

Fetal alcohol syndrome: dashed hopes, damaged lives

Since the term was coined about 40 years ago, fetal alcohol syndrome has slowly become recognized as a public health issue. Alicestine October reports from South Africa's Western Cape province, which has the highest reported rate in the world.

"When I was pregnant with my son I drank a lot – mostly on weekends," says Marion Williams, a 45-year-old mother who lost two of her five children in childbirth.

Williams lives in one of South Africa's famous wine-growing areas in the Western Cape. She started drinking as a teenager and was taken out of school, she suspects, to work to buy wine for her parents.

Her third child was "born slow", she says. She blames herself and her drinking for the disabilities he will live with for the rest of his life.

"There is a lot he wants to do, but I must remind him he's not like other kids: he can work with his hands and build cupboards but not a thinking and writing job," she says, regretfully. "He asks me why I drank so much [while I was expecting him]. I don't really have answers for him."

Heavy drinking during pregnancy can lead to spontaneous abortion or a range of disabilities known as fetal alcohol spectrum disorders, of which fetal alcohol syndrome is the most severe.

Children with this condition are born with characteristic physical and mental defects, including short stature, and small head and brain.

There is no cure. Treatment is focused on mental health and medical services to

manage the resulting lifelong disabilities that include learning difficulties, behavioural problems, language, delayed social or motor skills, impaired memory and attention deficits.

"It is estimated that at least one million people in this country have fetal alcohol syndrome and approximately five million have partial fetal alcohol syndrome and [other] fetal alcohol spectrum disorders. It's tragic because it's completely preventable," says researcher and human geneticist Denis Viljoen in Cape Town, the provincial capital of South Africa's Western Cape.

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Marion Williams

"Fetal alcohol spectrum disorder is the most common birth defect in South Africa, by far more common than Down syndrome and neural-tube defects combined," says Viljoen, who helped set up a

nongovernmental organization (NGO) called the Foundation for Alcohol Related Research in 1997, after reaching the shocking conclusion that one in 10 of the children he saw at the genetics clinic at a hospital in Cape Town was affected.

"I saw then that fetal alcohol syndrome was much more common than people thought ... Public awareness [in South Africa] started with our initial research," he says.

The NGO fights fetal alcohol syndrome on several fronts: it gathers scientific evidence to highlight the problem in the hope that government decision-makers will fund and initiate prevention programmes; it trains medical and social services staff to develop prevention programmes and it raises public awareness.

Based on his published work and ongoing research, Viljoen estimates that between 70 and 80 per 1000 babies born in the Western Cape have the syndrome – the highest known incidence in the world. And the problem is not just limited to the rural poor of the Western Cape. "We see an increasing number of children with fetal alcohol spectrum disorders from middle and higher socio-economic groups coming to our private practice," he says.

In developed countries, a recent surge in new cases is attributed to increased awareness and more doctors diagnosing the problem rather than a worsening of the problem. This is also the case in South Africa, Viljoen says.

There are no reliable global prevalence figures, but a 2005 study estimated a global incidence of 0.97 per 1000 live births based on research in the United States of America (USA).

Some governments run targeted prevention programmes, but in many countries this work is left largely to NGOs.

In the farming community where Williams lives, heavy drinking partly stems from the 400-year-old practice of giving slaves and their descendants alcohol in recompense and to keep them captive through addiction.

"Our work is largely confined to rural communities due to lack of funding to reach urban areas," says Francois Grobbelaar, who runs FASfacts, an NGO



WHO/Alicestine October

Marion Williams at her home in the wine-growing area of Stellenbosch

that works with farming communities to prevent fetal alcohol syndrome.

While the tot system, which was banned in the 1960s, entrenched a culture of alcohol abuse and still contributes to maternal drinking in the Western Cape, studies show that poor nutrition, ill health, stress and tobacco use also influence the severity of the effects of heavy maternal drinking. The communities most affected are often impoverished, poorly educated and socially deprived, such as indigenous populations in the Western Cape, who are partly of Khoisan descent, Aboriginals in Australia and Native Americans in the USA.

Awareness of the problem has grown ever since the term, fetal alcohol syndrome, was coined in 1973.

In the United Kingdom of Great Britain and Northern Ireland, NoFAS, an NGO, was set up in 2003 by the adoptive mother of a child with the syndrome and in 2007 the British Medical Association published a report on the problem calling on health professionals to step up efforts to prevent it.

In the Russian Federation, researchers from St Petersburg State University and Nizhny Novgorod State Pedagogical University have been working since 2003 on a project to prevent women from drinking during pregnancy. It is in collaboration with the University of Oklahoma Health Sciences Center and funded by the US National Institutes of Health and Centers for Disease Control and Prevention.

The project involves collecting data as an evidence base to develop prevention strategies, development of education materials for the public and doctors and a 20-site randomized trial to test a prevention intervention for women at risk. According to principal investigator

Tatiana Balachova, the clinical trial will be completed next year.

“You have to teach physicians and nurses how to talk to women in an effective way,” says Elena Varavikova, a leading researcher at the Federal Research Institute for Health Care in Moscow. “This should be included in their continuing medical education.” Doctors and other health-care professionals also need an incentive to do preventive work.

Funding for these activities should be covered by health insurers, she says.

“Our country has one of the highest levels of alcohol consumption with drinking among women on the rise, and recent studies found high rates of fetal alcohol syndrome in Russian orphanages. Now it is time to act,” says Varavikova, who is working on the project.

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Denis Viljoen

In South Africa’s Western Cape Province the syndrome is seen as part of the wider problem of alcohol abuse that carries a huge overall burden of disability due to injuries, often from interpersonal violence, and disease.

“We see that every Friday and Saturday night in our hospital trauma wards,” says Robert Macdonald, head of the substance abuse unit in the Western Cape Provincial Government. He hopes that the province’s Liquor Act, which comes into force this year, will reduce the alcohol supply by limiting access including closure of illegal *shebeens* (bars) and a ban on selling alcohol on credit. But he fears it will be difficult to police. “There are 37 000 illegal *shebeens* in the province and only a few hundred police officers available to enforce it.”

As Macdonald notes, the costs to society are high. “Fetal alcohol syndrome is also an issue because affected children require special-needs schooling and

other forms of specialized care. It really has knock-on effects.” He adds that the Western Cape Department of Health is launching “Booza TV,” a television series this year to help educate people about alcohol abuse.

A study published in the *American Medical Journal* in 2004 estimated the social costs, including loss of productivity, lifelong costs of medical care and rehabilitation in the USA, at around US\$ 4 billion in 1998.

Some children with fetal alcohol syndrome are not diagnosed because they are adopted or fostered and their new parents are not aware of their mother’s background of chronic alcohol abuse, campaigners say. Particularly in the case of fetal alcohol spectrum disorders other than fetal alcohol syndrome, they may look like other children, but their “difficult” behaviour may be misunderstood if they have not been diagnosed.

FASfacts runs fetal alcohol syndrome prevention campaigns for school pupils, other young people and adults. In addition, it works with bar owners by educating them not to sell alcohol to pregnant women and under-aged children. In one project, 100 pregnant women in high-risk communities are allocated mentors to support them and encourage them not to drink alcohol.

Viljoen says the Foundation for Alcohol Related Research’s training, prevention, research and awareness-raising work only receives “a little funding” from the departments of social development and agriculture and nothing from the health department of the Western Cape.

But despite these efforts, as long as alcohol is accessible, affordable and socially acceptable, prevention work will be an uphill struggle.

Given the addictive power of alcohol, some women still drink heavily during pregnancy despite receiving the right advice. Williams was advised to stop drinking while expecting her son: “I was hard-headed and just kept on drinking.”

It was only once Williams was expecting her youngest child that she managed to give up alcohol for good. The child “came out fine” and today her daughter is 12 years old and wants to be a teacher.

Additional reporting from Elena Zolotova in Moscow ■



Denis Viljoen stands in front of his campaign poster