Group Visits to Improve Pediatric ADHD Chronic Care Management

Bauer NS, Szczepaniak D, Sullivan PD, Mooneyham G, Pottenger A, Johnson CS, Downs SM.

Key Words: Attention deficit disorder with hyperactivity; primary care; intervention studies; delivery of healthcare; group visit

Short title: Group visits to improve pediatric ADHD management
Character Count: 49 (with spaces)

Abbreviations: Attention-deficit hyperactivity disorder (ADHD)

Financial Disclosure for All Authors: None of the authors have any financial relationships to disclose.

Conflict of Interest for All Authors: None of the authors have any conflicts of interest to disclose.

This is the author's manuscript of the article published in final edited form as:

Objective: Children with ADHD may experience continued impairment at home and school even after medication initiation. Group visits offer a way for pediatricians to provide more time to address ongoing needs. A pilot study was undertaken to examine whether a group visit model improved ADHD management in the pediatric medical home.

Method: Parents and children aged 6-18 with ADHD were recruited to and randomized to group visits or a usual care control. Data included attendance at ADHD follow-up visits, parent-rated ADHD symptoms, adaptive functioning, and quality of life. Longitudinal linear mixed models (continuous variables) and generalized linear mixed models (binary outcomes) were used to compare groups. In our statistical models, child and family were random effects; study assignment was a fixed effect.

Results: Twenty families representing 29 children participated (Intervention: 9 parents/13 children and control: 11 parents/16 children). Aside from race, baseline characteristics of participants were similar. None of the intervention families missed the expected 5 ADHD follow-up visits over 1 year; control families missed 1 or more visits over the same time period. Intervention families reported an improved level of adaptive functioning at 12-months compared to control (mean severity score: 3.7 vs. 4.4, p= 0.003). All families reported greater limitations and poorer quality of life compared to national norms.

Conclusion: Group visits in the pediatric medical home can improve adherence and preliminary results show a variety of improvements for the family.
INTRODUCTION

Pediatric ADHD is the most common neurobehavioral disorder in childhood, with a prevalence of 5-11% (CDC, 2013). The American Academy of Pediatrics (AAP)’s clinical practice guidelines advocate that pediatric providers should recognize ADHD as a chronic medical condition and manage it according to the principles of the chronic care model and the patient centered medical home\textsuperscript{1,2}. One of the guiding principles of pediatric chronic care management is facilitating adherence to treatment and supporting the family unit. Even though medications are efficacious and often lead to decreases in ADHD symptoms, families may continue to experience stress and children may have ongoing impairments in functioning at home and school\textsuperscript{3}. Moreover, it is not uncommon for parents to question whether medications should be initiated in the first place or whether medications should continue to be used; they often receive conflicting messages from family and friends that may cause confusion\textsuperscript{4-7}. Regardless of parental background and culture, parents desire more information about ADHD and the various treatment options that are available to support their children’s learning, behavior and overall functioning\textsuperscript{8-10}. Pediatricians are poised to help parents weigh these decisions during the medical encounter; however, there is not enough time in the typical 20-minute visit to address these types of concerns or additional needs\textsuperscript{11}.

One potential solution to current care is the implementation of a group visit model. While group visits in pediatrics are not new\textsuperscript{7,12,13}, they have yet to be adopted as part of mainstream outpatient practice. Group visits offer more time with a small group to facilitate an in-depth discussion. This model has been explored for well-child care\textsuperscript{12,13}, prenatal care\textsuperscript{14}, treatment of childhood
disruptive behaviors\textsuperscript{15}, and chronic care management for pediatric asthma\textsuperscript{16}. However, there are no studies in the literature examining its use for pediatric ADHD chronic care management. Given the complexities surrounding initiation and continuation of medication, as well as the myriad of unmet family needs, the use of a group visit model to deliver chronic care management warranted further investigation. We developed a curriculum designed to provide enhanced support to families dealing with ADHD and conducted a pilot study of using group visits in a busy pediatrics clinic. Process and satisfaction data were collected from the pediatrician, staff and family, in addition to objective parent-reported measures to determine the impact the intervention had on ADHD symptoms, quality of life and adaptive functioning. Process and qualitative outcomes are reported in a separate paper. The focus of this paper is to report what effect group visits had on adherence to ADHD follow-up clinic visits and preliminary intervention effects. We hypothesized that families participating in group visits would improve adherence to current guidelines of routine ADHD follow-up visits every 3 months and report improvements in overall functioning compared to control families.

**METHODS**

**Study Population & Design**

Children aged 6 to 18 years of age with a known diagnosis of ADHD, who received routine medical care at a general pediatrics clinic in an academic medical center, along with their parents, were eligible to participate. Stimulant naïve children were excluded due to the close monthly follow up required when first initiating and titrating medication. Children with conduct disorder, autism or moderate to severe intellectual disability were also excluded. Potential participants were identified by a physician referral or by self-referral. For self-referral, an
interest flyer was provided to eligible families during ADHD follow-up visits. Parents were informed about the study and, if interested, provided contact information. A trained research assistant contacted the family to conduct additional study screening by telephone. Siblings also meeting study criteria were allowed to participate. Initially, the clinic chose to make three separate cohorts of intervention families based on the child’s age (6-9 years, 10-12 years and 13-18 years). These age designations were proposed to facilitate pediatricians’ ability to address specific age-related parental concerns and child needs. Eligible siblings were allocated to the group of the youngest child. Prior to each initial group visit offered during the first three months of the study, families were given 3 weeks prior of to each of the scheduled group to enroll. All names obtained by self-referral or telephone contact by research assistant were compiled. Block randomization was done separately for each age group to keep siblings together and to balance the number of participants assigned to receive the group visit intervention or assigned as a control.

**Intervention**

Parents and children assigned to the intervention group were expected to attend five group visits, one every 3 months. The frequency of the intervention would allow families to obtain the maximum number of prescriptions at each clinic visit while adhering to the AAP recommendation that ADHD follow up should occur at 3 to 6 month intervals\textsuperscript{17}. Rather than an individual 20-minute appointment, up to 6 families were scheduled for a 90-minute appointment in the late afternoon so to not require children to miss school. For the first 60 minutes, parents and children participated in separate but simultaneously run groups in adjacent rooms. The remaining time allowed for up to three 10-minute individual visits for each parent-child dyad for
each of the two general pediatricians who facilitated the group portion of the visits. This individual time allowed for obtaining vital signs, monitoring of growth and refilling medications. Scheduling efforts were made to ensure groups were comprised of the same parent-child dyads throughout the study. Families who could not attend during their next quarterly visit were able to attend the same session another month. When only 1 or 2 families could attend a particular month, efforts were made to reschedule group to the next month to ensure sufficient families in attendance for optimal group dynamics. In order to accommodate families’ schedules, the initial age designation became a secondary consideration to scheduling subsequent group visits to the clinic. Moreover, pediatric facilitators were the same throughout the study (1 was a general pediatrician on faculty who saw a large majority of patients with ADHD in the practice; the other was a triple board resident).

A behavioral pediatrician (NB) and clinical child psychologist (PS) developed a study-specific group curriculum: one for parents and one for children. Briefly, the overall objective of the curriculum was to engage parents and children in ADHD chronic care and empower participants to learn skills related to self-care, communication and collaboration to improve functioning in both the home and school settings. Facilitator guides included a framework to help facilitators conduct in-depth discussions with small groups of participants rather than sharing information in a lecture format. The first session for parents and children was designed to help make participants comfortable talking and sharing in group, using a combination of “ice-breakers” and probes to stimulate conversation about what ADHD is, goals for the group sessions, and group rules. Parents were invited to share challenges of raising a child with ADHD and its impact on the family, as well as to reflect on their children’s strengths. Children were supported as they completed child-friendly worksheets to reflect on their own strengths and
challenges. They were encouraged to pick a behavior they wished to work on and begin to chart their progress using behavior charts provided during group. Other sessions were designed to be delivered in any order. Sessions for parents included: medications, educational advocacy, prevention of behavior issues, promoting positive parent-child relationships and handling common behavioral challenges. Topics covered in the children’s curriculum included: identification of feelings and handling negative emotions, friendships and social skills, organizational strategies and handling school work, and a dedicated session to review past topics. At the end of each session, parents were given a set of “take home points” and were encouraged to try activities at home with their children.

Measures

Once children are started on medication for ADHD, chronic care management is initiated and requires that pediatricians schedule follow-up visits to review medication effects, overall functioning, monitor vital signs and growth, in addition to refilling prescriptions. Our primary outcome of interest was determining the effect the intervention had on families’ adherence to routine ADHD care plan that included follow-up visits every 3 months. Therefore, the total number of clinic visits for routine ADHD follow-up was examined over the study period (expected 5 over 12 months), comparing visit rates between intervention and control patients. Intervention families were required to sign in at the beginning of each group visit. Therefore, these sheets were reconciled against electronic chart documentation. Clinic visits for control families were only captured by electronic chart documentation. As the primary outcome of interest was whether families adhered to routine ADHD follow-up visits, electronic chart abstraction data regarding visit type (group or individual) and reason for visit were coded for
each subject. Secondary outcomes of interest included measurement of the intervention’s impact on parent-reported ADHD symptoms, adaptive functioning and quality of life. Participants completed each of the following scales at two time points: baseline and at study completion 12 months later.

**NICHQ Vanderbilt ADHD Diagnostic Rating Scale-Follow Up (VADRS-F).** Parents were asked to complete the Vanderbilt ADHD Diagnostic Rating Scale-Follow up version at baseline. This validated parent-report instrument is designed to measure ADHD symptoms and impairments related to performance. Parents rated 9 symptoms comprising the hyperactivity/impulsivity subscale and 9 symptoms comprising the inattention subscale on a 4-point scale from “0” = not at all to “3” = very often. Total number of symptoms rated “2” or “3” are added for each subscale. A set of 8 performance items is rated from 1 to 5 with greater numbers indicating impairments. To meet diagnostic criteria for ADHD, scores of 6 or more and at least 1 performance score of at least 4 or higher are required. Consideration of the ADHD subtype (primarily inattentive, primarily hyperactive-impulsive or combined) was also done based on scoring of the VADRS-F. Data were re-coded so that if a child met diagnostic criteria for any subtype of ADHD based on clinical scoring of the VADRS-F was coded as “1” or not meeting criteria was coded as “0”. Parents were given the companion teacher-report form and instructed to provide the tool to their child’s teacher.

**Home Situations Questionnaire (HSQ).** The HSQ is a parent-reported measure designed to assess how various symptoms of ADHD affect children’s ability to function in the home environment and the extent to which ADHD symptoms disrupt daily activities. Parents rate
whether the child has difficulty following parental instructions regarding various tasks and if a problem, rate the severity of the situation on a 9-point scale (higher scores indicate more severity).

**Child Health Questionnaire-28 (CHQ-28).** Parents completed the CHQ-28, a validated quality of life instrument designed and normed for parents of children 5 to 18 years of age\textsuperscript{20}. The CHQ-28 is completed by the parent and when scored results in two component summary scores (physical and psychosocial). Two abbreviated versions (CHQ-50 and CHQ-28) were derived from the longer CHQ-87. The CHQ-28 demonstrates adequate discriminant validity and internal consistency for the 2 summary scales and significant test-retest reliability, particularly for the psychosocial summary scale\textsuperscript{21}. The CHQ measures 14 unique physical and psychosocial concepts. Responses can be analyzed separately and derive numerous profile scores or combined to derive CHQ summary scores, a physical and psychosocial score. Higher scores indicate more favorable health and well-being. This scale includes normative data to make it possible to interpret a child health scale score or the average score for a group of children by comparing study sample scores to the general US population of children with similar health conditions, such as ADHD\textsuperscript{22}.

**Parenting Sense of Confidence Scale (PSOC).** With this scale, parents rated their agreement to 16 statements on a 6-point Likert scale. The instrument has two factors, satisfaction and efficacy\textsuperscript{23}. 
Attitudes, Satisfaction, Knowledge and Medication Experiences with ADHD Medicine Treatment (ASK-ME) Survey. To measure parental knowledge and attitudes about stimulant treatment for ADHD, parents completed this survey comprised of 8 knowledge, 7 attitudinal and 8 satisfaction items. Scores are added within each subscale. Higher scores are associated with more knowledge, more positive attitude and more satisfaction towards ADHD medication treatment.

Sample characteristics and demographics. Parents were asked to report on their age, sex, highest level of education completed, marital status, race/ethnicity, and health literacy status (having 10 or more children’s books in the home, needing help understanding pamphlets, not feeling confident filling out medical forms). Parents also reported the child’s age and sex.

Statistical Analysis
Sample characteristics and number of visits for routine ADHD follow-up were examined for the entire sample, differences between subjects at baseline and follow up compared using Fisher’s exact test (if cells had fewer than 5) or chi square. For continuous variables (PSOC, CHQ-28, HSQ and ASK-ME), longitudinal linear mixed models were used to compare scores over time (baseline vs. one-year follow-up). Child and family were random effects and group was a fixed effect. The group by time interaction was included. If the interaction term was significant at the 0.10 level of significance, group effects were investigated at each time. A variance components variance-covariance structure was assumed. For binary variables (VADRS-F any diagnostic criteria met and combined criteria met), a generalized linear model approach (GEE) was used to test for the effect of group over time. The binomial response probability distribution and the
logit link function were used. When analyzing the CHQ-28 results, the population mean was obtained from the scoring manual and plotted on the graph to allow for easy comparison of the study sample average scores to the population mean by visual inspection; no formal statistical analysis was performed. The study protocol was submitted to our institutional review board and approved prior to the initiation of study procedures.

**RESULTS**

This pilot study started in September 2012 and the final data collection and group visit were completed in October 2013. A total of 47 families met study eligibility requirements. Of these, 24 were from parents who completed an interest form and an additional 23 were from our clinic registry or pediatrician referral. After initial telephone screening procedures to ensure study eligibility, parents and children were randomized into the intervention or control arms. The final enrolled sample consisted of 9 parents and 13 children (3 of the 9 families included multiple siblings) in the intervention arm and 11 parents and 16 children (5 of the 11 families included multiple siblings) in the control arm.

The average age of child participants was 10 years (range between 6-14 years of age), with a majority of the children being male (intervention: 62% or 8/13 vs. control: 81% or 13/16; p=0.41). All of the enrolled parents were female. There were no significant differences among parents assigned to the intervention or control on the basis of age, race/ethnicity, marital status, highest level of education and health literacy status. Eight of the children assigned to control and 10 in the intervention had comorbid oppositional defiant disorder per DSM-IV criteria. One child in the intervention group had a known diagnosis of post-traumatic stress disorder and was being
seen by a child psychiatrist for that condition. One child in the control group had Tourette syndrome. See Table 1 for study sample characteristics.

During the study period, 7 of 9 intervention families who attended the first group visit attended all subsequent sessions. The reason for intervention discontinuation for one family was a move out of state due to parent employment. The other family had significant psychosocial issues that prohibited participation. Intervention families attended all 5 expected routine follow up visits compared to an average of 3.4 visits for control families (p<0.01).

All the children were diagnosed with ADHD before the study started, using the AAP recommended guidelines. At the beginning of the study, the proportion of children treated but still meeting ADHD criteria, based on the VADRS-F, did not significantly differ between the groups (p=0.86). At baseline, 6/13 (46%) of the children in the intervention arm and 11/16 (69%) of the children in the control arm met DSM-IV clinical criteria. Trends were examined on the basis of the proportion of children whose parent-reported symptoms worsened, improved or stayed the same. While more intervention children continued to not meet criteria or showed improvement in parent reported symptoms (combined subtype at baseline and only hyperactive/impulsive subtype at follow-up) compared to control children, this finding was not significant (p=0.15).

There was a possible group by visit interaction for the proportion of children meeting the combined ADHD criteria (p=0.10) so group differences were tested separately at each visit. At baseline, 31% (4/13) children in the intervention arm and 44% (7/16) in the control arm had at least 6 parent-reported symptoms on both the hyperactive and inattention scales of the VADRS-F (p=0.63). At 1 year, 8% (1/13) children in the intervention arm and 56% (9/16) in the control
arm had at least than 6 parent-reported symptoms on both the hyperactive and inattention scales, thus meeting criteria for these ADHD subtypes (p=0.04). See Table 2.

Children in the intervention group had improved adaptive functioning compared to controls as measured by the HSQ severity subscale. There was a significant group by time interaction (p=0.03). The severity subscale score did not significantly change over time for controls (baseline mean = 4.7; 1-year follow-up mean = 4.4; p=0.8003). The severity score did significantly decrease in the intervention group (baseline mean = 5.5; 1-year follow-up mean = 3.7; p=0.004). There was not a significant group by time interaction for the Home Situations total score (p=0.20), nor was there a significant difference between the groups (p=0.11); however, the scores in both groups decreased over time (p=0.04). The mean total score within groups decreased from 8.7 to 7.6 for controls and 7.9 to 4.7 for families receiving the intervention. However, the difference in decrease between the groups was not statistically significant (p = 0.20). See Figure 1.

Results from CHQ-28 administration show that our entire study sample reported poorer quality of life, particularly within the psychosocial domain compared to the population mean. Study sample summary scores for physical functioning were not significantly different than the population mean. See Figures 2a-2c.

There were no significant changes for overall quality of life (CHQ-28), parenting confidence or parental knowledge (PSOC), attitudes or satisfaction with medication experiences (ASK-ME) over the course of the study. However, families in the intervention group had significant improvements in two subscales of the CHQ-28: general health perceptions (p = 0.05) and improved quality of life related to family activities (p=0.001). A trend towards improvement in the amount and performance of schoolwork and activities with friends was true for
intervention families over time (p = 0.07) as compared to the control group. See Figures 2a-c. Overall quality of life as measured by the CHQ-28 continued to remain lower overall when compared to families with children without the disorder.

Almost all children were on medications through the study period and medication titration per accepted standard of care occurred during the individual time with the pediatrician after group visits for families assigned to the intervention. Even though outside the scope of this paper, debriefing with families occurred throughout the study and at the last group session. We learned one child had not been on medications at the start of the study but by the end the parent had become more comfortable with the decision and started medication on the basis of what she had learned and heard from other parents in the groups. An additional parent ended up stopping her child’s medication by the end of the study due to the child expressing not wanting to be on it because of perceived side effects.

DISCUSSION

In our study, families who participated in group visits for ADHD follow-up completed more of the recommended clinic visits over the study period compared to families assigned to the control arm. Our findings are encouraging given that prior to the intervention the no-show rate at the study clinic for ADHD follow-up visits was 30%, whereas the overall no-show rate for all other patients was 20% based on monitoring by the clinic for quality improvement efforts. This was despite the fact that there existed a clinic policy that families bring children for an in-person examination on a quarterly basis to receive ADHD medication refills. We encountered a few months when postponement was necessary until the following month so at least three or more families could attend. Our families were willing to rearrange their schedules to be able to attend.
As our clinic made the effort to schedule the same groups of parent-child dyads together for subsequent visits, it is likely that families made the effort to attend subsequent visits for ongoing support from those they connected with and felt comfortable talking to. If families in the intervention arm had acute behavioral issues related to ADHD (for example, suspension), recommendations were made to schedule a separate individual visit to ensure adequate time to discuss this with the pediatrician and prevent too much of the group portion from being overly focused on a particular child. This decision was also in part to ensure all families attending group would be seen in a timely fashion and thus not prolong the overall appointment. Parents in the intervention reported fewer ADHD symptoms and improved child functioning in the home. Even though all families in our study reported poorer quality of life compared to the overall population mean, findings of a positive change within two psychosocial subscales show early promise that this intervention may improve the support families receive, yet the mechanism is still unclear (more time with the pediatrician to provide education, normalization of experiences from group discussion or both).

Parenting a child with ADHD is often challenging and often leads to profound parenting stress and poor parent-child interactions\textsuperscript{28-30}. Moreover, needs change over the course of the condition as the child matures. As with any pediatric chronic condition, it is imperative to engage both parents and children in the process of self-care to improve short and long-term outcomes\textsuperscript{21,31}. Our promising findings add support to the consideration of using a group visit model to improve adherence to recommended visits and medical home management of chronic conditions\textsuperscript{14,16,32,33}.

Similar to past studies our sample reported ongoing clinically relevant limitations in psychosocial functioning, but no significant impairments in physical health compared to
normative populations\textsuperscript{34}. However, we found as intervention parents reported a reduction in ADHD symptoms, there was a corresponding parent-reported increase in children’s adaptive functioning in the home. This finding is meaningful because even though combined treatment of ADHD with medication and behavioral strategies produces optimal outcomes related to functioning, access to such coordinated treatments in the community is unreliable and can also be difficult to access\textsuperscript{35,36}. At baseline, parents of children in both the intervention and control arms reported less than 6 ADHD symptoms overall. This was not surprising as parents of children who are on medication for ADHD often end up reporting less ADHD symptoms over time; however, these children often have residual impairment\textsuperscript{3}. This was the case in our study sample as evidenced by the higher HSQ severity scores at baseline for both groups that measured adaptive functioning. In addition, parents receiving the intervention also reported improved overall general health perceptions of their children. One possible explanation for this is that intervention families perceived their child having improved general health from overall improvement in parent-child relationships, child functioning and quality of life.

We have shown our intervention, delivered in the setting of a patient-centered medical home by two general pediatricians can be done despite the systems-level changes (i.e. scheduling) needed for its implementation. Even though we did not test intervention delivery by other providers who might be co-located in the pediatric medical home, such as social workers, nurses or psychologists, it is an important future direction. While outside the scope of this current paper, another important consideration is the impact group visit models have on overall visit time, the amount of effort needed to schedule groups and provider and family satisfaction. Our intervention included active communication, support and shared decision making between the pediatrician and family integrated within chronic disease management, which is an important
factor in promoting treatment adherence and visit attendance. In addition, we collected measurement of meaningful outcomes for families, albeit preliminary. It is important to not only include measurement of changes in ADHD symptoms via VADRS-F scores, but also on outcomes related to overall quality of life and adaptive functioning when assessing the impact of an intervention, especially if it necessitates a systems-level change.

There are a few limitations to consider when interpreting the results of this study and limit the generalizability of our findings. Our study sample was small and from one pediatric clinic. The general pediatric clinic was based in an outpatient center affiliated with a pediatric hospital and academic center. We reported national norms for the Child Health Questionnaire tool used to measure quality of life. While our sample was small and from one clinic, our sample of children with ADHD reported similar quality of life as compared to the population mean, which represents a larger and nationally normed sample. Moreover, even though residents are allowed to see patients on select days at this clinic, the lead pediatric facilitator had a large panel of ADHD patients. All but 2 families included in the study were from her panel. Additional study of this model is warranted in private practices or community practices to understand whether it can be done in other types of pediatric clinics. Pediatric facilitators running the group intervention also saw the individual families assigned to usual care. This may have led to some carry over of content taught during group to individual families assigned to the control arm. However, what was missing for the control families was exposure to the group dynamic. Moreover, families who participated were likely highly motivated and/or had less schedule conflicts to attend the group visits when offered. Clinics with the ability to offer multiple group visit appointments each month may be able to better accommodate families’ schedules. We conducted multiple measures, and a few of our study findings were not statistically significant.
but showed promising trends. In this pilot study, we lacked the power to achieve statistical significance on all of these changes or adjust for multiple comparisons. All data collection tools were based on parent-report, which are subject to social desirability and recall bias. However, while we sought to obtain teacher ratings on the VADRS-F per clinical care guidelines, so few were returned that we had incomplete data. However, this was a pilot study and more work is needed with a larger sample.

CONCLUSION

Group visits for ADHD chronic care management resulted in greater adherence of recommended ADHD follow-up visits to the clinic. Parents participating in group visits reported greater improvements in child ADHD symptoms and functioning in the home. Preliminary findings support the innovation of this intervention and its promise for improving family functioning with general pediatricians providing enhanced support to small groups of parents and children.

ACKNOWLEDGEMENTS

The authors wish to thank the clinical support staff, nursing and physicians at the study clinic who supported this study. We wish to thank all the parents and children who participated in the study. We also wish to thank the Pediatric Research Network (PResNet), especially XXXX and XXXX for conducting study procedures and working closely with the clinical staff to coordinate scheduling and research efforts. A special thank you XXXX for preparing parent and child folders prior to each group visit.
Table 1. Study sample characteristics

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Table 2. Parent VADRS-F Scores at Baseline and Follow-up by group

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Figure 1. Improvements in adaptive functioning by parent report on the Home Situations Questionnaire as change in mean severity scores over time.

A.
Figure 2. A. Changes in CHQ-28 psychosocial subscale scores for general health perceptions. B. Changes in CHQ-28 psychosocial subscale scores for parent-rated family activities. C. Changes in CHQ-28 psychosocial subscale scores for limitations due to emotional difficulties. CHQ-28, Child Health Questionnaire 28.
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Figure Legends.

Figure 1. Improvements in adaptive functioning by parent report on the Home Situations Questionnaire (HSQ) as change in mean severity scores over time.

Figure 2a. Changes in CHQ-28 psychosocial subscale scores for general health perceptions
Figure 2b. Changes in CHQ-28 psychosocial subscale scores for parent-rated family activities
Figure 2c. Changes in CHQ-28 psychosocial subscale scores for limitations due to emotional difficulties