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“Mama just won’t accept this”: Adult Perspectives on Engaging Depressed African American Teens in Clinical Research and Treatment

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Abstract

This manuscript focuses on qualitative data collected for AAKOMA Project, a 2-phase treatment engagement intervention trial for depressed African American adolescents and families. Data are presented from our phase I study of adult perspectives on African American adolescent depression, depression treatment, and research engagement. The research team conducted four focus groups ($N = 24$) and generated major themes from the data including ideas regarding the manifestations of depression in African American youth and psychosocial barriers to participation in depression research and treatment. Findings indicate that success in recruiting and retaining African American youth in depression research and treatment may include using innovative means to overcome the culturally embedded attributions of depression to non-biological causes, beliefs about the cultural insensitivity of treatments and challenges in the logistics of obtaining care. Adults report that encouraging youth and familial involvement in treatments and research should include targeted, community-partnered activities involving diverse staff in leadership roles and including community members as equal partners.

Keywords

Treatment engagement; Health disparities; Adolescent depression; African American youth; Community engaged research

African American adolescents and families face multiple barriers to obtaining quality psychiatric and behavioral health care given reported historical, socioeconomic and provider concerns (Breland-Noble, Bell, & Nicolas, 2006). For the purpose of this study, our research team identified African Americans as individuals with a predominant ancestry of Black

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African involuntary immigration to the US for the purpose of slavery and including more recent voluntary immigrants from African countries and the Caribbean (U.S. Department of Health and Human Services, 2001).

Of the historically relevant healthcare barriers for African Americans, one is a syphilis study conducted in and around Macon, Georgia by the United States Public Health Service; significant for both its duration and lasting negative impacts on African American trust in the medical profession (Corbie-Smith, 2004; Katz et al., 2008). Though the US Public Health Service Syphilis Study, widely identified as the Tuskegee Experiment, ended more than 30 years ago, it impacts African American perceptions of medical research, clinical care and impressions of clinicians and medical settings today (Brown & Moyer, 2010). The *Unequal Treatment* report published by the National Academy of Sciences was a seminal work highlighting the day-to-day disparities (like diagnosis and treatment bias) faced by diverse persons in the US healthcare system including African Americans (Smedley, Stith, & Nelson, 2002).

Breland-Noble et al. (2006) have reported the individual barriers faced by African Americans in obtaining psychiatric and behavioral health care including negative perceptions of mental illness and the use of alternate forms of care like the church and faith community (Molock, Matlin, Barksdale, Puri, & Lyles, 2008). Many African Americans view the church as a primary source of care given the perceived cultural congruence between faith leaders and African Americans' beliefs about mental illness including attributions toward lack of hardiness, lack of faith, racial discrimination, and heightened stress (Cauce et al., 2002; Kendrick, Anderson, & Moore, 2007).

Researchers have proposed numerous explanations for African American disenchantment with psychiatric and behavioral health care, focusing primarily on logistical and physical access to care barriers (Alegria et al., 2002; Snowden & Yamada, 2005). Additionally, research suggests that African American parents harbor grave concerns about negative consequences for accessing mental health care with fears including the potential mislabeling of children with severe behavioral disorders (like conduct disorder) and a lack of the provision of appropriate treatments (Chandra et al., 2009; Wu et al., 2001). Other literature points to a myriad of reasons for African American under-representation in psychiatric and behavioral research including lack of African American leadership; questioned motives of non-African American researchers; fears of exploitation and lack of knowledge about the process of medical research engagement (Brown & Moyer, 2010; Connell, Shaw, Holmes, & Foster, 2001).

Conversely, an emergent area of the literature regarding positive and protective factors affecting African American underutilization of psychiatric and behavioral health care focuses on "active coping" or a dynamic and adaptive response to stress. John Henryism (a synonym for "protracted individual struggles" experienced by oppressed people that carry high and usually detrimental health costs) is one example of active coping (Caldwell, Kohn-Wood, Schmeelk-Cone, Chavous, & Zimmerman, 2004; Kohn-Wood, 2008). As stated earlier, the African American faith community (commonly referred to as "the Black Church") serves as a protective factor in African American health promotion. One definition of the Black Church indicates that it is comprised of, "…independent, historic, and totally African American controlled denomination[s] that constitute[s] the core religious experience of the majority of African American Christians…" (Molock et al., 2008, pp. 324–325). Various researchers have studied attitudes of African American clergy regarding mental illness, depression and even suicide (Blank, Mahmood, Fox, & Guterbock, 2002; Farrell & Goebert, 2008; Kramer et al., 2007). Notably, our research team generated findings regarding African American support for church involvement in depression care (Breland-Noble, Burriss, Roley, Doyle, & AAKOMA Project Advisory Board, 2008).

Black churches have been proposed as useful entities for health promotion and health disparities reduction with a number of recent preventive intervention programs targeted to African Americans (Campbell et al., 2007). Generally, the health promotion activities implemented in Black churches have focused on physical health including topics like obesity, cancer prevention and nutrition. Psychiatric and behavioral health foci using church based health promotion is far more rare, though it has grown in recent years (Breland-Noble, Bell, Burriss, Poole, & AAKOMA Project Adult Advisory Board, in press; Molock, 2008).

Unfortunately, the current published literature offers little insight into the *non-financial* and youth specific barriers to psychiatric and behavioral health treatment faced by African American youth with a few notable exceptions (Breland-Noble, Burriss, & Poole, 2010; Kendrick et al., 2007; Molock et al., 2007; Rose, Joe, & Lindsey, 2011). Recent research does, however, address African Americans' reported experiences with psychiatric illness including beliefs regarding illness etiology, illness outcomes and ideas regarding efficacious engagement practices for underserved populations (Anglin, Alberti, Link, & Phelan, 2008; Cauce et al., 2002; Molock et al., 2008). While this emergent literature provides important advances, most of the evidence is adult specific. We therefore anticipate filling a critical gap in the literature, related to youth and familial psychiatric and behavioral health service underutilization, via the current study.

We elected to pursue research in the area of adolescent depression given the significant mortality and disability arising from this disease and with recent research reporting that approximately 3.7% of a nationally representative sample of US adolescents met criteria for a mood disorder (Merikangas et al., 2010). Depressive disorders are also associated with impairment in both social/interpersonal and academic/cognitive domains. Surgeon General Dr. David Satcher identified a limited research-base regarding the mental health of diverse youth and detailed the great risks associated with depressive disorders for African American youth specifically including increased risk of suicidal behaviors (NIMH, 2003; U.S. Department of Health and Human Services, 2001). Since African American youth are less likely to participate in research and to utilize mental health treatment, it follows that improvements in the engagement and treatment of this population constitute an important public health contribution.

Overall, the data reported herein was compiled to *provide a clear understanding of how adolescent depression is viewed by African American families; what steps families take when they identify adolescent depression as a problem and how mental health treatment and research are viewed by the families of depressed African American youth*. The goal in obtaining this data was to support the researchers' development of a testable intervention for increasing African American adolescent depression treatment engagement (Breland-Noble et al., 2006). Therefore, we identified a key set of variables of interest to guide our efforts in articulating previously underreported factors that might robustly contribute to racial disparities in depression care and research participation.

In summary, our study was designed utilizing a qualitative methodology, employing focus groups, grounded theory and the constant comparative method to elucidate the factors that the adults involved in African American teens' lives (i.e. parents, teachers, clinicians, etc.) consider salient regarding treatment and research engagement for depressed African American youth.

Method

Study Design

We utilized a focus group methodology for this study given its documented utility with African Americans in fostering discussions about issues of import to the community (Schulz, Caldwell, & Foster, 2003). The rationale for "adults only" focus groups was to gain insight from the "gatekeepers" of depressed African American youth's entry into mental health research and treatment. Additionally, the socioeconomic diversity of our sample was important to the research team for creating a full picture of the diversity existent within the African American community.

Participants

Knowledge Panel—We recruited our study sample via multiple means including parent seminars, school and church presentations, the PI's local media appearances, referrals from our adult advisory board and other means with a focus on Community Based Participatory Research (CBPR) principles (Breland-Noble et al., 2009). We used a systematic approach to community engagement entitled *The Seven Field Principles* (Bell & McKay, 2004). The *Seven Field Principles* represent an operationalized model of behavior change derived from the Theory of Triadic Influence; a well-established model of behavior change developed by Flay, Snyder, and Petraitis (2009). Of particular relevance to our successful study recruitment were principles (1) *Establishing the village*, (2) *Providing access to healthcare and* (3) *Improving bonding, attachment, and connectedness dynamics within the community and between stakeholders*.

We targeted outreach to persons knowledgeable about the topic of investigation (i.e. depressed African American adolescent entrée into clinical research and care) via systematic non-probabilistic sampling. Stated simply, non-probabilistic sampling *does not* involve random sampling of study participants as opposed to probability sampling which *does* involve random sampling. Our specific approach to non-probabilistic sampling involved purposive sampling (i.e. sampling with purpose), which requires investigators to identify and collect data from those persons most likely to provide information on the topic of interest (Mays & Pope, 1995; Trochim, 2006). There are multiple forms of purposive sampling, including modal instance, quota, expert and snowball sampling (see Trochim, 2006 for detailed descriptions) of which our research team utilized expert sampling. In essence, our use of the expert purposive sampling approach helped our research team ensure that, " …people who… possess characteristics or live in circumstances relevant to the social phenomenon being studied," were included (Mays & Pope, 1995, p. 110). For this study, these individuals were persons familiar with African American adolescent depression, depression treatment and clinical research participation.

Inclusion and Exclusion Criteria—Our primary study goal was to utilize data from phase I to inform the development of an intervention manual in phase II. Therefore, we enrolled persons self-identified as African American *or who reported long standing working relationships with African American adolescents*. As indicated earlier, we appreciate the within group diversity of African Americans including persons born in the US and voluntary immigrants from the Caribbean and Africa.

Our exclusion criteria were: adults with a diminished capacity to participate based on the PI's (a fully licensed psychologist) clinical evaluation of potential adult participants during both the phone screen and in person consent process. We defined capacity to participate as the ability to understand participation requirements and offer lucid (i.e. unimpaired) consent to participate. These guidelines were informed by the parent guidelines of the Treatment of

Adolescents with Depression Study (TADS) (Treatment for Adolescents with Depression Study Team, 2003). The PI conducted all informed consents in person with adult study participants and carefully queried potential participants regarding comprehension of informed consent form. After each page of the consent form was discussed, the PI asked potential study participants if they had questions or concerns and if they felt comfortable continuing. Subsequently, each potential participant was asked to initial each page to indicate his/her understanding of that page of the form. In this manner the PI (1) physically witnessed potential participants' responses to the consent form (i.e. looking for signs of cognitive impairment) and (2) assessed potential participants' understanding of what their participation involved and their rights as participants via the ensuing conversation. Persons with no familiarity with depressed African American youth, depression research or depression treatment were excluded from study participation as they did not meet the expert criteria.

Procedures

All procedures were reviewed and approved by the Duke University Medical Center Institutional Review Board. We conducted focus group meetings in the local facility of a long-standing community proprietor who was recommended by a local community member. As study incentives, we served a catered dinner and provided each study participant with $40.00 in travel compensation. We utilized the TADS study patient screening model consisting of a series of qualifying "gates" for study participants (May et al., 2007). A "Gate A" was required for review of subject inclusion/exclusion and implemented via a scripted phone screen. Study eligibility was confirmed at the time of the "Gate A" and an appointment established to meet with the PI for the next "Gate." During Gate B, study participants engaged in the informed consent process, reviewed inclusion and exclusion criteria, completed a demographic questionnaire and a participant tracking contact sheet. The adult participants were then informed of their eligibility to participate in a 2-hour focus group.

The PI and research team members were certified in focus group co-facilitation. The certification process included (1) a review of the full study protocol, (2) a one day seminar led by two external qualitative experts (a university associate professor and a paid mental health qualitative research consultant) specializing in conducting health related focus groups with African Americans, (3) readings from the *Focus Group Kit* (Morgan & Krueger, 1998) and selected journal articles from qualitative health research journals and (4) protocol re-review with the study PI. The PI and at least one research team member were present for each focus group. The focus group discussion was guided by a semi-structured interview developed by the PI, the research team and two trained qualitative experts. The experts also recommended data collection in written form using individual notebooks. Each of these processes was suggested to support data triangulation described by Guion as, "a method used by qualitative researchers to check and establish validity in their studies" (Guion, 2002).

To develop the interview protocol the PI and a research team member conducted a literature review on the topic of treatment engagement for African Americans. We derived an original set of stem questions prior to the certification training which our qualitative experts then reviewed and offered feedback on to enhance their utility for the study. The experts also recommended that the study team refine the questions (for clarity and relevance) after "testing" them in the initial focus group meeting, a recommendation we followed. The focus group written response notebooks included stem questions designed by the research team and consultants and refined during data collection by the research team and consultants. We further required that the research team member who was not facilitating the group take observational notes on the focus group discussion. A professional medical transcriptionist transcribed all focus group data and the individual response notebooks were scanned and saved in the NVivo software program.

The research team also conducted and recorded individual follow up interviews with 1–2 participants from each focus group to serve as "member-checks" and to enhance the completeness and accuracy our data collection. Specifically, the research team asked interviewees to comment on a brief verbal summary of the major ideas presented at their focus group and to offer any unexplored ideas that were not expressed during the meeting. This strategy was employed for quality assurance, data validation, and to provide the study team with a second opportunity to learn from study participants. The professional medical transcriptionist also transcribed these follow-up interviews. Taken together, our data collection process followed recommended practices for establishing rigor via qualitative data triangulation methods.

Qualitative Data Analysis and Interpretation Procedures—We used transcript based data analysis for the focus group data as it is considered one of the most rigorous forms of qualitative analysis (Krueger, 1998). We further elected to use the constant comparative approach or "… an inductive process for forming a categorical model to describe the data collected in a study" (Schwitzer, Griffin, Ancis, & Thomas, 1999, p. 192) coupled with a grounded theory approach. Grounded theory has been described as an approach to qualitative inquiry in which one generates an explanatory theory of processes as they occur in their natural environment (Starks & Brown Trinidad, 2007). Grounded theory is also said to address what Glaser calls the "six Cs" of social processes including causes, contexts, contingencies, consequences, covariances, and conditions" (Glaser, 1992; Starks & Brown Trinidad, 2007, p. 1374). In essence, our approach incorporated a continual reorganization of participant responses (via transcribed sessions) until the data fit into the fewest, most meaningful categories possible which then allowed for a "look for statements and signs of behavior that occur[ed] over time during the study," (Dye, Schatz, Rosenberg, & Coleman, 2000, p. 2). We elected to incorporate these methods to assist us in reporting new ideas and other themes previously unreported (or underreported) in the literature. For example, while financial barriers are often cited as a prime rationale for African American underutilization of mental health treatment; non-financial, psychological barriers are seldom considered.

Our process for organizing the data into what are commonly described as "codes" was based on thematic data analysis or generating identifiable themes and patterns of behavior using informant reports (Aronson, 1994). Our coding process began with the training of three coders via a formal QSR International (developer of NVivo qualitative coding software) 6 hour introductory training, followed by completion of the software tutorial and an introduction to AAKOMA Project led by the study PI. This process resulted in three trained coders (the PI and two study team members) who then individually performed open coding (i.e. grouping together concepts and identifying recurrent ideas). During open coding, coders discussed ways to resolve any sources of confusion and maintain fidelity to the overall analysis goal. Next, the coders created a thematic/coding frame (with key analytic constructs compiled in a preliminary codebook) from the transcripts, follow-up transcripts and all participant written response notebooks using the aforementioned NVivo 8 qualitative software package. This axial coding process involved each individual coder reading the full set of transcripts and all written response notebooks to create two categories of codes, broad easily identified themes (based on repetition by participants) and more abstract, complex themes (based on evidence of significance as reported by the participants). Our research team's creation of our initial codebook for selective coding of the data included established and accepted practices as described by Coffey and Atkinson's *Making Sense of Qualitative Data* (Coffey & Atkinson, 1996) and others (Ryan & Bernard, 2003; Silverman, 2001). We then regrouped to compare our individual codebooks and organize our codes to determine places of overlap and disagreement and resolve discrepancies where possible. Our process resulted in a group-derived codebook of axial and complex codes.

We completed the initial codebook under leadership from the study PI who was responsible for re-reviewing all adult focus group transcripts and individual written responses to ensure that the master set of axial and complex codes encompassed the focus group raw data. The group derived codebook, which included both the names of the derived codes and the frequency of their occurrence in the raw data for all coders, allowed the PI to organize the major themes in order of recurrence. To support accuracy and completeness of reporting, and enhance the scientific reliability of the results, the full research team then reviewed the axial and complex coding as organized by the PI. We arranged our final set of codes into a codebook listing themes by broad themes (which we identified as primary tree nodes within the NVivo software) and more abstract complex themes (which we identified as secondary tree nodes and free nodes within the NVivo software). Primary tree nodes reflected full agreement by all coders; secondary tree nodes reflected agreement between two of the three coders and free nodes reflected identification by a single coder. Our research team included graphical models of the final codes via bar charts representing the codes in order of salience. We completed the process by developing a booklet listing the salient themes (primary tree nodes) along with descriptions of each code. This portion of our process reflects data transformation (i.e. progressing from raw data through a series of steps to written prose) (Glesne, 1999).

Results

We report findings from our sample of 24 participants. The sample was young (Age_M = 40.78; range 24–59); predominantly female (21 women, 3 men) had limited diversity (23 African Americans, 1 White adult—all self-reported) and of varied income and educational levels (Income_M = $47, 369.00; Years of completed $\mathrm{education}_M$ = 10.74). Overall, our sample diversity reflected the diversity in our study catchment area.

Six primary/salient themes emerged from our data regarding mental health research and treatment engagement for African American adolescents and families. These were the themes reflecting consensus across all three coders among the over 25 themes generated from our qualitative analytic process. Listed in order of coding from highest recurrence to lowest our derived themes included *Mental Health Help Logistics, Stigma Perceptions, Social Support and Family, Faith Community and Church, Trust, and African Americans' Clinical Research Concerns*. Following, we provide descriptions and examples of the adult data.

Mental Health Help Logistics

This idea is best described using the words of one of the focus group participants.

> It's just really hard. It's really hard, it's really hard and it's really stressful, um, to do what all is required and what's necessary and to get people to help you advocate for these kids and what they need.

The adult participants reported many concerns with negative experiences related to the lack of immediacy in obtaining care and feeling as if care worked like a "revolving door" such that services are recommended but by the time the family is willing and/or able to access them, they are either no longer available or no longer relevant. Additionally, participants described feeling as though clinicians use a "boiler-plate" approach to providing care that leaves many youth feeling disconnected from the care. In the words of one parent (with echoes from many of the adult participants) youth who actually make it into care are often left thinking, “What am I here for?” and “You’re wasting my time.”

Stigma

Essentially, there was a strong indication that African American teens and families are apprehensive about the stigma often associated with depression specifically and mental illness in general. When asked to describe what mental health means to them, the adult focus group participants responded with comments like the following:

> So if you have a, uh, emotional problem, there is not like degrees of it—It’s just ‘Crazy’
>
> …I immediately think of medication, uh, I think of disturbed, and I think of somebody who needs help…
>
> …and being a kid who wants to be known as the ‘Crazy Kid’
>
> Crazy. That’s my first thought.

Adults reported three specific types of stigma; stigma associated with a child being labeled, stigma associated with others’ perceptions, and stigma associated with psychotropic medications. One of the most interesting findings was related to the importance of being African American and the necessity of distancing oneself from a stigmatized group. For example, many participants reported that any clinical reference to mental health is automatically associated with the word “crazy” and/or significantly negative connotations as in:

> …but we’re from [a distinct region of the Deep South] and if you say anything about mental health, ‘oh, they’re crazy…
>
> …and that stigma that’s attached to it and we don’t want people feeling this way about us
>
> [Referring to parents obtaining clinical treatment for a child] “…so they may be ready to end it because of what society may say”

Additionally, study participants referred to others’ impressions of a teen or family member with depression as a barrier to treatment engagement:

> be truthful about what’s actually going on because it could get to a point where people only want to tell part of the story for, you know, the lack of being embarrassed or whatever the situation may be…

Finally, medication concerns were expressed in relation to fears about developing addictions, length of time required for relief, and negative impressions of psychotropic medications based on family and friend report (e.g. “a lot of kids were doped up, drugged or medicated that didn’t need to be, and, uh, so I think that’s what we think about when we hear medication, the horror stories”).

Church/Faith Community

The Black Church and the Black faith community were repeatedly mentioned in the focus groups regarding their great potential as catalysts for clinical care and research engagement. Conversely, participants indicated their beliefs that the focal point of the African American community is the church and that one of the major cultural barriers to treatment engagement is the significance of prayer and lack of information about depression and mental illness shared “from the pulpit”. Essentially, participants indicated that though the church has great potential to be helpful in enlisting African Americans to participate in clinical research and treatment, the current worldview of the predominant churches (i.e. Christian denominations) in the African American community precludes its ability to serve in the engagement capacity. Examples of these sentiments included:

> we can handle this, um, we can pray about it,' um, and things like that,
>
> It is a culture difference. Because my students tell me all the time, especially my Caucasian students, 'Uh, you know, ya'll black people, y'all pray when y'all have problems.'

Social Support and Family

The role of the family as both a helpmate and hindrance was very clearly expressed. For instance, study participants described the importance of family and friends as frontline treatment seeking conduits:

> Yeah, and also I would seek the comfort of my friends and family just because you know, those people have been closest to you, advice from them is more, is going to be more sincere and honest.

and referred to instances when a problem may have been identified in a teen, but efforts in treatment-seeking were thwarted by family members:

> even talking with my [family member] and going through all the symptoms and everything that she had and she goes to the doctor the next day, but then mama tells her, "It's nothing wrong with you." So then she stops her psychotherapy. She stops her medication, everything, because mama won't accept this.

Trust

Trust was mentioned frequently in relation to prior negative experiences with treatment and research and as one of the greatest barriers to engagement with African American teens. Adults described the cultural disconnect between youth and clinical care providers as well as the sentiment that teens do not relate well to current forms of talk therapy and medication management. Study participants surmised that a crucial ingredient to encouraging engagement in treatment is the establishment of rapport and they offered advice on how such rapport might be developed in a culturally specific manner:

> Some kids, but a lot of kids get really angry and frustrated and you know, they don't trust grown-ups because a lot of them; the cause of their suffering comes from either negligent or abusive grown-ups. So, the thing is finding a way to develop trust with this person who claims that they are there to help you because sometimes help doesn't help.

It was clear from all of the focus groups that the adults in African American teens' lives suggest innovative mechanisms for engaging youth. Examples provided included, allowing teens to write their own "raps" (songs); providing incentives for therapeutic and research visits, meeting outside the traditional office setting for clinical care (e.g. on the basketball court) and single gender therapeutic and research groups.

Overall, study participants had very clear and well-articulated ideas regarding the multiple manners in which psychological themes exist as strong barriers to clinical and research engagement for Black youth and families.

Clinical Implications and Discussion

As reported earlier, our research team allowed the words of the study participants to guide us toward an understanding of adult perspectives on African American adolescent depression, research participation and clinical care engagement. Of all the barriers identified, the two barriers with the greatest reported impact were the logistics associated with obtaining care (i.e. obtaining an immediate appointment) and stigma. Study participants shared a number of instances when either they themselves or people they were close to had difficulty obtaining consistent, quality care (even when traditional socioeconomic and access barriers were non-existent). This idea does indeed reflect an access to care barrier as has been reported widely in the literature on African American underutilization of clinical care. However, it also points to a concern that we believe can be addressed specifically by psychologists in academic health centers, i.e. the provision of psycho-education about clinical depression care. In other words, one approach that psychologists in academic health centers are uniquely poised to provide is community-based education about the process of obtaining care for adolescent depression. In fact, in addition to the work of the AAKOMA Project team, this community based approach to depression and mental health awareness has been implemented by some notable programs including the Youth-Nominated Support Team for suicidal youth (King et al., 2009) and the Family Coping Skills Program for low-income Latino families with depressed mothers (Cardemil, Kim, Pinedo, & Miller, 2005).

We also identified a phenomenon that we refer to as “anticipatory stigma” which has also been described by Gary (2005) as “family and courtesy stigma” (stigma extended to the family members of a mentally ill person because they are relatives). Many scholars have described the manners in which African Americans already belong to a class that has historically been characterized negatively by society (U.S. Department of Health and Human Services, 2001). As one study participant indicated: “…and that stigma that’s attached to it and we don’t want people feeling this way about us”. Adults were concerned that if an African American teen was identified as having a depressive disorder, he or she would automatically be exponentially stigmatized. An unfortunate consequence of this perspective is that families may allow a depressed teen to suffer in silence as a means of “protecting” the teen from mental health stigma associated with seeking care. Corrigan suggests that an approach to reducing stigma involves beginning with the education of children in the school setting (2007) and given African American’s reported higher levels of mental illness stigma as compared to their white peers, it seems imperative for psychologists to participate in the implementation of stigma reduction programs (Carpenter-Song et al., 2010).

Many researchers suggest that African American families serve as gatekeepers for African American youth’s entre into mental health care (Breland-Noble et al., 2010; May et al., 2007). The data reported herein support that idea fully yet also indicate that extended family can serve as a barrier to care. In other words, even after a parent or family member identifies depression in a teenager, negative comments from aunts, uncles, grandparents and even fictive kin can become impediments. To acknowledge this significant finding as highly relevant for African Americans, we note the manifestation of this type of stigma in the manuscript’s title.

Regarding the faith community and the “Black Church” specifically, participants eagerly supported the idea of a more prominent church role in “spreading the word” about adolescent depression, clinical trials and research participation. They also agreed that the Black Church’s current approach to mental health issues (i.e. non-discussion) serves as one of the biggest barriers to African American youth and families’ participation in both clinical care and research. The adults juxtaposed the church as a cornerstone of African American life with its disconnection from the mental health problems of current teens. Further, participants in 75% of the focus groups indicated explicitly the need for churches to play an active role in assisting with education focused on adolescent depression research and treatment. Recent research suggests the utility of the Black Church as a mechanism for reaching out to African American families regarding depression and suicide prevention

(Molock et al., 2008). We reported earlier on Church Based Health Promotion as a growing approach to interventions for health awareness and prevention with African Americans (Campbell et al., 2007). In fact, members of the AAKOMA Project research team and adult advisory board are currently engaged in Church based health promotion for depression awareness and suicide prevention in our local African American community and this is yielding positive results. Future research might explore the similarities and differences between adult and youth perceptions of the utility of Church Based Health Promotion (Breland-Noble et al., 2010).

At study outset, the research team generated multiple expected themes from prior research and historical knowledge of African American involvement with the medical profession. Overall, a number of our expected themes were supported by the data. First, we anticipated that mistrust of the medical system, fears of exploitation by medical researchers and limited knowledge about the research engagement process would surface as important psychological barriers to care. Indeed some of the focus group discussions focused on the United State Public Health Service Tuskegee Syphilis Study which one participant described as a study in which, "…they tested on African American males, uh, with the syphilis virus. They gave them syphilis, and even after they found the cure, you know, to stop it, they still continued testing on all of them". Other study participants described personal experiences with clinical research study staff accessing their protected health information (PHI) without their consent and for the sole purpose of enrolling them in research studies without their consent. Though current research in the area of African American mistrust of the medical profession is equivocal with regard to quantifying concerns exhibited by African Americans, psychologists should be aware of the need for discussions with potential patients regarding culturally embedded fears of doctors and their motives for engaging in clinical care with patients. This is of particularly relevance for highly stigmatized illnesses like depression.

Based on the findings derived from our research, we believe that patient education is an important and significant tool for reducing the barriers to treatment and research engagement for African Americans. We believe that the innovation in our work purports that it is highly important to disseminate knowledge and empower African American families and youth by educating them into clinical treatment through the reduction of stigma.

Limitations and Future Directions

We acknowledge our methodological limitations including our volunteer sample and our sample size. If we had randomly selected youth and families from settings like primary care offices, school clinics, and church services, we might have yielded additional and possibly different results. However, the significance of the findings serve as an initial step toward better understanding how clinicians and researchers might better engage African American youth and families in depression research and treatment. Additionally, we recognize the difficulties associated with recruiting persons to participate in a study focused on *research participation*. While there is a natural question of how volunteers of this study differ from non-volunteers (who might be more reflective of the persons who would normally opt out of clinical research participation), we are confident that our use of CBPR methods, including the seven field principles, supported our ability to gain an accurate picture of diverse African Americans' thoughts and concerns.

We also acknowledge concerns regarding the potential limitations of our work related to methodology. Specifically, we note the possibility that our African American PI, who led or co-led all focus group interviews, may have impacted socially desirability among our focus group participants merely via her physical presence. Our research team discussed this possibility during the planning phase of the focus groups and consulted with our community advisory board. In both instances, it was deemed important for the PI to lead the focus groups to generate candid responses from participants. To provide counterbalance for this limitation we deliberately added racially diverse and multidisciplinary coders in order to support cultural distance between our study participants and our coders. Finally, we acknowledge that our findings are limited to our expert panel and may have limited generalizability to other geographic, age and ethnic groups. However, we concur with prior established reports of similar research in which investigators stress the importance of relying on persons with experiences most relevant for the topic of interest (Okello & Neema, 2007).

Regarding next steps, our research team recently completed and published our primary findings from our qualitative research with African American teenagers regarding adolescent depression, depression treatment, and research (Breland-Noble et al., 2010). Additionally, we have completed enrollment in the engagement intervention randomized controlled pilot phase of our study. Our future research includes examining our qualitative data for prominent secondary themes (like active coping and John Henryism), better understanding of the specific role of prayer as a coping mechanism for African Americans and determining the utility of our engagement intervention on acceptance of depression treatment.

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