Research in Developmental Disabilities 93 (2019) 103428

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families

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ARTICLE INFO

Number of reviews completed is 2

Keywords:
Fetal alcohol spectrum disorder
FASD
Families
Caregivers

ABSTRACT

Background: Fetal alcohol spectrum disorder (FASD) is of significant concern for Australians for many reasons, one being Australia's drinking culture which increases the potential for FASD to occur.

Aims: The current study aimed to explore the lived experiences of Australian caregivers who received a FASD diagnosis for a child in their care, using*the Australian Guide to the Diagnosis of FASD*.

Methods and Procedures: Semi-structured interviews were conducted with seven caregivers whose children were assessed for FASD by a multidisciplinary team. Interviews explored how families experienced the FASD diagnostic process, and sought insight into outcomes for families following diagnosis, particularly in relation to accessing supports and services.

Outcomes and Results: Through thematic analysis, five overarching themes were identified: (1) receiving a FASD diagnosis had a positive impact; (2) caregivers' evaluation of assessment process; (3) positive support services relative to FASD; (4) ongoing difficulties regardless of diagnosis; and (5) need for societal knowledge of FASD.

Conclusions and Implications: Given the global need for standardised FASD diagnostic procedures and accurate reporting of prevalence rates, the current study provides a contribution to the emerging diagnostic FASD literature, and insight into families' experiences who have children diagnosed with FASD.

What this paper adds: This study provides additional information to the developing pool of literature attempting to create a typical profile of FASD. Most importantly, this paper highlights the implementation of the *Australian Guide to the Diagnosis of FASD*, and evaluates caregivers' experiences of their child's FASD assessment process, within a public FASD diagnostic service, using the revised guidelines.

1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a diffuse brain injury that causes a broad range of impairments, often requiring additional and pervasive supports. The term fetal alcohol syndrome was first defined by Jones and Smith (1973) to describe the physical, cognitive, and behavioural characteristic of children who experienced high levels of prenatal alcohol exposure. During initial identification of fetal alcohol syndrome, it was noted that children showed abnormal facial characteristics, poor growth (prenatal and postnatal), failed to meet developmental milestones, and had difficulties with learning (Jones & Smith, 1973). Research

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https://doi.org/10.1016/j.ridd.2019.103428
Received 14 February 2019; Received in revised form 9 June 2019; Accepted 22 June 2019
Available online 26 July 2019

now shows that children exposed to alcohol during pregnancy are at risk of a range of morphological and neurocognitive difficulties due to alcohol's teratogenic effect (Cook et al., 2016). It is important to note however, that facial and physical abnormalities are not always present (Bower & Elliott, 2016). Contemporarily, FASD describes the broad spectrum of physical, behavioural and intellectual disabilities resulting from alcohol exposure during gestation (Cook et al., 2016).

FASD is widely recognised as a potentially preventable impairment (although prenatal alcohol exposure can happen prior to awareness of pregnancy confirmation), and is the leading cause of developmental disability in the Western world (Fitzpatrick & Pestell, 2017; Grant, Ernst, Streissguth, & Stark, 2005). In Australia, Roozen et al. (2016) estimated the prevalence of FASD to be 10.82 per 1000 births. FASD is a significant public health concern as it can result in life-long functional impairment, including poor educational attainment, high rates of unemployment, and over-representation in the foster care, juvenile and criminal justice systems (Chamberlain, Reid, Warner, Shelton, & Dawe, 2017). Due to long lasting impairment, individuals with FASD often require support from a variety of services throughout their lifespan, including prolonged support from caregivers (Ospina & Dennett, 2013; Popova, 2017). Secondary FASD-related disabilities can include poor academic, employment, mental health, and independent living outcomes (e.g., limited occupational options resulting in insufficient income; Spohr, Willms, & Steinhausen, 2007). Research suggests that early diagnosis of FASD can substantially ameliorate pervasive secondary disabilities that occur during adolescence and adulthood that develop due to untreated early developmental delays (Fitzpatrick & Pestell, 2017; Olson, Jirikowic, Kartin, & Astley, 2007).

While there are benefits of early intervention (Reid et al., 2015), few children in Australia who are diagnosed with FASD receive a diagnosis early enough to implement supports that show long-term effectiveness (Watkins et al., 2013). Potential reasons why children remain undiagnosed include, failure of health professionals and caregivers to recognise FASD symptomatology, lack of knowledge and training of health care professionals, and lack of funding to support a comprehensive, multi-disciplinary diagnostic assessment (Watkins et al., 2013). Caregivers, however, also report significant strain involved in raising a child with FASD, such as emotional-behavioural consequences of disrupted attachment and potential trauma, socio-economic disadvantage due to the cost of increased developmental and behavioural supports required, and difficulties with their child's education (Fitzpatrick & Pestell, 2017), communication, emotional regulation, adaptive functioning, attention, working memory and executive functioning (Peadon & Elliott, 2010; Vasilevski & Tucker, 2015). However, even once FASD has been diagnosed, caregivers report barriers accessing support due to lack of dedicated funding for public access treatment, lack of resources and support within educational settings, difficulties co-ordinating multiple interventions and services, challenges regarding the negative stigma of the disorder, and difficulty maintaining caregiver wellbeing and engagement in caregiver self-care (Bower et al., 2018; Fitzpatrick & Pestell, 2017).

Due to the potential of FASD to be wide spread within Australia (Bower et al., 2018), it is important that families are supported to best manage additional care requirements, and that health care policy acknowledges the complex needs of children with FASD and their families. The recovery-oriented framework for mental health services provides direction for policy to enhance and improve mental health service delivery within Australia (Australian Department of Health, 2013). The recovery-orientated approach draws on global research and lived experience to guide service delivery. The approach defines recovery as the ability to create and live a meaningful and contributing life within community, with or without, the presence of mental health issues (Australian Department of Health, 2013). This approach acknowledges individuals' ability to take responsibility for their own recovery and wellbeing in relation to their own goals. The recovery-orientated framework is applicable to individuals diagnosed with FASD, as while individuals cannot reverse the brain damage and relative impairments, they can learn new skills, adapt, and live fulfilled lives (Fitzpatrick & Pestell, 2017).

In Australia, the process of assessing FASD is provided by the *Australian Guide to the Diagnosis of FASD* (Bower & Elliott, 2016). Specifically, to meet the requirements for a diagnosis of FASD, an individual must have prenatal alcohol exposure, in addition to severe neurodevelopmental impairment—functioning at less than the third percentile on standardised testing compared to children their age—in at least three of ten specified neurodevelopmental domains (Bower & Elliott, 2016). Alcohol exposure (of any amount), in utero, has the potential to result in neurodevelopmental problems, even in the absence of facial and other physical features (Bower et al., 2018). Therefore, a diagnosis of FASD has two sub-categories: FASD with three sentinel facial features, or FASD with less than three sentinel facial features.

Due to validated standards for diagnosing FASD, alongside recovery-orientated frameworks, multidisciplinary FASD diagnostic clinics have been established (Queensland Government, 2008). One FASD diagnostic service was established in the Sunshine Coast in 2016 via Queensland Health's Child Development Service (CDS). In light of the recently endorsed *Australian Guide to the Diagnosis of FASD*, it is important for Australian FASD diagnostic services to be reviewed to ensure that ideal outcomes for families are provided in terms of offering effective support services post-diagnosis, as the recovery-orientated framework suggests. A candid way to assess the outcomes of a diagnostic service is to gather data from the families who experienced a FASD diagnostic service first-hand.

The current study evaluated a multi-disciplinary FASD assessment process for families with children who were assessed using the *Australian Guide to the Diagnosis of FASD*. The study aimed to identify how families experienced the FASD diagnostic process, and to explore ongoing difficulties for families following diagnosis, particularly in relation to accessing tailored supports and services.

2. Materials and methods

2.1. FASD assessment process

Children were referred to the Sunshine Coast CDS FASD clinic by medical practitioners. All FASD assessments were conducted as per the *Australian Guide to the Diagnosis of FASD*. The CDS FASD multidisciplinary team comprised of a paediatrician, psychologist, speech pathologist, occupational therapist, social worker, physiotherapist, and clinic management staff. The assessment process

included three phases: (1) conducting the assessment; (2) diagnosis and feedback; and (3) follow-up. Phases one and two were conducted over a four week period. Phase three was conducted 6 months after the feedback session.

Phase one included a clinical intake with the family, and where possible (or applicable), liaison with health-care providers, educators, and statutory child protection. Prenatal alcohol exposure was confirmed using a variety of methods, such as, confirmation from the biological mother, biological father, or maternal or paternal grandparent, reviewing prenatal medical records and Department of Child Safety notes. Where possible, the Alcohol Use Disorders Identification Test – Consumption (AUDIT-C; Dawson, Grant, Stinson, & Zhou, 2005) was used to quantify prenatal alcohol exposure. Sentinel facial features were assessed using *FAS Facial Photographic Analysis Software* (Version 2.0.0; University of Washington). Sentinel facial features of FASD are defined as: Mean palpebral fissure length (opening between the eyelids) > 2 standard deviations below the mean for age, gender and ethnicity norms (Z score of −2.0 or more), abnormal flattened philtrum (vertical indentation in the middle area of the upper lip; rank of 4 or 5 of a 5-point ranking system), and abnormal upper lip circularity (relating to thinness; rank of 4 or 5 of a 5-point ranking system). Using a battery of psychometric assessments (Appendix A), the 10 neurodevelopmental areas were assessed which included: brain structure/neurology, motor skills, cognition, language, academic achievement, memory, attention, executive functioning, affect regulation, and adaptive behaviour.

Phase two included reviewing results from the clinical intake, medical examination and psychometric assessments to formulate a potential diagnosis using the *Australian Guide to the Diagnosis of FASD* which included: FASD with three sentinel facial features; FASD with less than three sentinel facial features; *at risk of FASD* (where the child had some FASD features but was too young to completely assess all 10 areas of neurodevelopment); or, no diagnosis of FASD (when insufficient impairment was present). Children were also given co-morbid diagnoses, where applicable (e.g., intellectual disability). Caregivers were invited to attend a feedback session where they were provided with, and discussed, the clinical report, the assessment outcomes, and recommendations for future management. Where consent was given, a feedback session was also conducted with the child's key school teaching staff to inform them of the assessment results, and assist in formulation of individual educational and behavioural/social-emotional support goals for the child. Phase three included paediatrician follow-up with the family, 6-months post assessment, to discuss the child's progress, management plan and access to supports.

2.2. Design

The current study utilised a phenomenological approach which qualitatively assessed caregivers' lived experiences of engaging with a FASD diagnostic service, and their experiences beyond diagnosis. The study utilised a convenience sample comprised of families with children who were previously assessed by the Sunshine Coast CDS FASD clinic. For phenomenological studies, Creswell (1998) recommends five to 25 participants, and Morse (1994) suggests at least six, therefore the sample size in the current study was deemed adequate.

2.3. Participants

Participants were recruited from the patient sample of children, and their families, who attended the Sunshine Coast CDS for an assessment of FASD. Caregivers of children who were assessed prior to January 2018, and received either a FASD diagnosis or an *at risk of FASD* diagnosis, were eligible for inclusion in the study. A total of 37 children were referred to CDS for assessment in that time period. Participation was voluntary (nonconsequential withdrawal) and no incentives were provided.

Of the 37 children, 20 were diagnosed with FASD or *at risk of FASD*. Of those 20 children, 13 caregivers consented to be included in the study. Of the 13 caregivers who gave consent, attempts were made to complete a phone interview with all, however, only seven caregivers completed the phone interview. Participants were either the primary caregiver of the child, or in situations where caregivers were providing shared care, just one of the caregivers completed the phone interview.

The caregivers interviewed were aged 23–65 (M = 40.0; SD = 17.13), and were either employed, semi-retired, or full-time carers. With regard to caregiver roles, 42.9% of interviewees were the biological mother, 14.3% were the biological father, 14.3% were the maternal grandmother, and 28.6% were the paternal grandmother. With regard to ethnicity, 14.3% identified as Aboriginal, 71.4% identified as Caucasian, and 14.3% were unknown. With regard to legal guardianship, 85.7% had legal guardianship of the child, and 14.3% acted as the caregiver while legal guardianship resided with the Department of Child Safety.

The children sample consisted of 85.7% male, and ages at time of interview ranged from 3 to 13 years (M = 7.6; SD = 3.85). All children received a FASD diagnosis, except for one child who received an *at risk of FASD* diagnosis. With regard to the sentinel facial features, 14.3% showed no facial features of FASD, 28.6% showed one, 42.9% showed two, and 14.3% showed all three. Severe neurodevelopmental impairment ranged from three to six domains, with the majority of children meeting criteria for four domains (71.4%). Of the seven children, 85.7% received a co-morbid diagnosis of attention deficit hyperactive disorder ([ADHD] combined type; American Psychiatric Association, 2013). Additional co-morbid diagnoses included intellectual disability, specific learning disorder (numeracy), speech language disorder, and speech sound disorder.

2.4. Data collection

Retrospective consent to access information provided to the FASD Clinic on assessment, was sought from the legal guardian(s) of the child. Participant information sheets, informed consent forms, and reply-paid envelopes were posted to participants prior to analysis of previously collected data.

Phone interviews were conducted by the lead researcher, who was not a member of the diagnostic team at the time the child was assessed. Phone interviews were audio-recorded, transcribed verbatim, and all identifying information was removed. Semi-structured phone interviews were approximately 15–30 min in length, and were conducted up to two years, post-diagnosis. Guiding interview questions (Appendix B) comprised of three main areas: clarification of family history, caregivers' experience of the FASD assessment process and, future directions, post-diagnosis.

Data collection ceased when data saturation was deemed adequate. That is, the authors ensured they had deeply analysed all themes and exhausted the possibility of developing new themes, which resulted in producing subthemes to correctly represent the data (O'Reilly & Parker, 2013). Further, there were no new themes emerging from the data that were not coded, unless the data was outside of the intended research questions. Admittedly, however, the goal was to interview all 13 participants, although for various reasons all participants were not able to be contacted (e.g., homelessness; change of care placement of the child). Therefore, to further ensure data saturation completeness, completion of all intended interviews would have assisted; this is a limitation of the study.

2.5. Data analysis

Research ethics (HREC/17/QRCH/286) and governance (SSA/17/QNB/82) approval was acquired from Queensland Health, and from University of the Sunshine Coast (USC; S/17/1140). FASD assessment reports were collated and de-identified for review. Phone interviews were recorded and transcribed, and data was analysed and interpreted. All data analysed and published was de-identified. To further protect anonymity of participants, the child's gender for all interviews was modified to male. Any sensitive information was destroyed (e.g., voice recordings).

Thematic analysis is commonly used to explore under-researched areas and lived experiences (Braun, Clarke, & Terry, 2014). It is flexible in nature allowing themes to be organised, and in this study was used to identify unique experiences of caregivers of children with FASD. Using Braun and Clarke (2006) six phase approach to thematic analysis, themes from the phone interview data were extracted. The first stage consisted of data transcripts being cross-examined against the audio recordings, to ensure accuracy. Secondly, generation of initial codes was created, and was cross-examined by the second author. Thirdly, sub-themes and overarching themes were identified. Sub-themes emerged if three or more participants expressed a statement similar to others, and overarching themes consisted of three or more sub-themes with conveyed similarities. During the fourth stage, themes were revised and refined by the first, second, and fourth author. In full disclosure, the third author of this study was a member of the FASD assessment team, therefore, their role in the data analysis was limited, to avoid the potential for bias to influence the results. The fifth stage entailed defining and naming overarching themes and sub-themes, ensuring that the data extracted was directly related to the research questions. Throughout all of the data analysis and theme creation, a spreadsheet was kept which mapped the actual quotes/data next to the suggested theme, and use of colour codes and numbering systems were employed to organise data, and to ensure data did not overlap into multiple themes. Finally, the sixth stage involved producing the findings in a report which was guided by the *Standards for Reporting Qualitative Research* (O'Brien, Harris, Beckman, Reed, & Cook, 2014). Additionally, descriptive data was analysed using Statistical Package for Social Sciences (Version 22.0; IBM Corporation, 2013).

3. Results

Thematic analysis revealed five overarching themes, each having three sub-themes (see Fig. 1).

3.1. Theme one: receiving a FASD diagnosis had a positive impact

The first overarching theme incorporated the positive outcomes that resulted from the FASD diagnosis.

3.1.1. School feedback session created understanding of child's needs (sub-theme 1.1)

This first sub-theme described how caregivers believed that their child received more understanding from school staff, once school staff were informed of the FASD diagnosis. Furthermore, their child's time at school had improved as a result of the school feedback session. For example,

I don't think his teacher this year was aware of a lot of the issues and what's been going on, so I think that it [the school feedback session] was pretty helpful … they sort of understand a bit more, in the way that he works … (P116)

Several caregivers explained that once the school had become aware that the child's behaviour was related to FASD, the school made accommodations to assist the child's learning, and made the child more comfortable at school, and therefore more productive.

3.1.2. Caregivers' positive regard for child and aspirations for child's future (sub-theme 1.2)

This sub-theme identified the positive regard that caregivers had for their children, and the hope that their children would live fulfilled lives. For example,

I keep believing that as he gets older, if he really wants to make something of himself, he will. I really feel that the more we just give him the positives and just let him know that he is capable, it'll be okay. (P111)

It was evident that the caregivers were empathetic towards their children and understood that their children had certain needs that differ to other children, and were willing to support them, lifelong. Caregivers also described that although they had struggled initially to understand their child's behaviours, they now accept the child wholeheartedly. For example, "We'd do it again in a heartbeat [care for the child]. … we love him so much … and we want the best for him" (P106).

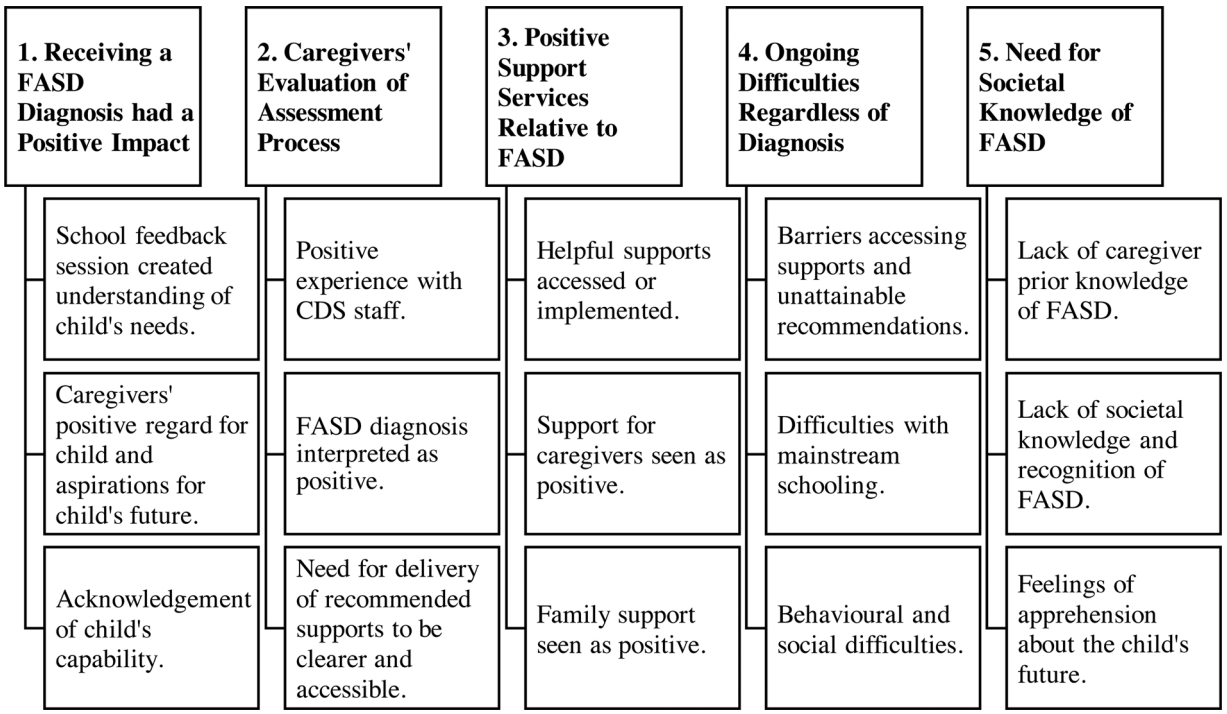

Fig. 1. Thematic map for each overarching theme and sub-theme.

3.1.3. Acknowledgement of child's capability (sub-theme 1.3)

Over half of the caregivers described accommodations they made to assist their child's success with everyday tasks. The diagnosis put into perspective certain tasks that the child struggled with, rather than thinking the child was wilfully being disobedient. For example,

As long as I've made lunch and have Weetabix out, ready for him, we can get to school exactly on time. And if that's what he can do, then I'm happy for that to happen … [Because] he forgets things, I only give him one activity at a time to remember, like, "Go and get your shoes," or, "Go and empty the rubbish bin." I don't sort of say, "You've got to do this, this, and this today." (P111)

Another participant described their new found understanding of their child's capabilities resulting from receiving the FASD diagnosis as,

We can make sense of everything … Just having that understanding why he's doing certain things, rather than thinking, "he's just not listening to me." …. for us we can put a name to what's going on … it helps knowing what is going on. (P115)

3.2. Theme two: caregivers' evaluation of assessment process

The second overarching theme was related to how caregivers interpreted the FASD assessment process conducted by CDS. The majority of caregivers viewed the assessment process as optimistic, had a pleasant interaction with CDS staff, and viewed the FASD diagnosis as helpful. However, some caregivers stated that the recommendations for ongoing supports, provided during the feedback session, could have been more salient, and supports offered could have been more accessible for the families.

3.2.1. Positive experience with CDS staff (sub-theme 2.1)

Over half of the caregivers contributed to this sub-theme and stated they had a positive experience when dealing with CDS staff. Caregivers reported that they did not feel judged or stigmatised, and felt supported throughout the assessment process. For example,

I did not feel judged at all. By any of the team because, like, you tell them the truth about your children and when you do, that's the last thing you wanted to … like, feel horrible about it. (P112)

3.2.2. FASD diagnosis interpreted as positive (sub-theme 2.2)

Caregivers also reported that receiving the FASD diagnosis for their child was positive, as it enabled caregivers to better understand why their child behaves in certain ways. While the children may not have been aware of the diagnosis they were given, it was still helpful for caregivers. For example, "Hearing about the diagnosis … made me … make sense of everything … In his eyes nothing's different …. But, for us, we can put a name to what's going on" (P115).

3.2.3. Need for delivery of recommend supports to be clearer and accessible (sub-theme 2.3)

For this sub-theme, five caregivers noted that they had no awareness that recommendations for ongoing supports were given (by

the assessment team), or if aware, they perceived the recommendations were beyond what the family was capable of accessing (e.g., financially unable to access supports, or supports were not accessible within reasonable proximity to where they were living). For example,

They [the recommendations] weren't ever an option … being, a young family … [the child] and my husband have disabilities. So, I'm a full-time carer … being a low-income family, we didn't have that [the recommendations] as an option. (P101)

Further, caregivers found that the additional information of recommendations for further supports was somewhat overwhelming. One participant when asked if they were aware of the recommendations provided, stated, "Not really. They [CDS staff] probably did point it out at the meeting … it's a lot of info to take in, though" (P106). Another participant stated, "We've got many forms here that …. They [CDS staff] go through them, of course, but, yeah [it's a lot to take in] …" (P106).

3.3. Theme three: positive support services relative to FASD

The third overarching theme highlighted the benefits of receiving recommendations, post-diagnosis. This theme also highlighted the need for caregivers to have/access social support/services specifically related to being a caregiver of a child with complex needs.

3.3.1. Helpful supports accessed or implemented (sub-theme 3.1)

Five caregivers identified that the recommendations they received had been helpful in improving their child's overall wellbeing. Helpful supports accessed included: an instructional book on pro-social behaviour; access to a special unit at school; medication to help the child with sleep; physical exercise regimes; medication to assist with symptoms of ADHD; occupational therapy interventions; support from the school's guidance officer; in home counselling; psychological intervention from a private psychologist; and speech therapy provided by CDS. Additionally, physical exercise was seen as helpful in assisting the child regulate and monitor their emotions. For example,

He gets a lot of frustration out in that boxing. The lady who takes him boxing says, "Has he had a bad day?" She says, "Oh, he's punching very hard today." …. we're sort of gauging emotions even in his boxing. (P111)

3.3.2. Support for caregivers seen as positive (sub-theme 3.2)

Caregivers identified the benefits of accessing supports to assist them personally. While supporting their children was identified as important, supporting themselves, psychologically and emotionally, was also regarded as important. For example, "I've already been in groups back when [the child] was about four, a women's health centre … it's somewhere that [I can go] if I do need to go" (P112).

3.3.3. Family support seen as positive (sub-theme 3.3)

Caregivers also identified the importance of social and family support. The benefits of support for the caregiver also decreased the need to access external supports. One participant stated, "Yeah, I think … I don't look for it [support] as much as I should. I think probably because we do have that support [through family]" (P112). A supportive partner also provided an opportunity for the child to learn new skills they might not have otherwise. For example, "We share [the caring load] … My husband shows him building things and they do things in the shed" (P106). Family support was also related to respite for the caregivers. For example, "It's nice when my parents take him away on holidays …" (P101).

3.4. Theme four: ongoing difficulties regardless of diagnosis

The fourth theme identified ongoing difficulties for families, regardless of the FASD diagnosis. Grouped into three sub-themes, difficulties included barriers accessing suggested supports, receiving suggestions for supports that were perceived by the family as not available or accessible, and ongoing behavioural and social difficulties for their child.

3.4.1. Barriers accessing supports and unattainable recommendations (sub-theme 4.1)

Five caregivers described difficulties accessing supports recommended in the assessment report, or felt that the supports suggested

Table 1
Barriers Accessing Supports and Unattainable Recommendations.

Participant	Response Provided in Relation to Barriers
P101	Being a young family. Both the husband and caregiver have disabilities. Being a low-income family. Being a fulltime carer. Living rural limited access to allied health practitioners. No ongoing support offered by CDS. Recommendations were not seen as a viable option.
Combined Participants: P106, P115, P119, P116[a]	Unable to book in with allied health professionals in a timely manner. Unclear on where to access allied health services; employment commitments (e.g., fulltime hours; shift work). Suggestions for learning and behaviour management strategies not implemented by school staff. Financial strain of accessing specialist services. Hopping between health professionals seeking assistance from someone experienced with FASD is exhausting. Difficult to identify which service to contact for each specific problem. Confusion around where to start (who to contact first). Feeling overwhelmed with too much information. Having multiple children to care for adds extra stress.

Note: [a]Responses combined as this group of participants gave similar responses.

for their family were unattainable (see Table 1).

3.4.2. Difficulties with mainstream schooling (sub-theme 4.2)

Several difficulties with mainstream schooling were also identified by caregivers. For example, one family found it easier to home school their child rather than deal with what they interpreted as an unhelpful environment at school. For example,

We pulled him out and home school now, because even when they [CDS staff] made the effort to go and have the meeting at the school with us and get things put in place … everything we said didn't matter. (P101)

Several caregivers also felt that they were not kept informed by school staff as to how their child was progressing at school, or if the FASD diagnosis had made any difference. For example, "I honestly have no idea [if the school visit was helpful] …" (P115). Another caregiver described that the diagnosis had not changed staff's [at school] attitude towards their child, and that school suspensions continued to be as frequent as they were before the diagnosis was shared with the school staff. For example,

One boy pushed and shoved him, so he pushed [the other child] back with his hands and then his teacher come up, and then he just lost it and the teacher tried to … calm him down and that, and then he swore back at the teacher. And then, they [the school] suspended him for 20 days for that and he had no help prior to that. (P119)

3.4.3. Behavioural and social difficulties (sub-theme 4.3)

Ongoing behavioural and social difficulties that the child faced included difficulties making friends and maintaining friendships, difficulties with emotion regulation, engaging in anti-social behaviours, being bullied by other students at school, and difficulties with school staff. For example, "When he has the meltdowns … he's broken two TVs. He keeps throwing things and will scream …. and, then he gets cranky and throws it, or breaks it. He loves breaking things at the moment" (P106). Further, FASD was seen by some caregivers as socially isolating their children, either due to the child not having the skills to be able to make friends, or, due to protecting the child from being bullied and negative interactions with other children. For example,

He doesn't have friends …. There is not one person, and there hasn't been for three years, that I can ring and say, "Hey, … can little so and so come and play with [the child]," or, "Can I take him to the movies with [the child]," or have party or something like that … just doesn't happen. (P111)

3.5. Theme five: need for societal knowledge of FASD

The final theme identified the need for increased societal awareness with regard to what a diagnosis of FASD can mean for the child and their family. In the final theme, it was identified that prior to the diagnosis of FASD, caregivers had little or no knowledge of what FASD was, or what symptoms of FASD may look like, and also that societal (and school's) knowledge and recognition of FASD needed improving. Caregivers also expressed apprehensions about their child's future due to their child's perceived inability to live independently without adequate supports.

3.5.1. Lack of caregiver prior knowledge of FASD (sub-theme 5.1)

More than half of the caregivers shared that they were unaware of FASD prior to the FASD assessment process conducted at CDS. One participant stated,

It's definitely not an easy disorder … It's kind of hidden in a way. … I didn't know about it until they flagged it when he was at the [CDS] doctor. I suspected, maybe he had some type of depression … because of, trauma and attachment with his mother. (P115)

This lack of understanding of FASD symptoms in the home and in the wider community often led to delayed assessment for FASD, and lack of understanding of the child's behaviours (prior to the FASD diagnosis).

3.5.2. Lack of societal knowledge and recognition of FASD (sub-theme 5.2)

Five caregivers reported that societal knowledge of FASD, including school staff's knowledge, required improvement. For example, "[I would like to see] a bit more awareness of what he's going through [from others] … at school, mainly" (P119). The lack of understanding from school staff was perceived as being a barrier to having the child adequately supported at school. For example,

My child needs support and he's not getting it. He is so behind in his schoolwork … supposed to be in grade three this year and we talked to everybody about repeating grades and the paediatrician and the school both just refused. (P111)

Lack of FASD knowledge was also evident in health clinicians. For example, "I said [to the nurse], 'Have you ever heard of Fetal Alcohol?' And, they [the nurse] hadn't heard of it …" (P106). The lack of FASD education in the medical profession indicated that, for some of the children, they were initially assessed for alternative medical conditions or mental disorders, rather than FASD. For example, "I described everything to the GP and he said it sounds like Autism" (P115). Caregivers also expressed hope that a FASD diagnosis would be recognised at a national level so that policy could be implemented to support their child adequately throughout their lifespan. For example,

I was thinking … [now the child has a diagnosis] he's going to get all the help he needs now, but, FASD it's not as well known ... there's not much help for FASD with anything, even in the school. (P112)

3.5.3. Feelings of apprehension about the child's future (sub-theme 5.3)

Over half of caregivers reported feelings of apprehension about their child's future, mostly due to concerns and fears that their child may not be able to live independently without adequate supports. For example, "I worry about what … his future holds … when he gets to 18 and it's time to get a job, move out of home … he probably won't be able to do those sorts of things" (P101). Caregivers

also reported feeling worried that they may not always be able to care for their child. For example,

I keep holding my breath, 'cause I keep thinking oh, when is, you know, when is the honeymoon gonna be over? I'm terrified that one day he's gonna blow up in my face, but so far, so good. (P111)

Concerns were also raised about the child's physical safety. For example, "I'm so worried that he's just going to take off. He's got no road sense … he will just take off on you and just doesn't think of the road he's going straight across" (P106). Caregivers were also apprehensive about the child's ability to be able to learn at school, and acquire skills they need to live independently. For example,

It's [FASD] something that he will have for the rest of his life and then gonna have to try to learn to live with properly and all that kind of stuff. My main concern for him is his ability to learn at school, so that he gets a good education and knows how to read and write and understand and stuff like that … (P116)

While many caregivers also reported worrying about their child's mental health into the future, one caregiver was worried about their child dying by suicide if their mental health was not nurtured. For example,

He has said it a few times, that he just doesn't want to be here anymore, just wants to be with his uncle up in heaven. He says that when he comes back from school, when they pick on him and carry on. (P119)

4. Discussion

This was the first study to utilise a qualitative approach to explore the experience of caregivers whose children received a diagnosis of FASD from an assessment clinic which utilised the *Australian Guide to the Diagnosis of FASD* (Bower & Elliott, 2016). Findings provided insight into the benefits of receiving a diagnosis, along with enduring difficulties, post-diagnosis. Analysis identified five overarching themes: (1) receiving a FASD diagnosis had a positive impact; (2) caregivers' evaluation of assessment process; (3) positive support services relative to FASD; (4) ongoing difficulties regardless of diagnosis; and (5) need for societal knowledge of FASD. In addition to qualitative data, this study also provided information for FASD profiles, and further confirmed the high prevalence of ADHD comorbidity (Fitzpatrick et al., 2015; Fryer, McGee, Matt, Riley, & Mattson, 2007; Reid, Shelton, Warner, O'Callaghan, & Dawe, 2017; Vaurio, Riley, & Mattson, 2008).

4.1. Theme one: receiving a FASD diagnosis had a positive impact

Given that both positives and negatives can be derived from a FASD diagnosis (Domeij et al., 2018; Helgesson et al., 2018), this theme is important as it provides insight into the positive impact that a diagnosis can provide. Caregivers in this study found the diagnosis to be positive for several reasons. Firstly, once the child's teaching staff were informed of the child's diagnosis and were provided with psychoeducation regarding the impact of FASD for the child, it allowed teaching staff to make accommodations to best support the child. These findings are supported by Basaraba (2016) who found that advancing classroom teachers' professional knowledge of the unique and complex learning challenges faced by children with FASD, resulted in the implementation of appropriate pedagogical practice to suit the individual challenges encountered by students with FASD. Basaraba also found that when teachers were supported in collaborative teams, which included caregivers, they were better able to design curriculum in support of students with FASD.

Secondly, gaining the FASD diagnosis enabled caregivers to be more empathic towards their child's difficulties as they were then able to separate FASD behaviours from what were previously perceived as defiant behaviours (Chamberlain et al., 2017; Pestell, 2018; Sanders & Buck, 2010). Further, caregivers were also able to identify realistic goals for their child in relation to living as an adult with FASD, suggesting the caregivers viewed their child's ability in terms of strengths rather than deficits (Brown, Kapasi, Nowicki, Cleversey, & Salahadin, 2017). Finally, the diagnosis allowed caregivers to gain a better understanding of their child's cognitive abilities, and as a result, caregivers were more able to make accommodations to provide their child with a better chance of successfully completing everyday tasks.

4.2. Theme two: caregivers' evaluation of assessment process

This theme considered caregivers' experience of the FASD assessment procedure as a whole. Overall, caregivers reported a positive experience, in particular, they reported feeling emotionally supported throughout the assessment process. For biological mothers, they reported feeling accepted, and did not feel stigmatised or blamed. This is important to note as biological mothers commonly report feeling a sense of shame or guilt relating to their child's impairment (Fitzpatrick & Pestell, 2017). It is clear from this theme that health professionals can aid in the de-stigmatisation of FASD to facilitate the process where more caregivers present their child for assessment and seek support from health services.

Further, the delivery of the diagnosis was conducted in a way that allowed the caregivers to reframe the diagnosis in a positive light. The assessment report provided to caregivers detailed strengths of the child's capabilities, and the deficits detailed were accompanied with strategies for the caregiver to assist the child in their management of the symptoms of FASD. However, several caregivers identified the need for the delivery of recommended supports to be clearer. This was particularly related to the way the report was formatted, as caregivers were not always clear that the reports entailed specific recommendations for their child. For example, there was a general consensus that when caregivers received the diagnosis, they were provided with the child's cognitive assessment information and while this was helpful, by the time they got to the end of the feedback session, they were overwhelmed with information, and were not able to fully comprehend the recommendations presented to them. Further, many caregivers stated that while they were grateful for the recommendations provided, they felt overwhelmed with the amount of services to coordinate,

or, felt that the recommendations provided were not achievable or, able to be easily accessed. As suggested by Bower et al. (2017), a report outlining the child's strengths and difficulties, and recommendations, should be provided to the family upon completion of the assessment. Bower et al. (2017) also states that the assessment process may be confronting for caregivers. Given this information, it is important for service delivery providers to ensure that caregivers are provided with recommendations in a way that is accommodating for the caregiver, and allows them to thoroughly understand the information provided (e.g., delivering recommendations over several sessions and assisting with coordination of services). It is important also that the recommendations are specific to the family, taking into account individual family circumstances.

4.3. Theme three: positive support services relative to FASD

The third theme highlighted the supportive and helpful nature of the recommendations, as reported by the caregivers. Further, this theme validated the importance of caregiver support, and the importance of the family unit working together to assist the child, and each other (Domeij et al., 2018; Dudley, Reibel, Bower, & Fitzpatrick, 2015; Reid et al., 2015). While there is research that shows the positive outcomes associated with stable home environments, understanding of cues between the caregiver and child, and being provided with encouragement by the caregiver, there is little research that identifies what adults with FASD require in order to achieve healthy development and overall wellbeing (Brown et al., 2017). Future research may benefit from evaluating the link between positive outcomes for children diagnosed with FASD as they develop into adulthood, and caregivers who incorporate a strength-based approach (and perhaps who also receive assistance from services that utilise a recovery-orientated framework) when guiding their child's development.

4.4. Theme four: ongoing difficulties regardless of diagnosis

The fourth theme is important because although previous themes highlight the positives of receiving the diagnosis, there were also negatives. This theme shed light on the barriers that the majority of the caregivers experienced in accessing supports, and that some caregivers found the recommendations provided as part of the assessment report to be unachievable given the individual circumstances of their family. Barriers to acting on the recommendations can be considered according to the following domains: the demographics of the family (e.g., age of parents, disabilities of others in the family, socioeconomic status); employment status of the caregivers (e.g., time availability); family's residence location (e.g., rural or regional); financial cost of recommended supports; availability of allied health professionals (e.g., waitlist times); specificity of recommendations and level of priority; and overload of information (e.g., delivering recommendations over a series of appointments to decrease feelings of burden).

The remaining barriers appeared to be more attributed to coordination and access difficulties within the broader Australian allied health system, faced by those living with, and caring for individuals with FASD. In particular, the difficulty of coordinating support services between multiple disciplines, particularly when some services are accessed publically, while others are accessed privately or through various non-profit organisations. For a caregiver, often caring for more than one child, whilst also managing other everyday tasks such as employment, running a household, liaising with schools, and so on, coordination of services across multiple sites can be understandably overwhelming. A potential solution to this allied health access barrier may be the introduction of specially trained staff able to case manage or coordinate support services, to assist the family in accessing the multiple supports. With tailored services coordinating care, it is likely to reduce caregiver burden and prevent against caregiver burnout, and therefore predict better outcomes for individuals and families (Fairthorne, de Klerk, & Leonard, 2016; Salahadin, 2016).

This theme also highlighted the ongoing difficulties some of the child experienced at school in regards to their relationship with teachers, lack of communication between school staff and caregivers, and continued school suspensions. Further, some of the children experienced ongoing behavioural and social difficulties such as difficulties making and maintaining friendships, difficulties with emotion regulation, continuation of anti-social behaviours, and experiencing bullying. While at the time of the interviews it was not made clear which of these children had received intervention (if any), the findings are still important as they highlight potential reasons why the difficulties persist (e.g., ineffectiveness of interventions; no implementation of intervention). Future research regarding symptoms reduction/management in the context of intervention efficacy is developing, and more work is this space would be welcomed.

4.5. Theme five: need for societal knowledge of FASD

The final theme identified the need for increased societal awareness of FASD. Firstly, several caregivers were unaware of FASD or FASD-related symptoms prior to their child's diagnosis. Research has shown that if caregivers are aware of FASD, it may lead to the decrease of prenatal alcohol consumption (Brussen, 2013; Change, 2004), and therefore aid in prevention of FASD. Furthermore, caregivers' awareness of FASD symptoms may lead to children presenting for assessment earlier, which would lead to early interventions, which has shown to predict better outcomes for both children with FASD (Reid et al., 2015), and adults with FASD (Helgesson et al., 2018).

Secondly, analysis showed that caregivers experienced lack of awareness of FASD from health professionals (outside of the CDS FASD assessment team) and the wider community, as a whole. What adds to the complexity of FASD is that it often presents as a *hidden diagnosis* (Allan, 2014), in that there are not always physical impairments present, which can add to the lack of understanding of certain behaviours that present in FASD (e.g., impulse control; deficits in socials skills).

Finally, the lack of societal awareness of FASD aided in caregivers' apprehension about their child's future, specifically in relation

to their child's capability to live independently, and to be accepted and understood by the wider community. Research by Baldwin (2007) supports caregivers' concerns which suggests that adolescents with FASD have features associated with risk factors for suicide, mental illness, alcohol and other drug abuse, and employment and relationship difficulties. Furthermore, research suggests that over half of individuals diagnosed with FASD will have some involvement in criminal activity (Mutch, Watkins, Jones, & Bower, 2013). Therefore, the potential for children diagnosed with FASD to encounter some mental health or legal implications throughout their life is high.

Petrenko, Tahir, Mahoney, and Chin (2014) propose a five systems-level model which identifies barriers to the prevention of secondary disabilities developing in individuals with FASD. Petrenko's systems model identifies many of the themes raised by caregivers in the current study such as difficulty accessing services, and poor implementation of services. Petrenko suggests that secondary disability prevention barriers are due to a pervasive lack of knowledge about FASD, that then permeates multiple systems and the community as a whole. It is then the results of poor support access that creates secondary FASD-disabilities. Petrenko further states that broad systems changes are needed at a public health level to support the prevention of secondary conditions in this population. In Australia, with future support and recognition from the National Disability Insurance Scheme, it is anticipated that caregivers will be more equipped to support their children long-term, and that children will continue to be supported by government funding throughout their lifespan. Recent research and publications have noted Australia's commitment to additional FASD research and advocates for supports on a national level (Petrenko & Davis, 2017).

4.6. Limitations

The current study is not without limitations. Given the small sample size, there are issues concerned with generalisability of findings, data saturation, and the type of qualitative analysis (e.g., whether interpretative phenomenological analysis [IPA] would have been better suited). IPA was considered for analysis, although, homogeneity of the sample could not be established therefore thematic analysis was employed. Future research may benefit from providing incentives to encourage participation and therefore increase sample size, however, this brings additional limitations (e.g., participation bias). Additionally, creation of smaller groups to meet homogeneity of the sample may also be of benefit. Furthermore, common to qualitative research, there is the potential for researcher bias when interpreting results. This aimed to be reduced by ensuring theme creation was conducted primarily by two authors who were not a part of the FASD diagnostic team, and data was cross-checked by the fourth author who was also independent to the FASD diagnostic team. However, future research would benefit from including both qualitative and quantitative analysis of a larger sample size, to allow for qualitative findings to be cross-referenced with similar quantitative findings.

A broader limitation of this study may be the lack of consideration when generalising the findings regarding long-term placement and legal guardianship for the children. While 85.7% of the sample had legal guardianship of the child assessed for FASD, and all interviewees were related to the child either as a parent or grandparent, this is certainly not always the case for many children assessed for FASD. Therefore, the findings of this study should be interpreted and applied in the context of biological family care findings, rather than considering these findings to be generalisable to children within non-family care placements.

4.7. Conclusion

Given the recent release of the *Australian Guide to the Diagnosis of FASD*, it is important that clinics using the guidelines are reviewed to ensure families are satisfied with the service they received. Australian prevalence rates of FASD and comorbid diagnoses are also important to document. This study provides foundational information across a broad array of areas in the developing FASD literature, focusing on the caregivers' experience of raising a child with FASD, the assessment process using the revised guidelines, and the benefits and deficits of gaining a FASD diagnosis for their child, along with adding to prevalence rates and comorbid diagnoses. This study also acts as a reference point for future research when comparing outcomes and efficacy between international FASD diagnostic guides.

Funding

A special acknowledgment is given to Professor Sharon Dawe of Griffith University for supplying AUD$300 of funding the transcription of qualitative data, using the grant Drug and Alcohol Program: Fetal Alcohol Spectrum Disorder Diagnostic Services and Models of Care Grant Opportunity [2017–2020; H1617G038].

Declaration of Competing Interest

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced the outcome.

Appendix A

List of Neurodevelopmental Assessments Used to Assess FASD

- Adaptive Behaviour Assessment System – 2nd Edition (ABAS-II)

- Autism Diagnostic Observation Schedule – Second Edition
- Beery-Buktenica Test of Visual Motor Integration (Beery)
- Behaviour Rating Inventory of Executive Functioning – Preschool Version (BRIEF-P)
- Bruininks-Oseretsky Test of Motor Proficiency – 2nd Edition (BOT-2)
- Can Child McMaster Handwriting Assessment
- Child Behaviour checklist (CBCL) Parent and Teacher Reports
- Childhood Autism Rating Scale – Second Edition
- Clinical Evaluation of Language Fundamentals – Preschool 2nd Edition (CELF-Pre2)
- Conners Early Childhood
- Differential Ability Scales – 2nd Edition (DAS-II)
- Miller Function & Participation Scale (M-FUN)
- Movement Assessment Battery for Children – 2 (M-ABC-2)
- NEPSY-II (A Developmental NEuroPSYchological Assessment)
- Rey Complex Figure Test (RCFT)
- Social Responsiveness Scale – Second Edition
- Test of Problem Solving 3 (TOPS)
- Wechsler Non Verbal Scale of Ability (WNV)
- Wechsler Preschool and Primary Scale of Intelligence – Fourth Edition (WPPSI-IV)
- Wide Range Achievement Test – Fourth Edition

Appendix B

Sample Phone Interview Questions Runsheet

Phone calls will be no longer than 20 min per participant. To ensure identification of the participant via phone conversation, the participant will be asked to confirm the name of their child whom was a client of the FASD diagnostic service. This information will be solely used for verification of identity, and will not be included in the data analysis. The phone interviews will use a phenomenological approach by asking parents/caregivers to describe their lived experience of engaging with, and the outcomes associated with the diagnostic process of the CDS FASD clinic for a child in their care. Further, parents/caregivers will be invited to discuss any barriers to implementing the post-diagnosis management plan that was provided as part of the diagnostic process. Questions will be asked using a semi-structured interview approach, comprised of four main sections:

Introductory questions:

- Give brief information about interviewee role and scope of the research.
- Confirm information gathered from cognitive report if correct.
- Reconfirm consent to participate, age of caregiver, ethnicity, and employment status.

Formal questions:

1 Caregivers' experience of the assessment process
2 E.g. "Could you please state what the experience of the FASD diagnostic process has meant to you and your child, and would you say your overall experience at the FASD clinic was a positive or negative experience?"
3 Did you feel emotionally supported during the diagnostic process?
4 Benefits of the post-diagnosis management plan/report recommendations
5 Did you receive a post-diagnosis management plan as part of the service offered by CDS?
6 Was the management plan followed?
  - Were you able to access relevant support service to assist you and your child in managing symptoms of FASD?
  - If no, why do you think that is the case?
  - If no, what were some of the barriers that prevented you from following the management plan?
  - If no, what do you think would be more helpful in the future in regards to supports service and post-diagnosis management?
  - If yes, were the support services useful?
  - If yes, are you continuing to access support services?
7 What were some of the key benefits you and your child experienced following the FASD diagnosis management plan that was provided at the end of the assessment process?"
8 Specifically, how useful was the in-person school feedback sessions? Any outcomes from that process?
9 Barriers to following the post-diagnosis management plan:
10 E.g. "Did you find there were any barriers which prevented you or your child from implementing aspect of the management plan? And if so, what were they?"
11 Did you feel emotionally supported afterwards?
12 Were you offered follow up appointments?
13 Future directions for the family following the assessment
14 E.g. "Looking forward, how do you think the formal FASD diagnosis will impact you and your child in the future? Has it made a

positive or a negative difference, or maybe no difference? Whichever the case, could you please provide some information around how the future has changed (or not changed) for you and your child as a result of the FASD diagnosis?

Questions asked of the parents/caregivers will also include items around psychosocial stressors that may have impacted the successful management of their child's FASD symptoms post-diagnosis.

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