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Fetal Alcohol Syndrome: Parental Experiences and the Role of Family Counselors

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Abstract

This paper discusses the experiences of foster/adoptive parents who raise children diagnosed with Fetal Alcohol Syndrome and the instrumental role family counselors can play regarding child management issues, intimate relationships, larger system collaboration, and research. For the actual study, six parents participated in individual, in-depth tape-recorded interviews. Each interview was transcribed, thematically analyzed, and revealed seven predominant themes including (a) constant vigil, (b) effects on marriages, (c) child management, (d) parental issues, (e) interactions with professional community, (f) emancipation concerns, and (g) medical implications. The ways in which family counselors can intervene are reviewed and include the role of clinician, facilitator, and researcher/educator.

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Fetal Alcohol Syndrome: Parental Experiences and the Role of Family Counselors

by
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Abstract

This paper discusses the experiences of foster/adoptive parents who raise children diagnosed with Fetal Alcohol Syndrome and the instrumental role family counselors can play regarding child management issues, intimate relationships, larger system collaboration, and research. For the actual study, six parents participated in individual, in-depth tape-recorded interviews. Each interview was transcribed, thematically analyzed, and revealed seven predominant themes including (a) constant vigil, (b) effects on marriages, (c) child management, (d) parental issues, (e) interactions with professional community, (f) emancipation concerns, and (g) medical implications. The ways in which family counselors can intervene are reviewed and include the role of clinician, facilitator, and researcher/educator. .

Introduction

Fetal Alcohol Syndrome (FAS) has been identified as the leading cause of mental retardation and is 100% preventable (Malbin, [1993](#); National Institute on Alcohol Abuse and Alcoholism, [1987](#)). It is caused by prenatal exposure to alcohol (Streissguth, [1997](#)). The diagnostic characteristics of FAS include specific facial features, deficiencies in growth, and central nervous system (CNS) dysfunction. Children born with this disability may exhibit varying degrees of effect ranging from mild effects and behavioral difficulties to severe cognitive impairment and multiple disabilities. Because of the varying degree of effects and the lack of training in this area for professionals, including medical personnel, teachers, and human service providers, children are often under-diagnosed and as a result do not benefit from appropriate interventions, teaching strategies, and services.

FAS is a condition that children do not outgrow. While some children are diagnosed with full FAS, others have only partial effects, usually central nervous system damage, without the facial features or growth deficiency (Streissguth, [1997](#)). Children who exhibit only some of these characteristics are referred to as having fetal alcohol effect (FAE). Many children with FAE can be considered to have a hidden disability as it is often under-diagnosed due to the lack of a readily apparent physical disability.

In 1990 the National Institute on Alcohol Abuse and Alcoholism (NIAAA) estimated that out of 1,000 children, 1.9 are born with FAS. This rate is nearly double the rate of Downs Syndrome and five times the rate of spina bifida. The rate of FAE is considered to be three times greater than FAS. If one were to extrapolate from these numbers, one out of the four million children

born each year in the United States, approximately 7, 600 could have FAS and 22, 800 could be affected by FAE. Actually, these types of extrapolated figures are likely underestimated as both FAS and FAE are often undiagnosed (Streissguth, [1997](#)).

Research (Streissguth, Barr, Kogar, & Bookstein, [1996](#)) has demonstrated that the secondary disabilities associated with FAS become more apparent as children mature. The primary secondary disabilities found in Streissguth's study include mental health problems, inappropriate sexual behavior, disrupted school experience, and trouble with the law.

Although FAS has been identified as occurring at higher rates among certain groups (May, Hymbaugh, Aase, & Samet, [1983](#)), prenatal exposure to alcohol affects children from all ethnic groups and socio-economic backgrounds. A Swedish study by Hagberg, Hagberg, Lewerth, and Lindberg ([1981](#)) found that more causes of mental retardation were from alcohol related birth defects than all genetic causes combined. It is now established that alcohol is toxic to the developing human nervous system and women who consume alcohol during pregnancy place their children at risk.

It has only been since the early 1970's that researchers in the United States have identified Fetal Alcohol Syndrome (FAS) (Jones & Smith, [1973](#)). Because alcohol is a teratogen (birth defects causing agent) and is a social drug that is used legally, it is difficult to comprehend the connection between alcohol consumption and FAS. For instance, in a survey of 13,000 women by Dufour, Williams, Campbell, and Aitken ([1994](#)), although 89%-92% knew that excessive alcohol consumption during pregnancy could increase the chances of birth defects, only 29% of the child bearing age respondents considered FAS as being born alcohol addicted as opposed to having brain damage from alcohol exposure. It has only been since 1981 that the Surgeon General issued a recommendation that women planning a pregnancy or who are already pregnant should refrain from drinking alcohol. Until that time many women thought or were told that light alcohol consumption during pregnancy or when breast-feeding was acceptable.

The level of neurological damage experienced by children is influenced by prenatal alcohol exposure related to the amount of consumption, when the alcohol was consumed during pregnancy, the particular conditions of the exposure, and the individual characteristics of the mother and the fetus (Streissguth, [1997](#)).

The annual estimated costs of FAS in the United States vary significantly. Estimates range from \$75 million (Abel & Sokol, [1991](#)) to \$9.7 billion (Harwood & Napolitano, [1985](#)). In response to the seriousness of the problem of children pre-natally exposed to alcohol, in 1994 the United States Congress mandated, in Section 705 of Public Law 102-321, the ADAMHA Reorganization Act. This act resulted in a study of FAS and related birth defects by the Institute of Medicine.

Research in the area of FAS has primarily focused on basic animal research, clinical, and epidemiological studies related to the effects of alcohol use by pregnant women, studies to define the scope of the problem, and prevention. A 1996 summary report developed by the Institute of Medicine noted that no agency had been able to support research on the clinical aspects of FAS, the medical treatment of children with FAS, or the education and remediation of these children

(Institute of Medicine, [1996](#)). The lack of research related to remediation compounds the struggles that face parents and helping professionals alike. Available literature suggests that long term outcome indicates that children with FAS can in fact be successful when provided with appropriate supports and interventions (Davis, [1994](#); Kleinfeld & Wescott, [1993](#); Malbin, [1993](#); Smith, Coles, Poulsen, & Coles, [1995](#); Streissguth, [1997](#)).

Although current information is essential to understanding the physical aspects of FAS, there is a dearth of information pertaining to experiences of foster/adoptive parents who raise children diagnosed with this disorder. The literature is restricted to parental stress toward the physical handicaps of infants and children (e.g., Beckman, [1983](#); Frey, Greenberg, & Fewell, [1989](#); Morrissette, Morrissette, & Naden, [1998](#); Patterson, [1985](#); Rolland, [1994](#)), long term pediatric illness (e.g., Holroyd & Guthrie, [1986](#); Tavormina, Boll, Dunn, Luscomb, & Taylor, [1981](#)) and pediatric terminal illness (e.g., Koch, [1985](#)). In an attempt to fill a void in the literature, this study attempted to systematically investigate the experiences of parents who raise children diagnosed with FAS and suggest ways in which family counselors can intervene.

Research Question

The nature of the research question is critical to the quest for rich description and interpretative understanding. Its purpose is to search for the meaning of a phenomenon so that it may be more fully understood (Ray, [1990](#)). The research question that was asked in this study was: What are your experiences raising a child diagnosed with Fetal Alcohol Syndrome? The impetus for this study stemmed from the absence of literature detailing the lived experiences of parents who play such a central role in the lives of children diagnosed with FAS. Although assumptions can be made about their daily challenges, it was hoped that the elicitation of actual stories would provide valuable insight for other professionals and prompt interest among researchers regarding the unique challenges and needs of these parents.

Methodology

Qualitative orientations are particularly well suited to counselling research (Gama, [1992](#); Nelson & Poulin, [1997](#)). Phenomenological research searches for a deeper understanding and insightful descriptions of lived experiences that can be shared by co-researchers. Within this process, researchers distinguish significant features of co-researcher experiences and present a perspectival understanding of the phenomenon. This study attempted to systematically investigate the experiences of foster/adoptive parents.

Co-Researchers

Criteria for co-researcher selection included foster/adoptive parents who were (a) actively parenting children with FAS, (b) willing to share salient experiences of the phenomenon in their everyday lives and, (c) willing to illuminate the phenomenon of interest (Osborne, [1990](#); Wertz, [1986](#)). Co-researchers were selected from the surrounding Missoula, Montana area.

The recruitment of co-researchers originated from an FAS parent meeting. The meeting was organized to provide parents with an opportunity to discuss general issues and concerns related

to services and supports. During the meeting participants were invited to participate in research interviews with the author. It was explained that the purpose of the study was to gain an understanding of the experiences of foster/adoptive parents who raise children diagnosed with FAS. Because of busy schedules, parents were informed that the interviews would be conducted at their preferred time and location. Permission was obtained from co-researchers to audio-tape the interviews. The co-researchers within the study consisted of one male and five females who were all Caucasian. The mean number of years of experience as a foster/adoptive parent for a child with FAS child was 10. Pseudonyms were assigned to each of the six co-researchers.

This study began with an indeterminate number of co-researchers and interviews continued until redundancy was heard. It should be noted that although additional co-researchers could have been recruited, it appeared unlikely that new information would be revealed based on the striking commonalities among co-researcher narratives. When new descriptions regarding the phenomenon from foster/adoptive parents no longer emerged, it was determined that a saturation point had been reached and consequently, the collection phase of this study ended.

Several authors have discussed the issue of a smaller sample size in qualitative research (Morse, [1994](#); Ray, [1994](#); Sandelowski, [1995](#)). According to Sandelowski ([1995](#)), "Adequacy of sample size in qualitative research is relative, a matter of judging a sample neither small nor large per se, but too small or too large for the intended purposes of sampling and for the intended qualitative product" (p. 179). The purpose of this present study was to embark on an intense analysis of the rich descriptions provided by the co-researchers.

Researcher

The research interviews and subsequent analysis was conducted by the author who was an experienced family therapist and faculty member in the Department of Counseling and Human Services at Montana State University-Billings. During his career, the author worked within family-centered inpatient and outpatient clinical settings in both Canada and the United States. As such, he had acquired extensive experience working with foster/adoptive parents who faced the challenges of raising children diagnosed with FAS (e. g., Jones & Morrisette, [1999](#); Morrisette, [1993](#), [1994](#), [1995](#), [1996](#)). Unfortunately, as previously mentioned, when turning to the literature it became abundantly clear that the lived experiences of parents remained unexplored. In an effort to contribute to a better understanding of these parents, the present study was initiated.

Procedure

Interview

The interview format was based on a three phase model proposed by Osborne ([1990](#)) and included (a) the establishment of rapport, (b) sharing of narratives and, (c) appropriate closure. During the engagement process with the co-researchers, roles were clarified and issues of confidentiality and anonymity were reviewed. The actual interview was open-ended and minimally structured with no time limitations to encourage co-researcher participation.

Each individual interview was approximately one to one and one half hours in duration and each interview was conducted by the author in person. All interviews were audio-taped and later transcribed verbatim. The initial statement made to the co-researchers was as follows: Please describe for me as completely as possible your experiences as a parent raising a child diagnosed with Fetal Alcohol Syndrome. Following this request, the co-researchers were invited to reflect and elaborate on their experiences for further articulation. During the course of the interviews, the co-researchers were asked to clarify and expand on issues that required further elaboration. When the co-researchers appeared to become detached from the topic, they were gently re-directed with such comments as: Can you share more about what that was like for you? When a point where the co-researchers' experiences had been fully articulated the following question was asked: Is there anything else that you would like to add that has not yet been addressed?

Stages of Data Analysis

In order to synthesize parental experiences into a logical and coherent whole, narrative analysis was based on guidelines as set forth by Colaizzi ([1978](#)) and Osborne ([1990](#)) as described below. Although a lengthy and arduous process, this specific form of narrative analysis was considered ideal because it allowed the researcher to remain close to the information that was gathered and sensitive to the common themes that eventually emerged.

First, immediately after each interview, the audio-tape was carefully listened to and reviewed in an attempt to gain an awareness of the experiences described by the co-researchers.

Second, each interview was transcribed into a written protocol and was then read in its entirety several times. During final readings of the entire protocol, significant co-researcher statements were extracted, paraphrased, and given a meaning.

Third, the significant statements, paraphrased meanings, and thematic descriptors were placed in a tabular form and were referred to as the First Order Thematic Abstraction of each parent experience (see [Appendix A](#)). This was essential in order to capture the unique experiences of parents and to compare experiential similarities and differences among the co-researchers.

Fourth, a Second Order Thematic Cluster was developed which involved clustering identified parent themes (as found in the First Order Thematic Abstractions). This thematic grouping was placed in tabular form with the inclusion of a general description (see [Appendix B](#)). These descriptions reflect the essence of the experience within the prepared themes of each co-researcher. They were further utilized when comparing experiences and essentially formed the basis for the synthesis of the co-researchers' experiences.

Fifth, a within person's analysis was developed. This analysis involved summarizing the co-researcher's overall experience. While completing this process, various themes surfaced and brought the researcher back to the original text and to the overall story that was described.

Sixth, the various themes that emerged from each protocol were reflected upon. This process provided another way of understanding the essential structure of each co-researcher's experience

while discerning the uniqueness of his or her experiences. The resulting overview provided an opportunity to compare experiences in a descriptive format.

Seventh, the clustered themes for all co-researchers were presented in a grid format (see [Appendix C](#)). The purpose of this format was to provide a quick visual reference regarding specific themes within each co-researcher's experience. This process was helpful when comparing experiences among co-researchers and in formulating a global picture of their experiences.

Trustworthiness of the Study

It is through the examination of subjective life world experiences of individual perspectives that researchers are able to establish an essential structure of meaning common to these perspectives. As discussed directly below, the guidelines set forth by Koch ([1994](#)) were used to strengthen the overall trustworthiness of this study.

The realization that researchers frequently select topics that are personally meaningful is well documented in the qualitative research literature (Berg, [1995](#)). Presuppositions and biases toward the phenomenon had to be identified and bracketed prior to the commencement of the research. The purpose of bracketing was not to achieve a state of absolute disinterest or objectivity but rather, to realize how personal interests in the topic could color the research activity (Colaizzi, [1978](#)). In short, beliefs about the phenomenon under study were recorded, temporarily set aside, and monitored so as not to obstruct a view of the narratives (Kvale, [1996](#)). More specifically, a concerted effort was made to remain cognizant of personal biases (based on previous clinical experience) that could have easily influenced the descriptions of each co-researcher. The bracketing process involved writing down and carefully considering pre-suppositions prior to the actual interviews and discussing reactions with colleagues throughout the interviewing process. Co-creating a context whereby the co-researchers felt comfortable to openly express themselves was critical to this study. The intent was not to seek validation for personal assumptions but rather, to hear the experiences of others. Therefore, the process of monitoring personal beliefs and reactions required ongoing vigilance.

Credibility (Guba & Lincoln, [1989](#)) for this study was accomplished through consultation with co-researchers during the collection and descriptive phases to ensure goodness of fit. This process provided an opportunity to share descriptions with co-researchers and the opportunity to ensure the congruence of descriptions with their experiences. For this study, co-researchers participated in a two phase process to strengthen the credibility of this research. First, they were asked to read their transcribed interview, the initial formulation of categories from their interview, and provide verbal feedback. Second, they were asked to further reflect on the documents and provide written comments regarding their impressions.

To enhance transferability, the essential structure of the co-researchers' experiences needed to resonate with the experiences of other professionals who were not in this study, yet familiar with this phenomenon. To accomplish this, two parents who were raising a child diagnosed with FAS were asked to review each protocol in its entirety. This triangulation process (e.g., Denzin & Lincoln, [1994](#); Mathison, [1988](#)) was employed to enhance confirmability of the study and

involved consultation with co-researchers as well as the participation of external participants. Permission to share co-researcher narratives was granted prior to the external review process.

The dependability/audibility of this study was based on a decision trail (Koch, [1994](#)) that involved coherent presentation, including (a) described interest in the study, (b) purpose of the study, (c) co-researcher selection, (d) narrative collection and its time line, (e) the context of the interviews and, (f) narrative analysis. Because the credibility of this study was established linguistically and not statistically, it was imperative that the research be presented as a persuasive argument and that reported findings were well grounded and supported.

Results

When analyzing the research findings seven predominant themes emerged. These included (a) constant vigil, (b) effects on marriages, (c) child management, (d) parental issues, (e) interactions with professional community, (f) emancipation concerns, and (g) medical implications. The way in which the themes recurred was striking thus, suggesting similar lived experiences.

Theme I: Constant Vigil

The co-researchers described their constant vigilance in an effort to ensure the well-being of their children. Due the unpredictable behavior of these youngsters, and their inability to protect themselves from exploitation, the co-researchers maintained a watchful eye. Consequently, concern translated into a sense of protectiveness and hypervigilance about present and future situations.

Protectiveness

The co-researchers elaborated on their protectiveness, particularly when considering the current and potential challenges confronting their children. In an attempt to guard their children from exploitation and physical harm, there was a tendency for parents to overextend themselves. Inherent in this process, was a simultaneous attempt to normalize the child's life. Helen recalled,

For the longest time I wouldn't let ___ in the kitchen and out the clear blue sky one day, my husband said to me, "Did ___ and ___ ever burn themselves or cut themselves or something"? And I said, "Oh yea, remember when...". I could remember stories, I remember when ___ stuck her finger in a can that she had opened to pull the lid out and almost cut off the end of her finger and stuff like that. He said, "why don't you let ___ do things, don't you think if he burns himself, if he cuts himself, so what"! So okay, I guess if ___ burns himself, hopefully he will learn from that or cuts himself or something. Yes, I think you can be too overprotective.

As some co-researchers projected into the future, rather than foreseeing an independent living scenario for their child they envisioned a supervised group home environment as more appropriate in providing the necessary care and protection. The co-researchers perceived their children as followers who were vulnerable and easily mislead. Alana noted,

I see ___ always been taken advantage of without a group home setting. Because kids are kids and we've had situations where ___ was definitely been taken advantage of. He's been taken advantage of and he doesn't even realize that.

Hypervigilance

The co-researchers reported being constantly alert to the behavior and location of their children. This hypervigilance was often culminated in physical and emotional parental exhaustion. Debbie stated,

I developed a suspicion, a certain amount of distrust, in social situations especially. I was reluctant to have her leave my side and interact with other people. A lot of times I wasn't sure what her behavior would be, her comments, she began to do things that were sort of disrupting to the family...

Helen added,

...but you know how it is when you get visiting and this and that and there is also lots of other people in those areas, and yes, I always felt like even though I was talking to you I was always looking over here where is he, and who is he with.

Helen goes on to describe how the constant supervision of a child can slowly wear on parents and eventually alter their perspective on raising children with FAS.

I think at that time he didn't realized the amount of hypervigilance that was required to supervise her, especially as she was becoming more sexually aware and more into junior high, drinking and the possibility of drugs, smoking and all of those kinds of things and I think it was very much a drain on him.

The commitment involved in providing ongoing supervision of their children sometimes translated into a lack of mobility for the co-researchers. As they became increasingly cognizant of the young person's needs, the co-researchers remained close to home. Alana remarked,

For quite a long time we didn't go much anywhere just because it was such a hassle because it was a constant to have your eye on him every minute.

Theme II: Effect on Marriages

The co-researchers discussed the varying degrees of stress and strain that can be experienced by couples when raising children with FAS. According to the co-researchers, it is imperative that couples continually share their frustrations and discuss their perceptions with one another to remain mutually supportive.

Helen said it this way,

I think it makes it better because as a joint effort you just pull together. I know ___ and I, when we took this child, well actually all foster children that have come in and out of the home, it is a joint effort and we realize we all have to work together. Not that we don't get mad and frustrated at one another sometimes, and I think we see that with one another more so with ___ than with our own two children. It's that sometimes he thinks I'm wrong and sometimes I think he's wrong and how we approach and how we do things.

The willingness of couples to remain committed to their relationship while processing difficult periods was considered vital to marital stability. Rather than becoming embroiled in disagreements about child-rearing practices, it is important that couples confirm their commitment to each other and the challenges they face. Jane and Alana reported:

A lot of families have broken up over it, but you know we are very fortunate that we both think the same way about the children. I think they have to have a pretty strong one (relationship) to start with and have that commitment to each other, you know, no matter what. I'm mad at you right now, but you know, I'm not going to leave, I'm mad. We'll get over it, we'll work this through.

The challenge inherent in raising a child with FAS can take its toll and can unfortunately eventuate in the dissolution of a marriage. Debbie and Fred respectively described the problems that can surface in a marriage and allude to the systemic implications of marital dissolution,

...it's exhausting and I think it is one of the things that precipitated the divorce in the family. The frustrations that we had all reached sort of a pinnacle of emotion frustration, mid-life crisis, maturing teenagers, empty nest, college coming, and these kinds of things were going on. If there is strain on that marriage and that marriage isn't working that's not good for those kids either. If the marriage breaks up obviously the placement breaks up too and there you go, your in this cycle of kids getting bounced form one home to another, to another.

Theme III: Child Management

Manipulative Behavior

The co-researchers recognized the ability of children with FAS to manipulate situations. Consequently, they emphasized the importance of parental collaboration to enhance consistency and to prevent children from forming a coalition with a parent. Kaye noted,

You know, first of all my husband and I have to figure out what our goals are going to be and how we are to approach _____ before we are going to do because she is real manipulative or she can be, you know. She would, if my husband and I would have an argument about something, she was ready to jump on his side and then I would be the bad guy.

Debbie concurred and said,

That was one of her coping skills. Verbally she coped very well, she could sort of blend right in, she could follow conversations and believed or lead people where she wanted them to be. ___ was a very good manipulator.

Unmanageable Behavior

An additional challenge of rearing child with FAS includes the threat of physical outbursts and violence. This becomes a heightened concern as children grow older and physically stronger. Kaye elaborated,

So I had a desk in the living room and this was where she was going to do her homework and she bit me one night. So there was something else going on here for her to be biting, I think she was in the fifth grade by this time.

Fred noted,

___ would go totally out-of-control. I would physically restrain him by holding him down so he wouldn't hurt himself or hurt anybody else, because he would kick and scream and bit and everything.

Disguising Their Disability

The co-researchers reported that their children were ashamed of their disability and often jeopardized their own development in an attempt to hide their limitations. In an attempt to be included in peer related activities, children with FAS sometimes behave in ways that paradoxically alienate them from their peers. Alana stated,

By hiding his disability he's kind of become the class clown, because he feels that way if they are laughing at him their laughing because he's trying to be funny instead of laughing at him because he's you know, different.

Kaye remarked,

You know, she was trying to hide the disability so much, she spending a lot of energy hiding her disability rather than being able to deal with it so we could get a handle on it.

A typical consequence of childrens' attempt to disguise their disability involved personal isolation or remaining inconspicuous in the classroom despite needing help and direction. Debbie commented,

She didn't feel always that safe, in that, one of the things with ____, she didn't want to stand out and I think that happens with a number of kids, normal kids too, that go through school, is that they don't want to draw attention to themselves by standing out and an ignorant way or a way that is popular and so rather than ask the questions that she needed to know, she would pretend to know the answers to things or pretend to follow directions... She would not acknowledge her

disability and then when she was in other mainstream classes she would not ask for help. She would just try to find her way going along with what everyone else was doing.

Sequence and Routines

The co-researchers commented on the importance children with FAS attribute to sequences and routines. They also highlighted the remarkable ability of their children to remember a sequence of events. When a sequence of events was disrupted, the children would sometimes react frantically. Fred related,

It seems like if you walk into a plan that you give him: A, B, C, D, but you better not go A, B, E,...

Jane and Alana describe similar experiences:

Monday we had an auditory appointment and on the way home I thought well, I'll take a different route. Well the minute I turned off the street normally stay on, ___ just came unglued. Crying and screaming because he didn't think we were going to go home. I can remember a couple of years ago, I would say, "Get ready __, we are going to Missoula and I have to get gas, go to the library, stop at a friend's house, go to the bank, and get groceries on our way home". His memory is like (snap!) for something like that. If I even deviate from that, like go to the bank first, he was in a panic.

Theme IV: Parental Issues

All co-researchers had successfully parented their own biological children. This factor proved to be important in that co-researchers reported a sense of inadequacy when unexpectedly encountering the unique challenges inherent in raising children with FAS. In other words, parenting strategies that were effective with their own biological children did not always transfer over to the parenting children with FAS. Experiencing a lack of success in teaching these children age appropriate skills, the co-researchers began to question and doubt their own abilities. As shared by Debbie:

And had we known more specifically about what was going on, I think it would have been easier for us to cope and for me, I was such a perfectionist that time, I kept thinking that we could do this and we could do it right and it never happened that way. ...I think when I finally did read about what FAS was about, it was like a weight was just lifted off my mind and I felt like, Oh, this is what I needed to know all these years.

Jane also remarked,

We've worked on the good times, we..., a lot of joy and yet there has always been this guilt feeling on my part. You know, why can't I do better. Why can't I make the right decisions, go in the right direction. So when they say that the birth moms who are raising these kids feel guilty, the adopted moms feel just as guilty because you want to do so much.

Parental Adjustment

The co-researchers described how their ability to effectively parent and accommodate children with FAS developed over time and with experience. Since they were unaware of the FAS diagnosis, the co-researchers explained that their skills developed through a process of trial and error. Alana explained,

It takes someone with a real high energy level to do it. You have to have the high energy level but still low key enough to let things run off your back. You have to draw the line and say this is what's important and this isn't...

Fred also mentioned:

On thing as far as consistency goes, I can agree with that to some point but then there is also each individual instance or thing that happens is different and requires a different way of handing it.

Alana commented,

Things change with a disabled child and you got to mellow out and also you get more experience. What things you have to expect and what things you can do something about and what things you can't. What things you have to learn for you to change not them.

Theme V: Interactions with Professional Community

Interactions with the professional community received mixed reviews by the co-researchers. On a positive note, professionals such as teachers, physicians, and social workers were perceived as helpful. There were also instances however, where professionals were considered disinterested and unsupportive. Jane said,

I've had physicians that just said, well that's the way it is, you know, and not really tried to dig and ferret out information. And I have had other ones that have just bent over backwards. Dr. ___has been involved, she has gotten me into so many things with FAS and gotten information for me.

Kaye noted,

I couldn't get the school to understand what her disabilities were to the full capacity.

Theme VI: Emancipation Concerns

The co-researchers expressed worry and anxiety about the eventual emancipation of their children. Without the necessary life and career skills, the co-researchers perceived their children as vulnerable and unable to care for themselves. Kaye, Debbie, and Jane commented respectively,

Well, I think I worry about when she grows up and how she would be when she is grown up. I want her to be able to go to school and her intelligence says she can. That's what my concern is

with these children and my daughter especially, she doesn't have any job skills and they are cutting back... She needs some kind of skill in a supervised atmosphere where she can function as a part of society and it never happened. I never saw it happen and I don't think it will in her life time now.

Transitional periods for these kids, puberty... I know they definitely think about sex just like any other normal child does. I guess I can see that as being a scary issue for ___ being exploited and taken advantage of sexually by the wrong people too and I don't know how that, we haven't gotten to that point yet, where we know how to handle that. How much he'll retain we don't know. And those are some things, issues that we don't even know where to go.

Theme VII: Medical Implications

The co-researchers underscored the extensive medical complications associated with FAS. Inherent in their stories, was the tenuous health of these youngsters and the enormous care that was required. In addition, the pain threshold of these children was described. Jane reported:

We met him at eight days, brought him home at 13 days, even though he only weighed four pounds and one ounce. Went through a lot of problems and all the time we were told that its low blood sugar, that's why his body trembles so much. Low blood sugar made him cry all night. We walked the floor from 10:00 at night til 7:00 in the morning, every night, eight months.

Helen stated,

For some reason ___ didn't have tear ducts... He has an incomplete eardrum on the left side... Both of ___ testicles were up, they were inside and they didn't come down.

Fred elaborated on the pain threshold of children with FAS and commented,

We first found out about that when they were little. We had a couch with big high arms and she was sitting on it with her arms up there. ___ pulled down on it and dislocated her elbow. She walked around and cried and she just held it up for a day or so and I looked at it and it just got worse than better. So I took her in and they straightened it out to X-ray it and it popped back in.

Discussion

This study explored the experiences of foster/adoptive parents who raise children diagnosed with FAS. Based on the findings, the potential role of family counselors in assisting these families was examined. When reflecting on the results of this study, it appears that family counselors can assist parents who face child management, relationship, and larger systems issues.

Although extant literature pertaining to FAS is important, it is limited to medical and behavioral issues. Consequently, there is an absence of information describing the experiences of foster/adoptive parents and more importantly, the implications of these experiences.

Unfortunately, without established research, findings from this study cannot be contrasted to expand existing knowledge regarding the experiences of families or potential family counselor involvement. As a first step, this study provides an initial glimpse into the world of parents and

suggests ways in which family counselors can begin assist foster/adoptive families who care for children diagnosed with FAS.

When considering the results of this study, it appears that family counselors can assume three roles including clinician, facilitator, and researcher/educator. Each role is briefly discussed below.

The Role of Clinician

As indicated in the results, child-related issues (e.g., behavior management, constant vigil, emancipation) were prominent among the co-researchers. Without an explanation or remedy for their child's behavior, parents can find themselves experiencing self-doubt and embroiled in marital disputes regarding child management strategies. Because FAS symptoms are not always detected or understood by the family counselors, parents can become isolated while grappling with issues and situations they face on a daily basis. Due to their knowledge about child development and parent-child issues, family counselors can intervene, suggest effective behavioral management strategies, and provide on-going support to parents and families.

The stress experienced by couples when providing care for children diagnosed with FAS can have a negative impact on their daily parenting efforts, personal well being, and overall marital relationship. Again, as indicated in the results, each co-researcher noted the potential negative effects of raising a child diagnosed with FAS could have on a marriage. If left unattended these issues can fester, transcend the couple, and affect the entire family system. For example, marital instability and/or the dissolution of marriages can result in children diagnosed with FAS experiencing multiple placements and eventual disruption in their social and academic routines. Consequently, counselor intervention and support is critical and increased attention needs to be devoted to prevention and the systemic implications associated with the stress involved in raising children diagnosed with FAS.

In summary, the clinical intervention by family counselors can involve child management, parent-child relationship, and marital issues. In terms of the latter issue, early intervention and educating parents about the demands and potential implications associated with raising children diagnosed with FAS appears critical.

The Role of Facilitator

As suggested in the findings, due to a lack of pertinent information foster/adoptive parents remain uncertain, frustrated, and worried about the current circumstances and future of their children. Being unaware of how children diagnosed with FAS generally fare in the future, parents remain apprehensive and rely on word of mouth and/or sporadic informational meetings to learn about personal experiences, concerns, and coping strategies. To ameliorate unnecessary stress, worry, and confusion, family counselors can assume a leadership role in organizing and facilitating large and small informational meetings/consultations for parents. Due to their training in systems theory, family counselors can be instrumental in bridging relationships and in facilitating a collaborative union between parents and family counselors (e.g., teachers, social workers, physicians). Appreciating the circumstances of both parents and professionals, family

counselors can co-create a cooperative context wherein frustration as well as success is shared. While assuming a meta-position, family counselors can work toward enhancing communication between parents and can underscore their common goal of providing a safe and fulfilling life for children diagnosed with FAS. Family counselors who understand larger systems issues (Imber-Black, [1988](#)) and the systemic implications of chronic medical conditions (e.g., McDaniel, Hepworth, & Doherty, [1992](#); Rolland, [1994](#)) can particularly helpful in co-creating collaborative environments.

The Role of Researcher/Educator

Counseling research can also be directed toward gaining increased insight into the structure and functioning of foster/adoptive families who raise children diagnosed with FAS. Future research ideas include investigating the differences between rural and urban families, the contrast between single and dual parent families, and the effects of caring for children diagnosed with FAS on biological offspring. To decrease parental isolation, frustration, and trepidation research findings can be disseminated to both professionals and parents through appropriate sources. As more data is gathered, services can be designed, implemented, and investigated to assist parents and children diagnosed with FAS.

Limitations of this Study

Despite the steps, which were taken to enhance the trustworthiness of the study, the subjective nature inherent in this research needs to be acknowledged. Further, criticism could be directed toward the sample size of co-researchers. It should be reiterated, however, that smaller sample sizes may afford researchers opportunities to get a deeper understanding of co-researcher experiences (Morse, [1994](#); Sandelowski, [1995](#)). Finally, no claim to universal generalizability of the results can be made.

Conclusion

Despite the high number of children diagnosed with FAS and the unfortunate ramifications associated with syndrome, the experiences and needs of parents who raise these children remains surprisingly under-investigated. To reverse this trend, this paper discusses findings of a study pertaining to the lived experiences of foster/ adoptive parents and the potential role of family counselors.

When reflecting on the data, and considering the unique needs of parents and families, it is suggested that family counselors are in an ideal position to assist families and professional colleagues as a result of their specialized training and relational skills. As elaborated in this paper, various counselor roles can include clinician, facilitator, and researcher/educator. Regardless of the role(s) they assume, however, family counselors can be instrumental in helping parents who raise children diagnosed with FAS and in better understanding the systemic effects of this syndrome.

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Appendix A

First Order Thematic Abstraction of Alana's Experience

Excerpts from transcribed interview	Paraphrase	Themes
<p>1. I wish somebody had been there for me. I wish somebody had said, "Gosh you can do it this way, it's going to make it easier. That's why I let people call me 24 hours a day if they want to. If they need me, call me, because nobody was there for me. I had nobody say, "It's going to be OK. so you failed in this particular spot, some you can't, we had an eight year old that couldn't tie his shoes, so you can't tie shoes, so what!"</p>	<p>Feeling alone and isolated increased her compassion for other parents who require support.</p>	<p>Increased empathy</p>
<p>2. OK, it's been a challenge. There has been the good times and the bad times but we don't focus on the bad times. We don't reflect on all the disappointments we had with the therapist and all of that. We try to think positive. We've worked on the good times.</p>	<p>Despite enduring hardships, a positive disposition is sustained.</p>	<p>Remaining optimistic</p>

Appendix B

Second Order Thematic Clusters of Helen's Experience

First Order Clusters	Cluster Description
<p>1. Contending with misinformed community professionals</p>	<p>Although invested in fulfilling her parental obligations, Helen discusses the obstacles parents face when attempting to secure necessary services and support.</p>
<p>2. Recognizing potential and appreciating the need for supervision and protection</p>	<p>Despite witnessing areas of growth and development, Helen realizes the limitations and vulnerability of FAS children and their need for ongoing protection.</p>

Appendix C

Second Order Themes

Co-Researchers

	Helen	Debbie	Jane	Alana	Kaye	Fred
Constant Vigil	X	X	X	X	X	X
Effects on Marriage	X	X	X	X	X	X
Child Management	X	X	X	X	X	X
Parental Issues	X	X	X	X	X	X
Interactions with Community Professionals	X	X	X	X		
Emancipation Concerns	X	X	X	X		
Medical Implications	X	X	X	X	X	X

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