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Caregiver Participation in Community-based Mental Health Services for Children Receiving Outpatient Care

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Abstract

Caregiver participation in child mental health treatment has been associated with better youth outcomes, but little is known about the amount and type of caregiver participation in usual care services for children. This study examined 1255 caregivers' reports of their participation in the outpatient services their children received through a large, public mental health system in the Southwest. The majority of the caregivers reported that they participated in their child's services. Extent of participation was associated with several factors including children's physical health, and caregivers' primary language, satisfaction with the services, feelings of support, and perceptions of barriers to participation. The findings offer some encouragement for the contextual fit for many evidence-based interventions that focus on caregiver involvement, and highlight which caregivers may need greater encouragement to participate in their child's care.

Keywords

caregiver participation; child mental health; community-based services; engagement

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Caregivers' participation in their children's mental health treatment is an important indicator of quality of care.¹ Meta-analyses have demonstrated that children whose caregivers participate in treatment fare better than children whose caregivers do not participate.^{2, 3} However, little is known about the ways parents participate in treatment, in particular in publicly-funded usual care (i.e., community-based, outside the context of a research trial).⁴

In general, caregiver participatory behaviors such as contact with the therapist, participating in treatment planning, and homework completion have been associated with improved child outcomes.⁵⁻⁸ Much of the existing research on caregiver participation has focused on prevention trials of manualized parenting programs,⁹⁻¹³ and those studies that have focused on treatment primarily examined the implementation of manualized interventions.^{5, 7} Yet, manualized treatment studies often take place within randomized controlled trials whose participants and service context (e.g., referral mechanisms, funding, therapist characteristics) may not be generalizable to public sector usual care.¹⁴

More specifically, a recent comparison of families with children who received treatment for disruptive behavior disorders in usual care versus families of children who received treatment in research trials of manualized interventions found several differences between the two groups. Caregivers of children who received usual care had more symptoms of depression, and were more likely to be single with lower incomes and levels of education than caregivers of children who received treatment in research trials.¹⁴ These findings suggest that caregivers of children in usual care may be harder to engage because caregivers who have their own mental health problems and few sources of support may be less able to participate in their child's treatment. Caregivers with these challenges may also participate in different ways (e.g., phone calls with the therapist instead of face-to-face meetings).

Furthermore, the structure to facilitate or encourage caregiver participation in the implementation of manualized interventions may differ from that in usual care. For example, many manualized interventions for children have components that explicitly require caregiver participation.^{15, 16} In contrast, treatment provided to children in usual care is eclectic and the potential avenues for caregiver participation may depend largely on the individual therapist.¹⁷ Without the instruction or support provided in the context of a manualized intervention implementation that includes a focus on caregiver participation, therapists in usual care settings may be less likely to engage parents, or they may encourage them to participate in ways that are different than the types of participation specified in manualized treatments.

To date, limited research has examined the ways caregivers participate in usual care. However, a few studies have focused on caregiver attendance at treatment sessions as one indicator of participation. Two studies from Norway examining outpatient adolescent services found 42-44% of sessions included a caregiver.^{18, 19} In addition, an analysis of outpatient therapy provided to 191 children ages 4-13 who received treatment for disruptive behavior disorders in San Diego's public mental health system found that some degree of caregiver attendance was the norm rather than the exception – caregivers attended at least part of 70% of coded sessions.²⁰ A follow-up analysis showed that, on average, therapists spent 44% of each session directing their treatment strategies to caregivers.⁴

Additionally, a study by Israel and colleagues examined predictors of caregiver attendance at treatment sessions for 20,856 children and adolescents receiving treatment through Norway's mental health service system. Caregivers of boys, younger children, and children with early-onset and/or externalizing disorders were more likely to attend sessions than caregivers of children with other demographic and diagnostic characteristics. Caregivers were also more likely to attend when children lived with both caregivers.¹⁸

While it is beneficial to understand caregivers' physical presence at sessions in usual care, it is also important to understand the variety of ways caregivers may participate in their child's mental health care in order to help inform efforts to enhance participation in the usual care context. Thus, the current study examines multiple ways caregivers may participate in care, beyond attending a session. Furthermore, most studies of caregiver engagement in children's mental health treatment have used therapist observations, independent observer coding, completion of homework assignments, and/or caregivers' general ratings of how much they participated to measure engagement. To date, limited research has examined specific caregiver self-reported behaviors that reflect different ways of participating in their child's care.

The current study is the result of a partnership between researchers and county administrators that was formed in order to evaluate the county's public mental health services system for children and adolescents, and to identify areas for quality improvement. The data collected through this partnership offer a unique opportunity to address the gaps in knowledge of how caregivers participate in usual care service systems. To address these gaps, this study examines the following questions:

1. What ways do caregivers report participating in their child's treatment?
2. Do demographics, satisfaction with services, and barriers that limit involvement in services predict the type and amount of caregiver participation in their child's treatment?

Caregivers of children who received outpatient usual care in the county's child mental health service system were surveyed about their involvement in, and satisfaction with the services for their child / family. Given the dearth of research characterizing caregivers' participatory behaviors, there were no *a priori* hypotheses. In addition, there was no intervention designed to impact participation.

Methods

Sample Selection

The sample was drawn from the population of children and their caregivers who received public mental health services in San Diego County in November 2010. Caregivers whose child had a billable service for outpatient, case management, or day treatment services were asked to complete the Youth Services Survey for Families (YSSF) at their service sites. The survey was available in English and Spanish languages. A total of 3916 caregivers met these criterion. Of these caregivers, 2198 (56%) returned at least partially completed surveys. The remainder declined to complete the survey or did not show up for their session during the two weeks the surveys were administered in November of 2010. From the completed surveys, a subsample was selected based on the following criteria: 1) children received outpatient services from agencies that provide treatment within a clinic (i.e., children receiving services from agencies that provided only school-based or home-based care were excluded to provide a more homogeneous service sample for investigation of parental participation); 2) children were ages 0-18; 3) children had received more than one mental health visit; 4) the caregiver completing the survey responded to the question "How did you participate in your child's treatment?" The final subsample included 1255 caregivers. To examine the representativeness of the subsample, the subsample's demographic characteristics were compared to the full population receiving services in the county. These analyses are reported in the results section.

YSSF Measure

Child background characteristics, caregiver satisfaction with services, caregiver participation in services and barriers to participation were all measured with the YSSF. This survey was developed by the Children's Indicator Workgroup for the 16 State Indicator Project within the Mental Health Statistics Improvement Program.²¹ It is available in both English and Spanish, and it has been used in several different states to assess consumer satisfaction with mental health services. The YSSF has excellent internal consistency reliability,²² and strong convergent validity.²³ The San Diego version of the YSSF includes questions regarding demographics, whether the child has an ongoing medical condition, and the length of time the child has been in services. These questions were added by the county of San Diego in order to gain more information about the characteristics of youth who participate in the county's mental health service system.

Satisfaction—The YSSF has 26 questions and respondents are asked to answer each of these questions using a 5-point Likert scale (from 1 = Strongly Disagree to 5 = Strongly Agree). The questions are separated into three sections and a confirmatory factor analysis on the 26 items indicated these sections represent distinct domains: 1) overall satisfaction with services, 2) positive outcomes as a result of services, and 3) having support outside the mental health system. The Cronbach's alpha for the overall satisfaction with services domain was .96 for the English version and .97 for the Spanish version. The alpha for the positive outcomes as a result of services domain was .94 for both versions. The alphas for having support outside the mental health system were slightly lower, .89 for the English version and .93 for the Spanish version. Finally, the overall Cronbach's alpha for both the English and Spanish versions was greater than .95, which is similar to the alpha reported in another study which examined internal consistency reliability.²²

Caregiver Participation and Barriers to Participation—Given the county's and the research group's interest in parental engagement in children's care, two additional open-ended questions were added to an earlier administration of the YSSF (2009) to generate information about the potential ways that caregivers participate in treatment and to identify possible barriers to their involvement (i.e., “What do you see as your role in your child's treatment?” and “What prevents you from being more involved in your child's treatment?”). Caregivers' responses to these open-ended items were transcribed and the research team classified responses into different categories representing types of participation and barriers to participation. This qualitative coding generated a list of potential participatory behaviors and potential barriers for participation that provided the response choices for two close-ended questions on participatory behaviors and perceived barriers added to the 2010 YSSF administration generating data for this study.

The first of the close-ended questions in the 2010 YSSF administration asks caregivers, “How did you participate in your child's treatment” and lists the following response options which are not mutually exclusive: did not participate, brought child in for treatment, had phone conversations with the child's therapist, met with child's therapist alone, met with child's therapist with child, took child to other services recommended by therapist, and carried out recommendations at home). The second question asks “What made it difficult to be involved in your child's treatment?” This question listed 14 possible response options (see Table 3), including but not limited to: work schedule, mental health problems, stress, therapist did not encourage parent to participate, etc. On both questions, caregivers could endorse multiple response options.

Procedures

The YSSF was distributed between November 8-21, 2010. All caregivers of children who received billable services from San Diego County funded mental health service providers, excluding crisis services and inpatient hospitalization services, were asked to complete this survey by their service providers. The children each had individual mental health service identification numbers, which were entered on the surveys. In order to maintain anonymity from the service providers, the surveys were returned in sealed envelopes that were then sent to an independent research team (including authors KFK, AG, EVT). Use of these data for secondary data analysis was approved by the University of California, San Diego Human Subjects Committee.

Analysis Plan

The data were analyzed using the SAS (version 9.2) statistical software package. Frequencies were calculated to determine how many caregivers reported engaging in each participation activity and the number of activities caregivers endorsed. The general linear model procedure was used to identify the factors that were significantly associated with engagement in multiple participatory activities. As a follow-up, two domains of participation activities were examined further: meeting with the therapist (i.e., having a phone conversation with the therapist, meeting with the therapist and child, or meeting with the therapist alone), and carrying out therapists' recommendations at home. Logistic regression was used to examine predictors of each of the two domains. Because respondents varied widely in how long they had been in services, which is likely to impact participation, length of time in treatment was included as a covariate in all analyses.

Results

Sample Demographics

When caregivers complete the YSSF they are asked to provide demographic information about their child who is receiving mental health treatment, rather than their own demographics. Thus, all demographic information refers to the children rather than the caregivers. A few surveys had missing information in the demographics section, but, for each demographic variable, information was available for 94%-100% of the sample. Additionally, while race and ethnicity were collected separately in accordance with federal guidelines, in order to avoid multicollinearity in the regression analyses, a single race/ethnicity variable was created. The majority of the children 61% were Hispanic and more than half of their caregivers (53%) (396) completed the survey in Spanish. Slightly less than a fourth of the children (24%) were Non-Hispanic White, 6% were Non-Hispanic African-American, 6% were Non-Hispanic Multiracial, and 3% were Non-Hispanic and endorsed a race not listed above. The majority (64%) of the children were male, the average age was 11 ($SD = 3.97$), and approximately 24% had a medical condition. At the time of the survey, 12% of the children had been in treatment for less than one month, 44% had been in treatment for one to five months, and 44% had been in treatment for six months or longer.

Overall, the demographic characteristics of this sample were very similar to the demographic characteristics of the entire population of children who received outpatient mental health services in San Diego County between July 2010 and June 2011. However, this sample had more Hispanic children (61% vs. 53%) and slightly fewer Non-Hispanic African American children (6% vs. 11%).

Caregiver Satisfaction

The results revealed that caregivers were highly satisfied with the treatment their youth received. The average score on the overall satisfaction with services domain was 63.54

(SD=9.82) (Range: 5-75). The average score on the positive outcomes as a result of services domain was 26.17 (SD=5.92) (Range: 2-35) and the average score on the support outside the mental health system domain was 16.73 (SD=3.05) (Range: 3-20).

Caregiver Participation

The first research question was: What ways do caregivers report participating in their children's treatment? As indicated in Tables 2 and 3, caregivers reported relatively high rates of participation across several different types of activities associated with their child's mental health care. The average number of participatory activities was 3.17 (SD=1.73) (Range: 0-6), and the most common form of participation was meeting with the therapist and the child. Slightly more than half of the caregivers reported that they carried out therapist's recommendations at home.

In contrast with the participatory activities, none of the barriers to participation were frequently endorsed (see Table 3). The most common barriers were logistical- work schedules and transportation problems, and these were only reported by 18% and 12% of the caregivers respectively.

Table 4 summarizes results of a regression model testing predictors of the number of participation activities endorsed. The results indicate that number of participation activities was significantly related to the caregiver's primary language, such that caregivers of Non-Hispanic White children were likely to engage in more types of activities than caregivers of Hispanic children who completed the survey in Spanish ($\beta=-0.32$; $p<.05$). Additional predictors of engagement in more types of activities included higher general satisfaction scores ($\beta=0.02$; $p<.05$), having a child with a medical condition ($\beta=0.42$; $p<.001$), and, paradoxically, endorsing more barriers to participation ($\beta=0.16$; $p<.001$).

In the logistic regression analyses, the significant predictors of caregiver engagement varied by type of activity (see Table 5). The only significant predictor of having contact with the therapist was having support outside the mental health system – caregivers who had higher scores on this domain ($OR=1.10$; $p<.05$) were more likely to speak with the therapist over the phone or meet with the therapist in person. Therapists' recommendations were more likely to be carried out at home by caregivers with higher scores on the general satisfaction domain ($OR=1.04$, $p<.001$), and those caring for a child with a medical condition ($OR=1.47$; $p<.05$). Caregivers who endorsed more barriers to participation ($OR=1.15$, $p<.01$) were also more likely to report that they followed therapists' advice at home.

Discussion

The results show that the majority of caregivers report that they are participating in their child's mental health care, and that they are participating in multiple ways. The most common form of participation was meeting with the child and the therapist, which indicates that many therapists in usual care are making an effort to include caregivers in therapy sessions.

Although most caregivers met with their child's therapist, 45% of the caregivers did not endorse following therapists' recommendations at home. This is slightly concerning as many evidence-based treatments for children involve practicing skill-building, including parenting skills outside of treatment sessions.^{24, 25} Given that another study has reported relatively low rates of assigning therapeutic "homework" in usual care,²⁰ it is quite possible that the moderately low rate of following recommendations outside of session reflects that fact that many therapists are not providing specific recommendations for home.

The multivariate analyses revealed that caregivers' participation in treatment was significantly related to several different factors. For example, the odds of participation varied by the caregiver's primary language; Caregivers of Hispanic children who completed surveys in Spanish participated in fewer ways than caregivers of Non-Hispanic White children, but the difference between caregivers of Hispanic youth who completed the survey in English and caregivers of Non-Hispanic White children was not significant. While language may be a barrier that prevents caregivers who primarily speak Spanish from engaging in some participation activities, San Diego County has many bilingual mental health service providers, and less than one percent of the caregivers in this study stated that it was difficult for them to participate because services were not offered in their primary language. A more plausible explanation is that caregivers of Hispanic youth who chose to complete the YSSF in Spanish may be less knowledgeable about or comfortable with the child mental health system in the United States, and therefore, less likely to pursue multiple avenues of participation. Language preference is often an indicator of acculturation,²⁶ and Latino caregivers who are more highly affiliated with non-U.S. cultures are less likely to enroll their children in mental health services in the United States.²⁷

In addition, having a child with a medical condition was a significant predictor of participation. Caregivers of these children may be more likely to get involved in their children's treatment because their children have multiple needs. Furthermore, if the children's mental health problems are related to their medical condition, these caregivers may feel less stigmatized about having a child with psychiatric problems, and therefore may be more comfortable participating in treatment. Research shows that there is less stigma associated with physical health problems in comparison with mental health problems,²⁸ and concerns about stigma can prevent caregivers from seeking mental health care for their children.²⁹

Overall, the majority of the factors that predicted participation were associated with the caregiver rather than the child; Caregivers' perceptions of barriers to participation, supportive relationships outside the mental health system, and satisfaction with services all predicted treatment involvement. Ironically, caregivers who identified more barriers to participation were more likely to participate in multiple ways and to carry out therapists' recommendations at home. It is possible that because these caregivers were more actively involved in treatment, they had more opportunities to encounter barriers and thus endorsed more barriers.

Caregivers may be more likely to overcome these barriers if they have strong support networks.³⁰ Higher scores on the support section of the parent report measure increased the odds that the caregiver would have contact with their child's therapist. Support networks may provide resources that enable caregivers to manage obstacles to participation. For example, a caregiver who does not have a car may be able to borrow one from a neighbor in order to attend their child's therapy session, or a caregiver with feelings of shame associated with their child's mental health problems may be more likely to call their child's therapist after receiving emotional support from a friend.

Finally, caregivers who have higher scores on general satisfaction may participate in more ways and follow therapist's recommendations at home because they are happy with the services they are receiving. The relationship between reported satisfaction and extent of participation is not surprising, but this cross-sectional survey cannot offer conclusions about the temporal sequence of these effects. Other studies have found that caregivers are more willing to participate in their children's treatment when they feel the treatment is acceptable.³

Strengths and Limitations

Two of the major strengths of this study are 1) it included a very large, heterogeneous sample of caregivers whose children received mental health treatment in community-based usual care, and 2) it utilized parents' own reports of their involvement in their children's treatment. Only a few other studies of parental participation have included samples who received usual care, and to the authors' knowledge, no other studies have used parent self-report to measure participation behaviors.

Although the use of self-report is one of the strengths of this study, the survey was voluntary and the extent to which those who completed the measure represent all caregivers in the service system is unknown. In fact, caregivers who did not participate in their child's treatment may have also chosen not to complete the participation section of the YSSF. Therefore, the sample may have included a higher proportion of caregivers who are engaged in their children's treatment than the general population of families whose children receive usual care.

Additionally, because the focus of the survey was on service satisfaction, only limited information about the clients was available, and there was no information about the caregivers or the therapists, which may have influenced rates and types of participation. As noted above, the cross-sectional design also prohibits conclusions regarding causal links between significant predictors and the participation outcomes. It is also possible that the impact of certain covariates on participation, such as barriers or satisfaction with services, vary over the course of treatment.

Implications for Behavioral Health

The fact that caregivers are participating in publically-funded, community-based usual care mental health services for children is a promising sign for the field of behavioral health care. Not only is family participation associated with better child mental health outcomes,^{2, 3} but many evidence-based mental health treatments have extensive family participation components, and it will be easier to disseminate and implement these practices in usual care settings if service providers already support family involvement.

The current study's results suggest that service providers should consider using engagement techniques specifically designed for minority populations and individuals who affiliate with non-U.S. cultures to encourage more caregivers to participate. Service providers could also help caregivers develop stronger support networks that may enable greater participation in treatment. Furthermore, therapists should check with caregivers to make sure they are satisfied with the services being provided to their children, as satisfaction is associated with following therapists' recommendations at home.

Meanwhile, additional research is needed on the characteristics of caregivers, therapists, and service contexts that influence parent participation. Studies that investigate the effectiveness of different strategies that therapists use to involve caregivers, or how organizational characteristics, such as structure and climate, help or hinder caregiver involvement, can inform engagement strategies in usual care. Another important topic for researchers to examine is the connection between the type and quality of caregiver participation and changes in children's symptoms and functioning over the course of treatment. A greater understanding of how to encourage caregivers to participate in their child's treatment in meaningful ways will lead to better outcomes for children served in community-based mental health services.

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Table 1

Types of participation activities (N = 1255)

Type of Activity	N	Percent
Brought Child to Treatment	825	65.74
Phone Conversations with Therapist	633	50.44
Met with Therapist and Child	996	79.36
Met with Therapist Alone	633	50.44
Took Child to Other Services	215	17.13
Carried Out Recommendations at Home	681	54.26

Table 2

Number of participation activities (N=1255)

Number of Participation Activities	N	Percent
0	25	1.99
1	306	24.38
2	140	11.16
3	208	16.57
4	230	18.33
5	223	17.77
6	123	9.80

Table 3

Barriers to participation (N=1255)

Barriers	N	Percent
<i>Logistics</i>		
My work schedule	224	17.85
Transportation problems	148	11.79
Custody or placement situation	55	4.38
I have too many other things to do	93	7.41
<i>Personal/Interpersonal Problems</i>		
I have a mental health or physical health problem	65	5.18
I am too stressed	104	8.29
Relationship problem with my child	78	6.22
Poor communication with my child	81	6.45
Child's problems are too difficult for me to handle	84	6.69
Child does not want me to be involved	39	3.11
<i>Service Provider Issues</i>		
Therapist did not encourage me to participate	17	1.35
I felt blamed by therapist for my child's problems	3	0.24
I was not told how I could participate	19	1.51
Services were not provided in my primary language	2	0.16
<i>Other</i>	76	6.06

Table 4

Predictors of number of participation activities (N=1065)

	Estimate	SE
<i>Time in Treatment (ref: <1 mon)</i>		
1-5 Months	0.36 *	0.18
6 or more Months	0.57 **	0.18
<i>Age (ref: 0-3)</i>		
4-11	0.54	0.28
12-18	0.51	0.29
<i>Gender (ref: Female)</i>	-0.16	0.11
<i>Race (ref: Non-Hispanic White)</i>		
Hispanic (EN)	-0.011	0.14
Hispanic (SP)	-0.32 *	0.14
Non-Hispanic African-American	-0.22	0.24
Non-Hispanic Multiracial	-0.07	0.24
Non-Hispanic Other	-0.52	0.33
<i>Satisfaction Domains</i>		
General Satisfaction	0.02 *	0.01
Outcomes	-0.00	0.01
Support	0.02	0.02
<i>Child has a Medical Condition</i>	0.42 ***	0.18
<i>Number of Barriers to Participation</i>	0.16 ***	0.18

*
p<.05**
p<.01***
p<.001

Table 5

Predictors of engagement in specific types of participation activities (N=1065)

	Had Contact with Therapist		Carried out Therapist's Recommendations at Home	
	OR	95% CI	OR	95% CI
<i>Time in Treatment (ref: <1 month)</i>				
1-5 Months	1.07	0.58-1.98	1.76 [*]	1.14-2.71
6 or more Months	1.16	0.61-2.20	1.94 ^{**}	1.25-3.02
<i>Age (ref: 0-3)</i>				
Age 4-11	1.33	0.53-3.36	1.01	0.51-1.99
Age 12-18	1.83	0.70- 4.73	0.80	0.40-1.59
<i>Gender (ref: Female)</i>				
	0.87	0.58-1.32	1.27	0.98-1.66
<i>Race (ref: Non-Hispanic White)</i>				
Hispanic (EN)	0.82	0.47-1.45	1.19	0.84-1.70
Hispanic (SP)	0.68	0.39-1.18	0.79	0.56-1.12
Non-Hispanic African-American	1.15	0.42-3.21	0.68	0.39-1.20
Non-Hispanic Multiracial	0.84	0.34-2.11	1.37	0.75-2.49
Non-Hispanic Other	0.52	0.18-1.52	0.55	0.25-1.22
<i>YSSF Survey Domains</i>				
General Satisfaction	1.00	0.98-1.03	1.04 ^{***}	1.02-1.06
Outcomes	1.01	0.96-1.05	1.00	0.97-1.02
Support	1.10 [*]	1.02-1.18	1.00	0.95-1.05
<i>Child has a Medical Condition</i>				
	1.60	0.94-2.75	1.47 [*]	1.08-2.01
<i>Number of Barriers to Participation</i>				
	0.90	0.79-1.04	1.15 ^{**}	1.04-1.28

*
p<.05**
p<.01***
p<.001