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Persons with FASD: Disability and Sexuality

Darlene Brackenreed¹

Abstract

Sexuality is an essential component of human beings that may be difficult for some people with disabilities to express in satisfying ways. A disability that is often overlooked, partly due to the fact that *The Diagnostic and Statistical Manual of Mental Disorders (DSM-V)* does not list it as a clinical disorder, is Fetal Alcohol Spectrum Disorder (FASD). Although Lemoine, Harousseau, Borteyrun, and Menuet first identified Fetal Alcohol Syndrome (FAS) in 1968, it is now recognized to be part of a greater Fetal Alcohol Spectrum Disorder (FASD), which refers to a range of effects that can occur in an individual whose mother consumed alcohol during pregnancy (Ryan, 2006, p. 1). These effects can be physical, mental, behavioural, and cognitive (Pelech, Badry, & Daoust, 2013, p. 121). The most common traits that are present in all children with FASD are cognitive confusion, learning and memory impairment, as well as the inability to understand the consequences of their actions (Blackburn, Carpenter, & Egerton, 2009, p. 141). For the purpose of this study adults with FASD and their partners or parents were interviewed to learn of the impacts of the condition of FASD. Their responses to the interview questions identified key areas of concern and needs that are largely not being met. An unexpected finding was the difficulties they have with relationships and sexuality. This article discusses that portion of the results that dealt with disability and sexuality.

Keywords: FASD, sexuality, maternal alcohol consumption, characteristics, critical issues, supports

1.0 Introduction

"To be human is to be sexual" (Winder, 1983)

The purpose of the research study was to identify and describe the needs of persons with FASD and the services that are currently available to the person with FASD in a community in Ontario. An unexpected finding of the study was the difficulties people with FASD face regarding relationships and sexuality. This article shares the findings that were related to disability and sexuality from interviews with eight adult volunteers.

2.0 Review of the Literature

2.1 Fetal Alcohol Spectrum Disorder (FASD)

FASD is an umbrella term used to describe persons affected by the consumption of alcohol by their mother while in utero. It is a disability that is largely overlooked in part due to the fact that the manual of the American Psychological Association, *The Diagnostic and Statistical Manual of Mental Disorders (DSM-V)* does not list FASD as a clinical disorder, negatively impacting the abilities and attitudes of physicians regarding the investigation into, diagnosis, and treatment of alcohol-related disorders. It is difficult to determine the incidence of FASD in Canada because of problems in obtaining a diagnosis, the variability in the rates of FAS among different populations, and different research methods used to study the problem (Chudley, Conry, Cook, Lock, Rosales, & LeBlanc, 2005; May & Gossage, 2001).

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However, Canada's Public Health Agency (2003) estimated the incidence of FASD to be approximately 9.1 per 1000 live births. Stade and her colleagues (2006) reported that the total adjusted annual costs associated with FASD per individual aged 1 to 21 years in this country were over \$14,000, depending on the severity of the child's condition and proximity to services. Little attention has been paid to the issues faced by adolescents and adults with FASD (Rutman & Van Bibber, 2010). Tinto (1975, 1997) investigated the experiences of adolescents and young adults with FASD. The characteristics reported by the participants were poor abstract reasoning and reading comprehension, behavioural problems such as lying, stealing, impulsivity, and attention problems and regulating emotions, especially anger and sexual urges. Impulsivity and a lack of ability to understand consequences is a frequently cited characteristic of persons with FASD. Secondary disabilities associated with FASD include inappropriate sexual behaviours, trouble with the law, confinement, alcohol and drug abuse and dropping out of school (Streissguth, Bookstein, Barr, Sampson, O'Malley & Young 2004). A lack of inhibitory control, together with an inability to understand consequences, can lead to significant problems (Fast & Conry, 2009). Streissguth, Bookstein, Barr, Sampson, O'Malley & Young (2004) examined 18 associated risk/protective factors using a Life History Interview with knowledgeable informants of 415 people with FASD. For adolescents and adults, prevalence rates were 61% for Disrupted School Experiences, 60% for Trouble with the Law, 50% for Confinement (in detention, jail, prison, or a psychiatric or alcohol/drug inpatient setting), 49% for Inappropriate Sexual Behaviours on repeated occasions, and 35% for Alcohol/Drug Problems. Streissguth and colleagues' study (2004) found that inappropriate sexual behaviour on repeated occasions was the most frequent adverse life outcome across the lifespan of individuals with FASD. Forty-eight percent of adolescents and 52% of the adults studied displayed inappropriate sexual behaviours. Among adolescents and adults, the most frequently noted behaviours were promiscuity (26%) and inappropriate sexual advances (18%) (Streissguth et al., 2004).

2.2 Human Sexuality

The Oxford English Dictionary defines sexuality as "capacity for sexual feelings" or "a person's sexual orientation or preference" (Oxford English Dictionary, 2014). The World Health Organization in 1975 stated that "Sexuality is an integral part of the personality of everyone: man, woman, and child. It is a basic need and an aspect of being human that cannot be separated from other aspects of human life. Sexuality is not synonymous with sexual intercourse (and it) influences thoughts, feelings, actions, and interactions and thereby our mental and physical health" (WHO, 1975). Sexuality is an essential component of human beings that may be difficult for some people with disabilities to express in satisfying ways. One of the many challenges people with disabilities face is the deceptive idea that people with disabilities are not sexual beings. There is a wide range of attitudes regarding sexuality for persons with disabilities ranging from the perception of such people as asexual to having deviant and overly sexual desires (Bogaert, 2006). It can be challenging for any person to have a satisfying intimate relationship but for persons with disabilities this may be an even greater challenge. Western culture historically has segregated and secluded people with disabilities (Smith & Routel, 2010), impairing their ability to meet and socialize with other people. It can be a difficult thing for families to accept that the person with the disability is a sexual being who wishes to express their sexuality in satisfying ways and in many instances it is the family who makes major decisions on their behalf, including opportunities for relationships with the opposite sex (Aspis, 2000). Expression of sexuality is influenced by self-esteem and self-perception. A disability may affect a person's self-perception and cause difficulties with sexual expression (Rainbow Rehabilitation Centers). Having a disability may cause a psychological barrier to intimate relationships as the individual feels inferior or unattractive and lacks self-confidence.

2.3 Sexual Identity, Sexual Behaviour, and Sexual Orientation

Sexual identity is how we think of ourselves in terms of who we are romantically or sexually attracted to. Sexual behaviour refers to actual sexual acts while sexual orientation refers to attraction to the opposite sex, same sex, or both (Senn, Carey, Vanable, Coury-Doniger, & Urban (2007). Transgender is the state of self-identification as a man or woman and a transgendered individual may identify as heterosexual, homosexual, bisexual, pansexual, polysexual, or asexual (Davy, 2011).

3.0 Purpose of the Study

As mentioned, the purpose of the research study was to identify and describe the needs of persons with FASD and the services that are currently available to the person with FASD. An unexpected finding of the study was the difficulties people with FASD face regarding relationships and sexuality.

4.0 Method

4.1 Research Design

A descriptive, exploratory qualitative research design was chosen to conduct this study. The data collected explains phenomenon from the perspective of the participants and describes variables that interact with it (Fraenkel & Wallen, 2006). Semi-structured interviews were conducted with the participants to elicit their stories. Semi-structured interviews are used in qualitative research as a strategy to acquire insight into participants' experiences and to discover the interviewees' personal understanding about a specific topic and how it directly relates to the participants (Buambusch & Clark, 2010; Crabtree & DiCicco-Bloom, 2006; Grindsted, 2005; Madill, 2011). Semi-structured interviews include "a set of open-ended questions that allow for spontaneous and in-depth responses" (Madill, 2011, p. 255). These answers provide researchers insight into the phenomenon being studied and how participants within the phenomenon understand themselves. The analysis was done by hand (Charmaz, 2000) to increase engagement with the data and interpretations were made using inductive reasoning (Patton, 2002). Data from the interviews was analyzed by "lean coding" all of the text, assigning minimal codes that later were used to create themes or categories that highlighted major ideas from the interviews. These themes were used as the framework for all written descriptions and was the navigating force for the results of the study (Creswell, (2008).

4.2 Participants in the Study

Eight adult people volunteered to be interviewed. Of those eight people, two were persons with FASD, one was a spouse of a man with FASD, two were parents, and three were mental health workers. The participants in the study are known as Matthew, two mothers of children with FASD, Mark, Curtis, and Carla, Marilyn, and Helen, a third mental health worker, talked openly about their lives as they relate to FASD and specifically the impact on relationships and sexuality. Matthew was a man in his early forties, married with one teenage son. Curtis was a single father also in his forties with a young adult son. Josh's mother and Amy's mother, each were in their mid-fifties. Mark, in his mid-thirties, described himself as being transgendered. Carla, Marilyn, and Helen were mental health workers; additionally Marilyn had a child with FASD.

4.3 Procedure

The participants were sent the list of interview questions ahead of time so that they might collect their thoughts and be prepared for the interview. They were invited to delete any question with which they were uncomfortable and did not wish to answer. The interviews were conducted at the location and time of the individual's choice. The sessions were recorded using a Smartpen with the participants' knowledge and consent. They were supplied with a transcript made with LiveScribe of the interview and invited to modify any part that they deemed necessary.

4.4 Findings of the Study

This article shares the findings of those interviews as they relate to disability and sexuality. The inability to get along with others was a common thread discussed by the participants. Impulsivity in relationships is evidenced when Matthew describes how two days after his eighteenth birthday he moved out of his parents' home, where both parents were alcoholics and abusive with their children. He met a girl on the Internet in another city and moved to be with her after knowing her for less than a week. As they move impulsively from relationship to relationship, these relationships appear doomed to fail.

Matthew talked about his relationship with his first wife breaking down.

When I got to be 28 – it was 1998 so it hasn't been that long – my ex and I broke up — and I went squirrely and I just said "What the hell! I can't hold this relationship down. I can't hold jobs down – people think I'm lazy. Another participant, Josh's mother, described some of the characteristics of FASD. "Our son is a superb liar. It's just right off his tongue all the time. We can't trust him at all because he steals as well as lies. We have to keep things under lock and key." She went on to describe Josh as being very smart, "his IQ is above average and when you sit down to talk with him, you'd never know he has FASD because he has the gift of the gab and he relates well to people." Unfortunately, despite his ability to converse, Josh never was able to establish and maintain meaningful relationships. His mother explained, "He was a victim. They beat on him, of course because he's native looking too. But they spat on him, name-calling, physically abused".

Josh always wanted to have friends but he did not know how to go about it. "He cannot organize his life and meet commitments," continued his mother, which has disastrous effects on relationships when one cannot make and maintain commitment to another person. Another mother of an adopted child talked about her 37-year-old daughter, Amy's, relationships with men. She described her as tending to get rashly involved with men who had problems. Her baby's father abused her, physically and mentally, and they were into drugs too. Her relationships have been terrible. It must be 3 years ago now, she met this guy downtown and they went into a restaurant and took something out of somebody's purse in the back. She didn't know him from 'Harry', you know. But she got tied up with him. She went on to say that Amy is going out with a fellow now who is probably the first boyfriend she has had that actually works steadily. Mark was a participant in this study who was open about being transgendered. He explained that he was able to come out when he was in a large city, but cannot come out when he is in smaller centres because it is not safe for him. He described his relationship with a woman who knows about his being transgendered as being rewarding and satisfying. Conversely, a friend of Mark's commented that, She's also an addict who is in recovery and she hasn't been doing drugs or drinking, but she cuts herself. That's her way of dealing with it. They have an on-an-off relationship. I don't think they're good for each other, but on the other hand they probably don't have anybody else. I don't know where that's going to go. Mark said that in the past he had had a good relationship with Brian, who he described as another needy type of person. They lived together in the city for a while but since being diagnosed with schizophrenia Brian is living with his family. "I think that was probably my best relationship. He got married. That was a lousy relationship. They fought all the time and I guess he did that just to prove to himself that he wasn't trans. So that wasn't a good relationship. "

Curtis was a participant who described his son's poor relationships in school when other kids bullied him. When he was in grade 4, this kid in grade 8 picked on him and said to him, 'Oh, you have sex with your Dad!' and Danny didn't like that. He punched the kid in the head, and the kid went down – boom! – ran into the school bleeding. "Danny hit me! Danny hit me!" So I go to school; I didn't know what was happening. So they told me, and I said "Grade 8!" It was noteworthy that Curtis appeared to be proud of his son's ability to fight, perhaps indicating that the difficulty with relationships was not limited to Danny. Curtis continued, "I don't want it getting physical. I used to joke about this, but I'm not now. I don't want it getting physical; he'll kick the shit out of me!" Further, Curtis said about his son, "I love him, but I can't live with him. I just can't. It's driving me nuts." He's a con artist, you know. He's very likable. I hate saying this, but I see him as a liar and a thief and not to be trusted. Last Christmas, he was given an Xbox – gone. He gave me a Sony DVD player – gone. My Kodak digital camera – gone. First week back, he stole 60 pills on me – clonazepam. In addition to interviewing persons with FASD and their families, three mental health workers agreed to participate. One of the workers, Carla, talked about women with FASD and their relationships with men. "Often the women I work with who have FASD, because their sense of self and their self-esteem has been so depleted, they often connect and engage with less than healthy people and then engage in less than healthy manners." When asked about partners, she said that she had not met any partners of people with FASD but "in my work in the Violence Against Women sector, I often worked with women who had FASD who were victims of significant abuse by their partners."

Marilyn also was a mental health worker and a mother of an adult daughter with FASD. Describing her daughter, Audrey, she said, "She got involved with the wrong kind of people. Just it always happens like that. Things go good for a while and then all hell breaks loose." Being a parent of a daughter with FASD meant that she was alone. "It prevents you from doing a lot of things. I haven't been in a relationship since my divorce." Marilyn went on further to say that Audrey was sexually abused as a child and professes to be lesbian. "Doesn't matter to me what she is, I still love her but I kind of feel its because of her background. It's a way of avoiding intimacy. She has a guy who is a friend of hers and wanted to be her boyfriend but she said no." Marilyn believes that Audrey has problems with forming relationships and that "few will be friends for best interest." In addition, Audrey has been to five alcohol treatment programs and "was kicked out of a couple." Audrey she says, "self medicates with marijuana a lot" which may fill her need for escape. Marilyn claimed, "Eighty percent of people with FASD have depression." If that is a fact, it may be another factor contributing to an inability to establish and maintain relationships. The third mental health worker interviewed, referred to as Helen, claimed that in families with one child with FASD there is a 90 percent chance you will divorce but with two children with FASD it jumps to a 100 percent likelihood that the marriage will end in divorce with the mother left alone to raise the children. And for persons with a spouse who has FASD, the relationship is strained, "they love their partner but it is almost impossible to live with them. They feel like they are the only parent and they've got another child." Helen added that the spouse with FASD usually is involved in some type of addiction and it tears families apart."

4.5 Discussion

The picture painted in these interviews might be viewed as bleak. Relationships are entered impetuously without consideration of the consequences. Common sense tells us that committing to a relationship with a person one has known for a week or less has little chance of success. Separation and divorce appear to be prevalent with unfortunate results for the children of these marriages, as the trend continues into the next generation. Being bullied as a youngster in many cases causes people to act as a victim and wait for negative outcomes, not believing that they have the power to change the outcomes. Do the bullied then become bullies themselves? Research says they do (Theravive, 2014). Does that account for the abusive behaviours that were mentioned in the interviews? Perhaps. Without readily accessible services for people with FASD in this community, there is no specific agency to turn to for support and the cycle of abuse remains unbroken. And as one participant in the study revealed, bullying and abuse occurs against at least transgendered individuals in this small community. The National Post survey conducted in 2012 is considered to be one of the best indicators of incidence of Gay, Bisexual, Lesbian, and Transgender (GLBT) in Canada. The survey concluded that 5 % of Canadians self-identified as GLBT, but in the age category of 18 to 34, 10% of the population self-identified compared to 2 to 3 % of the older age categories surveyed (National Post, 2012). Two of the participants in this study, aged 39 and 44, in the older age categories mentioned above, were identified as being gay and transgendered, representing 25% of the sample in this study. It is reasonable to assume that these individuals live in fear of being called out for their sexual identity and orientation and being victims of abuse as a result. The situation for people with FASD and their families is grim. The American Psychological Association does not include the condition in its manual, the *DSM-V*, resulting in a lack of diagnosis and identification by physicians. This may in turn, create a situation where the condition of FASD is not always acknowledged and supports are not offered to persons with the condition. In the world of agencies and special interests groups competing for attention and funding, this leaves the world of FASD under-recognized and under-served, resulting in heart-breaking and tragic results for people and their families.

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