

Research Article

Strengths and Challenges: A Young Adult Pictures FASD Through Photovoice

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Abstract: We initiated an individual case study with one young adult in Canada about everyday life with Fetal Alcohol Spectrum Disorder (FASD). Using Photovoice, we explored his experiences through photography and interviews. Findings highlight his multi-faceted identity based around ability and challenge negative stereotypes. The study supports Photovoice as a strategy to explore FASD experiences.

Keywords: FASD; Photovoice; qualitative research

What is it like to be a young adult living with Fetal Alcohol Spectrum Disorder (FASD)? Despite evidence that exposure to alcohol while in utero can have profound, lasting effects, the life experiences of young adults diagnosed with FASD have largely gone unexplored in research and more broadly. Previously referred to as fetal alcohol syndrome, FASD is the current umbrella term for three alcohol-related neurodevelopmental disorders: FASD with specific facial features, FASD without specific facial features, and Risk for FASD (Cook et al., 2016), each of which manifests as distinct combinations of biological, intellectual, and behavioral outcomes. Research supports that individuals experience diverse fetal alcohol effects, including characteristic facial features, intellectual disabilities, and/or behavioral anomalies (Cook et al., 2016). Therefore, outcomes and severity are variable, and individual experiences and support needs differ. It is thus crucial to recognize the subjective realities of individuals living with FASD, and avoid characterizing this spectrum diagnosis in a universal way.

Through an individual case study, we explored the experiences of a young adult with FASD using in-depth interviews and photography. Our aim was to understand FASD experiences during young adulthood because this life stage is a critical time for many individuals living with FASD, some of whom will age out of care, have fewer supports, and face increasingly negative stereotypes (Chatterley-Gonzalez, 2010; Dej, 2011; Salmon & Buetow, 2012). In addition, this life stage is largely absent from existing research. As such, we investigated the role of FASD in the transition to young adulthood, and self-identity relative to the condition. This specific focus reflects the interests of the research team - an education scholar, a sociologist, and two nurse researchers - that include self-identity, family systems, education, and health care.

The interview and photographic data generated insights into the process of identity

formation and how Nathan¹ negotiated FASD alongside other facets of identity. While the experiences described here are unique to this individual, the findings highlight processes that might be shared by young people living with FASD or similar conditions. In addition to offering valuable information about his lived experiences of FASD, the findings challenge negative characterizations of those affected by fetal alcohol exposure that permeate the socio-cultural landscape. Thus, we seek to stimulate dialogue and confront stigma surrounding this spectrum diagnosis with hopes of expanding how individuals with FASD are understood and supported.

Background

In 2012, over 1.5 million women in Canada participated in heavy drinking (Statistics Canada, 2016), suggesting that risk for fetal alcohol exposure is relatively widespread within the Canadian context. FASD prevalence is reported to be approximately 0.9% of the population in Canada, with indications that the rate is likely higher in reality (FASD Support Network of Saskatchewan, 2015). A recent report from Alberta estimated prevalence to be somewhat higher at 11.7 per 1000 people, with occurrence being consistently higher in males (Thanh et al., 2014). Comparable rates are reported in the United States, with wide variations across regions that might be due to differences in incidence or measurement (Hedwig, 2013). Regardless of variations in prevalence, these statistics emphasize that a significant segment of the Canadian and American populations live with FASD.

However, subjective experiences of FASD have been under-researched, with greater attention given to devising and evaluating prevention programs (Badry & Wight Felske, 2013; Hanson & Jensen, 2015). Studies about individual perspectives largely pertain to caregivers and health care and service providers' views of children with FASD, service delivery, and treatment (Green et al., 2014; Hedwig, 2013; Michaud & Temple, 2013). Meanwhile, research about those with FASD typically employs quantitative surveys or standardized tools (McLachlan, Roesch, Viljoen, & Douglas, 2014; Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004), omitting subjective experiences. The scant research that incorporates the voices of those with FASD focuses primarily on young people in school settings (Duquette & Stodel, 2005; Duquette, Stodel, Fullarton, & Hagglund, 2006; Ryan & Ferguson, 2006), with only a few exploring young adults' experiences (Duquette & Orders, 2013; McGregor, 2011; Rutman & Van Bibber, 2010; Salmon & Buetow, 2012).

Within this small body of literature, some studies document positive outcomes for those with FASD, despite overwhelming attention to negative issues. For example, Duquette and colleagues' research is quite unique in exploring persistence and success in high school and post-secondary experiences of young people with FASD. Their findings indicate that parental support and advocacy and peer support facilitate young people's success in educational endeavors (Duquette & Orders, 2013; Duquette & Stodel, 2005; Duquette et al., 2006), thus highlighting achievements. Another study examined the accomplishments of parents with FASD, describing successes related to: providing care, developing bonds, and finding strategies to meet their children's care needs (Rutman & Van Bibber, 2010). Evidence

is also given of support needs stemming from primary effects of FASD, such as issues with “memory and organization; perseveration; planning; generalizing from one situation to another... and impulsivity,” and secondary effects associated with substance use, deficiencies in support, problematic relationships, and poverty (p. 356). Accordingly, positive aspects of everyday parenting are somewhat overshadowed by discussion of numerous challenges. Therefore, despite some identification of positive outcomes, the overwhelming tendency in existing research has been to describe negative aspects, such as daily challenges and struggles (McGregor, 2011; Salmon & Buetow, 2012), adverse life outcomes (Streissguth et al., 2004), and unmet support needs (Ryan & Ferguson, 2006).

Beyond outcomes of FASD, some research has investigated intellectual disability experiences relative to self-identity and conceptions of self. Despite providing initial insights into this topic, studies about FASD and those more broadly focused on intellectual disabilities report inconsistent findings. Specifically, some research reveals that young people commonly conceptualize themselves as different. For instance, findings of one study of youth with FASD indicate that “feeling different than other children” was the essence of their experiences (Stade et al., 2011, p. e481). Another study about adolescents with various intellectual and developmental disabilities elicited their understandings of disability labels and self-perceptions (Jones, 2012), revealing that disability was frequently described in terms of social exclusion and limitations reflective of a deficit model (i.e., focus on what is lacking). Accordingly, feelings of difference were framed in negative terms, without much recognition of corresponding strengths.

However, evidence also exists that young people with FASD or other intellectual disabilities identify themselves as comparable to others their age, at least to some extent. A study about friendship experiences of young people aged 16 to 20 years with FASD suggests that both feeling different than and similar to others was common (Copeland, 2001). Another study about young adults’ understandings of prenatal alcohol exposure reports that they felt ‘pretty normal’ at times in their youth, although this perceived normalcy was disrupted by struggles as they grew older (McGregor, 2011). Thus, young people with FASD express perceptions of both difference and similarity.

Additional insight into identity formation emerges from research about youth with learning difficulties or intellectual impairments; participants described seeking to resist labels that emphasize difference, preferring instead to view themselves as ‘ordinary’ (Albjornslett, Helseth, & Engelsrud, 2014). Consequently, they wanted to shed disability labels and adapt to their unique situation. However, the researchers note that participants perceived social-structural and cultural barriers that reinforced their ‘disabling’ condition. Although young people might adopt positive identities, dominant socio-cultural constructions of disability can make this difficult. Individual experiences must therefore be examined within historical, cultural, and social contexts because constructions of FASD shape social interactions and opportunities.

In Canada, FASD has historically been characterized in terms of class- and race-based

stereotypes, often linked with poverty and labelled as an ‘Aboriginal problem’ (Chatterley-Gonzalez, 2010; Dej, 2011; Tait, 2007). Such constructions reflect medicalization of segments of the population who have been deemed problematic (Tait, 2007), and imply that FASD is a concern for only certain social classes and racialized groups. Such constructions influence who is assessed for and diagnosed with FASD, and their social treatment. In contemporary society, adults with FASD are particularly ostracized and receive less sympathy than younger people; children with FASD are framed as victims not responsible for the condition, while adults are labelled as deviants who lack potential and thus end up in the criminal justice system (Dej, 2011). Such stereotypes perpetuate belief that adults with FASD are a burden to society (Tait, 2007), leading to stigmatization and marginalization. While some efforts have been made to promote more accurate depictions of those with FASD, negative constructions remain a powerful influence on how this population is perceived and treated by others (Rutman & Van Bibber, 2010; Salmon & Buetow, 2012), resulting in exclusion and limited opportunities for social participation. These constructions can also shape individuals’ self-identity and outlook on life in a variety of ways; however, research has rarely examined the FASD label relative to self-identity (Rutman, 2013).

In summary, young adults’ experiences of FASD are largely absent from existing research, and there is a particular gap in understanding how these individuals navigate the implications of FASD in everyday life. This research makes an initial contribution by focusing on a young adult’s experiences of FASD and his self-perceptions. Given predominantly negative stereotypes of individuals with FASD and adults particularly, this case study challenges their stigmatization and reveals the multi-faceted nature of self-identity for those living with this spectrum diagnosis.

Theoretical Framework

This research was informed by Symbolic Interactionism, emerging from sociology, and Critical Disabilities Studies (Davis, 2006). Proponents of Symbolic Interactionism propose that meaning is attributed to experiences through interaction and engagement with broader aspects of society (Steckley, 2014), thus being socially generated. Regarding self-identity, Goffman (1963) argues that societies produce categories of normality and abnormality that influence social relations and construction of self-identity. Accordingly, individuals develop a sense of self through social interaction, conceptualizing themselves based on how they think others perceive them (Mead, 1964/1934, as cited in Germov & Hornosty, 2012, p. 192). Individuals who possess attributes deemed abnormal can encounter stigma that discredits them from their own and others’ perspectives (Goffman, 1963).

We therefore explored the subjective experiences and meanings of an individual living with FASD to gain insight into the negotiation of the FASD label relative to self-identity. Existing theorizing and research suggests that a disability label tends to dominate individuals’ self-identity because of powerful social connotations and associated stigma (Zola, 2003).

Such labels are deemed a ‘master status’ that overshadows other facets of identity (Hughes, 1945, as cited in Steckley, 2014). Consequently, a master status can affect everyday life by influencing self-perception and how an individual is perceived and treated by others. However, some individuals might work to conceal or overcome their stigmatized status, projecting a socially acceptable self-identity. As such, identity formation involves negotiation, and possible acceptance or resistance, of labels arising from diagnosis of disability. However, research has not elaborated such negotiation relative to FASD.

Additionally, our research incorporates a social constructionist model of disability according to the Critical Disabilities Studies literature (Davis, 2006). Supporters of this model address the social roots of disability, and connect so-called inabilities to barriers within social and physical environments. Accordingly, we recognize that the ‘disability’ label generates stigma and resultant barriers for individuals to whom it has been applied, rather than true inabilities. Thus, the social constructionist model reveals disabling qualities of social and physical environments, as opposed to individual traits (Davis, 2006). Furthermore, researchers adopting this model critique the concept of ‘normality’ and a normal-abnormal dichotomy, with recognition of ‘disability’ as a social process arriving with institutionalization (Davis, 2006). Therefore, physical and social environments are disabling when they do not accommodate a range of capabilities, despite wide variations in ability regardless of whether labelled as ‘abnormal.’ Accommodations made through physical and social environmental modifications, including shifts in societal characterizations of conditions, can remove barriers to social participation and inclusivity.

Nonetheless, recognition is also important of the embodied nature of disability via the impairments that individuals experience (i.e., cognitive, psychological, mobility, or sensory issues) (Shildrick, 2009; Coleman-Fountain & McLaughlin, 2012). This line of theorizing purports that impairments cannot necessarily be overcome through social-environmental accommodations, regardless of how they are characterized. Accordingly, we adopt a position that acknowledges embodied realities of impairment along with a social constructionist model of disability. Through this lens, we examine the everyday experiences of FASD for one young adult, his negotiation of impairment in daily life, and how social interactions and constructions of FASD shape his self-identity.

Method

Given limited attention to FASD experiences, a qualitative approach is suitable for accessing the unique realities of individuals and their subjective meanings (Merriam, 1998). Qualitative research generates information beyond that already known, thus furthering knowledge (Merriam, 1998). Aiming for rich data emerging from a small number of cases, even a single case can be studied qualitatively using multiple methods to gain holistic understanding of experiences and context (Boblin, Ireland, Kirkpatrick, & Robertson, 2013). Accordingly, we adopted a qualitative Photovoice methodology to explore a young adult’s life with FASD.

Photovoice is a participatory approach that privileges the voices of participants through participant-employed photography and individual or group interviews (Wang, 1999). Participants are engaged as experts on their lives and, through photography and verbal explanations, share what they believe is important, thus generating new understandings. Developed as a health promotion approach, Photovoice is flexible and adaptable to diverse populations (Wang, 1999), including youth (Vaughn, Rojas-Guylar, & Howell, 2008), and has been modified to study experiences of illness and embodiment due to its participatory, empowering nature and capacity for generating in-depth data (Burles & Thomas, 2014). For this study, the modified Photovoice approach involved completion of interviews and the photography project on an individual basis, rather than on a group basis.

An outcome of the photographic component is increased participant involvement in data generation and analysis. Participants determine the focus of their photographs and assign meanings during interviews, rather than being “passive subjects of other people’s intentions and images” (Wang & Burris, 1997, p. 371). Furthermore, participants capture photographs when they wish, outside the confines of research meetings, thus generating more authentic understandings of everyday life (Jurkowski, 2008). Additionally, participant-employed photography prompts heightened reflection because individuals must think about what to convey via their images (Burles & Thomas, 2014). Therefore, this approach can generate rich insights into subjective experiences and engage participants on an equitable level, producing participant-driven data reflective of lived realities rather than dominant constructions (Wang, 1999).

A Photovoice approach also promotes multiple forms of expression, which is beneficial because words cannot necessarily capture all aspects of experience (Guillemin & Drew, 2010). Visual expression can have advantages when completing research with populations who face communication challenges, such as individuals with language difficulties or intellectual or developmental disabilities (Jurkowski, 2008; O’Brien et al., 2009). Accordingly, participant-employed photography was deemed to have potential for capturing aspects of FASD that might elude verbal description. Additionally, Photovoice is reportedly effective in research involving individuals with intellectual disabilities because of the possibility of increasing involvement, pride, confidence, and empowerment, producing a sense of ownership over data, and generating valuable insights (Jurkowski, 2008; Ottomann & Crosbie, 2013; Povee, Bishops, & Roberts, 2013). Foremost, Photovoice offers participants with intellectual disabilities a voice and the opportunity to challenge stereotypes of disability, thus yielding transformative outcomes (Fudge Schormans, 2013). We therefore incorporated Photovoice to enhance the richness of data and meaningfulness of the research.

Recruitment & Data Collection

Upon ethical approval from a university research ethics board, we sought participants through advertisements at a local support organization and word-of-mouth. The target population was young adults, aged 18 years and older, with an FASD diagnosis who were willing to share personal experiences in interviews and Photovoice project. We also wanted to

include family members or support persons of young adults, if possible. We aimed to recruit a few individuals with whom we could pilot test our modified Photovoice approach to determine suitability for a larger study. One young man and his parents expressed interest and were enrolled in the study. This article focuses on findings emerging from the data generated with the young man, while other aspects are discussed elsewhere (Brenna, Burles, Holtslander, & Bocking, 2017).

Two members of the research team, a sociologist and nurse researcher, met with the family, first explaining the study aims, exploratory nature, and what participation involved. Next, we discussed ethical considerations, including the voluntary nature of participation and possibility of withdrawal, confidentiality, and knowledge dissemination. Once written consent was obtained from all participants, two separate audio-recorded interviews were performed; the first author interviewed the young adult in one room, and the second author talked with his parents in another room. Interviews involved open-ended questioning to elicit descriptions of FASD experiences from diagnosis to the present, which prompted participants to discuss life with this spectrum disorder in the past and at the present.

Following the interviews, the Photovoice project was explained, along with how to use the digital camera provided for taking photographs. We asked the young man to create images related to his experiences of FASD without specifying a focus, and suggested that any number of photographs could be generated but that he might aim for 4 to 12. We only requested that he refrain from including photographs of himself or others to ensure confidentiality, which might have influenced their content; specifically, the participant might have focused more on his relationships if this request had not been made.

The first author arranged a second meeting with the participant approximately two weeks later. This meeting involved an in-depth interview revolving around his photographs and follow-up questions. The digital images were uploaded onto a computer for viewing, and the participant was encouraged to select a photograph to begin with and control when to move on to a subsequent image. The researcher used an unstructured approach to interviewing the participant about the photographs, as the young adult took the lead by explaining each image and its relation to life with FASD. The participant generated six images and offered substantial commentary on the aspects of experience that they conveyed. When necessary, elaboration or clarification was requested. Once photographs had been viewed and discussed, the researcher asked follow-up questions about topics broached previously, which helped to confirm the researcher's understanding and interpretations. The participant was also asked whether there were any photographs not taken or topics not discussed. Once complete, interview recordings were transcribed verbatim, producing 34 pages of transcripts between the two interviews with many lengthy descriptions of the participant's life.

Data Analysis

Interview transcripts were analyzed using an inductive, thematic approach that included categorical and holistic analysis (Mason, 2003). First, preliminary readings of the data were performed to generate a holistic understanding of the participant's experiences.

Additional readings were then conducted regarding the literal and interpretive meanings of the data (Mason, 2003), attending to the concrete ideas expressed and interpreting what these revealed about life with FASD. To promote rigorous and unbiased findings, the first and third authors, a social scientist and a nurse researcher, performed separate analyses to identify emerging themes. We then met to discuss our impressions, debate differences in interpretation, and return to transcripts for context to ensure accuracy. These discussions generated a coding structure grounded in the data (Mason, 2003) that guided additional coding by the third author, resulting in a refined set of themes.

While analysis of visual data can be performed in various ways, we focused on the descriptions given by the participant. We reflected on what his explanation of each image revealed about his lived reality (e.g., specific strengths and challenges) and characterization of FASD. This analytic process prompted thematic categorization of images based on verbal descriptions, along with interpretation of how the meanings related to his holistic experiences. Although themes emerging from qualitative data are not generalizable, the rich data offer insight into this individual's experiences. Therefore, the findings foster holistic understanding of the participant's navigation of everyday life with FASD within his social context. We recognize that other individuals living with FASD might face unique impairments and variations in context, support, and resources; however, insights gained from this case study can increase awareness of experiences that might be shared by others and inform supportive practices (Boblin et al., 2013).

Results

The emerging themes revealed aspects of the participant's transition to young adulthood and formation of self-identity. These processes involved: recognizing strengths and challenges, seeking independence while maintaining support, reconciling FASD with a desire to fit in, and developing resilience and putting challenges in perspective. Nathan was negotiating FASD relative to self-identity, and his words and images emphasize that this diagnosis was one dimension rather than entirely defining him. Recognizing benefits and detriments, the FASD label existed alongside other facets of who he was and aspired to be. His self-awareness and adaptability highlight Nathan's resilience and efforts to move beyond negative characterizations of FASD to see his capabilities and future possibilities.

Recognizing Strengths and Challenges

Nathan demonstrated profound awareness of areas in which he thrived, and those that were challenging. He recalled subjects and activities with which he struggled during secondary school: "I'm not good at numbers or writing things down or anything like that." He elaborated on these perceived deficits when explaining an image of a pen and paper (Figure 1), noting that, along with mathematics, neat printing and productive typing took significant

effort. He also described reading difficulties relative to an image of an open book (Figure 2), indicating that he typically read slowly and was unfamiliar with certain words.

Figure 1. Pen and Paper

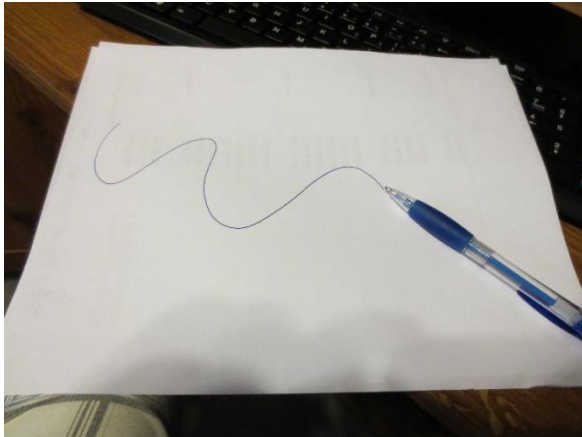


Image Description: This photograph is of a pen with a single wavy line drawn horizontally across a piece of paper, which Nathan described relative to difficulties with writing and similar tasks.

Figure 2. A Book

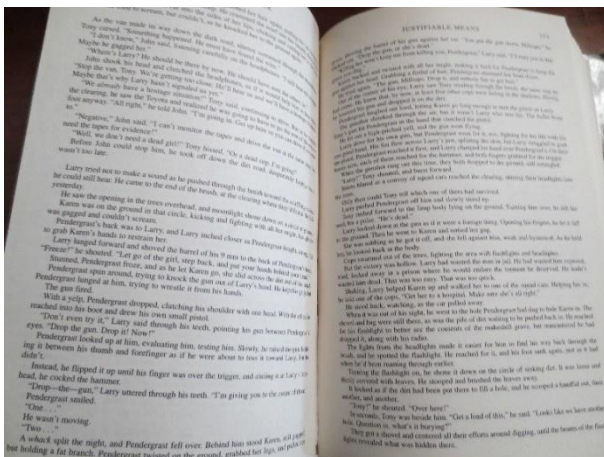


Image Description: This photograph shows an open book with pages filled with text, which Nathan used to represent challenges with reading.

Although he connected these deficits to FASD, Nathan believed that he could improve in these areas with greater effort. Furthermore, he framed some weaknesses in terms of disinterest, linking challenges to dislike of certain activities:

“Because I don’t want to be some accountant or anything like that, that’s not what I want to do, so it’s really good that I don’t have, I’m not strong in these subjects where I don’t want to be strong, I really don’t care, it doesn’t matter.”

Thus, Nathan viewed deficits as resulting from lack of effort, rather than in terms of disability. Consequently, perceived weaknesses were reconciled with his conceptualization of self and aspirations.

Alongside challenges, Nathan highlighted areas in which he excelled: “Those are my strengths that I do believe that FAS gave to me. Being able to observe and adapt quickly to things, and being able to work with my hands.” To illustrate strengths, Nathan shared two photographs. One depicted a screwdriver (Figure 3), conveying his ability to perform activities related to construction work. The second portrayed a theatre program in which he was featured (not shown), reflecting his acting prowess. Nathan explained how his adaptability was beneficial to acting, and that passion for it prompted him to find strategies to overcome challenging aspects, such as learning the script. For instance, he found singing lines assisted with memory, as did physical movement during rehearsal. Nathan also noted strength in visual learning and communication: “I always get pictures in my head and stuff like that... and I can really visualize what the character might look like.” Accordingly, Nathan’s words and images demonstrate recognition of strengths alongside challenges, and a self-identity founded on abilities rather than deficits.

Figure 3. Screwdriver



Image Description: This photograph is of a screwdriver with a yellow handle, which Nathan discussed relative to his ability to work with his hands and preference for active pursuits.

a Desire to Fit In

Throughout the interviews, Nathan described negotiating the FASD label in interactions with peers. Foremost, he emphasized not viewing himself as different or wanting others to see him as such. Calling himself a “normal kid,” he believed his challenges were comparable to those of others. Regarding his secondary school years, Nathan recalled that his diagnosis was not widely known: “Cause it’s not like any of the students or anyone knew, and [the teachers] didn’t make it clear. It was just me and the teachers and they wanted to help.” He reflected on disclosure to others, stating that he told only close friends who reportedly perceived him as normal and did not discuss it further.

Despite not feeling different or that others perceived him as dissimilar, Nathan recalled actively seeking acceptance by trying to fit in with peers. He described observing the behavior of those around him to use as a model, drawing upon his acting skills to present himself as similar. However, while in secondary school, he explained that he “started trying to do

Reconciling the FASD Label with

whatever to fit in,” referring to times when he acted out to gain peer acceptance. Thus, his desire to fit in sometimes led to behavior that he knew was inappropriate. Nathan also suggested that he gravitated toward ‘bad kids’ because of shared experiences of challenges. This example highlights Nathan’s awareness of friendship choices and the influence of his desire for acceptance from peers. While this might signal unconscious feelings of difference, it also suggests self-awareness related to acceptance and belonging.

Balancing Independence and Support

Another aspect of the transition to young adulthood and formation of self-identity involved negotiating independence alongside support from family and others. Nathan described challenges experienced during secondary school arising from wishes for autonomy: “From grade 8 to grade 11, that was like a really bad time for me and my family... ‘cause I acted out but, like I said, I just wanted to be independent.” Thus, he became resistant to his parents’ efforts to interject themselves into his daily activities. However, he has since realized that their assistance was crucial to navigating this difficult period: “My mom and dad, they never gave up. They always wanted to find help and everything like that, but I didn’t appreciate that.” Accordingly, he currently recognizes the significance of parental support to learning to cope with FASD-related challenges while pursuing education and extracurricular interests. Nathan further emphasized: “Support is something that definitely is positive and essential to FAS.”

Nathan also discussed wanting to strike a balance between independence and support as a young adult. He acknowledged difficulties with certain tasks, such as some forms of reading, writing and math, and continued to live with his family. He expressed appreciation of parental support with managing financial responsibilities and tasks like filing taxes, despite an immense wish for more independence. Nathan worked part time while pursuing acting in hopes of becoming financially independent. Reflecting on the transition to young adulthood and increasing independence, he expressed: “At the same time, doing stuff on my own excites me and scares me.” This statement highlights his feelings of anticipation and trepidation regarding the prospect of relying less on family. Thus, Nathan was amidst a process of striking balance between accepting assistance and managing independently.

Resilience and Putting Challenges in Perspective

Nathan conveyed understanding of how fetal alcohol exposure has affected him, contributing to deficits and unique abilities. He explained his attitude to life relative to one photograph (Figure 4): “This is of a *Life* cereal box, ‘cause when you have FAS, life is the hardest thing because you’re living it, and my life had its ups and downs.” Here, Nathan reveals the variable nature of FASD, noting both good and bad aspects that arise in day-to-day life. He expanded further when asked about advice for others: “Never think, ‘Oh, the FAS is 110% evil’ or something. It’s like, no, there’s bit of good [too].” This comment conveys Nathan’s understanding of FASD as having positive and negative outcomes. Consequently, despite facing FASD-related challenges, he demonstrated resilience by putting them in

perspective. When he encounters difficulties related to FASD (and Attention Deficit Disorder), he revealed: “If it comes up, I deal with it, then I go on living life because that’s, you never just give up or anything like that.” These words highlight Nathan’s coping ability and desire to avoid letting challenges defeat him.

Figure 4. “Life”



Image Description: This photograph is of a box of “Life” cereal, which Nathan used to highlight his approach to living with FASD.

He also discussed coping strategies relative to a photograph of running shoes (Figure 5):

“Every time I’m feeling stressed or overwhelmed, going outside and going for walks and doing anything active really helps a lot. It calms me down and everything, if I get frustrated, it’s a great stress reliever... the outdoors and everything like that [are] a good escape for me.”

Here, he expresses optimism and an interest in identifying ways to persevere through struggles. This resilience was evident at other times, but was especially notable in his management of reading difficulties when learning new lines for a theatre production; his passion for acting motivated his efforts and adaptation to deficits. Nathan summarized his outlook: “It’s always a good thing to find the motivation behind what you’re doing.”

Figure 5. Running Shoes



Image Description: This photograph is of Nathan's white running shoes, which have faint stains from being worn outside. Nathan explained that these shoes represent how he copes with emotions.

Discussion

The findings provide insight into the experiences of this young adult with FASD. The rich data obtained via Photovoice enable understanding of Nathan's life and his formation of self-identity that includes the FASD diagnosis alongside other facets. His experiences offer evidence of the ongoing negotiation of fetal alcohol effects and FASD label whilst encountering life events typical of young adulthood, such as establishing independence, making decisions about education and work, and establishing meaningful relationships. Recognition of strengths and challenges enabled Nathan to develop coping strategies and accept support with some tasks. While independence and acceptance were desired, Nathan forged a self-identity encompassing diverse abilities that allowed him to put challenges in perspective and resist the FASD label becoming his 'master status.' The themes, as depicted in Figure 6, reflect interconnected psychosocial processes that are related to the development of resilience.

Figure 6. Overview of Themes

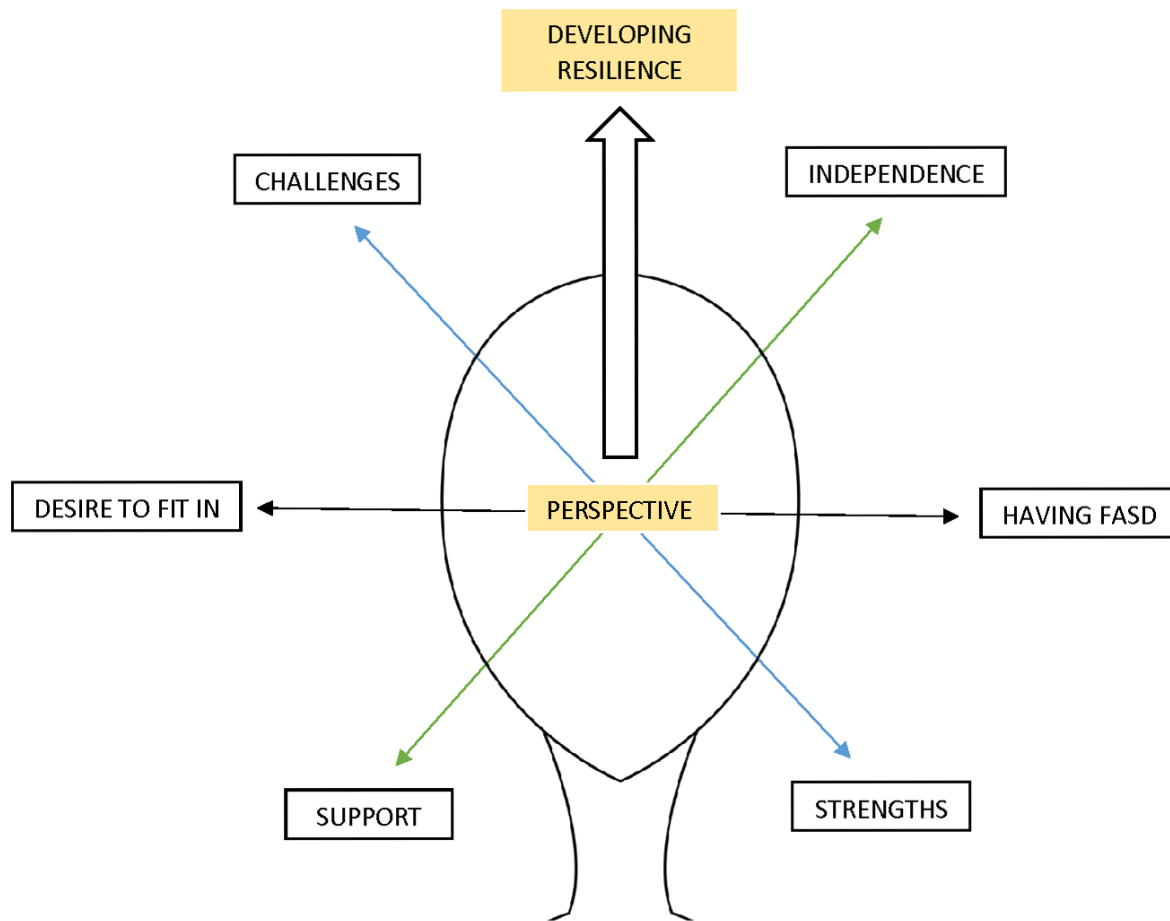


Image Description: This figure depicts the first three themes organized on axes around an outline of a face, which intersect at the word “perspective.” An arrow points upward from “perspective” to the words “developing resilience,” highlighting how putting difficulties in perspective contributed to resilience. Other arrows pointing out from “perspective” are challenges, desire to fit it, support, strengths, having FASD, and independence.

Within existing literature, the overwhelming focus is on negative outcomes associated with FASD (Salmon & Buetow, 2012; Streissguth et al., 2004). Such studies neglect recognition of positive aspects, reinforcing stigmatization of individuals with FASD and their characterization as burdens to society (Dej, 2011; Tait, 2007). In juxtaposition, the photographic and interview data generated in this study reveal another side of FASD, and emphasize the importance of identifying social-environmental barriers that hinder those with diverse abilities. Although the participant faced challenges through his education and transition to young adulthood, he also encountered supports that helped foster resilience, self-awareness of strengths, coping strategies, and recognition of how much he could accomplish on his own and with support. This young adult thus identified many positive aspects of life and placed emphasis on abilities rather than difficulties.

FASD includes spectrum disorders with varying implications across individuals. There remains stigma surrounding FASD, and individuals with this label tend to be negatively characterized regardless of abilities. However, the findings illuminate that individuals living with FASD possess positive attributes and strengths, alongside deficits and support needs in some areas. Therefore, we critique negative conceptions of individuals with FASD, and emphasize the imperative to re-frame FASD in terms of both strengths and challenges. Attention to positive attributes can help individuals with FASD and others to recognize their unique abilities, alongside areas in which they struggle, and facilitate development of a self-identity that transcends stigmatizing stereotypes. For Nathan, support from family, educators, and theatre production members was pivotal to recognition of his abilities and perceived 'normality.' Accordingly, he conveyed hope for happiness and success despite certain fetal alcohol-related difficulties.

Nonetheless, we acknowledge that some impairments associated with FASD cannot be easily overcome, such as cognitive and memory issues due to fetal alcohol exposure. Although Nathan was optimistic, he acknowledged weaknesses stemming from FASD, which prompted him to develop resiliencies and put challenges into perspective. He related that coping strategies and support were crucial for success, as emphasized elsewhere (McGregor, 2009). Exercise and being outdoors were especially beneficial to coping with overwhelming feelings. Although this strategy might not be effective for everyone with FASD, it is an example of how solutions can be developed to manage challenges. Thus, rather than suggesting that individuals learn to overcome impairments, which might be unlikely, efforts should be focused on fostering self-awareness and providing appropriate supports and accommodations.

Our findings also offer insight into Nathan's negotiation of identity formation during his transition from teenager to young adult. Prior research largely focuses on youth and adolescents with FASD, and those studies that include young adults pay insufficient attention to successes and accomplishments. Therefore, our pilot study helps to narrow the gap in knowledge of young adults' experiences of FASD and navigation of this life stage. Similar to many young adults, Nathan faces changes in everyday life and decisions about the future. Much discussion revolved around efforts toward independence, such as seeking financial independence through work, considering career options, and establishing important relationships outside his family. Furthermore, Nathan was concerned with acceptance and not appearing different than peers. Accordingly, the transition to young adulthood involved reconciling FASD and associated challenges with other aspects of self-identity, arriving at a multi-faceted sense of self: weaknesses were put in perspective by recognizing that he was not alone in having diverse abilities. Therefore, this study offers understanding of processes related to identity formation for this young adult.

Conclusions

This case study is an initial step to addressing the paucity of research on young adults' experiences of FASD. While many studies adopt quantitative methods or report on negative outcomes more so than positive ones, our research adds a strengths-based approach to the literature. This research reveals the multi-faceted nature of individuals with FASD who possess various abilities and deficits like everyone. Consequently, this study challenges negative stereotypes and stigma surrounding FASD, seeking to shift public discourse away from a focus on disability toward one of possibility.

The research provides evidence of the optimism and hope that exist for individuals with FASD; specifically, Nathan was negotiating the transition to young adulthood and finding his path in life, a common experience at this age. His experiences reveal his navigation of interests, difficulties, and abilities, and incorporation of the FASD label into a multi-dimensional identity. Central to this process of self-discovery was striking a balance between independence with support. Further exploration of this transition could yield additional insights into best practices for supporting individuals with FASD through this process, and identify possibilities for flexible support interventions, given that individuals have unique abilities and support needs. We have begun to outline such implications for curriculum in educational contexts (Brenna et al., 2017), but further work is needed, particularly related to work contexts.

Support for populations with FASD is emphasized as critical in the literature (Duquette & Orders, 2013; Duquette et al., 2006; Rutman & Van Bibber, 2010; Ryan & Ferguson, 2006), and Nathan's words resonate clearly about how support has benefitted him. Specifically, support is crucial so that young people who bring their best abilities to school or work settings are not disadvantaged by negative perceptions of disability or social-structural factors. However, the tension that Nathan experienced between independence and support also highlights the importance of developing of coping strategies for managing challenges and enhancing relaxation in people with FASD. Thus, we advocate for the creation of a 'toolkit' of ideas that could assist young people like Nathan in selecting techniques to try when faced with particular challenges. Also, access to the life stories of individuals with FASD has potential to assist with motivation to seek personal solutions. Participatory action research is recommended for developing and evaluating such a toolkit, and for further generation of life stories that illustrate authentic situations reflective of individual and universal challenges and possibilities. Because of the evocative nature of the photographs in Nathan's communication with our research team, photographs or images connected to these stories might operate as classroom or workplace cues. For example, a photograph of a running shoe could be used to communicate the need for a 'body break' when words are complicated.

Finally, this case study highlights the potential of Photovoice for research with this population. Visual methods have been incorporated into previous studies with people with

intellectual disabilities, but none are about everyday experiences of FASD. Given the range of impairments resulting from fetal alcohol exposure, we cannot conclude that a visual approach is universally suitable; however, the successful use of participant-employed photography with this participant suggests Photovoice as a possibility for effective and inclusive data generation, offering insight into everyday life with FASD. Additionally, Photovoice has potential to inform creative, adaptable support interventions. Future research should continue exploration of the suitability of visual methods with a larger sample of individuals with diverse FASD experiences. Therefore, our research raises the immense possibilities that exist for visual research to promote greater understanding and acceptance of those living with FASD.

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Endnotes

1. The participant was assigned a pseudonym to protect his identity from public recognition.