Identification of Patient Attitudes and Preferences Regarding Treatment of Depression

Lisa Cooper-Patrick, MD, MPH, Neil R. Powe, MD, MPH, MBA, Mollie W. Jenckes, MHS, Junius J. Gonzales, MD, David M. Levine, MD, MPH, ScD, Daniel E. Ford, MD, MPH

OBJECTIVES: To identify attitudes that influence patient help-seeking behavior and aspects of treatment that influence patient preferences for management of depression.

DESIGN: Three focus group discussions (two patient groups stratified by race and one professional group). Questions addressed experience with depression, help-seeking behaviors, treatment preferences, and perceived barriers to mental health care.

SETTING: Academic medical center.

PATIENTS/PARTICIPANTS: Eight black patients and eight white patients with depression; seven health care professionals (four physicians and three social workers).

MEASUREMENTS AND MAIN RESULTS: Discussions were audiotaped, transcribed, and reviewed independently by two investigators to identify and group distinct comments into categories with specific themes. Differences were adjudicated by a third investigator. Comments within categories were then checked for relevance and consistency by a health services researcher and a psychiatrist. More than 90% of the 806 comments could be grouped into one of 16 categories. Black patients raised more concerns than white patients regarding spirituality and stigma. Patients made more comments than professionals regarding the impact of spirituality, social support systems, coping strategies, life experiences, patient-provider relationships, and attributes of specific treatments. They discussed the role these factors played in their help-seeking behavior and adherence to treatment.

CONCLUSIONS: In-depth focus group discussions with depressed patients can provide valuable and unique information about patient experiences and concerns regarding treatment for depression. Clinicians, researchers, and policymakers need to incorporate the range of factors identified by patients into their decision making for individuals with depression.

KEY WORDS: depression; patient attitudes; patient preferences; patient-centered care.

J GEN INTERN MED 1997;12:431-438.

Depression is one of the most common major mental disorders, affecting approximately 5% of the general population, mostly young adults and women, in any one year.¹ Depressive disorders have a substantial effect on the individual, the family, and society and are associated with more functional disability than most chronic medical illnesses.^{2,3} Individuals with depression utilize health care services in the general medical and mental health sector three times as often as nondepressed controls, even after controlling for medical comorbidity.⁴

The majority of individuals with depression in the United States who seek care receive all or part of their

mental health care in primary care settings.⁴⁻¹⁰ Reducing the burden of suffering from depression in the population will therefore require enhancing diagnosis, treatment, and referral in primary care settings. Despite the availability of several treatment options with similar effectiveness in clinical trials, underrecognition and suboptimal treatment are common.¹¹⁻¹⁴ With conditions like depression, for which several viable treatment options exist, patient attitudes and preferences are important and may have a large impact on patient adherence and subsequent recovery. Few studies have incorporated patient perspectives in attempts to understand why certain patients drop out of treatment involving medications and counseling or fail to follow through on mental health referrals.

Depressed patients in ethnic minority groups may be at even higher risk of underrecognition and suboptimal treatment. Many studies have shown underutilization of specialty mental health services for psychiatric symptoms and disorders by African-Americans and Hispanics, even after controlling for levels of psychiatric pathology.¹⁵⁻¹⁹ These minority groups are less likely to ever be in contact with specialty mental health services, and they are likely to use them less frequently once in the system. However, blacks and whites have reported discussing emotional, nervous, drug, and alcohol problems in general medical settings at similar rates.²⁰ Barriers to mental health care, such as health insurance, do not explain differences in utilization by racial groups.²¹ Few studies have been conducted to understand black patients' attitudes toward mental health treatment and their preferences for treatment.

Received from the Division of General Internal Medicine (MWJ), Department of Medicine, Johns Hopkins University School of Medicine, and the Department of Health Policy and Management, Johns Hopkins University School of Hygiene and Public Health, Baltimore, Md. (LCP, NRP, DML, DEF); and the Department of Psychiatry and the Clinical Economics Research Unit, Georgetown University Medical Center, Washington, DC (JJG).

Presented at the 13th annual meeting of the Association for Health Services Research and the Foundation for Health Services Research, Atlanta, Ga., June 9-11, 1996.

Supported by research grants from The Commonwealth Fund and the National Institute of Mental Health (U01-MH54443). Dr. Cooper-Patrick is a Picker/Commonwealth Scholar.

Address correspondence and reprint requests to Dr. Cooper-Patrick: Welch Center for Prevention, Epidemiology, and Clinical Research, 2024 E. Monument St., Suite 2-600, Baltimore, MD 21205-2223.

In recent years, American medicine has experienced an accelerated refocusing on patients' perspectives in several areas of medical care.²² This evolution, termed "patient-centered care," has been defined as health care that is closely congruent with and responsive to patients' values, needs, and preferences.^{23,24} As part of this evolution, clinicians, researchers, health care administrators, and policymakers have devoted much attention to developing strategies to improve quality of care that incorporate patient perspectives. Strategies that use patient feedback to guide quality improvement in hospitals, managed care organizations, and physician offices are being developed.²⁵⁻²⁷ Researchers have also devoted much attention to developing health outcome measures that incorporate patient perspectives, such as patient-derived measures of functional status, quality of life, and satisfaction with specific experiences in health care.²⁸⁻³¹ As the first step in developing relevant patient evaluations of care for depression, we conducted focus groups with health care professionals and depressed patients to identify attitudes that influence patient help-seeking behavior and specific aspects of treatment that influence patient preferences for management of depression.

METHODS

Study Design

We held focus group discussions with three groups: (1) health professionals involved in the care of general medical patients with depression, (2) white patients with a recent episode of depression, and (3) black patients with a recent episode of depression. We held separate patient groups for blacks and whites to help us understand how patient attitudes, preferences, and help-seeking behavior might vary across racial groups. Focus groups have been shown to be particularly effective in providing in-depth information about what people think or feel about an issue or problem.³² A focus group is a carefully planned discussion designed to obtain perceptions in a defined area of interest in a permissive, nonthreatening environment.³² From the three focus group discussions, we created a taxonomy that groups the range of issues identified by patients and professionals into different aspects of help-seeking behavior and treatment.

Focus Group Population

Physicians and social workers involved in the care of general medical patients with depression were eligible to participate in the professional focus group. We called a sample of professionals to recruit them into the focus group, making a special effort to include men and women, blacks and whites. Approximately 50% of those invited agreed to participate.

To be eligible for the patient focus groups, patients had to be at least 18 years of age, English-speaking, and

able to give informed consent. They had to have experienced depression in the recent past. Patients were recruited with the help of primary care physicians, mental health specialists (private practitioners and directors of six community psychiatry programs), and community members (lay ministers and leaders of community organizations). We provided a standardized script to help these individuals recruit potential patients. We asked them to approach patients with a variety of experiences with depression, including those who had not been treated, those who had received care from primary care providers, and those who had received care from mental health specialists. We asked these individuals to keep record of refusals and the reasons for refusals.

One of the community psychiatry programs refused to participate because of concerns that participation in a focus group would interfere with the patients' therapy. Most individuals who were asked agreed to participate. The only reasons cited for not participating were scheduling conflicts. The majority of patients were recruited from community-based primary care practices.

Conduct of Focus Group Sessions

A trained focus group facilitator led the sessions after discussing the goals of the study in depth with the principal investigator and reviewing the literature regarding health services utilization and treatment options for depression. No study physicians were present during the focus group sessions. The focus groups lasted approximately 90 minutes and were entirely audiotaped. A small honorarium was offered to participants to cover travel and child-care expenses.

Professionals were asked a series of open-ended questions to elicit comments about specific aspects of help-seeking activity and care that they thought would be important to patients. Professional focus group questions were as follows: (1) "Based on your experience, why do people sometimes not seek care for depression?" (2) "When you discuss treatment for depression with patients, what issues and concerns do they raise?" (3) "How do you negotiate acceptance of the diagnosis of depression with patients?" and (4) "How do you elicit patients' preferences for treatment of depression?"

We asked the patient participants a series of open-ended questions designed to elicit comments about specific aspects of their experiences with seeking help and receiving care for depression. Patient focus group questions were as follows: (1) "What change in your life or yourself made you first wonder if something might be wrong?" (2) "What kinds of things (some good, some not so good) do you do to make yourself feel better if you feel like you're getting depressed?" (3) "When patients are depressed and need to get treatment, how do they decide where to go and who they should talk to?" (4) "What kind of treatments have your doctors recommended for you?" (5) "If there was one thing you could tell health professionals about

depression that you think they don't realize, what would that be?" As part of the fourth question, the focus group leader was asked to probe patients following their initial responses regarding advantages and disadvantages of each type of treatment for depression (e.g., medications, counseling, mental health referral, hospitalization).

Participants in the black patient focus group were asked one additional question: "Research shows that African-Americans with emotional and psychological problems use mental health services at half the rate of whites with similar problems. Why do you think this is?"

Data Analysis and Development of Taxonomy

Audiotapes of the focus group sessions were transcribed verbatim, masking the names of participants, providers, and institutions. Two study investigators read each transcript in its entirety, marking distinct comments that were felt to represent discrete thoughts or themes. Differences between the two investigators' choices of where comments began and ended were resolved in a meeting with an adjudicator (a third investigator). The resulting comments were then printed on separate pages and separated into categories with thematic labels driven by the actual words used by participants. These categories were used to develop a taxonomy for each focus group. Repeated or reworded statements of the same thought by the same participant were counted as one comment.

The categories of comments and the taxonomy for each group were then sent to two other study team members, one general internist and health services researcher (methodologist) and one psychiatrist (clinician) for independent review for relevance and consistency. This process resulted in the consolidation of some categories and separation of others into related domains. A consensus was reached on a final taxonomy of patient attitudes and preferences for management of depression.

RESULTS

Focus Group Participants

Seven health professionals (four physicians and three social workers; five women, three blacks) participated in the professional focus group. The professionals had a median of 5 years' experience in their discipline (range 1–26 years). The physicians were all practicing general internists, aged 30 to 40 years; three of the four worked in different community-based urban settings, and one worked in an academic faculty practice. The three social workers were women, aged 28 to 50 years, and all worked with medical and surgical inpatients and outpatients; none worked in mental health settings.

Sixteen patients participated in the two patient focus groups. There were eight black patients (mean age 42 years; five women; four college graduates; five patients

currently being treated for depression) in one group. There were eight white patients (mean age 47 years; five women; two college graduates; six patients currently being treated for depression) in the other group. Seven blacks and five whites reported receiving medications. Five blacks and four whites reported receiving treatment from mental health professionals. Six blacks and three whites reported receiving counseling. The majority of patients either had private health insurance or were members of a health maintenance organization. Most of the patients were under the care of their primary care physician for one or two other medical problems; two patients in the white group had comorbid psychiatric disorders (anxiety, eating disorder), and one patient in the black group had comorbid substance abuse.

Focus Group Taxonomy

In content analysis for all three focus groups, 806 distinct comments were identified and grouped into 16 broad categories or aspects of help-seeking activity and treatment to form the final taxonomy. Table 1 shows sample comments made by patients in each category in the taxonomy for which patient comments were available. Comments could be included in more than one category, but the number of double-coded comments was small (two for the professional group and black patient group and six for the white patient group). The category "access" included seven related domains (availability, location of care, patient time/convenience, provider time/convenience, impact of insurance, depression-specific factors, and general access). The category "attributes of treatment" included separate domains for medications, counseling (individual, group, and patient education), and inpatient treatment. Comments within a category reflected both positive and negative characteristics. The category "advice for health professionals" included one summary statement from each participant in the patient focus groups.

Table 2 shows the number of comments classified within each category of the taxonomy for the white patient group (total $n = 198$), the black patient group (total $n = 341$), and the professional group (total $n = 274$). For each group, more than 90% of the comments could be placed in one of 15 categories, while 10% of the comments were classified as being of a general nature. Black patients made more comments than white patients regarding the impact of spirituality and stigma on their help-seeking behavior and preferences for treatment. White patients made more comments than black patients regarding the various attributes of each type of treatment and the relation between physical health and depression.

As expected, patients made more comments than professionals regarding the impact of spirituality, social support systems, coping strategies, and life experiences on their help-seeking behavior and treatment preferences for depression. However, patients also identified more

Table 1. Categories of Help-Seeking Behavior and Treatment Identified and Sample Comments Made by Depressed Patients Participating in Focus Groups

Category	Sample Comment
Spirituality—coping strategies specific to religious practice and social support from religious community	"I did pray a lot. I'm a Christian and I would pray and pray and find verses of scripture."
Social systems/networks—family, friends, excludes church, religion	"I have a best girlfriend, which I can really talk to her, but . . . sometimes you don't really bring it up and out . . . I know I can, but I don't want to . . ."
Coping strategies—positive and negative, excludes spirituality	"I would shop. Spend money . . . That's what I did to make me feel better."
Life experiences—life events identified as triggers or results of depression	"Then I lost my brother, which was my good friend . . . Him and I were close, and that was devastating to me . . ."
Psychological receptivity—recognition and denial of depression, includes case histories of early symptoms and attribution	"It's not emotional. It's biochemical . . . in that context, I have absolutely no problem."
Stigma—social, race/culture-specific labeling, stigmas associated with institutions, type of provider, type of treatment, or mental health referral	"And I didn't want anyone to know that I was taking this prescription. I just didn't want to feel like I was crazy."
Recognition of depression by providers—ability of physicians to recognize patients' symptoms as psychiatric in nature	"My doctors weren't able to recognize that my chest problems may have been related to depression. They went all around Robin's barn; they really did."
Patient-provider relationships—providers' technical and interpersonal skills, trust in the provider, trust in health care system	"This guy [my doctor] was just a plain old nice guy, you know . . . he was very, very sharp . . . I thought, whatever this guy tells me for the most part, if it sounds sensible, I'll give it a try."
Impact of physical health—impact of depression on physical health and of physical health on depression	"It [my diabetes] bothers me now more, because I think I feel bad and I don't do the things I'm supposed to do, like exercising . . . I feel as though I want to, but I can't."
Attributes of treatment by type—positive, negative, and neutral comments	
Medication	"If it's gonna make me feel good, make me feel good right away so I can get up and start doing what I want to do. I don't want it to take a long time to kick in."
Counseling	
General	"I really got into therapy out of seeking help for my sons . . . you know, as a counselor, I needed guidance from her on what to do . . ."
Individual	"I figure individual therapy when it's something really personal and deep you want to let out, that's the best way to go."
Group	"The patients were very much a part of my therapy . . . your therapist can only be with one person at a time so if you had a situation and you needed somebody, there was patients that would . . . talk to you and listen . . ."
Patient education	"When you explain to me what the medicine's going to do and what I can expect from it, I feel much more comfortable."
Inpatient treatment	"I didn't want to leave that place [the private psychiatric hospital]. It was a wonderful experience."
Access	
Availability—adequate supply of trained personnel	"I was fortunate to have a very good African-American psychiatrist . . . there just aren't that many . . ."
Location of care—distance, travel	"I don't like the drive."
Patient time/convenience	"I said there's no way my job is going to give me time off . . ."
Impact of insurance—costs, coverage, managed care	"Everybody don't have insurance, you know, that will cover it [mental health treatment]."
General comments on access	". . . When I realized I was having these problems, I began to take advantage of a program we have at work."
Provider time/convenience	"Fifty minutes. You're here at 9, 9:50 you're gone."
General comments	"It's that independence, some say pride of wanting to handle it yourself [historically, as a black woman] is why you don't go to somebody else."
Advice for health professionals—answers to the question "If there was one thing you could tell health professionals about depression that you think they don't realize, what would that be?" Includes comments about unmet expectations for care	"Empathize, really, really try to put yourself in their [the patient's] shoes and find out how it is to go through a day in their life."

Table 2. Numbers of Comments in Each Category for Depression Focus Groups*

Category/Theme	Number of Comments White Patient Group (total n = 198)		Number of Comments Black Patient Group (total n = 341)		Number of Comments Professional Group (total n = 274)	
	n	(%)	n	(%)	n	(%)
Spirituality	6	(3.0)	34	(9.9) ^{††}	10	(3.6) [‡]
Social support	18	(9.0)	24	(7.0)	2	(0.7) ^{††}
Coping strategies	20	(10.1)	43	(12.6)	0	(0.0)
Life experiences	7	(3.5)	15	(4.4)	2	(0.7) ^{††}
Psychological receptivity	21	(10.6)	21	(6.2)	19	(6.9)
Stigma	3	(1.5)	26	(7.6) ^{††}	11	(4.0)
Provider recognition	7	(3.5)	7	(2.1)	14	(5.1)
Provider training	0	(0.0)	0	(0.0)	8	(2.9)
Provider treatment bias	0	(0.0)	0	(0.0)	15	(5.5)
Patient-provider relationships	11	(5.5)	30	(8.9)	19	(6.9)
Coordination/referral issues	4	(2.0)	0	(0.0)	19	(6.9) ^{†††}
Physical health and depression	15	(7.6)	11	(3.2) [†]	10	(3.6)
Attributes of treatment by type	83	(41.9)	75	(22.0) ^{†††}	34	(12.4) ^{†††}
Access	19	(9.6)	25	(7.3)	81	(29.6) ^{†††}
General comments	20	(10.1)	24	(7.0)	30	(10.9)
Advice for professionals	8	(4.0)	8	(2.3)	n/a	n/a

*Differences between black and white patients:

[†] χ^2 , 1 df, $p < .05$, ^{††} χ^2 , 1 df, $p < .01$, ^{†††} χ^2 , 1 df, $p < .001$.

Differences between patients and professionals:

[‡] χ^2 , 1 df, $p < .05$, ^{††} χ^2 , 1 df, $p < .01$, ^{†††} χ^2 , 1 df, $p < .001$.

attributes of specific treatments and discussed the role of these factors in their help-seeking behavior and adherence to treatment. Professionals made more comments regarding patient access to mental health care, provider training, recognition of depression, provider treatment bias, and coordination of care between general medical and specialty mental health providers.

DISCUSSION

Using focus groups, we identified a variety of issues that depressed patients feel are important determinants of their help-seeking behavior and their preferences for treatment. These issues involved attributes of different types of treatments, aspects of patient-provider relationships, social support systems and life experiences, as well as personal coping strategies, psychological receptivity, and perceptions of stigma. The issues raised by the patients and their relative importance frequently differed from those raised by the health care professionals. Similarly, a recent survey study regarding the importance of various aspects of outpatient care showed important differences in opinion between patients and physicians; specifically, this study found that patients placed substantially greater value on the effective communication of health-related information than did physicians.³³

Patients cited a wide range of strategies they used to cope with their depression before they sought medical attention. These coping strategies ranged from positive activities to denial and negative behaviors. Many patients

used spirituality as a way of coping with their depression, and black patients cited spirituality as a coping mechanism more frequently than white patients. Blacks also discussed using church and church members for support more frequently than whites. Despite the salience of spirituality, a relatively small number of patients felt that their spiritual beliefs caused them to delay seeking medical attention.

Social support was generally seen as positive and necessary. Most patients drew support from family members, friends, and coworkers. However, many patients felt that their usual support systems were ineffective during a depressive episode because of their own discomfort with asking for help, their need to appear strong to family members and friends, and the lack of understanding regarding depression on the part of many family members and friends.

Patients spoke of a variety of experiences that led to their eventual recognition that they were depressed (psychological receptivity). The experiences were similar and included most of the symptoms and signs known to be associated with depression. However, individual interpretations of symptoms varied, and patients had a wide range of attributions of their illness. Although some patients strongly believed that life experiences had led to their depression, others believed that medical problems contributed to their depression or that it was strictly a biological illness.

Stigma was perceived as a particularly important barrier to getting treatment for the black patients in this study. Many of them felt that the idea of professional help

for mental health problems was not culturally acceptable among their family members or peers. The number of comments regarding stigma was much smaller in the white group. However, patients in both groups said they felt there was a social stigma associated with having depression as well as getting treatment for it. One previous study of treatment seeking for depression suggested that blacks and whites have similar perceptions of mental-illness stigma; however, the same study found that blacks have more fears related to mental health treatment.¹⁸ Neighbors and Jackson, using data from the National Survey of Black Americans, showed that blacks with emotional problems and grief are more likely to use informal help only or no professional help at all as compared with their counterparts with physical problems.³⁴ It is unclear whether stigma related to mental illness could partially explain this pattern of help-seeking behavior.

Patients made numerous comments about the impact of their relationships with providers. In our study, as in previous work, patient attitudes toward caring (humane-ness) and curing (competence) aspects of physician behavior appeared to reflect the same dimension.³⁵ The providers' technical skills as well as their interpersonal skills were raised as important in patients' decisions of whether or not to disclose their innermost feelings and to complete the treatment. In the black patient focus group, the issue of cultural mistrust and concerns about being used as a "guinea pigs" for medical experimentation were raised.

Other researchers have cited the important influences of interpersonal trust and social trust on the quality of physician-patient interactions.³⁶ Interpersonal trust is deemed a prerequisite for many aspects of effective care, including patients' willingness to reveal potentially stigmatizing information about their health-related behaviors, to describe personal feelings and thoughts that are necessary to differentiate physical and mental disorders, and to accept prescribed changes in personal behavior or treatments that may have risks or be difficult to follow.³⁶ Social trust plays a different but important role; it tends to be influenced more by media exposure and general reputation than by firsthand knowledge.³⁶ Nonetheless, it is particularly important for individuals belonging to ethnic minorities, for whom distrust in the health care system may be connected to a general distrust in any social institution with a history of discriminatory practices.

Numerous attributes of each type of treatment were raised as concerns. For medications, concerns were raised about side effects, effectiveness, addiction potential, dependency on medication in order to function, and the length of time needed to complete treatment. For counseling, concerns were raised about its effectiveness, the frequency of appointments, the length of time needed to complete the treatment, the negative impact of discussing painful experiences, and the comfort level of talking about personal problems with others. For patient education, patients wanted to know what to expect from the various treatments and what the likelihood of a successful out-

come was for each type of treatment. In the black patient group, two individuals had been hospitalized for depression. The inpatient experiences were generally positive. The one major concern raised was the loss of autonomy.

Patients had a number of concerns related to access to care. The availability of mental health professionals belonging to one's gender, race, and religious background were raised as concerns more often by black patients. The location of care, patient and provider time and convenience, and the impact of insurance were also raised as concerns. Patients raised relatively few concerns regarding coordination of care between general medical and specialty mental health sectors. Most of these dimensions of access have been described in previous work.^{37,38} However, the patients in our study also noted specific characteristics of depression (fatigue, lack of motivation, self-blame) that presented challenges to obtaining care.

We asked each patient to give a summary statement of advice to health professionals regarding the treatment of depression. The summary statements indicated most patients had some level of expectation regarding the interpersonal aspects of care that were not met, and a few patients had expectations regarding diagnostic testing that were not met. Previous studies have shown that patient expectations of care are derived from several sources and are often not elicited by physicians.^{39,40} Health professionals could use information about these expectations to negotiate patients' acceptance of their diagnoses and recommended treatment.

There are some limitations of this study and its methodology. During focus group discussions, a small, relatively homogeneous group of people are invited to participate in a focused discussion in order to provide data of a qualitative nature. We formed only two patient focus groups, one black and one white. These two groups might have provided a narrow range of patient input. Because our focus group participants were from one geographic area, it is possible that they were not a representative group of all whites and blacks with depression in the United States. However, a large number of positive and negative aspects of help-seeking behavior and care were identified, suggesting that the representation was broad, if not comprehensive.

Second, the majority of patients in this study were receiving or had received treatment. Many of these individuals had delayed seeking treatment, and they discussed their reasons for delaying care as well as the decision-making process that eventually led to their receipt of treatment. However, their viewpoints and perceived barriers to treatment may differ from those of individuals who choose not to seek treatment at all.

Third, the possibility of response bias exists. Some participants may not have been honest and forthcoming with their opinions because of a lack of comfort with other group members, concerns about confidentiality, or a lack of comfort with the moderator. The level of participation and enthusiasm displayed by our study subjects makes

these biases unlikely. Because our moderator was a white female, the possibility exists that black patients were not completely honest about the issues that were related to race and mental health treatment. Further research using focus groups should be done to determine whether different issues of concern to patients arise with other groups of depressed patients, and with black patients talking with a black moderator. Finally, the focus group method is useful for identifying major themes, but because of the qualitative nature of the data obtained, analyses of subtle differences must be made with caution.

Notwithstanding its limitations, this study identified a wide range of attitudes and preferences deemed important to high quality of care for depression by individuals with a recent depressive episode. We used a comprehensive, rigorous, patient-centered approach, requiring independent review and agreement by several investigators and clinicians, to analyze the data. Our findings lay the foundation for the elements that should be measured by primary care physicians and researchers to assess patient attitudes toward and preferences for treatment of depression. These findings also provide early insights regarding the sources of differences between patients in receipt of any treatment as well as the type and adequacy of treatment received for depression. The use of a survey instrument that incorporates these findings to quantitatively assess patient attitudes and preferences might provide more definitive explanations. Clinicians, researchers, and policymakers need to incorporate the range of factors identified by patients into their decision making for individuals with depression.

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ANNOUNCEMENT

American Board of Internal Medicine

Important Note: The Board offers all of its Subspecialty Certification Examinations annually in November.

*1997 ABIM Recertification Examinations in Internal Medicine, its
Subspecialties, and Added Qualifications*

Registration Period: Ongoing and continuous since July 1, 1995

Final Examination Date: November 19, 1997

The Board's new comprehensive Recertification Program consists of an in-home, open-book Self-Evaluation Process (SEP) and a proctored Final Examination which will be administered annually in November. In order to be eligible to apply for the November Final Examination, Diplomates must return all their required at-home open-book SEP Modules to the Board office by August 1, 1997 and must submit their recertification Final Examination application by September 1, 1997.

For more information and application forms, please contact:

Registration Section
American Board of Internal Medicine
3624 Market Street
Philadelphia, Pennsylvania 19104-2675
Telephone: (800) 441-2246 or (215) 243-1500
Fax: (215) 243-1590 E-mail: request@abim.org