

Experiences of Health Care Professionals regarding Management of Fetal Alcohol Syndrome in the Khomas region of Namibia

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Abstract

The purpose of this study was to explore and describe the experiences of health care professionals regarding the management of Fetal Alcohol Syndrome (FAS) in the Khomas Region of Namibia. The study was qualitative, explorative, descriptive, and contextual in nature and was conducted at two state hospitals in Windhoek. The researcher used in-depth unstructured interviews and focus group discussions. Data was analyzed by using Tesch's method of qualitative data analysis. Ethical principles were employed to avoid acts that diminish self-respect and violate self-determination of research participants. The Findings of the study revealed four main themes on experiences of healthcare workers regarding management of FAS: Lack of knowledge about management of FAS; inadequate resources to facilitate the management of FAS; unconducive environment for mother and family; and lack of inter-professional collaboration. A total of ten sub-themes emerged from these four themes all of which indicated negative experiences that presented barriers to proper management of FAS. It is recommended that guidelines for health professionals should be developed to facilitate the management of children with FAS. In addition, healthcare workers knowledge and the clinical environment should be enhanced to enable effective management of this condition.

Keywords: fetal alcohol syndrome, experiences, healthcare, Namibia,

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Fetal Alcohol Syndrome (FAS) is a term referring to a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. FAS is a preventable condition while its effects are irreversible and last for a lifetime. It is a disease that has devastating effects on the baby, family, and the community in general (Popova, Lange, Probst, Gmel, & Jürgen, 2017). The effects of FAS include mental retardation, malformations of skeletal system and major systems such as heart and brain, inhibited growth, central nervous system (CNS) complications, memory difficulties, and poor social interaction skills (Popova et. al, 2017).

Alcohol use and abuse are common among people living in Sub-Saharan Africa and are characterized by patterns of misuse across many contexts and populations. It includes social strata, rural and urban environments as well as men and women (Hahn, Woolf-King, & Muyindike, 2011). Among individuals who consume copious amounts of alcohol, there is an increase in negative social and personal consequences; including risky behaviour, negative health outcomes, disinhibition, sensation seeking, and aggressive/violent behaviour.

In the 2014 Global Status Report on Alcohol and Health, Namibia was grouped along with countries with very highest levels of per capita alcohol consumption, particularly on the African continent. When examining both genders, Namibia had a higher percentage of persons with alcohol use disorders and alcohol dependence in comparison to the African Region (World Health Organization, 2014).

Literature Review

Alcohol consumption in childbearing women is a public health concern due to adverse health implications for the mother and the baby. The patterns of alcohol consumption among childbearing women have been well-documented in the literature. Estimates of prevalence of alcohol use by women indicate the following: Botswana (30%) and Namibia (47%) (Sayon-Orea, Martinez-Gonzalez, & Bes-Rastrollo, 2011).

Alcohol crosses the placenta from the mother's blood into the baby's bloodstream and the baby is exposed to similar alcohol concentration as the mother. The effects of alcohol on the foetus include harm to the development of the fetal nervous system, including the brain. Research has also shown damage to developing

brain cells, under-nourishment of the growing baby and triggering of changes in the development of the baby's face, resulting in the typical FAS facial features. There are a wide range of conditions that could be caused by alcohol consumption during pregnancy. These conditions are: Fetal alcohol syndrome (FAS), Partial fetal alcohol syndrome (PFAS), and alcohol-related birth defects [ARBD] (Popova et. al, 2017; World Health Organization, 2014). The use of alcohol among women during pregnancy is the most common teratogen affecting unborn babies and those with FAS, not only in Namibia but also worldwide. It is related as the most non-genetic cause of mental and behavioural problem in children (Emerson & Hatton, 2007). Pre-term delivery and stillbirth are associated with high levels of maternal alcohol consumption during early or late pregnancy and low to moderate levels of consumption are associated with an increased risk of stillbirth (Kesmodel, Wisborg, Olsen, Henriksen, & Secher, 2002).

The causes and consequence of FAS have been known for 40 years and affect millions of people worldwide; about one in every 1 000 live births (May et al. 2007). The World Health Organization (2014), declared that the protection of the health of populations by preventing and reducing harmful use of alcohol is a public health priority. Moreover, the stance of the WHO is to reduce the harmful impact of alcohol on the health of the population. The "vision of the strategy is to improve the health and social outcomes of individuals, families and communities due to harmful use of alcohol and their ensuring consequences" (World Health Organization, 2010, p. 8). Consumption of alcohol and problems related to alcohol vary widely around the world and the burden of disease and death remains significant in most countries.

Alcohol consumption is said to contribute to emerging social problems among adolescents and the youth in Namibia. One study estimates that 53.5% of the youth between 13 and 30 years old use alcohol (World Health Organization, 2010). There is high alcohol consumption in Khomas region and health care professionals face challenges with the management of FAS. They cited non-existence of protocols and guidelines to address FAS at the health facilities as the major reason for those challenges (Isaacs, 2007). He notes that the health care professionals also mentioned a lack of knowledge and skills, training opportunities, and inter-professional collaboration that inhibited a comprehensive approach to address FAS in Namibia.

Health care workers are required to have knowledge and skills for assisting the affected individuals from conception, during pregnancy, and into adulthood. The aim of this study was to explore and describe the experiences of health care professionals regarding the management of FAS in the Khomas Region of Namibia.

Methods

A qualitative approach with a descriptive, contextual design was adopted for this study. Health care professionals, including doctors, nurses and social workers

were selected to participate in this study. Participants were selected purposively depending on whether they had exposure to management of FAS. All participants were from the maternity and paediatrics wards of the state hospitals in Windhoek, Namibia.

Unstructured in-depth interviews as well as focus group discussions were the methods of data collection. Individual interviews were limited to ten for each hospital due to data saturation. Two focus group discussion were held, one at each of the state hospitals, comprising of six participants each. A single main question. "Tell me your experience regarding the management of fetal alcohol syndrome?", was asked in the interviews and focus group discussions followed by a series of probing questions to get obtain rich detail from participants. Data was coded and analysed using Tesch's 8 step method of data analysis (Creswell & Garrett, 2008).

Ethical approval to conduct the research was obtained from the University of Namibia Research and Ethics Committee and Ministry of Health and Social Services Namibia. Informed consent was utilized and respondents voluntarily participated in the study. The principle of respect, justice, autonomy and beneficence were observed and assured.

Results and Discussion

Four themes and ten sub-themes were identified by applying the techniques of reading, coding, displaying, reduction, and interpretation (Ngoma, Roos, & Siziya, 2015). The themes and sub-themes are illustrated in Table 1.

Table 1: *Theme and sub-themes from the study*

Themes Sub-themes

Theme 1: Lack of knowledge about management of FAS

- 1.1 Lack of knowledge on policies and guidelines for the management of FAS
- 1.2 Lack of knowledge about the factors contributing to FAS
- 1.3 Inadequate Knowledge of the impact of FAS on the mother, family and the community

Theme 2: Inadequate resources to facilitate the management of FAS

- 2.1 Educational information
- 2.2 Media for sharing information

2.3 Inadequate space for health education

Theme 3: Unconducive environment for mother and family

3.1 Unconducive living condition for the mother and family

3.2 Lack of family support to the mother

Theme 4: Lack of inter-professional collaboration regarding the management of FAS

4.1 Poor communication among health professionals

4.2 Lack of motivation and team work.

Theme 1: Lack of knowledge about management of FAS

Knowledge contributes directly to clinical decision-making and care plan. Health care professionals in this study expressed a lack of knowledge about the management of FAS. The knowledge they had was limited to providing quality care to the clients. The prevention and management as well as continued services for FAS requires a good understanding of these disorders among health care professionals; that includes their relationship with maternal alcohol consumption, what intervention strategies are effective, and how they are managed. Health care professionals have been reported to have a poor understanding of those conditions (Mukherjee, Hollins, & Turk, 2006). It is important that health care professionals understand and are trained on the adverse health outcomes of FAS to integrate the management, diagnosis, and prevention into everyday practice (Gahagan, et al, 2006).

1.2. subtheme: Lack of knowledge on policies and guidelines for the management of FAS. Clinical practice guidelines are the foundations of efforts

to improve health care. Guidelines are systematically developed statements to assist practitioners and patients with their decisions about appropriate care for specific clinical circumstances (Field & Lohr, 1992). It is important for the health care professionals to understand the mechanisms through which alcohol consumption impacts the development of a foetus (Klintsova et al, 2007). Guidelines and policies facilitate early identification of persons affected by prenatal exposure to alcohol so they and their families can receive services that they need. The individuals and families will be able to achieve healthy lives and reach their full potential. The participants expressed lack of knowledge of policies and guidelines to manage FAS at their health facilities where they interact with patients. While policies might be there in principle,

they might not be readily available to health care professionals at the facility level where interaction with patients is occurring. Some of the responses from the participants were that “information sharing about the impact of alcohol is not backed-up by official documents” and that “the babies are not growing normally and look very small.” Other participants said concrete understanding of the condition is an issue because of lack of IEC (Information, Education, Communication) material and that sometimes they consult social workers.

It is important to take cognizance of the role played by policies and guidelines that facilitate the appropriate and uniform approach to a given health condition. In this study, it was clearly indicated that these tools were not available at the health facilities. Absence or non-availability of the policies and guidelines hampers quality care provision. The participants had diverse opinions about managing babies born from mothers who were consuming alcohol during pregnancy. Policies are principles, rules, and guidelines formulated or adopted to reach long-term goals. Together, the policies and procedures ensure that points of view held by the institution, in this case the MOHSS, are translated into steps that result in an outcome compatible with that view. Fetal alcohol syndrome guidelines are intended to assist health care professionals to recognize the disorders associated with fetal alcohol exposure, promote early (infancy and pre-school) and accurate diagnosis, and prevent secondary disabilities through early diagnosis (Grant et al, 2005). The health care professionals are rightly concerned about the lack of guidelines and policies because it would assist them with managing the patients born with FAS.

Sub-theme 1.2: Lack of knowledge about the factors contributing to FAS.

Fetal alcohol syndrome is primarily caused by alcohol consumption during pregnancy. The factors that influence women’s attitude about consuming alcohol during pregnancy and their behaviour include a desire to drink alcohol, anxiety about the baby’s health, lack of knowledge, smoking, depression and misunderstanding the risks and effects to children with FAS (Lewis, 2008). Women who drink heavily and who have children with FAS are likely to have heavy drinking in their families of origin and in their peer groups (Kvigne et al. 2003). Another related study also revealed that domestic violence is a contributing factor with spousal abuse playing a critical role in FAS (May, et al., 2007).

In the current study, lack of knowledge about the contributing factors to FAS came to the fore. Some of the responses from participants were that they did not know what FAS was and its causes. While others said even if they tell the mothers, they do not understand the impact of alcohol to the unborn baby. One of the participants said they need training and guidance in the management of FAS, which was supported by another participant who said “I am also supporting that idea that

without knowledge about that condition among us nurses, we can't help the patient who is having such [a] condition."

Sub-theme 1.3: Inadequate knowledge of the impact of FAS on the mother, family and the community. Any type of alcohol consumption during pregnancy

has dire consequences. The alcohol can damage or affect the unborn baby's growth and general development. There could be in-utero brain damage of the unborn baby, as well as serious consequences to the mother. These consequences to the mother include that the body of the mother is worn out by tiredness, fatigue, nausea, and weakness during labour. The mothers can also lose consciousness, have increased urine output, loose electrolytes owing to vomiting and depleting nutrients. The mothers are likely to miscarry, because the foetus is no longer supported internally. Alcohol consumption during pregnancy disrupts the normal functioning of both the maternal and the fetal endocrine systems (Viljoen, Croxford, Gossage, Kodituwakku, & May, 2002). This may disturb the normal maternal-fetal endocrine balance. These alterations may adversely affect the development and organization of multiple systems in the fetus. The complex role of the placenta and the direct and indirect effects of maternal alcohol consumption on both the mother and the fetus are far reaching. Children born with FAS have destroyed brain cells that result in malformations of the developing brain structures. These children manifest developmental disabilities, attention deficit disorder, learning disabilities, developmental delays, and behavioural disorders. Children and families can benefit significantly from an early diagnosis. This information can help them to cope with the condition, shape their expectations, and obtain support from their families. FAS can affect an individual's ability to live independently in a community as a child or when they become adults (Kvigne et al, 2003). These individuals require a supportive environment. This is a great cost to affected individuals and to society which must provide educational and social services. Participants in this study could not relate the effect of FAS on the family or community due lack of knowledge of the condition. Participants said it is difficult to help someone or understand the effects if they do not know what the condition caused by alcohol is in detail. Some reiterated the need for extra training as well as provision of guidelines on how to diagnose and manage the condition.

Theme 2: Inadequate resources to facilitate management of FAS

Effective management of health condition requires the provision of adequate resources for such cases. It becomes difficult for health care professionals to provide quality health care to their patients where resources are limited. The

resources can cover a wide spectrum from financial, material and human resources; all having a different effects on the provision of services. The demand for health care resources will always and necessarily exceed supply. From the Hippocratic perspective, the focus of medical action gravitates towards the physician-patient encounter. It establishes a fiduciary relationship between the physician and the patient. In this study, the resources included human, material, and infrastructure. The serious shortage of health workers across the world has been identified as one of the most critical constraints to the achievement of health and development goals. The crisis impairs the provision of essential life-saving interventions; such as immunization, safe pregnancy and delivery services for mothers, and access to prevention and treatment. In Namibia, health workers are migrating between the public and private health sectors and like other developing countries, there is lack of adequate staffing for priority disease programs. This was also highlighted by participants in this study who indicated that the main problem is shortage of staff and one respondent saying that “many nurses resign and those remaining are overloaded with work.”

The countries with the poorest health indicators have the highest shortage of healthcare workers. Health worker shortages in Sub-Saharan Africa have many causes, including past investment shortfalls in pre-service training, international migration, career changes among health workers, early retirement, morbidity, and untimely mortality (Ayub, & Siddiqui, 2013).

Sub-theme 2.1: Educational information. The education of health

professionals needs a major overhaul. Clinical education simply has not kept pace with or is responsive enough to shifting patient demographics and desires, as well as changing health system expectations. These circumstances have an impact on evolving practice requirements and staffing arrangements, information, a focus on improving quality, and new technologies (Institute of Medicine (US), 2001). It is therefore important to ensure continual education of health care workers. The study revealed that participants were lacking in the latest information updates on FAS, thus they were not able to appropriately manage the condition. Some of the responses indicated that there is no information material to explain to the mothers either as leaflets or pamphlets as is available for other conditions such as TB. It is of paramount importance that healthcare workers are well informed with current and up-to-date information so as enable them to transfer such information in meaningful terms to the patient.

Sub-theme 2.2: Media for sharing information. From clinical health care to

public health campaigns, the health industry is increasingly turning to social media to support, promote, and increase the dissemination of information. This also improves the personal and community health practices. Social media have shared space for

preventative information, create enabling support structures to track personal health, and build patient-to-patient support networks. According to Guzman and Vis (2016), the media have been instrumental in bringing relevant changes to both personal and community health. This is most noticeable in the sharing of information and the local and international media play a vital role as a link between health workers and the wider public. In this study, the participants expressed concerns about the access to media for information sharing about FAS. The participants expressed the dire need for access to media as way to disseminate information to patients and the public. Some of the responses from the participants were that the “media can help in sharing information with our patients” as well as the use of “radio and television adverts [that] will allow us to reach our patients in their homes”

Access to media will enable increased interactions between healthcare workers and patients thereby providing a platform for constant reinforcement of information. It will also enable educational information to reach the wider community at relatively low cost.

Sub-theme 2.3: Inadequate space for health education. The physical

environment of an institution impacts programme outcomes for that institution. Facility design and renovation therefore provides an opportunity for interaction of the different elements within the facility. Conducive facilities ensure effectiveness of the health care team in providing care, as well as patient and practitioner satisfaction. Therefore, it is of utmost importance to provide space for patients and families to interact with health care workers. Health care practitioners are required to process different types of information. They communicate vital information to the patient, and need space conducive for this purpose (Mccarthy & Blumenthal, 2006). In this study, the participants expressed unhappiness due to lack of space to provide health education to the mothers.

The effectiveness and efficiency of health education processes are amplified by a conducive environment with appropriate space. The learning process should be discharged in a space at the health facilities with a conducive atmosphere for both healthcare professionals and patients.

Theme 3: Unconducive environment for mother and family impacts the management of FAS.

Mothers who give birth to children with FAS are usually discriminated against within the community. Many women in this situation feel ostracized and are reluctant to seek services and interventions to improve their quality of life (Gould, 2010). People condemn them for being unable to address their problematic alcohol consumption; they often experience judgmental attitudes from service providers;

have feelings of shame, guilt, depression, fear of losing children, poverty, low educational status and a low self-esteem (Komro, Livingston, Garrett, & Boyd, 2016). They also experience barriers to obtaining appropriate medical services and access to other health care professionals.

Parenting a child with FAS can be extremely exhausting and stressful for the mothers. Many individuals with FAS also have mental health issues. Society does not understand that FAS is a lifelong disability, which is at odds with social norms. Health care professionals need to apply their professional competencies to assess these individuals in terms of various environmental and social factors. The individuals must also be provided with support to help them modify their behaviour and reduce their exposure to risk factors, such as alcohol abuse. One of the concerns raised by one of the participants was that “the environment she is staying and how many kids she has” has an influence.

Characteristics of neighbourhoods can influence health; example accessibility to liquor stores, substandard housing, substance abuse, smoking, and violence. People living in poverty and social exclusion often have the greatest need for good health care, education, jobs, and housing.

Sub-theme 3.1: Unconducive living condition for the mother and family.

Health care workers connect the behaviour of recipients with the environment in which they live. There are several factors influencing health that have been identified and labelled as determinants of health outcomes. These influencing factors should be used to assist with changing behaviour and attitudes in a positive direction. The participants in this study were concerned that the mothers went back to the same circumstances in Katutura and became trapped in a vicious circle. This situation exposed the mothers to the same friends and families who were living in this unhealthy environment. It is therefore imperative to address alcohol consumption comprehensively in a community context to reach out to the Namibian population. Sentiments expressed by participants included: “When they go back to their homes they are with the same people and friends who are always drinking”; and “at home, these mothers ... [come under pressure] pressure from friends to drink”

Sub-theme 3.2: Lack of family support to the mother. In family settings, the

provision of some level of care and support is very important. For centuries, family members have provided care and support to one another during times of illness. Some situations might emerge such as depression and distress for family members that interfere with their ability to do so. These supporters will then fail to assist and subsequently stop interaction with the needy. Family members and caregivers should seek the assistance of health care professionals to manage their tasks and emotional

demands. Families are perhaps the most critical component of an early childhood system dedicated to promoting optimal development of young children. Families set the stage for a baby's development. It starts with prenatal care and promoting a healthy pregnancy. In this study, health care professionals mentioned lack of such support. One respondent said that "mothers [that] give birth to a baby with this condition hardly get support from the family". Another said that "you can see the pain in their eyes" when family members do not come to visit.

This indicates that mothers that give birth to children with FAS were left alone to deal with the situation even though family support is critical in this situation. The mothers of these children also need support from friends, and the community. Societies are complex and cannot be separated from health. The purpose of family support is to strengthen efforts and ensure family interaction to enhance the quality of life and community integration of families whose members have disabilities. This integration increases their access to support and services (Alldredge & Koda-Kimble, 2012).

Theme 4: Lack of inter-professional collaboration regarding the management of FAS

Inter-professional collaboration has been defined as "multiple health workers from different professional backgrounds working together with patients, families, caregivers and communities to deliver the highest quality care" (Schmitt, Gilbert, Brandt & Weinstein, 2013, p. 112). Poor communication among health professionals can be associated with a rise in mortality and longer stay in the hospital. Inter-professional collaboration is a dynamic process that may be strengthened by mutual appreciation of one another's roles through sharing, partnership, interdependency, and power (D'Amour, Ferrada-Videla, Rodriguez & Beaulieu, 2005). Teamwork should transform the traditional multidisciplinary approach to health care delivery in favour of a more interdisciplinary approach. The interdisciplinary approach recognizes and values expertise and perspectives of a variety of different health care providers. This study identified the issue of a lack of interdisciplinary teamwork. This is a great concern for the phenomena under study and has a devastating impact on the wider population. In recent years, medical training institutions have moved towards strengthening teamwork in the interest of the patient, family members, as well as the community. The participants echoed similar sentiments: One said that there is "no referral system in place" and that in instances when they refer cases to social workers follow-up is lacking". Others indicated that diagnosis is complex and needs a multi-disciplinary approach.

Sub-theme 4.1: Poor communication among health professionals.

The care of patients now almost inevitably involves many and different individuals all needing to share patient information and discuss their management. The use of

information and communication technologies becomes critical to support health services as information is the lifeblood of health care (Alvarez, & Coiera, 2005). The complexity of interactions within health care systems puts a heavy burden on the process of communication because miscommunication has terrible consequences. It is important that the communication system is efficient and effective. Health care professionals often lack the training needed to cope with their patients' communication difficulties. It is imperative that health care professionals possess communication skills to interact with fellow health care professionals and patients. Effective communication is an essential part of building and maintaining good physician-patient and physician-colleague relationships. In support of this, one of the participants said that no memorandum of understanding was signed with outside partners whilst another said "We tell them to stop alcohol consumption [because of the] consequences, but cannot refer them for continuum of services."

The management of mothers whose babies are born with FAS is multi-dimensional. Clients are supposed to receive services from a consolidated single point which offers the client continuity of the intended intervention plan. The health care workers must be familiar with protocols and Standard Operation procedures (SOPs) used by other health professionals. The paramount goal when dealing with alcohol abuse clients and in providing diverse services is to promote the clients' best interest. It is imperative to have strong bonds among health professionals.

Sub-theme 4.2: Lack of motivation and team work. Motivation is an

"individual's degree of willingness to exert and maintain an effort towards organizational goals and is closely linked to job satisfaction, which retains workers in their jobs (Alvarez, & Coiera, 2005). Keeping health workers satisfied and motivated helps the entire health system work smoothly. Poorly motivated health care professionals have a negative impact on the entire health system. Having strong human resources mechanisms in place within a health system can help to ensure that the right motivational factors are emphasized (Deussom, Jaskiewicz, Adams, & Tulenko, 2012). Motivation strategies should tackle these complex problems holistically, provide opportunities for career development, promote a positive work environment, and ensure the implementation of a support system (Luoma, 2006). Teamwork is becoming an important health intervention due to the complex nature of medical services. It reinforces the appeal to medical staff to assume the interdisciplinary health care approach. This approach would also take care of patients who suffer from multiple health problems (Luoma, 2006). Participants in this study indicated that they need patient history from the social worker, psychologist, physical assessments and other health professionals to effectively manage FAS.

McDonald (1985) explains that the diagnostic process could involve a single clinician if the condition is uncomplicated. In health care, teamwork is a dynamic process that involves complementary backgrounds and skills and the decision-making process is based on shared communication. (Xyrichis, & Ream, 2008). For complex disease conditions, there are five principles of team-based care. These principles include shared goal, clear roles, mutual trust, effective communication and measurable process and outcome. Thus the role of teamwork in health care cannot be over-estimated (Borrill, West, Shapiro, & Rees, 2000).

Conclusion

The study revealed four themes on experiences of healthcare workers regarding the management of Fetal Alcohol Syndrome in Khomas region, Namibia. The four themes are lack of knowledge about management of FAS; inadequate resources to facilitate the management of FAS; uncondusive environment for mother and family and lack of inter-professional collaboration. These four themes had eleven sub-themes all of which indicated negative experiences of healthcare workers during management of FAS. It is necessary that healthcare workers are empowered through knowledge provision in order to effectively manage FAS. Health facility environment need to be renovated and modified to create a conducive environment for both healthcare workers and patients to benefit optimally during FAS management. Teamwork and inter-professional collaboration need to be reinforced particularly in the process of FAS management for the benefit of the patient. Lastly the patients home and community environment will need to be made conducive through media awareness campaigns to create an enabling environment for patient recovery.

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