

The Complexities of Caring for Individuals with Fetal Alcohol Spectrum Disorder: The Perspective of Mothers

Abstract

Fetal Alcohol Spectrum Disorder (FASD) may be associated with a variety of challenges including developmental disabilities, hyperactivity, attention and impulse control problems, language delays, and social skills deficits. These problems can lead to "secondary disabilities" such as mental health issues, academic and vocational failure, substance abuse, and interactions with the justice system. Parents of children with FASD often struggle with the overwhelming demands of supporting their children. In this study Participatory Action Research was used to address two questions: What are the experiences of parents caring for children with FASD? and What do parents believe their families and children with FASD need to ensure good outcomes? The study included five mothers (either adoptive, foster or biological) of individuals with FASD. In their discussions participants described using unconventional parenting techniques and shared their guilt at being unable to meet the complex needs of their children. They expressed fear for the future as their children moved into adulthood. They discussed the need for lifelong parenting and for smoother transitions between children's and adult services. Participants felt empowered knowing that they were not alone in their challenges as parents.

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used to describe the range of disabilities caused by prenatal alcohol exposure. Disabilities associated with FASD may include developmental and intellectual disabilities, learning disabilities, attention deficits, hyperactivity, poor impulse control and social skills, and language and memory deficits (Health Canada, 2007). Sometimes these developmental delays appear subtly as poor judgment, lack of motivation, or inconstant performance (Buxton, 2004; Dorris, 1989; Graef, 2004; Wemigwans, 2005). FASD has been referred to as an "invisible physical disability," as it is often the brain that has been affected, making it very difficult to see (Malbin, 2007, p. 27).

Secondary disabilities associated with FASD occur when young people with FASD do not receive a diagnosis or the environmental support and modification they require (Doris, 1989; Buxton 2004; Malbin, 2007; Michaud, M. & Michaud, S., 2003). Buxton (2004) has referred to secondary disabilities as "tangled knot of connected problems" (p. 183). Streissguth and colleagues (1996) examined 473 individuals with FASD and defined several categories of secondary disabilities including mental health problems, school failure or dropout, substance abuse, inappropriate sexual behavior, trouble with the law, trouble maintaining employment or independent liv-

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ing, and trouble parenting (Streissguth, Barr, Kogan, & Bookstein, 1996). Streissguth and Kanter (1997) also identified factors that protect against the development of secondary disabilities, including early diagnosis (before the age of 6 years), living in a stable and nurturing home, having basic needs met, never experiencing violence against oneself, staying in each living situation for an average of more than 2.8 years, experiencing a good quality home-life from age 8 to 12 years, being found eligible for developmental disability services, and having a diagnosis of the full Fetal Alcohol Syndrome (pp. 22–64).

Due to this disability's invisible nature, parenting can be challenging. Parents can find themselves struggling with the overwhelming demands of supporting children, and not really knowing what is causing their child's behavior (Doris, 1989; Buxton 2004; Malbin, 2007). Graefe (2004) reported that the need for constant supervision and support can be exhausting for parents. As well, caregivers are frequently blamed for their child's behaviour and told the problem is poor parenting. Graefe (2004) also noted that early diagnosis and proper intervention is the key for families trying to safeguard against the secondary effects of alcohol exposure. She argued that the impairment caused by prenatal alcohol exposure can infiltrate even the best of environments to cause behavior problems and create serious parenting challenges. A diagnosis can help families understand and explain their child's behavior, and assists them in responding more effectively. It also helps families to change their expectations in order to build on the strengths of the child (Buxton 2004; Malbin, 2007, Streissguth et al. 1997).

In their research with families managing FASD, Brown, Sigvaldason, and Bednar (2004) reported that parents felt that their expertise regarding the needs of their children was not well received or well accepted by other professionals. Additionally, parents reported that they did not feel valued or a part of team when involved with service providers, which increased their stress. In her research with mothers of children with disabilities, Green (2007) reported that "they loved and valued their children and found significant benefits in the experience of raising them" (p. 161). Challenges associated with raising a child with FASD, included the

financial burden of raising children with disabilities and the difficulty of navigating social service systems that were poorly coordinated or non-existent. Mothers in the study stated that a great deal of parental stress was not caused by caring for the child, but rather dealing with the stigmatization in the community.

Brown and colleagues (2005) conducted a study with foster parents caring for children with FASD. Foster parents described the need for social support, material support, a structured home environment, professionals, other foster parents, an understanding of FASD, the right kind of personality, and organizational skills. They repeatedly mentioned the need for responsive professionals to deal with, and the need for these professionals to work together and treat them with respect.

The purpose of the present research was to address two primary research questions: (1) What are the experiences of parents caring for children with FASD?; and (2) What do parents believe their families and children with FASD need in order to ensure positive outcomes free from secondary disabilities? This paper is part of a Master's level research project entitled "Building Bridges: Understanding the experience of mothers who created 'Picture' This: Life as a Parent of Children with FASD."

Materials and Methods

Participants and Procedures

This study was reviewed and approved by the Research Ethics Board of a university in Ontario. It drew upon a group of five women who had previously participated in a photo voice project entitled: "Picture This": Life as a Parent of Children with FASD (Lauer, 2007). The five women were reconnected for this research study. The research took place in Sioux Lookout, Ontario.

Photo voice is a Participatory Action Research (PAR) strategy in which people are brought together to produce and discuss photographs in an attempt to create personal and community change (Creswell, 2007; Wallace, 2006; Wang, Yi, Tao, & Carovano, 1998). "Using cameras, participants document the reality of their

lives”(Wang et al., 1998, p. 75). By sharing and talking about their photographs, “they use the power found in visual images to communicate their life experience, expertise and knowledge” (Wang et al., 1998, p. 75). The project was later turned into a photo exhibit, podcast, and DVD film, all of which have been presented across Ontario and into Manitoba. The podcast can be seen online at the citizen shift website.

Procedure

This study employed a Participatory Action Research (PAR) model and honored the empowerment that was generated because of the women’s involvement in the original photo voice project. PAR is a qualitative research method that brings people together to facilitate collaboration, advocacy, and social change (Creswell, 2003; Wallace, 2006). It is meant to build upon relationships in order to facilitate transformation for the participants and change for the community (Wallace, 2006). Though PAR projects can vary in their methods and scope, they generally have the following basic steps: problem definition, getting to know the community, gathering participants, problem formulation, research design, data gathering, data analysis and utilization of results (Park, Brydon-Miller, Hall, & Jackson, 1993).

Data Collection

A total of five group sessions were conducted between November 2009 and May 2010. Each session was audio taped and transcribed. The first session was used to review ground rules and consent, discuss the risks inherent in this type of research, review the researcher’s role, define the research question, and develop ideas around data collection. In session two, the group re-examined the research questions and discussed the impact that photo voice had on their lives, as well as the lives of their children. A decision was made that participants would attend the next meeting with photos that had been taken for the original photo voice project but never used. During sessions three and four the group used these photographs to generate discussion, and invited a local professional (facilitator of the Healthy Generations Family Support Program) who had worked in the area of FASD, to attend. During these sessions, the

participants identified common themes that had emerged from the data and the local professional provided feedback in terms of themes consistent with her experience in work with other parents and children with FASD. Session five occurred four months after session four. The goal was to provide participants with information about the data analysis, results, and discussions. The participants were asked to review and edit the results. This was done to ensure that they felt their ideas were represented correctly. The women also discussed the action agenda and made concrete plans to take some next steps to act on the results of the project.

Strategies for Validating Findings

To ensure internal validity, the researcher used a variety of strategies identified by Creswell (2003), including member checking, using rich thick descriptions, clarifying researcher bias, demonstrating expertise, participatory verification and conducting of a peer review. Detailed and comprehensive descriptions of experiences or ideas were generated by the participants based on the data collected and the dialogue within the group process. Direct quotations were used for every concept (Park, Brydon-Miller, Hall, & Jackson, 1993).

Researcher bias was outlined at the onset of the project. This included a description of the first author’s (DM) life-long connection with a family member affected by FASD, as well as personal investment in the photo voice project as a participant and parent to children with FASD. DM has spent 14 years within the social work field in which clinical experience has been gained working with families and children living with FASD.

Member checking exercises were conducted regularly by providing transcripts to participants after each session to ensure that data was accurate. The group was asked to identify concepts and themes in all of the data. Members were also provided with a summary at the end of the project, and a group discussion was organized to confirm themes that had emerged, as well as make and decide which quotations should represent each theme, and make any modifications.

The facilitator of the Healthy Generations Family Support Program provided regular peer debriefing. This occurred in both a formal and informal manner, and happened at least three times in the course of the research. The facilitator has spent over 15 years working with families caring for children with FASD and provided important feedback on the validity of the information.

Results

Some of the major themes discussed and identified by the group are presented below along with direct quotations.

Theme 1: Everything We Have Learned as Parents Does Not Apply When Caring for a Child with FASD

The participants in this study felt that parenting could be challenging, but agreed that once they learned how to modify the environment for their children, rather than expect their children to change to fit the environment, it was easier. When discussing the challenges of parenting the way they were accustomed to operating before parenting children with FASD, one participant stated:

[It is challenging] if you are a care giver and if you can't parent the same as what has been taught to you or [the way] you understand parenting. And so everything you know doesn't apply. Everything you have been taught or [that] Dr. Spock taught you, whatever child management, behavior management, everything they teach you to do with kids doesn't work.

When caring for a child with FASD learning to change the environment to meet the needs of the child can be more effective than prescribing consequences for behavior or trying to change behavior (Buxton, 2004; Dorris, 1989; Malbin, 2007). Participants expressed remorse for falling back into old parenting patterns that they knew were not helpful for them or their children. These parenting techniques included yelling, talking too much, and prescribing consequences for misbehavior. Some participants stated:

And that has been my biggest struggle is getting that through to my head, in the heat of the moment. Like even today something came up, that I had to remind the boys of, again. And I am like how come I have to [pause] we are not going to finish that sentence.

I tried to punish [my child]. I tried to punish her, and punish her and punish her. And it got worse...

Theme 2: Walking a Fine Line

The participants agreed that it would not be easy to let their children go when the time came, and that it would be difficult to make the change from being completely responsible for their children to allowing them to make their own decisions and mistakes. One participant stated:

I don't even know how to let go, there ought to be training... after years and years of having been that intensely involved in another person's life, how do you let go? How do you do that? Cause I don't think that is going to be very graceful I can tell you that much, it is going to be pretty ugly. [all laughing]

Adolescence is a time of transition, where youth begin to aspire to have more independence and move away from parental controls. The women expressed concern that their children may not fully understand their disabilities or limitations and, because of this, might not accept help when they need it. They felt that this might compound the risks for their children. They also talked about the stress that would be caused in fighting with their children about accepting support. One participant stated:

Because you are not only fighting other people, you are fighting them too. That is the problem with it. You have to fight them too, to get the help. They have got to want to have help and they have got to want to... [pause]... that is going to be a big fight with him I think. I can see some of that already - like Mom, "go away."

The participants realized that they could cause damage to the relationship with their child if they were not careful in this process of providing ongoing support, yet allowing their children to grow up. For example, one participant stated:

What if you alienate your child? What happens if you, at that stage, end up losing your child through that? Which I know could easily happen to me.

You become the “society” that is giving him the secondary disability, because you just can’t give up control.

They recognized that their care and concern could be seen as judgmental in the eyes of their children. They worried that this might force their children out of safe relationships with them and into relationships with others who could be more accepting of their choices. A participant stated:

And if I was sitting in their shoes, would I want to be judged? As you get older you do get more sophisticated in your thinking but do I want to be judged in what I am doing or the choices I am making, even though I am making bad ones? Do I want my parent reminding me, all the time, that I am making bad choices? Probably not. I would want to stay far away from that. So... do you then gravitate towards more and more? Would my behavior then force that also? To follow that path to be with those people?

Young people who are welcomed home unconditionally and are treated with respect will continue to return home. Home is where they are safest. This, however, needs to be balanced with the need for constant supervision and support.

Theme 3: The Guilt of Letting Go

Two of the participants had the painful experience of asking that their children leave their home when the behavior became unmanageable and they feared for the other children in the home. They expressed a sense of failure at not being able to continue caring for their children. They stated:

I used to hide in my bedroom when she was drinking and my heart would be pounding... I would just be waiting for everything to break loose and a fight to start and I just couldn’t live that way. I am a pretty tough parent and I was hiding in my bedroom at night, [thinking] “you go get her” and I would hide under the cover.

But I was also in the same boat; I felt like I didn’t have the emotional fortitude to deal with the con-

stant addictions and always worried about them. They show up two or three days later – I am not good with that.

One mother felt that this decision had been beneficial for the relationship between her and her child. She stated:

We love each other and we don’t fight and we have a really, really good relationship because I don’t have to worry about all of that stuff. Somebody else is worrying about that and I am just loving her.

Theme 4: The Future

The mothers recognized that, because their children had unique needs the future might look different than they had planned. They predicted that the normal progression of life might not be an option for them and their families. They expressed some grief when they realized some of the milestones their children might not achieve. They stated:

Like you know how you have as a parent – you have a life that is expected, you are going to raise your kids, then they are going to go off to university and then they get married, and then they are going to have kids, and then they are going to get their job?

That it is not the same as some of the kids average lives and some of our kids may never be able to get jobs and we may be caring for them to our last dying breath and then find someone else to care for them.

The women expressed joy and gratitude at having the opportunity to get to know and love their children, but they were fearful about their future as parents and their ability to maintain the current level of care when their children were adults. Many people with FASD will struggle to live on their own successfully and will need life-long supports. Parents become burned out by their children’s behavior and there are few, if any, supports available for intact families. The emotional stress is one of the unspoken problems in taking care of a person with FASD; the demands are constant and ever changing. One parent stated:

I love being a parent it is beautiful, okay, but I am getting tired and sometimes I wonder if there is an end in sight. Will I have to parent my children with FASD forever and forever and ever. And if so, have I taken on too much?

This is so beautiful, but what is at the end? And is there an end, what is that going to mean? I love being a parent and it is so awesome. But I have control of my kids now and I don't know what that is going to look like when they are 18, 20's and having [their own] children.

Children living with FASD will be adults living with FASD. The limitations because of the physical damage to their brain do not change; however societal expectations become more complex. As they grow into adulthood their disabilities become more and more invisible and their limitations get masked behind secondary disabilities that look more like bad choices (Buxton, 2004; Chudley et. al., 2005; Dorris, 1989; Malbin, 2007; Mela, 2006).

Participants were well aware that the supports currently provided for their children would no longer be available to them as adults. They stated:

Well we institutionalize them and then they so easily move into the justice system. And all of the supports they get as children will be gone. So a child could be in the system ... getting support, getting assessment, getting counseling, the parents might be getting support. As soon as they turn 18 that service stops dead, and you have to reapply for any supports that are there for them after that. I almost hyperventilate when I think about what happens when they have children? What happens if they can't do it? What happens if they can't pay their rent? We talked about that yesterday - somebody called and said they couldn't pay their rent. Do you pay the rent? If so, why? If not, why? I don't know what to do so my future really scares me.

Despite concerns regarding an uncertain future, all of the women in the current study felt that, with the right supports, their children could do well in life. They had hope for the future. One participant stated:

My next one [picture of eaves trough with many cocoons] is the cocoon to butterfly. So we are

looking up at the kids and they are still in a cocoon developing and people may see them as stuck. They are just stuck and they are stagnant and they are not going anywhere in life. They just see them as that cocoon that they are not going to amount to anything as adults, as human beings. Yet, I see this butterfly they could be - chiefs of their communities, they could be the next Mayor of Sioux Lookout, they could be a teacher, they could be a great parent or whatever it is in life. They are a butterfly; you just have to be patient, if you are a person in the community to wait and not always view them as not worth anything or just a drain on society. Because I think that is what we do, advocate for our kids, is we are always trying to do, when someone has judged them and where they think they are going to go in life. We are there saying "one day, one day," we don't know when, but one day they are going to spread their wings and it is probably going to be pretty remarkable. So that is what this represented to me, all these cocoons don't look like much, and most people would want to clean them off.

Discussion

This research was designed to answer the question "What are the experiences of parents caring for children with FASD"? Using a PAR model, the researcher invited participants to describe their experiences in caring for children with FASD and identify what some of the difficulties were in terms of their children experiencing good outcomes.

The experiences of the women in this study were similar to those articulated by other caregivers who have come together to share common stories about parenting children with FASD (Berry, Propp, & Martens, 2006; Buxton, 2004; Dorris, 1989; Michaud, M. & Michaud, S., 2003). The women who participated in this project advised that there were many challenges involved in caring for a child with FASD. They described having to parent their children in ways that did not fit with conventional parenting techniques and shared their guilt at being unable to meet the complex needs of their children with FASD. All of the women expressed fear for their future, and for the future of their children, as the children move through adolescence and into adulthood. They realized that they might need to care for their children, in

some form, throughout their lives. This finding is consistent with what other parents have reported regarding difficulties sustaining the kind of intensive parenting and support that their children need for a lifetime (Buxton, 2004) and developing “compassion fatigue” (Gelo & O’Malley, 2003, p. 1). The parents in this study acknowledged that more support would be needed to accomplish lifelong parenting. Recognition of this requirement within the medical and mental health fields will be crucial for preventing burn-out for the parents and secondary disabilities for the children (Buxton, 2004; Rosenthal, 1993). The parents also saw a need for smoother transitions between children’s services and adult services and worried that their adult children would not qualify for support services in the future.

In terms of study limitations, with only five participants the results may not be generalized to all parents of children with FASD. Furthermore, the generalization of results is limited because the group resides in a relatively isolated northern community. The views represented here may not be representative of parents in other communities.

With regards to future directions for research, the PAR methodology coupled with the group process has significant promise for future social work research and social action. It is both a release and empowering for caregivers to understand that they are not alone in their challenges as parents. It has not been common, however, for researchers to bring together participants in a group process who are foster, adoptive and biological parents of children with FASD, and have them build relationships. Future studies might consider bringing together similar groups of parents living in more urban settings to duplicate these benefits in other communities.

Key Messages From This Article

People living with FASD: You have a right to be safe and accepted. You may need people to help you even after you are old enough to be on your own. That is okay.

Caregivers: Once caregivers learn to make changes in the environment instead of expect-

ing the child to change, things will get easier. A strong, accepting and loving relationship is the best tool you have to keep your child safe.

Professionals: Parents of children with FASD are not bad parents because things are not going well. A diagnosis may help prevent secondary disabilities

References

- Berry, M., Propp, J., & Martens, P. (2007). The use of intensive family preservation services with adoptive families. *Child and Family Social Work, 12*, 43–52.
- Brown, J., Sigvaldason, N., & Bednar, L. (2005). Foster parent perceptions of placement needs for children with a fetal alcohol spectrum disorder. *Children and Youth Services Review, 27*, 309–327.
- Buxton, B. (2004). *Damaged Angels*. Toronto, ON: Alfred A. Knopf of Canada.
- Chudley, A., Conroy, J., Cook, J., Lock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172*(5 Suppl.), S1–S21.
- Creswell, J. (2003). *Qualitative, quantitative and mixed methods approaches* (2nd ed.). London: Sage Publications, Inc.
- Creswell, J. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). London: Sage Publications, Inc.
- Dorris, M. (1989). *The Broken Cord*. New York, NY: Harper & Row Publishing.
- Gelo, J., & O’Malley, K. (2003). Family stress in parenting a child or adolescent with FASD. *Iceberg, 13*(1).
- Graefe, S. (2004). *Living with FASD: A guide for parents*. Vancouver, BC: Groundwork Press.
- Green, S (2007). “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*, 150–163.
- Health Canada. (2007, September 12). *It’s your health: Fetal alcohol spectrum disorder*. Retrieved from http://www.hc-sc.gc.ca/iyh-vsv/diseases-maladies/fasd-etcf_e.htm.
- Lauer, K. (2007). *“See” what I mean? A critical examination of photovoice as a participatory action research strategy*. Unpublished Masters dissertation. Queen Margaret University, Edinburgh, Scotland.

- Malbin, D. (2007). *Fetal alcohol spectrum disorder: A collection of information for parents and professionals* (2nd ed.). Portland, OR: FASCETS, Inc.
- Mela, M. (2006). Accommodating the fetal alcohol spectrum disorders in the diagnostic and statistical manual of mental disorder (DSM-5). *Journal of FAS International*, 4, 1-10.
- Michaud, M. & Michaud, S. (2003). *Beautiful smiles, gentle spirit: Fetal alcohol spectrum disorder: A misunderstood problem*. Calgary, AB: Brush Education.
- Park, P., Brydon-Miller, M., Hall, B., & Jackson, T. (1993). *Voices of change beautiful smiles, gentle spirit: Fetal alcohol spectrum disorder: A misunderstood problem*. The Ontario Institute for Studies in Education.
- Rosenthal, J. (1993). Outcomes of adoption of children with special needs. *The future of children: Adoption* 3, 77-88.
- Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1996). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effect (FAE). *Final Report. Centre for Disease Control and Preventions. Grant No. R04/CCR008515*.
- Streissguth, A., & Kanter, J. (1997). *The Challenge of fetal alcohol syndrome: Overcoming secondary disabilities*. Seattle and London: University of Washington Press.
- Wallace, B. (2005, May). Participatory action research can be complicated: Research and social worker. *Perspectives*, 16-17. Retrieved from <http://www.vipirg.ca/?s=Perspectives+may+2005>
- Wang, C., Yi, W., Tao, Z., & Carovano, K. (1998). Photo voice as a participatory health strategy. *Health Promotion International*, 13, 75-86.
- Wemigwans, J. (2005). *FASD Toolkit for Aboriginal communities*. Ontario Federation of Indian Friendship Centres.