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Staying the Course: Adherence to Depression Treatment Among Older Primary Care Patients

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Staying the Course:

Adherence to Depression Treatment Among Older Primary Care Patients

Christine Frauenhofer
Health and Societies Senior Thesis
April 2004
ABSTRACT

BACKGROUND: Measuring, assessing, and predicting patients' adherence to treatment remains a challenge for physicians. A more comprehensive understanding of the beliefs and motivations related to older adults' adherence behavior in the primary care setting can assist in developing more effective interventions. We will examine patient perspectives on treatment for depression and physical illness as expressed in qualitative, semi-structured interviews.

METHODS: An age-stratified sample of 2,560 adults aged 65 years and older was screened for depression at primary care practices in the Baltimore, Maryland area. Three hundred fifty-five of the patients are participating in standardized in-home interviews, which include additional information about sociodemographic factors, physical functioning, chronic medical conditions, use of medications and health services, and attitudes about depression and its treatment. The data from the standardized questionnaire will guide the analysis of the in-home interviews. Using this mixed methods approach, themes from both phases of the study will be linked to each other and to information obtained about patients and family members.

RESULTS: A number of themes emerged related to patient perspectives on treatment for depression and physical illness. Major themes include concerns about various aspects of treatment: side effects from medication, the number of medications currently prescribed, addiction or “drug” use, improper management of medication, and financial or social
difficulties in obtaining treatment. Many respondents also shared their views on the efficacy of various forms of depression treatment as it relates to their perception of the etiology of depression itself.

CONCLUSIONS: Since a patient's willingness to accept and sustain depression treatment is a deciding factor in the success of any given intervention, it is vital to understand more about the factors that promote or impede adherence behaviors. In the case of older primary care patients, for whom issues relating to medication are of extreme importance, physicians should make every effort to discuss antidepressant therapy and its potential effects and complications with patients before prescribing. It is also essential that physicians evaluate a patient's willingness to accept an antidepressant at all, since there are a number of factors that may make such a treatment unacceptable to certain individuals. While the constraints of an office visit may not allow for a thorough interview on the topic of depression, asking a few questions based on major themes of depression treatment can help physicians and patients determine an optimal treatment plan.

KEY WORDS: depression, adherence, treatment, elderly
INTRODUCTION

Depression has been recognized, and attempts made at its treatment, since the origin of the medical profession itself (Zax, Cowen 1976). Modern psychological and pharmaceutical interventions are undeniably more effective than the asylums and potions offered in centuries past, and greater understanding of the social and biological causes of depression has contributed to the de-stigmatization of what was formerly a shameful illness. Yet for all the knowledge that western biomedicine has gained, the fact remains that there is still no single accepted explanation for the biological and chemical causes of depression. The interaction of individual genetic, environmental, and societal factors in the development of the disease complicate both its diagnosis and treatment, made more challenging still in the context of the modern American health care system. Given these obstacles, it is not surprising that an estimated one in three patients does not complete depression treatment (Melfi et al. 1998). However, it indicates the potential – and need – for research to determine the specific causes of non-adherence in this group.

When compared with other illnesses, adherence to a treatment regimen is more difficult in patients suffering from depression. This is in part due to the illness’ many phases, the long-term nature of the treatments, and the constant potential for relapse. Several distinct factors can influence the ways in which depressed patients do or do not adhere to a treatment regimen, and analyses are often made more complicated by taking into account the probability of interaction among many of these factors (Kupfer 1995). Features of the antidepressant medications themselves can affect an individual’s willingness to adhere to a regimen. Some medications may produce unpleasant side effects that cause patients to cease treatment, especially if the side effects persist beyond the
lessening of the depressive symptoms. In addition to an individual's reaction to the medication, friends or family members may express fears, concerns, or judgments about side effects, behavioral changes, or dependence on medication that alters the patient's willingness to adhere to the medication regimen (Fawcett 1995).

Because depression treatment often incorporates both medication and psychotherapy, clinical factors may affect depression adherence even more than for other illnesses. Clinicians' expertise and points of view, as well as how those ideas are expressed, can also be factors that influence the degree to which a depressed individual adheres to a medication regimen. It has been suggested that the pharmacologic and psychotherapy treatments must be considered as an integrated whole by the clinician and must be presented as such to help the patient to understand that he or she must adhere to both regimens simultaneously (Fawcett 1995). However, medications are often prescribed by a primary care physician while counseling is provided elsewhere. This functional split in service can often compromise continuity of care and adherence to treatment.

Non-adherence to medication regimens in complex, chronic illnesses such as depression is a persistent and serious problem and requires multifaceted interventions. Many individuals who are seen in primary care and who begin antidepressant treatment stop taking medication during the first month (Johnson 1974, Katon et al. 1992). Providers that adopt one single approach to address the problem of non-adherence may offer a few important interventions that are necessary to enhance medication adherence. However, effectiveness is limited and may not account for methods that are required if long-term medication adherence is to be achieved. Simply providing information about depression
and required medication regimens to individuals may not be sufficient, and other complex factors may need to be explored with individuals and family members.

THE SPECTRUM STUDY

This thesis was researched and written as part of a study taking place at the Hospital of the University of Pennsylvania in the Department of Family Practice and Community Medicine. The Spectrum Study, begun in 2002, was designed to study the "spectrum" of depression among older adults who have recently been seen by their primary care doctor. The study consists of two phases, the latter of which is currently in progress. The first phase, Spectrum I, screened 2,560 people 65 years of age and older in the care of primary care physicians in and around Baltimore, Maryland. From this large group 355 persons were interviewed over a period of one year. The interviews collected information about the health of each person, including depression, anxiety, medical conditions, and life events.

While Spectrum I did generate a significant volume of quantitative data about the study population, the design of the survey instrument limited the amount and type of information that respondents could provide. Many respondents felt that these limitations impacted the quality or accuracy of the answers they gave, as evidenced by the final question in the Spectrum I survey. When asked, "Is there anything we haven't asked that you would like to tell the people who are conducting the study?", many respondents raised issues such as:
"I have a hard time going between agree and strongly agree."

"Difficult to answer some of the questions... with just the choices given."

"You should give the person a chance to explain answers."

"Some questions don't really cover the problems I want to talk about."

Respondents clearly expressed that the topics of depression, illness, aging, and medical treatment were issues much greater than could be addressed with the predetermined response choices they were given. Recognition of the need to understand the respondents' feelings and beliefs about depression led to the design and implementation of the second portion of the Spectrum Study, *Spectrum II*, in the summer of 2003. With funding from NIMH (National Institute for Mental Health), approximately 160 persons from the group interviewed in Spectrum I are being chosen to participate in additional interviews at home to discuss depression - its causes, treatments, and influence on relationships with friends and family. By gathering the opinions of a diverse sample of people about their knowledge of mild depression, Spectrum investigators hope to understand more clearly how to assist older adults in leading more fruitful lives. Our questions for those participating in the interviews have no right or wrong answers, for example:

"*What do you think causes depression?*"

"*What are people like who are depressed?*"

"*What is the value of medicine in helping patients feel better?*"

"*What is the role of a doctor, of family and friends in treating mild depression?*"
The interviews provide insight into ways that culture, homes, training, friends, and community are important influences on individual and collective beliefs. By gaining a greater understanding of exactly how these factors contribute to views on depression and its treatment, we hope to improve the diagnosis and management of depression in older adults.

SIGNIFICANCE

This study differs from previous investigations of depression and adherence in several key ways. First, it focuses on older adults in the United States, a population that is growing rapidly but has not yet received a corresponding increase in medical research attention. The number of persons aged ≥65 years is expected to almost double in coming decades, from approximately 35 million in 2000 to an estimated 71 million in 2030. The number of persons aged ≥80 years is also projected to double in size, from 9.3 million in 2000 to 19.5 million in 2030 (Administration on Aging 2002). The incidence of depression is also increasing sharply and is predicted to be the second leading cause of disability worldwide by the year 2020 (Murray, Lopez 1996). Given these numbers, it is essential to understand more about how depressive illness is experienced and perceived in this group in order to provide the most appropriate and effective care.

This study also allows for an understanding of depression that is more inclusive than the fairly specific criteria for its diagnosis in the DSM-IV. In addressing those additional physiological and emotional issues, this study has the potential to improve the identification of depression in older primary care patients by challenging current guidelines that do not include age variance in expression of this mental illness (Caine et al. 1994,
Gallo et al. 1994, Henderson 1994). This greater understanding of older patients' perspectives on depression and its treatment will lead to the development of specialized, targeted interventions and treatment plans.

Finally, this study approaches the issue of treatment adherence from a qualitative, respondent centered perspective. The majority of adherence research thus far has focused exclusively on quantitative data or has examined adherence in relation to only a few factors. And while the existing body of research has generated a substantial list of barriers that may decrease adherence (including physiological, behavioral/social, treatment, and provider/patient factors), significantly less is known about how and why specific barriers affect individual patients. Through interviewing respondents and having them explain their thoughts and feelings about various forms of medical treatment, we will gain greater insight into the specific treatment challenges facing older adults with depression and other illnesses. This knowledge, coupled with improved diagnostic criteria for depression in older adults, has the potential to greatly improve the identification and treatment of depression in this population.

**METHODS**

All recruitment, screening, and interviewing of respondents was done by trained staff of Battelle Memorial Institute through a contract with the Department of Family Practice. The initial study population is an age-stratified sample of 2,560 adults aged 65 years and older that was screened for depression at primary care practices in the Baltimore, Maryland area. Three hundred fifty-five of these patients participated in in-home interviews, which included additional information about sociodemographic factors,
physical functioning, chronic medical conditions, use of medications and health services, and attitudes about depression and its treatment. This quantitative phase was designed to identify and characterize eligible patients with regard to depressive symptoms and cognitive functioning (See Table 1, “Sample Demographics”). The survey interview data will be balanced with qualitative, semi-structured interviews for 160 patients, continuing to be conducted over the course of the next year.

I received copies of the interview transcripts as they became available, which I then read and coded to identify themes related to beliefs about depression and its treatment. Since there are various forms of treatment available for depression, I sought to understand respondents’ beliefs about them both individually and in relationship to each other, including preferences for treatment and factors that make a given intervention either acceptable or unacceptable. I expected that the nature of the semi-structured interview would reflect the unique viewpoints and experiences of each respondent and correspondingly noted the influence of individual experiences on answers. However, my main objective in this analysis was to search for themes expressed by more than one individual in order to gain a better sense of how older primary care patients, as a group, perceive and evaluate depression and its treatment. Particularly descriptive and relevant interview excerpts are included in the Results section to provide the verbatim patient perspective on these issues and convey some of the specific challenges that older primary care patients face in accepting and sustaining depression treatment.
### Table 1

**Sample Demographics**

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REVIEW OF THE LITERATURE

Adherence to treatment is an issue of great importance in virtually every health-related setting. From behavioral modification programs to prescription medication regimens, adherence is one of the central determinants of any intervention’s outcome. Not surprisingly, individuals who follow sound health advice are more likely to have favorable results from treatment than those who do not, yet multiple studies have also shown that patients who are adherent to a placebo treatment have better health outcomes than patients with poor adherence (Coronary Drug Project Research Group 1980, Horwitz et al. 1990). Clearly, adherence has the ability to significantly improve health care interventions, but our inability to understand the factors behind it have thus far made it a largely theoretical ideal. Even the definition of “adherence”, typically cited as “the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” (Haynes, Taylor, Sackett 1979) is a source of great complexity and debate. The distinction between “adherent” and “non-adherent” is subjectively constructed and not necessarily dichotomous, and most studies state their own specific criteria for adherence, making comparisons and conclusions across studies difficult.

What the body of research has demonstrated is that rates of adherence vary widely across illnesses and treatments and that significant variation exists within any given treatment (Leventhal, Cameron 1987). These differences suggest that non-adherence is a multifaceted problem and should be examined from a number of angles and perspectives in order to gain a more complete understanding of the issue. Until recently, common conceptions of treatment outside the hospital setting placed all responsibility with the
patient, hence the use of the word “compliance” in place of adherence in much of the older literature. Studies on aspects of patient-provider interaction such as shared decision-making and its positive impact on treatment outcomes have led to the use of “adherence”, reducing the subservience and potential blame that compliance/non-compliance implies. In fact, several studies have identified factors of the medical setting (beyond the patient’s control) that can affect adherence: length of time between screening and follow-up appointments, the amount of waiting time at clinic visits, the complexity of the regimen, adverse effects from therapy, and the cost of therapy (Haynes 2001). What studies have largely failed to do is identify patient-specific characteristics that directly correlate with adherence behaviors. Investigations of sociodemographic factors such as age, gender, socioeconomic status, intelligence, and marital status have not demonstrated any consistent findings, nor have any psychological characteristics of non-adherers been conclusively identified (Haynes 2001).

The two patient factors that have been strongly suggested to adversely affect adherence are difficult social circumstances (such as social isolation and unemployment) and mental disorders (particularly paranoia or depression) (Haynes et al. 1979; Nelson et al. 1975). Given the knowledge that individuals in these groups are already at high risk for low adherence and likely to encounter many of the clinical barriers detailed above makes it all the more vital to understand the reasons behind adherence behaviors. This study, with its focus on older adults and depression, investigates the issue of adherence in a population that has many of the factors shown to promote low adherence. But unlike other inquiries, which have attempted to improve short-term adherence targeted to a specific
pharmaceutical regimen, the goal here is to design widely applicable, sustainable interventions based on an understanding of patients' health and adherence beliefs.

CONCEPTUAL MODELS OF ADHERENCE

There are five major conceptual models used in treatment adherence studies: the biomedical model, the behavioral model, the communications model, the rational belief model, and the self-regulative systems model. All of these approaches incorporate the same processes: illness cognition, risk perception, motivation to comply, selection and acquisition of coping behaviors, and appraisal processes, yet vary in their emphases and contributions to our understanding of adherence as a whole (Leventhal, Cameron 1987). The models are summarized below, in terms of applicability, strengths, and weaknesses for use in adherence research studies.

**Biomedical Model:** This model, used by a number of medical practitioners, is also the dominant cultural model of health care relationships in the Western tradition. One of the defining characteristics of the biomedical model is its view of the patient as a recipient and executor of treatment regimens, which are given by the provider to be accepted and followed exactly (hence the use of “compliance” rather than “adherence” in this context) (Haynes 2001). Non-compliance is sometimes thought to rest almost entirely with the patient, with little or no attention paid to the potential effects of the clinical encounter. This model has directed research into demographic and personality characteristics related to compliance based on the assumption that likely non-compliant persons can be identified and targeted for the presence of these specific traits. However, the many studies
employing this model have been unable to pinpoint such characteristics, indicating that non-compliance results from something more complex than the demographics or temperaments of patients (Haynes 2001). While it is possible that relationships do exist in this context, the difficulty of producing statistically significant data about a particular trait and adherence in more than one study means that few firm conclusions can be drawn using this model.

**Behavioral Model:** This model became more popular in adherence research as investigators focused less on trying to identify specific patient characteristics associated with adherence and more on the adherence behaviors themselves. Using learning theory as a guide, researchers attempted to identify stimuli for adherence actions, the reinforcing rewards from these actions, and the short- and long-term effects of newly shaped behaviors. This approach has demonstrated some success in interventions designed to impact addictions or lifestyle factors, as well as long-term treatments where medicine should be taken on a consistent basis, yet behavioral programs are often subject to high attrition once rewards and reinforcements are decreased or eliminated (Leventhal, Cameron 1987). It is unclear which phase(s) of treatment require reinforcement for maximum adherence, and focusing solely on reinforcement has in many ways kept researchers from the more important task of determining the social, cognitive, and motivational processes that trigger change (Dunbar et al., 1979). Without knowing more about the specific pathways to behavioral change and how individual factors influence this process, the behavioral model cannot realistically be used to design the kinds of long-term interventions that behavior modification and chronic illness patients require.
Communications Model: Like the biomedical model, the communications model presumes a health hierarchy where the provider's role is to elicit patient compliance to a given treatment. However, this model details a specific set of six steps that comprise effective patient persuasion: generation of a message that includes specific goals and means of attainment, reception of the message by the patient, comprehension of the message, retention of the message, belief in the message, and compliant behavior resulting from the patient's assumption that the message is valid (Leventhal et al. 1984, McGuire 1980, McGuire 1985). By definitively including provider factors in the process of compliance, the communications model expanded the locus of responsibility beyond the individual patient, leading researchers to conduct analyses of discrete characteristics of the medical encounter for their ability to improve or decrease compliance. When it was demonstrated that a clearly stated treatment regimen, well-organized and well-timed, which came from a practitioner who was perceived highly by the patient led to increased compliance, a new emphasis was placed on the physician as participant in the adherence process (Leventhal et al. 1984, Ley 1977, Korsch, Negrete 1972).

However, while receiving, understanding, remembering, and accepting information about a particular illness and its treatment are essential for adherence, these elements are not sufficient (Leventhal, Cameron 1987). The communications model does not account for external factors such as social support, explain the ways in which new information may affect attitudes about illness, nor propose any specific or variant pathways to adherence based on these factors. Yet research suggests that cultural factors and subsequent beliefs about health can, in fact, have a significant impact on the performance of health-related
actions. For example, a study on the medication attitudes and behaviors of epileptic patients led to the theory that deviation from a given treatment plan may depend more on the social meanings of medication and self-regulation for the individuals who suffer from chronic illness than on their beliefs and understanding of the medical information provided (Conrad 1985). The researcher identified four primary reasons for deviation from suggested treatment: testing, dependency avoidance, destigmatization, and “practical” considerations. Patients may suddenly stop taking their medicine or somehow modify the dosage as sort of experiment to observe what the effects might be, hoping to assess how the disorder is progressing or to determine whether the medication seems necessary at all. And while taking medication theoretically increases a patient’s self-reliance by ameliorating or suppressing factors that negatively impact his or her health, some patients may perceive taking medications as a threat to self-reliance if they believe themselves to be somehow dependent on the treatment. Since medication dependence and the illness that prompts it may be viewed negatively in many social and cultural groups, avoiding medication can be a means of avoiding the stigma that is often attached to some chronic illnesses such as depression. Finally, some individuals in the study reported altering medications based on social circumstances, skipping doses to avoid mixing with alcohol or altering the dosage during episodes of “high stress”. In these cases, non-adherence did not result from a lack of understanding on the part of the patients, yet the communications model does not offer any alternative explanations as to why individuals might behave this way.
Rational Belief Model: The rational belief model is based on the theory that objective and logical thought processes determine human behavior. According to this model, if given appropriate medical information about an illness and treatments, individuals will act in the ways most likely to preserve or enhance their health. Therefore, non-adherence must result from a lack of such appropriate information in that it causes patients to make faulty assessments of the costs and benefits associated with a particular intervention (Fishbein, Ajzen 1975, Janz, Becker 1984).

The most widely used application of the rational belief model is the health belief model, which cites four bases for patient behavior: perceived probability of threat, perceived severity of threat, perceived feasibility and benefits of a health action, and perceived barriers to that action. In terms of these factors predicting health behaviors, it is an individual’s assessment of barriers that most strongly correlates with subsequent action, followed by probability, benefits, and severity in descending order of significance. (Janz, Becker 1984). However, these factors may combine and interact in a variety of ways to influence patient behavior, or certain aspects may not even be considered by patients at all (Weinstein, 1987).

One of the greatest weaknesses of the health belief model is that it defines both motivation and perception of risk by the same set of patient attitudes; clearly, motivation results from more than an individual’s likelihood and severity beliefs (Leventhal, Cameron 1987). The theory of reasoned action attempts to account for a component of motivation by arguing that perceived social and cultural norms have an effect on adherence and other health behaviors (Fishbein, Ajzen 1975). Yet this theory focuses only on the social perception of whether or not a particular health action is acceptable and does not address
ways in which social norms may contribute to an individual’s perceptions of threat probability. Furthermore, because of their focus on deliberate patient behaviors, neither the health belief nor reasoned action theory account for the potentially significant effects of unconscious action in health-related activities.

**Self-regulative Systems Model:** The self-regulative model conceives of the patient as an empowered, aware participant in the health relationship with an ultimate goal of decreasing the perceived difference between his or her current state of health and some improved or ideal state (Carver, Scheier 1982). There are three sets of variables which regulate the behaviors resulting from any health care encounter: the patient’s cognitive representation of the health threat, the ensuing action plan, and the reflective appraisal phase in which a patient assesses the level of success from action and modifies the plan accordingly (Leventhal, Nerenz, Steele, 1984). Unlike many other models, self-regulative systems allow for emotional factors to contribute to any of the phases, in fact suggesting that feelings may give rise to additional action plans and assessments.

Both the cognitive and emotional self-regulatory systems respond to stimuli from internal and external sources. This explains the wide variation observed across patients in their mental representations of the same type of illness and their equally variant beliefs about the validity of specific action plans. It has also been observed, especially in cases of chronic illness, that an individual may occasionally alter his or her perception of the illness and make according changes in action and assessment, even when these changes in perception do not correlate with any significant clinical developments (Leventhal, Cameron 1987).
Individual perceptions of illness, action plans, and appraisal measures are constructed from two types of memories: episodic memories, which reflect personal life experiences, and semantic memories, which are the result of abstract or conceptual knowledge about the world. In many cases, these memories convey conflicting messages that can, if not resolved, decrease the effectiveness of treatment. For example, episodic memories of past illness lead patients to have specific expectations about what happens when they get sick (such as the presence of symptoms), yet if an asymptomatic individual is diagnosed with a certain disease and prescribed treatment, the chances that he or she will adhere to that treatment are significantly decreased because the semantic concept of medical assessment is at odds with the apparent absence of any illness (Leventhal, Cameron 1987).

Evidence suggests that a patient’s perception of symptoms and his or her episodic memories are much stronger predictors of adherence than semantic convictions. In a study of patients with hypertension, 90% of respondents claimed they could tell when their blood pressure had risen due to the presence of symptoms, yet 80% of these individuals had stated earlier that patients are unable to independently perceive changes in pressure. This conflict between personal experience and understanding of hypertension led the majority of patients to take their medication in response to perceived symptoms rather than in the regulated manner prescribed (Meyer, Leventhal, Gutmann, 1985). Clearly, symptoms are a key factor in directing health behaviors, yet their influence is not limited to individual episodic memories. Many symptoms of illness also include a cultural, interpretive component that can be viewed as semantic memory of members of the same cultural group. Collections of individuals with commonalities such as age or health status are also
likely to share similar perceptions about the meanings of specific symptoms (Bishop 1977, Pennebaker 1982, Prohaska et al. 1985).

The many strengths of the self-regulation model also pose a significant challenge to its use in research. Addressing this variety of factors related to health behavior requires a more complicated study design than many of the other models, including the possible need for both quantitative and qualitative assessments. The conceptualization and measurement of so many types of variables can easily expand beyond a manageable scope, yet excluding data about any of the complicated individual or cultural features related to adherence could also significantly impact the validity of the results. In studies such as these, thorough background research on the population and illness of interest can help identify a core set of themes and concepts to be explored, focusing efforts and potentially increasing the significance of later conclusions.

**ADHERENCE TO DEPRESSION TREATMENT**

Studies suggest that adherence to short-term treatments (less than 2 weeks) can be increased through the use of clear instructions, specially designed pill containers, marked calendars, and educational efforts. However, adherence to long-term treatments is much more difficult to achieve and measure. Improving long-term medication adherence can require any of a number of interventions: clear instructions from a provider, patient self-monitoring of treatment outcomes, increases in social support systems, and rewards or reinforcement for behaviors consistent with the treatment plan (Haynes, Wang, Gomes 1987).
When compared with other illnesses, adherence to a treatment regimen is more difficult in patients suffering from depression. This is in part due to the illness' many phases, the long-term nature of the treatments, and the constant potential for relapse. Several distinct factors can influence the ways in which depressed patients do or do not adhere to a treatment regimen, and analyses are often made more complicated by taking into account the probability of interaction between many of these factors (Kupfer 1995).

Features of the antidepressant medications themselves can affect an individual's willingness to adhere to a regimen. Some medications may produce unpleasant side effects that cause patients to cease treatment, especially if the side effects persist beyond the lessening of the depressive symptoms. In addition to an individual's reaction to the medication, friends or family members may express fears, concerns, or judgments about side effects, behavioral changes, or dependence on medication that alters the patient's willingness to adhere to the medication regimen (Fawcett 1995).

Because depression treatment often incorporates both medication and psychotherapy, clinical factors may affect depression adherence even more than for other illnesses. Clinicians' expertise and points of view, as well as how those ideas are expressed, can also be factors that influence the degree to which a depressed individual adheres to a medication regimen. It has been suggested that the pharmacologic and psychotherapy treatments must be considered as an integrated whole by the clinician and must be presented as such to help the patient to understand that he or she must adhere to both regimens simultaneously (Fawcett 1995). However, medications often are prescribed by a primary care physician while counseling is provided elsewhere. This functional split in service can often compromise continuity of care and adherence to treatment.
Non-adherence to medication regimens in complex, chronic illnesses such as depression is a persistent and serious problem and requires multifaceted interventions. Many individuals who are seen in primary care and who begin antidepressant treatment stop taking medication during the first month (Johnson 1974, Katon et al. 1992). Providers that adopt one single approach, e.g., the communication approach, to address the problem of nonadherence, may offer a few important interventions that are necessary to enhance medication adherence. However, effectiveness is limited and may not account for critical mechanisms that are required if long-term medication adherence is to be achieved. Simply providing information about depression and required medication regimens to individuals, as the communication approach suggests, may not be sufficient. Other complex factors may need to be explored with individuals and with family members.

DEPRESSION AMONG OLDER ADULTS IN THE PRIMARY CARE SETTING

In 1999, the Surgeon General's report on older adults and mental health attracted both lay and medical attention to the growing problem of unrecognized and untreated depression among older adults (Mental Health: A Report of the Surgeon General – Older Adults and Mental Health, 1999). The number of persons aged ≥65 years is expected to almost double in coming decades, from approximately 35 million in 2000 to an estimated 71 million in 2030. The number of persons aged ≥80 years is also projected to double in size, from 9.3 million in 2000 to 19.5 million in 2030. The incidence of depression is also increasing sharply and is predicted to be the second leading cause of disability worldwide by the year 2020 (Murray, Lopez 1996). Given these numbers, experts agree that efforts need to be directed towards understanding more about the diagnosis and treatment of mental health issues in older adults.
The primary care setting plays a vital role in providing mental health care for older adults, yet depression is often under-recognized and under-treated by primary care physicians. One reason cited for the lack of adequate treatment of depression in late life relates to the heterogeneity of depression in presentation in the sociocultural context of medical illness and the cognitive, physical, and social losses that become more common with advancing age. Data from community surveys around the world show rates of major depression ranging from 3% to about 15% of older persons; however, if one expands criteria to include to include depression that does not meet full standard criteria for major depression but which may impair everyday functioning ("minor depression"), rates are even higher, ranging from 6% to over 20% (Gallo, Lebowitz 1999). Rates of depression in older adults with medical co-morbidities are higher still: approximately 40% in stroke, 35% in cancer, 25% in Parkinson’s disease, 20% in cardiovascular disease, and 10% in diabetes (Gallo, Lebowitz 1999).

While the human cost of depression is great, there are significant economic considerations as well. Studies have shown that common, persistent, depressive symptoms are associated with an average 50% increase in cost of general medical services, even after adjustment for age, gender, and the presence of chronic medical illness (Unutzer et al. 1997, Callahan et al 1997). However, despite these personal and financial costs to elderly patients and their families, primary care patients often do not accept or sustain depression treatment (Oxmar. et al. 2001). This issue of non-adherence, in light of the many challenges that older adults face in the health care arena, only further emphasizes the need to clarify the older patient’s perspective to design better interventions.
The last twenty years have certainly seen increases in the reliability of psychiatric diagnoses, including depression, through the use of standardized instruments for the description of clinical observations (Wing, Cooper, Sartorious 1974, WHO 1994, Ustun, Tien 1995, Gallo 1995). Recent inquiries have further extended the boundaries of the standard criteria for major depressive episode to include “atypical depression” (Aenissis et al. 1995), “mixed anxiety-depression” (Zimbarg et al. 1994), “minor depression” (Blazer 1991) “recurrent brief depression” (Angst et al. 1990), “minor depression without mood disturbance” (Broadhead et al. 1990), “subclinical depression” (Johnson et al. 1992), “subdysthymic depression” (Mossey 1995), and “nondysphoric depression” (Gallo et al. 1997). These additional proposals for significant depressive syndromes indicate a growing awareness that criteria in clinical use may be reliable, but not sufficient to describe all the ways in which a complicated illness like depression may manifest itself. In particular, reliability may come at the expense of usefulness in primary health care settings (Blacker, Clare 1987, Miranda et al. 1994, Schulberg, Burns 1987, Von Korff 1992), in different cultures (Angst 1973, Kleinman, Good 1985), and across the life course (Caine et al. 1994, Gallo et al. 1994, Henderson 1994), making older adults particularly vulnerable to mis- or under-diagnosis of depressive disorders. This further highlights the need for new, innovative research into improving our understanding of depression etiology and treatment in older primary care patients.

RESULTS

A number of themes emerged related to patient views on treatment for depression. These include concerns about side effects from medication, the number of medications
currently prescribed, antidepressant addiction or “drug” use, improper management of medication, and financial or social difficulties in obtaining treatment. In addition to sharing their views on the physiological, psychological, and financial implications of treatment, respondents expressed their varied beliefs about the efficacy of various treatment methods. By understanding more about the reasons respondents give for their perceptions, researchers and health care providers can gain insight as to why past interventions may have failed and how such treatment programs can be improved for patients.

**Side Effects**

One of the most frequently noted and thoroughly discussed issues surrounding depression treatment was the issue of side effects from medication. The semi-structured interview guide specifically elicits such information by asking, “What problems can be caused by medication for depression? Please give me some examples.” Respondents replied with personal experiences, stories from friends or family members, and reports from a variety of other sources. Several respondents also brought up the topic of side effects without being prompted or discussed them in relation to medications for other conditions besides depression.

“Well if they prescribe the wrong medication, it could cause side effects. Instead of helping it, it could cause them to get worse.”

“I think it’s true that you can have side effects. And if you do, like I take Prevachol for cholesterol and my sister in law couldn’t take it because she started, they say if you have achiness in arms – they, you have to do a blood test every few months for the liver thing, you know. And that’s a side effect for that. Your cholesterol will go down but your liver will conk out so,...And I think it’s true that any kind of medication and antidepressants is one of them that can give you side effects.”

“Quite often the side effects – some of the side effects of medication – and then they take more medicine rather than find one that takes care of it.”
“...Especially if the medicine isn’t working or makes them – makes the problem worse or the person decides not to take it after only a few doses. Medicine makes them feel funny, like dizzy or so; they may stop taking their medicine without the doctor knowing.”

“I’ll go on the computer or – I mean I watch TV but – I watch it more than I did I think because with all the medication and stuff, it even slows me down.”

“I didn’t use to ask ‘em [about side effects] but I do anymore because I guess I learned, heard a lot. so much about side effects so I – sometimes it’s better not to take the medicine if it’s going to hurt your other part of your body.”

“Sometimes you can take too much and just continue to - sometimes you – ‘cause a lot of ‘ems got side effects, your kidney, your liver – a lot of different, other things. And most of them don’t tell you nothing about no side effects. I never – unless I come right out and ask them for myself what kind of side effect it’s going to give but sometimes the side effects is worse than the pill.”

“There’s sickness going on. I get sick from some of the medication. Not sickness, what would you call it? I get a dry mouth, an upset stomach. Some of it don’t work too good. But it helps me.”

Presence, intensity, and specific nature of side effects appear to be significant factors in the informal, even subconscious, cost-benefit analysis that patients conduct when deciding whether or not to continue a given course of treatment. As multiple respondents stated, unpleasant or potentially harmful side effects may be more than enough to convince them to discontinue a drug regimen. It is also vital to note that patients may cease taking such medications without informing their physician, a practice which carries certain risk of adverse events as much or more than the medication itself.

**Number of Medications**

The concern about side effects is well-founded, especially given the potential for multiple drug interactions in this population. Quantitative data gathered from Spectrum I demonstrates that over half the respondents have been diagnosed with arthritis, high blood pressure, high cholesterol, and chest pain, and that respondents are currently taking
multiple medications or supplements, trying to coordinate as many as 20 of them (see Tables 2 and 3, "Number of Medications Currently Taking" and "Co-Morbidities of Study Participants"). Given the difficulties that many patients face in terms of obtaining and appropriately managing such a large number of medications, it is not surprising that many respondents expressed resistance to adding an antidepressant treatment to their current regimen.

"I hate to take medicine, especially insulin and liquid medicine. If I'm going to take anything I'd rather take pills than take liquid medicine."

"If you have a fistful of problems from being over medicated; now that can cause you physical problems...I guess it would make you sick, actually make you sick to your stomach or whatever if you took too much medication. Obviously it would make you sick if you are over medicated and I guess it's like these people — well Elvis Presley, I guess, is one. I assume he was over medicated, obviously."

"I've taken sleeping pills and so I've just decided I'm going to stop taking sleeping pills because I have other pills that I have to take and it's too much."

"I take Clidapan. I take Zoloft. What else is next? I don't know. Ninety million pills over there. And Prozac; I have Prozac too, but only on bad days."

"You write everything down and — same way with the medicine and then they switch medicines around and expect you — just about the time I get used to them I can tell what color, they turn and round and give you this generic brand and then I got about four or five pills now and they are all white. I said I'm used to taking you know, so many pills and different colors and all and then I look and I can't read on there 'cause it's so small. I said I don't know whether I'm taking the right pills or not...I take 18 different kinds, I'll tell you, and I have to take and I say I "Christ I can't half see" and I said "And then to try to remember...I can't pronounce the names of none of 'em hardly."

Interestingly, the issue of multiple medications was the theme most closely correlated with respondents' admissions that they might not be taking all their medications properly. The data from Spectrum I, which asked patients to self-report their adherence status to all medication regimens, returned an almost-universal profession of perfect adherence (see Table 4, "Number of Days Missed Medication Dose in Past Four Weeks"). This discrepancy, while not surprising or unusual, highlights the importance of the
<table>
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<tr>
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<tr>
<td>Parkinson's</td>
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</table>
Number of Days Missed Medication Dose in Past Four Weeks

Number of respondents

Days missed dose in past 4 weeks
qualitative interview as a means by which respondents can explain the reasons behind their non-adherence. Understanding more about the individual factors that contribute to non-adherence, such as multiple medications, can contribute to the development of more effective and sustainable interventions.

**Addiction to “drugs”**

One concern that respondents mentioned only in relation to medication for depression was the issue of medication dependence. Unlike pills prescribed for ongoing chronic physical conditions such as arthritis or diabetes, several respondents characterized depression medication as mood-altering and therefore similar to illicit drugs. This theme clearly has sociocultural overtones and implicit value judgments, all of which can be powerful motivators for or against treatment adherence.

“To talk about it [helps depression] instead of [getting] hooked on all that medication because you could become addicted to it.”

“It [medication for depression] just more or less lulls you down or something a little bit, instead of taking drugs like the druggies does but it’s still a drug prescribed by the doctor.”

For patients whose concerns about pharmacological treatment for depression are limited to medication management issues, it is possible that antidepressant medication may become acceptable once other factors, such as side effects or dosage timing, are controlled. However, for those individuals who reject antidepressants because of a fundamental belief about the nature of the medication itself, such interventions are not likely to be successful. It is vital that health care providers evaluate whether or not an individual will be receptive to antidepressant therapy before prescribing it, especially if the medication is intended as the only form of treatment.
Cost or Other Difficulty in Obtaining Treatment

For some respondents, expressed reluctance to accept medication had little or nothing to do with the nature of the medication itself or its effects on the body. Rather, there was a shared concern about the cost of pharmaceutical treatments and counseling. Individual situations varied; some respondents referred to health insurance coverage issues, others cited an inability to pay out of pocket. Some respondents also indicated that they did not seek treatment for depression because they were unsure as to what kind of treatment they needed or where to get help.

"Sometime, to me you go to therapy or you go to counseling, you — sometime I think some of them are just in for the money."

"What do we poor people do? My mother lived with us all her life so therefore she didn't have to pay rent. She had to use her whole social security check on medicine, you know, it's terrible. It's like once you get old, they go "Eh, who care about them?" you know, but when you need to make big decisions, when you're old is when you can least make those decisions, you know. You are not capable of making those decisions. That's when you really have the big ones to make."

"Doctor said to me, she said "Insurance don't want to cover these one pills." I said, "Why?" She said "They want you to take generic." "Generic I guess is alright." I said. They say it is, I said, I don't know."

Medications Managed Improperly

Another common concern, expressed not only in relation to depression treatment but to medication in general, was that such regimens were managed improperly. Respondents placed blame with providers, patients, or in some cases both, but most agreed that the mis-management or misuse of pharmaceutical interventions could have serious negative health consequences for the patient.

"I do not believe that the medication that the seniors are on are supervised properly because a lot of medication makes seniors more agitated or can have reverse — you know, I have had hallucinations from anesthesia."
"I don’t think people are treated – I think they are treated sometimes, especially the elderly, just to keep them...quiet."

Interviewer: “Do you think that doctors know how to treat depression?”
Respondent: “Yeah, if you go to the right one, other than just pill pushers.”

“It’s amazing but a lot of times it’s misused after it gets from the druggist to the home ‘cause I got two friends that they can take – the doctor will tell them to take two pills a day and they’ll just take one because that’s too many pills. And then I got another one that just takes it for a day or two and then she’ll just throw it in a bag and won’t take it no more. It’s not really the doctor’s fault but I don’t know.”

“Well when she [a friend] hasn’t – when they’ve been trying to get her on medication, they give the wrong one and she ended up in the hospital.”

Both accidental and conscious non-adherence can, in fact, have potentially dangerous complications for patients on any type of medication. It is vital that providers, pharmacists, and patients all work together to generate the most appropriate dosing plan and that patients are assisted in finding ways to make following that plan a reality. Those respondents who were concerned about their physician’s motives for prescribing antidepressants would likely benefit from further explanation as to why the medication was being prescribed and a discussion of its intended effects.

**Effectiveness of Medication for Depression**

While respondents were clearly aware of problems that could occur with antidepressant medications, this did not stop many of them from stating that, if used properly, such interventions could be effective depression treatments. To support their statements about the effectiveness of antidepressants, virtually all respondents cited either their own or friend/family member experiences with successful pharmaceutical treatment. The frequency of this theme indicates that antidepressants do in fact have a role in
alleviating minor depression in older adults, and respondent statements show that the improvement can be significant and long-term.

Interviewer: “What do you think is the best way to treat depression?”
Respondent: “Medication helps. Nothing we can do can help and she’s on medication; it helps a lot so I would think medication.”

Interviewer: “Do you think medication can help people who are depressed?”
Respondent: “It can – straightens out their brain or something, whatever they take because when she’s not on medication, you know it... the medication really helps keep her even.”

Interviewer: “Do you think medication can help people who are depressed?”
Respondent: “Yeah I think if they give them medication for it, it can help them.”

Respondent (in response to vignette character description): “Well I think she should like get some medication for that depressed state, state of mind, you know... She could see a psychiatrist and then see a counselor and they can prescribe the medication she could take. And she also could seek medication for maybe she’s like, needs medication for her nerves, you know?”

Interviewer: “Has the way that you feel changed since you first thought you were depressed?”
Respondent: “Oh, I’m not depressed anymore. I’m very active and feel good about everything.”
I: “Why do you think that feeling changed, how has that changed?”
R: “From the medications and the lessons I’ve learned I guess; mainly the medications.”

Interviewer: “With regard to your depression, how do you think it will turn out?”
Respondent: “You know I haven’t been depressed for 20 years so – and I do take my medications to keep it from happening.”

Interviewer: “What do you think is the best way to treat depression?”
Respondent: “Oh probably with medication, I would think, in this day and age.”

Interviewer: “Do you think medication can help people who are depressed?”
Respondent: “Oh it has to, because it does. How it does I don’t know how it does; I just assume – I know it does.”
I: “How do you know?”
R: “Because I take an antidepressant.”
I: “Can you explain what it does for you?”
R: “Oh I just think it calms you.”

Interviewer: “Do you think medication can help people who are depressed?”
Respondent: “Yes.”
I: “How might it help them?”
R: “Make them feel more self worth, happier, alert, aware, wanting to go out, go for a walk.”

Interviewer: “Do you think medication can help people who are depressed?”
Respondent: Oh yeah I think it can so long as it’s done the right way and took the right way.”

Medication Not Enough

There was a shared sense among many respondents, even those who spoke strongly about the effectiveness of medication, that depression may be a complicated medical problem beyond the curative scope of a single pill. Their answers to the interview question “What do you think causes depression?” were varied and often lengthy, with the complex treatments corresponding to the complex etiologies. While obtaining and sustaining such comprehensive, multifaceted treatment is obviously not a simple proposition, many respondents stressed the necessity of the patient being a motivated, active participant in his or her own recovery.

Interviewer: “Why do you think these feelings [of depression] started when they did?”
Respondent: “I think a lot of things together resulted in the problem.”

Interviewer: “What do you think is the best way to treat depression?”
Respondent: “Well possibly medication but to me, medication is just a partial fix.”

“Now, as I say, the medication can help pull her up so that she can do it but I honestly think that a person’s got to be responsible for their own piece of mind, their own outlook and – you know, I feel sorry for people who can’t.”

“I say OK, go with the medication but the medication is only to help to break that habit of being depressed.”

“I think she let her – about her being tired, I think she needs like vitamins and maybe medication for her nerves and still seek counseling, a psychiatrist if she needs that...to talk with and someone to prescribe medication for her and like I said, get out to get back on the same thing and go on with her trips or playing cards or – she doesn’t have that energy ‘cause she’s not eating well, she’s losing weight but she don’t have an appetite.”

Interviewer: “What do you think is the best way to treat depression?”
Respondent: "Best way to depression? Listen to a person and be kind. The best - I think, plus if they really need medication, go get it. But don't just keep giving it to every - giving it, giving it just to get rid of 'em or shut them up."

Interviewer: "What do you think is the best way to treat depression?"
Respondent: "I think listening and if they really need medication and they'll follow through with it, that's great."

CONCLUSIONS
The diagnosis and management of depression in older adults is a challenge in the primary care setting, with patients, providers, treatments, and the health care system itself all presenting potential barriers to effective interventions (Callahan et al. 1992, Gallo et al. 2002, Glasser, Gravadal 1997, Gallo, Ryan, Ford 1999). Given the difficulties that older adults face in this context, it is all the more important that researchers work to design new interventions specifically for the needs and characteristics of this population. The themes expressed in the preceding excerpts may have some similarities to commonly held beliefs amongst younger age cohorts, but it is also likely that there are some concerns and issues about depression treatment considerably more prevalent, if not exclusive to, older age groups.

Most of the work on depression in late life thus far has been guided by an epidemiologic perspective and has not resulted in any clear guidelines assisting primary care providers in treating these patients. From the interviews, it appears that many respondents feel they need more time with their physician to explain problems like side effects and medication management. However, in the absence of dramatic change in the design of the American health care system, it is unlikely that physicians will be able to find more time to meet with their patients. Therefore, the most realistic and beneficial change that primary care physicians can make is to ask key questions that assess an older patient's
beliefs about and willingness to use antidepressants and/or counseling, taking these preferences into account when designing a treatment that will be both efficacious and acceptable to the patient.

Physicians should also stress the importance of adherence and the health risks of non-adherence, encouraging patients to re-evaluate unsuccessful or unacceptable treatments with their physician instead of making changes to or stopping medications entirely on their own. While it may be difficult to obtain accurate reports of patient adherence, creating a supportive environment that stresses the patient as an integral part of the treatment decision and evaluation process can be helpful in creating rapport and promoting communication. As one respondent noted, "You just have to realize it and the doctor has to be close enough to you that you can tell him "I think this is bad." If you don't say anything, if you just let it go, then you are going to hurt yourself." While this friendly, open, patient-provider relationship is certainly idealized and not widely achievable in the modern medical environment, there are definitely aspects of it that can be created by carefully managing the time of the office visit and knowing what questions, beyond the basic physical and lifestyle ones, to ask.

Although this research is still in progress, I am confident that future interview transcripts will both support the themes presented here and introduce important new ones. Combined with the quantitative data obtained from Spectrum I, these themes have the potential to give health care providers a much more complete picture of geriatric depression, as well as highlight the value of qualitative inquiry in medical research. It is my hope that this increased depth of perspective on the complexity of depression treatment and adherence can serve as a foundation for further research, leading to the creation of
more effective treatment guidelines and evaluations for older primary care patients with depression.
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