Parenting Children With Fetal Alcohol Syndrome Disorders (FASD)

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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 life time 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 it is 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 (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.

References

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