Leveraging a Community-Based Research Approach to Explore Research Perceptions Among Suburban Poor and Underserved Populations

Melissa A. Simon  
_Northwestern University, m-simon2@northwestern.edu_

Daiva M. Ragas  
_Northwestern University, d-ragas@northwestern.edu_

Colin Willis  
_Northwestern University, colin.willis@colostate.edu_

Nadia Hajjar  
_Northwestern University, nadia.hajjar1@northwestern.edu_

XinQi Dong  
_Rush University Medical Center, xinqi_dong@rush.edu_

See next page for additional authors

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Leveraging a Community-Based Research Approach to Explore Research Perceptions Among Suburban Poor and Underserved Populations

Melissa A. Simon, Daiva M. Ragas, Colin Willis, Nadia Hajjar, XinQi Dong, and Kara Murphy

Abstract

This qualitative study explored perceptions of research among a rapidly growing underserved population within a suburban community, a setting that has yet to be sufficiently explored using a community-based research (CBR) approach. We recruited community members from community health care agencies in DuPage County, Illinois, and 79 participants were enrolled in the study. Community researchers conducted nine focus groups comprised of agency clients and eight stakeholder interviews to collect community perspectives regarding the meaning of research and its community impact, current and desired channels of research information, and research motives, discrimination, and funding. Findings revealed four major themes: community members 1) often associate research with medical research or community engagement; 2) rely most heavily on the internet for research information; 3) perceive financial barriers, rather than racial or ethnic barriers, as a significant obstacle to receiving the benefits of research; and 4) trust research conducted by academic institutions.

Health disparities research among low-income, minority populations has centered on urban and rural communities (Ansell, Grabler, Whitman, Ferrans, Burgess-Bishop, Murray, Rao, & Marcus, 2009; Corbie-Smith, Akers, Blumenthal, Council, Wynn, Muhammad, & Sith, 2010; Meade, Menard, Luque, Martinez-Tyson, & Gwede, 2011; Williams, Mabisco, Todem, Hammad, Hill-Ashford, Hamade, Palamisono, Robinson-Lockett, & Zambrana, 2011). These communities typically provide affordable residential areas for minority groups, making these areas convenient and meaningful locations for CBR. When successful, CBR fosters community-led initiatives intended to create and sustain improved health and well-being (Ramsden, McKay, & Crowe, 2010). Undergirding CBR is a recognition that communities are rich in assets that, when harnessed, result in impactful social change. Communities must therefore have an active and engaged voice alongside their academic colleagues, in both goal setting and interventions. Unlike traditional methodologies, the researchers, specifically in the case of health care providers, are responsible for facilitating community members to examine their local needs in areas such as personal health and community well-being, and to develop potential strategic solutions in the form of interventions (Ramsden, McKay, & Crowe, 2010). The overall goal of this approach is to develop interventions that are appropriate and meaningful for the particular community context. This ideal could not be achieved without the involvement of community voices and agents in every stage of research.

While previous studies have examined both rural and urban communities within a CBR framework, suburban communities are underrepresented in the literature (Meade, et al., 2011; Rodriguez, Bowie, Frattaroli, & Gielen, 2009; Scarinci, Johnson, Hardy, Marron, & Partridge, 2009). Further, research into the health care challenges and needs of low-income, minority individuals in suburban areas is distinctly lacking, despite evidence of increasing suburbanization of both minority populations and poverty. A dramatic rise in poverty rates in Midwestern and Southern suburban areas, as indicated by the 2006 Brookings Institute Report, has provoked new health care disparities that current research is unequipped to handle (Berube & Kneebone, 2006).

DuPage County is a collar county near Chicago, Illinois in which the population of low-income, ethnic minority residents has risen swiftly and the number of limited English proficient residents has increased dramatically in recent decades (Barbieri & Iverson, 2005). Between 2000 and 2009, the percentage of DuPage County residents living below the federal poverty line rose by 182% (U.S. Census Bureau, 2010a). Furthermore, over the past two decades, Latinos, African Americans, and Asians in DuPage have increased by 253%, 173%, and 134%, respectively, while the percentage of non-Hispanic Caucasians has declined by 9.6% (U.S. Census Bureau, 1990,
Lacking infrastructure to support increased poverty density, suburban low-income, minority populations present novel challenges to health care providers. Many suburbs have limited access to safety net health services like free clinics and federally qualified health centers, with available services exacting higher cost to consumers. Furthermore, suburban facilities are often unequipped to serve non-English speaking and limited English proficient patients. (Marmot, Ryff, Bumpass, Shipley, & Marks, 1997). Together, this environment presents low-income, ethnic minority populations with significant barriers to acquiring adequate health care and culturally appropriate health information.

Derived directly from community-identified needs, this study seeks to bridge a gap in research knowledge, education, and communication by strengthening a budding academic-community partnership between Northwestern University and DuPage Health Coalition, a mature collaboration of 215 health, human service, and governmental partner organizations, coordinating affordable health care for a rapidly growing population of low-income DuPage County residents. Together, the academic and community partner’s recent history of collaboration in community-engaged research lays the foundation for this community-based research study. Our academic-community partnership leverages the community partner’s local knowledge and engagement with an academic partner’s established record of community-engaged research in underserved populations. This relationship aims to reduce health disparities in DuPage County by improving communication between underserved suburban populations and medical research through partnership with community health care agencies and stakeholders.

To our knowledge, this is the first CBR study to elicit perceptions of research within an underserved suburban community. To drive future research and interventions within this community, we qualitatively examined community members’ knowledge and attitudes about research using focus groups and semi-structured interviews. Our study seeks to strengthen future CBR research implementation, evaluation, and dissemination focused on improving understanding of and participation in research within a rapidly growing, underserved suburban population.

**Methods**

**CBR Framework.** CBR methodology drives researchers to become intimately involved in the community, which, especially in highly diverse areas, can cause tension (Green, 2004). This quality of CBR, coupled with cultural sensitivity to poor quality or unethical research throughout history, requires a set of principles that provides the tools to navigate potential personal and communal conflicts (Wallerstein & Duran, 2010). We developed this study following the principles and recommendations outlined in Israel, Parker, Rowe, Salvatore, Minkler, López, Butz, Mosley, Coates, Lambert, Potito, Brenner, Rivera, Romero, Thompson, Coronado, and Halstead (2005). Three principles in particular guided this study: 1) a focus on the perspective of the community with regard to local health issues; 2) the mutual learning and empowerment of community partners; and 3) the use of community knowledge to develop respective interventions. Together, these principles provided a foundation to explore perceptions of research within the DuPage County community, allowing for future context-specific and culturally appropriate research and interventions.

The study was initiated in close collaboration with DuPage Health Coalition, the community partner. Academic and community partners both identified the low prevalence of basic research knowledge and education among underserved populations within DuPage County. Building on a desire to enhance the research literacy of the community, the research team, comprised of academicians from Northwestern University and community leaders from DuPage Health Coalition, sought input on study design and implementation from a diverse group of community members using a grassroots approach. Through snowball sampling, we reached out to community leaders representing civic and political sectors, faith and religious institutions, health care, and social and non-profit organizations. We conducted meetings to learn more about the needs of DuPage County residents and to seek recommendations on securing community support and engagement. We discussed the goals of the project, study procedures, expectations of residents, as well as risks and benefits at the individual and community levels. To adequately align scientific goals with community concerns, community members further refined common goals and recommended new avenues of academic pursuit.

**Sampling and data collection.** Once the interview tool was developed, we recruited participants from a convenience sample of local health and human service agencies, seeking recipients of direct services as well as...
The community partner conducted focus groups and stakeholder interviews on-site at the community agencies from May 2009 to December 2009. To recruit focus group participants, community partners placed flyers in health and social service affiliated local care sites. English or Spanish-speaking DuPage County residents, aged 18 or older, were eligible for focus group participation. Ultimately, nine focus groups formed from eight community agencies represented, with each group consisting of six to eight participants. The Young Parent Group accounted for two of nine focus groups. For the stakeholder interview portion of the study, the community partner personally invited constituents to participate in individual interviews. Invited community leaders were also required to live in the community, and no minors were permitted.

A mixed methods design utilizing a combination of qualitative, semi-structured focus groups and interviews and demographic data collection provided an apt framework to actively engage study participants from the community. The research team developed the interview guide based on a culturally appropriate, community-focused baseline needs assessment of knowledge and attitudes regarding research in the community. Interview questions prompted participants to discuss community definitions of research, personal topics of interest, areas of interest for future research, the current status and availability of research in the community, and the most trusted sources for research in the community. Additionally, each participant completed a form reporting demographic data.

A bilingual/bicultural, trained community researcher conducted focus groups in English or Spanish on-site at the community agencies, in private spaces sensitive to cultural and social norms congruent with participating groups. A team member accompanied the community researcher to record data and group observations. The academic partner transcribed the audio recordings of each focus group and interview, while the academic partner and community partner collaborated in analyzing the

### Table 1. Focus Group Descriptions

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Description of Recruiting Activity</th>
<th>Focus Group Demographic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young Parent Groups</td>
<td>Non-profit agency providing comprehensive services and programs related to young pregnancy and parenting</td>
<td>18-31 years old; male and female; Honduras, Guatemala, Mexico, Poland, U.S.; majority insured</td>
</tr>
<tr>
<td>Care Connection Group</td>
<td>Non-profit organization connecting health care professionals with organizations servicing free clinics, to address health disparities among homeless and low-income minority residents whose primary language is not English</td>
<td>23-33 years old; female; Mexico; uninsured</td>
</tr>
<tr>
<td>Child Enrichment Program Group</td>
<td>Federally-funded child development program providing health and educational services, experiences, and counseling for parental involvement to help prepare low-income children and children with disabilities to enter and succeed in school</td>
<td>25-51 years old; female; Honduras, Mexico; uninsured</td>
</tr>
<tr>
<td>Community Clinic Group</td>
<td>Free community clinic providing low income, medically uninsured residents with primary medical care, specialty medical care, and/or or mental health services</td>
<td>21-48 years old; female; Philippines, U.S.; majority uninsured</td>
</tr>
<tr>
<td>Recovering Substance Abuse Group</td>
<td>Addictions treatment facility providing holistic treatment and services for individuals recovering from chemical dependence and substance abuse</td>
<td>23-52 years old; male and female; U.S; uninsured</td>
</tr>
<tr>
<td>Conflict Safe House Group</td>
<td>Multilingual, multi-cultural social and health service agency serving South Asian, Middle Eastern, and Bosnian Communities; promoting physical and emotional health and psychological well-being of individuals and families</td>
<td>24-80 years old; male and female; Pakistan, U.S.; majority insured</td>
</tr>
<tr>
<td>Poverty-Stricken Group</td>
<td>Non-profit agency providing support and services to the homeless, including crisis intervention and support, screening and needs assessment, permanent supportive housing, and life skills coaching</td>
<td>20-61 years old; male and female; Poland, U.S.; majority uninsured</td>
</tr>
<tr>
<td>Private Insured Group</td>
<td>Residents with private medical insurance</td>
<td>20-45 years old; female; Syria, U.S.; insured</td>
</tr>
</tbody>
</table>
transcripts. Participants provided written informed consent and were moderately reimbursed for their time. The study was approved by the Northwestern University Institutional Review Board.

**Data analysis.** Following an inductive approach, the data analysts (Willis, Hajjar, and Ragas) analyzed each focus group and stakeholder interview transcript to synthesize data and identify themes, and subsequently organized and summarized transcripts in a qualitative database. Quotations that directly addressed each question and added to discussion were captured in the database. For each question, the research team identified emerging themes, discussed and integrated the main findings, and identified exemplary quotations for the findings. Analysis continued until no new themes emerged and thematic saturation was reached. Status updates on the study and our findings were presented at regularly-held community advisory board committee meetings, and feedback from these meetings influenced the interpretation of the findings.

**Results**

**Sample characteristics.** The study sample included eight community stakeholders and 71 clients from eight community health care agencies. Of the 79 community members enrolled in the study, 70.9% were female. Participants’ mean age was 32.9 years (n = 74), with a range of 18 to 80 years old. Participants had lived in DuPage County from five to 50 years and originated from the United States (57.0%), Latin America (Colombia, Guatemala, Honduras, Mexico; 26.6%), Asia (Pakistan, Philippines, Syria; 11.5%), or Europe (Poland; 2.5%). All stakeholders and 33 agency clients were privately insured. Of participants, 55.7% were employed, 29.1% were unemployed, and 15.2% were students (see Table 2).

**Qualitative results.** We identified theme categories from larger patterns that emerged from focus groups and stakeholder interviews. These categories include: Understanding Research, community members’ definition of research and its significance; Community Impact, the relationship between a group’s community and its members’ positive or negative perception of research; Research Awareness, community members’ awareness of current research and potential research topics; and Research Intentions/Prejudice, community members’ perception of bias, prejudice, or discrimination in research. These categories provide a consistent, explicative means to grouping themes that emerged from transcript analysis.

**Understanding of research.** Participants were asked to define research and specify, if possible, the differences between “medical” and “scientific” research. All focus groups alluded that research is a process of or a set of tools for gathering information, and most stakeholders elaborated on the formal research process:

…finding the symptoms and solutions to an illness, or the answers to many questions. A research is based on finding the truth and finding answers to many questions that perhaps we don’t have very clear. (Care Connection Group)

…[T]he formal process of either making observations or taking measurements and collecting and aggregating those for different groups along the lines of a formal research study with independent variables.
and dependent variables ... that’s just one model, but to determine if there’s a relationship between those variables, and if so to try to determine to the extent possible if there is a causal relationship or what is the nature of that relationship. Then in common everyday usage, I think people use the term just to mean finding out more information about something. (Stakeholder)

While many participants defined research in the context of advancing general knowledge, some focus groups and most stakeholders set research into the context of health and medicine. The Young Parent and Care Connection Groups focused on research as finding a cure to a disease or improving a standard of care. Of those focus groups that did not mention medicine specifically, responses tended to include aspects of research design such as experiments, statistics, data, and methodology. The Private Insured Group elaborated on the details of research, using terms like “placebo,” “hypothesis,” and “data-driven”. The Young Parent Group agreed upon the following definition:

…[Y]ou start out with a problem or a question. Research is what you do...when you study using surveys, experiments, questions, discussions. There are probably lots of other tools there in order to study health or your problem in order to find a solution to gather information to look for an answer to your problem. (Young Parent Group)

While the notion of scientific research frequently prompted descriptions of laboratories, sophisticated methodologies, and a specific goal or hypothesis, medical research was defined differently. Participants described their understanding of medical research similarly to community engagement; they reported that medical research functioned by assessing individual and community health, involving the community, or interacting with a health care practitioner on a personal level. Focus groups differentiated the personal nature of medical research from scientific research:

I think the difference is with scientific they’re in a lab and they have a set study that they’re working on specifically. In a health study it could be like you come to like a particular group whether it’s a doctor’s office or a lab or whatever that is specifically focused like on the study of say something within diabetes or the thyroid or cancer and you go through a series of certain number of weeks or months for the research to find out whether sub group A has this finding or sub group B has that particular finding. (Community Clinic Group)

Community impact. Participants were asked to consider whether research helped or harmed themselves or their communities, whether research was appropriate for their communities, and whether community values should be considered during research. Most participants, regardless of background, age, or focus group, identified research as beneficial, and examples were most often related to community health. Instances when a family or community member benefited from medical research were frequently reported; otherwise, many participants hoped that future research would ameliorate systemic public health problems, such as smoking and diabetes.

One of the primary benefits research offered this community was access to care: Individuals who might not otherwise qualify for health insurance expressed gratitude for the services medical research provided to them. The Child Enrichment Program Group articulated this benefit of research:

…[A]s Latinos, there are many people that don’t have the means to have medical insurance.....You have a chronic illness and you don’t know where to go. So right now what we’re seeing is that...people like you, that make a lot of research to see who really needs and who’ll get help... Well, it does benefit us.

The Private Insured Group, who recognized the mutually beneficial relationship community engagement creates, extended this notion:

For a long time we thought only certain health research or scientific research are done in this big bubble but now it’s extending to everyday life...and we’re feeling the benefits and...the research community is feeling the benefits that if you’re taking quotes from the people you can get better results...
Furthermore, the group indicated that the community engagement process, actively involving the community in discussion and research, has secondary benefits such as the fortification of personal relationships between the community, health practitioners, and the research team. A participant from the Poverty-Stricken Group reflected:

I think research really helps the community a lot in my opinion because when you really get in there and get enrooted to what the real person, not just something on a piece of paper, is feeling, then you know what you’re writing is something that’s real.

Some participants, however, raised critical opinions regarding research practices and discussed questionable research motives. Participants who suggested that research could cause harm often raised concerns about the motives of for-profit entities, like pharmaceutical companies:

I think specifically when it comes to pharmaceuticals they tend to have it be faster than what it is. Because for example they say it can cure this symptom but then afterwards you have five different symptoms which had nothing to do with the original illness. (Poverty-Stricken Group)

Further, participants indicated that research could be misleading to uneducated members of the community or that researchers could misinterpret or inflate data, possibly leading to exaggerated results and implications.

When the results of research are taken out of context there is a danger…reporting bias...that studies finding a negative result or an insignificant result are rejected by journal publications or not even submitted. (Stakeholder)

Other participants discussed issues regarding research dissemination, use, and applicability to the community. A common concern was the readiness of research to be released:

I think if information is thrown out there too soon to the public it can cause a panic. You know not enough information provided when it’s first exposed to the general public that it can cause a panic. So it could be harmful if it’s not done in the right way. (Community Clinic Group)

Finally, participants discussed whether community values should be considered in research. The Young Parent Group offered an analysis of community values, concluding that targeting at-risk groups will most involve the community in research:

…[I]f they come and ask us about something that’s not affecting us, then we’re not going to go anywhere. So if the community participates and they say that they’re interested in a research about autism or obesity in kids or cholesterol that is affecting kids and adults…well, then the community will be more involved, and it will be better suited for the necessities we have.

The Care Connection Group offered another reason to consider community values, specifying personal motivations and cultural influences:

That us Latinos are sometimes afraid to speak of the problems we have…for example, when they’re asking us about a disease we have…. Sometimes we don’t say it all, what we feel and what we want to know, for fear, because we don’t feel comfortable…. Other cultures don’t have this fear.

The Child Enrichment Program Group, one of the strongest supporters of medical research in the community, also discussed a fear salient in the minds of this underserved group:

Is it beneficial? Yes and no at the same time…. One gets intimidated, like her. Right now she doubted because she thinks, what’s happening? What am I signing? And we’re all like that. And there are times where not all of us speak up for fear that…what if it’s for migration? What if they call? What if they knock on my house? And the way the situation is right now, many times you don’t answer many things because of the fear of being researched thoroughly.
Research awareness. Participants were prompted to list where they learned about research, how they wanted to learn about research, and which topics they deemed relevant for research. The most commonly reported sources for research information among focus groups were the Internet, particularly Google Search or WebMD sites, the news, and a personal physician. Other participants reported their children’s schools, radio, magazines, the library, and word-of-mouth as sources for research. Some stakeholders additionally mentioned the Centers for Disease Control and Prevention, the state health department, community health organizations, professional associations, and academic journals as current sources of research awareness.

Focus groups found that the potential sources to which they could have access for research information outnumbered their current sources. Potential new sources reported by focus groups included the Internet, overt advertisements like billboards, radio ads, advertisements in grocery stores, public flyers, and mailings. Participants were also asked to discuss research topics that were relevant to their lives. Topics of interest among focus groups and stakeholders included mental health, women’s and children’s health, diabetes, smoking cessation, health disparities, healthy lifestyle promotion, and other issues related to health behaviors. The Young Parent Group captured the sentiments of many participants:

I live in DuPage County now…. [T]here’s a gap. There’s a big variation in classes and I guess I would overall like to see some type of research and a…change in that gap. So research how to even the playing field.

Research intentions and prejudice. Participants were asked to consider whether health research benefited the poor and uninsured, whether research was affected by prejudice or racism, and whether knowing who funds research was important to the community. Most participants indicated that research intended to help the uninsured, but some participants disagreed:

The research is directed towards the people who can actually go into the doctor’s office or find out about medical trials through their doctors and get the information that the sick person who can’t afford to go to the doctor can’t. (Young Parent Group)

I think sometimes yes, it helps everyone across the board and then sometimes I think there are studies or there are findings specifically that are going to pertain to persons who can afford health care that have definite insurance or have the ability to pay. If you’ve got money, then you’re going to get whatever you want. If you don’t have money, then you have to wait. (Community Clinic Group)

Many focus groups and stakeholders perceived that money was the greatest factor in determining the purpose of research and the scope of its benefits. The Recovering Substance Abuse Group, on the other hand, recognized that health research has far-reaching benefits:

It helps all people across the board. You know? Of course, if you’re doing research, disease isn’t biased. It just affects the rich or the poor or the black or the white or, you know Mexicans. It helps all mankind. It’s just that some people are so readily available to receive it. You’ve got people that live in Third World countries that aren’t going to have the same medical options that people do in Western cultures and societies.

Most focus groups and stakeholders acknowledged the presence of racism or prejudice in research, but emphasized an association with financial barriers:

…but when we look at the discrepancies of mortality rates, you look at OK this year so many blacks dying from this disease while you have a much lower number of whites or Hispanics or whatever, well, why does that happen? So I would say that I don’t know if it would go back to what I said at the beginning about insurance, are they treating you better because you are white and you have money or you have a good insurance versus you’re black and you don’t have money, you don’t have insurance, you know? So there are so many things that are linked together. (Stakeholder)
Another stakeholder added that research can be prejudiced when population demographics are not adequately considered:

Indirect in the sense that medical research is biased though. Medical research is biased because most of the times... their research participants are from the mainstream community. They do not take into the consideration, you know, the demographic of DuPage County is not Caucasian.

Participants were somewhat divided on whether knowing who paid for research was important. Some focus groups mentioned apprehension of the government:

...[J]ust because of African Americans’ history dealing with the government and the different type of research, I would be more apprehensive. African Americans typically speaking...are more apprehensive when it comes to law enforcement or government officials than maybe say other ethnic groups because of our treatment historically here in America. (Young Parent Group)

Many focus group participants favored research conducted by academic institutions, while stakeholders spoke positively of government-funded and academic research:

I would probably be the most green light with the academic research institution because that is sort of their expertise, and then if I thought that the study sounded sound I would be eager to participate in a government-funded study because I would want them to have more valid data that I can contribute to, and when it’s a private corporation running the study I kind of feel like my voice has less of an impact.... I would see a private enterprise as potentially more biased. (Stakeholder)

More commonly, participants were indifferent about who funded research:

I think that it’s more about knowing where we are getting the support from. Not so much knowing that they are paying for it. (Care Connection Group)

Discussion

Results revealed that DuPage County community members have many insights from which researchers can learn to improve future interventions. Four major themes arose from the analysis of focus groups and stakeholder interviews: 1) community members’ understanding of community engagement in defining research and determining its value; 2) the Internet as a dominant source for research awareness; 3) concerns regarding the effects of privately funded and commercial research on the community; and 4) financial barriers to research and health care.

When asked to discuss the difference between “scientific” and “medical” research, the notion of medical research subsumed scientific research. Furthermore, participants frequently equated medical research to community engagement, likely because the research most familiar to and most easily defined by the community is research which involves the community most. Focus groups often pointed to the personal connections made during community interventions and clinical interactions as the creation and fortification of their positive view of research. It is therefore critical that researchers are genuine and perform community-centric research as such a degree of involvement will leave an impression on the community, affecting future research.

Although participants’ access to research was limited, a number of resources were repeated: the Internet, personal physicians, the news, and publications. Nearly all focus groups mentioned the Internet as a resource that they used most and wanted to use more. Participants mentioned physicians as sources for research information as much as the Internet; however, unlike the Internet, physicians were not mentioned as a potential new source for research, suggesting some untapped potential in the Internet as a research dissemination tool. For instance, the Internet could be tailored even more toward delivering useful, personalized information, such as local research. Further, while our findings suggest that current sources of research are meager, as some focus groups did not report any research sources, each group reported numerous possibilities for how they could be informed of research. In this community, an apparent imbalance exists between the potential and current level of research awareness. It is likely and acceptable that this will always be the case; however, the current disparity warrants investigation into how to best disseminate research to this population.
Despite the prevailing positive perception of research throughout focus groups and stakeholder interviews, a number of key concerns regarding the intentions and dissemination of research arose. Participants feared that some researchers may have questionable motives and distrusted for-profit entities. While many participants appeared indifferent to who conducted research, others criticized pharmaceutical companies for engaging in research that primarily served to develop drugs or treatments for profit. Participants both praised and criticized government entities. Perhaps unsurprisingly, minority-centric focus groups expressed unease for government institutions due to immigration issues or past treatment. Other focus groups and stakeholders were less reactive to the government conducting research, as they believed governmental research intended to benefit people. The academic institution emerged as the most trusted research entity, an expected finding due to this community’s past involvement with academic research. Participants feared that researchers, or research disseminators like the news, may frame a study in such a way to appear more successful or significant, which can pose major implications in a community. Participants voiced concern that research tends to be released in ways that cause a fad, such as a new diet, or panic, like the vaccination-autism scare. These fears suggest that research dissemination is not ideal; rather, the examples participants provided suggest that the media’s spin on research has a significant, at times negative, effect on research perceptions.

Although some focus groups discussed sensitivity to immigration issues, when asked about the relationship between racism or prejudice and research, participants predominantly discussed financial prejudice and identified financial obstacles as the most significant barriers to care. Some participants, however, equated financial barriers to a different form of prejudice, as economic burdens are more commonly born by minority populations. Nonetheless, participants generally felt that financial barriers were unrelated to racism, pointing to otherwise positive interactions with clinicians.

While the design of our study elicited important findings, the results are limited by the sample. Although 79 participants composed the sample, there were typically only 6-8 participants per focus group. Furthermore, all study participants were volunteers, which likely resulted in response bias. These factors combined with a lack of demographic data—namely, lack of ethnicity data, incomplete demographic data due to self-report, and the inability to individually identify the speaker of a particular focus group quotation—inhibit the generalizability of our results to other populations.

In addressing the need for greater understanding of research perceptions and means for dissemination, our study followed the recommendations outlined by Glasgow, Marcus, Bull, and Wilson (2004), Montoya and Kent (2011), and Wallerstein and Duran (2010). Specifically, a bicultural/bilingual community researcher conducted all interviews in which the research team directly addressed the perceptions of many segments of the community while building upon previous work in developing trust and rapport in the DuPage County community, extending recommendations by Alexander and Richman (2008). While previous research has noted that one individual performing in both a service provider and focus group leader role can cause complications (Smith, 2008), this relationship instead allowed our research methodology access to otherwise guarded thoughts and insights from the community that will help future research initiate community-appropriate interventions. Future studies should consider involving the community more in data collection, as past research has demonstrated that community members are as effective at collecting data as traditional academic data collectors (Brugge, Kapunan, Babcock-Dunning, Matloff, Cagua-Koo, Okoroh, Salas, Bradeen, & Woodin, 2010).

This study sought to expand the literature by adding valuable CBR data on the growing underserved low-income, minority communities in suburban areas. Findings suggest that CBR is well-received and salient in this community and, as a whole, participants reported positive attitudes regarding research. Considering the rapid growth of underserved communities in suburban areas, CBR will become an instrumental tool in navigating the inevitable tensions between a growing community and an area traditionally unfamiliar with these new populations. Likewise, further research into suburban low-income, minority communities is necessary to gain a proper understanding of the needs of both the new and old communities before initiating interventions. Creating and maintaining social services, such as the programs offered by DuPage Health Coalition, will be invaluable to communities and researchers alike in the next decade (Cargo & Mercer, 2008).

Key take-home points. Future research
and interventions resulting from this study should address three things. First, expanding the community’s understanding of research should be a goal to prevent community members from avoiding or missing research that may benefit them. Second, exploring the potential of the Internet as a means for research dissemination would be highly valuable following the conclusions of this study. Given the ease of access to the Internet and the ease of developing web pages with today’s resources, the ability to generate low cost, local resources for research dissemination is unprecedented. Finally, following the community’s focus on financial barriers to research participation or awareness and resulting health care, investigation into the pervasiveness of this barrier and means to deconstruct it are needed. Developing resources to increase research participation and awareness among low-income, minority members of DuPage County would be a major step toward better understanding and preempting health disparities in this rapidly growing, underserved suburban community.

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About the Authors
Melissa A. Simon is an associate professor in Obstetrics and Gynecology, Preventive Medicine, and Medical Social Sciences at Northwestern University Feinberg School of Medicine. Daiva M. Ragas is research project coordinator at Northwestern University Feinberg School of Medicine. At time of acceptance Colin Willis was a research intern at Northwestern University Feinberg School of Medicine and student at Lake Forest College. Nadia Hajjar is project coordinator, and patient navigator at Access DuPage/Northwestern University. XinQi Dong is associate director of Rush Institute for Healthy Aging and an associate professor of medicine at Rush University Medical Center. Kara Murphy is executive director of Access DuPage/Northwestern University.

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