BARRIERS TO TREATMENT COMPLETION IN LOW-INCOME FAMILIES OF YOUNG CHILDREN WITH BEHAVIOR PROBLEMS

by

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ABSTRACT BARRIERS TO TREATMENT COMPLETION IN LOW-INCOME FAMILIES OF YOUNG CHILDREN WITH BEHAVIOR PROBLEMS

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Marquette University, 2009

This study examined the barriers to treatment completion among twelve mothers with young children with significant behavior problems. The mothers had several characteristics that were previously associated in the literature with premature termination of treatment (e.g., lower socioeconomic status, single parent, minority race). The mothers and their children began mental health treatment but terminated before completion.

Qualitative interviews were conducted in the mothers' homes and were subsequently recorded and transcribed. The data were then analyzed utilizing the methodology of Consensual Qualitative Research (CQR; Hill, Knox, Thompson, Williams, Hess, & Ladany, 2005; Hill, Thompson, & Williams, 1997). The mothers were asked a sequence of questions about their reasons for beginning mental health services, their experiences in treatment, and their reasons for terminating services. In addition, the *Barriers to Treatment Participation Scale – Parent Version* (Kazdin, Holland, Crowley & Breton, 1997) was used to assess the number of barriers experienced.

During the qualitative interviews, the mothers reported that their children benefitted from treatment and that their child's challenging behaviors decreased and/or prosocial behaviors increased. Some of the unhelpful aspects of treatment included the treatment strategies not consistently working or their child not benefitting due to personal

factors (e.g., child having a cognitive delay). Most mothers reported that services ended due to external factors such as conflicts with other appointments or the mothers' own personal problems (e.g., mental health and medical concerns). Results from the *Barriers to Treatment Participation Scale – Parent Version* (Kazdin, Holland, Crowley & Breton, 1997) indicated that the mothers experienced a moderate number of barriers (e.g., difficulty in scheduling appointments, treatment being somewhat different than expected) which were less frequent than those experienced by non-completers in previous research. Other studies have found that as the number of perceived barriers increased so did the likelihood that the family would terminate from treatment prematurely. Considering this study found that mothers reported a fewer number of barriers on the scale, it appears that specific, individual barriers (e.g., difficulty scheduling appointments and caregivers' problems) were more associated with premature termination from treatment. The study's limitations, clinical applications, and suggestions for future research are also discussed.

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CHAPTER1: INTRODUCTION

Infant mental health is an emerging area in the field of psychology due to the realization that very young children may have significant emotional and behavioral problems early in their development. While mild behavior problems such as tantrums and aggression are common in young children, 10-15% of preschoolers have more serious behavioral difficulties with approximately half of this population continuing to have problems into adolescence (Campbell, 1995; 1990; Feldman, Hancock, Rielly, Minnes, & Cairns, 2000). The prevalence of behavior disorders is three to four times more common in children with developmental delays than the typically developing population (Baker, Blacher, Crnic, & Edelbrock, 2002; Roberts, Mazzucchelli, Taylor, & Reid, 2003), and these challenging behaviors can occur as early as 18-24 months of age (Green, O'Reilly, Itchon, & Sigafoos, 2005). These problems include aggression, poor impulse control, hyperactivity, and oppositional behavior (Keenan & Wakschlag, 2000; Lumley, McNeil, Herschell, & Bahl, 2002), as well as significant temper tantrums and self-injury (Varley & Furukawa, 1990).

Fortunately, there are empirically-supported treatment programs available to successfully manage the emotional and behavioral disorders of young children with and without developmental delays (Eyberg et al., 2001; Fox & Holtz, in press; Kazdin, 1995; Tucker, Gross, Fogg, Delaney, & Lapporte, 1998; Webster-Stratton & Hammond, 1990). The majority of these treatment programs focus on improving parenting practices, in an effort to teach the parents how to strengthen their children's prosocial behaviors, while also using effective discipline strategies to reduce the challenging behaviors, within the

context of maintaining appropriate developmental expectations for their children (Fox & Nicholson, 2003).

While there are successful treatments available for the emotional and behavioral disorders of children, many children do not receive the maximum benefits from treatment because of premature termination (Kazdin & Wassell, 1998). Premature termination rates generally range from 40-60% (Kazdin, 1995), but can be as high as 85% (Novick, Benson & Rembar, 1981). Several factors have been associated with attrition from mental health treatment including family characteristics (e.g., socioeconomic disadvantage, minority race, higher levels of familial stress), and barriers to treatment participation (e.g., conflict with other family members about receiving treatment, perceived relevance of treatment, poor therapeutic relationship).

Statement of the Problem

Behavior problems are a significant concern among children with developmental delays (Baker et al., 2002; Roberts et al., 2003). However with the high rates of premature termination (Kazdin, 1995; Novick et al., 1981), often these children do not benefit from treatment (Kazdin & Wassell, 1998). The professional literature has begun to identify factors associated with premature termination from mental health treatment. However, the majority of these studies do not focus on families living in poverty with children who have developmental delays and comorbid mental health disorders. Furthermore, the existing literature on premature termination has focused primarily on demographic and participant variables (e.g., younger mothers, minority race, and larger family size) that are unlikely to be subject to change. Further research is needed to understand if there are other factors that affect progress and/or premature termination

from treatment and whether those factors can be changed. Research has begun to explore various barriers to treatment completion. However, the research regarding these areas has been limited and doesn't address the reasons people disengage from treatment or fail to make progress in a way that would lend itself to modifying our approach with these families to maintain their engagement in treatment. Thus, the available research has identified participant factors and barriers to treatment completion and ways that they affect premature termination from treatment, but has not focused on families of young children living in poverty with comorbid developmental delays and mental health disorders. The available research has not addressed ways to modify the treatment regimen to increase this populations' engagement in treatment.

Purpose of the Study

This investigation sought to examine each caregiver's unique reasons, in an openended manner, for disengaging or failing to progress in their child's mental health treatment. The goal was to collect information that ultimately provided direction for improving family participation in mental health treatment programs for their very young children.

Consensual Qualitative Research methodology (CQR; Hill, Knox, Thompson, Williams, Hess, & Ladany, 2005; Hill, Thompson, & Williams, 1997) was utilized to examine the barriers caregivers experience when receiving mental health services for their child's challenging behaviors. Participants included 12 caregivers who attended an intake interview and a minimum of three treatment sessions through a community mental health clinic, but who failed to make progress in treatment or prematurely terminated. Participants were recruited using criterion sampling techniques (i.e., participants were

selected based on predetermined criteria), and were interviewed face-to-face for approximately $1 - 1\frac{1}{2}$ hours. The interviews were digitally recorded and transcribed. Subsequently, the information was coded into domains and core ideas, and then analyzed across cases to attain a clear understanding of the participants' experiences and how they were similar and different.

Research Questions

This study focused on families whose characteristics have been found to be associated with premature termination (e.g., low-income, single mothers), to understand the perceptions of their experience with a community based mental health clinic and what contributed to their lack of progress in treatment and/or their premature termination. The specific questions the study addressed were:

Research Question 1: What influenced the families' failure to progress in treatment or terminate prematurely?

Research Question 2: What aspects of the treatment process did families find useful and what aspects of the process were not useful?

Significance of Study

The main purpose of this study was to determine what factors affected treatment progress and treatment completion among families receiving services for their child's emotional and behavioral problems. By interviewing caregivers who experienced difficulties with participation in treatment, the researchers obtained a firsthand account of what barriers these families experienced. There were several reasons for focusing on families who lived in poverty and who had children with developmental delays and behavior disorders. First, there has been an increased recognition of mental health

disorders in these children and more research is needed to advocate for providing services for this population. Secondly, research has supported the effectiveness of various treatment programs; however, research indicates that these benefits are not attained when families do not participate. Furthermore, the purpose of the study was to identify specific factors that clinicians can consider when working with families living in poverty and receiving services for their children so that they remain in treatment.

Identifying the factors that contributed to premature termination and the failure to progress in a mental health treatment program could provide information that can later be incorporated into treatment-oriented studies to determine ways to keep families involved in mental health treatment programs. By keeping families engaged in treatment, the effective intervention programs can minimize the chance of the children's emotional and behavioral disorders escalating into more serious problems as they mature.

CHAPTER 2: REVIEW OF THE LITERATURE

Studies have consistently demonstrated the effectiveness of treatment for children with behavior problems (Eyberg et al., 2001; Kazdin, 1995; Tucker et al., 1998; Webster-Stratton & Hammond, 1990). Behavioral parent training approaches (Webster-Stratton & Hammond, 1990) focusing on improving play skills and reinforcement of prosocial behaviors, followed by instruction on non-punitive discipline techniques and problemsolving approaches, have been found to be effective in reducing behavior problems in children with conduct problems. Kazdin (1995) reported support for parent management training (PMT), which includes adaptive parenting practices to promote the child's prosocial behaviors and child-parent interaction patterns, while also altering the child's challenging behaviors, and allowing children to learn cognitive problem-solving skills. A similar approach, parent-child interaction therapy (PCIT; Eyberg et al., 2001), that teaches parents how to reinforce prosocial behaviors and manage challenging behaviors, has been shown effective in the treatment of disruptive behavior disorders including oppositional defiant disorder and attention deficit hyperactivity disorder.

However, for children and families to realize the potential benefits of these treatment programs, they need to complete the full treatment regimen (Kazdin & Wassell, 1998). Kazdin, Mazurick, and Siegel (1994) found that children referred for the treatment of behavior disorders who completed treatment showed greater amounts of change among several outcome variables than children who did not complete treatment. Unfortunately, several studies have shown that many who start psychological treatment do not finish the complete regimen. In a meta-analysis of 125 studies on therapy dropout, Wierzbicki and Pekarik (1993) found that 46.8% of adult and child clients dropped out of

therapy or terminated treatment prematurely. Other studies focusing on child psychotherapy exclusively have found that dropout rates tend to be even higher, 40-85% (Kazdin, 1995; Novick et al., 1981; Pekarik & Stephenson, 1988). To understand the reasons clients terminate psychotherapy prematurely, research has started to address several characteristics related to the family and barriers to treatment.

Family Characteristics

Current research shows that family characteristics are related to whether a client completes treatment or prematurely terminates from treatment. There were, however, earlier studies that did not find consistent relationships between family characteristics and treatment completion. Cohen and Richardson (1970) assessed whether there were differences between cases that dropped out of a child psychiatric clinic and those who did not. Participants included 350 children, 250 children who dropped out of treatment and 100 control cases. The children who dropped out of treatment where divided into two groups; those who terminated during the intake or diagnostic phase (pre-therapy) and those who terminated during the treatment phase (therapy). The researchers did not find any significant differences between the groups regarding length of distance to travel to the clinic, race, or socioeconomic status. Gould, Shaffer, and Kaplan (1985) reviewed the characteristics of children who dropped out of treatment compared to those who attended treatment. Participants included 345 children (67% male and 33% female) ranging in age from 4-16 years. Of the participants, 16.2% were White, 30.7% were Black, 50.4% were Hispanic, and 2.7% were "other." Participants were considered "dropouts" if they failed to attend the next scheduled appointment after the initial screening. The researchers found no significant differences in demographics in terms of ethnicity, socioeconomic

status, or marital status of the mother, nor did the two groups differ in regards to severity of externalizing and internalizing behaviors of the children. The researchers did, however, find significant differences between the groups regarding caregiver symptomatology and referral source. Families who dropped out of treatment had caregivers with greater levels of psychopathology and were more often referred to treatment by other sources (e.g., school personnel). The results also indicated an interaction between these factors. The school referrals whose families did not attend treatment included parents with more symptomatology than the families referred by the school who did not drop out of treatment.

Ewalt, Cohen, and Harmatz (1972) conducted a study to assess which factors contributed to the continuance of treatment among families referred to a child guidance clinic. Participants included 253 families who were interviewed using a standard set of questions after the initial evaluation at the clinic. The participants were separated into two groups: those who pursued treatment after the initial evaluation and those who decided not to pursue treatment. The researchers found no significant differences between the two groups in regards to social class, age of parents, beliefs about causation of the problem, or family size.

In a study by Weisz, Weiss, and Langmeyer (1985), they assessed whether children who dropped out of treatment were different than those who remained in treatment. Participants included 469 children ranging in age from 6-17 years. Participants who dropped out of treatment (treatment was recommended and offered, but neither the child nor family members attended any sessions after intake) included 91 boys and 75 girls; 75.3% were White, 24% were Black, and 0.7% was Native American. Participants

who continued treatment (child or family member continued treatment for five or more sessions) included 86 boys and 52 girls; 79% were White, 20% were Black, and 1% was Native American. Across the two groups, children attended treatment at nine different clinics and were assigned to a total of 61 therapists. The researchers assessed whether there were differences between the two groups based on demographic characteristics (i.e., age, socioeconomic status, and number of miles to travel to the clinic), child psychological problems (i.e., scores on the Child Behavior Checklist and Children's Depression Inventory), therapist age and sex, and parent perceptions of the clinic and child (i.e., improvement in child's symptoms, whether change was due to services at the clinic, and whether they would seek services from the clinic again). The results indicated no reliable group differences between those children who completed treatment and those who dropped out.

In one of the earlier studies that focused on factors of premature termination, Pekarik and Stephenson (1988) compared adults (18 to 68 years old) and children (3 to 17 years old) seen at an outpatient mental health clinic. The results indicated that 65% of the child clients and 47% of the adult clients dropped out of treatment. Referral source, type of treatment, and therapist experience were significantly different between adults who continued treatment and those who prematurely dropped out. For example, those adults referred by outside sources instead of making a self-referral were more likely to terminate prematurely. The same was true for adults in long-term psychoanalytic treatment receiving services from therapists with fewer years experience in the field. These factors were not significant for children receiving treatment. Instead, children from higher socioeconomic classes, as determined by Hollingshead classifications, were more

likely to complete treatment than drop out prematurely. The researchers also found that preschoolers from larger families (M = 3.73 people in family, SD = 1.62) were more likely to drop out of treatment than children from smaller families (M = 2.62 people in family, SD = .65).

Other studies have shown that termination rates differed by age levels and were influenced by other family characteristics. In a retrospective study, Novick et al. (1981) assessed termination rates of 720 children between the ages of infancy and 18 years old seen at an outpatient facility. The researchers distinguished between those clients who terminated treatment against the recommendation of the therapist (non-agreed termination) and those that terminated with the recommendation or support of the therapist (agreed termination). Results indicated that among 720 cases, 615 ended in nonagreed terminations, indicating an 85.4% non-agreed termination rate. The authors concluded that younger children (6-8 years) had the highest percentage of agreed termination, while non-agreed termination was highest for adolescent clients (15-18 years). African American clients were less likely to complete treatment than White clients or clients who were identified as "other" races. Children whose parents had higher status occupations and higher levels of education were more likely to have agreed termination. However there was not a simple linear relationship between education and dropping out of treatment. For mothers, it was not the level of education attained, but whether or not she completed her education. Regardless of the level of schooling, there was a positive correlation between mothers who dropped out of school and later dropped out of treatment. Furthermore, the families who lived closer to the clinic (within 35 miles) had more agreed terminations than those living farther distances. Post-hoc

analyses revealed that families who had both higher socioeconomic status and lived closer to the clinic had higher rates of agreed termination.

A study conducted by McMahon, Forehand, Griest, and Wells (1981) assessed pretreatment factors that distinguished which parent-child dyads dropped out of treatment (dropped out prior to attending any treatment session, or did not attend more than five treatment sessions) and which dyads completed treatment. Participants included 48 mother-child dyads, where the children were referred for treatment of noncompliant behaviors. Of the 48 families receiving parent behavior training, 8 families dropped out before the completion of treatment. Results indicated that those dyads that dropped out were lower in socioeconomic status and had caregivers who were more depressed than those who remained in treatment.

Alan Kazdin and his colleagues conducted several studies assessing family factors related to completion of child therapy. In these studies, children were referred to an outpatient clinic for oppositional, aggressive, or antisocial behaviors. Families whose children were six years old or younger received parent management training (PMT), which included adaptive parenting practices to promote the child's prosocial behaviors and child-parent interaction patterns to alter the child's challenging behaviors at home and school. Families whose children were older than six years received PMT, while the child attended individual sessions on cognitive problem-solving skills training (PSST). This treatment program has been shown to be effective in reducing children's behavior problems, increasing social competence, and increasing adaptive functioning (Kazdin, 1995).

In one of the first studies, Kazdin (1990) examined the differences between families and children who completed treatment (completion of 75% or more of the sessions) and those who terminated prematurely (dropping out after completing fewer than 25% of the sessions). Participants included 15 girls and 66 boys ranging in age from 7-13 years (M = 10.3); 65.4% of the children were White and 34.6% were African American. Principle psychiatric disorders for the children included conduct disorder (51.9%) and oppositional defiant disorder (39.0%). The primary caretakers were biological mothers (86.7%) whose ages ranged from 25 to 59 years (M = 34.7) and 49.4% of families were headed by single-parents. Families were from the following socioeconomic classes based on Hollingshead and Redlich's (1958) classification, with Class V indicating lowest socioeconomic level and Class I indicating highest socioeconomic level: Classes V (26.0%), IV (39.7%), III (23.3%), II (11.0%) and I (0%). Of the families, 26.7% received social assistance. Parents and children also completed a number of self-report instruments (i.e., the Parenting Stress Index, the Beck Depression Inventory, the Risk Factor Interview, etc.). Kazdin discovered that families who terminated prematurely had higher levels of child dysfunction, higher parental stress, and were more often socioeconomically disadvantaged. Contrary to predictions, parents who terminated prematurely did not show greater frequencies of depression. Children who terminated prematurely evidenced a greater number of symptoms of conduct disorder, more delinquent behavior, and lower educational status. According to the scores on the Parenting Stress Index, mothers' from families who terminated prematurely were more likely to rate their children as less able to adapt to changes in the environment, less acceptable and attractive in relation to physical, intellectual and emotional characteristics,

and more unhappy or depressed. Families who terminated prematurely also showed greater amounts of stress from parent-child interactions and stressful life events.

Kazdin, Mazurick, and Bass (1993) examined the differences between children and families who completed treatment (completion of the full treatment regimen, 7-8 months) and those who terminated prematurely (completion of 6 or fewer treatment sessions). The study included 160 families whose children (36 girls, 124 boys) ranged in age from 5 to 13 years old (M = 10.1 years). The majority of children were Caucasian (60.6%). Other participants were African American (36.9%) and Hispanic (2.5%). The majority of children (72.4%) met the criteria for more than one psychiatric disorder (M =2.3). Biological mothers were identified as the primary caregiver in most families (89.5%). Families were from the following socioeconomic classes based on Hollingshead and Redlich's (1958) classification from lower to higher: Classes V (28.3%), IV (35.2%), III (27.6%), II (6.9%) and I (2.1%). Of the families, 26.4% received social assistance. The researchers discovered that younger mothers and single-parents were more likely to terminate treatment prematurely. Also, families from minority groups (African American or Hispanic) were slightly more likely to terminate prematurely (53.2%) than Caucasian families (46.8%). Families that terminated treatment were more socioeconomically disadvantaged, had more parental stress, included mothers with a history of antisocial behavior, and families that utilized adverse childrearing practices. Children from families who terminated prematurely had higher levels of antisocial behavior, a greater number of psychiatric diagnoses, greater academic/educational dysfunction, and more frequent associations with antisocial peers. The researchers also assessed the affect of numerous risk factors (i.e., number of diagnoses, income level, public assistance, life stressors, etc.)

on termination. Families who terminated treatment prematurely had more risk factors (M = 8.71) than those who completed treatment (M = 5.03). Additionally, as the number of risk factors increased so did the proportion of cases that terminated treatment; 50% of families who terminated had 8 or more risk factors.

Using a similar battery of assessments to measure family characteristics and child functioning, Kazdin and his colleagues (1994) conducted a study with three groups of participants to access differences between families who completed treatment (completion of full treatment regimen, 7-8 months) and those that terminated prematurely (terminated after 10 sessions of treatment, but did not complete the regimen). Twenty-five families who completed treatment were matched on demographic characteristics (race, one or two parent household, socioeconomic class, mother's age, and child's level of deviance) with 25 families who dropped out of treatment prematurely. The group who dropped out of treatment was also compared to 25 families who completed treatment but who were not matched on demographic characteristics. Participants included 14 girls and 61 boys ranging in age from 4-13 years (M = 10.0); 64.0% of the children were White, 32.0% were African American, 4.0% were Hispanic American, and 3% were from other racial groups. The majority of children had one or more psychiatric diagnoses. The primary caretaker included biological mothers (94.7%); mothers ages ranged from 25 to 46 years (M = 34.2) and 37.3% of families were headed by single-parents. Families were from the following socioeconomic classes based on Hollingshead and Redlich's (1958) classification: Classes V (26.8%), IV (26.8%), III (28.2%), II (12.7%) and I (5.6%). Of the families, 23.9% received social assistance. The researchers analyzed whether treatment completers and dropouts varied on demographic characteristics and child