FEELING DIFFERENT: THE EXPERIENCE OF LIVING WITH FETAL ALCOHOL SPECTRUM DISORDER

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This paper is dedicated to the memory of Kim Meawasige who was a mentor and a true friend. Her love for her own children and others will sustain her memory forever.

ABSTRACT

Background

In Canada the incidences of Fetal Alcohol Spectrum Disorder (FASD) is estimated to be in 1 in 100 live births Caused by prenatal exposure to alcohol, the disorder is the leading cause of developmental and cognitive disabilities among Canadian children and its effects are life lasting. No research has attempted to describe the experience of living with FASD from the perspective of Canadian children.

Purpose

The main purpose of this study was to describe the children’s experience of living with FASD.

Methods

A qualitative method was used to examine the children’s experiences. Twenty-two (22) children, aged 6 to 18 years, living in urban and rural communities across Canada participated in an unstructured in-depth interview. Data was analysed using Colaizzi’s qualitative method.

Results

For all children in this study, living day-to-day with FASD meant ***feeling different***. Within this construct *knowing the disability*; *feeling alone-feeling supported*, and *overcoming the disability* were dominant themes which emerged.

Conclusion

Implications for practice and research have been described.

Keywords: *Fetal Alcohol Spectrum Disorder, children’s experience, qualitative research*

Fetal Alcohol Spectrum Disorder acknowledges that Fetal Alcohol Syndrome (FAS) is a continuum, with differing degrees of expression of dysfunction and malformation. The full Fetal Alcohol Syndrome is characterized by the triad of signs: 1) prenatal and postnatal growth retardation; 2) characteristic facial anomalies including short palpebral fissures, flat philtrum, and thin vermilion border of the upper lip; and 3) central nervous system dysfunction demonstrated by intellectual impairment and/or structural abnormalities, microcephaly, developmental delay, and a complex pattern of behaviours.[1-5] Children with FAS often display characteristics such as extreme hyperactivity, aggressiveness, poor judgment, speech and language difficulties. Other clinical manifestations of FAS may include cardiac anomalies, urogenital defects, skeletal abnormalities, visual, hearing problems and others. Two other diagnostic terms within the Fetal Alcohol Spectrum: “Partial Fetal Alcohol Syndrome (PFAS)”, and “Alcohol-Related Neuro-Developmental Disorder” (ARND) are used to describe cases of lesser severity in terms of organ anomalies, but often with very serious evidence of neurotoxicity.[1,3,4,5]

Research on the topic of Fetal Alcohol Syndrome has demonstrated the physical, cognitive, and behavioral characteristics of the condition.[1-8] The characteristics of FASD described in past research suggest the impact that prenatal exposure to alcohol has on the day to day life of those living with the condition. Two studies have explored living with FASD from the perspective of young adults.[9,10] One study examined persistence in high school among students with Fetal Alcohol Spectrum Disorder (FASD).[11] However, no study has sought to measure the impact of FASD on the day-to-day life of Canadian children. Thus, this study will explore the children's experiences.

METHODS

As little is known about the children's experience, the qualitative method was most appropriate for exploring the phenomenon of living day to day with FASD. Researchers using the qualitative approach often see their work as having its theoretical underpinnings in phenomenology. This perspective focuses on the subjective experiences of persons in everyday life. It emphasizes in-depth qualitative analysis of data to gain an understanding of how people interpret and give meaning to their situation.[12,13]

RESEARCH DESIGN

Research Question

What are children's experiences of living day-to-day with Fetal Alcohol Spectrum Disorder?

Setting and Sample

As the goal of the qualitative method is to provide an accurate description to uncover the "meaning" inherent in a particular experience, in this study the researcher sought to interview children diagnosed within the overall category of FASD. In consultation with both parents and expert clinicians who have worked with children with FASD, it was decided that children as young as 6-years of age may have the cognitive ability and verbal skills to participate in the interview.

Selection Criteria

The participants in the study were:

1) Diagnosed with FAS, PFAS, or ARND.
2) Six (6) to 18 years of age.
3) Able to speak and understand English well enough to participate in an in-depth interview.

In keeping with the qualitative approach, the sample size was small. Qualitative research does not aim to generalize findings. Rather, an in-depth description of the phenomenon under study was provided. In this study, 22 children diagnosed within the Fetal Alcohol Spectrum were interviewed. The qualitative method does not seek to impose restrictions on variables and supports using a heterogeneous sample. Therefore, a sample which represented differences in age, gender, severity of illness, and location was recruited. The sample was recruited on a convenience basis from 18 FASD support groups across Canada. A designated contact person(s) in each parent group, across Canada, recruited children who met the selection criteria. The study was approved by the joint university/institutional Research Ethics Board and all participants/guardians provided written informed consent.

Data Collection Procedures

A very important tool for gathering data in a qualitative study is the open, unstructured interview. All of the children were interviewed in their own homes. Researchers support the use of this strategy to elicit emic data and to gain a better understanding of the participant's experience.[14] In order to facilitate the interview, the researcher attempted to establish a rapport with the informant, and to establish a reasonable degree of comfort and trust.

To obtain a complete description of the children's experience, each participant was interviewed up to three times for approximately 30 to 45 minutes. Interviews were conducted once a week or every other week. The data were collected in a relaxed atmosphere with sufficient time allowed to communicate an interest in understanding the informant's experience and to encourage a full description. In the course of the interviews, the researcher asked the children to respond to the following broad questions:

1) What does Fetal Alcohol Spectrum Disorder mean to you?
2) How does having Fetal Alcohol Spectrum Disorder make you feel?

3) Please tell me about your day-to-day experiences of living with Fetal Alcohol Spectrum Disorder. Tell me about living with Fetal Alcohol Spectrum Disorder.

The object of the qualitative interview was not to direct the individual's descriptions, but rather to let the conversation flow from the informant.[15,16] Therefore, in the study, care was taken not to rephrase the participants' words as this would tend to direct, or lead the discussion. Interviewing techniques such as restating the informant's exact words were used to encourage the child to describe his or her experience in more depth. The use of probing questions was avoided, as this technique also tends to direct or lead the conversation. Throughout the child's description of their experience, questions were asked only when it was necessary to clarify what the informant was relating.

In the qualitative interview, it is important to record the informant's description of his or her experience as accurately and completely as possible.[12] Thus, permission to tape-record the interview from the parent/and or child was sought. Two children aged 16 and 18 refused to be tape-recorded. When consent was denied, the researcher relied solely on careful note taking during and immediately after the interview.

Data Analysis Procedures

All interviews were transcribed word by word onto the computer program Microsoft Word by the Principal Investigator (PI). An adaptation of Colaizzi's[17] phenomenological method for analyzing written documents was conducted. Colaizzi[17] clearly defined a seven-step procedure allowing others not involved in the research to follow the analytic process. Unlike other phenomenological methods, Colaizzi's[17] procedure calls for a final validation of the findings to be achieved by returning to each of the participants. This final validation serves to increase the credibility or internal validity of the research. The following seven-step procedure for analyzing qualitative data was conducted. The researcher first read through the entire interview several times for a sense of the whole.

1) "Significant statements" which are phrases or sentences that directly pertain to the investigated phenomena were identified in the transcript and underlined.
2) The next step of data analysis involved formulating meanings that emerged from the significant statements. Here, the researcher used creative insight to move from what the participants literally said, to what they meant.
3) When formulating meanings, the researcher took into account the context in which the statements were said and the non-verbal behavior of the participant. Formulated meanings can be a very difficult aspect of data analysis. To ensure validity of the data another researcher on the research team audited the formulated meanings of one of the interviews.
4) The formulated meanings of all of the transcripts were then organized into clusters of themes. Organizing the meanings into clusters allowed for the emergence and identification of themes common to all interviews.
5) The PI then returned to the original transcripts of all of the interviews. She read the transcripts again to determine if anything contained in the original interviews are not accounted for in the clusters of themes. She also determined whether the clusters proposed anything which was not implied in the original transcripts. Colaizzi[18] noted that if the cluster contains themes which are alien to the original interviews, then the first four steps of the analysis must be re-examined or conducted again.
6) In the next step of the analysis, all of the findings were integrated into an exhaustive description of the phenomenon of living with FASD. This description was a narrative integration of the formulated meanings, themes, and theme clusters.
7) Next, this exhaustive description of the findings was reduced to a descriptive summary. The descriptive summary was an integration and synthesis of the common components of the experience described in the more lengthy exhaustive description.

8) In the last step of Colaizzi's[17] procedure of analysis, the researcher returned to each participant to ask if the descriptive summary described his or her experience. This step was important for validation of the formulated meanings and allowed children to validate the findings as accurately representing the experience of living with FASD. When validating the findings with the participants in this study, the researcher also read sentences from the exhaustive description to ensure the children understood the descriptive summary. Two of the younger children, aged 6 and 9 years, did not want the descriptive summary read to them. The other 20 children agreed with the findings as representing their experience.

RESULTS

Characteristics of the Sample

It is not the aim of the qualitative method to locate and compare subgroups within a set according to characteristics. Rather the aim is to describe the members of a self-defined social set. Twenty-two (22) children participated in the phenomenological interview. All of the children were diagnosed within the Fetal Alcohol Spectrum. All of the children were aware of their diagnosis. Demographic characteristics were obtained and are presented in Table 1.

TABLE 1 Characteristics of the Children

Characteristics		**Number**	**Percentage (%)**
Sex:	Male	12	54.5
	Female	10	45.5
Diagnosis:	ARND	11	50
	PFAS	6	27.3
	FAS	5	22.7
Cultural Group:	Native Canadian	9	40.9
	Euro-Canadian	11	50.0
	Jamaican-Canadian	01	0.45
	Romanian-Canadian	01	0.45
Age (years):	6-8	6	27.3
	9-11	6	27.3
	12-14	5	22.7
	15-18	5	22.7
Mean Age = 11.2 years			
Median Age = 11.0 years			
Relationship to Parent:	Biological	3	13.6
	Kinship	2	9.1
	Adoptive	12	54.5
	Foster	5	22.7
Cognitive Delay*:	Not Delayed	4	18.7
	Mild	12	54.5
	Moderate	6	27.3
	Severe	0	0
Place of Residence:**	West	8	36.4
	Central	8	36.4
	East	6	27.3

The level of disability – mild, moderate, severe - was a clinical judgment determined by a health professional, in collaboration with the caregiver, based on deficits in intellectual, adaptive behaviour, and/or organ anomalies that significantly limited an individual's effectiveness in meeting the standards of maturation, learning, personal independence, or social responsibility that is expected of the individual's age-level. ** <u>West</u>: Saskatchewan, Alberta, British Columbia, and the Yukon/North West Territories; <u>Central:</u> Ontario and Manitoba; <u>East:</u> Newfoundland, New Brunswick, Nova Scotia, and Quebec.

Twenty-two (22) of the children participated in the in-depth interview. Twelve (12) of the participants were male and 10 were female. They ranged in age from 6 to 18 years with a mean age of 11.2 years. Eleven (11) of the children were Euro-Canadian. Nine (9) of the children were Native Canadian and represented the Cree, Sioux and Ojibwe people of Canada. One (1) child was Jamaican-Canadian and 1 was Romanian.

Five (5) of the twenty-two children had been diagnosed with Fetal Alcohol Syndrome, 6 had been diagnosed with PFAS, and 11 had been diagnosed with Alcohol-Related Neuro-developmental Disorder.

Two (2) of the children were living with their biological father, 1 was in the care of his biological mother, 2 were living with paternal grandparents, 12 of the children were living with adoptive parents, and 5 children were living with foster parents.

Eight (8) of the children had a history of health problems such as cardiac defects, feeding issues, respiratory illnesses, dental problems, and skeletal defects. At the time of the interview, all of the children identified themselves as healthy. Six (6) of the children were identified as having moderate cognitive delay, 12 had mild cognitive delay, and 4 children demonstrated no cognitive delay. All of the 22 children had behavioural problems including hyperactivity, poor judgment, aggressiveness, impulsiveness, immature social skills and others. All of the children openly described their day-to-day experiences of living with FASD.

Analysis of the data revealed three dominant themes which overlapped and supported one overarching construct. Two of the themes were constituted by subthemes. “Knowing the Disability” emerged as a dominant theme and was constituted by the subthemes: “Understanding the Limitations of the Disability” and “Experiencing the Unfairness of the FASD Etiology.” “Feeling Alone-Feeling Supported” was also a dominant theme and comprised of the subthemes “Feeling Alone with Other Kids” and “Feeling Supported by Parents.” “Overcoming the Disability” was the final dominant theme identified in the analysis of the data. “Feeling Different” emerged as an overarching construct which was central to the children’s experiences and encompassed all of the three dominant themes.

The three dominant themes were common to all of the children’s experiences despite age, gender, ethnicity or place of residence. Analysis of the data suggested that the experience of living with FASD was predominantly shaped by the characteristics of disability.

The findings of this study are presented theme by theme. The findings are illustrated by direct quotes from the participants. As much as possible, the researcher took care to ensure that all participants were represented in the quotations presented. When participants emphasized a word or phrase, that term is presented in ***bold italics.*** To facilitate clarity of the child’s words, if needed, the researcher entered her words in brackets after those of the child.

Exhaustive Description

Knowing the Disability

Knowing the Disability was a theme that was common to all of the children’s experience of living with FASD. The theme was constituted by two subthemes: “Understanding the Limitations of the Disability” and “Experiencing the Unfairness of the FASD Etiology.”

Understanding the Limitations of the Disability

All of the children understood the nature of the disability and how it affected their day-to-day life. Responses suggested that the participants attempted to understand the nature of their disability by identifying specific attributes that limited them or how FASD impacted on their daily functioning. Children spontaneously discussed issues such as learning problems, attention and behavioural problems, motor disabilities, and social difficulties associated with FASD.

> An 18-year-old stated: “It’s hard dealing with work because of attention and stuff with friends. I say things they (his friends) wouldn’t. … (I) can’t keep focused. ”When asked how FASD affects his day to day life, a 14-year-old stated: “Sometimes I have trouble concentrating. I am concentrating on one (activity), then I get distracted.”
>
> A 6-year- old stated: “My hands (his fine motor skills) don’t work as well as other kids”.

> A 10-year-old girl aware of the impact that prenatal exposure to alcohol had on her day-to-day learning stated: "Learning is hard. The teachers don't explain things (in a manner that allows her to understand)".

> An 8-year-old understood the nature of his disability: "(It's) hard, hard to keep out of trouble, and I am not that smart. I have to think. Like when I want to push a little kid. I have to stop and think."

For one participant, awareness of the diagnosis only came in late adolescence. This awareness gave her a better understanding of the nature of her disability and better insight into her behaviours. She stated:

> "It (the awareness of FASD) explained a lot of things. Before I heard (about the diagnosis) … It (the diagnosis) helped to explain how I handled things (emotional reaction to situations and her relationships) and possibly affects my temper".

Experiencing the Unfairness of the FASD Etiology

For all but one, knowing the disability meant experiencing the unfairness of the etiology of FASD. These participants understood that FASD was caused by prenatal exposure to alcohol, and were aware of the significant impact of drinking in pregnancy.

> An 18-year-old stated: "It's totally preventable…(people have) freedom, think about drinking during pregnancy. She (his biological mother) didn't stop. Didn't know (she was pregnant)… and she stopped when she knew". Later the same boy when talking about his experience living with FASD stated: "I realize it was not a choice. It was not a choice I could have made. (His exposure to alcohol before birth). ***It is a choice I had made for me."*** He demonstrated his frustration when he very poignantly stated: ***FAS is an unfair thing***. Seeing normal kids do things that are hard for me to do."

> A young 6-year-old stated: "Why did she have to make (use) alcohol. Our life (her and her brother's) could have been a better life".

> A 12-year-old girl stated: "Maybe it wasn't her (the biological mother) fault - look what it did to me. Sometimes I get really sad, and hoped she loved me".

Feeling Alone-Feeling Supported

Feeling Alone-Feeling Supported was the second dominant theme that was common to all of the children's experiences of living with Fetal Alcohol Spectrum Disorder. This theme was comprised of two sub-themes "Feeling Alone with Other Kids" and "Feeling Supported by Parents."

Feeling Alone With Other Kids

For children in this study, difficulty in making and keeping friends was demonstrated in the sub-theme "Feeling Alone with Other Kids." This subtheme implicitly emerged through the course of the interviews. All of the participants said they had friends, but no child in the course of the in-depth interview spontaneously described a close relationship with friends. Interviewing techniques consistent with the phenomenological method, such as restating the informant's exact words, were used to encourage the children to describe friendships, but no friendships were described. Nor did any child describe situations which included interactions with friends. Even when the researcher stepped away from the phenomenological method and asked the children to describe their friends, only one 8-year-old boy offered a name of a child who he liked and could talk to. Four (4) children did explicitly state that living with FASD meant feeling alone with other kids. For example,

> An 8-year-old stated: "No one likes me. There's… no one plays with me at recess."

> A 9- year-old stated: "I don't think I will ever have a friend like the other kids have."

> An 18-year-old talked about his difficulty in social situations with friends. He stated that unlike himself: "Others (kids his age) …socially deal with it, coping at (social interactions)… they are socially fit."

> A 10-year-old boy stated: "Even if they (the other children in his neighbourhood) don't play with me, I have my brother. (His brother was 16-years old). My brother really likes me."

Feeling Supported by Parents

For all children in this study, feeling supported by parents was a central feature of their experience of living with Fetal Alcohol Spectrum Disorder, and they spontaneously reported feeling supported and cared for by the parents. For example,

> An 11-year-old stated: "They love me and help me all the time." When talking about people in his life, another young boy with significant cognitive disabilities, stated: "Oh yeah, my parents. They are great." He talked about how his mom and dad helped him "concentrate and join things (play activities)."
>
> Similarly, a 10-year-old girl stated: "My dad and mom are great. My mom plays with me and my dad takes me fishing."

Participants often attributed success in handling their disability to the parent. For example,

> A 13-year-old boy stated: "I am glad I am on Dexedrine. It was my dad who thought of that (of using Dexedrine). It's good and helps me to focus. My dad helps me the most."
>
> A 6-year-old stated: "She (his mother) won't let them (teachers and other kids) be mean to me. She talks to them and ***loud***, and I do better at school. She's my mum."

Although children with FASD felt a special connection with the parent, and felt supported, they were also aware of the negative effects that their disability had on their parents.

> One 11-year-old boy who described himself as being very close to his mother, stated very seriously and somewhat sadly: "It (FASD) effects my family too. When I do something wrong, it emotionally bothers them."
>
> Similarly, a 9-year-old, after talking about the love he felt for his parents stated: "I argue too much with my mom."

Overcoming the Disability

Overcoming the Disability was a major theme in this study. All of the participants talked about how they tried to participate in life, despite their disability.

> A 12-year-old stated that having FAS "effects my concentration. If I concentrate on something. I can get distracted. But for me it feels normal." He then went on to describe how he participates in art, games and school despite problems in concentration.
>
> Similarly, a 9-year-old, despite significant cognitive and behavioural sequelae of prenatal exposure to alcohol, told about how he likes to participate in sports. "I like to play hockey. It's, I play on a team."
>
> An 11-year-old stated: "I ask my brother to help me with my homework. Uh, I am not going to look stupid. If I try and he helps me it really helps."
>
> A 9-year-old stated: "FASD is being sick a long, long time. But I can try and have a **very great life.**"

Feeling Different

Feeling Different emerged as an overarching construct in this study. For all of the 22 participants, the ongoing experience of living day-to-day with Fetal Alcohol Spectrum Disorder meant feeling different than other children. Feeling different was central to the children's experience and encompassed the three dominant themes. For example, as the children gained knowledge of their disability they compared their behaviours and performance to other healthy children. In their comparison of themselves to other children, there was an awareness of *feeling different.* Feeling different was also evidenced in the children's experience of feeling alone with other kids despite their connection to parents. Within the experience of feeling different these children struggled to overcome their disability, and not to use their disability as an excuse for not trying.

All children implicitly talked about how they felt different than others. For example, when asked, "How does having FAS make you feel?", or "What does FAS mean to you?", the children talked about how they were different than other children in "concentrating", in "focusing" and in "dealing with things (other people and situations)". Other children were more explicit in describing how they felt different. For example,

> An 8-year-old describing how he had no friends to play with at school stated: "I think differently from everyone. Everybody makes fun of me."

> An 18-year-old stated: “They (teachers, employers) expected me to do things I couldn’t. I have a hard time doing some things.” Others (kids his age) do things easier, get through work ….”

Descriptions of feeling different were often accompanied by feelings of frustration, sadness, and anger. For example, one boy talking about his experience of living with FASD stated with frustration and anger: “In the world it (FASD) is a mental disability. FAS is an ***unfair*** thing.”

> A 9-year-old boy talked about how he was in a special class in school, and stated very quietly: “I don’t feel smart.”
>
> Finally, an 8-year-old, talking about feeling different, both in his ability to think and his ability to attract friends, stated very poignantly: “It (the effects that FASD has on his life) is ***very*** sad.”

Descriptive Summary

The main purpose of this study was to describe the children’s experience of living with Fetal Alcohol Spectrum Disorder. Through unstructured in-depth interviews with 22 children, important insight was gained into that experience.

Specifically, for children in this study, living with FASD meant knowing the disability. All children had come to some understanding of how FASD impacted their day to day lives. For these children, FASD caused problems in learning, attention, focusing on a task, behaviours and relationships. For all but one of the children, knowing the disability meant experiencing the unfairness of the etiology of FASD. For all of the 22 participants living with FASD meant feeling unconnected with friends. No child spontaneously described their relationship with friends, and 4 children explicitly described their difficulties in making friends. However, for all of the 22 children, living with FASD meant feeling supported by their parent(s). The children felt cared for and supported by their parents, and often attributed success in handling their disability to the parent. Living with FASD also meant overcoming the disability. Despite their disabilities and the emotions that accompanied them, these children participated as much as they could in day-to-day life. Finally, living day-to-day with Fetal Alcohol Spectrum Disorder meant feeling different. Feeling different was the overarching construct in this study and it encompassed all of the dominant components of the children’s experiences.

DISCUSSION

The current research adds to the body of knowledge about the experiences of children living with a disability. In a review of the relevant research, only 10 studies could be identified that focused on the children’s perceptions of living with a disability.[18-27] The children in these studies lived with epilepsy, learning disabilities, and physical disabilities such as cerebral palsy. No study has examined the experience of children living with Fetal Alcohol Spectrum Disorder.

Children with FASD in this study demonstrated insight into the nature of their disability. Children spontaneously discussed issues such learning problems, attention and behavioural problems, motor disabilities, and social difficulties associated with FASD. This finding is consistent with other studies examining the experience of children with disabilities.[18,21-24,27] No past research could be identified that discussed children who struggled with the unfairness of the etiology of their disability. This may be unique to FASD given that it is an explicitly preventable condition, or may be due to the paucity of studies examining the experiences of children with other disabilities. Further research is needed.

For all participants in this study, “Feeling Alone” was a major sub-theme of the experience of living with FASD. In the course of the interviews, while some of the children stated that they had friends, these children did not talk about their friendships or the activities that they and their friends engaged in. Some children described their difficulty in making and keeping friends. This is in keeping with past research in which children with disabilities, particularly those with cognitive or behavioral problems, often described difficulty with peer relationships.[23,26]

For all children in this study, establishing a close relationship with their parent(s) was central to their experience of living with FASD, and they reported feeling supported and cared for by their parents. Participants often attributed success in handling their disability to the parent. A study by Chen and others[20] focusing on the experience of living with epilepsy, supported the current findings and found that coping with epilepsy meant “seeking support from family members”. Duquette and others[11] found that parental advocacy is an environmental factor that may protect adolescents with FASD from dropping out of high school.

Interestingly, the results of this study supports the results of a study examining the parents’ experience of Fetal Alcohol Syndrome.[28] For parents in the earlier study, raising a child with FASD meant honouring a commitment which evolved out of love for the child and often out of an awareness that the child needed them desperately. It would be interesting to see if improvement in peer relationship would impact on the child-parent relationship among children with FASD.

Overcoming the Disability was the third major theme of this study. All of the participants talked about how they tried to participate in life, despite their disability. This finding is consistent with the results of 4 past studies describing children’s experiences of disability.[19,22,25,27] .For example, Shikako-Thomas and colleagues[25] examined quality of life of adolescents with cerebral palsy, and found that these children wanted to participate in activities they valued. Berntsson and others[19] found that children with chronic diseases and disabilities identified personal growth in life as important for them to “feel good.”

Hightower and colleagues[22] found that children with epilepsy participated in sports, and were cognizant of ways to prevent seizures in order to cope with day-to-day life. Similarly, Stewart and others[27] found that students with learning disabilities employed a variety of coping techniques in an effort to successfully manage their disabilities in school, and get on with their life. The efforts that children with FASD make to successfully cope with day-to-day life demands that teachers and health professionals provide the necessary supports for these children to succeed.

Finally, all of the children who participated in this study reported that living with FASD meant Feeling Different. “Feeling Different” emerged as an overarching construct which was central to the children’s experiences and encompassed all of the three dominant themes. The children’s awareness and understanding of their disability, particularly their learning and behavioural problems, were key features of their Feeling Different. The theme of “Feeling Different” is in keeping with the results of a study by Barga[18] which found that children with learning disabilities experienced labeling, and stigmatization throughout their school years.

Limitations

The children spoke about being supported by their parents. The participants were recruited through parent support groups, suggesting a certain level of advocacy on behalf of their children. However, 50 percent of the participants did not attend the parent groups. Rather, they were known in their specific community to be raising children with FASD.

The majority of participants in the study were raised by adoptive or foster parents, and not biological parents. Available research indicate that children with FASD are cared for by adoptive and foster parents and suggest that participants in this study did not misrepresent the total population.[1] However, more data related to children raised in their biological homes may have resulted in additional findings.

Implications for Practice

The findings of this study suggest 4 implications for practice:

1) Socialization programs provided early in life may assist children to make and keep friends. However, creation of such programs is necessary. General programs, used by children with similar conditions, are either not available or have long-waiting lists. Government funding to allow already burdened families to utilize programs is crucial.

2) The children’s awareness of their limitations is clearly apparent in this study. Identifying and fostering strengths is an important intervention for these children. Parents should be assisted to identify programs, and be assisted to pay for programs that are not without costs. After- school educational programs to strengthen learning skills may be beneficial to some children, and some children may be interested in attending. Similarly, programs such as art classes, horse-back riding, and other recreational activities may make life much better for some children affected by FASD.

3) We must avoid managing or using “formulas” to assist children with FASD, but rather support their efforts to overcome their disability, and treat them as individuals. De-emphasizing labeling and

strengthening self-esteem is necessary. Like all children, children with FASD have tremendous strengths. Taking courses and building understanding of FASD is valuable, but we must all realize that no one child with FASD is the same, each comes to us with different genetic make-up, different life experiences, and different strengths and weaknesses. When the researchers initiated this study, there were many professionals who felt that children with FASD did not have the insight and ability to participate in this study. Not only did the children participate, but they told us what they need and how they desperately want to feel “less different” than other children.

4) Finally, dissemination of these study results may help professionals to learn from the children, assist policy makers to develop more programs, and foster government to fund program for children with FASD.

Implications for Research

Not only is there a need to implement programs, but there is a need to evaluate programs - both current general programs, and future FASD focused programs on the outcomes of children with FASD.

1) More in-depth research on why children with FASD often have difficulty making and keeping friend would be beneficial. Are the children not able to approach children to initiate friendship?

2) Do their behaviours make other children reluctant to have them as friends? Are children with FASD unable to maintain reciprocal conversation or play? All these questions need answering.

3) Having children identifying what life change could make them feel “less different” may lead to more effective programs than we (the study researchers) have identified.

4) Finally, larger studies to identify what age(s) or developmental stage(s) is the most difficult for the child with FASD may be beneficial. This may allow us to target the more vulnerable groups.

CONCLUSION

For all children in this study, living day-to-day with FASD meant ***feeling different***. Within this construct **knowing the disability**; **feeling alone-feeling supported** and **overcoming the disability** were dominant themes which emerged. Implications for practice and research have been described.

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