

The Challenges for Primary Caregivers of Adolescents with Disruptive Behavior Disorders

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### Abstract

Adolescents with Disruptive Behavior Disorders (DBD), including Oppositional Defiant Disorder and Conduct Disorder, present unique challenges for their families. Though, most empirically supported treatments for DBD are family-based, the emphasis is typically on the behavior of the child rather than on the life challenges and resultant distress experienced by the family members. Fifteen families of adolescents with DBD were recruited from a large publicly funded community mental health center. For this report, data from in-depth interviews with the adolescents' primary caregivers were analyzed by standard content analytic procedures to describe the challenges they experienced living with and caring for the adolescents. The primary caregivers reported that the challenges were overwhelming, demanding, and unrelenting. The two most salient challenges were (1) managing the adolescents' aggressive, defiant, and deceitful behaviors and (2) interacting frequently with a number of child serving agencies. A number of clinical implications are drawn from these findings.

*Keywords:* Challenges, primary caregivers, adolescents, disruptive behaviour disorders,

### **The Challenges for Primary Caregivers of Adolescents with Disruptive Behavior Disorders**

Disruptive behavior disorders (DBD) are prevalent and serious mental disorders first diagnosed in childhood (Handwerk, Field, Dahl, & Malmberg, 2012). DBD include Oppositional Defiant Disorder (ODD), which is characterized by hostile, noncompliant, and defiant behaviors, and the more serious Conduct Disorder (CD), which is characterized by persistent violations of social norms and antisocial behaviors (Brown, 2008). Community surveys in the United States reveal that the median 12-month prevalence rates for ODD range between 2.8% and 5.5% and for CD range between 2.0% and 3.32% (Merikangas, Nakamura, & Kessler, 2009). CD and ODD are more prevalent in boys than in girls (American Psychiatric Association [APA], 2013; Merikangas et al., 2009). DBD often occur with Attention Deficit Hyperactivity Disorder (ADHD) and are frequently accompanied by mood and anxiety disorders (Merikangas et al., 2009). DBD account for almost half of all referrals for outpatient services and the majority of psychiatric hospitalizations for children in the United States (Handwerk et al., 2012).

Research indicates that parents and guardians of children with mental health problems (referred to as primary caregivers) often report high levels of negative affect, poor psychological well-being, and various somatic symptoms (Ha, Hong, Seltzer, & Greenberg, 2008; Nelson, 2002; Oruche, Gerkenmeyer, Stephan, Wheeler, & Hanna, 2012; U.S. Public Health Service, 2000). They are often challenged by financial burdens related to their child's mental health care, the stress of managing their child's problematic behaviors, limitations in life activities ( Ha et al., 2008; Oruche et al., 2012), the emotional burden of dealing with the stigma associated with mental illness (Higgins, Bailey, & Pearce, 2005; Oeseburg, Jansen, Groothoff, Dijkstra, & Reijneveld, 2010), and worry about the child's future care (Ha et al., 2008; Oruche et al., 2012).

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The distress associated with these challenges may in turn result in ineffective parenting, lack of warmth and nurturance toward the child, negative views of one's role as a parent, and perceptions of interactions with the child as alienating or frustrating (Costa, Weems, Pellerin, & Dalton, 2006).

Primary caregivers of children with a DBD may be at particular risk for distress because their children's behaviors are extremely difficult to manage and can considerably disrupt family functioning (Beernink, Swinkels, Rutger Jan, & Buitelaar, 2012; Cox, 2003; Rosenwald & Bronstein, 2008; Scharer, 2002; Schneiderman & Villagrana, 2010 ). This distress may be especially acute when parenting adolescents with DBD who are also experiencing the rapid physical, cognitive, emotional, and social changes of adolescence (APA, 2002). In addition, these youth are faced with the development tasks of establishing independence from their families, developing a coherent sense of identity, and engaging in normal risk behaviors (APA, 2002). Although research regarding parental distress in DBD has been conducted with younger children (Beernink et al., 2012; Latimer et al., 2012), little is known about the specific challenges of primary caregivers of adolescents with DBD.

Though most empirically supported treatments for DBD are family-based, the emphasis is typically on the behavior of the child rather than on the life challenges and resultant distress experienced by the caregivers. Multisystemic Therapy (MST), for example, has shown the most promise as an intervention for adolescents with severe DBD (Handwerk et al., 2012). MST is an intensive home- and community-based treatment approach that addresses environmental systems that affect youth behavior, including family, school, neighborhood, and friends. Therapists work with parents and caregivers to help them facilitate behavioral improvement in their children. MST has been shown to be effective in decreasing arrests and delinquency and improving school attendance and family functioning in youth (Curtis, Ronan, & Borduin, 2004),

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but there is little evidence that it relieves parental distress. Family-focused interventions are therefore needed that specifically address the burdens experienced by the caregivers of adolescents with DBD.

Understanding the distress of these primary caregivers of adolescents with DBD is essential not only for the caregivers' well-being, but for developing effective interventions for the adolescents. For example, dropout from treatment is a significant problem in the treatment of child problem behaviors (Friars & Mellor, 2007). These treatments frequently require parents to change their own behaviors to facilitate improvement in their children's behaviors (Fernandez, Butler, & Eyberg, 2011; Friars & Mellor, 2007). Not surprisingly, research has shown that parents who experience higher levels of parenting stress are more likely to drop out of treatment (Friars & Mellor, 2007). Finding approaches to directly address this distress is therefore essential not only for improving the mental health of the caregivers but for improving the effectiveness of treatments for their children (Fernandez et al., 2011).

Although research has shown that caregivers of adolescents with DBD experience significant challenges, an in-depth account of these challenges from the perspectives of the caregivers themselves is needed. Our research team is conducting an on-going study, "The Families of Adolescents with DBD Study," (referred to as the parent study) to prepare for the development of an intervention that addresses the needs of all family members of adolescents with DBD. The study we describe in this report (referred to as the current study) uses data from the parent study to provide a comprehensive description of challenges reported specifically by the primary caregivers, since their challenges differed substantively from those of other family members and were particularly dire. To provide the context of the current study, we will first describe the conceptual framework that guides our work and then briefly describe the parent

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study.

### **Conceptual Framework**

The parent study was guided by the Double ABCX Model of Family Stress and Adaptation (McCubbin & Patterson, 1983). The model proposes that families experience normal and non-normal life events or stressors ranging from the daily demands of parenting children to the serious illness of a family member. Stressors produce changes in family boundaries, goals, patterns of interactions, roles, and/or values, and they can lead to financial, emotional, and social hardships that affect all family members. Families attempt to manage these hardships with minimal disruption to the family system. If the demands of an individual family member exceed a family's capabilities, family stress emerges. Based on this model, we believe that caring for an adolescent with a DBD is a demand that may exceed the family's capacity to meet that demand, potentially resulting in altered family functioning, emotional stress, and the need for outside support.

### **Parent study: The Families of Adolescents with DBD**

The purpose of the parent study was to describe the functioning of families of adolescents with DBDs, the levels of emotional distress of the adult family members, and the experiences and perceived needs for services of all family members. The setting of the parent study was a large, publicly funded community mental health center (CMHC) in a Midwestern city in the United States. Families of adolescents currently receiving services from the Child and Adolescent Program were recruited. Following receipt of Institutional Review Board approval at the investigators' university and institutional approval at the CMHC, a clinical supervisor at the CMHC generated a case list of adolescents aged 13 to 18 who had a diagnosis of ODD and/or CD from the electronic medical records. The list was distributed to the licensed mental health providers in the Child and Adolescent Program, who were asked to invite eligible families from

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their caseloads to participate in the study. The clinic support staff also distributed study flyers to families during registration and asked them to speak with their provider about the study or to call the Principal Investigator (PI) to discuss participation. In addition, a letter with information about the study was mailed to eligible families, after which the research project coordinator called the parents or guardians to ascertain the families' interest in the study.

A brief telephone screening was conducted with each interested parent or guardian. Because the perspectives of multiple family members were needed to meet the aims of the parent study, at least three family members - a primary caregiver, another significant adult family member, and the adolescent with DBD - needed to agree to participate. Siblings over the age of seven (i.e., the age of assent) were eligible to participate.

A team of two to four mental health professionals met each of 15 families at a locale of their choosing. The team conducted semi-structured interviews with each family member individually. Eleven families were interviewed in their homes, three at the mental health clinic, and one at the investigators' university. The adults provided signed informed consent for their participation, and parents/guardians provided signed informed consent for children under 18. The interviewers obtained verbal assent from children aged 7 to 10 and written assent for children aged 11 years or above.

The participants were variously asked to describe their experiences of being, living with, or caring for an adolescent with a DBD and discuss what services they might need from mental health professionals. The interview for the adolescents with DBD focused on their needs for support from their family and mental health professionals. The questions were open-ended so that participants would have ample opportunity to discuss their experiences from their own perspectives. The interviews lasted from about 45 to 60 minutes. The interviews were digitally recorded, professionally transcribed, de-identified, and uploaded to an encrypted file server.

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### **Current Study: The Challenges of Primary Caregivers of Adolescents with DBD**

The purpose of the current study was to describe the challenges that primary caregivers experienced in living with and caring for the adolescents with DBD. The sample for the current study includes 15 participants who identified as primary caregivers. They included 12 biological mothers, one adoptive father, one grandmother, and one aunt. Two biological mothers were married and two were in serious relationships with male partners, the adoptive father was widowed, and all other primary caregivers were single or divorced. Nine caregivers were African American, five were Caucasian, and one categorized herself as “other.” The average age of the participants was 45 years, and the median household income bracket was \$10,000 to \$19,000. The participants were parenting 10 boys and 5 girls with DBD. The average age of the adolescents was 14.7 years.

Qualitative Descriptive methods as described by Sandelowski (2000) were used to analyze the narratives of the primary caregivers about the challenges they were facing. Qualitative description can be used to obtain a rich description of the everyday experiences of a group experiencing common challenges, with the goal of providing straight-forward answers to questions critical to intervention development (Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). Purposive sampling, moderately structured interviews, and low-inference content analysis, all of which were used in this study, are common in Qualitative Description (Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005).

Standard content analytic procedures were used to analyze participants’ responses to the following questions: (a) Please tell me how [adolescent’s name]’s behaviors affect you? and (b) Could you tell me about some specific experiences you have had that would help me better understand how [adolescent’s name]’s behaviors affect you in your day-to-day life? To ensure quality and rigor by obtaining multiple perspectives, five researchers participated in data



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analysis. This team included two doctorally prepared faculty members, one nursing doctoral student, one master's student in nursing, and one master's student in social work. The team first highlighted and extracted all text units (i.e., relevant words, phrases, or paragraphs) from the transcripts related to the participants' experiences of the challenges of living with or caring for an adolescent with DBD. Each text unit was coded (labeled) to reflect the content of the raw data. Categories were created by bringing similar codes together. All major analytic decisions were made by consensus in team meetings. A case-ordered meta-matrix was used to organize, code, and summarize the data (Miles & Huberman, 1994). An audit trail was kept to track all team decisions regarding the formation of the categories.

### **Results**

The participants provided rich information about the challenges of living with and caring for adolescents with DBD. Although multiple family members, including older siblings or parents living out of the home, had some responsibilities regarding the adolescents' care, the onus of the responsibility fell on the primary caregivers. These primary caregivers indicated that parenting adolescents with DBD could be demanding and overwhelming. Some were depressed or anxious, a few indicated they had received psychiatric care, and most described their primary emotional response to parenting as stress. One mother of a 14-year-old daughter diagnosed with ODD, when asked to describe her own experiences, stated, "Stress. I will say that out loud. I want you all to hear it again. It's stress. It is stress." The majority of families in the study had more than one child diagnosed with DBD or other serious psychiatric disorder, thereby compounding the challenges experienced by the primary caregivers. In addition, many families experienced additional hardships due to poverty or limited financial resources; neighborhood deterioration including violent crime; and/or family adversity, including parental absence or incarceration, substance abuse, serious chronic physical illnesses, and interpersonal violence.

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The primary caregivers emphasized that much of the strain of parenting stemmed from the need to provide constant supervision due to the adolescents' troublesome behaviors. Many reported that parenting was a "24/7" responsibility and they had little respite or time to themselves. Some indicated that the demands of raising adolescents with DBD, including constant involvement with child service (i.e., juvenile justice, school, mental health, and child welfare) systems, prevented them from working or engaging in any form of relaxation or recreation. Many caregivers lamented about being unsure how to handle the adolescents' behaviors. "Not knowing what to do" contributed to their sense of frustration and their fear that the "the worst" would happen. The caregivers were especially concerned that the adolescents might seriously injure the caregiver or other family members or commit a serious crime and therefore be lost to the family.

The primary caregivers identified two types of challenges as particularly salient in parenting adolescents with DBD. The first set of challenges was related to the need to manage the adolescents' disruptive behaviors, and the second was related to the need for frequent interactions with child service systems. Descriptions and examples of how the caregivers were challenged by the adolescents' behaviors and interactions with child service systems are provided below.

### **Being Challenged by the Adolescents' Disruptive Behaviors**

The major challenges identified by the primary caregivers were those related to the disruptive behaviors. The primary caregivers felt responsible for managing the adolescents' aggressive behaviors, dealing with their defiant behaviors, and remaining vigilant due to their deceitful behaviors.

**Managing aggressive behaviors.** A major challenge for the primary caregivers in regard to the adolescents' behaviors was the need to manage the adolescents' aggression. The

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participants described how the adolescents would fight constantly with their siblings, have physical altercations with adults, and destroy property. The frequent “knock down drag out fights” with siblings were most troubling to caregivers. One mother described her 14-year-old daughter’s fights with an older sibling: “[They] used to fight all the time. I mean, literally throw blows, physically, and tear the house up, fighting.” The adolescents’ aggressiveness towards siblings could be particularly violent and mean-spirited. Another mother of a 14-year old son diagnosed with ODD described the following incident:

I kept hearing a mumbling noise in my sleep, and I woke up and went in there, and he was on top of his brother with a pillow over his face....He just seemed like another child. He was just angry, upset. I had to wrestle with him, fight with him, snatch the pillow from him, ask him what his problem was, shake him up a little bit, and he just, I don’t know, it’s like something had gotten into him.

The adolescents were also aggressive toward adults. The primary caregivers described being pushed, slapped, and choked by the adolescents. One adolescent hit a caregiver “in the mouth” and another threw a phone book at his caregiver. A number of caregivers described how the adolescents brandished objects or weapons during these altercations. The adolescents were also physically and verbally aggressive toward teachers and caseworkers. Aggressive incidents against adults were often triggered by an adult request of the adolescents and their refusal to comply. Destruction of property was also common. The adolescents “punched holes” in walls and doors, destroyed games and furniture, threw household objects out of windows, set fires, and broke windows in cars.

The primary caregivers were especially challenged by these behaviors because they felt responsible for controlling the behaviors, preventing escalation, and averting serious consequences, such as the injury of another person. Attempts to deter fighting among siblings

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were particularly distressful because these fights were constant. To prevent violence against people outside the family, the caregivers often kept the adolescents in the home, resulting in more altercations with siblings and more stress for the caregivers. Some caregivers lamented that they lacked the resources and time to engage the adolescents in “one-on-one” activities and in other positive activities outside the home, and they believed that this contributed to the aggression at home. The caregivers often needed another adult(s) to contain the adolescents’ violent outbursts and, in many instances, had to call the police for help. A few caregivers described being “so fed up” with the aggressive behaviors that they had responded with physical violence themselves. Some caregivers spoke of putting the adolescents “in a hold” or grabbing, slapping, or hitting them. As the adolescents got older and bigger, the caregivers became concerned for their own safety. One grandmother of a 14-year-old boy who was diagnosed with ADHD and ODD and who was obese stated:

I’m afraid. I mean he’s getting bigger all the time and I’m scared of what he’s going to do next. If he can pick up a brick and throw it through my window, who’s to say he’s not going to pick up something and hit me with it and kill me, or hurt his little brother bad?

**Dealing with defiant behaviors.** Another aspect of the challenge of dealing with the disruptive behaviors was the need to deal with the adolescents’ defiance. The adolescents would frequently “talk back” to the primary caregivers and other adults, act willfully, refuse to comply with requests by adults, ignore “house rules,” and refuse to do chores. One mother of an 18-year old daughter diagnosed with ODD said:

She frustrates me more than anything. I am not angry with her. It is just frustration because it is her just doing whatever she wants to do. That is why she has that nonchalant attitude of I can just do whatever. And I don’t like that.

Dealing with defiance caused great consternation for the primary caregivers. Because

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the behaviors were persistent and the participants were unsure how to respond to the behaviors effectively, they felt exasperated and drained. Several indicated that they had “lashed out” at the adolescents out of frustration. One caregiver of her 17-year-old nephew who was diagnosed with ODD described her response to his defiant behaviors and those of his siblings:

It's harder with these kids and their mouth and being so disrespectful, you know what I'm saying. I have to go back and tell them if you'll just do what I ask I think a lot of times a lot of things wouldn't get out of proportion. But you won't do it. Then I have to ask the first time, the second, the third, and the same question. Come back, still ain't done. Then there I go. ... I'm escalating and I try not to go there and I try to do it the way the counselors say do it and I can find myself still falling back because they don't want to do it. Clean up your room. They don't do much. Come back, ain't clean. Didn't I ask you to clean up your room? Well, I did it. It's not clean. Then by the time that third time, that's it. Then I'm going to say some things I probably shouldn't have said.

**Being vigilant due to deceitful behaviors.** A third aspect of the challenge related to disruptive behaviors for the adult caregivers was the need to remain vigilant due to the adolescents' deceitful behaviors. The adolescents would often steal, lie, “sneak off,” and manipulate others. Lying and stealing were particularly common and troubling to the caregivers. One mother of a 14--year-old son diagnosed with ODD stated, “His favorite lie is ‘I stayed late after school or the bus ran late,’ or it's just always an excuse or a lie where he stays out late.” Incidents of theft included pocketing cash from a caregiver's purse, stealing money from teachers at school, and pilfering food while the family was sleeping. One 15- year-old boy diagnosed with ODD regularly stole his brother's car, leading in one instance to a high-speed police chase. Some adolescents were described as manipulative because they presented themselves in a positive light to get what they wanted from others, whereas other adolescents

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were described as “sneaky” because they would “run off” or hide to avoid consequences to their misdeeds.

Because the caregivers could not trust the adolescents, the adults were always “on guard.” This vigilance included not leaving the adolescent alone, keeping one’s purse nearby at all times, locking up valuables, waiting anxiously for adolescents to return after they had “snuck off,” and always being wary of the adolescent’s lies. The need to remain constantly aware of the adolescents’ behaviors was draining on the adults. One grandmother of a 14-year-old boy diagnosed with ODD described the strain of never sleeping in her bed because she felt she needed to prevent her grandson from stealing food:

I sleep here in this chair so I can watch the kitchen... Every night.... I can’t remember when I didn’t sleep in the chair. I don’t trust him. If he wakes up in the middle of the night, how am I supposed to know what he’s doing?... He gets up in the middle of the night. Usually, he goes in there and steals food... Before he went to the hospital, he got up and came in there and stole food: cookies, candy, whatever he can find. And sometimes I’m sleeping so hard because I’m so tired that I don’t hear him... Pop tarts, that’s a big one. He’ll take it back in his room and eat. He was on Abilify, which is one I guess that makes him hungry all the time.

### **Being Challenged by Interactions with Child Service Systems**

The participants spoke often about their second large category of challenges, the frequent and taxing encounters they had with child service systems, including the criminal justice system, the school system, mental health agencies, and child welfare agencies. Although some participants acknowledged that these agencies were helpful, interactions with the agencies were often stressful.

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**Interacting with the criminal justice system.** These primary caregivers were challenged by their interactions with the criminal justice system. They often had to call the police during physical altercations or to report the adolescents had run away or had stolen from the family or others. Several reported that, although it was difficult to have to call the police on one's own children, it was necessary because the adolescents' physical aggression often put the family in danger.

The main challenge that interacting with the criminal justice system presented for the primary caregivers was the stigma of having the police being called to one's home and, in some instances, the constant presence of the police in the families' lives. One caregiver of a 14-year-old boy diagnosed with ODD stated, "It's embarrassing. Every police officer in this neighborhood knows [my grandson] because we call them that often."

**Interacting with the school system.** The primary caregivers were also challenged by their interactions with the school system. In school, the adolescents often refused to do assigned work, disrupted the classroom, and engaged in verbal and physical altercations with other students and teachers. As a result, many of the participants were frequently called to the school to attend meetings, pick up their adolescents, or "calm them down" Several participants reported getting multiple e-mails and text messages from the school each day. Some of the adolescents were expelled and the caregivers then needed to monitor the adolescents at home. One mother of a 15-year-old boy diagnosed with ODD explained,

[He] get in school and get put out [for] not minding the teachers and not doing what they asked him to do and not finishing his work. The school calling you to come and get him. Either they don't put him out or he got suspended. It got to the point where it [the calls] was an everyday thing. It wasn't just once a month or once a week. It was every day. Every day the school called about [him] doing something.

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The main challenge that interacting with schools presented for the primary caregivers was the constant disruption to their daily lives. Because they were constantly “on call” to respond to problems at school, many found it difficult to work outside of the home or have time to themselves. One caregiver of 14-year-old boy diagnosed with ODD remarked,

If I had to go out and work, I couldn't, because I have to be available for these guys.

[My grandson] has his problems at school. His teacher calls me. He's out of control, doing this, that, or another thing, throwing a desk, throwing his books, ripping up his school work. I have to talk to him on the phone for just a few minutes and get him redirected, and then he's fine.

**Interacting with the mental health system.** The primary caregivers were also challenged by their interactions with the mental health agencies. The caregivers had to arrange multiple appointments, often with a cadre of different providers in multiple agencies. Several of the adolescents also had had multiple in-patient hospitalizations. As with the involvement with the schools, the frequent interactions with mental health providers demanded much of the caregivers' time and attention.

Several caregivers expressed concern that the mental health treatment the adolescents were receiving was ineffective. One caregiver of a 13-year-old boy diagnosed with ODD stated, “We have been seeing a therapist ever since he was like...3 or 4... I haven't found anything that is working now.” Several participants indicated that they or their adolescents did not have a good relationship with the providers. One caregiver of a 15-year-old boy diagnosed with ODD and CD said, “This was his fourth therapist... He did not get along with one therapist. He did not like them. It was just clash, clash, clash.”

The adolescents' medications were also a major source of concern for the primary caregivers. They often lamented that the medications did not control the adolescents' behaviors



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and came with troublesome side effects such as sedation and weight gain. The adolescents often resisted taking the medications, creating another problem for the caregivers to “deal with.”

Several caregivers were distressed by the lack of information and education they had received about the adolescents’ condition from mental health professionals. Many wished they had more of a “voice” in the adolescents’ treatment and that providers solicited more of their input. A caregiver of a 14-year-old diagnosed with ODD who had had a nine-day hospital stay explained,

I had one family counseling meeting over the phone. They didn’t even request I be there, which I don’t think was very good. I think I should have been face to face. ... These people [hospital staff] had him for nine days. And I told them I wasn’t sold on the medicine that they were going to put him on because I looked it up. It is a very scary medicine. I told them I am not sure about this. They said, ”let’s try it and see if it works.” And [the adolescent] had been on it one other time, and it made him more angry.

**Interacting with the child welfare system.** The primary caregivers were also challenged by their interactions with child welfare agencies, which were often involved with the families because of the adolescents’ violent behaviors or because of the caregivers’ physical violence towards the adolescents. A few caregivers used physical force to contain the adolescents’ violence and were “reported” for child abuse. One father of a 15-year-old boy diagnosed with ODD explained, “Well, we did have a big fight Saturday night. There again, [the fighting] started with [the adolescent and his sibling]. CPS [Child Protective Services] was involved with this now. They have got open cases with the boys.” Some of the caregivers resented the intrusion of child welfare agencies in their homes and were distressed that these professionals did not understand how difficult it was to manage the adolescents’ violent behaviors. One caregiver of a 15-year-old boy diagnosed with ODD explained,

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Matter of fact, the other day when [social worker] from CPS was there talking to me, meeting me and the kids, it was 5 o'clock and I was going to give [his son] his evening medicines, and he started going off, started getting all stupid. "I don't want to live with this douche bag." I said to him, "Do you want to be removed from this household?"

"No, but I don't want to live with you." I am like, "Okay." And this guy is watching the whole thing, what I go through.

Although some of the challenges that arose from interactions with the child service systems were unique to the type of agency, involvement with any of the agencies regularly demanded the time and attention of the participants, often intruded into their daily lives, and, in several instances, prohibited them from working or engaging in leisure activities. Additionally, some participants believed that all the agencies "assumed the worst" about the adolescents, blamed the caregivers for the adolescents' behaviors, and were ineffective in helping the caregivers manage the adolescents' behaviors. The challenges were intensified if the caregivers needed to interact with more than one type of agency at the same time, which frequently occurred as the adolescents' disruptive behaviors escalated.

### **Discussion**

This research report focuses on the challenges experienced by primary caregivers of adolescents with DBD. Consistent with findings of research on caregivers of children with mental health disorders generally, the primary caregivers in this study described their challenges as overwhelming, demanding, and unrelenting, and they reported that they had little time to relax, engage in pleasurable activities, or be gainfully employed outside the home (Gerkenmeyer et al., 2013; Ha et al., 2008; Oeseburg et al., 2010; Oruche et al., 2012). Our findings also reinforce other studies finding that parents of adolescents whose behaviors defy social norms and threaten the safety of the family and others experience particularly acute distress (Cox,

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2003; Rosenwald & Bronstein, 2008; Schneiderman & Villagrana, 2010).

This study adds to the literature on caregiver burden in this population by providing an in-depth description of the challenges experienced by the caregivers from their own perspectives. The participant narratives allowed us to differentiate specific caregiver responses to three types of disruptive behaviors, thereby providing a more nuanced understanding of their challenges and providing clear targets for clinical interventions with caregivers. For example, when the adolescents engaged in aggressive behaviors, the caregivers were fearful and most concerned about preventing escalation and ensuring their own and other people's safety, whereas when the adolescents engaged in deceitful behaviors, the caregivers felt disrespected and frustrated, often causing them to lash out at the adolescents. Deviant behaviors resulted in a need for vigilance and constant monitoring, which was exhausting for the caregivers. Family practice nurses, armed with the knowledge that each type of behavior brings its own challenges, can engage caregivers in discussions about effective responses to specific types of disruptive behavior. In addition to discussing strategies that can be used for each type of behavior, interventions aimed at reducing caregiver burden should address in particular the fear associated with aggressive behaviors, the frustration associated with defiant behaviors, and the need for vigilance associated with the deviant behaviors.

The identification of challenges associated with each type of child service system and the overall level of distress provoked by interactions with multiple agencies also extends the literature on caregiver burden in this population and has implications for family nursing practice and policy initiatives. In addition to addressing the challenges associated with the adolescents' behaviors, nurses and other clinicians should inquire about distress stemming from the caregivers' dealings with child service systems. Family practice nurses and other clinicians should recognize and discuss with caregivers the burden placed on them by frequent summons

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from the schools, the frustrations they experience when their input is not sought by mental health providers, and the embarrassment and guilt that stem from criminal justice and child protection involvement. In addition, policy changes and service delivery modifications that consider the unique needs of caregivers, including their desire for more information about their child's disorder and treatment, are recommended. For example, given the number of child service systems typically involved with adolescents with DBD, it is crucial to have a care coordination plan that includes all systems involved with the family and gives caregivers an active role in planning their adolescent's care.

The findings should be understood in the context of several study limitations. The study sample was from one large, publicly funded CMHC in a large city in the Midwestern United States. Comments about interactions with child service systems may therefore be specific to this CMHC and other child service systems within this geographical area. In addition, the interviews were held on one occasion and might not have captured changes in how the caregivers perceived the challenges over time. Because an inclusion criterion was that the adolescent with DBD and a family member other than the primary caregiver needed to agree to participate, caregivers with particularly defiant adolescents, or those who were hospitalized or incarcerated, and caregivers with no other support persons may not have been eligible, thereby perhaps eliminating the caregivers with the most severe challenges. Future multi-site studies using longitudinal designs could further explicate the challenges experienced by caregivers of adolescents with DBD as the illness evolves throughout adolescence.

Consistent with the assumptions of the Double ABCX Model of Family Stress and Adaptation (McCubbin & Patterson, 1983), the caregivers in this study were confronted with exceptional challenges that taxed the resources they had available to them and resulted in significant stress. The two constructs of the model most evident in this sample were

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disturbances in family interaction patterns due to the adolescents' disruptive behavior and strains on family boundaries due to problematic interactions with the child service systems. The study clearly supports the need for a family-focused approach that addresses not only adolescents' disorder but aims to improve the quality of life of their caregivers as well.

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