



Rutgers Center for
State Health Policy

The Institute for Health, Health Care Policy and Aging Research

Perspectives on Urban Health Care: Patients with Chronic Medical or Mental Health Conditions

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Acknowledgements

Karen Jaffe of Rutgers Center for State Health Policy and Teresa Vivar of Lazos America Unida in New Brunswick conducted the excellent interviews with families in this study. We acknowledge the valuable comments and encouragement of Dr. Joel Cantor and Dr. Peter Guarnaccia of Rutgers Center for State Health Policy. We also thank the families who participated in this study for their willingness to share their stories with us despite often difficult circumstances.

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Abstract

Fifteen individuals with chronic medical or mental health conditions from an urban community were interviewed about the history of their conditions, diagnoses, treatment, self-management, and health information seeking. Themes present in patient narratives included: multiple health problems within families affected care-seeking and self-management; patients had great appreciation for local providers but noted specific problems; individuals experienced difficulty navigating the health care system; patients expressed strong trust in providers to supply health condition information but informal networks were important too. Findings indicate the critical role primary, specialty, and mental health service providers play in creating positive health care experiences for and offering information to their urban practice patients. Provider efforts can be enhanced, however, by better coordination with other health and social service providers in communities. Collecting personal narratives is an effective method of identifying health needs within a community and obstacles patients face in seeking care or doing self-care.

Keywords: Chronic illness, Mental health and illness, Self-care, Health, Experiences

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Introduction

Understanding the personal perspectives of individuals receiving care for chronic medical or mental health conditions is important for identifying barriers to care within a health care system. Allowing consumers to describe health care encounters in their own words can highlight variations in quality of care, obstacles created by cultural differences between patients and providers, and personal circumstances that facilitate or obstruct disease control, health maintenance, and good mental health. Hearing from patients receiving care within an urban environment is particularly important because these patients tend to have complex medical problems and treating them is often more challenging for providers than suburban or rural patients. For example, Blankenfield, Goodwin, Jaen, and Stange (2002) found that inner city patients of family practices had more visits for chronic illnesses, had more problems addressed in visits, and reported more emotional distress than rural or suburban family practice patients.

Although urban areas have more providers within shorter distances compared to rural and suburban environments (Baldwin, et al., 2006; Johnson, Brems, Warner, & Roberts, 2006), urban patients with chronic conditions do not necessarily receive appropriate care. Many sociodemographic and community characteristics affect health access and quality, for example insurance status, poverty, health beliefs, and local resources (Anderson, 1995; Stanley, Cantor, Guarnaccia, 2007). Cunningham and Kemper (1998) found considerable variation in uninsured patients' level of difficulty in obtaining care across several metropolitan sites. This variation was not explained well by individual level characteristics, indicating that community level factors such as health system organization and local policies are more relevant for fostering access.

Chronic disease medical care and self-management is complicated further for urban patients who also have a mental illness. Recent studies show that individuals with mental illness are at higher risk for medical disorders and vice versa (Chwastiak, et al., 2006; Dickey, Normand, Weiss, Drake, & Azeni, 2002; Frayne, et al., 2004; McIntyre, 2006) and also have higher health service utilization (Druss & Rosenheck, 2000). Additionally, those with both medical and mental health conditions report higher degrees of functional disability (Druss, et al., 2000) and a greater duration of disability as measured by the number of days spent in bed (Marcus, Olfson, Pincus, Shear, Zarin, 1997).

For urban patients with both a chronic medical condition and a mental illness, stigma can be a powerful barrier to health maintenance and continued care. Individuals who experience stigma usually fear being labeled by their chronic condition and discriminated against by their peers. Link, Yang, Phelan, and Collins (2004) state that stigma is more complex than being labeled by others because of a particular characteristic that is different from the dominant group. They argue stigma involves several interrelated components that originate with labeling and then proceed to other social phenomenon like stereotyping, separating, emotional reactions by both the stigmatizer and the stigmatized person, and loss of status and discrimination.

Social stigma certainly surrounds chronic disease, mental health conditions, and physical and developmental disabilities. Particular illnesses may be perceived by the individual and his or her culture as “different” and result in loss of status and intolerance for those with the illness. For example, in the Chinese culture, mental illness is highly stigmatized and believed to be reflective of a poor family lineage (Ng, 1997); hence it is rarely acknowledged and professionally treated (Tata & Leong, 1994). Similarly, among Latinos and African-Americans stigma and mistrust play a significant role in where individuals seek treatment, with many turning to non-specialty care settings such as churches or emergency rooms for mental health issues (Cauce, et al., 2002; Cooper-Patrick, Crum & Ford, 1994; Snowden, 1998; Vera, et al., 1998).

Patients’ reflection on chronic medical and/or mental health care within an urban health care delivery system can and should inform medical practice within that system (Grypdonck, 2006) by

highlighting successful practices as well as inefficiencies and opportunities for improvement. Work on chronic disease self-management demonstrates that patients are not simply passive recipients and followers of medical professional advice, but actors who make decisions on care by considering both medical information and their personal circumstances and beliefs (Coats & Boore, 1995; Peyrot, McMurry, & Hedges, 1987; Glasgow, Wilson, & McCaul, 1985). Practitioners' knowledge of patients' lives outside their offices and their health care decision making processes, can inform treatment decisions and help them judge when deviation from standard treatment procedures may be appropriate (Grypdonck, 2006).

To explore patient perspectives on care within an urban health care system, we conducted follow-up qualitative interviews covering aspects of residents' health care experiences with a small sub-sample of respondents to an earlier survey of families in New Brunswick, New Jersey.

Methods

The Healthier New Brunswick Community Survey provides in-depth information about the health and health care of local residents including questions on health insurance status, access to care, health status, and demographic and socioeconomic characteristics. The telephone survey was conducted in 2004 by the Rutgers Center for State Health Policy in collaboration with New Brunswick Tomorrow, Robert Wood Johnson Medical School, and community advisors, with financial support from Johnson & Johnson and the Robert Wood Johnson Foundation (Guarnaccia, 2006). The primary survey sample was drawn by random-digit-dial methods of the full-time residents of New Brunswick and contiguous areas. Within each selected household, the person most knowledgeable about the family's health and health care was asked to respond on behalf of all family members (defined as all persons living in the household related by blood, guardianship, marriage or domestic partnership). For this sub-study, respondents who answered in the survey that someone in the family had a chronic health condition or had sought help for mental health issues were selected and contacted for a phone interview in July and August of 2006. A total of

fifteen New Brunswick area residents were reached and completed the interview via phone. Seven interviews were conducted in Spanish.

Respondents were asked open-ended questions about the history of their or a child's chronic health or mental health condition, diagnosis, treatment, disease management, health care coverage, and health information seeking behaviors. Interviewers informed all respondents that the interviews were voluntary and any information they provided would be kept confidential. Each interview lasted up to 45 minutes and the respondents were paid fifteen dollars for their participation. This study was reviewed and approved by the Rutgers University Institutional Review Board for the Protection of Human Subjects.

Analysis

Full transcripts of interviews were made, analyzed, and coded for themes occurring across interviewees using Grounded Theory method. Grounded Theory is an inductive reasoning approach where investigators do not enter analysis with hypotheses to test, but rather allow themes and findings to emerge from data collected on a specific area of study. Emerging themes are developed by close reading of text and systematically refined by returning to the data. The grounded approach starts with the open-coding of interview content not grouped by demographic or other categorical variable and codes are assigned to clusters of text, for example sentences or paragraphs. Sub-codes of initial themes are developed in the same manner by close re-reading of text. After a strong coding scheme has been developed, investigators can begin analyzing themes by categorical variables such as race or income levels of respondents to discover any response patterns within and across groups (Strauss & Corbin, 1990). For this study, two investigators reviewed all transcripts multiple times and came to mutual agreement on the coding categories.

New Brunswick Context

The city of New Brunswick, New Jersey is a small urban community of approximately 50,000 residents with rich ethnic and racial diversity. Sixty-three percent of the population in the 2004 Healthier New Brunswick Community Survey sample were Latino, 25% were African-American, and 7% of other ethnic background. Half of Latino adults in New Brunswick are of Mexican descent, distinguishing this city from other Northeastern cities with larger representation from the Caribbean region. Fifty-five percent of residents live in families with at least one immigrant member and 56% live in families that do not speak English at home. Many families in the city are low-income, with 60% having incomes below 200% of the poverty level in 2004.

In the Community survey, Mexican children and adults in New Brunswick reported worse general, dental, and mental health than other groups in the city. Also, poor individuals, those with less than high school education, and those without insurance also reported worse health. Overall, 24% of the sample reported being in fair or poor general health, 31% in fair or poor dental health, and 10% in fair or poor mental health. Among children, asthma is the most common childhood chronic condition, with African- American children most at risk. Among adults (ages 19-64) the two most common chronic conditions are hypertension and high cholesterol. Thirty-three percent of adults and 17% of children in the city area are uninsured while 9% and 42% respectively are publicly insured.

New Brunswick – known as the Health Care City – has many health care resources including two major teaching hospitals, a medical school, a Federally Qualified Health Center, and other community health centers. Residents rely heavily on the local health centers for care yet significant numbers of survey respondents reported health service access problems,

particularly facing long waiting periods for appointments and not being able to get needed care for children (Guarnaccia, 2006; Cantor, Guarnaccia, Brownlee, Schneider, & Nova, 2006).

Overall, New Brunswick’s diverse population and its need for access to quality medical and mental health services, provides a rich environment to explore personal experiences with use of the local health care services.

Findings

Our interview sample reflected the racial, ethnic, and income diversity in the New Brunswick area.

Table 1: Respondents’ Socio-demographic Characteristics

Characteristic	No. of Respondents
<i>Race/Ethnicity</i>	
African American/Black (non-Hispanic)	3
European American	4
Latino	8
<i>Immigration Status</i>	
US Citizen	10
Not US Citizen, in country for at least 5 yrs	5
<i>Income</i>	
0-200% of Federal Poverty Level 2004	5
201-350% FPL 2004	5
350% or more of FPL 2004	5
<i>Education</i>	
Less than High School	5
High School or Equivalent	3
More than High School	5
Unknown	2
<i>Employment Status</i>	
Not in Labor Force	4
Working Full-Time	11
<i>Insurance Status</i>	
Public Insurance	6
Private Insurance	7
Uninsured	2

The majority of our interview respondents were female (n=12) and the size of respondents’ households ranged from 1 to 9 persons, with an average of 3.8.

Multiple Serious Conditions

The strongest theme emerging from our qualitative analysis was the high prevalence of multiple health conditions per family. Although we contacted respondents to discuss health service experiences for one particular condition, in most cases asthma or a mental health problem, in the course of the interview the majority of respondents mentioned at least one other serious condition for which health services were sought or needed. The number of conditions mentioned per household ranged from 1 to 7, with an average of 3.6 conditions per household. For example, in one of the most complicated cases, a 70 year old grandmother is paralyzed from the waist down and also suffers from depression, her daughter is diabetic, the daughter's son was born deaf and developmentally disabled, and her daughter suffers from severe dental problems resulting in painful and bleeding gums. In another case, the respondent has breast cancer and also suffers from depression. This respondent's son suffered from severe depression and was suicidal. In addition, after having a mastectomy and radiation for the breast cancer, she was later misdiagnosed with sciatica for a case of what was really bone metastasis when her cancer spread.

The existence of multiple health conditions in a single family created particular barriers to maintaining health and obtaining needed care for respondents. For example, when asked about treatment for her diabetes, the woman with a disabled mother and son told us:

I work a lot. I have a problem because I have to eat. If I don't eat I get very nervous. I eat what I can. I don't follow a diet because I can't. My mother is an invalid who lives with me also. I have to help her with everything. She's in a wheelchair all the time and her feet don't work at all. If she falls on the floor she has to stay there the whole time. So, yes I don't have any time to check my diabetes or anything. I used to have a [glucose meter] but I threw it in the trash. I use my insulin, when I have to eat I eat. At 11 and 4 AM I get hungry because I work at night.

The family's multiple illnesses converge to create heavy responsibilities for this woman and prevent her from managing her own diabetic condition adequately. Families experiencing the convergence of medical and mental health problems likewise face barriers to positive health behaviors. The woman mentioned above, whose son was suicidal, delayed seeing both a mental health counselor and a doctor for emerging symptoms of breast cancer after her son's crisis. She explains:

Because before it was just sort of a lump, but then, after my son's [problem], it just grew. But I didn't [go] or tell her [my counselor] because I knew she would say "Well, why don't you go to the doctor?" I couldn't handle that at that moment. Because it was too much to handle. I needed to deal with one thing at a time and my son was [most] important. I did [eventually] go to the doctor, not very soon after that, but about a year. And then we started massive treatment and I did call [my counselor] but she said she wasn't practicing anymore.

Her son's depression and her inability to emotionally handle any additional burden, led her to avoid seeking treatment for obvious cancer symptoms for a prolonged period of time as well as avoid speaking with her mental health counselor.

Although less common, the convergence of medical and mental health problems within a family can motivate individuals to focus on their own health and seek treatment. This quote comes from a woman whose husband was bi-polar and whose son was severely disabled (both deceased):

Yet, for the most part, I'm a fairly healthy person. Because of my husband's death, it made me realize just how much grief, what grief does to you physically. He died of a heart attack a month after [our son died]. He was 48 years old. And he, again, he had all his [mental health] issues and he also had physical health issues. So, I'm not going to say that it was all the grief, but grief was a big contributor. So, it made me be a little more aware of my own body and taking care of myself and going to my doctor, more than when I'm just sick as a dog.

Assessing whether multiple chronic medical and mental health conditions exist within a family, and how patients cope with them, is important for New Brunswick providers to know, as such convergence affects patients' ability to manage diseases and seek care and they may require additional support services to maintain good health.

Personal Experiences with Providers

Respondents reported both negative and positive experiences with providers in every phase of the health care seeking process. All but two mentioned at least one positive interaction with a local provider. Individuals seeking care for a medical condition as opposed to a mental health condition were most likely to have a positive experience. These respondents described their providers as caring, understanding and supportive during treatment for their (or their child's) medical condition, like the woman below who is very grateful for the hospital staff who helped her disabled son.

Yeah, I got to say that they [hospital staff] were wonderful. My son was diagnosed in that last half of a month, and within that half a month, we were out of the hospital, into rehab, to learn, to come home, to get nursing. You know, everything happened immediately once his diagnosis happened. And they were incredible in getting all that to happen.

Respondents who sought help for mental health care experienced more negative interactions with providers which often hindered their efforts to receive help. This was especially true among those individuals who sought help from non-specialty providers. One woman who sought care at a hospital emergency room for her bouts of depression and anxiety found that the staff lacked sympathy and understanding.

I would go to the emergency room and the people there would treat you really bad. They're not—how you would call it – they're not nice. They're not gentle. They treat you like you are crazy. I mean, I hate to say it like that. But some of them don't have no – I don't know what you say – sympathy...

Because of these experiences, this woman is now reluctant to seek care for her symptoms.

Well, you know, I learned one thing about going to the hospital with anxiety or depression. You know, you try not go because, I mean, that's what I learned. I try not to go. I try to work on it, or work it out the best way I could.

Other respondents who obtained care from non-specialty mental health providers were more likely to change providers rather than avoid care. Unable to locate an appropriate mental health provider to treat her depression, a respondent asked her primary care physician to prescribe her medication. She recalled this interaction – the request for medication – as awkward and damaging to their relationship.

The result was like, afterwards, our relationship did not continue being good because then, that affected the rest of my relationship with my doctor. I have depression and when I have an episode, of course, I'm affected, but once I'm back to normal, you know, the doctor did not forget about that, and that created some tension, and so, I changed primary care physicians.

This respondent reported a change in her relationship with her primary care physician, a change that extended to her believing her physician could no longer distinguish between an actual medical ailment and one that was due to her “mental” condition. She felt that this provider judged and defined her by her mental illness. She stated:

He sort of like thought that if I went back to see him, sometimes, it was just because I needed attention, like I was lacking company or something like that...

Subsequently, this respondent changed primary care physicians because she could not endure the “tension” between them.

Patients seeking care for mental health needs often had difficulty finding providers they were comfortable with, even when receiving care from specialists. Several respondents contrasted their experiences with “good” and “bad” therapists.

Well, with her, she was great. I mean, she was wonderful. She helped me when I really needed it. She was great. That's why I went back to her, even though she went into private practice and I had to pay, you know, on a sliding scale at that time. But then she stopped practicing. So I didn't want to start off with anybody else, and I didn't have enough money to go through this whole thing [paying for care] again. And the ones [therapists] that the health insurance company pays for, they're just no good. I tried one. I mean, it was a terrible experience. So, you know, I'm sort of hesitant to want to go back to somebody that I don't know.

Difficulty in finding an appropriate or compatible provider was a problem faced by several respondents seeking care for a medical need as well. The reasons for these difficulties ranged from a lack of or limited insurance coverage to having few choices of available local providers. Consequently, some respondents experienced negative interactions or outcomes that they attributed to provider incompetence. Respondents explained their experience of misdiagnoses of medical conditions; providers that were not culturally competent and hence created an environment where patients were misunderstood; therapists that demonstrated no affect; and medical offices that were inefficiently managed causing delays and inappropriate care. A striking example of some of these problems is explained by a woman of Mexican origin who sought care at a community health clinic because of a lump in her breast.

I have something in my right breast...[and] I tell this to the doctor [gynecologist] on March 15th. He says, Ok, I'm going to send you to the clinic so that you can have a kind of mammogram...Then, he gave me the paper and told me to hand it in at the clinic. So, I get to the clinic and they give me an appointment for May 6th, something like that. I go there May 6th and the doctor says that this is not where you're supposed to have this done. She asked a couple of questions. Then she says that we can't do this here, what the gynecologist is asking for...Then, she writes a note on the same paper I had taken and asks me to take it to the gynecologist. So, I take it to the other clinic [where the gynecologist is] that same day. I tell the receptionist if I can hand this to the [gynecologist]. She says that I can leave it here and I ask her if she'll give it to [the gynecologist]. She says yes. They had given me an appointment for June 15th. I arrive on

June 15th and I tell the [receptionist] that I left a paper. She said she had never gotten the paper to give to the gynecologist.

This woman experienced an inefficient office staff, a gynecologist who may have directed her to the wrong location for her procedure, a receptionist who did not show urgency in her care, and delayed care for a condition that could potentially be serious. This same woman also reported experiencing long waiting periods at these provider offices and a bill for these visits that she could not pay.

The types of events described above were fairly common for respondents of Latino origin. Language barriers were the cause of some of these difficult encounters, for example, in the case of one man who told us directly that he always has a hard time at doctors' offices because he does not speak English. Many Spanish speaking respondents received care at clinics with bi-lingual office staff and physicians or interpreters available for appointments, however. This fact indicates that navigating the health care system can be difficult for Latino patients even when language services are available.

Health Information Seeking

We asked interview participants a series of questions about how they sought and received information about their medical or mental health condition. For example, we asked where they would first turn for health information, if they did additional research outside of materials received from physicians or therapists, and what specific information sources they used.

Our participants most commonly responded that they would first turn to physicians and mental health therapists with questions about their illnesses. The following two quotes reflect that many would rely on verbal communication with doctors and therapists as well as written materials from these medical professionals:

Well, I would go to my doctor. When I go in the office and I see booklets on it [depression] or anything like that, I'll take it and bring it home and read it.

I mean, she [Dr.] gave me material that I read because I wanted to read up on the medications that [my daughter] was on for asthma.

Beyond doctors and materials from them, most participants mentioned other sources of health information that were particularly important to them in understanding their medical or mental health conditions, including books, the Internet, family and friends, and the community church. Four individuals said they had not done any additional research on their or a family member's health condition.

Three participants mentioned books as a primary source of health information for them. Here, a woman who struggled with several mental health conditions explains:

Maybe I am a book person so I did read different books on different issues. [I read] on depression, and I did some on stress, and I also did some research on mental health.

Another woman who was not able to receive mental health services because of lack of insurance coverage, turned to books to help understand her condition and explore strategies for helping herself:

When I couldn't find any help, I did find some books and read about depression and how to treat it and alternatives that I could do at home without getting prescriptions.

Only two of our respondents had used the Internet to seek health information but both found it very useful and turned to it as a first source of information. The following young man explains the value of the Internet for him and how it goes beyond the help doctors can provide.

[I've been using the Internet] for the past several years. [It's more helpful] than going to the doctor. You know, because you're only talking to the doctor for so long. You can be online for an unlimited amount of time and you can figure out pretty much everything you want to.

Four respondents, all but one Latino, also mentioned family and friends as a major source of health and treatment information. When asked where she obtains the most information about health topics outside the doctor's office, one Mexican American mother of a son with asthma answered:

From my [female] friends. They tell me what I have to do with my son.

In another interview with a Dominican woman whose sister suffered from diabetes, she told us that her sister relies primarily on family for any information she needs concerning her disease. She explains:

[She gets most information] from her family. She doesn't read books or watch television. She only has her family.

Other community-level sources of information were important for some of our respondents. For example, for the disabled grandmother mentioned earlier, her church is the place she most values for receiving health advice. She understands seeing the doctor is important for her health and she goes out of necessity, but she actively seeks out a priest to talk to and values assistance received from the church most.

I would go to church. That's what helps me. I have to go the doctor's [office] but I go to church to talk with a priest.

Overall these residents of New Brunswick use various sources of information to understand their health conditions and how to treat them. They rely most heavily on physicians and mental health professionals to provide them with verbal and written guidance and some rely exclusively on this information, not seeking anything additional. Some turn to family, friends, and churches as primary health information resources.

Although health care professionals seemed to be the first source for information for the participants, it is not clear how much time providers spent with them to explain the nature of their health issues or how helpful information was. In addition, most respondents did use other sources to gather more information but none mentioned any structured system to help them look for information. For example, no one mentioned awareness of a central community level location, other than doctors' offices, to go for health information.

Discussion

Our findings indicate the critical role primary, specialty, and mental health professionals can play in providing information to and creating positive health care experiences for patients trying to manage chronic medical or mental health conditions. The ability to help families contend with the convergence of health conditions and provide them with needed information, however, lies not only with health care providers, but requires coordination of health and social service providers and other community groups. For example, several families in our sample would have benefited from a combination of financial, medical, and respite care services. Health care provider recognition of the complexity of patients' lives can be a first step in connecting them to other support services that in turn will improve illness management. Also, reaching patients with important disease specific information will require a community level effort since many residents seek out and receive much of their health information from informal sources. Families in New Brunswick could benefit from a wider distribution of health information to community locations like local churches and other organizations. Self-management strategies involving community members, for example peer training and support, hold promise for improvement in symptoms for those with chronic medical or mental illness (Newman, Steed, & Mulligan, 2004; Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Additionally, having materials available in multiple languages could provide information to those patients who encounter difficulty communicating with their providers.

Our finding that those seeking mental health services encountered problems with availability and appropriateness of care reflects other work in this area. For example, the majority of American adults who meet the diagnostic criteria for a mental disorder do not use mental health services, in part due to lack of access to providers (Center for Mental Health Services, 2001). Members of racial and ethnic minority groups receive lower quality mental health services on average and are more likely to leave care prematurely than non-minority group members (Snowden, 2003). African-Americans and to some degree,

Hispanics, have a clear mistrust of professional health care services (Sussman, Robins, & Earls, 1987) and are less likely to seek care in formal care settings (Vera, et al., 1998; Cooper-Patrick et al., 1994). Additionally, Alegria et al. (1991) suggest that part of the decision to continue care depends on the experiences individuals have with their initial contact with a provider. Based on this experience, individuals continue care with the same provider, change providers, or avoid care. Interactions with providers affected the future care of the respondents in this study, with some shunning or altering care for their mental illnesses because of negative encounters with providers.

Providing appropriate, coordinated health care and health education to residents with complex medical conditions and life circumstances remains a challenge to the practice of urban medicine. Safety net providers are often operating at full capacity and are not funded to do comprehensive follow-up or health education activities. Furthermore, coordinating services across several providers is not always probable particularly when individuals with chronic conditions do not access or face significant barriers in accessing specialty care services (Stanley, et al., 2007). In New Brunswick, despite the city's relative abundance of safety net providers, these challenges to increasing health care service access remain.

Despite these challenges, the need to better understand patients' lives outside the doctor's office and develop interventions to help them manage chronic diseases and mental health conditions within their complex lives, seems clear. Allowing patients to discuss their personal experiences with health care, as this study has done, is one way to identify critical needs within a community and personal narratives are a source of information for strategizing effective solutions. Narratives can clearly show what things prevent patients from seeking care or adequately doing self-care. The disparaging treatment received in an emergency room or the competing demands on time and resources, mentioned by respondents in this study, are examples of such barriers. Qualitative studies of specific patient populations are one way to connect medical and social service providers to knowledge of patients' lives, beliefs, and behaviors, and inform their service and treatment decisions.

Our small sample size did not allow for sub-group analysis but pointed to group differences in health care experiences and health seeking behavior. For example, we identified the higher likelihood of

Latino residents to have navigation difficulties and to use informal health information networks. Previous studies on the experiences of Latinos in help-seeking have found similar results, with many Latinos obtaining care in non-specialty locations or through informal sources (Alegria, et al., 2002; Cauce, et. al., 2002). Further qualitative research should explore how chronically ill patients experiences vary by income, race, and ethnicity and how different life circumstances influence interactions with health care providers and the ability to manage illnesses.

References

- Alegria, M., Canino, G., Rios, R., Vera, M., Calderon, J., Rusch, D., et al. (2002). Inequalities in the use of specialty mental health services among Latinos, African Americans, and non-Latino whites. *Psychiatric Services*, 53(12), 1547-1555.
- Alegria, M., Robles, R., Freeman, D.H., Vera, M., Jimenez, A.L., Rios, C., et al. (1991). Patterns of mental health utilization among island Puerto Rican poor. *American Journal of Public Health*, 81, 875-879.
- Andersen, R.M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior*, 36, 1-10.
- Baldwin, L.M., Patanian, M.M., Larson, E.H., Lishner, D.M., Mauksch, L.B., Katon, W.J., et al. Modeling the mental health workforce in Washington State: using state licensing data to examine provider supply in rural and urban areas. *Journal of Rural Health*, 22(1), 50-8.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48, 177-187.
- Blankenfield, R.P., Goodwin, M., Jaen, C.R., & Stange, K.C. (2002). Addressing the unique challenges of inner-city practice: A direct observational study of inner-city, suburban, and rural family practices. *Journal of Urban Health*, 79(2), 173-185.
- Cantor, J.C., Guarnaccia, P.J., Brownlee, S., Schneider, C., & Nova, J. (2006, April). Health and Health Care of New Brunswick's Children. Retrieved November 30, 2007 from <http://www.cshp.rutgers.edu/Downloads/6510.pdf>.
- Cauce, A.M., Domenech-Rodriguez, M., Paradise, M., Cochran, B.N., Shea, J.M., Srebnik, D., et al. (2002). Cultural context influences in mental health help seeking: a focus on ethnic minority youth. *Journal of Consulting and Clinical Psychology*, 70(1), 44-55.
- Center for Mental Health Services. (2001). Mental Health, United States, 2000. DHHS Pub No. (SMA) 01-3537. Washington, DC: Supt. of Docs., U.S. Govt. Print. Office.
- Chwastiak, L.A., Rosenheck, R.A., McEvoy, J.P., Keefe, R., Swartz, M.S., & Lieberman, J.A. (2006). Interrelationships of psychiatric symptom severity, medical comorbidity, and functioning in schizophrenia. *Psychiatric Services*, 57(8), 1102-1109.
- Coats, V.E., & Boore, V.R.P. (1995). Self-management of chronic illness: implications for nursing. *International Journal of Nursing Studies*, 32(6), 628-640.
- Cooper-Patrick, L., Crum, R.M., & Ford, D.E. (1994). Characteristics of patients with major depression who received care in general medical and specialty mental health settings. *Medical Care*, 32,15-24.
- Cunningham, P.J., & Kemper, P. (1998). Ability to obtain medical care for the uninsured: How much does it vary across communities. *Journal of the American Medical Association*, 280, 921-927.

- Dickey, B., Normand, S.T., Weiss, R.D., Drake, R.E., & Azeni, H. (2002). Medical morbidity, mental illness, and substance use disorders. *Psychiatric Services*, 53(7), 861-867.
- Druss, B.G., Marcus, S.C., Rosenheck, R.A., Olfson, M., Tanielian, T., & Pincus H.A. (2000). Understanding disability in mental and general medical conditions. *American Journal of Psychiatry*, 157,1485-1491.
- Druss, B.G., & Rosenheck, R.A. (2000). Use of practitioner-based complementary therapies by persons reporting mental conditions in the United States. *Archives of General Psychiatry*, 57,708-714.
- Frayne, S.M., Seaver, M.R., Loveland, S., Christiansen, C.L., Spiro III, A., Parker, V.A. et al. (2004). Burden of medical illness in women with depression and posttraumatic stress disorder. *Archives of Internal Medicine*, 164,1306-1312.
- Glasgow, R.E., Wilson, W., & McCaul, K.D. (1985). Regimen adherence: a problematic construct in diabetes research. *Diabetes Care*, 8(3), 300-301.
- Grypdonck, M.H.F. (2006). Qualitative health research in the era of evidence-based practice. *Qualitative Health Research*, 16(10), 1371-1385.
- Guarnaccia, P.J. (2006, October). Health in the New Brunswick Community:Focus on Mexican Immigrants. Retrieved November 30, 2007, from <http://www.cshp.rutgers.edu/Downloads/6750.pdf>
- Johnson M.E., Brems C., Warner T.D., & Roberts L.W. (2006). Rural-urban health care provider disparities in Alaska and New Mexico. *Administration and Policy in Mental Health and Mental Health Services Research*, 3(4),504-507.
- Link, B.G., Yang, L.H., Phelan J.C., & Collins, P.Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30(3),511-541.
- Marcus, S.C., Olfson, M., Pincus, H.A., Shear, M.K., & Zarin, D.A. (1997). Self-reported anxiety, general medical conditions, and disability bed days. *American Journal of Psychiatry*, 154(12),1766-1768.
- McIntyre, R.S., Konarski, J.Z., Soczynska, J., Wilkins, K., Panjwani, G., Bouffard, B., et al. (2006). Medical comorbidity in bipolar disorder: Implications for functional outcomes and health service utilization. *Psychiatric Services*, 57(8),1140-1144.
- Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *Lancet*, 364, 1523–37.
- Ng, C.H. The stigma of mental illness in Asian cultures. (1997). *Australian and New Zealand Journal of Psychiatry*, 31, 382-390.
- Peyrot, M., McMurry, J.F., & Hedges R. (1987). Living with diabetes: the role of personal and professional knowledge in symptom and regimen management. In J.A. Roth, P. Conrad (Eds.), *Research in the sociology of health care: The experience and management of chronic illness*. London, J A I Press Inc.
- Snowden, L.R. (1998). Racial differences in informal help seeking for mental health problems. *Journal of Community Psychology*, 26(5), 429-438.

Snowden, L.R. (2003) Bias in mental health assessment and intervention: theory and evidence. *American Journal of Public Health*, 93,(2), 239-243.

Stanley, A., Cantor J.C., & Guarnaccia, P. (2007). Holes in the safety net: A case study of access to prescription drugs and specialty care. *Journal of Urban Health*, Submitted for Publication.

Strauss, S., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: SAGE Publications.

Sussman, L.K., Robins, L.N., & Earls, F. (1987). Treatment-seeking for depression by black and white Americans. *Social Science and Medicine*, 24, 187–196.

Tata, S.P., & Leong, F.T.L. (1994). Individualism-collectivism, social network orientation, and acculturation as predictors of attitudes toward seeking professional psychological help among Chinese Americans. *Journal of Counseling Psychology*, 41(3),280-287.

Vera, M., Alegria, M., Freeman, D.H., Robles, R., Pescosolido, B., & Pena, M. (1998). Help seeking for mental health care among poor Puerto Ricans. *Medical Care*, 36(7),1047-1056.