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Fragmented Care for Inner-city Minority Children with Attention-Deficit/Hyperactivity Disorder

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Abstract

Objectives—To identify systematic problems in coordinating care for inner-city minority youth with attention-deficit/hyperactivity disorder (ADHD).

Design—Focus group study.

Setting—We recruited participants from inner-city minority communities in a single metropolitan area. We held separate meetings for pediatricians, mental health therapists, school staff, and parents (both African-American and Latino).

Procedures—We audiotaped and transcribed the meetings. We identified themes by consensus and used Root Cause Analysis as a conceptual framework to guide our analysis.

Results—We held 13 focus group meetings. Participants uniformly perceived insufficient communication and coordination of care. Five themes representing system and human factors emerged that contributed to this fragmentation in care: 1) a lack of consensus about who should oversee care; 2) changes in health care providers or teachers; 3) uncertainty in the diagnosis, insufficient training, and few resources; 4) distrust and blame that emerged when relationships among people caring for the child were absent or otherwise inadequate; 5) lack of support from employers, friends, and family to engage in collaborative care.

Conclusions—Using a Root Cause Analysis framework, we identified system- and human-level factors that were perceived to impede communication and coordination of care for this population

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Authorship

JG conceived of the study, participated in the design of the study, the collection of data, and the analysis of data, and wrote the manuscript for publication. CF, DR, TP, RE, and DS participated in the design of the study, the analysis of data, and the writing of the manuscript. SN participated in the design of the study and the analysis of data. AR and JO participated in the collection and analysis of data.

of children with ADHD. These results suggest that better organizational policies that define provider responsibilities and accountability, support the coordination of care, bridge relationships between agencies, and provide additional education and resources may improve collaboration. Further study is needed to assess the generalizability of these findings to other settings.

Keywords

attention deficit disorder with hyperactivity; children; qualitative research

Introduction

Attention-deficit/hyperactivity disorder (ADHD) is among the most prevalent behavioral conditions affecting school-age children in the U.S.¹ Clinical practice guidelines endorsed by the American Academy of Pediatrics have recommended that practitioners collaborate with schools and mental health agencies to coordinate the care of children with ADHD.² This recommendation reflects the importance of input from various stakeholders and the need for broad expertise in treatment.

Despite these recommendations, practitioners may not collaborate with schools and mental health agencies leading to care that is fragmented and disorganized.³ This fragmentation may occur for a number of reasons. First, primary care practitioners may experience difficulty communicating with schools to obtain academic information or to solicit input on the effects of treatment regimens.⁴ Second, primary care practitioners may encounter problems making referrals to mental health providers,^{5, 6} or making contact with mental health providers to obtain consultation or to discuss treatment plans.⁴ Third, managed care policies may contribute to this fragmentation by creating carve-out plans that limit communication between primary care practices and mental health agencies.⁷ Other contributing issues have not been explored adequately. A better understanding of the factors that contribute to fragmentation may assist in the design and implementation of interventions to link systems of care.

We therefore sought to explore the causes for fragmentation in ADHD care by systematically gathering data on the perspectives of parents, pediatricians, mental health providers, and school staff through a series of focus groups. Focus groups and other qualitative methods derive from an inductive process that strives to generate hypotheses about the processes whereby events and actions take place.⁸ We felt that these methods would be most appropriate to explore the depth and breadth of causes for fragmentation in care since little is known in this area. Qualitative methods can also be used to gather data to inform future quantitative study.

We targeted urban African-American and Latino children and the agencies that serve them for a focus group study. These children may have greater health needs but may experience substantial disparities in the use of services to address those needs.^{9–11} It is not known what factors impede care coordination in this setting. In this study, we sought to identify system-level problems in the communication and coordination of care provided to minority children with ADHD in a single inner-city area. We used root cause analysis (RCA), a technique honed in the patient safety literature, as a conceptual framework to classify themes regarding causality into separate categories.

Methods

Setting

We recruited 3 primary care clinics, 4 community mental health clinics, and 3 public K-8 schools that serve predominately inner-city African-American or Latino children from a single large metropolitan area to participate in our focus group study. The sites were selected due to

their location in or near large urban minority communities and their stated mission to serve urban poor children. The three primary care clinics were affiliated with a large urban children's hospital and provided care to over 20,000 children of whom the majority were African-American (93%) and insured through Medicaid (72%). The four non-profit community mental health clinics were geographically separate and contracted separately with the city's behavioral management plan to provide a range of treatment services for both adults and children with public or no health insurance. The public schools all were within the same urban school district. The majority of children attending were poor (80% qualified for free or reduced lunch programs) and ethnic minorities (65% African-American and 15% Latino).

Participants

We recruited primary care providers, mental health therapists, and school staff at participating sites to attend the focus groups. The meetings were open to all interested staff and were scheduled at convenient times, e.g. after school for school staff or during lunch for pediatric and mental health staff. Primary care providers at participating sites consisted of board-certified general or adolescent-trained pediatricians and pediatric nurse practitioners. Therapists at participating sites consisted of masters-level psychologists and social workers. School staff at participating schools consisted of regular and special education K-8 teachers, counselors, psychologists, and nurses. We conducted separate focus groups for staff at each site except for one mental health site in which we were unable to conduct a meeting due to scheduling conflicts. To ensure anonymity of responses and prevent identification of participants at focus group meetings, we did not collect any demographic information on participants.

We identified children with ADHD at these sites using computerized patient records that listed ADHD as a diagnosis or through patient rosters compiled by individual providers. We recruited parents of children with ADHD from two of the primary care sites and one of the mental health sites. In all instances, clinic staff approved the final list of potential recruits and internally recruited parents using letters of invitation and telephone solicitation. We conducted two parent groups consisting of African-American parents and two consisting of Latino parents. The latter two groups were conducted in Spanish and English to accommodate participants' language preferences.

Our intent was to recruit 3 to 4 focus groups per participant type, so as to allow for saturation of themes, i.e. when we no longer heard new points of discussion. Saturation of themes allows one to be confident that important points have been aired and further discussion will not likely produce new themes. Participants received a meal, a small monetary inducement (\$20), and childcare when needed for participating in the meeting. The study received approval and a waiver of written informed consent from the institutional review boards at the Children's Hospital of Philadelphia and the School District of Philadelphia.

Procedures

We conducted 13 focus groups, each involving 4–10 participants.¹² The meetings lasted for approximately one hour. The goal of the meetings was to identify perceptions of how care was provided and coordinated for inner-city minority youth with ADHD from the vantage point of each participant group. Meetings were led by experienced facilitators (JOF, AR) and consisted of open-ended questions followed by group discussion. An example of a scripted line of questioning that we used for pediatricians was, "I am interested in understanding how you coordinate care with mental health providers and schools. What processes make it go smoothly? What barriers do you encounter? If you could change the system for children with ADD, what would you suggest?" Similar lines of questioning were adapted for each of the other participant groups. An investigator (JG) was present at all meetings to record field notes.

Meetings were audiotaped and transcribed. Transcripts were entered into Ethnograph 5.0 (Qualis Research Associates, Thousand Oaks, CA), a qualitative software program that allows users to code, organize, and conduct searches for themes across transcripts. To improve the validity of our findings, we summarized the main ideas and sought participant feedback at the conclusion of each meeting. We also held an investigator debriefing session following each meeting to review the main ideas and to compare findings with those from earlier groups. Finally, we used field note data to supplement information from the transcripts.

Analysis

All transcripts were initially read by at least 3 investigators (JG, CF, DR, RE, TP, DS) to identify major themes. This pool of investigators included a diverse array of individuals with expertise in general pediatrics, adolescent medicine, psychology, and qualitative methods. To ensure reliability in the selection of themes, we held an investigator meeting to arrive at consensus for the overall themes. Based on this list of themes, two investigators (JG, SN) independently reread and coded all transcripts. Disagreements were settled by consensus. We used the constant comparative technique in which we sought to identify quotes supporting or refuting a given theme across participant groups.¹³ In this way, we were able to “triangulate” or compare responses between and within participant groups.

We applied root cause analysis (RCA), a process for identifying basic or causal factors that underlie variation or errors in the performance of systems, as a conceptual framework to guide the interpretation of transcripts.¹⁴ RCA has traditionally been used in the assessment of patient safety processes.¹⁵ Using RCA, investigators seek to drill down and identify the root causes for an adverse incident. RCA generally categorizes root causes from among three broad categories: technical factors, organizational factors, and human factors. In a similar way, we sought to categorize major themes and subthemes into one of these three categories. Similar to the study of adverse events, we felt that this conceptual framework would provide insight into potential mechanisms underlying the behavioral system’s poor performance in coordinating care.

Results

Participants varied in their experience caring for children with ADHD. Some participants described themselves as seasoned veterans with decades of experience raising, educating, and providing care for children with ADHD. Others described themselves as neophytes with limited experience. Despite these differences, all participants agreed that communication and collaboration across groups was lacking. As one teacher remarked, “There’s definitely a breakdown in communication and interaction between parents, schools, physicians, teachers, and counselors.”

This breakdown in collaboration was not perceived as a result of a lack of will or desire. All participants including parents desired better communication and collaboration. Some participants described occasional success stories that reflected effective collaboration, but these stories were few and far between and required enormous effort on the part of participants to overcome obstacles. Participants held up as an example a joint program involving mental health agencies and schools that mandated collaboration on behavioral plans for children with serious emotional and behavioral problems. Confidentiality concerns were not viewed by participants as a serious impediment to collaboration unless families refused consent. As one therapist remarked, “I don’t think that confidentiality is a major issue in referrals. We just get a release of information from the parents. If parents don’t want us to share information, [then] that makes things more difficult.”

The fragmentation in care described by participants suggested to us a system failure that inhibits effective communication and coordination of care. We identified 5 themes from the focus group transcripts that contributed to this system failure. We categorized three themes, “lack of accountability”, “discontinuity in care”, and “lack of support”, as representing organizational factors. We categorized two themes, “limited knowledge and resources” and “finger-pointing”, as representing the human factors. We triangulated these themes across participant groups.

Lack of Accountability

There was a lack of consensus among participants regarding who should oversee care for children with ADHD. This lack of consensus was evident within as well as across groups. Some participants felt that therapists should assume overall responsibility, given their perceived expertise in mental health care. Others presumed that pediatricians would assume responsibility, given their experience in coordinating care for children with physical conditions. Still others felt that schools should assume this responsibility, given that children spend the majority of their time at school. A number of providers and school staff who advocated for other groups to assume responsibility expressed their discomfort with assuming overall responsibility for ADHD care. For example, a pediatrician remarked,

I don't feel comfortable with the medications currently available to be the main prescriber and controller of ADHD medications... I can't offer them the time that they need to discuss the problems. I can't offer them behavior therapy, and they need that.

There was, however, consensus among participating providers and school staff that most parents in this setting were not capable of assuming responsibility for coordinating care. Parents were perceived as disorganized, misinformed, and inconsistent. The reasons for this perception of parents varied. For example, a teacher speculated,

You know it could be a whole laundry list of things. They could be on drugs or they could be working. We really don't always know. But there's specific problems with certain kids, and they're having difficulty succeeding here. And we're trying to solicit parental help or to make suggestions, and we can't get that message across. There's no phone; there's nobody home; or there's no one willing or able to come here. And that's one of the problems, probably the biggest.

Parents responded to this criticism that their concerns were frequently dismissed by providers and school staff. They perceived that providers and teachers do not appreciate issues from their perspective, and this may compel parents to seek help elsewhere. Many parents identified relatives or close friends in their community whom they trusted and presented concerns to. For example, a parent remarked about her difficulty getting providers to listen to her,

My son got in a little tuss with my girlfriend's one and only child, and he pushed the child in front of a trolley, and that's what's pushing me to the point. Somebody's gotta do something, and I think for all parents you just keep fighting everybody until somebody listens. I took him to CHOP [ER], and I signed a thing. I sat in a chair in triage. I said you will see nobody else until somebody helps my child. I said call security, do what you need to do. But until ya'll do something to help my boy, nobody else will be seen in here today. And that was the first point somebody listened to me.

Discontinuity in Care

All participants perceived that discontinuity in providers and teachers led to interruptions in care that contributed to fragmentation. Discontinuity in care occurred when children transitioned to new providers or teachers, who were unfamiliar with their diagnoses or treatment plans. New relationships needed to be forged to replace previously established relationships. These transition points were perceived by participants as requiring substantial

effort to connect new and existing providers or teachers. Participants were aware of few transition processes that had been established to facilitate contacts for new teachers or providers.

For school participants, transition points occurred mainly at the beginning of a new school year. At this time, teachers were often unaware of a child's diagnosis, since parents were perceived to not routinely inform teachers prior to the start of the school year. Instead, teachers relied on their ability to observe consistent patterns of disruptive behavior in children with potential ADHD. This was perceived as causing delays in implementing an educational plan, unless the child had already qualified for an individualized educational plan or 504 accommodations the previous year. In this case, information on a child's behavioral diagnosis was known. As one teacher remarked,

When you have 30 kids in your class, you don't get a list in September that says Juan is oppositional, Jose is ADD. We don't get that information; you have to get that on your own.

For pediatrics and mental health participants, transition points occurred throughout the year whenever changes in providers occurred. At community mental health clinics, participants perceived frequent turnover in personnel, as established providers opted for either better paying or less stressful jobs elsewhere. At pediatrics clinics, children with ADHD were perceived as shuffling among different providers due to differential availability of specific providers or to changes in insurance coverage that mandated provider changes. A pediatrician described such transitions as chaotic: "the providers change, everything's turned around, shuffled around from system to system."

Parents perceived discontinuity in care when their children went to stay with relatives or another parent living apart from them. These relatives or other parents may not adhere to their understanding of ADHD and may not continue existing treatment, particularly stimulant medications.

Limited Knowledge and Resources

Participants perceived limitations in their knowledge of ADHD and in the availability of community resources to assist them to coordinate care. This perception did not vary across groups. There were three reasons given for these limitations. First, there was uncertainty as to whether ADHD was the cause of a child's symptoms. Many children in this setting came from chaotic family environments, and it was difficult to disentangle the effects of their home environment from their ADHD. Many children also suffered from multiple behavioral problems, so it was difficult to judge which problem was contributing to observed behaviors. Finally, parents and schools did not reliably return requested information that could inform diagnoses. For example, a pediatrician remarked,

Is this really a kid that has ADHD? So sometimes the families are not able to give a great story. So it's difficult to say where they do have problems and where they don't have problems. So even getting those Conner scale checklists filled out, it's not as easy as you would think it would be.

Second, participating primary care providers and teachers acknowledged limitations in their training related to ADHD. Even among those who felt more competent in their ADHD care, they acknowledged that the field was rapidly changing, and they might not be able to stay abreast of new developments. There was also a perception that available information on ADHD was not applicable to the inner-city setting. A pediatrician remarked,

A lot of us have taken more of a role in ADHD management than we were probably trained to do. And we all picked it up on the fly, and I think one of the frustrations

that we have is that all the ADHD programs and materials that are put out by the AAP, and the different organizations, are designed for a middle- to high-income family that's highly organized. So to try and follow those sort of protocols in our population, it [protocol] has to be modified so severely.

Third, participants perceived few available resources for ADHD in the community. Some primary care providers relied on a few dedicated social workers to provide counseling services, but most providers were not able to identify necessary resources such as parent training classes or parent support groups. Teachers, meanwhile, were concerned with a perceived shrinking pool of school psychologists and counselors to assist with classroom behavioral management. Parents expressed a desire for parent support groups but were unaware of any such groups for ADHD in the area.

Finger-pointing

When relationships between pediatricians, therapists, and teachers were weak or nonexistent, participants expressed dissatisfaction with care and blamed others for the lack of coordinated care. This finger-pointing bred distrust. For example, a pediatrician remarked about local mental health agencies,

How do they get the diagnosis? Like what concrete evidence are they getting that the mom is saying he's bouncing off the walls. I don't think they're talking with schools. I don't think they're getting the teachers' questionnaires. It's disconcerting to me about how they are reaching whatever diagnosis they are getting.

Parents were often caught in the middle of these conflicts. They perceived having to play the role of arbiter among providers and school staff over disagreements in care. Here, a teacher remarks on the role parents play at the schools,

It seems like here, the doctors are making a recommendation to the parents who are interpreting it, interpreting the doctor's recommendation, coming to school with their interpretation of what the doctor has said.

On the other hand participants, both providers and school staff who related that they were able to develop relationships with other providers or teachers, took a more positive view of their relationships. They expressed an appreciation for the value of working with others. In general, they were more empathetic and understanding of behaviors and decisions made by others.

Lack of Support

Participants uniformly perceived a lack of support in efforts to provide and coordinate care for children with ADHD. For parents, this lack of support became evident when well-intentioned friends or family members provided conflicting advice about ADHD. Parents perceived skepticism regarding the legitimacy of ADHD or denial of the existence of any problems from friends and family. For example, a mother related,

He [child] doesn't do nothing around his father to a point where he [father] doesn't believe half the stuff I say. He [child] don't think like when he's with his dad and I have to go to work on Saturday and his dad doesn't give him that medicine, he need that medicine. When I come home he is perfectly normal sitting down doing what he is supposed to do. But as soon as his dad walks out that door, he is a completely different person...because, I find out that the men tend to look at it completely different especially if they are boys. He's just a boy.

Parents also perceived a lack of support from their employers. They related that it was difficult to attend school conferences or medical appointments during work hours. This necessitated

parents scheduling appointments on their days off or using vacation days in order to attend meetings or clinic visits. One therapist remarked,

I have one parent who bitterly spends her days off coming here or going to some other treatment. So it may look like, non-compliance, because they're not coming every week. But they can't, and people get to the point where they might lose their job.

Among school participants, teachers perceived a lack of support by school administration. They reported that school policies emphasized test scores and achievement with little support dedicated to classroom behavioral management. One teacher remarked,

I think the teachers get a little disgusted because again with the time frame, it seems like all this paperwork [related to assessment procedures] they do, and then nothing ever happens. We also don't have enough psychologists... So the school itself doesn't have enough support to do what they are supposed to do and what they could do if they had the support.

In the clinics, therapists and primary care providers also perceived a lack of support from their administration. They related that there were no directives to encourage them to establish collaborative ties with outside providers or teachers. In fact, they sensed increasing productivity demands, limited time, and dwindling reimbursements, which made it difficult for them to find the time to reach out to others. For example, a pediatrician stated,

I don't think it's my role to talk to the schools, coordinate the evaluation, get the evaluation, coordinate this and get everything together and be up to date on all the latest medications. I think that it goes beyond what I want to do as a general pediatrician. I don't have the time.

Discussion

In the field of patient safety, RCA has been advocated as a means to identify the technical, organizational, and human factors that contribute to adverse events or near-miss events.¹⁴ The emphasis is on system-level approaches and minimization of individual blame. In this study, we used RCA as a conceptual framework to categorize themes that contributed to fragmentation in care for children with ADHD. These themes included organizational factors: lack of accountability, lack of support, and discontinuity in care. These themes also included human factors: limited knowledge and resources and finger-pointing. We did not identify in our focus groups any technical factors that contributed to fragmentation, but one could argue that technical innovations might address many of the human and organizational factors that lead to fragmentation. For example, most participating pediatricians, therapists, and school staff had access to email, which could be utilized to facilitate communication and care coordination, but were unaware of email addresses for outside providers or school staff.

The notion that fragmentation in behavioral care represents a system-level problem has only been addressed in a limited way in previous studies. For example, Leslie and colleagues undertook a qualitative study to identify barriers to ADHD care.⁴ Using focus groups involving providers, they found that ADHD clinical guidelines were well accepted but not fully implemented. Among the barriers to implementation, they identified managed care plans that made it difficult for primary care providers to access mental health providers, few available community resources, and a sense of difficulty obtaining information from schools. The authors of this study did not elaborate on the potential root causes for the fragmentation they observed.

It was surprising that there was such profound disagreement on accountability among study participants. The lack of consensus on accountability over care coordination may represent an important modifiable factor. We speculate that this lack of accountability may be attributed in part to variations in treatment principles across disciplines. For example, therapists may ascribe

to the systems of care philosophy, which assigns the coordination of care to mental health agencies.^{16–18} Pediatricians, on the other hand, may ascribe to the medical home concept in which care is overseen and coordinated by a primary care provider.^{19, 20} This is clearly not the whole answer, since there were significant within group differences. The lack of consensus may also be attributed to variations in education and training regarding ADHD management. Some providers and teachers may be more self-efficacious in coordinating ADHD care than others due to a greater amount of training and/or interest. We speculate that those with better training may be more likely to assume responsibility for ADHD care.

There are limitations to our findings. First, the information we present may not be generalizable. We conducted our study in a single geographic area using a non-random sample. Thus, the participants in our study may not be representative of all individuals providing ADHD care, and the identified themes may be shaped by the relatively resource-poor environment (including home, school, and behavior health care environments) inhabited by participants. Second, our findings should not be interpreted as causal but rather as hypothesis-generating. Qualitative studies such as this one do not quantify associations, but rather provide important information regarding the depth and breadth of issues. For example, future study regarding the quality of care for children with ADHD should expand the scope of hypotheses to address the influence of excessive transitions in health care or education, and the importance of clearly demarcated accountability among providers. Third, the validity and reliability of our findings are not evident. To enhance the trustworthiness of our findings, we conducted multiple focus groups with different participants to reach saturation of themes. We also utilized multiple reviewers with heterogeneous backgrounds to read the transcripts and to arrive at consensus on major themes.

Despite these limitations, there are important implications to these findings. First, the ability of a single individual (provider, teacher, or parent) to leverage the resources and expertise available in the system are limited which necessitates collaboration. However, without an identified leader to orchestrate the care, fragmentation ensues. In low-income urban populations where parents are perceived to be disorganized, misinformed, and inconsistent, it becomes vitally important for providers or school staff to assume the responsibility for coordinating behavioral care. Future study should be directed to testing different models of providing care coordination in inner-city settings. Second, discontinuity in care without plans to smooth transition points and a general lack of support further hinders coordination of services. These results suggest that organizations may play an integral role by providing resources and education for ADHD and directing policies that encourage collaboration with outside agencies, establish accountability, and smooth transitions. Further study, both qualitative and quantitative, is needed to explore these findings in other settings and confirm proposed associations. For instance, the themes identified in this study may not be relevant in middle to upper class suburban or rural communities.

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