AN ABSTRACT OF THE THESIS

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This thesis is based on a study conducted for the state of Oregon's Office of Mental Health Services (OMHS). OMHS' primary research objectives included 1) the identification of the unfunded population (individuals who are uninsured and ineligible for Medicaid) who seek services at community mental health programs and 2) an examination of this group's access to atypical antipsychotic and antidepressant medications. OMHS sought this data in order to inform legislative decisions regarding a forthcoming state budget proposal for a specialized atypicals fund. The author collected ethnographic data through semi-structured interviews with 57 mental health clinicians and 41 mental health advocates throughout Multnomah, Linn and Lincoln counties.

While answers to the primary research objectives were inconclusive, the qualitative data characterizes the target population and contextualizes the unfunded client's medication access issues at county-related mental health clinics. Specifically, the study results indicate that 1) the complex characteristics of the unfunded population and the inadequacies of the available medication resource programs should be examined more

thoroughly before allocating appropriated funds, 2) insufficient mental health services in general is the foremost problem for unfunded clients, and that which contributes to difficulties in accessing psychotropic medications, and 3) appropriated funds from the state's budget would not adequately resolve the medication needs for the target population. The study findings suggest that the state's concern with atypical medications overshadows existing practical, everyday problems in the clinics.

The author analyzes the study from a Critical Medical Anthropology perspective, examining the relationships between the global and local contexts surrounding atypical medications, and discussing the practical use of the research data. From this perspective, the state's preoccupation with supplying atypical medications for the target population appears to be driven more by the pharmaceutical industry's profit-making interests and the historical role of the public psychiatric field than by quality health care decisions. The author also discusses medical hegemony in terms of the psychiatric field, and the ways in which this effects the asymmetrical power within the Oregon mental health system.

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Prescribing Politics: An Examination of the Local and Global Factors Which Govern Access to "Atypical" Psychotropic Medications for Oregon's Unfunded Clients

by

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A THESIS

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I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

Judith L. Maxey, Author

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Prescribing Politics:

An Examination of the Local and Global Factors Which Govern Access to "Atypical" Psychotropic Medications for Oregon's Unfunded Clients

INTRODUCTION

In February 1999, the Oregon State University (OSU) Anthropology Department received a research grant from the Office of Mental Health Services (OMHS), a division of the Oregon Department of Human Resources. Dr. Sunil Khanna, principal investigator for the study, employed me to assist with the research and conduct the necessary fieldwork. OMHS had proposed a study with the following main goals:

- 1) To identify the uninsured population who suffer from mental illnesses and seek services from county-related mental health clinics, and
- 2) To better understand the distribution and accessibility of atypical antipsychotic and antidepressant drugs at those clinics.

The resultant ethnographic data for the study, which I gathered from March-June of 1999, serves as the basis for this thesis paper.

In the following pages, I will first provide information regarding the study's local and global context, including background information on "atypical" medications, a brief explanation of mental health services in Oregon and the study's genesis. Secondly, I will discuss Critical Medical Anthropology--the theoretical and practical perspective which informed my approach to the research. Third, I will present and analyze the qualitative data from the study interviews, and summarize the conclusions. In the discussion, I will consider the political-economic and socio-cultural factors associated with the study, and

¹ OMHS is Oregon's primary administrative agency for mental health services. OMHS oversees the Community Mental Health Programs, and is comprised of the following units of operation: Children's Services, Adult Services, Quality Assurance, Extended Care Management and Budget and Operations.

their role in both the global hegemony of biologic psychiatry and the daily use of atypical medications in Oregon mental health clinics. Finally, I will describe how OMHS made use of the research within their agency, and offer suggestions for ways in which the data might be further utilized and expanded upon.

LOCAL AND GLOBAL CONTEXT

"Medicine is nothing more than politics on a grand scale."

-- Rudolf Virschow

Like most contemporary health issues, the research conducted for OMHS can be viewed from a macrolevel, or global perspective, as well as the microlevel, or local perspective. Research that includes pharmaceuticals, in particular, deserves a comprehensive approach, one which carefully considers macro-micro relations. The following section provides multifarious contextual details related to the OMHS study.

"Atypicals"

Central to the OMHS study is the newest class of psychiatric medications, most commonly known as "atypicals". The atypicals include both antidepressant and antipsychotic medications, and currently consist of 13 prescription medications manufactured by a host of pharmaceutical companies. (New atypicals continuously enter the market. See Appendix 1 for a list of the drugs included in this study). Copious information exists regarding this new generation of drugs. Scientists, medical experts, economic advisors and social scientists have written abundantly on these somewhat controversial medications. The literature topics range from the scientific details of their chemical processes to the social ramifications of their use. Here, I will provide brief

² Hereinafter, I will use the term atypicals to refer to all atypical antipsychotic and antidepressant medications related to the OMHS study.

synopses of the topics most germane to the OMHS study, and those which will serve as fundamental background knowledge for the reader.³

What are "atypicals"?

The term "atypical" essentially designates the newer, more expensive psychotropic medications currently available on the market. This term may soon become obsolete, however, as the use of this class of medications becomes more typical each day. Atypicals can be distinguished from the older, "conventional" medications by their distinct chemical mechanisms. Like the older medications, the use of atypical antipsychotics and antidepressants is based on the assumption that mental illnesses are biologic. This theory posits that mental illnesses stem from chemical imbalances; "abnormalities" in behavior, emotions and cognition are assumed to be produced by biochemical alterations in the brain. (Khan, 1999)

While explicit information regarding the clinical use of atypicals is not necessary to substantiate the main arguments of this paper, brief summaries of the current research and controversies surrounding atypicals assist in providing a context for the study. Of notable interest are the debates concerning the atypicals' efficacy, particularly in contrast to older medications. As very little research simultaneously considers antidepressants and antipsychotics, I will first discuss them separately.

³ While I cite references for my statements in this section, I have in no way performed an exhaustive literature review on atypical medications. Lengthy volumes could be written on all of the various studies of the efficacy and cost-effectiveness of atypicals. The citations I have included should be seen as examples of the work, not comprehensive references.

⁴ See Khan's *How Do Psychotropic Medications Really Work?* (1999) for a detailed descriptions of the chemical mechanisms of atypical antipsychotic and antidepressant medications.

Atypical Antidepressants.⁵ The atypical antidepressants include four Selective Seratonin Reuptake Inhibitors (SSRI's)--Prozac, Luvox, Paxil and Zoloft⁶--which make up the most popular group of antidepressants, and five other new generation antidepressants which have no particular pharmacologic connection between them. The medications in this second group-- Effexor XR, Serzone, Desyrel, Wellburtrin SR and Remeron--are relatively new and less researched. For simplicity, I will discuss the antidepressants as a whole. However, the reader should note that, like the individual characteristics of the antidepressants--side-effect profiles, for example--the quantity and quality of research for each antidepressant medication varies greatly. This applies to the atypical antipsychotic medications as well.

Since the rise of the SSRI's at the beginning of the 1980's, the dominant literature has reported that atypical antidepressants are superior to the older medications. Although the efficacy, of SSRI's at least, has generally been noted as equal to that of the older medications, *effectiveness* has been reported as greater because of relatively more favorable side effect profiles--fewer and different side effects than the older medications. Atypical antidepressants have generally been noted to promote higher patient adherence to medication regimens due to these less troublesome side effects. (NIMH, 1995; Harrison, 1994; Pinkowish, 1997) Moreover, many studies have concluded that SSRI's are less toxic overall than older medications. As antidepressant poisoning accounts for nearly 5% of documented suicides (Owens, 1994), some clinicians have argued that older

⁵ This discussion only includes studies which have been conducted for the use of antidepressants for depressive disorders. However, antidepressants are increasingly used for other disorders, such as premenstrual syndrome, chronic pain, eating disorders and obsessive-compulsive disorder. (Ross-Flanigan, 1999)

⁶ Brand names will be used throughout this paper.

medications should be consigned to second or lower choice. (Fradd, 1992, Milne, Alcorn, & Bell, 1993)

Research in the 90's has greatly challenged these widely accepted assertions about antidepressants. In fact, recent studies have shown "no clear difference" between the benefits of the older and newer medications (Song et al., 1993; Rush, Koran, & Keller, 1998; Simon et al., 1996). Even the one seemingly irrefutable benefit to the atypical antidepressant—the reduced possibility of overdosing—has been disputed. (Owens, 1994) This year, in a landmark study, the US Department of Health and Human Services confirmed that SSRI's are no more effective at treating depression than older classes of drugs.

Peter Rubin, a psychiatrist, offers the following comment to summarize the efficacy debate of antidepressants: "The appeal of drugs that are selective in their action (SSRI's) is that they are more likely to do what you want and not do what you don't want. However, they will not necessarily do what you want any better than a drug which is less selective." Rubin concludes that the primary advantage to the arrival of new antidepressants "seems to be that it has substantially increased the therapeutic options for depression" (1994).

Atypical Antipsychotics. Antipsychotic drugs, otherwise known as nueroleptics or major tranquilizers, are medicines used to treat psychosis and other mental conditions, most commonly schizophrenia. The new atypical antipsychotics have been referred to by many as "magic bullets". Many studies have concluded that the novel antipsychotics demonstrate superior symptom control, an improved safety profile and benefits to quality of-life, while generating fewer side effects, thus removing a major cause of non-

adherence. (Levinson, Umapathy, & Musthaq, 1999; Marder, 1999; Wahlbeck, Cheine, Essali, & Adams, 1999) Although these medications have been available for only a short time (about 10 years in the US), and there is relatively little scientific literature on the subject, many recent studies have concluded that, because of their more desirable side effect profile, they should be seriously considered as a first-line therapy, especially for a first-episode of psychosis. (Conley & Buchanan, 1997; Sheitman, Lee, Strauss, & Lieberman, 1997) However, the long-term risks of all of these medications are virtually unknown, and long term, well-conducted and reported trials are lacking. (Kennedy, Song, Hunter, & Gilbody, 1999; Rascati & Rascati, 1993; Rush et al., 1998) One of the difficulties with antipsychotic medications is that their functions, and why they affect individuals the way they do, remain a mystery. In fact, in one of Eli Lilly's medication package inserts, the company notes that how Zyprexa works, or any other antipsychotic, is unknown. (Valenstein, 1998)

As evident, research concerning atypicals is inconclusive and inconsistent.

Critiques of the research itself question such details as the accuracy of comparing medications with placebos (Frank, 1991) and the selective disclosure of clinical trials-only publicizing those trials which support the use of the medications public. (Kirsch & Sapirstein, 1998; Moore, 1999) Furthermore, there is an absence of the consumers' perspective regarding the efficacy and characteristics of atypicals. Most scientific literature addresses the ways in which drugs work in general, on the "typical" patient, despite the unpredictable nature of individual patient response.

Finally, the objectivity of the prevalent pharmaceutical company-funded studies which dominate the current literature is disputable. Despite the objective quality our

culture assigns to "scientific", "technical" research, one must consider the role of the dominant social and economic forces on scientific endeavors. As R.C. Lewontin so poignantly states, "Science is molded by society because it is a human productive activity that takes time and money, and so is guided by and directed by those forces in the world that have control over money and time" (Lewontin, 1991, p. 3).

One thing is certain; the sheer quantity of research and popular literature which promotes the use of atypicals outweighs that which criticizes it. The notion of the superiority of atypicals permeates the current literature—the body of literature which James Healy, author of *The Antidepressant Era* (1997) refers to as the "politically dominant literature". Moreover, in the US, the National Institute for Mental Health (NIMH), The National Alliance for the Mentally Ill (NAMI) and the American Psychiatric Association (APA)—three of the most influential national organizations in terms of mental illness treatments—support and promote the use of atypicals.

Pharmacoeconomics

Economic evaluation of pharmaceutical products, or pharmacoeconomics, is a rapidly growing area of research. Over the last few years, the rigor of this field has increased greatly. While some medical experts question the basic concept of pharmacoeconomics--disputing, among other issues, the accuracy of the data available for economic evaluation (Schulman & Linas, 1997)--pharmacoeconomic evaluations are prevalent in medical literature. These evaluations guide clinicians' and state and federal administrators' choices about new pharmaceutical products.

Officials from all parts of the world voice have expressed their concern about the cost-effectiveness of mental health medications. In the US, research shows that treatment for mental illnesses is an increasingly large expense for both federal and state governments. NIMH reports that each year more than 17 million Americans develop clinically identified depression. (1999) Similarly, 1991 NIMH report stated that the US spent 65 billion dollars on schizophrenia alone. (Wyatt, Henter, Leary, & Taylor, 1991) Furthermore, the National Advisory Mental Health Council estimates that in any given year 2.8 percent of all adults and 3.2 percent of adolescents suffer from a severe psychiatric disorder, defined as "disorders with psychotic symptoms such as schizophrenia, schizo-affective disorder, manic-depressive disorder, autism, as well as severe forms of major depression, panic disorder, and obsessive-compulsive disorder" (NAMHC, 1993). This year's Surgeon General's seminal report on mental illness evinces the growing frequency of mental illness diagnoses. (NIMH, 1999)

Consequently, several pharmacoeconomic studies target the new antipsychotic and antidepressant medications. A vast number of these studies focus on the uninsured and underinsured, particularly the homeless population and those individuals diagnosed with schizophrenia. (Andrews et al., 1985; Frank, Goldman, & McGuire, 1996; McGuire, 1991; Remillard & Johnson, 1993; Wyatt et al., 1999) Although fewer studies have addressed the cost-effectiveness of depression (Hotopf, Lewis, & Normand, 1996), an explosion of studies have concluded that the long-term cost-effectiveness of the antipsychotic atypicals might save local governments billions of dollars. (Davies & Drummond, 1993; Glazer & Mhonstone, 1997; "US Health", 2000; Jonsson &

Bebbington, 1994; Meltzer et al., 1993; NIMH, 1999; Revicki, 1999; Williams & Dickson, 1995).⁷

While statistics from these studies have been cited frequently, some mental health experts have challenged these figures. Counter-arguments point out such details as an actual *shift* in costs (from services to medication costs), rather than a cut in cost from the medicines. (Viale et al., 1997) Although less in number, the results of these maverick studies, must be equally considered, since the pharmaceutical companies themselves also finance much of today's pharmacoeconomic research.

Because of this flood of pharmacoeconomic debate, state governments have been urged to evaluate client access to atypicals. Consequently, many states in the nation have "adjusted their funding" for at least atypical antipsychotics for schizophrenia. Texas legislators, for example, just approved nearly 50 million over a two-year period to give residents free access to atypicals. (USA Today, 1999)

Other Financial Matters

Two other financial concerns may have an impact on states' decisions regarding atypical medications. First, state governments must now consider law suits while deliberating access to atypicals. Prescribing psychiatric medications has become a legal matter. The following is an excerpt of a letter written by Steve Hyman, director of the NIMH, sent to Medicaid directors nationwide:

⁷ These studies generally consider the state's direct costs (hospital/institution cost, health care provider fees prescription drugs), indirect costs (reduced/lost productivity due to morbidity or mortality) and other costs including productivity of family caregivers. When considering the treatment for individuals suffering from disorders with psychotic symptoms, such as schizophrenia, schizo-affective and manic-depressive disorder, hospitalization and crisis-care expenses are weighed heavily.

There is one other financial issue that should be considered in this regard, and that is the potential cost of lawsuits that may result when patients now are started on standard antipsyhotic medication (rather than new atypicals) and later develop persistent tardive dyskinesia. It would presumably take only one or two lawsuits of this sort to make up the difference between the cost of generic standard antipsychotics and the atypical antipsyhotic medications currently available. (1998)

In fact, in 1997, patients sued psychiatrists in two states, holding them liable for the side effects caused by their mental health medications. In both lawsuits, the patients alleged that the state and the state-employed psychiatrists were liable for the side effects. (Barker, 1997)

Second, generic drug companies have launched an escalating war on research-based pharmaceutical companies. Patent challenges by generic makers are currently on the rise. For instance, in February 1999, Barr Laboraties, a generic drug company, challenged Eli Lilly & Co.'s patent on Prozac. This occurred when Barr noticed that Lilly had filed multiple subsequent patents on a drug. (US News & World Report, 1999) This risk of losing extremely lucrative patent rights may prompt pharmaceutical company lobbyists to become more aggressive with the promotion of their products.

Pharmaceutical Profits

The price of atypical medications in the US, including both antidepressants and antipsychotics ranges from approximately \$60 to \$250, for a standard dosage of a one month's prescription. (See Appendix 2 for a current list of individual medication prices.)

Consequently, the sales of these new generation medications, greatly influences the stock

⁸ See *A Big Downer for Prozac* (US News & World Report, 1999) for an in-depth discussion of how companies such as Eli Lilly & Co. have considered "payouts"-- annual settlements to generic drug companies until patents expire. This allows the generic companies to make a financial killing without ever producing any medication, while the branded companies continue to earn their normal profits.

market. The North American market is, in fact, dominated by the US-based pharmaceutical companies. Profit levels indicate that pharmaceutical companies selling in the US continue to have one of the highest profit margins of any American industry. (Sasich, Torrey, & Wolfe, 1999) For example, a 1999 US News and World Report stated that Eli Lilly and Company's profit from Prozac--the most popular antidepressant-closed in on \$3 billion, about 30% of Lilly's total revenue. (1999) The economic power behind atypicals sales is unmistakable.

Interestingly, a 1999 study by the Public Citizen's Health Research Group showed that the price of eight of the atypical medications included in the OMHS study were highest in the US, compared with 17 other European and North American countries. On the average, these eight drugs were twice as expensive in the US. Individually, some medications were as much as six times higher. (Sasich et al., 1999)

At the local level, the Oregon Health Plan (OHP)⁹ spent \$26.5 million on Prozac, Paxil and Zoloft, just three of the atypical antidepressants available as outpatient drugs. At the same time, the cost to Oregon taxpayers for these drugs increased 19% in 1998. According to figures supplied by the Office of the Oregon Health Plan Policy and Research, 43,919 OHP members received at least one prescription in 1998 for Prozac, Paxil or Zoloft. (Oregon Health Forum, 1999)

As the authors of *The Anthropology of Pharmaceuticals*, so precisely state, pharmaceuticals are "symbols of hope and health in and of the promise of advanced technology", while on the other hand, "they are part of the international flow of capital and commerce" (van der Geest, Reynolds Whyte, & Hardon, 1996, p.1).

⁹ Oregon's Medicaid expansion program which extends managed care benefits to people with low incomes.

The Clinical Use of Atypicals

As previously mentioned, mental health professionals prescribe atypicals based on the theory that mental illnesses are, at base, the result of chemical imbalances of the brain. This type of treatment is generally referred to as biologic psychiatry, or biomedical psychiatry. In this section I will present a brief overview of the controversies which surround the practice of biologic psychiatry, and a description of the local clinic settings involved in the OMHS study.

Biologic Psychiatry

Elliot Valenstein, Professor Emeritus of Psychology and Neurosciene, summarizes American psychiatry as having changed from "blaming the mother to blaming the brain" (Valenstein, 1998, p. 1). Until approximately fifty years ago, most mental health professionals subscribed to the idea that the cause of mental disorders was rooted in early experiences within the family. The majority of mental health professionals employed some variation of psychoanalytic therapy with their clients.

Today, the biochemical theory of mental illnesses dominates the psychiatric field. Most authorities, and the public, believe that the "disturbed thoughts and behavior of mental patients are caused by a biochemically defective brain" (Valenstein, 1998, p. 1). This radical shift in etiology has drastically changed psychiatric practices.

Some mental health professionals consider the chemical alterations of atypicals as a tool for treatment, a way to sufficiently control clients' symptoms of mental illnesses to take advantage of other forms of treatment, such as psychoanalysis. Others promote the continuous use of atypicals, especially in acute cases of schizophrenia for example, which often result in an individuals' inability to cope with the ordinary demands of life. While

many mental health professionals still acknowledge individual experience as an element of the origins of many disorders, post traumatic stress or some levels of depression for example, the basis of biologic psychiatry calls for an alteration of the brain's chemistry.

Today, one often hears the analogy that as a diabetic takes insulin, most people with serious mental illness need medication to help control symptoms. Neuroscientists and mental health professionals promote the existence of a "normal" level of various chemicals in the brain, which, if unbalanced, causes particular mental illnesses.

Schizophrenia, for example, is commonly claimed to be caused by an excess of neurotransmitter dopamine, and depression by a deficiency of serotonin. (Valenstein, 1998) These widely accepted scientific causes of mental illness--today's "breakthroughs" in neuroscience--have caused a pharmacological revolution in psychiatry. Experts note that neuroscience has made so many new research discoveries about the chemical aspects of the brain, so quickly, that the entire shape of the the pychiatric field and related research has changed.

In Arthur Kleinman's *Rethinking Psychiatry*, he notes that since the 1980's, psychiatry has virtually been overtaken "with a fervor for biological explanations" (Kleinman, 1988, p. 1). Over the last two decades, the discovery and development of pychoactive medications with specific effects on particular disorders has been the focus of the psychiatric field. The following message from the Director of the National Institute of Mental Health exemplifies the widely accepted biomedical theory underlying biologic psychiatry, and its implications for the psychiatric profession and those suffering from mental illnesses:

Throughout the past 50 years, the results of research supported by the National Institute of Mental Health have brought new hope to millions of people who suffer from mental illness and to their families and friends. In work with animals as well as human participants, researchers have advanced our understanding of the brain and vastly expanded the capability of mental health professionals to diagnose, treat, and prevent mental and brain disorders.

During this last decade of the twentieth century--designated 'The Decade of the Brain' by the U.S. Congress--knowledge of brain function has exploded. Research is yielding information about the causes of mental disorders such as depression, bipolar disorder, schizophrenia, panic disorder, and obsessive-compulsive disorder. With this knowledge, scientists are developing new therapies to help more people overcome mental illness. (NIMH, 1995)

This relatively new etiology of mental illness, and the consequent use of psychoactive medications as the main tool of biologic psychiatry, have been largely accepted by contemporary society. In particular, atypical antipsychotic medications have been heralded as "magic bullets", and the names of many atypical antidepressants, like Prozac, have become part of everyday language. In short, the use of atypical medications is predominantly viewed as the most successful treatment for individuals suffering from mental illnesses. Yet, without discounting individual successes with biologic psychiatry, a body of literature has evolved which sharply criticizes biologic psychiatry.

Critics, which comprise professionals from a variety of fields, including psychiatry, and those suffering from mental illnesses, denounce biologic psychiatry on political, historical and cultural bases. Much of the current literature has grown out of the anti-psychiatry movement of the 60's, which initially brought the critique of biologic psychiatry into public view. This movement evolved partially in response to the first psychoactive medications discovered in the 50's, and was largely comprised of members

of the psychiatric profession. Their work initiated a shift of focus, from clients to the psychiatric field at large. (Ingleby, 1980)

Those analyzing biologic psychiatry cite a plethora of explanations for their critiques, which primarily involve the historical, political and social forces which have shaped the field of psychiatry. Their theories about the evolution of the psychiatric field range from Foucault's classic socio-political-historical explanation of the state's treatment and definition of the mentally ill (Szasz, 1994) to more concrete details such as the pharmaceutical industry's intentional monopoly on new drug education for physicians. (Healy, 1997) Here, I offer a few of the primary arguments included in the recent critiques of biologic psychiatry. ¹⁰

Critics question the scientific view of modern psychiatry. Horacio Fabrega notes that a fundamental tenet in the "critical psychiatry" literature addresses the "inappropriateness of using the positivistic paradigm of the natural sciences (i.e., its concern with causality and the behavior of physical objects) to explain phenomena of a social and political nature, wherein the notions of meaning, symbols, and interpretation properly apply" (Fabrega, 1993, p. 185). Critics state that the scientific, reductionist ideology of mental illness tends to obscure other essential aspects of client treatment, mainly listening to the patient. Biologic psychiatry is criticized for placing too much emphasis on pinpointing which medications might best alleviate the client's symptoms. (Kaiser, 1996) In Peter Kramers' nation-wide bestseller, *Listening to Prozac*, he states, "In clinical pharmacology, contemporary technology plays a dominant role in shaping ideology. What we look for in patients depends to a great degree on the available

For detailed accounts of the socio-political forces behind biologic psychiatry, see works by Thomas Szasz, David Inglebury, David Kaiser, Elliot Valenstien, Arthur Kleinman and Horacio Fabrega.

medication" (Kramer, 1993, p. 35). Furthermore, critics note that most biologic psychiatrists seem unaware that "psychiatric concepts, research methodologies and even data are embedded in social systems" (Kleinman, 1988, p. 3).

Furthermore, the underlying scientific causes of mental illnesses, which serve as the basis for biologic approach to treatment have never been proven (Kaiser, 1996). In fact, many point out that there is no convincing evidence that most mental patients even have any chemical imbalance. (Valenstein, 1998) David Kaiser, a psychiatrist, claims that biologic psychiatry is "essentially a pseudo-scientific enterprise that grew out of modern psychiatry's desire to emulate modern medical science, despite the very real possibility that psychic pain, because of its existential nature, may always elude the capture of modern medical discourse and practice". He argues that the biomedical model finds easy acceptance in the US due to many cultural phenomena, including a belief in limitless scientific progress, a penchant for quick-fix approaches and drug dependence. (Kaiser, 1996)

The relationship between the field of psychiatry and the pharmaceutical industry serves as another primary source of conflict for critics of biologic psychiatry. In Robert Fancher's Cultures of Healing: Correcting the Image of American Mental Health Care, he simply states, "drugs drive biological psychiatry" (1995, p. 263). Basically, critics believe that the commercial motives of pharmaceutical companies cannot be removed from any of the industry's involvement with the psychiatric field. In fact, pharmaceutical companies have an enormous influence in promoting their products to both physicians and to the potential consumers of drugs. Among many issues, critics scrutinize the pharmaceutical industry's editing power over drug studies in the leading psychiatric

journals, the financial perks offered to private physicians for using new medications and the substantial financial backing the APA receives from the industry at large. (Valenstein, 1998).

The following excerpt from David Kaiser's Against Biologic Psychiatry summarizes much of the debate surrounding biologic psychiatry:

As a practicing psychiatrist, I have watched with growing dismay and outrage the rise and triumph of the hegemony known as biologic psychiatry. Within the general field of modern psychiatry, biologism now completely dominates the discourse on the causes an treatment of mental illness, and in my view this has been a catastrophe with far-reaching effects on individual patients and the cultural psyche at large. It has occurred to me with forcible irony that psychiatry has quite literally lost its mind, and along with it the minds of the patients they are presumably supposed to care for. Even a cursory glance at any major psychiatric journal is enough to convince me that the field had gone far down the road into a kind of delusion, whose main tenets consist of a particularly pernicious biologic determinism and a pseudo-scientific understanding of human nature and mental illness. (1996, p. 1)

Oregon Mental Health Clinics and the "Unfunded" Population

The OMHS study revolved around access to atypicals from community mental health programs (CMHP's)--the public mental health services located in each county seat of the state. In an attempt to create a "comprehensive snapshot", the OMHS staff chose a metropolitan county, a frontier rural county and a medium density county--Multnomah County, Lincoln County and Linn County, respectively-- as the three county study sites. These counties vary immensely according to their clinic populations and the funding sources for their programs. Generally, however, CMHP's receive funding from state and county funds, and in some cases, from private organizations and grants. Capitation

¹¹ Unlike Linn and Lincoln counties, Multnomah County contracts out all of the mental health services that would normally be provided at one community mental health program to a variety of private agencies.

payments from OHP clients serve as the primary source of funding for all three counties. 12

Most CMHP's offer a variety of services and therapies. Normally, a client will be attended by several categories of employees, including but not limited to the following: intake personnel who assess the client upon arrival; skills trainers and case managers who assist the client with their daily life and treatment plans, depending on the severity of their illness, a variety of therapists; and nurse practitioners and psychiatrists who prescribe medications.

Currently, none of the clinics in the state are designed to regularly pay for any type of medication for unfunded clients¹³; the state does not maintain a budget for medications for indigent clients. In the case that a client does not qualify for OHP, nor any of the federal and state programs designed to assist the unfunded population with their medication needs, each county must utilize their own budgeting creativity and/or outside resources.¹⁴ If no resources can be established, the client is responsible for the costs of their medication.

¹² Public mental health services in Oregon are administrated by Mental Health Organizations (MHO's). CMHP's and county-related clinics essentially serve as subcontractors for these MHO's. Each month the state pays the MHO's a set capitation fee for OHP enrollees' mental health services. These fees form a large portion of the clinics' annual funding. For further details on managed care and the mental health system, see Koyanagi's What is "Managed Care"?

¹³ We chose to use the term unfunded, rather than uninsured, as some of the clients seeking medication funding actually have inadequate or exhausted private insurance.

¹⁴ At the time the study was conducted, Multnomah County had recently implemented a program called the Indigent Medication Program (IMP). The IMP is a unique funding option for unfunded clients who meet designated criteria. Funds for the program are limited, and agencies are urged to use any other resource for medications first, including pharmaceutical scholarships. Because of the new status of the program and its uniqueness to Multnomah County, it will not be addressed fully in this paper. However, future studies should review this program, as it addresses many of the medication access problems revealed in this study.

Genesis of the OMHS Study

An examination of the origin of the OMHS research is critical in establishing the study background. The following paragraphs provide the formal version of the genesis of the research. OMHS staff members provided the OSU Anthropology Department with this information.

In July of 1997, state legislators appropriated \$23.2 million to the Emergency Board of the state of Oregon. This Board provides general fund allocations to state agencies (such as OMHS) for unanticipated needs when the Legislature is not in session. Within the \$23.2 million general purpose appropriation, 1.3 million dollars was reserved to provide medication to citizens who are seriously and persistently mentally ill, and who do not otherwise qualify for the Oregon Health Plan or the Family Health Insurance Assistance Program.

OMHS staff members worked together with a task force in order to distribute these funds to the various counties in Oregon. ¹⁵ After using an allocation formula to equitably distribute the funds throughout the state, a small sum of money remained. The Legislation agreed to allow OMHS apply these funds to relevant research.

Although a legitimate description of the study's evolution, this account does not identify the driving forces behind many of the decisions involved. In fact, lobbyists for various pharmaceutical companies who manufacture atypical medications played a large role in establishing the initial allocation of 1.3 million dollars to OMHS, and the creation

¹⁵ In fact, at the time of the study, the counties were utilizing these funds for medications *and* other mental health services. The 1.3 million had initially been designed exclusively for atypical medications. Only upon the urging of the individual counties did the requirements change to include treatment and medication for the unfunded. The three counties in the study appeared to be using their funds in distinct ways. However, these funds can generally be characterized as a last resort fund for emergencies in all of the counties.

of the research objectives. As an OMHS staff member expressed their involvement, the pharmaceuticals lobbyists "sanctioned" the use of the money.

Opinions vary about the role of pharmaceutical company lobbyists, and their influence on state decision-making. On one hand, they can be seen as disreputable influence peddlers who attempt to buy votes with campaign contributions, for the sake of private interests. On the other hand, they can be viewed as important resources who educate policymakers about the medication options for those citizens who suffer from mental illnesses. Regardless of one's opinion of the lobbyists, the profit-making ramifications for the companies they represent are unambiguous.

In the case of the lobbyists in Oregon, the 1.3 million allocation was a mere foreshadowing of a future pursuit. During the 1999 July Legislative sessions, the lobbyists intended to recommend a line item in the state's budget which would be designated specifically for the purchase of atypical medications for county clinics. ¹⁶ This was a central aspect to the OMHS study. The lobbyists based part of their argument for the special budget on their perception that the unfunded population's atypical needs were being met primarily through sample medications and patient assistance programs (also known as scholarships) which individual pharmaceutical companies provide. For this reason, the lobbyists agreed upon research regarding access to atypicals. OMHS suggested an access review in order to investigate the situation further.

¹⁶ OMHS staff members mentioned a rumor which suggested that pharmaceutical lobbyists would receive a substantial bonus if they succeeded in pushing through a proposal such as this. Although I did not investigate this subject, the states of California and Texas were experiencing similar legislative lobbying at the time of the study.

An informal call to one of the pharmaceutical lobbyists provided more insight to the interests of the industry. After explaining my role as a researcher for the OMHS study, the lobbyist expressed his knowledge of the source of money from which the research funds originated. In particular, he noted that he had "fought hard" for those funds because his company was "tired of paying for all of the medications."

These lobbyists appear to wield a great deal of power. While conducting preliminary research for the study, my curiosity concerning the initial allocation of money during the 1997 meetings grew. If this substantial sum of money had been dedicated to the same individuals as those in the target population of the study, how had their need been documented? Yet, when I asked to view the information used by the lobbyists to support their argument for the allocation, I was told that none existed. An OMHS staff member reported that the decision had been made in the weaning hours of the session, a "back-of-the-napkin kind of deal".

¹⁷ See Feit's Let Them Eat Prozac: How the Drug Lobby Stopped the Oregon Health Plan's Effort to Protect Lives and Save Money (1998) for an example of the lobbyists' political strength and the ways in which they influence public health policy.

CRITICAL MEDICAL ANTHROPOLOGY: AN APPLIED PERSPECTIVE

"Medicine cannot be described apart from the relations of power that constitute its social context".

--Lorna Amarasingham Rhodes

Applied Medical Anthropology

Although an historical look at the field of anthropology would show interests in making its research useful since the discipline's inception, one now finds "applied" works in unprecedented numbers. Moreover, many applied anthropologists currently hold nonacademic roles, often working in institutional settings. While crystal-clear boundaries do not always exist between applied research and conventional, or traditional, research, some generalizations can be made. Applied research is more often funded by a contract, and is a response to a sponsor's expressed interest in a topic. Applied anthropologists more often tend to seek application of their findings, data and analyses beyond the academic arena. Most importantly, the focus of applied anthropology is to generate useful, practical information.

Medical anthropologists represent a large portion of those now working in the applied field. Generally, medical anthropology can be defined as "anthropological theory and methods devoted to the topics of health illness and health care" (Chrisman & Johnson, 1996, p. 89). In the past, research within applied medical anthropology has predominantly been conducted abroad, focusing on issues such as the introduction of Western biomedicine in developing countries. Today, more and more US anthropologists have begun to devote attention to domestic research. Applied medical anthropology

¹⁸ See van Willigen's Anthropology in Use (1991) for a listing of applied studies since the 1950's.

research in the US currently addresses a wide array of topics, ranging from more macrolevel studies concerning health policy and health care systems to individual-level studies such as community-specific AIDS prevention (Singer, Irizarry, & Schensul, 1991) or infant mortality in the African American community (Boon, 1982).

Theory in applied medical anthropology (and the discipline at large) has served as the source of a flurry of debates for the last few decades. During this period, anthropologists, both new and old to the field, have grappled with the proper role and definition of theory for applied medical anthropology. While some assign the development of theory to a "secondary role", one situated behind the solutions to specific practical questions about health and illness (Pelto & Pelto, 1990, p. 270), others stand firm behind the philosophy that theory constantly informs our work, as "[t]here is no atheoretical way to describe and understand reality" (Lett, 1987, p. 3).

As debate is wont to do, theoretical bases for the field became more clearly defined during this time. In particular Critical Medical Anthropology (CMA) emerged as a new theoretical, and practical, perspective, and is now a firmly established term in the field. It is with this perspective that I approached the OMHS study.

Critical Medical Anthropology Defined

Merrill Singer defines CMA as a way of understanding health issues in "light of the larger political and economic forces that pattern human relationships, shape social behavior and condition collective experience, including forces of institutional, national and global scale" (Singer, 1986, p. 128). One of the defining features of CMA is its explicit historical, political and economic foci. While these approaches are certainly not

¹⁹ See, in particular, *Medical Anthropology* Vol.14, 1992, entitled Theory in Medical Anthropology.

new, their emphasis addresses the political economy of health, which has been long criticized as a "missing link" (Morsy, 1979) in medical anthropology. CMA has often been characterized as a "critical redirection" (Baer, Singer, & Susser, 1997, p. 26) to medical anthropology.²⁰

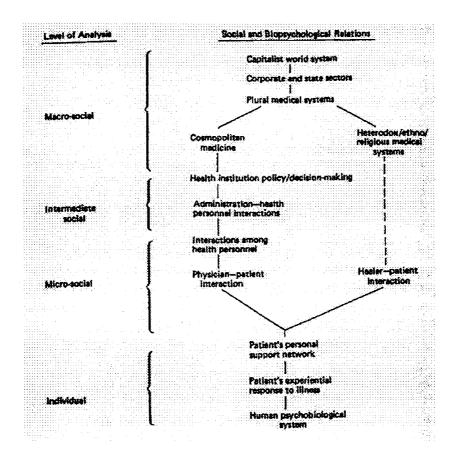
A defining characteristic to CMA is its sharp emphasis on the relationships between the global and local aspects of health. CMA is considered by many as a perspective, and a set of concepts, to guide the analysis of micro-macro relations pertaining to health issues. CMA stresses the examination of contending forces in and out of the health arena that have an impact on health and healing. In Baer, Singer and Susser's Medical Anthropology and the World System: A Critical Perspective, they present a schematic diagram which shows the many levels in health care systems. (See Baer, Singer and Susser's Diagram of Levels in Health Care Systems.) CMA recognizes the power relations between these levels, and the ways in which they impact the delivery of health care services. The dominant ideological and social patterns in medical care are seen as being "intimately related to hegemonic ideologies and patterns outside of biomedicine" (Baer et al., 1997, p. 26).²¹ In fact, Baer, Singer and Susser claim that the "ultimate character of health care systems is determined outside the health sector by dominant social groups, like insurance companies and large corporations, such as pharmaceutical companies" (Baer et al., 1997, p. 5). An understanding of local contexts

²⁰While CMA did not become a well-defined perspective in the field until the mid-80's, proponents claim that its roots can be traced to the symposium "Topias and Utopias in Health" at the 1973 Ninth International Congress for Anthropological and Ethnographical Sciences. (Baer et al., 1997)

²¹ The authors utilize Gramsci's concept of hegemony, which they refer to as "the process by which one class exerts control of the cognitive and intellectual life of society by structural means as opposed to coercive ones", and which is achieved through the "diffusion and reinforcement of certain values, attitudes, beliefs, social norms and legal precepts that, to a greater or lesser degree, come to permeate civil society" (Baer et al., 1997, p. 14).

in relation to their place within the larger global context--one shaped largely by capitalism--is an essential element of CMA.

Baer, Singer and Susser's Diagram of Levels in Health Care Systems from Medical Anthropology and the World System (1997)



Intrinsic to CMA is a focus on the global hegemony of biomedicine. CMA seeks to "understand who ultimately controls biomedicine and what the implications are of such control" (Baer et al., 1997, p. 27). The CMA perspective advocates that this can only be accomplished through critically examining the often overlooked power relationships within health care systems.

Finally, individuals dedicated to the CMA perspective search for appropriate application of critical knowledge to the practical domain of health. CMA requires that "anthropologists 'study up' and seek answers that call for change in the ways that health care is currently organized" (Coreil & Mull, 1990, p. 49). CMA views research as a "potentially potent weapon" (Singer, 1995, p. 99) which should be used to combat the consequences of asymmetrical power within health care systems.

A critical examination of the macro-social, or global, forces which influence the utilization and distribution of atypical medications--specifically the pharmaceutical industry and Oregon state politics--served to inform my perceptions of our findings at the clinic level. This political economic perspective provided insight into the rationale for the study itself, Oregon state policy-making and the particulars of the delivery of mental health care in Oregon CMHP's. By situating the local results within the larger global context, the application of the OMHS study might better serve all stakeholders.

METHODOLOGY

"We need to remember that the numbers we are crunching contain many stories, joys, and tragedies."

--Susan Wadley

Numbers and Narrative

The decision to include a qualitative aspect to their research led OMHS staff members to the OSU Anthropology Department. The main objectives for their study included the identification of the unfunded population, and an examination of the distribution and accessibility of atypicals for this target population. The "numbers and narrative" approach, a research design which has gained increasing popularity in the social sciences, and one used frequently by medical anthropologists, seemed appropriate for achieving OMHS' research goals. This style of research aims at combining personal narratives with relevant quantitative data in order to form richer, more comprehensive (yet sometimes contrasting) descriptions of situations than those which would emerge from statistics alone.

Specifically, OMHS hoped to show the number of unfunded clients served by county CMHP's and the quantity of atypicals prescribed to them via county clinicians. Qualitatively, OMHS sought the characteristics of the unfunded population and, if problematic access to atypicals was indeed discovered, an examination of the responsible barriers. OMHS realized that a thorough investigation of the access issue would entail interviewing a broad spectrum of individuals, including mental health clinicians, clinic administrators, clients and mental health advocates.

Anthropological methods suited the qualitative goals of the study well. Ethnographic methods appealed to OMHS staff members since they assumed that the possible barriers to atypicals access might stem from a variety of reasons, ones which would best be uncovered through face-to-face interviews with an assortment of individuals. OMHS presumed that clinicians' personal prescribing preferences, for example, might account for the inaccessibility of atypical medications. OMHS also recognized the possibility of multiple interpretations of reality, such as the perception of access in contrast to the clinicians' perception of access.

Central to ethnography is the search for an understanding and description of a situation from the emic, or insider's perspective. Furthermore, anthropology's holistic orientation acknowledges that every social scene and situation exists within a multilayered, yet interrelated context. An ethnographic description derived from local knowledge would aptly provide the "narrative" element to the research.

Preliminary Research

Applied anthropologists have written extensively on the challenges of designing and implementing "agency" research. Agency research, such as the work involved in the OMHS study, requires a great deal of flexibility. One must promptly acquire appropriate terminology, interpret the agency's role within larger systems and adapt to the culture of the agency. Ferreting out appropriate, reliable sources of data is another common challenge, and that which ultimately most affected our choice in methods for the OMHS study.

²² See van Willigen's Making Our Research Useful (1989) for a comprehensive look at this topic.

Our research team, together with OMHS staff members, had initially created a research design which would include collecting both qualitative and quantitative data in order to answer the study questions--the numbers and narrative method. Yet, preliminary research revealed a various obstacles which ultimately prohibited this approach.

First, I quickly learned that systematic and reliable quantitative data pertaining to the unfunded population does not exist. While each county data specialist could roughly estimate the number of unfunded clients served per year, these numbers are not precise. The county and state computer programs simply have not been designed to accurately track unfunded clients.

Furthermore, no systematic method exists to generate lists of clients whose medication history might be relevant to the study. In other words, lists of those individuals who have been prescribed atypical medications, or who have desired to attain an atypical prescription were inaccessible. Consequently, we were deterred from gathering the clients' perspective on access to atypical medication.

These restrictions prohibited us from performing out initial holistic research objectives. From a CMA perspective, the research would lack perspectives from the micro-social level and the individual level in our research within the Oregon state mental health system. However, the remaining groups contributed copious information. In fact, the ways in which the clinicians and the advocates contextualized the issue ultimately shed light on the study in a way that no statistics could have achieved.

Preliminary research also revealed that the clinics do not maintain records of the sample medications distributed or a list of clients enrolled in pharmaceutical companies' patient assistance programs. Furthermore, clinicians informed me that samples are

actually utilized in many circumstances, including the following: the time period before OHP enrollment activates, any sort of interval between funding changes (which occurs quite often for members of the unfunded population), or as a trial medication period.

Only individual charts contain the funding status of the individual while given samples, and the rationale for their use.

Methods

I collected information from two distinct groups in each county: (1) county mental health practitioners (MHP's or clinicians) and (2) mental health advocates (advocates). With the first group--the MHP's--I carried out individual and group interviews with a wide range of staff members including, administrators, program directors, case managers, psychiatrists and nurse practitioners (prescribers), skills trainers and intake personnel. These individuals represented a variety of special areas including family and children teams, the chronically mentally ill team, crisis teams, and adult outpatient teams.

Most interviews with MHP's were performed in focus groups. The exceptions included interviews with the county directors and the prescribers. I scheduled meetings with the administrators and their assistants separately in order to confidentially discuss the financial aspects of access to atypical medications. Similarly, I interviewed prescribers separately, in order to promote an environment in which they could speak openly about their possible prescribing preferences.

The second group of interviewees--the advocates--also consisted of a variety of individuals, including advocacy group leaders, current and past county clients and their family members. Some of the group members had been unfunded clients in the past, and

almost all members had been acquainted with an unfunded client at one time. With the exception of one interview with an advocacy group director, I interviewed advocates focus groups which varied in size from 5 to 15.

All interviews were semi-structured. I asked open-ended questions regarding the two principal questions for the study--'Who are the unfunded?' and 'Is this population able to access atypical medications?' While these two broad topics guided the interviews, I also asked questions specific to the individuals in the group, such as how their work related to the unfunded population. Additionally, OMHS staff members sought specific information on a few issues: prescribers' preferences as possible barriers to atypical medications, the frequency of the use of cheaper medications for the target population and utilization patterns of sample medications. I addressed all of these topics during interviews. (See Appendices 3, 4, 5 and 6 for lists of specific questions.) Although I loosely followed written lists of questions for each group, interviews tended to be casual, meandering through various related topics, ²³ and information from each interview allowed me to build on the questions for subsequent interviews.

Descriptions of the study and its main objectives were given to all participants prior to the meeting times. On average, each interview lasted between one and two hours. All interviews were taped and transcribed upon the approval of the interviewees.

²³ Since many of the participating individuals in the advocacy groups were, or had been, county mental health clients, they felt inclined to voice their concerns and complaints about various issues related to county mental health services. Maintaining a focus on the study objectives was often problematic.

²⁴ For example, once case managers indicated that their time with clients was limited, I began asking clients in the advocacy groups if they felt the time allotted to them during their appointments was sufficient.

Sample Size

In total I interviewed 57 MHP's and 41 advocates. In Linn and Lincoln counties, I interviewed all available MHP's. The only staff members excluded from these interviews were two prescribers in Linn County. This county employs its child psychiatrists on a contract basis. In order to avoid additional billing to the county, I did not meet with two of the three contracted psychiatrists. I conducted a brief phone interview with the third prescriber.

In Multnomah County, we initially chose to interview only staff members from one private agency which contracts services for the county--Unity-Mental Health West.

County data revealed that this agency works with the largest number of unfunded clients. However, at the time of the study, this agency was experiencing enormous budget cuts, layoffs, resignations, and consequently, a dramatic increase in caseload sizes. The agency did not feel that scheduling interviews with their staff members would have been appropriate or possible. Therefore, interviews were limited to select personnel capable of scheduling an interview. To increase the number of interviewees from Multnomah County, we interviewed various staff members from Mt. Hood Community Health, another agency which works with a high number of unfunded clients

In order to maintain confidentiality, I have not distinguished interviewee quotes by job description or by county, unless necessary for emphasis (and tracking would be impossible). Furthermore, I have synthesized material from all three counties. Although counties did, in some cases, present distinctive information, very few topics of discussion

²⁵ Delays on OMHS' part postponed the beginning of the qualitative research until mid-March. Clinicians' limited schedules further tightened the window of time for fieldwork, analysis of the data and report preparation. These time constraints also limited the number of interviews possible.

were limited to individual counties. I have chosen to note the few topics which surfaced in only one county because of their significance.

TONES, PERSPECTIVES AND A CHANGE IN EMPHASIS

"An ethnographer is a human instrument and must discriminate among different types of data and analyze the relative work of one path over another at every turn in fieldwork, well before any formalized analysis takes place."

-- David Fetterman (from Ethnography)

Multiple Voices

Interviewees' responses to the study varied between the two primary groups of informants, and by occupation among the clinicians. The receptiveness to participate for all interviewees can be characterized by "somewhat skeptical" to "enthusiastic". While all advocates appeared eager to share their experiences and knowledge related to the study objectives, many relayed their skepticism towards "state-funded research". They anticipated an agenda for the research that would ultimately not be to their benefit, and claimed that they were "tired of all the (blue cover) reports that don't change anything". In response to these sentiments, I encouraged participants to speak freely, and assured them that I would incorporate their information as accurately as possible. However, I did point out to all interviewees that the OMHS staff would have ultimate editing privileges on the final public document.

Despite the mandatory nature of the interviews, most MHP's also seemed to welcome participation in the study. A general lack of time proved to be the main impediment to clinician interviews. With both groups, verifying my neutral role--not being a state employee nor a pharmaceutical representative--seemed crucial to establishing rapport. Overall, most interviewees generously offered their perspectives.

The type of information relayed by the interviewees varied greatly. Each subgroup contributed a slightly different perspective to the primary questions. The clinic administrators and directors offered more managerial and budget-oriented comments. They also presented summaries of clinic procedures which affect services for the unfunded population. Prescribers contributed many specific examples of the ways in which they utilize atypicals, and a number of prescribers focused on their perception of the efficacy of atypicals. Discussion of the prescribers' gatekeeper-like role proved extremely valuable in understanding access to medications. Case managers and skills trainers generally gave more detailed examples of the practical reasons for unfunded clients' ability or inability to access atypicals. This group's experience with negotiating between the prescribers and the clients, enrolling clients in the various funding programs and tending to the everyday needs of the clients lends them a more client-oriented perspective.

Similarly, the various members of the advocacy groups offered unique perspectives on the study questions. All advocacy group leaders recounted work experiences with unfunded clients, and their roles enabled them to survey the issue from outside of the clinic environment. Some advocates offered first-hand information as unfunded clients, while others added perspectives as consumers of atypical medications. This multivocal perspective helped shape an understanding of the complexities to the study.

Candid Comments Shape the Nature of Interviews

Interviewees' placed varying levels of emphasis on the political-economic aspect of the study. Many advocates took a more immediate political stance, while case managers and prescribers, for example, tended to comment first on clinic procedures or the idiosyncrasies of a particular funding source. However, all interviewees addressed the

political underpinnings of the topic in one way or another. For instance, almost every interviewee inquired about the source of funding for the study, and for whom the research was being conducted.

Addressing the political nature of the study right from the start proved to be a crucial feature of the interviewing process. This became evident during one of the first official interviews for the study. After describing the research goals to a Multnomah advocacy group, one of the members promptly asked, "So, this is about the line item in the state's budget, right?". The advocate asked this question in a tone which suggested that I had intentionally withheld this aspect of the research. Subsequently, I stressed the importance of my goal to provide an impartial description of the unfunded clients' access to atypicals. By acknowledging the political aspect of the study directly and openly, and, in fact, encouraging the interviewees to comment on the idea of a state atypical fund specifically, interviewees provided valuable insight.

The first few interviewees' reactions towards the specificity of the research goals also effectively shaped the course of the study. Initial interviewees--both advocates and clinicians--pointed out that unfunded clients face many other challenges which supersede and contribute to the difficulties of accessing medication. They asserted that by focusing only on access to atypicals, other relevant problems might be overlooked. One advocate simply stated that the study was "ridiculous" its narrow perspective on medication access. As a result, in all subsequent interviews, I urged individuals to interpret the notion of "access" as they saw appropriate. In other words, if they considered the lack of appropriate staffing, prescriber preferences or any other circumstances as barriers to atypical access, they were encouraged to comment on that topic. Consequently, the

question of atypical access evolved into a much broader discussion regarding treatment access in general. This "iterative" approach (Bebee, 1995) to the interviewing proved invaluable.

In the end, interviewees offered few definitive answers to the primary research questions. The meaning of the terms "unfunded" and "access", in this case, are filled with complexities and ambiguities. For example, no conclusive statement can be made about the unfunded population's access to atypical medications. Accessibility appears to be driven by individual circumstances. Prescribers' practices vary; each client's case varies; individual county funds vary. While one prescriber firmly stated, "If they (the unfunded clients) need them, they get them (atypical medications)", another clinician noted that some of her clients "simply go without". Certainly, no statewide conclusion can be drawn from the OMHS study.

The ethnographic data depicts the unfunded population as a diverse, problematic group of clients, not one group requiring a single, simple solution. Interviewee's comments suggest that the state should further investigate the causes of clients' unfunded status. Distinctions must be made, for example, between those clients who are chronically, temporarily unfunded and those who require constant assistance.

Interviewee remarks also implied that some unfunded clients might actually be eligible to receive atypicals, if the available assistance programs were better managed. Many of these ideas will be discussed more thoroughly further.

Though information from the interviews did not provide simple answers for the primary study questions, the interviewees' insightful comments *did* produce a clear

picture of the context in which these questions are asked. While interviewees' personal and group biases towards the research topics undoubtedly influenced their remarks (case managers' unwieldy workloads or an advocate's focus on clients' rights, for example), their comments served to expose many realities of the unfunded client's experience in the state system, atypical utilization and the general disarray of services. Specifically, their remarks accentuate an insufficient infrastructure to serve the unfunded population, myriad problems with the existing avenues to atypicals access and the ambiguous perceptions of atypicals utilization. It is these aspects of the data which will be presented in the following pages.

WHO ARE THE UNFUNDED?

Interviewees' remarks indicate that two categories of unfunded individuals actually exist: those who attain service from the CMHP's and those who are referred to other organizations. Comments regarding this second group suggest that, in Multnomah county at least, it may be even more numerous than the first. Unfortunately information about this segment of the unfunded population is impossible to gather. It is important to note, however, that the following information applies only to those individuals who have reached the clinic doors, not necessarily all of the unfunded clients seeking services.

When discussing the characteristics of the unfunded clients with interviewees, I asked the following sub-questions: Why are they unfunded? Who do you perceive as the largest segment of the unfunded population? Responses to these questions varied according to clinicians' specialty areas or which population an advocacy group worked with most frequently. Interviewees did confirm, however, that the unfunded population consists of five main categories of unfunded individuals. This section includes interviewees' descriptions of the unfunded.

The Uninsured

Individuals might be uninsured for various reasons. One of the most frequently mentioned sub-populations of the uninsured group is those individuals who earn too much money to be eligible for OHP, sometimes only a few dollars, yet not nearly enough money to purchase private insurance. This group also includes individuals who have

²⁶ Without scouring individual charts for personal information, precise numbers of each sub-population are impossible to generate.

fluctuating incomes throughout the year, due to seasonal or insecure employment. Many people suffering from mental illnesses tend to work in lower paying jobs, which situate them in this category. These individuals form the very troublesome population of clients who consistently go off and on of OHP, and consequently only sporadically access needed mental health services. Other uninsured individuals are those who have exhausted their insurance benefits. Interviewees offered the following remarks about this group:

An advocate describes a client's circumstances...

His access problem has to do with the fact that his wife is a nurse, and when she works full-time, they get benefits. But mostly she works just under, like 36 hours. So then they have nothing, but she makes too much for them to get OHP.

An MHP gives an example from his caseload...

He represents one of the most frustrating situations for me that I've chronically dealt with. He's one of those people that makes 1 dollar over the cut-off, kind of crap. So he winds up getting nothing. So, we have to try to help him out in the various ways we can. That's the biggest group. The ones that make a few dollars over and above.

There are a few people on my caseloads that work. So, they work parttime, or almost full-time. And they make maybe a thousand dollars a month, and they're not eligible. And they don't have other insurance. --MHP

Lincoln County MHP's specifically commented on the large proportion of clients who fall into this category at their clinic. The following quotes illuminate the specifics for this county:

There's a lot of unfunded people that have come in that before weren't being seen, that have anxiety disorders, or are bipolar, or any number of disorders. And, they're not funded because, they are either working, or their spouse is working and they have too much money to qualify for OHP and not enough for (insurance). I mean this is a pretty poor county in a lot of ways. A lot of unskilled labor. A lot of transient kinds of things. A lot

of people working in hotels and motels, and the tourist industry in general. So, making minimum wage, they just don't qualify. --MHP

Well, you've got basically sort of working poor--who either don't have any insurance or have lousy insurance. And those folks can be anybody. I mean there's not a lot of really good paying jobs around here. I mean most of it these days is service industry stuff. And none of those jobs have any kind of insurance. But you probably earn enough not to qualify. So, you know all of those folks--young folks, old folks, men, women, I mean, anybody. --MHP

We certainly have a lot of employers who don't have insurance for their employees. --MHP

The Underinsured

Another group of individuals included in the unfunded population are those who have inadequate insurance. Insurance plans often exclude mental health coverage. The following remarks describe this group of clients:

An MHP gives an example from his caseload...
He has insurance. It doesn't cover any of what he comes in here for.

There are a lot of people who have insurance that doesn't cover psychiatric problems. In fact, I mean, those insurances are probably more common than other insurances. You know, that don't cover seeing us and they don't cover the medications. It's really like they have absolutely nothing.
--MHP

But there's all sorts of folks. (It) really is a big group--people that have insurance. They tend to be in the lousier jobs, that have lousier insurance. --MHP

Those People In Between Insurance Programs

Clinicians repeatedly mentioned that a unique sub-group of the unfunded are those people in between insurance programs. An MHP describes the many circumstances in which this can occur:

People who are in between. They've applied for the Oregon Health Card, and they haven't got it. Or they're transferring from another county, and that isn't complete yet, but they need the medications. That's another group of people that I would put in there. I mean they are kind of funded, but they are kind of not. We do a lot of that. Or their private insurance has expired and they haven't gotten on the OHP yet, but they've got to have these medications. We do a lot of that. We do see a lot of that.

--MHP

Medicare Recipients

Medicare recipients form another sub-population of the unfunded. Medicare—a federal program which offers assistance to those with disabilities (including individuals with mental illnesses) and the elderly, does not typically cover the costs of outpatient prescription drugs used in the treatment of mental disorders. (Sherman, 1996) Moreover, enrollment in Medicare disqualifies an individual for other types of assistance. Although a unique program exists for the medication needs of Medicare recipients, it is not entirely successful. (This program, The Medically Needy Spend Down Program, will be discussed at length further.) The following quotes describe the predicament of those receiving Medicare:

Folks call and say, 'We've been diagnosed. We've been given subsidy to live on, because we have a disability, but we can't pay for the meds.'
--advocate

I run into this all the time. People that have Medicare are not getting on the OHP, or they make just a little bit too much, maybe 30 or 40 dollars too much to qualify for the OHP. And so they're not getting medications. --advocate²⁷

That's a big problem with our population. We deal with the folks with the chronic mental illnesses, who are just about all on disability. So, meds? Spend Down for some. Others...they can't afford it. --MHP

²⁷ Members of one advocacy group in Multnomah county suggested that it was no coincidence that the income level for OHP eligibility is lower than the average Medicare income.

Medicare people totally get screwed incidentally. If you are an old person...well... if you are young and you just don't make very much money, you are going to get the red carpet treatment. They are going to come in here, they are going to get individual therapy, group therapy. They are going to be able to see the doc, get the medicine, they'll be able to get all those things. If you are an older person who has worked your whole life, you're screwed. You're not going to get anything. And that really sucks.

Children

Children, mostly teenagers, also comprise a portion of the unfunded population.

Interviewees noted that homeless teens, in particular, are a "growing population".

Funding for this group is problematic. Family dynamics and the persistent stigma of mental illness often impede this group from receiving needed treatment. MHP's offered the following remarks about children:

The teenagers are interesting. Because a lot of times, if they were at home, they'd qualify. And we get a message that, 'Well, because they're not at home, they can't get it (OHP).' So, if you're fifteen and you're living in the park, and you have absolutely no money, you can't get on OHP. That is my understanding. And, that's been really difficult. I don't know if it's because the parents are still trying to say that the kid's at home, because they're getting welfare for him or something, or what, but that certainly is a group of people. And teenagers tend to be some of the toughest.

There a lot of homeless teens that aren't covered because they are on the outs with their parents, or their parents refused. They don't have an address. They are moving from house to house, staying with friends. They're just always moving.

There's very high percentage of kids in this county who do not have a permanent address.

Sometimes you get these families that aren't necessarily insured. But, you have these kids that are sort of living on their own. They don't have ANYTHING. And it's a little more uncomfortable handing out, say samples, to a teenager. Which I really don't like to do. ... So, the ones that have no solution, tend to be teenagers. And that's for a number of issues that don't necessarily have to do with money for the drugs.

MHP's also noted that private doctors often refer to CMHP's when teenagers want to keep their mental health services confidential, specifically from their parents.

However, their family insurance then becomes inaccessible. Family dynamics also appear to greatly influence a child's treatment access. A lack of support, both financially, and with treatment plans prohibit children from proper services. The following comment exemplifies the troubles for many teenagers:

I think she was 17, but her parents would not support her, and wouldn't keep her on their medical (card). But because she was under 18, she couldn't get county programs or other things that were happening. So, she was definitely between a rock and a hard place, and ultimately didn't get any services until she turned 18, and could advocate for herself. --advocate

While interviewees most commonly referred to the five aforementioned groups, they also noted that caregivers of the disabled; individuals who cannot afford their OHP premiums; people who do not meet assistance program eligibility criteria; and those individuals whose mental illness provokes an extreme case of paranoia also make up part of the unfunded population. No insurance programs suit these individuals.

DISCLOSURES: INFRASTRUCTURE, RESOURCES, AND UTILIZATION

As mentioned previously, many new topics emerged from conversations regarding access to atypicals. These subjects tended to address three general themes: poor clinic infrastructures; problematic medication resourcing for unfunded clients; and ambiguous perceptions of atypical utilization. The following sections include interviewee quotations and summaries regarding these topics.

Poor Infrastructure: Limited Access and Services for the Unfunded

Getting it (an atypical medication) prescribed for them? I think, before that, they have to get in to see somebody. I think that's the obstacle right there.

--advocate

Interviewees repeatedly commented on the assumptions implicit in the question of accessibility to atypicals. They noted that although obtaining medication resources for unfunded clients is a major concern, the target population faces numerous challenges before confronting the cost of their medication. Specifically, interviewees pointed out that questioning access assumes that the unfunded population has knowledge of the county services available to them, can secure an appointment and that sufficient staff exists to provide service. Both MHP's and advocates affirmed the inaccuracy of these assumptions. The following sections illustrate that the system is clearly not equipped, or intended, to facilitate the unfunded population.

Services Unknown

Many interviewees proposed that unfunded individuals would probably not be aware of the mental health services available to them unless they had prior experiences with county-related clinics. In fact, upon defining the target population (as those people who are unfunded and seeking mental health services from county clinics), numerous advocates claimed that they "didn't know you could go to the county". Specific to medication, another advocate noted, "I've not ever heard of a health program in this county that offers any meds." Advocates in another focus group reiterated these ideas, responding firmly and with a sense of resentment:

Interviewer: So do you think that if you were in a situation where you weren't insured by anybody, would you know to go to the county to get mental health treatment?

advocate #1 (and county client): No.

advocate #2: No.

advocate #3 (and county client): No.

advocate #1: Because nobody would inform them.

advocate #3: I'm not even sure if the doctors know that.

Similarly, an MHP made the following comment: "If they are transplants, and have a history of coming to community mental health, we'll probably see them. But, I imagine that there are a lot of citizens who don't know we're even here, or what services are available".

Both MHP's and advocates offered a variety of possible reasons for the lack of knowledge of services, including mixed messages about eligibility for services, little marketing and poor outreach. Interviewees indicated that deceptive messages might be given to the unfunded population, and that Oregon citizens probably assumed CMHP's service only those people who qualify for state assistance. And, in fact, most of the clinics within the state's mental health system *do* primarily serve the funded population.

Therefore, this would be a logical assumption, and one that is reinforced by a lack of marketing which states otherwise.

For those individuals who begin their search for mental health services at the Disability Services Office (DSO), and are told that they do not qualify for OHP, the notion of receiving services from a county office would seem unlikely. Interviewees observed that no clear message exists to explain that an individual who has been denied state assistance can utilize county mental health services. An advocate offered these thoughts:

That seems to me like a mixed message. Why would they (DSO officers) say, 'You're not eligible. You make too much money to be a part of the services (state-funded OHP), so you can go to the (primarily state-funded) county if you need services.'? That to me is not what they are telling the person walking out on the street. Cause then they are saying you're not eligible, but you are. You know, you're not eligible but we'll pay for your services.

The following comments from advocates who had previously been unfunded clients support this idea:

So, that was a barrier for me, that the system said, 'You're not eligible for the system.' So I didn't keep pursuing that system.

So, from my point of view, from someone outside of the public system, my interface with the public system was to get [on] the Oregon Health Plan. But my income excluded me. But I had no insurance and there was no other way in the public mental health system. There was nothing offered. There was no route. So it would never have occurred to me. I wouldn't even have known to find a county mental health agency. I mean, I wouldn't even have known where to look. So that was the end of my contact with the public mental health system, when they said your option is to stop working for two months, or pay for your own private insurance, or pay for your own medical care. So that was it.

An advocate summarizes, "So people that aren't eligible for Oregon Health Plan, that aren't on any form of public disability, they don't come in the doors of the places to sign

up". Moreover, a Multnomah County advocate expressed skepticism towards the idea that many unaffiliated first time clients even seek services from county-related mental health clinics:

I just can't get over the idea that there is a swelling of a population who fits this--who aren't eligible for Medicaid. ... So even if one or two folks...or even if ten or twenty folks have figured out to go that route, to ask for public assistance with this, the majority are not going to go that route because it doesn't exist. That doesn't exist as a route for folks to go.

Many advocates stated that they felt the state purposefully withheld this information from the general population. An advocate gave his opinion about the availability of public services:

As somebody who's been an advocate for several years now, for low income issues in general, especially housing and disability, one of the things that I've learned over the past few years is that for all low income people its kind of a variation of the old survival of the fittest, social darwinism paradigm, except it is no longer survival of the fittest so much as it is survival of the smartest. There is stuff out there, it's all under publicized, and under advertised.

MHP's affirmed this lack of marketing, making comments such as, "We're a well kept secret." and "Number one, they don't know we're here.". When asked if he believed that the public was aware of county mental health services, a clinic administrator gave the following response: "I think they are beginning to know that more. That might be an area that could be worked on more. We haven't done that because we haven't wanted more business. But, we have tried to make ourselves accessible and more consumer-friendly and stuff like that".

When I asked MHP's about their local outreach programs, their responses mirrored the previous comment:

When you talk about outreach, I have to kind of chuckle. Because we don't do any outreach. They have to come to us. And most of us are

overwhelmed with the load that we have. So, there is no outreach that I know of.

When we get the message to do penetration out in these different areas, we set up programs to do that. But, the truth is that we don't have time to do them. I don't have time go creating more clients when I'm overwhelmed with what I have. I feel like it's a game. It's creating the illusion of penetration, when the reality is that we are overwhelmed. Our staff doesn't want more work. Not that there isn't a need. And that shouldn't be happening. There's just not enough manpower to then do it if we bring them in.

An administrator explained the financial reasons for his county's paucity of marketing:

Financial does play a role. For example, if any person off the street, that didn't qualify for OHP, came in and was seen by us, and we got them into see our doctors, and we gave them meds, that would hugely impact the OHP people. They wouldn't be able to be seen. And we would go out of business. Some other agency would grab the managed care contract, and I tell you, services would be less.

This comment implies that, administratively, the unfunded population is not, and cannot be, the clinics' priority. A primary source of funding for the clinics is OHP reimbursement. While the unfunded clients may benefit from the OHP-generated resources—in that these funds provide the basis for the clinics' operation—the OHP clients must be given priority in treatment. These qualifying factors vary in each county, as each clinic works with a very distinct mix of county and state funding. However, the managed care context does ultimately affect the unfunded population. An MHP explained these dynamics in Lincoln County:

So now we have this bigger pool of people who are eligible to be seen (because of OHP) and basically we have to deal with their psychiatric needs. And when we started doing this, we said, 'We don't want to discriminate against people because they don't have OHP. So we're going to see everybody for all of these conditions.' And...I think we sort of stayed doing that for about a year, and, ultimately got to the point where we have no one to see the folks, and we had to say, 'If you're unfunded,

you go on a waiting list'. And, we worked really hard to get people on OHP. And, that is a bit of a barrier in itself, it seems. Yeah, because they have to do certain things to get on it. They have to bring in papers. They have to go to the office. They have to apply. And a lot of our folks ... they're not doing it. Whether they're not able to, or they don't want to. But, it is a bit of a barrier. And, so now we do have a waiting list for those folks.

Being Turned Away

The screening/triaging process established at each of the study sites (and most counties throughout the state) poses another difficulty for the unfunded client. Although each county maintains slightly different regulations, clinics generally triage the clients that walk through the doors. In most cases, an individual must be "in crisis" to ensure attention from clinicians.²⁸ One MHP noted that in her clinic, the unfunded client could be seen once, and only if in crisis. Because of this triaging process, many individuals so do not receive services at the county level. As one MHP indicated, "It's true. The triage process might be a barrier." Furthermore, an MHP noted that the results of this triaging process might be more devastating to the unfunded client:

The people that are not meeting the crisis criteria... WE don't see them. And we may refer them to places that maybe don't provide medications. So they've got that many more barriers to face. Not only do they not have funding for medicine, but for counseling too.

Advocates, particularly those who had been unfunded in the past, definitely perceived the screening process as a barrier to access for the unfunded client. Many claimed that an unfunded individual might be turned away upon arrival. A number of

²⁸ The criteria for this status appeared to vary slightly in each county, and by individual client. However, according to OMHS documents, the Oregon mental health system prioritizes adults' eligibility for publicly funded mental health services based on risk of hospitalization and/or posing a hazard to the health and safety of themselves or others. The guidelines for children are substantially more complicated. For further details on these guidelines, see *Overview of the Public Mental Health System in Oregon* (OMHS, 1999).

advocates mentioned that they had been turned away simply due to a lack of insurance coverage:

You're usually told things like 'This is the income level for eligibility.' If you don't meet it, that's the end of the story.

They tell you that it's just for people who are under income.

The unfunded are screened out at almost every step.

MHP's showed an interesting varied knowledge of service eligibility. In particular, prescribers commented in the following ways:

But, I think it generally is true, that if a person has 3rd party reimbursement other than OHP, they're not seeing us. That would screen out that population.

I don't know who we can see. I don't know what the insurance thing is. You'd have to talk to X out front to find out what type of population we see.

Yeah, I don't know what's true about that. I try to let the office staff do their job.²⁹

Finally, numerous MHP's and advocate's noted that all of the confusion, lack of marketing and systemic barriers are particularly difficult to wade through for the population seeking services, and ultimately pose a threat to those in need of services.

The following quotes illustrate this sentiment:

One of the big problems is that people with mental disabilities are not always in the best shape to do their own research. It's rough, and its not easy to access this information unless you know where to go or who to talk to. That's what makes it rough, the system makes it very difficult for people to access the necessary information, it is very unforthcoming with providing information. --advocate

²⁹ For more detailed knowledge of the ways in which a client's insurance coverage and income influence entrance into county CMHP's, I suggest an in-depth study which would include thorough interviews with front desk receptionists, crisis line operators and central intake workers employed in Multnomah (who field calls for county-wide services). Comments from both MHP's and advocate/clients suggest that this first contact, either by phone or face-to-face in clinics, might be a point which bars access to atypicals for the target population.

I wonder how many lives we could actually save if we didn't have all the bureaucratic stuff that would prevent them from being served immediately. It's a tragedy. We don't ever need to lose a life to mental illness, but we lose a lot. --MHP

Understaffing

Interviewees repeatedly mentioned insufficient staffing as an obstacle to services. Both MHP's and advocates considered understaffing a direct barrier to treatment, and consequently medication access, in every clinic. In fact, a general understaffing problem exists in all three counties to various degrees. In some cases, the unfunded, unless in crisis, simply cannot receive services because of the lack of staff. This forces MHP's to refer out or create waiting lists. A lack of specialized staff also poses a barrier for particular sub-groups of the unfunded population, such as seniors and children; MHP's mentioned a lack of geriatric and child specialists in all three counties.

While MHP's commented on general understaffing at each study site, interviewees most commonly remarked on the inadequate number of prescribers and case managers. Regarding prescribers, MHP's comments can be characterized by the following statement: "We just don't have the capacity of people to see them (unfunded clients)". Similarly, advocates frequently noted that "there are too many patients per doctor".

The following prescriber's quote emphasizes the importance of prescriber availability, and succinctly provides perspective to the unfunded population's predicament:

³⁰ For a detailed description of the gravity of Multnomah County's budget crisis, see the July 1999 and December 1999 issues of *Oregon Health Forum*.

Probably the biggest barrier is being able to see someone to prescribe it (atypical medication). I would say that there are certainly more people in the category of 'there's no one to evaluate and prescribe their medicine for them'. That group is bigger than the people who have someone to prescribe the medicine, and they can't afford the prescription. I mean the first thing about access is that you have to have a prescription. And, so it doesn't matter whether you can pay for it or not, or your insurance, or anything. I mean, you do have to see someone that is able and willing to prescribe it. So, that certainly is the biggest access issue...treatment in general.

Case managers also provide critical services to the unfunded client, most importantly, assistance with medication funding. Yet, case managers reported client loads which had recently doubled, and in some cases almost tripled, in number. These unwieldy caseloads often prohibit the case managers from attending to the unfunded clients' most basic needs.

Case managers explained that the enormous caseloads had even prohibited them from assisting with Medicaid applications. They noted that the paperwork often bewildered the clients. One case manager mentioned a client who had held onto his paperwork for months, claiming, "I don't know where to start." The case manager explained the situation as a common problem, describing the application paperwork as "too much for someone who is depressed or suffering". Unmanageable caseloads prohibit case managers from assisting clients with these sort of tasks. The same case manager asserted that, consequently, many of the unfunded--who might actually qualify for funding--never complete the process for a medical card, or have substantial delays in enrollment. Interviewees remarked on the insufficient number of case managers:

I think for a lot of these people who are unfunded, more case management is needed. Having some money available for case management for them. Sometimes they don't know things that are out there that they could get or they might be qualified for. Having some money to spend on our case managers, helping them get set up with services, would be good. --MHP

Case managers have upwards from 55 clients. They don't have time to explain the programs. --advocate

Additionally, MHP's made the following comments about the ways in which these increased caseloads affect their general service, medication access, in particular, and ultimately the well-being of their clients:

People can slip through the cracks. You might not hear from them. They miss an appointment, and you'll be so busy, and they won't call back. And you won't have time to set up another one. And they can be slipping through the cracks, and then we will hear about it.

You know you can't empty the state hospitals, and then cut back our ability to see people. People WILL suffer. So, if you want to know how people are suffering, that's how they are suffering. When I first started here, I had 25 people on my caseload, and I attended to those people damn well. When my caseload got up to the 40's, 50's, -- and now it's a lot higher than that even---there's the same amount of hours. You cannot do the job as well. It's a problem. ... And then what happens is that people get off their meds quicker. They end up in the hospital. Costing more money. So, it's a huge vicious cycle.

Another MHP frankly weighed increasing case managing staffs against providing money for medications:

It might cost a whole lot less to get a case manager to spend a few hours with this person to find out what they could use and get them hooked up, than to ... certainly to buy them a month's worth of medications, which would be really expensive. Sometimes the money you could spend in organizing--in helping this person get set up--is the best spent on them. To help them know what there is. And to feel like they are not all by themselves. The system is so daunting to people on the outside.

Interviewees also directly linked OHP to the issue of understaffing. The ways in which OHP has been implemented and the increase of clients it has created were given as the main reasons for inadequate staffing. Although MHP's mentioned the numerous benefits from OHP, the ways in which the administrations have managed the contracts was highly criticized. The following MHP comments illustrate this point:

I don't know if it has to do with a lack of funds from the state, so much it is as the way the funds are managed. Because since we've had the OHP contract, you can hear any of the therapists... I commonly hear them as they sit in my office... say 'The illusion is that we are offering more care, and that we are serving more people'. But the reality is that we are being pushed to close more cases, so that we have time to do the paperwork. Because they are not hiring people. They are understaffed. And they've been understaffed. And all of a sudden you get the OHP, and so you have this tremendous influx of people that you have to care for. And the staff is not hired accordingly. Now, it seems to me that if the OHP is paying you this pot of money to take care of these people, then part of that pot of money ought to be to hire sufficient staff. And that's not being done. We are at the same staffing level, nearly, as we were before the OHP contract was awarded. So what are the managers doing with the money? I don't know. I suspect it's more than not enough money from the state being awarded. And that's a real bone of contention here. So, we're providing the illusion of more service. And yet, at the same time, we're closing cases right and left and telling people that we can't see them. Yes, that's definitely a barrier.

They're not interested in keeping adequate staff, they're just interested in being able to present pretty statistics. And you can make statistics, or research, say anything. You can manipulate numbers to make them say anything you want. And that's exactly what they are doing. They are presenting the state with a whole bunch of numbers that mean ABSOLUTELY NOTHING.

I really resent what management has done with the money. And the patient is taking the shaft.

Paths to Atypical Access: Deficiencies and Insufficiencies

"It's really been a drag, as far as I'm concerned, to see how they have always forced clinicians in the middle of worrying about funding sources. It's not the way to provide care."

--MHP

Various paths to medication access exist. For an unfunded client, gaining entrance into any one of these paths is based on a number of variables, including program eligibility criteria, the client's income level, the severity of his or her illness and who is in the position of locating the resources. A clinicians' first attempt at funding medications,

in most cases, is to assess a client's eligibility for OHP/Medicaid. The last option for medication funding would be for the county to absorb the costs of a prescription. In some cases, MHP's noted that they had been forced to suggest that their client request funds from community organizations such as the Salvation Army. Obviously, counties would not be able to continue covering the cost of an atypical prescription for an extended period. Clinicians would consider other funding options first, depending on the client's qualifying factors. Interviewees most frequently mentioned the following as the primary sources for medication for the unfunded population: The Medically Needy Spend Down Program (commonly referred to as the Spend Down Program) for those who receive Medicare, Regional Funds for crisis intervention, private pharmaceutical companies' Assistance Programs (also referred to as scholarship programs) or sample medications.

Are unfunded clients ever maintained on samples? Clinicians did speak frankly about "working" pharmaceutical representatives to ensure a constant supply of medications. However, from clinicians' remarks, I concluded that these supplies were not routinely used as a substitute for a prescription. While prescribers mentioned a few cases in which clients had received samples for an extended period of time, I believe the use of samples can best be described as a stop-gap measure for various conditions. Clinicians voiced serious concerns about maintaining clients on samples, and pointed out that it had occurred only as a last resort in extremely difficult cases.

Interviewees' comments suggest that inadequacies within the state-related programs and insufficient staffing to manage the programs, and the samples and scholarships, contribute to the unfunded population's difficulties with medication access.

Interviewees' remarks indicate that fewer clients might attain an unfunded status--and consequently be funneled toward samples or often unreliable patient assistance programs --if proper program management and procedures, and clinic staffing problems could be remedied. The following section includes interviewees' observations about the various medication resources.

The Medicaid System

Numerous interviewees complained about the difficulties within the OHP/Medicaid enrollment process. Primary concerns included the length of time necessary for a client to receive a medical card, and therefore benefits such as medications, the lack of communication between agencies serving the enrolled population, and the general confusing nature of the enrollment requirements. These particular matters can potentially cause an individual to retain their unfunded status, and be denied access to any type of medication.

Furthermore, MHP's knowledge of the enrollment process, even within the same clinics, was inconsistent. For example, while many MHP's believed that their clients could receive services immediately, upon signing up for assistance, others complained about the delay in benefits. Not only does a time lag impede the clients' access to services, but the MHP's' conflicting information about the program potentially acts as a barrier to services and medication access. An advocate's remark about delayed benefits illustrates the significance of well-run programs for patients suffering from mental illnesses: "By the time they get their medical cards, it's too late." An MHP noted the primary problem with the Medicaid/OHP process and recognized the inconsistencies within the system:

Confusion and length of time between applying for the OHP and getting it! And we have a wonderful DSO office where we can send people in and they walk out that day with a card, but for most people that's not the case. They're waiting for two months. And that's a very long time.

Another MHP described the consequences of the lack of communication between the DSO and the CMHP's:

Case managers would really like it if DSO could contact them if their client's situation is going to change. What happens is that the DSO will cut off the assistance, and the case managers won't know about it for a month. Then, the client is unfunded.

Many MHP's expressed their frustration with the enrollment process, and with the clients themselves for either not maintaining their enrolled status or for delaying enrollment. Yet, while applying for a medical card may seem like a simple task for many, advocates/clients reported that it can be a confusing and dehumanizing process.

Advocates/clients voiced their personal frustrations, and concerns about enrolling for a medical card:

One thing you should realize is that most of these programs are so complicated and difficult to use. And, most of us come to need them when we're not in very good shape and don't really have the energy to go through fifty-eight little bureaucrats who are going to fuck with your head. That's the way they're set up, so that we don't use them. ... It's really hard. And I have had a lot of support and help, but that is one of the things that's going on. It's not user friendly.

Another advocate described the enrollment process in this way: "It's designed to shame you and humiliate you at every step of the way".

The "Spend Down" Program

MHP's frequently referred to "The Medically Needy Spend Down Program" (The Spend Down Program) as a common method for Medicare recipients--a sub-group of the unfunded--to obtain their atypical medications. In fact, interviewees confirmed that many

clients rely on this system as a way to fund their mental health medications. As previously mentioned, Medicare does not pay for medication. Aging and Disability Services generally describes the Spend Down Program as a program which "provides some medical benefits to individuals who have high medical expenses, but whose income is too high for other Medicaid programs" This program requires a "spend down" each month to be eligible for benefits—one must spend or accrue a certain amount of medical bills to meet the eligibility lines. After the "spend down" for the month occurs, the individual is eligible for prescription coverage, some mental health benefits and medical transportation for the remainder of the month. An MHP describes the program in this way:

So you get a thousand dollars a month (from Medicare/Social Security). And say, for instance, that the OHP cut-off is 700 dollars and you earn a thousand. If you accrue three hundred and one dollars worth of medical expenses in the month, it puts you under the limit and then you get a medical card for that month.

While the Spend Down Program serves as a valuable, and much needed, resource for hundreds of individuals, MHP's, advocates and clients highly criticized the program. One advocate (and enrollee in the Spend Down Program) considered the program "stupid". He stated that his impression of the program was that one must "be sure to spend all of their (the state's) money, so they (the state) could then turn around and pay for your medications". In fact, many MHP's and advocate's similarly denounced the program, noting that a more sensible plan might pay for the medications from the start.

³¹ To qualify, the individual must be blind, have a disability, or be over age 65.

³² According to the program guidelines, the amount of income remaining after the cost of medical expenses can be no more than \$413 for an individual or \$526 for a couple. The first \$20 of income each month is not counted.

While many MHP's noted that the program was "actually better than it used to be", MHP's in each county complained repetitively about its inefficient and confusing nature. The program's perplexing qualities inhibit both MHP's ability to serve potential and established enrollees, and the clients' ability to understand and participate in the program. Two main aspects of the Spend Down Program present difficulties for the clinicians and the clients: unclear guidelines and case management.

First, although most case managers described using this program regularly, many remarked on the confusing nature of the guidelines. MHP's complained that numerous clients simply do not understand them. One MHP described the program as "this amorphous, mysterious Spend Down thing". MHP's also noted the increased work that results from the confusion, "Yeah, they don't comprehend it all. And WE get the legwork with all that." The following MHP remarks illustrate the difficulties:

When I explain the Spend Down, they just say, 'No, just skip it. Talk to my mom'.

Something that we deal with continually is the Spend Down status. It's difficult to explain this to people. You're saying, 'You don't really have to spend this money. You're incurring an expense.' We've used thermometers and all sorts of things to show it.

And trying to explain this to people! It's not that it's not understandable. Almost (laugh). But, trying to explain this to people that are in need, and broke, I mean these folks are poor. And their minds aren't working terribly well either. And aged, and sick. Those are barriers.

On a similar note, an advocate stated, "Clinicians cannot adequately explain the Spend Down program."

Second, managing the Spend Down cases and ensuring that the clients meet the "spend down" numbers is problematic and extremely time-consuming. MHP's described their work with the Spend Down program as a constant battle, endlessly making certain

that the clients accrue the proper expenses. An MHP said that one way to ensure the "spend downs" involves enrolling the clients in higher priced treatment programs. In this way, the client's medication funding is guaranteed.

The most recurrent complaint, however, centered on the onerous task of completing the complex paperwork for the program. MHP's offered the following remarks:

It is unwieldy, because you have to see them at the beginning of the month and you have to help them get it each month, and it's a lot of paperwork.

I had an individual that we tried to switch to Zyprexa (an atypical antidepressant). He would have met his Spend Down. But, to him, to even have me do it with him, to go through all of the paperwork, and all the business of getting his bills together, and getting it to the DSO office, it was too much for him. He said he just wanted to be on his regular meds. He didn't want to mess with Zyprexa.

It's all a lot of paperwork that has to be done. A lot of people might qualify for a Spend Down, but again, it takes someone to walk them through the process, because most of them aren't capable of understanding the process. They just don't understand the Spend Down. It's very confusing for them.

Finally, MHP's noted that inconsistent requirements from the DSO office contribute to the aggravations of case managing Spend Down clients:

It's just really inconsistent with the DSO office in terms of how the Spend Down is treated. I haven't really reviewed this with all of our case managers recently, but it used to be that one DSO worker would say, "Send me something once every 3 months." Another worker would say "Every 6 months." You got different treatment from different Disability workers in terms of what sort of documentation to track down. And it's really difficult for case managers, as their caseloads have gotten bigger.

Patient Assistance Programs

Patient Assistance Programs, or scholarships, which various pharmaceutical companies offer, serve as another avenue for access to atypical medications. Though

programs vary, requirements generally include specific income levels and proof of need documented by a prescriber. Interviewees criticized two main aspects of the programs: the extremely low income level criteria and the amount of documentation required for many of the application forms. MHP's also complained about the unreliability of the enrollment systems. A few MHP's mentioned that there had been numerous "lost applications" on the pharmaceutical companies' part. MHP's remarks illustrated the difficulties that the enrollment process poses for the clients and the clinicians:

The problem with the scholarship programs too is that the client ends up having to go to DSO to get letters as to why they aren't eligible and this, that and the other. And oftentimes the client has no means of doing that on their own.

They make them work hard to get them. They ask for the client's family income. So, I was at this one family's house searching for their bank accounts!

Furthermore, many MHP's simply do not trust scholarships as reliable sources for medications:

Those programs are not the most reliable things in the world. You know, we'll have a person covered by the manufacturer of Risperdal for a while, or whatever. And then we'll get a notice that that program is no longer available. Or that person has used up their benefit. Or something like that.

Well it's a pain in the butt too. To write the letters to the companies. And always be re-upping them. Every three months you need to reapply. And there have been some companies just all of a sudden cut off their program. And where is the client left then?

That's actually one of the things that holds me back from getting some of these people from conventional medicines onto the atypicals. Because I'm afraid that at some point down the road they are going to have to drop out of it again.

These program nuisances do not encourage the clinicians to utilize scholarships.

Both understaffing restraints and excessive requirements appear to prevent clients from applying. The following comments show clinicians' frustrations:

With all of the patients that you see, by the end of the day, you're too tired to go through all of that patient assistant stuff, and look up all this stuff. Does this person qualify? And that sort of thing.

We are wheeling and dealing constantly. We always have to do that stuff. If you have 60 people (on your caseload), guess what? You have less time to wheel and deal. You think I'm going to be writing the Paxil company, and asking them for money when I have all kinds of other crap going on?

It's way easier to give samples. And, so, in some ways we haven't really pushed [scholarships].

While most clinicians showed great familiarity with patient assistance programs, the following case manager's comment shows the inconsistency of medication resource knowledge: "Something that is a little interesting is that I didn't even know the programs are available until just a short time ago... I don't know who mentioned it me".

Interestingly, advocates offered a drastically different perspective on the use of patient assistance programs. First, many advocates/consumers did not have any prior knowledge about the patient assistance programs before the interviews. While this might have been due to the fact that these clients had not fallen into the eligibility level for the programs, (in which case their MHP's would not have had reason to advise them about the programs), their remarks deserve attention.

Advocates felt strongly that clinicians should better educate clients and their family members about scholarships. As one advocate noted, unfunded individuals might have family members that could assist with the requirements, if the county could not

provide assistance. The following quotes illuminate the advocates' and consumers' frustrations with the lack of information about patient assistance programs:

Interviewer: Have you ever been given information on how to get a scholarship for medications? Pharmaceutical companies have scholarships for people who can't afford medications.

Advocate #1: They (clinicians) don't even bring that up.

Advocate #2: How do you get that information?

Advocate #1: They do not inform you. You have to be smart enough to ask them the questions. If you don't know how to ask them, then you aren't going to get any answers, and they aren't going to volunteer them. That's just the way the system runs.

Advocate #3: In this county if you don't know about it, they aren't going to tell you.

An advocate offered the following remark about prescribers in his county: "I don't even think the doctors know half of this (information about patient assistance programs)".

Another advocate similarly noted, "Families don't know about the drug scholarship programs. They find out through support groups, or maybe a GOOD case ". When I asked an MHP about the idea of starting support groups to educate clients and their families about services for the unfunded, the issue of understaffing rose again:

The problem is if you educate family members--and they should be educated--they're going to come to us, and we're not going to have the staff to do it. So, I'm not sure if that's helpful unless we have the resources. So, yes they should be educated, be we need [the information and the increased staff] to go hand in hand.

The Confusion of Resourcing

The previous sections illuminate the general disorder and lack of cohesion within the state system and the various programs for medication. This confusion undoubtedly serves as a barrier to quality treatment for all clients. Moreover, MHP's complained about the complications it adds to their work. Clinicians viewed managing and staying up-to-date with the various program eligibility lines as a particularly onerous task, one

which they often simply could not accomplish. The following MHP exemplifies the situation: "You got this set of rules for this income, and this set of rules for this income, and we can't even stay up on it". When asked if barriers existed at the *clinic* level, an MHP replied, "Yeah, having the knowledge of what's available, and having the time to figure out what program the client can qualify for, and how much a client can do on their own".

An MHP voiced the following solution:

It would be nice to have someone who knows all of the in's and out's on site. To help clients with OHP (or CAAPCare), or scholarship programs. Just one person who knows all of that stuff, and that's what they did, help the person get on the program that they qualified for. Because it's all so fragmented, and it changes all the time. We cannot possibly keep up with it.

Interviewees offered the following comments on the confusing aspects of medication resourcing from the clients' perspective:

These folks in general are disabled. And by disabled, it's not a matter of intelligence. Our group is on a regular bell curve of intelligence. It's that mass of trying to think straight about all of those papers. --MHP

People, some people, their symptoms have their motivation down as low as it can be. So, it's just the complication of another system, and they give up. And they often go without. --advocate

I think another big barrier to getting medications for this population is the confusion of the system. And how to get funds. For myself it is very confusing. And when you have a major, severe mental illness on top of that, I can imagine that it's very confusing. ... I'd give up, you know. I mean why would I want to chase around these medications, and try to fund my medications? --MHP

As the quotations show, both advocates and MHP's complained about "the system" incessantly. One MHP simply stated, "Oh yeah, the system is a barrier in itself".

The following quotes further illuminate frustrations in regard to "the system", and finding the appropriate resources for funding atypical medications:

One of the big problems is that people with mental disabilities are not always in the best shape to do their own research. It's rough, and its not easy to access this information unless you know where to go or who to talk to. That's what makes it rough, the system makes it very difficult for people to access the necessary information, it is very unforthcoming with providing information. --advocate

I think the process needs to be simpler and clearer, for both the client and the agencies. --advocate

Creativity for survival. If you can't deliver services, you've got to be creative. Because the system itself isn't designed to be easy to work. --MHP

The Reality of Atypical Utilization for the Unfunded

"I think the physician and the patient should choose which medication is working best for that patient. And that is the medication that should be funded. Whatever, it might be."

--MHP

With the understanding that OMHS sought data to inform decisions concerning a state atypicals budget, I asked interviewees for their opinion on this subject. In general, interviewees responded negatively or skeptically to specialized funding for atypical medications. While every interviewee commented on the great need for increased financial support, even money dedicated to medications, most opposed this sort of categorized funding. Interviewees (primarily MHP's) voiced ethical, practical and political concerns which suggest that the state's approach to providing psychiatric medications is negligent. Their comments imply that compartmentalized funding overlooks the reality of atypical utilization. In particular, a fund specifically for atypicals fails to consider the following:

- 1) atypicals may not be effective for all clients,
- 2) not all unfunded clients may currently use or desire atypicals,
- 3) not all prescribers consider atypicals as "first-line" medications, and
- 4) appropriate treatment for mental illnesses requires more than psychiatric medications. Additionally, MHP's pointed out numerous logistical concerns for the implementation of such a fund. The following sections illuminate these concerns.

Atypicals May Not Be For Everyone

While many interviewees mentioned the success of clients' treatment with the new generation medications, and the importance of their availability, numerous MHP's cautioned that atypical medications do not meet the needs of every client. A prescriber noted, "While they do sometimes offer better alternatives to the older medications, it's not necessarily cut in stone that they will be the superior option". Because individuals react uniquely to psychiatric medications, and in some cases even to the same medication at different times, atypicals simply cannot be assumed to be the appropriate medication for all patients. While some of the advocates/consumers offered positive remarks about atypicals, such as "If I had to go back to the old drugs, I just wouldn't take any.", others said that the atypicals "just didn't work" for them. MHP's described cases in which atypicals were, in fact, not effective for their clients:

I have got several clients that Stelozine works the best with. Atypicals don't work as well for them. Stelozine is an old medication. It's not a medication of choice. But, it's the one that works for these clients.

And, I've actually tried this person on atypicals. I think it was Risperdal. And maybe there was even a short course on Zyprexa. But, she just didn't do well with it. And, she does much better on a blend of the old-fashioned. And I mean blend. She's kind of precariously balanced on

some Haldol and some Meleril. She just doesn't do very well with any other combination.

What I'm saying is that it totally depends on the patient. One medication may not work, and that medication may be "atypical". But, then for another patient, it may be.

Furthermore, clinicians noted the "improvisatory nature" involved with prescribing psychiatric medications. A prescriber explains, "There is no formula for treating mental illnesses". The following remark illustrates the roulette game of which atypicals are a part:

I was in a meeting last week with a psychiatrist and a patient, and the psychiatrist was explaining to the patient, 'Look we have 16 medications that we can try, to resolve the problem of your voices. We're going to start with this one, and if that doesn't work, we'll try this one. But, we will find one that works.' It may take the sixteenth medication to find the one that works.

While MHP's commented on the beneficial aspects to atypical medications, they recognized the complications which might arise from only funding specific medications for an entire population. In particular, they noted the practicality and ethical aspects of such funding. They viewed an atypicals fund as exclusionary, and consequently, "inadequate" and even "unethical" service. The following comment summarizes the prevailing attitude expressed by most clinicians during interviews:

I don't want to say that the atypicals are not the ones that are going to work the best, by far they've got the best profile for patient comfort. But I don't think we should exclude.

Additionally, MHP's pointed out that some unfunded clients simply may not want to use atypical medications. MHP's included resisting new medications, fearing side effects and incorporating past experiences with medications as possible motives for

opposing atypical medications. Some MHP's even considered clients' resistance to try new medication as a "barrier" to access:

He's another guy that is quite happy to stay on atypicals. A little [non-atypical medication], and little [non-atypical medication], and he's fine. And that is a barrier, as much as the payment issue is a barrier. There's some people that just don't want to experiment that much.

MHP's mentioned the adverse side effects of atypical medications as another possible deterrent:

I think the medications themselves are a barrier. The people don't want to take them. People don't want the side effects of being sleepy. They don't want to take medications.

They don't want to take the medication because they don't want to take it at 5:00 in the afternoon when it is delivered to them. And it's delivered once a week. And we can only watch them take it one time. And they could cheek it. So, they don't want to take it. It makes them too sleepy.

In fact, numerous consumers in the advocacy groups did complain about this side effect of the atypical medications.

Finally, some clients entering the county system have already established successful treatment plan which include older medications. Many prescribers noted that they were not inclined to change these clients' prescriptions to atypicals. One prescriber stated, "Some of the unfunded are just not on atypicals. They came to me that way. They seem to be doing OK. There have been no compelling reasons to change." Another MHP made a similar comment:

I think restricting it to atypicals is not okay because a lot of the people that we have helped with our fund (the extra money that the counties currently have in their budgets for the unfunded) are NOT on atypicals. ... (in response) And they are doing FINE on other meds; they don't want to change. So that would sort of force them to the atypicals.

Prescribers' Preferences

In several interviews, MHP's mentioned prescribers' varying utilization patterns.

As one MHP summarized, "You certainly won't find everyone agreeing on how best to treat someone". Another remarked, "We have some prescribers that just won't prescribe certain things". Interviewees offered various reasons for not prescribing atypical medications, including comfort with older medications:

And there are people (prescribers) who like the old medicines that they're used to. They know best and use those. So, that exists. --MHP

And it's because they've prescribed these drugs for years, they're comfortable with that. And they don't want to step outside their comfort zone. --MHP

Out of the ten prescribers interviewed for the study, one showed a reluctance towards atypicals. Although his colleagues referred to him as a possible "barrier" to access, he described his prescribing preferences as cautious. In particular, this prescriber mentioned not always considering an atypical medication as the first option for his clients. All other prescribers generally regarded atypicals as first line medications. Considering the comments from clinicians and advocates, I concluded that although prescribers' preferences certainly do exist, they could not be categorized as a distinctive barrier to access. (Clients' perspectives on this topic may differ. This is one of the many issues that deserves the consumer's point of view.)

Interestingly, doubts about the efficacy of atypicals did arise in conversations with both MHP's and advocates. In particular, one clinician remarked on the assumption of superior efficacy in an atypical fund. While discussing this presumption, he adamantly remarked, "That's not true. Unfortunately there's a lot of people propagating that message. And, it's not true." Other prescribers offered similar remarks:

And I don't see anybody who has made this miraculous turnaround. Oh, God, I'm cured because of taking a certain medication. Certainly some of them are functioning better. There's not a miracle medication out there.

... But it was that way when Thorazine (an older antipsychotic) first was made. It was the miracle drug. It was going to make everybody better. And then Clozaril came around. IT was supposed to fix everybody. And, then, now it's Zyprexa and the rest. There's really not a lot of difference.

I think the advertising hype is not in line with reality. I mean if you believe that Risperdal does not cause EPS (extrapyramidal symptoms)³³, I've got a bridge to sell you. On the other hand, for the most part, Zyprexa does seem to be fairly clean of EPS, but it's fairly sedating, and it causes people to gain weight. So, people want to go off of it for that reason. And, so does Clozaril for that matter. Risperdal can as well, but less so. So, the promise is different from the outcome.

An advocate/ex-client perceived a similar disparity between the current propaganda and the actual effects of the newer generation antipsychotics:

If you look at them (antipsychotic medications) across the board, the efficacy variability to reduce psychosis or psychotic episodes is pretty much flat across the board. Some make you sleep more, some make you retain water, some affect your muscular system and nervous system differently. But the efficacy of diminishing your burden or distancing you emotionally from your psychotic experiences is pretty much equal to the ones discovered in 1952.

Interviewees also considered availability as a factor in a prescriber's decision-making processes. While one might assume that prescribers utilize atypicals less for the unfunded population because of cost, remarks from MHP's reflected that the opposite occurs. Many prescribers and other clinicians as well, mentioned that the unfunded population actually receives more atypical medications than non-atypical because of the constant source of samples available:

It's actually easier to have someone on one of the atypicals because they're so expensive. It's really easy to meet the Spend Down requirements just

³³ EPS is a movement disorder side effect that is the most common treatment concern for patients taking antipsychotic medication.

based on medications. ... So, if they are medication only, they don't need a lot of other services, they won't meet the Spend Down with one of the older antipsychotics and antidepressants. Because they're not that expensive.

I mean it is true that things we haven't gotten samples for, we don't use as much.

Furthermore, when I asked prescribers about the frequency of prescribing non-atypicals because of cost, they generally gave four reasons for this decision: the clinic is experiencing a shortage of appropriate samples; an affordable medication is needed until the client receives a medical card which will cover more expensive medications; sustainable funding for more expensive medications is unavailable, or the client does not wish to take atypicals. Unfortunately, no members of the advocacy groups could provide a client's perspective for this issue either. An MHP candidly summarized the role to prescribers' preferences: "I don't know how much of the atypical vs. more of the traditional medications, is driven by economics and how much is driven by our psychiatrists' preferences".

Holistic Treatment

While interviewees valued the state's concern for the unfunded population's medication access, (particularly the problematic high costs of the atypicals), MHP's and advocates repeatedly clarified its myopic focus. Prescribers made comments such as "There is no such thing as medication management only.", "I work here as part of a team." and "It takes a lot to manage these things (psychiatric medications)". In other words, the prescribers involved in this study believe that proper treatment plans require more than administering psychiatric medications. As previously mentioned, unfunded clients must first access a prescriber—a service that CMHP's cannot currently guarantee

for the unfunded population. An MHP comments on the importance of consistent appointments with prescribers:

In order to get plugged in and make it (treatment) workable, there's also a bunch of other things that would have to be in place. They have to be able to see somebody, and have it financed. Have the money to pay for that, so the medicines can be monitored and adjusted. If all of THAT is in place, and the only issue is how to pay for the medicine, certainly that would be helpful.

Interviewees questioned the state's ability to pay for the necessary increase in services should the number of atypicals prescriptions grow, chiefly the monitoring of patients who begin taking atypicals. The following quotes highlight unfunded clients' struggles to finance all the components of mental health treatment:

I'm thinking of the process of fine tuning medications. That takes a lot of visits to the doctor. A client I'm thinking of... this family owns their home outright, because they sold property in another state. But they are living on -- a family of four--under a thousand dollars a month. And they own cars too. Because when they sold this property, they thought, 'Well, let's get secure.' And their child was prescribed one of the atypicals through Dr. X (a local private doctor). And the process of fine tuning that ... I think she took a month's supply and has quit taking it. One of the (comments) of the family (was) 'Gee these appointments are so expensive'. I mean, they are paying for the appointments outright, and then the medication on top of it. And so, she's quit taking it. And she's a kid that needs to be taking, if not Zoloft, then something else. And the process needs to be fine tuned. But, the family is just [saying] 'God, how much is this going to cost?'.

I was thinking of one specific case, a 17-year-old that meets all the criteria for majorly high risk, suicidal behavior. I believe she's headed toward a diagnosis of bipolar, although she's with a major depression. She's taking an antidepressant. But, part of the problem is that she lives 30 miles from here. She has two parents that are disabled, and on SSI. And, for some reason--and I've never really been able to understand this--she does not qualify for OHP, the family doesn't. I think they make too much money on disability. And, so there are no resources in terms of insurance. There's nothing there. So, she does see [our psychiatrist] because of her high risk behavior. I've had to access other funds in order to just get gas money for her to make it to her appointments. And this takes a lot of work to do this resourcing. And so then yesterday she cancels her appointment

today because she's got a job interview. But, then her mother says to me, 'I hope she can make it tomorrow. Her car is acting up.' So, now we've got the funds to pay for her gas so that she can make it to her appointments, and we've been giving her samples when she comes in so that she has her medication. But, it's looking like she's going to need a stronger atypical medication as time goes on. But the assessment can't be done appropriately because she can't make it every week. ... So there are those kinds of family dynamics. So, I'm really having to baby-sit this girl. Hopefully there's going to be a connection in there at some point. But, a lot of it has to do with funding and their ability to pay for the whole thing. There's the medication issue. But, the whole thing is going to get more expensive.

Another MHP responds... And the idiosyncratic complexity of the case she's talking about is pretty representative of the clients that we work with. It isn't just an isolated, really complex one. In general that's representative of the clients we work with.

One MHP also questioned the ethics of administering atypical medication if the proper support and community is not in place for the client. Although an extreme example, the importance of providing holistic treatment shines through in the following story:

I had a client who been very, very sick. She had been in and out of hospitals and forced on medications a lot for years without a lot of improvement in her mental status. And then we got her on Risperdal which she took and we started seeing changes. Attention to hygiene. Really lots of positive improvements that we had been working toward. She also realized that she was 45, and hadn't gone to college, no husband, no children. It's like we set people up. We say, 'Okay, yeah, we'll talk about it in our next session.' Blah, blah, blah. Well, somewhere during all that, she went home and hung herself. She gained a lot of insight due to her meds. So, what did that bring her? I mean it would be like if you woke up and realized, 'God, I've been living on the street for 10 years. I gave my kids up for adoption. And I did all these things based on my mental illness. And now I'm pretty much written off as a mentally ill person even if I take these meds.' So, even though these new meds can put the right chemicals in these people so they can think clearly, without support and community and acceptance and integration ... I don't know.

Administrative Concerns

MHP's voiced practical concerns about administering and managing a specialized medication fund. These apprehensions, again, stem from the realities of atypicals utilization. Foremost among their concerns are the sustainability of an "atypicals" fund, the consequences of an additional administrative task and the lack of client-centered treatment which might result from such a fund.

Staff members constantly remarked on the importance of being able to sustain treatment for their clients once they become adjusted to an appropriate medication. The following MHP comments illustrate MHP's' fear that a special fund for atypicals would not be able to create this sustainability:

It's good to have a little bit of a fund the way WE use it. For people for a couple of months, to get them over the humps. But, for ongoing? And then what happens? The way the funds are, and the way the budget always is, something always has to go. So we have a lot of people on it, and then they end up cutting it out of the budget. Then what? That's a big issue as well.

Let's just think of an example. We have so much money for an atypicals fund. And in time, we lose money. The budget reduces. What has to go? Two therapists who are seeing 160 people? Or that fund? In the long run, the therapists, and the things that they can do with connecting people to all of the stuff that we use, is much more cost effective too. Yeah, I think that that is NOT the solution.

What happens at then end of every year? Would we have the money within our own budget to continue some of these people who have been started on atypical meds and are doing well?

MHP's also anticipate that a specialized budget would increase their already unwieldy paperwork load. The time which the staff members must spend completing paperwork for the state, the county and other various related agencies was actually repeatedly identified as a barrier to all aspects of treatment, including medications.

Simply, the time dedicated to paperwork overrides time spent treating clients. MHP's discuss this overload in relation to an atypicals fund:

Anytime you designate a fund in the budget, there is a paper trail that goes behind it. So, what it is going to mean for us is an increase demand for documentation.

The state will want some means of being accountable for those monies. And that usually comes down to US doing the paperwork. If we designate time to do the paperwork, it detracts from more time for patient contact.

Although an extra form to access an atypical medication may seem a trivial concern, any addition to the staffs' workload detracts from quality client service. In Lincoln County, for example, where unfunded clients must regularly wait over a month to see a prescriber, every appointment is crucial. The following comment pertaining to the already limited amount of time for clients provides a background for the distress of additional paperwork:

You write a prescription. You document. We have a record index. Did the person show up? Who saw them? If you talk with any of the docs, you have to do a dictation on that. You have to write a prescription for the patient. Plus you have to write it in the chart. The documentation alone, per visit, is almost fifteen minutes. So, if you manage to get any patient care in at all....90% of what we do is paperwork, and very little patient care. And that is very frustrating to me. ... When my patients walk out of here, I want them to know what their diagnosis is, why they are diagnosed that way, what they should be looking for in their family, what their medications are, what the risks and benefits of those medications are, and what the alternatives are if these medications don't work, and what they should be looking for, and how to access me, or who they should be accessing. And that, in a fifteen minute time frame?

Additionally, an atypicals fund essentially creates a formulary for the unfunded. One interviewee noted, "It (an atypicals fund) has its own problems. Because then you have a limit. So how are we going to deal with that?" Staff members worry that the following types of questions would then color client treatments: Have you made sure that every

other drug has been tried before you go using something not on the formulary? or Who needs this amount, as opposed to this person over here? A prescriber noted that an atypicals fund might "force the use of certain medications that fit into the funding stream".

As noted in the following quotes, MHP's worry that an atypicals fund would direct treatment options, rather than allowing clients' needs and the expertise of the mental health workers to guide the course of treatment.

It's a barrier to care that you need to make decisions based on money. You know, really based on money and not what the client needs.

They create systems that create barriers to the delivery of services.

I think it is a lousy idea. The problem that we have in this state politically, is that we have historically created these little silos of unique funding. The concept of letting the funding follow the client has never dawned on a politician in Salem. ... It does not make sense. It is another category. We have tons and tons of categories.

The choice of treatment needs to be left to the physician and the individual patient. It should not be made by the pharmaceutical companies. It should not be made by politicians. And, if we are going to create funding for mental health treatment, then we are going to have to consider the client. Now if the atypical medications are worth their salt, then they are the ones that are going to be prescribed. But, if they don't work, then we're not going to prescribe them.

Another MHP's responds... The other way around, you've got the tail wagging the dog.

Finally, emphasizing the political economic nature of an aytpicals fund, an MHP summarized, "To have a fund that is only for atypicals, only benefits the pharmaceutical companies that manufactures them, it's not going to help the clients".

DISCUSSION AND CONCLUSION

No person is an island. Neither is a sector of the economy, or social institution. Yet if such an institution—the health care system for example,—is consistently viewed in isolation, if those who study it refuse to explore systematically the myriad ways it is tied into the power and control systems of the wider society, then a disservice is done to those whose basic interests are at stake.

-- Elliott Krause (from Power and Illness)

Summary of Findings

OMHS' research objectives included the identification of the unfunded population, and the accessibility of atypicals for this target population; the agency also wished to examine the factors which possibly bar the unfunded population's access to atypicals. OMHS staff members hoped to attain this information in order to better inform their recommendations on an impending state budget proposal for an atypicals fund for the target population.

Although precise quantitative data regarding the number of unfunded clients served and the quantity of atypical medications dispensed from county-related clinics were inaccessible, abundant ethnographic material was gathered through numerous interviews with mental health clinic administrators, prescribers, a variety of clinicians and mental health advocates. This ethnographic information provided qualitative descriptions of unfunded clients and detailed descriptions of various complications within mental health clinics, including medication access. Although interviewees' responses could not provide direct answers to many of OMHS' concerns, their comments (1) provide a context for the unfunded client's predicament with county-related clinics, (2) clarify the complexities of atypicals utilization and (3) clearly show the inappropriateness

of a specialized line item in the state's budget for the unfunded population's atypical prescriptions.

The OMHS study should be considered a preliminary study, a "rapid appraisal" (Bebee, 1995) of the ways in which three Oregon counties address the inherent complications with unfunded clients, their medications needs in particular. This research demonstrates a need for many further detailed studies, including the impact of clinic understaffing, the effects of OHP, the needs of various sub-populations (children, Medicare recipients, individuals with fluctuating OHP eligibility, etc.), the efficiency of state-funded resource programs and a client-centered perspective to medication access. Nonetheless, three primary conclusions can be drawn from this study.

First, the ethnographic material suggests that the barriers which prohibit the unfunded population from receiving atypical medications may not be based simply on a lack of funds for medications. Unfunded clients attain their status for various reasons. This research identified five primary categories of unfunded clients: the uninsured, the underinsured, those individuals in between insurance coverage, Medicare recipients and select children. Interviewees' comments indicate that instead of providing outside funding for these individuals, their needs might be met by rectifying the inadequacies within the clinics (primarily general understaffing and a lack of medication resource knowledge) and the applicable state and federal-funded programs (the Medically Needy Spend Down Program and the Medicaid Program).

The public rhetoric which encompasses an atypicals fund emphasizes the possible long-term savings for the state, and the ethical obligation of providing the latest medications for unfunded mental health patients. Yet, we know of the pharmaceutical

lobbyists' political power, and their blatant effort to secure the fund as a way to supplant medication sample supplies. The study results imply that better knowledge of sample use would be necessary to thoroughly justify even this politically-driven reasoning for a specialized budget, specifically, a more explicit study designed to accurately examine the ways in which county prescribers utilize samples. This sort of study might show whether prescribers dispense samples to those clients who simply do not have the funds to cover medication costs, or as the easiest method to provide medications for those individuals who suffer the consequences of a poorly designed system. While the state might see an atypicals fund as a quick-fix for both categories of clients, such a drain of public funds, which OMHS staff members predicted would be over 1 million dollars, warrants closer scrutiny.

Second, interviewees' comments indicate that medication access is only one of the myriad problems faced by unfunded clients in the three county study sites. In fact, the data show that a lack of appropriate mental health services, in general, is the foremost problem for many unfunded clients. The inaccessibility to prescribers, a severe shortage of necessary case management and insufficient outreach, for first time clients in particular, precede and compound the challenges of medication access.

Finally, interviewees' remarks clearly showed the inappropriateness of a line item in the state budget for the purchase of atypical medications. Although mental health professionals noted the importance of the availability of atypicals, they ultimately viewed such a budget as an inadequate and myopic solution to meeting the unfunded population's needs. Interviewees cited a number of factors which render such a budget problematic, including its inability to address the variability of individuals' response to psychotropic

medications, the lack of personnel and services to monitor an increase in atypicals prescriptions and the uncertainty of the fund's sustainability. Instead, clinicians suggested an increase in general clinic funds to be applied on an individual basis to address the idiosyncrasies of each client's case.

Contextualizing the Data

The contextualization of data, placing observations into a larger picture, serves as one of the primary attributes of anthropological research. The highly political context in which atypical medications are embedded is inevasible. The study results imply that, for Oregon state policy-makers, the political-economic concerns surrounding atypicals eclipse quality mental health care. Moreover, a specialized budget for atypicals appears to better serve the narrow interests of a small, privileged sector of society, than the medication needs of Oregon's unfunded clients. Allocating thousands of appropriated dollars to a system which is suffering from great financial despair, and an inability to serve the current client load, is simply irrational.

The Critical Medical Anthropology perspective advocates the examination of asymmetrical power within health systems. Clearly, the decision to create an atypical fund would be a politically-driven, top-down approach to the provision of mental health care. What forces drive state policy makers to consider such an action? I believe the answers to this question lie within a complex web of political-economic, historic and cultural factors.

The pharmaceutical industry's very visible influence over state legislation is an easy answer, and one that undoubtedly weighs heavily. The magnitude of pharmaceutical industry political contributions, industry representative's personal incentives and simple

dollar profits cannot be overlooked. Other tangible factors might include the state's deliberation of potential lawsuits or the authoritative persuasion of pharmacoeconomic studies.

Considering the influence of societal values, one wonders to what extent our culturally predominant reductionist view of illnesses has influenced our lawmakers, or if the state's historical propensity to medicate the mentally for social control lies silently at the base of legislative decisions. Perhaps the media hype over the efficacy of atypicals governs state policies, and the ubiquitous medicalization of our society has usurped the emphasis on human experience in the field of psychiatry.

Medical hegemony, defined by Singer, Baer and Susser as the "process by which capitalist assumptions, concepts, and values come to permeate medical diagnosis and treatment" (Baer et al., 1997, p. 14) has undoubtedly transformed the psychiatric field at large. While the study's research goals did not involve a critical examination of the treatment of mental illnesses, the effects of contemporary hegemonic forces appear throughout various levels of the OMHS study, even the creation of the study itself. However, these conclusions would not have been appropriate for our final report for OMHS, nor did we believe that a critical analysis would have been efficacious for OMHS' needs. Instead we delivered a detailed summary of our findings at the local clinic level. Essentially, our report documented inadequacies of the state mental health system, and the intricacies of atypical medication use and access for the unfunded population. We provided ample material to OMHS staff members and, by extension, Oregon Legislation to inform their future decisions regarding atypical medications and the general needs of the unfunded population.

Epilogue: Knowledge Utilization

During the July 1999 Legislative Session, in which the state's annual budget is determined, the Legislature reserved \$1.9 million for use on atypical antipsychotic medications. In September, an OMHS staff member reported that the agency was researching ways in which the money could best be utilized. OMHS had first proposed a jail-related medication and case management program as an aim for the money. However, the pharmaceutical industry representatives had "essentially shot it down and declared that all of the money should be used for medications".

In the limited correspondence I have had with OMHS staff members, I learned that the research data had been referred to in conversations with the pharmaceutical industry lobbyists. An OMHS staff member noted that, in response to a pharmaceutical lobbyist's request to allocate the money to the unfunded population's needs in county clinics, she had cited the OMHS study. In particular, the staff member noted that the study results demonstrated that "the need is essentially being met where people seek service through traditional channels". I was impressed by her skillful word choice. Our research had been utilized in a limited sense, at best.

In a recent article in *Medical Anthropology Quarterly*, P. Stanley Yoder comments, "Anthropologists have long lamented the fact that the results of their applied research are often ignored by policy makers and administrators" (1997, p. 132). This is particularly frustrating in the case of the OMHS study, since the sponsors for the study appear to be the policy makers who are averting utilization. I am reminded of a remark by Merrill Singer, in his article *Beyond the Ivory Tower: Critical Praxis in Medical*

Anthropology: "The answers generated by medical anthropologists may not be those that are welcomed by power wielders" (Singer, 1995, p. 82).

The material in our final report elucidates deficiencies and problems within the mental health system at the county, state and federal level. Although all of the issues mentioned relate to the accessibility of atypical medications, the information could potentially be utilized as formal documentation for many matters. OMHS may or may not utilize the information in terms of the atypicals fund, or otherwise. However, CMA is about bringing the local context to the forefront.

Part of the philosophy of CMA is the "commitment to the development of appropriate practical expression" (Baer et al., 1997, p. 33). The OMHS study results should not be restricted to the issue of an atypicals fund. Should OMHS choose not to utilize the results, advocacy groups, for example, might benefit from the official documentation of understaffing or inadequate services, for example. In fact, other organizations may more readily interpret the information from the report as effects of the macro-level systemic forces underlying problems within the state mental health system. The next step for our research team entails providing access to the study material to various stakeholders and advocacy groups. In this way, our work might assist in making beneficial changes to policies for the unfunded mental health clients of Oregon.

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APPENDICES

Atypical Medications

Antipsychotic Medications

Clozapine (Clozaril)
Olanzapine (Zyprexa)
Quetiapine (Seroquel)
Risperidone (Risperdal)

Antidepressant Medications

(Selective Serotonin Uptake Inhibitors)
Fluoxetine (Prozac)
Fluvoxamine (Luvox)
Paroxetine (Paxil)
Sertraline (Zoloft)

(Other New Generation Antidepressants)

Venlafaxine XR (Effexor XR)

Nefazodone (Serzone)

Trazodone (Desyrel)

Bupropion SR (Wellburtrin SR)

Mirtaxapine (Remeron)

Price List for Atypical Medications

The following prices were quoted by a pharmacy in Corvallis, Oregon during January 2000. It must be noted, however, that pharmaceutical prices vary significantly, according to vendor, dosage and time on the market. Furthermore, individual clients' dosages vary greatly. This list merely serves as a reference for the reader.

Antipsychotic Medications Clozapine (Clozaril) 100 mg	\$104.99
Olanzapine (Zyprexa) 5 mg	249.09
Quetiapine (Seroquel) 25 mg	59.69
Risperidone (Risperdal) 1 mg	110.99
Antidepressant Medications	
Fluoxetine (Prozac) 20 mg	84.79
Fluvoxamine (Luvox) 50 mg	120.59
Paroxetine (Paxil) 20 mg	102.09
Sertraline (Zoloft) 50 mg	74.29
Venlafaxine XR (Effexor XR) 37.5 mg	90.79
Nefazodone (Serzone) 150 mg	86.99
Trazodone (Desyrel) 50 mg	83.29
Bupropion SR (Wellburtrin SR) 150 mg	66.89
Mirtaxapine (Remeron) 30 mg	104.89

Interview Questions for Prescribers

What is your role with the client?

Approximately how many of your patients are unfunded?

How would you describe the unfunded population? (size, reason for no funding, social/demographic information, etc.)

Do you always know the funding status of your clients?

What have been some of your experiences with prescribing atypical drugs to the unfunded population?

Do you think barriers exist that prevent the prescription of atypical drugs to this particular population of patients that you see? Explain the barriers.

As a prescriber, have you experienced any situations in which there were barriers to prescribing the drugs?

How do you think these barriers might be removed? What specific changes could be made in the system at the county level or state level?

Do you have any other suggestions that might help this particular population?

Have you ever been forced to prescribe lower cost medications due to a lack of county funds to cover the cost of atypicals?

Does a county patient ever have to have his/her medications changed because of drug availability? Are there resources available for this transition period?

What is your opinion on atypical anti-depressants and anti-psychotics?

Can you describe your experience with prescribing these various medications?

Do you feel that you have enough information about these drugs to be able to prescribe them?

What is your opinion on the idea of a line item in the state budget for atypical medications for this target population?

Interview Questions for Clinicians

What is your role?

In what way do you have contact with the unfunded population?

How would you describe the unfunded population? (size, reason for no funding, social/demographic information, etc.)

Do the clients talk to you about their medications? Any specific conversations about atypicals?

Do you feel that the county is able to meet their needs in general? Specifically, do you feel that this population is having their medication needs met? Does this include the atypical drugs central to this study? Discuss anti-depressants vs. anti-psychotics.

How do you think your clients perceive their access to atypicals? Do you think your clients perceive problems in accessing the medications they think they need, specifically atypicals?

Do you feel the county is able to offer treatment with atypicals for all those who might benefit from it?

Do you have any suggestions on how to better meet the medication needs of this population or their related needs?

What is your opinion on the idea of a line item in the state budget for atypical medications for this target population?

Interview Questions for Advocacy Groups*

What does your organization do?

Are any of the people you represent/or any of the group members here today part of the "unfunded" population?

How would you characterize the "unfunded" population? (size, reason for no funding, social/demographic information, etc.)

Are you familiar with the "atypical" drugs?

Is it your impression that this population has access to the atypical medications, from the county-related clinics? If not, why?

Have any of you had or heard of others' experiences regarding access to these drugs from county-related clinics?

What do you think can be done to improve access (if access is problematic)?

Is your group working on any remedies to these problems?

Have any of the people you represent tried these new medications? What have their experiences been?

Are there other related needs for the "unfunded" population?

What is your opinion on the idea of a line item in the state budget for atypical medications for this target population?

^{*}These questions varied slightly depending on whether the interviewees were strictly advocacy group leaders or a mixture of leaders and mental health patients.

Interview Questions for Clinic Administrators

How is the nature of your work related to the "atypical" category of medication (e.g. tracking prescriptions, allocating funds for medications, etc.).

How would you describe the unfunded population? (size, reason for no funding, social/demographic information, etc.)

What kind of funds do you have available for the unfunded client?

Do you keep records of the prescription and /or purchase of specific drugs?

Do you keep records of the samples of atypical drugs which are given out from your clinic?

How many clients were prescribed antidepressant and antipsychotic drugs during the 1998-1999 fiscal year? How many of these clients were unfunded?

Do you feel that the current distribution of payment for atypicals in your county creates barriers to access? If yes, specify the problem(s) you perceive with the current distribution of payment for the atypical drugs in your county. What would you suggest to remedy the problem(s)?

Do you keep records of the number of mental health clients who receive scholarships from pharmaceutical companies?