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## STRUCTURAL AND HIDDEN BARRIERS TO A LOCAL PRIMARY HEALTH CARE INFRASTRUCTURE: AUTONOMY, DECISIONS ABOUT PRIMARY HEALTH CARE, AND THE CENTRALITY AND SIGNIFICANCE OF POWER

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### Abstract

**Purpose:** To examine a local primary health care infrastructure and the reality of primary health care from the perspective of residents of a small, urban community in the southern United States.

**Methodology/approach:** Data derive from 13 semi-structured focus groups, plus three semi-structured interviews, and were analyzed inductively consistent with a grounded theory approach.

**Findings:** *Structural barriers* to the local primary health care infrastructure include transportation, clinic and appointment wait time, and co-payments and health insurance. *Hidden barriers* consist of knowledge about local health care services, non-physician gatekeepers, and fear of medical care. Community residents have used home remedies and the emergency department at the local academic medical center to manage these structural and hidden barriers.

**Research limitations/implications:** Findings might not generalize to primary health care infrastructures in other communities, respondent perspectives can be biased, and the data are subject to various interpretations and conceptual and thematic frameworks. Nevertheless, the structural and hidden barriers to the local primary health care infrastructure have considerably diminished the autonomy community residents have been able to exercise over their decisions about primary health care, ultimately suggesting that efforts concerned with increasing the access of medically underserved groups to primary health care in local communities should recognize the centrality and significance of power.

**Originality/value:** This study addresses a gap in the sociological literature regarding the impact of specific barriers to primary health care among medically underserved groups.

### Keywords

*Structural and hidden barriers; Local primary health care infrastructure; Autonomy; Decisions; Power; Health disparities*

### Introduction

In 2000, former United States Secretary of Health and Human Services Donna E. Shalala and former Assistant Secretary for Health and Surgeon General David Satcher challenged the nation to accomplish the agenda set forth in *Healthy People 2010*, an ambitious array of health-related objectives and focus areas intended to increase the life quality and expectancy

among all Americans by 2010 and to entirely eliminate health disparities. Diversity is one of the country's most important attributes, Shalala and Satcher declared, but it also presents an enormous challenge with respect to improving the health of the American population, in particular "the principle that—regardless of age, gender, race or ethnicity, income, education, geographic location, disability, and sexual orientation—every person in every community across the Nation deserves equal access to comprehensive, culturally competent, community-based health care systems that are committed to serving the needs of the individual and promoting community health" (U.S. Department of Health and Human Services, 2000, p. 16).

That *Healthy People 2010* sought to ensure equal access to community-based health care systems for "every person in every community across the Nation" reconfirmed that a substantial portion of Americans confronted numerous barriers to health care in their local community, this despite myriad efforts since the mid-19th century to reduce such barriers (see Dell & Whitman, 2011; U.S. Department of Health and Human Services, 1990; Williams & Sternthal, 2010). As we detail shortly using data that convey the long-term relevance of this *Healthy People 2010* principle, less pronounced in the current *Healthy People 2020* report (U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion, n.d.), barriers to health care in local communities have included transportation (e.g., Ahmed, Lemkau, Nealeigh, & Mann, 2001; Carr, Ibuka, & Russell, 2010; Horton & Johnson, 2010; Pesata, Pallija, & Webb, 1999; Rittner & Kirk, 1995; Silver, Blustein, & Weitzman, 2012), wait time for medical care (e.g., Carr et al., 2010; Green et al., 2008; Kaplan et al., 2006; Pesata et al., 1999; Rust et al., 2008), treatment costs and inadequate or no health insurance (e.g., Ahmed et al., 2001; Horton & Johnson, 2010; Seccombe & Amey, 1995; Snead & Cockerham, 2002; Stevens & Keigher, 2009), scarce information about health services (e.g., Ahmed et al., 2001; Kirby & Kaneda, 2006; Silver et al., 2012; Thiede, 2005; Umberson & Montez, 2010), run-ins with non-physician staff at community clinics (e.g., Arber & Sawyer, 1985; Barr & Wanat, 2005; Ford, Tilson, Smurzynski, Leone, & Miller, 2008; Hughes, 1989; Kaplan et al., 2006), and the unintended consequences of medical diagnoses (e.g., Darby, Davis, Likes, & Bell, 2009; Ford et al., 2008; Green et al., 2008; Jutel, 2009; Martin et al., 2010). The research literature has of course covered how race, ethnicity, and socio-economic status can act as barriers to health care (e.g., Barr, 2008; Budrys, 2010; Cockerham, 2007; Eiser & Ellis, 2007; Hoberman, 2012; Horton & Johnson, 2010; Kasper, 2000; Kirby & Kaneda, 2005; Kronenfeld, 2005, 2010; Lichtenstein, 2003; Link & Phelan, 1995; Lutfey & Freese, 2005; Martin et al., 2010; Mechanic, 2002; Williams, 2012; Williams & Collins, 1995; Williams & Sternthal, 2010) as well as methods utilized to handle these barriers (e.g., Boyd, Taylor, Shimp, & Semler, 2000; Brown & Segal, 1996; Eiser & Ellis, 2007; Koenig, McCullough, & Larson, 2001; Malone, 1995; Martin et al., 2010; Rust et al., 2008; Shippee, Schafer, & Ferraro, 2012; Walls, Rhodes, & Kennedy, 2002).

Barriers to health care in local communities, however, do not simply limit access to health care in general. More to our focus, barriers to health care in local communities limit access to local systems of health care clinics and hospital services that comprise a local primary health care infrastructure. One route to better understand barriers to a local primary health care infrastructure, including the broader significance of these barriers to the individuals who confront them, is to consider the perspectives of community residents whom the infrastructure should serve. Indeed, a "micro-community" approach is suited to capture "local level" perspectives (Channing, 2011, p. viii) about barriers to health care (U.S. Department of Health and Human Services, 2000). Community-specific data can expose local barriers to a primary health care infrastructure and strategies local residents use to manage these barriers (see Shah, Whitman, & Benjamins, 2011).

In this chapter, we examine a local primary health care infrastructure from the perspective of residents from seven different zip codes of a small, urban community in the southern United States. What we conceptualize as *structural barriers* to the local primary health care infrastructure include transportation, clinic and appointment wait time, and co-payments and health insurance. *Hidden barriers* to the local primary health care infrastructure consist of knowledge about local health care services, non-physician gatekeepers, and fear of medical care. Residents we spoke with have used home remedies and the emergency department at the local academic medical center to manage these structural and hidden barriers. Berger and Luckmann (1966) contend that “everyday life presents itself as a reality interpreted by men and subjectively meaningful to them as a coherent world” (p. 19). To understand this reality, “account must be taken of its intrinsic character” (Berger & Luckmann, 1966, p. 19). The reality of primary health care from the perspective of community residents is that the structural and hidden barriers to the local primary health care infrastructure have limited the access they and other community members have to primary health care. More intrinsically, however, the structural and hidden barriers to the local primary health care infrastructure have considerably diminished the autonomy community residents have been able to exercise over their decisions about primary health care, ultimately suggesting that efforts concerned with increasing the access of medically underserved groups to primary health care in local communities should recognize the centrality and significance of power.

## Methods

Data for this chapter derive from 13 semi-structured focus groups with three to nine respondents in each, plus three semi-structured interviews (due to unforeseen respondent scheduling matters), conducted by study personnel with experience in qualitative methods between March 2006 and September 2006. To promote the study, we displayed posters about the research at the local academic medical center and at the medical center’s adjacent health care clinic that identified recruitment sites, explained recruitment procedures, and listed the location of focus groups. We also distributed flyers with this information in the emergency department waiting area of the local academic medical center and in the waiting area of the medical center’s adjacent health care clinic. To be included in the study, respondents needed to reside in one of seven zip codes that comprise the focus area of the Excellence in Partnerships for Community Outreach and Research on Disparities in Health and Training (EXPORT), an initiative sponsored by the National Institutes of Health that encourages collaboration among academic and community groups. Individuals younger than 19 years of age, persons with a psychiatric diagnosis, and residents of the EXPORT focus area who did not speak English were excluded from the study.

We recruited a total of 75 respondents: 39 respondents at two Federally Qualified Health Centers (FQHCs) and at the local academic medical center’s adjacent health care clinic that both served the uninsured and underinsured, 21 respondents at a local not-for-profit social service agency for the disadvantaged, including the uninsured and underinsured, and 15 respondents at a church and a public library. Each respondent provided informed consent and received \$15.00 for participating in the research. To preserve the anonymity of respondents since over half of the study participants (52%) were recruited at the two FQHCs or at the local academic medical center’s adjacent health care clinic where they had visited and could visit again, we did not record their names or identifying background or demographic information, although based on observations almost all respondents were African-American and the vast majority were female (M. I. Arrieta, personal communication, June 22, 2012). Throughout the chapter we do identify by code, where appropriate, the focus group or interview from which data derive: FG = focus group and I = interview. The number adjacent to these codes represents the order in which the focus

groups and interviews were conducted. The University of South Alabama Office of Research Compliance and Assurance approved the study protocol.

Four focus groups were conducted at the FQHCs, three focus groups and the three interviews were conducted at a public library neighboring the local academic medical center's adjacent health care clinic, and six focus groups were conducted at the not-for-profit social service agency, the church, or the public library where we recruited a portion of respondents. Each focus group and interview was tape-recorded and 45 minutes to two hours in duration to elicit the perspectives of respondents about the local primary health care infrastructure, in particular perspectives about infrastructure services, primary health care needs in the EXPORT focus area, and what it means to have a primary health care provider. In 2006, the local primary health care infrastructure consisted of 18 health care clinics and six hospitals, but usually respondents talked about a more select group of facilities, mainly those clinics with which they were most familiar, that to protect the location of the study we do not identify by name.

Consistent with a grounded theory approach (e.g., Glaser & Strauss, 1967/2006; Grbich, 2007; Liamputtong, 2011), we analyzed the focus group and interview data inductively using the qualitative analysis program Atlas.ti to organize the information. In the course of reading each focus group and interview transcript, the lead analyst (CRF) followed an open coding scheme to identify phrases, sentences, and segments of focus group and interview text that yielded 15 emerging analytic categories. These categories were: "agency and autonomy," "context," "continuity," "cost," "elderly," "emergency room," "fear," "gatekeeping," "homeless," "home remedy," "knowledge," "solutions," "transportation," "treatment and insurance," and "wait time." Next, the lead analyst reexamined each of the coded focus group and interview transcripts to confirm the accuracy of these analytic categories. During this stage of analysis the lead analyst also coded additional phrases, sentences, and segments of focus group and interview text missed during the first level of open coding. These data corresponded to one or more of the original 15 analytic categories, exposed new analytic categories, and, following an axial coding scheme to reach thematic saturation, required that some of the first-level analytic categories be combined under an existing or renamed thematic code or be omitted from the analysis altogether because of insufficient data. With consensus from the research team, the lead analyst then reorganized the focus group and interview data under 10 main thematic categories: "community context," "cost," "fear," "gatekeeping and mistreatment," "home remedies," "hospital emergency department," "knowledge," "solutions," "transportation," and "wait time." These thematic categories provide the conceptual and organizational basis for the chapter and point to a link between structural and hidden barriers to the local primary health care infrastructure and autonomy over decisions about primary health care.

## **The EXPORT Focus Area: Community Demographics and Health-Related Challenges**

Before we present the structural and hidden barriers to the local primary health care infrastructure that respondents identified, we should first describe the basic demographic composition of residents who lived in the EXPORT focus area in 2006 and, briefly, specific health-related challenges that respondents reported area residents confront.

African-Americans comprised between 41% and 99% of the total population of each EXPORT focus area zip code (U.S. Census Bureau, 2000a). Approximately 88% of residents in the EXPORT focus area were employed, the median household income was \$21,033, and 20% to 51% of the total population of each EXPORT focus area zip code lived below poverty (U.S. Census Bureau, 2000b). Thirty-one percent of residents in the

EXPORT focus area had earned a high school diploma while another 30% did not complete high school (U.S. Census Bureau, 2000c). Between 2004 and 2007, nearly 85% of residents from the EXPORT focus area who were admitted to the local academic medical center for treatment were uninsured or relied on Medicaid or Medicare to pay for health care (Gulati, Mohammad, & Arrieta, 2009; see Table 1 for more information). Correspondingly, 80% of the respondents in this study were recruited at sites that served the uninsured or underinsured (see above).

Respondents described their neighbors as “very sick” and neighborhoods in the EXPORT focus area as “infested” (FG-8) with high blood pressure, high cholesterol, and diabetes. “Lifestyle [and] bad diets,” “eating habits,” “the way you prepare your food,” and “lack of exercise” (I-2) have contributed to these conditions. In addition, “a lot of people will opt for medication other than doing what it takes to try to [be healthy]” (I-2) whereas others, as we explain later in the chapter, “are just treating themselves ... because they can’t see anybody [a primary care provider] because they don’t have the funds” (FG-11). One informant argued that “a health care problem ... could consist of ... something that was a risk to everybody’s health.” For example, “I live right on the corner where the ditch forever holds water,” this informant described, “and that water is a breeding ground for mosquitoes, rodents, and other little pests that will come in your house” (I-3). Focus groups discussed neighborhood violence and identified “gunshot wounds” and “stabbing” (FG-2B) as familiar reasons for emergency medical care. “I just see [my neighbors] get shot and [the] ambulance ... takes them out,” one respondent stated. “I try not to associate with anybody ... so I won’t be in none of that trauma” (FG-2A). Indeed, residents in some EXPORT focus area zip codes “don’t seek health care” because they are “scared to get out” (I-2).

## Structural Barriers to the Local Primary Health Care Infrastructure

### Transportation

Respondents seldom mentioned access to private transportation to get to and from medical facilities of the local primary health care infrastructure. They did, however, frequently criticize public bus transportation. The wait for the public bus was a source of frustration as was the distance between bus stops and homes and local clinics. Other problems with public bus transportation included travel time to, and personal safety in, some of the areas where health care clinics were located. The following statements illustrated the disadvantages of public bus transportation:

If you don’t have a car and you have to wait for the bus, it kind of makes you mad (FG-12). The bus don’t [drop] you off in your community (FG-9).

I had to walk 10 blocks from the bus stop. It hard to be traveling to these clinics (FG-9).

They [the bus] always go way over here somewhere or over there somewhere.... You might as well get ready to be on a bus for an hour (FG-10).

It’s still a kind of problem with the bus because of security. The bus is still a barrier. The problem is the area getting off the bus getting to the doctor (FG-9).

Elderly residents too frail to ride the public bus, as well as their family members, have dealt with additional transportation challenges. “Some people might not have anybody to help them” (FG-12) such as “an older lady [with] Alzheimer’s [who] says that there is never no one around to take her to [the] doctor” (FG-3). As it happens, younger relatives have moved from the local area. Family members who do live close to aging loved ones have had to miss work to make certain older relatives promptly receive the primary care they need. The



comments below typified these challenges, and uncertainty about who is responsible for health care for the elderly:

Some of them [elderly residents] just can't get around. Their relatives, children's children's, have moved out (FG-9).

My aunts and all of us are taking off from work to ... make sure they get to the doctor's.... So that's kind of hard (FG-4).

You may have where the family member can't ... take them, so maybe they won't go that time. They will go eventually, but not like when they need [to] (I-1).

I am thinking responsibility for care to the elderly. I am wondering who that falls to (FG-4).

### Clinic and Appointment Wait Time

Long wait times for medical care at clinics in the local primary health care infrastructure were common. Focus groups attributed long waits to physician staffing shortages. One clinic, for instance, "only have two doctors, so it take like all day to get waited on." This clinic opened at 8:00am, but one of its physicians "only get there like at 9:00 or 9:15. And then he [the physician] have like 20 people up in there waiting." At another clinic, "it just takes a long time [to see the physician] because it's only him and he got like a few trained people who are helping him" (FG-3). Wait times in excess of three to four hours have persuaded area residents to delay primary health care. "Some of them will get up and leave" after deciding "[I] ain't going to stay no longer" (FG-12). This decision can be permanent:

I'm not going to go to a doctor when I'm sick, because I can't wait (I-3).

I am not coming back (FG-12).

Fixed appointment times have not reduced long waits, especially if "you got 30 people coming in for one appointment" (FG-7). Moreover, long gaps between appointments have made preexisting medical conditions such as chronic arthritis worse. Consider the following:

I had an appointment like 7 o'clock in the morning. I don't leave up out of [the clinic] until 4 o'clock in the evening. I have six kids. I have to be home to get my kids off the bus. I have to let my kids in the house. And that just makes it very hard on me (FG-2A).

Once you do call and try to make an appointment, your appointment is so far away (FG-12). They [the clinic] say, 'We want to see you in six months,' [but] they won't make you no appointment. If he [the physician] want to see you [in] three months, they will not make appointments. They will tell you to call them. But when you call back, they will put you off.... I swells up sometimes. I can't turn over. I can't move.... I make myself deal with the pain, but it's not right (FG-11).

### Co-Payments and Health Insurance

To reiterate, in 2006 the median household income in the EXPORT focus area was \$21,033. In one EXPORT focus area zip code, 51% of residents lived below poverty. "People in the community ... don't go to the doctor because they don't have the money. They would like to go, but they don't have the money" (FG-11). Co-payments particularly discouraged respondents from seeking care through the local primary health care infrastructure. Furthermore, some infrastructure facilities refused to treat patients without the required co-payment:

You would go if you could get in there—if they will just accept you without the co-pay (FG-7).

Sometimes that \$5.00 can add up by me going regular like I should instead [of only] on the days that I can (FG-10).

Once they bring you up, they will ask you for your money. [Without the co-payment], you can't be seen (FG-2B).

If I don't have the co-pay, they might just say, 'The doctor can't see you today' (FG-12).

Respondents also saw a connection between health insurance and the quality of medical care, from the speed with which services were rendered to the treatment patients received. They expressed considerable frustration, directed at physicians, about health care costs and about health insurance in general. Amid the comments in reference to these issues were:

Somebody comes in and they don't have any insurance, nor do they have Medicaid. They [the primary care facility] wait on them more slower (I-3).

I got two kids. One got Blue Cross and one has Medicaid. The one that got Blue Cross, they put him in a private room. The one with Medicaid, they want to put him in a different one. I said, 'No, I want them in the same room'.... It look like the one with Medicaid got treated a little bit better when he was in the room with the good insurance. It's a difference (FG-4).

I was watching the animal program one day and the dog couldn't have the operation because the lady didn't have the money to pay for it.... They had to put the dog to sleep. I think we are about the same way. When we don't have our insurance, I think they [physicians] would put us to sleep too. But they don't put us to sleep because they have to take a Hippocratic Oath. They just put us on the bottom end (I-3).

## **Hidden Barriers to the Local Primary Health Care Infrastructure**

### **Knowledge about Local Health Care Services**

A number of respondents reported that their neighbors lacked information about the services offered through the local primary health care infrastructure: what facilities to go to for primary health care, the nature of the assistance offered, and the cost of medical treatment. For example, when an informant identified a health care clinic whose pharmacy dispensed free medication, "I know that," said someone in the same focus group, "but everybody don't" (FG-6). It seems that communication and networking among area residents about health-related issues have rarely occurred. Typical remarks about these matters included:

They don't know what places to go to [for primary health care] (FG-2B).

[They] don't know that you can go places where [medical care] is affordable or even free (I-2). The other day this man was talking. He didn't go [to a clinic] because he didn't have any money.

They don't know about the benefits they could get.... I think that people would go more if they knew (I-3).

[Health care] is not really nothing that you have a conversation about.... I really never had a conversation with anybody about where you go.... Just never thought about bringing it up, or nobody ever talked about [it].... We don't never sit and talk about [the] doctor. We don't never say, 'Who your doctor?'... We don't dwell on that conversation (I-3).

## Non-Physician Gatekeepers

Gatekeepers “grant or withhold benefits on behalf of the employing institution that possesses and disburses them” (Freidson, 1986, p. 167). Non-physician staff, mostly in health care clinics, have acted as gatekeepers vis-à-vis the authority they have to “put [you] on the back burner” (I-3). To be sure:

You just have some, ... they want to take control and take over. They think they own the place (FG-12).

Those ladies that be sitting out there in the front desks, they sit out there [and] run their mouth. They would not call you for nothing. They sit up there and talk about who went to bed with who, who dated who, what happened last week (FG-12).

You out there standing two or three hours ... [while] they are back there gossiping (FG-11).

A receptionist at one clinic ignored a patient who could not afford high blood pressure treatment. “She [the patient] didn’t see a doctor. The receptionist stopped it cold” (FG-11). At a different clinic, a respondent waited “practically three hours” for care. “My doctor had to go to the emergency room. I blame the nurses and the people in the back that didn’t let me know” (I-3).

In the medical profession, support staff seek to reduce obstacles that interfere with their carrying out assigned tasks (Freidson, 1970). Patients who non-physician gatekeepers perceived as troublesome or otherwise difficult, therefore, occasionally experienced disrespect. This happened to one informant at the very clinic where we conducted one of the focus groups:

Yesterday, because they changed my appointment, I came in here [irritated].... The security guard grab me. He bruised my arm.... [I said], ‘If he put his hands on me I was going to kick his [expletive]’ .... Came in here today and the man out there told me if *he* [italics added] had been here yesterday, ‘What happened yesterday wouldn’t have happened’ .... He had no business saying nothing to me. You have some people up in here that are so nasty. They think ... just because they work behind the desks that we are supposed to take all the mess that they want to issue out (FG-12).

The confrontation that ensued after a respondent asked a clinic staff member for a doctor’s note ended just as badly. “It was the way that the lady spoke to me.... Her and I had words and then the receptionist jumped in and said, ‘You need to take your trashy butt on out of here’” (FG-11). One informant remembered when a staff member at a local facility suggested that the side-effects of the medication he was prescribed were no excuse for “a man” to miss work:

One lady, one time, had pulled my sleeve up. She said, ‘You see them muscles you got there? You can work.’ I said, ‘Madame, these papers say for me not to drive, not to work, not to operate no machine, or nothing. You see all this medicine here? If I take this medicine now, I won’t be able to do nothing.’ [She said], ‘But you are able now to do something. You are [a] man. You are not a woman. You are not wearing a dress’ .... I mean, really, this is what I was told (FG-9).

We cannot assume that racial prejudice provokes these types of attitudes. Indeed:

A lot of times it be some of our race ... that does it towards us (FG-6).

It don’t have to be somebody White that’s doing it towards somebody Black. We go against our own race (FG-6).



## Fear of Medical Care

Occasionally, respondents mentioned rather familiar fears about medical care such as “the thought of having to stick a needle in me” (FG-11). More commonly, however, they expressed fears about receiving an adverse medical diagnosis. One informant, for instance, raised the topic of HIV-AIDS. “As long as a person don’t know that they got something, life goes on. Once they know about these things, it kills them. The body and the mind just deteriorate” (FG-9). Still broader comments related to fears about receiving an adverse medical diagnosis included the following:

They may tell me something that I don’t want to hear (FG-7).

I don’t want to know something that’s going to make me scared (FG-7).

They may make matters worse (FG-7).

A lot of people fear what is wrong ... [because they] just can’t afford it.... They don’t have any insurance (FG-7).

A respondent in one focus group experienced “a lot of incidents [as a child] where I did not go to the doctor. I slammed my fingers in an iron door and [my mother] wouldn’t take me to the hospital.” Participants in the same focus group explained. “If her mom would have taken her to the hospital, they [hospital staff] might have said, ... ‘Who slammed your finger in the door?... Did your mom slam your finger in the door?’” In short, “they want to report you to [child protective services]” (FG-4). An informant and her brother had to contend with a situation like this when she was a young girl. As this informant recalled:

We were playing in the backyard and he [the informant’s brother] dislocated his elbow. When he got to the hospital he kept saying, ‘My sister did it.... We were just playing.’ But when my mom left out of the room for a minute, the police asked my brother, ‘Who really did this? Did your mom do it?’ He kept saying, ‘My sister made a mistake.... We were just playing’.... [The police] would wait a few minutes and then come back in and ask him to see if he was telling the same thing (FG-4).

Not surprisingly, fear of being accused of child abuse has posed serious health consequences. In one especially alarming case that a respondent cited:

I know this lady [with] two small children. [One child’s] skin had broke out real bad and [the lady] come knock on my door. And I was like, ‘I don’t know you,’ but she [the child] had an allergic reaction to something. I was like, ‘Go on and take her to the hospital.’ [The lady] was like, ‘Oh no, no, no’ and she kept putting it off. Fifteen minutes later she come beating on my door talking about, ‘Let me use your phone. My baby is over there having [a] seizure’ (FG-4)!

The lasting emotional effects of racial oppression have also generated fear of medical care. According to one informant, “all the Black people are a little bit afraid of White people, and that from slavery—all older Black people in their 70s and 80s.” In fact, “the majorities [of Black people] are fearful [of White doctors],” this informant continued. “My mother ... was afraid to go to them and her condition had got severe—too severe” (I-3).

## Strategies to Manage the Structural and Hidden Barriers

### Home Remedies

For some respondents, one strategy to manage the structural and hidden barriers to the local primary health care infrastructure has been to “treat their own selves” (I-3) with home remedies. “You don’t need to go running to the doctor [when] you don’t feel good” (I-1) because, as one informant asserted, “whoever at home ... [can] tell you what to take, and you get cured at home sometimes” (FG-2B). Home remedies have included “green water

and juice” for the chicken pox, “the yoke from inside the raw egg” for a boil (FG-8), and “turpentine and sugar” (FG-9) for the common cold. A respondent suffering from back pain “just deal[s] with it” to which someone else replied, “that’s a home remedy” (FG-4). In addition:

When I was a little girl I stepped on some nails in a block and it went through my feet. My mom did not take me to the hospital. She took me upstairs, got a hammer, and beat the palm of my feet ... to get [the] bad blood out (FG-4).

Everything is, ‘Take a laxative.’ If your stomach hurts, ‘Take a laxative.’ If your back [or] ... your head hurts, ‘You just need to be cleaned out’ (FG-4).

We got a ‘neighborhood doctor’ .... He ain’t really no licensed practiced doctor. We go to him under the table when [we] can’t afford a doctor (FG-9).

“Older people think the home remedy is going to fix it all” (FG-4). One informant told us about a toothache his father once had. “He wouldn’t go to the dentist. He would take something like ‘oral gel’” (I-2). A respondent’s grandfather with severe calluses on the bottom of his feet refused repeatedly to see a podiatrist. “He just say, ‘I’ll just put some lotion on it’ .... I keep telling him if it gets any worse, you can lose your feet” (FG-4). Residents in the local area have also looked to spiritual faith as a home remedy. One informant’s grandfather apparently died because of his spiritual faith. “He wasn’t supposed to believe that God was going to let him get sick because, ‘God don’t do no evil’ .... He died with cancer because he wouldn’t go to the doctor” (FG-8). Other statements about prioritizing spirituality over primary health care were:

You got people that believe, ‘Nothing is wrong with me and I don’t care ... if [the physician] believe any different. I believe in Jesus Christ’ .... They won’t go [to the doctor] for that reason (FG-8).

[You] really don’t have to take any medicine. All you have to do is give it some time and eat right and your body will cure itself. That’s the way God made it (FG-8).

Can’t anybody cure but Jesus (FG-7).

### **The Emergency Department at the Local Academic Medical Center**

At about the time this study was conceived, 61% of emergency department visits at the local academic medical center were for conditions that could have been managed in a primary care setting (Arrieta & Mulars, 2006). “Some people think everything is [an emergency]” (FG-4) including, as respondents listed, a headache, coughing, cramps, diarrhea, and gas. “I got my toenail removed,” one informant acknowledged, “because it was in trauma” (FG-2B). Others described the emergency department, especially at the local academic medical center, as a “fellowship” (FG-9) that “a lot of the people think ... is funny. ‘There goes Ms. Jones going to the emergency room again’ .... [However], they don’t look down on them” (I-1).

Indeed, area residents have not stigmatized individuals who have taken advantage of emergency department services, and have themselves sought primary health care from the emergency department at the local academic medical center, knowing that neither cash nor health insurance is needed to receive treatment. But more than this, for a majority of emergency department patients at the local academic medical center, as many as 77% of whom once had a primary care provider (Arrieta & Mulars, 2006), the emergency department has been “the best resource” (FG-2B) for primary health care compared to the alternative:

If I'm sick, I'm not going [to the doctor] just to sit (I-3).

Say you're not in dire, dire need but you feel like you need to be checked on. That's the time your doctor's office may be closed.... [In] the emergency room, [you] find out tonight (I-1).

When you call the doctor and tell them you are having problems, ... they will tell you they don't have any openings, so you might as well go to the emergency room (FG-6).

I call my doctor and he doesn't call me back. I go to the hospital for just about anything (FG-3).

## Autonomy, Decisions about Primary Health Care, and Power

The general sentiment among respondents was that they and other area residents “wait until they get to their weakest point” before they seek primary health care, or claim “I ain't sick, it will pass, it will go away” (FG-12) to avoid primary health care altogether. These decisions reflect the reality of primary health care for respondents. Berger and Luckmann (1966) contend that “everyday life presents itself as a reality interpreted by men and subjectively meaningful to them as a coherent world” (p. 19). To understand this reality, “account must be taken of its intrinsic character” (Berger & Luckmann, 1966, p. 19). The reality of primary health care from the perspective of respondents is that the structural and hidden barriers to the local primary health care infrastructure have limited the access they and other area residents have to primary health care. More intrinsically, however, the structural and hidden barriers to the local primary health care infrastructure have considerably diminished the autonomy respondents and other area residents have been able to exercise over their decisions about primary health care. “Power has to do with whatever *decisions* [italics added] men make about the arrangements under which they live” (Mills, 1958, p. 29). Respondents and other area residents have suffered “a feeling that have them down where they just can't do anything about [primary health care]” (FG-4).

To illustrate, we can revisit the structural and hidden barriers to the local primary health care infrastructure and speculate, where appropriate, about links between these barriers and some of the health-related challenges local residents have confronted. For example, neighborhood violence and concerns for personal safety in areas where health care clinics are located have forced respondents and other residents to decide whether or not to travel—by public bus or otherwise—for primary health care. Violence and safety concerns have also compelled local residents to disassociate from one another, a decision that might explain the reported lack of communication and networking about health-related issues. Perhaps we should not attribute the decision elderly residents have had to make to delay or do without primary health care to their transportation challenges per se but to a corresponding and equally compulsory decision second and third generation relatives have made—their “children's children's” (FG-9) who maybe once provided transportation—to move to communities that are not a “breeding ground” (I-3), to repeat one informant, for emergency medical care or poor health and disease (see, e.g., Klinenberg, 2002; Wilson, 1987). Family members who remain in the area have had to choose work or offer this transportation, a decision possibly imposed by a rigid day-to-day schedule dictated by the constraints of underemployment (indicated by high employment rates in the EXPORT focus area but a low median household income) and the threat of job loss from what is likely a surplus pool of low-wage workers (see, e.g., Newman, 1999; Wilson, 1996). To miss work can mean less money for these family members to pay for their own primary health care and thus less autonomy over their own primary health care decisions.

It seems fairly clear how public bus transportation, long wait times for medical care and appointments at local clinics, and unaffordable co-payments as well as inadequate or no health insurance coverage can all unduly influence decisions about primary health care. Remember one respondent, for instance, who “had to walk 10 blocks from the bus stop” (FG-9) to a local clinic, a focus group member who was “not coming back” (FG-12) to a clinic because of long waits, or the informant who felt “on the bottom end” (I-3) of health care priorities due to costs and no insurance coverage. We should also reiterate that non-physician gatekeepers, in the course of exercising authority as the agents of administrative and medical leadership, have required respondents and other area residents to wait extensively and sometimes needlessly for treatment, have disrespected patients, including other African-Americans, and have exploited, at least in one reported case, gender stereotypes, each of which might trigger a decision to postpone or forgo primary health care. And recall fear of medical care: as one respondent acknowledged, medical care, particularly receiving an adverse medical diagnosis, “comes with that fear because ... [it is] going to add up to a responsibility” (FG-12). But how can respondents and other area residents fulfill this responsibility—that is, self-assuredly decide to “seek *technically competent* help ... and to *cooperate* ... in the process of trying to get well” (Parsons, 1951, p. 437)—and thereby reduce their fear of medical care if burdened by primary health care costs or accusations of child abuse by hospital staff, state officials, or local law enforcement (especially against minority women) or by worries of racism that elements of American medical science have fueled among African-Americans since slavery (e.g., Hoberman, 2012; Jones, 1981; Skloot, 2010; Washington, 2006)?

We should not be surprised if home remedies or the emergency department at the local academic medical center have provided respondents and other area residents with a measure of autonomy over their decisions about primary health care. Reconsider, for example, how some respondents and area residents have decided to put home remedies, from laxatives to spiritual faith, before primary health care, or the account from one informant about how area residents have not stigmatized individuals who have taken advantage of emergency department services, this perhaps signaling that community members have recognized inherent value in incorporating the emergency department into decisions about primary health care despite the drawbacks of emergency department treatment (e.g., Moskop, Sklar, Geiderman, Schears, & Bookman, 2009a, 2009b). Autonomy over primary health care decisions could also increase, respondents might propose, if local clinics established a “first come, first serve” (I-3) policy, if all infrastructure facilities “[saw] people whether they have money or not” (FG-11), or if local officials organized “health fairs” (FG-11) to educate the public about fit lifestyles and primary care options.

The point is this: the structural and hidden barriers to the local primary health care infrastructure that have necessitated these strategies and stimulated these ideas from respondents in the first place, compounded by health-related challenges that stem from broader social issues such as urban violence, urban disrepair, intra-urban migration (e.g., Brown & Moore, 1970), and underemployment that we allude to in this discussion, have not simply limited access to primary health care but have also considerably diminished the autonomy—the power—that respondents and other area residents have been able to exercise over their decisions about primary health care. Accordingly, because “freedom requires access to the means of decision” (Mills, 1958, p. 31), and because health disparities will diminish only when individuals become empowered with full access to health care (U.S. Department of Health and Human Services, 2000), it would seem that efforts concerned with increasing the access of medically underserved groups to primary health care in local communities, whether initiated by elements of a local primary health care infrastructure, locally “elected corporate people” (FG-9), or even state or federal decree, for instance, local implementation of the new Patient Protection and Affordable Care Act (see One Hundred

Eleventh Congress of the United States of America, 2010), should give practical thought and due standing to the centrality and significance of power.

## Conclusion

This study has several limitations. The research sample was purposive to elicit the perspectives of focus group and interview respondents about the services of the local primary health care infrastructure, primary health care needs in the EXPORT focus area, and what it means to have a primary health care provider. In other words, our findings and interpretations might not generalize to local systems of health care clinics and hospital services that comprise a local primary health care infrastructure in other small, urban communities. Respondent perspectives, of course, can be biased: area residents more satisfied with the local primary health care infrastructure may well have been disinclined to participate in the study. Correspondingly, because we recruited a number of respondents ( $n = 39$ ) at two FQHCs and at the local academic medical center's adjacent health care clinic, we cannot be certain that these respondents represented those in the local area most vulnerable to the structural and hidden barriers to the local primary health care infrastructure. Four focus groups ( $n = 26$ ) were conducted at the FQHCs during operating hours. No representatives of these facilities, including caregivers or gatekeepers, were present during the focus groups and study personnel reminded the respondents in these focus groups about the freedom they had to candidly express their perspectives about the local primary health care infrastructure. We grant, however, that having conducted focus groups on the premises of the FQHCs could have reduced the comfort level of these respondents to speak openly. Missing background information from respondents limited conclusions we could draw about demographic variables and the local primary health care infrastructure while, by and large, focus group and interview data are subject to various interpretations and conceptual and thematic frameworks. Lastly, research that asks disempowered groups to identify the sources of their disempowerment risks increasing the vulnerability of these groups to injustice or maltreatment. We have no evidence to indicate any respondents experienced this outcome, but we feel this is an important caveat to mention.

These limitations notwithstanding, "the goal of creating a healthier, more productive community is not dependent on sophisticated clinical interventions but on understanding the community and its needs" (Channing, 2011, p. viii). Having set out to understand the reality of primary health care from the perspective of residents in the EXPORT focus area, we argue that the structural and hidden barriers to the local primary health care infrastructure have not only limited the access of respondents and other area residents to primary health care but have also considerably diminished their autonomy over primary health care decisions, ultimately suggesting that efforts concerned with increasing the access of medically underserved groups to primary health care in local communities should recognize the centrality and significance of power. Indeed, to give practical thought and due standing to the concept of power is to more fully comprehend, and to thereby draw nearer to appreciably diminishing and eventually eliminating, health disparities. We hope this chapter can make a small contribution toward achieving these worthy objectives.

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**Table 1**  
EXPORT Focus Area Zip Code Delimited Population by Poverty, Race, and Insurance Status

Insurance Status <sup>4,5</sup>											
Zip Code	Total Population	Below Poverty <sup>1,2,3</sup>	White <sup>1,3</sup>	African-American <sup>1,3</sup>	Uninsured	Medicaid	Medicare	Private	Military	Other	Unknown
-02	867	22.3	54.8	42.0	0.3	0.3	0.2	0.0	0.0	0.2	0.0
-03	12,526	50.6	6.1	92.6	3.0	3.8	3.2	0.3	0.0	0.3	0.7
-04	11,533	26.6	44.6	53.0	2.3	1.7	1.2	0.3	0.1	0.2	0.4
-05	33,471	28.1	36.4	61.1	5.9	7.7	4.0	1.7	0.2	0.5	1.2
-06	19,007	19.9	56.5	40.5	2.9	2.0	2.0	0.7	0.1	0.3	0.8
-10	19,717	49.1	2.8	96.3	9.3	11.0	6.4	1.3	0.1	0.2	1.6
-17	16,158	30.3	0.8	98.5	5.2	6.4	6.1	1.4	0.2	0.3	2.1

<sup>1</sup> Source: U.S. Census Bureau (2000a, 2000b)

<sup>2</sup> Among individuals for whom poverty status is determined

<sup>3</sup> % of total population

<sup>4</sup> % of admissions ( $N = 1,510$ ) to local academic medical center, 2004-2007 (based on the latest encounter) (M. I. Arrieta, personal communication, February 20, 2011) Percentages do not total 100 due to rounding.

<sup>5</sup> Source: Gulati, Mohammad, and Arrieta (2009)