Fetal alcohol spectrum disorders in South Africa

Summary

The Current Scenario

The FASD journey in South Africa has just begun. The wealth of information available about the condition, the international and South African research findings and lessons learnt from 20 years of community engagements, provided enough information to start this exploratory journey. It is now imperative to evaluate some of these interventions as to create appropriate and effective programmes for FASD awareness, prevention and management. In doing so, sound theoretical and evidence based programmes, that relate to the specific needs of the different cultural groups and clients in urban and rural communities, should be developed. That being said, it is evident that the solution does not lie in one generic intervention, but rather in a flexible programme that could be revised as the needs of the clients and their environment change. Proper planning of health promotion programs, using approaches like Intervention Mapping, should provide the necessary empirical baseline to develop scientifically sound interventions.

To date the role of the woman has received most of the attention. Some have raised the concern that by placing the burden of responsibility and blame on women, society might come close to violating the rights of women in making informed decisions about their own health and the well-being their off-springs. Health promotional messages, and media reports advocate that no alcohol is safe during pregnancy. It calls on pregnant women to be responsible and good mothers by abstaining from alcohol use as 'FASD is 100% preventable'. By doing so, society continues to put all the pressure and responsibility on pregnant women and women of childbearing age. It implies that women who are using alcohol during pregnancy are perceived as bad and irresponsible mothers. Determinants such as confusing, and often contradicting, messages provided by health providers, limited access to education, as well as pressure from family and friends are not adequately acknowledged.

In South African studies, researchers have consistently reported on the defencelessness of women as so many are unemployed, unmarried and stressed. Family planning services are not optimally utilized, often resulting in unplanned pregnancies. Many children are raised by maternal headed households and fathers are frequently absent due to work circumstances, failed relationships or death. The burden placed on women, in often dire circumstances, is significant. As this is a regular occurrence, it seems as if

some communities have accepted it as the norm. Although men are regularly being blamed for being absent, one wonders how these communities would define responsible fatherhood.

Environmental and cultural factors, for example poverty, family practices, cultural beliefs, limited access to health and substance abuse facilities, further disadvantage women of childbearing age. Breaking the cycle of poverty and high-risk behaviour require more than mere health promotion messages. The need to be socially acceptable and to socialise are often stated as reasons why pregnant women continued to use alcohol. Despite of this, very few interventions focus on the role of the family and friends in terms of FASD prevention. The African proverb "It takes a village to raise a child" should encourage actions to appeal to the community's sense of responsibility and accountability in supporting pregnant women in their prenatal alcohol-free months.

Scientist have reported on the importance of maternal nutrition and concern has been raised about the increased vulnerability of women with low Body Mass Indexes. Various South African reports alert to the high prevalence of malnutrition and stunting in women of childbearing age. Coupled with high levels of alcohol abuse, especially binge drinking, these women are especially at risk of having children with FASD. Despite of this, little is known about the role of vitamins and micro-nutrient which might be crucial determinants in providing some protection against severe prenatal damage.

Late confirmation of pregnancy leaves fetuses exceptionally vulnerable, especially during the first trimester. This is often an indication of poor access or attendance of antenatal services, but also raises the concern about possible stigmatisation. At present there is no policy or guidelines on the management of pregnant women who are abusing alcohol in the Department of Health. By reporting her risky behaviour, a pregnant woman might run the risk of receiving a reprimand and a reminder about the harm that she is doing to her unborn child. It is highly unlikely that she will receive a referral for substance abuse counselling and support. In communities where there is an emerging awareness of FASD, but little collective responsibility in terms of prevention and support, the pregnant woman might even be ostracized and stigmatized. Being already in a compromising position, it might be easier for her not to disclose her prenatal alcohol use.

Raising a child with FASD in South Africa is a lonely journey. With little resources and adequately trained professionals, it is highly unlikely that the affected child will receive a diagnosis, let alone an early diagnosis, which is vital for early intervention. Even if the child receives a correct diagnosis there are very few resources available with limited accessibility to therapeutic interventions such as occupational, physio and behavioural therapy. Due to the country's inclusive education policy, it is compulsory for children to be enrolled for school at the age of seven. Children with learning disabilities, might be identified as they progress through school, and if severely affected, might be referred to schools for children with special needs. In some provinces access to appropriate educational services is less problematic than in others. Support to those who are affected

with FASD and their families are in general non-existent, leaving families spending their already limited resources on seeking services and assistance.

Moving forward

As stated, the FASD journey in South Africa has just begun. The aforementioned might provide a bleak and dooming picture, but there is enough information and experience available in South Africa to enable the country to acknowledge the problem and to take action. Knowing the challenges, enables one to address it. Factors for consideration in this process include the following:

Research questions

Reviewing the existing research findings in the country, as well as international research reports, raise a myriad of questions about determinants such as the impact of maternal malnutrition and low Body Mass Index, especially in terms of vulnerability. Would food fortification be beneficial in providing some protection to exposed fetuses, especially in this country where so many women are malnourished?

The same question applies to children with FASD. Infant malnutrition is common in South Africa. The effect on children's immunity, cognitive development and overall performance has been described. Food fortification, with the relevant vitamins and micro-nutrients, might enable a child with FASD to reach his full, albeit limited, potential, thereby improving his quality of life and ultimate functioning within the community.

The impact of paternal alcohol abuse is currently being researched and might provide interesting information which has the potential to decrease the blame and shame burden from women.

Political will

In a developing country like South Africa health and social problems are competing to gain acknowledgement and access to scarce resources. The HIV/AIDS denialism in 1999 - 2008 is a good example of how a country's ability to progressively address a problem can be derailed. The fear is that a lack of political recognition regarding South Africa's FASD problem might lead to a delayed action which is going to cost the country dearly. FASD is but a symptom of a much bigger problem, namely alcohol abuse. The country's draft Liquor Bill is currently being reviewed and addresses the main challenges such as marketing, distribution, liquor trading and outlets, under-age drinking, selling of alcohol to pregnant women, litigation and accountability. The Department of Social Development's Substance Abuse Programme provides a framework and guidance for service delivery. Unfortunately, these services are lacking in many communities, especially in

rural areas. Of great concern is the numerous missed opportunities within the Department of Health, due to a lack of policy and guidelines for the management of pregnant women at risk and diagnostic services for FASD.

Service delivery

The FASD diagnostic criteria currently used in South Africa is complex and expensive. Given the limitation on resources, it is imperative to develop practical and reliable methods and tools to increase the accessibility to diagnosis. At present highly skilled and trained medical specialists and psychologists/psychometrists are responsible for these assessments. Maternal interviews are fortunately already done by trained community workers. Increased availability and affordability would require the training of new cadres of workers. Options such as surveillance systems or brief-screening methods will have to be explored.

Training of professionals is essential. National policy and guidelines on the management of FASD will steer and focus limited resources and alleviate possible duplication and wastage of means.

Support groups providing information and guidance to people living with FASD, parents and caregivers will capacitate those who are facing the multitude of challenges on a daily basis. Networking and good infrastructures will alleviate the pressure on limited service resources, freeing the latter up for more pressing needs and enable better service delivery.

Awareness and prevention

Implementation of the above-mentioned is however, no guarantee for a reduction in the country's FASD prevalence rates. If the person at risk is not ready and prepared to accept the message and to change the harmful behaviour, there will be no positive impact on the problem. A concerted effort should be made to identify interventions needed by communities and parents at risk to actively engage them and to bring about behaviour change.

Pressure is put on women to protect their children, but in order for them to change their behaviour, they have to be willing to act in a certain way and have the necessary knowledge and skills to perform the required behaviour. People will only do so if they believe that their current behaviour is harmful and if they see the advantages of the new behaviour. Given the quest for social acceptability and support, it is important to receive support and positive encouragement from peers and family to implement and maintain the changed behaviour. High levels of self-efficacy and a positive self-esteem, coupled with a believe that one is capable to perform the behaviour, provide the necessary assertion needed for sustained behaviour change.

In true African spirit the country not only needs the proverbial village to raise a child, but it also needs the village to support the individual with FASD, his family, educators and other service providers. FASD can only be optimally addressed and combatted through concerted and collaborative action and by the implementation of a clear vision with the child's best interest at heart.

Samevatting

(in Afrikaans, the author's first language)

Die huidige senario

Die FASA (Fetale Alkohol Spektrum Afwykings) reis in Suid Afrika het maar so pas begin. Die skatkis van inligting wat tans oor die toestand beskikbaar is, die internasionale en Suid-Afrikaanse navorsingsbevindinge en die lesse wat gedurende die afgelope 20 jaar oor gemeenskapskakeling geleer is, verskaf genoeg inligting om hierdie ontdekkingsreis te begin. Ten einde toepaslike FASA bewusmaking-, voorkoming- en hanteringsprogramme te kan ontwikkel, is dit gebiedend noodsaaklik om sommige van hierdie intervensies te evalueer. Sodoende kan betroubare teoretiese en bewys-gedrewe programme ontwikkel word. Toepaslik programme moet spreek tot die spesifieke behoeftes van die verskillende kulturele groepe en kliënte in stedelike en landelike gemeenskappe. Daar moet egter aggeslaan word daarop dat 'n enkele generiese program nie noodwending die antwoord gaan bied nie. 'n Buigsame program wat volgens die kliënte se behoeftes en hul omgewing aangepas kan word, is meer toepaslik. Noukeurige beplanning van gesondheidsbevorderingsprogramme, met die gebruik van benaderings soos Intervensiekartering, behoort die nodige empiriese basis te verskaf om programme op 'n wetenskaplike manier te ontwikkel.

Tot op datum het die rol van die vrou die meeste aandag geniet. Kommer is al uitgespreek oor die gemeenskapsdruk en blaam op vroue. Sommige meen dit grens aan 'n skending van vroue se regte om ingeligte besluite rakende hul eie gesondheid en die van hul kinders te maak. Gesondheidsbevorderingsboodskappe en mediaverslae, propageer dat dit nie veilig is om alkohol tydens swangerskap te gebruik nie. Daar word 'n beroep op swanger vroue gedoen om verantwoordelike en goeie moeders te wees deur hul van voorgeboortelike alkoholgebruik te weerhou, want 'FASA is 100% voorkombaar'. Sodoende plaas die gemeenskap meer druk op swanger vroue en vroue van kinderbarende ouderdom. Dit impliseer ook dat vroue wat alkohol tydens swangerskap gebruik, slegte en onverantwoordelik moeders is. Faktore soos verwarrende, en dikwels teenstrydige, boodskappe wat deur gesondheidswerkers verskaf word, beperkte toegang tot opvoeding, asook druk van familie en vriende, word nie genoegsaam erken nie.

Navorsers in Suid-Afrikaanse studies, rapporteer deurlopend oor die weerloosheid van vroue, aangesien baie van hulle werkloos, ongetroud en gespanne is. Gesinsbeplanningsdienste word nie optimaal benut nie en dit lei dikwels tot onbeplande swangerskappe. Baie kinders word deur huishoudings grootgemaak waar vroue aan die hoof is en vaders dikwels afwesig is as gevolg van werksomstandighede, gefaalde verhoudings of die dood. Die las op vroue, wat hul dikwels in haglike omstandighede bevind, is beduidend. Aangesien dit so 'n algemene verskynsel is, het baie gemeenskappe dit reeds as die norm aanvaar. Alhoewel mans gereeld vir hul afwesigheid geblameer word, is dit 'n ope vraag hoe hierdie gemeenskappe verantwoordelike vaderskap sou definieër.

Omgewings- en kulturele faktore, soos armoede, familiegebruike, kulturele tradisies, gebrekkige toegang tot gesondheid- en middelafhanklikheidsfasiliteite, benadeel vroue van kinderbarende ouderdom nog verder. Om die siklus van armoede en hoë-risiko gedrag te verbreek, vereis meer as net blote gesondheidsbevorderingsboodskappe. Die behoefte om sosiaal-aanvaarbaar te wees en om te sosialiseer word dikwels as redes aangevoer waarom swanger vroue voortgaan om alkohol te gebruik. Ten spyte hiervan fokus baie min intervensies op die rol van die familie en vriende in die voorkoming van FASA. Die Afrika-gesegde 'dit vereis 'n dorp om 'n kind groot te maak' behoort as aanmoediging te dien om 'n beroep te maak op die gemeenskap se sin vir verantwoordelikheid en aanspreeklikheid ter ondersteuning van swanger vroue in hul voorgeboortelike alkoholvrye maande.

Wetenskaplikes wys op die belang van moederlike voeding en kommer is reeds uitgespreek oor die verhoogde weerloosheid van vroue met lae Liggaamsmassa-indekse. Verskeie Suid-Afrikaanse verslae waarsku oor die hoë voorkoms van wanvoeding en groeivertraging in vroue van kinderbarende ouderdom. Tesame met die hoë vlakke van alkoholmisbruik, veral fuifdrinkery, is hierdie vroue onder groter risiko om kinders met FASA te baar. Ten spyte hiervan is min bekend oor die rol van vitamiene en spoorelemente wat dalk kritiese bepalende faktore mag wees in die beskerming teen erge voorgeboortelike skade.

Laat bevestiging van swangerskappe laat fetusse uitermate weerloos, veral gedurende die eerste trimester. Dit is dikwels 'n aanduiding van swak beskikbaarheid of bywoning van voorgeboortedienste, maar dit wek ook kommer oor moontlike stigmatisering. Tans is daar geen beleid of riglyne in die Departement van Gesondheid vir die hantering van swanger vroue wat alkohol gebruik, nie. As sy haar risiko gedrag sou bekendmaak, loop die swanger vrou die risiko om 'n teregwysing te ontvang en daaraan herinner te word dat sy haar ongebore baba beskadig. Dit is hoogs onwaarskynlik dat sy 'n verwysing vir berading en ondersteuning vir haar middelafhanklikheid sal ontvang. In gemeenskappe waar daar 'n ontluikende bewussyn van FASA is, maar min kollektiewe verantwoordelikheid ten opsigte van voorkoming en ondersteuning, mag swanger vroue selfs verwerp en gestigmatiseer word. Siende dat sy haarself reeds in 'n netelige posisie bevind, mag dit vir haar makliker wees om nie haar alkoholmisbruik bekend te maak nie.

Om ‘n kind met FASA in Suid-Afrika groot te maak is ‘n eensame tog. Met min hulpbronne en ‘n gebrek aan toepaslik opgeleide professionele persone, is dit hoogs onwaarskynlik dat die geaffekteerde kind gediagnoseer gaan word, wat nog te sê van ‘n vroeë diagnosering, wat so belangrik vir vroeë intervensie is. Selfs al sou die kind die korrekte diagnose ontvang is daar beperkte hulpbronne beskikbaar met min toegang tot terapeutiese intervensies soos arbeidsterapie, fisioterapie en gedragsterapie. As gevolg van die land se ingeslote opvoedkundige beleid, is kinders teen sewejarige ouderdom skoolpligtig. Kinders met leergestremdhede mag dalk geidentifiseer word soos hulle deur hul skoolloopbane vorder, en kinders met erge gestremhede, sal dalk na skole vir kinders met spesiale behoeftes verwys word. In sommige provinsies is toegang tot toepaslike opvoedkundige dienste minder problematies as in ander provinsies. Ondersteuning aan diegene met FASA en hul gesinne, is meestal afwesig en dit noodsaak die gesinne om hul alreeds beperkte bronne in die soektog na dienste en ondersteuning te spandeer.

Die pad vorentoe

Soos genoem, het die FASA reis in Suid-Afrika maar so pas begin. Die voorafgaande verskaf dalk ‘n triestige en verdoemende prentjie, maar daar is genoeg inligting en ondervinding beskikbaar in Suid-Afrika om die land in staat te stel om die probleem te erken en tot aksie oor te gaan. Faktore wat tydens hierdie proses in ag geneem moet word, sluit die volgende in:

Navorsingsvrae

‘n Hersiening van die beskikbare navorsingsbevindinge in die land, asook internasionale navorsingsverslae, opper ‘n legio vrae rakende die oorsakende faktore soos moederlike voeding en lae Liggaamsmassa-indeks, veral in terme van weerloosheid. Sal voedingsverryking voordelig wees in die beskerming van blootgestelde fetusse, veral in hierdie land waar soveel vroue wangevoed is?

Dieselfde vraag is op toepassing van kinders met FASA. Kinderwanvoeding is algemeen in Suid-Afrika. Die effek op die kinders se immuniteit, kognitiewe ontwikkeling en algehele prestasie is reeds beskryf. Voedselverryking, met die toepaslike vitamiene en spoorelemente, mag dalk die kind met FASA in staat stel om sy volle, alhoewel beperkte, potensiaal te ontwikkel en sodoende sy lewenskwaliteit en uiteindelike funksionering in die gemeenskap te verhoog.

Die impak van vaderlike alkoholmisbruik word tans nagevors en mag dalk interessante inligting verskaf. Dit het die potensiaal om die las van skande en blaam op vroue te verlig.

Politieke wil

In ‘n ontwikkelende land soos Suid-Afrika kompeteer gesondheids- en sosiale probleme om erkenning en toegang tot beperkte hulpbronne. Die MIV/VIGS ontkenning in 1999 – 2008 is ‘n goeie voorbeeld van hoe ‘n land se vermoë om progressiewe aksie te neem, ontspoor kan word. Die vrees bestaan dat ‘n gebrek aan politieke erkenning rakende Suid-Afrika se FASA probleem kan lei tot vertraagde aksie wat die land duur te staan gaan kom. FASA is in werklikheid net nog ‘n simptoom van die veel groter probleem, naamlik alkoholmisbruik. Die land se konsep Drankwet word tans hersien en spreek die hoof uitdagings soos bemarking, verspreiding, drankhandel en afsetpunte, alkoholgebruik op ‘n te jong ouderdom, verkoop van alkohol aan swanger vroue, vervolging en verantwoordelikheid aan. Die Departement van Maatskaplike Ontwikkeling se Middelafhanklikheidsprogram verskaf ‘n raamwerk en riglyne vir diensverskaffing. Ongelukkig skiet hierdie dienste in baie gemeenskappe te kort, veral in landelike areas. Kommerwekkend is die verspeelde geleenthede binne die Department van Gesondheid, wat toegeskryf kan word aan ‘n gebrek aan ‘n beleid en riglyne vir die hantering van hoë risiko swanger vroue en diagnostiese dienste vir FASA.

Diensverskaffing

Die FASA diagnostiese kriteria wat tans in Suid-Afrika gebruik word is kompleks en duur. Gegewe die beperkte hulpbronne, is dit gebiedende noodsaaklik om praktiese en betroubare metodes en meetinstrumente te ontwikkel om die toeganklikheid tot ’n diagnose te verhoog. Tans is hoogs opgeleide en vaardige mediese spesialiste en sielkundiges/psigometriste verantwoordelik vir hierdie ondersoeke. Moederlike onderhoude word gelukkig alreeds deur opgeleide gemeenskapswerkers gedoen. Verhoogde beskikbaarheid en bekostigbaarheid sal die opleiding van ‘n nuwe kader werkers noodsaak. Moontlikhede soos siftingsprogramme of blits-assesseringsmetodes moet ondersoek word.

Opleiding van professionele werkers is noodsaaklik. Nasionale beleid en riglyne rakende die hantering van FASA sal die beperkte hulpbronne kan rig en bestuur om sodoende duplisering en vermorsing te bekamp.

Ondersteuningsgroepe wat inligting en leiding aan persone met FASA, ouers en versorgers verskaf, sal hul beter bemagtig om hul magdom daaglikse uitdagings te trotseer. Skakeling en goeie infrastruktuur sal die druk op beperkte diensbronne verlig, dit in staat stel om op dringender behoeftes te fokus en sodoende beter dienslewering bewerkstellig.

Bewusmaking en voorkoming

Implementering van bogenoemde is egter geen waarborg tot ‘n daling in die land se FASA voorkomssyfers nie. Indien ‘n risiko-persoon nie gereed en ontvanklik vir die boodskap is nie, en nie bereid is tot gedragsverandering nie, sal daar geen positiewe impak op die probleem wees nie. ‘n Daadwerklike poging behoort aangewend te word om intervensies te identifiseer wat gemeenskappe en risiko-ouers aktief sal betrek en tot gedragsverandering sal lei.

Die druk is op vroue van kinderbarende jare om hul kinders te beskerm. Ten einde gedragsverandering teweeg te bring, moet hulle bereid wees om hul gedrag te verander en oor die nodige kennis en vaardighede beskik om op die verlangde manier op te tree. Mense sal dit slegs doen as hulle glo dat hul huidige gedrag skadelik is en hulle aan die voordele van die nuwe gedrag glo. Gegewe die behoefte aan sosiale aanvaarding en ondersteuning, is dit noodsaaklik dat die portuurgroep en familie die nodige ondersteuning en positiewe aanmoediging gee om die implementering en volhouding van die nuwe gedrag aan te moedig. Volhoubare gedragsverandering vereis hoë vlakke van selfhandhawing, ‘n positiewe selfbeeld, asook die vertroue in jou eie vermoëns.

In tipiese Afrika-gees benodig die land nie net die spreekwoordelike dorp om die kind groot te maak nie, maar dit vereis ook dat die dorp die persoon met FASA, sy familie, opvoeders en ander diensverskaffers ondersteun. FASA sal slegs optimaal aangespreek en bekamp kan word met behulp van daadwerklike en samewerkende aksie en deur die implementering van ‘n duidelike visie wat die kind se beste belange vooropstel.