ORIGINAL ARTICLE



Perspectives of Policymakers and Service Providers on Why Fetal Alcohol Spectrum Disorders Remain Unabated in South Africa: a Qualitative Study

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Abstract

Fetal alcohol spectrum disorder (FASD) remains one of the leading sources of non-genetic intellectual and developmental disabilities globally. South Africa (SA) could be considered to bear the greatest burden of FASD globally with the recorded prevalence of FASD ranging from 29 to 290 per 1000 live births. Despite several efforts to reduce the incidence and prevalence of FASD in SA, its incidence and prevalence remain high. In this study, we examined the factors behind the sustained high incidence and prevalence of FASD in SA. Using an exploratory qualitative design, we explored the perspectives and experiences of 10 policymakers and 65 service providers on why FASD remains unabated despite various efforts to address the problem in SA. Ten in-depth interviews were conducted with policymakers and nine focus group discussions were conducted with the service providers in the Western Cape Province of SA. Data were analyzed inductively using the thematic analysis approach and emerging themes were deductively classified using the ecological model. Our findings revealed several reasons for the sustained high prevalence and increasing incidence of FASD in SA. At the individual level, late antenatal booking, alcohol consumption during pregnancy, and socio-economic conditions of individuals were identified as relevant factors driving the FASD prevalence in SA. Inadequate support groups for women were reported at the interpersonal level. The widespread availability of illegal liquor stores and inadequate specialized prevention programs were reported as community-level challenges. At the institutional level, the reasons included inadequate training of professionals and inadequate collaboration between government departments. At the policy level, the absence of a specific policy addressing FASD constitutes a significant barrier to the unabated FASD. The study findings suggest a cascade effect within the different levels of the ecological model highlighting the need for a holistic and systemic approach to preventing FASD in SA. The design and implementation of holistic, human rights-based, and interdepartment policies and programs addressing the social determinants of FASD should be considered.

Keywords South Africa · FASD · Incidence · Prevalence · Policymakers · Service providers · Qualitative study · In-depth interview · Focus group discussion · Ecological model

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Fetal alcohol spectrum disorder (FASD) is the leading cause of developmental and intellectual disabilities constituting a lifelong disability. FASD includes fetal alcohol syndrome (FAS), partial (pFAS), alcohol birth-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD) (Cook et al., 2016). Although no evidence-based treatment option has yet been discovered, early and appropriate interventions have shown promising outcomes (Reid et al., 2015). Thus, there is a need to understand why the prevalence of FASD remains high to inform the implementation of evidence-based strategies for the prevention of FASD in South Africa (SA) (Olivier et al., 2016).

Alcohol consumption is a problem in SA, especially binge drinking (Vellios & Van Walbeek, 2017). In SA, high FASD prevalence has been linked to the "dop" system — a system in which farmers were paid either partly or in full using alcoholic beverages (London, 1999; McKinstry, 2005). Although this payment practice has been abolished, the lingering effects influence drinking patterns in SA (May et al., 2019). SA has an alcohol consumption rate of 11 liters per capita, which is one of the highest in the world among those who consume (WHO, 2014). The lifetime consumption of alcohol is 49% for men and 22% for women (Statistics South Africa, 2016). In SA, the reasons why men and women consume alcohol are similar — retaining social connection, coping mechanism for socioeconomic condition, and easy access to alcohol (Lesch and Studies RC-AJ of D and A, 2019; Setlalentoa et al., 2010). Women may additionally drink as a coping mechanism for domestic violence (Pitpitan et al., 2013) while men may drink to uphold social and cultural norms (symbol for superiority in status and authority) (Agenda, 2011).

While the global prevalence of FASD is estimated at 8 per 1000 among children and youths (Lange et al., 2017), the prevalence varies from one country to another. For example, in Canada, Popova et al. (2019) reported the prevalence of FASD to be 18.1 per 1000 among elementary school students. The prevalence of FASD was estimated to be 23 to 47 per 1000 in first-grade pupils in Italy (May et al., 2006), while in four communities of the USA, the prevalence was reported to be 11 to 50 per 1000 children (May et al., 2018). In Australia (secluded indigenous population), the prevalence was 194.4 per 1000 children (Fitzpatrick et al., 2017) and in Croatia, it was reported to be 40 per 1000 in elementary school children (Petković & Barišić, 2013).

The national prevalence of FASD in SA ranges from 29 to 290 per 1000 live birth in 2016 (Olivier et al., 2016). The prevalence varies from one province to another with the Western Cape province having the highest (196 to 276) per 1000 in first-grade pupils in 2017 (May et al., 2017). Although this prevalence in itself is exceedingly high, what is worrisome is the continuous increase in the prevalence of FASD from 2007 to 2017 in the province. The prevalence of FAS and pFAS in first-grade pupils in 2007, 2013, and 2017 was (68.0 and 89.2), (104.6 and 160.6), and (158.2 and 223.7) per 1000 pupils, respectively (May et al., 2007; May et al., 2013; May et al., 2017). Although these prevalence studies were conducted in different communities within the region within the period mentioned, these communities have similar characteristics. Therefore, it is appropriate to suggest there was an increase in the prevalence of FASD during this period.

Many prevalence studies have been conducted in South Africa to estimate FASD. However, most of the prevalence studies have been conducted in a unique population (subgroups of the general population). Also, when estimating the prevalence of FASD in some of the studies, wide ranges were reported (Olivier et al., 2016). In addition, the maternal interviews were not conducted immediately after birth (May et al., 2017). Therefore, caution should be exercised when comparing the prevalence estimate in South Africa with other countries. However, some of the studies reported that the prevalence of ARND is likely under-evaluated and under-estimated (May et al., 2017; Olivier et al., 2016).



The South African government at the national and provincial levels has acknowledged FASD as a priority birth defect (London leslie, 2015). Some of the national and provincial governments' policy documents contain clauses that are directly or indirectly focusing on the prevention of FASD (Adebiyi et al., 2019a). The current efforts by the South African government, non-profit organizations (NPOs), and researchers seem not to be yielding the needed results considering the trend in the prevalence of FASD reported above. The lack of observable impact could be attributed to the limited understanding of the social context of South African pregnant women (Kelly & Ward, 2018). In a study exploring the perspectives of South African women attending drinking venues, drinking during pregnancy is considered a social norm underpinned by the lack of attachment to the pregnancy, resistance to motherhood, and alcohol addiction (Watt et al., 2014). Other social factors such as easy access to alcohol and exposure to alcohol advertisements constitute FASD drivers (Amanuel et al., 2018).

Studies conducted in six European countries and Canada show that women who experience unintended pregnancy are more likely to drink alcohol during pregnancy (Lukasse et al., 2015; Sanders & Currie, 2014), which means the developing fetus might have been exposed before the pregnancy state is known. It has also been reported in studies conducted in SA that women use alcohol before and during pregnancy as a coping mechanism for the socio-economic and socio-political realities of their everyday lives (Cloete & Ramugondo, 2015; Fletcher et al., 2018). Furthermore, studies conducted in Canada and the United Kingdom found that health professionals — general practitioners, pediatrics, midwifery, health visitor, nurse social workers, mental health — may not be skilled enough to counsel women about alcohol use during pregnancy (Mukherjee et al., 2015; Poole et al., 2016).

Although some of the drivers of FASD are well documented, to the best of our knowledge, no study has explored the perspectives of policymakers and service providers working on FASD. There is a need to gain a contextual understanding of these factors from these stakeholders to facilitate a holistic and comprehensive strategy to reduce the prevalence of FASD. Therefore, we aimed to explore the perspectives of policymakers and service providers who are involved in policy development and implementation and service provision on why the prevalence of FASD remains unabated in SA.

Methods

Study Setting

The study was conducted in the Western Cape province of South Africa. The Western Cape was selected because it currently records the highest FASD prevalence in SA. The Western Cape is the fourth largest and the third most populous of the nine provinces, with an estimated 6.6 million inhabitants in 2018 (Statistics South Africa, 2018). Alcohol consumption is a significant public health problem in the province and the origin of the drinking problem has been largely attributed to the "dop" system (London, 1999; McKinstry, 2005). The province has recorded rates of 20 to 43% of alcohol consumption during pregnancy (Culley et al., 2013). The drinking pattern in general and during pregnancy is facilitated by the presence of numerous illegal liquor stores "shebeens" (Bowers et al., 2014), making alcohol accessible to anyone with little or no restriction. In addition to the presence of illegal liquor stores, there are other socio-economic and socio-political realities such as high



unemployment rates and poverty driving the demand for alcohol in this group (Lukasse et al., 2015; Sanders & Currie, 2014).

Study Design

We used an exploratory qualitative research design with an interpretive paradigm as it allows for the detailed exploration of relevant stakeholders' experiences and perspectives on the phenomenon (Creswell & Creswell, 2017).

Sampling Procedure

A selective purposive sampling approach – the identification of settings and populations before data collection – was adopted. We applied a two-step purposive sampling approach. In step one, we selected appropriate departments and institutions to recruit participants: Three departments were selected as they have the most relevant stakeholders – policy-makers (PM) and service providers (SP) with the requisite knowledge on FASD. We also selected relevant institutions – the department of education, health and social development, healthcare facilities, schools, and non-profit organizations (NPOs) that were involved in delivering FASD-related services.

In step two, we selected the study participants. The following inclusion criteria were considered: (1) works in any of the abovementioned departments and institutions; (2) has at least five years' experience in FASD-related policymaking or implementation and services delivery; and (3) is a member of the multidisciplinary team working on FASD.

We purposively selected individuals from 13 institutions for the focus group discussions (FGDs) based on the abovementioned criteria. We considered the individuals from the same institution as a focus group. This is because they share a common work environment and we assumed that they would share similar experiences. All the institutions consented to participate but three were not able to participate in the study due to time constraints and the organizations' workload.

For the in-depth interviews, fifteen participants were purposively selected based on the abovementioned criteria and twelve consented to participate, but two later declined due to time constraints. Ten policymakers (directors, assistant directors, heads of programs, policy administrators, policy developers, policy monitoring, and evaluation officers) and 65 service providers (health and allied health, medical, teacher, and social service providers) were included. Table 1 shows the characteristics of the 75 participants that were included in the study.

Data Collection

The participants were invited via emails and phone calls to participate in in-depth interviews (IDIs) and focus group discussions (FGDs). Ten IDIs and nine FGDs were conducted in English between September 2016 and 2017, each lasting 30–60 min. We asked the participants open-ended questions to start the conversation and sequel questions to probe for additional elucidations when necessary. The participants were asked questions relating to the unabating incidence of FASD in SA.

All the IDIs and FGDs were audio-recorded with permission from the participants. Also, during data collection, data saturation was reached when no new information



Table 1 Characteristics of the study participants

Characteristics	Participants (N = 75)
Types	,
Policymakers Service providers	10 65
Gender	
Male	9
Female	66
Working experience (years)	
1–10	36
11–20	22
21–30	12
31–40	4
41–50	1
Profession	
Allied health	25
Medical	10
Nurse	6
Teacher	26
Others	8

was prompted with the subsequent IDIs and FGDs (Bowen, 2008; Brod et al., 2009). The IDIs were conducted in the offices of the participants in the different government departments. FGDs were conducted in the schools, hospitals, and NPOs' offices of the corresponding service providers. The IDIs and FGDs were conducted by the first author.

Data Analysis

We used the ecological framework (Mcleroy et al., 1998) to guide data analysis. The ecological approach focuses on the interrelationships between individuals and the various environmental levels (Mcleroy et al., 1998). The ecological model assumes that suitable changes in the social environment may lead to changes in individuals and in turn, the implementation of environmental changes requires the support of individuals. In this regard, the ecological model considers the role of interventions directed at changing interpersonal, organizational, community, and the public to promote and maintain healthy behaviors. We found this model suitable to unpack the individual, interpersonal, health system, environmental, and policy-level factors responsible for the unabated increase in the incidence of FASD. The model consists of the following five levels: (1) intrapersonal or individual factors, (2) interpersonal factors, (3) institutional or organizational factors, (4) community factors, and (5) public policy factors.

The data analysis was done by (1) reading and re-reading the transcripts for data familiarization, (2) generating the initial and refined codes inductively from identified key and recurrent issues emanating from the data, (3) organizing similar codes into sub-themes and similar sub-themes into themes, and (4) arranging the themes (factors) deductively into the appropriate levels within the ecological framework.



Trustworthiness and Rigor

We established rigor and trustworthiness through the following activities (Lincoln & Guba, 1985). First, the interview and FGD guides were developed by the research team in consultation with the literature on FASD. The authors discursively developed a codebook to inform the data analysis. The coding, development of themes, and conceptualization into the framework were an iterative process done through a discursive process between both authors.

In reporting, we followed the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007). Open-ended questions were asked to allow the participants to express themselves freely and avoid guided responses. A detailed description of the methodological process has been provided in the methodological section to allow replication of the study. Findings from this study are supported by the inclusion of verbatim transcription of some of the participants' responses. At the end of each interview and discussion, a summary of the interview and discussion was done to ensure that the responses of participants were accurately captured. The research process was documented through the use of a reflective journal. The journal contained the discussions, deliberations, and decisions made by the research during the entire process.

Results

Figure 1 illustrates the salient themes that were obtained from the data analysis as informed by the ecological model. Based on our findings, most of the factors driving the increasing prevalence of FASD in SA are found at the institutional level and the least at the interpersonal level.

Individual-Level

These are biological and personal history factors contributing to the unabated increase in the incidence of FASD. They also refer to factors that influence behaviors such as knowledge, attitudes, beliefs, and personality.

Social and Economic Conditions

Social conditions that drive women to drink continue to drive FASD in SA. The discussions with the participants revealed unemployment and poverty as some of the conditions that drive women to drink during pregnancy.

Unemployment and poverty, all form (part of) the problem. We have lots of people in the streets who do not have jobs; unemployed (SP; Health Professional 2).

Living Condition

Individuals who are homeless or live in shelters resort to drinking as a heating mechanism during winter. A service provider explained that they use alcohol and sex to keep



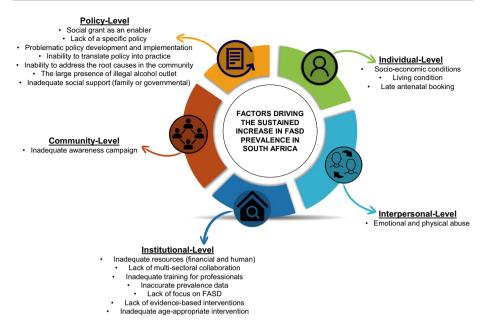


Fig. 1 Identified factors driving the increasing rates of FASD in South Africa

themselves warm increasing the likelihood of falling pregnant and the fetus being exposed to alcohol.

They drink because it keeps them warm at night and they have sex because it keeps them warm at night, but then she comes to the clinic nine months later to give birth to a FASD child, which she is completely unaware of because she is uneducated (SP; Health Professional 3)

Late Ante-natal Booking

A respondent reported how women fail to book early for their antenatal care making it hard to identify any alcohol-related problems and suggests a proactive tracking of alcohol abuse.

By the time the mom is pregnant and says I have got a problem with alcohol abuse, it is already too late; I think a lot of them are late bookers..., so they enter the health system as the pregnant person (**SP**; **Health Professional 1**).

Interpersonal-Level

Interpersonal-level factors look at factors involving relations and interactions between persons that may increase the likelihood of women to use alcohol during pregnancy.



Emotional and Physical Abuse

A service provider also suggested that women also drink because they see drinking as a form of relaxation and coping strategy.

When we ask women if they drink a lot during pregnancy, 99 percent of them say 'yes'. 'I know that I should not drink when I am pregnant. I was very stressed because my husband left me, it [drinking alcohol] was nice, it helps me relax.' (SP; Health Professional 1).

Emotional and physical abuse, they all form (part of) the problem (SP; Health Professional 2).

Institutional or Organizational-Level

Institutional or organizational factors include the role of the different governmental departments including health system factors, which relate to how health services in relation to drinking during pregnancy are organized and delivered.

Inadequate Resources

Inadequate resources contribute to the continuous increase in the incidence of FASD. The participants reported the lack of both financial and human resources affecting the effectiveness of interventions aimed at reducing the incidence of FASD in South Africa.

They [Department Social Development] do not have sufficient resources to provide the service that we are doing. I think the whole problem is about funds. At the moment, we do not have sufficient funds to cover all areas and many areas with such problems and people need the list of services, but the funds are not coming especially from the government's side (SP; Social Service Professional 2).

Another participant reported on the shortages of staff, especially the social workers who are at the forefront of providing FASD prevention services.

They say the Department of Social Works should be doing X and Z, but practically we all know that social workers are massively overwhelmed (SP; Social Service Professional 1).

Inadequate Age-appropriate Intervention

The lack of appropriate interventions for different ages, especially adolescents contributes to the persistent increase in FASD. A service provider reported that adolescents sometimes develop a drinking culture due to a lack of age-appropriate services and interventions.

There is such a severe lack of services for our teenagers and adolescents and I ask myself continuously what happens to them when they reach past schooling age? What services are available for them out there? Thirteen-year-olds are now having sex and they are starting to drink at that age (SP; Allied Health Professional 1).



Lack of Multi-sectoral Collaboration

The departments of Education, Health, and Social Development are directly implicated in the prevention of FASD; therefore, these departments must work together to reduce the incidence and prevalence of FASD. However, the participants do not think these departments are working together to address the issue.

The health, education, and social development need to work more together you know, they need to develop programs together and not in isolation, not different programs for different departments (**SP**; **Educator 1**).

Inadequate Training for Professionals

Participants reported inadequate training for the professionals working on FASD. Suboptimal training has the potential to affect the effectiveness of interventions aimed at reducing the incidence and prevalence of FASD.

You never get the training where you need on how to manage this (FASD). It [training] is more about information giving on FASD, so it is not something you say that you are confident after the training (SP; Health Professional 1)

Inaccurate Prevalence Data

To develop appropriate interventions to address FASD in SA, the incidence and prevalence must be accurately determined.

We do not know the extent of the problem. We only know in the areas that have been researched and the research was done in areas of high incidents. We do not have provincial research (**PM**; **Education Department 1**).

A policymaker said that there are other competing causes of developmental delay and so the diagnosis of FASD is more complex and difficult.

We do not know how many of those children are with or without attention deficit hyperactivity disorder have got this disposition due to alcohol or drug use in pregnancy (PM; Health Department 1).

Lack of Focus on FASD

FASD is not a priority in terms of awareness and prevention programs. FASD is seen in the context of a broader social issue.

So basically, there is no priority focus or primary focus on FASD in terms of awareness and prevention. It is an alcohol and drug abuse awareness program (PM; Social Development 1).



Lack of Evidence-based Interventions

Evidence-based interventions can potentially reduce the incidence of FASD. However, participants perceived that there was a lack of such intervention for FASD prevention — a perception that is not, in fact, accurate.

There is no evidence-based, academic-based, or theoretical-based developed program to address FASD. So, it is just a general awareness and prevention services when it comes to FASD (**PM**; **Social Development 1**).

Community-Level

These are factors related to the community that can promote healthy or unhealthy behaviors.

Inadequate Awareness Campaign

Lack of an on-going campaign is another major issue in the effort to reduce the incidence and prevalence of FASD. People need to be continuously informed of the dangers of drinking alcohol during pregnancy. However, participants felt this is not currently happening and emphasized.

People should be aware of the impacts of primary and secondary disabilities ...If the awareness was there then prevention this would prevent more children to be born (SP; Social Service Professional 1).

Policy-Level

These include provincial and national-level policies that regulate or support actions and practices for the prevention, early detection, and management of FASD and the use of alcohol.

Social Grant as an Enabler

Service providers also reported that social grants promote drinking during pregnancy as some women resort to drinking to advertently give birth to a child living with FASD to qualify for social grants.

A mother is giving birth to a second child diagnosed with fetal alcohol syndrome I do not think they must receive a social grant. For the first child, maybe she was uneducated and got pregnant because some of the mothers get a child to get a child grant (SP; Social Service Professional 2).



Inadequate Support

The participants elucidated on the need for more support for women with alcohol problems. This means the current support is not enough to reduce the incidence and prevalence of FASD.

Those people need a lot of support; they need to have one-on-one counseling sessions. But, the Department of Social Development has other priorities before they start providing a lot more support to women (SP; Social Service Professional 1).

A policymaker also highlighted the need for various types of support that should be made available for pregnant women.

Firstly, no safe house and referral pathway. if I am a heavy drinker and I realize today that I am pregnant. If I am living in an abusive relationship where I am drinking with my husband to ensure that we are both on the same level, what it is in place for me if I want to stop drinking today and leave this abusive drinking husband? (PM; Health Department 1).

Availability of Illegal Alcohol Outlet

The ubiquitous presence of *shebeens* and taverns makes alcohol easily accessible and available to everyone including pregnant women contributing to the unabated prevalence of FASD.

Many illegal taverns are prevalent in farming areas. Those are the things we need to look at and address it, not just to look at the FASD. There is a huge problem, people have access to cheap alcohol (**PM**; Social development 2).

Less Attention to Addressing the Root Causes in the Community

One of the reasons for the sustained increase in the incidence of FASD is that the root cause is not being addressed. Policymakers and service providers agreed the root causes of FASD are not being tackled.

We have not addressed the roots cause [of FASD], the bigger problems in our communities. People are suffering, they are unemployed, and they live in poverty. There is a huge problem, people have access to cheap alcohol (**PM**; **Social development 2**).

Lack of a Specific Policy

The participants reported a lack of policy for FASD, which means effective interventions are not being developed and implemented to arrest the continuous increase of incidence and prevalence of FASD.

There is no guideline to guide us on how to do things, how to deliver our services better than we are doing at the moment (SP; Social Service Professional 1).



Although clauses for FASD can be found as add-ons in other policy for FASD-related condition, FASD is not the main focus of these policies; therefore, this could affect how the intervention will be carried out.

We currently have no policy guidelines for FASD within our department, so currently, fetal alcohol spectrum disorders are incorporated with other alcohol and drug-related policy (**PM**; Social Development 1).

Problems Associated with Policy Development and Implementation

A policymaker reflected on the practicalities of having a separate policy for FASD and its implementation.

If it is practical you know, the first thing that we look at its practicality. Can it be implemented? Can the policy address the issue, and can it serve the purpose that it is being developed for? (PM; Education Department 2).

Inability to Translate Existing Policy Statements into Practice

A policymaker suggested that although there are policy statements toward preventing FASD, these interventions have not been translated into practice.

We have a provincial policy, which has not been translated into practice. An intervention should be in all the areas where the incidence is high (**PM**; **Education Department 3**).

Discussion

Herein, we used the ecological model as a framework to unpack the factors fueling the incessant increase in the incidence of FASD in SA. The individual factors that we identified included socio-economic and socio-political factors such as poverty, unemployment, and living conditions. The abovementioned factors are risk factors for FASD and they have been considered to be endemic in SA (Esper & Furtado, 2014). High incidence and prevalence of FASD have been reported in areas where the above factors are common (May et al., 2007; May et al., 2013; May et al., 2017; Olivier et al., 2016). It has also been reported that many women abuse or misuse alcohol to cope with the socio-economic and socio-political realities confronting them (Cloete & Ramugondo, 2015).

According to the South African government policy, women with alcohol problems are supposed to be identified during their first ante-natal visit. However, it has been reported that many women (including women with alcohol problems) are late bookers (Ebonwu et al., 2018; Solarin & Black, 2012) — most times, they are not aware that they are pregnant. Therefore, their fetuses might have been affected before their first antenatal visit (National Organization on Fetal Alcohol Syndrome, 2018). Late bookings are related to unplanned pregnancies (du Toit et al., 2018) and not being aware of one's pregnancy status may contribute to the high prevalence of FASD as women sometimes inadvertently drink while pregnant. The lack of preconception health care and high rates of unplanned



pregnancy has been identified as a barrier to FASD prevention in the United State of America (USA) (Waterman et al., 2013).

Some factors that could make women book late for antenatal care (ANC), which need to be addressed to improve pregnancy outcomes for women (Ebonwu et al., 2018; Selala, 2017). These factors for late booking may include health system — health care workers' attitude, long queues at ANC clinics, communication to attend ANC; patient-related — unplanned and non-acceptance of pregnancy, and avoiding HIV testing and fear of parents' reaction; and socio-economic — transport cost, partner neglects and loss or lack of support, and working in another province. In addition to the above, individual perception and knowledge — the experience of previous pregnancy, late booking had less ANC visits, no medical problem, and other commitments over ANC, and failure of family planning — using injectable contraception and termination of pregnancy inaccessible, were also responsible for late bookings.

At the interpersonal level, we identified emotional and physical abuse of women as a factor sustaining the high prevalence of FASD in South Africa. Globally, 30% of all women who have been in a relationship have experienced physical and/or sexual violence by their intimate partner. In some regions, 38% of women have experienced intimate partner violence (World Health Organization, 2008). South Africa was reported as one of the highest rates of intimate partner or domestic violence in the world (Abrahams et al., 2009). Also, a systematic review of clinical studies from Africa reports prevalence rates of 23–40% for physical, 3–27% for sexual, and 25–49% for emotional intimate partner violence during pregnancy (Shamu et al., 2011). Intimate partner violence during pregnancy is associated with adverse health outcomes for the pregnant woman and her baby (Pal & Rao, 2020). The intimate partner violence experienced by women may lead to psychological trauma/stress and psychological trauma/stress could make women consume alcohol (Pal & Rao, 2020; World Health Organization, 2008). Therefore, if the consumption of alcohol occurs during pregnancy, it may lead to FASD (Pal & Rao, 2020).

The lack of resources (financial and human) was identified as an institutional-related factor. In a study conducted in Canada, insufficient capacity for holistic and tailored programs, limited resources for programs, limited funding, space, and professional staff, were major barriers to the prevention of FASD (Poole et al., 2016). Although there are evidence-based interventions (Adebiyi, Mukumbang, & Erasmus, 2019), the effectiveness of the available interventions has been negatively affected by the shortage of financial and human resources. A study has reported that resource shortage can hinder the expansion of evidence-based prevention interventions (Adebiyi, Mukumbang, Cloete, et al., 2018). In addition to resource shortage, poor multi-sectoral collaboration was identified as a contributor to the ever-rising rates of FASD in SA. The departments such as Education, Health, and Social Development must collaborate for policies and interventions to prevent FASD to work (Rasanathan et al., 2018). Multi-sectoral action has been highlighted as a way to achieve better child health and a child's well-being (Zaidi et al., 2018). Health goals and targets of the Sustainable Development Goals (SDGs) cannot be realized unless sectors such as health, education, finance, trade, and social welfare work together in an integrated fashion (Blomstedt et al., 2018; Boerma et al., 2018). Therefore, the lack of multi-sectoral collaboration and the fragmentation of services among departments represents a significant barrier to the efforts toward preventing FASD in SA (Adebiyi, Mukumbang, Cloete, et al., 2018).

Our study identified the lack of age-appropriate interventions as many of the current interventions target women who are already pregnant — midstream interventions (Sanders & Currie, 2014). The lack of age-appropriate interventions was also reported in Canada



— the inability to meet the treatment needs of pregnant girls and women at the highest risk (Poole et al., 2016). The lack of referral and access to appropriate treatment services for alcohol-abusing women was reported as a barrier to FASD prevention in the USA (Waterman et al., 2013). To reduce the prevalence of FASD, researchers advocate for addressing upstream interventions — targeting the women of childbearing age, including adolescents, and addressing the social determinants of health (Sanders & Currie, 2014) in addition to the midstream interventions.

Inadequate training of professionals was identified as a stumbling block for addressing the sustained incidence of FASD in SA. Addressing problems with alcohol requires highly skilled professionals to be able to screen and counsel women with the problem. This is because it is difficult for women to admit the use of alcohol especially during pregnancy for fear of being judged and stigmatized (Bell et al., 2016). Studies that reported on the training of professionals working on FASD highlighted the lack of skills to counsel women with alcohol problems (Mukherjee et al., 2015; Poole et al., 2016). A study conducted in the USA revealed that low levels of service provider training on screening, assessment, and treatment of alcohol use in women (pregnant and nonpregnant) as a barrier to FASD prevention (Waterman et al., 2013). Another barrier to the prevention of FASD identified in the same study was the lack of consistent and appropriate screening of women (nonpregnant and pregnant) regarding alcohol use. In Canada, a study reported the lack of skills to counsel women with alcohol problems as a barrier to FASD prevention (Poole et al., 2016).

At the community level, we identified that only a few evidence-based interventions have been implemented in South Africa to prevent FASD (Adebiyi, Mukumbang, & Erasmus, 2019). Although awareness and education form part of the interventions aimed at reducing the incidence and prevalence of FASD, there is a lack of ongoing awareness and education in various communities. There is evidence that awareness and education may be effective at reducing the prevalence of FASD in areas where awareness and education are low (Chersich et al., 2012).

At the policy level, we identified the lack of a separate policy for FASD in SA as a pertinent deterrent to the efforts to address FASD. The lack of an effective policy targeting FASD has been previously identified as an obstacle to address FASD (Adebiyi, 2019; Adebiyi et al., 2018; Rendall-Mkosi et al., 2008). Although clauses that could be associated with the prevention of FASD exist in other policy documents, these clauses have not been effective in addressing FASD in SA (Adebiyi et al., 2019a). This is because these clauses are generic and poorly implemented or translated into effective programs and interventions. Some policymakers associate the development of a separate policy to increase commitment to addressing the incessant rise in FASD prevalence (Adebiyi et al., 2021; Adebiyi et al., 2019d; Adebiyi et al., 2019).

We identified inadequate support for women before, during, and after pregnancy at the policy level. A similar finding was reported in Canada as a barrier to the prevention of FASD (Poole et al., 2016). Various factors such as socioeconomic conditions and lack of coping mechanisms (Fletcher et al., 2018) have been reported to predispose women to drink during pregnancy. A study conducted in Canada has reported that lack of psychosocial support for pregnant girls and women at the highest risk and continuing support for women predispose them to uncontrolled alcohol consumption (Poole et al., 2016). The lack of psychosocial support may also prevent women from seeking assistance for their alcohol-related problems for fear of being stigmatized. Therefore, women with alcohol problems should be assisted instead of seen as perpetrators of FASD (Hunting & Browne, 2012). A study has also identified that access to social support through their partners helps women to stop drinking during pregnancy (Kelly & Ward, 2018).



At the policy level, we noted that the root causes of FASD in the community have not been addressed. "Dop" system was identified as one of the root causes of FASD (London, 1999). Although the system has been outlawed in SA (May et al., 2019), it contributes to current risky drinking behavior such as binge drinking and drinking during pregnancy (Chambers, 2018; Vellios & Van Walbeek, 2017). This behavior is enhanced by the presence of illegal alcohol outlets (*shebeens* and taverns), which make alcohol available and accessible to all groups with little or no restrictions (Bowers et al., 2014).

Another factor identified at the policy level, which is peculiar to the South African context is related to the social grants—financial support provided to poor families and families having children living with disabilities. Social grants may contribute to the prevalence of FASD in two ways. First, money is usually given to the beneficiary or the caregiver of these beneficiaries. Therefore, this money can be misused—it may be used to buy alcohol—considering other intrapersonal factors (socio-economic and socio-political) of these individuals (Fletcher et al., 2018). Also, studies have reported the misuse of social grants by the caregivers (purchase of alcohol), especially young mothers (Khosa & Kaseke, 2017; Mutshaeni, 2009).

Second, it was observed that these individuals may continue to drink during pregnancy so that they can give birth to a fetus with disabilities to get more money. Although the myth that women are becoming pregnant to access social grants has been debunked (Department of Social Development, SASSA, UNICEF, 2012; Makiwane, 2010), our finding shows that this myth may persist among the service providers. The implication for the persistence of this myth is that service providers may treat women as perpetrators of the problem of FASD. Therefore, treating women as perpetrators may prevent women from seeking assistance for alcohol problems, which then fuels the FASD problem.

From our findings, it is clear that stress is one of the major determinants for alcohol use during pregnancy. Therefore, it is imperative to explore and address factors that could predispose women to stress before, during, and after pregnancy. The issue of gender inequality in child-rearing, a situation whereby rearing of children is considered as women's job (Poduval & Poduval, 2009; Verma, 2020), is considered a critical source of stress for these women. Rearing children without support from partners can be particularly stressful. The role of partners/fathers in supporting women before, during, and after pregnancy was not overemphasized (Alio et al., 2013; Cheng et al., 2016). Women who feel supported by their partners before, during, and after pregnancy may feel happier and less stressed (Alio et al., 2013; Cheng et al., 2016). The happiness they experienced shows the importance of the presence of partners during these periods. Also, when women are exposed to intimate partner violence, it can lead to stress (Pakhomova et al., 2021) and women may use alcohol as a coping mechanism (Pitpitan et al., 2013).

The social–ecological framework has levels that contain factors that can be used to explain alcohol use (Sudhinaraset et al., 2016). Individual-level factors — race/ethnicity and immigration and socioeconomic status — that influence alcohol use are nested within interpersonal/institutional factors — home, work, and school environments — which are nested within the larger community-level factors — community, cultural, and gender norms and attitudes regarding alcohol use. Furthermore, policy level-factors, for example, exposure to advertising, may influence family and peer network attitudes and norms, which in turn affect individual attitudes and behaviors (Sudhinaraset et al., 2016). In addition, according to the Centers for Disease Control and protection, when applying the social–ecological model for the prevention of FASD, it is necessary to act across multiple levels of the model at the same time to achieve population-level impact (The Social-ecological



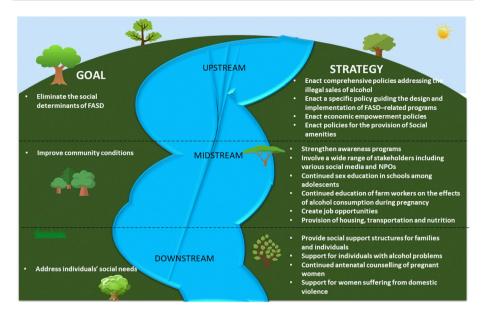


Fig. 2 Conceptualizing the approaches to addressing FASD in South Africa using the stream analogy

model, 2021). Therefore, the strategy proposed in Fig. 2 should be implemented across multiple levels of the framework.

The ecological model recognizes multi-level factors that can influence individuals' health behavior. These factors are interdependent; thus, challenges at one level can have a causal loop effect on other levels. For example, the lack of a political will to implement the liquor policy to regulate alcohol outlets in the community makes cheap alcohol available to individuals. To cope with the socio-political and socio-economic realities facing these individuals (in this case pregnant women) as a result of challenging social and living conditions, they can access alcohol from these unregulated outlets. Also, inadequate training and lack of skills prevent health professionals from assisting individuals to avoid drinking during pregnancy. The inadequate awareness of the dangers of consuming alcohol during pregnancy because of inadequate information received from healthcare facilities can hardly deter individuals from drinking when confronted with other individual-level challenges. Furthermore, inaccurate prevalence data for FASD could be the reason for the lack of a specific policy to address FASD. Therefore, to address FASD, a holistic approach must be considered.

We applied the public health approach to the issue of FASD by adapting the WHO public health approach for the prevention of violence (WHO, 2021). The principles of public health provide a useful framework for both continuing to investigate and understand the causes and consequences of FASD and for preventing FASD from occurring through primary prevention programs, policy interventions, and advocacy. This public health approach to FASD prevention seeks to improve the health of all individuals by addressing underlying risk factors of FASD. The approach consists of four steps as follows: (1) defining the problem through the systematic collection of information about the magnitude, scope, characteristics, and consequences of FASD; (2) establishing why FASD occurs using research to determine the causes and correlates of FASD, the factors that increase or decrease the risk for FASD, and the factors that could be modified through interventions; (3) finding out



what works to prevent FASD by designing, implementing, and evaluating interventions; and (4) implementing effective and promising interventions in a wide range of settings. The effects of these interventions on risk factors and the target outcome should be monitored, and their impact and cost-effectiveness should be evaluated.

We also considered WHO's Social Determinant of Health framework, the circumstances in which people are born, grow, live, and work affect their health (World Health Organization, 2010). The WHO's framework shows how social, economic, and political mechanisms (structural determinants) give rise to socioeconomic positions, which in turn shape specific determinants (intermediary determinants) of health status (World Health Organization, 2010). Applying the Social Determinants of Health's framework to our findings suggests that the low socioeconomic status (low income, low level of education, and unemployment) of individuals shapes their alcohol consumption behavior, which consequently drives FASD. Also, low-income earners who drink tend to experience a higher burden of alcohol-related harm because they consume more alcohol per day (Probst et al., 2018).

The Way Forward and Recommendations

Our study identifies a multi-level and complex interplay of factors contributing to the persistent rise in FASD in SA according to policymakers and service providers. The health service and policy implication for our findings is that policies and programs meant to reduce FASD should also be multi-dimensional and comprehensive. Addressing FASD will require a concerted effort to addressing the social determinants of health and other factors and this will lead to a reduction of the incidence and prevalence of FASD. In the short term, the government can start with the training of professionals on FASD. Also, taxes on alcohol can be increased and the revenue generated should be used to fund prevention intervention programs for young people, women of childbearing age, and pregnant women.

Public health interventions are always discussed using the metaphor of a stream, with upstream factors bringing downstream effects. Therefore, in the long-term, using the upstream, midstream, and downstream metaphors, we propose systemic changes necessary to address the root causes of FASD (Fig. 2). We are suggesting that social and economic interventions at both the community and individual levels are required to systematically address FASD.

At the upstream level, we recommend the development of policies that could control the illegal sales and use of alcohol and a separate policy for FASD in SA, which will, in turn, facilitate the design and implementation of holistic and inter-department/multisectoral prevention interventions. These proposed policies can work better with the creation of other such as economic empowerment policies and policies for the provision of social amenities. The effects of these policies should trickle to the midstream through social determinant interventions such as providing education, housing, nutrition, and transportation, which can influence health outcomes and health care use for vulnerable populations (Nichols & Taylor, 2018). Addressing these social needs will flow to the lower stream to reduce individual and interpersonal issues such as gender-based violence, which are the downstream manifestations of the impact of the social determinants of health.



Strengths and Limitations

We used multiple data collection methods (in-depth interviews and FGDs) to strengthen the outcomes of the study. The adoption of the ecological model helped us to unpack the various factors contributing to the incessant rise of FASD incidence in SA in a systematic manner. A limitation of this study is the conspicuous absence of the contributions for other stakeholders such as pregnant women, people living with FASD, researchers, and various community representatives.

Conclusion

Our findings indicate a multi-level of complex, dynamic, and interrelated factors responsible for the sustained increase in incidence and prevalence of FASD in SA. This highlights the need to change the current symptom-driven approach to the prevention of FASD in SA to addressing the social determinants of FASD.

Abbreviations FASD: fetal alcohol spectrum disorder; NPO: non-profit organization; FAS: fetal alcohol syndrome; PFAS: partial fetal alcohol syndrome; ARND: alcohol-related neurodevelopmental disorder; ARBD: alcohol-related birth defects; FARR: foundation for alcohol related research; SDG: Sustainable Development Goal; COREQ: consolidated criteria for reporting qualitative research; FGD: focus group discussion; PM: policymaker; SP: service providers

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Availability of Data and Materials More information on data from this study is available by contacting the corresponding author.

Author Contribution Conceptualization, B.O.A and F.C.M.; methodology, B.O.A. and F.C.M.; validation, B.O.A. and F.C.M.; formal analysis, B.O.A. and F.C.M.; investigation, B.O.A. and F.C.M.; data curation, B.O.A.; writing—original draft preparation, B.O.A.; writing—review and editing, B.O.A. and F.C.M.; visualization, B.O.A. and F.C.M.; supervision, F.C.M.; project administration, B.O.A. All the authors read and approved the final manuscript.

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Declarations

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