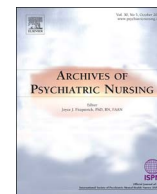




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Developing a Multiple Caregiver Group for Caregivers of Adolescents With Disruptive Behaviors

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ABSTRACT

This article describes the development of a 6-week multiple caregiver group intervention for primary caregivers of adolescents diagnosed with Oppositional Defiant Disorder or Conduct Disorder in low-income African American families. The intervention is aimed at increasing the primary caregivers' self-efficacy in managing interactions within the family and especially with child serving educational, mental health, juvenile justice, and child welfare systems. Development of the intervention involved seven iterative activities performed in a collaborative effort between an interdisciplinary academic team, community engagement specialists, members of the targeted population, and clinical partners from a large public mental health system. The intervention development process described in this article can provide guidance for teams that aim to develop new mental health interventions that target specific outcomes in populations with unique needs.

Caregivers of adolescents who are diagnosed with Oppositional Defiant Disorder (ODD) and/or Conduct Disorder (CD) experience significant challenges (Author et al., 2015; Viana et al., 2013). ODD/CD are serious mental disorders, which are generally diagnosed first during childhood (Frick & Dickens, 2006; Nock, Kazdin, Hiripi, & Kessler, 2007). ODD is characterized by an angry/irritable mood and defiant, negative, and hostile behaviors, while CD is characterized by a pattern of aggressive and destructive behaviors and serious violations of rules (Frick & Dickens, 2006; Nock et al., 2007). In the United States, 10% of adolescents 13 to 18 years of age are diagnosed with ODD/CD and account for half of all child referrals to outpatient mental health clinics (Handwerk, Field, Dahl, & Malmberg, 2012; Merikangas et al., 2010). The median age of onset of these behavior disorders is 11 years, with some children being diagnosed much earlier, and the severity of the illness typically intensifies as the child gets older (Merikangas et al., 2010).

Adolescents with ODD/CD, compared to younger children, pose particular challenges for primary caregivers because of increasing physical size and strength, need for autonomy, peer pressure, and risk-taking behaviors (Steinberg, 2007). Adolescents with ODD/CD are at risk for negative outcomes such as poor educational achievement, substance abuse, and involvement with the criminal justice system, and

these effects often extend to adulthood (Conway, Swendsen, Husky, He, & Merikangas, 2016; Heflinger & Humphreys, 2008; Merikangas et al., 2011; Petitclerc & Tremblay, 2009; Sayal, Washbrook, & Proper, 2015).

The primary responsibility of caring for adolescents with ODD/CD is typically assumed by a parent or another adult family member (referred to as the primary caregiver). Primary caregivers often report high levels of stress (Author, Author, Alkhattab, Knopf, & Mazurcyk, 2014; Author, Gerkenmeyer, Stephan, Wheeler, & Hanna, 2012; Rosenzweig & Kendall, 2008; Shin & Brown, 2009) due to the high demands of managing the adolescents' disruptive behaviors, often over the course of many years (Author et al., 2012; Author et al., 2014; Cox, 2003; Rosenwald & Bronstein, 2008; Schneiderman & Villagrana, 2010). Primary caregivers must also manage frequent interactions with the many child serving systems that provide mental health, educational, child welfare, or juvenile justice services to the adolescent and family (Author et al., 2015; Saunders, 2013; Valenzuela & Smith, 2016). In addition, due to the nature of their adolescents' behaviors, primary caregivers often report experiencing social stigma (Mukolo, Heflinger, & Wallston, 2010). The stress of caring for an adolescent with ODD/CD can lead to the development or exacerbation of a number of negative health outcomes, including anxiety, depression, and physical health problems as well as impairment in the quality of life and disruptions

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in family functioning (Author et al., 2012; Author et al., 2015; Saunders, 2003).

The challenges of caring for adolescents with ODD/CD are often accompanied by other adversities such as parental drug or alcohol use, parental incarceration, interpersonal violence, neighborhood deterioration, and socioeconomic disadvantage (Alegria, Green, McLaughlin, & Loder, 2015; Author et al., 2015; Copeland, 2006; Grimm et al., 2016; Sydow, Retzlaff, Beher, Haun, & Schweitzer, 2013). African American (AA) families of adolescents with ODD/CD are especially affected by these adversities due to their overrepresentation in socioeconomically disadvantaged populations (Byck, Bolland, Dick, Ashbeck, & Mustanski, 2013; Grimm et al., 2016; Simons et al., 2016). Adolescents with ODD/CD in the low-income AA families often receive poor quality mental health services, frequently drop out of care, and experience discrimination in their interactions with child serving systems (Alegria et al., 2015; Copeland, 2006; Grimm et al., 2016; McKay & Bannon, 2004; Office of Surgeon General, 2001).

Several psychosocial interventions such as Multisystemic Therapy and Brief Strategic Family Therapy have been shown to be effective for adolescents with ODD/CD and their families (Burns, Fisher, & Ganju, 2011; Epstein, Fonnesebeck, Potter, Rizzone, & McPheeters, 2015). These interventions teach primary caregivers how to manage the adolescents' disruptive behaviors and improve parent-child interactions. To our knowledge, no published intervention has thus far addressed the stressors of primary caregivers of adolescents with ODD/CD particularly those related to difficult interactions within the family or with child serving systems. To fill this knowledge gap, our research team developed the FAmily Management Efficacy (FAME) intervention for low income AA primary caregivers of adolescents aged 12 to 17 years old and diagnosed with ODD/CD.

The purpose of this article is to describe the development of FAME. The intervention was developed by an interdisciplinary academic research team with backgrounds in nursing, sociology, psychology, and music therapy in collaboration with a variety of community partners. The following activities comprised the intervention development process: (1) conducting a preliminary descriptive study, (2) forming community advisory boards, (3) determining the theoretical basis for the intervention, (4) identifying the primary treatment approach, (5) finalizing the conceptual framework, (6) determining the primary features of the intervention, and (7) identifying the intervention components, including the intervention content and the activities for each session.

Conducting a preliminary descriptive study

Because the research team was initially interested in developing treatment strategies for all family members of adolescents with ODD/CD, we first conducted a preliminary qualitative descriptive study to identify the challenges and needs of all family members (i.e., primary caregivers, siblings, and other significant adult caretakers) of AA adolescents with ODD/CD. This study, which included semi-structured interviews with 15 adolescents diagnosed with ODD/CD and their family members, including 15 caregivers, 10 other adult family members, and 12 siblings, has been described in detail elsewhere (Author et al., 2014; Author et al., 2015).

Because the interviews revealed that primary caregivers experienced pronounced and unique challenges that were burdensome and unrelenting, we determined that an intervention was needed for the primary caregivers specifically, and we thus focused on the data they provided. The two most salient problems they identified were the adolescents' disruptive behaviors and stressful interactions with child serving systems (Author et al., 2014; Author et al., 2015). The primary caregivers were overwhelmed by having to constantly manage the adolescents' aggressive, defiant, and deceitful behaviors and feeling responsible for the adolescents' safety and the safety of others threatened by the adolescents' behaviors. Some primary caregivers had to remain vigilant for fear that the adolescents would engage in dangerous

or criminal activities. In addition, the primary caregivers felt burdened by frequent and often unscheduled meetings with child serving systems (e.g., being "called to" school or having the police "show up" at their house). They often felt blamed for their adolescents' behaviors in these meetings, were left out of treatment decisions, and were frustrated by the lack of effective programs and services (Author et al., 2014; Author et al., 2015). The caregivers expressed a desire to meet with others who experienced similar problems and recommended interventions that focused on family communication, conflict resolution, education about the adolescents' disorder, and strategies to improve interactions with child serving systems (Author et al., 2014; Author et al., 2015).

Forming community advisory boards

We convened two community advisory boards to inform the development of FAME: a Family Advisory Board and a Professional Advisory Board. The Family Advisory Board included five caregivers of AA adolescents with ODD/CD who were recruited from a child and adolescent program of a large publicly funded community mental health center. The Professional Advisory Board included six professionals who worked with the population of interest and were employed by the same mental health center. Members of the Professional Advisory Board included a nurse, a psychiatrist, a counselor in a school-based mental health program, a counselor in a juvenile justice-based mental health program, and a case manager.

The principle author of this study worked with the Indiana Clinical and Translational Sciences Institute Patient Engagement Core to develop facilitation strategies for advisory board meetings. The Patient Engagement Core is an interdisciplinary team that works with investigators to develop robust and collaborative community engagement approaches. With the assistance of Patient Engagement Core graphic, visual, and service design specialists, the research team developed meeting materials to elicit discussions with advisory board members about proposed intervention content, procedures, and targeted outcomes. Prior to each board meeting, the principle author met with the Patient Engagement Core team to review audio recordings and field notes from the previous meeting and to discuss goals for upcoming meetings.

We held two separate meetings of the Family Advisory Board and Professional Advisory Board followed by one joint meeting with both boards. The attendance rates at these meetings were 100%. All meetings were facilitated by the principle author. Family Advisory Board members were compensated for their time and travel with a \$50 gift card for each meeting attended. Light refreshments were also served at the Family Advisory Board meetings. The Professional Advisory Board members were not compensated for their board membership because meetings were held during regular work hours.

The advisory boards provided critical input for the development of the intervention. The board members confirmed that primary caregivers of AA adolescents with ODD/CD experience multiple and severe stressors and could benefit from an intervention that addressed their major concerns. Both boards recommended that the intervention be conducted in a group format so that primary caregivers could learn and receive support from others who experienced similar challenges. Both boards highlighted the importance of strengthening interactions within the family and with child serving systems. They stressed that in AA communities, families are often comprise of biological or marital relatives such as parents, siblings, uncles/aunts, and grandparents (kin) and intimate family friends (fictive kin). The advisory boards recommended that the intervention include kin and fictive kin to provide support to the primary caregivers.

While it was clear that managing the adolescents' disruptive behaviors was an on-going concern of the primary caregivers, evidence-based interventions have been developed to improve behavioral management strategies (Epstein et al., 2015). In addition, parental strategies for managing the adolescents' disruptive behaviors are often addressed

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