

The Impact of Fetal Alcohol Spectrum Disorders on Families: Evaluation of a Family Intervention Program

Lindsey S. Leenaars · Kennedy Denys ·
Dorothy Henneveld · Carmen Rasmussen

Received: 27 April 2010 / Accepted: 7 June 2011 / Published online: 18 June 2011
© Springer Science+Business Media, LLC 2011

Abstract The main purpose of the present study was to conduct a preliminary evaluation of the coaching families (CF) program, which aids families and caregivers raising children with fetal alcohol spectrum disorders (FASD). Mentors in the program work with families to educate them about FASD, access resources, and advocate on their behalf. Retrospective data from 186 families were analyzed from pre- to post-program. As expected, among caregivers there was a significant decrease in needs and increase in goal attainment from pre- to post-program. Further, there was a significant decrease in caregiver stress from pre- to post-program. Families reported high overall satisfaction with the CF program. The limitations, directions for future research, and implications for service providers were also discussed.

Keywords Fetal alcohol spectrum disorders · Community · Program evaluation

Introduction

Fetal alcohol spectrum disorders (FASD) is an umbrella term used to refer to a set of more specific diagnoses which identify a group of effects that occur in individuals with

prenatal alcohol exposure (see Chudley et al. 2005). In the United States, FASD occurs in approximately 1/100 children (May and Gossage 2001) and is one of the leading known causes of mental retardation (NIAAA 1990). Children with FASD have a number of neurological and cognitive impairments (Kodituwakku 2007), and poor behavioural, mental health, and adaptive outcomes (Rasmussen et al. 2008). In their longitudinal study, Streissguth et al. (2004) found very high rates of mental health problems, inappropriate sexual behaviours, disrupted school experiences, problems with the law, and alcohol and drug problems among those with FASD. Streissguth et al. identified five protective factors including living in a good quality, stable home environment, infrequent changes in living arrangement, not being exposed to violence, receiving services for developmental disabilities, and being diagnosed before the age of 6.

Across studies (Brown and Bednar 2004; Gardner 2000; Grantisas 2004; McCarty et al. 1999), caregivers of children with FASD expressed concern over the development of their child, lack of self-care, social support, respect and empathy from professionals, their parenting ability and their child's future. Resources needed include greater education on FASD for caregivers and the larger community, collaboration between systems, respite care, strong advocates, and financial support (Brown and Bednar 2003; Brown et al. 2005; Giunta and Streissguth 1988). Further, studies have found that fewer family resources and the presence of secondary problems associated with FASD were related to higher levels of family stress (Paley et al. 2006, 2005). These studies highlight that the effects of FASD extend beyond the individual to their families and caregivers.

It is commonly noted across the literature that support services and resources for families are essential (Chudley et al. 2005; Streissguth and O'Malley 2000). Although a

L. S. Leenaars (✉)
Department of Educational Psychology, University of Alberta,
6-102 Education North, Edmonton, AB T6G 2G5, Canada
e-mail: leenaars@ualberta.ca

K. Denys · C. Rasmussen
Department of Pediatrics, University of Alberta,
10230 111 Ave, Edmonton, AB T5G 0B7, Canada

D. Henneveld
Catholic Social Services, Edmonton, AB, Canada

number of programs offer clinical services for families and caregivers of children with FASD, the majority of these programs are not evidence-based, and thus the effectiveness of such programs remains unclear. However, in a review of five FASD interventions, Bertrand (2009) found that the key elements of success were the education of caregivers on FASD and its consequences, training in specific parenting strategies, and collaboration with community services.

Present Study

The main goal of the present study was to examine the efficacy of, and families' satisfaction with the coaching families (CF) program run through Catholic Social Services (CSS), which provides support, education, advocacy and referrals to families of children with FASD. It was hypothesized that there would be a significant overall decrease in families' needs and an increase in goal achievement from pre- to post-program, and a significant reduction in caregiver stress.

Method

Participants

The sample consisted of 186 families parenting at least one child with FASD. The contact caregiver for 88% of the families was female, and the mean age was 46 years (Range 24–69 years). Approximately 30% of the caregivers were foster parents, 23% adoptive, 19% biological mother or father, 15% kinship or biological relative, and 9% were permanent guardianship order (PGO). Seventy-eight percent were Caucasian, 18% First Nations Canadian, and 4% other. Sixty-seven percent had one child with FASD living in the household, 22% had two children, 10% had three or more children, and 2% were unknown due to incomplete case files. Approximately 59% of the children were male with the age ranging from less than 1–23 years (Mean = 10 years). Sixty-six percent of the children had a confirmed FASD diagnosis, 27% were coded as possibly having FASD, but maternal drinking was not confirmed, and 7% were suspected of having FASD, but had not yet been assessed. All FASD diagnoses made at the Glenrose Hospital are formulated based on the FASD Diagnostic and Prevention Network (FASD DPN) 4-digit coding system (Astley and Clarren 1999). Evidence of growth deficiency, facial dysmorphology, and brain dysfunction are evaluated and ranked independently on a 4-point Lykert scale, with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. The diagnostic process involves assessments conducted by a

multidisciplinary team using standardized tests, rating scales, interviews, clinical observations, photographic analysis, and information from families, caregivers, schools, and community clinicians.

Measures

Needs and Goals

Upon intake into the program, caregivers and mentors collaboratively rate the family on 37 needs (e.g., Housing & Transportation, Family Parenting, Community Development) from 0 (At all times this is not a service issue, requires no attention) to 4 (Priority issue, which always requires immediate and intense attention). The caregiver(s) and mentor work together to establish program goals, which are updated, closed, or renewed every 3 months. Families can either write their own goals or choose from nine pre-written goals. Goals are rated from –2 (A priority service goal which requires immediate and intense attention) to 2 (At all times this is not a service goal and requires no attention).

Stress Scale and Client Satisfaction Surveys

The Stress Scale, developed by the CF team, covers many topics including parental physical and emotional health, finances, hope, and resources, and is completed at wait-list, intake, and discharge. Parents rate 16 statements such as "I feel tired/exhausted" and "I feel frustrated with the school system" on a scale of 0 (Never) to 4 (Constantly). Parents are asked to anonymously fill out the Client Satisfaction Surveys at discharge by rating the program on a four-point scale (1 = a highly negative response; 4 = a highly positive response) and completing open-ended questions. Rates of non-participation in the client satisfaction surveys have not been noted.

Procedure

A retrospective analysis was conducted using anonymous case file data collected by CF. The restrictions for inclusion included closed case files of families for which at least one post needs or goals measure was available.

Program Description

A critical component of the CF program is the establishment and maintenance of strong relationships between the mentors and families, which allows the mentors to work successfully with families in identifying strengths, assessing family supports, and accessing community supports. CF mentors play an educational role, support families in

learning about FASD, and help caregivers integrate knowledge and understanding of their children's abilities and disabilities. Often mentors will support caregivers in accessing functional assessments within the community, learning how to advocate with systems such as the school system, and finding resources needed to help their child succeed. Mentors often encourage caregivers to find, fund, and access respite, and identify and utilize other self-care strategies. The CF program works to help families cope and succeed in lengthening placements and reducing family breakdown.

The family often experiences a profound sense of grief and loss in coming to terms with their child's FASD diagnosis. The length of time spent in the CF program is often related to the level of complexity of the issues faced by the family; for instance, if a family requires assistance from the mentor in accessing more basic supports such as finding financial resources, it can take many more months or even years of work together with a mentor to accomplish their goals.

Employment as a CF mentor requires 2 years of post-secondary education (diploma/degree) and a minimum of 2 years of work experience in a related field. Mentors receive extensive training in areas that include First Aid/CPR, FASD, Ethics, Personal Safety, Aboriginal Awareness, and Professional Boundaries, as well as supervision from the Program Supervisor. In addition there are bimonthly team meetings with a clinical supervision component, monthly staff meetings with the full FASD staff, and bimonthly collaborative supervision team meetings.

Results

A correlational analysis was run to investigate whether the difference scores from pre- to post-program for the needs and goals were related to length of time in the program, age of the target child, and number of children with FASD in the home. Length of time in the program was significantly related to both needs ($r = -0.27$, $P < 0.001$) and goals ($r = 0.22$, $P < 0.001$) indicating that the longer families spent in the program, the greater their reduction in needs and achievement of goals. All other correlations were non-significant and there were no gender effects.

Results from a repeated measures ANOVA indicated that overall, needs significantly decreased from pre- to post-program, $F(1, 187) = 152.69$, $P < 0.001$, $\eta^2 = 0.45$. Using the Bonferroni Correction procedure ($\alpha = 0.004$), multiple paired samples *t*-tests were conducted on the types of needs with 13 of the 14 categories showing a significant decrease including Housing & Transportation (Pre $M = 4.26$, Post $M = 2.34$), Family Parenting (Pre $M = 5.70$, Post $M = 2.34$), Community Development (Pre $M = 3.16$, Post

$M = 1.69$), Community Resources (Pre $M = 2.90$, Post $M = 1.52$), Relationship & Peers (Pre $M = 3.04$, Post $M = 1.68$), Family Situational (Pre $M = 2.68$, Post $M = 1.28$), Grief & Loss (Pre $M = 3.07$, Post $M = 1.86$), Immediate Family & Marital Conflict (Pre $M = 3.26$, Post $M = 2.06$), Health Issues (Pre $M = 2.28$, Post $M = 1.28$), Motivational (Pre $M = 2.11$, Post $M = 1.15$), Extended Family Contact & Relationships (Pre $M = 2.19$, Post $M = 1.41$), Family Neglect (Pre $M = 2.11$, Post $M = 1.33$, and Other (Pre $M = 2.85$, Post $M = 1.06$). There was also a significant increase in goal achievement from pre- to post-program, $F(1, 165) = 317.46$, $P < 0.001$, $\eta^2 = 0.66$. Using the Bonferroni Correction procedure ($\alpha = 0.008$), all six goal categories demonstrated significant increase from pre- to post-program: Parenting (Pre $M = -1.43$, Post $M = 0.79$), Resources (Pre $M = -0.76$, Post $M = 0.76$), Community Connection (Pre $M = -0.35$, Post $M = 0.95$), Personal Skills Management (Pre $M = -0.68$, Post $M = 0.54$), Assessment (Pre $M = -1.04$, Post $M = 0.63$, Self Care & Health (Pre $M = -0.92$, Post $M = 0.12$).

There was a significant decrease in overall levels of caregiver stress from pre- to post-program, $F(1, 72) = 39.409$, $P < 0.001$, $\eta^2 = 0.354$. Further, 98.0% of caregivers reported that they were satisfied with the CF program and 99.0% would return to the program if needed. As a result of the program, 32.1% of caregivers reported parenting and handling their child(ren) better, 28.2% reported understanding their child(ren) and/or FASD better, and 14.5% reported feeling less stressed, having increased patience, and being more positive. Although the majority (65.6%) reported that they had not experienced any problems with the program, caregivers reported a few challenges including feeling that the mentor did not really understand what it was like to live with a child with FASD, difficulties collaborating with other services (e.g., school system), and a need for longer-term support. When asked how they would improve the CF program, 38.8% reported that there was no need for improvement or were unsure (28.2% did not respond).

Discussion

Given the lack of evaluative information on programs for families of children with FASD, the goal of the present study was to evaluate CSS's CF program using retrospective data on pre- to post-program needs and goals, parental stress, and overall satisfaction with the program, which were regularly collected and utilized as part of the function and operation of the intervention program. As predicted, families demonstrated a decrease in needs scores and an increase in goals scores from pre- to post-program. There was a significant reduction in every category of needs with

the exception of Mental Health Issues. The types of needs that showed the greatest reductions from pre- to post-program were Housing and Transportation, Family Parenting, Community Development, and Community Resources. Needs that had the least amount of change from pre- to post-program were Motivational, Family Contact and Relationships, Family Neglect, and Mental Health Issues, which are areas that may be more difficult to change. The types of goals that displayed the greatest improvements from pre- to post-program were Parenting, Resource, and Community Connection. Goals that showed the least amount of increase were Personal Skills Management, Assessment, Self Care and Health, however, as stated previously, all of the goals showed significant improvement.

The results of this study can be expected given the nature and purpose of the CF program, which is to educate, advocate, and help families access resources in their communities. Needs and goals, such as improving family parenting and accessing community resources, are directly addressed in the CF program, whereas issues, such as the mental health of caregivers are either not addressed or indirectly addressed by the mentors. It should also be noted that a more substantial reduction in those categories which exhibited a large, significant decrease (e.g., Housing and Transportation and Parenting) is to be expected as a greater number of families reported these needs and goals, whereas fewer families reported needs and goals in those categories that did not show a large reduction (e.g., Mental Health Issues and Personal Skills Management).

Caregivers' levels of stress significantly decreased from pre-to-post program as hypothesized. However, the results from the Family Stress Scale questionnaires must be interpreted with caution given that the scale has unknown psychometric properties as it was created by CSS. This questionnaire was implemented as a screening tool to support understanding the needs of families entering the program, and therefore may not be generalizable to the larger population. Families reported great satisfaction with the program and the mentors, and stated that they would return to the program in the future if necessary, as well as recommend it to others. These results must also be interpreted with caution, as the psychometric properties of the Satisfaction Survey, which was also constructed by CSS, are unknown.

The CF program extends beyond simple education about FASD in programs, and demonstrated improvement in other aspects of the families' lives, such as parenting, housing and transportation, and community involvement. In line with previous research on FASD and its effects on children and their families, the families in this study were dealing with problems and issues above and beyond those directly related to FASD. For example, 89% of the children had at least one comorbid disorder. Paley et al. (2006) and McCarty et al. (1999) found a significant relationship

between the presence of externalizing and internalizing disorders and parental stress for parents of children with FASD. The success of CF may be partially attributed to the fact that the program addressed these additional stressors by providing parents with information, support, and advocacy, and thus contributed to the overall reduction in stress from pre- to post-program observed in our study.

Chudley et al. (2005) and Streissguth and O'Malley (2000) argue that it is crucial that the needs and concerns of families with children with FASD be addressed, and that such programs be evaluated for their effectiveness. Although additional research is needed to rectify the methodological limitations of the current study as discussed below, it appears that CF fills the gap in services and programs provided for individuals with, and affected by, FASD by working with their families. CF may be effective not only in improving needs and goals, but for improving the overall functioning and well-being of families with children with FASD.

Limitations and Directions for Future Research

Due to the restrictions set for inclusion, many files were not included in the main analyses and therefore warrant caution when generalizing to the larger population; however, there was a substantially large sample size ($n = 186$). Given the nature of the CF program being an intervention program, we were unable to compare those participating in the program to a control group, which would allow for greater confidence in the effectiveness of the CF Program. Similarly, we were unable to control for extraneous variables such as quality of mentorship, participation in other community or professional services, or family variables, which may influence the degree of success of CF. Designing and implementing a method for program evaluation at the outset of an intervention program such as CF would have helped to address these limitations.

Implications for Service Providers

From previous research and this preliminary evaluation, it appears that programs like CF, which focus on educating and supporting families, are successful at addressing a wide range of needs and goals. Service providers should be flexible and strive to understand and support the uniqueness and complexity of each family's needs and goals, and should receive supportive and thorough training in a wide variety of areas. Further, the success of a program like CF would likely increase by collaborating with mental health professionals with family consultation and intervention skills. Finally, the opportunity to participate in a research study evaluating the effectiveness of the CF program has afforded program staff, supervisors and directors the

unique opportunity to reflect upon the practices of the program. As part of this research project, feedback was given to the CF team on findings, successes, and areas for improvement, and CSS has used this information to improve its practices. Specifically, program practices around what and how information is collected (such as comorbid mental health diagnoses) have improved. Mentors also have reported having a renewed connection to the program's purposes and have enjoyed receiving feedback about the program's success.

References

- Astley, S. J., & Clarren, S. K. (1999). *Diagnostic guide for fetal alcohol syndrome and related conditions: The 4-digit code (2nd edn.)*. University of Washington, Seattle: FAS Diagnostic and Prevention Network.
- 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*, 986–1006.
- Brown, J. D., & Bednar, L. M. (2003). Parenting children with fetal alcohol spectrum disorder: A concept map of needs. *Developmental Disabilities Bulletin, 31*, 130–154.
- Brown, J. D., & Bednar, L. M. (2004). Challenges of parenting children with fetal alcohol spectrum disorder: A concept map. *Journal of Social Work, 8*, 1–18.
- Brown, J. D., Sigvaldason, N., & Bednar, L. M. (2005). Foster parent perceptions of placement needs for children with a fetal alcohol spectrum disorder. *Children and Youth Services Review, 27*, 309–327.
- Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172*, S1–S21.
- Gardner, J. (2000). Living with a child with fetal alcohol syndrome. *American Journal of Maternal/Child Nursing, 25*, 252–257.
- Giunta, C. T., & Streissguth, P. (1988). Patients with fetal alcohol syndrome and their caretakers. *The Journal of Contemporary Social Work, 69*, 453–459.
- Grantisas, J. (2004). Experiences of adoptive parents of children with fetal alcohol syndrome. *Clinical Excellence for Nurse Practitioners, 8*, 22–28.
- Kodituwakku, P. W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: A review. *Neuroscience and Behavioral Reviews, 31*, 192–201.
- May, P., & Gossage, J. (2001). Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research & Health, 25*, 159–167.
- McCarty, C., Waterman, J., Burge, D., & Edelstein, S. B. (1999). Experiences, concerns, and service needs of families adopting children with prenatal substance exposure: Summary and recommendations. *Child Welfare, 78*, 561–577.
- National Institute of Alcohol Abuse, Alcoholism (NIAAA). (1990). *Seventh special report to the U.S. Congress on alcohol and health. (DHHS Publication No. ADM 90-1656.)* Washington, DC: U.S. Government Printing Office.
- Paley, B., O'Connor, M. J., Frankel, F., & Marquardt, R. (2006). Predictors of stress in parents of children with fetal alcohol spectrum disorders. *Developmental and Behavioral Pediatrics, 27*, 396–404.
- Paley, B., O'Connor, M. J., Kogan, N., & Findlay, R. (2005). Prenatal alcohol exposure, child externalizing behavior and maternal stress. *Parenting Science and Practice, 3*, 29–56.
- Rasmussen, C., Andrew, G., Zwaigenbaum, L., & Tough, S. (2008). Neurobehavioural outcomes of children with fetal alcohol spectrum disorders: A Canadian perspective. *Paediatrics & Child Health, 13*, 185–191.
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics, 25*, 228–238.
- Streissguth, A. P., & O'Malley, K. (2000). Neuropsychiatric implications and long-term consequences of fetal alcohol spectrum disorders. *Seminars in Clinical Neuropsychiatry, 5*, 177–190.