

Multiple Comorbidities and Interest in Research Participation Among Clients of a Nonprofit Food Distribution Site

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Abstract

Background: Persons accessing food from nonprofit distribution sites face numerous challenges and typically have significant unmet health needs. However, given limited and intermittent healthcare system engagement, this vulnerable population is underrepresented in clinical research. We sought to better understand the health needs of a nonclinical population to inform future research and interventions.

Methods: Focus groups were conducted in English ($n = 4$) and Spanish ($n = 4$) with clients of Crossroads Community Services (CCS), the largest distributor of North Texas Food Bank. Discussions probed participants' health status, healthcare utilization, understanding and utilization of mammography, and attitudes toward participation in research.

Results: Participants included 42 CCS clients, primarily Hispanic or African American women. Participants reported multiple comorbid conditions among household members, yet utilization of health services was often limited by cost. The majority expressed interest in participating in research to communicate their health concerns and obtain emotional support.

Conclusion: CCS clients represent a high-need, under-reached population willing to engage in health-related research that affords them opportunity to connect with peers in group settings and obtain information to improve management of daily life challenges. The Community Assistance Research (CARE) Initiative, a community-academic collaboration, establishes a much-needed opportunity for ongoing clinical research and intervention among this underserved population. *Clin Trans Sci* 2015; Volume 8: 584–590

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Introduction

An estimated 14% of American households¹ and nearly one quarter of all Texan households² experienced food insecurity in 2013, defined by the U.S. Department of Agriculture (USDA) as having inconsistent access to adequate food due to lack of financial and other resources.¹ People in food-insecure households face ongoing challenges in meeting basic needs like food, rent, and medicine. While publicly funded programs like the Supplemental Nutritional Assistance Program (SNAP) and Supplemental Nutrition Program for Women, Infants and Children (WIC) provide significant assistance to low-income families,³ not all food-insecure households meet eligibility requirements. Many households seek additional or intermittent assistance from nonprofit food distribution sites in order to meet their nutrition needs⁴ or reallocate money, for example, when faced with a medical crisis.⁵

The USDA has conducted some health assessments of SNAP participants, primarily related to nutrition and diabetes.^{3,6} Recently, the annual Hunger in America Report of 2014 included for the very first time a brief section on health-related issues.⁷ The report's findings were consistent with other studies, which indicate significant unmet health needs and limited utilization of healthcare services among individuals from food insecure households.^{8–11} Food insecurity leads individuals to delay medical care except in cases of emergency,^{11–13} resulting in poorer health outcomes,¹⁴ unmanaged chronic conditions,¹⁰ and higher healthcare costs.⁹ Furthermore, physical and emotional consequences of food insecurity are well-documented, and include diminished immune health, malnutrition, and increased stress-related disease, depression, anxiety, and substance abuse.^{5,14,15}

Food-insecure populations are underassessed given their underrepresentation in clinical research at academic medical

centers,^{13,16,17} despite evidence of the viability of strategies to recruit from the community.^{18–20} For this reason, clinical researchers at UT Southwestern leveraged the Community Assistance Research (CARE) Initiative,²¹ a collaboration of community and academic organizations, to facilitate research with food-insecure populations.

In North Texas, Crossroads Community Services (CCS) is the largest distributor of the North Texas Food Bank, and a member of the CARE collaborative partnership. CCS represents an emerging model of a sophisticated, high-capacity operation that distributed 2.6 million pounds of food to 5,524 households in 2014, through 30,616 client visits. CCS distributes food through its in-house pantry and a network of 73 community distribution partners in the Dallas metro area. CCS clients are low-income and primarily female (77%), with mean age of 50 years. Approximately 53% are African American, 37% are Hispanic, and 76% completed high school. The average family size is 4.7 people; 54% of households have a family member under age 18.

This paper reports findings from a qualitative study of the health characteristics, healthcare utilization behaviors, and attitudes toward participation in future health-related research in a sample of CCS clients. By utilizing a community-engaged recruitment approach facilitated by CARE, this research enhances our understanding of the health needs of a population with limited healthcare system engagement in order to inform future research and develop interventions to improve their health status.

Methods

Data collection

Three facilitators recruited CCS clients to participate in focus group discussions.²² Clients were approached in the CCS waiting

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area by researchers fluent in English and Spanish; eligibility was limited to registered CCS clients, receiving services and willing to participate that day, and able to communicate in English or Spanish. Focus groups were conducted in a private room at CCS. Participants with young children were offered the option of CCS-staff supervised play in an adjacent room. The study was approved by the UT Southwestern Medical Center's Institutional Review Board (STU 072013-090, PI: Pruitt).

Focus group discussions were structured around key concerns related to: health status, access and utilization of health services, other life challenges, awareness and utilization of mammography, and participation in future research (see Appendix). We included questions about mammography as an example of a recommended preventive health behavior that is common but underutilized, and relevant to the majority of CCS clients who are female.

Data analysis

Focus groups and debriefing discussions among the three focus group facilitators were audio-recorded and transcribed. Transcripts were analyzed in NVivo 9.0 (QSR International, Australia) using codes corresponding to the focus group guide questions (see Appendix). Once coding was completed, comprehensive code reports were reviewed by members of the research team to determine the most salient themes. Themes were identified by frequency (how many times participants mentioned an idea) and qualitative emphasis (how emphatically participant(s) communicated their responses). Researchers chose the focal points of this manuscript from among these themes.

Results

Eight focus groups were conducted: four in Spanish and four in English, with four to seven participants per group. Groups lasted an average of 67 minutes (range of 48–82 minutes). Of 47 participants, 38 were female (81%), approximately 90% were Hispanic or African American, and ages ranged from “early 20s” to “83 years” by self-report.

Health characteristics and impact on daily functioning

Participants described a broad range of health problems. Of 27 issues raised, the most common were mental health, high blood pressure, high cholesterol, arthritis, and diabetes (see Table 1).

Many participants reported contending with multiple comorbidities among themselves and household members, with many caring for multiple family members.

I'm a diabetic, I have high blood pressure, I have heart problems, I have kidney problems, I have liver problems, and I am raising my 2 grandchildren. My youngest grandchild is a boy. He's got mental issues and he also has a growth hormone deficiency which Children's Medical is giving him medication every month to help his body grow cuz he's too small.

I'm a Marine Corp veteran. I am currently suffering from type 2 diabetes and I also have a dormant hepatitis. I'm taking 2 types of insulin. I'm currently on lisinopril for my high blood pressure and I haven't received any treatment for my hepatitis. I have arthritis in my knee and arthritis in my spine. I've also had a percutaneous disc excision in my back at level 6 and level 5 and those are the medical issues that

Most frequently reported	Reported fewer than three times
Mental health problems, including depression, bipolar, schizophrenia, PTSD, anxiety, stress, ADD ($n = 22$)	Heart disease
High blood pressure ($n = 21$)	Liver problems (e.g., hepatitis)
High cholesterol ($n = 8$)	Neuropathy
Arthritis ($n = 8$)	Allergies
Diabetes ($n = 7$)	Migraines
Dental problems ($n = 4$)	Stroke
Alcoholism, substance abuse ($n = 3$)	Gastritis
Asthma ($n = 3$)	Lupus
Thyroid disease ($n = 3$)	Domestic violence
Kidney disease ($n = 3$)	Several other items reported once

Note: In response to the focus group prompt: tell me about some of the health challenges that you and your family members face.

Table 1. Health challenges by participant report.

I'm facing. I'm currently 62 years of age... The other challenge that I have is I'm currently married... and she has a diagnosis of bipolar, paranoid schizophrenia, depression, and ADD.

I have high blood pressure, neuropathy... I have hyperthyroidism and I had an x-ray and they told me I had tumors in my stomach and it's about to my esophagus... I have health problems that come and go but I deal with pain on a daily basis... The situation in my home is that I have two daughters... one is an addict... and it has really deteriorated her. She's 37, but it's deteriorated her thinking and her actions down to like a 12-year-old. She has [multiple children, and I have custody of the youngest now].

Many participants experienced health problems so severe that they were unable to function on a daily basis.

I've been diagnosed with bipolar, depression. I am a diabetic. I have arthritis in my back. I go to the doctor on a regular basis and take me medication. I don't eat well. ... as far as my health is concerned I feel like it's deteriorating. A lot of times I don't have no energy. I can't hardly sleep.

I had high blood pressure but they say it's because of the depression and feeling worry. That's what everything else came from. It's all the same, depression, nervousness, stress; it all develops in different parts of the body and my nerves, stress, and anxiety... They tell me to relax, not to worry, not to feel pressured, but you just can't do that.

Well actually, my challenge is just not to be worse. The majority of the time I'm feeling hopeless and worthless. I can't work outside of this and I'm just stuck. The part that gets to me is well, connecting with society. You know, cause as far as my depression, it's hard for me to connect with the other people.

Insufficient health insurance coverage and inability to afford healthcare

Participants reported various types of healthcare coverage, including county hospital medical assistance program, Medicare/Medicaid/disability/SSI, insurance for veterans, and various other supplemental and managed care plans. Few were completely uninsured; most participants seemed to be underinsured, with insufficient coverage to meet all of their health needs.

Medicaid and Medicare don't cover nobody with teeth and I have no bone structure up in the gum and it causes chemicals to go into my stomach and it causes me to be sick a lot from my teeth and I can't get no help getting them fixed.

I'm able to get my diabetic pills through [Medicaid] and they expensive. I not able to test myself because Medicaid will pay for a certain strips, but they don't pay for the same monitor that goes to that strip. What sense does that make?

Whether underinsured or uninsured, many participants expressed an inability to afford medical care or treatment that they knew they or their family members needed.

[My mom] suffers from diabetes and high blood pressure and intense pounding headache...all 24 hours, it's like torture, but we don't know what it is. We're supposed to take her to the neurologist, but the neurologist is going to charge us the visit and that's why we haven't gone. I also suffer from fluid retention, cholesterol, and I have something in my bones, I walk to the side, crooked, but who knows what's wrong with me, because I haven't gotten screening.

Mammograms cost \$200-300...with that money I could buy groceries, the \$200 were for groceries.

Awareness and utilization of preventive care

Participants were mixed in both their level of understanding and utilization of mammograms. For example, some women voiced clear opinions about the importance of mammograms for early breast cancer detection, whereas others confused mammography with other medical procedures (e.g., pap smears and gynecological surgery). Two female participants stated:

I want to talk about something. It's very important. I've listened to all of you talking about not going to [local safety net clinic] so as not to lose a day or a night, but you don't realize that if you don't lose a day, a night, a week, it's better than losing your life. My experience with my sister-in-law—She didn't go so as not to lose a day of work, but she lost her life to cancer.

[Mammograms are] when you have a hysterectomy...where the doctor give you the hysterectomy.

Responses about why women did or did not get regular mammograms varied. Many women acknowledged the importance of obtaining mammograms, but reported difficulty affording them on a regular basis. Other women did not seek care unless they had pain or alarming symptoms. Some women said they got a “free mammogram” (i.e., offered at no cost to patients); at the same time, a few who were aware of opportunities for “free

mammograms,” for example, at community health fairs, said they did not get them. For example, in a focus group of nine women, six commented:

I was never able to reach them.

For me it's because of lack of support and financial help...

It's been laziness for me. I have time although I have a big family. They offer [mammograms] for free. You have to find time for your health.

I would rather lose my job than not get checked. You can get a new job but not a new life.

You have to make time for your health...

It's because of laziness. People only focus on daily life and time passes by and you don't remember.

We don't care for our health...get a checkup, a mammogram or a pap smear... We don't pay enough importance to our bodies.

Research participation

Despite reporting numerous challenges to obtaining health services and basic needs, most participants were eager and willing to participate in future research. Their comments revealed that they understood the voluntary nature of research and our efforts to preserve their privacy, and they appreciated our small monetary incentive (\$20 for approximately 1 hour).

We didn't have to do what we didn't want—we came on our own. [regarding participation in current focus group]

As long as it's confidential, I don't have a problem with that [researchers viewing a participant's medical records, hypothetically speaking].

It make you feel better...somebody cares and somebody's trying to help.

I have so many medical problems, but when [the facilitator] mentioned the research, you talking about [health issues], that was fine. I would have did it anyway, but when they offered the \$10 that even sweetened the pot.

Several clients expected to obtain more health-related information by participating, whether about their illness specifically or about health services and insurance generally.

If you're going to ask, while you're at it, they can ask if anybody in the family is sick and they can let you know if there will be a free health fair for people that don't have insurance or if there's a way to know where people can go, if they qualify for some type of health service.

I'm sitting here talking to someone and they're asking me questions about my health, I expect them to have some resources to give me.

Many participants cited the group discussion itself as a positive aspect of research participation. For example, several

equated focus groups to informal support groups where they could learn from peers and receive emotional support and information regarding common challenges.

You hear other people and the smallest thing can be useful to you, and you take it, being conscious and respectful about what everyone says.

I think it's better in a group because you listen to other situations and you tell yourself, wow, I need to improve here in these areas.

For me it's better to speak than on paper. Besides being faster you open up more.

Additionally, several said they preferred to receive information through “word of mouth” and did not read information that was given to them in flyers or handouts (e.g., CCS recipes); indeed, researchers noted that participants asked for information that was already available from CCS.

Yes, sometimes they have brochures, we just don't read them. Sometimes they have them in those plastic things, even on how to look for a job, or what clinic to go to.

Instead of just giving it to us...make a class.

Yeah, instead of giving us papers when we leave...

Show me how to do it. [original emphasis]

However, some focus group participants also stated having paid careful attention to written materials.

I asked for information regarding all that, so I get information about my father's disease. My dad reads that a lot, so I want to be informed.

In both cases participants indicated that communication of information was important and, once received, routinely shared with others in their social network.

Clients reported high levels of trust in CCS and CCS staff. Participants also appreciated the opportunity to share their experiences and felt that focus group facilitators genuinely cared for them. This trust and appreciation may facilitate clients' candor and willingness to participate in future CARE research.

I've gone through a lot, I trust in God, and this place has helped me a lot. I have three children and, should this place not have existed, I think it would have been a little harder to get food for my children, so I'm thankful to God that this place exists. Mrs. [CCS staff] is a very good person, she's always taking care of—she's always worrying about me.

You know, you can tell when anybody...take the time.

It's like...y'all are taking the time for us. You're a little blessing...I was just sitting there but then we have opened up. When they was telling you all of their...I said well let me just lay my cards on the table.

Discussion

This study contributes qualitative data from the perspective of individuals in food-insecure households. Our findings are consistent with recent literature that indicates that a large proportion of individuals from food-insecure households are challenged by multiple comorbidities, untreated medical problems, significant healthcare-related costs and debt, and competing household needs.^{5,7,8,13}

Our study raises several important considerations for future research with clients of nonprofit food distribution sites. First, as other community-engaged recruitment studies have shown, word-of-mouth reputation and trust (in CCS and their staff, in our case) played a major role in participants' willingness to engage with research staff working in partnership with a highly trusted organization.²³⁻²⁵ This finding also suggests that additional community partnerships (e.g., with charity medical providers) could further serve this population by leveraging clients' existing trust and access to this under-reached population.

Second, CCS clients, like many other health research participants, expressed both altruistic and utilitarian motivations regarding potential participation in future research.^{19,23,26,27} Clients were eager to share their experiences and they hoped their own feedback might help others. Notably, clients also appreciated water or small refreshments, gift cards or cash payment, and assistance (e.g., information about their health condition, referrals to service providers). Many participants expressed gratitude to researchers for “caring about us” and “showing us respect”; this is consistent with existing literature that indicates the importance of reciprocity in community-engaged research participation.^{28,29}

Effective logistical planning may have also played a role in the effectiveness of our study's recruitment and execution of focus groups. For example, clients appreciated the less formal “chat” (in Spanish, “una platica”) format of the focus group and the fact that questions and comments were welcomed during the consent process and focus groups themselves. Additionally, several indicated that returning to their “place in line” after the focus group was an important factor in their decision to participate so that they would not be delayed in obtaining their grocery selections. In sum, by investing added time and care in logistical and interpersonal details, researchers demonstrate mutual respect, awareness, and sensitivity to clients' needs and priorities. In turn, this may encourage participants to engage in a more open exchange of personal information.

Third, many participants mentioned preferring to receive and provide information *verbally* rather than in writing. Researchers must be thoughtful in designing research protocols that can accommodate greater time and specific communication skills, which are required to verbally execute recruitment, consent, and data collection from persons with limited health literacy and/or language proficiency.^{30,31} At the same time, as expected and demonstrated in the focus groups, participants varied regarding education level and exposure to health information. While researchers should not assume that participants will be averse to receiving written information, they should be equally prepared to discuss information with participants with extensive health-related knowledge and experience. Moreover, given that information-sharing commonly occurs across social networks by word of mouth,³²⁻³⁴ researchers can leverage further dissemination by attending to the importance of communication with “key informants” across multiple communication modes.^{35,36}

Our study is subject to limitations. First, of 14,959 CCS clients we enrolled just 47. Second, while questions were structured to promote open-ended discussion, we targeted specific topics of inquiry and are limited in extrapolating implications of these findings. Third, like many qualitative studies, our sample may be skewed toward clients who were willing to share their personal challenges or were motivated to participate as a potential learning opportunity. As one participant commented, “[CCS clients not in the focus groups] are not here now because they have low self-esteem... I think we’re here because we’re brave, because we want to know more.” Individuals declining focus group participation may be more responsive to discreet (e.g., one-on-one interview) or anonymous (e.g., survey) data collection modes. Using multiple data collection modes may enable investigators to engage a more diverse sample.^{37,38}

Despite these limitations, our study demonstrates the value of engaging nonclinical populations by establishing academic partnerships for research with trusted community organizations. The positive reputation and staff rapport that CCS enjoys with its clients, as well as the focus group format of our study, facilitated remarkably candid and detailed information about the multiple challenges faced by participants. The use of qualitative methods was effective in yielding both an enhanced understanding of the health needs and behaviors of a population with limited healthcare system engagement as well as unexpected insights about this population that may inform future interventions to improve their health status.³⁹ The ease of recruitment for this study and participants’ positive attitudes toward future research participation suggest that CCS will be an ideal location for continuing to design and implement future research and interventions.

Conclusion

CCS clients represent a high-need, under-reached population that is willing to engage in health-related research that affords opportunity to connect with peers in group settings and obtain information that enhances their ability to contend with daily life challenges. Participants were open to discussing their health status, knowledge and utilization of health services. Partnerships like the CARE Initiative can facilitate recruitment of an otherwise under-reached, low-income, underinsured/uninsured, racial/ethnically diverse people. With an enhanced understanding of attitudes and behaviors, the CARE Initiative is well-positioned to undertake future research and intervention in this vulnerable population that might otherwise remain understudied by clinical researchers.

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Appendix. FocusGroup Guide Questions

Topic	Key questions (to all focus groups) Prompts (as necessary)
Intro-duction	*How many people live in your household? For example, you could say 5 - me, my husband, my 2 kids, and my mother.
	How long have you been coming to +CCS? For example, you could say '4-5 times a year or once a month for the past 2 years'.
Health status	*What are some of the main health issues you and your family face? Do these health problems get in the way of your daily life? Do you think a lot of other +CCS clients have [health problems mentioned] too? Why do you think that is/isn't? Do you think other people in the community outside of +CCS have [health problems mentioned] too? Why do you think that is/isn't?
	*When you or a member of your family has a health problem, where do you usually go for help? For example, do you go to a doctor's office, or the Emergency Room, or a Parkland clinic or a hospital? If you have a question about your health or your family's health, where do you go to find the answers or more information? Is there anything that +CCS could do to help you with these health issues?
	General challenges
	We know that many people have challenges in their daily lives. What are some of biggest challenges you and your family face? These can be temporary problems, or daily challenges. Has coming to +CCS helped you in handling these challenges? How has it helped? For example, has getting the food and clothing assistance from Crossroads helped you to do other things that you weren't able to do before? Has coming to Crossroads changed any part of your family life? How do you think Crossroads will help you in the future? It sounds like many of you take care of a lot of people. Are there people in your life who help you when you need help? For example, do you turn to a family member, a friend, a priest?
Mammo-graphy	*How many of you know what a mammogram is? *How many of you have had a mammogram? When was the last time you had a mammogram? Do you get them regularly? Where do you go to get a mammogram? Do you think that women who come to Crossroads get mammograms?
	*Why do you think some women don't get mammograms?
	Future research
	*If +CCS and UTSW wanted to do more research like this in the future, how many of you would you feel comfortable participating? *What concerns would you have about talking about your health with +CCS or UTSW staff and volunteers? For example, would you be embarrassed to talk about your health issues? *If we wanted to ask +CSS clients about their health, do you have suggestions for how we should do this? For example, would you prefer to answer questions in a private space, or in a group like this? Would you feel comfortable answering questions about your health during your regular +CCS intake? Now I'd like you to imagine that a researcher from UT Southwestern, such as myself, asked you to be in a research study in the future, and we wanted to look at your medical records as part of that study. How many of you would be interested in participating in a study like this? For example, this might be a telephone survey where we ask you more detailed questions about high blood pressure and then examine your health records to see how many times you've visited the doctor for this problem. Or this might be a face-to-face survey for women here at Crossroads where we ask about mammography and examine your health records to find out when you had your last mammogram, and what the results were. *What concerns would you have about us looking at your health records? Would you feel embarrassed? Would you worry about your privacy?

*Topics reported on in this manuscript
+CCS = Crossroads Community Services