



# HHS Public Access

Author manuscript

*Int J Ment Health Addict*. Author manuscript; available in PMC 2019 April 23.

Published in final edited form as:

*Int J Ment Health Addict*. 2012 December ; 10(6): 791–803. doi:10.1007/s11469-012-9376-3.

## Comparing the Effectiveness of On-Line versus In-Person Caregiver Education and Training for Behavioral Regulation in Families of Children with FASD

**Julie A. Kable,**

Marcus Autism Center, Children's Healthcare of Atlanta, Atlanta, GA, USA

Department of Pediatrics, Emory University School of Medicine, Atlanta, GA, USA

Marcus Autism Center, 1920 Briarcliff Road, Atlanta, GA 30329, USA

**Claire D. Coles,**

Marcus Autism Center, Children's Healthcare of Atlanta, Atlanta, GA, USA

Department of Pediatrics, Emory University School of Medicine, Atlanta, GA, USA

Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, GA, USA

**Dorothy Strickland,** and

Virtual Reality Aids, Inc., Raleigh, NC, USA

**Elles Taddeo**

Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, GA, USA

### Abstract

Different formats for delivering parent education designed to improve the functioning of children with FASD were evaluated. Participants were randomly assigned to a treatment condition: (1) Community Standard/Informational Packet, (2) Group Workshops, and (3) Internet Training. Overall satisfaction was high for all formats but the Workshop group received higher ratings on usefulness, understandability, amount, overall satisfaction, and willingness to recommend than did the Community group and higher ratings than did the Internet group on amount of information and overall satisfaction. All three groups improved in their knowledge of behavioral learning principles but only the Internet and Workshop groups made significant gains in knowledge of FAS and advocacy. Improved behavior was only found in the Workshop and Community conditions. The results suggest all forms of parent education have some benefits but the child's degree of alcohol-related impairment, severity of behavioral symptoms, and overall goals of the intervention may influence optimal choice.

### Keywords

Prenatal alcohol; Intervention; Parent training; Fetal alcohol syndrome

---

Research on the teratogenic effects of prenatal alcohol exposure over the past 35 years has documented a range of physical, cognitive, and behavioral abnormalities, which are commonly referred to as Fetal Alcohol Spectrum Disorders (FASDs, (Warren et al. 2004)). Fetal Alcohol Syndrome (FAS) is the most severe condition along this range and is characterized by a distinct pattern, including specific facial dysmorphism, growth retardation, and central nervous system dysfunction (Stratton et al. 1996). Despite attempts to prevent alcohol consumption during pregnancy, estimates of the prevalence of FAS within the United States have ranged from 0.5 to 3.0 cases per 1000 live births (May, Gossage, Smith, et al. 2009) and as many as 1 in 100 live births have been estimated to fall within the spectrum of fetal alcohol effects, known as FASDs (Cordero et al. 1994; May, Gossage, Kalberg, et al. 2009; Sampson et al. 1997). There is widespread recognition that FASD occurs across various ethnic groups throughout the world (Bray and Anderson 1989; May et al. 2008; May, Gossage, Smith, et al. 2009; May et al. 2004; May et al. 1983; O’Beattie et al. 1983; Olegard et al. 1979; Spohr and Steinhausen 1984; Streissguth et al. 1993; Tanaka et al. 1981). The annual estimated cost associated with this disability has ranged from US\$74.6 million (Abel and Sokol 1991) to US\$5.0 billion (Burd et al. 2003). Because total prevention of FASDs remains unattainable at this time, effective strategies for the treatment of FASDs are needed and providing such care, in readily available format, was the top priority identified in a series of “town hall” meetings conducted with affected families across the United States (Ryan et al. 2006).

A critical component of facilitating habilitation and positive adaptation for children with FASD is informing caregivers of the nature of the neurodevelopmental deficits that their children have, explaining to them the impact of these deficits on their child’s everyday functioning, and arming them with effective strategies to provide positive behavioral supports. In our previous work, we implemented caregiver training programs delivered via workshops within the context of a comprehensive habilitative program that was designed to improve math and behavioral functioning (Coles et al. 2009; Kable et al. 2007). The training programs were well received, improved caregiver knowledge, and improved behavioral functioning as rated by parents and teachers at a 6-months post-test (Coles, et al. 2009). Other parent or caregiver training programs have also had similar success (Bertrand 2009; Olson et al. 2009) in working with caregivers of children with FASDs and these findings are not surprising as parent training programs have been found to be beneficial for children with other developmental disabilities (Matson et al. 2009; Wade et al. 2008; Wade et al. 2009).

The current study explored delivering parent or caregiver education to families in different formats within the context of a randomized clinical trial. This allowed us to further evaluate the workshop intervention as our previous work provided only information regarding changes in the outcomes using a simple pretest to posttest design. In addition, we opted to explore the impact of packaging the information within the context of a web-based distance learning caregiver/parent training program. There is a paucity of diagnostic and treatment clinics for children with FASDs. This often means that families travel long distance to obtain treatment services. From our own experiences in our clinic, we knew that distance to our treatment facilitate was often a barrier to obtaining services and access to community therapists was often limited for our clients living in rural geographical areas. Community therapists having the appropriate expertise in FASD and its neurodevelopmental

consequences were virtually non-existent. As such, we were interested in the efficacy of a distance-learning model for delivering the information to families.

Parent training programs have been successfully adapted to an interactive CD-ROM format resulting in improved parental knowledge and parenting skills and reductions in child behavior problems (Gordon 2000) and to web-based format resulting in improved knowledge of basic parenting skills and high ratings of satisfaction (Bert et al. 2008). This methodology has been applied to specialized parent training, including a program for caregivers of foster-care children (Pacifi et al. 2006) and children with head trauma (Wade, et al. 2009). These outcomes suggest that distance-learning techniques are promising tools for reaching caregivers of children with FASDs who do not have immediate access to specialty clinics and services.

Although there are many web-based sites that provide basic information about FAS, including what it is and how to diagnosis the disorder, none provide additional information to families on how to support their child's positive behavioral functioning. Consequently, we translated our workshop-based parent training programs into a web-based format. We hypothesized that parent training programs delivered via a workshop or web-based format will be viewed positively by caregivers and result in improved knowledge for caregivers and a reduction in problem behaviors for their children.

## Materials and Methods

### Participant Recruitment

Participants were recruited from a multidisciplinary FAS diagnostic clinic in the Atlanta metropolitan area using an archival clinical database and active case logs collected during the recruitment period. Children qualifying for the study were identified by clinicians from medical records under a HIPAA partial waiver. After an initial screening, qualifying guardians completed a consent procedure and signed an informed consent document approved by the Human Subjects Committee of the Emory University School of Medicine. All participants were required to have a clinical diagnosis of FAS or partial FAS using the Institute of Medicine criteria (Stratton, et al. 1996) or significant levels of alcohol-related dysmorphology. Children who did not show any evidence of physical effects of alcohol exposure were not recruited for participation.

The assessment of the physical effects of prenatal alcohol exposure was done through an existing fetal alcohol diagnostic clinic. During their clinical visit, all children received a physical examination using a standard pediatric dysmorphia checklist (Coles, et al. 1997) by a pediatric geneticist with specialized training in assessing alcohol-related dysmorphic features. This Checklist is a modification of the usual "genetics" checklist where characteristics associated with the disorder are listed and weighted based on their saliency for the diagnosis (e.g., hypoplastic philtrum is a "3"). The items are summed to yield a dysmorphia index. Scores greater than 10 are assumed to indicate significant levels of alcohol-related dysmorphology. The Checklist has been evaluated repeatedly as part of longitudinal research studies from birth to adolescence with individuals prenatally exposed

to alcohol receiving higher total scores in comparison to non-exposed controls (Coles et al. 1991; Coles et al. 1997b).

Participants were randomly assigned to a treatment condition. The first condition consisted of being given a packet of information regarding FASD (Community group). The packet contained basic information regarding how the diagnosis was made, what the neurodevelopmental consequences (i.e. cognitive, emotional, and behavioral) were, and how to access a variety of community services and information sources. This packet was typically given to individuals diagnosed with an FASD in the existing clinic and represented the community standard of care.

The second condition consisted of two workshops (Workshop group) delivered to caregivers. The first workshop educated parents about FAS and provided information about special education and methods for advocating for their children with school systems. The second provided training in how to build positive behavioral regulation skills in children. The parent training workshops were conducted by the investigators or graduate students in clinical psychology who were trained and supervised by the investigators. Workshops were held in evenings or weekends and lasted for 2 hours each. Parents were given an informational manual elaborating workshop content to take home to use as a reference.

The web-based parent education program (Internet group) was developed in collaboration with the Virtual Reality Aids, Inc (VRA). The company specializes in providing education resources materials for families and children with developmental disabilities and other special education needs and previously collaborated with the investigators in developing software to teach safety skills to children with FASDs (Coles et al. 2007). The web-based delivery of the parent education material consisted of web pages in html format and a web-based database that collected information regarding the pre- and post-test knowledge tests. The web material was housed on a server owned by VRA and was accessible over the internet. The database was password protected and information was collected regarding caregivers' history of logging onto the site, accessing the various webpages, and responses to knowledge questionnaires. In addition, caregiver manuals were accessible via the web in Adobe pdf format. The webpages were designed to parallel the workshop information. This was accomplished using similar graphics from the power point slide show used in the workshop on the webpages and incorporating the information provided by the speaker in written text form on the webpage. Families who did not have access were allowed to use the computers in the family resource room at the treatment center. Consultation regarding use of the software, computer, and accessing the materials via the web was provided as needed.

As part of their routine clinical care, all participants had exposure to a verbal feedback regarding their child's comprehensive multidisciplinary assessment, discussion of their child's medical diagnoses and referrals to appropriate treatment services as needed, including a community FAS support group. To control of individual differences in baseline levels of knowledge regarding FAS among the participants, a repeated measures (baseline and post-treatment) experimental design was used to assess treatment effects.

## Assessment Procedures

Parents were assessed prior to being assigned to a condition and then after completing their training experience. Outcome data was collected on parental satisfaction, knowledge of information delivered, and perceived behavioral changes in the child.

**Satisfaction**—Caregiver satisfaction was assessed using Likert scale responses to questions regarding their experiences with the specific treatment components and interactions with staff members. The scale ranged from 0–4 with 4 indicating strongly agrees and 0 indicating strongly disagrees. Participants were also given an opportunity to provide open-ended responses to items asking for “Suggestions for improvement” and “Comments” on the material and the overall program for each group. Those in the Internet condition were also asked for this information regarding their satisfaction with using the internet software and those in the Workshop condition were asked similar questions regarding their instructor after providing satisfaction ratings.

**Treatment and FAS Knowledge**—Caregiver knowledge regarding the neurodevelopmental compromises associated with prenatal exposure to alcohol, the specific challenges to learning presented by these difficulties, and behavioral regulation principles were assessed by two questionnaires using multiple choice formats: (1) the Caregiver Advocacy Knowledge Questionnaire and (2) the Behavioral Regulation Knowledge Questionnaire. Analogous forms were given before the interventions and at post testing, with order of items and their respective choices randomized for each of the assessment points to minimize practice effects.

**Behavioral Outcomes**—To measure the caregivers’ perception of their children’s behavior, the Child Behavior Checklist (Achenbach 1991a) was administered at pretest and post-test. The test includes 100 problem behaviors that are rated as “not true,” “sometimes true,” or “very true” by the reporter. Derived scores are a T-Score with a mean of 50 and standard deviation of 10 points with higher scores reflecting more behavioral disturbance. Items are clustered into subscales, which are then aggregated into summary scores. An overall Total Problems scores is reported as well as summary scores for Internalizing and Externalizing Problem Behaviors. Internalizing problem behaviors include symptoms of anxiety and depression and being socially withdrawn. Externalizing problem behaviors include symptoms of poor attentional regulation, aggression, and misconduct or acting out.

## Results

### Attrition

Eighteen of 24 (75.0%) in the Community group and 23 of 29 (79.3%) in the Workshop group completed post-testing. Of the six lost in the Workshop group, 2 did not attend any workshop, 2 completed only 1 workshop, and 2 completed both workshops but failed to complete the post-testing forms. Within the Internet group, 18 (62.1%) participants completed post-testing and 11 (37.9%) participants did not. As the software used to present the web-based information also logged the participant’s access to the various web-pages, we were able to monitor compliance on the web-based program. Of the 18 participants who

completed post-testing, 16 participants accessed all of the web pages. Of the 11 who did not complete post-testing, 9 participants did not access any pages. Of the two who accessed the pages, one accessed only 4 pages and the other accessed all 16 pages but failed to complete the post-testing questionnaires. Although the Internet group had the highest rate of attrition, the differences were not statistically significant. Distance to the treatment center had no impact on attrition rates.

### Group Characteristics

Table 1 provides sample characteristics by group status. Comparisons of demographic, birth, and neurocognitive characteristics of the participants and child protective service involvement, yielded no significant group differences but there was a trend for fewer males being assigned to the Internet group (33.3%) than in the Workshop group (43.5%) or the Community group (66.7 %) and for more Caucasians in the Internet group (61.1%) than the other two groups (Community- 27.8% and Workshop-43.5%). Although there were no group differences in percentage who had an FAS or pFAS diagnosis, there was a significant group effect on the total dysmorphia score ( $F(2, 55)=4.4, p<.017$ ). The average dysmorphia score was significantly lower in the Internet group than in the Workshop group. To determine if this was a chance group difference or an effect of the differential attrition by group, an analysis of variance with group and status of study completion (yes vs. no) as factors was conducted on the total enrolled participants. Main effects for group ( $F(2, 75)=3.1, p<.053$ ) and completion status ( $F(1, 75)=4.1, p=.048$ ) were found and a trend was found for an interaction between the two effects ( $F(2, 75)=1.9, p<.16$ ). Those in the Internet group had less dysmorphia than those in the Community group and those completing the study had less dysmorphia than those who did not. Comparisons of dysmorphia within each group by completion status, indicated that less dysmorphia was seen in those who completed the study within the Internet group ( $F(1, 27)=6.3, p<.017$ ) than those who did not complete. A trend was found for a similar effect in the Community group ( $F(1, 22)=3.1, p<.090$ ) but there were no group differences between those who completed the study or not in the Workshop group ( $F(1, 26)=.17, ns$ ). See Fig. 1 for further details. No group differences were found in the interval between pretest and post-test ( $x=140.8$  days,  $STD=97.5$ ).

### Satisfaction

A significant multivariate group effect was found in overall satisfaction ( $F(12, 128)=2.2, p<.015$ , partial eta-squared = .159) with specific univariate effects on easy and understandability ( $F(2, 69)=6.3, p<.003$ , partial eta-squared = .154), amount of information ( $F(2, 69)=6.3, p<.003$ , partial eta-squared = .154), overall satisfaction ( $F(2, 69)=5.7, p<.005$ , partial eta-squared = .142), and willingness to recommend the program ( $F(2, 69)=3.3, p<.003$ , partial eta-squared = .086). Post hoc comparisons indicated that the Workshop group gave significantly higher ratings on usefulness, understandability, amount, overall satisfaction, and willingness to recommend the program than did those in the Community group. The Workshop group gave significantly higher ratings of satisfaction than did the Internet group on amount of information presented and overall satisfaction but did not differ on the remaining satisfaction variables. In general, the Internet group's satisfaction ratings fell between those of the Workshop and Community groups but there were no significant differences between their ratings and the Community group ratings. Table 2 contains the

mean levels of satisfaction by item and the percent who agreed by group status. Distance to the treatment facility, which may have influenced motivation and receptivity to the treatment options, was not significantly related to any of the perceived satisfaction variables.

The results of the open-ended responses regarding suggestions for improvement and general comments were limited by a generally low response rate that varied as a function of group (i.e. for materials suggestions: Community-27.8%, Workshop-13.7%, and Internet 5.6%). In general, those in the Community group provided positive comments regarding the program but requested more information, that the information be packaged for other professionals who work with their children (i.e. teachers), or that they have access to face to face instruction. Comments from the Workshop group were overwhelmingly positive but requests were made for more examples and more information. Generally, complimentary statement provided by those in the Community packet group were less enthusiastic (i.e. “very informative”) than the Workshop group (i.e. “Great!” or “Very Good meeting and very helpful love it”). Comments provided by those in the Internet group were generally negative and focused on frustration with having to navigate in a specific path through the web-based information and with expense of printing out portions of the material.

## Knowledge

Paired samples t-tests were performed for each group on each measure of knowledge change to assess improvements within each treatment condition. The Community group made significant gains in knowledge on behavioral regulation (BR:  $t(17)=-2.7$ ,  $p<.01$ , partial eta squared = .305) but only had a trend for improvement on the caregiver advocacy knowledge (CA:  $t(17)=-1.9$ ,  $p<.08$ , partial eta squared = .170). The Internet group made significant gains in both areas of knowledge (CA:  $t(11)=-2.8$ ,  $p<.02$ , partial eta squared = .412; BR:  $t(11)=-3.4$ ,  $p<.005$ , partial eta squared = .526) as did the Workshop group (CA:  $t(21)=-3.9$ ,  $p<.001$ , partial eta squared = .422; BR:  $t(11)=-6.7$ ,  $p<.000$ , partial eta squared = .668). Examination of the magnitude knowledge change scores across participants suggested that they were normally distributed. See Table 3 for the means by group at each time point.

To compare the gains across treatment condition, a repeated measures analysis of variance was conducted separately on the CA and BR knowledge data. Time (pretest vs. post-test) was the repeated measure and group (Workshop, Internet, vs. Community) was the between measure. A significant time or change effect was obtained from pre to post test across groups on both measures (CA-  $F(1,49)=22.4$ ,  $p<.000$ , partial eta squared = .313; BR-  $F(1,50)=51.6$ ,  $p<.000$ , partial eta squared = .508). A significant main effect for group was also found on both measures (CA-  $F(2, 49)=4.2$ ,  $p<.021$ , partial eta squared = .146; BR-  $F(2, 50)=3.2$ ,  $p<.049$ , partial eta squared = .113) with the Internet group demonstrating higher scores than the Workshop group on the CA responses and the Community group on the BR responses. There was not a significant group \* time effect, which would have indicated a differential treatment effect, on CA but a trend was found on the BR data ( $F(2,50)=2.0$ ,  $p<.152$ , partial eta squared = .073).

Additional analyses were conducted to assess the role that caregiver education level may have played in their ability to benefit from the instructional programs. Although caregiver education was significantly related to knowledge gains at each time point (CA Pretest:  $r=.57$ ,

$p < .000$ ; CA Posttest:  $r = .52$ ,  $p < .000$ ; BR Pretest:  $r = .34$ ,  $p < .000$ ; BR Posttest:  $r = .51$ ,  $p < .000$ ), there were only trends found in the relationship between the gain as a function of treatment (CA:  $r = -.21$ ,  $p < .13$  and BR:  $r = .23$ ,  $p < .10$ ). Examination within treatment groups indicated that the strongest relationship between caregiver educational level and knowledge gains was in the Community group (CA:  $r = -.36$ ,  $p < .16$  and BR:  $r = .44$ ,  $p < .08$ ) as compared to the Workshop (CA:  $r = -.15$ ,  $p < .52$  and BR:  $r = .25$ ,  $p < .26$ ) and Internet (CA:  $r = -.03$ ,  $p < .93$  and BR:  $r = .18$ ,  $p < .57$ ) groups.

### Child Behavioral Functioning

Dependent t-tests were carried out for each group to assess change from pretest to posttest. For total problem behaviors, a significant effect was found in the Workshop group ( $t(1, 21) = 2.7$ ,  $p < .014$ , partial eta squared = .254) and a trend was found for the Community group ( $t(1, 17) = 1.8$ ,  $p < .09$ , partial eta squared = .164). A trend was found in the Community ( $t(1, 17) = 2.0$ ,  $p < .06$ , partial eta squared = .192) on the externalizing problem behaviors scale as well. There were no significant changes on the internalizing problem behaviors for any of the groups and there were no significant change effects in the Internet group.

A repeated measures analysis of variance was then conducted on the behavioral outcome data to compare the level of change across groups. An initial examination of the pre-existing group differences (gender, race and dysmorphia) and their relationships to the behavioral data was done to determine if it was important to use them as covariate. Dysmorphia level and race were not significantly related to any of the three behavioral indices at either time point but trends were found for relationships between gender and pretest total problem scale and post-test externalizing problem scale. As a result, gender was used as covariate in the analysis. The least squares means are presented in Table 3 for each measure by group and treatment period. On the total problems scale, a trend was found for an overall treatment effect ( $F(1, 50) = 3.2$ ,  $p < .081$ , partial eta squared = .060) and a significant treatment by group effect was found ( $F(2, 50) = 3.2$ ,  $p < .048$ , partial eta squared = .115) with improvements in behavioral ratings only in the Community and Workshop groups. On the externalizing scale, a significant general treatment effect by gender ( $F(1, 50) = 5.3$ ,  $p < .026$ , partial eta squared = .096) was found with males showing greater improvements than females and a trend was found for a time by group effect ( $F(2, 50) = 2.9$ ,  $p < .064$ , partial eta squared = .104) with those in the Community and Workshop group showing improved behavior but those in the Internet group not. Finally, for the internalizing scale, there was a trend for a general treatment effect ( $F(1, 50) = 2.2$ ,  $p < .14$ , partial eta squared = .043) with post-test scores being lower than those at pretest.

Examination of the pattern of change scores found on the externalizing and total problem scores suggested that the treatment effects were skewed (Externalizing = 1.175 and Total = 1.492) such that about 50% of participants made positive gains with half of these making what could be termed clinically significant changes ( $> 1/2$  of standard deviation).

### Discussion

Parents or caregivers of children with FASDs have been disappointed in the availability of appropriate interventions to facilitate their child's everyday functioning. Providing families



basic information about the neural damage that their child may have experienced and the impact this damage has on their child's adjustment and attainment of basic life skills is a first step in developing a family-centered rehabilitative care plan. The results of this study indicated that parents were generally satisfied with the information provided to them, regardless of the modality with which the material was presented as over 70% endorsed agreement with positive statements about their intervention experiences. The educational interventions also resulted in parents increasing their knowledge about their child's neurodevelopmental functioning, advocacy, and behavioral regulation learning principles. Both the workshop intervention and the community packet of information resulted in gains in overall behavioral functioning but no such effects were found for those who received their information over the internet.

Although the Internet and Workshop groups made comparable changes in knowledge, the Internet group was not able to effect as much change in behavior as did the Workshop group where the greatest behavioral improvements were seen. The only differences in these two conditions were the availability of a therapist for interactive questioning during the learning process and other participants who could provide advice, counsel, and support within the context of the learning environment. Future investigations of web-based learning may want to consider the use of "webinars" where a therapist could deliver the talk, field questions, and allow for group discussion to see if behavioral outcomes are improved.

The lack of behavioral change in the children whose parents participated in the web-based delivery of parenting information is difficult to interpret given that many other web-based parent training programs do not assess actual changes in child behavior (i.e., (Bert, et al. 2008; Pacifici, et al. 2006)) and among those that do assess changes in child behavior, the results have been ambiguous. Using a CD-ROM parent training program, reductions in child behavior problems were reported (Gordon 2000) but in a sample of parents with a child who had a traumatic head injury, researchers found high satisfaction ratings and improved parental behavior but only a trend for decreasing problem behaviors and no change at all in the intensity of the child's problem behaviors (S. L. Wade, Oberjohn, et al. 2009). Unique factors related to participants in this group may have also contributed to lack of behavioral change. Although participants were randomly assigned to group, those in the internet group were found to differ on three factors. The Internet group tended to have fewer males, a greater percentage of Caucasians and to have less dysmorphia. Although racial identity and dysmorphia were not related to behavioral outcome, trends were found for the relationship between gender and behavioral functioning and the analysis indicated that males were more responsive to the intervention. The unique combination of slightly higher attrition in this group and fewer males may have diminished the potential for treatment effects.

To explore potential reasons for the higher rate of attrition in the internet group, we accessed the log records among those who did not complete the study and discovered that 9 of 11 participants who did not complete the study had failed to log in at all. This suggested that the content and formatting of the web material was not related to attrition. Instead, the initiation of the internet-based learning experience appeared to be the biggest hurdle. In addition, knowledge gains were comparable to those in the other groups suggesting that once they logged on this method was effective in educating parents.

The magnitude of behavioral changes was not normally distributed as was the change in parental knowledge, suggesting not all participants behavioral functioning benefitted equally from the interventions. Examination of the pattern of change scores suggested that about half of the children demonstrated improvements in behavioral functioning with about half of these (25% of the whole sample) demonstrating what could be termed as clinically significant gains ( $> 1/2$  of a standard deviation). This suggests that parental education programs may provide significant improvements for some children but not all and should be used as one component in an arsenal of treatment options for children and their families affected by FASDs.

Scores on the dysmorphia checklist reflect the cumulative index of physical alterations associated with prenatal alcohol exposure and has been found to be predictive of neurodevelopmental status (Blackston et al. 2005). The finding that level of dysmorphia was lower in those whose caregivers completed the study, suggests that compliance with parent or caregiver educational programs may be adversely impacted by the level of severity of impairment in the target child. This appears to be especially true for those in the internet group but was minimized in the workshop intervention that provided face-to-face therapeutic contact, suggesting choices about the method of information delivery should take into account the level of severity of the child's impairment.

Parental education level was an important predictor variable of knowledge scores for both caregiver education and behavioral regulation material at each time point but the gains in knowledge as a function of treatment were only trends. Parental education tended to be positively related to gains in knowledge of behavioral regulation material but tended to be negatively related to gains in caregiver advocacy. Parents who were more highly educated may have acquired knowledge of FASDs from other sources and thus benefited less from basic information about FASD provided in the caregiver advocacy information. Although the estimates of this relationship within each treatment group are limited by power, the results suggested that this effect was strongest in the group who received the community packet of information where the greatest level of independent study was needed.

Careful attention was paid to equating the content of the information provided to the participants in the Workshop and Internet conditions but this was not the case in the Community group. This was because the primary focus of the study was to determine if the parent education program utilized in our previous study (Coles, et al. 2009; Kable, et al. 2007) could be packaged and delivered via a web-based format. The Community group was included to provide a contrast regarding the traditional standard of care available in the community. This limits the conclusions that can drawn regarding the overall satisfaction, gain in knowledge, and improvements in behavior associated with providing information in only a manualized format as it is possible that these effects were limited in this condition as a result of the content differences. Future research would need to be done equating the information content between the Workshop and Community group to make further conclusions regarding these group differences.

Another limitation of this study is that only individuals with alcohol-related dysmorphology were included. This was done as research has shown that the severity of dysmorphia is

positively associated with severity of impact of the alcohol-related neurodevelopmental affects (Santhanam et al. 2009). Additional research should be done to determine the effectiveness of these interventions with children and their families across a full range of the spectrum of alcohol-affects.

The selection of treatment group in this study was randomized but therapists and counselors working with caregivers of alcohol-affected children have the luxury of considering many factors when making the choice of the method of delivery of information needed to assist families in understanding their children. The provider should consider the family's strengths and weaknesses in learning, including their ability to study independently, and their receptivity to computer-based learning. Finally, the provider should consider characteristics of the child in making a selection. The child's level of alcohol-related impairment may adversely impact the family's ability to complete a program that requires independent study or may not provide enough information to meet the family's needs resulting in their discontinuing the program. The results of this study suggest that parents of children who are more impaired may require more interactive face-to-face consultation to achieve behavioral change.

A multi-level system of parental support has been recommended by the developers of the Triple P-Positive Parenting Program (Sanders and Murphy-Brennan 2010). A similar perspective is also needed for parent educational interventions for children with FASDs as they come from a variety of families with varying backgrounds, learning styles, and preferences but further research is needed to assist clinicians in making empirically-based decisions regarding the selection of the various treatment options needed to optimize these children's habilitation and positive adaptation over the lifespan.

## Acknowledgements

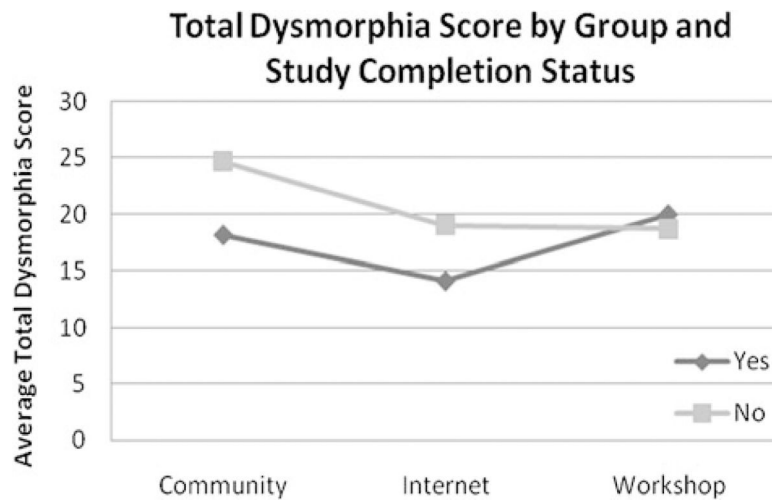
This research was carried out by with the support of the Centers for Disease Control and Prevention (CDC) Cooperative agreement # U01-DD000039-01. The authors would like to thank the children and families who participated in this research.

## References

- Abel EL, & Sokol RJ (1991). A revised estimate of the economic impact of fetal alcohol syndrome. *Recent Developments in Alcoholism*, 9, 117–125. [PubMed: 1758979]
- Achenbach T (1991). *Manual for the child behavior checklist/4–18 and 1991 profile*. Burlington: University of Vermont Department of Psychiatry.
- Bert SC, Farris JR, & Borkowski JG (2008). Parent training: implementation strategies for adventures in parenting. *Journal of Primary Prevention*, 29(3), 243–261. doi:10.1007/s10935-008-0135-y. [PubMed: 18446440]
- Bertrand J (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities*, 30(5), 986–1006. doi:10.1016/j.ridd.2009.02.003. [PubMed: 19327965]
- Blackston RD, Coles CD, & Kable JA (2005). Evidence for Severity of Dysmorphology in Fetal Alcohol Syndrome and Direct Correlation with Developmental Behavioral, Social and Educational Outcomes and to Psychotropic Medications. Paper presented at the David Smith Dysmorphology Meeting, Iowa City, Iowa.
- Bray DL, & Anderson PD (1989). Appraisal of the epidemiology of fetal alcohol syndrome among Canadian native peoples. *Canadian Journal of Public Health*, 80(1), 42–45. [PubMed: 2702544]

- Burd L, Cotsonas-Hassler TM, Martsolf JT, & Kerbeshian J (2003). Recognition and management of fetal alcohol syndrome. *Neurotoxicology and Teratology*, 25(6), 681–688. [PubMed: 14624967]
- Coles CD, Brown RT, Smith IE, Platzman KA, Erickson S, & Falek A (1991). Effects of prenatal alcohol exposure at school age: I. Physical and cognitive development. *Neurotoxicology and Teratology*, 13(4), 357–367. [PubMed: 1921915]
- Coles CD, Fernhoff PM, Lynch ME, Falek A, & Dellis E (1997). Manual for scoring the dysmorphia checklist: Newborn version. Unpublished manuscript. Emory University.
- Coles CD, Platzman KA, Raskind-Hood CL, Brown RT, Falek A, & Smith IE (1997). A comparison of children affected by prenatal alcohol exposure and attention deficit, hyperactivity disorder. *Alcoholism, Clinical and Experimental Research*, 21(1), 150–161.
- Coles CD, Strickland DC, Padgett L, & Bellmoff L (2007). Games that ‘work’: Using computer games to teach alcohol-affected children about fire and street safety. *Research in Developmental Disabilities*, 28 (5), 518–530. doi:10.1016/j.ridd.2006.07.001. [PubMed: 16965894]
- Coles CD, Kable JA, & Taddeo E (2009). Math performance and behavior problems in children affected by prenatal alcohol exposure: intervention and follow-up. *Journal of Developmental and Behavioral Pediatrics*, 30, 7–15. [PubMed: 19194327]
- Cordero JF, Floyd RL, Martin ML, Davis M, & Hymbaugh KJ (1994). Tracking the prevalence of FAS. *Alcohol And Health Research World*, 18, 82–85.
- Gordon DA (2000). Parent training via CD-ROM: Using technology to disseminate effective prevention practices. *The Journal of Primary Prevention*, 21(2), 227–251. doi:10.1023/a:1007035320118.
- Kable JA, Coles CD, & Taddeo E (2007). Socio-cognitive habilitation using the math interactive learning experience program for alcohol-affected children. *Alcoholism, Clinical and Experimental Research*, 31(8), 1425–1434.
- Matson JL, Mahan S, & LoVullo SV (2009). Parent training: A review of methods for children with developmental disabilities. *Research in Developmental Disabilities*, 30(5), 961–968. doi:10.1016/j.ridd.2009.01.009. [PubMed: 19246176]
- May PA, Hymbaugh KJ, Aase JM, & Samet JM (1983). Epidemiology of fetal alcohol syndrome among American Indians of the Southwest. *Social Biology*, 30(4), 374–387. [PubMed: 6336013]
- May PA, Gossage JP, White-Country M, Goodhart K, Decoteau S, Trujillo PM, et al. (2004). Alcohol consumption and other maternal risk factors for fetal alcohol syndrome among three distinct samples of women before, during, and after pregnancy: The risk is relative. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, 127C(1), 10–20. doi:10.1002/ajmg.c.30011.
- May PA, Gossage JP, Marais AS, Hendricks LS, Snell CL, Tabachnick BG, et al. (2008). Maternal risk factors for fetal alcohol syndrome and partial fetal alcohol syndrome in South Africa: A third study. *Alcoholism, Clinical and Experimental Research*, 32(5), 738–753. doi:10.1111/j.1530-0277.2008.00634.x.
- May PA, Gossage JP, Kalberg WO, Robinson LK, Buckley D, Manning M, et al. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews*, 15(3), 176–192. doi: 10.1002/ddrr.68. [PubMed: 19731384]
- May PA, Gossage JP, Smith M, Tabachnick BG, Robinson LK, Manning M, et al. (2009). Population differences in dysmorphic features among children with fetal alcohol spectrum disorders. *Journal of Developmental and Behavioral Pediatrics*, 31(4), 304–316. doi:10.1097/DBP.0b013e3181dae243.
- O’Beattie J, Day RE, Cockburn F, & A. Gargm R. (1983). Alcohol an the fetus in the west of Scotland. *British Medical Journal*, 287(17–20).
- Olegard R, Sabel KG, Aronsson M, Sandin B, Johansson PR, Carlsson C, et al. (1979). Effects on the child of alcohol abuse during pregnancy. Retrospective and prospective studies. *Acta Paediatrica Scandinavica - Supplement*, 275, 112–121. [PubMed: 291283]
- Olson HC, Oti R, Gelo J, & Beck S (2009). “Family matters:” fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews*, 15(3), 235–249. doi:10.1002/ddrr.65. [PubMed: 19731388]

- Pacifici C, Delaney R, White L, Nelson C, & Cummings K (2006). Web-based training for foster, adoptive, and kinship parents. *Children and Youth Services Review*, 28, 1329–1343.
- Ryan DM, Bonnett DM, & Gass CB (2006). Sobering thoughts: town Hall meetings on fetal alcohol spectrum disorders. *American Journal of Public Health*, 96(12), 2098–2101. doi:10.2105/AJPH.2005.062729. [PubMed: 17077397]
- Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, & Dehaene P (1997). Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. *Teratology*, 56(5), 317–326. [PubMed: 9451756]
- Sanders MR, & Murphy-Brennan M (2010). The international dissemination of the Triple P—Positive Parenting Program In Weisz JR & Kazdin AE (Eds.), *Evidence-based psychotherapies for children and adolescents* (2nd ed., pp. 519–537). New York: Guilford.
- Santhanam P, Li Z, Hu X, Lynch ME, & Coles CD (2009). Effects of prenatal alcohol exposure on brain activation during an arithmetic task: An fMRI study. *Alcoholism, Clinical and Experimental Research*, 33(11), 1901–1908. doi:10.1111/j.1530-0277.2009.01028.x.
- Spohr HL, & Steinhausen HC (1984). Clinical, psychopathological and developmental aspects in children with the fetal alcohol syndrome: A four-year follow-up study. *Ciba Foundation Symposium*, 105, 197–217. [PubMed: 6563987]
- Stratton K, Howe C, & Battaglia F (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention and treatment*. Washington: National Academy Press.
- Streissguth AP, Bookstein FL, Sampson PD, & Barr HM (1993). *The enduring effects of prenatal alcohol exposure on child development: Birth through seven years, a Partial Least Squares Solution*. Ann Arbor: University of Michigan Press.
- Tanaka H, Arima M, & Suzuki N (1981). The fetal alcohol syndrome in Japan. *Brain & Development*, 3 (3), 305–311. [PubMed: 7197126]
- Wade C, Llewellyn G, & Matthews J (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 351–366. doi: 10.1111/j.1468-3148.2008.00449.x.
- Wade SL, Oberjohn K, Burkhardt A, & Greenberg I (2009). Feasibility and preliminary efficacy of a web-based parenting skills program for young children with traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 24(4), 239–247. doi:10.1097/HTR.0b013e3181ad668000001199-200907000-00003. [PubMed: 19625863]
- Wade SL, Walz NC, Carey JC, & Williams KM (2009). Brief report: Description of feasibility and satisfaction findings from an innovative online family problem-solving intervention for adolescents following traumatic brain injury. *Journal of Pediatric Psychology*, 34(5), 517–522. doi:10.1093/jpepsy/jsn081. [PubMed: 18667477]
- Warren K, Floyd RL, Calhoun F, Stone D, Bertrand J, Streissguth AP, et al. (2004). Consensus Statement on FASD. FASD Terminology Summit Retrieved 03/01/2011, from <http://www.nofas.org/advocate/terminology.aspx>



**Fig. 1.**

The average of the total dysthormia (Pedscore) is displayed as a function of group status and whether or not they completed the study. Main effects were obtained for group ( $F(2, 75)=3.1, p<.053$ ) and completion status ( $F(1, 75)=4.1, p<.048$ ) and a trend was found for an interaction effect ( $F(2, 75)=1.9, p<.16$ )

**Table 1**

## Characteristics of sample

Variables	Groups			Statistic
	Workshop <i>n</i> =23	Community <i>n</i> =18	Internet <i>n</i> =18	
Child Gender- Males (%)	43.5	66.7	33.3	$\chi^2(2)=4.25, p<.119$
Child Age in Years (M, SD)	6.72 (3.4)	6.17 (2.9)	7.34 (2.7)	F (2,56)=.65, ns
Ethnicity (% Caucasian vs. Other)				$\chi^2(2)=4.1, p<.131$
Caucasian, Non Hispanic	43.5	27.8	61.1	
African American	47.8	55.6	22.2	
Mixed Race	4.3	16.7	16.7	
Primary Caregiver Education (yrs)	13.8 (2.8)	15.2 (3.0)	14.5 (2.3)	F (2,55)=1.3, ns
Living with Biological Mother (%)	56.5	35.3	35.3	$\chi^2(2)=1.8, ns$
Caregivers in Current Home	2.1 (1.2)	2.2 (1.0)	2.1 (.7)	F (2,53)=.01, ns
Number of Children in Home	1.8 (1.6)	1.6 (1.5)	1.9 (2.0)	F (2,54)=.23, ns
CPS Involvement Ever %	78.3	83.3	66.7	$\chi^2(2)=1.5, ns$
Physical Abuse %	28.6	25.0	27.8	$\chi^2(2)=.06, ns$
Sexual Abuse %	18.2	6.3	11.1	$\chi^2(2)=0.2, ns$
Number of Placements	2.5 (1.8)	1.9 (1.3)	2.5 (1.8)	F (2,56)=.68, ns
Distance to Treatment Center (miles)	31.4 (15.6)	31.9 (25.1)	33.9 (27.0)	F (2, 56)=.07, ns
Diagnosed FAS/pFAS %	95.7%	88.9%	88.9%	$\chi^2(2)=.83, ns$
Pedscore <sup>I</sup> (total dysmorphia)	20.0 (7.3)	18.2 (6.6)	14.2 (3.9)	F (2,55)=4.4, <i>p</i> <.014

<sup>I</sup>The Pedscore is the sum of the 30 weighted items on a standard pediatric dysmorphia checklist (Coles et al., 1997) used to identify alcohol-related dysmorphic features

**Table 2**

Reported satisfaction with training conditions

	Parent Intervention Condition					
	Workshop <i>n</i> =40 <sup>1</sup>		Community <i>n</i> =18		Internet <i>n</i> =17	
	Mean <sup>2</sup>	% Agree <sup>3</sup>	Mean <sup>2</sup>	% Agree <sup>3</sup>	Mean <sup>2</sup>	% Agree <sup>3</sup>
Information Useful <sup><i>T</i></sup>	3.60 (.67)	90.0	3.17 (.62)	88.9	3.29 (.92)	82.4
Info Easy to Understand **	3.75 (.44)	100.0	3.28 (.58)	94.4	3.47 (.72)	88.2
Info Presented in the Right Amount **	3.68 (.57)	95.0	3.06 (.94)	83.3	3.12 (.99)	70.6
Info Clear and Easy to Follow	3.52 (.75)	85.0	3.29 (.69)	88.2	3.47 (.72)	88.2
Overall Satisfaction **	3.62 (.63)	92.3	2.88 (.93)	76.5	3.18 (.88)	82.4
Recommend the Program *	3.59 (.68)	89.7	2.89 (1.0)	77.8	3.24 (.97)	76.5

<sup>*T*</sup>Trend

\* &lt;.05

\*\* &lt;.01

\*\*\* &lt;.001

<sup>1</sup> Only 23 participants assigned to this group but some families brought more than one person and everyone who attended was asked to complete satisfaction surveys<sup>2</sup> Using a Likert scale ranging from 0–4 with 4 indicating strongly agree and 0 indicating strongly disagree<sup>3</sup> Percent in agreement indicates the percentage who stated they agreed or strongly agreed with statement



**Table 3**

Outcomes: comparison of caregivers' knowledge and child behavior at pre and post test

Knowledge Area	Parent Intervention Group					
	Workshop <i>n</i> =22		Community <i>n</i> =18		Internet <i>n</i> =16	
	Pretest	Posttest	Pretest	Posttest	Pretest	Posttest
Caregiver Advocacy	14.3 (4.1)	16.4 (4.4)	16.3 (4.8)	17.8 (2.9)	16.3 (4.8)	20.3 (3.5)
Behavioral Regulation	10.2 (3.4)	13.5 (3.3)	10.2 (3.8)	11.9 (4.0)	12.6 (3.2)	15.7 (3.4)
CBCL Total Score <sup>a</sup>	64.4 (2.5)	61.8 (2.6)	66.5 (3.3)	65.2 (3.4)	62.8 (3.3)	64.5 (3.5)
CBCL Internalizing <sup>a</sup>	60.1 (2.5)	58.2 (2.6)	61.0 (3.3)	60.0 (3.3)	59.1 (3.4)	30.7 (3.3)
CBCL Externalizing <sup>a</sup>	62.6 (2.8)	60.6 (2.9)	66.7 (3.6)	64.3 (3.9)	61.0 (3.7)	64.3 (3.8)

<sup>a</sup>Values are least square means of Child Behavior Checklist (Achenbach 1991) scores after controlling for gender