Perceptions of quality of medical care among consumers with schizophrenia who have a comorbid medical illness

THESIS

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Abstract

Mortality and morbidity rates are higher among people with severe mental illnesses than the general population. While many studies have examined this phenomenon from the perspective of the provider, few researchers have worked with consumers to gain their perspective on this issue. As pointed out by researchers who have examined this from the perspective of the providers, there are clear structural (e.g. access to care) disparities in care for consumer diagnosed with schizophrenia. Nonetheless, research demonstrates other barriers to essential care such as consumer perceptions of health care and its providers. There is a need for additional research to examine perceptions of quality of care from the viewpoint of the consumer.

This study used both qualitative and quantitative methodologies to examine how twenty-five consumers at a local community mental health center diagnosed with both schizophrenia and a chronic physical illness (heart disease, diabetes, hepatitis C, HIV, or obesity) perceive the physical medical care they receive from their primary care physicians. The study was designed to gain more information about what these consumers define as high-quality medical care, and to determine in which areas they may perceive barriers to care.

The study was both quantitative and qualitative. The quantitative portion was composed of questions regarding five dimensions of care: communication, empathy, the doctor’s perception of schizophrenia, the doctor’s medical knowledge, and the patient’s perception
of their own health. The quantitative results were analyzed in SPSS using nonparametric tests due to the small sample size. The qualitative portion asked the respondents to describe good and bad experiences they had with their primary care physicians. The qualitative results were obtained using Grounded Theory. During data analysis, an overarching theme emerged: respondents connect high quality health care with good communication, empathy, accessibility, and provision of basic medical treatment. The quantitative results did not demonstrate a correlation between demographic information and any dimension of quality of care, but the dimensions of quality of care were correlated. There was a significant correlation between a diagnosis of diabetes and higher ratings in the Communication and Empathy dimensions. The qualitative results showed that consumers with SMIs and a comorbid diagnosis of diabetes as well as those with HIV should be studied further: if researchers can better identify the specific activities this group associates with high quality care perhaps this can act as a blueprint for better care for people with SMIs and other comorbid chronic illnesses. The author also identified issues that occurred for all diagnostic groups. Respondents reported communication and trust issues with their doctors. Additionally, respondents stated they had problems accessing care, which then exacerbated their psychiatric symptoms. Respondents with hepatitis C regularly perceived disparities in the care that they received, especially regarding lack of treatment. The results indicate a need for further research to investigate ways to improve communication between consumers and
providers and better accessibility to primary care physicians for this population, as these were the most commonly mentioned problems with care in the qualitative interviews.
Dedicated to my father, Eric Fredin
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Major Field: Social Work
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CHAPTER 1: INTRODUCTION

Problem Statement
People who have been diagnosed with severe mental illnesses (SMIs) have shorter lifespans than the general population. Surprisingly, this disparity is not due to suicide; but rather due to heart disease (Felker, Yazel, & Short, 1996). The research shows that individuals with a major mental illness who also have a comorbidity (e.g. heart disease, diabetes, obesity, etc.) are less likely to receive needed surgeries, necessary medications secondary to the comorbidity, have necessary lab work requested by their physicians, are not provided critical consumer education, and even are less likely to have their blood pressure taken (Druss, Rosenheck, Desai, & Perlin, 2002; Lawrence, Holman, Jablensky, & Hobbs, 2003; Frayne et al., 2005; Dixon et al., 2004; Roberts, Roalfe, Wilson, & Lester, 2006). Clearly, consumers with a severe mental illness who seek medical care for a comorbid physical illness, the primary focus of this study, face poor quality of care. Unfortunately, this is not a new problem.

History
Robert Phillips noted in 1937 that a very high percentage of consumers coming into the mental hospital had serious physical conditions, in particular heart disease and diabetes.
He stated at that time that while it was impossible to give an exact cause, a partial explanation was that consumers with mental illnesses “neglect their physical wellbeing” (Phillips, 1937). Since Phillips’s article other theorists have hypothesized about the situation. For example, during the 1960s some scholars questioned whether mental illnesses actually existed (Szasz, 1960). While this view has since been largely discredited, it created more barriers for those who were dealing with mental illness and co-occurring physical illnesses at that time. While almost no medical professionals accepted his theory, his books were widely read by the general public. These books influenced the views people with SMIs took of themselves, as well as how their friends and families perceived them – the theory discouraged from seeking psychiatric medication and it vilified psychiatrists. This viewpoint led to people who were experiencing severe psychiatric symptoms not seeking out psychiatric care, and instead blaming themselves for their very serious symptoms (Davidson, 1964).

In the late 1970s and early 1980s the perspective of people with SMIs and comorbid physical illnesses changed with a new study by Goodwin, Goodwin and Keller (1979). The researchers found that physicians were spending less time with patients with SMIs who came in with physical complaints and were less willing to request labs for them. The researchers theorized that consumers with SMIs were less likely to take care of their physical wellbeing because their physicians were not showing concern about their health. This constituted a clear disparity in care with serious consequences (Goodwin et al, 1979). Subsequently, in the late 1990s and early 2000’s a few researchers began to look at perceived barriers to care specifically from the consumers’ perspective and they found
that consumers felt that their physical complaints were being discounted by physicians due to stigma against people with mental illnesses and because of poor communication between doctor and patient. Consumers stated that both doctors and patients had to build better communication skills (Dickerson et al., 2003; O'Day, Killian, Sutton, & Iezzoni, 2005).

Background

It is well documented that consumers with severe mental illnesses suffer excessively from high comorbidity rates as well as higher mortality rates compared to the general population (Felker et al., 1996). People with schizophrenia are experiencing a twenty percent reduction in lifespan yet there is insufficient research investigating what these consumers perceive as barriers to physical medical care (Lawrence et al., 2003; Felker et al., 1996; Newman & Bland, 1991).

Druss, Bradford, Rosenheck, Radford, and Krumholz, (2000) as well as Felker et al. (1996) state that people with SMI tend to have higher rates of heart disease although exact numbers are unknown. Researchers have found that consumers with schizophrenia are 1.8 times more likely to die of heart disease compared to the general population (Lawrence et al., 2003). Multiple studies attribute this mortality rate to disparities in cardiac care for people with severe mental illnesses. Researchers found that consumers with SMI are less likely to receive medication and surgeries for cardiac disease (Druss et al., 2000; Young & Foster 2002, Wang et al., 2006). It is clear that consumers are not
merely imagining lower quality care, nor is it due to their lack of concern regarding their “physical wellbeing” as Phillips theorized (1937). Rather, these consumers are receiving lower quality care. Such disparities in care lower quality of life as well as increase morbidity and mortality rates for this population.

Researchers have reported high rates of mental illness among people diagnosed with diabetes. Frayne et al. (2005) found that in a study of over 300,000 subjects with diabetes at a Veteran’s Association, 25% had a mental illness. Wilkinson (1981) found that people with schizophrenia are at higher risk for contracting diabetes than the general population. He states that there is a correlation between high stress levels that are present in this population and metabolic changes such as ketoacidosis. Mukherjee (1995), Mukherjee, Decina, Bocola, Saraceni, and Scapicchio (1996), and Dixon et al. (2000) state that approximately 4% of the US population has diabetes type II, while 16-25% of Americans with schizophrenia have this a diagnosis (as cited in Dixon et al., 2004).

Although the author is unaware of any research on the mortality rate for patients with SMIs and diabetes, researchers have found that physicians are less likely to provide basic testing for patients with an SMI and this comorbidity, which certainly increases their risk of death (Dixon et al., 2004, Frayne et al., 2005).

Researchers have also found that people with schizophrenia have higher rates of HIV than the general US population (Fremont et al., 2007). One group of researchers found that out of 971 psychiatric patients in an inpatient setting, 5.2% were HIV positive (Cournos, Horwath, Guido, McKinnon, K, & Hopkins, 1994, as cited in Blank, Mendell, Aiken, & Hadley, 2002). Essock, Boaz, and Friedrich (1994) mention that people with
schizophrenia that are diagnosed with HIV are at risk for a shorter life span compared to people with HIV who do not have an SMI. They found that common cognitive impairments as well as the mental illness itself can interfere with medication compliance (as cited in Fremont et al., 2007). While this does support Phillips’ statement (1937) that consumers with SMIs tend to “neglect their physical wellbeing”, Fremont et al. (2007) also attribute higher mortality rates among patients with SMIs and HIV to disparities in health care for this population, poor coordination between psychiatric and physical care, poor doctor-patient communication, and socio-economic problems.

In addition, 15-20% of psychiatric patients have hepatitis C, compared to 1-2% of the general population (Rifai & Rosenstein, 2004; Strader, Write, Thomas, & Seef, 2004, as cited in Rifai, Moles, & Short, 2006). Rifai et al. (2006) state that people with psychiatric illnesses are often denied treatment for hepatitis C because the treatment can exacerbate their psychiatric symptoms, and without treatment hepatitis C can often lead to death.

Finally, studies regarding obesity found that people with a serious mental illness were substantially more likely to be obese as compared to those without a SMI (Daumit et al., 2003; Fontaine, et al., 2001; Hommel, Casey, & Allison, 2002; Holt & Peveler, 2009), although the exact numbers vary due to methodological limitations (as cited in Dickerson et al., 2003). Obesity is associated with health complications and premature mortality (Dickerson et al., 2003; Holt & Peveler, 2009). It often leads to cardiovascular disease and diabetes, both of which can significantly shorten one’s lifespan (Dickerson et al., 2003; Dixon et al., 2004; Frayne et al., 2005; Lawrence et al., 2003). Henderson et al.
all found that medication commonly prescribed for schizophrenia, in particular
Olanzapine and Clozapine are associated with weight gain and this often results in
noncompliance with treatment (as cited in Dickerson et al., 2003).
Meta-analyses also bear out what research has found for specific conditions. For
example, a recent meta analysis examined research on quality of medical care for
consumers with mental illness (Mitchell, Mallone, & Doebbeling, 2009). Mitchell et al.
(2009) found that in the twenty-seven studies examined nineteen found that consumers
were experiencing inferior medical care. Mitchell et al. (2009) described research done
with consumers who had SMIs and comorbid chronic physical illnesses including heart
disease, diabetes, HCV and HIV. Phelan, Stradins, and Morrison (2001) examined
consumers with SMIs and heart disease and they state that “Poor quality of medical care
may partly explain the excess mortality seen among consumers with psychiatric or
substance use disorders after myocardial infarction”. Druss et al. (2000) cite low quality
of care as one of the factors in the excess mortality of elderly consumers with SMIs.
Young and Foster (2000) repeated Druss et al.’s study and found that this excess
mortality is also present in the younger population who have SMIs, particularly in the
case of schizophrenia. The only area where care was close to equitable was in the field of
HIV treatment, and researchers attributed this to the longstanding high levels of case
management in this field (Fremont et al., 2007).
While many studies noted poor outcomes for consumers with SMIs and a comorbid chronic illness, almost none examined the consumers' perceptions of their medical care. This lack of focus on consumer perception represents a barrier in and of itself. The choice not to involve consumers in this research also demonstrates the ongoing stigma against people with SMIs in the world at large and within the medical professional community. Only when researchers in the field can gain knowledge about the consumers’ perspective on the issue can the providers begin to work *with* the consumers to solve the problem. The present study aims to address this issue by focusing on consumer perceptions of care. To date few studies have asked consumers about their experiences with doctors (O’Day et al., 2005; Schuze & Angermeyer, 2003; Finzen, 1996). In research by O’Day et al., (2005) the participants stated repeatedly that doctors lacked empathy, did not understand the nature of SMIs, and lacked current information on psychotropic medication. The participants also stated that providers often did not understand that their psychiatric disabilities themselves often made it hard to schedule and attend appointments, and to communicate their medical symptoms. Schulze and Angermeyer (2003) found that some consumers felt their doctors viewed them as illnesses, not people. The present study will build on these previous studies to gain more information about consumer perceptions of medical care.

Statement of the Problem

If both groups – consumers and providers – agree that communication is a major barrier to treatment, it is surprising that there have not been more efforts made to improve
communication, and that no other studies have examined this issue from the perspective of the consumers. People with SMIs are dying from preventable and treatable illnesses as well as suffering from very preventable disabilities because they are not receiving the care that they need. Specifically, these people are dying at a younger age than Americans without SMIs (Newman & Bland, 1991), and the number one cause of death in this group is heart disease (Lawrence et al., 2003). The literature demonstrates an ongoing issue of disparities in quality care for people with schizophrenia with a comorbid chronic physical illness.

Consumers in one of the few studies done from their perspective report they dislike doctors (doctors in general, not specific kinds of doctors) because the doctors lack empathy/don’t communicate/don’t trust them/don’t believe them (O’Day et al., 2005). Other studies state that doctors feel uncomfortable around patients with SMIs and dislike treating them (Frayne et al., 2005; Felker et al., 1996). Multiple studies clearly show the denial of necessary care to consumers with SMIs, in particular, cardiac care (Young & Foster, 2000; Druss et al., 2000; Wang et al., 2005). All of these facts demonstrate a need for further research.

**Purpose of this study**

This study is intended to advance the field’s knowledge of communication breakdowns between health care professionals and consumers with SMIs and to examine a possible method of improving communication. The previous section discussed the gaps in current knowledge regarding perception of barriers to care as well as the disparities in
care and it is clear that a study exploring these issues from the point of view of the consumer would be invaluable to improving medical healthcare for people with SMIs. That is, a better understanding of consumers’ experiences with health can provide critical information regarding one factor that may contribute to health disparities that lead to higher rates of morbidity and mortality for persons living with a serious and persistent mental illness.

Research question

There is a demonstrable lack of research regarding how consumers diagnosed with both an SMI and a chronic physical illness feel about the care they receive from their primary care physicians (Lawrence et al., 20003; Felker et al., 1996; Newman & Bland, 1991). The literature demonstrates that there is overall poor quality of care and a lack of communication between consumers and their doctors (O’Day et al., 2005).

This study will examine consumers’ attitudes toward their medical care. Thus I pose the question: how do consumers who have been diagnosed with schizophrenia and a co-occurring chronic medical illness feel about the quality of care that they receive from their primary care physicians? Specifically, this study will attempt to answer the following research questions:

- Do consumers with schizophrenia believe they receive high quality medical care?
- In which dimensions (communication, empathy and trust, the doctor’s perception of schizophrenia, the medical knowledge of the doctor, and the consumer’s perception of their own health) do consumers perceive a high quality of care?
which dimensions do consumers perceive a low quality of care?

- Are there differences in reported perceptions of quality care based on gender, mental health diagnosis, or medical diagnosis?

- How do qualitative and quantitative measurements of perception of quality of care in the five dimensions compare?

- What are some barriers consumers perceive to obtaining high quality care?

- What areas of this topic require further research?

For the purposes of this study “quality of care” will be defined using the Institute of Medicine’s definition: the “Degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Lohr, Donaldson, & Harris-Wehling, 1992) and will be measured along five dimensions: communication, empathy, the doctor’s perception of schizophrenia, the doctor’s medical knowledge, and the consumer’s perception of their own medical knowledge. The questions of the survey and interviews will examine whether consumers feel that they are experiencing lower quality medical care due to their diagnosis of schizophrenia.

Implications of the field of social work

As social workers we are bound to a code of ethics which states that we will work to advocate for those who are disenfranchised. This research will explore the attitudes of a vulnerable population that we are striving to assist, and it will at the same time encourage
client autonomy and self determination by actively involving the consumers, rather than the providers of care. This thesis, which will test how people with SMIIs and a co-occurring diagnosis of a chronic illness perceive their quality of care, will help inform both social policy and direct intervention practice models for similar populations.
CHAPTER 2: LITERATURE REVIEW

Researchers demonstrate the higher comorbidity rates of chronic illnesses for people with SMIs due to multiple reasons. Felker et al., (1996), Druss et al., (2000), and Lawrence et al. (2003) state that people with SMIs have higher rates of heart disease, although to this author’s knowledge, no study has explored the possible reasons for this elevated morbidity rate. In regards to diabetes, a study by Ryan, Collins, and Thakore (2003) that looked at people with schizophrenia who were not on any medication showed that schizophrenia itself is actually linked with impaired fasting glucose tolerance, which is the stage before diabetes (Yovtcheva, Rifai, Moles, & Van Der Linden, 2001). Koro et al. (2002), Sernyak, Leslie, Alarcon, Losonczy, and Rosenheck (2002), as well as Newcomer et al. (2002) state that people with schizophrenia often have high risk behaviors that can lead to diabetes, such as a sedentary life style, higher obesity rates, poor diet, a higher smoking rate, cognitive impairment, and limited support (as cited in Dixon et al., 2004). Seidman, Cassens, Kremen, and Pepple (1992) as well as Braff et al. (1991) both report that second-generation antipsychotics which are commonly prescribed to people with schizophrenia, in particular Olanzapine and Clozapine are also associated with higher rates of diabetes (as cited in Dixon et al., 2004). There are only two studies known to this author that explores the comorbidity of hepatitis C and serious mental illness. As mentioned previously, rates of hepatitis C in the population are estimated to be 15-20%
Yovtcheva et al. (2001) found that of 306 clients at a Veteran’s Association who were diagnosed with Hepatitis C, 34% had a mood disorder, 26% had an anxiety disorder, 30% had a personality disorder, and 17% had a psychosis disorder, with 12% having a schizophrenia diagnosis. It should be noted that many of these clients had more than one psychiatric disorder while other subjects had no psychiatric diagnosis. However, researchers (Davis et al., 1989; Dieperink, Willenburg, and Ho, 2000; Hunt et al., 1997; Pariente, Orru, Baita & Farci, 1999 and Sing, Gayowski, Wagener, & Marino, 1997) demonstrate that there is a high frequency of hepatitis C among those diagnosed with an SMI (as cited in Yovtcheva et al., 2001).

Research also shows higher rates for HIV in people with SMIs (Blank et al., 2002; Gottesman & Groome, 1997; Seeman, Lang, & Rictor, 1990). Research demonstrates that there are higher rates of risky sexual behavior, higher rates of drug use, and cognitive victimization for this population (as cited in Fremont et al., 2007).

Additionally, in regards to obesity rates, Dickerson et al. (2003) found that 50% of women and 41% of men in community-based psychiatric care are obese compared to 27% of women and 20% of men in the general population. Additionally they found that 17% of women who had schizophrenia had a BMI over 40 while this number for women in the general US population was approximately 5%. Holt and Peveler (2009) state that the higher obesity rate is not just due to overeating, but also results “from complex interactions of the genotype and environment of the person with mental illness, the mental illness itself, and antipsychotic medications” (p. 673).
The consumer’s point of view

Given this pattern of finding significant health risks for a variety of serious and life threatening health problems for individuals with a serious and persistent mental illness, researcher have offered several hypotheses as to what is the cause for these findings and the resultant limited life expectancy for this population. A small minority of researchers appear to fault the consumer; for example, Bunce, Jones, Badger, and Jones (1982) state that psychiatric consumers often present with atypical symptoms and Berren, Santiago, Zent, and Carbone (1999) mention that psychiatric symptoms may make it difficult or even impossible to detect certain physical symptoms. Additionally, some studies point out that patients with SMIs often have poor insight into mental and physical symptoms that they may experience (Cradock-O’Leary, Young, Yano, Wang, & Lee, 2000; Bunce et al., 1982). The majority of the studies reviewed for this thesis, in particular those done in the past ten years place the blame on healthcare providers (Dickerson et al., 2003; Dixon et al., 2004; Druss et al., 2000; Frayne et al., 2005; Goodwin et al., 1979; Graber et al., 2000; Lawrence et al., 2003; O’Day et al., 2005; Rifai et al., 2006; Roberts et al., 2005; Sternberg, 1986; Young & Foster 2002). Researchers cite reasons such as denial of treatment based on psychiatric diagnoses, lack of attempts at consumer education and poor efforts at communication. Many researchers cite a lack of trust both from the doctor and the consumer’s perspectives (O’Day et al., 2005; Druss et al., 2000; Sternberg, 1986; Goodwin et al., 1979; Graber et al., 2000).

Recently a study entirely from the consumer’s perspective was completed. The researchers reported many of the same perceived barriers to care that previous researchers
had found when examining barriers to care from the provider’s perspective (O’Day et al., 2005): the doctor denies the consumer treatment, medication, or education because the doctor is uncomfortable or unwilling to work with those diagnosed as severely mentally ill (Cradock-O’Leary et al., 2002; Daumit et al., 2007; Druss et al., 2002; Dixon et al., 2004; Frayne et al., 2005; Lawrence et al., 2003; Penn & Martin, 1998; Roberts et al., 2006). The consequences of this low quality care are deadly, as demonstrated by the higher mortality rates in consumers with SMIs (Lawrence et al., 2003).

Healthcare disparities: Denial of treatment

General medical care for people with SMIs

When examining general medical care for consumers with SMIs and comorbid physical illnesses researchers found major disparities in quality of care as well as perceived disparities on the part of consumers. Consumers with SMIs who see a physician for general medical care face much lower quality of care. These consumers are significantly less likely to be treated for a comorbid physical illness (Reidelmeir, Tan, & Booth, 1998). For example, they are less likely to receive mammograms, pap smears, and even having their blood pressure taken in the doctor’s office (Salsberry, Chips, & Kennedy, 2005; Roberts et al., 2005). They are less likely to be diagnosed with diabetes, chronic obstructive pulmonary disease, and hypertension despite the fact that past research demonstrates higher rates of these diseases among people with SMIs than the national average (Cradock-O’Leary et al., 2002; Druss & Rosenheck, 1997). These consumers are
less likely to receive forms of treatment that require multiple care providers. For example, a patient with heart disease would be less likely to be sent from a primary care physician to a cardiologist and from there to a surgeon, even if they had a cardiac problem for which surgery was recommended (Druss et al., 2002). Additionally, because these consumers have many different medical issues doctors are unable to spend as much time on each problem (Druss et al., 2002). The single study that did not find any disparities in physical care was done through the Veteran’s Association that has a fully integrated medical and mental health treatment system, which may explain such results (Desai, Rosenheck, Druss, & Perlin, 2002a). This theory of superior care through integration of mental and physical care in the Veteran’s Association is also mentioned by Cradock-O’Leary et al. (2002) in their research on veterans with mental illnesses and co-occurring medical illnesses.

In addition, Cradock-O’Leary et al. (2002) that found that clients with an SMI in addition to a chronic physical illness were less likely to schedule doctor’s appointments. One wonders if these consumers schedule fewer appointments because they receive lower quality care from their physicians (Reidelmeier et al., 2008; Desai et al., 2002a; Cradock-O’Leary et al., 2002; Dickerson et al., 2003). Indeed, the fact that every one of these studies found perceived disparities in care and yet none of them focused primarily on the consumers’ experiences demonstrates a large gap in the field’s knowledge.

Diabetes, hepatitis C and HIV care for people with SMIs
A number of studies demonstrate health disparities across a number of comorbidities for consumers with SMIs. One of the most glaring inequities occurs in hepatitis C treatment. Rifai et al. (2006) found that consumers with hepatitis C (HCV) and an SMI only received HCV treatment two-thirds of the time. Although HCV treatment is contraindicated for consumers with SMIs because it can cause irritability, psychosis, anxiety, and depression which can lead to suicide (Rifai et al., 2006; Yovtcheva et al., 2001), these side effects are estimated to occur in less than 5% of patients who receive the medication (El-Serag, Kunick, Richardson, & Rabeneck, 2002). Dobmeier, Frick, Frank, Franke, and Wolfersdorf (2000) state that neuroleptics medications given to people with schizophrenia can worsen Hepatitis C infection which makes these patients more likely to develop liver cirrhosis or hepatocellular carcinoma so they recommend Hepatitis C treatment for patients with schizophrenia only if it is recommended by the hepatologist. Rifai and his colleagues believe that treatment of those with a comorbid SMI (particularly in an integrated care facility) would dramatically reduce both the mortality rate due to HCV as well as the spread of the disease (Rifai et al., 2006). During Rifai et al.’s study (2006) 11% of their consumers died, mostly due to cirrhosis. These statistics paint a disturbing picture. Rifai et al. (2006) state, “The exclusion of patients with a psychiatric illness from interferon-alpha treatment is stigmatizing and may be associated with measurable mortality for a particularly vulnerable population no less deserving of treatment than Hepatitis C patients without illness” (p. 572).

Much work has been done on diabetes occurring in consumers with SMIs as people with SMIs have very high rates of diabetes compared to the general population (Dixon et al.,
2004; Frayne et al., 2005). Once again the research was rife with disparities in quality of care. Frayne et al. (2005) found that people with a mental illness and diabetes experience disparities in every aspect of diabetes care that they measured. Clients with mental illnesses, particularly schizophrenia, are less likely to have crucial blood tests such as hemoglobin A\textsubscript{1c} and low-density lipoprotein cholesterol ordered, are less likely to have an eye exam, and are less likely to receive regular monitoring for their symptoms. The lack of regular blood testing among people with diabetes and SMIs is problematic because consumers who are prescribed Olanzapine, a common psychotropic medication, are more likely to experience obesity and metabolic issues which cause higher levels of hemoglobin A\textsubscript{1c} (Frayne et al., 2005). Likewise, Sullivan, Han, Moore, and Kotrla (2007) state that clients with a mental illness and diabetes are less likely to be hospitalized. Jones, Clark and Carney (2007) found that although consumers with diabetes and an SMI utilized the healthcare system more often than consumers without an SMI, those with SMIs were less likely to receive a hemoglobin A\textsubscript{1c} test or a cholesterol test. The vast majority of researchers found some form of inferior care being provided to consumers with diabetes and a mental illness (Li, Glance, Cai, & Mukamael, 2007; Jones et al., 2007; Sullivan et al., 2006; Weiss et al., 2006; Dixon et al., 2004; Kreyenbuhl et al., 2006; Goldberg et al., 2007). One study was as exception to this (Krein et al. (2005). It is possible that like other SMI and medical co-morbidity studies conducted at a VA, Krein et al. (2005) did not find disparities in care because physical and mental health care are fully integrated at this agency.

In regards to HIV care, most researchers found no difference in quality of HIV care for
those with or without an SMI (Butt, Wagener, Shail & Ahmed, 2005, Bogart et al., 2006). Nonetheless, Fremont et al. (2007) examined quality of care for people with an SMI and HIV in Los Angeles and New York City and found that they received poorer quality care in Los Angeles but equal care in New York, although they did experience problems accessing care in New York. Fremont et al. attributed this to better case management services in New York City. Fremont et al. (2007) also found that patients with HIV and co-occurring serious mental illness actually had higher CD4 counts than HIV-positive patients without a mental illness. Bogart et al. (2006) supported this research and found that patients with co-occurring mental illness also tended to have lower viral loads.

Generally speaking, HIV care had the most equitable levels of quality of care for consumers with a mental illness, although such clients did report some trouble accessing treatment; they were less likely to recommend their provider (Fremont et al., 2007).

As mentioned previously, many researchers including Daumit et al., 2003, Fontaine et al., 2001, Hommel et al., 2002, and Holt and Peveler, 2009 found that obesity rates in people with SMIs are much higher than in the general population (as cited in Dickerson et al., 2003). Russell and Mackel (2001) and Lipkovich et al. (2006) state that there are multiple reasons for this including genetics, environment, and mental illness (as cited in Holt & Peveler, 2009). Elman, Borsook and Lukas (2006) found that people with serious mental illnesses tend to eat more carbohydrates and less fiber, fruit, and vegetables compared to the general populations, possibly because they have deficient reward mechanisms (as cited in Holt & Peveler, 2009). O’Donovan, Williams, and Owen (2003) and Gough and O’Donovan (2005) found that genes associated with schizophrenia are
also associated with obesity, metabolic syndromes, lipid metabolisms and type two diabetes (as cited in Holt & Peveler, 2009). This means people with schizophrenia are more likely to be obese even if they are not taking medications that cause weight gain, such as second generation antipsychotics. This author is not aware of any studies done specifically on disparities in care for people who are obese and have a co-occurring mental illness, however, obesity leads to cardiovascular disease and there are major disparities in care in this arena (Dickerson et al., 2005). Additionally, there is a lack of weight loss programs for people who are obese and have a serious mental illness. This is very problematic because people who have serious mental illnesses are often obese for other reasons than the general population, so standard treatment options for obesity may not be as effective. Multiple researchers including Baptista et al. (2008) and Faulkner, Cohn and Remington (2007) emphasize the need for these groups, which could potentially greatly reduce mortality rates for people with SMIs because obesity leads to premature death (as cited in Holt & Peveler, 2009). Russell and Mackel (2001), Lipkovich et al. (2006), and Isaac and Halloway (2005) name several factors associated with obesity that are commonly found in people with serious mental illness including genetic polymorphisms, cannabis use, psychosis, and especially the side effects of second generation antipsychotic medications that are often prescribed to people with schizophrenia (as cited in Holt & Peveler, 2009).

Cardiology

As stated previously, heart disease is the number one cause of death for consumers with
schizophrenia which highlights the severity of this comorbidity for this population. People with schizophrenia are 1.8 times more likely to die from heart disease than the general population and yet they continue to receive lower quality care (Lawrence et al., 2003; Young & Foster, 2002; Druss et al., 2000; Wang et al., 2005). Consumers with SMIs who had a heart attack were 41% less likely to receive cardiac catheterization and significantly less likely to be prescribed beta blockers (Druss et al., 2000; Young & Foster, 2002). Additionally, consumers with SMIs were less likely to be prescribed antihypertensive medication compared to consumers with asthma and chronic obstructive pulmonary disease (Wang et al., 2005). Young and Foster (2002) found that consumers with SMIs and heart disease were significantly less likely to receive any type of revascularization procedure such as cardiac catheterization, percutaneous transluminal coronary angiography or coronary artery bypass graft surgery. Hippisley-Cox, Parker, Coupland, and Vinogradova (2007) found that consumers with schizophrenia or bipolar disorder were less likely to receive statin prescriptions. Li et al. (2008) found that consumers with SMIs or substance use disorders were more likely to be assigned to low-quality surgeons when they did receive heart surgery. Thus it is not surprising that in a study of 201,129 people who accessed mental health services in Western Australia over an eighteen-year period, Lawrence et al. (2003) found that “Men with schizophrenia were only 60% as likely to be admitted for ischemic heart disease as those in the general population despite being 1.8 times more likely to die from ischemic heart disease” (p. 33). Lawrence et al. (2003) also stated that consumers with psychoses are much less likely to receive revascularization procedures.
The single study that demonstrated the lowest rate of disparities in care was once again conducted through the Veteran’s Association, and even this found that consumers with SMIs were less likely to receive angiograms (Desai, Rosenheck, Druss, & Perlin 2002b). Desai et al. (2002b) again point out that VA physicians are more accustomed to working with patients who have SMIs because approximately twenty percent of veterans have been diagnosed with a mental illness. Likewise, as previously noted, medical and mental health care are more fully integrated, which physicians and patients like. Mitchell’s 2009 meta analysis regarding cardiac care demonstrated that 100% of included studies found some form of disparity in quality of care, and those that examined perceptions of quality of care also found disparities. None of the studies asked why the consumers perceived barriers to care which begs the question, why hasn’t this been researched when heart disease is killing this population at such a high rate?

Healthcare disparities: Denial of education

The research on healthcare education for people with SMIs was limited to the study of diabetes care. Dixon et al. (2004) found that people with schizophrenia and type II diabetes have significantly lower levels of diabetes education than people with type II diabetes who do not have schizophrenia. Dixon et al. (2004) distributed the Diabetes Knowledge Test to consumers with and without SMIs and found significantly lower levels of diabetes education among the population with SMIs. This was supported by research done by Jones et al. (2007) which found that clients with an SMI and diabetes had lower levels of education about healthy blood sugar levels as compared to clients
without an SMI diagnosis. These findings are especially problematic because people with schizophrenia are four to five times more likely to have diabetes than the general population of the United States (Dixon et al., 2004). This is partly due in part by the side effects of psychotropic medications that are commonly prescribed. Additionally, Phelan et al. (2001) make an important point when they state that people with schizophrenia do not eat healthy foods, do not exercise as much, and are more likely to smoke than the general population all of which can contribute to higher risks for development of diabetes or to a more problematic prognosis if diabetes is present.

The consequences of little to no health education can be devastating if what was found about health education with diabetes is similar with other comorbidities. Indeed, because many healthcare professionals are uncomfortable working with people with schizophrenia, people with schizophrenia are at high risk for not receiving the education that can help prevent illnesses or improve the overall course of any illness that is present (Goodwin et al., 1979; Frayne et al., 2005). It is interesting that people with SMIs die at a higher rate from heart disease but no research has examined whether doctors attempt to educate this population regarding their cardiac health.

What contributes to healthcare disparities?

Stigmatized consumers

Much of the research about how stigma might impact quality of medical care was done using samples of people diagnosed with schizophrenia. Many of these studies found that
negative doctor-consumer interactions were a factor in care: Sternberg (1986) states that when physicians interact with psychiatric consumers they are more likely to make premature diagnoses and less likely to take full histories or order complete lab work. Goodwin et al. (1979) as well as Frayne et al. (2005) found that primary care doctors may dislike consumers with schizophrenia and that this affects the quality of care. Graber et al. (2000) elaborated on this, stating that medical providers often have the same preconceptions about people with SMIs that the rest of society does. Consumers with SMIs from a focus group affirm Graber’s statement. One said, “Once a doctor finds out I have a psychiatric disability, he’ll question my judgment on all kinds of things and wonder whether I’m reporting them accurately” (O’Day et al., 2005, p. 341).

Finzen (1996) describes how schizophrenia is accompanied by a “second illness”: people with schizophrenia must deal not only with the diagnosis of mental illness but also with the reaction of society, and the amount of stigma that they face means fewer opportunities for work, increased social isolation, and makes those facing the illness less willing to seek help (as cited in Schulze & Angermeyer, 2003). Schulze and Angermeyer (2003) demonstrate that consumers diagnosed with schizophrenia experience more stigma than consumers with any other mental illness. In focus groups these consumers stated that they felt doctors did not take enough interest in them as people, but rather only saw the illness. Consumers also expressed concern that psychiatrists saw medication adjustment as the only answer to their symptoms.

Perceptions of care: Communication and trust
Other researchers cited poor communication as the main source of inferior care. Daumit et al. (2006) examined adverse events that happened to consumers with schizophrenia who were hospitalized for medical reasons. Daumit et al. (2006) define an adverse event as “injuries caused by medical management rather than underlying disease” (p. 267). The researchers describe how the various health care professionals, whether they are specialists, physicians, surgeons, nurses, or techs, may misinterpret the consumers’ somatic complaints because they have a psychiatric illness, particularly if they are currently experiencing psychosis. Daumit et al. (2006) state, “Health care professionals may minimize or misinterpret somatic symptoms and delay diagnosis and treatment of conditions needing attention, particularly if consumers experience active psychosis, display aggressive behavior, or have difficulty communicating” (p. 267). Daumit et al. suggest that consumers’ aggressive behavior may lead to inadvertent over-sedation which then causes higher levels of respiratory failure in this population.

This is supported by Young and Foster’s research (2000), in which they found that there is an eighty-six percent increased likelihood of death when people with schizophrenia are receiving inpatient care for physical illnesses. This is also supported by the focus groups in Schulze and Angermeyer’s study (2003), in which one consumer described his experience in the hospital as follows: “When you get to the hospital, the first thing is sedation. Nobody is talking to you. You have no idea what is going on…it’s only after a few days that a patient is asked what is actually wrong with him” (p. 304). Additionally, McDonald, Frakes, Apostolidis, Goldblatt, and Bernardo (2003) report that nurses were found to attribute cardiac consumers’ symptoms to something other than chest pain if the
consumers were taking psychotropic medications.

Bunce et al. (1982) found that psychiatric consumers report trouble communicating their symptoms. Cradock-O’Leary et al. (2000) support Bunce et al. in a more recent study of veterans with chronic physical illnesses and a co-occurring mental illness. Cradock-O’Leary state that these consumers may have trouble communicating or even identifying their symptoms, and that many people with schizophrenia or bipolar disorder have higher tolerances for physical pain and thus do not see physicians as often. Penn and Martin (1998) believe that some consumers with SMIs have trouble communicating symptoms to doctors because they believe the doctors do not trust them, while other consumers have cognitive difficulties that present a barrier in communication. This is supported by Phelan et al. (2001). DiMatteo, Lepper, and Croghan (2000) agree that distrust is often an issue, and that it plays a major part in noncompliance with treatment.

As mentioned previously, only one study by O’Day et al. (2005) asked focus groups about their experiences with their primary care physicians. The consumers with SMIs in this study who participated in focus groups agreed with Penn and Martin’s analysis, although the focus group members emphasized the need for the consumers to take the initiative to find a doctor they can trust, rather than expecting all doctors to treat people with SMIs appropriately (O’Day et al., 2005). Druss et al. (2002) state that “Providers tend to ascribe many of these consumers’ somatic complaints to their psychiatric disorders, which may result in an underestimate of the pretest probability of other medical conditions,” which leads us back to the consumer’s earlier statement, “[doctors] will question my judgment” (O’Day et al., 2005, p. 341). The study by O’Day et al.
(2005) is groundbreaking in that is the first to investigate quality of care from the consumers’ perspective. The work by O’Day et al. (2005) is an invaluable first step in bringing consumer advocacy into this problem of disparities in care but more research is needed to find specific ways to improve care. O’Day et al. (2005) chose to use a qualitative analysis, and this author’s research attempts to find correlations between the different dimensions of quality of care using a quantitative measure as well. With more data, it may be possible to suggest concrete ways that providers and consumers can work together to improve barriers to care, particularly in the areas of communication and trust brought up by these focus groups brought up (O’Day et al., 2005).

Barriers consumers perceive to receiving care

Again and again the literature has shown that people with SMIs are dying at younger ages than the rest of the people in the United States. There are many theories as to why this is the case, including lack of communication, lack of education, stigma, and denial of care. While these theories have merit, there is only one study to this author’s knowledge (O’Day et al., 2005) that directly asks people with schizophrenia how they feel about the care that they receive. As previous cited, O’Day et al (2005) held a series of focus groups and found that consumers did not feel comfortable with their physicians. Group members reported that they felt doctors were not empathetic and that they did not want to deal with consumers with SMIs. Group members believed that the doctors were skeptical when they described symptoms – they stated that physicians would attribute their physical symptoms to their mental illnesses. The focus groups talked about communication being
a problem, but stated that both the consumer and the provider would need to do work to improve the situation: people with SMIs would need to work harder to advocate for themselves, to keep appointments, and to describe their symptoms, while doctors had the responsibility to keep up to date on information about SMIs and available medications, and they needed to educate themselves about the nature of mental illnesses and how to be better communicators (O’day et al., 2005). One man stated,

“Primary medical needs are the same no matter what other diagnoses the consumer may have. If he has diabetes, and also happens to have psychotic delusions, it’s not up to the doctor to solve everything. But the doctor shouldn’t just throw up his hands and say, ‘Since he thinks the CIA is after him, there is no point in treating the diabetes.’ This is a non sequitur” (O’Day et al., 2005, p. 342).

In another study by Schulze and Angermeyer (2003) asked consumers with schizophrenia were about their experiences with stigma. While consumers were not asked about their interactions with medical professionals many brought these up and mentioned that they felt they were often over-sedated and they perceived that doctors saw them more as an illness than as a person managing an illness.

Implications of perceived barriers to care

Because of the aforementioned reasons – denial of treatment, denial of education, and the stigma of mental illness, people with SMIs do not often use preventative care.
Researchers have found that clients with severe mental illnesses utilize the emergency room at a much higher rate than those without SMIs (Berren et al., 1999). Researchers also found that this population frequently depends on their psychiatrists for treatment of all chronic medical conditions, rather than utilizing a primary care physician for their non-psychiatric illnesses (Phelan et al., 2001). Thus, when chronic health conditions are diagnosed it often does not occur until there is a real problem including a life-threatening situation.
CHAPTER 3: METHODOLOGY

Measures

Interview procedure

For this project the author used a survey methodology to explore the research questions. The author created a written questionnaire to obtain basic demographic information as well as to ask about how consumers feel about the quality of care they receive from their medical doctors. The questionnaire asked for the subjects’ age, gender, and income level, their medical diagnoses, psychiatric diagnosis, and most recent date when they saw their primary care physician, which had to be in the last twelve months in order to participate in the study. It then had consumers rate how much they agreed or disagreed with a series of statements about the five dimensions of the concept of quality of care: communication, empathy, the doctor’s perception of schizophrenia, the doctor’s medical knowledge, and how knowledgeable the consumer felt about their health. Due to lack of previous research, the hypothesis regarding direction of impact (whether it improves or decreases a consumer’s perception of quality of care) remained open.

Description of the quantitative measure

There is some lack of agreement about the definition of “quality of care” (Donabedian, 1988; Campbell et al., 2000; Blumenthal, 1996; Bokhour, 2009). For example,
Donabedian states in his 1988 paper that quality of care is based on how well doctors perform their medical duties, and on their interpersonal skills, which should include “privacy, confidentiality, informed choice, concern, empathy, honesty, tact, sensitivity – all these and more” (Donabedian, 1988). The Institute of Medicine (IOM) defines quality of care as the “Degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Lohr et al., 1992). Campbell et al. (2000) believe that quality of care should examine whether treatments used are appropriate (not under or overused) and whether the doctor demonstrates trust, empathy, provides enough time to discuss treatment, and permits maximum consumer involvement (autonomy) in regards to treatment.

Bokhour’s research (2009) focuses on ways of effectively developing measures of quality of care. She emphasizes that patient satisfaction is different from patient perception of care, and that patients can be both dissatisfied with their care and aware that it is not low quality care. Bokhour identified four major dimensions of quality of care based on focus groups: access to care, technical aspects of care, patient-doctor communication, and interpersonal aspects of care. Bokhour’s research is interesting in that the requests from the consumers in her study regarding quality of care are very similar to those from the focus groups that O’Day et al. conducted (2005). Both groups of consumers who are dealing with very different illnesses request similar things: better communication from the doctors, particularly regarding the nature of the illness and the nature of the medications they have been prescribed, more reminders from doctors, more honest communication, and more patience from doctors.
While all of these studies defined quality of care in slightly different ways, most describe quality of care as being measured across two major dimensions: whether the practitioner is medically knowledgeable, and to what degree they are able to demonstrate important interpersonal skills. As none of these studies actually provide a scale for measuring of care, this study created a series of questions based on the common dimensions quality of care research. This author contacted O’Day regarding the measures used in her study (2005) but was unable to obtain further information regarding the scale that her group used. It was not possible to obtain details on O’Day’s scale beyond the basic information given in her paper, so the scale for this study was created based on the concept of quality of care as defined by Donabedian (1988), Campbell et al., (2000), and Bokhour (2009). These studies repeatedly emphasized the dimensions of communication, empathy, education, accessibility, the doctor’s perception of the patient, and the doctor’s medical knowledge. Thus, for the quantitative measure of this study, statements about quality of care were created in five dimensions. The statements in each dimension were based on the components of communication, empathy, the doctor’s perception of the patient, and the doctor’s medical knowledge, as defined by the researchers Donabedian (1988), Campbell et al. (2000), and Bokhour (2009), as well as quality of care issues that were brought up repeatedly in the O’Day et al. (2005) focus groups.

The first dimension was communication, which included aspects of quality of care mentioned by multiple studies, such as listening, answering questions, spending enough time with the patient, and giving the patient as much autonomy as possible regarding choice of treatment. The second dimension was empathy, including statements about
trust, whether the doctor cared about the patient, and whether the doctor was polite. The third dimension was regarding the doctor’s perception of the patient. Because this study focuses on people diagnosed with schizophrenia, the questions in this section asked respondents whether they felt judged or treated differently due to their mental illness, and whether the doctor asked them about their psychiatric health. The fourth dimension was about the doctor’s practical knowledge. Respondents rated statements in this section regarding their doctor’s knowledge on how their psychiatric medications might affect the treatment of their comorbid chronic illness, and if their doctor was knowledgeable about schizophrenia. The final dimension addressed the patient’s perception of their illnesses. Again, while it was not possible to obtain the actual scale that O’Day et al. (2005) used, their results describe psychiatric patients requesting more education from their doctors so they can better understand their own health. Thus, the statements in this dimension were regarding to what degree respondents felt they understood their mental illness, their comorbid chronic illness, and the medications they took for these. The author consulted with Bonnie O’Day prior to scale creation, which provided guidance and expert feedback on scale development, which improved overall face validity.

The subjects were asked to rate each statement in all five dimensions on a Likert Scale. Preceding the statements was a universal, “Think about the times you saw your physician over the past year. For each of these statements, please rate how much you agree or disagree with each of the following statements on a scale of 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”. Respondents were repeatedly reminded that they were to rate their primary care physician, and not their psychiatrist. Consistently low sums in a
dimension indicate the possibility of a perception of low quality care. Correlation between the dimensions indicates that the questions are related and the possibility that low quality of care in one dimension predicts low quality of care in another dimension. Please see the Appendix A for the scale.

Description of the qualitative interviewing process

The study also used a qualitative format so as to allow subjects to fully elaborate on their attitudes and to explain why they feel the way they do. The format of the qualitative section of this study is based in Grounded Theory as well as the Critical Incident Technique (Padgett, 1998; Flanagan, 1954).

Padgett (1998) explains that the goal of qualitative interviewing in Grounded Theory is goal directed conversation. She states that the interviewer should make an effort to build rapport early in the interview and gently guide the respondent to stay focused on the topic of interest. She emphasizes that the interviewer must ask probing questions to gain details without asking questions that would lead the respondent to give specific answers. She also explains that the interviewer should create a safe space for the respondent to experience any emotions that come up but the interviewer should not attempt to elicit any specific emotions from the respondent.

The Critical Incident Technique was also used as a basis for the interviewing process.

Beech and Norman (1994) describe Critical Incident Technique (CIT) as

A systematic, inductive, open ended procedure for collecting direct observations
of human behavior (critical incidents). The advantage of focusing on incidents is that in addition to facilitating recall, respondents can identify and clarify feelings and meanings which they may attach to these, but otherwise be unable to articulate. (Beech & Norman, 1994)

Padgett (1998) recommended using a brief interview guide, thus the author had three predetermined questions for respondents. These questions asked respondents to provide specific examples of high quality and low quality medical care, which related back to the CIT technique of focusing on incidents to create better recall (Beech & Norman, 1994).

It was important to include both qualitative and quantitative methods in this study because a quantitative format, even with such a small subject group, can yield very valuable data and could provide indications for further research since currently time and funding limitations of a thesis does not permit the author to work with a large number of subjects. Please see Appendix B for the qualitative questions.

Sample

To participants were recruited from a local community mental health agency. The consumers were required to have a diagnosis within the schizophrenia spectrum of disorders as well as a diagnosis of heart disease, hepatitis C, HIV, diabetes, or obesity and be at least eighteen years of age. Some consumers had more than one of these comorbid physical illnesses. The consumer also had to have seen his or her physician in the past twelve months.
Case managers gave the recruitment letter to potential subjects based on the above criteria. Recruitment posters were also placed in the lobby of a local mental health agency. Upon given permission from the consumer, agency staff provided contact information to the author so that she could contact the consumer and invite him/her to participate in the study. The author also came to the agency regularly and invited consumers to be a part of the study. The author explained the purpose of the study to consumers and asked eligibility questions as part of the recruitment process. The study was approved by the OSU IRB board for human subjects.

Summary of the procedure

This research was conducted in an attempt to answer the following questions:

- Do consumers with schizophrenia believe they receive high quality medical care?
- In which dimensions (communication, empathy and trust, the doctor’s perception of schizophrenia, the medical knowledge of the doctor, and the consumer’s perception of their own health) do consumers perceive a high quality of care? In which dimensions do consumers perceive a low quality of care?
- Are there differences in reported perceptions of quality care based on gender, mental health diagnosis, or medical diagnosis?
- How do qualitative and quantitative measurements of perception of quality of care in the five dimensions compare?
• What are some barriers consumers perceive to obtaining high quality care?

• What areas of this topic require further research?

Analysis of data based on gender, mental health diagnosis, and medical diagnosis was done to see whether any general variables might confound the results. Data was collected at one time point for each participant. The primary methodology for data collection was interviews with subjects using both quantitative (first part of interview) and qualitative (second part of interview) methodology. During the first part of the interview, the author read the quantitative statements to the participants and marked down the answers. The author read the statements aloud rather than having consumers read the questions because consumers may have low reading levels. The consumers were repeatedly redirected to focus on the care received from their primary care physicians, rather than their psychiatrists. The subjects were instructed to rate their experiences with physicians in the past twelve months. Participants rated their physicians on their communication skills, their ability to demonstrate empathy and trust, their perception of schizophrenia, and their medical knowledge. Participants also rated themselves on how well-educated they feel about their diagnoses of one or more chronic physical illnesses previously mentioned and schizophrenia/schizo-affective disorder. The measure that was used is included here as Appendix A.

During the second part of the interview, the author asked the participants a series of questions asking for specific examples of interactions they had with their primary care physician. The interview questions allowed the participants to elaborate on the questionnaire by asking for specific examples of positive and negative interactions with their physicians. The primary purpose of this method was to capture any themes or issues that may have been missed by
quantitative measures. The list of questions used is included here as Appendix B. The subject’s answers were recorded using audio equipment.

Data Analysis

Quantitative Analysis

The analysis of the quantitative portion of the interviews examined several aspects of the medical care provided by calculating the mean and standard deviation of each subscale. Because of the exploratory nature of the study, several variables were tested to see if these were related to the results of the subscales. Nonparametric analytic techniques were used to analyze the data given the small sample size (Knoke, Bohnstedt, & Potter, 2002). Spearman’s rho is the statistic procedure that is appropriate for nonparametric analyses testing bivariate relationships (Knoke et al., 2002). The author used Spearman’s rho to determine whether any variable, including individual subscales, were correlated with one another. The Mann-Whitey test is appropriate when looking for non-parametric relationships between a two-choice nominal variable and an interval variable and was thus used to test for any bivariate relationships between categorical values and sub-scales (Knoke et al., 2002). All analyses were done using SPSS 17.0.

Qualitative Analysis

The qualitative data was analyzed using the grounded theory approach created by Glaser and Strauss (1967). This is a sequential approach, wherein analysis is done as data is collected.
In the first stage of this approach, the author immersed herself in the raw data through repeated review. Next, the author coded the data. Corbin and Strauss (2008) describe this process as

Taking raw data and raising it to the conceptual level…it involves interacting with data (analyzing) using techniques such as asking questions about the data, making comparisons between data…and in doing so, deriving concepts to stand for those data, then developing those concepts in terms of their properties and dimensions. (p. 66)

Coding entails the researcher reviewing the data and noting relevant concepts in the margins. Each concept has a number associated with it so the data can then be organized by concept. Coding yields a large number of concepts which then must be reviewed and merged into new concepts – the process involves constantly modifying and merging these codes. Throughout this process the researcher takes notes called memos that describe the researcher’s thoughts the concepts that are emerging and the reasons for choosing these concepts (Corbin & Strauss, 2008; Padgett, 1998).

Once the author coded and recoded the data many times concepts became better defined. These were used to come up with a core variable – the overarching idea that explained the participants’ responses in the study. The core of this study is that respondents connected high quality health care with good communication, empathy, accessibility, and provision of basic medical treatment. The transcripts were then recoded selectively based on these core concepts relating to this core variable; concepts which did not relate were discarded. From these concepts, overarching categories emerged. Five of the categories were also identified
previously by research on quality of care: communication, empathy, the doctor’s perception of schizophrenia, the doctor’s medical knowledge, and the patient’s perception of their own health. Three additional categories were identified through the coding process – Axis IV issues, accessibility, and provision of basic medical treatment. As these categories were developed, the author continued to write memos that detailed how the concepts in each category related to one another and noted similar incidents described by multiple respondents. These memos were sorted and new memos summarizing the sorted memos were written. These summary memos were in turn used to create an overall theory explaining respondents’ perception of their medical care. In this case the basic theory varied only slightly from the earlier core variable – the author theorizes that respondents connect high quality health care mostly with provision of basic medical treatment and easy access to treatment, but they also value good communication and high levels of empathy. Finally, the memos were written up based on the categories they fell under and these were organized into tables for the convenience of the reader (Padgett, 1998). In short, this method of analysis is a process of constant comparison, where the data is repeatedly and methodically examined for similarities and differences until patterns become visible (Corbin & Strauss, 2008).
CHAPTER 4: RESULTS

Demographics

There were twenty-five participants in the study. Fourteen (56%) were female and eleven (44%) were male. Subjects ranged in age from twenty-four to sixty-seven with a median age of 46.2. Twenty-three of the participants (92%) had an annual income of $9,999 or less and two participants (8%) had an income between $10,000 and $19,000 per year. Thus, at least 92% of the participants had an income that was below $10,890, the Federal Poverty Guidelines for a household of one person in 2011-2012 (U.S. Department of Health and Human Services, 2011).

Of the participants, twenty (80%) were diagnosed with schizophrenia and five (20%) were diagnosed with schizo-affective disorder. Only four (16%) of these subjects received their psychiatric medications from their primary care physician, the rest stated they obtained their medications from a psychiatrist. In regards to medical diagnoses, fifteen subjects (60%) had one diagnosis (heart disease, diabetes, hepatitis C, HIV, or obesity), seven (28%) had two of these diagnoses, and three (12%) had three of these diagnoses. Six participants (24%) had a diagnosis of heart disease, eleven (44%) had diabetes, two (8%) had HIV, eight (32%) had hepatitis C, and ten (40%) were obese.
Quantitative results

Analysis of dimensions of care

As mentioned previously, each statement was presented on a Likert Scale of 1-5 with “1” being “Strong Disagree”, “2” being “Disagree”, “3” being “Undecided”, “4” being “Agree”, and “5” being “strongly Agree”. In general, respondents gave their doctors higher scores in all dimensions, although the standard deviations suggest some variations across respondents’ responses. The results for each of the dimensions are noted below. Likewise, Table 1 demonstrates that all dimensions were correlated with one another. Communication and empathy were highly correlated while the other dimensions were moderately correlated.

<table>
<thead>
<tr>
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<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Communication</td>
<td>1.00</td>
<td>.87***</td>
<td>.62**</td>
<td>.71***</td>
<td>.59**</td>
</tr>
<tr>
<td>2. Empathy</td>
<td>1.00</td>
<td>.70***</td>
<td>.67***</td>
<td>.67***</td>
<td></td>
</tr>
<tr>
<td>3. Dr’s perception of Schizophrenia</td>
<td>1.00</td>
<td>.65</td>
<td>.68***</td>
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<tr>
<td>4. Dr’s medical knowledge</td>
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<td>1.00</td>
<td>.71***</td>
<td></td>
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<tr>
<td>5. Patient’s health</td>
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<td>1.00</td>
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Table 1: Correlations between dimensions of care

*** indicates a 2-tailed significance of less than .001
** indicates a 2-tailed significance of less than .00
* indicates a 2-tailed significance of less than .05
N=25
Do consumers believe they receive high quality care?

Respondents appeared to generally believe they receive moderate to high quality care based on the scores of the five dimensions (see Table 2).

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Mean</th>
<th>Standard Deviation</th>
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<tbody>
<tr>
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<td>6.18</td>
</tr>
<tr>
<td>Empathy</td>
<td>3.96</td>
<td>4.85</td>
</tr>
<tr>
<td>Dr’s perception of schizophrenia</td>
<td>3.92</td>
<td>4.46</td>
</tr>
<tr>
<td>Dr’s medical knowledge</td>
<td>3.72</td>
<td>3.56</td>
</tr>
<tr>
<td>Patient’s health</td>
<td>3.68</td>
<td>4.95</td>
</tr>
</tbody>
</table>

Table 2: Means and standard deviations

N = 25

As previously noted above, respondents gave the highest ratings in the empathy dimension (M= 3.96, SD = 4.85) and the lowest ratings in the dimension evaluating the perception of their own health (M = 3.68, SD = 4.95). This suggests that consumers feel they have empathetic doctors, which is defined here as doctors who demonstrate that they genuinely care about their patients, who have a trusting relationship with their patients, and who believe what patients say.
Respondents gave high scores (M=3.92, SD = 4.46) on their doctor’s perception of schizophrenia, indicating that most consumers did not feel discriminated against based on their mental health diagnosis. Additionally, respondents gave slightly lower scores in the communication dimension (M=3.76, SD = 6.18) with a standard deviation that suggests a broad range of responses. This was also the case with the mean score in the dimension of doctor’s medical knowledge was (M=3.72, SD = 3.56). Finally, the lower rating in the dimension evaluating consumers’ perceptions of their own health (M=3.68, SD = 4.95) may indicate that they do not feel they have enough information about their diagnoses and medications or that they do not understand their health as well as they would like to.

Are there differences in perception of quality of care based on gender, mental health diagnosis, or medical diagnosis?

The Mann-Whitney test was used to look for a relationship between gender and each of the five dimensions measured (communication, empathy, the doctor’s medical knowledge, the doctor’s perception of schizophrenia, and the consumer’s perception of their own health). No significant relationships were found. In addition, the Mann-Whitney test was used to test for a relationship between diagnosis and each dimension. Again, no significant relationships were found.

The Mann-Whitney test was also used to see if the ratings in each dimension of quality of care were significantly different by medical diagnosis. There were no significant relationships between dimensions for the diagnoses of heart disease, HIV, hepatitis C, or obesity. As noted in Table 3 respondents with diabetes did have significantly different
scores in the communication dimension than any other dimension of care: respondents with diabetes had a mean score in the communication dimension of 4.21 (SD = 5.33), which was slightly lower than their scores in empathy (M = 4.34, SD = 4.39) and higher than their scores in the doctor’s perception of schizophrenia (M = 4.09, SD = 4.89), the doctor’s medical knowledge (M = 3.84, SD = 3.93), and the patient’s perception of their own health (M = 3.76, SD = 5.54). It was also notable that these respondents rated empathy higher than the other dimensions and this score approached significance (.057).

<table>
<thead>
<tr>
<th></th>
<th>Communication</th>
<th>Empathy</th>
<th>Doctor’s perception of schizophrenia</th>
<th>Doctor’s medical knowledge</th>
<th>Patient’s health</th>
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</thead>
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<tr>
<td>Mann-Whitney U</td>
<td>38.00</td>
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<td>56.00</td>
<td>58.50</td>
<td>63.50</td>
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<tr>
<td>Wilcoxon W</td>
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<td>168.50</td>
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<tr>
<td>Z</td>
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<tr>
<td>Asymp. significance</td>
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<td>.283</td>
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<td>.702</td>
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<tr>
<td>Exact significance</td>
<td>.041</td>
<td>.062</td>
<td>.311</td>
<td>.387</td>
<td>.709</td>
</tr>
</tbody>
</table>

Table 3: Diabetes and quality of care
* indicates a significance of less than .05.
N=25
Finally, the Kruskal Wallis was used to compare mean scores in each dimension based on medical diagnosis. No significant relationships were found.

Qualitative results

As stated earlier, once the interviews were transcribed, coded, and recoded, several categories emerged. The five dimensions used by the author to define quality of care; namely, communication, empathy, the doctor’s perception of schizophrenia, the doctor’s medical knowledge, and the patient’s perception of their own health, were used as categories in this analysis, and the data yielded three more categories: provision of basic medical treatment, Axis IV issues, and accessibility. Based on an intensive review of the data in these categories, the author theorizes that respondents connect high quality care with the provision of basic medical treatment and easy accessibility to health care, but good communication and high levels of empathy are also important factors. These data were compiled into charts for each dimension, and then the charts were redrawn in such a way that the major themes that emerged from the interviews would be more apparent.

Communication

In this study the dimension of communication had a number of components: it involved the doctor’s ability to listen to the respondent, whether the respondent felt able to ask questions, to what extent the doctor’s statements made sense to the respondent, whether the doctor provided the respondent with education on his or her condition and available treatments for it, and how well the respondent understood the education provided.
Communication was also closely related to empathy in that many of the components of good communication helped build an empathetic relationship between the respondent and doctor. Themes from this dimension are summarized below in Table 4.

**Communication: Respondents with heart disease**

A few respondents felt they needed time to get to know their doctors before good communication could occur. One woman explained, “I didn’t feel comfortable talkin to him at first, because I was so used to the first doctor I had.”

Most respondents with heart disease emphasized the importance of a primary care physician who advised them on how to handle their psychiatric symptoms and who took the time to listen to them when they were having problems with their mental illnesses. One person stated, “I was kinda upset when I seen him and he told me to have love instead of havin hate for people...so it just brought me down to that point.” Another person said, “He’ll try to give me some advice on how to deal with my darkness spells...I try to get good advice from him on how to deal with being around people, and my darkness spells, how do I deal with them and how they can happen to me.” Yet another respondent stated, “He explained my illness to me, and certain things I was doing that were causing mood swings, and he talks me through it.”

Respondents felt that a good primary care physician needed to incorporate advice on dealing with mental illness into their practice. Some also explained that they relied on their physician as a person to contact when they felt unsafe. For example, one person stated, “Well, a couple weeks ago I couldn’t find nobody to call and I found his number.
and I was thinkin of suicidal...and he came to my – he came to my house and he told me to get some stuff and he took me to OSU.”

Other respondents felt that their doctors did not listen. One simply said, “It seems like he doesn’t listen to me when I tell him the medicine isn’t working.” A few respondents were very concerned because their doctors did not seem to listen when they were experiencing psychiatric symptoms. One stated,

    Most times, you know, he, he busy with other people – clients – you know I be wantin to take time out to talk to him, with like how to deal with other people, like society out here, cause a lot of people don’t know how to take me... you know what I’m sayin? Next thing I’m gonna have to argue with them or beat up someone then I come to him for advice and most times he be busy.

Another respondent felt similarly, as though her doctor did not care or did not have time to deal with her mental illness: “One time I was on the phone with him and... it was a bad experience I went through because he wasn’t really hearing me. He really wasn’t listening, like, I was trying to tell him, ‘I’m depressed, no one cares, do you?’”

Some respondents felt that their doctors did not educate them on their conditions or medication, or when they did provide explanations it was not done in a way that the consumer could understand. One woman said, “I wanted Percosets but I couldn’t understand why he wouldn’t give me none, he says the other medication I take makes them too strong to add that to it but I still didn’t understand.”

Many respondents, whether they had heart disease or another comorbidity, indicated that their doctors provided them with brochures to explain their illnesses. While no one stated
during the recorded portion of the interviews that they were unable to read, a large number of respondents indicated this during the consent process. It is concerning that physicians would rely on reading material to provide education for a population that may have such a low literacy rate. An excerpt from one interview exemplifies this:

Researcher: Do you feel like they educate you?
Subject: Well, they give me brochures to read up on... [subject is illiterate]
Researcher: Do you feel like they run the appropriate tests for you?
Subject: I’m not sure with all that medical jargon, I don’t know...

A few respondents were concerned that their physicians failed to communicate with their psychiatrists. One states:

Subject: The mental doctor’s the mental doctor, and a physical doctor’s a physical doctor. And they don’t agree sometimes, and I’m stuck in the middle, so, I just listen to so much of what one says and then the other, I still take meds regardless.
Researcher: So they don’t agree with each other?
Subject: They don’t even – I don’t know – they don’t even know about each other, I think.

*Communication: Respondents with diabetes*

Most respondents with diabetes reported positive experiences in communicating with their physicians. Many respondents stated that their doctors spent enough time with them, and this allowed them to have all their questions answered. One respondent stated, “We talk, I be takin up all his time even though he got other patients to see.” Another
said, “He take time out, he ask me questions and run tests.” In general, respondents with diabetes were much more likely to report that they had all their questions answered during their doctors’ appointments.

Some respondents stated that they trusted or liked their doctor because the doctor spoke to them about subjects that weren’t related to their symptoms. For example, one respondent said, “She asks me about the future, and my condition at home, and how I’m doing, and she asks me if I’m taking my meds when I’m supposed to...she is really excellent.” Another felt she could trust her doctor to treat her well because he knew how to take care of his daughters: “He tells me about his daughters, he knows what to do about his daughters, so he knows what to do about me.” In this case, it appears that the doctor’s self disclosure (mentioning his children) made the client feel at ease. One client, however, felt that his doctor asked inappropriate questions that were irrelevant to his care: “She asked me some personal questions about my father’s remarriage, and I don’t know, it just got me very upset, real bad...and she just smiled about it.”

**Communication: Respondents with HIV/AIDS**

There were only two respondents with HIV/AIDS, but both reported that their doctors were very good about communicating with them. They both felt that their doctors made an effort to explain the illness and to help the respondents find appropriate treatment. One respondent stated, “When I first found out I had HIV they explained stuff and told me what to do and how to go in the right direction.” Another respondent explained,
They give me very up-to-date information, very good information about my diet. They keep me well informed of all the new medications that are coming out, and the risks, and the, you know, pros and cons of taking the medications, so they keep me up-to-date.

This respondent felt that she was provided with good education and then given the autonomy to decide her own course of treatment, and that was very important to her.

*Communication: Respondents with hepatitis C*

While half the respondents with hepatitis C reported positive experiences in communication with their doctors, the other half were dissatisfied with their care and many of those respondents felt uninformed about their illness and any available treatment for it.

The respondents with positive experiences reported that their doctors asked them questions and listened to their responses. One stated, “He talks to me, asks me what’s wrong with me, how I’m feeling and stuff. And he asks me how my medicine’s workin and stuff.” Another explained that he likes his current doctor because they have good communication, but in the past he had bad experiences: “The more and more I go [to the doctor], I understand my sickness, because he talks to me now, lets me know what’s what, but I think that some doctors, especially psych doctors, use us for guinea pigs.” Other respondents stated that their doctors did not listen or attempt to understand them. One just said, “He don’t listen...when I say something wrong he don’t believe me.” Another said, “Sometimes she [the physician] don’t understand when I tell her stuff.”
Some respondents indicated that they had no information on the disease or treatment:

Researcher: Do they tell you much about hep C?

Subject: Nope.

Researcher: Do they give you medication for it?

Subject: No.

Researcher: Have they told you why?

Subject: I don’t know, no, no, I don’t know why.”

Some respondents who didn’t receive treatment wanted medication and did not know why it was not being provided:

Researcher: Do you feel like you have enough information about your Hep C?

Subject: No, I just know it’s a liver disease and it’s killin me. But they said I’d start turnin yellow first, my eyes would turn yellow and then I’d die. I ain’t got none of that, so I ain’t really worried about it. But if I could get treatment for it... I know it’s non-curable, but if they could slow it down I’d be more than willing to participate in something.

Researcher: Did they say why they’re not treating you?

Subject: Who, my doctor? I had told him that I did the Infantron [Interferon] and that seemed like that was kinda it. He didn’t wanna give me medicine or nothing for it.

One respondent said his doctor discussed his illness but he was unable to understand the explanation. He states, “He explain things to me but he don’t, you know, he still don’t make no sense to me.” This suggests that when doctors do try to explain things to
consumers with schizophrenia they may need to use different methods than they are accustomed to in order to provide effective education. For example, as mentioned earlier, many consumers in this group indicated that they cannot read, so providing literature on the topic is not an effective strategy.

Respondents with hepatitis C were the most likely to report that their doctors had not educated them on the illness or on any medication they might be receiving, and they were the most likely to feel that their doctors did not listen to them.

Communication: Respondents with obesity

Respondents with a diagnosis of obesity were usually pleased with the way their doctor communicated with them, although there were exceptions. One respondent explained that there was no real communication between her and her physician:

Researcher: Do you feel like he [the physician] answers your questions?
Subject: We never really talk about anything.

Another respondent felt that his doctor didn’t have time to answer questions:

If he was busy I would just go and get my meds and I’d have to go, didn’t get a chance to tell them what was going on…it’s not that the doctor would rush me, it was that the doctor had other people to see and I didn’t get to tell them what my sister wanted me to tell them.

Most respondents, however, felt that they were listened to. One stated, “I like her [the physician] because she always listen and we go over my medicines.” Another explained,
“She [the physician] would tell me about anything I needed to know about.” One respondent was pleased that her doctor listened to her concerns and helped her to relax. She stated,

When something is going wrong with me, they can tell something’s going wrong with me, you know, he’s, he’s there for me and he calms me down. I be havin a lot of things on my mind that I need to talk about, that I need to talk about and he’s, you know, he’s there for me to calm me down, to tell me things that I really need to hear, you know.

Another respondent liked his physician because she talked to him about issues besides his physical health, and because she encouraged him to take control of his own life:

Subject: I had a good experience with her [the physician]. Even though I have a payee she was saying she believed in me, that I could, you know, be my own payee.

Researcher: So she had faith in you?

Subject: Yeah.

This statement also relates to the doctor’s perception of schizophrenia: the physician described recognizes that the respondent has a mental illness but she still believes he’s capable of autonomy and living a full life, and she is encouraging him to do so.

<table>
<thead>
<tr>
<th>Respondents from all diagnostic groups</th>
<th>• Respondents state that discussion of non-medical issues, such as hobbies and family life is important to build rapport.</th>
</tr>
</thead>
</table>

Table 4: Common themes in the communication dimension

54
Table 4 continued

| Respondents from all diagnostic groups | • A common theme among respondents was that good doctors provide advice on dealing with psychiatric symptoms as well helping with medical problems.  
• Some people reported that there is a lack of communication between psychiatrists and doctors.  
• Four people said that their doctors answered all questions: they provided education on medical problems as well as education about medications, but an equal number stated that the doctor did not answer questions or provide education.  
• Multiple respondents stated that their doctors would provide them with pamphlets but that the respondents had trouble reading. |
| Heart disease | • Respondents state that good doctors provide advice on dealing with psychiatric symptoms as well as helping with medical problems.  
• No respondents with heart disease described their doctors as good listeners. |
| Diabetes | • Respondents emphasize that small talk is important to build rapport.  
• Respondents with diabetes generally felt their doctors were good at answering all their questions and that they provided proper education. |
| Hepatitis C | • Respondents with HCV were divided as to whether their doctors answered questions and provided education.  
• While many of the respondents were happy with their education, an equal number were concerned – they were aware they had a potentially fatal illness and felt they knew almost nothing about it. |

Continued
Table 4 continued

<table>
<thead>
<tr>
<th>HIV</th>
<th>• Respondents with HIV felt their doctors provided excellent information on diet, new medication, and staying healthy with the illness.</th>
</tr>
</thead>
</table>
| Obesity | • Respondents with obesity were most likely to mention the importance of small talk to build rapport.  
• The majority of respondents with obesity felt their doctors were good listeners and that they had received good education, although an equal number did and did not feel that they had all their questions answered. |

Empathy

The dimension of empathy was comprised of multiple concepts in this study. It included whether the respondents felt their doctors cared about them, whether respondents felt their doctors trusted them, to what extent respondents felt they could trust their doctors, and whether respondents felt their doctors believed their statements. Another crucial part of empathy for the respondents was whether or not they felt their doctors respected them and were polite to them. Some respondents related a lack of respect to the stigma from their diagnosis of schizophrenia.

Responses indicate that empathy was closely related to communication in the qualitative analysis. As noted in Table 4 above, many respondents explained that it took good communication with their doctors to build trust. Respondents who felt respected and cared for also generally were pleased with the level of communication they experienced.
with their doctor. Nonetheless, subjects often reported that they sensed that their doctors disliked them or were uncomfortable with them which led to poor communication (see Table 5).

**Empathy: Respondents with heart disease**

Some respondents with heart disease felt that their doctors were kind and respectful, but others perceived a lack of trust. One respondent stated, “She’s [the physician is] always polite,” while two respondents stated their doctors were “nice.” No respondents with heart disease talked about ways in which their doctors demonstrated that they cared about them. One subject mentioned that her doctor did not believe that she was in pain. This was also a common comment among respondents with hepatitis C and seemed to be linked to a history of intravenous drug use:

Subject: I had really bad pain and I felt like, if you’re a doctor then…if you was in my shoes, um, you want something a little strong for pain also.

Researcher: So do you feel like he believed you were in pain?

Subject: No. I felt like he thought I just needed it for...a narcotic, like for, to take place of my drug habit, I felt that’s what he was thinking.

One respondent felt that his doctor had problems dealing with his personality, and “got tired” of him:

Subject: Sometimes he understands me, sometimes he don’t.

Researcher: When he doesn’t understand you, why do you think that is?

Subject: Because he probably get tired of me.
Researcher: He gets tired of you?

Subject: Right.

Researcher: Why do you think he gets tired of you?

Subject: I think it’s my personality. My personality sometimes get in the way.

_Empathy: Respondents with diabetes_

Respondents with diabetes generally had very positive things to say in this category. Many brought up the concept of respect. One stated, “If he wasn’t respectful I wouldn’t mess with him.” Another explained, “A good experience was when I went to get a pap smear, and everything went fine: I could trust him, and he was polite. I feel like they try to be nice and clean and be respectful.” A third respondent with diabetes stated, “They treat me like a human being.”

Multiple respondents stated they felt their doctors cared for them. One stated, “He lets me know that he cares.” In another interview, a respondent explained she liked seeing the doctor, saying, “I feel good because I know they gonna take care of me.” One respondent described a very close connection with her doctor:

He’s been like a father to me…he’s just been there for me for the past four years, and I love him so much… I love my doctor. He’s an amazing person. He’s been there, somebody I can talk to, not just like a doctor, he’s been like a father to me, someone I can count on, so, I mean, I love him, I really do.

There was only one respondent with diabetes who felt a lack of empathy from his doctor, he stated, “She tried to belittle me.”
Empathy: Respondents with hepatitis C

While some respondents with hepatitis C felt that they were cared for, treated with respect, and believed, an equal number did not experience these components of empathy. As mentioned previously, a perception of lack of empathy seemed to be linked with the respondent’s history of intravenous drug use. One client, who explained after the recorded interview that she had a history of intravenous drug use explained that her doctor does not seem to believe she is in pain:

Researcher: Do you feel like she [the physician] treats you with respect?

Subject: Well, you know what, sometimes when I go in there I don’t feel that way.

Researcher: Can you tell me more about that?

Subject: Well, the thing is, sometimes, she don’t understand, when things are going on with me…like when I fractured my ankle, and I had to go and they did a CAT scan, and it was fractured for a long time, and so I told her that my ankle hurt really bad, and she said, well, you know, ‘I don’t think it hurts that bad,’ or something like that…. She doesn’t always trust me when I, if I have an ailment or something, she acts like, you know, she makes me feels like I don’t know what’s going on with my body, you know what I mean? She made me feel like maybe I was over-exaggerating or something like that, you know, and I wasn’t.

Another respondent described a similar experience:

Subject: He took my pain medication from me.
Researcher: Did he say why?

Subject: No, he said they was addicting and I didn’t need them. So they just recently sent me for an MRI of my back, and they said I had arthritis and two herniated discs in my back.

Researcher: Do you feel like he believes you when you said how it hurts?

Subject: No, no I don’t feel that he does.

Researcher: Why do you think that is?

Subject: I can’t explain it. I called him and told him how I felt, and he’d come over and give me aspirins for my back pain. I’m not a drug addict; I just need what’s owed to me. I mean, I’m crippled. I can’t make a bed, I can’t mow the grass, I can’t do nothing without my back going out. And then I’m down for days, I can’t even get out of bed…some mornings I can’t even tie my shoes…he’s a big man, he’s a bully. That’s my honest opinion of him.

Empathy: Respondents with HIV

The two respondents with HIV did not bring up empathy but they did briefly answer the author’s questions about respect and good treatment. One respondent was reluctant to elaborate on any of his answers, but he did say the following:

Researcher: Do you feel like they [your physicians] respect you?

Subject: Sometimes.

The other respondent reported only positive experiences:
Researcher: Do you feel they [your physicians] treat you well?

Subject: Yes I do.

Researcher: Have you had a bad experience with either of them?

Subject: No.

**Empathy: Respondents with obesity**

Respondents with obesity generally felt that their doctors were empathetic, that they were respectful, caring, and believed what their patients said. Many of the respondents with obesity also had a diagnosis of diabetes and were quoted previously in the diabetes section as reporting that they perceived respect and high levels of trust and caring from their doctors. One respondent with a diagnosis of obesity described how his doctor was one of the few people he knew that cared about him:

One time I got arrested and was put on probation and uh, she wasn’t mean but I could tell that she cared about it…I could tell she cared…she was nice, but like I said she was concerned, and it made me aware that someone cares, besides just my family.

Only one respondent did not have completely positive things to say about her doctor’s level of empathy. She simply said, “It’s not a trusting relationship.”
| Respondents from all diagnostic groups | • Most respondents felt their doctors were respectful and genuinely cared about them.  
• Respondents were equally split on whether their doctor trusts them, and they were also split on whether their doctor believes what they say. |
| Heart disease | • Some respondents felt respected and cared for, while other felt their doctors did not trust them.  
• One respondent felt his doctor got tired of his personality. |
| Diabetes | • A majority of respondents felt respected and cared for.  
• None of the respondents stated that their doctors did not trust them. |
| Hepatitis C | • Respondents felt respected and cared for with one exception.  
• None of the respondents felt that their doctors believed what they said, particularly in regards to their stated pain levels. |
| HIV | • Respondents were neutral about whether their doctors respected them. |
| Obesity | • All respondents but one in this category felt cared for and respected. |

Table 5: Common themes in the empathy dimension

The doctor’s perception of schizophrenia

The doctor’s perception of schizophrenia is a dimension that investigates how doctors perceive their patients who have this mental illness – it investigates whether respondents feel judged by their doctors as less competent or trustworthy than people without mental
illnesses. Almost all respondents reported feeling that they were not treated any differently from others due to their diagnosis of schizophrenia (see Table 5).

*Doctor’s perception of schizophrenia: Respondents with heart disease, diabetes, HIV/AIDS, and/or obesity*

In this study, no respondents with heart disease, diabetes, HIV/AIDS, or obesity felt treated any differently by their doctors because of their mental illness, although the experiences they describe in their interviews do suggest that there are barriers to care and that they do experience disparities in care. As mentioned previously, one respondent with obesity described positive experiences with a doctor who made it clear that she believed in his ability to be independent and accomplish his goals (such as having his own payee) despite his mental illness. No other respondent with these chronic illnesses brought up the way their doctor treats them based on their mental illness – but every respondent in this category who was asked “Do you feel like your doctor treats you any differently because of your schizophrenia?” said “No.” One woman with diabetes did discuss how she thought the general public perceived people with mental illnesses; she stated,

> A lot of people with mental illness are basically throw-away people. They make less money, I mean, I think I’m pretty sure they make less money anyway, they tend to be sicker, they tend to be overweight, I mean, they’re throw away people to other people….it’s obvious that….these are the people to be shelved.
Doctor’s perception of schizophrenia – Respondents with hepatitis C

Three respondents with hepatitis C answered “No” when asked if they felt treated any differently by their doctors based on their mental health diagnosis, but two felt discriminated against. One respondent described the following:

Subject: He [the physician] treats me like a little…yeah, like a little kid.

Researcher: Can you tell me more?

Subject: I tell him I’m a grown man, I’m not a little kid, I’m a grown man, and he just blows me off and grabs his little folder and folds it up and leaves my house. He acts like I’m a little kid, he wants to see my pill bottles every month from home, I gotta keep them even when I go and get a refill, I still gotta keep the bottles for him to see.

Researcher: Do you think he judges you at all because of your hep C?

Subject: He’s throwed it in my face a couple times, about, umm, the drug, interventional [intravenous] drug use… I kinda felt like he was, uh, downgrading me, sure. Yeah, I do.

In this case the subject feels judged both because of his mental illness and his diagnosis of hepatitis C. He describes an instance where his doctor does not trust him to take his pills. The following respondent also describes a doctor who does not trust her, and she feels it is due to her mental illness. It is of note that both respondents who felt they were treated differently due to their mental illness were intravenous drug users.

Researcher: You said you feel like she doesn’t listen to you?

Subject: Sometimes. Not always, but sometimes, yeah, I do feel that way.
Researcher: Why do you think that is?

Subject: Because of my mental illness I think. I think she thinks that, you know, because I have mental illness I, you know, maybe I don’t understand what’s going on with me, but that’s not true all the time. I’m gonna tell you honestly how I feel because I’ve seen a couple of different doctors… they act like you over-exaggerate, you don’t know what you’re talking about, it must be your mental illness, and that’s not right.

<table>
<thead>
<tr>
<th>Respondents from all diagnostic groups</th>
<th>• All respondents with the exception of those with hepatitis C felt that their doctors did not discriminate against them due to their mental illness.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• All respondents who brought it up felt that their doctors understand Schizophrenia and how to work with people with the diagnosis.</td>
</tr>
<tr>
<td></td>
<td>• One respondent described a physician who encouraged him to be more independent – who believed in his abilities, suggesting that the doctor had a positive outlook on his diagnosis of schizophrenia.</td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>• Some respondents with HCV felt their doctors did not trust them because of their mental health diagnosis. One stated he felt he was treated like a child and his doctor bullied him.</td>
</tr>
</tbody>
</table>

Table 6: Common themes in the doctor's perception of schizophrenia dimension
Doctor’s medical knowledge

This dimension describes to what extent the respondents feel their doctors know about their illnesses and the appropriate treatment for them. It includes the doctor’s knowledge of the respondents’ chronic illness(es), the medications available for them, and whether their doctors are aware of the potential interactions between the multiple medications that respondents are often prescribed, both for medical and psychiatric reasons (see Table 7).

Doctor’s medical knowledge: Respondents with heart disease, diabetes, and obesity

No patients with these comorbidities brought up their doctor’s knowledge about their diagnoses. Most respondents with these illnesses, particularly those with diabetes and obesity, described their doctors as “good” or “nice” and felt they were well taken care of.

Doctor’s medical knowledge: Respondents with hepatitis C

One respondent with hepatitis C stated that his doctor did not seem to be knowledgeable about the illness and appropriate medications. He states, “He [the physician] came in and took all my medicines from me, the ones from my last doctor, and he started me on his own medicine. He gave me Ibuprofen which I can’t take because of my liver disease but he still prescribes it to me.” This respondent was not on any medication for hepatitis C and was not sure why. He indicated that he felt that his doctor did not know about medication interactions, but also that his doctor did not take the time to educate him on the course of the illness or explain why he was not receiving treatment.
Doctor’s medical knowledge: Respondents with HIV

Both respondents with HIV mentioned that they felt their doctors were highly knowledgeable about HIV and the available treatments, and both felt that their doctors made an effort to communicate these treatment options to them and educate them about the course of the illness. One respondent was very pleased with her doctor because he also advised her on maintaining a healthy diet as well. She states, I feel they [the physicians] are very knowledgeable…they give me very up-to-date information, very good information about my diet…they keep me well informed of all the new medications that are coming out, and the risks, and the, you know, pros and cons of taking the medications.

The other respondent with HIV reported that his doctor was good about explaining his illness to him, but his doctor was not always very respectful and this had a negative impact on his care. He states, “When I first found out I had HIV they explained stuff and told me what to do and how to go in the right direction” but goes on to say that “sometimes they do [respect him] and sometimes they don’t.”

| Respondents with heart disease, diabetes, or obesity | No respondent from these groups mentioned whether they felt their doctors were knowledgeable about their illnesses or medical care but most indicated that they liked their doctors. |

Table 7: Common themes in the doctor’s medical knowledge dimension

Continued
| Hepatitis C | • Only one respondent with this illness brought up his doctor’s medical knowledge. He states he was prescribed a medication that he was unable to take because it would injure his liver. |
| HIV       | • Both respondents mentioned that their doctors were knowledgeable about their illnesses and good at explaining them. One was especially pleased about her doctor’s knowledge of the latest available medications. |

The patients’ perception of their own health

This dimension describes to what extent the respondents feel they understand their chronic illnesses, their mental illness, and the medications prescribed for them, and whether they currently feel that they are in good health (see Table 8). This dimension is closely related to the communication dimension because the respondents often depend on their doctors for education about their illnesses and medications, and whether education is provided or not depends on the level of communication between doctor and patient. Many respondents emphasize the importance of taking their psychiatric medications every day as prescribed; they are acutely aware that they need these medications to maintain stability. Most respondents look forward to appointments even if they dislike their doctors because they want to know if they are healthy. The exception to this was respondents with HIV, who both said they disliked seeing their doctors because they were
worried about what the results of their blood work would show. Respondents with hepatitis C often felt they lacked information about their illness.

*Patients’ perceptions of their own health: Respondents with heart disease*

Multiple respondents with heart disease indicated that they understood the need to keep their psychiatric symptoms under control as much as possible by taking their psychiatric medications as prescribed. One respondent stated, “I’m just tryin to be stable, it’s like I can’t be stable without my medicine.” Most respondents felt they were well educated about heart disease, but one respondent said, “He explains them [my medical conditions] to me but still yet he don’t make no sense to me.”

*Patients’ perceptions of their own health: Respondents with diabetes*

Respondents with diabetes also emphasized the importance of taking their psychiatric medications to stay healthy. One woman said, “I call them and let them know I take my medicine. I don’t have no problem with taking my medicine on time.” A man stated, “I do remember to take my meds. Cause if I don’t take them, I can’t function.” Most respondents with this chronic illness felt they were well educated about it.

*Patients’ perception of their own health: Respondents with hepatitis C*

Three respondents with hepatitis C stated it was important to them to see the doctor regularly to stay healthy. One stated, “I like going [to see the doctor] ... because I, I have to have medication for certain things.” Another said, “I like going to the doctor cause I
like knowing what is happening.” A third stated “I feel good about seeing my doctor…I feel good about tryin to take care of myself.” This was interesting because respondents with hepatitis C were the least likely to feel respected, cared for, or believed by their doctors, and yet they looked forward to their appointments because their healthcare is a priority to them.

As mentioned previously, two respondents were not receiving medication for hepatitis C and did not know why, and neither felt they understood the course of the illness. They both indicated that they did not know much about their health but they wanted education. One of these respondents also stated, “They told me I needed a Pap smear. What you need a Pap smear for?” This suggests that in addition to not explaining the course of hepatitis C to this respondent, her doctor has also failed to explain the need for basic regular examinations to maintain all aspects of her health.

*Patients’ perception of their own health: Respondents with HIV*

As mentioned previously, both respondents with HIV stated that their doctors explained the course of the chronic illness to them and one respondent felt her doctor did an excellent job explaining her treatment options. Because these respondents are receiving education on HIV/AIDS this may suggest that these respondents feel they have a good understanding of their chronic illnesses. Both respondents indicated during the quantitative portion (which was not recorded) that they felt very nervous about seeing their doctors because they never know what the results of their T-cell or viral load tests will be (these are tests that measure the body’s ability to defend itself against HIV and the
current amount of the virus in the body). This suggests that fear from not knowing what the illness will bring is a big part of these respondents’ perceptions of their own health. With regards to mental illness, one respondent stated that she understands her diagnosis of schizophrenia, and the other respondent did not discuss his mental health diagnosis. Respondents in this group indicated that they had a much better understanding of their chronic illness than respondents in other groups, suggesting that education strategies for people with SMIs and HIV might be adopted for people with SMIs and other chronic illnesses.

Patients’ perceptions of their own health: Respondents with obesity

Many respondents with obesity also had a comorbid diagnosis of diabetes and were quoted previously as saying that taking their medications on a daily basis was very important to them. They indicated that they were aware of the importance of maintaining their psychiatric health. One stated, “If I have all my meds I be functioning very well but if I don’t have them I get kinda lopsided, y’know?” Only one respondent mentioned she felt uninformed about her current state of health. She said “She [her physician] got rid of it [shingles], I think she said. I don’t know if I have that or what.” This respondent did, however, have a diagnosis of dementia as well so it is unknown whether her doctor explained her diagnosis of shingles and treated it.
| Respondents from all diagnostic groups | • Several respondents emphasize the importance of taking their psychiatric medications in order to maintain stable mental health. |
| Heart disease | • Respondents emphasize the importance of taking psychiatric medications.  
• Some respondents feel that their doctors do not explain their chronic illnesses to them, or the respondents are unable to read the brochures provided, so they do not understand their diagnosis of heart disease. |
| Diabetes | • Respondents emphasize the importance of taking psychiatric medications. |
| Hepatitis C | • Respondents emphasize the importance of taking psychiatric medications.  
• Respondents enjoy going to the doctor because they want to know if they are healthy.  
• Respondents state that their health is very important to them.  
• One respondent was unsure why she needed a Pap smear |
| HIV | • Respondents feel well educated about HIV and treatment options, suggesting they feel they understand the course of the illness.  
• Respondents perceive that their health changes over time based on the level of the virus in their blood and their body’s ability to defend itself, and this creates anxiety about seeing the doctor. |
| Obesity | • Respondents emphasize the importance of taking psychiatric medications.  
• One respondent was unsure whether her shingles had been treated. |

Table 8: Common themes in the patient's perception of their health dimension
Provision of basic medical treatment

This dimension was created based on a reoccurring theme among respondents: When asked, “Can you give me an example of a good experience you had with your physician?” respondents repeatedly described instances in which their doctors had mended broken bones, checked their blood pressure, checked their blood glucose, or provided other types of care that the general population might expect from any doctor, good or bad. Concepts in this dimension of basic medical treatment are summarized in Table 9.

This dimension also includes the issue of lethality checks, i.e. when doctors ask their patients if they have any thoughts or intentions of hurting themselves or others. Multiple respondents brought up the fact that it was important to them that their primary care physician ask them whether they intended to hurt themselves or others, and a few stated that they depended on their physician as someone whom they could contact if they were having these thoughts of self-harm or harming others.

Provision of basic medical treatment – Respondents with heart disease

Some respondents with heart disease stated that good experiences with physicians involved provision of medical care that anyone might expect from a doctor. The following is an example:

Researcher: Can you give me an example of a good experience you had with your doctor?

Subject: Well, it’s kinda hard to say…yeah, I had a broken finger, he took care of it.
Some respondents mentioned that they were pleased with their doctors because they ordered routine blood tests, but one subject felt his doctor did not do so.

Researcher: Do you think he [the physician] runs the appropriate tests on you that he’s supposed to?

Subject: No.

Researcher: Why do you think that is?

Subject: I don’t know, it’s just the way he is.

Provision of basic medical treatment: Respondents with diabetes

Respondents with this chronic comorbidity also frequently mentioned basic medical care or routine testing as examples of “good experiences” with their physicians:

Researcher: Can you give me an example of a good experience you had with your doctor?

Subject: Yeah, he fixed my foot. I was having foot trouble.

Another respondent stated, “Good experience? Well, this week, it was just this week, it was okay [seeing the physician], cause everything went fine, and she checked me over, she checked my sugar, and they even checked for my temperature, my blood pressure, my pulse…” Yet another respondent, when asked about a good experience with his doctor stated, “They always check my sugar, see what level it is…or I ask and see if they can check it if I haven’t checked it in the morning when I get there.” This statement is notable because the respondent indicates that he advocates for himself; if he hasn’t checked his blood sugar he feels comfortable requesting that his physician do so.

Another respondent stated that he had a good experience with his doctor when “He [the
doctor] sent me to a specialist and all that stuff; they took care of it [a broken bone] really quick.” Yet another simply said her experience with the doctor was good because, “The doctor’s office was clean.” Again, these are examples of “good care” being associated with the kind of “basic care” that most people might expect from any doctor they visit. It is possible that these respondents have lower expectations from their physicians because they have experienced disparities in care and barriers to care.

One respondent mentioned that he expected his doctor to check whether he was a danger to himself or others at each visit, and it bothered him that she did not:

Subject: She [the doctor] asked me about my past a little bit, and got me upset, and she wasn’t supposed to do that then…she let me leave, out the building, and it was, I guess you’d say, in a way that she wasn’t supposed to, that I could have hurt somebody or myself.

Researcher: Do you have any advice for doctors like that?

Subject: Not to let them leave upset and angry, to the point that the person is able to hurt somebody, an innocent person, that is…like I said, an innocent person coulda got killed, or if they didn’t they coulda been in the hospital by mistake…I think I had spoke to somebody on the board, and maybe somebody on the board should have, um, said something about it, and that way they woulda known what had happened.

*Provision of basic medical treatment: Respondents with hepatitis C*
Respondents with hepatitis C indicated that they often did not receive basic components of medical care such as medication for their chronic illnesses, for other problems they were having, or for pain. One respondent stated, “I had this back problem and he took my pain medicine from me. I don’t get pain medicine no more.” Another said, I asked can I get some medication for menopause and they didn’t give me the medication. One doctor said she would give me some medication for my menopause and another doctor said she wouldn’t… cause I’m sweating very bad, my clothes is drenched at night. I’m losing weight.

When asked what he would like his doctor to do for him, one respondent stated, “Be on time, come in the morning, and maybe give me some treatment for my hep C, I don’t wanna die!”

_Provision of basic medical treatment: Respondents with HIV_

Respondents with HIV felt that they received appropriate education on the illness but one was concerned that his doctor did not perform routine testing:

   Researcher: Do you feel like your doctors do all the tests they’re supposed to do?
   Subject: Sometimes I do and sometimes I don’t.
   Researcher: Why do you think that is?
   Subject: Like when I ask them something or I’m feeling some type of way they don't really follow through…I don’t know.

_Provision of basic medical treatment: Respondents with obesity_
Respondents with obesity also tended to describe their doctors ordering tests for them when they were asked about “good experiences.” One stated, “Good experience? They run tests, they run tests on me and give me my medicine.” Another said, “She [the physician] would check me over real well and gave me the right medications…I’ve got no problems with her.” In general, respondents with a diagnosis of obesity felt well educated on their conditions and believed that their doctors ordered the necessary tests for them.

| Respondents from all diagnostic groups | • Multiple respondents, when asked to name what they liked about their doctors, stated that they were pleased that their doctors fixed their physical ailments such as broken bones. |
| | • Nine respondents felt that their doctors ran appropriate tests on them, but two respondents did not and one was unsure. |
| | • Many respondents were pleased that their doctors prescribed medications, but some respondents felt that their doctors provided inappropriate medications for them, failed to provide needed medications, or did not communicate why they were not providing medications the respondents wanted. |
| | • Two respondents were pleased that their doctors performed regular lethality checks. One respondent experienced a crisis because his doctor did not perform a lethality check. |

Table 9: Common themes in the provision of basic medical treatment dimension

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<table>
<thead>
<tr>
<th>Disease</th>
<th>Details</th>
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<tbody>
<tr>
<td>Heart disease</td>
<td>• Respondents were generally pleased that their doctors provided basic care. Only one patient had an issue: namely, that his doctor did not do appropriate tests on them.</td>
</tr>
<tr>
<td>Diabetes</td>
<td>• Six respondents mentioned that their doctors performed appropriate testing on them and four stated their doctors provided them with appropriate medication – these were generally the stated reasons why they liked their physicians.</td>
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<tr>
<td>Hepatitis C</td>
<td>• Most respondents felt that their doctors performed the appropriate tests and provided medication for various illnesses other than hepatitis C</td>
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<td>• Of the eight respondents with HCV, two of them were not on medication for the virus and neither understood why.</td>
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<tr>
<td></td>
<td>• Many stated that their doctors refused to provide them with pain medication. All of the respondents who made these statements related this to their doctors’ knowledge of their history of IV drug use.</td>
</tr>
<tr>
<td>HIV</td>
<td>• Only one person discussed an issue in this category; he stated he was unsure if his doctor ran the appropriate tests.</td>
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<tr>
<td>Obesity</td>
<td>• Responses for this group were almost all positive in this category – respondents liked that their doctors ran tests and provided medications. The one respondent that dissented stated that her doctor did not run tests because he is part of an HMO.</td>
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Axis VI issues

Three respondents made statements that fall into this dimension. Two respondents (with diabetes and obesity) stated that their doctors asked them about whether their various
nonmedical needs were being met, such as whether they had stable housing and enough food. One, who was quoted previously, states, “Even though I have a payee she was saying she believed in me that I could, um, you know be my own payee.” He continues, One time I got arrested and was put on probation and uh, she wasn’t mean to me but I could tell she cared about it, I could tell she care how she talked to you…she was just concerned and stuff, to me. And, and it made me aware that someone cares, besides just my family.

Another respondent describes his new doctor saying, “She asks me about the future, and my condition at home…she is really excellent, how she handles each client.”

These respondents both were pleased that their doctors made sure their basic needs were being met. A third respondent, who had heart disease, stated that she saw a need for integrated care, where people could receive assistance with physical problems and mental illnesses and get social services all at one location:

Researcher: Is there anything you would like to see doctors in general do differently for people with mental illnesses?

Subject: Umm…education, social work, nutrition management…believing in helping the person to help themselves, I mean, caring more about what goes on in their home, the more social work type of things, so to speak…social work and doctors and psychologists are sort of tied up together. And you see that in some offices but in some offices you don’t.
It appears that doctors who incorporate psychosocial issues such as housing and food into the care they provide have patients who feel respected and cared for, and they are more likely to have better doctor-patient communication.

Accessibility

Access to healthcare was another dimension identified in the process of analysis. This refers to respondents’ ability to see their physicians when they are ill, whether they can easily make appointments, and issues they may have with wait times (see Table 10). Lack of access to care was the most common “bad experience” listed by respondents. Respondents reported that they have trouble getting in to see their doctors when they experience physical illnesses, which then aggravates their mental health symptoms. Many respondents want to have regular phone contact with their physicians, and this may be something that a registered nurse could assist with. Some respondents saw the inability to get an appointment with their doctors as a personal rejection from the doctor and that the doctor “does not like them,” which in turn made their mental health symptoms significantly worse.

Accessibility: Respondents with heart disease

Many respondents with heart disease stated they had trouble accessing care; only one respondent stated that she could easily see her doctor when she needed to. One respondent describes a bad experience he had with his physician as “It was the time I had to wait to see him…I had to sit and wait to come up and see him. And then I was sick, I
was sick, I was a sick man back then. Bad experience.” Two respondents mentioned that they felt their doctors were too busy to spend enough time with them. One respondent felt this was because the doctor had a large caseload:

Researcher: Do you feel like he spends enough time with you?
Subject: Uh, not really.
Researcher: He doesn’t?
Subject: No. Cause he’s got to see other clients. He got other people he gotta see, there’s a whole bunch of people he sees.

Another respondent felt accessibility issues had to do with the fact that the doctor wanted to do other things than treat him: “Well, bad experience is when he don’t have time when I need to see him, he’s busy, you know, busy, or he wanna see somebody else or he already got plans and I really need to see him… and that’s a bad thing when it happens…that’s when I might go out and do something wrong, or be hurt, and it hurts me like he turns me down.” The language in this response is interesting: the respondent states that the doctor “already got plans” and he “turns me down.” It suggests that the respondent feels a sense of personal rejection when the doctor is unable to see him, which may aggravate his psychiatric symptoms.

Accessibility – respondents with diabetes

Respondents with diabetes were split as to whether their doctors were easily accessible. Some felt that they were able to make appointments when necessary, whereas others could not get in to see their doctor, and some were unhappy with the time they spent in
the waiting room. One respondent, when asked if she was able to make appointments, stated, “Oh yes, no problem at all.” Conversely, another said,

I don’t like to go see him [the physician] cause sometimes when you have a set appointment time you don’t never get in to that appointment time so you wait till later, but it’s understandable though, cause they got other patients they gotta see too.

Another respondent had no problem with the physician but had trouble with the people who worked in the office:

Researcher: Can you give me an example of a bad experience you had with your doctor?

Subject: The secretary, the new one, it’s not the doctor but the secretary… I got down there at seven-thirty and the place didn’t open until nine, and I was the first one there, and two people came right after me, and they told the secretary they was going in order, first come first serve, and they told them [the secretary] I was first, but she still put me third anyway. And I was really mad about that. I was really upset. Cause they told them [the secretary] that I was there before they were, she still took everybody before me.

R: Why do you think she did that?

S: I have no idea. Maybe she thought she knew who got their first. I was sittin out in the cold that day too.

Accessibility: Respondents with hepatitis C
Respondents with hepatitis C generally were more focused on lack of education and lack of treatment than on accessibility to care, but two respondents did comment on accessibility. One stated, “It’s hard to reach him on the phone,” but indicated after the recording session that he was able to get timely appointments. Another respondent, however, stated,

He [the physician] called me three months, back to back in a row, and did not show. He’s been sick, he said, and the visiting physicians did not send another doctor to me for three months… but in the sadness and all the bad he’s done to me he’s made up for it by showing up lately, and being on time.

This statement is interesting, because although this respondent stated previously that his physician does not give him education on hepatitis C, does not provide him with treatment for the illness, and prescribes him medication that he is unable to take because it causes liver damage; he likes the physician simply because he shows up.

**Accessibility – Respondents with HIV/AIDS**

Neither patient with HIV mentioned accessibility to care, either in a positive or negative light.

**Accessibility: Respondents with obesity**

One respondent (quoted in the communications dimension) explained that he is uncomfortable asking his doctor questions because he perceives that his doctor is in a
hurry. Another respondent also stated she does not get to spend enough time with her physician:

Researcher: Can you tell me about any bad experiences you’ve had with him [your physician]?

Subject: Waiting three hours in the waiting room, when I had a scheduled appointment.

Researcher: Do you feel like he spends enough time with you?

Subject: No.

Only one respondent reported a positive experience with accessibility. She states, “I have their [physician’s] personal phone number where I can call him, you know, whenever- if there’s something where I need to talk to him.”

| Respondents from all diagnostic groups | - The most common negative experience reported in the qualitative section was that of the doctor being inaccessible in a time of need. Many respondents relied on their primary care physicians as someone they could contact when they were experiencing suicidal ideation, and it became a serious issue when their doctors were inaccessible.  
- Multiple respondents stated that they had a problem with waiting several hours in their doctors’ offices when they had scheduled appointments. |

Table 10: Common themes in the accessibility dimension
| Respondents from all diagnostic groups | • Many respondents stated that their doctors were very busy and because they were aware of how busy their doctors were they felt they could not ask the questions they wanted to ask about their medical care – they didn’t want to take up the doctor’s time. Those whose doctors made house calls did not experience this problem. |
| Heart disease | • Respondents with heart disease had multiple complaints in this area stating that they were served out of order, that seeing their doctors took up too much time, and that they had long wait times even with a scheduled appointments.  
• Only one respondent had a positive experience with accessibility. He stated that he was easily able to reach his doctor via phone. |
| Diabetes | • Respondents with this illness were split on accessibility. Two reported problems with being served out of order or having trouble obtaining appointments, while two stated they were easily able to contact their doctors and make appointments.  
• One respondent stated that he felt his doctor was too busy so he was uncomfortable asking questions. |
| Hepatitis C | • Respondents with this illness had positive and negative experiences.  
• One respondent stated that his doctor had not shown up for three scheduled house calls in a row, with no explanation, but he was grateful his doctor made house calls at all.  
• One was uncomfortable taking up his doctor’s time, knowing that the doctor had many people in the waiting room. |

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<tr>
<td><strong>Hepatitis C</strong></td>
<td>• One respondent was very distressed that he could not reach his doctor by phone because he felt his doctor should be available when he had lethal thoughts.</td>
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<tr>
<td></td>
<td>• Two respondents expressed positive experiences with regard to the ease of making appointments.</td>
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<tr>
<td><strong>HIV</strong></td>
<td>• No respondents mentioned accessibility issues.</td>
</tr>
<tr>
<td><strong>Obesity</strong></td>
<td>• Multiple respondents complained that their doctors are very busy and felt that they have to keep their visits as short as possible, and they don’t get their questions answered.</td>
</tr>
<tr>
<td></td>
<td>• One respondent complained of long wait times.</td>
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<tr>
<td></td>
<td>• Only one respondent had a positive experience being able to reach the doctor to make appointments.</td>
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While there were both positive and negative statements in all dimensions, some clear themes emerged for each diagnostic group. Respondents with diabetes and heart disease had both positive and negative things to say about their doctors – it was generally dependent on the doctor they saw. Some were very pleased with communication and empathy from their physician and some were not. Many reported accessibility problems. Respondents with hepatitis C were the most displeased with their physicians in all dimensions. They were unhappy with communication, especially the lack of education they received on medication and the illness. Some were unsure about why they did not receive treatment for the virus, indicating a major communication lapse. Many felt
disrespected by their physicians due to their mental illness or due to the stigma associated with the virus and they felt their doctors did not trust them or believe the things they said. Patients with obesity had very positive experiences with communication and empathy although they were displeased with the brief face-to-face time they had with their doctors and many were reluctant to ask questions. In general, patients with HIV reported almost entirely positive experiences in all dimensions. This is consistent with research done by Butt et al. (2006), who found no disparities in care for patients with HIV and an SMI.
CHAPTER 5: DISCUSSION, CONCLUSIONS

Discussion

The main purpose of this study was to test whether consumers with schizophrenia believe they receive high-quality medical care and to find out in which dimensions of care they perceived barriers. This study used both qualitative and quantitative methodology to test this, and then compared the results from these methodologies to provide a richer picture of the experiences of this often overlooked population. The majority of respondents reported a high quality of care as seen in the high scores in the quantitative results and the positive comments in the qualitative results; however, there were differences across dimensions, diagnostic categories, and across quantitative and qualitative results. While quantitative results reported high-quality care in all dimensions, qualitative reports were generally less positive but provided more specific information about how quality of care might be improved. While the responses were varied, an overarching theme did emerge: respondents connected high-quality care with the provision of basic medical treatment and easy access to health care, although they also mentioned the importance of good communication and high levels of empathy.

Communication and quality of care
One of the principle questions of this study was “In which dimensions of quality of care do consumers perceive high-quality care?” In the quantitative analysis, respondents gave their doctors fairly high ratings in the first dimension of quality of care: communication. This is notable because statements in the qualitative interviews regarding communication varied widely, ranging from respondents who were very happy and felt that their doctors made small talk with them and took extra time to answer all their questions to respondents who felt their doctors did not explain anything to them. Respondents with diabetes, obesity, and HIV were generally pleased with their doctors’ ability to communicate and usually felt well educated about their chronic illnesses while respondents with heart disease and hepatitis C were more likely to perceive problems in communication. Thus, consumers with schizophrenia and a comorbid medical illness might experience broad differences in their experiences dependent on their comorbidity. This is also noted in all the other dimensions tested in the study.

In the qualitative analysis, respondents connected good communication with the creation of trusting, caring relationships with their physicians. These results correspond with the quantitative analysis, in which the dimensions of communication and empathy were highly correlated (.87). In fact, the literature shows that a sense of trust and caring are components that are viewed as integral parts of empathy (Donabedian, 1988; Campbell et al., 2000; Bokhour, 2009).

While respondents rated their understanding of their illnesses and medical care as high in the quantitative section, in the qualitative interviews, several respondents reported that they felt they did not understand their illnesses very well, nor did they feel educated...
about the medications they had been prescribed, which suggests problems with communication between the respondents and their physicians. Respondents related these problems to their doctors not providing enough information and failing to answer their questions. Thus, they connected lack of communication with poor knowledge of their own health. This was interesting because these reports conflicted with the quantitative results, which indicated no correlation between the communication dimension and the patients’ understanding of health issues dimension. This issue of lack of education on the illness and on available medications was most often brought up by respondents with a diagnosis of hepatitis C.

Empathy and quality of care

The study also provides interesting information about how this sample experienced the level of doctor’s empathy. In the quantitative analysis respondents gave high ratings to their doctors’ levels of empathy (M = 3.96, SD = 4.85), a dimension comprised of questions asking whether respondents felt their doctors cared about them, trusted them, believed their statements, and respected them. In the qualitative analysis, most respondents felt that their doctors genuinely respected and cared for them, but a large number of respondents did not feel that their doctors believed what they said, and some did not feel their doctors trusted them to carry out their instructions. Respondents with hepatitis C were the most likely to feel that their doctors did not believe them, particularly when they stated that they were in pain. Many of these respondents related this lack of trust to their history of intravenous drug use.
The doctors’ perceptions of schizophrenia and quality of care

This study also asked respondents whether they felt that their physicians treated them differently because of their diagnoses of schizophrenia. In the quantitative results respondents gave their physicians high ratings in the dimension of the doctor’s perception of schizophrenia. This was generally supported by the qualitative analysis, in which all respondents with heart disease, diabetes, HIV, and obesity felt that their doctors did not discriminate against them due to their diagnosis of schizophrenia. As in other dimensions, some respondents with hepatitis C did perceive discrimination based on their mental illness.

The doctors’ knowledge and quality of care

In this study respondents were also asked whether they felt their doctors had an appropriate knowledge of their chronic illnesses and of schizophrenia. Respondents rated their doctors’ knowledge of their chronic illnesses and of schizophrenia as moderate to high in the quantitative results. This finding relates to the qualitative results in which consumers with heart disease, diabetes, HIV, and obesity indicated their doctors were very knowledgeable about their diagnoses and provided good treatment. Respondents with HIV, in particular, felt that their doctors were very knowledgeable about the latest medications available for the illness, and they expressed that their physicians were very good about communicating treatment options to them and explaining the benefits and
risks of various medications. This contrasts with respondents with hepatitis C: while some felt that their physicians were well educated, others expressed concern that they were not receiving treatment for hepatitis C, and one mentioned that his doctor had prescribed medication that could potentially damage his liver.

While the dimension of the doctors’ medical knowledge was not correlated with either the communication dimension or the patients’ health dimension in the quantitative analysis, these dimensions were closely related in the qualitative interviews. During the qualitative interviews, respondents emphasized the importance of their doctors explaining to respondents the course of their chronic illnesses and possible medical treatments.

Although most respondents felt that their physicians took the time to educate them on their illnesses, some respondents with heart disease and hepatitis C stated that their doctors either did not take the time or were unable to explain the course of the illnesses to the respondents, and as a result, they did not have basic information about their current state of health or of available medical treatments. This was especially applicable for the two respondents with hepatitis C who explained that they were not on medication for the illness, did not know why that was the case, and were unsure what the illness would do to their bodies.

Patients’ knowledge of medical illness

Respondents were also asked to rate their knowledge of their own health; that is, how well that they felt they understood and managed their schizophrenia, whether they felt
they were educated about their chronic illnesses, and whether they regularly took any prescribed medications. Respondents rated their knowledge of their own health the lowest of any dimension (i.e. communication, empathy, doctors’ perception of schizophrenia, doctors’ medical knowledge, and patients’ knowledge of their own health) in the quantitative analysis. This is supported by comments in the qualitative interviews in which several respondents with heart disease and hepatitis C stated that they did not have their questions answered by their doctors and did not have enough education about their diagnoses, or that when their doctors provided them with educational information they were not able to understand it. These results contrasted with respondents with HIV who reported they were well educated about their illnesses and emphasized that their doctors were good about communicating their treatment options to them.

Demographic characteristics and quality of care

This study also looked for any differences reported in quality of care based on the demographic characteristics of gender, mental health diagnosis, and medical diagnosis. Although there were no significant differences in the quantitative analysis in perceptions of quality of care based on gender, mental health diagnosis, or medical diagnosis, some differences were noted in of perceptions of quality of care based on medical diagnosis in the qualitative results. In the qualitative results, respondents with heart disease had mixed feelings about their quality of care in each dimension. Respondents with diabetes and obesity tended to report excellent communication with their doctors, and generally felt well educated about their illnesses. Although there were only two respondents with
HIV, both stated that their doctors were well educated and that they gave them a number of treatment options. Respondents with hepatitis C had much more negative perceptions of quality of care compared to those with other chronic illnesses. While some did feel they received high-quality care, respondents in this group were the most likely to feel a lack of communication and empathy, to feel judged based on their diagnosis of schizophrenia, to believe that their doctors were not well educated on their chronic illness, and to feel a lack of education about their illness.

Perceived barriers and quality of care

This study sought to answer the research question, “What barriers do respondents perceive that prevent them from receiving high-quality care?” The research question was chosen because barriers to care for this population are associated with increased mortality and morbidity rates (Druss et al., 2002; Lawrence et al., 2003; Frayne et al., 2005; Dixon et al., 2004; Roberts et al., 2006). Although respondents in this research study raised a multitude of issues, three potential barriers to care came up repeatedly: low literacy levels, dependence on primary care physicians for mental health crises, and accessibility issues that aggravated psychiatric symptoms.

It became apparent during the consent process that many respondents were unable to read and write. While no formal count was taken, it appeared that a majority of the respondents were unable to read the consent forms and several did not know how to write the date. This is problematic because respondents often reported that their doctors
provided them with brochures to explain their illnesses and potential side effects of medication. Some people may feel ashamed that they are unable to read and write and may be reluctant to tell their physicians that brochures about their illnesses are not an effective means of education.

Another issue that respondents brought up was the tendency to depend on their primary care physicians as a resource during mental health crises. Some people with a diagnosis of schizophrenia experience symptoms that put them at risk for hurting themselves or others (Radomsky, Haas, Mann, & Sweeney, 1999). As mentioned in the qualitative results, some respondents stated that they wanted their primary care physicians to ask them at every visit if they had any thoughts of hurting themselves or others, and these respondents expected their primary care physicians to be available if they were having these thoughts. Multiple respondents stated that when they experienced mental health crises they expected their primary care physicians to be available to treat them. One respondent indicated he had experienced a crisis because his doctor caused his psychiatric symptoms to be aggravated and then allowed him to leave the office without asking if he was a danger to himself or others. Another stated that when he could not reach his physician he felt rejected, and this sometimes led to him having thoughts of hurting other people. Consumers with potentially lethal symptoms need to be able to contact someone when they are in crisis, and if their primary care physicians are unavailable, then consumers require clear instructions as to whom they can then call or where they can go in order to stay safe. Although it is possible that their local mental health agency has
provided some of this information, it behooves all medical professionals who work with this population to provide the same sort of information in their practices.

A similar issue was identified when respondents were asked to describe a bad experience with their primary care physicians. The most common answer was that they were unable to see their doctors when they were ill. This was particularly distressing for respondents who reported poor communication with their doctors and who perceived themselves as “disliked” patients – they personalized the problem and viewed the inability to make an appointment as a rejection by the doctor, which in turn aggravated their psychiatric symptoms. This issue also highlights a re-occurring theme found in this study; namely, the respondents’ lack of overall accessibility to their doctors. Such feelings and experiences may stem from a lack of communication and demonstrated empathy from the doctor as noted above. While it is a universal problem to have to wait to see a doctor, whether the wait time is weeks to get an appointment or hours in the waiting room, respondents reported that such waits caused quite a bit of emotional distress; this tendency towards personalization is not seen as commonly in the general population. It is clear that this is a serious problem from this population and it could be alleviated if the doctor communicated more clearly with them explaining why there were wait times and emphasizing that wait times did not relate to any “dislike” of the patient. The results suggest that these respondents did not seem to have adequate information as to what other care options were available if they could not see their doctors as soon as was needed.
Components of high-quality care

What do the results suggest regarding how these respondents felt about high-quality care, and what such care would look like? As noted previously, several respondents explained that they liked their doctors simply because the doctors provided basic testing such as checking glucose levels, or because their doctors prescribed needed medication for chronic conditions. Although it is important that doctors provide such services, respondents should expect more than just the most basic medical services because it has been demonstrated that people with schizophrenia have a higher mortality rate than the general population (Lawrence et al., 2003; Felker et al., 1996). Many respondents stated they felt uncomfortable questioning their physicians’ actions and so they did not address any lack of medical care, even basic care that they had experienced.

While the vast majority of respondents in this study did not perceive disparities in care due to mental illness, that does not eliminate the possibility that disparities are occurring. The majority of respondents stated that they did not perceive disparities in care, but their concepts of “good care” are generally very different than those of people without SMIs. Respondents in this study generally associated “good care” with simply receiving any medical treatment for their physical health problems, regardless of whether their doctors displayed empathy or good communication skills. In contrast, researchers who asked subjects without SMIs to define “quality of care” found that in addition to provision of basic medical treatment, these subjects without SMIs reported that communication, empathy, and high levels of medical knowledge are also very important skills for providing good care (Donabedian, 1998, Campbell et al., 2000, Bokhour, 2009).
The fact that respondents who participated in the study focused more on whether they receive basic medical treatment as an indicator of high-quality care suggests that this group does not expect as much empathy or good communication from physicians or at least do no associate these characteristics with a basic level of high quality care. These lowered standards for quality of care may relate to the tendency towards concrete thinking for some people diagnosed with schizophrenia. If respondents have trouble understanding abstract concepts such as empathy this may not factor in to their expectations of high quality care. Regardless, this does not mean that this population should be treated with any less respect, empathy, or trust than any other group who may actively expect such things. Even if many respondents did not explicitly identify communication and empathy as necessary parts of care, respondents have demonstrated that kindness and having their questions answered (both components of empathy and communication) are crucial in improving the quality of their medical care.

Many of respondents with a diagnosis of hepatitis C stated they were treated differently because of their diagnosis of schizophrenia and because of their diagnosis of hepatitis C. In particular, respondents who had a history of intravenous drug use felt that their doctors discriminated against them. This is an important issue as the literature shows that many people with SMIs can have co-occurring substance abuse issues including IV drug use (Essock et al., 1994). Indeed, they felt that their doctors were less likely to believe what they said and that their doctors disliked them because of their diagnoses. As mentioned earlier, twenty-five percent of the respondents with hepatitis C stated that they were not receiving any medical treatment for their hepatitis and none of them had been told why
this was the case. This evidence of lack of treatment for hepatitis C for people with schizophrenia supports the research that demonstrates clear disparities in care for patients with both hepatitis C and a severe mental illness with potential life threatening consequences (Rifai et al., 2006).

Limitations

The study is limited in that the group of respondents interviewed was a small sample. Additionally, it was also a sample of convenience. Nonetheless, this study is exploratory and a first of its kind. Hence, any findings that come out of this study can prove critical in beginning to understand how individuals who are living with schizophrenia and who have a secondary medical problem perceive of their medical care. Despite the small sample size, the results point toward distinct themes that clearly demonstrate the need for further research.

This study is also limited by the way in which respondents were recruited and then interviewed. The interviews were conducted at a community mental health center and most respondents were recruited as they were waiting to see their psychiatrists. During the qualitative portion of the study several subjects talked about positive and negative experiences with their psychiatrists rather than their primary care physicians, which may have been secondary to their having an appointment with their psychiatrist immediately after the interview process. Thus, many respondents had to be frequently redirected and some may have been referring to their psychiatrists at times despite being redirected to discuss their primary care physicians. Because this was such a common issue in the
qualitative portion, it is also possible that in the quantitative portion some respondents were rating their psychiatrists, despite frequent reminders to focus on the treatment received from their primary care physicians.

Another limitation was related to the location where the interviews took place. Because respondents were waiting to see their psychiatrists during the study, they would want to finish the interviews as quickly as possible – they were concerned that they would lose their place in line. Thus, respondents were often reluctant to elaborate on answers and they were eager to end the qualitative part of the interview process. This may also explain why some respondents would repeatedly attempt to rate statements on the quantitative portion before the author had finished stating each one, suggesting that some respondents had selected a rating prior to hearing the entire statement.

Additionally, during data collection it became apparent that many of the subjects had the same primary care physician, who happened to be trained to work with people with mental illnesses. This may have been why so many subjects reported positive experiences with their primary care physicians. Nonetheless, the results suggest a basic blueprint for creating recommendations for other physicians who work with consumers with severe mental illnesses. Note that despite this unique situation for the sample, many respondents still expressed clear concerns about how their medical care was delivered and possible complicating factors secondary to also having a psychiatric disorder.
Recommendations

Respondents identified multiple barriers to care in all dimensions. As mentioned earlier, barriers to care are associated with increased morbidity and mortality in this population (Druss et al., 2002; Lawrence et al., 2003; Frayne et al., 2005; Dixon et al., 2004; Roberts et al., 2006). In particular, many respondents had issues with poor communication and lack of education from their physicians. They reported problems with accessibility, particularly when experiencing crises, and some respondents, particularly those with hepatitis C, indicated that they were not receiving treatment or routine tests to monitor their chronic conditions. Recommendations for further research focus on these issues.

Improving communication

Based on responses in the qualitative portion of the research in this study, there are multiple actions that primary care physicians could take to improve care along all dimensions studied. With regard to communication, respondents would like doctors to spend more time with them, particularly taking the time to provide education on medical conditions and treatment in such a way that the respondent can understand. This would require that the doctor be skilled in communicating with consumers who may need repeated explanations and who may also have lower reading levels than other consumers treated. Doctors may benefit from special training in communicating with patients with SMI if they have a large number in their practice.

Respondents with diabetes tended to report good communication with their physicians.
Interactions between consumers with SMIs as well as diabetes and their physicians could be further studied to increase doctor-patient communication for people who have SMIs in addition to other chronic illnesses. While there were only two respondents with a diagnosis of HIV/AIDS, both reported that their doctors had excellent knowledge about their illness and the latest treatment methods, and they stated that their doctors were good at communicating this information and providing them with as much autonomy as possible with regard to treatment. Butt et al. (2006) found that while most studies analyzing quality of medical care for consumers with an SMI and a co-occurring chronic illness show severe disparities in care, those studies that look at consumers with an SMI and HIV generally do not show disparities in care. Fremont et al. (2006) attribute this to better case management. Further research should be done in this area so that perhaps communication strategies that are utilized between these providers and consumers with an SMI and HIV/AIDS can be studied and reproduced to improve care for consumers with diagnoses of an SMI and a different chronic illness.

Empathy and communication were shown to be closely related in both the qualitative and quantitative sections and respondents repeatedly indicated that doctors might improve doctor-patient communication by spending more time at the first appointment establishing rapport. Respondents stated that when their doctors spent time talking about non-medical issues such as asking the respondents about their home lives, asking them about hobbies, or talking about common interests, they felt that their doctors cared about them and the respondents then felt more likely to trust their doctors and confide in them. Although physicians certainly have a limited amount of time they can spend with
patients, it may be beneficial for them to take a few minutes when meeting patients with SMIs to build rapport. Without this establishment of trust, it appears that communication becomes impaired, which then leads to lower quality of medical care because the consumer does not feel comfortable enough to ask questions or describe symptoms. As in the communication dimension, respondents with diabetes gave their physicians high scores in empathy. Again, it is possible that the positive interactions these consumers experience with their physicians could be explored to reduce barriers to care for people with SMIs and other comorbid chronic illnesses.

Reducing risk of harm to self or others

It also became clear in the qualitative piece of the study that respondents who are asked about thoughts of harming themselves or others at visits then expect that their doctors should be available to contact when they are feeling unsafe. These respondents see the questions about feelings of self-harm or harming others as statements that the doctor cares and will be available as a contact in a crisis. If the doctor is unavailable at a time of crisis, the respondent often experienced aggravated symptoms. This might be remedied if the doctor either agreed to become a reliable contact for a consumer in psychiatric crisis, or if the doctor stated very clearly during visits why he or she was not available for this service and provided the consumer with other resources that could be used even if the consumer had a very low reading level.
Reducing disparities in receiving medical treatment

Many respondents indicated they were not receiving basic care such as blood tests or medication. This was especially true for respondents with hepatitis C. This finding is not surprising; multiple studies have found that patients with SMIs are less likely to have necessary tests and procedures performed (Druss et al., 2002; Lawrence et al., 2003; Frayne et al., 2005; Dixon et al., 2004; Roberts et al., 2006). Furthermore, Rifai et al. (2006) report that many consumers with an SMI and hepatitis C do not receive treatment. These results suggest a disparity in care. Lack of medical treatment or testing to monitor chronic illnesses can lead to increased mortality and morbidity rates for this population (Lawrence et al., 2003; Felker et al., 1996). It is clear that more research is necessary so that effective approaches are found to remedy this problem.

Improving accessibility

Many respondents were unhappy with their doctors’ accessibility and some believed that when their doctors were unable to see them in a timely fashion it was because of the doctors’ personal feelings about the consumers. Some respondents reported that when they were unable to see their physicians their psychiatric symptoms became aggravated. This situation could be improved with clear communication at the first visit. The doctor could explain the nature of his or her practice and the process of making appointments and make it clear that accessibility has nothing to do with the consumer.
Psychiatric nurses as care coordinators

One interesting possibility that might help resolve issues of communication as well as accessibility is the advent of psychiatric nurses as care coordinators. Although there are no published articles that directly address the consumers’ perception of the efficacy of psychiatric nurses as care coordinators, there is recent research in which consumers describe what they perceive as “high quality” or “low quality” care from a psychiatric nurse. Beech and Norman (1994) interviewed patients in psychiatric wards about the quality of care they received from their nurses. They found that these patients associated high-quality psychiatric nursing care with good communication, specifically, patients stated that nurses who made time to talk to patients, who were active listeners, and who explained the actions they were taking, were providing good care. It is possible that these psychiatric nurses could help increase communication and perhaps increase communication between psychiatrists and primary care physicians as well as Axis IV services, as many consumers in this author’s research study requested.

In 2009, one local mental health center in central Ohio began using psychiatric nurses as care coordinators for some of their consumers with SMIs and chronic medical conditions. The model proposes a new way to catch consumers who have too often “fallen through the cracks” of the traditional medical system, as the coordinator of care is trained to evaluate both medical and psychiatric symptoms and make the appropriate referrals. It is extremely relevant because a high proportion of people with SMIs depend on their psychiatrists for medical referrals (Okin & Fink, 1996). This new care model is relevant because people with SMIs have a long history of seeking emergency medical services for
problems that could have been prevented through regular primary care (Hackman, et al., 2006, Berren, Santiago, Zant, & Carbone, 1999). If psychiatric RNs are able to catch these problems before they become emergencies, the community can save money and the hospital will have more space for other consumers. Based on Beech and Norman’s (1994) research as well as Svedburg, Jormfeldt, and Arvidsson’s (1995) study, it is possible that psychiatric nurses with good training in communication could be an extremely valuable asset to patients with SMIs and chronic medical conditions. Implementation of psychiatric nurses as care coordinators could reduce mortality rates in this population. A consumer's perspective of this new care would be invaluable, particularly because much of the previous quality-of-care research has been conducted from a non-consumer perspective.

Conclusions

This study demonstrates that for this sample of people with schizophrenia and a co-existing medical disorder, high-quality care is associated with good communication, high levels of empathy, easy accessibility, and the provision of basic medical treatment. Although respondents generally gave their physicians high scores in the quantitative section, many indicated in the qualitative interviews that they perceived multiple barriers to their medical care, in particular, they had trouble accessing care in times of crisis and not all respondents’ physicians were monitoring or treating the respondents’ chronic illnesses. These perceived barriers to care should be further studied because they may be contributing to the
populations’ increased mortality and morbidity rates (Lawrence et al., 2003, Felker et al., 1996).

Based on both quantitative and qualitative results, it is clear that consumers want their doctors to do simple things such as spending time getting to know them as individuals and not just as an illness. They want doctors that are accessible and who understand their psychiatric disorder, provide treatment for their chronic illnesses, and educate them. Themes in quality of care such as those mentioned here indicate the need for more research to explore these disparities in care. At the same time, further research should be done regarding those populations who are pleased with their quality of care, particularly in the dimension of doctor-patient communication for consumers with diabetes, and all dimensions of quality of care for consumers with HIV. If it is possible to identify exactly why these groups are more pleased with care, then perhaps these successes could be applied to other populations.
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Appendix A: Quantitative questions for subjects taking part in this study

Part I: Communication

Think about the times you saw your physician over the past year. For each of these statements, please rate how much you agree or disagree with each of the following statements on a scale of 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

1. The doctor spent enough time with me.

   1  2  3  4  5
   Strongly disagree Disagree Undecided Agree Strongly agree

   disagree

2. The doctor did not rush me.

   1  2  3  4  5
   Strongly disagree Disagree Undecided Agree Strongly agree

   disagree
3. The doctor gave me enough education about my medical illness.

   1  2  3  4  5
   Strongly Disagree Undecided Agree Strongly agree
   disagree

4. The doctor answered all my questions.

   1  2  3  4  5
   Strongly Disagree Undecided Agree Strongly agree
   disagree

5. The doctor listened to me.

   1  2  3  4  5
   Strongly Disagree Undecided Agree Strongly agree
   disagree

6. The doctor helped me make informed choices about my treatment.

   1  2  3  4  5
   Strongly Disagree Undecided Agree Strongly agree
   disagree

Part II: Empathy/Trust

Think about the times you saw your physician over the past year. For each of these
statements, please rate how much you agree or disagree with each of the following statements on a scale of 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

7. The doctor cared about me.

1 2 3 4 5

Strongly Disagree Undecided Agree Strongly agree

disagree

8. The doctor was polite to me.

1 2 3 4 5

Strongly Disagree Undecided Agree Strongly agree

disagree

9. I felt like I could trust the doctor.

1 2 3 4 5

Strongly Disagree Undecided Agree Strongly agree

disagree
10. I felt comfortable with my doctor.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree

disagree

11. I felt like my doctor trusted me.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree

disagree

12. I felt like my doctor trusted me to follow her/his instructions.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree

disagree

Part III: Doctor’s perception of schizophrenia

Think about the times you saw your physician over the past year. For each of these statements, please rate how much you agree or disagree with each of the following statements on a scale of 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

121
13. The doctor understood my mental illness.

1 2 3 4 5
Strongly Disagree Undecided Agree Strongly agree

14. The doctor did not judge me because of my mental illness.

1 2 3 4 5
Strongly Disagree Undecided Agree Strongly agree

15. The doctor did not treat me differently because I have a mental illness.

1 2 3 4 5
Strongly Disagree Undecided Agree Strongly agree

16. My doctor asked me about my psychiatric health.

1 2 3 4 5
Strongly Disagree Undecided Agree Strongly agree
17. My doctor asked me about my psychiatric medications.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree

disagree

18. My doctor asked me about my medical illness.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree

disagree

Part IV: Medical knowledge

Think about the times you saw your physician over the past year. For each of these statements, please rate how much you agree or disagree with each of the following statements on a scale of 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

19. My doctor is well educated about schizophrenia.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree

disagree
20. My doctor is well educated about the medications I take for schizophrenia.

1 2 3 4 5

Strongly Disagree Undecided Agree Strongly agree

disagree

21. My doctor understands how my psychiatric medications interact with my other medications.

1 2 3 4 5

Strongly Disagree Undecided Agree Strongly agree

disagree

22. My doctor explains my medications to me.

1 2 3 4 5

Strongly Disagree Undecided Agree Strongly agree

disagree

Part V: My health

Think about the times you saw your physician over the past year. For each of these statements, please rate how much you agree or disagree with each of the following statements on a scale of 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

124
23. My diagnosis of schizophrenia has affected the treatment of my medical illness.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree disagree

24. The treatment I get for my medical illness has not been affected by my mental illness.

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree disagree

25. I feel like I understand my mental illness

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree disagree

26. I understand what my psychiatric medications are for

1  2  3  4  5

Strongly Disagree Undecided Agree Strongly agree disagree
27. I remember to take my psychiatric medications

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28. I am educated about my medical illness

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29. I remember to take my medication for my medical illness

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30. I am able to see a doctor when I have problems with my mental health

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31. I am able to see a doctor when I have problems with my medical illness

1 2 3 4 5
Strongly disagree Disagree Undecided Agree Strongly agree

32. I know when I need to see a doctor

1 2 3 4 5
Strongly disagree Disagree Undecided Agree Strongly agree

Appendix B: Interview questions for subjects taking part in the study

Part I: Questions for all subjects

- Can you give me an example of a good experience you had with your doctor?
- Can you give me an example of a bad experience you had with your doctor?
- How do you feel about seeing your doctor?
Appendix C: Coding

Open coding – version 1

1. Communication

2. Empathy

3. Doctor’s perception of schizophrenia

4. Doctor’s medical knowledge

5. Patient’s knowledge of their own health

6. Other issues

Open coding – version 2

1. Communication
   a. Non-medical conversation
   b. Distressing topics
   c. Answered questions

2. Empathy/trust
   a. Respect/disrespect of patient
   b. Trust/mistrust of patient
   c. Expressing concern for patient

3. Doctor’s perception of schizophrenia
a. Association of intellect level or trust level with mental health diagnosis

4. Doctor’s medical knowledge

5. Patient’s knowledge of their own illnesses

6. Provision of basic medical care

7. Accessibility

Axial coding

1. Communication
   a. Non-medical conversation
   b. Distressing topics
   c. Communication between doctors and psychiatrists

2. Empathy/trust
   a. Respect/disrespect of patient
   b. Strengths-based approach
   c. Trust/mistrust of patient
   d. Expressing concern for patient

3. Doctor’s perception of schizophrenia
   a. Association of intellect level or trust level with mental health diagnosis

4. Doctor’s medical knowledge

5. Patient’s knowledge of their own illnesses

6. Provision of basic medical care
   a. Appropriate testing
b. Medications

c. Evaluation of lethality

d. Education

7. Discussion of Axis IV issues

8. Accessibility

9. Judgment of patient based on medical diagnosis

Selective coding

1. Communication
   a. Non-medical conversation
   b. Distressing topics
   c. Communication between doctors and psychiatrists
   d. Education
   e. Literacy

2. Empathy/trust
   a. Respect/disrespect of patient
   b. Strengths-based approach
   c. Trust/mistrust of patient
   d. Expressing concern for patient

3. Doctor’s perception of schizophrenia
   a. Association of intellect level or trust level with mental health diagnosis
   b. Judgment of patient based on medical diagnosis

4. Doctor’s medical knowledge
5. Patient’s knowledge of their own illnesses

6. Provision of basic medical care
   a. Appropriate testing
   b. Medications
   c. Evaluation of lethality

7. Discussion of Axis IV issues

8. Accessibility