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The prevalence of fetal alcohol spectrum disorder in South Africa: A study in a Free State Province community

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Background. South Africa (SA) has the highest reported prevalence of fetal alcohol spectrum disorders (FASDs) globally, estimated at 111.1/1 000 (95% confidence interval (CI) 71.1 - 158.4) or 11.11%, but rates as high as 276.2/1 000 (95% CI 215.3 - 337.1; 27.62%) and 310/1 000 (95% CI 283.4 - 336.7; 31%) have been reported. There are still four provinces with no published prevalence for FASDs. At the time of the present study, only one study had been conducted in a Free State Province community.
Objectives. To establish the prevalence of FASDs in a rural town in Kopanong Local Municipality in the Free State.
Methods. This was a cross-sectional epidemiological study using active case ascertainment. A tiered recruitment and screening process was used for FASDs. Three schools were included in the study, and 122 children were invited to participate. Prevalence figures were calculated using two denominators, eligible participants and consented participants. Demographic data and anthropometric measurements were compared between FASD cases and controls. Maternal demographic, anthropometric and alcohol use data were also compared between FASD cases and controls.
Results. In total, 119 participants consented to the study, with 106 given a primary healthcare and anthropometric screening. Of these, 80 received a paediatric and dysmorphology examination, of whom 64 were referred for maternal interviews and neurodevelopmental assessments. After a case conference, 22 were diagnosed with an FASD. Of 46 controls, 29 were unaffected and 17 were diagnosed with an FASD. Using all eligible participants as denominator, the prevalence was 180/1 000 (95% CI 117 - 260) or 18.0%, and using all consented participants, it was 185/1 000 (95% CI 120 - 266) or 18.5%. Of the 106 recruited participants, 48 were male and 58 female. The mean (standard deviation) age of participants was 7.55 (0.56) years, with diagnosed participants 7.75 (0.69) years old on average, and controls 7.52 (0.54) years old. Mothers of children diagnosed with an FASD differed significantly from mothers of controls on maternal weight (p=0.038, 95% CI –26.58 - –0.795 kg), household income (p=0.036, 95% CI –11 523.861 - –411.139 ZAR), standard drinks consumed on one occasion before pregnancy (p<0.001, 95% CI 2.718 - 6.546), and educational attainment (median Grade 8 v. Grade 12, p=0.001). Maternal age at the birth of the participants, body mass index and standard drinks per week were not significantly different.
Conclusion. This study adds to existing research identifying SA as the country with the world's highest reported prevalence of FASDs. It was the second study in the Free State and should highlight the need for expanded services, surveillance and research in this province.

Keywords: fetal alcohol spectrum disorder, prenatal alcohol use, FASD, prevalence, South Africa, maternal alcohol use

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South Africa (SA) has the highest reported prevalence of fetal alcohol spectrum disorders (FASDs) globally.[1,2] The prevalence has been estimated by meta-analysis at 111.1/1 000 (95% confidence interval (CI) 71.1 - 158.4; 11.11%).[2] Rates as high as 276.2/1 000 (95% CI 215.3 - 337.1; 27.62%) in Northern Cape Province[3] and 310/1 000 (95% CI 283.4 - 336.7; 31%) in Western Cape Province[4] have been reported, compared with the estimated global prevalence of 7.7/1 000 (95% CI 4.9 - 11.7; 0.77%).[2] While epidemiological research on FASDs has been ongoing since the first study in 1997,[5] to the authors' knowledge these studies have only been conducted in five of SA's nine provinces.

There have been multiple studies in the Western Cape,[5-14] Eastern Cape[3,7] and Northern Cape provinces.[3,7,15-17] At the time of the present study, one study each had been reported in Gauteng[18] and Free State provinces.[3]

To establish a reliable national prevalence of FASDs, it is important to conduct prevalence studies in those provinces where no studies have been done. Additional studies in Gauteng and Free State communities are needed, as a single study cannot be generalised to an entire province. In Gauteng there is a reported prevalence of 26.5/1 000 (95% CI 11.8 - 41.7; 2.65%),[18] and in the Free State a rate of 126.2 /1 000 (95% CI,86.1 - 166.4; 12.62%).[3]

The primary objective of the present study was to establish the prevalence of FASDs in a rural town in Kopanong Local Municipality in Free State Province. This was the second prevalence study conducted in the Xhariep District Municipality. The previous study was in Letsemeng Local Municipality. Secondary objectives included comparing mothers of children diagnosed with an FASD with those of randomly selected controls in terms of demographic and household characteristics, and comparing children diagnosed with an FASD with controls, based on anthropometric and physical characteristics.

Methods

Study design

This was a cross-sectional epidemiological study using active case ascertainment. As in previous epidemiological studies on FASDs in SA, case ascertainment was done in the context of primary schools where a tiered diagnostic process was followed. The study site was identified in consultation with local and provincial government departments, funding organisations and civil society.

Setting

The town in which the study was conducted is in the Kopanong Local Municipality in the Free State. It is a rural town situated off the N1 national highway, which runs through SA. All three primary schools in the town were invited to participate in the study.

Participants and recruitment

After obtaining ethical approval from Stellenbosch University (Health Research Ethics Committee ref. no. N13/01/008) as well as approval from the provincial Department of Education and the local primary schools, the parents of all Grade 1 learners were invited to have their children participate in the study. Informed consent was obtained from the parents or caregivers of all participants, after which a control group was randomly selected from the list of consented participants. A random number generator was used to select from the alphabetical class lists.

Inclusion criteria

To be eligible for participation, children had to be enrolled in Grade 1 at any of the participating primary schools. Children repeating Grade 1 at the time of the study were also allowed to participate.

Exclusion criteria

There were no exclusions. If a participating child could not be reached during any part of the study, they were categorised as lost to follow-up after three attempts to contact the family. Parents or caregivers were also free to withdraw consent at any point during the study.

Screening and diagnosis

A tiered recruitment and screening process was used for FASDs (see Fig. 1 for overview). In the first tier, all children participating in the study underwent anthropometric screening focusing on their height, weight and occipitofrontal circumference (OFC). If participants screened positive in this tier, they were further examined for physical and dysmorphic features associated with FASDs. If the participants screened positive for features of an FASD, they were referred for neurodevelopmental assessment and a maternal interview took place. This study used the Institute of Medicine (IOM) criteria for diagnosing FASDs,[19] following the guidelines set out by Hoyme *et al.*[20] as described in Viljoen *et al.*[21] There were four diagnostic labels for children with an FASD, namely fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related birth defect (ARBD), and alcohol-related neurodevelopmental disorder (ARND).

Anthropometric screening

Participants' height for age, weight for age[22] and OFC[23] were compared with the relevant growth charts for the USA. According to the criteria described by Viljoen *et al.*,[21] a participant screened positive if their height and weight were less than or equal to the 10th centile, or their OFC was less than or equal to the 10th centile, or both. In this study, the anthropometric screening criteria were changed to be in line with the Hoyme *et al.*[20] guidelines. A participant screened positive if one or more of their height, weight and OFC were less than or equal to the 10th centile.

The screening was conducted by registered nurses who also screened for additional health concerns. If any were identified, participants were referred to the local primary healthcare clinic for follow-up of minor concerns. In the case of uncertainty or serious health concerns, participants were flagged for further examination by the clinicians in tier 2, regardless of anthropometric measurements. All participants in the control group were advanced to tier 2, regardless of anthropometric measurements.

Dysmorphology and paediatric examination

During the dysmorphology and paediatric examination, clinicians looked for features associated with FASDs and scored them on a weighted list. Features that are strongly associated with prenatal alcohol exposure, such as a thin vermilion border, were scored 3. Features with a less strong association, such as clinodactyly, were scored 1. In addition, clinicians looked for the facial gestalt associated with FASDs.[19] Both the weighted scores and gestalt are discussed in detail in the article by Viljoen *et al.*[21] The Viljoen *et al.*[21] criteria differ from the 2016 version of the Hoyme *et al.*[20] criteria, specifically in terms of the weight assigned to specific dysmorphic features, as well as the inclusion of the gestalt to inform the final diagnosis.

All participants with a weighted score ≥11, or presenting with an FASD gestalt, were referred for neurodevelopmental assessment, and a maternal interview was carried out. In addition to screening for FASDs, a brief paediatric examination was also conducted on all participants referred to tier 2. All participants in the control group were advanced to tier 3, regardless of the outcome of the examination. Any health concerns were referred to primary healthcare clinics, social workers or specialist follow-up, as necessary.

Neurodevelopmental assessment

All participants advancing to tier 3 received neurodevelopmental assessments using the NEPSY-II.[24] The domains assessed included fine motor skills, memory and learning, language, visual perception, attention and executive functioning. The NEPSY-II has been extensively used in FASD research.[25-27] It has also been used in SA populations,[28,29] but there are no norms for SA populations, and the results are therefore interpreted with caution. Assessors were blinded to the outcomes of tier 2 and whether participants were in the control group.

Maternal interview

The structured interview used in this study was specifically developed for FASD epidemiological studies and has been extensively used in previous studies.[3,7,15] Questions cover demographic and social variables, information on previous pregnancies, and questions regarding alcohol, tobacco and other drug use. Self-reported alcohol, tobacco and other drug use was estimated for the time of pregnancy only. For alcohol use, a timeline follow-back method was used, in addition to a question on the extent of one recollected instance of alcohol use before pregnancy. Interviews were conducted with biological mothers by trained community workers, in one-on-one sessions. Where biological mothers could not be reached, a suitable proxy (father, caregiver, relative or foster parent) was interviewed. Interviewers were blinded to the outcomes of tier 2 and whether participants were in the control group. Community workers were recruited from the local community, and received extensive interview training.

Diagnosis

After all participants had progressed through all three tiers, a multidisciplinary case conference was held to discuss each case with the clinician making the final diagnosis after considering input based on feedback from the maternal interviewer and an overview of the neurodevelopmental assessments. Diagnoses were made according to the IOM criteria[19] as described in Viljoen *et al.*[21] The clinical team, including the clinicians, was blinded to whether participants were in the control group during the case conference. For final analysis, participants diagnosed with an FASD were removed from the control group and included in the diagnosed group.

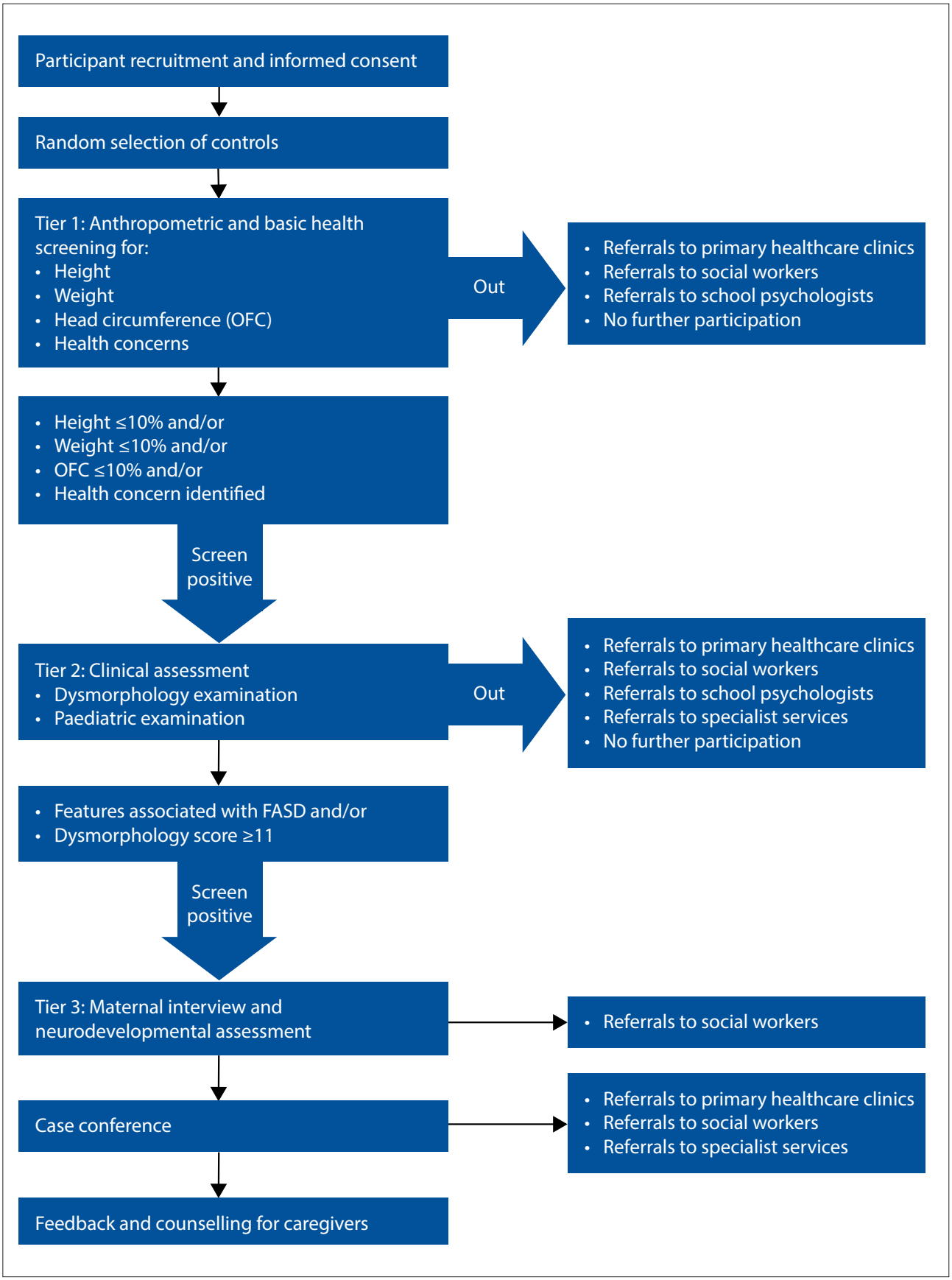

Fig. 1. Overview of recruitment and screening. (OFC = occipitofrontal circumference; FASD = fetal alcohol spectrum disorder.)

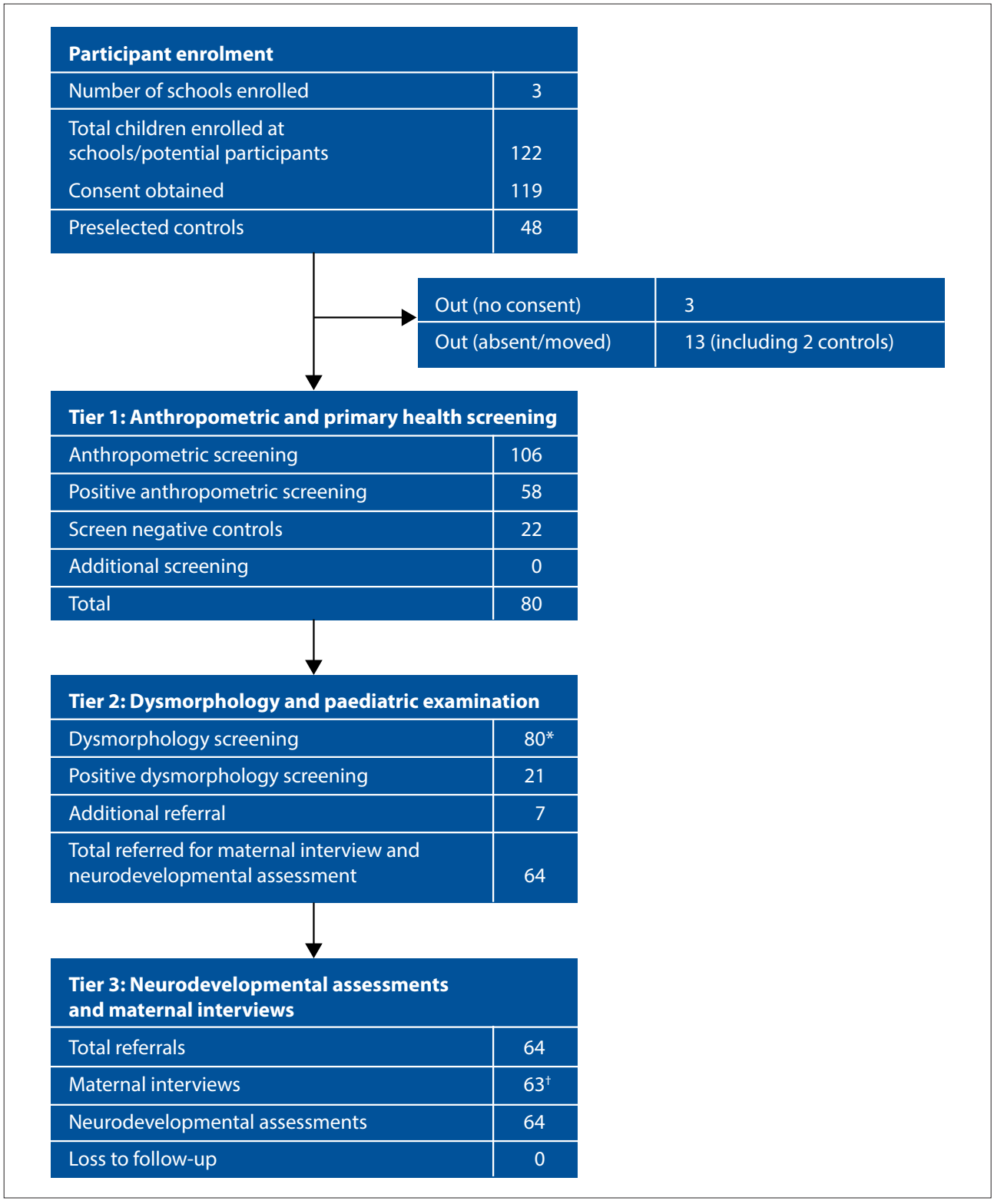

*Fig. 2. Participant flow diagram. (*No loss to follow-up as both screenings conducted on the same day; †One referral for twins.)*

Prevalence calculation

To determine the prevalence of FASDs in the community, cases per 1 000 were calculated with two different denominators. Total cases of FASDs were divided by the total number of consented participants, with the 13 participants who were absent, or had moved from the area, included. To estimate the lower bound prevalence, the total number of eligible participants, based on the initial class list from the schools, was used as the denominator with the assumption that none of them would have received a diagnosis of an FASD.

Feedback and counselling

Once diagnoses were made, all parents or caregivers of children participating in the study received feedback on the outcome. Parents of children who were not discussed at the case conference were

Table 1. Demographic and anthropometric comparisons of participants diagnosed with an FASD and controls

	FASD, *n*=22 (12 female, 10 male)	Control, *n*=29 (14 female, 15 male)	*p*-value (95% CI where applicable)
Participant age (years), mean (SD)	7.75 (0.69)	7.52 (0.54)	0.189 (–0.116 - 0.573)†
Participant BMI, mean (SD)	14.75 (1.44)	15.28 (2.37)	0.36 (–1.68 - 0.621)†
Participant dysmorphology score,¶ mean (SD)	8.18 (6.17)	5.31 (3.27)	0.057 (–0.088 - 5.831)‡
Mother age at birth of child (years),‖ mean (SD)	26.44 (4.92)	28.89 (6.65)	0.216 (–6.387 - 1.492)†
Mother weight (kg),‖,* mean (SD)	68.05 (18.15)	81.74 (20.70)	0.038 (–26.58 - –0.795)†
Mother BMI,‖ mean (SD)	27.11 (7.59)	31.27 (7.20)	0.091 (–9.015 - 0.692)†
Household income (ZAR per month),‖,* mean (SD)	4 132.50 (3 135.77)	10 100 (10 612.94)	0.036 (–11 523.861 - –411.139)‡
Mother standard drinks per week (during pregnancy),‖ mean (SD)	6.47 (4)	4.33 (3.16)	0.068 (–0.166 - 4.428)†
Mother standard drinks on one occasion (before pregnancy),‖,** mean (SD)	7.26 (3.03)	2.63 (2.86)	<0.001 (2.718 - 6.546)†
Participant height centile,††,* median	11th - 25th	26th - 50th	0.049§
Participant weight centile,†† median	11th - 25th	26th - 50th	0.160§
Participant head circumference (OFC) centile,‡‡ median	11th - 25th	26th – 50th	0.052§
Mother educational attainment,‖,** median (IQR)	Grade 8 (4.25)	Grade 12 (1.5)	0.001§

FASD = fetal alcohol spectrum disorder; CI = confidence interval; SD = standard deviation; OFC = occipitofrontal circumference; IQR = interquartile range; BMI = body mass index.
*$p<0.05$, **$p<0.001$.
†Student's *t*-test.
‡Welch's *t*-test conducted owing to unequal variance.
§Mann-Whitney *U* test.
¶Maximum score of 50.
‖Interviews with biological mothers only (*n*=40).
††Kuczmarski *et al.*[22]
‡‡Rollins *et al.*[23]

given feedback by letter, and if there were any minor health concerns they received an additional copy of the referral letter. Caregivers of children diagnosed with an FASD, a severe developmental delay or a serious medical condition received one-on-one feedback. During the feedback sessions, any diagnoses were discussed and basic recommendations to support the child were shared. Where serious health concerns were identified, those giving feedback would confirm whether any action had been taken, and if not, encourage the caregiver to follow up with the local clinic or specialist.

During the feedback sessions, informed consent was sought to share any diagnosis with the child's local primary school. These diagnoses could support the school in accommodating the child. Even if consent was obtained, schools were only given diagnoses if one or more of their foundation-phase educators attended training on managing FASDs in the classroom provided by author JGL.

Ethical considerations

Ethical approval was obtained from Stellenbosch University (Health Research Ethics Committee ref. no. N13/01/008). The potential risks identified for this study were parental distress and stigmatisation of the participants and their parents or caregivers. Project staff providing the feedback to parents were trained to give support to parents or caregivers upon sharing the diagnoses. There were also referral pathways in place with the local departments of social development and health, should additional support be required. To prevent stigmatisation, it was emphasised from the outset that the study was not only looking for FASDs and that there were control participants. Educators, parents and government departments were all sensitised to the risks of stigmatisation.

Participant incentives

There were no incentives given to participate. If a mother, or a proxy, was invited to participate in a maternal or proxy interview, they were compensated for their time by means of a voucher to be used at a local supermarket. The value was ZAR80.00 (USD5.29 at the time of the study). As there are limited healthcare resources in the area, the opportunity to have a child undergo a paediatric examination may have served as an incentive.

Data storage and analysis

Data were captured and managed using the REDCap (Research Electronic Data Capture) tool.[30] Descriptive and comparative analyses were conducting using JASP version 0.19.3 (JASP Team, 2024).[31] Prevalence figures were calculated using two denominators: (*i*) all children enrolled at participating schools at the start of the study (eligible participants); and (*ii*) all participants included in the study (consented participants). Demographic data and anthropometric measurements were compared between FASD cases and controls. Maternal demographic, anthropometric and alcohol use data were also compared between FASD cases and controls, only for those mothers who could be personally interviewed. Data gathered by proxy were excluded from these analyses.

Results

There were 122 children enrolled in the three primary schools, and consent was obtained for 119 (97.5%). A group of 48 controls were randomly selected from the class lists. At the time of assessment, 13 participants were absent, of whom 2 were preselected controls. The mean (standard deviation) age of participants was 7.55 (0.56) years, and 48 participants were males and 58 females. As tier 1 and 2 assessments were conducted on the same day, there was no further loss to follow-up. There was also no loss to follow-up in tier 3 (see Fig. 2 for participant flow).

Of 63 referrals for maternal interviews, 15 had to be conducted with a proxy because the mother was not available. All proxies were judged to be able to give accurate information on whether alcohol use was present, as all were family, extended family or close friends of the mothers.

After discussing the 64 cases at a case conference, 22 were diagnosed with an FASD. One was diagnosed with FAS, 3 with pFAS,

and 18 with ARND. Additionally, 10 participants were diagnosed with neurodevelopmental delays. In the control group, 17 participants were diagnosed with an FASD, leaving 29 unaffected controls. Two prevalence figures were calculated. Using all eligible participants as denominator, the prevalence was 180/1 000 (95% CI 117 - 260; 18.0%), and using all consented participants, it was 185/1 000 (95% CI 120 - 266; 18.5%). Additional referrals included 41 referrals for oral health, 27 for occupational therapy, 12 for a school psychologist evaluation, and 2 to social workers.

The FASDs diagnosed case group was similar to the control group in terms of age and gender. The median centile for anthropometric measurements was lower for height, weight and head circumference, with cases in the 11th to 25th percentile and controls in the 26th to 50th. Only the difference in height was statistically significant (p=0.049). The difference in FASDs dysmorphology score, calculated based on clinical examination, was also non-significant (p=0.057). The scores were compared using Welch's t-test, as the assumption of equal variance was violated. See Table 1 for details.

There were no significant differences between the ages of mothers of cases and controls at the time of the child's birth (p=0.216). The average age at the birth of their child was 26.44 years for mothers of cases, with a minimum age of 16.37 years and a maximum of 34.9. Mothers of controls were on average 28.89 years old, with a minimum of 18.01 years and a maximum of 39.44 at the birth of their child. There was a significant difference in weight (p=0.038) at the time of interview, with mothers of diagnosed children weighing less on average. However, there was no significant difference in body mass index (p=0.91). See Table 1 for details.

The mothers of children diagnosed with FASDs differed significantly from controls in educational attainment (p=0.001), with mothers of controls having reached a median of grade 12 and mothers of diagnosed children grade 8. There was also a significant difference in household income between the groups (p=0.017), with households of children diagnosed with an FASD having a lower income.

Alcohol exposure during pregnancy, based on self-report, was significant in terms of an estimate of the amount consumed on one occasion before pregnancy (p<0.001), but not when calculated using a timeline follow-back for an entire week during pregnancy (p=0.068). All mothers of cases reported alcohol use on one occasion, with a minimum of 3.3 standard drinks, while 9 mothers of controls reported no alcohol use. There were 3 mothers of cases, and 5 mothers of controls, who reported no alcohol use in the timeline follow-back report. Mothers of children diagnosed with an FASD reported 7.26 standard drinks on one occasion, and 6.47 standard drinks during a week, while mothers of controls reported 2.63 standard drinks on a single occasion and 4.33 over a week. See Table 1 for details.

Discussion

The 180/1 000 lower bound estimate of FASDs prevalence, using all eligible participants as denominator, is significantly higher than the estimated global prevalence of 7.7/1 000 (95% CI 4.9 - 11.7; 0.77%) and the estimated SA national prevalence of 111.1/1 000 (95% CI 71.1 - 158.4; 11.11%).[2] It is also higher than the upper bound prevalence of 128.8/1 000 (95% CI 87.9 - 169.8; 12.88%) in the Letsemeng Local Municipality, the only other FASDs prevalence available for the Free State.[3] Of note is the 18 diagnoses of ARND compared with 1 of FAS and 3 of pFAS, which is unusual when compared with other recent prevalence studies with more restrictive inclusion criteria,[3] and more in line with studies with oversampling.[11] The high number of ARND diagnoses could be due to differences in method between the present study and the previous study in the Free State,[3] as well as the number of initially selected controls who received diagnoses regardless of initial anthropometric screening.

The preponderance of ARND diagnoses could account for the lack of statistical significance of the anthropometric measurements and dysmorphology scores of cases and controls. The differences in dysmorphology scores cannot be directly compared with other recent studies owing to the difference in weighting of the features.[20,21] However, maxillary and mandibular arcs, as well as outer canthal distance, have been shown to discriminate between ARND and controls in recent studies.[4,11] These were not measured in this study, which is a missed opportunity.

As this study relaxed the screening criteria to be more in line with the Hoyme *et al.*[20] criteria and subsequently reported a significant number of children with ARND, it supports the use of less restrictive screening measures such as the Hoyme *et al.*[20] criteria. To enable comparison, it is crucial that clinicians work towards consensus on national diagnostic criteria. Where weighting of dysmorphic features is used, it is important that the weights are also standardised to enable comparison.

The previously identified maternal risk factor of maternal size[4] was only partly supported in this population, with maternal weight lower, but maternal BMI not significantly different. This finding could again be due to the preponderance of ARND diagnoses, although a recent study found that mothers of children with ARND also differed significantly from mothers of controls in terms of BMI.[11] The lower household income and educational attainment of mothers of cases indicated lower socioeconomic status (SES), also in line with previous studies.[4,14] However, there was significant variance in the control group in terms of household income.

In terms of maternal characteristics, of particular interest are the results of the analyses of drinking before pregnancy, using recall of one occasion and the timeline follow-back method. These responses are not used on their own to determine alcohol use during pregnancy, but are rather used to help mothers identify whether some of that alcohol use may have occurred during pregnancy (due to late recognition), and a mother has to confirm alcohol use during pregnancy afterwards. The only time this is not explicitly required is for a diagnosis of FAS, provided that all other clinical features are present.[20,21]

The difference in measures may be due to mothers recalling different events or time periods. They may generally not have used alcohol, and/or only used alcohol on special occasions. There may also have been occasions where their alcohol use exceeded their norm, and this event may be reported when referring to one instance. It is beyond the scope of this article to examine this in detail, but future research comparing similar questions would be valuable, especially as one instance of alcohol use can have a harmful impact on the fetus.

There were a number of referrals to other services. There were 41 referrals for oral health, 27 for occupational therapy, 12 for a school psychologist evaluation, and 2 to social workers. This finding is a matter of concern, and it indicates that primary healthcare screening is required in the community. As only children with significant developmental delays were referred to school psychologists, the question arises why their delays were not identified earlier by parents, caregivers and educators. There is obviously a sizeable gap between the services available in the area and the services required.

Even with oversampling in FASDs prevalence studies, using the Hoyme *et al.*[20] criteria it is likely that an indeterminate number of children with ARND will be lost during the screening and diagnostic process. The controls diagnosed with ARND would have been excluded from the study in tier 1. For a true prevalence of FASDs it

may be necessary to start with either maternal interviews for alcohol exposure, or with neurodevelopmental screening. This is unlikely to be feasible in large-scale prevalence studies, but in communities like the one discussed here it could be possible. The current study's sample size remains too small for significant generalisation; however, it does suggest that the true prevalence of ARND is vastly underestimated even when oversampling.[4,11]

The biggest strength of this study is the use of active case ascertainment in identifying cases of FASDs in the community. It supports the findings of multiple previous similar studies in SA,[3-18] particularly in terms of the influence of maternal educational attainment and low SES on the risk of having a child with FASD. As with more recent studies, it also highlights the concern related to the undercounting of ARND.[3,4,11] While SA has the world's highest prevalence of FASDs, the school-based active case ascertainment studies conducted here,[3-18] including the present study, are at the forefront of FASD research and can serve as a template for countries where no prevalence figures are available.[1,2]

The main limitations of this study include the lack of appropriate norms for growth in SA communities in this age group, and reliance on international norms. Similarly, the NEPSY-II neurodevelopmental assessment, although widely used, does not have SA norms. Reliance on maternal self-report of alcohol use is also a limitation, as is relying on proxy reports where mothers are not available.

It was not possible to follow up on the additional healthcare referrals during the study. The study was followed by an antenatal care programme, implemented in the area by the Foundation for Alcohol Related Research, the organisation that conducted the present study. Project co-ordinators could therefore follow up on referrals at a later date.

Conclusion

This study adds to the existing research identifying SA as the country with the world's highest reported prevalence of FASDs. This was the second study in the Free State and should highlight the need for expanded services, surveillance and research in the province. This study has also shown that the prevalence of ARND, previously diagnosed less frequently, should be a major concern.

Data availability. The dataset is not available.

Declaration. None.

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Author contributions. Each author certifies that their contribution to this work meets the standards of the International Committee of Medical Journal Editors. JGL conducted the data analysis, wrote the first draft of the article and did the subsequent revisions. MB oversaw data collection and capturing, and curated the database. She also contributed to the first draft and revisions. DV was involved in the conceptualisation of the study, provided project leadership and was the primary investigator of the parent study. LO was involved in the conceptualisation of the study and contributed to the revisions of the article. She also provided project leadership and was the overall project manager for the study. All authors read and approved the final version of the article.

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AI contribution. No artificial intelligence-assisted technologies were used in the production of the submitted work.

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