Parenting Children with Fetal Alcohol Syndrome Disorders (FASD)

Corresponding Author:
Ms. Maggie H Phung,
Health Science, A.T Still University- Arizona School of Health Science, CA94501 - United States of America

Submitting Author:
Dr. Maggie H Phung,
Health Science, A.T Still University- Arizona School of Health Science, CA94501 - United States of America

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Parenting Children with Fetal Alcohol Syndrome Disorders (FASD)

Author(s): Phung M H, Wallace L, Alexander J, Phung J

Abstract

Fetal alcohol syndrome disorders (FASD) are one of the leading causes of mental impairments, birth deformities, and neurological development problems in America (Astley & Clarren, 2000). Children with FASD can have permanent disability such as physical, behavior, and learning dysfunction. There is no treatment for FASD, but many studies indicate that early treatment services can ameliorate the child’s prognosis. The treatments include medication, behavior, and education therapy, and parent training (Streissguth, et al., 2004). Parents of children with FASD are dramatically significant resources that can provide a loving, nurturing, and stable home to improve the child’s quality of life. Therefore, analyzing the experiences of parents raising children with FASD is a necessity to enhance the well-being of both caregivers and their children. This qualitative study explored the experiences of parents raising children with FASD to determine if special education programs and social support services are needed to improve children's quality of life and that of their parents. A total of five participants volunteered from a group of parents with disabled children in Alameda, Northern California. The participants consisted of biological, adoptive, and foster parents. Semi-structured interviews were comprised of a series of fundamental questions to ask participants. Participants reported, in summary, that good living conditions, special education programs, and social support services are crucial factors to improve the quality of life of children with FASD and that of caregivers. In conclusion, the integration of diagnosis, interventions, and social assistance for these children, and additional support services for families, are necessary to establish successful family functioning and, in turn, to promote the success of children with FASD.

Introduction

According to Albel and Sokol (2004), over 40,000 babies are born with symptoms of prenatal alcohol exposure each year. These symptoms vary in severity, and include physical defects, cognitive deficits, and behavior problems. The costs of FASD to society and for each alcohol-affected individual are very high. Harwood and Napolitano (2005) have reported that FASD cost the nation $4.2 billion each year, and the lifetime cost for each child with FASD is $2.2 million. According to the National Research Council (2001) on Alcohol Abuse and Alcoholism and Ryan and Ferguson (2006), children with FASD suffer from the following problems: (a) facial abnormalities and neurology development impairments, (b) cognitive dysfunction, (c) lack of critical thinking, (d) disqualified memory and judgment, (e) poor communication and language deficits, and (f) challenging behaviors. Overall, the complications seen in children with FASD are permanent, requiring special education and lifetime social support services (Streissguth, et al., 2004). Many studies indicate that accurate diagnosis and early interventions help children to achieve higher education levels and avoid future problems (Ryan & Ferguson, 2006).

Because family status is an important factor in helping FASD children achieve good outcomes (Streissguth et al., 2004), additional assistance for parents is in demand (Brown & Bednar, 2003). The needs of families raising FASD children include a support network of families, friends, and communities; experienced and compassionate professionals who are knowledgeable about FASD; available community resources; a good relationship between families and schools; special education programs, including teaching specialists of FASD with strategies to promote learning; income assistance to help with expenses such as medical and supply costs; and a strength-based program for parents, taking into account each child’s unique abilities and difficulties (Brown & Bednar, 2004).

Purpose of Study

The purpose of this qualitative study was to explore the experiences of parents raising children with FASD to determine if social support services and special education programs are needed to enhance the well-being of children with FASD and their parents.

Methods

Research Design

This is a qualitative study. A
phenomenological-hermeneutic method is applied to discover the experiences of parents raising children with FASD (Van Manen, 1990). Rehorick & Taylor (1995) have introduced the need to comprehend human experiences “as-is.” The “as-is” experiences of parents are not limited to emotions, observable happenings, judgments, and backgrounds. Rather, un-observable cognitive processes permeate human experiences (LeVasseur, 2003). In order to facilitate the contribution of “as-is” experiences, a semi-structured interview format is highly recommended, asking questions that encourage parents to reveal what is it like raising children with FASD and how they think they affect their children’s lives. Semi-structured interviews are comprised of a series of fundamental questions to ask participants (Table 1). This type of interview provides the researcher with an opportunity to explore participants’ perceptions and to add questions as needed. It also promotes divergent discussions about critical and noteworthy information (Pitney & Parker, 2009). In general, semi-structured interviews are the most effective method for this study.

**Study Participants**

The participants qualify to participate in the study if they are currently raising a child with FASD in their home. A total of 5 participants volunteered from a group of parents with disable children in Alameda, Northern California. The participants consisted of biological, adoptive, and foster parents. The participants included one-Asian American, two-African Americans, and two-Caucasians. The age range of the participants was 32-58 years, with a mean age of 41.8. The age range of FASD children was 9-15 years, with a mean age of 12.0. Table 2 presents demographic information on the parents, including their ages, employment status, marital status, and social status. Overall, five participants with different cultural backgrounds can address the study purpose and respond to the research questions (Pitney & Parker, 2009). The cultural diversity of the participants may provide different themes for this study to enrich the data from the perspectives of parents with distinctive backgrounds.

**Data Collection and Analysis**

The topic of this study is the experiences of parenting children with fetal alcohol syndrome disorders. It is a qualitative study and data were collected using semi-structured interviews, where the researcher elicited information from the participants by asking them to respond to interview questions. The researcher used questions that address the same issue in an open-ended manner (Pitney & Parker, 2009). The interviews lasted 40 to 60 minutes and were transcribed and then analyzed inductively. The inductive analysis followed grounded theory procedures. Data were collected until a saturation of the theory was achieved. In grounded theory, the researcher focused first on coding the available collected data. Coding was employed to identify and label parts of information and experiences that answered the research questions (Pitney & Parker, 2009).

The first step in analysis was open coding, which developed and organized the data categories and then subcategories. The researcher continued selecting data codes for similar concepts to create particular categories (Strauss & Corbin, 1990). The second step of analysis was axial coding. Axial coding connected the data between the categories and subcategories so that the researcher could recognize the relationship between the emerging categories (Mills, 2007).

The last step was the selective coding process of analysis. In this step, the researcher determined a main category to which all other categories were related. The researcher created a set of explanatory concepts that depicted the connection between the main category and other categories, developing the theory (Pitney & Parker, 2002). In general, selective coding synthesized the categories into a larger theoretic scheme, and arranged the categories around a principal explanatory concept, specifically, enhancing the well-being of children with FASD and their parents.

Analysis of the interview transcriptions was completed to determine the main themes (Van Manen, 1990). NVIVO 8 (qualitative data analysis software) was used to identify, classify, and compare the themes. As the main themes were discovered, they were categorized in to sub-topics. To assist with the identification and coding process, the main themes were written based on quotations provided by the participants so that clarification and arrangement of themes were accurate and the data spoke for themselves (Kodituwakku, 2007).

**Trustworthiness**

In participant checks/member checks, participants were asked to confirm the results based on their experiences and knowledge. Participant checks were conducted before generating a formal report (Mills, 2007). In this strategy, participants were asked to verify interpretations of the study’s outcomes, called interpretive verification. Participants were provided a clarification of the study’s emergent themes as well as the supporting quotes for their interviews, so they
could comment on the credibility of the research findings. Furthermore, the researcher explained to participants the organization of the transcripts. By doing this, the researcher was able to confirm that interpretation of the data was valid. It was seen that if participants disagreed with a finding, the researcher must comprehend why. Participants had permissions to make any necessary corrections, and their explanations allowed the researcher to reformulate the study’s interpretations and alter the outcomes.

Results

During the open coding process, the identified concepts were classified into three categories that described the experiences of parents raising children with FASD: (a) exploring the quality of life of children with FASD and their parents; (b) discovering the schooling of FASD children; and (c) determining the needs for social support services and special education programs for children with FASD and their parents. The axial coding process allowed for connecting among categories and comprehending the factors that improve the FASD children’s quality of life and that of their caregivers. In addition, the selective coding process assisted to discover an overarching theme (Table 3), the well being of parents and children with FASD.

Exploring the Quality of Life of Children with FASD and Their parents.

Depression and guilt. Parents II are biological parents of a child with a neurological disorder whose behavior is unstable from day to day. Parents II had a difficult time helping their child follow directions, household rules, and school regulations. Mom II stated, “Every direction given to our girl needs to be repeated. Mom or dad has to be with her all the time. She is unable to complete any task or respond to a typical request without mom/dad’s assistance.” Dad II also said that the girl has a hard time answering a question; she slowly puts single words together, and sometimes, she only nods her head instead of responding to a question.

Mom II expressed feeling “incredible guilt” for her daughter’s retardation: “I have lived with my guilt for several years and I am in a deep depression. I cry a lot every day because I damaged my little girl. I ask myself what kind of mother I am to ruin my own child.” Mom II has experienced regret regarding her baby, and lived her life with grief every day.

Living in a violent environment and a chaotic home atmosphere. Children with FASD display serious behavioral challenges, including tantrums, belligerence, and destructiveness (Mills, 2007). Parents expressed the difficulties dealing with these obstacles, which have affected family members’ mental health and relationships. Mom I reported that her child broke her nose and arms, and punched her face. Mom III said, “I must give the family dog away because he would kick the dog, hit the dog with the chair, pick the dog up, and throw it.” Mom III also notes that anything could trigger him. He would get angry, he would damage things, he would get in a fight, and he becomes violent.

Parents demonstrate that living in a violent environment can create a chaotic home atmosphere. Dad I stated, “It is very difficult to make a family seem like a family with a war environment.” Dad II noted that a violent atmosphere has impacted family member’s feelings, mental health, and relationships. Mom II also shared that raising a child with FASD has affected their social life significantly. Mom III stated, “The behavior of my foster child has influenced my attitude; I become aggressive.” In addition, Mom III talked about her break up with her boyfriend: “We lived together for seven years before fostering the child. My ex-boyfriend couldn’t take it anymore because of the child’s misbehavior and violence. Finally, he ran away without saying a word. This hurt me badly.”

Community and school services. Parents shared their opinions regarding receipt of supports from community and school-based services for FASD children and their families. Parents II stated, “We are on our own with some social and school support services.” Parents I expressed their appreciation for local social service agencies assistance: “These agencies provide guidance and resources to deal with our difficult situation.” Dad II explained that learning about FASD children does not come from the books. It must come from hands-on experiences. Dad II continued to say that we can read about fetal alcohol syndrome disorders; we can identify FASD diagnosis and characteristics; we comprehend that FASD children are affected physiologically and intellectually; however, the most challenge is how we deal with FASD children in the real, everyday world.

Mom I reported that there are assistance programs from social service agencies and schools for FASD children and their families. Her son receives community supports and school counseling. Dad II stated, “I called for help and people from social service agencies showed me how to get supports for my FASD child.” Mom III shared that she receives respite care from her church.
In general, the parents in this study expressed that social and school support services help them to succeed in controlling the daily problems. The challenging behaviors of their children are pervasive, persistent, and overwhelming. Therefore, the assistance of communities plays an important role in promoting a better life for their children and families.

**Understanding the Schooling of FASD Children.**

According to Mattson, Calarco, and Lang (2006), children with FASD confront many obstacles in school, and they are at-risk of school drop-out. These disadvantages are displayed in this study as parents depict their children’s struggles with low-grade performances, and poor attendances in school.

The schooling of FASD children. Mom I reported, “I took off many days from work because I received several phone calls from his school telling me that he was unable to understand the lectures; he didn’t follow the class and school rules; he fought with his friends; and he urinates on his classmates.” He explained to his mom that his friends punched him first and they also peed on him first. He continued to cry and told his mom that his friends called him a retarded boy. Moreover, his teachers didn’t like him, didn’t pay attention to him, and didn’t listen to him.

Mom and Dad II shared the experiences of their girl: “We asked help from teachers; most of teachers told us that they didn’t have time for our girl because they divided time equally for other students.” The teachers complained that they spent too much time to teach her, including repetition, consistency, and daily practices, and they didn’t get paid for doing these. Therefore, they advised us to seek a special education program for our child.

Mom III stated, “He was kicked out of schools for a variety of issues.” Mom III described her son as a “follower,” who took off his cloth in the classroom after his friends convinced him to do so; these actions resulting in the child being school suspended. Mom III, after confronted with her child’s suspensions, had to find out about specialized school programs to meet her child’s education needs.

Social relationships of FASD children. According to Koren and Navioz (2003), there are challenges for children with FASD to develop and maintain friendships. Parents in this study indicate that FASD children often do not have good friends, and sometimes these children are taken advantage of by their friends. Mom I described how her child establishes friendships: “He bought foods, drinks, or cigarettes for other children to make friends with them.” Dad II spoke about his girl: “She must clean shoes for a group of girls at school to join their team.”

Mom III sighed deeply when mentioning her son: “He stole money to buy his friendships.” Teenagers with FASD are at high risk of getting in trouble with the law (Pardini, Obradovic & Loeber, 2006). Parents I expressed concern about their child’s potential for criminal and gang involvement. Their son told them that some boys in the neighborhood forced him to participate in their team. His duty was to sell drugs and he didn’t know that selling was illegal. They intended to report the situation to the police but worried that this would put him at risk. Finally, they decided to lock him in at home. However, sometimes he escaped from home and they ran around looking for him.

Mom III shared her son’s story: “Some of gang members trained him to be a shoplifter.” She told him that this was a wrong thing to do, and he could end up in jail. She taught him what the right things were to do and he forgot the next day. She said she must repeat things every day when he is going out of the house. She tries her best to do anything she can to keep him from any danger.

Creating a bubble. Because children with FASD are at risk of social problems, parents have to find ways to protect them from harm (Armstrong, 2003). Dad I controls his son’s environment so that his son can avoid gang involvement. Dad I reported, “My child was in restraints.” My child must be really careful about where he went and who he hung out with. Mom III expressed that she is unable to control people who want to take advantage of her son. Therefore, she must control her son as much as she can to keep him safe from criminal involvement.

**Determining the Needs for Children with FASD and Their parents.**

**Getting support.** Parents report barriers and successes in getting assistance from medical and mental health professionals; federal and state support networks; local agencies; and schools. Parents II have regretted to have had to put their son through the mental health system for 18 months. The doctor gave him the medication to control his agitation, but this made him feel sedated, and he gained weight. The treatment had negative effects on him so he was afraid to see the doctor. Sometimes he got really sick but he refused to see a doctor because of his mental health experiences.

On the other hand, Parents II appreciated the assistance of a local hospital that provides good advices and great resources for parenting FASD children. These social support services have had a
positive impact on the lives of their child and their family. Mom II used to be very stressed until she was educated by her physicians and nurses. Dad II learned how to treat the girl in an appropriate way and he is more patient with her. The girl has been changed also; she doesn’t yell and throw things at parents as usual, and she doesn’t get angry as easily as she used to. Parents II concluded that their lives became much happier after they received supports from the community.

**Social support services and special education programs are needed to enhance the well-being of children with FASD and their parents.** Dad I said, “We used to have a difficult time with him at school, but no more. He was placed in a special education program, and he is doing well now.” Mom I explained that this program offers a great opportunity for her child in that one teacher is assigned to one student. The teachers are well trained to work with FASD children. Parents II shared, “Our girl improves a lot when participating in the special education programs.” Parents II believed that these programs can promote the success of FASD children. Mom III said, “I feel a lot better; my son can compare things, be more concentrated, and is able to follow instructions.” Mom III also believed that these programs have a major effect in enhancing the quality of life of FASD children.

**How communities can improve the quality of life of children with FASD and their parents.** Studying the experiences of parenting children with FASD in this study indicated that FASD children and families face many challenges in their lives. According to Rasmussen (2006), integrating supports between diagnosis and interventions can benefit FASD children and their families. From the perspectives of parents in this study, combining diagnosis, treatments, therapies, and special education programs for FASD children; and receiving formal and informal assistances for families; all contribute to promote the well-being of FASD children and families.

**Discussion**

Because of the great demands placed on parents raising children with FASD, parents need many social support services to promote success for their children. The support needs of parents include a social support network, support services of professionals who are knowledgeable about FASD, special education programs, and a strong mutual relationship between families and school (Brown, 2004). This study supports the findings of previous research that special education programs and social support services help to improve children’s quality of life and their parents. Analysis of the data has revealed three main categories that represented the parents’ perspectives when determining the critical needs of children with FASD and their caregivers. The first category was to explore the quality of life of children with FASD and that of their parents. As mentioned, FASD children suffer from reasoning deficits, negative attitudes, language difficulties, and poor social communication. Consequently, children with FASD had a high rate of dropping out of school, problems with the criminal justice system, trouble with sexual behaviors, and alcohol or drug addiction. In general, the challenges of parents in this study were varied, and many problems added up to increase overall parenting struggles and anxieties.

The second category was to understand information relating to the schooling of FASD children. Children with FASD suffered from cognitive impairments that can lead to demeanor problems as well as secondary disabilities such as mental illnesses, hyperactivity, belligerence, and destructiveness (Mattson & Riley, 2004). Children with FASD in this study experienced problems in controlling anger, lack of decision-making abilities, difficulties in concentrating on school, and negative attitudes. Fortunately, children with FASD who were diagnosed early and raised in a good environment have escaped from school failures, problems with the law, inappropriate sexual manners, and alcohol/drugs problem (Ryan & Ferguson, 2006). Overall, this study has demonstrated that good living conditions, special education programs, and social support services are crucial factors to improve the quality of life of children with FASD.

The third category was to determine the needs for social support services and special education programs for FASD children and their parents. Streissguth et al (2004) have suggested that FASD children who have stable families with enduring relationships can avoid adverse life outcomes. This study has confirmed that it was important to provide social support services to establish good living environments for families with FASD children, in turn, to promote the success of these children.

**Limitations of Study**

First, the findings represented the perspectives of five participants who were in residence at Northern California area. Including participants across America may result in richer data and additional categories. Second, the study focused on three FASD children. As such, the findings were applicable only to these three children’s lives. In general, small sample size in terms
of parents and children cannot be generalized to larger populations.

Implications for Future Research

Potential research topics for future research include: (a) What specific types of interventions and social support services are the most effective for FASD children and their caregivers? and (b) How can social, cultural, economic, and political factors improve quality of life for FASD children and their parents?

Recommendations and Practical Applications for FASD Children and Their Parents

The perspectives of parents in this study specified the critical needs of children with FASD and their caregivers. To improve the quality of all affected, the following four strategies should be considered: (a) create integrated support services across social service agencies to connect a medical diagnosis with interventions, special education programs, and community assistance programs; (b) develop additional programs and services to aid these children and their families; (c) train health care professionals, special educators, special teachers, and social workers who can provide assistance to FASD children and their families; and (d) develop new special education researches, and program implementation agendas for social service agencies that are involved with FASD children and their families.

Government should provide funding to state, local, and health organizations to implement evidence-based prevention, and diagnosis and intervention programs such as (a) FASD Prevention Program helps to reduce incidence of FASD by eliminating alcohol consumption by pregnant women; (b) FASD Diagnosis and Intervention Program assists to enhance the functioning and quality of life of FASD children and their families.

Conclusion

The purpose of this study was to identify the significant factors to improve the quality of life of FASD children and their parents. The findings demonstrate when addressing the needs of these children, diagnosis should be followed by interventions, and services, as well as determining the community aids available for their caregivers. Overall, the integration of diagnosis, interventions, and social assistance for these children, and additional support services for families, are necessary to establish successful family functioning and, in turn, to promote the success of children with FASD.

The results of this study indicate that federal, state, and local supports and services help to minimize or even avoid problematic outcomes of these children, including disruptive home experiences; suspensions or expulsions from school; dropping out of school; problems with the criminal justice system; trouble with sexual behaviors; and alcohol or drug addiction. In addition, the study has highlighted the positive effect that government and community assistance can have on the lives of FASD children and families. In general, this study has confirmed health care professionals, educators, teachers, social workers, politicians, and policymakers play an important role in promoting the success of FASD children by meeting the challenges and needs of these children and their parents, implementing strategies for enhancing education programs, creating positive behavioral supports, and instituting coordinated systems.

References


Illustrations

Illustration 1

Table 1: Semi-structured Interview Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
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<tbody>
<tr>
<td>1) Please tell me what it is like raising children with FASD in your home?</td>
<td></td>
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<tr>
<td>2) Please describe a typical day as parents/caregivers of FASD children?</td>
<td></td>
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<tr>
<td>3) Please describe a typical week as parents/caregivers of FASD children?</td>
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<tr>
<td>4) Please tell me what your responsibilities are as parents/caregivers?</td>
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<tr>
<td>5) Please describe your caring duties?</td>
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<tr>
<td>6) Please tell me what supports you receive as parents/caregivers of FASD children?</td>
<td></td>
</tr>
<tr>
<td>7) Please tell me what supports you need as parents/caregivers of FASD children?</td>
<td></td>
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<tr>
<td>8) Are social support services and special education programs needed to enhance the well-being of you and your child? Please explain.</td>
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<tr>
<td>9) Does your child receive any social support services and/or special education programs? If not, please answer # 10.</td>
<td></td>
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<tr>
<td>10) What have you done to deal with these challenges?</td>
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<tr>
<td>11) Please tell me what effect you feel you have on your child’s life?</td>
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