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Utilizing non-traditional research designs to explore culture-specific risk factors for eating disorders in African American adolescents

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Abstract

Over the past three decades, there has been an increase in the number of empirical investigations of the phenomenology of eating disorders among African American adolescents. Despite efforts to understand racial/ethnic differences, relatively few eating disorder models address the important sociocultural factors that exert powerful influences on beliefs and behaviors related to weight status and eating patterns in this population. Nevertheless, researchers must be culturally competent in order to develop appropriate models. Therefore, we propose an approach to developing researcher cultural competence by addressing potential barriers that may hinder efforts to explore relevant, culturally appropriate factors that contribute to eating disturbance in African American girls. In this regard, we highlight the importance of integrative collaboration that can assist in identification and exploration of potential risk factors that may lead to model generation. We believe such information will lead to the development of culturally appropriate assessments, models, and, ultimately, interventions.

Keywords

eating disorders; African American; cultural competence; risk factors

Introduction

As the U.S. population becomes increasingly diverse, so does the cultural fabric of the nation. With growing numbers of culturally diverse groups with greater access to mental healthcare, the need for culturally competent researchers and clinicians is paramount. Cultural competence refers to the appropriate acknowledgement *and* incorporation of cultural beliefs, perceptions, and behaviors into research and clinical care (Brislin, 2003; U.S. Department of Health and Human Services [DHHS] Office of Minority Health, 2013). Cultural competence involves the recognition of culture's role in well-being in addition to

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the ability of researchers and clinicians to function effectively in the context of another's cultural background (U.S. DHHS Office of Minority Health, 2013). In this paper, we focus primarily on the role of clinical researchers and scientists.

Decades of research with racial/ethnic minorities demonstrate that eating disorders are not limited to upper-class Caucasian females (Marques et al., 2011; Pike, Dunne, & Addai, 2013; Polivy & Herman, 2002; P. Robinson & Andersen, 1985; Striegel-Moore & Smolak, 2000). Yet, efforts to conceptualize and integrate relevant sociocultural variables in research exploration and development lag behind. Indeed, even with increases in investigations of the phenomenology of eating disorders in racial/ethnic women and girls (Taylor et al., 2013), relatively few theoretical models have specifically examined unique variables contributing to disordered eating in these individuals (Harrington, Crowther, & Shipherd, 2010; Rogers Wood & Petrie, 2010). While researchers acknowledge the existence of eating disorders in this group and the role of ethnicity and culture (Striegel-Moore & Smolak, 2000), several barriers may hinder utilization of such knowledge. First, uncertainty may exist regarding relevant and appropriate research questions that account for unique sociocultural variables. Secondly, collaborations predominantly occur with colleagues in similar research areas, which potentially hinder innovative explorations. Additionally, researchers may be apprehensive about disseminating interpretations regarding an unfamiliar cultural group, especially one outside of their own culture. Lastly, a perceived lack of support from the broader scientific community to engage in creative, non-traditional investigations may impede scientific discovery.

To address these barriers, we will i) briefly review the history of research in racial/ethnic minorities, ii) propose collaborations with individuals outside of the scientific community that may lead to novel research questions, and iii) discuss the potential for non-traditional scientific endeavors that translate to model development and adaptations of measurements and interventions. Furthermore, using a recent community-based study of loss of control eating behaviors in African American girls as an example, we highlight an alternative approach to exploring eating pathology in racial/ethnic minority groups. With this commentary, we advocate for improvements in cultural competence of all eating disorders researchers, regardless of their particular knowledge of, or experience working with, racial/ethnic minority groups.

Although we will focus on African Americans socialized in the U.S., we caution readers that African American girls are not a homogenous group, but can differ significantly by ethnicity, socioeconomic status, education, region, and country of origin. Additionally, while eating disorders occur in both males and females, our discussion will be limited to females.

Looking Back: A Brief History of Eating Disorders and Risk Factor Models

Some of the earliest reports examining eating disorders in African American girls occurred in the mid-1980s (Lawlor & Rand, 1985; Pumariega, Edwards, & Mitchell, 1984). Contrary to former notions, anorexia nervosa and bulimia nervosa were discovered in samples of African American girls (VanThorpe & Vogel, 1985). In subsequent years, there was an

increase in reports examining anorexia nervosa, bulimia nervosa, and binge eating in African American females (Austin et al., 2011; Field, Colditz, & Peterson, 1997; Johnson, Rohan, & Kirk, 2002; Neumark-Sztainer et al., 2002; Neumark-Sztainer, Story, Falkner, Beuhring, & Resnick, 1999; Neumark-Sztainer et al., 1997; Story, French, Resnick, & Blum, 1995; Striegel-Moore, Schreiber, Pike, Wilfley, & Rodin, 1995; Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011; Vander Wal, 2004). Similar to data in other racial and ethnic groups, anorexia nervosa is rare in comparison to other eating disorders (Striegel-Moore et al., 2003). However, evidence consistently demonstrates that African Americans indeed present with all forms of eating disorders.

Despite these data, theoretical models based upon upper-class Caucasian females in food-abundant cultures—likely due to their internalization of the “thin ideal”—are still prominent (Polivy & Herman, 2002). Indeed, accepted theoretical models mainly underscore the roles of restraint (Herman & Polivy, 1980; Stice, Presnell, & Spangler, 2002), low self-esteem due to body weight and shape concerns (Heatherton & Baumeister, 1991), and body dissatisfaction (Stice et al., 2002). While these models have increased our understanding of eating disorders considerably, the factors involved and their theoretical underpinnings may not be completely relevant for African American girls (George & Franko, 2010; Rhea & Thatcher, 2013; Rogers Wood & Petrie, 2010). Rather than eliminating current models, we advocate the need to build upon knowledge gained from existing theories by focusing on cultural relevance. For instance, in a more culturally sensitive model, Wilfley and colleagues (1997) proposed an interpersonal functioning pathway to the development of eating disorders, which has also been extended to adolescents (Tanofsky-Kraff, Wilfley, et al., 2007). The interpersonal model posits that deficits in social relationships lead to negative affect, which subsequently precipitate disordered eating as individuals use food to cope with negative emotions (Tanofsky-Kraff, Wilfley, et al., 2007; Wilfley, Pike, & Striegel-Moore, 1997). Since African American adolescents may be at increased risk for stressful life events (Wilfley et al., 1997), such as overt racial discrimination or micro-aggressions (Brody et al., 2006; Lambert, Herman, Bynum, & Ialongo, 2009; Sue et al., 2007), the interpersonal model may more appropriately describe the etiology of disordered eating symptoms in this group. Notably, treatment using the interpersonal model targets patients’ particular social stressors and subsequent negative affect, regardless of the circumstance. Therefore, the interpersonal model is well poised to address culturally specific stressors for African Americans. For instance, role plays and communication analyses (Young, Mufson, & Davies, 2006) may be used with African American youth who experience racial discrimination to support effective communication of distress and to obtain support from others. Although further testing is required, the interpersonal pathway may be an especially appropriate theoretical model to date for conceptualizing the development of disordered eating in African American adults and adolescents.

Nevertheless, most theoretical frameworks rarely account for other variables that may impact development of disordered eating behaviors in African Americans. Striegel-Moore and Smolak (2000) discuss the critical importance of examining culture-specific risk factors for developing disordered eating in women. Notably, researchers have discussed factors that may more aptly identify risk within minority cultures; specifically, acculturation and acculturative stress (Gordon, Castro, Sitnikov, & Holm-Denoma, 2010), socioeconomic

status, trauma, racial discrimination, and ethnic identity (Rhea & Thatcher, 2013; Shuttlesworth & Zotter, 2011; Striegel-Moore & Smolak, 2000). While these stressors are certainly relevant, other factors may be worth exploring as well. For instance, while African Americans of higher, versus lower, socioeconomic status have demonstrated increased risk of developing eating disorders (T. N. Robinson, Chang, Haydel, & Killen, 2001), social standing (Adler & Ostrove, 1999)—which persists even with changes in socioeconomic status—may be a more potent indicator of disorder risk (McLaren, deGroot, Adair, & Russell-Mayhew, 2012). The extent to which these—or other—risk factors may impact the development of aberrant eating in African American girls warrants further study.

Elucidating culturally relevant risk factors may involve adopting a socio-ecological perspective regarding individual eating behaviors (Levine & McVey, 2012). This “public health approach” places individual factors in the context of larger socio-cultural, economic, and political influences (Levine & McVey, 2012). Such a framework not only highlights the importance of adopting systems-level thinking, but also diverse collaborative efforts across various systems. Such perspectives may be particularly salient when exploring risk factors among African Americans. Indeed, numerous investigations have utilized this approach (Wilfley, Vannucci, & White, 2010) and described risk factors fit this theoretical model (Striegel-Moore & Smolak, 2000), yet few studies have utilized such methods to generate novel precipitants of disordered eating behaviors in African American females.

Moving Beyond the Silos: Improving Diverse Collaborations and Research Designs

Navigating collaborators and defining key issues

Collaboration with African American communities and the organizations functioning within these communities are essential for innovation and rich scientific discovery. The development of effective community collaborations, cultural competency, and an understanding of how to build upon prior literature to develop novel research approaches are three broad areas of expertise required to further our understanding of eating disorders and their treatment in African Americans. Potential collaborators include, but are not limited to, individual community members, community leaders, churches, schools, public health entities, and professional groups. Thus, the definition of “community” depends heavily upon the issues or questions being addressed. To define key issues, researchers must engage with stakeholders to uncover questions relevant to the community rather than scientist alone. Although researchers are well equipped to address questions within their area of expertise, there is a tremendous need to develop partnerships with individuals outside of the eating disorders research community to expand upon such knowledge towards more novel approaches (Becker, Stice, Shaw, & Woda, 2009). Ideally, important areas to explore should be examined from the viewpoints of multiple stakeholders. For instance, in the case below, we discuss the need to address adolescent obesity prevention efforts in conjunction with adolescents, their parents/guardians, and community leaders in the community.

Cultural competence and mutual respect

When developing collaborations, researchers must have a certain level of cultural competence to enable respectful interactions with community members. Mutual respect is a critical component in community collaborations and is the pivotal point from which all work must operate (Horowitz, Robinson, & Seifer, 2009). While deceptively simple, such respect may be difficult if researchers approach communities from the proverbial savior perspective, “I am here to help.” While seemingly benign, such an assumption can be, at best, presumptuous, and at worst, condescending or patriarchal. Instead, researchers must adopt the belief, “I am here to listen and learn.” The commitment to learning from communities to collaboratively tailor research ideas and develop new programs requires a willingness to surrender positions of authority, regardless of his or her training or cultural expertise. Such willingness empowers community partners to comfortably educate researchers on unknown elements of the community, guide researchers’ in their understanding of implicit community values, explain relevant historical and cultural backgrounds, and provide researchers an open forum for candid inquiry regarding the community. Each of these components is a key feature in promoting cultural competence (Anderson, Calvillo, & Fongwa, 2007) and, ultimately, improving the partnership and final research product (Horowitz et al., 2009).

Effective engagement with community collaborations through Community-Based Participatory Research

Ongoing engagement is at the foundation of community-academic partnerships and is captured by the techniques of Community-Based Participatory Research (CBPR; Agency for Healthcare Research and Quality (AHRQ, 2002)). Within CBPR, community stakeholders are viewed as equitable partners in the development of research projects serving their communities. Thus, stakeholders incorporate their own perspectives and expertise in design, implementation, and dissemination (AHRQ, 2002). Community stakeholders may be less likely to limit their research ideas based solely upon well-established theoretical models within eating disorders, which promotes novel exploration and innovative ideas. Indeed, researchers in other fields have discussed the invaluable contributions of community partners within academic-community collaborations (e.g., (Horowitz, Williams, & Bickell, 2003).

CBPR outlines several stages involved in the ongoing process of effective community engagement: 1) defining the key questions or issues of interest for the community, 2) developing research strategies and methods that respect community values, 3) engaging in outcome assessments that involve the community in interpreting findings, and 4) utilizing the information gained in a manner that is helpful to the community, not solely the researchers (AHRQ, 2002). This process underscores the importance of involving community members in each notable step of the research process.

Collaborating with qualitative researchers is also necessary to generate novel ideas about risk factors that may impact African Americans (Levine & McVey, 2012). While qualitative data has been historically considered less rigorous than quantitative data, such misperceptions can be attributed to misunderstandings regarding the role of qualitative data (Krueger & Casey, 2000). Unlike quantitative data, qualitative data does not propose to

explore relationships, determine cause and effect, or predict outcomes through exerting control. By contrast, qualitative methodologies aim to observe, document, and report uncontrolled human experiences (Krueger & Casey, 2000). Furthermore, systematic and verifiable procedures are utilized that substantiate scientific rigor (Krueger & Casey, 2000). For instance, focus groups allow participants (e.g., community members) to provide opinions and insights about particular issues (Krueger & Casey, 2000). As a result, group participants provide valuable data for researchers to learn from others while potentially generating new research ideas. Qualitative data may then be used to develop methods to conduct quantitative analyses.

While diverse partnerships may be especially useful for illuminating or explicating unique risk factors, extending beyond traditional research designs primarily used within the field of psychology, such as randomized-controlled trials (RCTs), is required as well. While RCTs have been considered the gold standard for testing interventions (Barton, 2000; Concato, Shah, & Horwitz, 2000), such designs may pose ethical and logistical challenges in community research, particularly among those historically underserved (Michener et al., 2012). Ethnic minorities with a mistrust of medical research may interpret randomization to signify being used as proverbial “guinea pigs” (Freimuth et al., 2001). Additionally, with the longer research timeframes involved in CBPR designs (Horowitz et al., 2009), waiting to begin clinical trials once individuals have been fully randomized may unduly extend trial initiation. This delay can result in frustration and distrust by community participants. Other quantitative designs, such as case control and cohort studies, utilized by some eating disorder researchers (Fairburn, Cooper, Doll, & Welch, 1999; Fairburn et al., 1998; Neumark-Sztainer et al., 2006) should also be embraced, particularly for use within specific communities. While balancing community partnerships with scientific rigor is critical, diverging from traditional methodologies may prove crucial to adequately address relevant sociocultural concepts and needs (Horowitz et al., 2009; Michener et al., 2012). As a result, the scientific community should be encouraged to broaden their understanding of the utility and importance of CBPR, qualitative methods, and non-traditional designs.

Now What: Appropriate Dissemination of Relevant Data

Diverse collaborations are a first step that must be followed by analysis and dissemination. However, researchers without expertise or a particular interest in cultural/ethnic factors may be hesitant to interpret or apply results. Factors driving such reluctance likely include different philosophies about taxonomy, contrasting beliefs regarding the need to classify individuals by race/ethnicity, various assumptions about the significance of cultural differences, or simply being uncomfortable interpreting results. Nevertheless, sharing empirical data regarding notable ethnic differences is essential and assists in the collective advancement of the field (Sarafino, 2005). A greater acceptance of alternative collaborations will promote scientists conducting cultural and ethnic research to disseminate their work through conference presentations, publications, social and news media, and community outreach. Dissemination will provide credibility for such work, encouraging researchers to continue to move the field forward.

Dissemination through adaptation and development

The majority of eating disorder assessments are normed in predominantly Caucasian samples (Fairburn & Beglin, 1994; Fairburn & Cooper, 1993; Garner, Olmstead, & Polivy, 1983; Gormally, Black, Daston, & Rardin, 1982). While some data suggest comparable reliability and validity among African American women (Atlas, Smith, Hohlstein, McCarthy, & Kroll, 2002; Bardone-Cone & Boyd, 2007), evidence is mixed (Fernandez, Malcarne, Wilfley, & McQuaid, 2006; Kelly, Cotter, & Mazzeo, 2012), particularly in pediatric samples (Franko et al., 2004). These limited data support the need to determine whether current assessment methods adequately capture disordered eating in African Americans. Evidence also underscores the need to develop new measures. Simply conducting psychometric evaluations of previously established measurements might still lack the ability to inform our understanding of eating pathology in this group. Based upon a CBPR approach, focus groups with multiple stakeholders can be utilized to address whether known constructs in assessments have cultural equivalence. To our knowledge, there have not been any culturally specific measurements developed to assess disordered eating in African American youth utilizing this method. Therefore, developing appropriate measures appears to be a reasonable next step.

Data regarding differences among African American girls are also required in order to adapt interventions. While empirical support is still necessary to determine whether cultural adaptations are more efficacious compared to non-tailored interventions (Huey, Tilley, Jones, & Smith, 2014), efforts that garner community insights to inform program development will likely improve acceptability and sustainability (Kumanyika, 2010; Kumanyika et al., 2007). Such considerations will assist in closing the gap in the development of interventions for African American girls and moving towards required efficacy studies. Moreover, analyses of relevant moderators of race/ethnicity are required to further adjust therapies to be culturally sensitive and fully effective.

Heterogeneity within African Americans

In an effort to account for sociocultural factors impacting risk and onset of eating disorders in African Americans, we caution researchers against ignoring the heterogeneity of the African American experience by collapsing within-group differences (Kumanyika et al., 2007). Similar to other racial/ethnic majority groups, all precipitating factors may not generalize to all African Americans. While a shared African American culture exists—and exerts powerful influences on behavior—the way one's culture uniquely applies to an individual may substantially differ based upon socioeconomic status, ethnic identity, or urban versus rural experiences (Brislin, 2003; Henrickson, Crowther, & Harrington, 2010; Kumanyika et al., 2007). Although we advocate the need to account for unique sociocultural factors impacting African Americans, we also underscore the importance of carefully applying such concepts to each sample being studied.

A Case Example: The POWER-UP Study

To illustrate the ways in which collaboration may be used to generate research ideas that lead to adaptations of interventions or measurements, we have included a case example of a

recent community-based study. We recently completed Phase I of a multi-site CBPR project to adapt interpersonal psychotherapy for the prevention of excess weight gain to be more culturally appropriate for African American girls (Cassidy et al., 2013). During the initial phase, we collaborated with researchers and community members to conduct focus groups with rural African American girls, their caregivers, and community members to gain perspectives regarding obesity, loss of control (LOC) eating, and a proposed eating disorder and obesity prevention program.

While heterogeneity undoubtedly exists within African Americans, we attempted to recruit individuals with commonalities over and beyond race/ethnicity, such as age, sex, weight, and shared community experiences. Participants included residents of the same rural community on the eastern shore of Maryland; females between age 12 – 17 years who were overweight or obese and reported disordered eating behaviors; and caregivers of the adolescent girls. Furthermore, community leaders were all women with professional experiences in a health-related field, many of whom worked with youth in the rural community. Although the sample cannot account for the myriad characteristics existing within the African diaspora, we anticipated that these commonalities would allow generalizability to other rural African Americans, particularly those living in the same area. Indeed, our aim was to develop a program especially suited for this specific rural community. Our collaboration with qualitative and community partners during this project was invaluable. We worked closely with qualitative researchers to develop suitable questions in accordance with focus group methodology. After our study team drafted the original focus group questions, the questions underwent numerous iterations before completion. Factors to consider during this process were the quantity of questions, whether questions were closed- or open-ended, use of psychological jargon; and appropriate flow of questions through the opening, introduction (e.g., warm up), transition to the central discussion, and closing questions (Krueger & Casey, 2000). Guidance from qualitative experts greatly improved the rigor of question development, and ultimately, focus group delivery. Importantly, reciprocal training took place: qualitative partners educated our study team about focus group development and we trained our partners on relevant constructs, such as LOC eating. This mutual collaboration not only led to a productive outcome, but an important learning experience for both teams.

We also partnered with community stakeholders who assisted in the coordination of our recruitment efforts. Our partners not only provided relevant expertise in content areas such as health and nutrition, but held specific knowledge about the community (for example, food availability) that was indispensable. However, coordinating with community members was not without its challenges. We experienced several delays when initiating the project due to misunderstandings about inclusion criteria, appropriate recruitment strategies, and timelines. Yet, with patience and respect for each other's knowledge and expertise, the focus groups were effectively carried out and well-received by the community participants. Indeed, after each session, parent and child participants expressed gratitude to the study team for the opportunity to share their concerns with individuals with common experiences—an opportunity they had not been previously afforded. Moreover, participants were excited about the potential impact of our work within their community. Despite the challenges of CBPR, the response proved invaluable and the potential impact appears promising.

The results of the focus groups are detailed elsewhere (Cassidy et al., 2013). In brief, focus group moderators queried participants on the potential causes of LOC eating in their community. Several responses supported published data, such as eating in response to sadness, anger, boredom, guilt, or conflicts with peers or family members (Steiger, Gauvin, Jabalpurwala, Seguin, & Stotland, 1999; Tanofsky-Kraff, Goossens, et al., 2007; Tanofsky-Kraff et al., 2011; Wilfley, Wilson, & Agras, 2003). However, differences in conceptualization of disordered eating behaviors emerged as well. For example, girls rarely endorsed that they experienced “loss of control” eating, even if they described well-established features (APA, 2013) and endorsed many of the correlates, such as eating more than planned or eating in the absence of hunger (Tanofsky-Kraff, Goossens, et al., 2007). Indeed, we learned that the use of different terminology to describe LOC eating was common, suggesting that rural African American girls likely have a distinct conceptualization and experience of LOC eating. Such realization has prompted a more in-depth exploration of culturally appropriate assessments in these groups.

Community leaders described additional factors such as cultural and physical isolation, a lack of self-efficacy, dependence on the farming industry, and limited access to healthy foods as possible risk factors for aberrant eating behaviors. While participants were not asked to elaborate on potential mechanisms, the role of these factors on the development and maintenance of LOC eating warrants investigation. For instance, cultural and physical isolation may elicit negative affect, like loneliness, leading to disordered eating. These influences may further interact with environments with an abundance of processed and highly palatable foods, promoting the development of disordered eating behaviors (Gearhardt, White, & Potenza, 2011). Given that social determinants of health are inherently shaped by larger economic and political systems (World Health Organization, 2013), it is important for researchers to investigate upstream levels of influence that may inform risk factor models and potential interventions. Therefore, two main questions emerged from these responses and insights: are environmental or policy level factors more salient in racial/ethnic minority groups? Will changes in the environment (e.g., increase in healthy food options) decrease the risk of developing or maintaining disordered eating in this group? Exploration of such factors is required.

Conclusions and Future Directions

While current research acknowledges the important role culture plays in the development of disordered eating, the field has yet to move toward translation of such knowledge into culture-based theoretical models and adaptation of measurements and interventions. While such work is essential, it will require researchers to participate in less traditional research methodologies and collaborate with individuals in fields outside of their expertise. Such involvement may provide hypothesis-generating insights that have not been previously considered and, ultimately, improve cultural competence of researchers.

We recognize that such change cannot occur without the support of the larger eating disorders scientific community. We urge professional organizations, peer-reviewed journal editors, and funding agencies to embrace research designs that may not subscribe to the traditional scientific method. While classic methodologies have led to substantial scientific

discoveries, these methods are not always culturally competent and may lack the generalizability and sustainability to meet the current and future needs of diverse populations. We look toward a new wave of diverse collaborations and non-traditional research methods to effectively meet the diverse needs of racial/ethnic minority communities.

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