked out a treatment plan together with their doctors.



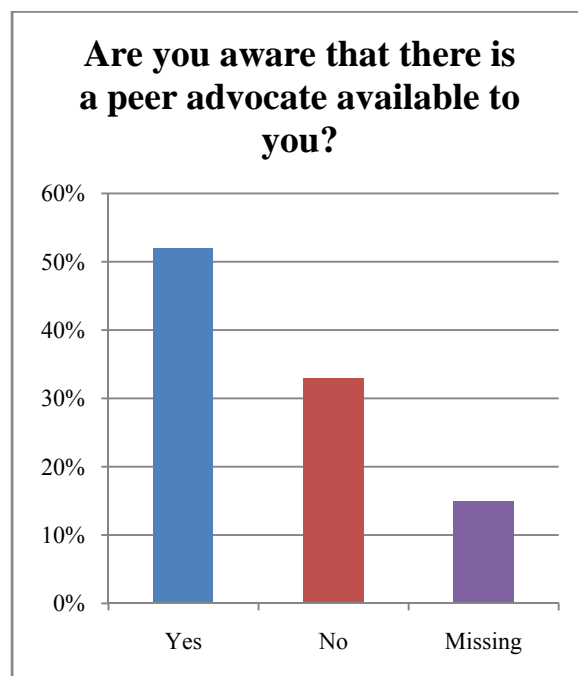
Finally, women felt that their doctors and office staff were kind to them. Over 90% of women surveyed felt that their doctors gave them support and encouragement, and over 80% of women reported that office staff were rarely or never rude.



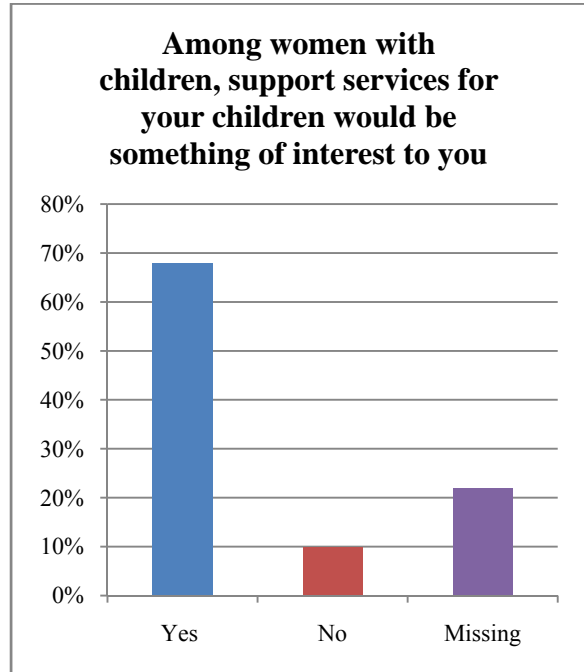
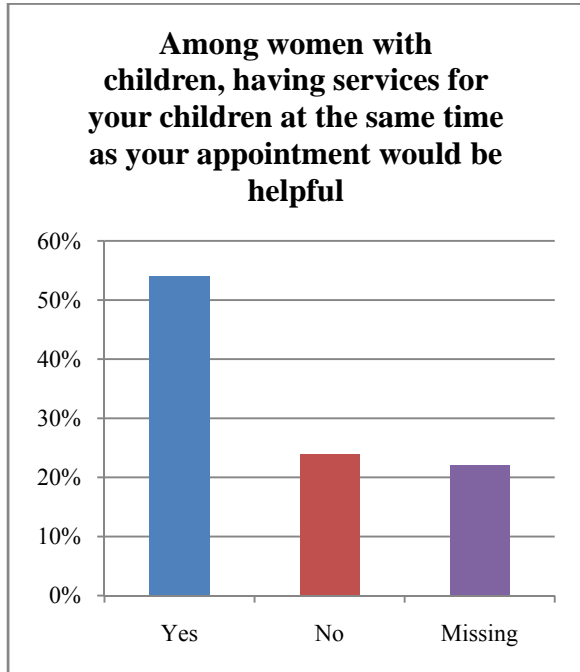
These results suggest that DFAN women experience very positive physician-patient relationships. In addition, the women in the focus groups raved about the quality of care they were receiving from their physicians. Research suggests that doctors who adequately inquire about their patients' HIV symptoms are often viewed as being empathetic and understanding and are better able to improve their patients' quality of life.¹¹ Additionally, the literature has shown that positive physician-patient relationships, and especially good communication between physicians and HIV-patients, are positively associated with medication adherence.¹²⁻¹³ Indeed, after adjusting for race and age in this study, we found that women who had more positive relationships with their doctors were less likely to be careless about taking their medications. Thus, the positive physician-patient relationships observed among DFAN women suggest that these women are receiving high-quality care that is likely to improve their quality of life.

NEED/AWARENESS OF SERVICES

About 35% of all survey respondents were unaware of the peer advocate program, suggesting that there is a need for increased communication of the availability of some services.



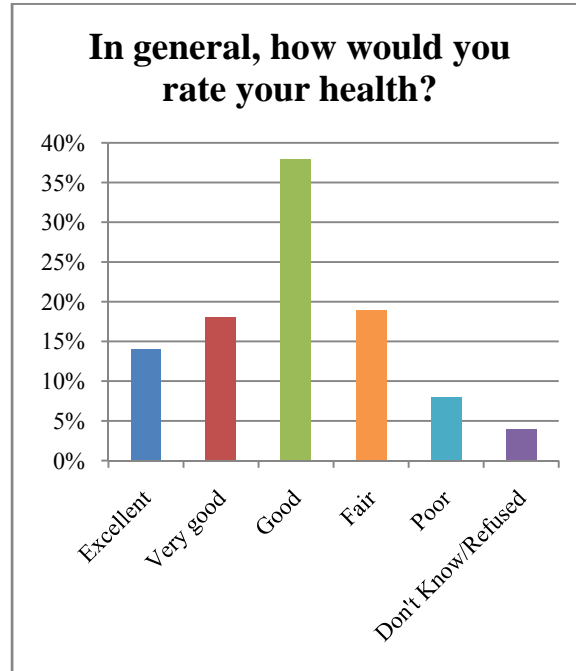
Among women with children, support services for their children were highly desired. Almost 70% of women with children said that having support services available for their children would be helpful. Fewer women (54%) said that they needed services for their children during their doctor's appointments. This may suggest that while childcare during medical appointments is a need for many women, childcare at other times and/or other support services are in even higher demand.



PHYSICAL HEALTH

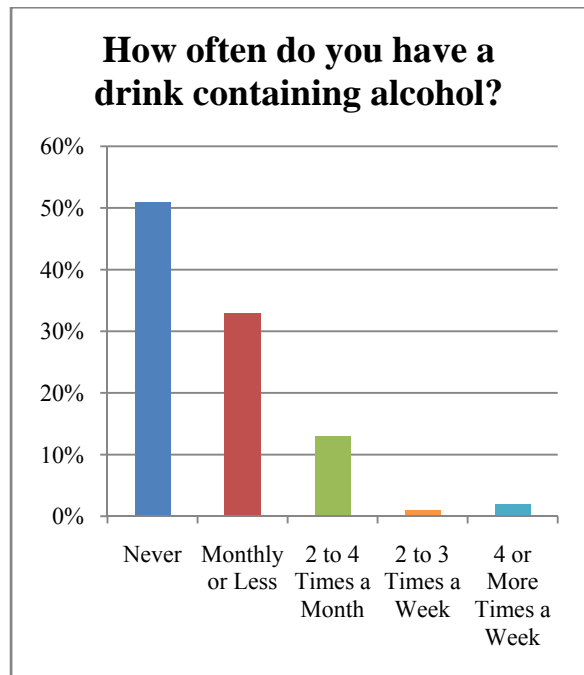
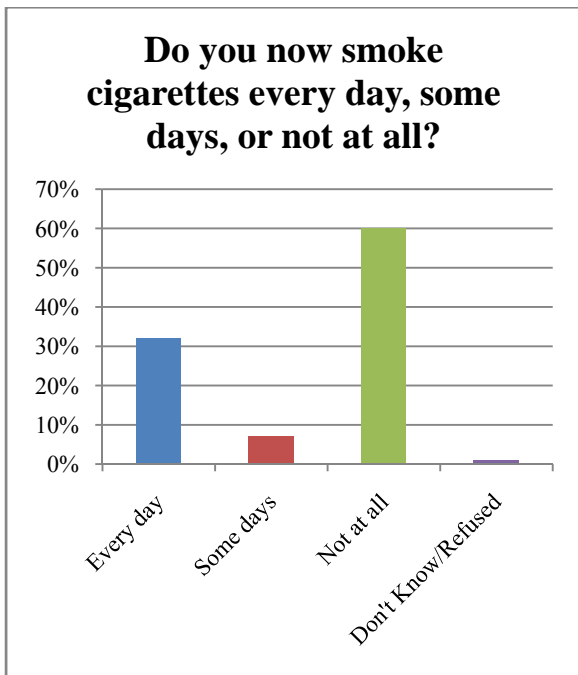
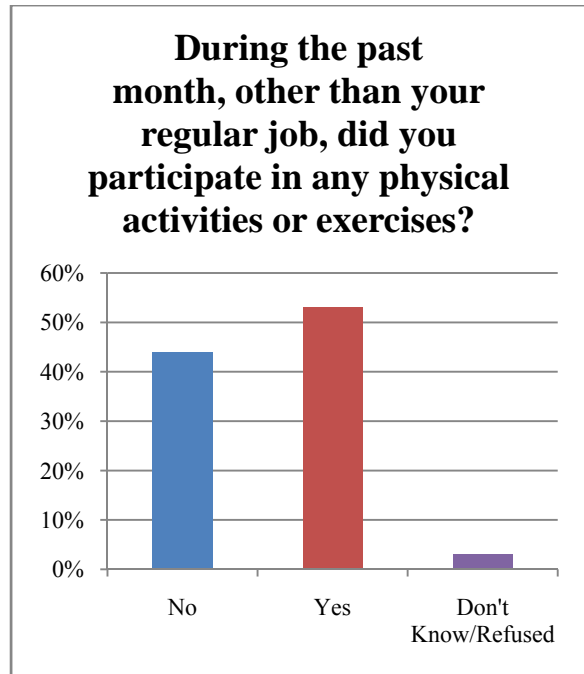
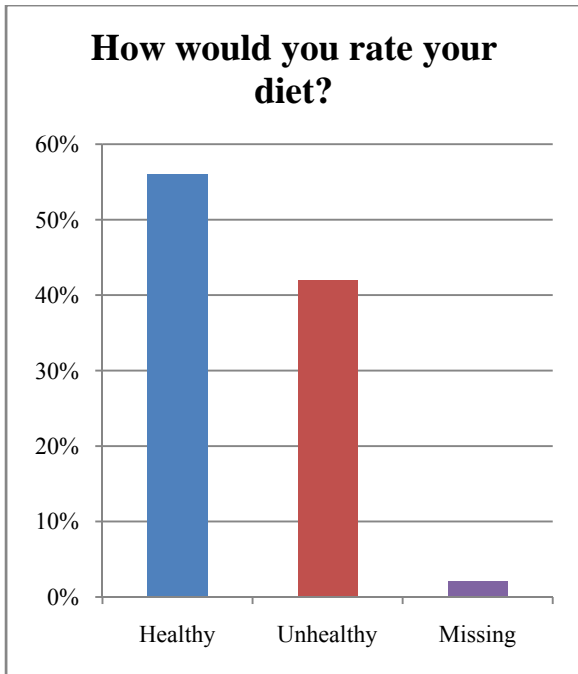
GENERAL HEALTH

Overall women rated their health very highly. This may suggest that women in care are receiving good treatment and that their quality of life (at least as it relates to physical health) is not suffering from their HIV diagnosis.



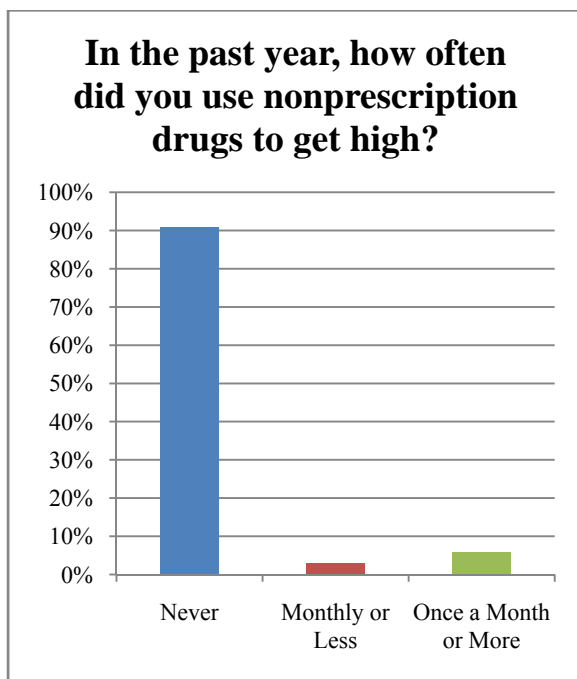
HEALTH BEHAVIORS

A little over half (56%) of respondents reported having a healthy diet, defined as consuming a high amount of fiber, fruits, vegetables, poultry, and fish, as opposed to an unhealthy diet, defined as consuming a majority of red meats, fried foods, and fast foods. Similarly, a little over half (53%) of women reported engaging in physical activities outside of their regular job at least once in the past month. As a comparison, in 2006, 75% of the general Dallas population reported exercising in the past month.¹⁴ Thus, it seems women in this survey exercise less than the general population.



With 39% of women reporting smoking, tobacco use was much more prevalent among this population than among the general population of Dallas. According to the 2006 Behavioral Risk Factor Surveillance System (BRFSS) data, 87.5% of Dallas-ites reported not being current smokers.¹⁵ Reports of alcohol consumption and illicit drug use were similar to the general

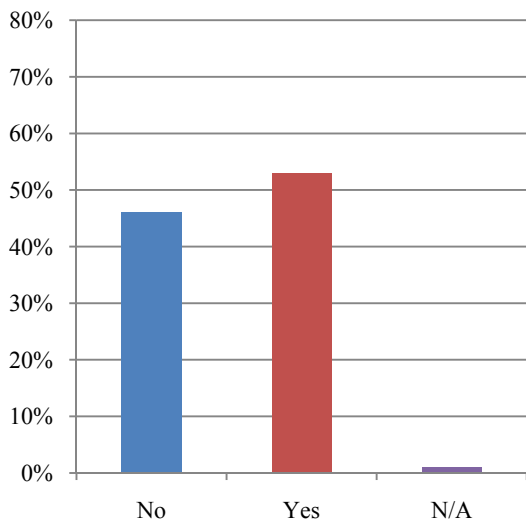
population, though. About 51% of survey respondents and about 53% of the 2006 general Dallas population reported not having a drink within the last month.¹⁶ Similarly, 9% of survey respondents reported using nonprescription drugs to get high in the past year, and almost 8% of the 2004 general American population, 12 years of age or older, reported using illicit drugs within the past month.¹⁷



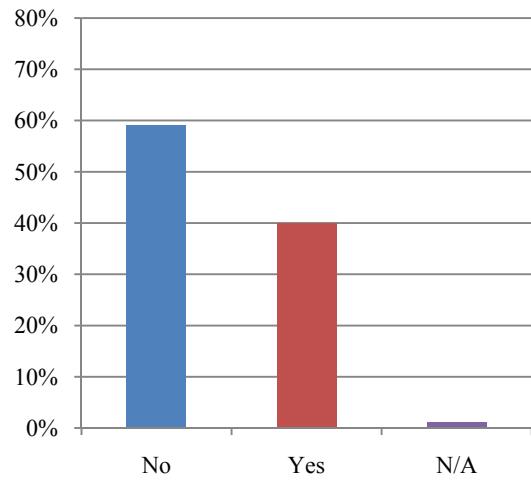
MEDICATION ADHERENCE

A little over half of women surveyed sometimes forgot to take their medications, and 40% of respondents reported being careless at times about taking their medications. But only about 25% of women said they sometimes stopped taking their medications when they felt worse. This may suggest that women are not having many negative side effects to their medications or that women recognize that their medications are helping their health, despite any potential side effects.

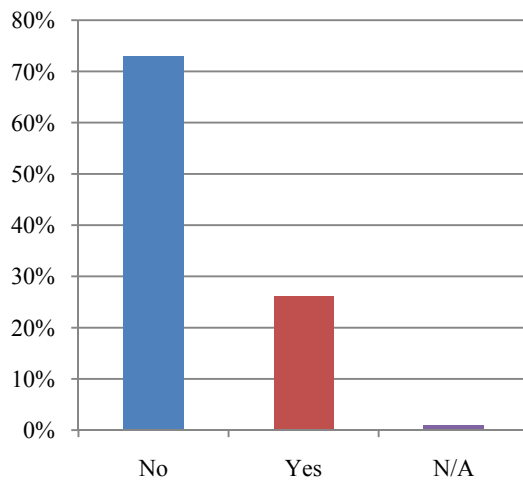
Do you ever forget to take your medicine?



Are you careless at times about taking your medicine?

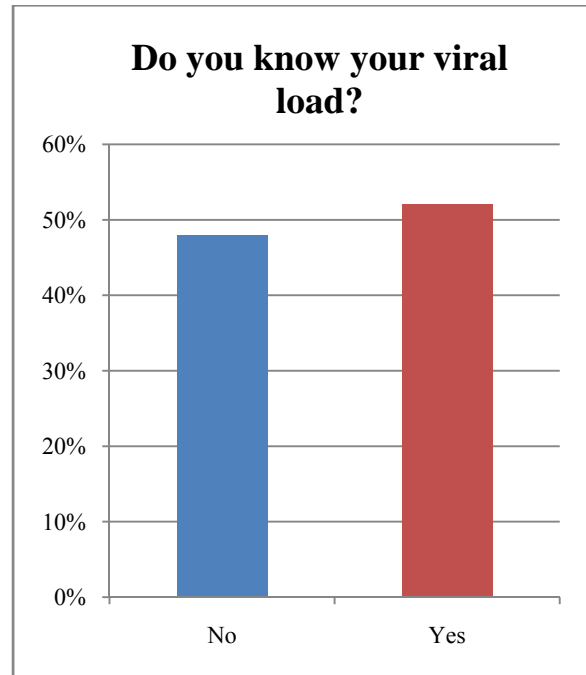
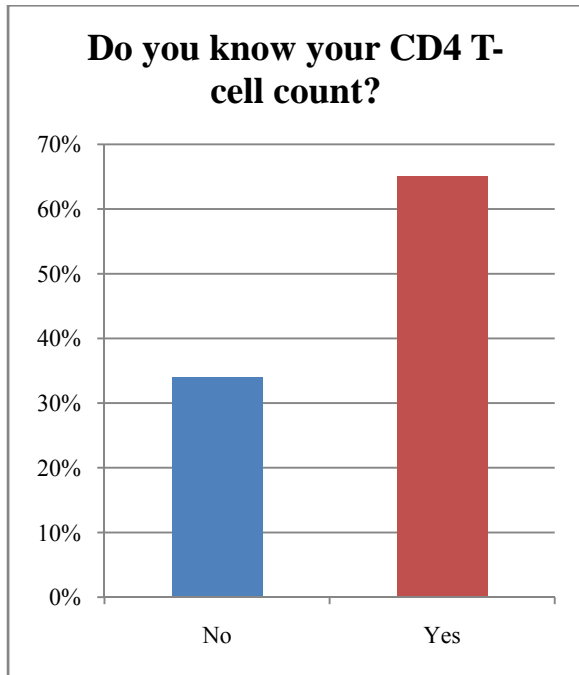


Sometimes if you feel worse, do you stop taking your medicines?



HEALTH LITERACY

Studies have linked a lack of knowledge of CD4 T-cell counts and viral load to lower levels of health literacy;^{18,19} and lower levels of health literacy have been linked to lower CD4 counts, higher viral loads, a higher number of hospitalizations, poorer health, and poorer perceptions of their health care.²⁰ Among DFAN survey respondents, 65% of women knew their CD4 T-cell count, and 52% of women knew their viral loads.

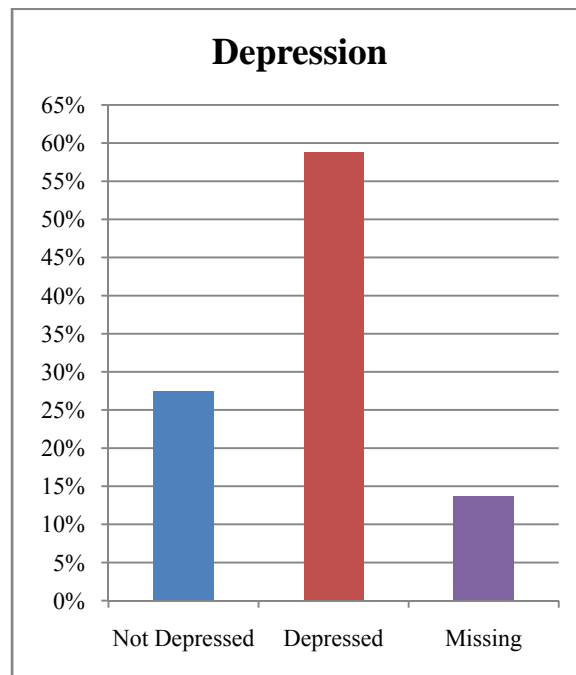


MENTAL HEALTH

DEPRESSION

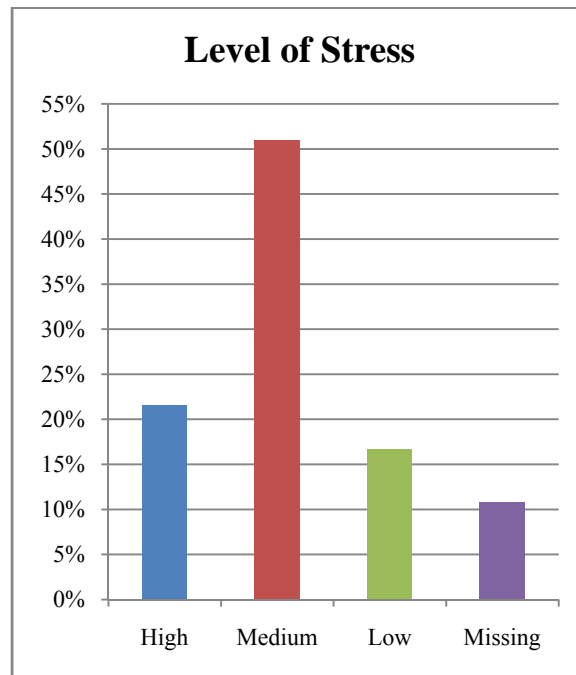
Depression is a major barrier to care among HIV-positive women. People who are depressed are less likely to take care of themselves or to seek out health care. Furthermore, research suggests that depression is associated with a higher viral load, higher activated CD-8 T lymphocyte counts, and lower natural killer cell activity.²¹ Other research suggests that depression is also associated with low socioeconomic status, injecting drug and crack cocaine use, and high risk sexual behavior, factors which, themselves, can be barriers to care among women.²²

Almost 60% of the women in this survey were categorized as depressed. In comparison, only about 11% of women in the general Texas population have frequent mental distress, a rough correlate of depression measured by the Behavioral Risk Factor Surveillance Survey.²³ Although the cross-sectional nature of the data inhibits our ability to make causal inferences, it seems intuitive that an HIV diagnosis and the effects of the diagnosis on one's lifestyle (medications, illness, need to quit working, stigma, issues of disclosure, etc.) have a negative impact on mental health.



STRESS

Stress may also be a barrier to care in this population. Almost 75% of women experienced moderate to high levels of stress. In healthy populations, high levels of stress can lead to decreased immune functioning and to the number of virus-specific antibodies in the blood stream.²⁴ The literature shows that psychosocial resources mediate the effects of stressors on mental health,^{25,26} so the continued provision of support services is likely needed among HIV-infected women in this population.



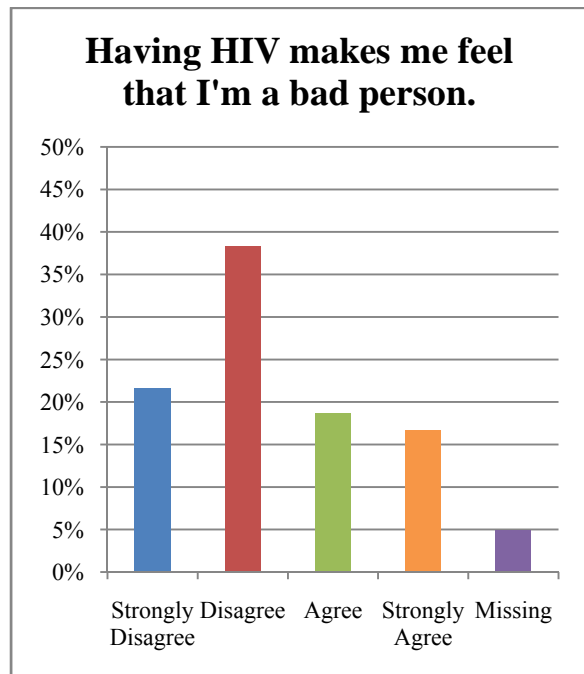
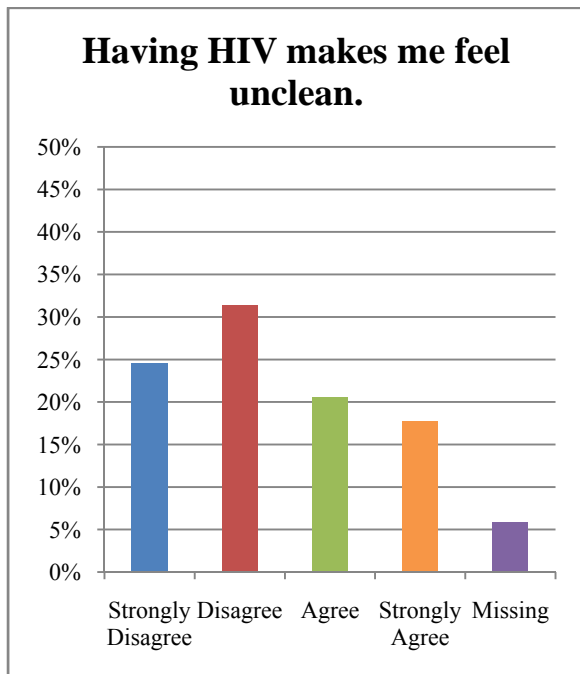
HIV STIGMA

Stigma is a major issue in the HIV community. It is a barrier to care in that it decreases the likelihood that women will get tested, enter and stay in care, tell others that they have HIV, and ask for support from friends/family.^{27,28,29} Stigma and non-disclosure are also associated with depression and negative self-image.³⁰

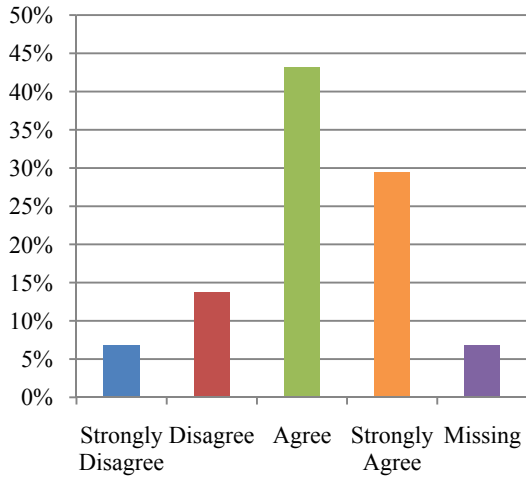
Recent studies have shown that about 20% of Americans fear persons living with HIV/AIDS (PLWHAs), about 17% have feelings of “disgust” toward PLWHAs, and about 20% believe that people who were infected through sex or drug use have gotten what they deserve.³¹ But perhaps more important than the reality of the stigma present in America are the PLWHAs’ perceptions of stigma. After all, it is the women’s perceptions of stigma that will affect their mental health and potentially keep them out of care.

This survey included 40 questions regarding HIV stigma felt or experienced by respondents. Questions covered four major subthemes: how the respondent feels about having HIV, how the respondent feels about disclosing her HIV status, what the respondent thinks others believe about people who have HIV, and what the respondent has experienced when she has disclosed her HIV status to others. We have extracted responses to some questions from each of these subthemes for analysis.

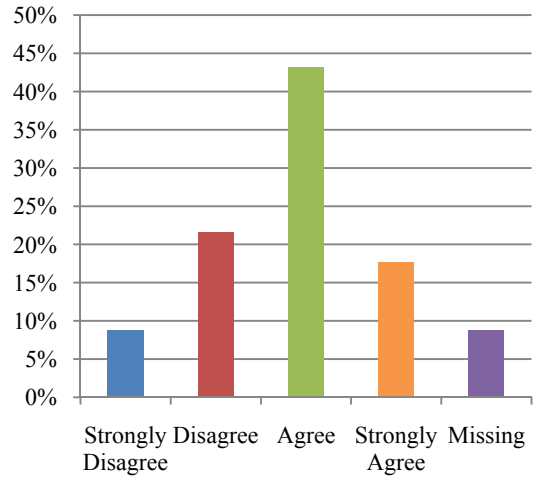
Over half of the women taking the survey disagreed that having HIV made them feel unclean (56%) or like a bad person (60%). But despite the fact that they did not have a negative self-image, many respondents believed that others' had negative perceptions about them and/or about other PWLHAs because of their HIV status. Over 70% of women believed that most people would reject someone with HIV if they found out, and 61% of women believed that employers would fire someone if they found out they had HIV. Furthermore, about 80% of respondents believed that telling others that they had HIV was risky, and 59% reported that in many areas of their lives, no one knew they had HIV.



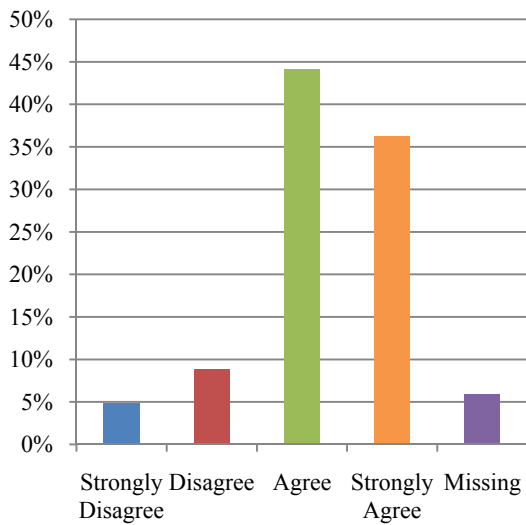
Most people with HIV are rejected when others find out.



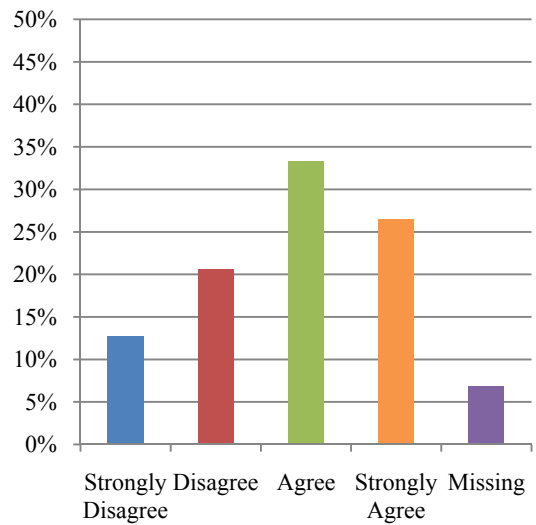
People with HIV lose their jobs when their employers find out.



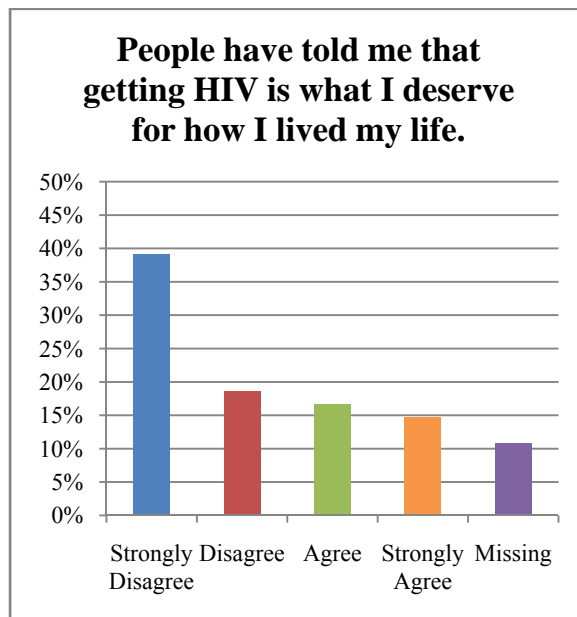
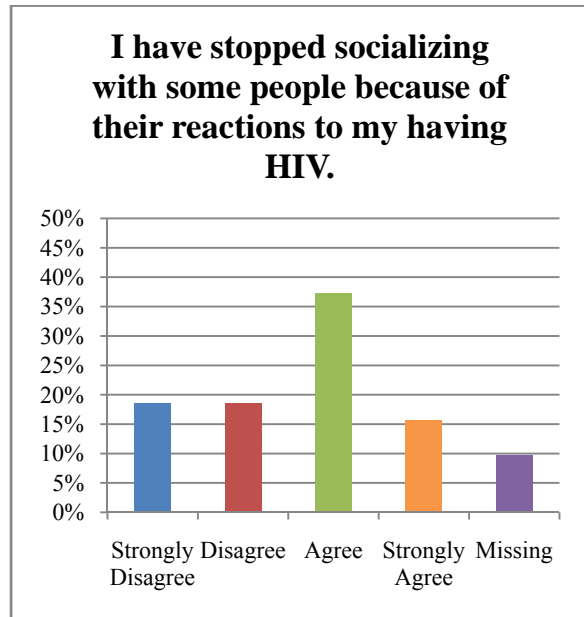
Telling someone I have HIV is risky.



In many areas of my life, no one knows I have HIV.



The women's beliefs about how others would perceive their HIV status seem to be somewhat founded by the actual reactions they received when they disclosed their status. More women agreed (54%) than disagreed (37%) that telling others about their HIV status had been a mistake, and over half (53%) of the respondents reported that they had stopped socializing with some people because of their responses to the women having HIV. Additionally, over 30% of women had been told that getting HIV is what they deserved for their lifestyle.



PROVIDER SURVEY RESULTS

The provider survey asked respondents two questions:

1. How could you make your service provision to HIV+ women, children, infants, youth, and their affected families even better?
2. What additional resources/education do you need to improve your service provision to HIV+ women, children, infants, youth, and their affected families?

Overall, providers seemed very knowledgeable about the barriers to care experienced by their clients and highly motivated to remove those barriers. Major themes found in their responses included a desire to provide additional services, to improve the infrastructure/system of service delivery so that they could reach more women, and to collaborate more effectively with network partners. Not surprisingly, however, limited resources seemed to be preventing them from offering the variety and quality of services they felt were necessary. Providers discussed the need for additional funding, training opportunities for staff, and educational materials for their clients, as well as improved communication between HIV service providers, both within and external to DFAN. The major themes found in our analyses of their responses, as well as some specific ideas mentioned by providers are listed below.

HOW COULD YOU MAKE YOUR SERVICE PROVISION...EVEN BETTER?

Provide Additional Services

- Provide mental health services on-site
- Provide/facilitate support groups for newly diagnosed women geared toward the
 - Hispanic women
 - Caregivers
 - HIV+ youth
 - Families
- Provide more/better educational materials and opportunities, and have this information available to give to clients upon request
 - Education geared toward adolescents and children
 - Education geared toward women so they can make better health decisions
 - Health providers available to an open forum for women to ask questions
 - Inform women of the availability of the Women's Clinic and other HIV/social services available to them
- Provide Emergency Financial Assistance for HIV+ women and their families
- Provide better transportation (especially for those in areas not served by DART)
- Provide childcare in more convenient locations and allow women to access it for reasons other than doctor's appointments (i.e. while women work, etc.)

- Provide more regular outreach to identified target communities

Improve the Infrastructure/Service Delivery System

- Increase the number/types of staff available to clients
- Train staff about current trends within the DFAN population
- Provide services at more convenient times for women (i.e. in the evening)
- Be available in the community, not just in the clinic
- Have a better electronic system for tracking patients through the system (missed appointments/referrals, rescheduling, etc.)

Collaborate More Effectively with Network Partners

- Have case managers work more closely with referral agencies
- Have case managers located offsite at other providers' locations
- Expand the concept of the Women's Specialty Clinic to additional areas throughout Dallas
- Continue to improve the quality management/CQI

WHAT ADDITIONAL RESOURCES/EDUCATION DO YOU NEED TO IMPROVE YOUR SERVICE PROVISION...?

Funding to Cover the Following:

- Support group programs
- Transportation (especially for those in areas not served by DART)
- Childcare services on-site or in additional locations throughout the community
- Mental health services on-site or in additional locations throughout the community
- Prevention and client education activities
- Building infrastructure
 - Update computers/technology
 - Increase number of staff and amount of staff salaries
 - Cover indirect expenses
- Staff training opportunities/attending national conferences
- Compliance activities (data collection, documentation, etc.)

Opportunities for Staff to Be Trained in the Following:

- National best practices
- Trends of infection
- Financial planning
- Computer training
- Cultural issues
- Issues related to HIV stigma
- Conflict management
- Dealing with stress
- Dealing with mental illness/substance abuse issues
- Setting effective boundaries

Educational Materials for Clients

- Provide a list of all resources available within each agency in the DFW area
- Materials should be available in Spanish
- Materials should be available in video format
- Materials should cover the following topics:
 - Sex
 - Drugs
 - Bullying
 - Peer pressure
 - HIV and other STDs
 - Importance of PAP smears
 - Dental care

Improved Communication between HIV Service Providers

- Receive notification when DFAN agencies are sponsoring events so others can invite their clients
- Partner with other providers to share educational opportunities
- Facilitate monthly provider meetings to identify women's needs, identify new resources to address those needs, and discuss ways to reduce the barriers to their care
- Create a one-stop-shop where women can receive medical treatment, transportation, donated goods, childcare, mental health/substance abuse services, case management, emergency financial assistance, and other needed services
- Create an Emergency Financial Assistance fund that is available to women, youth, and families

LIMITATIONS

There were a number of limitations present in this study. Due to constraints on our time and resources, we used a convenience sample of women for both the face-to-face surveys and focus groups, so the results obtained in this study are not necessarily generalizable to all DFAN women. The women in this study were all currently receiving health care from one of the DFAN clinics and probably differ significantly from women who have dropped out of care. The study likely suffers from self-selection bias, as well, with women who had healthier behaviors and were more satisfied with their health care being more likely to enter the study.

After discussing the results with providers, it seems likely that there was some prevarication bias, as well. While the providers agreed with the majority of the results based on their own observations of their clients, they felt that the women over-reported satisfaction with their health care providers and greatly underreported smoking, alcohol, and drug use. On these questions, women may have felt pressure to provide the answers that they thought researchers wanted to hear. Additionally, because the interviews and focus groups took place in the health care clinics, women may have feared that their answers would be shared with their health care providers despite the researchers' assurance that their responses were confidential.

Despite these limitations, the results are useful in that some psychosocial barriers to care, including depression, HIV stigma, and a lack of stable housing, transportation, child care, and employment, were identified. Even if these results do represent women with greater satisfaction and involvement in their health care, the fact that satisfied women still experience these barriers suggests that they are important barriers to address. If women in care are experiencing these barriers to care, women out of care are likely experiencing them as well, and reducing or eliminating these barriers may help to attract out-of-care women and retain other women in care.

POLICY IMPLICATIONS

Data from this report indicate that DFAN's female clients experience a wide array of physical, emotional, mental, and social problems. Although many of the physical health issues can be addressed through medical care, many of the other issues serve as barriers to seeking treatment and so must be addressed first or at least along with the medical care. Fortunately, through the quality medical and social services already being provided by DFAN, many of these issues are already being addressed. But, as shown by both the client and provider feedback, more can be done to improve outcomes for DFAN women.

Depression emerged as a major issue for this group of women, one that is likely to hinder women from seeking the care they need. Policies and programs should be put into place that will allow for the timely identification and treatment of this condition. Examples include: 1) screening all women for depression at intake and at regular intervals throughout the course of their treatment; 2) establishing relationships with local mental health care providers and developing processes for linking up women with these providers; and 3) creating support groups for women who are struggling or who have struggled with their HIV/AIDS diagnosis and/or the stigma and relationship issues surrounding this diagnosis. Support groups and other forms of peer advocacy may be especially beneficial as women can learn from one another, allowing both women to become empowered through the process.

Poor health literacy and medication adherence may also be barriers to care among DFAN clients. The providers suggested a number of interventions to promote health literacy, including: 1) providing brochures and/or videos to educate clients about HIV-related issues; 2) having an open forum in which clients can speak to providers about their health concerns; and 3) increasing the number of educational sessions available to clients. Additionally, interventions more specific to clients at high-risk of non-adherence may help to improve client outcomes. For example, the Connecticut HIV Medication Project provided high-risk women with one-on-one education with an on-site adherence nurse after their regular medical appointments. The nurses developed intervention plans, tailored to each client, which included adherence counseling, pillboxes to organize medications, audio or vibrating medication reminders, referrals to social support service agencies, etc. Women who were successfully followed up by the adherence nurses had significantly improved adherence and significantly decreased viral loads.³²

Employment was another challenge that DFAN clients face as only about 20% of participants worked. The following policies and programs may help to empower women to seek employment opportunities: 1) integrate health and support services to minimize the amount of time women spend attending HIV-related appointments; 2) provide job skills training and employee rights education opportunities; 3) increase the scope of currently provided services, such as transportation and child care, so that women may take advantage

of them for employment, in addition to health care, purposes; 4) create support groups for employed women to discuss coping strategies for the stresses and stigma they experience in the work place; and 5) work with women to reduce their medication side effects so that they are less limited by their HIV diagnosis.

Among women with children, a lack of child support services was another important barrier to care. Increasing the number and expanding the types of child support services available to women would likely improve the women's ability to seek treatment. Specific recommendations include: 1) providing child care and other child support services in multiple locations throughout the network to make them more convenient to mothers; 2) providing child care on-site at women's health care appointments; and 3) providing regular child care apart from health care and social service appointments (i.e. to allow women to seek employment opportunities). Such services will free the women to focus on their own health needs, feeling comfortable that the needs of their children are being met.

Finally, in order to engage in any of these activities, DFAN must increase and diversify its funding. Part D of the Ryan White HIV/AIDS Program limits the use of its funds such that it will not pay for outreach activities or social services, which cannot be directly linked to medical treatment. However, many other funding agencies, both governmental and non-governmental, fund these services. Supplementing the money DFAN receives from HRSA with other funding sources will serve to expand its impact on the Dallas community and to improve the quality of life of their clients.

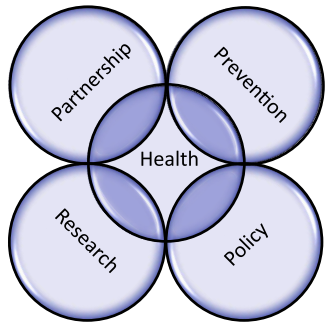
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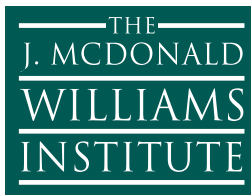
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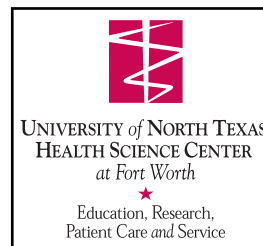
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