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CRITICAL REVIEW

Factors to be considered as part of a holistic assessment for fetal alcohol spectrum disorder: A scoping review

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Abstract

We undertook a scoping review to identify the factors outside of current fetal alcohol spectrum disorder (FASD) diagnostic criteria to be considered as part of a holistic assessment process. This included physical, social, cultural, mental health and wellbeing factors to inform targeted recommendations and supports to improve outcomes for individuals with FASD. Evidence from this review will be used to inform the revision of the Australian Guide to the Diagnosis of FASD. Six electronic databases were searched. Studies were eligible if they included factors outside of the diagnostic criteria that cover dysmorphology, growth restriction, neurodevelopmental impairments. Data charting and content analysis were performed to synthesize the results. One hundred twenty-one studies were included that spanned 12 key areas These included physical health, sleep, adverse postnatal experiences, substance use/other risk-taking behaviors, contact with the criminal justice system, mental health, First Nations cultural considerations, transition to adult roles, involvement with the out-of-home care system, feeding and eating, strengths/interests/external resources and incontinence. Areas to be considered as part of a holistic assessment and diagnostic process spanned individual, family, and system level factors. Results provide guidance for clinicians on the wide range of factors that could influence long-term health, development, and wellbeing for individuals with prenatal alcohol exposure and FASD. In practice, this guidance can be used to inform an individualized assessment process to facilitate tailored recommendations and supports to best meet the complex needs of individuals living with FASD and their families.

KEYWORDS
adverse child experiences, fetal alcohol spectrum disorder, first nations cultural considerations, holistic assessment, physical and mental health

INTRODUCTION

Alcohol exposure has long been documented to affect fetal growth and development (Brown et al., 2019). Several different diagnostic criteria and terms have been used to summarize the spectrum of disorders that can manifest following prenatal alcohol exposure (PAE, i.e., fetal alcohol syndrome [FAS], partial FAS, alcohol related neurodevelopmental disorders, and fetal alcohol spectrum disorder [FASD] with or without sentinel facial features [SFFs]). Diagnostic criteria vary in detail, but all include consideration of SFFs, central nervous system impairments and PAE, with some also including growth deficiency (Astley, 2013; Cook et al., 2016; Hoyme et al., 2016; Landgraf et al., 2013).

In 2016, the Australian Government funded the development of the Australian Guide to the Diagnosis of FASD henceforth referred to as 'the Guide,' to assist clinicians in diagnosis, referral and management (Bower & Elliott, 2016). The Guide specifies that FASD diagnosis requires objective evidence of severe impairment in brain functioning in at least three of the 10 specified domains. Unknown PAE can be accepted if three SFFs are present (Bower & Elliott, 2016). While diagnosis of FASD is important, focusing on impairments and diagnosis alone can overlook nondiagnostic personal and environmental factors that could support an individual in reaching their potential and maximizing their overall health and wellbeing across the lifespan (Allen et al., 2014). Taking a holistic (i.e., physical, psychological, spiritual, and social, strengths, needs and systems-level) approach to assessment aims to support the whole person, not just their medical condition. Further, holistic assessment aligns with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); and the prioritized equity principles embedded in the Declaration of the Rights of Indigenous Peoples (UNDRIP); and Leave No One Behind (LNOB). To comply with UNCRPD, UNDRIP and LNOB, impairments and activity limitations should not be the only considerations in diagnostic assessment processes. Assessments should also outline social determinants of health and wellbeing, environmental barriers, and support requirements of persons with disabilities. This approach also aligns with recent research in the field of FASD, highlighting the importance of holistic and integrated care approaches to enable targeted and meaningful supports for people with FASD (e.g., Himmelreich et al., 2020; Masotti et al., 2015; Pei et al., 2021; Reid et al., 2021).

The current scoping review forms part of a larger evidence review process (e.g., see Hayes et al., 2022; Hayes et al., 2023; Hewlett et al., 2023) supporting the review and update of the Guide. The current review focused on identifying the factors outside of the diagnostic criteria (i.e., PAE, dysmorphology, neurodevelopmental impairments, and growth restriction) that could be part of a holistic assessment process when considering a FASD diagnosis as one possible outcome. By performing an in-depth exploration of the available literature, this review will aid further understanding of the wide range of potential factors that could be part of an assessment process, informing the development of more individualized and holistic recommendations and support approaches to enable improved health and wellbeing for individuals with FASD and their families.

Notably, one key area being considered in the revision of the Guide is how to increase cultural responsiveness of the assessment process (Hayes et al., 2022; Hewlett et al., 2023). Despite being a culturally diverse nation with over 60,000 years of history, Australian clinical practice guidelines have not always considered historical and cultural context (Laycock et al., 2011). The current review of the Guide will include consideration of cultural factors of Aboriginal and Torres Strait Island peoples and other Australians relating to assessment and diagnosis. We acknowledge and respect the diversity of Aboriginal and Torres Strait Islander peoples and Indigenous peoples from other countries and will respectfully use the term 'First Nations' when discussing relevant literature.

METHODS

Research question

What broader factors (i.e., outside of the components of the diagnostic criteria) should be considered for holistic care/support when undertaking an FASD diagnostic assessment?

Context

A scoping review to map the available evidence was undertaken to inform revision of the Guide. A scoping review methodology was selected for three key reasons: (1) to provide a broad overview of available evidence that explores health and wellbeing outcomes in individuals with FASD that are not currently covered by diagnostic criteria; (2) to be more inclusive of diverse types of evidence relating to health and wellbeing outcomes in individuals with FASD and; (3) to report on the types of evidence available and ascertain if further systematic reviews are appropriate in specific areas (Munn et al., 2018).

Protocol and registration

A scoping review protocol was published on the Open Science Framework (OSF) Registries (osf.io/7rcfs). The review was designed and reported according to the Preferred Reporting Items for Systematic Review and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018; see Table S1 for the PRISMA-ScR checklist).

Eligibility criteria

Published peer-reviewed articles were eligible for inclusion, including both systematic reviews and original research, inclusive of quantitative, qualitative, and mixed methods designs. No restrictions were placed on location of studies, publication dates, or age of participants.

Information sources and search strategy

Six electronic databases were searched (PubMed, EMBASE, Web of Science, PsycInfo, Cochrane Library & CINAHL). Database searches were initially conducted on Febuary 2, 2021 and an updated search was conducted on September 27, 2022. Reference lists of included studies were hand searched and experts in the field were contacted to identify any additional studies for inclusion. See Table S2 for full search strategies applied to each database.

Selection of sources of evidence

Search results were downloaded to Endnote and uploaded to Covidence (Veritas Health Innovation, Melbourne, Australia) for screening. Duplicate removal was undertaken by one author (NR). Title/abstract and full-text screening was completed by two independent reviewers (NR and NHa), and a third reviewer (LA) resolved any conflicts. Studies were eligible for inclusion if they reported on any broader elements that could be considered as part of a holistic assessment process (e.g., health, social, psychological, occupational, or other behavioral/mental health factors not typically considered in FASD diagnosis). The list of inclusion areas was determined through the authors' knowledge of commonly co-occurring experiences and/or conditions and in consultation with the Project Steering Committee comprised of researchers, clinicians, and individuals with lived experience of FASD (membership listed in the Acknowledgements section).

Studies were excluded if they did not focus on FASD; were exclusively preclinical studies, placenta studies or in utero studies, were not peer-reviewed or were conference abstracts, theses, government, or other reports, FASD guidelines, intervention or prevention studies, or studies that focused only on components of the diagnostic criteria (i.e., dysmorphology, growth impairments, neurodevelopmental impairments). Individual studies captured as part of included systematic reviews were excluded.

Data charting process and items

A standardized form was developed that included key study elements (i.e., study author, date, location, design, aims, and key findings; Table S3). This was piloted by one author (NR), applied by multiple authors (NHa, NHe, KB, NB, SG, TT & NK), and checked by one author (NR). Studies were grouped by two authors (NR and NK) based on key areas of interest covered by each of the studies. The key areas of interest were first inductively derived from broader elements outlined for study inclusion (health, social, psychological, occupational, or other behavioral/mental health factors not typically considered in FASD diagnosis). Additional key areas of interest were deductively created as the content analysis progressed to facilitate a detailed description of all included studies. All authors provided feedback to refine the key areas of interest based on the content analysis.

Synthesis of results

Content analysis was utilized to synthesize results, which is a method for providing a systematic, yet simple way of condensing and describing data (Cavanagh, 1997; Downe-Wamboldt, 1992). The process involves coding and grouping available text into similar groups and then counting the number of times each of the groupings occurs (Hsieh & Shannon, 2005). Coding was undertaken and frequency of studies addressing each key area of interest was calculated. Within each key area of interest, content analysis identified subareas of interest and frequency of studies addressing each subarea of interest was calculated. Content analysis was undertaken by one author (NK) and verified by another author (NR). Studies addressing multiple subareas were counted across applicable key areas/subareas of interest.

RESULTS

Selection of sources of evidence

An initial search identified 5897 records. After removal of 3827 duplicates, 2070 records underwent title and abstract screening. A further 1883 articles were excluded, leaving 187 full-text articles for eligibility assessment. Of these, 116 articles were excluded. Reference list searches led to the inclusion of an additional 36 articles and an updated search before submission yielded 14 additional articles. See Table S4 for a summary of publications excluded at the full-text level with reasons for exclusion. In total, 121 studies were included in the review (Figure 1).

Characteristics of sources of evidence

Included studies originated from 12 countries, including 45 from the United States (U.S.), 27 from Canada, 13 from Australia, five from the United Kingdom, four from South Africa, three each from Germany and Sweden, two each from the U.S./Canada and Poland, and one each from Chile, New Zealand, Norway, and Russia. The remaining studies were from international samples ($n=2$) or were systematic reviews. Of the 121 included studies, 60 were cohorts (49.5%), 32 were case–control studies (26.4%), 13 were qualitative studies (10.7%), 11 were systematic reviews (9%) and 5 were mixed-methods studies (4.1%).

Synthesis of results

Twelve key areas of interest were identified from the included studies: (1) physical health, (2) sleep, (3) adverse postnatal experiences, (4) substance use and other risk-taking behaviors, (5) contact with the criminal justice system, (6) mental health, (7) First Nations cultural considerations, (8) transition to adult roles, (9) involvement with out-of-home care (OOHC), (10) feeding/eating, (11) strengths/interests/external resources, and (12) incontinence. Figure 2 and Table S3 provide an overview of the results synthesis.

Physical health ($n=21$ studies)

Subareas identified: bone/teeth health, eye/ear health, cardiovascular/renal health, metabolic health, nervous system development/function, respiratory/immune system health, reproductive health, and health service utilization.

Overall, studies highlighted that, there is some clinical evidence for altered metabolic (Akison, Reid, et al., 2019; Kable et al., 2021), cardiovascular and renal (Akison, Moritz, & Reid, 2019; Carter et al., 2007; Cook et al., 2019; Reid et al., 2021), and reproductive function (Akison, Moritz, & Reid, 2019) in individuals with PAE, however much of the currently available research is preclinical (and therefore findings of the preclinical studies were not included in the current review). PAE was associated with CNS damage

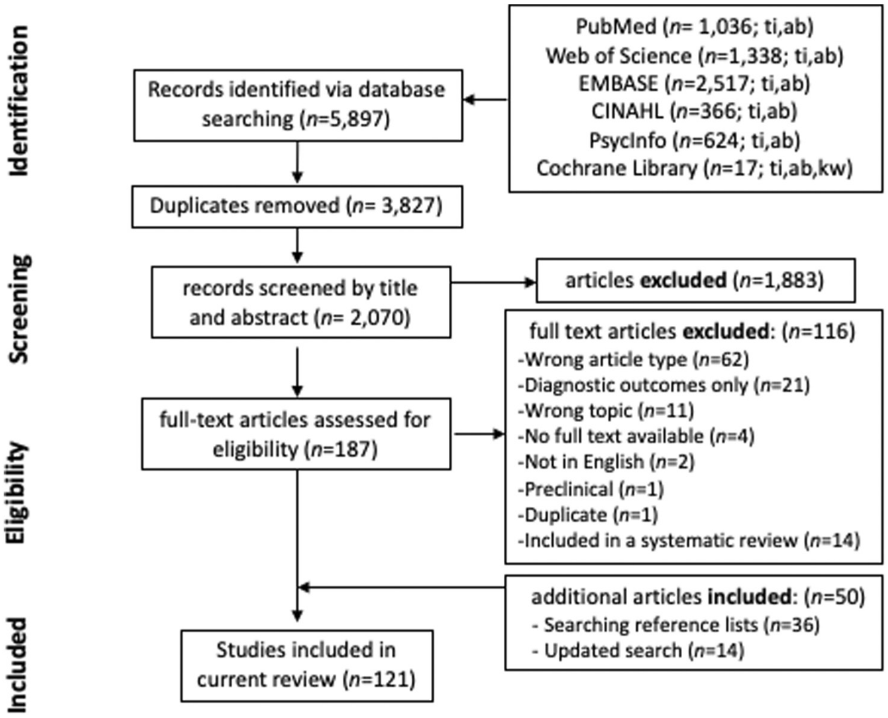

FIGURE 1 PRISMA flowchart depicting number of articles identified, screened, assessed for eligibility, and included in the scoping review. Only Cochrane reviews (17) included. Cochrane protocols, editorials, and special collections were excluded from review. Trials were excluded as were all interventions. The search was repeated on September 27, 2022. ab, abstract; kw, keyword; ti, title.

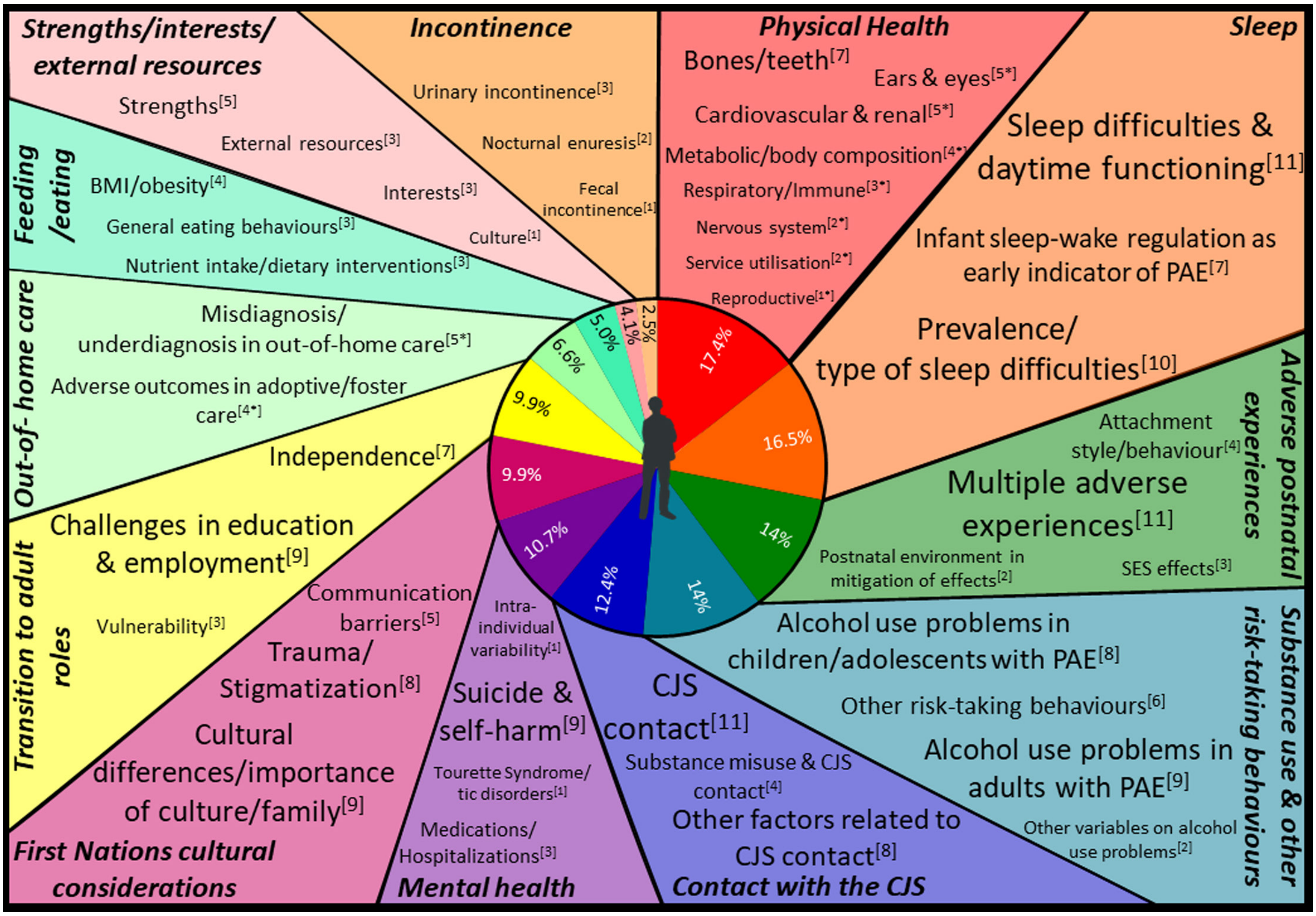

FIGURE 2 Summary of all key areas and subareas of interest identified from content analysis that should be included as part of a holistic assessment for FASD. The size of the font and number in superscript brackets depict the number of studies that addressed each subarea. * = subareas that included systematic reviews, BMI, body mass index; CJS, criminal justice system; PAE, prenatal alcohol exposure; SES, socio-economic status. Some studies were included across 2–3 key areas of interest, and therefore, the sum of the percentages does not equal 100%.

(Avaria et al., 2004; Popova et al., 2016) and altered insulin sensitivity dependent on the body mass index (BMI) of the individual (Kable et al., 2021). Delayed skeletal maturation (Habbick et al., 1998), reduced bone mineral density (Young et al., 2022), and sex-specific dentofacial anomalies and tooth disturbances (Naidoo et al., 2005, 2006) were also reported.

Ophthalmic complications (Gummel & Ygge, 2013; Reid et al., 2021; Tsang et al., 2022), structural and functional ear complications were associated with FASD (Cheung et al., 2022; Popova et al., 2016), increased infection risk, asthma and skin conditions (Reid et al., 2019, 2021) were all commonly reported in children with FASD/PAE. First Nations peoples in Canada with FASD (aged 20–42 years) reported complex physical needs such as respiratory diseases, cardiovascular complications, gastrointestinal issues, chronic pain, and dental issues (Flannigan, McMorris, et al., 2022). Higher service utilization was reported in individuals with FASD compared to controls (aged 0–34 years), including health services, social services, and education services (Brownell et al., 2013; Loney et al., 1998).

Sleep ($n = 20$ studies)

Subareas identified: prevalence/type of sleep difficulties in children with PAE, associations between sleep difficulties and daytime functioning, and infant sleep–wake regulation as an early indicator of PAE.

Persistent sleep problems were common in children with PAE/FASD (55%–85%; Alvik et al., 2011; Chandler-Mather et al., 2021; Chen et al., 2012; Dylag et al., 2021; Goril et al., 2016; Hayes et al., 2020; Ipsiroglu et al., 2013; Mughal, Hill, et al., 2020; Mughal, Joyce, et al., 2020; Rosett et al., 1979; Scher et al., 2000). Disrupted sleep patterns were attributed to challenging night behaviors (Chen et al., 2012; Dylag et al., 2021; Hayes et al., 2020; Ipsiroglu et al., 2013; Mughal et al., 2021; Mughal, Joyce, et al., 2020; Spruyt et al., 2016; Wengel et al., 2011), in addition to behavioral, emotional and cognitive functioning difficulties (Alvik et al., 2011; Hayes et al., 2020; Mughal et al., 2021; Mughal, Hill, et al., 2020; Spruyt et al., 2016; Troese et al., 2008). Differences in processing auditory and multisensory stimuli during sleep may impact the ability to fall asleep and increase the incidence of night wakings (Wengel et al., 2011). Some predominately early research focused on the use of neonatal electroencephalogram to explore disruptions to sleep–wake state regulation as a possible early indicator of PAE (Chernick et al., 1983; Scher et al., 1988, 2000; Troese et al., 2008).

Adverse postnatal experiences ($n=17$ studies)

Subareas identified: risk of multiple adverse experiences, the postnatal environment in the mitigation of the effects of prenatal alcohol exposure, socioeconomic effects, and attachment style and behavior.

Experiences of inequitable access to health and wealth for all people globally drives social disadvantage and places children at greater risk of adversity (Allen et al., 2014). As such, FASD was reported to be more common among lower socioeconomic groups (Bingol et al., 1987). Estimates indicated 50%–66% of children and adolescents with PAE were exposed to adverse child experiences (ACEs; Flannigan, Kapasi, et al., 2021; Kambeitz et al., 2019; Lebel et al., 2019). Individuals with PAE were more susceptible to negative effects of poor postnatal environments (Pfinder et al., 2012; Yumoto et al., 2008), possibly due to a greater prevalence of neurological deficits (Andre et al., 2020; Hemingway et al., 2020; Uban et al., 2020), and hypothalamic–pituitary–adrenal (HPA) axis disturbances (McLachlan et al., 2016). Environments lacking enrichment worsened outcomes (Jacobson et al., 2004), as did experiences of trauma (Pfinder et al., 2012; Price et al., 2017). PAE was associated with insecure attachment in children and adults (Flannigan, McMorris, et al., 2022; O'Connor et al., 1987, 1992, 2002). Intellectually stimulating and protective environments buffered further adverse outcomes (Jacobson et al., 2004; McLachlan et al., 2016).

Substance use and other risk-taking behaviors ($n=17$ studies)

Subareas identified: alcohol use in children/adolescents with PAE, risky alcohol use in adults with PAE, effects of other variables on alcohol use problems, and other risk-taking behavior excluding alcohol use in individuals with PAE.

Prenatal alcohol exposure was associated with increased prevalence of alcohol and other drug (AOD) use in teenagers and adults (Cornelius, De Genna, et al., 2016; Cornelius, Goldschmidt, & Day, 2016; De Genna & Cornelius, 2014; Flannigan, Tremblay, et al., 2022; Goldschmidt et al., 2019; Lees et al., 2020; Lynch et al., 2017; McLachlan et al., 2020; O'Brien & Hill, 2014; Yates et al., 1998). This may be due to a biological origin of early onset alcohol use disorders (Alati et al., 2006, 2008) and the reported increased hedonic value of alcohol odors (Hannigan et al., 2015). Children from higher socioeconomic groups and educated families more frequently reported alcohol experimentation by 9–10 years of age, while children from ethnically diverse families were less likely to experiment with alcohol (Lees et al., 2020).

Other variables reported to be associated with alcohol use in adolescence included parental laxity (i.e., less parental strictness, and involvement), greater maternal hostility during childhood, and greater exposure to child maltreatment and violence (Cornelius, De Genna, et al., 2016). The number of substance dependence symptoms were higher in males than females (Yates et al., 1998). PAE was associated with an increased likelihood of adolescents engaging in risky sexual behaviors, defined as two or more sex partners in the past year (De Genna & Cornelius, 2014). However, as this study did not assess sex education or access to contraception (De Genna & Cornelius, 2014), future work should consider the role of kinship support, peer influences and contraceptive use.

Contact with the criminal justice system ($n=15$ studies)

Subareas identified: the effects of PAE on contact with the criminal justice system (CJS), interactions between risky AOD and CJS contact, and other factors related to CJS contact.

In children and adolescents, PAE was associated with lower levels of moral maturity, which was secondary to lower verbal cognitive abilities. PAE was also associated with a higher number of conduct-related behaviors, which were related to specific abilities in moral judgment and reasoning (Schonfeld et al., 2005). Rates of offending were often higher in individuals with PAE and related to age, sex, geographic location, IQ, and degree of PAE-related dysmorphia (Lynch et al., 2017; McLachlan et al., 2020; Streissguth et al., 2004). Although this was not always the case, with two studies from Sweden and one from the United States reporting no difference in rates of criminality in FASD populations compared to individuals without FASD (Lynch et al., 2003; Rangmar et al., 2015, 2017). Other factors that interacted with PAE to predict higher risk of offending behavior and CJS involvement were AOD use, higher levels of stress and lower parental supervision (Currie et al., 2016; Lynch et al., 2003). While living with a caregiver as an adult and early diagnosis were reported to reduce the risk of offending (Clark et al., 2004; Currie et al., 2016). One qualitative study (Pei et al., 2016) described how individuals with FASD experienced biological, psychological, and social factors that placed them as increased risk of contact with the CJS and increased risk of experiencing barriers when interacting with the system.

The disproportionate involvement with the CJS for individuals with FASD is compounded for First Nations peoples as a consequence of the ongoing impacts of colonization and intergenerational trauma, in addition to barriers enforced by colonial policies and practices (Flannigan, Tremblay, et al., 2022). First Nations youth diagnosed with FASD often have high rates of involvement with child welfare and justice systems and were more likely to be charged with a crime than non-First Nations individuals (Brownell et al., 2019; Hamilton, Maslen, Best, et al., 2020). Culture and family, cultural connections, belonging, resilience, and overall ethnic identity were all associated with lower rates of offending (Rogers et al., 2013). Development of a "mobile-needs focused court," a hybrid model involving the integration of First Nations perspectives, including Aboriginal Elders with the Victorian Neighborhood Justice Centre model, was suggested as a solution to reduce contact with the CJS for First Nations youth with FASD in Australia (Blagg et al., 2017).

Mental health (*n* = 13 studies)

Subareas of interest identified: suicide/self-harm, medications/hospitalizations, intra-individual variability, and Tourette syndrome/tic disorders.

Compared to controls, individuals with FASD had higher prevalence of Tourette syndrome or tic disorders (Mathews et al., 2014), intra-individual variability (Ali et al., 2018), challenging behaviors toward others, and hallucinations (Rangmar et al., 2017). They also had higher prevalence for psychiatric care, hospitalizations and diagnosed psychiatric disorders, and higher rates of prescription psychotropic drugs (Rangmar et al., 2015; Streissguth et al., 2004).

High rates of suicidal ideation and suicide attempts were also reported in individuals with FASD/PAE (Flannigan, McMorris, et al., 2022; O'Connor et al., 2019). The high risk of suicide in First Nations peoples with FASD can in part be attributed to legacies of colonization and ongoing impacts of racism and discrimination (Brownell et al., 2019; Flannigan, Tremblay, et al., 2022).

In general, factors contributing to increased suicide risk included co-occurring health conditions, poor education and social outcomes, increased number of home placements for those in OOHC, sociodemographic characteristics, substance use, early life trauma, familial conflict, stigma, geographic region (rural vs urban), COVID-19, late/nonexistent access to services, and affect regulation impairments (Harding et al., 2022; O'Connor et al., 2019; Rangmar et al., 2017; Temple et al., 2019). Protective factors relating to suicidality included pursuit of personal interests, physical activity, helpful interactions to improve wellbeing, and time in nature (Flannigan, McMorris, et al., 2022; Harding et al., 2022).

First Nations cultural considerations (*n* = 12 studies)

Subareas identified: trauma/stigmatization, communication barriers, and cultural differences/the importance of culture and family.

FASD in First Nations populations was discussed as a direct consequence of colonization, intergenerational trauma, and ongoing systemic racism (Flannigan, Tremblay, et al., 2022; Gonzales et al., 2018; Miller et al., 2022). There can be a level of shame associated with FASD for individuals and families (Hamilton et al., 2019; Hamilton, Maslen, Best, et al., 2020) but it was discussed how shame was not a barrier for individuals when a culturally safe space is provided. Thus, there is great need for building a culturally responsive workforce as an antidote to the impacts of shame related to FASD diagnosis, colonization, intergenerational trauma, and systemic racism. It is also important to develop a collective sense of understanding and compassion for those who use alcohol to alleviate and cope with trauma (Flannigan, Tremblay, et al., 2022, Miller et al., 2022).

Importance of connection to community, country, culture, and family were common across several studies from Australia, New Zealand, and Canada, and were reported to improve resilience, allow individuals to focus on strengths, and promote health and healing (Crawford et al., 2020; Gonzales et al., 2018; Hamilton, Maslen, Best, et al., 2020; Rogers et al., 2013). Barriers to effective communication were commonly cited to interfere with provision of effective services to First Nations individuals with FASD (Hamilton et al., 2019; Hamilton, Maslen, Best, et al., 2020; Miller et al., 2022). Poor communication and information access, inadequate resourcing and limited professional development of health practitioners were cited as barriers to service delivery (Hamilton et al., 2019). Similarly understanding diagnostic reports and the implications for their child was reported to be difficult for First Nations caregivers due to the complicated medical terminology and inherent power imbalances that exist in a colonial controlled system (Hamilton, Maslen, Watkins, et al., 2020).

Transition to adult roles (*n* = 12 studies)

Subareas identified vulnerability, independence, and challenges in education and employment.

Individuals with PAE were more vulnerable to physical, sexual, or verbal assault, and exploitation or manipulation by those close to them (Clark et al., 2004; Freunscht & Feldmann, 2011; McLachlan et al., 2020). Adults had challenges with living independently (Lynch et al., 2015, 2017), and they often required moderate–high levels of care (Clark et al., 2004), lived in dependent circumstances (Freunscht & Feldmann, 2011), accessed social welfare (Rangmar et al., 2015), experienced social problems (Freunscht & Feldmann, 2011), and struggled with the transition into adult roles (Lynch et al., 2015; Temple et al., 2011).

Adults with FASD commonly experienced early life school disruptions (Freunscht & Feldmann, 2011; McLachlan et al., 2020; Streissguth et al., 2004), and thus reported lower educational attainment and higher rates of unemployment (Rangmar et al., 2015), highlighting the need for further understanding of vocational opportunities for adults with FASD and education and support for their caregivers (Currie et al., 2016; Duquette et al., 2006; Duquette & Orders, 2013). First Nations adults with FASD identified concerns relating to finances, education, and employment (Flannigan, Tremblay, et al., 2022). However, there was also hope reported for future education experiences and pro-social community activities identified in their future goals (Hamilton, Maslen, Best, et al., 2020).

Delayed diagnosis was associated with poorer outcomes (Freunscht & Feldmann, 2011; McLachlan et al., 2020; Rangmar et al., 2015; Streissguth et al., 2004). However, longer-term outcomes for adults could be improved through early diagnosis, and individually tailored long-term supports provided in a stable and nurturing home environment (Currie et al., 2016; Duquette & Orders, 2013; McLachlan et al., 2020; Miller et al., 2022; Streissguth et al., 2004).

Out-of-home care (*n* = 8 studies)

Subareas identified: misdiagnosed/undiagnosed children in adoptive/foster care, and adverse outcomes associated with children with PAE/FASD living in adoptive/foster care.

Youth with FASD in OOHC in rural and urban areas were commonly misdiagnosed with ADHD, and youth in rural OOHC also experienced higher rates of co-occurring mental health disorders relative to youth in urban populations (Chasnoff, Telford, et al., 2015; Chasnoff, Wells, & King, 2015). Of individuals with FASD living in foster/adoptive care, 78%–80% had not received a diagnosis of FASD prior to the includes studies (Chasnoff, Wells, & King, 2015; Patel et al., 2020). One hindrance to diagnosis may be underreporting of PAE to child protective services due to lack of staff awareness of FASD and/or lack of systematic PAE data collection processes (Richards et al., 2020). Inability to access specialized services for children and adolescents in adoptive/foster care meant that needs were often overlooked (Bakhireva et al., 2018; Chasnoff, Wells, & King, 2015). Screening of all youth in care using an integrated community approach employing existing child protection and physician services and referral for appropriate follow-ups was proposed as a solution to missed diagnoses of children in OOHC (Patel et al., 2020). Foster care introduced additional risk factors for children with FASD. This included increased risk of experiencing sexual or physical abuse and increased risk of involvement with the CJS (Burns et al., 2021). However, there was no difference reported in psychiatric conditions, medications, convictions, or cognitive, academic, and executive functioning in individuals with FASD who remained with their biological family or were placed in OOHC (Rangmar et al., 2016; Victor et al., 2008).

Feeding/eating (*n* = 6 studies)

Subareas identified: effects of PAE on general eating behaviors, nutrient intake in children with FASD and the opportunity for dietary intervention to improve outcomes, and sex-specific effects of PAE on BMI and obesity prevalence.

Caregivers reported disrupted eating behaviors among children with FASD, including increased rates of oral aversion, food refusal, challenges using cutlery, not feeling full, poor appetite, and self-regulation (Amos-Kroohs et al., 2016). Children with FASD were reported to be "picky" eaters, which may affect nutrient density of their food intake (Nguyen et al., 2016; Werts et al., 2014). Accordingly, 50%–100% of children with FASD often did not meet the recommended daily intake for several nutrients and minerals (Werts et al., 2014). Males with FASD were more likely to experience hyperphagia (i.e., excessive eating) without weight gain (Amos-Kroohs et al., 2016) and lower obesity prevalence (Werts et al., 2014), while females with FASD were more likely to experience overweight or obesity (Hayes et al., 2021; Werts et al., 2014). Finally, children and adolescents with partial FAS reported the highest prevalence of overweight/obesity, while FAS was associated with being underweight (Fuglestad et al., 2014).

Strengths, interests, and external resources (*n* = 5 studies)

Subareas identified: personal (internal strengths), personal (internal) interests and external supports (i.e., supportive environmental factors), and connection to culture.

Strengths of individuals with FASD included strong self-awareness, receptiveness to support, capacity for human connection, perseverance through challenges/positive efforts/persistence or resilience, willingness to change, social motivation, individual aptitudes and skills, positive mood states and personality characteristics, and hopes for the future (Flannigan, Wrath, et al., 2021; Kautz-Turnbull et al., 2022; Pei et al., 2016). A survey of 30 caregivers of children with FASD reported the four most common positive influences of their child on the family were that they: (1) tangibly contributed to the family (e.g., through assisting with household tasks), (2) provoked parental and personal growth (e.g., introducing caregivers to new experiences), (3) brought about social and/or family togetherness (e.g., increased time spent together, a sense of unity as a family), and (4) emotionally contributed to the family (i.e., showing affection and bringing joy/happiness into the home; Kautz-Turnbull et al., 2022). By leaning on external supports and resources, embracing assistance provided by caregivers and friends, and incorporating talents and interests into activities, individuals with FASD are better equipped to perform challenging activities (Skorka et al., 2022). The importance of having a unique identity was evident through interviews with young people with FASD, as it provided them with the opportunity to showcase their personality, characteristics, values, and strengths (Skorka et al., 2022). A qualitative study by Hamilton, Maslen, Watkins, et al. (2020) described how First Nations young people found happiness through their culture and had a range of specific interests associated with this that could be fostered to further support their wellbeing.

Incontinence (*n* = 3 studies)

Subareas identified: urinary incontinence, fecal incontinence, and nocturnal enuresis.

Individuals with FASD aged 6–25 years experienced higher rates of incontinence (20%–32%) compared to nonalcohol exposed individuals (<1%–14.3%; Reid et al., 2021; Roozen et al., 2017, 2020). Nocturnal enuresis was also reported in two studies, affecting 9.9%–16.2% of individuals with FASD (Roozen et al., 2017, 2020).

DISCUSSION

The intention of this scoping review was to identify broader factors outside the components of the diagnostic criteria that could be considered as part of a holistic assessment process when considering FASD as one possible outcome. Overall, the available literature highlighted that people with FASD can experience a wide range of complex individual, family, and system level factors, which can impact their health and wellbeing. The most researched areas were physical health problems, sleep problems, ACEs, and engagement in risky AOD use and other risk behaviors.

From a system-level perspective, studies noted high levels of involvement with OOHC and justice systems, which was magnified for individuals from First Nations backgrounds. First Nations peoples experience ongoing systemic racial discrimination, which has led to significant overrepresentation in child welfare and justice systems. For example, in child protection systems, systematic racism manifests through the privileging of colonial perceptions of superiority, western ways of parenting and norms of what 'family' is. These negative assumptions have contributed to the oppression of the rights of First Nations people to culture and to raise their own children (Choate & Tortorelli, 2022). In contemporary times in Australia, there continues to be poor compliance with the First Nations Child Placement Principle within child protection, resulting in more First Nations children not being placed in kinship care arrangements (Krakouer et al., 2018). Cultural connections and developing a strong cultural identity was found to reduce recidivism and improve health and wellbeing (Rogers et al., 2013). Thus, gathering and prioritizing information about a person's culture and identity should be considered a critical component of a holistic assessment approach (Hewlett et al., 2023). This is also fundamental to the development of recommendations and support plans for all Australians, especially First Nations peoples and those from culturally and linguistically diverse backgrounds.

Evidence summarized in the current review also highlighted the high level and variability of mental health challenges individuals with FASD can experience. This brings attention to the inconsistencies in how mental health challenges are included or conceptualized as part of current FASD diagnostic criteria. The Australian Guide, which is based on Canadian diagnostic criteria, requires diagnosis of a psychiatric condition (i.e., anxiety or depression) to meet criteria for 'affect regulation' impairments, whereas other criteria consider the presence of self-regulation (Kable et al., 2016), or mood/behavioral regulation impairments (Astley, 2013; Hoyme et al., 2016). The wide range of mental health challenges documented in the current scoping review (i.e., including suicidal ideation and attempts) supports a more generalized conceptualization of self-regulation impairments than the current Australian Guide. Requiring individuals to meet strict diagnostic criteria for anxiety and depression is likely to limit understanding of the self-regulatory challenges experienced by individuals with FASD (Reid & Petrenko, 2018). Several external and personal factors were identified to be associated with mental health challenges for individuals with FASD. Further understanding of external and personal factors that place people at increased risk of mental health challenges, including suicide, and interplay of these factors for individuals with FASD is critical. Awareness and inclusion of these factors in a holistic assessment approach offers clinicians an opportunity to implement tailored supports to improve long-term mental health and wellbeing for individuals with FASD.

Current diagnostic criteria, including the Australian Guide, include assessment of SFFs, but also highlight the need for the collection of information on other dysmorphic features and major birth defects affecting the cardiac, renal, ocular, auditory, and skeletal systems (Chudley et al., 2005; Leibson et al., 2014; O'Leary et al., 2010). In line with current recommendations, this scoping review identified a high prevalence and wide range of physical health conditions. Therefore, interprofessional assessment should continue to include consideration of all physical health conditions. This scoping review also found that reproductive (Akison, Moritz, & Reid, 2019), immune (Reid et al., 2019), and metabolic health (Akison, Reid, et al., 2019; Amos-Kroohs et al., 2016; Fuglestad et al., 2014; Hayes et al., 2021; Kable et al., 2021; Werts et al., 2014) may also be affected in individuals with FASD. However, further research is required to characterize the extent to which these systems may be affected by PAE.

Detrimental eating behaviors and poor nutrient intake has potential to compound poor metabolic outcomes for individuals with FASD. Improving nutrition may provide a window of opportunity during childhood to support various physical health concerns some individuals with FASD can experience. Gathering information regarding food intake and eating behaviors as part of a holistic assessment process could, therefore, inform recommendations and dietetic referrals to support individuals with FASD to achieve recommended daily intakes of key nutrients and optimize health and well-being. Additionally, the association of FASD with urinary and fecal incontinence issues were found to affect quality of life (Reid et al., 2021, Roozen et al., 2017, 2020). Currently, the Guide does not consider incontinence issues. Overall, the current findings support wider consideration of physical health, feeding/eating behaviors, and toileting as part of a holistic assessment processes.

Finally, several studies identified disrupted sleep and challenging nighttime behaviors in children with FASD (Alvik et al., 2011; Chandler-Mather et al., 2021; Chen et al., 2012; Dylag et al., 2021; Goril et al., 2016; Hayes et al., 2020; Mughal et al., 2021; Mughal, Hill, et al., 2020; Mughal, Joyce, et al., 2020; Skorka et al., 2022; Spruyt et al., 2016; Troese et al., 2008; Wengel et al., 2011). As behavioral concerns are associated with sleep problems (Hayes et al., 2020), early interventions targeted toward improving sleep outcomes should be a therapeutic priority as it may lead to improvements in cognitive outcomes (Mughal, Hill, et al., 2020; Mughal, Joyce, et al., 2020). Some interventions proposed included a clinical health assessment (Chen et al., 2012), a multidisciplinary evaluation of the child's sleep, including an occupational therapy evaluation of sensory processing (Fjeldsted & Hanlon-Dearman, 2009; Wengel et al., 2011) and improving sleep awareness and educational initiatives for caregivers (Spruyt et al., 2016). Consequently, gathering information regarding sleep problems during the assessment and diagnostic process could help inform targeted supports to improve both sleep and daytime functioning for individuals with FASD.

Recommendations for future research and practice

Several key areas of interest were identified that impact health and wellbeing for individuals with FASD. The findings emphasize the importance of assessing broader individual, family, and system level factors as part of a holistic assessment process when considering FASD as one possible outcome. There are multiple areas that could benefit from future research attention. While there was a relatively large amount of research documenting the wide range of physical health concerns individuals with PAE/FASD may experience, future research could further elucidate the prevalence of physical health challenges and determine how to support early identification of health problems in this population. Importantly, this was identified as a key area in need of future research by adults with FASD, who have strongly advocated for FASD to be considered as a 'whole-body diagnosis' (Himmelreich et al., 2020).

A key area impacting on the long-term health and wellbeing of individuals with FASD was mental health/self-regulation challenges. Further research is required to understand the best way to conceptualize these challenges for assessment and diagnostic purposes. Additionally, future research is urgently needed to effectively adapt standard psychological treatments for individuals with FASD (Flannigan et al., 2020), increase dissemination and implementation of current FASD specific self-regulation focused interventions and explore the development of targeted interventions for adolescents and adults with FASD (Reid et al., 2015). It should be noted, only a small proportion of included studies focused on long-term outcomes in adults with FASD, suggesting this is currently an understudied area. Future research is needed to support the development of effective assessment and diagnostic approaches for adults with PAE.

Results from this review highlighted the available body of research exploring ACEs and other postnatal environmental factors within the context of PAE. Studies have only recently started to explore differences between individuals who have experienced PAE in isolation or in combination with adverse postnatal experiences. Historically, PAE literature lacked consideration of adverse postnatal experiences, but this is also true of the ACEs literature, which lacked consideration of PAE as a confounding variable when examining developmental outcomes. Future research is needed to better understand the differential impacts and interplay between ACEs and PAE and the most effective ways to assess and support individuals with co-occurring ACEs and PAE.

Australia is a diverse nation that needs to include cultural considerations in the assessment and diagnosis of FASD if the support needs for First Nations peoples and other Australians are to be met. Results from this review only skimmed the surface on the links between strengths of cultural connections, self-identity and health and wellbeing. Further research should focus on the specifics of what information should be collected as part of the assessment process, and the most appropriate ways to collect this information to effectively inform holistic assessments for First Nations peoples (Hewlett et al., 2023). Understanding what culture-centered assessment and diagnostic processes look like will increase cultural responsiveness and contribute to improved outcomes for First Nations people with FASD. Further, while the current review identified several studies that had focused on cultural considerations for First Nations peoples, no studies were identified that focused on other marginalized groups of people. Nor was intersectionality considered, that is, how a person's multiple identities (e.g., gender, sexuality, race) can interact to lead to unique patterns of oppression (Bowleg, 2012; Crenshaw, 1991). Future research is needed to investigate the experiences of a wider range of people from differing and intersecting marginalized groups to understand how assessment and diagnostic services can be specifically tailored to meet people's unique needs.

Notably, there is need worldwide for increased availability of assessment and FASD diagnostic services. Given the limited clinical capacity it can be challenging to meet the needs for individuals with PAE/FASD. Consequently, adding additional assessment areas to an already complex assessment process may seem overwhelming for clinicians and services. Personalized collaborative goal setting is one approach that can support clinicians to apply a holistic approach to assessment based on individual strengths and needs. This can involve collecting information regarding child and family strengths and needs across a wide range of areas using standardized or locally developed and culturally informed goal setting tools (Reid et al., 2022).

To the authors' knowledge there is no research currently available that explores the extent to which assessment and diagnostic practices include the holistic factors identified in the current review. While we posit that the inclusion of these wider holistic factors should lead to improved long-term outcomes for individuals with FASD, no research has yet been undertaken to explore holistic approaches to assessment and diagnosis of FASD. Future research could seek to understand the extent to which clinicians take these factors into consideration as part of assessment and diagnostic processes, how/if awareness of these factors influence treatment/support, and whether these personalized adaptations to treatment/support are associated with better health and wellbeing outcomes compared to treatment as usual.

Strengths and limitations

The current scoping review has provided a comprehensive overview of a large number of studies across a diverse range of areas relating to PAE/FASD. The significant diversity of outcomes within key study areas currently limits the ability for quantitative synthesis to be undertaken. As research increases across these key areas there may be more prominent, shared outcomes and measures that can inform more robust GRADE-based recommendations for future revisions of the Australian Guide for diagnosis of FASD. The current review was limited to peer-reviewed research studies, which means that other types of clinical publications and gray literature were excluded. Future research could focus on specific subareas of the current review, which could enable the inclusion of a wider range of literature types. The Australian literature on FASD is constantly evolving, particularly with regards to First Nations peoples and culturally responsive research approaches. As research approaches further integrate Western and Indigenous methodologies (Sharmil et al., 2021), future studies will undoubtedly expand our understanding of cultural considerations.

CONCLUSIONS

This scoping review provides evidence that a range of individual, family and system-level factors could be considered in assessment processes for FASD. This could inform more tailored and holistic recommendations leading to more effective ongoing treatments and supports for individuals with FASD and their families. Results highlighted that early diagnosis, interprofessional supports, and adapted approaches to learning for individuals with FASD have potential to improve long-term outcomes. Findings of the current review can be utilized to continue to improve assessment, diagnostic and support practices, and inform future policy and resourcing decisions regarding service design and delivery.

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CONFLICT OF INTEREST STATEMENT

Authors have no conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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