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Lives in Isolation: Stories and Struggles of Low-income African American Women with Panic Disorder

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Research evidence points to the existence of racial-ethnic disparities in both access to and quality of mental health services for African Americans with panic disorder. Current panic disorder evaluation and treatment paradigms are not responsive to the needs of many African Americans. The primary individual, social, and health-care system factors that limit African Americans' access to care and response to treatment are not well understood. Low-income African American women with panic disorder participated in a series of focus-group sessions designed to elicit (1) their perspectives regarding access and treatment barriers and (2) their recommendations for designing a culturally consistent panic treatment program. Fear of confiding to others about panic symptoms, fear of social stigma, and lack of information about panic disorder were major individual barriers. Within their social networks, stigmatizing attitudes toward mental illness and the mentally ill, discouragement about the use of psychiatric medication, and perceptions that symptoms were the result of personal or spiritual weakness had all interfered with the participants' treatment seeking efforts and contributed to a common experience of severe social isolation. None of the focus-group members had developed fully effective therapeutic relationships with either medical or mental health providers. They described an unmet need for more interactive and culturally authentic relationships with treatment providers. Although the focus-group sessions were not intended to be therapeutic, the women reported that participation in the meetings had been an emotionally powerful and beneficial experience. They expressed a strong preference for the utilization of female-only, panic disorder peer-support groups as an initial step in the treatment/recovery process. Peer-support groups for low-income African American women with panic disorder could address many of the identified access and treatment barriers.

Introduction

Racial and ethnic disparities in access to and quality of mental health services have been well documented, and overcoming culturally based treatment barriers is a national health priority [1]. African Americans have been particularly affected by these disparities in mental health care. Compared with Caucasian Americans, African Americans are less likely to receive accurate psychiatric diagnoses [2], less likely to be prescribed psychotropics for mental health problems [3], and less likely to receive guideline-concordant treatment [4,5]. Research evidence confirms these inequalities, even after controlling for socioeconomic factors, and highlights the need to

better understand the culturally based biases and behaviors of both health-care providers and African American consumers [6].

Panic disorder is a condition particularly predisposed to cultural differences in both the behavioral presentation of the illness and beliefs about its etiology. Panic-like symptoms have been connected with a wide range of culture-bound syndromes such as "Ataques de Nervios" in some Latin cultures [7] and "Sore Neck Syndrome" in Southeast Asians [8]. Idiomatic folk disorders occurring in some African American communities, such as "Nerves," "Falling-out," "High blood," and "Stress," have been hypothesized to be culture-based manifestations of panic and other anxiety disorders [9,10].

While the incidence of panic disorder is similar across ethnic groups, African Americans who develop panic disorder have a more chronic course [11]. This chronicity may in part relate to the greater reluctance of African Americans to seek mental health treatment [12–15]. Using data from a national epidemiological study, Horwath et al. [16] found that African Americans with panic disorder were only one-fifth as likely as Caucasians to seek treatment from mental health professionals in private practice. Neal-Barnett and Crowther [17] studied 15 middle-class African American women with panic disorder and found less than half sought therapy or counseling. Among those who did seek mental health treatment, all except two did so for reasons other than panic disorder.

Even more concerning is the poor quality of mental services provided to African Americans seeking treatment for panic disorder. African Americans are more likely to be misdiagnosed (particularly with psychotic disorders) and are less likely to receive care that is concordant with standard treatment guidelines [18,19]. Moreover, African Americans experience poorer treatment outcomes even when state-of-the-art behavioral and pharmacological therapies are provided [20,21]. These findings indicate that the current panic disorder evaluation and treatment paradigms don't meet the therapeutic needs of many African Americans.

As a first step toward designing a more effective and culturally informed treatment program for low-income African Americans with panic disorder, we conducted a two-phase qualitative study using focus-group methodology. In the first phase of this research, we conducted three separate focus groups of low-income African American, Caucasian, and Hispanic women with panic disorder and compared the three ethnic groups on their social network experiences, treatment seeking experiences, and treatment [22]. In contrast to the Hispanic and Caucasian groups, the African American group reported a much greater fear of disclosing panic symptoms,

a much higher expectation of stigmatizing reactions from social network members, a more profound deterioration in social support, greater ambivalence about treatment, and more dissatisfaction with the quality of their treatment experiences. When asked about treatment needs and preferences, the African American women focused to a much greater degree on their need to meet others with panic disorder and gave greater priority to the need for a peer-support group as a component of treatment.

In order to further explore and extend the themes identified in the initial African American focus-group session as well as to engage the participants in the process of designing a culturally tailored panic disorder treatment program, we conducted two additional focus-group sessions for the African American women. In this report we will outline the major themes expressed during this series of three African American focus-group sessions and describe the participants' perspectives regarding the optimal therapeutic approach to their panic disorder treatment.

Methods

Overview

The project was completed in two phases. During the first phase, we conducted three one-session focus groups—one each for Caucasian women, Hispanic women, and African American women with panic disorder. In the second phase, we conducted two additional focus-group sessions with the African American women in order to explore and extend prominent themes identified during the initial meeting. This report focuses only on the data from the three African American focus-group sessions.

Participants

Candidates for the study were low-income patients in a hospital-based primary care clinic at a University of Florida affiliated medical center in Jacksonville Florida. They were initially identified by two primary care physicians (one a Hispanic female, the other a Caucasian male), who referred a total of 16 African American women diagnosed with panic disorder. We were able to contact 11 of the 16 and all of these consented to participate in an initial clinical telephone interview. Ten of the eleven were found to meet diagnostic criteria for panic disorder. All of the 10 with confirmed panic disorder agreed to participate in the focus-group research, and nine ultimately attended at least one of the three focus-group sessions. For the first focus-group session, eight were scheduled and five of these attended. Women who didn't come to the initial session were allowed to participate in the second two sessions. This allowed us to

determine whether the findings from the initial session actually reflected the perspectives of the larger identified study group. The second focus-group session consisted of four members from the first focus meeting and three additional members. All of these participated in the third focus-group session along with one new member who was not available for the previous two meeting.

Procedure

The project was conducted at a University-affiliated primary care center serving a large, low-income, inner city population in Jacksonville, Florida. Informed consent was obtained for all subjects after the nature of the procedures was explained. The research project was reviewed and approved by the Shands Jacksonville Hospital Institutional Review Board.

Focus-group sessions were structured using standard methods for their design and implementation [23,24]. A professional moderator (Caucasian male) was contracted from a private research company (Ulrich Research Services, Jacksonville, Florida) to conduct the first session. The second and third focus-group sessions were conducted by an independently contracted post-doctoral researcher (Caucasian female), who had extensive prior experience conducting focus groups with ethnic minorities.

At the beginning of each focus-group session, the moderator described the research purpose of the meeting and reviewed rules and procedures. Participants in the second and third sessions were informed that the additional sessions were being held to gain a deeper understanding of the issues raised during the initial session and to ask for their recommendations for designing a culturally relevant panic disorder treatment program. The moderators were instructed to guide the discussion using a set of predeveloped probe questions but to avoid restricting the discussion so as to allow for the spontaneous emergence of unexpected themes.

Probe questions for the first group were designed to explore three general areas: (1) Social network experiences ("How do people in your community and families talk about problems with panic disorder and anxiety?" "How much do they know about panic disorder and how do they view people suffering from this problem?" "How have people in your families and your community responded to you since you began having panic disorder?" "Who have you been able to turn to for help?" "Did others make it easier or harder for you to get help?"); (2) Treatment-seeking experiences ("Describe your experiences getting treatment for panic disorder," "What type of help were you hoping for?" "How satisfied have you been with the treatment you have received?" "What have you liked/disliked about it?"); and (3) Treatment needs and

preferences ("How could things be changed to improve your treatment experience?" "Who would you prefer getting treatment from—your primary care doctor, a psychiatrist, a trained nurse, a counselor or therapist, other?" "Where would you feel most comfortable going for help—primary care clinic, mental health clinic, other location?" "How important is the gender or race of the person you are working with?", "How important are each of these treatment components to you—medication, individual psychotherapy, group therapy, support group?").

Probe questions for the second and third focus groups were designed to allow further exploration and natural expansion of major themes identified during the first group as well as to allow the identification of newly emergent themes. Our goal for the second group was to focus on previous and current experiences with panic disorder, i.e., "How it is/has been." The categories and specific probes used for the second group were as follows: (1) Individuals' illness experiences, coping strategies and beliefs about causality ("How has having panic disorder affected your life—work, family, social activities, physical health?" "How have you coped with this illness?" "How has your spirituality and faith affected this illness (and vice versa)?" "What do you believe is causing you to have this illness?"); (2) Social network experiences ("How have your friends, close family, and church community members responded to you since you began having problems with panic?" "Who have you been able to talk to about it?" "Who wouldn't you talk to?" "Who has helped you the most?" "Who has made it most difficult?" "What are you afraid would happen if you sought comfort from others?"); and (3) Treatment seeking experiences ("What have treatment providers done that made you feel better/worse?" "Who have you had the best/worst experiences with?").

In the third focus group we asked participants to discuss the types of changes they would like to see for themselves and within their social network as well as to describe how the health-care system could be changed to better fit their treatment needs and preferences, i.e., "How it could be." The categories and specific probe questions for the third group were as follows: (1) How it could be on a personal level ("How would you like to be at the end of the healing process?" "What would you be able to do that you can't do now?"); (2) How it could be on a social network level ("What could be done to reduce stigma about panic disorder in your community?" "What role could the church play in helping people cope with this illness?" "What other community resources would you like to have available?"); and (3) How it could be on a treatment system level ("What needs to be changed about how doctors, nurses, therapists talk to you about this problem?" "What other changes in the health-care

system would be most important—financial, scheduling, appointment length, process for mental health referral, other" "What changes would be most helpful to give people the feeling that it would be okay to tell their doctor about their symptoms?" "What types of treatment would you prefer and how should it be provided?" "How would a peer-support group help you?" "What would be the most important goals of a peer-support group?" "How would a peer-support group work—who would be included, e.g., where should it meet, who would run it, how often should it meet, what types of activities would take place, would there be a spiritual component?").

Data Analysis

All focus-group discussions were audio taped and transcribed verbatim. We utilized standard qualitative data analytic procedures that have been previously delineated [25]. A verbatim transcript of the first focus-group session was independently read and organized into themes by each of the four primary investigators (two Caucasian males, one African American male, and one Hispanic female). The four raters then met to compare analyses and to construct an initial consensus taxonomy consisting of primary and secondary themes. The transcript was subsequently entered into ATLAS.ti, a qualitative data analysis program [26]. Using this program, individual quotes were connected to thematic labels. A complete list of quotations for each theme category was printed out and again reviewed independently by each of the four raters who met to develop the final coding structure. The themes retained in the final coding structure were then organized into the set of probe questions that guided the discussions in the second and third sessions. Verbatim transcripts from these two focus-group sessions were subsequently analyzed using the same inductive process leading to the final thematic taxonomy. Finally, the research group selected the quotations that best represented the larger group of statements for each of the identified themes.

Results

The primary and secondary themes identified from transcripts of the three focus-group sessions are presented in Table 1. The themes are organized into the four general areas explored during the focus groups: individual illness perspectives and experiences; social network experiences; treatment seeking experiences; and treatment preferences.

Table 1 Primary and secondary themes

Individual illness perspectives and experiences
  Fear of confiding panic symptoms to others
    Lack of acceptable explanation for symptoms
    Could only be understood by someone with the same problem
    Unable to find anyone else with panic to confide in
    Fear of being stigmatized
  Withdrawal from usual sources of social support
  Reliance on spirituality for coping
    Crisis of spirit as faith has not been enough to overcome panic
Social network experiences
  Stigmatizing attitudes and behaviors
    Hurtful language to describe mentally ill
    Stigma about use of psychiatric medications to cope with emotional problems
  Negative change in behavior of social network members toward them
    Others withdrawing and avoiding them
    Perceived as being potentially dangerous or contagious
  Crisis of faith
    Perceived as being spiritually weak
    Ultimate withdrawal from church community
Treatment seeking experiences
  Prefer primary care to mental health providers but dissatisfied with treatment
    Too much emphasis on medication
    Too little time to talk
    Feeling misunderstood
    Cultural barriers to communication
  Desire for talk based therapy but dissatisfied with psychotherapy experiences
    Therapist behavior didn't fit needs
    Too clinical, emotionally detached
    Not interactive enough
    Belief that therapists who hadn't had panic disorder would not be able to understand or know how to help
Treatment preferences
  Desire for peer-support group therapy
    Immediate benefit from focus-group participation
    Preferred elements for design of peer-support groups
    Panic disorder only
    Females only
    Opportunity to meet someone who has recovered from panic disorder
    Group support for overcoming agoraphobic fears
    Long term groups
    Ability to call other groups members when needing support

Individual Illness Perspectives and Experiences

Fear of confiding anxiety symptoms to others was the first theme to emerge in the initial session and recurred frequently throughout the subsequent meetings. All of the women described having kept their panic symptoms hidden.

When you look at people you're not gonna give them an inkling that anything's wrong.

And so that's why you don't talk to anybody because that might tip them off that something's wrong with you

Related to this were the belief that no one else would understand and the fear that the absence of an acceptable explanation for the panic symptoms would result in stigmatized and rejecting reactions.

I don't really want them to realize how I feel. Because I haven't figured it out completely.

The women shared a common and frequently expressed belief that only someone who also suffered from panic disorder could understand and accept them. However, most of the women reported they had never known anyone else having panic attacks prior to the focus groups. As a result, they had come to believe that either they were the only one in their community suffering with this problem, or if there were others, they would never be able to know who they were, because they would be hiding too.

Couldn't no one look at you and tell. I always feel like that. I'm in this by myself. I can't believe nobody else is going through this. And just listening to you all...I know other people are, but you know it's just that on sight you can't pick them out.

And you know this disease...you can't look at a person and...you would never know. They could be so beautiful and so...you know...well dressed, well to do, you would never know.

All of the women described feeling isolated and alone within their community. They had all withdrawn from usual sources of emotional support and prayer had become a primary source of comfort.

I said who can I call? Can I call this one or can I call that one? They're not really going to talk to me about anything. So I pray.

However, many of the comments reflected a belief that spirituality and faith alone would not be sufficient to overcome their panic and agoraphobia.

Because he's one of those ones that ...well... if you're praying, and if you're doing this—you get up and do that, you'll be alright. And I know that's not going to work. I pray just to go to the grocery store.

Social Network Experiences

Feeling hurt and stigmatized by social network members was a powerfully resonant and emotional theme throughout the groups. The prevalent use of derogatory and stigmatized language had been particularly painful.

And that's why they use the terms—'Oh you crazy', 'She done clicked', 'She done snapped off' or whatever.

Social network members had often discouraged them from seeking mental health treatment and the use of psy-

chotropic medications for panic was particularly stigmatized. Use of psychiatric medication had been seen as a sign of weakness. As a result, most of the women hid their medicine use from others.

It's like you can see that they're the one that needs to know. You know what I'm saying. You can't slip up. You have to sneak and take medicine. Because you don't want no one to know you're on all this medicine.

The onset of panic attacks and subsequent development of agoraphobic behavior patterns had caused catastrophic changes in the quality of all the participants' social network ties. A large number of comments reflected the pain felt when social network members who had previously been important sources of emotional support now reacted to them with fear, antipathy, and avoidance.

They don't look at you the same way. They don't speak to you the same way. They don't greet you the same way.

They treat me like somebody they don't want to be around.

Many of the participants reported that people in their social network had begun treating them as if they had become dangerous or contagious.

I could see people look at me, and whisper and you know they don't like get up close to you. They don't want you to touch them or something like that.

Two group members even experienced the spread of false rumors that they had AIDS.

I've never had an attack around them...you know, where I couldn't breathe or something like that...and maybe they're thinking it's something else. Cause they always want to think the worst. Like when I was in the hospital for 37 days...they swore to God that I had AIDS.

All of the focus-group members reported that their spirituality and religious faith were fundamental sources of comfort and support throughout their illness. However, continuation of emotional symptoms had often been perceived by social network members as a sign of insufficient faith.

Most feel that your faith in God is not strong enough

Negative reactions from others in their church-based social network had led most of the women to reduce or discontinue church attendance.

Sometimes when I go to church...when I walk in, it seems like everybody is looking at me. And they won't speak to me. I go to a small church, but they'll speak to the next person. And that makes me feel real bad, because by going to church you think you're going to get some more support in the church than out of the church. But it's not like that. And I stopped going to church for that reason.

Treatment Seeking Experiences

All of the group members indicated that they preferred seeking help for panic symptoms from their primary

care clinicians rather than from mental health providers. However, most of their comments reflected negative and/or unsatisfying experiences in primary care. The structure of primary care visits—particularly the problem of having too little time to talk—was commonly mentioned as a barrier to getting help with emotional problems. Many comments reflected concern that the clinicians seemed to be in too much of a hurry, were seeing too many other patients, and didn't have enough time to deal with their emotional problems effectively.

> I don't have much confidence in doctors. Because when I go in there and I tell them, 'Look, my wrist hurts, my shoulder hurts, I've got a bad headache, my back hurts…my knee and my leg', he's only going to address one thing.

Feeling misunderstood by health care providers was a particularly common theme. Many of the comments indicated that cultural differences between the providers and themselves had contributed to this problem. One woman related that her lack of faith in health care providers stemmed from a particularly negative experience with doctors when she sought help in the emergency room after a severe panic attack.

> And when I told him that I talk to God and God talk to me, he said 'Excuse me one second', and he went out of the room and came back in with another doctor. He said to tell this doctor what I told him. And I did. And then he said, 'Well excuse me a minute'. And he went out and got another doctor. Now here's three doctors standing here looking at me. I felt like I had lost my mind. I had no idea that I was going through any type of sickness. I was there because I was hurting about something. I think I went in because I had had pains in my chest. And then by me telling this doctor, 'Well I talk to God'. I guess he thought I had flipped my wig. So I knew he wasn't at the level where I was. Cause he probably doesn't talk to God.

Almost all of the participants reported that their primary care clinicians had prescribed them psychotropic medications that had been helpful. However, the group universally expressed a preference for treatment that involved talking to someone about emotional problems. And many described feeling frustrated by clinicians' emphasis on medication therapy.

> I'm basically dealing with this on my own. I tell my primary doctor that and she says 'Well, you got any more Zoloft? I got some free samples'. And that's the end of it. But I know that through myself, it's not helping just to take the medicine and go to sleep.

The unmet need to talk in more depth about their illness and the preference for talk-based treatment were very strong themes. Almost all group members reported having seen a therapist at some point during their illness. However, most of the comments reflected the negative aspects of these experiences. The largest number of comments reflected dissatisfaction with the "unnatural" way therapists had behaved. They seemed emotionally detached and unwilling to engage.

> The counseling that I had…I did not like it. He just sat there. He wasn't giving me no advice…how you go about dealing with it. And I wasn't getting no help. So I stopped going to him.

Therapists who listened passively were perceived as uncaring, unable to understand them, and uninterested in trying to help.

> He would just listen to what I said. Then I figure that's maybe because it's the first visit and that's what you do. But it was every time I came in there. He never had no motivation to get up and try to help you go through what you were going through.

The failure of therapy was also attributed to the fact that the therapists themselves had never suffered from panic disorder.

> If you've never had a panic attack …you don't know what a panic attack is. And the book is not going to show you everything. The book is going to miss some things somewhere along the line. That person who wrote the book wasn't a person who had panic attacks or depression

Treatment Preferences

In response to questions about treatment preferences, almost all of the group discussion revolved around the desire for continued peer-support group experiences. Although the focus groups had not been designed to be a therapeutic experience, there was universal agreement that participation in the group had been a positive and emotionally uplifting experience for them. Many of the participants reported that the focus-group experience had provided needed relief from their loneliness and social isolation.

> But everybody don't have someone they can talk to. But this group thing here, I think is the best thing that ever happened. Because you know that you're not alone.

The opportunity to meet other women suffering from panic disorder, who had gone through many of the same problems, was seen as a key to allowing this positive emotional experience.

> That you could kind of feed off of each other, cause one thing about it…the family is not going through it, the preacher is not going through what you're going through. But when you are around others that are having these same feelings you are.…

Problems with agoraphobic anxiety were a particularly negative result of panic disorder, and several women reported feeling a greater willingness to face their fears after participating in a focus-group session.

Yesterday was a great day. I did things yesterday afternoon (after the second group meeting) that I hadn't done in a long time.

The fear of never recovering from their illness was frequently expressed. Many of the women reported feeling that the group experience had led to feeling of greater "normalcy" and a renewed sense of hope for recovery.

I attended the group yesterday, and it was very supportive to me and I know that things are going to get better.

One respondent eloquently articulated how the group had addressed one of their most commonly expressed unmet needs—the desire to feel understood.

I think, you know, the support group would be a good thing. It kind of helps you to understand what you're going through, because you're not alone. Because I always felt like I was the only one, but I see now that I'm not alone. I'm with someone that do understand what I'm going through and really listen. And not just listen to what I'm saying…but hearing what I'm saying.

When asked about how such a peer-group experience should be designed, the women expressed a preference that the groups only include those suffering from panic disorder. This preference related to the recurrent theme that only someone with the same problem would be able to understand them. There was also a strong preference for groups that were all female. There was general agreement that the inclusion of men would make it more difficult to talk freely.

I think that if there were men sitting in the group, we wouldn't be as open.

The participants identified a number of particularly important functions for a peer-support group. They expressed particular excitement about the possibility of meeting someone who had recovered from panic disorder.

So there are people who totally recover from all this? Can we talk to some of them? Tell us how they got through it or something. (Help understand) how come some people can go through it for 20 years or 10 years and like that?

Other desired elements of a peer-support group included the opportunity to learn methods of coping with panic attacks and the availability of group support to overcome agoraphobic fears

We know some are scared to go out, some are scared to mingle, some just don't want to be around a bunch of people. Once we all get together and be open like we is now, maybe we can all get together and say, 'Well okay, let's take this chance. Let's all of us try to go out and mingle and go to the store….So this is one way of getting you out to get that feeling again that you used to have by being in the store. Cause you're probably not afraid because you're with us.

Many of the comments emphasized the need for stable and reliable treatment and particularly the fear of losing access to effective therapy. One of the woman described feeling abandoned when a previous panic disorder group had been discontinued.

Before the group ceased, they should have had someone to pick it up and carry on. (If not) that leaves us right back where we started…or worse.

More than any other benefit, participants focused on the hope that a peer-support group could provide people they could turn to, not just during meetings, but also during their everyday struggles to cope with panic disorder.

But remember this if you don't remember nothing else. And I am learning this here myself. You're not the only one feeling like that. You're not alone. Whenever you feel like you're alone, if you feel comfortable talking to one of us, get our number.

Discussion

The major themes elicited during the focus-group sessions pointed to culturally specific individual, social network, and health-care system barriers to treatment for this group of low-income African American women with panic disorder. On an individual level, fear of confiding panic symptoms to others was a central and resonant theme. This fear had not been an identified theme during our earlier groups of low-income Caucasian and Hispanic women with panic disorder, which suggests this may be a culturally derived response. A similar result was described by Snowden [27] who found that African Americans were more reluctant than Caucasians to confide mental health problems to a friend, family member, or religious figure.

Fear of stigma was an important theme in the African American focus-group sessions. Fear of being stigmatized and desire to avoid being perceived as personally or spiritually weak were the most common reasons given for decisions to isolate from family, friends, and church networks. While stigmatizing social network responses had been reported by the Caucasian and Hispanic women, comments in the African American groups suggested that they felt greater harm from these experiences and made greater efforts to avoid situations due to fear of being stigmatized. These results are consistent with other research evidence indicating fear of being stigmatized with a mental disorder is a more important treatment barrier for African Americans than for Caucasians [28–30].

During the first two focus-group sessions, the participants spent substantially more time discussing their feelings about being alienated and isolated from their social network than any other topic. In comparison, these were relatively minor themes in our previous Caucasian and Hispanic focus groups. The basis for this disparity

could relate to ethnic differences in social network structure. Granovetter [31] has proposed a model of social network function that characterizes social relationship ties as being either "strong" (a close relationship with frequent contacts and mutual confiding) or "weak" (an acquaintance relationship). Social networks in traditional African American communities consist of higher numbers of "strong" and fewer "weak" ties compared with Caucasian communities [32,33]. Theoretically, a social network with many strong ties could have an emotionally protective effect that would enhance the group members' ability to cope with common stressors. However, Granovetter [31] theorizes that individuals living in close-knit networks with few outside connections may be at a disadvantage when coping with a novel stressor about which little information or awareness exists among social network members. Most of the African American participants reported knowing very little about panic disorder themselves and indicated that it was not a well-recognized concept within their social network. For many, the absence of an acceptable explanation for panic symptoms had been an important factor in the decision not to confide in others. A commonly expressed belief was that they needed to understand the problem better before they could safely talk to anyone who had not experienced the same problem. This belief along with the lack of social network awareness about panic disorder, made the inability to locate other individuals also suffering from panic disorder a critical barrier to understanding and coping with their illness.

All of the women turned to their health-care providers for help in understanding and treating their panic disorder. However, discussions about treatment seeking experiences were almost entirely focused on negative and unsatisfying encounters. Most of the negative comments about clinical interactions in primary care situations focused on the overly short time frames for visits and the overemphasis on medication rather than talking therapy. Despite the preference for talk-based therapy, interactions with therapists had also not addressed their needs. There was particular emphasis on discomfort with the behavioral style of therapists. Their comments suggested they held an unmet expectation for a more mutual, emotionally interactive therapeutic relationship unlike the clinically detached style more typical of mainstream treatment models.

While the focus groups were not designed to be therapeutic, the benefit of participation in the groups became a dominant spontaneous theme. All of the members reported that they had initially felt apprehensive about participating in the focus groups, and some reported that they had not planned to say anything. In the initial study, the extraordinarily tense atmosphere at the beginning

of the African American focus-group session had been remarkably different from the relatively relaxed emotional tone at the outset of the Caucasian and Hispanic meetings. Within a short time, however, the interactions among the African American women became the liveliest of the three groups. Participants reported experiencing a deep sense of relief once they were able to openly relate their panic experiences to others with the same problem. During the subsequent focus-group sessions, many of the women reported that the previous group experience had significant positive residual effects, including increased willingness to confront agoraphobic fears and a greater sense of hope that they would recover. When we asked about treatment preferences during the third session, the desire for a female-only panic disorder peer-support group was virtually the only approach strongly endorsed.

Although compelling, our findings need to be interpreted in light of study design limitations. As we discovered, fear of talking about panic symptoms was a core issue for this group and very likely contributed to the lower participation in the first session. Ideally, the nine participants would have attended all three of the sessions. While including the new participants for sessions two and three allowed us to get a much deeper and more detailed perspective on the themes identified in the first session, it is possible that the findings were over-balanced toward the viewpoints of those participating in all three sessions. The use of a new moderator for the second and third sessions could also have influenced how the participants responded. The lack of quantitative data regarding participants' panic severity and treatment history limited our ability to clinically characterize the group for comparison with other clinical and research samples. Generalization of these findings is also limited by the small number of participants and the exclusion of other important target groups (e.g. male panic sufferers, individuals who had not yet sought treatment, and those whose phobic anxiety prevented participation in a group process). The social network characteristics described here may also not be representative of higher socioeconomic populations or of communities in different geographical areas. Studies with larger and more diverse samples would be needed to determine the validity and generalizability of our findings.

Despite these limitations, however, our results do underscore the critical need for new and more culturally appropriate treatment models for low-income African American women struggling to cope with panic disorder. Our results suggest that incorporation of panic disorder peer-support groups into existing treatment programs could allow greater therapeutic engagement and ultimately better treatment outcomes. Peer-support groups have already been found to be an effective and culturally

consistent therapeutic approach to helping African American women cope with a variety of medical disorders [34–36]. Mental health problems may be particularly responsive to the use of such groups. Neal-Barnett [37] has developed a model for treating African American women with anxiety disorders that incorporates cognitive behavioral therapy into meetings of "Soothe Your Nerves Sister Circles." Results from this study provide additional support for the appropriateness and desirability of a "Sister Circle" treatment model for panic disorder. Incorporation of such peer-support groups into existing primary care and mental health programs would directly address identified treatment barriers including social stigma, social isolation, lack of access to information about panic disorder, and need for more authentic therapeutic relationships.

The participants in this research eloquently articulated their desire for a new therapeutic approach. The continuous inclusion of their voices in the work of developing and implementing culturally competent panic treatment programs is a key to the ultimate success of such efforts.

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Conflict of Interest

The authors declare no conflict of interest.

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