Adherence to Treatment Among Economically Disadvantaged Patients With Panic Disorder

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Objective: **The purpose of this study was to examine the feelings of disadvantaged patients about and experiences of treatment for anxiety disorders in primary care settings.** ***Methods:*** **The patients had participated in the Collaborative Care for Anxiety and Panic study, which tested the effectiveness of an intervention to help primary care providers treat panic disorder. The treatment comprised cognitive behavioral therapy (CBT) combined with pharmacotherapy administered by primary care physicians with the expert advice of a psychiatrist. Post hoc semistructured interviews were conducted with 21 intervention participants who were classified according to adherence or nonadherence to treatment. The interview focused on reactions to CBT; reactions to the different features of the intervention, such as therapy sessions, demonstration videotapes, exercises, and a workbook; and comfort with the therapist. Two members of the research team independently coded, analyzed, and interpreted the data.** ***Results:*** **Three themes emerged: information was empowering and reduced the sense of isolation experienced by participants, participants engaged in a dynamic and iterative personalized assessment of the intervention, and barriers to adherence were predominantly logistical.** ***Conclusions:*** **Results indicate that the extent to which patients chose to remain in treatment and follow treatment recommendations was rarely an all-or-nothing phenomenon. In a disadvantaged population such decisions seem to be influenced by the beliefs of the patient about what will and will not be effective in his or her individual case, an ongoing self-assessment of well-being, and the logistical barriers that come into play. (*Psychiatric Services* 57:1745–1750, 2006)**

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Depression and anxiety disorders are more prevalent in economically disadvantaged populations (1,2), and disadvantaged patients are more likely to seek treatment in primary care than mental health specialty settings (3). Furthermore, impoverished persons with anxiety disorders have demonstrated poor clinical outcomes (1). Patients with anxiety disorders frequently leave the physician-patient transaction feeling dissatisfied or discontinue recommended treatment (4), and economically disadvantaged patients often experience more barriers to treatment engagement and adherence (5–7), possibly because of early trauma, chronic stress, and lack of social support (8–10).

Little is known about how patients perceive their mental health care, especially care delivered in primary care settings (11). In this study we examined disadvantaged patients' feelings about and experiences of treatment for anxiety disorders in primary care settings. We selected disadvantaged patients because the research literature suggests that this population often experiences more barriers to engagement and adherence, resulting in suboptimal treatment—something we recently observed in a larger data set (12), of which this sample is a part.

Unlike research that uses structured surveys to assess attitudes toward and satisfaction with mental health services (13), this study used

qualitative methods. These methods are widely used in exploratory studies for their capacity to reveal unexpected and serendipitous material. Interactive questioning allows flexibility in the structure and content of interviews and facilitates exploration of individual circumstances and experiences. Although a qualitative approach does not produce results that are statistically representative of populations, it typically elicits concepts and themes that may not be available with structured, quantitative techniques.

The goal of the study was to better understand disadvantaged patients' views of mental health care received in primary care settings and provide an opportunity for them to express their needs and explain their service and treatment choices.

Methods

Our participants had been part of the Collaborative Care for Anxiety and Panic (CCAP) study, which tested the effectiveness of a collaborative care intervention to help primary care providers treat panic disorder (14). Drawn from six university-based primary care clinics in three West Coast cities (Seattle, Los Angeles, and San Diego), the participants had been randomly assigned to receive either a program of cognitive-behavioral therapy (CBT) delivered by a behavioral health specialist, combined with pharmacotherapy (largely antidepressants of the selective serotonin reuptake inhibitor type or serotonin-norepinephrine reuptake inhibitor type, with little use of benzodiazepines) by the primary care physician and optimized by expert advice from a psychiatrist. Disease management was offered for 119 participants, and 113 participants received care as usual. The behavioral health specialist served as a care manager and, in addition to delivering CBT, sought to potentiate treatment adherence by calling patients who missed appointments, challenging negative beliefs among patients who were disinclined to pursue either treatment, and optimizing medication effects by relaying expert psychiatrists' advice about dosage and side effect management to prescribing primary care physicians.

In addition to CBT, participants in the treatment group were provided with educational aids that comprised a demonstration videotape and workbook. The videotape demonstrated the components of CBT and discussed the biology and pharmacotherapy of panic, the most common medication side effects and how to overcome them, strategies for increasing medication adherence, and the role of cognitive-behavioral factors in anxiety. The workbook was a revised and condensed version of *Mastery of Your Anxiety and Panic (MAP-3)* (15). The control group of 113 patients received care as usual by the primary care physician, which usually consisted of medication, augmented by a medication algorithm, and information from participants' diagnostic interviews that was provided to their primary care physicians at baseline. Care as usual allowed specialty mental health referral, which occurred for 16 patients (about 15 percent).

Sampling frame

The recruitment and longitudinal data collection for CCAP began in spring 2000 and continued until spring 2003. At the completion of the CCAP study, the post hoc qualitative study was conducted with 21 of the participants from the intervention group, all of whom were below the poverty line in terms of family income. Fourteen participants were from the Seattle site, six were from the San Diego site, and only one was from the University of California, Los Angeles, site. The qualitative interviews were conducted between June 2002 and April 2003, and the time between study completion and interview for each participant ranged from three to 12 months after final study contact. Fourteen participants (67 percent) were women. Eleven (52 percent) were white, six (29 percent) were African American, three (14 percent) were Hispanic, one (5 percent) was Asian, and one (5 percent) was of another ethnicity. To compare, the demographic characteristics for the treatment group of the main study were 68 percent women, 67 percent white, 13 percent African American, 11 percent Hispanic, and 8 percent "other" ethnicity. The sample ranged in age from 23 to 59 years, with a mean±SD age of 41.2±11.3 years. Measures of income were derived from self-report of annual income and family size at the baseline telephone assessment. We used 2001 Federal Poverty Guidelines (16) and indexed the categorization to family size.

Intervention participants who completed the CCAP study were eligible to be included in this qualitative study. A purposive sampling design was adopted, and participants from all three project sites (Seattle, Los Angeles, and San Diego) were selected. Because we were interested in the relationship between participation in treatment and participants' beliefs and perceptions, we classified participants as "adherent" or "nonadherent" to treatment on the basis of quantitative data available from previously obtained outcome assessments. For CBT, adherence was defined as receiving at least four of the six CBT sessions. Patients attending at least three sessions could receive further sessions on the phone. Ten participants (48 percent) were adherent (nine patients with six sessions [43 percent] and one patient with five sessions [5 percent]), and 11 (52 percent) were nonadherent (one patient with no sessions [5 percent], three patients with one session [14 percent], six patients with two sessions [28 percent], and one patient with three sessions [5 percent]). For medication, adherence required taking an appropriate dose for six weeks. Fourteen participants (67 percent) were nonadherent, with most not taking medication at all or for more than a few days.

Nine participants (43 percent) were nonadherent to both CBT and medication, five (24 percent) were adherent to both CBT and medication, two (9 percent) were adherent to medication but nonadherent to CBT, and five (24 percent) were adherent to CBT but nonadherent to medication. Participants were contacted by phone, and if they agreed to be interviewed, a convenient time was scheduled. Consent forms were

mailed to participants with an enclosed postage-paid envelope for return of completed forms. Patients were paid $20 for their participation.

Procedures

The interview focused on reactions to the different features of the intervention (behavioral health specialist sessions to deliver CBT and potentiate medication adherence; experience of the CBT treatment itself; and videotape, exercises, workbook, and medication) and comfort with the therapist. All interviews were audiotaped and transcribed verbatim. The interviews lasted between 45 and 60 minutes. Interviewers kept participants engaged by asking them to elaborate upon their answers (17), especially if they answered in simple sentences or phrases. Interviews were conducted after obtaining patients' signatures on the consent forms approved by the institutions' review boards. Interviewers had not been involved in the participants' treatment but had served as outcome assessors for the study. Therefore, they were not technically blind to whether participants had been adherent. Patients were told that information in the interviews would not be disclosed to their clinicians.

Data analysis

Two members of the research team independently coded, analyzed, and interpreted the data. Raters engaged in an iterative process to independently create codes and check agreement for each interview. They then reached an agreement on the overarching codes that spanned interviews. A codebook was developed with standard procedures (18,19). The transcripts were closely examined for metaphors, repetitions across informants, and shifts in content (20). With a grounded theory approach (21), we compared the transcripts for descriptive categories, which were then grouped to form themes. These were discussed by two researchers, who, after separately examining portions of the transcripts, reached consensus about which general themes should be examined in detail. The themes, taken from literature reviews, investigators' a priori understanding, and the text itself (22), were named, defined, and illustrated.

Results

Three themes emerged: information was empowering and reduced participants' sense of isolation, participants engaged in a dynamic and iterative personalized assessment of the intervention, and barriers to adherence were predominantly logistical.

Empowerment by information

In general, many participants felt that information was empowering; this was especially so for the five participants who were adherent to both treatments and the five who were adherent to only CBT. Participants experienced a sense of relief in understanding their disorder and a sense of power when using skills and techniques taught in CBT. One participant adherent to both treatments commented, "Just to know that there's a real diagnosis for what I was going through [was helpful]. I didn't even have a name for what I was feeling. . . . The key thing your study did was to help me help myself. I'm never gonna recover from those panic attacks . . . but I certainly can handle it and deal with it and recognize the triggers."

The extent to which patients choose to remain in treatment and follow treatment recommendations is rarely an all-or-nothing phenomenon.

A CBT-adherent participant said the program "taught me I could deal with it. It gave me some tools that I hadn't dealt with before. . . . Follow-up interviews were very helpful so that I could gauge my progress and get some reminders for behavior. . . . Talking with someone else made me realize how I was acting." These participants learned new skills and developed the ability to use the tools (workbooks, videotapes, and exercises) and techniques to recognize symptoms and self-monitor their condition. A participant indicated that the "workbook . . . explained the cycle of fear and I found that to be helpful not only for my panic but for other areas in my life." Several participants found the videotape helpful; a CBT-adherent participant endorsed it thusly: "The video was extremely powerful. And to say, 'Oh, wait a minute, there's other people who've gotten through this.'"

The participants, particularly those who adhered to both medication and to CBT, emphasized that only the CBT sessions gave them the opportunity to rehearse real-life scenarios and develop skills to assess themselves. They learned "to stop, think, and work through panic attacks." Using the skills seemed to increase self-efficacy: "The cognitive stuff helped me to really learn how to work through things and recognize what's happening. Also, it pushed me beyond what I feel my limits are . . . and kinda pushed me to take a little bit more of a risk. I gained confidence from doing that."

As stated by an adherent participant, the intervention reduced patients' sense of isolation: "Just knowing that I wasn't an isolated case, that it was a real diagnosis for which I could get help. Without a diagnosis you just suffer in silence."

Dynamic iterative assessment of the intervention

Participants were constantly monitoring and assessing the treatment's effectiveness and making decisions about adherence to CBT and medications on the basis of these assessments. Decisions to continue with CBT, medication, or both depended on participants' sense of well-being

and beliefs about their efficacy. A nonadherent participant described the monitoring process: "For the first week or so the new drugs calm you down, but you get used to them, and after a while your body just goes back into the same stage." A CBT-adherent patient acknowledged, "I took myself off meds before the study. I thought that if I needed to go back on, well, I would. I was graduating from law school and taking the bar. . . . I actually wanted to see if I could do the whole thing without [medications]." Two participants mentioned that they had quit their medication because they did not get panic attacks over a span of time.

In general, participants displayed a preference for CBT over medication. Most expressed negative feelings about medication. They were suspicious of it and feared loss of control over themselves and their lives. One CBT-adherent patient stated, "I wasn't quite ready to take medication. . . . I thought it wasn't such a useful tool." One medication-adherent participant said that "the medicine didn't make me feel that much in control of things. . . . I was a little worried about that, because I still have to control my mind, I have to control myself."

One participant thought medication could trigger panic attacks. A CBT-adherent participant said, "I felt that group therapy and therapy would be more helpful to me [than medication]. I just wanted to talk and listen to other people to see how they're dealing with their kind of insecurities." Still another said, "Only extreme cases need medication. I'd rather learn how to control certain things than have medications cover [them] up."

Some feared that stigma might be associated with using medication. One CBT-adherent patient was afraid that information about medication in his medical records might jeopardize his chances of employment: "If I tried to run for office or something, I'm a little concerned that my history of having Zoloft will come to surface somehow. . . . I am that much concerned that our medical records are not protected."

Some patients, however, felt that medications were important for treatment. A medication-adherent participant said, "I think that medications are necessary. You know, you can't do it alone. Some people have it more severe than others, and medication [is] definitely important. . . . It's calming and keeps you on an even keel." A nonadherent participant stated, "I believe that a big part of my panic was biochemical, so I think that having the meds along with the sessions would have been helpful."

Some participants expressed fear of medication side effects. One who was adherent only to CBT said, "I had a lot of fears about taking pharmaceuticals. Mostly side effects and the unknown—I don't like fooling around with my body's chemistry." One adherent participant expressed a similar apprehensiveness as well as ambivalence, although he took the medication and nevertheless "wondered how long you could take it without messing you up. . . . But it was definitely a help. Whether you want to do it or not, it was a help and you need it."

Logistical barriers involving time and travel affected CBT adherence but not medication adherence.

Barriers to patient participation were largely logistical. Nonadherent participants provided insight into the barriers they encountered in completing the program. Two participants cited work constraints as a problem. Three others had transportation problems. One participant admitted that his medication nonadherence was due to lack of finances. In general, treatment-adherent patients cited fewer logistical barriers.

When asked for recommendations to improve the logistics of the program, respondents suggested that it was important that all patients receive the videotape and workbook. Some respondents suggested that the sessions last longer, that telephone sessions take place on Saturdays, and that providers more assiduously follow up with participants.

Although most barriers identified by respondents were logistical, a number of them mentioned that their comorbid conditions influenced their decision to stop participating in the program. These conditions ran the gamut of bipolar disorder, agoraphobia, prescription medication addiction, arthritis, and seizures. At least four participants reported multiple conditions for which they took multiple medications. A nonadherent patient explained, "I stopped taking [the medications the study prescribed] because they told me that I had migraines and that I [had] to go on some meds for the headaches which would interact negatively with the [medication for panic disorder]. . . . I could not take both, so I decided to stop the panic medication."

Discussion

The extent to which patients choose to remain in treatment and follow treatment recommendations is rarely an all-or-nothing phenomenon (23). Our data suggest that in a disadvantaged population adherence seems to be related to the patient's beliefs about what will and will not be effective in his or her individual case, the patient's ongoing self-assessment of his or her well-being, and logistical barriers. It seems that even when patients are given choices in determining their treatment, most actively monitor treatment outcomes to make decisions about adherence. One can speculate that, given beliefs about medications and therapy and both real and perceived barriers to care, patients select a level of adherence to medication or psychotherapy that is subjectively determined to be optimal. What is optimal is likely to vary considerably from person to

person. Thus, from the patient's perspective, adherence or nonadherence to any form of treatment may result from a rational decision-making process (23). Additional research is needed to better understand patients' definitions of well-being and the levels of symptoms and functioning that denote "equilibrium," especially because this equilibrium appears to be related to decisions about adherence.

In general, many participants in this study expressed strong negative feelings toward medication. Consistent with other research (24), we found that many patients were uncomfortable with the idea of taking medication but did so because it had been strongly recommended. Common issues were fear of losing control and concerns about side effects. Several patients expressed the belief that anxiety is psychological and psychotherapy can help control and manage it and that only people with extreme symptoms need medication.

Our participants were all socioeconomically disadvantaged, which may explain the types of barriers they identified, although the absence of a comparison group of more economically advantaged patients limits our ability to say that findings were specific to economic disadvantage. Logistical barriers, especially those that reflected a lack of resources, were key for these participants. Not surprisingly, barriers involving time and travel affected CBT adherence but not medication adherence. Medication adherence was often influenced by the existence of comorbid disorders for which patients were already taking medications, which prompted concerns about combining them with those prescribed for panic disorder. These data are also consistent with the hypothesis that many patients engage in an implicit cost-benefit analysis in which beliefs about the necessity of their various medications are weighed against concerns about the potential adverse effects of taking them (25).

This study has a number of limitations. First, aspects intrinsic to the study design limit our ability to discriminate effects or assign them to specific factors. We cannot separate factors related to nonadherence to medication versus nonadherence to CBT because two-thirds of the sample were adherent or nonadherent to both. Participants' open-ended responses did not allow separation of logistic from other barriers and did not allow determination of whether some transportation difficulties were due to phobic avoidance rather than logistical barriers. Second, the sample cannot be considered to represent the population of interest because it was a convenience sample of those who agreed to participate in the study after being selected. Furthermore, as participants in a randomized trial, these patients received extra support to maximize treatment engagement, and so nonadherent participants likely represented the extremes of nonadherence.

The data cannot be used for hypothesis testing, and the results of this project, compared with studies using a systematic standardized sampling design, may not be replicable. However, the insights gained about treatment perceptions and opinions of this low-income sample could be valuable for informing future interventions. Second, social desirability may have played a greater part than usual because the interviewers were also study coordinators or were involved in the patients' care process. Unlike quantitative methods, qualitative data collection focuses on building trust and rapport between interviewer and interviewee. This dynamic may come into play particularly when sensitive topics are being investigated (26), especially among vulnerable low-income participants. Third, the quality of the data collection and the results are highly dependent on the skills of the interviewer and the rigor of the analysis. Although highly experienced in conducting telephone interviews, some of our interviewers had less experience in conducting qualitative interviews. However, the respondents had spoken with the interviewers on several occasions throughout the previous year-long study and so may have trusted them more than they might have otherwise. That rapport was an advantage when interviewing, as evident from the nature of some of the patients' unsolicited comments.

Conclusions

A number of clinical implications can be gleaned from these data. First, clinicians and staff should be particularly sensitive to the barriers that confront low-income patients. There may be a need to routinely assess the availability of transportation, money to buy medications, ways to provide for the care of children or elders for whom the patient is responsible, and so on. Second, education about panic disorder is particularly needed for this population. They are likely to have less formal education than the general population and thus may not have access to information available to individuals with greater resources. Educational videotapes and other materials were highly valued by these participants. Education often resulted in a sense of empowerment.

Finally, it is very important for clinicians to understand how their patients define illness and health. Patients have their own logic about adherence to treatment and seem to follow an algorithm that best meets their needs. It is vital to educate patients about the need to continue treatment at least in some instances, even when symptoms have improved (27). Thus it behooves providers to tailor initial discussions of diagnosis and treatment to patients' beliefs about health and to revisit these beliefs if a problem with adherence arises, rather than label the patients "nonadherent."

Traditionally, there has been a tendency to place the onus of responsibility for adherence upon the patient (28,29). In the context of collaborative care it becomes imperative to view adherence as a part of the therapeutic relationship. To deliver optimal care, providers need to make an effort to understand patients' decisions about adherence in the context of their beliefs, attitudes, and perceptions of well-being.

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