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EVALUATING THE PATIENT-CENTEREDNESS OF MEDICARE PART D

By

Melissa Anne Hensley

A dissertation presented to the  
Graduate School of Arts and Sciences  
of Washington University in  
partial fulfillment of the  
requirements for the degree  
of Doctor of Philosophy

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## **ABSTRACT**

The implementation of the Medicare prescription drug benefit (“Part D”) has brought about many changes in the provision of prescription medications to adults with serious mental illness. Existing research on the impact of Part D on this population, for the most part, examines the benefit from the perspective of the physicians who treat these individuals. This research seeks to use a framework of patient-centered care to examine the impact of the Part D benefit on adults with mental illness, from the viewpoints of beneficiaries themselves and the case managers (“community support workers”) who serve them. In addition, data from the Medicare Web site and the Centers for Medicare and Medicaid Services are used to examine the patient-centered characteristics of the Part D program. The Medicare prescription drug benefit is meeting the needs of adults with serious mental illness, but this is largely because of the assistance that beneficiaries receive from community professionals. The Medicare Part D program meets some expectations of a patient-centered program, but there are also definite areas for improvement, such as involvement of patients and information and education for beneficiaries.

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## CHAPTER I: INTRODUCTION

The Medicare Prescription Drug, Improvement, and Modernization Act (MMA) marks the largest change in Medicare policy since its inception in the 1960s (Oliver, Lee & Lipton, 2004). By introducing a prescription drug benefit (“Part D”) into the Medicare program, the MMA has substantially changed the way prescription medicines are financed not only for senior citizens, but also for those living with disabilities (Donohue, 2005). When the Medicare Modernization Act was passed in 2003, there was much uproar in the health care advocacy community concerning the effect that this new benefit would have on people with disabilities. Lengthy reports were published and distributed, predicting turmoil and discontinuities in coverage for many Medicare beneficiaries (Kaiser Family Foundation, 2004; Medicare Rights Center, 2005; Medicare Rights Center, 2006). There was concern among health services scholars, as well, about the impact of Part D implementation on poor and disabled beneficiaries (Donohue, 2005; Elliott et al., 2005; Avorn, 2006; Simoni-Wastila et al., 2008; Neuman & Cubanski, 2009).

Significant problems were predicted in particular for adults disabled by serious mental illness. Advocates predicted that the structure of the Medicare prescription drug benefit would lead to disruptions in coverage and difficulties in obtaining psychotropic medications, despite regulations specifically mandating coverage of these drugs (MRC, 2006). It was predicted that the switch from one state-administered benefit under Medicaid to multiple private plans in the Medicare Part D program would confuse many dually-eligible beneficiaries and complicate access (Perry, Kitchman, & Guyer, 2005; Avorn, 2006).



The reality of what has happened since the inception of Medicare Part D is somewhat different, however (Duggan, Healy & Scott Morton, 2008; Shrank & Polinski, 2009). Research using pharmacy data and Medicare claims information has produced a mixed picture of the impact of Part D. Part D has, in many cases, resulted in increased prescription drug utilization and has not substantially increased cost-related non-adherence or created disruptions in coverage (Madden et al., 2008; Basu et al., 2010). For beneficiaries whose only health care coverage was through Medicare, Part D has meant assistance with prescription medications for the first time (Levy & Weir, 2009). Access issues remain, especially for low-income beneficiaries, as illustrated by the studies conducted by West et al. (2007, 2009) and Huskamp et al. (2009). However, it is not clear that the switch from Medicaid to Medicare has made these problems worse (Reschovsky & Felland, 2009).

Surveys of older adult (age 65 and older) beneficiaries indicate high levels of satisfaction with the program (Healthcare Leadership Council, 2008; Skarupski et al., 2009). For example, a 2008 survey of older adults found that 86% of beneficiaries stated that their co-payments were affordable, and 91% said that their Part D plans were a good value (Healthcare Leadership Council, 2008). The qualitative data that exist show overall high rates of satisfaction with the Part D benefit, with few beneficiary reports of problems with access or coverage (Kaiser Family Foundation, 2006; Perry, Dulio & Cubanski, 2006; Dulio, Perry & Cubanski, 2007; Hargrave et al., 2008). However, very little of this research focuses specifically on the experiences of adults with serious mental illness. The papers that do address beneficiaries with serious mental illness do so from

the viewpoint of psychiatrists (West et al., 2007; Huskamp et al., 2009; West et al., 2009).

The purpose of this dissertation is to give a voice to Medicare beneficiaries with serious mental illness and the case managers (community support workers) who serve them. More knowledge is needed about the impact of Part D on the everyday lives of people disabled by mental illness. This study will provide first-hand information about the experiences of Medicare stakeholders with Part D, as well as interpretation of data provided by the Centers for Medicare and Medicaid Services. The data obtained from these sources will be examined through the lens of patient-centered care, an important conceptual framework for 21<sup>st</sup> century health care. Out of the many questions that arise in considering the impact of Part D on adults with mental illness, this study will focus on three in particular. The overall goal of the three questions is to assess the degree to which Medicare Part D is a patient-centered policy, particularly for adults with mental illness. These questions will be answered using a mixed-methods approach that incorporates quantitative data and qualitative inquiry. The questions to be addressed in this study are as follows:

Research Question 1: How do Part D stakeholders perceive the patient-centeredness of the Medicare prescription drug program?

Research Question 2: What elements of patient-centered care are recognized by stakeholders as most critical to an effective prescription drug program?

Research Question 3: How do the “benchmark” plans in one Midwestern state perform on the measures of patient-centeredness considered most crucial to stakeholders?

This chapter will introduce the special concerns of Medicare beneficiaries with mental illness. It will also provide background on the Medicare prescription drug program and summarize the research that has been conducted on Part D and older adults, as well as on Part D and persons with disabilities. The chapter will conclude with a discussion of questions that have yet to be answered about the experiences of beneficiaries with mental illness with the Part D benefit, followed by an outline of the dissertation as a whole.

### **A Profile of Medicare Beneficiaries with Serious Mental Illness**

People with serious mental illness make up a substantial proportion of low-income Medicare beneficiaries. In 2006, approximately two million of the six and a half million people who received both Medicare and Medicaid benefits had a serious mental illness (Donohue, Huskamp, & Zuvekas, 2009). Serious mental illness is defined as a mental illness, such as schizophrenia or bipolar disorder, which causes disability and impairs normal functioning (Spaulding, Sullivan, & Poland, 2003). The prevalence of mental illness is higher among dually-eligible beneficiaries than among other Medicare recipients (Donohue, 2006), and public funding makes up a large share of spending on psychiatric medications (Donohue, Huskamp & Zuvekas, 2009). In 2006, Medicare financed 16 percent of spending for antidepressants, 21 percent of spending for antipsychotics, and 16 percent of spending for anticonvulsants (Donohue, Huskamp, & Zuvekas, 2009). Mental illnesses are among the conditions that have driven the increase in spending on Medicare over the past two decades (Thorpe, Ogden & Galactionova, 2010). Because dually-eligible beneficiaries with serious mental illness are especially

reliant on public benefits for health care as well as income support, changes in public policy and program administration can disproportionately affect them (Kennedy & Tuleu, 2007). It can be particularly difficult for beneficiaries with mental illness to navigate public systems of care (Elliott et al., 2005; Kaiser Family Foundation, 2005). However, well-administered public programs can also be of tremendous benefit to individuals with serious mental illness.

Dually-eligible beneficiaries as a whole are more likely to have poor health status than higher-income beneficiaries. They are also more likely to be members of minority groups and tend to have less education than higher-income beneficiaries. These characteristics can create additional vulnerability to program changes, as well as the potential to benefit from program improvements (Elliott et al., 2005).

#### **Background of Medicare Part D**

Prior to 2006, dually-eligible beneficiaries with serious mental illness received prescription drug benefits through the Medicaid program. In the state of Missouri, individuals with disabilities with incomes of less than \$768 per month are eligible for the full Missouri HealthNet program, and some individuals with higher incomes are able to use the MO HealthNet Medically Needy program (Missouri Department of Social Services, 2010).

Though prescription drug coverage is not a required benefit under Medicaid, all of the fifty states have chosen to include this benefit as a part of their Medicaid programs. Before the Medicare Modernization Act, people with serious mental illness who received SSI benefits or who bought into the Medicaid program through state Medically Needy (“spend-down”) programs were able to obtain their medications, for psychiatric and

medical conditions, at a very low cost. For example, in the state of Missouri, co-payments for Medicaid-covered prescriptions ranged from fifty cents to two dollars at most. Some states, such as Missouri, had imposed certain utilization management tools on their Medicaid prescription drug benefits, in order to prevent antipsychotic polypharmacy and other non-evidence-based prescribing practices (Parks & Surlles, 2004). However, for the most part, people with serious mental illness were able to obtain the medicines that had been prescribed to them using their Medicaid benefits.

This situation changed with the implementation of Medicare Part D in 2006. Dually-eligible beneficiaries—those who received Medicare and Medicaid benefits—were auto-assigned to private Medicare Part D prescription drug plans, and they were no longer allowed to use their Medicaid benefits for most of their medications (Morden & Garrison, 2006). Dually-eligible beneficiaries were automatically enrolled in stand-alone prescription drug plans under Part D if they did not choose a plan for themselves in the Fall of 2005. Some beneficiaries (approximately 11 percent in 2008) opted to enroll in Medicare Advantage (Part C) plans which provided managed-care coverage not only for prescription drugs but also for services ordinarily covered by Parts A (inpatient) and B (outpatient; physicians' services) of Medicare (Neuman & Cubanski, 2009; Donohue, Huskamp, & Zuvekas, 2009). However, most dually-eligible beneficiaries with mental illness (89 percent) were enrolled in stand-alone, private prescription drug plans in 2008. Auto-enrollment was an efficient way to maximize continuity of access for dually-eligible beneficiaries. However, because beneficiaries were randomly assigned to basic prescription drug plans with low premiums, the plan to which a particular beneficiary was assigned was not necessarily the best “fit” in terms of formulary or pharmacy network.

This led to the need for some beneficiaries to switch plans to ensure that their particular medicines were covered and that they could use their preferred pharmacy.

The Medicare prescription drug program is structured and administered very differently from state-run Medicaid programs. Although most Medicaid prescription drug programs are operated through state governments, Medicare prescription drug benefits are administered through a variety of private insurance company plans, including stand-alone prescription drug plans and Medicare managed care plans (Bakk, 2009). Though some protections are in place to ensure that psychotropic medications are covered by Medicare prescription drug plans, many beneficiaries have a less comprehensive benefit under the Medicare program than they had under Medicaid (Kaiser Family Foundation, 2004). Medicare Part D co-payments are often higher than co-payments under Medicaid, and because of competition among Part D plans, Part D plans have greater incentives to restrict their formularies or to put utilization management restrictions in place (Donohue, Huskamp, & Zuvekas, 2009).

For beneficiaries who did not qualify for the low-income subsidy under Medicare Part D, the “doughnut hole” coverage gap was also a concern. The Medicare Part D program is structured so that in 2010, Part D plans cover 75% of prescription drug expenses up to an out-of-pocket spending limit of \$2,830 in drug costs. Between \$2,830 and \$6,440, beneficiaries are responsible for 100% of prescription drug costs. When a beneficiary’s expenses are greater than \$6,440, “catastrophic” coverage takes effect, and the Part D plan covers 95% of expenses above that amount for the rest of the year (Kaiser Family Foundation, 2009).

The low-income subsidy for Medicare Part D fortunately covered the cost of the Part D premium for basic plans (also called “benchmark” plans). It also covered the expenses incurred by low-income beneficiaries in the “doughnut hole” coverage gap. Part D formularies were required by CMS regulations to cover “all or substantially all” drugs in several classes of medications important to those with severe mental illness, such as antidepressants and antipsychotics (Huskamp et al., 2007). However, the imprecise definition of “substantially all” meant that some formularies did not cover certain medicines needed by beneficiaries, and some important medicines were placed on restrictive “tiers” of coverage requiring prior authorization (Donohue & Frank, 2007). In addition, certain classes of drugs, such as benzodiazepines, were forbidden by federal law from being covered in Part D plans (Yang et al., 2008). Co-payments are also higher under Part D than under Medicaid; in 2010, co-payments for low-income subsidy participants were \$2.50 per prescription for generic drugs and \$6.30 per prescription for brand-name drugs (Centers for Medicare and Medicaid Services, 2010).

Anecdotal information from mental health providers has suggested that cost and access problems have resulted from the change in prescription drug benefits, and a recent survey of psychiatrists suggests that a number of patients have experienced disruptions in coverage which have, in some cases, led to poor mental health outcomes (West et al., 2007; Huskamp et al., 2009; West et al., 2009). In addition, the exclusion of benzodiazepines from coverage under Part D has created problems for some beneficiaries because disabled Medicare beneficiaries, especially those disabled by serious mental illness, are more likely to use this class of medicines than older adult beneficiaries (Yang et al., 2008). Because dually-eligible beneficiaries are more likely to have higher

prescription drug costs, disruptions in access can cause major health problems (Kennedy & Tuleu, 2007; Simoni-Wastila et al., 2008; Riley, Levy & Montgomery, 2009).

Information is conflicting, however. Basu, Yin, and Alexander (2010) studied the impact of Part D on dually-eligible beneficiaries' medication utilization and did not find evidence of disruptions in coverage or access problems. Reschovsky and Felland (2009) reported that access issues existed for non-elderly Medicare beneficiaries, but that the switch from Medicaid to Medicare does not appear to have made this problem worse. In contrast, Jacobson and Anderson (2010) reported that coverage and access problems did occur for dually-eligible beneficiaries during the switch from Medicaid to Medicare. Donohue, Huskamp, and Zuvekas (2009) examined access to prescription medicines among dually-eligible Part D beneficiaries with mental illness and found that there were fewer benchmark plans serving dually-eligible beneficiaries in 2009 than there had been the year before, and that some incentives existed for prescription drug plans to restrict access to people with mental illness through use of utilization management tools.

The next section will provide an overview of studies that have examined use of Part D and Part D-related outcomes among predominantly older adult populations. Three main themes will be explored.

### **Impact of Part D on the Elderly**

Since 2007, a number of studies, using a variety of sources of data, have explored the impact of the Medicare Part D program on older adults (defined as adults aged 65 and over). Three themes that appear frequently in these papers are characteristics of older adults who enroll in Part D; prescription drug costs and utilization among Part D



participants; and cost-related non-adherence following the implementation of Part D.

The following table outlines these studies, the questions they asked, and their findings.

Table 1.1 Studies of Part D and Older Adults

Authors	Data Source	Research Question	Findings
Neuman et al. (2007)	National survey of older adults	Assessing how many older adults are enrolled in Part D; comparing out-of-pocket spending and cost-related non-adherence between those with Part D and those with other types of prescription drug coverage	Out-of-pocket spending and cost-related non-adherence were greater among Part D enrollees than those with VA or employer-sponsored coverage.
Hsu et al. (2008)	Survey of older adults with Medicare Advantage coverage in Northern California	Assessment of older adults' knowledge of their prescription drug benefits and their ways of coping with drug costs	40% of participants were aware of the Part D coverage gap; 15% reported cost-related non-adherence.
Madden et al. (2008)	Medicare Current Beneficiary Survey (older and disabled adults)	Assessment of cost-related non-adherence following Part D implementation	There was a small reduction in cost-related non-adherence among beneficiaries after Part D, but those with the most severe health problems still frequently reported cost-related non-adherence.
Shrank et al. (2008)	Pharmacy dispensing data related to five classes of study drugs: clopidogrel, proton pump inhibitors, warfarin, statins, and benzodiazepines	Evaluating medication use, out-of-pocket spending, and medication switching during the transition from Medicaid to Medicare Part D for older adult dual	Medicare Part D had no significant effect on use of any of the drugs studied. Co-payments went down, except for benzodiazepines. Rate of switching drugs went up for

		eligibles	PPIs but stayed the same for all others.
Yin et al. (2008)	Pharmacy claims data	Estimation of changes in older adults' prescription drug utilization following Part D implementation	A modest increase in drug utilization and a small decrease in out-of-pocket costs were reported.
Zhang et al. (2008)	Pharmacy claims data	Assessing effect of Part D on generic drug utilization	From 2005 to 2006, use of generics grew more slowly among Part D beneficiaries than among those with other kinds of coverage.
Briesacher et al. (2009)	Pharmacy dispensing data	Calculation of enrollment of nursing home residents (older and disabled adults) in Part D; assessment of effect of Part D on out-of-pocket drug spending	81% of nursing home residents were enrolled in Part D in 2006. The proportion of prescriptions for nursing home residents paid for out-of-pocket decreased from 11% to 8% from 2005 to 2006.
Fung et al. (2009)	HMO claims data	Calculation of impact of coverage gap on older adults with diabetes enrolled in Medicare Advantage	Prescription drug spending and cost-related non-adherence were higher for those with coverage gap than for those without a gap in coverage.
Joyce et al. (2009)	Part D administrative data from CMS	Assessment of impact of Part D on older adults' out-of-pocket drug spending and prescription drug use.	Cost savings associated with Part D were concentrated among low-income beneficiaries. Part D was associated with decreased out-of-pocket spending and increased medication use.
Levy & Weir	Health & Retirement	Estimation of the	Take-up of Part D

(2009)	Survey	impact of Medicare Part D on prescription drug coverage among older adults and determine predictors of program enrollment among older adults with no prior drug coverage	was high among those with no previous drug coverage. Demand for prescription medicines was the biggest predictor of Part D enrollment.
Pedan et al. (2009)	Pharmacy dispensing data	Examination of drug consumption patterns among older adults to determine which beneficiaries reach the coverage gap.	About 1/5 of beneficiaries reached the coverage gap but only a small number of these reached catastrophic coverage levels. Patients with chronic conditions reported the highest drug consumption.
Reschovsky & Felland (2009)	2003 Community Tracking Study Household Survey; 2007 Health Tracking Household Survey	Exploration of access to prescription medicines following implementation of Part D	There was very little change in older adults' tendency to skip filling a prescription following Part D implementation.
Safran et al. (2009)	Longitudinal data from CMS	Examining changes in older adults' prescription drug use and spending as a result of Part D	Those who lacked drug coverage in 2003 had increased utilization, reduced out-of-pocket spending, and reduced cost-related non-adherence following enrollment in Part D.
Schneeweis et al. (2009)	Pharmacy dispensing data	Calculating effect of Part D implementation on older adults who had lacked prior drug coverage	Part D increased utilization, until beneficiaries reached the coverage gap, when utilization decreased.
Skarupski et al. (2009)	Cross-sectional data from Chicago	Examining racial differences in Part D	African-American older adults enrolled

	Health and Aging Project, a population-based biracial survey of older adults	enrollment	in Part D are more likely to have chronic health conditions and low incomes than White older adults in Part D.
Zhang et al. (2009a)	Medicare Advantage plan data from a large insurer in Pennsylvania	Examination of whether older adults' prescription drug spending following Part D implementation was associated with reductions in other medical spending	There was an increase in prescription utilization but only a minimal offset of other medical costs in the Medicare Advantage program.
Zhang et al. (2009b)	Enrollment, benefits, and claims data from a large insurer in Pennsylvania, from an employer-based plan and an individual Part D PDP	Comparing prescription drug usage of older adults in an employer group with no coverage gap with usage among older adult members of a Part D PDP group with a coverage gap or generic coverage in the gap	More beneficiaries reached the "doughnut hole" level of spending in the plan that had no gap, as compared to the plan that had a gap. Those lacking coverage in the gap reduced their spending on prescription drugs.
Zivin et al. (2009a)	Longitudinal survey data from the Health and Retirement Survey	Calculation of rates of enrollment in Medicare Part D by older adults with depression and cognitive impairment	Older adults with depression and cognitive impairment were more likely than other beneficiaries to sign up for a Part D plan.
Zivin et al. (2009b)	Medicare Current Beneficiary Survey	Calculation of cost-related non-adherence among beneficiaries with depression following implementation of Medicare Part D	Cost-related non-adherence did not decline among beneficiaries with depressive symptoms relative to those without depressive symptoms.
Basu et al. (2010)	Pharmacy claims	Examination of the	The implementation

	data	effect of Part D on dually-eligible older adults' prescription drug use and expenditures	of Part D had no effect on dually-eligible beneficiaries' use of prescription medicines or their expenditures on medicines.
Maciejewski et al. (2010)	Medicare Current Beneficiary Survey	Examining patient factors and medication acquisition strategies impacting enrollment in prescription drug plans among beneficiaries with no prior drug coverage.	Older adults without prior drug coverage were more likely to enroll in Part D if they were younger (age 65-74), female, non-Hispanic white, or married or widowed. A greater number of self-reported medical conditions was also associated with enrollment in Part D.

### **Beneficiary Enrollment**

The literature on characteristics of beneficiaries who enroll in Part D tends to indicate that more vulnerable groups of beneficiaries were actually more likely to sign up for Medicare Part D than healthier, higher-income beneficiaries (Levy & Weir, 2009; Skarupski et al., 2009; Zivin et al., 2009a). Maciejewski et al. (2010) found that beneficiaries with greater numbers of self-reported health conditions were more likely to enroll in Medicare Part D than beneficiaries who reported themselves to be healthier.

### **Utilization and Costs**

The evidence on the effect of Part D on utilization and costs is mixed. It seems that beneficiaries who had no drug coverage prior to Part D tend to experience increased utilization as well as decreased costs (Yin et al., 2008; Joyce et al., 2009; Safran et al.,

2009). For dually-eligible beneficiaries, who had Medicaid drug coverage prior to Part D, implementation of the Medicare drug benefit seems to have had little impact on costs or utilization (Basu et al., 2010).

### **Cost-Related Medication Non-Adherence**

Cost-related non-adherence also varies according to whether a beneficiary had coverage prior to Part D. Among those who had no coverage before Part D, cost-related non-adherence tended to go down following Part D implementation (Madden et al., 2009; Safran et al., 2009). For beneficiaries with depressive symptoms who enrolled in Part D, cost-related medication non-adherence stayed about the same (Zivin et al., 2009b). Beneficiaries who entered the “doughnut hole” coverage gap were more likely to report non-adherence (Fung et al., 2009; Zhang et al., 2009b).

Overall, older adults expressed satisfaction with the Part D program, and they reported few problems with access and cost. Cost-related non-adherence went down among those who had not had prior prescription drug coverage, and it tended to stay the same for other beneficiaries. There appears to have been some adverse selection of sicker people into Part D plans. An important question to consider is whether the same assertions can be made for younger Medicare beneficiaries with disabilities, and whether their situations might differ substantially from elderly program participants.

### **Impact of Part D on Individuals with Disabilities**

Relatively little attention has been directed toward studying the effects of Part D on beneficiaries with disabilities. Beneficiaries with disabilities are defined as Medicare beneficiaries under age 65 who have a diagnosis that prevents them from being able to maintain employment (Hall, Kurth, & Moore, 2007). Of those studies that have

examined the impact of Part D on this population, most have looked specifically at beneficiaries with serious mental illness. Studies of Part D and individuals with disabilities have rarely surveyed beneficiaries themselves, instead relying on other informants and sources of information.

Stuart, Simoni-Wastila and Chauncey (2005) used data from the Medicare Current Beneficiary Survey from 1998-2000 to predict the impact of coverage gaps on individuals with chronic illness, specifically diabetes, chronic lung disease, and mental illness. They predicted that beneficiaries who have these chronic conditions but are not eligible for the low-income subsidy would have a higher-than-average likelihood of reductions in medication use and drug spending during the “doughnut hole” coverage gap. Because medication therapy is often very important in managing chronic illness, Stuart et al. (2005) noted that this sensitivity to costs could have an adverse impact on patients’ health.

Hall, Kurth, and Moore (2007) found that many younger dually-eligible beneficiaries with a variety of disabilities had experienced disruptions in coverage as well as difficulties with the information provided by the Centers for Medicare and Medicaid Services and their prescription drug plans. The two main problems that Hall et al. found were difficulties in accessing needed medications and insufficient knowledge of program rules. Beneficiaries commonly switched plans because they were unable to obtain the medications that they needed, yet over half of beneficiaries surveyed did not know how often they were allowed to change Part D plans.

Donohue and Frank (2007) examined the rate of medication switching that was occurring among dually-eligible beneficiaries with mental illness as a result of formulary

restrictions in Part D. They found that a relatively small percentage of beneficiaries (2 to 10 percent, depending on the class of drug) had switched medications as a result of formulary restrictions and utilization controls. Most dually-eligible beneficiaries experienced continuity of prescribed medication under the Part D benefit.

West, et al. (2007) surveyed almost six thousand psychiatrists in order to assess the impact of Part D on dually-eligible beneficiaries with mental illness. They found that a little over half of the psychiatrists reported that at least one patient had experienced a medication access problem. Among the patients who had had access problems, about one-quarter had had a “significant adverse clinical event” such as a trip to the emergency room or an inpatient hospitalization (West et al., 2007, p. 789). A little less than ten percent of psychiatrists reported that patients had experienced improved medication access as a result of Part D.

Wilk, et al. (2008) studied the administrative burden of Part D participation on the psychiatrists of dually-eligible Medicare beneficiaries. They found that in many cases, psychiatrists spent one hour on prescription drug-related administrative tasks for every one hour spent in direct client contact. Administrative tasks included facilitating prior authorizations for the use of certain prescription drugs, as well as other tasks related to obtaining medicines for dually-eligible patients. This paperwork burden could discourage psychiatrists from treating dually-eligible patients; it could also have implications for quality of care delivered to these patients, as psychiatrists are less and less able to devote sufficient time to face-to-face clinical care.

Huskamp et al.(2009) also surveyed psychiatrists who treated dually-eligible patients. They found that during the 2006 calendar year, 44% of the patients reported on



by these psychiatrists had experienced some sort of access problem related to Part D. Access problems were associated with increased use of the emergency room for psychiatric treatment, but not with increased inpatient hospitalization.

West et al. (2009), using data provided by psychiatrists treating dually-eligible patients, also examined access problems among dually-eligible beneficiaries with mental illness. Their findings were similar to Huskamp et al (2009); 43.3% of dually-eligible patients for whom data were provided had experienced access problems with prescription drugs during 2006. Part D plans' use of utilization management tools, such as step therapy, prior authorization, and quantity limits, were associated with access problems. Access problems were associated with an increased risk of adverse events such as emergency room visits and increases in suicidal behavior.

Yang et al. (2009) examined non-adherence to prescription medicine regimens among Part D enrollees with diabetes in six states. They looked at data from both older adult beneficiaries and younger adult beneficiaries with disabilities. Yang et al. found that beneficiaries who were under age 65, as well as women, black, or Hispanic patients, were less likely to be adherent to medications for glycemic control and for cardiovascular complications of diabetes.

Many beneficiaries with disabilities have experienced very little disruption in their prescription drug benefits as a result of the implementation of Part D (Donohue & Frank, 2007). However, some disabled beneficiaries, particularly those with mental illness, have experienced interruptions in coverage as well as cost and access problems that have resulted in clinically significant problems (West et al., 2007; West et al., 2009;

Huskamp et al., 2009). In addition, insufficient knowledge of plan rules and guidelines appears to be a barrier to utilization of benefits (Hall, Kurth, & Moore, 2007).

### **Questions that Remain**

There needs to be a more thorough examination of the impact of Medicare prescription drug coverage on the lives of people with severe mental illness. We do not fully understand how Part D has changed the health and health care of individuals with psychiatric disabilities, particularly those with low incomes. We especially lack an understanding of how well the Medicare prescription drug benefit is meeting the unique needs of beneficiaries who have mental illness. As policy-makers focus more and more on health reforms that are “consumer-directed” and “patient-centered” (Benjamin & Fennell, 2007), we will need a more in-depth knowledge of the capacity of this new Medicare benefit to address the financial and other challenges that individuals with psychiatric disabilities face.

Some of the questions that remain to be answered regarding the impact of Part D on beneficiaries with mental illness include the following.

What constitutes a true and accurate picture of the effect of the Medicare prescription drug program on disabled adults with mental illness?

How have Medicare beneficiaries with mental illness made use of this new program, and what have their experiences been?

What is an appropriate conceptual framework with which to examine these questions?

What has been the impact of changes in co-payments on beneficiaries' ability to obtain the medications they need?

How have variations in formulary inclusiveness among plans affected beneficiaries' continuity of care?

What sources of information do beneficiaries with mental illness rely on to understand and utilize their Part D benefits?

Who helps beneficiaries with mental illness to negotiate the paperwork and service systems associated with the Part D benefit?

How good is the "fit" between the attributes of Medicare prescription drug plans and the specific needs of beneficiaries with mental illness?

To assess the performance of the Medicare Part D program, it is helpful to consider the needs of beneficiaries as the first priority. Health reform initiatives of the last ten or fifteen years have frequently emphasized the importance of patient-centered care—care that is focused on the needs and wishes of the patient, rather than the convenience of the care provider (Gerteis et al., 1993). This idea is somewhat late in coming to the mental health sector (Borg et al., 2009; Pincus et al., 2007). Nonetheless, the notion of patient-centered care is one that can be used to assess the impact of Part D coverage on people with severe mental illness. This study will use the framework of patient-centered care, as developed by the Picker Institute, to evaluate how well Medicare prescription drug coverage is meeting the needs of this very vulnerable group of beneficiaries. It will examine the impact of the Medicare prescription drug benefit on adults with mental illness, and attempt to understand what has gone well for these beneficiaries, as well as what may have gone wrong. It will examine not only whether beneficiaries are satisfied with the Part D program, but also why.

This dissertation aims to address in a more comprehensive way some of the questions surrounding mentally ill beneficiaries' use of the Part D benefit.

Methodological triangulation—using both qualitative and plan comparison data—is employed (Speziale & Carpenter, 2005). Qualitative data from two distinct groups of Medicare stakeholders, both beneficiaries and their community-based case managers, are examined and analyzed. In addition, plan comparison data from [www.medicare.gov](http://www.medicare.gov) and Medicare Part D Performance Data are considered. The conceptual framework of patient-centered care is used as a way to organize the questions asked of the data, and as a way to understand the results obtained.

Chapter 1 has provided an introduction to the Medicare Part D program and an outline of the study. Chapter 2 offers an explanation of the conceptual model being used and reviews the patient-centered care literature from a variety of disciplines. Chapter 3 is an overview of the research design and methods. Chapter 4 describes the results of the qualitative and plan comparison data. Chapter 5 provides a discussion of the results and their application to patient-centered care, as well as implications of the findings for research, policy and practice, and social work education.

## **CHAPTER II: CONCEPTUAL MODEL: PATIENT-CENTERED CARE**

### **Introduction**

Patient-centered care is a concept that is used in the health services literature to describe health care that is guided by the needs and values of the patient, rather than the health care system, organization, or professional (Institute of Medicine, 2001). It has been used as a framework for evaluation of health care services and for proposing reform of the health care system. Patient-centered care (also called person-centered, client-centered, or patient-focused care) has been adopted as an ideal of practice in a number of health care professions, including medicine, nursing, occupational therapy, and rehabilitation (Mead & Bower, 2000; Radwin et al., 2009; Sumsion, 2005; Leplege et al., 2007). This chapter will discuss the origins of the patient-centered care concept and the use of this idea in health services research and policy, including its use in mental health. The use of patient-centered care in health research, as a dependent variable and as an independent variable, will be reviewed. This chapter will also outline the use of patient-centered care as a method for evaluating health care systems and programs and describe this investigator's framework for evaluating the patient-centeredness of the Medicare Part D program.

### **Use of the Term, "Patient-Centered Care"**

"Patient-centered care" is a term that has its origins in conceptual writings from the 1960s (Balint, 1969; Balint, Ball & Hare, 1969). Enid and Michael Balint, psychoanalysts from Great Britain, conducted seminars for primary care practitioners and medical students in which they taught physicians to "examine the whole person" (Balint, 1969, p. 269) instead of looking only at physical symptoms of illness. The

original aim of patient-centered care was to integrate psychotherapeutic methods into medical practice so that psychological causes of illness would be more likely to be discovered and explored (Balint et al., 1969).

Patient-centered care was introduced as a clinical method for primary care physicians in the mid-1980s, by several physician-researchers in Canada and South Africa (McCracken et al., 1983; Levenstein et al., 1986). These physicians believed that patient-centered medicine was a set of skills that could be taught to family practitioners, to help them to consider the patient's experience and definition of illness as well as the "pathological diagnosis" (Levenstein et al., 1986, p. 24). They believed that to provide adequate and appropriate primary care services, the practitioner needed to understand the patient's emotional needs.

Patient-centered care was introduced to the health services research field in the late 1980s by the Picker/Commonwealth Program for Patient-Centered Care, now the Picker Institute (Picker Institute, 2008). The Picker/Commonwealth Program produced a volume entitled *Through the Patient's Eyes*, which proposed reform of health care in the United States, based on eight principles which they identified as constituting patient-centered care (Gerteis et al., 1993). Those principles are as follows:

1. Respect for the patient's values, preferences, and expressed needs: This involves including patients in decision-making processes to ensure that treatments that are chosen are congruent with the patient's values and preferences. It means that patients need to have options available to them that are in line with their values and preferences. It also involves defining needs according to the patient's perspective, rather than the health care provider's opinion of what the patient

needs. This principle of patient-centered care also includes sensitivity to a patient's cultural values and the impact those values may have on his/her perceptions of health care processes.

2. Information and education. This means that patients need information about their diagnosis and prognosis, as well as education about treatment options that are available. They also need information about how health care organizations and programs work so that they can use them effectively.
3. Access to care. Patients need to be able to get timely appointments and need to be able to obtain care in a location that is convenient for them. Access can also involve affordability of care; patients must be able to pay for their care in order for it to be accessible.
4. Emotional support to relieve fear and anxiety. Patients need emotional support from providers to help them address fear and anxiety associated with diagnosis and treatment of their condition. Emotional support can be just as empowering as involvement in treatment decisions, according to the Picker Institute (2010).
5. Involvement of family and friends. Patients should be permitted to involve family and friends in decisions about treatment as well as processes of care.
6. Continuity and secure transitions between health care settings. The process of being referred or transferred from one source of care to the next should operate seamlessly, with the patient being able to switch providers or programs free of interruptions in care.

7. Physical comfort. Patients should receive assistance with pain management and maintaining physical comfort. Physical comfort can also involve assistance with activities of daily living.
8. Coordination of care. Providers should communicate with each other so that services operate in a coordinated way. Providers from different disciplines or offering different services should coordinate their efforts so that patients experience care in a less confusing, more continuous way.

(Audet, Davis & Schoenbaum, 2006; originally from Gerteis et al., 1993; Picker Institute, 2010).

From this basic definition of patient-centered care developed in the early 1990s, many other iterations of the patient-centered care concept have arisen. “Patient-centered care” has continued to be used both in the health services research literature and in the government- and privately-sponsored literature on health care quality. Many different organizations and researchers have promoted patient-centered care as an ideal for which the health care system should strive.

Unfortunately, there is little agreement about the definition of patient-centered care. A variety of attributes of quality health care have been labeled as patient-centered, including respect for patients’ preferences, adequate access to care, patient empowerment through information and education, offering patients choices among treatments, attractive physical design of health care settings, and palatable food choices. Hobbs (2009) points out that this lack of conceptual clarity has made it difficult to conduct meaningful research on attributes of patient-centered care. Leplege et al. (2007) discuss the fact that it is difficult to reduce patient-centered care to a single idea because the concept of



patient-centered care is inherently anti-reductionist. Nonetheless, additional clarity regarding the use of the term patient-centered care would be helpful to researchers and policy-makers.

Saha, Beach and Cooper (2008) mention the development of patient-centered care from a concept used to describe a particular clinical method to a set of characteristics of health care systems and organizations. This evolution can be seen in the development and promotion of many different definitions of patient-centeredness, which are outlined below. The table below provides a summary of some of the major definitions of patient-centered care, including information on the aspect of the health care process described and the profession addressed by the definition. “Clinical method” refers to interpersonal processes between providers and patients. “Processes of service provision” includes communication between provider and patient but includes other aspects of the process of health care delivery. “Health care organizations” involves organization, system, and policy processes and their impact on the patient. Application of each definition to system and organizational issues—clinical definitions as well as those involving processes and organizations—is discussed.

Table 2.1 Patient-Centered Care Definitions

Authors or organizations promoting definition	Aspect of the health care process described	Profession	Dimensions of the definition	Application to health care systems and programs
Picker Institute (Gerteis et al., 1993)	Processes of service provision	Not specified	Respect for the patient's values, preferences, and expressed needs. Information and education. Access to care. Emotional support to relieve fear and anxiety. Involvement of family and friends. Continuity and secure transition between health care settings. Physical comfort. Coordination of care.	Access, secure transition, and care coordination are all potentially system attributes.
Law, Baptiste & Mills (1995)	Clinical method	Occupational therapists	Individual autonomy and choice Partnership Therapist and client responsibility Enablement Contextual congruence Accessibility Respect for diversity	Contextual congruence and accessibility are program characteristics.
Bechel, Myers & Smith (2000)	Processes of service provision	Not specified	Involving the patient in treatment decisions Increasing patient communication with providers and patient understanding of what to expect from treatment plans, recovery, and aftercare Involving family members in care	Mentions the importance of patient involvement in decision-making
Mead & Bower (2000)	Clinical method	Physicians	Biopsychosocial perspective "Patient-as-person" Sharing power and responsibility Therapeutic alliance "Doctor-as-person"	"Patient-as-person" and power-sharing dimensions can be applied to the structure and operation of health care programs
Institute of Medicine (2001)	Processes of service provision	Not specified	Coordination and integration Provision of information and education to patients Attention to physical comfort Emotional support Involvement of family and friends	Care coordination and provision of information and education to patients can be program or system characteristics.
Little et al. (2001)	Clinical method	Physicians	Exploring the experience and expectations of disease and illness	Partnership between

			Understanding the whole person Finding common ground regarding management (partnership) Health promotion Enhancing the doctor-patient relationship Realistic use of time	providers and patients can be a program- or system-level approach to service provision.
Berry, Seiders & Wilder (2003)	Processes of service provision	Physicians	Availability Appropriateness Preference Timeliness	Mentions the importance of restructuring delivery systems to facilitate patient-centered access.
Planetree Alliance (Frampton, Gilpin & Charmel, 2003)	Clinical method	Inpatient care teams	Healing human interactions Patient and family education Involvement of patient's support network Nurturing through food Addressing spiritual needs of patients Human touch Use of arts in healing Alternative and integrative medicine Innovations in architecture and design	Emphasizes patient participation in care decisions.
Sumsion (2005)	Clinical method	Occupational therapists	Provide information to enable choice Participate in negotiating goals Overcome fear	Mentions clients' appreciation of programs that respect their needs.
Bergeson & Dean (2006)	Health care organizations	Physicians	Improving access to and continuity with clinicians Increasing patients' participation in care Supporting patient self-management Establishing more efficient and reliable mechanisms for coordinating care	Addresses structures of care provision and health care organizations
Scholle et al. (2006)	Health care organizations	Physicians	Ease of obtaining information Swiftness of practitioner response to patient inquiries Referral to educational opportunities Availability of care management	Addresses structures of care provision and health care organizations.
International Alliance of Patients' Organizations (2007)	Clinical method and health care organizations	Not specified	Respect. Choice and empowerment. Patient involvement in health policy. Access and support.	Stresses patient involvement in health policy.

			Information.	
Leplege et al. (2007)	Clinical method	Rehabilitation professionals	Addressing the person's specific and holistic properties Addressing the person's difficulties in everyday life The person is an expert; participation and empowerment Respecting the person 'behind' the impairment or the disease	Emphasizes participation and empowerment.
Robert Graham Center for Policy Studies in Family Medicine and Primary Care (2007)	Processes of service provision	Physicians	Personal physician Physician-directed medical practice Whole person orientation Care is coordinated and/or integrated Quality and safety Enhanced access Payment reform	Discusses reform of payment system; stresses enhanced access and coordinated care.
Shaller (2007)	Health care organizations	Not specified	Education and shared knowledge Involvement of family and friends Collaboration and team management Sensitivity to non-medical and spiritual aspects of care Respect for patients' needs and preferences Free flow and accessibility of information	Applies patient-centered care principles to health care organizations.
Saha, Beach & Cooper (2008)	Clinical method and health care organizations	Not specified	Within healthcare organizations: Services aligned to meet patient needs and preferences, e. g., 1. Coordinated/integrated/continuous 2. Convenient/easily accessible 3. Attendant to health promotion and physical comfort. Within interpersonal interactions: Provider understands each patient as a unique human being, e. g., 1. Uses biopsychosocial model 2. Views patient as person 3. Shares power and responsibility 4. Builds effective relationship 5. Maintains and is able to convey unconditional positive regard 6. Is aware of the "doctor as person"	Stresses access and service coordination as important system characteristics.
Radwin et al. (2009)	Clinical method and health care organizations	Nursing	Responsiveness Individualization Coordination Proficiency Patient advocacy	Patient advocacy is included in the model.

## **Patient-Centered Care in Mental Health**

Patient-centered care has been promoted as a useful approach to the management of chronic illnesses, because it values patient preferences and stresses the involvement of patients in decision-making about care. This idea may have utility in the mental health sector, in particular. Sharfstein and Dickerson (2006) point out that mental illnesses can be particularly costly over the long-term, not just in terms of health care expenses, but also in terms of the impact on the patient's sense of self. Patient-centered care processes may be helpful in restoring control and self-esteem to individuals with serious mental illness.

The Institute of Medicine report on improving mental health and substance abuse care (2006) gives priority to the idea of patient-centeredness as a framework for reform of the mental health system. Principles such as respect for patients' values, preferences and expressed needs; information and education; and emotional support and alleviation of fear and anxiety; are quite relevant to mental health services. Too often in the past, activities such as assessment and treatment planning in the mental health sector have centered on professionals' perceptions of patient needs rather than on the priorities of the patient him/herself (Starnino, 2009). A shift to patient-centeredness would serve to empower patients to make their own choices.

Despite the potential that patient-centeredness holds, and despite the mention of patient-centeredness in the IOM report, this notion has been used very little in the mental health literature. The President's New Freedom Commission on Mental Health (2003) put forward as one of its goals the idea that mental health care should be "consumer and

family driven” (p. 27); however, it does not appear that this criterion is being widely-used to evaluate mental health programs. There are concepts such as shared decision-making (Schauer et al., 2007) and certain uses of the terms “empowerment” and “recovery” that mirror the values of patient-centered care (Salyers & Tsemberis, 2007). Empowerment in the community mental health field is frequently used to describe treatment-planning processes that are driven by the client, rather than determined by the mental health professional (Corrigan, 2003). Similarly, recovery is seen as a process of healing from mental illness that the person with the illness directs (Starnino, 2009). However, the actual term patient-centered care is rarely used in the mental health literature (IOM, 2006). Leplege et al. (2007) discuss the fact that the field of psychiatric rehabilitation embodies many of the ideas involved in patient-centered care, and they note that psychiatric rehabilitation scholars and practitioners have seemed to avoid the use of the term patient-centered care even though they are in agreement with many of its main concepts.

Mechanic (2007), in his editorial on the state of psychiatric services in the United States, emphasized the importance of patient-centered mental health care, but it appears that the implementation of patient-centered care principles in mental health is still in its early stages. Pincus et al. (2007) discuss the fact that the mental health service delivery system in the United States needs to increase its focus on the needs and preferences of patients, as well as involvement of family and friends in decision-making processes. Pincus and his colleagues also mention that the profession of psychiatry needs to let go of some of its control to allow patients’ ideas about appropriate care to carry more weight.

The concept of “personalized medicine” has gained increasing popularity in psychiatry in recent years (de Leon, 2009). Personalized medicine refers primarily to the tailoring of pharmacological treatments to individual patients using genetic and other types of biological information (Moller & Rujescu, 2010). Personalized medicine shares with patient-centered care the notion that communication with patients is of critical importance to appropriate provision of care. Several writers who describe the use of personalized medicine in mental health discuss the primacy of effective provider-patient communications (de Leon, 2009; Koslow, Williams, & Gordon, 2010).

Wills and Holmes-Rovner (2006) also discuss the adoption of patient decision-making processes that respect patients’ preferences. Shared decision-making has become an increasingly common element of innovative mental health programs. In their review paper, Adams and Drake (2006) discuss the use of shared decision-making in mental health services and point out the association between adoption of shared decision-making practices and positive outcomes such as decreased symptom burden and increased satisfaction with services. Swanson, Bastani, Rubenstein, Meredith, and Ford (2007) also make the connection between use of shared decision-making in depression care and increased patient satisfaction. Shared decision-making is a practice that fits well with several patient-centered care principles, including information, communication, and education.

The term “person-centered care” has recently become more widely used to discuss delivery of mental health care that respects patient preferences; Borg et al. (2009) report on two programs that exemplify what they call “person-centered care”; one of these is a U. S. program, and the other is a mental health service innovation from Finland.

Patient-centered care has the potential to reduce stigma in patient-professional relationships, as well. By increasing the level of information and education that patients have, patient-centered care promotes empowerment and choice (Picker Institute, 2010). Program approaches such as teaching skills of independent living and management of mental health symptoms give mental health clients more control over their services and can increase self-direction (Starnino, 2009). Use of these principles in service delivery can not only decrease self-imposed stigma among mental health patients, but it can also reduce the negative opinions that professionals may have of mental health patients, by encouraging them to be more honest and respectful (Corrigan, 2003).

Patient-centered care may have utility as a guide to provider-patient interactions in the mental health sector as well as program- and system-level reforms. Cott (2004) discusses the importance of “the expertise of the client” (p. 1411) in designing rehabilitative services. Starnino (2009) further explores “increased emphasis on mutuality in the client-worker relationship” (p. 827) as an integral part of recovery-oriented service provision. Actions can be taken at all levels of the care process to give increased voice to patients’ concerns and introduce patients’ perspectives into decision-making processes.

### **Empirical Research Using Patient-Centered Care**

Given the volume of commentary related to patient-centered care and the frequency with which patient-centered care is invoked as an ideal for health care professionals and systems, there is a surprisingly small amount of empirical research that uses measures of patient-centered care. There are a few studies that use patient-centered care as a dependent variable, examining the impact of certain health care practices and



organizational characteristics on perceptions of patient-centered care. Patient-centered care has also been used as an independent variable, to assess the effect of patient-centered care practices on certain kinds of health care outcomes. Both types of research are important in advancing an understanding of the significance of patient-centered care for clinical practices and health care organizations.

## **Patient-Centered Care as a Dependent Variable**

There have been several studies that have examined the factors which contribute to a perception of patient-centeredness in health care. The methodology used in these explorations has varied, including survey methods and qualitative interviewing. In addition, several different sites of care have been examined, including outpatient settings and acute care.

One of the earliest examinations of factors that contribute to patient-centered care was the Picker-Commonwealth Survey of Patient-Centered Care (Cleary et al., 1991). In this survey, adult patients who had recently been discharged from the hospital were surveyed regarding their perceptions of hospital practices contributing to patient-centeredness. For many of the questions, patients indicated a high level of satisfaction; for example, few patients reported problems with physical care. However, on questions related to trust and relationships with physicians and hospital staff, there was more variation in responses, indicating that hospital staff needed to do more to build trust with patients.

Another study which used Picker-Commonwealth surveys to examine the quality of hospital care was Gooding et al. (1999). Patients who had recently left the hospital were asked questions about the occurrence of various patient-centered practices. A fairly low percentage of patients reported problems with physical comfort, but a higher proportion of patients reported problems during their hospitalization with receiving emotional support and information/education.

Little et al. (2001a) explored patients' preferences for physicians' use of the patient-centeredness outcomes of communication, partnership, and health promotion, as

well as patients' desire for a prescription or a physical examination. They found that patients expressed a strong desire for physicians to use patient-centered approaches in their consultations, stronger than their desire to receive a prescription or a physical exam.

The Commonwealth Fund undertook a national survey of primary care and specialty care physicians in 2003 to assess the extent to which patient-centered care was practiced by U. S. physicians (Audet, Davis, & Schoenbaum, 2006). Certain patient-centered care practices, such as care delivered by multidisciplinary teams and efforts to share medical records with patients, were supported broadly by most physicians. However, other practices, such as using e-mail to communicate with patients and eliciting systematic feedback from patients, had been less widely adopted.

Smith, Mitchell & Bowler (2007) reviewed studies of asthma education materials to assess the patient-centeredness of these educational programs. They associated patient-centeredness with learner-centeredness in the educational context. They found that most asthma education materials did not meet expectations of patient-centeredness.

Sumsion and Law (2006) conducted a literature review in which they examined articles concerning client-centered practice in health care. They sought to identify common elements of the various definitions of client-centered care. They found that factors which contribute to client-centeredness included listening and communicating, partnership, hope, and choice. Sumsion and Lencucha (2007), in a qualitative study interviewing occupational therapists, explored client-centered collaboration in occupational therapy practice. The occupational therapists who were interviewed identified several actions and attributes that contribute to client-centeredness: these include negotiation, advocacy, and partnership.

The role of certain factors in the delivery of patient-centered education efforts has also been examined (Zubialde, Eubank & Fink, 2007). Zubialde, Eubank and Fink described patient-centered education as an outcome of the use of adult learning models, stressing such characteristics as humanities skills, caring, and self-directed learning skills.

Helitzer et al. (2010) conducted a randomized controlled trial in which patient-centered communication was the outcome variable. They examined the effects of communication training on primary care providers' patient-centered communication skills, and they found that training did significantly increase providers' abilities in this area. Furthermore, when the providers' communication skills were assessed two years after the training, their increased capacity to provide patient-centered communication had persisted.

### **Patient-Centered Care as an Independent Variable**

Patient-centered care has also been examined as a health care process leading to certain kinds of health and patient-satisfaction outcomes. Some studies have shown significant associations between the adoption of patient-centered care practices and improved health care outcomes. Other studies are less conclusive.

An early study of patient-centered care as an independent variable was conducted by Henbest and Stewart (1990), who examined the association of patient-centered care with improved patient outcomes. They found that the physician's use of patient-centered care was associated with the patient's perception that the doctor understood his or her concern, and with the perception that his or her concern had been resolved.

In a study of patient-centered care in diabetes management, Kinmonth et al. (1998) implemented a training program in patient-centered communication for nurses and

general practitioners working in southern England. They found that patients whose providers had completed the training were more satisfied with their communication with their doctors and had greater satisfaction with treatment than the patients in the comparison group. However, patients whose providers had completed patient-centered care training had higher body mass indices and higher triglyceride levels. Kinmonth et al. theorized that these patients' indicators of physical health had not improved despite good communication with their physicians because physicians, in their desire to make a positive connection with their patients, had not been as confrontational as usual in addressing issues such as diet, exercise, and weight loss. In sharing the implications of their study, Kinmonth et al. stressed that focusing on patients' psychological well-being should not preclude discussion of important health and preventive behaviors with patients.

Bechel, Myers, and Smith (2000) examined the implementation of patient-centered care in the inpatient setting. They defined patient-centered care using the Picker Institute dimensions. Using data from 20 acute care hospitals in Michigan, they determined that patient-centered care was significantly associated with better patient outcomes in terms of mortality and complications. However, patient-centered care was also associated with increased costs of providing care. Bechel et al. suggested, however, that these increased inpatient costs might be compensated for later in the care process, as more healthy patients required less outpatient follow-up in the community following their hospitalizations.

Stewart et al. (2000) examined the association of patient-centered communication in outpatient encounters with health outcomes and patients' perceptions of their health

status. They found that adherence to expectations of patient-centered care was associated with improved health status and increased efficiency in the care encounter. Patients who felt that they had been treated in a patient-centered manner during the encounter with the family physician tended to have fewer follow-up tests ordered for them and fewer referrals to other providers.

Little et al. (2001b) explored the impact of patients' perceptions of patient-centeredness on their experiences of enablement, satisfaction, and reduction of symptom burden in primary care consultations. They found that patient-centered practices led to a greater sense of enablement, satisfaction, and reduction of symptom burden. Use of patient-centered practices was also associated with a lower rate of referrals.

Mead and Bower (2002) reviewed the literature on patient-centered communication in primary care consultations and patient satisfaction outcomes. They found eight studies which evaluated the patient-centeredness of primary care physicians' communications, and they concluded that the link between patient-centered communication styles and patient satisfaction was weak. There did not appear to be much of a relationship between the degree of patient-centeredness in the physician's consultation with the patient and the patient's level of satisfaction with the visit.

Mead, Bower and Hann (2002) conducted a study in which they used the Roter Interaction Analysis System to assess the degree of patient-centeredness of 173 videotaped general practitioner consultations. The Roter Interaction Analysis System is a coding scheme for analyzing the empathy and responsiveness in physicians' communications to patients. They sought to discover whether there was an association between a patient-centered consulting style and patient satisfaction and enablement.

They found that patient-centered behaviors on the part of the physician did not predict satisfaction or patient enablement.

Patient-centered communication with breast cancer survivors was studied by Mallinger, Griggs & Shields (2004). They examined breast cancer survivors' experience with information and education provided by their oncologists, and they found that patients' perceptions of patient-centered behavior were strongly associated with satisfaction with information provided, both about treatment and about cancer survivorship.

Ciechanowski and Katon (2006) undertook a qualitative exploration of the patient-provider relationship in diabetes care. In their study, patients with fearful attachment styles reported that providers' patient-centered behaviors helped them to trust the care process more and to participate more fully in the patient-provider encounter.

The Massachusetts Ambulatory Care Experiences Survey (Safran et al., 2006) sought to examine the contribution of several provider behaviors and organizational features during primary care encounters to perceptions of patient-centered care. They found that organizational access and care integration were organizational characteristics associated with patient-centered care. In addition, provider behaviors such as help making health behavior changes and communicating trustworthiness were associated with a perception of patient-centeredness.

Zandbelt et al. (2007) examined the importance of patient-centered communication by internal medicine physicians. They found that physicians' patient-centered communication was associated with patients' active participation in the health care encounter. Surprisingly, they found that physicians' inhibiting behavior, which was

considered not to be patient-centered, was also positively associated with patients' active participation in the visit. They hypothesized that inhibiting behavior was the physicians' response to patients' increased participation in the visit.

Patient-centered care principles have been associated with a recovery orientation in the rehabilitation of patients with severe physical disabilities (Stineman, Kurz, Kelleher & Kennedy, 2008). Stineman et al. (2008) used a technique called Recovery Preference Exploration to determine the relative significance of a variety of functional activities to people with severe disabilities. RPE enabled the participants to specify which activities were most important to them in their rehabilitation. Stineman et al. concluded that RPE was a patient-centered method for conducting treatment planning and assessment with people in rehabilitation settings.

In a study of patient-centered nursing practices on a bariatric unit, Wolf et al. (2008) found no differences in any of the health outcomes measured between patients in the intervention group and patients in the control group. All patients had good health outcomes on measures such as post-operative complications, falls, or nosocomial infections. Provision of patient-centered nursing care also did not create significant differences in patients' perceptions of quality of care or patients' reports of satisfaction with care received. The authors noted that this may have been because the study was conducted in a Bariatric Center of Excellence, and the quality of care in the control group was most likely quite high as a result.

Radwin, Cabral & Wilkes (2009) explored the relationship of several patient-centered nursing interventions—individualization of care, responsiveness, proficiency, and care coordination—with outcomes for cancer patients. They found that



individualization of care was associated with three desired health outcomes: authentic self-representation, optimism, and sense of well-being. The patient-centered nursing interventions of responsiveness and proficiency were related to subsequent trust in nurses.

### **Empirical Research Using Patient-Centered Care: Conclusions**

The empirical research on patient-centered care indicates that there is a connection between patient satisfaction and patient-centered care practices. The link between patient-centered care and positive health outcomes has been less strongly established. Patient-centered care appears strongly related to empathetic communication between providers and patients. In addition, patients seem to value and prefer patient-centered approaches to communication, treatment planning, and care provision, even when strong links to better outcomes cannot be made. This provides one substantial argument for continued use and study of patient-centered care practices in both direct care and programs/policies.

The current observations from research support continued refinement of the concept of patient-centered care as it is used in health services research. They also indicate that approaches to health care that focus on patients' needs and preferences may have value in ways that cannot yet be adequately measured. Further research using patient-centered care as a dependent and as an independent variable may reveal new ways to assess patient-centered care and its impact on health care processes and outcomes. In examining health care policy such as Medicare Part D, the lessons contributed by the existing studies emphasize the importance of communication to patient satisfaction, as well as the role of patient choice in perceptions of empowerment. However, there

continues to be a need to establish stronger links between patient-centered care practices and positive outcomes.

### **Patient-Centered Care as an Evaluation Framework**

Despite the somewhat tenuous relationship between patient-centered care practices and better health care outcomes, patient-centered care is increasingly being used as a framework for the evaluation of health care services. The constructs comprising patient-centered care have been used extensively as a way to evaluate aspects of clinical interventions, such as patient-provider communication, physical comfort of patients, and coordination of clinical services (Picker Institute, 2008). As discussed above, patient-centered care is also commonly used to describe aspects of direct care that emphasize patient empowerment and involvement in decision-making, as well as providers' efforts to honor patients' needs, values, and preferences.

Some recent research suggests that adherence to patient-centered care principles, on both the clinical and system levels, can improve care efficiency and reduce inequities (Radwin et al., 2009; Little et al., 2001b). Patient-centered care has also been associated with higher levels of satisfaction and patient trust (Ciechanowski & Katon, 2006; Zandbelt et al., 2007). The Agency on Healthcare Research and Quality, in their 2009 report on health care quality, connected the use of patient-centered care with a variety of positive health outcomes, particularly reduction in symptoms of illness (AHRQ, 2009). Delbanco (1995) has also described the ethical responsibility of providers to listen to patients and consider their concerns foremost. In a line of reasoning similar to Delbanco's assertion, Schauer et al. (2007) have stressed the importance of client-

centered approaches to the values systems of health care providers and have emphasized the need to evaluate services on the basis of client-centered care principles.

The Picker Institute (2008) has pioneered the use of patient surveys in health care settings that not only assess patient satisfaction with services, but also measure the occurrence of certain health care practices that embody patient-centered care. The Picker Institute has stressed the importance of measuring specific practice behaviors rather than simply asking patients whether they are satisfied. Global satisfaction surveys frequently report highly positive results; however, when patients are asked whether their health care providers helped them in certain ways, the results are quite different (Picker Institute, 2010).

The Institute of Medicine, in its report, *Crossing the Quality Chasm*, identified patient-centered care as an important criterion for evaluating health care (IOM, 2001). The 2001 IOM report includes patient-centeredness as one of its “six aims for improvement” in the health care system (IOM, 2001, p. 41). The IOM report places an especially strong emphasis on individual choice and decision-making as a part of patient-centeredness. In addition, the importance of tailoring care to meet the needs of the patient, rather than the preferences of the provider, is stressed. The IOM emphasized patient-centeredness not only in its 2001 *Quality Chasm* report, but also in its 2006 report on quality in substance use and mental health care (IOM, 2006).

The International Alliance of Patients’ Organizations has embraced the adoption of patient-centered health care as one of its goals (IAPO, 2008). IAPO emphasizes the importance of collaboration between patients and health care providers at all levels. IAPO is a coalition of health care consumer organizations from around the world,

representing many different conditions, such as cancer, diabetes, epilepsy, and other serious health diagnoses. IAPO has promoted the adoption of patient-centered care principles, including patient involvement in the formulation of health care policy, as a way to evaluate the success of the health care system (IAPO, 2007).

The Agency for Healthcare Research and Quality (AHRQ) has used patient-centered care for the past five years in its report on the quality of U.S. health care (AHRQ, 2005-2009). AHRQ has adopted patient-centered care as one of its leading indicators of health care quality. Patient-centered care has assumed enough importance in the AHRQ's definition of quality that patient-centered care data has been given its own chapter in the National Health Care Quality Report for the past several years (AHRQ, 2006-2009). According to the AHRQ, patient-centered care encompasses a variety of characteristics. One of these is patients' experience of care, which primarily centers on the patient's ability to communicate effectively with the provider. AHRQ also evaluates care coordination, integration of information, and continuity of care transitions as components of its patient-centered care definition (AHRQ, 2009).

### **Broadening Our Concept of Patient-Centered Care: The Patient-Centered Program**

The idea of patient-centered care has been used mostly as a measure of clinical care. Some of the aspects of patient-centered care, as described by Gerteis et al. (1993) and as described by some other patient-centered care definitions, are particularly focused on transactions between the health care provider and the patient. These include emotional support and physical comfort, for example. However, there are a number of attributes of patient-centered care that can be used to evaluate health care programs and

systems. Some of the definitions of patient-centered care described in Table 2.1 are especially concerned with the application of patient-centered care to health care programs, such as Shaller (2007) and Saha et al. (2008). Many of the conceptualizations of patient-centered care include ideas that are applicable to health care programs. Some of these ideas are as follows:

- **Accessibility.** As a clinical attribute, accessibility largely concerns being able to see a provider at the time and place that are most convenient to the patient. As a program attribute, accessibility can include affordability of care, as well as access to customer service in a timely manner (Gerteis et al., 1993; Berry et al., 2003; Shaller, 2007).
- **Care coordination.** Individual providers play a role in coordinating care, but care coordination can also be supported by efficient structuring of health care programs to support communication between providers and smooth “hand-offs” between services (Graham Center, 2007; Saha et al., 2008).
- **Involvement of the patient.** This can include shared-decision making in clinical situations, and it can also include the provision of a variety of care options and control given to the patient to make the choice among those options. It can also mean that patients have a meaningful role in policy-making (Mead & Bower, 2000; Bergeson & Dean, 2006; Radwin et al., 2009).
- **Information and education.** In addition to provision of information to patients about treatment options, information and education can include provision of information about how health care systems and programs work, so that patients

can use those programs most effectively and efficiently (Bechel et al., 2000; IOM, 2001).

- Secure transitions. As with coordination of care, secure transitions can involve “micro”-level clinical transitions, as well as structuring health care systems so that patients can move seamlessly from one program to another (Gerteis et al., 1993; Berry et al., 2003).

The concept of patient-centered care has changed expectations in a number of health care professions regarding the way that providers should communicate with patients about their care. This has led to more meaningful informed consent, greater trust and comfort on the part of patients, and more open communication between providers and patients (Schauer et al., 2007; Ciechanowski & Katon, 2006). The principles of patient-centered care can also be applied on a broader scale, to make the provision of health care in particular programs and systems more humane and centered on the needs and values of the patient. Even in a large bureaucracy like the Medicare program, principles of patient-centered care can aid our understanding of how this system can be improved for the benefit of patients.

### **Application of Patient-Centered Care to the Medicare Program**

Prior research on the Medicare program has examined some of the characteristics of patient-centered policy as they apply to the Medicare benefit. Researchers have examined the decision-making of Medicare beneficiaries as they use their values and preferences to choose specific plans. In addition, the role of Medicare patient informational and educational materials has been examined. The Access to Benefits

Coalition (ABC) has examined the impact of “person-centered outreach” approaches specifically related to Part D enrollment (ABC, 2006).

One application of the notion of patient-centered care to the Medicare program can be seen in research concerning the decision-making process of health insurance consumers when it comes to selecting health plans. Much of this literature emphasizes the importance of cost in beneficiaries’ choice of plans (Scanlon, Chernew, & Lave, 1997). However, there is some evidence to suggest that beneficiaries of public health insurance programs such as Medicare and Medicaid have somewhat different priorities than those who are privately insured. In particular, Medicare and Medicaid beneficiaries are quite concerned with access and convenience associated with their health plans—factors such as geographical location of plan providers and having a wide choice of plan providers matter much more to Medicare and Medicaid beneficiaries than they do to those who hold private insurance policies (Farley Short et al., 2002). In addition, other research suggests that in a health care environment dominated by managed care strategies, non-cost factors will become increasingly important in all consumers’ choices of health insurance products (Scanlon et al., 1997). This suggests that patient-centeredness is most likely a very relevant construct in Medicare beneficiaries’ prioritization of Part D plans. Accessible information about plan choices and provider locations contributes to patient-centered policy.

Another aspect of Medicare policy in which concerns about patient-centeredness are very relevant is in the quality of information provided to Medicare beneficiaries. Harris-Kojetin et al. (2001) and McCormack et al. (2001) examined the impact of Medicare information materials, such as the *Medicare and You* booklet and the booklet

describing the Medicare version of the Consumer Assessment of Health Plans Survey (CAHPS), on elderly and disabled Medicare beneficiaries' perceptions of the benefit. Both of these studies found that beneficiaries valued these materials, and McCormack et al. (2001) found that having these materials helped beneficiaries to feel more confident in their health plan choices. These informational materials support patient-centeredness in the delivery of the Medicare program, although dually-eligible and disabled beneficiaries did report in some cases that they would have appreciated more information about how the Medicare and Medicaid programs coordinate benefits (Harris-Kojetin et al., 2001).

As mentioned above, the Access to Benefits Coalition has found that outreach programs seeking to enroll vulnerable beneficiaries in the Part D low-income subsidy programs are more efficient and effective when they take a “person-centered” approach. This includes collaborating with individuals and organizations that are trusted by the beneficiary, as well as providing one-on-one counseling regarding eligibility and providing access to enrollment in other needs-based programs for which the beneficiary may be eligible (ABC, 2006).

Patient-centered care can be a useful conceptual framework for considering the impact of Medicare prescription drug policy. Accessibility, information and education, and coordination of care are all relevant to Medicare policy in general, as well as to the operation of Medicare Part D.

### **Goals of this Research**

This study will use the dimensions of patient-centered policy outlined above as a framework for evaluating the impact of the Medicare prescription drug benefit on the lives of an important subgroup of beneficiaries: adults with serious mental illness.



Information from the Centers for Medicare and Medicaid Services, as well as the lived experiences of Medicare stakeholders, can provide a window into the workings of Medicare Part D “through the patient’s eyes” (Gerteis et al., 1993). An assessment of the degree of patient-centeredness of the Medicare Part D program can contribute to our understanding of beneficiaries’ experiences with the program and provide direction to health care reform efforts based on that understanding.

It is important to explore the extent to which the Medicare program is patient-centered because the Medicare program serves some very vulnerable beneficiaries: senior citizens and people with disabilities. These beneficiaries may not be as well-connected in the community as non-disabled adults, so it may be harder for them to get what they need from their health care benefits. Also, seniors and people with disabilities are likely to have a number of medical and mental health co-morbidities which makes it particularly important for them to be able to get the drugs they need. They are more likely to have chronic concerns for which ongoing pharmaceutical treatments are especially important. Psychiatric issues, in particular, may require careful medical follow-up and attention to the appropriate pharmaceutical treatment, as Huskamp et al. (2007) state that psychotropic medications are not as “therapeutically interchangeable” as medicines for other conditions (p. 308).

Donohue (2006) points out that “The extent to which Medicare beneficiaries benefit from the new drug benefit will depend on the previous sources of coverage, level of drug spending, and specific characteristics of the plan they choose” (p. 717). This study will examine the important “specific characteristics” of these plans and their contribution to

patient-centeredness, and it will explore their priority among adults with mental illness and their case managers.

## **CHAPTER III: OVERVIEW OF RESEARCH DESIGN AND METHODS**

### **Introduction**

This chapter provides a detailed description of the design and procedures used in this study. The conceptual framework of patient-centered care and its application to health care programs is reviewed. The overall study design and rationale are outlined. Qualitative methods are described, including topics to be considered in data collection, as well as procedures to be followed. The methods used for collecting and evaluating plan comparison data are provided, along with a description of the procedure for integrating and triangulating qualitative and plan comparison information. The chapter concludes with a summary of the research questions.

### **Conceptual Framework: Patient-Centered Programs**

There are five main principles of patient-centered care that can be used on a more “macro” level—that apply to health care programs. As reviewed earlier, they are accessibility, care coordination, involvement of the patient, information and education, and secure transitions. These principles can be used in both qualitative explorations of stakeholders’ experiences as well as examination of plan performance data. These principles of patient-centered care form a useful framework for the evaluation of health care programs such as Medicare Part D because they provide insight into patients’ perspectives on the functioning of the program.

### **Design**

This study sought to determine not only whether Medicare stakeholders were satisfied with the Part D program, but also reasons why they were or were not satisfied. In order to accomplish this goal, methodological triangulation was employed (Speziale &

Carpenter, 2007). Methodological triangulation involves using more than one research methodology to explore a particular question; for example, employing both a qualitative research approach and a quantitative approach (Bernard, 2002). The purpose of triangulation is to increase the validity and reliability of study findings. It is thought that if qualitative and quantitative methods yield similar answers to a research question, the results are more trustworthy (Bernard, 2002).

First, the lived experiences of Medicare stakeholders were explored using focus groups and key informant interviews. Data about stakeholders' perceptions of the Medicare prescription drug benefit were gathered, allowing beneficiaries and their community helpers to speak for themselves. The methodology of phenomenological analysis was used to collect the focus group and interview data (Padgett, 2008). Phenomenological analysis emphasizes learning through direct observation and the description of reality through words rather than numbers (Bernard, 2002). The researcher is trying to see reality "through another person's eyes" (Bernard, 2002, p. 23). This approach was used in an attempt to understand stakeholders' experiences with and feelings about Medicare Part D. It also fits well with the patient-centered conceptual framework of the study, in which health care is examined "through the patient's eyes" (Gerteis et al., 1993).

In addition to the qualitative component of this study, plan comparison data from [www.medicare.gov](http://www.medicare.gov) and the Centers for Medicare and Medicaid Services were examined to compare the degree of patient-centeredness of the various low-income-subsidy-covered (also known as "benchmark") plans available in the St. Louis, Missouri area.

The findings from different data sources and methods serve to reinforce one another and give confidence to the study results (Speziale & Carpenter, 2007).

Following the collection of these data, the experiences of Medicare stakeholders were analyzed according to their relevance to various principles of patient-centered care. The perspectives of beneficiaries and community helpers were examined to see which aspects of patient-centered care were most important in their assessment of the Medicare program, and to evaluate how well the Medicare prescription drug benefit met expectations of a patient-centered program. The approach of content analysis—examining focus group transcripts to detect the presence of certain salient themes and ideas—was used to analyze these results (Bernard, 2002).

Plan comparison data were triangulated with the qualitative data. The principles of patient-centeredness identified as most critical in the qualitative inquiry were used to evaluate performance data on the six benchmark plans. Plan comparison data were used to affirm the lived experiences of Medicare stakeholders (Padgett, 2008), to see whether benchmark Part D plans possessed the characteristics of patient-centeredness that stakeholders viewed as most important.

The conceptual framework of patient-centered care (Gerteis et al., 1993) was used to guide the analysis, but the exploration of the data was not limited to patient-centered care concepts. A content analysis approach was used, in that the investigator explored presence of themes related to patient-centered care; however, codes were not imposed upon the data prior to analysis. The investigator attempted to allow the data to speak for themselves in the collection, coding, and analysis processes (Speziale & Carpenter, 2007). The investigator familiarized herself with principles of patient-centered care prior

to data coding, but during the process of data coding and analysis, she let the voices of the stakeholders guide her.

### **Qualitative Methodology**

In this study, focus groups and key informant interviews were used to obtain qualitative data from participants. Focus groups are facilitated group discussions, generally consisting of between four and ten participants. The facilitator asks questions of the group dealing with a focal topic, and discussion of the topic among group members is encouraged (Bernard, 2002). Focus groups were chosen as the main method of data gathering because the investigator wished not only to discover stakeholders' opinions about the Medicare prescription drug program, but also to understand the reasons why they held those opinions. The methodology of focus groups allowed stakeholders to talk with one another about their perspectives.

Key informant interviews were also used with two Medicare beneficiaries. These beneficiaries were seen as articulate, well-informed individuals with well-thought-out opinions on the Medicare Part D program (Bernard, 2002). They were not available to participate during the scheduled focus groups, but they volunteered their perspectives, so the investigator chose to interview them separately and include their contributions in the qualitative data that were gathered.

Qualitative methods have not been used often to examine the Medicare Part D program. Two focus group studies of the Part D program have been conducted in the past six years. The first, conducted by researchers affiliated with the Kaiser Family Foundation (Perry, Kitchman, & Guyer, 2005), was not a study of the Part D program itself, but rather explored the opinions and perspectives of dually-eligible Medicare

beneficiaries regarding the impending implementation of the Medicare prescription drug program. In this study, one focus group was conducted specifically with dually-eligible beneficiaries who had mental health-related disabilities. The other focus group study of Medicare Part D was a study of access-related issues related to Part D conducted for the Medicare Patient Advisory Commission by researchers at University of Chicago and Georgetown University (Hargrave et al., 2008). This study included focus groups with beneficiaries, physicians, and pharmacists.

The Kaiser Family Foundation has sponsored two projects conducting qualitative interviews of Part D stakeholders. The “Voices of Beneficiaries” project (Kaiser Family Foundation, 2005; Kaiser Family Foundation, 2006; Perry, Dulio & Cubanski, 2006; Dulio, Perry & Cubanski, 2007) interviewed several dozen Part D beneficiaries, ten of whom were dually-eligible for Medicare and Medicaid, about their opinions and experiences related to Part D. They interviewed beneficiaries in Lincoln, Nebraska; Baltimore, Maryland; Sacramento, California; and Miami, Florida and produced four qualitative reports detailing the responses of the interview participants. These interviews were mostly conducted by telephone, though some were in person. The Kaiser Commission on Medicaid and the Uninsured (Buchsbaum et al., 2007) also sponsored an interview study of “key informants”: health care and social service providers as well as community leaders who had experience in working with dually-eligible beneficiaries.

A qualitative approach is particularly useful in examining the Medicare prescription drug benefit because it goes beyond the story told by pharmacy claims data and beneficiary surveys to explore experiences and opinions of stakeholders. The objective pursued in the qualitative component of this study was to give voice to stakeholders—

particularly those with mental illness and their helpers—regarding their perceptions of Medicare Part D.

### **Sampling Strategy**

As mentioned above, the qualitative component of this study consisted of a series of focus groups and key informant interviews conducted with Medicare Part D stakeholders. The purpose of the qualitative component was to obtain in-depth narrative information about stakeholders' perceptions of the degree of patient-centeredness in the Part D program. Focus groups were used in order to obtain the opinions of a range of people, to understand the factors that influence these opinions, and to generate new ideas (Krueger & Casey, 2000). Key informant interviews were used to gather information from stakeholders who had difficulty making time to attend a focus group. The focus groups and interviews were used to generate new ideas related to the application of patient-centered care principles to health care policies. The value of focus groups in eliciting viewpoints of health care stakeholders, and in reducing the distance between consumers and policy-makers, has been discussed by Delbanco et al. (2001). Rauktis, Feidler, and Wood (1998) have discussed the role that focus groups can play in evaluation of programs for people with mental illness. They discuss the fact that focus groups can be helpful in obtaining information about reasons why consumers are satisfied with particular programs (Rauktis et al., 1998). Though focus groups are often used in marketing and business settings, they have been increasingly utilized in social research on a variety of topics (Bernard, 2002).

Mental health agencies from which participants were recruited were selected because they provided in-depth case management services to a population of adults with



serious mental illness. These agencies also serve a large number of adults with low incomes, who use both Medicare and Medicaid to obtain their health care. This led to the ability to conduct an intensive exploration of the phenomenon of Medicare Part D utilization (Ulin, Robinson, & Tolley, 2005).

To learn the perspectives of Medicare beneficiaries with mental illness, six focus groups and two key informant interviews were conducted at three community-based mental health agencies. Two focus groups and one key informant interview were conducted at Agency A, a non-profit agency in the City of St. Louis that provides housing, psychosocial rehabilitation, integrated dual-disorders treatment, and assertive community treatment to adults with severe mental illness. One focus group and the interview were conducted at the Agency A club house. The other Agency A focus group was conducted at an assisted-living facility operated by the agency. Two focus groups were held at the headquarters of Agency B, a non-profit agency in the City of St. Louis that provides case management, integrated mental health and chemical dependency treatment, and assertive community treatment. Two focus groups and one key informant interview were held at Agency C, a non-profit agency in the City of St. Louis that provides supported employment services, psychosocial rehabilitation, and case management, as well as other mental health services. The groups and interview at Agency C were held at the agency's main headquarters, which houses the agency's club house program.

Community support workers' and nurses' perspectives were also important to this project. Community support workers and nurses were recruited through Agency A and Agency C. One focus group was held at Agency C, and two were held at Agency A.

One community support worker focus group was held at Agency C's headquarters. One community support worker-nurse case manager group was held at Agency A's assisted-living facility. The other community support worker focus group was held at the headquarters of Agency A.

### **Inclusion Criteria**

Qualitative data were gathered from two different groups of Medicare stakeholders. Stratified sampling was used to conduct focus groups of Medicare beneficiaries with mental illness and of community support workers who serve adults with mental illness.

First and foremost, it was important to obtain information about beneficiaries' experiences with the prescription drug benefit. Individuals with mental illness were recruited for these groups by word-of-mouth and through flyers posted at the agencies. In addition, at Agency A and Agency C, the investigator gave brief research presentations to clubhouse members to provide information about the study and encourage clubhouse participants to sign up for the groups.

Community support workers and nurse-case managers also play an important role in assisting individuals with mental illness to use Part D (Mishler, 2009). Community support workers and nurses were recruited for focus groups via word-of-mouth and through informational flyers distributed at the agencies. At Agency A, two team leaders volunteered their community support teams to participate in groups. At Agency C, community support workers and team leaders responded to information made available at the agency. Although groups were open to both community support workers and to

nurse-case managers, the groups are referred to as community support worker (CSW) focus groups, as only one nurse-case manager participated.

**Inclusion criteria for each stakeholder group.**

To participate in the study, Medicare beneficiaries needed to be clients of the participating agencies. In addition, they were required to be their own legal guardians, and they had to be beneficiaries of both the Medicare and Medicaid programs. A brief assessment of each Medicare beneficiary's cognitive capacity to complete the interview was conducted before the focus groups began.

Community support workers and nurse-case managers had to be employed by the agency hosting the focus group in order to participate. They were also required to be engaged in a direct practice capacity with adults with mental illness.

**Data Collection**

**Protection of human subjects.**

All study procedures related to collection of the qualitative data were reviewed and approved by the Washington University Human Research Protection Office. The Institutional Review Board of Agency A also approved the study procedures. The clinical directors at Agency B and Agency C gave approval for collection of qualitative data at their agencies. The Washington University Human Research Protection Office waived written consent for this study because the written consent form would have been the only document identifying participants by name. Verbal consent was obtained from all participants at the time that demographic information was collected. In addition, the investigator conducted a brief assessment of each participant's cognitive capacity prior to the start of each focus group and interview. A study information sheet was provided to

each participant outlining the kinds of information that would have been in a consent form, and the requirements of study participants were explained to all group members and interviewees. Refreshments (cereal bars, granola bars, and cookies) were served to focus group and interview participants. All focus group and interview participants were offered a \$10 gift card to a local grocery store to thank them for their participation.

The digital voice recorder containing focus group and interview recordings, hard copies of study transcripts, and demographic data sheets were stored in a locked file cabinet in a locked office at the George Warren Brown School of Social Work.

### **Focus groups and interviews.**

Focus groups and interviews were held in a variety of settings at the participating agencies. At Agency C, the focus groups and the interview were held in conference rooms at the agency headquarters. At Agency A's assisted-living facility, focus groups were held in the group home office and in the living room of the group home. At Agency A's headquarters, the consumer focus group was held in a conference room, the consumer interview was held in the clubhouse, and the CSW focus group was held in the community support team office. At Agency B, both consumer focus groups were held in an agency conference room. Due to resource constraints, the investigator conducted all focus groups and interviews by herself.

Demographic information on race/ethnicity, gender, educational level, and zip code of residence was collected. Twenty-nine of the 31 consumer participants provided all demographic data requested. All fifteen of the CSW/nurse case manager participants provided all demographic data requested.

Focus group questions addressed stakeholders' perceptions of various attributes of Part D plans, particularly those attributes which are relevant to the Picker Institute definition of patient-centered care. Examples of focus group questions that were used include the following.

Table 3.1. Focus Group Questions by Stakeholder Group

	Consumer	Community Support Worker/Nurse Case Manager
Transition from Medicaid to Medicare Part D	How did your health care change when you switched from Medicaid drug coverage to Medicare?	How did your work with clients change when dually-eligible clients were switched from Medicaid to Medicare Part D?
Respect for patients' needs	How well does your Medicare prescription drug insurance meet your needs for prescription medicine?	How well is the Medicare Part D program meeting the medication needs of your clients?
Availability of choices	How would you describe your prescription drug insurance in terms of the choices it offers you?	
Comprehensiveness of coverage	How would you describe your prescription drug insurance in terms of the coverage that it offers? (Probes: for example, how are the copayments? How are the premiums?)	How comprehensive is the Medicare Part D benefit in covering the medications needed by your clients?
Sources of information	What is your main source of information about your prescription drug insurance?	What is your main source of information about Medicare?
Communication with beneficiaries	How does your prescription drug insurance plan communicate with you? (Probes: do you receive written communication, telephone calls, e-mails?)	How could Medicare Part D plans communicate more effectively with their beneficiaries?
Coordination of benefits		How well-coordinated is Medicare Part D with other health care programs? (such as Medicare A and B; Medicaid)

Services and supports provided to beneficiaries	What kind of help have you received in using your prescription drug insurance?	What kind of help do you provide to your clients in using their Medicare Part D benefits?
Becoming more patient-centered	How could the Medicare prescription drug program be more patient-centered? How would Medicare drug coverage change if it became more patient-centered?	How could the Medicare prescription drug program be more patient-centered? How would Medicare drug coverage change if it became more patient-centered?

Focus groups ranged in length from 45 minutes to one hour; key informant interviews ran from 30 to 45 minutes. The length of each group was somewhat shorter than the usual length for a focus group; this occurred for a number of reasons. First of all, groups and interviews with consumers were kept somewhat shorter than usual to accommodate the energy levels and attention spans of participants with thought disorders (Rauktis et al., 1998). Focus groups with CSWs were kept short because groups were held in conjunction with team staff meetings, and the amount of time that these case managers were willing to allot to a research project was limited. It was determined that it was better to facilitate a short focus group than not to collect the data at all.

In the process of data collection, the investigator sought to obtain an “insider” point of view on Medicare (Padgett, 2008). Questions were formulated to go inside of stakeholders’ experiences and understand the benefit from their viewpoint. Patient-centered care concepts were used as an organizing principle, but narratives of stakeholders’ experiences were sought in the focus groups and interviews. The investigator was partially successful in achieving this “insider” perspective. In several of the focus groups, participants “warmed up” to the investigator after several introductory questions and assurances of confidentiality. Information shared in the groups tended to

become more detailed as the groups progressed. Participants were encouraged to share detailed examples of their own experiences, and many chose to do so. The investigator observed that she was able to gain a greater insider viewpoint when talking to community support workers, as these participants knew that the investigator had once worked in a community mental health setting in a position similar to their own. Community support workers appeared eager to share “war stories” about the Medicare prescription drug benefit, whereas beneficiaries for the most part expressed few complaints.

### **Data Entry and Management**

Interviews and focus groups were recorded using a small digital voice recorder. The digital voice recorder was stored in a locked file cabinet in a locked office at the George Warren Brown School of Social Work. The investigator transcribed all interviews and focus groups *verbatim*. Following the transcription of interviews and focus groups, all transcripts were entered into the NVivo data management program (QSR International, 2009). Transcripts were coded using a strategy of phenomenological analysis (Padgett, 2008). Sorrell and Redmond (1995) have discussed the use of small group interviews to obtain “pictures” of the lived experiences of participants (p. 1120). Consumer and CSW transcripts were coded separately to allow each stakeholder group to speak for itself. Recurrent, salient, words and ideas were identified throughout the transcripts and coded and sorted accordingly (Morse & Field, 1995). Codes were then grouped into major themes for each stakeholder group.

### **Collection of Plan Comparison Data**

The sources of data for comparison of the six benchmark Part D plans were the [www.medicare.gov](http://www.medicare.gov) Web site and the Part D performance report card data from the

Centers for Medicare and Medicaid Services. The [www.medicare.gov](http://www.medicare.gov) Web site has been used in previous research on Medicare Part D formularies; Tseng et al. (2007) used [www.medicare.gov](http://www.medicare.gov) to obtain information about drug coverage variation among Part D plans. They used the information obtained from the Web site to evaluate the proportion of Part D plans in California and Hawaii that covered certain commonly-prescribed medications. They noted that abstracting these data from the Medicare Web site took a considerable amount of effort but made no comments about advantages or disadvantages of using the prescription drug plan finder. Davis et al. (2007) also used the Formulary Finder to obtain information about coverage of medications by different Part D plans; they used the information to compare the generosity of Part D coverage among various states. Domino et al. (2008) used the Formulary Finder on the Medicare Web site to estimate changes in prescription drug costs for non-dually-eligible beneficiaries over the course of a typical year. They also made mention of the fact that using the Formulary Finder to abstract data about plan coverage was time-consuming. Joyce et al. (2009) used the [www.medicare.gov](http://www.medicare.gov) Web site to abstract information about formularies and out-of-pocket spending for beneficiaries after their first two years in the program.

Researchers from the Kaiser Family Foundation have also used the prescription drug plan finder on the Medicare Web site to obtain information on covered medications and the use of utilization management tools in the formulary coverage of Part D plans (Hoadley, Hargrave, Cubanski & Neuman, 2008).

Data were abstracted from the Medicare Web site by entering the names of prescription medicines into the Formulary Finder and obtaining information about the coverage and use of utilization management by each benchmark plan. This was an



important exercise not only because it provided data about each plan's formulary, but also because it approximated the process that the Centers for Medicare and Medicaid Services expects Medicare Part D beneficiaries to go through each year when they are choosing a Part D plan. As noted by several of the other researchers who have used the Formulary Finder to inform their studies, it is a time-consuming and cumbersome process.

The Part D performance data are publicly available in an Excel spreadsheet that can be downloaded from the CMS Web site. The performance data are collected by CMS during their monitoring activities; they are not reported by Part D plans. Plan ratings are released each fall by CMS (Lee-Martin, personal communication, 7/27/09). This Medicare Part D "Report Card," as it is called, has not been used in Part D published research. It is used by the Centers for Medicare and Medicaid Services for their monitoring of Part D plans. Plans that receive low ratings on the performance criteria may receive follow-up attention from CMS or be required by CMS to improve their ratings (Lee-Martin, personal communication, 7/27/09). The published research studies on Medicare Part D tend to use pharmacy claims data (for example, Yin et al., 2008; and Lichtenberg & Sun, 2007) or to use other national surveys of Medicare beneficiaries, such as the Medicare Current Beneficiary Survey (Madden et al., 2008). For the purposes of these studies, claims data and survey data are appropriate because the studies are examining characteristics of individual Part D beneficiaries and their utilization of prescription medications. For this study, Medicare Part D performance data are appropriate because they contain information on beneficiary satisfaction with Part D plans, on the level of the Part D plans themselves. The Part D performance data contain

up-to-date, accessible information on a variety of aspects of consumer satisfaction with Part D plans. Since this study is evaluating plans, the performance data are at the right level of analysis.

Formulary and utilization management information was abstracted from the [www.medicare.gov](http://www.medicare.gov) Formulary Finder in August, 2009. Plan comparison data from the Centers for Medicare and Medicaid Services Part D Performance Data were downloaded from the CMS Web site in July, 2009.

### **Plan Comparison Data Sampling Strategy**

The six benchmark plans in the St. Louis, Missouri area whose premiums were fully-covered by the low-income subsidy in 2009 will be examined. These are: Aetna Medicare Rx Essentials, Community CCRx Basic, First Health Part D – Premier, HealthSpring Prescription Drug Plan – Reg 18, Medco Medicare Prescription Plan – Value, and Medicare Rx Rewards Standard. These plans were identified using the [www.medicare.gov](http://www.medicare.gov) Plan Finder.

The State of Missouri will be used because Missouri has had a reasonably generous drug benefit under Medicaid, and because Missouri has a variety of low-income-subsidy-eligible Part D plans from which beneficiaries can choose. Missouri is also the site of this research because of the feasibility of collecting qualitative data on stakeholders in the St. Louis region.

### **Variables**

Data on the various Part D plans were obtained from the Centers for Medicare and Medicaid Services and the [www.medicare.gov](http://www.medicare.gov) Web site. The purpose of the quantitative analysis was to examine attributes of Medicare prescription drug plans that contribute to

patient-centeredness. Plans were compared on five attributes to determine which plans were more or less patient-centered. Each attribute corresponds with one of the identified dimensions of patient-centered care. Attributes include formulary inclusiveness, implementation of utilization management tools, beneficiary perception of plan information, rate of plan complaints, and rate of complaints about plan switching. A percentage or rate was calculated for each attribute of each plan.

Table 3.2. Part D Plan Attributes

Attribute	Dimension of Patient-Centeredness	Attribute Definition	Attribute Score	Source of Information
Formulary inclusiveness	Respect for patients' values, preferences, and expressed needs	What percentage of the drugs in Huskamp et al.'s (2007) list of psychotropic medications does the formulary include?  (15 anticonvulsants; 19 antidepressants; 12 atypical antipsychotics)	Percentage of medications included in the formulary	<a href="http://www.medicare.gov">www.medicare.gov</a>
Implementation of utilization management tools	Access to care	What percentage of the drugs in the Huskamp et al. list require the use of utilization management tools such as prior authorization, quantity limits, or step therapy to be covered by the plan?	Percentage of medications that require utilization management tools	<a href="http://www.medicare.gov">www.medicare.gov</a>
Rate of complaints about the drug plan benefits and access to prescription medications	Coordination and integration of care	What is the rate of complaints about drug plan benefits and access to prescription medications that have been lodged with the Centers for Medicare and Medicaid Services?	Rate of plan complaints per 1,000 beneficiaries	Centers for Medicare and Medicaid Services
Drug plan's ability to provide information or help when members need it	Information, communication, and education	What is the percentage of plan members who feel that the drug plan has provided them with the information and help they have needed?	Percentage of plan members who report that their drug plan has provided them with information or help when they have needed it	Centers for Medicare and Medicaid Services

Rate of complaints about plan switching	Continuity and secure transitions	What is the rate of complaints lodged with CMS about joining or leaving specific prescription drug plans?	Rate of complaints per 1,000 beneficiaries	Centers for Medicare and Medicaid Services
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For data on the plan formularies, each drug being considered was entered into the Formulary Finder on the [www.medicare.gov](http://www.medicare.gov) Web site to determine whether it was included in the plan formulary. The list of prescription drugs that was used was taken from the Huskamp et al. (2007) article in *Psychiatric Services*, in which the authors used a list of commonly-prescribed psychotropic medications to compare the inclusiveness of Part D formularies. The Huskamp et al. list includes 15 anticonvulsants, 19 antidepressants, and 12 atypical antipsychotics. This list does not include several brand-name and generic medications that were approved by the Food and Drug Administration after the article was published. For example, generic risperidone is now available in many Part D plans, but when the Huskamp et al. article was published, only brand-name Risperdal was available to consumers. This may lead to percentages of drugs covered by plans that do not include medicines recently added or taken out of plan formularies. Some plans routinely remove brand-name preparations from formularies once a generic is approved, so using a list that is two years old may mean that percentages of drugs covered seem unusually low. Other plans may continue coverage of all preparations but use quantity limits or other utilization management tools more extensively with brand-name versions of drugs.

Even so, the Huskamp et al. list comprises a reasonably comprehensive list of psychotropic medications that are prescribed to individuals with chronic psychiatric disorders in three major categories: anticonvulsants (used in mood disorders),

antidepressants, and atypical antipsychotics. Although the rates of covered drugs and rates of drugs affected by utilization management may be slightly different as a result of new brand-name preparations and generics entering the market, the overall picture of drug coverage provided by use of the Huskamp et al. list is fairly realistic and includes almost all drugs commonly prescribed for persons with serious mental illness.

The use of this list also mirrors a real-life problem that many stakeholders face in using the formulary finder. Though beneficiaries are restricted in the number of times that they can change plans, Medicare Part D plans can change their formularies whenever they choose. Keeping up with the rapid pace of changes in plan formularies is difficult even for the savviest beneficiary. Beneficiaries may not know which of their medications are available as generics or may not have the most up-to-date knowledge of new preparations. This makes it difficult to keep track of the many changes in plan formularies that can happen within a short period of time.

The Formulary Finder on the Web also provided information on which drugs required utilization management tools such as prior authorization, step therapy, and quantity limits. Each drug on the Huskamp et al. (2007) list was entered into the Formulary Finder, and the information provided about utilization management tools was recorded into a table. The Formulary Finder provides information about prior authorization, step therapy, and quantity limits. Prior authorization means that the beneficiary must receive special permission from their health care provider before he/she can have a prescription for that particular drug filled. In step therapy, the beneficiary is required to try a lower-cost alternative medication first, and to show that he/she has failed to have a therapeutic response to that medication, before he/she is allowed to fill a

prescription for the more expensive medication. A plan uses quantity limits when it requires a beneficiary to be limited to a certain quantity of the medication per month, such as 30 tablets per month for a medication that is taken once a day.

Two different rates of plan complaints were obtained from the Part D performance data made available by CMS. The first was the rate of plan complaints about drug plan benefits and access to prescription medicines. The other was the rate of complaints about joining or leaving different prescription drug plans. Complaints about drug plan benefits and access to medicines provide information about the patient-centered care attribute of coordination and integration of care. Complaints about joining and leaving prescription drug plans give insight into transition and continuity of care among plans. The percentage of plan beneficiaries who believe they get the information or help they need from their plan has also been taken from the Part D performance data. This helps to determine the plans' adherence to the attribute of information and education for beneficiaries.

### **Methodological Triangulation**

The qualitative and plan comparison findings were obtained sequentially, and focus group and interview findings were triangulated with plan comparison information. For example, qualitative findings related to satisfaction with Part D plans, experiences with formularies, and perception of information and communication from Part D plans were compared with the quantitative data related to these same concepts. This approach was chosen to increase confidence in the results of each method. When two different research methods, such as a qualitative and a quantitative approach, are used together and the results compared, and similar findings are uncovered, the validity of the findings

increases (Bernard, 2002). The investigator examined the plan comparison data for aspects of patient-centered care that appeared most important to Medicare stakeholders. Performance of benchmark Part D plans was assessed using attributes of patient-centered care. This helped the investigator to determine whether Part D plans were adhering to patient-centered care characteristics that mattered most to stakeholders. In the interpretation of the data, findings were merged so that a unified outcome could be achieved (Speziale & Carpenter, 2007).

### **Summary of Research Questions**

Through collection of qualitative and plan comparison data, this study sought to answer three research questions.

Research Question 1: How do Part D stakeholders assess the patient-centeredness of the Medicare prescription drug benefit?

Research Question 2: What elements of patient-centered care are recognized by stakeholders as most critical to an effective prescription drug program?

Research Question 3: How do the “benchmark” plans in one Midwestern state perform on measures of patient-centeredness considered most crucial to stakeholders?

Focus groups and interviews were conducted to determine the attitudes and experiences of Medicare stakeholders regarding the Part D benefit. The qualitative data collection also enabled the author to consider the elements of patient-centered care that stakeholders viewed as most important, and how these elements related to their experiences of the Part D program. By examining plan comparison data, the author was able to take these patient-centered care attributes and apply them to the performance of the six benchmark Part D plans in Missouri in 2009. Assessment of benchmark plans



relative to the most important patient-centered care attributes gave further insight into the adequacy of the Part D program in meeting the needs of beneficiaries with mental illness.

## **CHAPTER IV: RESULTS**

### **Introduction**

In this chapter, results of the qualitative data collection and the quantitative plan comparison data collection are described. For the qualitative data, the results from the focus groups and key informant interviews serve to answer the first two research questions: Research Question 1: How do Part D stakeholders assess the patient-centeredness of the Medicare prescription drug benefit? and Research Question 2: What elements of patient-centered care are recognized by stakeholders as most critical to an effective prescription drug program? These results are organized by first describing the sample, both mental health consumers and community support workers/case managers. Following this, the analytic process is described, and codes for both consumer and community support worker (CSW) data are outlined. Major themes of consumer and CSW data are put forth, along with illustrative quotations from the qualitative data.

Following the presentation of the qualitative findings, quantitative plan comparison data are discussed. These data answer Research Question 3: How do the “benchmark” plans in one Midwestern state perform on the measures of patient-centeredness considered most crucial to stakeholders? The sources of the plan comparison data are described, and the variables to be considered are outlined. This is followed by a description of the questions answered by each variable explored.

## Qualitative Data: Sample Description

### Consumer Focus Groups

There were 29 participants in six consumer focus groups and two participants in key informant interviews that took place over a ten-week period in Fall, 2009. The breakdown of participants in each focus group was as follows:

Table 4.1 Focus Group and Interview Participants

Group/Interview	Participants
Agency A Group #1 9/15/09	3
Agency A Interview #1 9/16/09	1
Agency A Group #2 11/19/09	10
Agency B Group #1 9/9/09	2
Agency B Group #2 9/16/09	4
Agency C Group #1 8/31/09	2
Agency C Interview #1 9/3/09	1
Agency C Group #2 9/8/09	8

### Consumer Demographics

Demographic characteristics were collected on consumer participants.

Participants tended to be middle-aged and older; the youngest participant was 28 and the oldest was 74. The mean age for consumer focus group/interview participants was 51.5. Seventeen (54.8%) of the consumer participants were female, and 14 (45.2%) were male.

All 31 consumer participants reported their race/ethnicity. Nineteen participants (61.3%) were African American. Eight participants (25.8%) were Caucasian; one (3.2%)

was Asian American. Two (6.5%) reported their race/ethnicity as “American,” and one (3.2%) was American Indian.

Table 4.2 Race/Ethnicity of Consumer Focus Group and Interview Participants

<b>Race/Ethnicity</b>	<b>Number</b>	<b>Percentage</b>
African American	19	61.3%
Caucasian	8	25.8%
Asian American	1	3.2%
“American”	2	6.5%
American Indian	1	3.2%
Total	31	100%

Twenty-nine participants reported their educational level. Over half of the participants had a high school education or less; eight (27.6%) had less than a high school education, and eight (27.6%) were high school or GED graduates. Ten participants had taken some college courses (34.5%), two (6.9%) were college graduates, and one (3.4%) had a master’s degree.

Table 4.3 Educational Level of Consumer Focus Group and Interview Participants

<b>Educational Level</b>	<b>Number</b>	<b>Percentage</b>
Less than high school	8	27.6%
High school/GED	8	27.6%
Some college	10	34.5%
College graduate	2	6.9%
Master’s degree	1	3.4%

Missing	2	6.9%
Total	31	100%

Twenty-nine consumer participants reported their zip code of residence.

Consumer participants came from ten different zip code areas, mostly in St. Louis City.

Three participants reported that they lived in St. Louis County. Fourteen of the participants (49.3%) came from 63110 or 63108, which are zip code areas very close to the locations of the community mental health agencies where they were receiving services. Both of these zip code areas contain high percentages of individuals living below the poverty line. In zip code area 63110, 22.2% of residents are living below the poverty line, and 9.6% of residents are living below 50% of the poverty line (“63110 Zip Code Profile,” 2010). In zip code area 63108, 29.4% of residents are living below the poverty line, and 14.2% of residents are living below 50% of the poverty line (“63108 Zip Code Profile,” 2010). This is in comparison to an overall poverty rate in the city of St. Louis of 24.6% in the year 2000 (City of St. Louis CDA, 2005). These numbers are considerably higher than the averages for the entire state of Missouri, which has 13.4% of residents living in poverty and 5.5% of residents living below 50% of the poverty line (“63108 Zip Code Profile,” 2010).

**Community Support Worker Focus Groups**

Three focus groups were conducted with community support workers over a three-month period in 2009-2010. Participants were as follows:

Table 4.4 Summary of CSW Focus Group Participants

<b>Group</b>	<b>Participants</b>
Agency A Community Support Team 1/16/10	5
Agency A Assisted Living Facility Team 1/16/10	4
Agency C Community Support Workers 10/28/09	6

One focus group was conducted at Agency C, with community support workers and team leaders. One focus group was conducted at Agency A’s assisted-living facility, with a team leader, two community support workers, and one nurse-case manager. The last focus group was held at Agency A, with a team leader and community support workers.

### **Community Support Worker Demographics**

In terms of ethnicity, ten community support worker participants were Caucasian, three were African-American, one was Asian, and one, who had emigrated from Germany to the United States, identified herself as “German.” Ten community support workers were female, and five were male. The average age of community support workers was 39.5, with the oldest being 66 and the youngest being 26. Six of the CSW participants reported their residence as being in the City of St. Louis, while nine reported living in suburban areas.

Ten of the CSW participants had master’s degrees, and five had a college education. Nine of the participants did not specify the discipline of their degree. Three

stated that they had degrees in social work; two had graduate degrees in psychology; and one had a bachelor's degree in nursing.

### **Qualitative Results**

Focus group transcripts were analyzed using phenomenological analysis (Padgett, 2008). The goal was to identify themes that would provide insight into stakeholders' experiences with the Medicare prescription drug program. Denzin and Lincoln (2005) discuss the use of focus groups and other qualitative approaches in an applied manner, with the goal of informing public policy and professional practice. The intent was to use the lived experiences of Medicare stakeholders to provide information about the operation of the Medicare prescription drug program in the lives of a very vulnerable group of beneficiaries. The juxtaposition of a phenomenological approach with the use of patient-centered care themes has benefits and drawbacks. Exploring the personal experiences of stakeholders provided rich, detailed knowledge of the workings of the Medicare benefit. Using patient-centered care themes to structure these observations gave immediate practical relevance to the findings and aided in understanding the meaning of stakeholders' experiences. However, by using these constructs to shape observations regarding the data, other themes and experiences may not have been considered. The investigator attempted throughout the data collection and analysis process to hear the voices of stakeholders as they discussed their perceptions of satisfaction and areas of concern related to Medicare Part D.

A content analysis of the focus group data, looking for particularly relevant constructs and themes, was employed (Morse & Field, 1995). Focus group and interview transcripts were entered into NVivo (QSR International, 2009) for coding and analysis.

The transcripts were examined line-by-line for recurring themes and important concepts related to the lived experience of Medicare stakeholders. Community support worker and Medicare beneficiary focus groups were coded separately. However, many codes revealed similar themes across stakeholder groups. For Medicare consumer data, nineteen codes were identified. They are as follows:

Table 4.5 Consumer Data Codes

<b>Data Code</b>
Concerns about health care reform
Co-payments okay
Co-payments not okay
Costs okay
Costs not okay
Dental insurance problems (this relates to a Medicaid cut; it does not relate directly to Medicare Part D but it is on the minds of many consumers)
Formulary problems
Generic drugs okay
Generic drugs not okay
Help from mental health agencies
Help from pharmacists
Information from Medicare helpful
Information from Medicare not helpful
Medicaid spend-down (again, not directly related to Medicare Part D but on the minds of many consumers)
Not satisfied with Part D (General comments related to dissatisfaction with Part D)
Satisfied with Part D
Paperwork
Problems with Medicare Advantage
Problems with utilization management (in Part D plans)

All codes related to consumers' experience with Medicare prescription drug benefits, except for "dental insurance problems" and "Medicaid spend-down." Data



concerning these two codes were identified and coded because these two issues were on the minds of many Medicare consumers and in some cases affected consumers' perceptions of the utility and affordability of the Medicare program.

The analysis attempted to strike a balance between a search for themes that have already proven relevant in other studies of patient-centered care and Medicare and openness to new topics and ideas expressed by focus group participants. The investigator accomplished this by reviewing the patient-centered care literature prior to coding the data, but allowing the coding process to be shaped by themes brought up by participants. Specific patient-centered care principles were mapped onto data codes after the coding process was completed, so that themes would not be limited to principles of patient-centered care.

Data from the CSW focus group transcripts were coded and sorted in a process similar to that used for the consumer data. There was no particular effort made to create codes that were similar to the consumer codes. However, many of the codes share characteristics with consumer codes. Fourteen codes were developed for the CSW data.

Table 4.6 Community Support Worker Data Codes

<b>CSW Data Code</b>
Action on Behalf of Consumer
Communication with Members
Costs Not Okay
Costs Okay
Dealing with Bureaucracy
Health Care Reform
Part D Okay
Pharmacies Helpful
Prescription Issues
Problems with Medicare Advantage
Problems with Physicians
Problems with Switching Plans
Stress for Consumers
Utilization Management

### **Consumer Results**

Consumer data codes have been summarized below in six main categories that appear consistently throughout the coding. Categories were chosen as significant based on the frequency with which that particular theme appeared in the transcripts. Categories are as follows: Overall satisfaction, affordability, paperwork, satisfaction with generic medications, interactions with pharmacists, and interactions with mental health agencies.

#### **Overall satisfaction.**

Overall satisfaction with the Medicare prescription drug benefit was high among beneficiaries. Many interview participants stated, “I don’t have no problems with Medicare.” For example, one participant stated, “So, uh, the Part D...I have (Part D plan) now, and I’m really satisfied with them.” Another participant mentioned, “I don’t have no problems. I’m very happy for me.” Another beneficiary commented, “I guess I’m basically satisfied. Because, I’m thinking it might be just the medication, I take medication for mental health, you know, depression, anxiety, stuff like that, and then I

take the medications for blood pressure, and I guess I could be on more medication, if I didn't try to take care of myself, you know, I could be on heart medications and stuff like that.”

Some participants then went on to describe the processes by which they were able to obtain their medicines, which frequently involved help from a community support worker (CSW), nurse, or pharmacist. One participant mentioned, regarding her plan paperwork, “And, like if I need to go to the offices over any of that stuff, she (community support worker) will let me know, and if she's available, she'll go down there with me; if she ain't, she'll instruct me where to go and stuff like that.”

Beneficiaries themselves did not seem to make the connection that they had few problems because they were receiving a great deal of help, but the help they received was frequently mentioned after they stated that they had few or no problems. As one beneficiary commented, “So really, it's kind of a blessing to have this, because I used to live on the street, and everything like that, until I got on the medicine and got involved with this place (community mental health agency).”

“Having no problems” with Medicare equated with being able to get one's medicines easily and at a low cost, which most beneficiaries were able to do. An interviewee offered the following comment regarding Part D satisfaction: “Well, I get every medication that I need, everything that I'm prescribed by my doctor, by my doctor here (at the mental health agency), or my doctor at my medical doctor's office, every prescription they prescribe, I just take it to the same place, and they fill it. It's no problem.”

Several beneficiaries commented that they could not think of any way that the Medicare prescription drug program could be made any better. For example, “Now, I don’t know, but I don’t think, like personally, they can’t do nothing to make an improvement to it, because my needs are being met.”

**Affordability.**

The phrase “I don’t have no problems” came up frequently in discussions of cost, as well. Affordability of medications was the biggest factor influencing access, according to these beneficiaries. If the co-payment was low, then the medication was accessible. Most people did seem to think that their medications were affordable under Part D. In fact, many consumers stated that they had very low co-payments, or that they did not pay co-payments at all at the pharmacy they used. One consumer said, “...I don’t have no problem; I just call them (prescriptions) in and...go pick them up, and they’re ready. I don’t have to pay for them. Everything’s covered.” Low cost-sharing was of great benefit to these participants. As another beneficiary mentioned, “Both (mental health agency) and (independent pharmacy) absorb my co-pay, of three dollars or two dollars or whatever it is, because it’s so low, you know.”

All beneficiaries in the sample were dually-eligible for Medicare and Medicaid. However, perceptions of affordability were affected by the type of Medicaid coverage in which the beneficiary was enrolled. Most beneficiaries in the sample had incomes that were low enough that they received full Medicaid coverage with no premium requirement. A few of the beneficiaries had somewhat higher incomes and participated in the Missouri HealthNet (formerly Medicaid) Medically Needy program, or “Medicaid Spend-Down.” Medicaid spend-down (Medically Needy) is a program under the

Missouri HealthNet program under which individuals whose incomes are above the maximum for full MO HealthNet coverage can “spend down” their income each month to become eligible for MO HealthNet coverage. These beneficiaries must incur and pay for a certain dollar amount of medical expenses each month to activate their Medicaid coverage. This dollar amount, the “spend-down,” is seen as a sort of premium for the Medicaid program. Beneficiaries in this category may or may not be eligible for full “extra help” under Medicare Part D.

People whose prescriptions were entirely paid for tended to be individuals with full Medicaid coverage—known by beneficiaries as “straight” Medicaid. Not only did these individuals have the full “extra help” subsidy under Medicare Part D, but several local pharmacies also waived their co-payments. For example, “Uh, I have a co-pay, like maybe a dollar-fifty. Because I got a deal with Medicare Part D. And they don’t pay all of it. But (independent pharmacy), (mental health agency), absorbs my dollar-fifty.”

Higher co-payments, or premiums for prescription drug insurance, made it harder to access medications. People who were enrolled in the Missouri HealthNet Medically Needy program—referred to as Medicaid spend-down, whose incomes were a little bit higher than those of people on “straight” Medicaid, were more likely to report problems with co-payments or premiums, even though the Medicare program itself does not have a spend-down. People in this situation frequently felt that their co-payments and premiums under Medicare were more than they could afford. In addition, because their medications were being paid for under Medicare Part D, their expenses for prescription medicines no longer applied toward meeting their “spend-down,” so their eligibility for the Medically Needy program was sometimes affected.

Problems with Medicaid coverage affected perceptions of affordability. Problems with Medicaid spend-down tended to impact people's perceptions of the entire system. Even though consumers with Medicaid spend-down could still get their prescription drugs through Medicare, the existence of the spend-down frequently confused and embittered consumers. Several consumers also expressed bitterness over the lack of dental coverage for adults under the Missouri HealthNet (Medicaid) program. Even though these issues do not directly affect Medicare coverage, they influenced consumers' perceptions of health care access and affordability.

One issue that did affect affordability was the use of utilization management tools by prescription drug insurance plans. A few beneficiaries mentioned that they were not able to obtain the number of pills prescribed by their doctor for a month. One woman was taking Effexor twice a day, but her Part D plan would allow her to purchase only 30 capsules a month. She stated that she had to obtain samples or pay cash for the remaining capsules to get the medicine she needed. Several other beneficiaries mentioned similar situations, not only with psychotropics but with blood pressure medicines and other medications. They reported running out of medication in mid-month and not being able to obtain any more pills. One beneficiary commented, "For your psychotropic medications, for certain medications, the pharmacy gives you exactly thirty days. But your appointment for the doctor isn't exactly thirty days. So what do you do in between, then?"

Only a few beneficiaries had encountered formulary problems that affected cost and access. Beneficiaries were concerned about formulary restrictiveness even if they had not experienced this problem personally, however.

### **Paperwork.**

Participants were split down the middle in terms of their opinions regarding information from Medicare and their Part D plans. About half of beneficiaries reported that this information was helpful and that they were able to get the information they needed from the materials sent by their plans and by the Medicare program. The other half indicated that the information they received from their Part D plans and from Medicare was confusing, not helpful, and much too voluminous to be useful to them. One typical phrase was, "It's like a foreign language." Another common word that was used was "confusing." One beneficiary went so far as to say, regarding the statements he received from Medicare Part D, "Now me, I probably get the bill in the mail, I might throw it away, but really, I'm not neglecting the bill, like I'm not going to pay it...but, I just, you know, I can't afford it." These statements were not actually bills, but the beneficiary did not understand their purpose and was throwing them away because he felt that he could not afford another medical bill.

Several participants who reported that the Medicare Part D information was helpful stated that they routinely brought their statements to their caseworkers, who helped them interpret the information. Those who found Part D information to be helpful also seemed to appreciate the regularity with which statements and information came in the mail to them. As one beneficiary said, "It's like clockwork."

Those who found Part D information not helpful also occasionally mentioned that they brought their statements to their caseworkers. A couple of beneficiaries who found the information not helpful had negative things to say about their case workers, seeming

to indicate that these individuals were too busy to provide them with the information and guidance they were seeking.

Very few participants mentioned using the Medicare Web site. A few mentioned calling Medicare's help line or calling their prescription drug plan for help with problems. Those who mentioned that they had used the help lines stated that they frequently were kept on hold for long periods of time and that they were still unable to get the information that they needed, although some reported satisfaction with the Medicare phone help line. "I just call...Medicare...and I tell them if I'm having a problem what the problem is, and they tell me if it's my problem or if it's the doctor or hospital's problem."

Paperwork itself was a slightly different theme in beneficiaries' comments. Beneficiaries seemed to say, "No problems, just paperwork." Across the three agencies, beneficiaries stated that there had been many forms to fill out and many letters sent from their Part D plans, but most beneficiaries were not bothered by the amount of paperwork. Again, many beneficiaries mentioned help from case workers. For example, "I wish they would send me more information about my Medicare stuff, but my information comes from the people here, at (mental health agency). What I would like is to get more information through the mail."

#### **Satisfaction with generic medicines.**

Opinions about the use of generic medicines by Part D plans varied. Many beneficiaries noted that their Part D plans preferred to pay for generic medications. Most of these beneficiaries thought that generics were okay, but those who had experienced difficulties with generics were very vocal and concerned about this issue. One



beneficiary commented, “See, I have pins and stuff in my legs, and they have me on, like, this, it’s supposed to be like Vicodin, but it’s the generic, and it doesn’t work the same; it really doesn’t, like, I have to take more of that, and, I would just take, like one of the other, you know, and that’s the only problem I have with that, and see, most of my pain medication that they give me is a generic. I think that’s the only problem I have, you know, with that. When it comes to pain, chronic pain like that, we should be able to get the right thing for it, you know.”

Those who did not mind generics felt that the fact that they could save money by using generics was very important. A common theme among those who did not mind generics was, “They’ve got the same potency (as the brand-name).” Another common statement was, “It (the generic) works just the same.”

Among those who objected to generics, most had had a bad experience at one point with taking a generic form of a medication. Others had experienced periods of stability on brand-name medications and did not want to risk switching. Several beneficiaries mentioned feeling somewhat threatened by their Part D plan—that they would be forced to accept a cheaper medication instead of the brand name that was working well for them. For example, one woman had been taking a name-brand antipsychotic for five years and had stayed out of the hospital for that time; her Part D plan sent her “memos” with her monthly statement encouraging her to discuss a cheaper medication with her doctor. She was reluctant to do so because the name-brand drug had worked so well for her, and no generic form of that particular medication was available. In her own words, “Like Abilify, they keep telling me I need a prescription for something different, because they say Abilify costs too high, in the market. I can’t—they ain’t got

no generic for Abilify! I ain't taking a different psychotic! Before I got started on Abilify, I was in the hospital like every three months. I'm on Abilify now and I've gone for five years and I ain't been in the hospital!"

### **Pharmacy interactions.**

Help from pharmacists came mostly in the form of waived co-payments.

Pharmacists also gave individualized help to beneficiaries when they ran out of medicines at the end of the month, perhaps lessening the effect of quantity limits. As one beneficiary stated, "If I, run into a problem like I did this past weekend—I ran out of medications because I don't see the doctor till today, and...the pharmacist at (independent pharmacy) knows me, right? So he gave me eight days' of medication."

Interviewees also reported that the transition that had taken place between Medicaid drug coverage and Medicare Part D had gone smoothly from the pharmacy perspective. For example, "And none of it has changed, the medicines are all the same, the companies may have changed, with the generics, and some of the generics look different. And almost everything I get is a generic, but I don't remember, if there was a change, it was a smooth transition."

Participants reported high levels of satisfaction with the customer service offered to them at their pharmacies. They gave examples of personalized service and effective communication with their pharmacists. One beneficiary said, "I go to (independent) Pharmacy, and they know my medicines already, and I know the boss there; he knew me when I was at (assisted living facility), so I will be able to get my medicines. Medicaid and Medicare, they don't bother me."

Beneficiaries were more likely to report individualized assistance from independent pharmacies, but those who used chain pharmacies also seemed to be satisfied. In fact, one participant who used a chain pharmacy reported the following: “My pharmacy, dealing with them, they will help you find where you need to go. They can be more compassionate, as far as providers that you come to, not only with these mental health consumers but with other people. In terms of getting my medicine on time, the pharmacy intervention, they were right there with me. I give them an ‘A’.”

Another participant commented about using a chain pharmacy, “I had to go to the emergency room for my breathing. And I needed a prescription filled...and the hospital prescription place at that time was overcrowded, and they couldn’t take me, so I had to go to like (chain pharmacy) or someplace like this, and since (chain pharmacy) was open 24 hours, and it was close to where I lived, I got it taken there to get it filled, which was great, you know.”

### **Mental health agency interactions.**

The phrase, “I don’t have no problems” also appeared frequently when beneficiaries were discussing help that they got from mental health agencies. Most beneficiaries who received help from a nurse or social worker expressed confidence that the helper could take care of whatever difficulty they were experiencing and resolve the situation. For example “You know, I called my case manager; my case manager told me what to do. So I did that, sent it in, they haven’t sent me another bill.”

However, a few (from one agency in particular) stated that although their community support workers tried to be helpful, they were powerless to change the system. One participant commented about her community support worker’s struggles by

saying the following, “I have the best CSW in this place, who has advocated very aggressively on my behalf. It is just that she is not able to do anything about it. The problems that I’m having with my medications, and getting that straightened out, she is still fighting for that.”

Mental health agency staff played a big role in making sure people got their medicines. Beneficiaries reported that agency staff assisted with co-payment costs, helped beneficiaries with picking up their medicines, helped to fill medicine planners, and communicated with physicians’ offices when formulary problems arose. Several beneficiaries reported that they took the statements that they received from Medicare directly to their community support workers, so that they could get help in interpreting and understanding the content of these documents. As one interviewee stated, “...the wording of the things, it’s like, we’re supposed to understand (laughs). I don’t understand, so, you know, that’s why I had to have help with it, you know. But like I said, I’m fine with it now, you know; as long as I get my meds, I’m good (laughs).” Another participant noted, “Well, I would say, my case manager said, tell me what to do, put those numbers in, and send it in, and I haven’t received another bill.”

### **Community Support Worker Results**

Four themes were identified throughout the community support worker coding. They are as follows: Managing beneficiary problems, stress for beneficiaries, information and paperwork issues, and concerns about health care reform.

#### **Managing beneficiary problems.**

Managing beneficiary problems was by far the most frequently-occurring theme in the community support worker transcripts. One aspect of this involved direct action or

advocacy that CSWs were taking on behalf of beneficiaries on Part D-related concerns. CSWs mentioned that they spent a considerable amount of time side-by-side on the phone or on the Medicare Web site, helping consumers to obtain the information that they needed to use and make decisions about their prescription drug benefits. CSWs stated often that they felt that consumers would have had a great deal of difficulty managing these transactions on their own.

Problems also arose with physician interactions and with the process of plan switching. Community support workers had to advocate on behalf of consumers with their physicians to obtain changes in prescriptions or to obtain necessary information to circumvent various utilization management issues that were standing in the way of consumers' getting their medicines. CSWs reported that dealing with physicians was difficult due to delays in obtaining the information that they needed. For example, "...that's been one issue, getting the physicians to fill out needed paperwork. It's an issue, unless they really are hot for the medication to get it approved, you know." CSWs also reported that physicians in general had little awareness of the details of Part D and were particularly lacking in knowledge regarding plan formularies: "It's like the doctors don't know. They don't know what's covered and what's not covered."

In contrast to physicians, pharmacists were universally perceived by CSWs as knowledgeable and helpful. As with beneficiaries, CSWs were more likely to bring up specific examples of help provided by independent pharmacies, particularly the two independent pharmacies with which their agencies had collaborative relationships. However, they, too, also seemed satisfied with services provided by chain pharmacies. As one CSW mentioned, "I think they, they've been working harder with our members

and stuff than Medicaid or Medicare, with what was going on.” Regarding formulary negotiations, another CSW stated, “They’re really good about, you know, calling and trying to get things covered or at least trying to get something comparable to what’s not covered.” CSWs frequently collaborated with pharmacists to ensure that their clients were able to obtain the medicines they needed, both for physical and mental health needs. “I think because of our situation, because we mostly work with (independent pharmacy), a lot of those things were a lot smoother.”

Plan switching also brought up problems for CSWs in helping beneficiaries. CSWs did not like the randomness of plan switching that occurred with the low-income plans each year and found themselves having to go on line or call the various plans to obtain formulary and premium information for beneficiaries’ assigned plans. The process of going on-line to switch plans and obtain information was not easy for many CSWs to negotiate, especially in the first year of the Medicare Part D program: “...there really wasn’t anyone around to kind of help you navigate on the Internet and figure, and do the formulary and all that stuff so you can actually sign up on-line. So that was, that was kind of, it was kind of aggravating, but, like I said, after a couple of times of doing it, you kind of figure it out.”

Community support workers did mention, however, that the overall implementation of Part D had gone more smoothly than they had expected. They noted that consumers’ medication coverage had not lapsed, and that access to medicines at a low price was still a reality for almost all of their clients.

**Stress for beneficiaries.**

Interestingly, community support workers perceived the Medicare prescription drug program as confusing and frightening for beneficiaries, despite the fact that the consumers themselves did not usually characterize the program this way. Community support workers' perception was that Part D was associated with a number of significant problems for beneficiaries. Community support workers stated that the Medicare Part D program was a source of anxiety for many consumers and that changes in formularies, the large quantity of information sent by the plans, and the technical language used in plan communications all caused problems for consumers. Regarding the language used by plans, one CSW mentioned, "It's like that weird medicalese and legalese, and the average person—it's not written for the average person to understand."

There was a great deal of stress and anxiety related to transition points with the benefit, as well; when consumers were switched from one plan to another, or when formularies underwent changes. Community support workers noted that beneficiaries did not have a clear understanding of which health care program was paying for which health care benefits. One CSW stated, "I think it's incredibly stressful for them because they don't know if the meds that they are on now are going to be covered under their plan, and, uh, there's a little stress on them, if they're going to have to start paying a monthly co-pay if they don't switch plans..." Another CSW commented on the plan switching process, "They say, you don't have to do this, but they make it sound so bad, and you have to pay so much money if you don't, that you're kind of forced into whatever they want you to do."

CSWs characterized consumers as "frustrated" and "confused" regarding their health care benefits. This may have been a reflection of the workers' own feelings in

dealing with plan switches, formulary issues, and costs. CSWs mentioned several points regarding their own confusion. “I mean, I find it difficult to understand, and you know, for them, yeah, it’s like, if we’re having trouble understanding it, they’re like, it’s Greek to them.” Another CSW stated, “I never understood when they first came out with the whole Part D thing and we all got the information, and that was so confusing, and it was terrible because you had these clients asking all these questions, and you’re like, I don’t know, you know (laughter). Because I don’t get it either, which is not very comforting.”

### **Information and paperwork issues.**

Community support workers were especially concerned with the volume of paperwork associated with using the Medicare prescription drug benefit. One team leader noted that the government “has wasted a lot of paper” on communications associated with the prescription drug benefit. Community support workers did state that they felt that Medicare and the Part D plan sponsors had improved over the past several years in terms of communication and organization, but even as of 2010, some problems remained.

One issue related to information and paperwork was the observation by CSWs that beneficiaries frequently could not discern the difference between advertisements sent to them by Medicare Advantage and Medicare prescription drug plans, and consumer information related to their benefits. Beneficiaries had difficulty telling the difference between communications from their plan to which they needed to respond and advertisements attempting to recruit them into a new benefit plan. This led to some beneficiaries’ enrollment in Medicare Advantage plans that limited their access to needed medications and providers, and CSWs reported spending quite a bit of time dis-enrolling



consumers from Medicare Advantage plans. One team leader noted regarding Medicare Advantage plan promotions, "...misrepresenting themselves, to put it mildly, to a lot of our members, and signing people up, and then, then they find that their doctors don't take it; they can't use it to pay doctors, and, and, in the meantime they've kind of run up a medical bill that the doctor can't send to original Medicare." A CSW mentioned similar problems at her agency, "They (clients) get tripped up with the Advantage Care plans. The Medicare Advantage plans. Because they see that and they think, well, I have to switch to this, not realizing that, yeah, you gain some stuff, but you lose some benefits, too."

CSWs also observed that some beneficiaries' distrust of "the system" and in some cases, symptoms of paranoia, led to problems in using the Part D benefit. CSWs reported that some consumers had concerns about identity theft and destroyed needed documents related to their Part D plans. Other consumers were mistrustful of switches in medications and coverage which led them to conclude that their medicines were being "tampered with."

A common theme among community support workers was that they resented the time that they had to spend deciphering Part D paperwork and explaining consumers' benefits to them. CSWs felt that this time could be better spent on other interventions related to rehabilitation and community support. For example, "We have to spend so much time, every year, going through this, these changes, and that's time we could be spending doing other things with our clients."

### **Concerns about health care reform.**

Cynicism about health care reform efforts was common among these community support workers. Their perception was that the current reform efforts underway at the federal level were going to lead to more confusion and less access to affordable care for their clients. They expressed a wish that the federal government would eliminate the two-year waiting period for disabled adults to receive Medicare, but doubted that this reform would actually take place.

One desire expressed by CSWs related to health care reform was the need for better communication regarding Medicare and the prescription drug benefit. Several CSWs noted that at the state level, representatives from the Division of Medical Services had hosted town hall meetings and informational events to explain changes in Missouri HealthNet benefits. These CSWs expressed the wish that representatives from Medicare or from Part D plan sponsors would host similar forums for their consumers. CSWs felt that this face-to-face communication from Medicare to the beneficiaries would eliminate confusion and give consumers an opportunity to voice their concerns and opinions. One team leader noted that a representative from a Medicare Advantage plan had hosted an informational event at her agency, and that this had helped consumers to understand the benefit better. There was a desire on the part of CSWs to have this information separate from advertising or recruitment efforts related to specific plans, however.

### **Plan Comparison Data: Results**

The purpose of the quantitative analysis was to use formulary and performance data on the Part D program to compare plans on various attributes that contribute to patient-centeredness. By evaluating the extent to which plans have attributes related to patient-centeredness, it is possible to determine to some degree how well plans are

meeting the needs of adults with mental illness. Formulary and performance data were used to answer questions about respect for patients’ needs and preferences, access to care, information and education provided to patients, and coordination of care.

**Part D Formularies**

To examine the comprehensiveness of the formularies of the Part D plans, the [www.medicare.gov](http://www.medicare.gov) Formulary Finder was used. The following table outlines these findings.

Table 4.7 Formulary Comprehensiveness

<b>Plan</b>	<b>Anticonvulsants Covered</b>	<b>Antidepressants Covered</b>	<b>Antipsychotics Covered</b>
Aetna Medicare Rx Essentials	100%	100%	100%
Community CCRx Basic	80%	47%	82%
First Health Part D-Premier	80%	47%	82%
Health Spring Prescription Drug Plan-Reg 18	87%	47%	91%
Medco Medicare Prescription Plan-Value	67%	47%	82%

The Medicare Rx Rewards Standard Plan is not included in this table because formulary data for this plan were not available at the time that the data were being collected. Coverage for anticonvulsants is quite comprehensive with the first four plans examined, although Medco Medicare Prescription Plan-Value covers only 2/3 of the anticonvulsants in Huskamp et al.’s list. Coverage for antidepressants does not appear to be as good, with four of the five plans covering less than half of antidepressants on the list. However, many of the antidepressants that are not covered are those brand-name

drugs that have generic equivalents at this time, such as Celexa, Prozac, and Paxil.

Coverage for antipsychotics is fairly good, with the lowest percentage of antipsychotics covered at 82% for three of the five plans. Coverage for anticonvulsants and atypical antipsychotics may be better than coverage for antidepressants because there are fewer generic alternatives for many of the anticonvulsants and antipsychotics than there are for the antidepressants. This is consistent with the Centers for Medicare and Medicaid Services regulation stating that “all or substantially all” drugs in these classes must be covered by all Part D plans (Huskamp, 2007).

Aetna Medicare Rx Essentials covers all of the three classes of drugs listed, but this plan also uses quantity limits for almost all antidepressants and antipsychotics on the list.

#### **Part D Utilization Management Strategies**

The [www.medicare.gov](http://www.medicare.gov) Formulary Finder was also used to identify which utilization management strategies are being used by each Part D plan. Utilization management strategies are processes used by prescription drug insurance plans to limit coverage of expensive medications. The three primary utilization management strategies used by Part D plans are prior authorization, quantity limits, and step therapy. Prior authorization is used when a Part D plan requires written permission from a beneficiary’s prescribing health care provider before a particular drug will be prescribed. Quantity limits are enforced when a beneficiary can only receive a certain quantity of medication during a specified time period. For example, a beneficiary may be limited to obtaining thirty tablets of a medication during a 30-day period. Step therapy, also known as “fail-first,” occurs when a beneficiary must provide evidence to his/her prescription drug plan that a less expensive medication is ineffective for him/her before a more expensive

(usually brand-name) medication will be covered. The following table outlines the percentage of each class of medications that is subject to each form of utilization management.

Table 4.8 Utilization Management Strategies

<b>Plan</b>	<b>Prior Authorization</b>	<b>Quantity Limits</b>	<b>Step Therapy</b>
<b>Aetna Medicare Rx Essentials</b>			
Anticonvulsants	0%	13%	7%
Antidepressants	0%	100%	68%
Antipsychotics	0%	81%	27%
<b>Community CCRx Basic</b>			
Anticonvulsants	8%	17%	0%
Antidepressants	0%	56%	22%
Antipsychotics	11%	100%	0%
<b>First Health Part D-Premier</b>			
Anticonvulsants	8%	17%	0%
Antidepressants	0%	33%	11%
Antipsychotics	56%	89%	0%

<b>HealthSpring Prescription Drug Plan –Reg 18</b>			
Anticonvulsants	0%	0%	0%
Antidepressants	0%	78%	0%
Antipsychotics	0%	80%	0%
<b>Medco Medicare Prescription Plan- Value</b>			
Anticonvulsants	0%	0%	0%
Antidepressants	0%	100%	0%
Antipsychotics	0%	78%	0%

Prior authorization was used relatively infrequently by all five plans. The highest use of prior authorization can be seen with First Health Part D-Premier, in its coverage of antipsychotics, in which 56% of atypical antipsychotics covered by the plan require prior authorization from a health care provider before the plan will pay for them. When prior authorization is used, it is often used with brand-name drugs that are quite expensive and that have no generic alternative.

Quantity limits were the most commonly-used utilization management strategy, employed by all five of the plans. Quantity limits were especially common in coverage of antidepressant medications; two of the five plans required quantity limits for all antidepressant prescriptions, and two additional plans required quantity limits for more

than half of antidepressant prescriptions. Quantity limits were also frequently employed with atypical antipsychotic medications, with all five plans using quantity limits for over three-quarters of atypical antipsychotic prescriptions. For most patients, the use of quantity limits does not affect access to the medicines they need, but for patients who require more than one daily dose of a particular medicine, quantity limits can create a problem.

Step therapy was not used at all by two of the five plans. Aetna Medicare Rx Essentials required step therapy for about two-thirds of antidepressants. Community CCRx and First Health Part D-Premier used step therapy for a small number of medications. Plans may use step therapy because they want patients to try cheaper medications first before switching to expensive brand-name drugs. Both prior authorization and step therapy require considerable documentation and paperwork on the part of patients' physicians.

There is a certain amount of interplay between formulary coverage and use of utilization management tools. Some plans take the approach that they will have all drugs on formulary, but will restrict their use through quantity limits or step therapy (for example, Aetna Medicare Rx Essentials). Other plans have more limited formularies, but they do not use utilization management tools as extensively (for example, Medco Medicare Prescription Plan).

### **Medicare Part D Performance Data**

The Medicare Part D performance data were used to answer three questions related to the patient-centeredness of the benchmark plans. The first question was: What percentage of plan members feel that the drug plan provides information or help when

members need it? Adequate information and education about health care has been identified as a key aspect of patient-centered care. The following table summarizes the percentage of members in each plan who expressed satisfaction with the information and education provided by their plan.

Table 4.9 Provision of Information and Help When Members Need It

<b>Plan</b>	<b>Percentage of plan members who feel that the plan provides information or help when members need it.</b>
Aetna Medicare Rx Essentials	77.7%
Community CCRx Basic	76.8%
First Health Part D-Premier	79.1%
Health Spring Prescription Drug Plan-Reg 18	79.0%
Medco Medicare Prescription Plan-Value	80.4%
Medicare Rx Rewards Standard	75.4%

Over three-quarters of members in every benchmark plan felt that information and help was provided by the plan when they needed it. The lowest percentage was Medicare Rx Rewards Standard, for which 75.4% of members expressed satisfaction with information and help provided by the plan. The highest percentage was Medco Medicare Prescription Plan-Value, for which 80.4% of members expressed satisfaction with information and help provided by the plan. There is so little variation that the question of patients' diligence in reporting problems and satisfaction is raised.

A second question that was asked using the Medicare Part D performance data was: What is the rate of complaints about drug plan benefits and access to prescription



drugs? This is an important question because it touches on levels of satisfaction regarding beneficiaries' ability to obtain certain medications and to use their benefits to get what they need. The rate of complaints in this area was extremely low across all of the plans studied. This may be because patients do not complain to the Centers for Medicare and Medicaid Services when they have problems with their plans. Patients may not even realize that they have the right to register a complaint. Alternatively, it may also be because most people are getting what they need from Part D.

Table 4.10 Rate of Complaints About Drug Plan Benefits and Access to Prescription Drugs

<b>Plan</b>	<b>Rate of complaints (per 1000 members)</b>
Aetna Medicare Rx Essentials	0.07
Community CCRx Basic	0.04
First Health Part D-Premier	0.07
HealthSpring Prescription Drug Plan-Reg 18	0.05
Medco Medicare Prescription Plan-Value	0.04
Medicare Rx Rewards Standard	0.05

The third question examined using Part D performance data was as follows:

What is the rate of complaints about joining or leaving specific prescription drug plans?

This is a particular issue for dually-eligible beneficiaries because they may be randomly assigned to plans that are not the best “fit” for their needs and may need help switching to a plan that has a more appropriate formulary or pharmacy network.

Table 4.11 Rate of Complaints about Joining or Leaving Specific Prescription Drug Plans

<b>Plan</b>	<b>Rate of complaints (per 1000 members)</b>
Aetna Medicare Rx Essentials	0.61
Community CCRx Basic	0.39
First Health Part D-Premier	0.87
Health Spring Prescription Drug Plan-Reg 18	0.31
Medco Medicare Prescription Plan-Value	0.61
Medicare Rx Rewards Standard	0.37

Rates of complaints about this aspect of the prescription drug plans appeared very low, as well, although they are higher than rates of complaints about benefits and access. As with complaints about access and benefits, patients may not be aware of the mechanisms for registering complaints with CMS. In addition, there may be few complaints because patients do not switch plans very often (Dulio, Perry, & Cubanski, 2007).

### **Conclusion**

The qualitative and plan comparison data examined here offer a look inside the world of the Part D benefit. That world is characterized by satisfaction on the part of beneficiaries, and cynicism on the part of community support workers. The plan comparison data reinforce the high levels of beneficiary satisfaction.

The overwhelming perspective of beneficiaries seems to be that Medicare Part D works well in providing low-cost, accessible prescription medications. Though satisfaction is high and complaints are low, there are still a few access issues, as well as problems with information and education about plans. However, the impact of existing problems with Medicare Part D appeared to be moderated by the assistance provided by community support workers and pharmacists. Interviewees frequently mentioned the importance of the help they received in being able to use their prescription drug benefits. Beneficiaries acknowledged the extensive assistance they received both from mental health agencies and from pharmacies in using their Part D benefits and accessing their medications. The consistent mention of the critical role of this help came as a surprise.

Community support workers were much more likely than beneficiaries themselves to mention problems with access and plan information. Many community support workers had experienced problems with plan switching and with confusing information provided by plans. Community support workers reported spending considerable amounts of time deciphering plan information and negotiating the Medicare Web site with their clients. An attitude of cynicism and frustration permeated CSWs' discussion not only of the Part D program, but of national health reform efforts, as well.

Plan comparison information revealed only a few complaints about the Part D program. In some respects, the plan comparison data painted an even more positive picture of the patient-centeredness of the Part D program than even the qualitative findings from beneficiaries. The low incidence of complaints about Part D plans was somewhat surprising. Formularies appeared to cover the majority of psychotropic medications, but there were some access issues concerning brand-name drugs that

affected a few beneficiaries. Utilization management tools, especially quantity limits, were a common cost-containment strategy for Part D plans. Satisfaction with information provided appeared high overall, and rates of complaints about benefit plans and plan switching were extremely low. Examination of the plan comparison data in light of the qualitative findings will reveal further insights into the patient-centeredness of the Medicare Part D program.

## **CHAPTER V: DISCUSSION AND CONCLUSIONS**

### **Introduction**

This chapter discusses the qualitative and plan comparison findings and their relationship to patient-centered care. Principles of patient-centered care are compared with codes discerned in the qualitative data, as well as with findings related to the plan comparison data. Focus group and interview data are triangulated with plan comparison data to determine whether “benchmark” plans are adhering to important principles of patient-centered care. Following this discussion, the findings are summarized, and implications for social work research, policy and practice, and education are outlined.

### **Qualitative Data Analysis: Consumer Codes and Patient-Centeredness**

After stakeholders’ experiences with the Medicare program were coded and sorted, data were examined to discover relationships between experiences with Medicare Part D and principles of patient-centered care. A deductive approach was used; concepts related to patient-centered care were used to organize and understand the data codes (Morse & Field, 1995). With the consumer data, each code was found to relate to at least one patient-centered care characteristic, as seen in the following table.

Table 5.1. Consumer Data Codes and Patient-Centered Care Principles

<b>Data Code</b>	<b>Patient-Centered Care Principle(s)</b>
Concerns about health care reform	Information and education
Co-payments okay	Access to care (there is not a patient-centered care principle directly related to cost)
Co-payments not okay	Access to care
Costs okay	Access to care
Costs not okay	Access to care
Dental insurance problems	Respect for the patient's values, preferences and expressed needs; access to care
Formulary problems	Respect for the patient's values, preferences and expressed needs; access to care
Generic drugs okay	Respect for the patient's values, preferences, and expressed needs; access to care
Generic drugs not okay	Respect for the patient's values, preferences, and expressed needs; access to care
Help from mental health agencies	Information and education; emotional support to relieve fear and anxiety; continuity and secure transitions between health care settings; coordination of care
Help from pharmacists	Information and education; continuity and secure transitions between health care settings; coordination of care
Information from Medicare helpful	Information and education; coordination of care
Information from Medicare not helpful	Information and education; coordination of care
Medicaid spend-down	Access to care; continuity and secure transitions between health care settings; coordination of care
Not satisfied with Part D	Respect for the patient's values, preferences, and expressed needs
Satisfied with Part D	Respect for the patient's values, preferences, and expressed needs
Paperwork	Information and education; coordination of care
Problems with Medicare Advantage	Access to care; coordination of care
Problems with utilization management (in Part D plans)	Respect for the patient's values, preferences, and expressed needs; access to care

Patient-centered care principles are relevant to the concerns of individuals with serious mental illness because there are so many similarities between the concept of patient-centered care and principles of quality mental health care (Mechanic, 2007; Pincus et al., 2007). The most critical principles of patient-centered care for adults with serious mental illness, according to this analysis, appear to be access to care (which includes affordability); respect for the patient's values, preferences, and expressed needs; and information and education.

Another reason that patient-centered care principles are important to adults with serious mental illness has to do with the impact of mental illness stigma. The stigma of mental illness has left many adults with mental illness disempowered and disenfranchised (Corrigan, Watson, Byrne, & Davis, 2005). When health care programs enact principles of patient-centered care, they can accomplish much to undo the harmful effects of stigma. Respect for patients' values, as well as information and education, are particularly important in this regard.

### **Consumers' Assessment of Patient-Centeredness of Medicare Part D**

In terms of access and attention to individual patients' needs, beneficiaries gave the Part D program high marks. With a few exceptions, most beneficiaries felt they were able to obtain their medicines through Part D inexpensively and without much hassle: "I don't have a problem getting my medicine" and "Part D is working for me." This is congruent with the observations of Neuman and Cubanski (2009) regarding low-income subsidy-eligible beneficiaries, who had lower out-of-pocket costs than they had had under Medicaid. Duggan et al. (2008) also note that overall, Medicare Part D has increased access to prescription medicines for beneficiaries. Qualitative observations from the

“Voices of Beneficiaries” project also note high overall satisfaction with Part D access and cost (Kaiser Family Foundation, 2006; Perry et al., 2006). Though there were a few complaints about access to brand-name medications, for most beneficiaries this was not a problem.

In terms of information and education related to Part D plans, beneficiaries were not as satisfied. Though some consumers appreciated the information provided by Part D plans, others found the amount of paperwork confusing. Some beneficiaries found plan communications to be helpful in deciphering their benefits, but others felt that the language used in statements sent by plans was not easily understood. As one interviewee noted, “It was hard for me to understand the way that some of that, the way they word it, you know, it’s really difficult.” Dulio, Perry & Cubanski (2007), in their interviews of Part D beneficiaries, found similar results—that beneficiaries had difficulty understanding paperwork associated with the benefit.

The “piece of the puzzle” that seemed to make the prescription drug benefit manageable for these beneficiaries was the extensive help they got from pharmacists and workers at community-based mental health agencies. This help from pharmacies and mental health agencies was directly associated with the patient-centered care attribute of continuity and secure transition between health care settings. This assistance made the program more patient-centered for participants, enhancing perceptions of respect for patients’ values and needs, as well as access to care. As one beneficiary mentioned about his pharmacy, “I guess I don’t have a problem. They (the pharmacists) know who I am when I call.” The Part D benefit itself did not adhere so well to expectations of patient-centeredness, but the assistance provided by community helpers definitely seemed



focused on the well-being of the consumers. Perry, Dulio and Cubanski (2006) also mention the role of pharmacists as advocates for Part D beneficiaries, and an earlier Kaiser Family Foundation report (2006) discusses the role of community-based case managers in assisting with plan selection. Shrank et al. (2006) mention the assumption of many physicians that it is the role of pharmacists to assist patients in managing costs. In terms of managing the stress and anxiety associated with Part D, as Zagar states, “The technical components of Medicare Part D can be ‘learned,’ but the emotional aspects associated with this program can only be ‘experienced.’” (2007, page 5). Community support workers and pharmacists not only provided the technical help with interpreting benefits and obtaining medications; they also supported beneficiaries and lessened anxiety and confusion about use of the program.

#### **Qualitative Data Analysis: CSW Codes and Patient-Centeredness**

CSW codes were also mapped onto patient-centered care characteristics using a deductive theory approach.

Table 5.2 Community Support Worker Data Codes and Patient-Centered Care Principles

<b>Data Code</b>	<b>Patient-Centered Care Principle(s)</b>
Action on behalf of consumer	Information and education; emotional support to relieve fear and anxiety; continuity and secure transitions between health care settings; coordination of care
Communication with members	Information and education; coordination of care
Costs Not Okay	Access to care
Costs Okay	Access to care
Dealing with Bureaucracies	Information and education; coordination of care
Health Care Reform	Information and education
Part D Okay	Respect for the patient's values, preferences, and expressed needs
Pharmacies helpful	Information and education; continuity and secure transitions between health care settings; coordination of care
Prescription Issues	Respect for the patient's values, preferences, and expressed needs; access to care
Problems with Medicare Advantage	Access to care; coordination of care
Problems with physicians	Coordination of care; continuity and secure transitions between health care settings
Problems with Switching Plans	Coordination of care; access to care
Stress for consumers	Information and education; access to care; emotional support to relieve fear and anxiety
Utilization Management	Respect for the patient's values, preferences, and expressed needs; access to care

Community support worker codes were mapped onto patient-centered care principles because CSWs play a critical role in ensuring that beneficiaries experience health care in a patient-centered way. The concept of client-centeredness has been used to assess the quality of public social services, and is considered important in understanding reasons for clients' satisfaction with such programs (Jindani & Murdock, 2009). The most important principles of patient-centered care for the community support workers interviewed for this study appear to be access to care, coordination of care, and information and education. Coordination of care appears as a prominent principle of

patient-centered care for these CSWs, most likely because they play such an important part in coordinating programs for the beneficiaries they serve.

### **CSWs' Assessment of Patient-Centeredness of Medicare Part D**

Community support workers were not as positive as beneficiaries in their evaluation of the Medicare prescription drug benefit. CSWs felt that continuity and secure transition between plans and between formularies was lacking, and that they were frequently called upon to make these transitions happen. Community support workers were almost entirely negative about the information and education provided by Part D plans, feeling that there was too much of the wrong kinds of information. CSWs noted repeatedly that they themselves had difficulty understanding communications from Part D plans, and they observed that individuals with less education or lower literacy would have an even harder time deciphering plan information. As one CSW stated, "For me, I know it was confusing for a lot of people." Another CSW recommended, "Give members greater understanding. Members want more information."

Community support workers expressed cynicism and frustration with the operation of Part D plans, and even though CSWs noted that the implementation of Part D had not been quite as chaotic as they had expected, there were still substantial problems with plan communications. Nonetheless, in terms of access to care, community support workers did note that beneficiaries were able to obtain their medicines cheaply and that few lapses in coverage had actually taken place. One community support worker noted, "But as far as their psych meds, everything's pretty much covered; um, their regular medical meds are pretty much covered. We haven't had too many issues." The resounding theme of CSWs' comments, however, was that consumers would not be able

to manage this benefit on their own. Not only instrumental help, but the emotional support to relieve consumers' fear and anxiety, were viewed as essential to assisting consumers to manage the Part D program. A CSW mentioned, "It's scary for someone who's paranoid already."

Community support workers put a great deal of effort into making the Part D benefit plan work well for their clients, but they rated the Part D plan quite poorly in terms of continuity of care and access to care. These findings are similar to the observations of Buchsbaum et al. (2007), who found in their key informant interviews that health care and social service professionals had to provide much assistance to dually-eligible beneficiaries related to Medicare Part D. From case managers' perspectives, beneficiaries experienced satisfactory access and continuity/secure transitions because of the assistance they received; for example, "It took hours and hours to, on the computer, with the member sitting next to me, to plow through the system and try to get some information."

### **Plan Comparison Data: Discussion**

Plan comparison data were used to assess five different patient-centered care characteristics. These were as follows: Respect for the patient's values, preferences, and expressed needs (formulary coverage); access to care (use of utilization management tools); coordination and integration of care (complaints regarding plan benefits); information, communication, and education (satisfaction with plan information); and transition and continuity (complaints regarding plan switching).

Formulary coverage is a key dimension of respect for patients' needs. Formulary restrictions are commonly used by both commercial and publicly-funded prescription

drug plans to control costs, and some research shows that the cost-containment function of formulary restrictions is fairly effective (Maio, Pizzi, Roumm, Clarke, et al., 2005). In terms of formulary coverage of psychotropic medications in the six benchmark plans studied, most plans appeared to have fairly comprehensive coverage. The only exception to this was that certain brand-name antidepressants which have generic equivalents were not covered. This creates a problem for beneficiaries who cannot tolerate generic preparations, but for most patients this is not an issue. In the qualitative data collected regarding use of generic medicines, most beneficiaries appeared satisfied with generic preparations. One beneficiary did state that generic medicines were not effective for her, and that her physician had specified that she should take a brand-name drug. Duggan et al. (2008) mention that Part D plans frequently put in place strong incentives for beneficiaries to use generic medicines; for most beneficiaries, this is not viewed as a problem. Huskamp (2003) has noted that therapeutic substitution of one mental health drug for another is less easily done than with drugs for other medical conditions, but for most of the beneficiaries in the qualitative sample, this was not an issue.

Focus group participants—both beneficiaries and community support workers—agreed that plan formularies rarely caused a problem for them, as the medicines beneficiaries needed were almost always covered. Plans did reasonably well in respecting the patient’s values, preferences, and expressed needs. The “incented formulary” (Maio et al., p. 121) structure of these plans—placing generic and brand-name drugs on different tiers of coverage—did not bother most beneficiaries and seemed to serve their needs reasonably well, as even co-payments for brand-name preparations were fairly low and often waived by pharmacies.

Use of utilization management tools varied among the plans. The only utilization management tool mentioned often by beneficiaries was quantity limits. According to Olson (2003), quantity limits are frequently used by commercial pharmacy benefit plans as a way to contain costs. Though they are somewhat effective at managing prescription drug spending, quantity limits can create problems. For example, one study found an association between plans' use of quantity limits and transfers of beneficiaries to higher levels of care (Olson, 2003).

In the focus group data collected, one beneficiary in particular had experienced difficulty obtaining adequate amounts of an antidepressant she needed. She reported that this had resulted in an unwanted hospitalization. Several other participants reported encountering quantity limits in prescriptions for medical conditions, such as hypertension. Beneficiaries saw quantity limits as unfair, feeling that the insurance company should not have the right to specify how much medicine their doctors could prescribe for them. Community support workers also reported problems with quantity limits, stating that when their clients dropped or lost medicine, or were "overcompliant," they could run out of medicine and not be able to obtain more when they needed it.

The literature on utilization management tools in pharmacy benefit plans makes frequent mention of prior authorization as a cost-control strategy (Olson, 2003; Maio et al., 2005). Prior authorization is seen as effective at reducing utilization of new and expensive medications, but it involves a considerable administrative burden that can actually increase costs to prescription drug plans (Olson, 2003). This additional administrative cost is one likely explanation for the infrequent use of prior authorization among the Part D benchmark plans studied.

In terms of access to care, plans frequently used utilization management, especially quantity limits, to control costs. Some beneficiaries were upset by this, but overall, utilization management was not a common barrier to obtaining the medicines that beneficiaries needed or preferred. This is in contrast to the observations of Donohue et al. (2009) who stated that implementation of utilization management tools for psychotropic medications was likely to increase.

Medicare Part D performance data revealed some interesting information about consumer satisfaction with several aspects of their prescription drug benefits. One of the most fascinating aspects of these data is the overwhelmingly high levels of satisfaction with Part D plans expressed by beneficiaries. This is in contrast to much of the literature on satisfaction with managed care plans, which indicates that benefit plans that highly “manage” (Landon, Rosenthal, Normand, Frank, et al., 2008) provision of services to beneficiaries tend to have lower satisfaction ratings (Schur, Berk, & Yegian, 2004; Landon et al., 2008). Gillies, Chenok, Shortell, Pawlson, & Wimbush (2006) also found that affiliation with a national managed care organization (a frequent feature of Part D plans) was correlated with lower patient satisfaction ratings. One interesting assessment of consumer satisfaction with managed care, however, found that the level of care management in benefit plans did not affect the satisfaction ratings of patients with depression (Grembowski, Paschane, Diehr, Katon, et al., 2007).

In terms of satisfaction with information and help provided by plans, over three-quarters of plan respondents stated that they were satisfied with these aspects of their Part D plans. These results correspond well with the qualitative data on overall levels of satisfaction that were collected, in which very few beneficiaries expressed dissatisfaction

with their Part D plans. The rate of satisfaction with plan information and help seems somewhat high compared to the qualitative question of plan information, in which about half of beneficiaries reported having some problem understanding or interpreting information they received from their plans. However, the qualitative data come from a small and non-representative sample, so a discrepancy between the qualitative data and the Part D performance data is not unexpected. Beneficiaries polled by the Centers for Medicare and Medicaid Services expressed high levels of satisfaction with plan information, and there was little variation among the plans. Beneficiaries surveyed were mostly happy with the information provided by their plans. An interesting discovery about communication is that a higher percentage of people are satisfied with their drug plan's communication with them than are satisfied with their physician's communication with them (CMS, 2009, AHRQ, 2008). The qualitative results are definitely more mixed, it may be that the Part D program appears to be doing well on information, communication, and education for beneficiaries largely because of the help that beneficiaries receive from pharmacists, nurses, and community support workers.

Another question asked of the plan comparison data concerned the rate of complaints among plans regarding plan benefits and coverage. Complaints about plan benefits appear to be very infrequent in all plans. There is very little variation among plans with this question. In the qualitative findings explored in this study, it did appear that most beneficiaries questioned about formulary and access issues appeared highly satisfied about this aspect of their prescription drug plans. Beneficiaries reported being able to obtain the medicines they needed from their chosen pharmacies. Some coordination and integration issues arose with plans during the switch in 2006 from



Medicaid to Medicare for dually-eligible beneficiaries. Coordination and integration of care, though noted in the qualitative findings as a source of some initial problems for beneficiaries and case managers, did not appear as an area of difficulty in the plan comparison data. The rates of complaints regarding plan benefits and ability to obtain prescription medications were very low. This is a positive finding for beneficiaries with mental illness, as Simoni-Wastila et al. (2008) found that Medicare beneficiaries with severe mental illness were less likely to obtain prescription drugs for their mental health conditions if they had discontinuities in their drug coverage. A finding of adequate coverage and benefits for Medicare beneficiaries is also positive because limits on prescription drug coverage can be associated with non-adherence and later health problems (Hsu et al., 2006).

The final question that was asked of Part D performance data concerned the rate of complaints about plan switching. There is more variability among plans on this question, but rates of complaints are still very low. Although beneficiaries did not frequently mention problems with plan switching during the qualitative data collection for this study, community support workers did mention plan switching as a source of stress both for themselves and for the beneficiaries they were working with. Community support workers noted that using the Internet to switch a beneficiary's plan could be a confusing process for the client. It may be, however, that beneficiaries and their helpers are not using formal avenues for filing complaints to register the problems they are having with the plan switching process. Transition and continuity were sources of some complaints on the part of beneficiaries, as they noted some problems with the plan switching process. This appeared as a bit of a flashpoint in the qualitative data for CSWs,

as well, as they mentioned frequently problems with plan switching among their clients. Neuman and Cubanski (2009) have noted that the random assignment of dually-eligible beneficiaries to benchmark plans can be a source of trouble and confusion.

### **Summary of Findings**

The goal of this study was to use the framework of patient-centered care to gain a better understanding of how well Medicare prescription drug policy meets the needs of beneficiaries with severe and persistent mental illness. Eliciting the perspectives, experiences, and opinions of Medicare Part D stakeholders has illuminated the various policy dimensions that are considered the most important in prescription drug benefit plans. A look at data comparing “benchmark” plans confirmed the opinions and experiences of beneficiaries and their helpers.

Several conclusions can be drawn from the findings of this study. One important observation is that low-income beneficiaries with mental illness express high levels of satisfaction with the Medicare Part D program. Beneficiaries report few problems with the benefit and seem, for the most part, to accept the costs and paperwork associated with the Part D benefit.

For dually-eligible beneficiaries, the switch to the Medicare prescription drug program from Medicaid has not meant big problems, but it has not improved access or affordability (Donohue & Frank, 2007). Beneficiaries report high levels of satisfaction with their prescription drug benefits, and they do not report many problems with obtaining medications as a result of switching from Medicaid to Medicare. Costs seem about the same. In addition, there is much more paperwork and bureaucracy to deal with than there was under a single state-administered program (Hall, Kurth, & Moore, 2007).

Beneficiaries report receiving monthly statements from their prescription drug plans, enabling them to track more closely their prescription drug expenses but also giving them one more piece of paper to read each month. Communications from Medicare and Part D plans are appreciated, but not always experienced as readable or ultimately very helpful.

It is important to note, too, that for low-income people using Medicare Part D, access often equals affordability. Comments about how much things cost were much more prominent than other access-related concerns such as pharmacy networks. This may have been because their pharmacies accepted their plans, or because under current Part D regulations “all or substantially all” of mental health drugs must be covered by plan formularies (Huskamp et al., 2007). Major patient-centered care themes for beneficiaries were access to care; information, communication, and education; and continuity and secure transitions.

Beneficiaries with mental illness used the services of their community support workers extensively. Case workers are spending a great deal of time and energy on the paperwork associated with this benefit program. This is a source of frustration for community support workers, who would like to spend their efforts on more fruitful rehabilitative services.

Community support workers’ perspective on this benefits program is quite different from that of beneficiaries. Though Medicare beneficiaries did not mention stress associated with using their prescription drug plan, community support workers perceived Part D as a source of stress for their clients. Also, a frequent theme in CSWs’ comments about this program was dealing with problems associated with the benefit. Problems included issues with paperwork and bureaucracy, communication with other

professionals, and plan switching. Community support workers noted frequently the importance of emotional support to relieve fear and anxiety, as well as adequate plan information and communication, to effective use of the Part D program.

When examining plan comparison data, it appears that formulary coverage for most psychotropic medications is quite good. Plans do use some utilization management tools to control costs. Data on plan complaints and plan satisfaction seem to confirm what consumers have to say about Part D; that is, that most beneficiaries are satisfied with most aspects of their benefit plans. It is difficult to say whether these high levels of satisfaction truly reflect beneficiaries' experiences with Part D, or whether beneficiaries are not empowered enough to register their complaints. Participants in the qualitative focus groups and interviews, however, seemed reasonably empowered to express their opinions, and they did report overall satisfaction with the Part D program. Plan comparison information does seem to capture the most relevant aspects of patient-centered care for beneficiaries and their helpers, with the exception of emotional support, which neither Medicare Web site nor Part D performance data are able to describe adequately.

### **Conclusions: Is Medicare Part D A Patient-Centered Program?**

To assess the patient-centeredness of the Medicare Part D program, it is beneficial to re-visit the five attributes of patient-centered care identified by the investigator as applying to patient-centered programs (see pp.46-47) . These are accessibility, care coordination, involvement of the patient, information and education, and secure transitions. These will be considered one at a time to determine how they apply to Medicare Part D.

## **Accessibility**

Access comprises several different ideas, including affordability as well as ability to obtain needed medications. In terms of affordability of care, Part D seems to meet this criterion of patient-centeredness. Neither beneficiaries nor community support workers reported major issues with co-payments or other issues related to affordability. In addition, access to needed medications was generally perceived as acceptable. Only a few beneficiaries reported problems with generic medications or formularies. Beneficiaries who were participating in the Medically Needy (“spend-down”) program or who had mistakenly enrolled in Medicare Advantage plans reported some access problems, but these were not frequent complaints.

## **Care Coordination**

Beneficiaries experienced coordination of care, but it was not due to any effort by Medicare Part D plans or the Medicare program itself. Care coordination was a function of the persistent advocacy of community support workers and other helpers on behalf of their clients. Community support workers in particular noted that coordination between Medicare and Medicaid programs was lacking, and beneficiaries often had little awareness of which program was paying for what health care service. Medicare Part D does not offer much coordination of care to beneficiaries.

## **Involvement of the Patient**

Through Web-based tools such as the formulary finder and on-line plan enrollment, Part D attempts to involve patients in choices about their own care. The Part D program has made an effort to empower patients to make plan decisions. Unfortunately, these Web-based sources of choice and information are often not

accessible to the most economically vulnerable Medicare beneficiaries. Low-income Medicare beneficiaries with mental illness reported that they rarely used the Internet to make plan comparisons or enroll in Part D plans. Community support workers had become adept at using the [www.medicare.gov](http://www.medicare.gov) Web site out of necessity, but involvement of CSWs does not equate with involvement of beneficiaries. Beneficiaries were auto-enrolled into Part D plans in 2006 and again as the “benchmark” status of their plans changed, and they rarely challenged or changed these enrollments unless urged to do so by a community support worker.

### **Information and Education**

Again, through Web-based resources, the Medicare program is attempting to provide information and education to Medicare beneficiaries. Monthly statements also provide communication from Part D plans to their enrollees. Information from plans and from Medicare remains confusing, however, and in the case of Web-based information, largely inaccessible to those who need it most. The Medicare Part D program needs much improvement in the area of keeping beneficiaries informed and educated.

### **Secure Transitions**

By auto-enrolling dually-eligible beneficiaries into “benchmark” Part D plans, the Medicare program did ensure continuity of care for these individuals as they transitioned from Medicaid to Medicare. Auto-enrollment each year as benchmark plans change also ensures secure transitions. However, random plan assignment does not always ensure that beneficiaries are enrolled in the plan that best suits their needs. That said, beneficiaries registered few complaints about plan switching in the Part D performance data.

## **Limitations**

This study is limited by the fact that the qualitative sample was composed of a convenience sample of beneficiaries and community support workers from a very specific agency context in the City of St. Louis, Missouri. All three of the agencies from which participants were drawn have a reputation in the community for excellent case management services, which may have affected the findings. Beneficiaries from these three agencies may receive more services, of a higher quality, than community mental health clients at other agencies or in other parts of the United States.

There were some limitations to the use of a volunteer sample for the focus groups and interviews. Some of those who volunteered to participate in these groups and interviews were individuals who have had particularly negative experiences with Medicare, and who were looking for a forum in which they could air their complaint. Some participants may have offered to take part so that they could obtain the gift card, snacks, and bus passes that were offered to all who took part, even though they did not have particularly well-thought-out opinions about Medicare. The author attempted to minimize this possibility by emphasizing in recruitment materials that participants needed to have experience with the Part D program, and that the research was focused on looking for perspectives and opinions about that program.

An additional limitation was that several of the focus groups were quite small, involving only two or three individuals. However, Toner (2009), in a recent article on qualitative methods, has pointed out the value of very small focus groups in eliciting deep yet focused information from participants. In addition, with participants who had a diagnosis of mental illness, smaller focus groups actually functioned extraordinarily well

and enabled interviewees to stay closer to the main topic of discussion and avoid unnecessary “detours” into other topics.

The quality of focus group and interview data was also affected by the fact that most of the consumer focus group and interview participants had significant thought disorders. Though the majority of participants were able to stay on task and contribute to the data collection process in a clear and organized fashion, there were times when participants’ thought disorders affected the coherence of their speech. Saavedra, Cubero & Crawford (2009) offer interesting insights into the coherence of the narratives of individuals with schizophrenia, and they point out that despite significant thought disorder, many individuals with schizophrenia are able to tell a narrative of their life experiences. By transcribing focus groups and interviews shortly after conducting them, and by keeping groups small, the investigator was able to decipher participants’ narratives and understand their contribution to the process.

Furthermore, the quantitative findings were limited by the small number of benchmark Part D plans available to Missouri beneficiaries in 2009. With only six plans to compare, the ability to draw conclusions about benchmark plans is constrained. The limited variability in the plan attributes also affected the ability to analyze these data in a meaningful way.

### **Implications for Social Work Research**

The finding in this study that most beneficiaries are quite satisfied with their Part D benefits is counterintuitive, when compared with the predictions of Medicare advocacy groups (MRC, 2005) and the observations of psychiatrists who have been surveyed about Part D (West et al., 2007; West et al., 2009). Therefore, there needs to be further study of



dually-eligible Medicare beneficiaries with mental illness, to examine more thoroughly the reasons for their high level of satisfaction with Part D. It would be useful to undertake a broader survey of beneficiaries with mental illness, so that broader trends in Part D could be examined. The findings of this study are limited by their geographic specificity; use of a Medicare beneficiary survey to collect more representative data on mentally ill beneficiaries' satisfaction would provide valuable insights.

In addition, research needs to be conducted to determine whether dually-eligible older adult beneficiaries with mental illness have different needs than younger Medicare beneficiaries disabled by mental illness. The sample in this particular study included mostly beneficiaries under age 65; older adult beneficiaries with mood disorders or schizophrenia may have different needs, especially related to medical co-morbidity. Studies of older adult Medicare beneficiaries have not attempted to disentangle the experiences of beneficiaries with mental illnesses from the larger population of elderly Medicare participants.

Another implication for social work research is that the role of social workers in assisting mentally ill beneficiaries with their Part D benefits needs to be more adequately studied. The Mental Health Part D Web site discusses the importance of community case managers, residential and inpatient staff, and assertive community treatment team members in accessing and utilizing Part D benefits for adults with mental illness, but the exact roles and tasks undertaken by these professionals, many of whom are social workers, have gone unstudied until now. This study found that St. Louis-area community support workers and case managers were very active in a variety of tasks related to accessing medication, medication adherence, and use of insurance programs.

Further study of social workers' roles regarding access to Part D, as well as the pharmacological management of mental illness, would be useful.

Research also needs to be conducted to determine how much social workers and other community-based case managers know about the Medicare Part D benefit. Ferri and Cox (2009) discovered that social work students were not very knowledgeable regarding the Medicare prescription drug program. It would be useful to survey social workers and case managers in community settings to assess their knowledge and understand where gaps in program understanding may be occurring. This would greatly enhance efforts to educate community-based mental health professionals about the use of the Part D program.

In addition, patient-centered care principles should be used more frequently in social work research. Though "client-centered care" is occasionally mentioned in the social work literature (Jindani & Murdock, 2009), the principles of patient-centered care as they are described in the health care literature are relevant to social workers. Patient-centered care is applicable to many typical social work roles, such as advocacy, care coordination, and rehabilitation services. Patient-centered care can be used not only in health services and health policy research, but also as a tool for assessing social service and mental health programs dominated by social work professionals. Leplege et al. (2007) have mentioned that non-medical mental health professionals have shied away from the term "patient-centered care." Nonetheless, social work and psychiatric rehabilitation professionals should embrace the principles underlying the concept of patient-centered care and use them to evaluate the quality of community mental health services.

## **Implications for Health Care Policy**

It appears that Medicare Part D is here to stay (Kaiser Family Foundation, 2010). The new health reform law includes a few provisions related to Part D, the most important of which is probably the effort to close the “doughnut hole” coverage gap over the next several years. This will likely have little impact on dually-eligible beneficiaries, however, as they already have low-income subsidy assistance in the coverage gap. For beneficiaries with slightly higher incomes, the closing of the “doughnut hole” will be extremely helpful, as it will reduce out-of-pocket costs for these individuals.

The newly-initiated efforts within the Centers for Medicare and Medicaid Services to coordinate Medicare and Medicaid benefits have the potential to improve access to coverage for many dually-eligible beneficiaries (Kaiser Family Foundation, 2010). Coordination of benefits provided by the Medicare and Medicaid program could lead to better coverage and fewer gaps such as the current gap in dental care for low-income beneficiaries. It could also help ensure that at least some drugs not covered by Medicare Part D will be paid for by the Medicaid program. The Centers for Medicare and Medicaid Services do need to take constructive action to ensure better coordination between the Medicare and Medicaid programs. At present, the coordination of these programs is largely left in the hands of community professionals and helpers; better organization on the system level would take a large burden off of case managers and pharmacists.

The Centers for Medicare and Medicaid Services also need to take action to ensure better information and communication from Part D plans to stakeholders. Advertisements for Part D plans and Medicare Advantage plans need to be monitored and

clearly identified as advertising, so that beneficiaries do not switch plans or dis-enroll from a plan because they believe they are “required” to do so. Too much of the current advertising appears in a form that is interpreted by beneficiaries as a directive from the Medicare program.

Furthermore, the level of health literacy of beneficiaries needs to be taken into account in Medicare communications. The Centers for Medicare and Medicaid Services need to recognize that terms such as “catastrophic” and “benchmark” may confuse beneficiaries. Reading levels of Medicare materials must be brought down, and at the same time, CMS needs to undertake community-level efforts to improve the health literacy of lower-income Medicare beneficiaries.

### **Implications for Social Work Policy and Practice**

Clients need help to use this benefit. The nature of the paperwork and the language used by benefit plans are such that the average citizen has a hard time understanding them (Cummings, Rice, & Hanoch, 2009). In the stakeholder focus groups, not only beneficiaries but also community support workers expressed their difficulties in comprehending the Part D paperwork. In addition, low-income beneficiaries did not have extensive computer access, so Web-based tools and information, on which community support workers were reliant for knowledge of the Part D benefit, were not available or particularly helpful to beneficiaries. Beneficiaries with disabilities are likely to face similar problems as older adults experience in using the Medicare Web site, so resources need to be more accessible (Czaja, Sharit, & Nair, 2008). Research on computer use among the elderly has confirmed that those with disabilities and those with lower incomes have less access to computers (Wright & Hill,

2009). For adequate information, communication, and education to be provided to beneficiaries and their helpers, print resources need to be available to beneficiaries. Printed materials should be distributed through community mental health agencies, in addition to being mailed to beneficiaries. Furthermore, greater computer/Internet access needs to be provided to mental health consumers in clubhouse settings.

Web-based resources should be more broadly promoted among community support workers and nurse-case managers, so that they can use these tools to help their clients obtain what they need from the Part D program. There are many Web sites with valuable information about accessing the Part D benefit, not only the official Medicare Web site, but also a number of informational Web sites sponsored by non-profit organizations and advocacy groups. These resources need to be more widely publicized so that community-based mental health professionals can more easily take advantage of them.

Furthermore, there needs to be a mechanism for paying for community-based service coordination for dually-eligible beneficiaries with mental or cognitive conditions. Part D provides a mechanism for pharmacists to be reimbursed for medication therapy management (MTM) services to Medicare beneficiaries with chronic conditions, but many pharmacists do not take advantage of this source of payment. This may be in part because they view MTM as a way for the Medicare program to contain costs, rather than as a mechanism for effective and compassionate service provision to medically vulnerable beneficiaries. In addition, there is no provision for social workers or other community providers to be paid for the work that they do in coordinating prescription drug benefits (Kravitz & Chang, 2005). It is not clear whether Medicare Part D should

pay for this service, or whether funding should come from another federal or state source. Currently, the services of community support workers at mental health agencies are largely financed through Medicaid. The examination of patient-centered care principles in the Part D program illustrates the tremendous importance of care continuity and emotional support. Community-based service coordination should be reimbursed (National Health Council, 2009; Thorpe et al., 2010).

The services of State Health Insurance Assistance (SHIP) programs, at least in the state of Missouri, need to be more broadly promoted. Stakeholders, be they beneficiaries or their helpers, do not know where to go to get help related to Part D. Not a single focus group or interview participant mentioned Missouri CLAIM (Community Leaders Assisting the Insured of Missouri; Missouri's SHIP program) as a source of information about Part D. Collaboration between the CLAIM program and community mental health agencies, similar to the collaborations between the CLAIM program and agencies that serve the elderly and people with physical disabilities should be encouraged. CLAIM may even be able to train volunteer counselors from mental health agencies, as they have done with volunteers from agencies for the aging. This would lead to greater education and empowerment—key aspects of patient-centered care.

“Smart” methods of assigning benchmark plans to low-income beneficiaries must be used, so that beneficiaries and their helpers do not have to spend a great deal of time and energy determining whether the prescription drug plan to which the beneficiary has been randomly assigned is the best fit for him/her or not (Summer et al., 2008). The switching process should not be as burdensome to beneficiaries as it is under the current system of re-assigning prescription drug plans. This would contribute greatly to the

patient-centeredness of the Part D program, by promoting coordination of care as well as continuity and secure transitions (Neuman & Cubanski, 2009).

### **Implications for Social Work Education**

It is clear from this study that generalist social workers, those who are likely to be in case management positions helping adults with mental illness, need a thorough knowledge of Medicare. It needs to be stressed in bachelor's- and master's-level social policy courses that Medicare is not just the territory of the elderly, but an important resource to many men and women with permanent disabilities. Education of generalist social workers also needs to emphasize the fact that low-income Medicare beneficiaries are more likely to have serious mental illness than higher-income beneficiaries. Current research indicates that social work students do not know very much about Medicare Part D; this situation needs to be addressed in social work curricula (Ferri & Cox, 2009).

Another implication for social work education is that there is a need, more than ever, for social workers to be able to communicate across health care disciplines. Case managers are often in the position of having to communicate about clients' medication needs with nurses, pharmacists, and physicians, and the ability to "speak a common language" affects the case manager's ability to meet the client's needs.

The important role of social workers in medication access and adherence has not been stressed enough in social work education or in the professional literature. Case managers not only assist people with benefits information and statements from their prescription drug plans; they are also helping people to obtain their medications and filling medicine planners. Graduate social workers in particular need knowledge of psychopharmacology and health care policy to be effective in their community roles.

Further examination is needed of the roles social workers play in medication adherence in the community. As Pedan et al. (2009) have stated, health care providers have a responsibility to raise awareness among their clients regarding their prescription drug coverage and costs; educating social workers for this role is essential.

The knowledge generated in this study will not only advance our understanding of the Medicare prescription drug benefit as it has been implemented thus far, but will also help researchers and policy-makers to understand how Medicare policy can be reformed to better serve the needs of adults with serious mental illness. A better knowledge of stakeholders' priorities and an accurate understanding of the patient-centeredness of the various Part D plans will enable policy-makers to undertake legislative and regulatory changes that can make this program work better for some of its most vulnerable beneficiaries.



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