

# Women's experiences of receiving a child's fetal alcohol spectrum disorder diagnosis: A Western Cape study

By

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## Declaration

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## Abstract

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There are a range of conditions, collectively known as fetal alcohol spectrum disorders (FASD), which result from the exposure of a developing fetus to alcohol. South Africa has among the highest rates of FASD reported in the world, especially among the impoverished communities in the Western Cape region, with rates of up to 208.8 per 1000 first grade learners being reported. The need for screening, surveillance and immediate prevention work has been stressed. Limited research has been conducted on understanding the experiences of parents who raise children with FASD. This is invaluable in understanding what needs, support, services, education and funding is required. The Foundation for Alcohol Related Research (FARR) recently conducted a FASD epidemiological study to assess the burden of FASD and guide the implementation of prevention work in high risk areas. Grade one learners from 14 West Coast schools were diagnosed, and their mothers received a diagnostic feedback and counselling session. The aim of the research project was to explore the experiences of women who have received an FASD diagnosis for their child and to understand their comprehension, feelings and needs. Thirteen participants were recruited through FARR and semi-structured interviews were conducted at Vredenburg Private Hospital in the West Coast region of South Africa. Additionally, three community workers were interviewed. The data was analysed using a thematic content analysis approach and five themes were identified. The research identified that the social context in which these women live has caused them to fall victim to their circumstances, contributing to their drinking habits. Their experiences of living with an FASD child are difficult and most women feel guilty while others are in denial. Although these women know that alcohol was the cause of their child's problems, there were a number of misconceptions such as the amount of alcohol to cause harm, which parent was responsible and that drugs are safer than alcohol use during pregnancy. Furthermore, the mothers found it helpful to know the diagnosis. This helped them understand their child's problems. They felt strongly that they will abstain from alcohol use during pregnancy and that they will encourage other women to do the same. There was a need for further education and context-sensitive intervention work. This research will impact strategies to support families, help to improve services and guide prevention work in this area.

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## List of terms and abbreviations

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ADH	Alcohol Dehydrogenase
ARBDs	Alcohol Related Birth Defects
ARND	Alcohol Related Neurodevelopmental Disorder
FARR	Foundation for Alcohol Related Research
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorders
HIV	Human Immunodeficiency Virus
HPV	Human Pappilomavirus
IPA	Interpretative Phenomenological Analysis
NIAAA	National Institute on Alcohol Abuse and Alcoholism
pFAS	Partial Fetal Alcohol Syndrome
TCA	Thematic Content Analysis
TV	Television
WHO	World Health Organisation

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## Chapter 1: Introduction

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### 1.1 Literature review

#### 1.1.1 Introduction

This section will review previous literature on fetal alcohol spectrum disorders (FASD) and what the risk factors for an alcohol exposed pregnancy are. Furthermore, the prevalence rate and burden of FASD in South Africa, the historical events which have shaped this problem, current strategies to reduce the FASD burden and the role of the Foundation for Alcohol Related research (FARR) will be discussed. Lastly, the gaps in research and the importance of addressing these in the future will be described. This literature review will serve as background information to provide the necessary context for the research question, formulating a compelling rationale for the study.

#### 1.1.2 An introduction to FASD

Alcohol is a teratogen which causes harmful effects to the developing fetus (Armstrong, 2003). There are a range of conditions, collectively known as FASD (Warren *et al.*, 2004), which result from the exposure of a developing fetus to alcohol, of which fetal alcohol syndrome (FAS) is the most severe (Riley *et al.*, 2011). The four main disorders which fall into this spectrum, as classified by the Institute of Medicine, include FAS, partial FAS (pFAS), alcohol related birth defects (ARBDs), and alcohol related neurodevelopmental disorder (ARND) (Stratton *et al.*, 1996). While pFAS, ARBDs and ARND are not as severe as FAS, they are characterised by some, but not all, clinical features seen in FAS (Clarke & Gibbard, 2003). In order to make a FASD diagnosis, specific criteria, including the physical, developmental and structural defects of an individual; the neurobehavioural and cognitive dysfunctions; as well as the maternal drinking behavior, need to be recognised (Stratton *et al.*, 1996). More specifically, FAS is diagnosed through clinical evidence of facial dysmorphism, growth deficiencies and central nervous system dysfunctions such as intellectual disability, learning difficulties and neurocognitive deficits (Bishop *et al.*, 2007; Hoyme *et al.*, 2005).

During the embryonic and fetal developmental stage, both ethanol and drugs have been found to cross the placenta, resulting in teratogenic effects. In an alcohol exposed pregnancy, these teratogenic effects can occur at any gestational stage (Thompson *et al.*, 2009) and may include neurological dysfunctions, craniofacial dysmorphologies, central nervous system damage, growth deficiencies and alterations to brain morphology and neuronal development. (Behnke & Smith, 2013). Both ethanol and common drugs can alter the levels of neurotransmitters in the brain which play an important part in the neurodevelopmental process. Common drugs, such as methamphetamine and cocaine, have been found to cross the placenta and blood-brain barrier, altering neurotransmitter systems which result in brain morphologies and causing cortical neuronal effects resulting in severe brain abnormalities (Thompson *et al.*, 2009).

The major public health implications for the harmful effects of an alcohol exposed pregnancy are progressive, irreversible and severe (Riley *et al.*, 2011). FASD influences an affected individual's behavioural, physical, mental and cognitive development. If the cognitive development is affected, learning difficulties, low levels of intellectual disability, impaired memory, speech and language acquisition difficulties, poor problem solving abilities, planning and organisation difficulties, poor social conduct, emotional challenges, impulsivity, attention and behavioural issues, as well as consequential thinking difficulties may result (Whitehurst, 2011; Rutman & van Bibber, 2010). Secondary issues can occur in adolescence and adulthood, of which relationship problems, mental health problems, alcohol and drug abuse, school drop-out, unemployment, criminal activity, and homelessness are examples. Both the primary and secondary effects have a great effect on the mother, family and surrounding community (Whitehurst, 2011) and while the primary effects are congenital abnormalities which are irreversible, secondary results could be reduced or prevented if an understanding of the diagnosis is known and appropriate interventions are put in place (Rutman & van Ribber, 2010).

### 1.1.3 Risk factors for maternal drinking and the severity of the disorder

An alcohol exposed pregnancy is the most preventable cause of birth defects and intellectual disability as FASD is completely avoidable if a woman abstains from alcohol during her pregnancy (Floyd *et al.*, 2009). The risk factors for FASD during an alcohol exposed pregnancy are multidimensional and include a combination of factors (May & Gossage, 2011). These include, but are not limited to, the quantity of alcohol which the mother consumes during her pregnancy, the frequency with which drinking episodes occur, and the timing of alcohol exposure in comparison to the gestational stage of the developing fetus. Depending on the specific stage at which a drinking episode occurs, various anatomical defects, cognitive or behavioural effects may result if this falls at a critical stage in the developmental process (Hoyme *et al.*, 2005). These effects are dependent on which organs are developing at the time of alcohol exposure. For example, the brain is continuously forming throughout pregnancy and therefore can be affected at any stage. Additionally, higher gravidity (number of pregnancies), parity (the number of times the mother has given birth) and maternal age have been found to increase the risks for FASD if the mother is drinking prenatally as well. Furthermore, maternal body mass, nutrition, metabolism, socioeconomic status, religion and spirituality, depression, drug and teratogen use, social relationships (May & Gossage, 2011) and ethnicity are further contributing factors (Urban *et al.*, 2015).

The role of genetic and epigenetic factors, as an additional risk factor for FASD during prenatal alcohol exposure, have been further described (Warren & Li, 2005). The metabolism of alcohol varies between individuals and genetic and environmental factors influence the way in which alcohol is processed. In a South African study conducted by Khaole *et al.* (2004), it was found that women bearing children diagnosed with FAS were significantly less likely to have the protective genetic variants of the enzyme alcohol dehydrogenase (ADH), namely ADH1B\*2 and ADH1B\*3, known to metabolise alcohol faster and consequently reduce the effects of alcohol teratogenicity in a fetus, than women who did not bear FAS children. Similar findings were reported in additional population

studies conducted by Jacobson *et al.* (2006), Viljoen *et al.* (2001) and Warren & Li (2005). Further research exploring the association between behavioural, physical and genetic factors, and the associated increased risk of having a child with FASD, are however needed (May & Gossage, 2011).

Environmental and social risk factors associated with a woman being more susceptible to drinking during her pregnancy include alcohol and substance use, being at reproductive age and not using effective contraceptives, psychosocial and partner characteristics, single parent families, low levels of education, low religiosity, lack of alternative recreational activities, and socio-economic disadvantaged contexts (Olivier *et al.*, 2013; Morojele *et al.*, 2010). Population based studies in South Africa have reported that populations who live in the poorest rural communities, in the worst living conditions, where poor nutrition is common and recreational binge drinking is a norm, are at risk for both an alcohol exposed pregnancy and the increased risk for having an child with FASD (May & Gossage, 2011). Marginalised and poverty-stricken communities use alcohol as a method of recreational activity as it is freely available and relatively inexpensive. A cycle of poverty and lack of education leads to women drinking alcohol when they are pregnant or before they realise that they are pregnant. Additionally, a mother of a child with FASD is at further risk for becoming part of a vicious cycle where she may continue to misuse alcohol in order to escape the pressures and stresses of her daily struggles and circumstances (Campbell, 2007). These contextual factors may result in a woman being vulnerable or feeling hopeless, when faced with difficult social difficulties such as food insecurities, domestic abuse and crime for example.

There is consequently a great need for context-sensitive and location-specific national alcohol prevention and intervention programs (Morojele *et al.*, 2010), especially for those pregnant women who reside in the world's most vulnerable and high risk populations (Russell *et al.*, 2013). Poor socio-economic indicators and unplanned pregnancies emphasise the need for intervention and prevention programs (Chersich *et al.*, 2012) for both pregnant and non-pregnant women at risk for an alcohol exposed pregnancy (Floyd *et al.*, 2009). Prevention of an

alcohol exposed pregnancy is more cost effective than the management and treatment of the spectrum of disorders themselves, and prevention and intervention programs should be motivated for and implemented in high risk communities.

#### *1.1.4 Burden of FASD in South Africa and its historical context*

South Africa has among the highest rates of FASD reported in the world (May *et al.*, 2007; 2013). More specifically, alarmingly high rates of FASD are endemic in impoverished communities in the Western and Northern Cape regions of South Africa (Olivier *et al.*, 2013), particularly among the mixed ancestry populations who reside in rural areas and small towns (Urban *et al.*, 2015). The Western Cape has reported rates of FASD as high as 208.8 per 1000 (20.88%) first grade learners (May *et al.*, 2013), while a Northern Cape prevalence study reported FAS and pFAS rates of up to 119.4 per 1000 (11.94%) first grade learners (Urban *et al.*, 2008). Although high rates of FASD have been reported in certain South African populations, nationwide data is currently not available (Urban *et al.*, 2015).

Several studies have indicated that these FASD prevalence rates have dramatically increased over the last number of years. According to May *et al.* (2000), prevalence rates of FAS amongst grade one learners in Wellington, a Western Cape community in South Africa, were reported as 46.4 in every 1000 first grade learners (4.64%) in 1997. Viljoen *et al.* (2005) conducted a similar study to determine the prevalence rate in a second primary school cohort in the same community (Wellington). They reported that up to 74.2 in every 1000 (7.42%) first grade children were found to have FAS in 1999. In 2002, in a third primary school cohort in this same community, prevalence rates of FAS and pFAS had risen to 89.2 per 1000 (8.92%) grade one learners. It was stressed that preventative programs and intervention work in the area were needed to reduce the reported rates (May *et al.*, 2007). In 2013, May *et al.* reported increased FASD prevalence rates of up to 208.8 per 1000 (20.88%) individuals in a fourth study of grade one children in the same community in South African.

These alarming rates were among the highest reported in any community in the world (May *et al.*, 2013). In a separate isolated rural West Coast community (Aurora village) in the Western Cape, Olivier *et al.* (2013) conducted an FAS and pFAS school prevalence study where 17.5% of the learners screened were found to be affected. They concluded that FAS prevalence rates in isolated communities or particular hotspots are high. It is important to note that only a few of the studies report on the total FASD rate in an area while many report on only the FAS and pFAS rates. This is because FASD are broader and less well defined and may push up the prevalence rate in the particular area studied.

In two towns in the Northern Cape, namely De Aar and Upington, FAS and pFAS rates among school entry children were reported as high as 119.4 per 1000 (11.94%) children and 74.7 per 1000 (7.47%) children respectively between 2001 and 2004 (Urban *et al.*, 2008). Recently, a study was conducted by Urban *et al.* (2015) which determined the prevalence rate of FASD amongst black African and mixed ancestry populations in Kimberley in the Northern Cape Province of South Africa. A FASD prevalence rate of 6.4% was reported.

These alarmingly high rates reported indicate the burden of FASD in South Africa. In comparison, areas of the United states have reported rates of up to 8.4 per 1000 (0.84%) children with FAS and up to 48 per 1000 (4.8%) children with FASD (May *et al.*, 2014). Comparative rates in Italy were found (May *et al.*, 2006; 2011b). Worldwide, FASD occurs in one in every 100 live births (May *et al.*, 2009). Table 1 provides a summary of these prevalence rates reported.



**Table 1. FASD prevalence rates among grade one learners in diverse communities**

<b>Epidemiological Study</b>	<b>Prevalence rate (%)</b>
Wellington, Western Cape (May <i>et al.</i> , 2000)	4.1 – 4.6 (FAS)
Wellington, Western Cape (Viljoen <i>et al.</i> , 2005)	6.5 – 7.4 (FAS)
Wellington, Western Cape (May <i>et al.</i> , 2007)	6.8 – 8.9 (FAS and pFAS)
Wellington, Western Cape (May <i>et al.</i> , 2013)	13.6 to 20.9 (FASD)
Aurora, Western Cape (Olivier <i>et al.</i> , 2013)	17.5 (FAS and pFAS)
Upington, Northern Cape (Urban <i>et al.</i> , 2008)	7.5 (FAS and pFAS)
De Aar, Northern Cape (Urban <i>et al.</i> , 2008)	11.9 (FAS and pFAS)
Roodepan and Galeshewe, Northern Cape (Urban <i>et al.</i> , 2015)	6.4 (FASD)
Midwestern community, United States (May <i>et al.</i> , 2014)	2.4 to 4.8 (FASD)
Rome, Italy (May <i>et al.</i> , 2011b)	2.3 to 6.3 (FASD)

In addition to having the highest rates of FASD reported in the world, South Africa has one of the highest rates of alcohol consumption per capita of any country in the world (Seggie, 2012). Consistent patterns of weekly heavy (binge) drinking is common in South Africa. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) defines binge drinking among women as the consumption of four or more alcoholic drinks in a period of two hours (NIAAA 2004). May *et al.* (2007, 2008) revised this definition to the consumption of three or more alcoholic drinks per occasion following studies associating this level of drinking with dysmorphism and behavioural problems as seen in FASD individuals. Harker (2000) reported that 20% of women residing in the rural parts of South Africa, and 15 – 16% of women residing in the urban areas of South Africa, portray heavy binge drinking habits. Significantly higher rates of FAS and pFAS have been found among children who reside in rural areas (May *et al.*, 2007).

As a result, the most common drinking pattern among pregnant women in South Africa, which results in FASD, is heavy-episodic (binge) drinking (Chersich, 2012). Binge drinking has been found to affect the developing fetus most negatively when considering all alcohol consumption behaviours (May & Gossage, 2011). Additionally, populations such as South Africa, which have high and consistent patterns of weekly heavy binge drinking activities have significantly higher rates of newborn babies diagnosed with FASD, in particular FAS and pFAS (May *et al.*, 1983, 2000, 2007; Urban, 2008; Viljoen *et al.*, 2005). Studies conducted by May *et al.* (2000, 2007) and Viljoen *et al.* (2005) have reported extremely regular binge drinking activities in populations where high rates of FASD have been reported and that mothers of FAS or pFAS diagnosed children binge drink on average two days per weekend while consuming on average six and a half standard drinks per occasion (a standard drink is defined as either 340 milliliters of beer, a glass of wine or a single tot of spirits). Severe episodes of drinking on weekends among mothers of children who have been diagnosed with FAS and pFAS accounts for 96% of all alcohol consumed (May *et al.*, 2007). In comparison to this, Italy, where the normative pattern of consumption of alcohol is moderate and is usually accompanied with meals, has significantly lower rates of FASD (May & Gossage, 2011). These drinking patterns are amendable by intervention as stated by the World Health Organisation (WHO) (2001), as is not always associated with alcohol dependence (Chersich, 2012).

In South Africa, binge drinking patterns are most prevalent among the poorer mixed-ancestry populations in the Western Cape Province where the agricultural economy is dominated by wine and grape production. These patterns of consistent and heavy drinking have been normalised and are deeply rooted in, but not restricted to, South Africa's past history of what was traditionally referred to as the „dop“ system (Olivier *et al.*, 2013; Koyana, 2011).

The „dop“ (meaning alcoholic drink) system was a method in which farm workers were paid in the form of wine, instead of in monetary terms. In this process, farm owners could dispose of excess amount of wine in return for „cheap“ labour.

Consequently farm workers grew dependent on alcohol, leading to a cycle of alcohol addiction, dependency and poverty (London, 1999). Currently, the „dop“ system is illegal and has been outlawed but patterns of regular and heavy drinking continue. In the Western Cape Province, fruit, grape and wine production are known to dominate the province’s agricultural sector and consequently weekend binge drinking activities are a common recreational activity (Viljoen *et al.*, 2005). The drinking habits of the Cape coloured (mixed ancestry) population, which comprise 57% of the Western Cape population (May *et al.*, 2013), are associated with high rates of alcohol abuse and recreational binge drinking (Crome & Glass, 2000; London, 2000; Mager, 2004), resulting in high rates of FASD which has become a major health concern (Khaole *et al.*, 2004; Morojele *et al.*, 2010). Wine production has visibly influenced the moral drinking patterns in the country and consequently rural, farm based women are at increased risk. The increased availability of inexpensive alcoholic beverages in take-away bags (papsakke), as well as the presence of informal drinking establishments and illegal shebeens (an unlicensed establishment or private house selling alcohol), has added to the cycle of drinking and poverty (Koyana, 2011). In addition, studies have shown that papsakke have unacceptable chemical contaminant levels and this combination with ethanol may cause more damage to the developing fetus than ethanol alone (London *et al.*, 2008). Currently FASD is on the increase in both the rural and urban areas of South Africa. This is most likely due to low socio-economic status, high unemployment rates, crime, poverty, increased access to teratogens, unplanned pregnancies and poor education (L Olivier 2014, personal communication, August).

The burden of FASD in the Western Cape Province has previously been ignored despite the fact that it has social and financial implications for the rest of the country (FASD prevention symposium, 2008). FASD has had devastating impacts on both the Western Cape health care system and economy (Crede *et al.*, 2010). The average annual health care costs per child affected by FASD in South Africa has been reported as 1039.38 dollars (14 901.23 South African rand). The total annual societal cost for the Western Cape has been reported as

70,960,053.68 dollars (over one billion South African rand) (Crede *et al.*, 2011). In 2009, alcohol abuse was estimated to cost the country 37.9 billion rand (Matzopoulos *et al.*, 2014). Olivier *et al.* (2013) described this public health concern as being under recognised which directly impacts local measures for the prevention of FASD. FASD in South Africa is a significant yet underestimated health problem and screening, surveillance and immediate preventative intervention programs are needed.

#### 1.1.5 *The Foundation for Alcohol Related Research*

South Africa has alarmingly high rates of FASD which are of great concern to the country. As a result, several funded intervention and prevention programs have been implemented, particularly in the Western Cape Province. FARR is the leading non-government organisation for research on FASD in South Africa. Their aim is to reduce the rates of FASD across South Africa.

Each project which FARR aims to undertake is initiated by a prevalence study to better understand the scope of the FASD burden in a particular area. Based on the findings from the prevalence study initiated, FARR targets specific areas, which have been found to have the highest FASD rates, and undertakes intervention and prevention work in that specific area (Urban *et al.*, 2015). The data gathered from the epidemiological studies (and the resulting prevalence rates) is then used by FARR to identify and target high risk areas, and will be used as a guide to plan and implement prevention and intervention programs in the area.

Currently, FARR is involved in identifying antenatal clinics in these high risk areas, in which nursing sisters interact with and educate pregnant women as part of a „healthy mother healthy baby“ program. FARR has also conducted several parenting courses which aims to improve the self-image, as well as parenting skills, among individuals in the community. Several industrial theater groups have also been conducted in which FAS, domestic violence, substance abuse and other relatable contextual issues are addressed during interactive plays. These have been found to be very popular in the community. FARR is

also involved in training educators, social workers and healthcare providers. The foundation spends a maximum of three years in each high risk area to spread awareness and train healthcare providers, after which they focus on a new area as their main goal is not to function as a service provider (C Lombard 2015, personal communication, July).

#### 1.1.6 *Untangling South Africa's growing problem*

In order to make an FASD diagnosis, a multidisciplinary team is required. In South Africa, there is currently a limitation to these teams, including diagnostic and counselling support systems, and those teams which do exist (for example FARR) are limited in terms of being both overworked and overwhelmed by the great degree of needs which are being exposed (C Lombard 2015, personal communication, July). In addition, there is limited awareness of FASD among the population and health care professionals, making it difficult to identify affected individuals, address their needs and to further determine the degree to which current services are meeting the needs of those affected individuals identified (FASD prevention symposium, 2008). There are very few alcohol abuse rehabilitation programs available in South Africa, many of which are inaccessible due to their scarcity, high cost and urban location (Chersich *et al.*, 2012). Additionally, there is insufficient enforcement of legislation to protect pregnant women from alcohol use and abuse and there is limited support for management of those women who have a child with FASD (FASD prevention symposium, 2008).

In order to address the FASD burden in South Africa, attention needs to be focused on what the community understands and interventions need to be put into place to educate the community on what is unknown (May *et al.*, 2011a). FASD remains undiagnosed in South Africa, indicating a lack of awareness among communities and healthcare professionals (Urban *et al.*, 2015). Currently in South Africa, efforts to intervene and provide preventative options are restricted by the lack of knowledge on the effects of alcohol use during pregnancy (Eaton *et al.*, 2012). Population-level knowledge of the harms of

alcohol consumption during pregnancy therefore remains low (Chersich *et al.*, 2012).

In an intervention study conducted by Chersich *et al.* (2012) in South Africa, it was found that only 50% of participants were aware that alcohol can affect the developing fetus prior to an intervention program. Eaton *et al.* (2014) studied the beliefs about FASD among South African men and women at alcohol serving establishments in a township in Cape Town. About 50% of pregnant women and men with pregnant partners believed that women can consume alcohol during pregnancy without causing an effect on the developing fetus. In addition, 31% of the pregnant women believed that three or more drinks per day could be consumed without causing harm and 35% of pregnant women believed they could drink at least monthly. Around 54% of both pregnant and non-pregnant women admitted to drinking at least two to four times per month and 57% of these women said that they consume three to four alcoholic beverages per occasion. Eaton *et al.* (2014) found that both high rates of alcohol consumption and high frequencies were the norm in this community in South Africa and suggested that daily routines and social connections would need to be changed in order to reduce these rates of regular alcohol intake. The study also highlighted that a substantial number of men believed that a woman could consume alcohol safely during her pregnancy and suggested that the immediate social environment would need to be changed to influence alcohol use.

In 2012, Chersich *et al.* conducted the first prevention study in South Africa using the FASD outcomes from two Northern Cape Province towns of South Africa proven to have a high burden of FASD. The primary aim of the study was to raise awareness on the effects of maternal drinking and alter social norms and beliefs regarding consumption of alcohol during pregnancy. The effectiveness (before and after interventions) of the study was further assessed. They found that pre-intervention, maternal knowledge about the effects of alcohol was low and the prevalence of FASD was 8.9%. Post-interventions, knowledge levels increased substantially and FASD prevalence dropped to 5.7%. They reported that universal interventions could reduce FASD rates by

approximately 30% and this may have a great effect on the population. They emphasised the need to intensify universal interventions where knowledge levels are low.

Stade *et al.* (2009) identified four FASD prevention trials which together suggested that a brief psychological (motivational counselling) and educational intervention may help to reduce alcohol consumption among pregnant women. Floyd *et al.* (2009) reported the high efficiency of reducing the risk for alcohol exposed pregnancies among women of childbearing age by introducing screening and brief interventions such as counselling and clinical advice. It was further reported that there is a great need for community based interventions for high-risk women. In 2011, Ceperich & Ingersoll conducted a study in which they found that high risk women who underwent motivational interviewing at a university in the United States halved their risk of an alcohol exposed pregnancy. These studies highlight the importance of prevention and intervention work to reduce the rates and consequential effects of FASD.

## 1.2 Rationale for the study

Parental experiences often describe destructive and challenging cognitive, emotional and behavioural characteristics in their FASD affected child (Whitehurst, 2011; Phung *et al.*, 2011) and coping with these problems has a direct impact on family dynamics and relationships, leading to difficult home environments and a lifetime of struggles on behalf of the mother and family (Snaders & Buck, 2010). Progressive behavioural problems and feelings of a lack of support are more prominent in mothers with FASD children when compared to those mothers of children with any other disability (Whitehurst, 2011). Furthermore, parents often describe a general lack of support in terms of managing their child and addressing his or her educational needs and often do not know who to turn to for information and support (Whitehurst, 2011; Snaders & Buck, 2010). Stigmatisation and judgment are commonly associated with the diagnosis (Whitehurst, 2011; Salmon, 2008) and consequently strong emotional

reactions in biological mothers, such as frustration and guilt, commonly occur (Phung *et al.*, 2011; Snaders & Buck, 2010).

Understanding the experiences of parents and caregivers who raise children with FASD, and the daily realities and complex problems which impact and shape their lives, are invaluable in understanding what needs, support, services, education and funding the mother, family and affected child requires (Salmon, 2008). A lack in understanding of the nature and prognosis of the disorder and a lack of support can very often leave mothers and parents feeling lonely, isolated and unable to cope (Whitehurst, 2011). Limited availability of care, failure to identify and address needs, lack of support and lack of access to services has devastating societal and personal consequences and can even lead to a worsening of symptoms in the child (O'Connor & Paley, 2009).

While most FASD research has focused its attention on the identification, diagnosis and epidemiology, as well as the medical and behavioural aspects of FASD, understanding the psychosocial issues has been neglected. The impact of such a diagnosis on the mother and family and the psychosocial effects of raising affected children has been underinvestigated (Whitehurst, 2011; Snaders & Buck, 2010). An understanding into the psychosocial aspects which contribute toward maternal drinking is further lacking. This directly impacts strategies to support families (Whitehurst, 2011; Campbell, 2007) and research in this area is highly stressed (Ryan & Ferguson, 2006).

Few studies have explored the experience of parents who raise children with FASD. In a study conducted by Phung *et al.* (2011) in Northern California, the experiences of both foster and biological parents raising children with FASD were explored and they found that good living conditions, specialised educational programs and social support services are fundamental in improving the quality of life of both the child diagnosed and the caregivers. Giving the diagnosis, intervention programs, additional support services and social assistance are key factors in this process. Brown & Bednar (2004) found that a support networks including family, friends and the community; support services



from knowledgeable healthcare professionals; a specialised education program; access and availability of community resources; school relationships and involvements; and financial assistance is required. The role of family members, school teachers, healthcare professionals and the community can help to support both the child diagnosed with FASD and the family involved (Snaders & Buck, 2010).

Worldwide, no studies have been conducted to explore the experiences of women who receive an FASD diagnosis for their child. More specifically, an organisation such as FARR has never received feedback on the patient perspective following their epidemiological studies. The experiences of women who raise FASD children, and an understanding into how the social context in which these women live shapes this, has been understudied. The mother's comprehension and knowledge of the disorder, as well as her level of understanding regarding the risks associated with an alcohol exposed pregnancy, needs further investigation. The needs of the mother, and the potential roles of health care professionals or the improvement of current services to address these needs, have not been explored in South Africa. Furthermore, exploring the mother's feelings with regards to drinking during a future pregnancy or managing her child with FASD following a diagnosis is unknown.

The aim of the research is therefore to explore the experiences of mothers who raise children with FASD and who have received their child's diagnosis through FARR. The comprehension, feelings and needs of mothers will be explored. These findings will be invaluable and will contribute towards strategies for preventative and intervention work, as well as to identify areas in which current families with FASD children can be better managed and supported. This research falls into an understudied area within the broader FASD research field and is thus highly valuable.

### 1.3 Research aims and objectives

#### 1.3.1 *Aims*

The aim of this study was to explore the experiences, comprehension, feelings and perceived needs of mothers who have a child recently diagnosed with FASD. The child was identified through the FARR epidemiology study.

#### 1.3.2 *Objectives*

1. To explore the experiences of mothers (biological or foster) who raise a child with FASD
2. To explore the mother's comprehension, feelings and perceived needs after receiving her child's diagnosis
3. To explore the mother's feelings with regards to drinking during future pregnancies following the diagnosis
4. To explore the mother's feelings with regards to the management of her child following the diagnosis

## **Chapter 2: Methodology**

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### 2.1 Introduction

This chapter will describe the research design and methodological framework used to conduct the research. The study population, size and recruitment process; as well as the study participants, research assistant and community workers, will be described. Furthermore, the research setting, data collection and analysis process, ethical considerations, and how academic rigour was ensured, are further explained.

### 2.2 Research design

Qualitative methodology, utilising a phenomenological and cross-sectional design, was used for the research proposed. Denzin and Lincoln (1994) define qualitative research to be “a commitment to study the world from the perspective of the acting individual.” In 2005, they later defined qualitative research to be a study of things in their natural setting, in an attempt to interpret and make sense of things in terms of the meaning people bring to them. Qualitative research therefore aims to determine an individual’s perception and understanding of the world based on the experiences they face (Merriam, 2009). In order to explore the experiences of mothers who have received an FASD diagnosis for their child, a qualitative research approach was appropriate for the purposes of this study in order to generate rich and detailed descriptions by encouraging participants to discuss their experiences, understanding, feelings and further needs following such an diagnosis (Tuli, 2010). This research was conducted in such a way to encourage participants to provide a narrative description of their lives and their experiences encountered (Parkinson & Drislane, 2011). These interpretations were influenced by personal, professional, political and contextual factors and therefore differed between participants in the same situation (Beeson, 1997).

An interpretative phenomenological analysis (IPA) was used in this qualitative research approach. The foundation of IPA is built on understanding an

individual's perceptions, feelings and lived experiences and the meaning which they attach to these experiences (Smith *et al.*, 2009). IPA originates from the field of phenomenology, which aims to understand and interpret an individual's world by listening to their biographical story and exploring the way in which participants make sense of their experiences, by looking at the process they have been through and through self-reflection (Brocki, 2006). It looks at individuals' experiences, understandings, perceptions and views (Reid *et al.*, 2005). IPA also takes into account that the researcher is exploring the participant's personal world and that a joint reflection and interpretation from both the participant and the researcher takes place (Brocki, 2006). These interpretations are restricted by the ability of the participants to articulate their thoughts and experiences (Baillie *et al.*, 2000) and the ability of the researcher in turn to reflect on and analyse these experiences described (Brocki, 2006). As the researcher is a genetic counselling intern, she has a good understanding of the psychosocial realities (high burden of disease, unemployment, poverty, lack of education, abusive relationships) the South African population is faced with, especially those who fall into a low socioeconomic category, as this is part of what the researcher observes in the clinical environment in which she works. The researcher therefore has a much greater understanding into the daily issues that this population group experiences, which reduces her own personal bias. It is however acknowledged that the researcher may have been biased in reflecting on some of the participants experiences described. This was kept in mind and a conscious effort was made to reduce such bias by discussing the findings with the researcher's supervisors, research assistant and research colleagues. Although these measures have been put in place, it is impossible to alleviate all bias.

An interview approach was used to obtain in-depth and information rich data on the participants' experiences. The purpose of interviewing is not to test a hypothesis or obtain specific answers but to rather understand the practical experiences of individuals who are raising children with FASD. It allows us to put individuals' behaviours into context and allows us to understand the reason

behind these behaviours and actions, allowing professionals to identify areas which can help to deal with the problem. Face-to-face interviews are beneficial as they allow the researcher to pick up on various social cues. In this study it allowed the researcher to make observations on both the non-verbal as well as verbal behaviours of the participants, further enriching the data (Opdenakker, 2006). This interview approach was therefore most appropriate to determine the participants' experiences of receiving a diagnosis and the meaning that they brought to that experience (Seidman, 2013). Furthermore, in depth interviews with question guides are an ideal method for IPA (Smith *et al.*, 2009).

As data from the interviews was collected at a single point in time, no-follow-up period occurred and each participant was interviewed at a similar time following the diagnosis (in February and March 2015 after receiving a diagnosis in November and December 2014), a cross-sectional design approach was utilised. Cross-sectional designs are advantageous in that they are short and inexpensive, a researcher can study several outcomes at one time and there is no room for participants being lost to follow-up. A disadvantage of a cross-sectional design approach is that the participants' circumstances may change over time (Brink, 2006), however a longitudinal approach was not possible due to the time constraints of the project.

### 2.3 Study population

The study population comprised of women whose children had been diagnosed with FASD in the FARR West Coast epidemiological study. These women had been through the diagnostic feedback and counselling session and had received a positive FASD diagnosis for their child (or the child that was in their care). They resided in the West Coast region of South Africa and their child(ren) attended one of the 14 schools in the Saldanha Bay Municipal area, which FARR targeted for their prevalence study.

### 2.4 Recruitment and study sample

Since 2013, FARR initiated one of their studies in the Saldanha Bay Municipal area in the West Coast region of South Africa. This region is characterised by

endemic poverty, high rates of substance abuse, high teenage pregnancy rates and a sharp increase in the crime rate over the last couple of years (L Olivier 2014, personal communication, August). As part of the first stage to this study, FARR screened grade one learners, whose parents had given consent, across 14 schools in the West Coast region of South Africa, in order to identify the prevalence and burden of FASD in this region.

For each child screened, a physical growth and dysmorphism analysis was performed. All children whose height and weight or head circumference fell below the 10th percentile were referred to a medical geneticist, Prof. Dennis Viljoen, who conducted a clinical examination. Those children who met the clinical criteria for FASD (received a score of 11 or higher out of 50) were referred for a neurocognitive assessment. In addition, a maternal interview was conducted, where maternal reporting of alcohol consumption was recorded (Urban *et al.*, 2015). Furthermore, the final diagnosis was discussed and finalised in a formal, data-driven case conference (Hoyme *et al.*, 2005). During this case conference, representatives from the team who were involved in the prevalence study discussed each child's results in detail and decided on a final diagnosis. The representatives from this team included the medical geneticist who reported on the physical examination, a psychologist who reported on the neurodevelopmental assessment, and a community worker who reported on the maternal interview. Before a final diagnosis was made, results from all three of these reports were taken into account. In the case of an FAS diagnosis, no formal confirmation of maternal alcohol consumption was required as many of the mothers have been found to be deceased or the child is out of their care. A list of names of the grade one learners who received a positive FASD result was then compiled and the exact diagnosis was recorded. A suitable and convenient appointment was then made with the learners' parents where the final diagnosis, the neurodevelopmental report, and additional recommendations and referrals (where applicable) were conveyed during a diagnostic feedback and counselling session. Additionally, if any other serious problem was identified (e.g. if a child presented with severe developmental delays that could not be attributed to

alcohol exposure during pregnancy) feedback was given during the session, together with the neurodevelopmental report and further recommendations.

These diagnostic feedback and counselling sessions were conducted by four FARR staff members, each with diverse background training including genetic counselling, psychology, project coordination, nursing and social work. One-on-one sessions took place with the parents or guardians of the child and a FARR member (C Lombard 2015, personal communication, July).

In addition, the learners' diagnoses will still be reported back and shared with the teachers and principal at each school if the parent or guardian of the child has signed a consent form, granting permission to share this information. According to the FARR policy, this will only take place after the teachers and school principals have attended a training course presented by FARR which is specifically designed for educators in order to increase their knowledge of FASD and to equip them with the necessary skills to work with affected children in the classroom. In specific cases, FARR also makes appropriate recommendations and referrals to special needs schools in cases where affected individuals are unable to cope in mainstream classes (C Lombard 2015, personal communication, July).

In total, FARR screened 1452 grade one learners from the 14 primary schools in the Saldanha Bay Municipal area. The research was initiated in 2013. Of the learners screened, 116 diagnoses of FASD were made and these results were fed back to parents through a personal diagnostic feedback and counselling session, which took place in November and December 2014. During this time, purposive sampling was conducted to recruit and invite participants who met the inclusion criteria to take part in the current research project. FARR identified 116 children with FASD and the research project was briefly explained to all 116 parents or guardians who attended the diagnostic feedback and counseling session. This was conducted by the FARR members involved. Twenty-five mothers gave written consent and agreed for FARR to give their contact details to the researcher. Of the 25 participants who agreed to give their number to the

researcher, 18 participants were contactable. The research study was described telephonically to these individuals by the researcher and participants were invited to take part in an interview. Sixteen participants agreed to meet for an interview at a convenient time and date and interview appointments were scheduled in February and March 2015. In total, 13 participants arrived and were interviewed, while three participants were lost to follow up. Of the 13 participants interviewed, 11 participants were biological mothers of the child with FASD, and two were foster mothers. In addition to the 13 participants interviewed, three community workers, who were directly involved in the feedback process and had interacted with these mothers, were interviewed together.

The inclusion criteria for the participants recruited into the study is as follows:

- Women who have a child (or child in their care) who was diagnosed with FASD through the FARR epidemiology study, and who received this diagnosis during a diagnostic feedback and counselling session offered by FARR

In total, 13 individual interviews and a group interview comprising three community workers was conducted. Saturation is defined as the point at which the collection of new data will not introduce any new or relevant information to the study (Glaser & Strauss, 1967). Reaching saturation is an ideal goal for the purposes of the research but is challenging due to the time constraints of the current project and the nature of a minor dissertation (a time limit of eight months to complete the research and submit the findings was given for the current study). As the research was conducted up the West Coast, both cost and time were limiting factors. Despite these challenges, themes reoccurred throughout the data collected from the 13 interviews and the three community workers, and the researcher felt that saturation was met for the major themes described in this research.

This small sample size is characteristic of phenomenological methodology where the methods aim to study individual cases in detail to gain rich and in



depth information, rather than generalising the data from a large sample (Whitehurst, 2011). As generalisability is not the ultimate goal of this study, and there is great value of a small sample size in qualitative research in order to obtain in-depth and information-rich data, this sample size was adequate to conduct the research proposed (Marshall, 1996). Furthermore, the group interview with the three community workers added further insights and value to the research and added to the interpretation of the themes identified.

## 2.5 Description of participants

A summary of the socio-demographic characteristics of the participants interviewed is presented in Table 2 below.

All 13 participants were of mixed-ancestry descent; spoke Afrikaans as their first, and most often only, language; and were classified in a lower socio-economic category. Eleven of the participants are the biological mothers to the child diagnosed with FASD, while two women are foster mothers to their child and were related in some way. The children are in their care following either the inability of the biological mother to take care of the child due to her drinking habits (participant five) or the death of the mother (participant nine). The average age of the 11 biological mothers was 41 years. Eleven children had been diagnosed with FAS and two children had been diagnosed with ARND through FARR. Including both the biological and foster mothers, none of the participants had completed school. Five women were married, seven women were single and one woman was a widower. Of the 13 participants, seven were employed, five were unemployed and one participant had part-time (seasonal) employment.

**Table 2. Summary of participants' socio-demographic data**

Participant Code	Age	No. of children	Diagnosis of child through FARR	Child's school	Level of education	Marital status	Employment status	Current occupation	Place of residence
P1	44	4	FAS	St Andrews Primary	Grade 10	Married	Employed	?	Diazville
P2	48	4	ARND	Diazville Primary	Grade 9	Married	Employed	Domestic work	Saldanha Bay
P3	40	3	FAS	Diazville Primary	Grade 9	Single	Employed	House keeping	Diazville
P4	39	3	FAS	Eden Primary	Grade 8	Single	Unemployed	-	Vredenburg
P5*	48	6 biological, 2 foster	ARND	Eden Primary	Grade 9	Married	Unemployed	-	Vredenburg
P6	42	2	FAS	Diazville Primary	Grade 8	Married	Employed	Domestic work	Saldanha Bay
P7	29	1	FAS	St Andrews Primary	Grade 11	Single	Employed	Oyster / fish factory worker	Saldanha Bay
P8	41	2	FAS	Diazville Primary	Grade 7	Married	Seasonal employment	Grape picker	Saldanha Bay
P9*	69	3 biological, 2 foster	FAS	Diazville Primary	Grade 6 (biological mom)	Single	Unemployed	-	Diazville
P10	42	4	FAS	Panorama	Grade 7	Single	Employed	?	Vredenburg
P11	52	5	FAS	Eden Primary	Grade 8	Widowed	Unemployed	-	Vredenburg
P12	29	1	FAS	St Andrews Primary	Grade 7	Single	Unemployed	-	Diazville
P13	42	7	FAS	Panorama	Grade 6	Single	Employed	Domestic work	Vredenburg

\* Foster mother

## 2.6 Community workers

The three community workers interviewed all had a three year employment contract in Vredenburg with FARR. They had received intensive FARR training and attend annual refresher courses pertaining to the FASD work that they do. These women were all involved in the diagnostic feedback and counselling sessions with the parents as part of the prevalence study, and are actively involved with community visits in the West Coast region as part of FARR's prevention work. These women all had social work backgrounds; one woman was a qualified nursing sister. They were passionate about people and the work that they were involved with and emphasised that they wanted to motivate, encourage and make a change and difference in the lives of the individuals in the community.

## 2.7 Research assistant

An experienced research assistant helped the researcher with aspects of the study. The research assistant is a Masters student in Social Anthropology at the University of Stellenbosch, with experience in qualitative research. Her experience involves conducting Afrikaans interviews with participants recruited through the public schooling system and focuses on research on the Human Pappilomavirus (HPV), specifically regarding the biopolitics of cervical cancer in South Africa. She therefore had the relevant healthcare and qualitative research background to help with the research. The research assistant is fluent in Afrikaans, the preferred home language of the participants, and helped to obtain consent and conduct the interviews in the language of choice (Afrikaans). In addition, she helped with the transcription and translation of the raw data and added great value to the process of obtaining data based on her experience.

## 2.8 Research setting

Permission was granted to conduct all interviews at the FARR office at Vredenburg Private Hospital. The participant interviews and group interview with the community workers were conducted at this venue, situated in the West Coast region of South Africa. Vredenburg Private Hospital is accessible by

public transport services and is situated nearby the residence of all participants. This provided convenience for the participants to attend the interview. A 120 rand Pick n Pay food voucher was given to each participant and compensated for any costs incurred in attending the interview. Some participants did not have cash on them for transport money to return home, and in such cases transport money was given in addition to the voucher to cover these costs. This is acceptable practice in all FARR studies, as participants are doing researchers a favour by partaking in a study which provides them with no additional benefits and may otherwise be viewed as exploitation (L Olivier 2014, personal communication, August). In addition, refreshments (coffee, tea, biscuits, donuts, cake) were offered to promote comfort.

This private setting provided benefits over a home environment, as home settings often pertain to a distracting environment and may hinder and restrict participants expressing truthful feelings and experiences with the fear of being over heard by family members or children. This venue ensured privacy as it allowed the participants to seclude themselves from their community and express themselves exclusively, without being identified, labeled or judged by other community or family members and without disruption. This alleviated any risk of family or community members learning that the participants were involved in such a study, or the risk that they may overhear the interview or question why the participant was being interviewed.

## 2.9 Data collection

Face-to-face interviews were conducted to obtain the raw data for the study. Before each interview was conducted, the researcher or research assistant explained the purpose of the research project to each participant in the language of their choice and obtained written consent to take part in the study and for the interview to be audio recorded. Time was spent going through the information form in detail. Confidentiality and anonymity were ensured and the voluntary nature of the study was emphasised. Lastly, written consent was obtained for each participant (Appendix B). Each participant received an information form,

the contact details of the researcher, research supervisor and Human Research Ethics Committee, and a duplicate copy of the consent form which they had signed. This was available in both Afrikaans and English.

A question guide (Appendix A) was designed by the researcher in such a way to allow participants to express their viewpoints, perceptions, feelings and experiences freely, providing rich qualitative data (Turner, 2010). The question guide comprised of open-ended questions which focused on the comprehension, feelings and needs of the mothers, and explored the mothers' feelings in terms of drinking alcohol in future pregnancies or managing her child currently following the diagnosis. These open-ended questions were carefully worded in a neutral and non-bias manner (McNamara, 2009) and provided flexibility for the interviewer to ask probing questions as a means of follow-up. To ensure that all questions were answered in full and participants were kept on track, neutral follow-up prompts were erected to further understanding and exploration into the mothers' experiences and feelings (Creswell, 2007). These open-ended questions were critically reviewed by three independent supervisors (Dr Tina-Marié Wessels (PhD in genetic counselling involving qualitative research), Leana Olivier (FARR CEO) and Chanelle Lombard (FARR researcher and genetic counsellor)), peer reviewers as well as a specialist in qualitative research, namely Prof. Chris Colvin (associated professor and head of division of Social and Behavioural Sciences). Closed-ended questions were only used to obtain socio-demographic information about the participants. The first interview was used to assess the interview process and to determine if the question guide was appropriately addressing the research questions. Appropriate adjustments were made accordingly following this interview, such as rewording certain questions which were misleading or adding additional follow-up prompts which were better understood and interpreted by the participants.

The researcher felt that the participants should be given the opportunity to express their experiences freely in the language of their choice, which would further enrich the data (Murray & Wynne, 2001). The researcher can understand and partially speak this language of choice but was not completely confident in

conducting the interviews in Afrikaans. The research assistant therefore conducted the interviews to alleviate any language issues which may have arisen, and to probe more effectively. The researcher was however present in all interviews, observed both the verbal and non-verbal behaviour of the participants, recorded notes, directed the session where appropriate, and answered any questions which arose.

In general, the research assistant followed the question guide and asked suitable follow-up prompts where appropriate. In the few instances where she struggled and was misguided, the researcher redirected the interview. Although some participants were reserved and reluctant to open up, the majority of the participants interviewed were communicative, open and honest, providing rich and in-depth qualitative data.

In total, two trips up the West Coast region of South Africa were arranged in February and March 2015. The research assistant accompanied the researcher on both trips. Seven interviews were conducted on the first trip and six interviews were conducted on the second trip. The duration of the interviews ranged from 25 minutes to 75 minutes and for each session two voice-recorders were used to record the interviews. In addition, the researcher recorded field notes and made observations which added value to the research. Prior to the session, the women were asked to attend the session alone, however participant 10 brought her daughter to the session and participant nine (foster mother) brought her older biological daughter to the session. This did not change the dynamics of the session and in the case of participant nine, it added value and provided further insights into the research. One interview was stopped at 25 minutes due to participant distress and a suitable post-interview referral was arranged. One participant required a letter of attendance for work which was given to the employer (with the researchers contact details) without disclosing the reason for the interview.

Data was collected from the three community workers in the form of a group interview. The primary aim was to generate information on the collective views

of the community workers, and the meaning behind such views (Gill *et al.*, 2008). In order to obtain data about the community and interpretation of the burden of FASD from the collective perspective of these community workers, a group interview was most appropriate. The group interview was not recorded as themes were not generated from the raw data. This group added further insights into established themes generated from the participants' interviews.

As the mothers were disclosing personal and sensitive information stemming from a different vulnerable perspective, a one-on-one interview approach was most appropriate for obtaining such data. This method is most appropriate for exploring personal and sensitive topics which participants may not feel comfortable sharing in a group environment (Gill *et al.*, 2008).

#### 2.10 Data analysis

The raw data obtained from the audio recordings was transcribed using a software program called Express Scribe Transcription Software. The transcribed material was later translated from Afrikaans into English. The research assistant helped with the transcriptions and translations and this was cross-checked by the researcher as well as an individual fluent in Afrikaans to check for any inconsistencies. In addition, the researcher corrected all spelling and grammatical errors found in the final translated material. The final translations were compared to the researcher's field notes to check for transparency. An alpha numeric character was assigned to each participant (e.g. P1) and these were used during the production of the transcriptions and translations in order to protect the participants' identities.

The analysis of the final translated material was conducted in two phases. In the initial phase, a thematic content analysis (TCA) was undertaken to analyse the data. In this analysis, the data was sifted to identify similar patterns which were later grouped together to identify themes (Hansen, 2006; Holloway, 2008). This analysis was ongoing until a point of data saturation was met where the main themes were identified. To do this the researcher repeatedly listened to the audio recordings and read through the translated material to familiarise herself

with the data. Initial ideas were noted and provisional themes which arose and captured the essence of the text were identified. As more interviews were analysed, these provisional themes were listed and refined into developed themes and appropriate excerpts were highlighted which were relevant and best depicted each theme. QSR NVivo 10 software was used to organise the themes and sub-themes identified. These themes were identified separately for the interviews with the foster mothers, biological mothers, community workers and research field notes. Main themes were then extracted from the data collected from the biological mothers, and the same themes emerging from the data from the foster mothers, community workers and field notes were compared and used to provide further insights and validate these themes. A thematic map was then drawn up, analysing the entire data set to define and name themes and to interpret the connections between themes. Throughout this process, the research question was kept in mind (Vaismoradi *et al.*, 2013).

These themes were reviewed by the researcher's supervisors (with specialised training in qualitative research and in dealing with mothers of FASD affected children) which ensured that the data was evaluated appropriately and that over analysis or emphasis of specific parts of the data collected did not taken place, which eliminated research bias (Creswell, 2007). Additionally, the research findings were presented at a Clinical Research Centre Qualitative Forum meeting, attended by specialists with valuable experience in healthcare communications and qualitative research, which aided the researcher to reflect on, discuss and shape the research findings and ideas. Peer comments were also incorporated in this data analysis process. In the final phase, the findings were interpreted through comparison and referencing to previous literature. Therefore, phase one aimed to generate inductive themes while phase two interpreted these themes within a broader theoretical framework.



## 2.11 Ethical considerations

### *2.11.1 Ethical approval*

Ethical approval was granted for this study by the Medical Research Ethics Committee of the University of Cape Town (HREC/REF: 811/2014, Appendix D).

### *2.11.2 Consent*

Consent was initially obtained from all parents in the FARR epidemiology study. Mothers involved in this study were informed of and counselled about their child's diagnosis in November 2014. At this time, FARR explained the purpose of the current research study and it was stressed that participation in the study was voluntary and that participants could withdraw from the study at any time. Individuals who agreed for FARR to give their details to the researcher gave written consent. The consent forms explained the study purpose, voluntary nature of the study and that by signing, the mother gives permission for FARR to give her number to the researcher (Appendix C). Prior to the interview, an information form was given to each participant describing the nature of the study (Appendix B). Written consent was obtained from each participant agreeing to take part in the research and for the interview to be audio recorded (Appendix B). These forms were available in both English and Afrikaans, catering for the particular language preference of the participants. All women had the capacity to give consent.

### *2.11.3 Confidentiality*

The audio recordings of the interviews conducted were transcribed and translated as soon as possible following the interview. Data, such as consent forms, audio recordings, translated and transcribed verbatim as well as observation notes were stored safely in locked cabinets and on password-protected computers. Transcribed and translated data was backed-up on an external hard-drive which was stored in a locked cabinet. Access to this data was limited to the researcher, the research assistant and supervisors only. In order to ensure anonymity, only an assigned alpha numeric character for each

participant was recorded on the interview question guide, notes and transcribed and translated material and the collection of personally identifiable information, which was not of value to the study, was avoided. No full names of the participants were recorded or noted. In some of the excerpts the participants make reference to specific individuals in their family or community. Fictitious names were consequently assigned to ensure anonymity for the individuals mentioned. All data collected was discarded after the research had been conducted. These terms of confidentiality were described to the participants, and it was ensured that the participants would remain anonymous and no details would be given to any family or community members.

#### *2.11.4 Risks/ benefits to the subject*

Participants who were recruited into this study were emotionally vulnerable in terms of both receiving their child's diagnosis and falling victim to the circumstances and context in which they lived. Evoking an emotional reaction following the discussion of such sensitive information was therefore a potential risk to the participants. These risks and discomforts were minimised as the researcher and research assistant were sensitive and empathetic toward the participants' emotions and feelings and responded in a manner which did not make the participants feel judged or misunderstood. In addition, information which the participants did not feel comfortable discussing was avoided and the participants' wishes were respected. It was discussed before the interview began that should the researcher feel that any emotional response evoked by a participant warrants the need for a counselling session, an appropriate referral would be made. One of the participants did experience an emotional breakdown and consequently the interview was stopped and an appropriate referral was made through FARR for psychotherapy (following the consent from the participant).

Despite the potential risk of evoking an emotional response, there was also a therapeutic benefit to discussing one's experiences and feelings. This was the case for many participants interviewed as it was found that several participants

had previously struggled to trust and open up to someone about their feelings and in some cases, the interview was the first time that they had opened up to anyone following the diagnosis. Following the interviews, the participants had the opportunity to ask the researcher any questions about FASD or FARR. In cases where the researcher was unable to answer the questions asked, FARR's contact details were given to the participants. Due to the benefits of the study, these justified and out ruled the potential harm.

## 2.12 Ensuring academic rigour

In order to enhance the rigour of qualitative research, the research must be credible, dependable, confirmable and transferable as first proposed by Lincoln and Guba (1985). Credibility refers to how believable and trustworthy the findings are (Polit & Beck, 2006). Dependability refers to the concept of reliability in quantitative research and is used to assess how consistent the data is (Rolfe, 2006). Confirmability is associated with dependability and refers to the neutrality and accuracy of the data (Tobin & Begley, 2004). Transferability refers to whether the findings can be generalised and transferred to other contexts and settings (Leininger, 1994).

The concepts of validity and reliability will be described in detail to demonstrate how the researcher ensured academic rigour in the study. The four areas of criteria required to enhance rigour, namely credibility, dependability, confirmability and transferability, will be incorporated in this discussion.

### 2.12.1 *Validity and reliability*

Validity pertains to the degree to which the data collected accurately represents what it is supposed to. Internal validity is defined as the degree to which a participant's viewpoints have been accurately defined and reflected and that the findings are credible and depict a truthful explanation or interpretation of the phenomenon being studied (Hesse-Biber & Leavy, 2010). The credibility of the current research was enhanced through triangulation, whereby data was gathered from several sources, such as the participants', community workers' and foster mothers' perspectives, in order to confirm the findings. This

generated confidence in the credibility of the findings. This method was also used to ensure completeness of the data as multiple perspectives were gathered from a variety of sources to get as clear a picture of the phenomena being studied (Murphy & Casey, 2009). A major strength of the study was therefore the usage of different sources of information in the form of triangulation.

External validity pertains to the degree to which conclusions are appropriate outside of the study and is defined as the extent to which findings are generalisable and are comparable to a similar group of participants in a particular context (Beeson, 1997). In qualitative research, external validity is replaced by the concept of transferability. Rich, in depth and vigorous descriptions of the findings, in addition to excerpts and through comparison to previous literature, enhanced the transferability of the findings (Graneheim & Lundman, 2004). These descriptions allowed the reader to determine how applicable these findings were to specific contexts.

In order to ensure validity in the current study, raw data in the form of audio recordings, transcribed and translated verbatim accounts and notes were used as proof to depict accurate and complete records of the data. This raw data was read and reread several times and the transcribed and translated verbatim was cross-checked. The final themes were compared to the audio recordings to ensure that accurate and precise conclusions had been drawn and that no observer bias, in which case the researcher may only describe research findings which are significant to her work, had occurred. The themes were described together with excerpts from the raw data to provide proof and validity of the interpreted findings. The interpreted findings were discussed in detail between the researcher and research assistant. Furthermore, neutral and independent supervisors, qualitative research specialists and peers reviewed the findings to provide further credibility and reduce any research bias. The use of external and expert professionals is invaluable in supporting the credibility of the findings through peer debriefing to prevent researcher bias (Casey 2007). The research findings were also presented and discussed at a Clinical Research Centre

Qualitative Forum meeting. Through the direction of qualified supervisors, both the researcher and research assistant had ample training to conduct the interviews. The current research findings and interpretation thereof was compared to previous literature and strong arguments were made for this knowledge claim within the wider research community, making the research more valid and trustworthy (Kvale & Brinkman, 2009).

In order to enhance the trustworthiness of the study, the process in which the findings were made and conclusions were reached was described in detail. The use of NVivo software enhanced the rigour of the research as it represents a comprehensive trail of decisions which were made during the data collection and analysis process (Silverman, 2010) and this process provided a record of the process of decisions made during the analysis of the data. As NVivo was used to identify and link themes from different transcripts, this ensured that this was found for several participants and not just one which guaranteed dependability in different contexts (Houghton *et al.*, 2013).

Reliability pertains to precision and is achievable when the same data is replicated when the study is repeated by an independent researcher. It refers to the consistency of the findings (Kvale, 1996). Reliability was ensured in the current research by ensuring that all the interviews were conducted by the same interviewer and that the same question guide was used for each participant. This ensured consistency.

## Chapter 3: Results and discussion

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### 3.1 Introduction

This chapter will present and discuss the major themes and relevant sub-themes which emerged from the research. These themes are exemplified by including excerpts from the raw data which provide further validation and proof of the findings. Furthermore, interpretation of the themes is discussed by referring and comparing the results to reported literature.

In general, themes were extracted from the data obtained from the biological mothers, as the study's purpose is to explore the experiences of mothers who received their child's diagnosis of FASD after the child was identified through the FARR epidemiology study, and to explore their feelings in terms of drinking in future pregnancies and managing their child currently following the diagnosis. The findings from the two interviews with the foster mothers and group interview with the three community workers are included as they provide further insight and validation of the themes identified and therefore add value to the study. Findings from these two groups which link and add to these themes are therefore incorporated where appropriate. To ensure confidentiality, the participants were assigned an alpha numeric character which will be used for their identification in this chapter. In some of the excerpts, the participants make reference to specific individuals in their family or community. Fictitious names have consequently been assigned to ensure anonymity for the individuals mentioned, and are denoted by an asterisk (\*).

### 3.2 Themes identified

The themes and sub-themes were identified and developed by the researcher by listening to the audio recordings and reading through the transcripts several times, and by comparing those to the researcher's field notes (observations which stood out during the interview process). The themes and sub-themes were compared and discussed with the research supervisor, which further validated the themes. Related excerpts are used to illustrate each theme in order to provide proof and strengthen the arguments made. The excerpts are presented in English in this chapter and transcripts of the original language (Afrikaans) can be found in Appendix E. A discussion and interpretation of each theme and sub-theme accompanies each result and incorporates relevant published research where appropriate. The themes are presented in a particular order to allow the next theme to build on from the previous one. Table 3 provides a summary of themes and subthemes identified in the research.

**Table 3. Summary of themes identified**

Theme	Sub-theme
1. The community: Life is hard	<ul style="list-style-type: none"> <li>• <i>Role of the man</i></li> <li>• <i>Drugs and alcohol abuse are rife</i></li> <li>• <i>Illness and death</i></li> <li>• <i>Poverty</i></li> </ul>
2. The experience: Living with my child	<ul style="list-style-type: none"> <li>• <i>Problems with the child</i></li> <li>• <i>Change in management following the diagnosis</i></li> <li>• <i>Mothers feelings about the diagnosis</i></li> <li>• <i>Family and faith as a coping mechanism</i></li> <li>• <i>Clinics and schools as current sources of support</i></li> </ul>
3. Comprehension: A mixed understanding	<ul style="list-style-type: none"> <li>• <i>Incoherent understanding of the diagnosis</i></li> <li>• <i>How much alcohol can cause harm to an unborn fetus?</i></li> <li>• <i>Misconception about the effects of drugs on the unborn fetus</i></li> </ul>
4. Needs: Help or hindrance	<ul style="list-style-type: none"> <li>• <i>Wanting to know more</i></li> <li>• <i>Educational needs and awareness</i></li> <li>• <i>Need to change the social context in which these women live</i></li> </ul>
5. Prevention of FASD	<ul style="list-style-type: none"> <li>• <i>Prevention in future pregnancies</i></li> <li>• <i>Encouragement within the community</i></li> </ul>

### 3.3 Theme 1. The community: Life is hard

The trips up the West Coast and introduction into the women's lives were emotional and quite overwhelming. There is great disfunctionality in the community and immense psychosocial issues in the lives of the women. It was evident that these daily psychosocial issues and challenges were often greater than that of the FASD diagnosis received and the corresponding problems encountered in the child. While the problems in the child were of great significance to the mothers, it was yet another hurdle they had to deal with in life. Limited support from the man, broken families and relationships, the realities of drug and alcohol abuse and misuse, illness and death, and poverty were some of the bigger subthemes which emerged from the research, which will be further discussed in this chapter.

These issues and stories of a hard life do not justify the reason for drinking during a pregnancy, but it gives insight into the reason behind these actions. I often felt sad when sensing the pain and suffering the women had to endure in their lives, and empathised with their emotional reactions following a description of the problems which dominated their lives. Understanding the experiences of mothers who raise children with FASD, and the daily realities and complex problems which impact and shape their lives, is invaluable in understanding what needs and support the mother, family and affected child requires (Salmon, 2008). Familial, cultural and contextual circumstances have been found to influence a women's drinking behaviour (Jonsson *et al.*, 2014), and an insight into the lives of these women illustrates the complex cycle of daily challenges, and how alcohol abuse plays a fundamental role (Eaton *et al.*, 2014). This theme provides the social context to the research and underlines an aspect of vulnerability and disempowerment in the lives of these women, as they have fallen victim to their circumstances.

#### 3.3.1 *Role of the man*

A theme which kept emerging from the research was that of the role of the man. There appeared to be a general lack of support and leadership from the man, which further lead to broken relationships and dysfunctional families. Underlying this theme, there was a sense that the man ruled and dictated the



life of the woman and her family. It appeared that the partner was often a disappointment to the family. The family could not depend on him and this led to a great degree of struggle and suffering from the women's point of view. Many women were single and the father of their child was not involved in their lives. They often described their experience of having little to no support from the father of their child, both in terms of being involved in the life of the child and from a financial point of view. The following excerpt illustrates this:

***“He gives something one month and then not again. So I thought that I would rather leave it and support my own children by myself.”***

(Example 3.3.1.1, participant 4, single mother)

Many of the women were single parents and as a result of lack of support, they were forced to be the sole provider for their child. This was the case for participant 12. She is a 29 year old single mother who has supported her son for most of his life.

***“No, I don't care about the father. He was nine months old when I left his father and he lives behind the Seven Eleven here in the bay and I have told him nothing of this. But he, how can I put this, he doesn't want to give money for the child. It's the reason I don't care about him anymore. I will raise the child on my own with the all-pay that I receive to raise and care for him and my mother and father helps with him as well.”***

(Example 3.3.1.2, participant 12, single mother)

Very few of the women who were married described a happy relationship. From the experiences that the women spoke of, when the man was non-supportive, their lives seemed dysfunctional. However, if the man was supportive, the family had a chance to function and there was a sense of direction and stability. This was evident in the story told by participant 11, who recently lost her husband.

***“You shouldn't complain to other people about what you are going through but... lets rather leave that [started crying]. I am alone now, my life partner left me and now I don't take care of myself at all.”***

(Example 3.3.1.3, participant 11, widower)

In the interview with the three community workers, it was described that from their observations the fathers of the children are not as involved as that of the

mothers, which further validates these findings of lack of involvement and support from the man. This highlights the importance of men in terms of leadership in the community and how the women and families depend on them for family functionality.

The role of the man and the connection between his absence of support and leadership and a dysfunctional family was further validated by the story which foster mother P9 told. Participant nine was a 69 year old single mother who was looking after two foster children diagnosed with FASD. Her biological daughter was very unhappy about her mother being responsible for these foster children and believed that another woman in the family, who has a husband, should rather take care of the children as a male figure in the home will provide the much needed structure. The following excerpts illustrate this:

***“When there is a man then that child can be taught but when there isn't a man in the house then the children will do just what they want. If they feel they want to throw something and it hits your head, they'll do it.”***

(Example 3.3.1.4, participant P9's biological daughter)

Many women blamed the man for the reason for them drinking. In these stories, the women described drinking during their pregnancies because the men would either abuse or showed aggression towards them, were serially unfaithful, or abandoned and left them to look after the family and support the child alone. Participant four is a single mother who has raised her children alone. Her children's father was unfaithful towards her and gave little support to her, as described in the following excerpt:

***“He had another girlfriend. I don't know if they have children but I just felt that I cannot take it anymore. He can't have his bread buttered on both sides.”***

(Example 3.3.1.5, participant 4, single mother)

Some of these women would therefore drink due to the problems in their lives, which were often associated with the lack of support, leadership and trust in the man. There was a general sense of intimidation and fear of the man, yet a degree of dependency and submission. This was evident in the experiences described by participant one, who is in an unhappy marriage and has been abused by her husband for years.

***“I have not actually told my husband because my husband was in the army and to be honest I don't have a great marriage. I wanted to divorce him and I took to the Lord because we have been married now for 16 years and I hung in there for 10 years for my children and I trusted in the Lord that he will bring back my husband. He abused me. He is a different man when he's drinking than when he is sober because when he is sober you will not say there is a man in the house. But when he gets drunk he worries me because I'm scared I'm afraid he blames me and I know he won't be able to cope with it and I am not able to cope with it alone.”***

(Example 3.3.1.6, participant 1, married)

Several of the women described drinking alcohol during their pregnancy to keep up with the man and the lifestyle that he led. Other women described drinking to keep their man calm so he would not abuse or show aggression toward them, or due to their hopeless and vulnerable situation they found themselves in. The following excerpt shows this:

***“And she [participant's cousin] always had to drink with her boyfriend to keep him calm during her pregnancy because he was a bit rough.”***

(Example 3.3.1.7, participant 7, single mother)

The following excerpt describes the story of foster mother P5 who drank during her pregnancy due to the influence of the man in her life. She then divorced him and married a man who turned her life around. She now has a strong marriage with great support from her husband. He supports her and has a great relationship with all their children, including their two adopted children. As a team, they are a great support system and inspiration in the children's lives, as well as other children in the community which they occasionally care for.

***“No, I didn't really drink, with the third one. The first three children are from my first marriage, but I had an awful husband. He used to hit and kick me and I had to drink with him ... Then I started drinking beer again because of the life that I had then, you just go with the flow because he was a wild man and I didn't grow up like that. It's dances and places like that I had to go with to or else I didn't fit in. So later I just went with to fit in and then drank beer and then onto the stronger things. I didn't care back then because my life was what I thought it would be, a flop, and so I drank.”***

(Example 3.3.1.8, participant 5, foster mother)

May *et al.* (2005, 2008) found that domestic violence (spousal abuse) as well as poor parental relationship is significantly higher with children diagnosed with FASD and that the households which the children grow up in are unstable and chaotic as a result. This may in turn add to the poor behavioural traits in the child. In South Africa, rates of alcohol use and interpersonal violence or partner abuse are among the highest in the world and are connected to the social context in which they are found (Russell *et al.*, 2013). Olivier *et al.*, (2013) described that one reason for a woman's heavy drinking pattern often includes being a single parent, as seen in this research. Excessive drinking habits may stem from worries, vulnerabilities and frustrations due to lack of support they receive from the man and pressures of being a single parent. Further research has shown that a woman's risk for an alcohol exposed pregnancy include alcohol and substance abuse and partner characteristics (Morojele *et al.*, 2010). Such partner characteristics may include abuse, unfaithfulness and lack of leadership and accountability as described in these research findings. Furthermore, partners of women who misuse alcohol, portray violent behaviours, portray little to no support during pregnancy and who demand their pregnant partner should drink with them are jointly responsible for the FASD outcome (Jonsson *et al.*, 2014). This research validates that a man's character and tendency to abuse his woman often is associated with alcohol abuse and misuse in the woman and thus an increased risk for an alcohol exposed pregnancy. The research findings are therefore similar to what has been previously reported.

The research findings are valuable as little research has been reported on the paternal influence (Eaton *et al.*, 2014). These critical and understudied findings contribute toward the gap in this research which is required to better understand the reasons behind high rates of maternal alcohol consumption during pregnancy. In general, this subtheme demonstrates that there is a lack in male responsibility, support and accountability in the community. It further illustrates a woman's dependency on the role of a man and when a man cannot be depended on, it opens these women up to vulnerability.

### 3.3.2 *Drugs and alcohol abuse are rife*

From the stories told, it was evident that there is a culture of heavy drinking and drug abuse among the men in the community. In turn, this seemed to rub off on and influence the women. According to May & Gossage (2011), partners of women who bear FASD children are almost always heavy drinkers, whether it is heavy binge drinking episodes or chronic consumption of alcohol. Salmon (2008) explored the experiences of mothers who have FASD children and found that many of the women studied described having an alcoholic partner at the time of conception of their child and described a dysfunctional and broken relationship and family structure due to their partner's drinking habits.

More generally and looking at the community as a whole, the research found that there is a great burden of both alcohol and drugs, and that „tik“ (methamphetamine) abuse is common in the community. Several women spoke of the use of drugs prevailing most commonly among individuals of the younger generation, however it was evident that the misuse of both drugs and alcohol was widespread across the community. There seemed to be a general lack of responsibility among the youth as drugs and alcohol use as well as teenage pregnancies is a growing concern. Many women spoke of one or both of their parents or grandparents misusing alcohol, which indicated that this drinking culture has existed for many generations and has now become what is considered a way of life. Salmon (2008) found that women with FASD children often describe coming from families where alcohol consumption is a normal behaviour. Almost every women spoke of a personal experience of someone they knew who was caught in the trap of drug or alcohol abuse or misuse. The following excerpts provide proof of this finding:

***“But he is so deep in the drugs I don't want to talk about it...”***

(Example 3.3.2.1, participant 7, age 29)

***“No mam, how can I put it. They are more involved with drugs and tik.”***

(Example 3.3.2.2, participant 8, age 42)

***“Oh, don't even mention that... a lot of them tik... it's a big big problem. It's not just you thats affected, the baby is affected even more especially if you see how these people use drugs, its not worth it at the end of the day. Especially if you're pregnant, and you dont know that you're in trouble because you're already on it. You'll find out later, maybe a maximum of two or three months. You'll find out you're not feeling very well and your clothes aren't fitting very well and you end up going to the doctor to find out whats going on. Then you get a shock and try and do it right. But they hear they are pregnant and they just carry on. So who's fault is it now that the child isn't healthy. I feel like its the mothers fault, but moms these days aren't that type of person. Moms these days are younger and younger. It dangerous whats going on nowadays.”***

(Example 3.3.2.3, participant 9's biological daughter)

In general, the use of alcohol and drugs was both a way of life and recreational activity in the community. It was obvious that both drugs and alcohol are very accessible, and that many individuals in the community spend a large proportion of their weekly wage or monthly salary on the purchase of these items.

My overall impression was that this problem stemmed from peer pressure in the community. Boredom, as a result of unemployment and dropping out of school, was another factor. The reason behind school drop-out could be to find work, due to teenage pregnancies, because they got involved with drugs, or because they ran away with a partner at a young age. It was found that substance abuse was used as a way to deal with or numb the emotional reactions and vulnerable feelings of unworthiness emerging from a life of hardships. There was a sense of hopelessness in addressing such problems. Common reason for substance abuse have been reported to include peer pressure, boredom, a way to deal with hardships and financial issues, teenage rebellion and problems in life (Alcohol Rehab, 2014), as confirmed in this research. Participant 11's story demonstrates this finding. Her son got involved with drugs when he was in school and he has since made several bad decisions in his life. He is currently in prison.

***“He almost got to Standard 10 when he got involved with tik like all the other children here in Vredenburg.”***

(Example 3.3.2.4, participant 11)

The interview with the three community workers and two foster mothers re-emphasised this finding. The community workers stressed that alcohol and drug abuse is rife in the community, especially „tik“. They believed that unemployment, peer pressure (to fit in) and domestic issues were strong contributing factors. Foster mother P9’s daughter, who is more in touch with the community, said that drugs and excessive alcohol consumption, especially among the youth, is common. Her beliefs as to why this is a problem in the community are described in the following excerpt:

***“Maybe it is the life but maybe it is when I have a hard time. When I was a child and I see the way how I was grown up then I think wow why must I do something when I just can go and do nothing with my life. There are other cases here, maybe you are brought up in a house where there is alcohol. The mom though, you’ve got a sober mom. Maybe you have a father that abuses alcohol, but then you grow up and you can see what the best is for you. You make a choice, as a child you make a choice and as a child you make a choice as to what’s best for you. If you can make a positive choice then it will end positively. If you make a negative choice though, it will end negatively. What you put in is what you get out. If you believe you’re negative everything you touch is negative then it will be negative but if you have a positive mind then everything is positive for you.”***

(Example 3.3.2.5, foster mother P9’s daughter)

From the observations made and field notes reported, I suspect some of the women interviewed behaved as if they may possibly have been under the influence of alcohol or drugs at the time of the interview. Some might possibly be affected by FASD themselves. While this is only a speculation and not a diagnosis, I felt that it is important to describe such observations, as it makes this theme a reality, and illustrates the continuous cycle of problems associated with drug and alcohol abuse from one generation to the next in the community.

For example, participant three had a peculiar behaviour. She followed the interviewer around the room in the beginning stages of the interview; she fidgeted a lot and was hyperactive. Participant four smelt of alcohol and she kept putting her hand over her mouth and turning her head away when she spoke. Her eyes were swollen and her head shook. She was a single and unemployed mother, her child’s father had cheated on her and her child had been diagnosed with leukemia in addition to FAS. Participant 12 stormed into

the room during a previous interview without knocking, an hour before her appointment time. She portrayed peculiar behaviour as she was very fidgety and moved from side to side on the couch she was sitting on. She looked rough and badly groomed. She had a big scar across face, rotten teeth, was very thin, her finger nails were black (bruised) and several of the nails were completely broken and damaged. This participant didn't accept that her child's problems were due to her drinking during pregnancy and she blamed the father for drinking excessively. She did not open up and was closed with her responses. As she left the interview, she stumbled and fell down the stairs.

While these were only a few participants, these observations indicate both the effects of alcohol from the actions of previous generations, and the fact that the problem is still common among individuals of the community today. The ongoing cycle from one generation to the next of drug and alcohol addiction is likely to stem from the poor psychosocial context in which these women live.

According to previous research, the burden of drug use has been described to be greater in the Western Cape than in any other province in South Africa (Williams *et al.*, 2014). Williams *et al.* (2014) conducted a study in the Western Cape to assess the rates of alcohol and other drug use among pregnant women attending public sector antenatal clinics. Urinary testing indicated that at least 8.8% of these women tested positive for at least one drug, of which methamphetamine („tik”) was the most common. In addition, several studies have shown that mothers who bear FASD children often use other drugs, in addition to consuming alcohol (May & Gossage, 2011).

As described in detail in chapter one, South Africa has among the highest rates of FASD reported in the world (May *et al.*, 2007; 2013), especially among the impoverished communities in the Western Cape (Olivier *et al.*, 2013), reaching levels of as high as 208.8 per 1000 first grade learners (May *et al.*, 2013). Furthermore, South Africa has among the highest rates of alcohol consumption per capita among individuals who consume it (Parry, 2010). The drinking habits of the Cape coloured (mixed ancestry) population, the population group studied in this research, is associated with high rates of



alcohol abuse and recreational binge drinking which has been a way of life for centuries (Crome & Glass, 2000; London, 2000; Mager, 2004). This has resulted in high rates of FASD over the generations (Khaole *et al.*, 2004; Morojele *et al.*, 2010). Therefore, this research depicts these contexts which have been described in previous literature.

Building on the previous subtheme, it has been found that the major risks for interpersonal violence among pregnant women in Africa include alcohol and drug use, amongst other factors (Shamu *et al.*, 2011). Studies confirmed the same in South Africa, where alcohol use increased such rates, leading to a cycle where interpersonal violence increases alcohol use and alcohol use contributes to interpersonal violence (Russell *et al.*, 2013). This indicates that male characteristics (e.g. the tendency to abuse) and substance abuse, as well as other factors which are still to be mentioned in this theme, all contribute towards the context in which these women live which increases risk for an alcohol exposed pregnancy. These research findings therefore support what has been found in previous studies.

### 3.3.3 *Illness and death*

A theme which emerged from the research was the burden of illness in the community. The women shared many personal experiences of death and diseases, and how this was a great burden in their lives. It seemed as if the current diagnosis given by FARR was not the biggest concern in comparison to other illnesses which the women face in their community on a daily basis. In many of the experiences described, there was a sense of fear of who would look after the children if the mother were to pass away, reiterating the point that the child's father was not viewed as a reliable source of support. Death and illness was a daily challenge and concern that the women encountered in their lives.

For example, participant 11 shared her experience of raising a child with the challenge of being partially blind and suffering from chronic hypertension. Her husband recently passed away from a stroke and she described her challenges of not being able to work and in raising a child with the disability that she is living with. She depended on her neighbour to bring her to the

interview. Participant 12 described her experience of living with a congenital heart problem and the financial burden she encounters in having to travel to Tygerberg hospital for medical care. She described missing many appointments as she was scared she would need surgery and was frightened to receive this in case she died as there would then be no one to look after her child. Participant four's child, in addition to being diagnosed with FAS, also attends Red Cross Children's Hospital as she is a leukemia patient. Participant 13 described her one daughter being deaf and she herself was recently diagnosed with HIV. We had to stop the interview with her as she was so overcome by emotion and described not coping with her own diagnosis and the guilt from her child being diagnosed with FAS.

***"..... (silence and crying) ..... I am very stressed. I am very sick and that makes me think that I won't always be able to be there for her."***

(Example 3.3.3.1, participant 13)

Both foster mothers also spoke of death and illness. Foster mother P5 was still grieving the loss of her son, while foster mother P9 had lost two out of her three children. Their experiences of death may have been a possible reason for why they decided to take on the role of caring for other foster children. There was also a lot of fear surrounding not always being around to take care for the children. This indicated the vulnerabilities of life in the community and how death was a reality. Participant nine describes the situation in which her foster child often cries and fears that her foster mother may abandon her or pass away, as illustrated by the following excerpt:

***"What happens if Ouma [foster mother] dies and my mom dies. Then I tell her it's still a long time before that and the Lord will take of that day. You shouldn't think about that now. The Lord will provide and you shouldn't worry about that day now."***

(Example 3.3.3.2, participant 9, foster mother)

Foster mother P9 spoke of her foster children's biological mother's death and the illnesses which she suffered from. There was a great deal of confusion over what illness the biological mother had, as well as a misconception of such illness being caused by an episode of drinking. Regardless of this, there was a great sense of pain and suffering. When the biological mother was

discharged from hospital in the last stages of her life, and was sent home to die, she went drinking. This further validates the thought that alcohol is used to numb the pains of life and that life is so vulnerable in such contexts.

***“The cousin’s father and mother did say that she saw \*Nellie had a drink. Auntie didn’t mix her drinks then but \*Nellie drank it neat and when she came again the bottle was finished and there was also flu in the air. Many children got flu and they got better but \*Nellie didn’t get better. \*Nellie was sent to hospital later and then also to Groote Schuur. She had sores on her lungs and her windpipe, her windpipe was also too narrow and then they did an operation on it. We then went to visit her in hospital and you could see that she wasn’t ok, her heart wasn’t there, you could see that she was struggling to breathe and she had pipes down her throat so she couldn’t talk. We didn’t know it was cancer then so she came back and I went back to the clinic and asked what the pain was because she coughed and struggled to breathe and eat and so I told them to tell me what was really going on. So he pointed to \*Nellie’s lung and drew around it and told me the one lung was completely full of slime and the other one has holes in it.”***

(Example 3.3.3.3, participant 9, foster mother)

According to literature, the mortality rate for mothers of FASD affected children is high. In a study conducted by Urban *et al.* (2015), this rate was 29% among the Black African population group and 9.7% among the mixed ancestry group in the Northern Cape Province of South Africa. The mortality rate in this study is 7.7%, and again demonstrates how death is a pertinent reality. As a result, many children with FASD are placed in foster care (Whitehurst, 2011), as demonstrated in the current study. Common causes of maternal death among FASD affected children, which results in the high mortality rates reported, is associated with high levels of health issues, such as HIV and tuberculosis. Violence is an additional cause of death (Urban *et al.*, 2015)

Both Alio *et al.* (2011) and Laisser *et al.* (2011) found that communities in which there are high rates of substance abuse, increased poverty and increased assault rates, are more likely to experience negative health outcomes compared to other communities and that such negative health outcomes result from a complex chain of events common in communities which foster these outcomes, such as the community studied in this research. Alcohol abuse is common among the South African population

(World Health Organisation, 2014) and it has been found that such drinking habits are the most modifiable risk factor for bad health outcomes in the country (Lim *et al.*, 2012).

Foster mother P9 describes the biological mother's (of her adopted children's) life before she died. Both illness and domestic abuse were part of the same social context, which is in line with what is described in literature, as well as the current research findings from the biological mothers.

***"I think he was seven years old when his mom got involved with that man and he abused his mom terribly and his mom was sick at that time. He was very close to his mother ... That afternoon the man hit and abused her and \*Lial was too small and he naturally didn't know what was going on."***

(Example 3.3.3.4, participant 9, foster mother)

#### 3.3.4 Poverty

Poverty and financial burden was evident in the lives of the women. Many women, including their family members, were unemployed, and for those that managed to have found employment, their income was very little and often the families struggled to cover the basic costs of living such as food and shelter. In a study conducted by Urban *et al.* (2015), 43% of the women studied reported long-term unemployed. The burden of unemployment seemed to be a daily struggle and a great stress in the lives of the women studied. Again, the father of the children offered little financial support. There was a strong sense of dependency on members in the community, be it family members or non-relatives, for survival. Many women spoke of receiving a grant from the government, and while this helped, it only contributed toward covering basic essentials needed for survival. Overall, there was a sense of hopelessness and desperation, as seen in the following excerpts:

***“Because sometimes the school will ask for money and sometimes there is none. Like I had to buy her a new school uniform but I didn’t have enough money to do that but the school was very adamant about it. I had to buy a new school uniform for her. Because I have to buy food as well from my salary and then I still need to buy her a school uniform as well and her grant money is not enough and it doesn’t cover everything that she needs. I have a job but I don’t receive much. I work for R100 a day for three days and that is it for the month.”***

(Example 3.3.4.1, participant 10, employed)

***“I don’t want to send him to school without having him eat something in the morning. Then I go to the churches and ask around for some bread or people that I know.... And my son tells me that I shouldn’t buy him shoes but rather spend the money on electricity and some food for the house. He would rather go barefoot. But then I feel so hurt because of it.”***

(Example 3.3.4.2, participant 11, unemployed)

I felt that many of these women attended the interviews with a hidden agenda, which was to receive their R120 voucher. This once again emphasises the sense of desperation which comes with living on the bread line and how these women live from day to day looking for opportunities to survive, not knowing what the next day will bring.

The previous subthemes described illness in the community, and could be linked to the sub-theme of poverty. If the families in the community struggle to afford basic necessities, then luxuries such as medical care or transport money to receive such care may not be a possibility. Financial burden and poverty may directly relate to the increased rates of illnesses in the community described. The following excerpt captures this and indicates the harshness of the lives the women lead and how each day is a struggle for survival:

***“Because his father didn’t want to say anything to us and I had to clean him [father] and put on nappies because he couldn’t walk anymore. And everything cost a lot of money. And I have told him [son] that it is much better that his father is gone because how would we have survived, we can’t afford all of it.”***

(Example 3.3.4.3, participant 11, describing the financial burden of caring for her husband when he was dying)

Financial burden, hopelessness and anxiety may also contribute to the drinking habits of the community. This act may numb the harsh realities and

financial stressors in their lives, as evident in the words spoken by participant 11:

***“Until the man returns and before that I would have to ask his boss to help me out and I would ask him to just explain to them that the man is coming and he will pay the rent. Then I would go to the bar and drink myself silly and then I would come back. I didn’t want to see or hear from anyone. That was what it was like at that time.”***

(Example 3.3.4.4, participant 11, unemployed and now single)

Marginalised and poverty-stricken communities use alcohol as a method of recreational activity as it is freely available and relatively inexpensive. A cycle of poverty and lack of education leads to women drinking alcohol when they are pregnant or before they find out they are pregnant (Campbell, 2007). Olivier *et al.* (2013) described low socio-economic circumstances as a reason for heavy drinking in communities. Population based studies in South Africa have reported that populations who live on the poorest rural farms, in the worst living conditions, poor nutrition is common and recreational binge drinking is a norm have the highest rates of FASD (May & Gossage, 2011). Furthermore, it has been found that more severe forms of FAS and pFAS are most common among women who fall into a lower socio-economic category. This has been found in various countries in the world (May & Gossage, 2011). As the majority of children in this study who received a positive diagnosis were diagnosed with FAS (the severest form of FASD), and the mothers interviewed fell into a low socioeconomic category, the current research findings supports such literature.

Comparing the findings in this sub-themes to the others mentioned in this theme, Russell *et al.* (2013) sited that women who experience interpersonal violence are more likely to categorise their health as poor, and that these rates are concentrated in impoverished communities where women have lower educational levels and suffer from great financial burden. Furthermore, when pregnant women reside in socio-economic disadvantaged contexts, health consequences are amplified (Russell *et al.*, 2013). Singer (1996) introduced the public health term syndemic which describes the relationship between health problems and the context which shapes them (Singer & Clair, 2003). For prevention of syndemics one needs to address the contextual

factors which connect the disease outcome (Millstein, 2001). In South Africa, factors contributing to negative health outcomes include alcohol abuse, interpersonal violence among pregnant women and poverty (Russell *et al.*, 2013). High rates of these factors are found in South Africa when compared to women around the world. They emphasised the need for recognition of the psychosocial and contextual factors which lead to FASD. Surveillance of the prevalence of alcohol consumption among pregnant women as well as future interventions is highly stressed (Russel *et al.*, 2013).

### 3.4 Theme 2. The experience: Living with my child

The experience of living with a child with FASD is one among a multitude of struggles which the women face in their social context on a daily basis, as seen in the previous theme. This theme describes how the women experience and manage their child, how they feel about being the cause of their child's problems, how they cope and where their support systems lie.

#### 3.4.1 *Problems with the child*

In general, the women were very open and honest about the problems they encounter with their child on a daily basis. The women were frustrated in terms of dealing with the child's problems, and this caused huge stress in their lives. Specifically, the women spoke of issues at school and that their child struggled to learn. They described their child as being „slow“ (delayed development) which caused a lot of worries regarding both their schoolwork and progress academically. Many women admitted to their child needing additional help and support, with some of the children having already been held back a year or two at school. Coupled with this, the women spoke of concentration and behavioural problems, which further added to the stress and frustration of the mother. A lack of concentration was often described as „forgetfulness“ or „tiredness.“ This problem further aggravated and added to the struggle of learning new work as well as the child remembering to do his or her homework or household chores. The mothers also described hyperactivity, or as they would call it „being wild,“ as a major behavioural problem. Overall, the women portrayed acute frustration in dealing with their

child and his or her symptoms, especially in terms of learning and behaviour. The stories told by participant six describe this well:

***“Look the reason why I said that he can participate is because he has problems with learning. And he is now in grade two. He had to redo grade one twice ... because he has difficulties with learning and he plays a lot.”***

***“Like with his shoes. I would have mine on already and then I ask him to put his on as well. Then he would put his shoes on the wrong feet. But I say to him that he is a big boy now and he needs to know how to do things. I don't want to get angry with him about it or make it stressful for him. But I do keep telling him that he will need to work harder at his schoolwork.”***

***“I told him yesterday when he gets back from school in the afternoons when he changes his school clothes from normal clothes that he should put them all in a pile on his bed and not throw it on the floor like he usually does it in the afternoons. He does this every single day and I talk to him every single day about this. And that is my problem, every single day it is the same problem.”***

(Example 3.4.1.1, participant 6)

The interview with foster mother P5 further validated these findings, where learning and behavioural concerns were once again one of her greatest challenges in managing her foster child. As findings from the foster mothers was the same as that of biological mothers described, it provides further insight into this subtheme.

***“There was already a learning problem at school, so they asked me if the child could hear properly because she doesn't concentrate and it doesn't seem like she listens. They have to repeat things a few times... She can read, but doesn't really read ... When it comes to the reading though, she'll find the difficult names and then carry on reading after that and she just skips over the word. She's making progress though.”***

***“Then she sat there for two or three years and only then got to grade one and then she sat there for two years and then she passed.”***

(Example 3.4.1.2, participant 5, foster mother)

Participant nine attended the interview with her biological daughter. The biological daughter portrayed great anger and frustration towards the foster children. She did not like the childrens behaviour and how they treated and disrespected her mother. It was clear that this had strained the relationship between her and her mother. This caused a fight to break out in the interview



as foster mother P9 defended the children. Foster mother P9 felt responsible for them and did not want the children to be split up into different foster homes. She did however admit to the children being a challenge for her. This illustrates the destruction that these children can cause within family dynamics. The following excerpt illustrate the feelings P9's biological daughter portrays:

***"I'll be very honest, I will be very honest if I am gonna tell you now. I don't like them, I am very honest. I don't like them because their behaviour, oh man. You won't believe it, I don't like them. Because you know why, I am the only child of my mom. We was three but the other two passed away. So the words they give to her, say to her, the swearing and the things they do, no man. And my point of view is, she is my mother and I didn't do that to her. I have five kids and none of them do that to her. See? And my five kids is her only grandchildren and none of them do that to her. Really now. I don't like them. I will say not really like them but I really don't like them. But no man... their manners I don't like at all. There's no manners you see. So where is the bigger people, where is the elder and where is the child and who is the youngest and who is the elder. You see?"***

(Example 3.4.1.3, foster mother P9's biological daughter)

Granitsas (2004) found that foster parents caring for FASD children experience feelings of frustration regarding the challenges associated with medical, learning and behavioural problems seen in their child. Parents of children with FASD often describe destructive and challenging behavioural characteristics and that coping with these traits has a direct impact on family dynamics and relationships, leading to chaotic home environments. Furthermore, mothers often experience frustration when dealing with their child's learning and memory challenges as well as high levels of stress (Snaders & Buck, 2010). This was evident in the current research findings.

Salmon (2008) conducted a study looking at the experiences of biological mothers who raise children with FASD in New Zealand. Educational problems and delayed milestones; cognitive concerns such as lack of concentration, impaired memory, difficulties understanding new information and inability to understand consequences; as well as behavioural concerns such as hyperactivity, aggression and destructiveness were among the greater challenges they experience with their child. Parents raising children with FASD therefore experience great challenges associated with the child's

behavioural, concentration and associated problems at school, causing a lot of stress and frustration in their lives (Phung *et al.*, 2011). Understanding the experiences and challenges faced by mothers and parents raising children with FASD is essential to understanding their needs and to provide appropriate support (Whitehurst, 2011). The findings described in this subtheme, which are similar to previous research reported, may help to identify such needs and provide the support required by both biological and foster mothers of FASD children. These needs will be further discussed in theme four.

#### *3.4.2 Change in management following the diagnosis*

Although it was an emotional experience receiving their child's diagnosis, the women seemed grateful for having gone through the process and for receiving the information they had at the time of the diagnosis through FARR. The women seemed to have benefitted and had a greater awareness for and understanding of the problems in their child as well as a greater tolerance for their child's behaviour. From this knowledge they felt empowered to manage their child better and it gave them something to hold on to which encouraged, motivated and directed the mothers in terms of managing their child. They obtained information in the process which has helped them to feel like they are making a difference and can help their child in some way. Many of the mothers spoke of helping their child with his or her homework and followed the instructions and tasks which FARR, as well as the teachers at the school, had given them. It was also evident that the teachers who knew about the diagnosis were better equipped to help the child and advise the mother further following the diagnosis.

***“That’s why I feel like I want to help \*Austin much more.... because to be honest no one understands him they think he is naughty. And I have also said that about him ... But now I understand him maybe someone else doesn’t but I know now how to help him and how to work with him.”***

***“Yes, I know now what he is experiencing and know now how to help him.”***

***“Yes because otherwise I would have never known that I am doing something wrong and now I know I need to be patient with him.”***

(Example 3.4.2.1, participant 1)

***“When I sit and think about what I understand about the syndrome she is born with then I just read the letter that they gave me. I forgot to bring it along today but it is in my file. I always page through it. I always help her with her tenses and I let her wash her own socks or things. Sometimes I would give her a dirty shirt of hers and let her rub that. They told me that that’s how her muscles develop.”***

(Example 3.4.2.2, participant 4)

These findings were further validated through the experience of the foster mothers. They said that they valued the information given by FARR and said that it has helped in their management of the child going forward.

The women were also more conscious of their child and his or her problems and seemed to put more effort into building relationships with him or her. The relationship between the mother and child seemed to be stronger as they both depended on each other to get through the struggles in their lives. As the man was not so involved, the mother and child had learnt to depend on each other.

These findings are in keeping with research in which parents of children with FASD have indicated that their ability to care has improved following the diagnosis and a better understanding of their child’s symptoms. Parents in general show both concern and frustration around their child’s challenge to learn and remember information, however following the diagnosis, they had a better understanding of their child’s challenges which altered their management (Snaders & Buck, 2010). In a study exploring the experiences of foster and biological parents caring for a child diagnosed with FASD, both foster and biological mothers felt regret for mishandling their child in terms of his or her symptoms before they were aware of the child’s diagnosis, but felt relief and validation following a better understanding of the child’s challenges after receiving the diagnosis (Snaders & Buck, 2010). Previous research, in conjunction with the current research findings described, indicate the value of receiving a child’s FASD diagnosis in understanding the child’s problems and changing the management of the child in a positive manner. In addition,

studies have revealed the importance of an accurate diagnosis and early intervention which directly helps FASD children achieve a higher educational level (Ryan & Ferguson, 2006) and contributes towards the prevention of future social problems (Snaders & Buck, 2010).

### *3.4.3 Mothers feelings about the diagnosis*

It was found that many women were overcome by emotion during the interview process. Many of the women were nervous (often intimidated and scared), anxious and reluctant to open up, but after they settled into the interview, they felt safe and revealed their vulnerabilities. In addition, the women benefitted from talking about their feelings. Amongst the biological mothers, there was a lot of guilt, blame, shame and anger. It was also found that the emotions they were experiencing had not been expressed or dealt with previously.

For example, participant one was overwhelmed by guilt, anger (at herself and the situation) and shame. She started crying within the first minute of her interview. Towards the end of the session, she could not stop talking and had released emotions or feelings which had been bottled up. It was evident that she had many issues that she had not yet dealt with. Participant eight was very uncomfortable and anxious, she did not open up during the interview and admitted to not telling anyone about her child's diagnosis. The researcher felt that this participant felt guilty and ashamed and had not processed any emotions. Participant 13 was so overcome by sadness, guilt, shame and vulnerability and was not coping with the current problems in her life. She had an emotional breakdown during the interview, and for ethical reasons the interview was stopped and arrangements were made to refer her for psychotherapy. In comparison, foster mothers P5 and P9 were very open and honest and did not portray any signs of guilt or shame. This was interesting as they were not the cause of their foster children's problems.

Guilt was therefore a dominating and overwhelming emotion experienced by these women. These women were ashamed as they were the cause of their child's problems. This was evident as many women had not really told anyone about the diagnosis and were overwhelmed by emotion. They only

shared this information with close family members whom they felt they could trust, or individuals in their lives who were helping them with the management of their child. Additionally, many of the women feared being blamed. As they blamed themselves and were struggling with feelings of guilt, these women often struggled to accept their child's condition or that the problems in their child were a result of them drinking during pregnancy. These women were overwhelmed by emotion and were struggling to cope. The following extract illustrates this finding:

***“Yes, because I am blaming myself even. I said that I cannot take it even if I only think about it and I am not a drinker... and if my mom hears that I drank during, I would die because it is the truth...”***

(Example 3.4.3.1, participant 1, married but has not told her husband about the diagnosis)

As described in previous research, in which the experiences of women who raise children with FASD were explored, many women feel conflicted and are overcome by feelings of guilt following their child's FASD diagnosis (Phung *et al.*, 2011; Snaders & Buck, 2010; Campbell, 2007). In addition to guilt, Phung *et al.* (2011) found that these women often sense feelings of grief and regret while Snaders & Buck (2010) found that the women feel hopeless in terms of their child's future. Whitehurst (2011) found that a great deal of emotional conflict was experienced by parents of FASD children, as they often are stressed and experience emotions such as anxiety, fear and guilt. Overall, these parents view life as a continuous struggle and they are often left desperate and vulnerable. The findings therefore support previous literature.

Many women spoke of the fact that there were very few people in the community who they could trust and as a result they often isolated themselves from the rest of the community. They had a negative attitude towards the community and described experiences of judgment, gossip and distrust amongst the women in the community, or even amongst the children towards each other at school. Due to the dynamics in the community and the fact that these women cannot open up about their feelings or wrong doings, this may contribute towards and further prohibit the women from overcoming feelings of guilt and shame and moving on to a stage of acceptance.

Additionally, as women cannot open up and share their experiences, this further prohibits awareness in the community. Participant one and participant eight describe these findings well:

***“I live in a very different environment ... I will never ever tell them. They gossip way too much. I have only told my sister and mom but not outside people at all. I don’t even want to tell my own husband about it because I don’t know how he will react if I do. I only trust my mom and sister because \*Austin is with them during the day and they need to know so they know how to handle him as well and they won’t then be able to say but they weren’t aware of it.”***

(Example 3.4.3.2, participant 1)

***“The people there are ugly, and they are big drinkers ... its better if I work through things in my own way, because they tend to talk a lot, they’ll say I went looking for it.”***

(Example 3.4.3.3, participant 8)

Mothers of children with FASD often describe feelings of judgment by other individuals as people often assume that they are a certain type of mother (Whitehurst, 2011; Salmon, 2008). Both a lack of understanding and support in communities can very often leave the mothers of FASD children feeling lonely, isolated and unable to cope (Whitehurst, 2011). In comparison, individuals who were diagnosed with FASD often feel stigmatised because of their diagnosis (Rutman & van Bibber, 2010). According to literature, foster mothers and biological fathers often express anger and blame towards biological mothers who have drunk alcohol during their pregnancy (Snaders & Buck, 2010; Gardner, 2000).

In general, the women were disappointed in themselves and regretted what they had done. They were hard on themselves and wished that things could have been different, or that they had known about the effects of alcohol beforehand.

***“I felt a bit sad because it was my fault. I caused it. If I didn’t drink then it wouldn’t have happened. I did feel very sad and down but I will not let that get me down. I’m going to try and forget about it. Not to forget but to be better by helping him with schoolwork or anything that he maybe has difficulties with.”***

(Example 3.4.3.4, participant 7)

While most of the women admitted to drinking during their pregnancy and acknowledged that the problems seen in their child were associated with this, there was a sense of defensiveness and denial (either that their child has problems or that they were the cause of the problems). In a study conducted by Urban *et al.* (2015), maternal alcohol consumption was denied in 12% of the participants studied and it was cited that stigmatisation among the community is a common reason for under reporting alcohol use. Participants six and 12 blamed their partners for being the cause of their child's problems, while participant two was in denial over her child's diagnosis.

***“But my baby, he is healthy. He is healthy, and he is eight years old and he is healthy. It is just that he has difficulties with learning. I am 42 years old now and his dad is 50 years old. His dad was much older when I took him and then I fell pregnant. He drank a lot and I don't know if that could be the reason why. Because I didn't drink or smoke.”***

(Example 3.4.3.5, participant 6)

***“No, there is no problem with her. No problem.”***

(Example 3.4.3.6, participant 2)

It was found that many women were shocked about the diagnosis when they received it through FARR. It was not something that they expected or had heard about previously. This may have impacted on the amount of information that they recalled from the day. Participant 10 illustrates this point:

***“It was a shock to him as well because both of us didn't know, we thought that she was a normal child.”***

(Example 3.4.3.7, participant 10)

The news that a parent receives that their child has a developmental disability is among the most frightening and confusing information parents receive and often leaves parents in a state of shock (Beckman & Beckman Boyes, 1993). Supporting and encouraging women who raise children with FASD may help to allow the women to accept the condition and process the overwhelming emotions experienced.

#### 3.4.4 Family and faith as a coping mechanism

During the interviews, it was found that family was an area of support in the women's lives. It seemed that these women depended on specific close family members for survival and in dealing with life's struggles, whether it was from a financial perspective or with helping them with the management of their child (i.e. looking after the child when the mother was at work, helping with homework, etc). In turn, these women would return the favour and look out for their own family members. The role of older siblings to bring up the younger siblings was also evident. It was made clear that the women were not particularly close to other members in the community, and could not depend on the father of their child. They however put their trust in certain family members, who very often were the only other people that knew about the diagnosis.

This concept of family dependency was evident in the stories told by both foster mothers. Both women were responsible for caring for children in their family where the biological parents no longer could. It was almost expected and a given that they would take on the new role and responsibility of caring for the children, even though this was not their problem to begin with. Previous literature has shown that social assistance and close support networks such as family, friends and trustworthy members in the community is a fundamental aspect in terms of improving the quality of life of that of a child with FASD and his or her parents (Phung et al., 2011).

The role of the grandmother was very significant in the research. Very often it was spoken of the grandmother looking after or bringing up some of the mother's children. The family seemed to respect the grandmother, which emphasised her power and the importance of her leadership within the family dynamic.

***“Because mamma keeps on pushing; that it is for her that we are doing this ... My sister helps but my mother keeps pushing this. She told me that I shouldn't go to work, I should rather take her to the doctor today.”***

(Example 3.4.4.1, participant 3, single mother of 3)

When asked about how they were currently coping with their situation and the problems in their lives, many women described a strong faith and their



dependency on God to provide for them and help them through their daily struggles. In addition to faith as a means to cope with the struggles of life, there was a perception that those individuals in the community who were „church-going“ people, were good, trustworthy people who were not involved in drinking, drugs or any wrong doings in the community. Some of the women found the church approachable as a source for food and support. Several studies in South Africa, two Italian studies and two studies conducted in the United States found that women who attend regular church services and adhered to religious and spiritual practice were less likely to drink alcohol and have drinking habits pertaining to that that would cause FASD (May & Gossage, 2011). The following excerpts illustrates the importance of faith in some of the lives of the women:

***“Always. It is now stronger than before. I can’t say have not always been a believer but there comes a time in your life that you want to give up on life... it looks like this and if you have a marriage like mine... I don’t drink anymore because I am religious now.”***

(Example 3.4.4.2, participant 1, in an abusive marriage)

***“I am actually fine with it. God has a plan with everything. I know that he will help us through it... I ask my Lord every night to help me with that situation and I don’t have a problem with that and I pray to him every day.”***

(Example 3.4.4.3, participant 7, single mother)

### *3.4.5 Clinics and schools as current sources of support*

As discussed previously, the women felt that they could not trust other women in their community, and they said that other women would not listen to them if they gave them any advice. There was however respect for individuals of higher authority working in credible organisations, such as hospital staff at the clinics or the teachers at the school.

The three community workers described a good and supportive health care system in the West Coast region. They said that the women in the community, which they had informed about the effects of alcohol, were grateful for receiving this information and did not have a bad attitude. According to them, these women did not previously know that the effects of alcohol were so bad.

Most of the participants spoke of the clinic (especially the nursing staff) being a valuable resource in terms of education and awareness. They spoke of being informed about the effects of both alcohol and drug use at the clinic during their visits. The following excerpts illustrate how these women view the clinic as a valuable resource for information:

***P: “I will speak with her but the clinic tells and shows things on the TV...”***

***I: “Is this at the clinic, about FAS?”***

***P: “About pregnancy and alcohol and sometimes about drugs and what tik causes and that type of thing.”***

(Example 3.4.5.1, participant 8)

***“Yes, she is older and knows much more than I do about these things. Because when there are information sessions at the clinic she would go and she reads all the posters that are on the walls of the clinic about all the syndromes.”***

(Example 3.4.5.2, participant 4)

The women also spoke of the nursing staff and health care professions being a good source for support. There seemed to be a lot of trust and respect for those who worked and helped them at the clinic, and had received good advice and encouragement from them in the past. These findings were also found by Chersich *et al.* (2012) who reported that nurses at clinics were an important and the most frequent source of information mentioned among women with children who had been diagnosed with FASD. Overall, the women seemed to trust and depend on the clinic and hospital system, they viewed it as an approachable resource for support and education and a place they could depend on if they needed any medical help or advice.

Participant four’s daughter has leukemia and attends a regular clinic at Red Cross War Memorial Hospital. She described how supportive and encouraging the nursing staff is at the clinic, as illustrated by the following excerpt:

***“Yes, like the other lady that works at the school she would always ask me how \*Dana is. And the clinic comes around sometimes to ask how she is doing. Like \*Brenda at the Hanna Coetzee clinic, she usually comes in and tells me that I need to be strong and that I should look after her.”***

(Example 3.4.5.3, participant 4, daughter has FAS and leukemia)

These findings of the nursing staff being a valuable resource in terms of education, encouragement and support was further validated in the stories told by the foster mothers. Foster mother P9 mentioned that she had received good advice from the nursing staff to help her manage her child. One of the nurses had such a personal relationship with her that the nurse even promised her that she would take care of her child if she were to pass away.

***“Its that white nurse. She says that the day that I'm not there anymore then she can stay by her, but then she needs to come visit now already. She told me the other day that she wants to go visit the nurse. The nurse said that she can come visit her any afternoon, many days she'll say „Ouma, pack my bag“; so I told her to rather wait.”***

(Example 3.4.5.4, participant 9, foster mother)

Overall, the women appeared to trust in and depend on the schooling system for support. Many of the women spoke fondly of the teachers at the school and how they appreciated the help they had received from them in terms of managing and helping with their child's current problems. The women spoke of signing consent forms to inform the school and teachers about the child's diagnosis to better manage him or her. Many women described how the school and teachers understood the child's problems following the diagnosis and supported the mother in terms of providing advice and support where possible. They were encouraging and helpful in terms of managing the situation. This was interesting as FARR has not yet informed the teachers about the diagnosis. These teachers have to attend formal training before the child's diagnosis is discussed as this is a FARR policy. This training has not yet taken place (C Lombard 2014, personal communication, July). This indicates that the mothers most likely disclosed the diagnosis to the teachers themselves, and if this is the case, it highlights the trust the mothers hold with the teachers. The role of the teacher was thus very valuable in the

progression of the child and supporting and encouraging the mother to manage her child better. This finding is further validated by the descriptions told by participants one and participant 11:

***“His first teacher was always communicating with me about him. She always came over to chat to me about \*Austin... She usually writes me a letter to let me know about what he needs to catch up on, and then I have to do it with him at home. I am just saying that any other teacher wouldn't go through this much trouble.”***

(Example 3.4.5.5, participant 1, child diagnosed with FAS)

***“Just his teacher from last year and that teacher always helped him a lot and that is why he passed. He has been in Sub A for two years and then he passed and then the teacher knew how to work with him. But the teacher said that his work is good. They have said that he doesn't finish his work quickly enough so the teacher would send him with his books home and a note for me to help him finish his work for the day.”***

(Example 3.4.5.6, participant 11, child diagnosed with FAS)

The mothers felt that the school was genuinely interested in the overall wellbeing of the child, and supported the child and family where possible. The foster mothers also validated these findings by mentioning that the school was valuable in providing advice, help and referrals. The following excerpt illustrates this:

***“The school always tries to help out with books that they give to her and my two boys. They also offered to give them backpacks. She recently got a new backpack from them ... Yes, and there is someone who works at the school who would always come around and ask me if there is anything that we need like books or rulers.”***

(Example 3.4.5.7 participant 4, single and unemployed)

Previous literature has shown that the role of family members, school teachers, healthcare professionals, community workers and the community can help to support both the child diagnosed with FASD and his or her family (Snaders & Buck, 2010). These findings support such literature as family members, healthcare professionals at the clinics and teachers at the schools are current sources of support for these women.

In order to identify and diagnose a child with FASD, a multidisciplinary team is required. Teachers and nursing staff play a fundamental role in this as they may help to identify affected children or may help with the management of

the child. Additionally they can provide support to parents. Nurses play an important role as they directly interact with women at the clinic. They can encourage women not to consume alcohol during pregnancy and can identify those women who do. Furthermore they may facilitate a referral if they suspect a child may have FASD based on the maternal drinking history. This is important for an early diagnosis and for early intervention. In turn, teachers need to be trained to work with children with FASD and play an important part in encouraging and supporting parents (Godel, 2002).

### 3.5 Theme 3. Comprehension: A mixed understanding

The following subthemes will explore a woman's understanding of her child's diagnosis and the corresponding cause of the disorder in more detail. While most of the women had a basic understanding that alcohol can affect the developing fetus and that the problems in their child are associated with drinking alcohol during pregnancy, there were some important areas which highlighted confusion in terms of the amount of alcohol it takes to cause an effect, an incoherent understanding of the disorder, and misconceptions about alcohol and drug use during pregnancy. This theme will explore these areas of confusion among the women studied, which has opened them up to vulnerabilities stemming from these naiveties.

#### 3.5.1 *Incoherent understanding of the diagnosis*

Most of the women acknowledged that their child had certain problems and linked these problems to drinking alcohol at some stage during their pregnancy. However, many of the women arrived at the interview with unanswered questions in terms of specific aspects of the diagnosis as well as the future progress of the child. They illustrated confusion in certain areas regarding what the diagnosis entailed. They were unclear as to what such a diagnosis meant for the future of the child.

***“He just told me the reason for her brain thing. That she's got something on her brain and it is because I drank during pregnancy. But while I was pregnant I didn't know what the effects were. And after I gave birth to her no one told me that there is something wrong with her. It has only been a year since they told me about what she's got.”***

(Example 3.5.1.1, participant 10, child diagnosed with FAS)

***“I only found out now, the other lady told me about it last year, that they found alcohol in him.”***

(Example 3.5.1.2, participant 8, child diagnosed with FAS)

***“They said that half of \*Lewellyn’s brain is, how can I say this, is deformed. He doesn’t have his whole brain and that he will never progress to a higher grade in school. He will always be behind and then they asked me what he wants to become when he grows up. I told them that he wants to become a lawyer and then they said that he will never be able to do that.”***

(Example 3.5.1.3, participant 7, child diagnosed with FAS)

Salmon (2008) conducted a similar study to explore the experiences of biological mothers whose child had been diagnosed with FASD children in New Zealand. The findings reported that all the women studied were unaware of FASD, the effects on the fetus as well as the future prognosis of the child. All of the women interviewed feared for their child’s future as they were unclear as to what to expect. These findings are consistent with the current research findings.

The women did not seem to know why the tests were being conducted on their child prior to the diagnosis given by FARR. There was a lot of confusion over what forms had been filled in, the testing process and the role the researcher had in the process. Many of the women had several questions and arrived at the interview with the expectation that these would be answered.

***“Now, that is the reason why I came today. I want to know what the problem is. That is why I actually came to you today.”***

(Example 3.5.1.4, participant 6, child diagnosed with FAS)

The community workers believed that the women understand what FASD is and that during the diagnostic and feedback sessions, the women understood all the information given to them. This perspective did not reflect what the participants had said.

### ***3.5.2 How much alcohol can cause harm to an unborn fetus?***

In general, there was a lack of understanding about the amount of alcohol it takes to cause an effect on the unborn fetus. Most women understood that alcohol consumption during pregnancy can cause harm to a fetus (the

community workers further validated this as they mentioned that these women do know that alcohol can cause damage), however only in cases where a woman consumes excessive amounts of alcohol on a daily basis. Most women did not know that low alcohol drinks (such as ciders or beers) which are consumed on a regular basis, but not in excess, could cause problems in a child.

Some women reflected feelings of anger and confusion, and in some cases denial, as they did not understand or believe the diagnosis given and mentioned that they did not drink what they thought was enough alcohol to cause a problem in their child. This is a fundamental finding in terms of prevention in a region which is dominated by recreational drinking activities and high rates of FASD.

As one of the participants said:

***“I thought that it was only people that drank all day long but I didn't know that it was possible to have an alcohol syndrome baby by drinking only one or two beers.”***

(Example 3.5.2.1, participant 7, child diagnosed with FAS)

Participants one and two also did not feel that drinking several ciders could cause harm to the fetus:

***“I have never been a drinker. How can I put this, you just drink a drink. I will only drink at special occasions or not at all. Maybe I will drink just two or three ciders that is enough. It was very upsetting when the previous lady told me about the outcome. The fact that there are so many women and girls drinking here and their babies are fine. How can that be, they are drinking week days and weekends”.***

(Example 3.5.2.2, participant 1, child diagnosed with FAS)

***“Yes [alcohol can affect the baby] but certainly not a cider or so. We only drink light drinks.”***

(Example 3.5.2.3, participant 2, child diagnosed with ARND)

Some women said that they did not drink much alcohol and blamed the problems in their child on the fact that their partner at the time drank excessive amounts of alcohol, as shown by the following excerpt:

***“I felt bad about it but it is actually the father’s fault. He drank too much alcohol ... He drank too much at the time when we were, how can I say this, having sex. And so, that’s when he drank too much...”***

(Example 3.5.2.4, participant 12, child diagnosed with FAS)

This highlights the fact that there is both a lack of understanding about the process in which alcohol causes harm to a fetus (i.e. the dependency of fetal growth on the mother’s input), as well as an aspect of guilt, denial, misbelief and lack of acceptance that these women were accountable for the problems in their child.

Eaton *et al.* (2014) studied the beliefs about FASD and alcohol consumption during pregnancy among 1047 men and women at alcohol serving establishments in a township in Cape Town, South Africa. The findings showed that many men and women do not have a clear understanding of how alcohol can cause harm to a fetus and that women use their own experiences as a point of reference as to how much alcohol can be consumed, as well as the frequency of alcohol intake, without causing harm in a pregnancy (Eaton *et al.*, 2014). Fifty-four percent of both pregnant and non-pregnant women admitted to drinking at least two to four drinks per month and 57% of these women said that they consume three to four alcoholic beverages per occasion. Thirty-five percent of pregnant women believed they could drink at least monthly. Furthermore, about half of pregnant women and men with pregnant partners believed that a woman can consume alcohol during her pregnancy without causing an effect on her baby. In addition, 31% of the pregnant women believed three or more drinks per day could be consumed without causing harm (Eaton *et al.*, 2014). In a study conducted by Chersich *et al.* (2012), the research findings reported that only 50% of participants were aware that alcohol can affect the developing fetus prior to intervention program. Population-level knowledge of the extent of the harms of alcohol consumption during pregnancy remains low (Chersich *et al.*, 2012). Both the current research and previous literature therefore indicates that overall there is a lack of understanding in terms of the harms of alcohol consumption during pregnancy.



### 3.5.3 *Misconception about the effects of drugs on the unborn fetus*

While the purpose of this research project is focused on alcohol consumption during pregnancy and the effects it may cause in a child, it was found that drugs, specifically „tik“, is a great problem in the community, and many women use this during pregnancy. Furthermore, there were some misconceptions around how „tik“ can cause harm to a fetus, or that it is better to use „tik“ than alcohol during pregnancy, as described by participant 12:

***“They say that drugs are better to use than drinking wine they say... because the women that drink so much don't know anything that they did the next morning.”***

(Example 3.5.3.1, participant 12, age 29)

***“I have told one of my friends that she should stop using tik when she was pregnant with her baby and they say that tik eats you from the inside. And so I told her to stop using, it's not good for you. That tik.”***

(Example 3.5.3.2 participant 7, age 29)

While it has been found that mothers who bear FASD children often use other drugs in addition to consuming alcohol (May & Gossage, 2011), little is known about the nature, extent and impact of this drug use among pregnant women, especially in South Africa (Stein *et al.*, 2007). According to previous literature, there has been an increase in the rate of babies being born to substance-abusing mothers (especially „tik“) in the Western Cape (Williams *et al.*, 2014). For example, in 2006, 10% of a sample group of pregnant women studied admitted to using „tik“ during pregnancy (Dr. B Vythilingum 2014, personal communication, December). In a separate study conducted between 2006 and 2007 in the Western Cape, drug use among pregnant women was reported as high as 15% (Everett-Murphy *et al.*, 2010). Williams *et al.* (2014) conducted a study in the Western Cape to assess the rates of alcohol and other drug use among pregnant women attending public sector antenatal clinics. They reported that 8.8% of these women tested positive for at least one drug, of which methamphetamine („tik“) was the most common. While the women in this study did not admit to using „tik“ in their pregnancy, it was evident that „tik“ is accessible to the community, and that many pregnant women use this drug. This was evident in some of the personal stories told by the participants. These findings therefore support previous literature.

### 3.6 Theme 4. Needs: Help or hindrance

The study revealed a number of needs which the women had, many of which being the root of the problem to the issues described in the previous themes. This theme will discuss these needs in detail, and the concluding remarks about how these needs can be addressed to resolve the problems which emerged from the research will be discussed in the final chapter. Further information and follow-up sessions following a diagnosis, the need for special education for the child and greater education among women in the community, as well as the need to change the social context in which these women live were most evident in the research, and will be described.

#### 3.6.1 *Wanting to know more*

Overall, the women benefitted from the diagnosis, information and advice given by FARR in terms of their current understanding and management of their child. There was however a great need for further follow-up sessions and further communication incorporating additional information and advice on the ongoing management of the child. This was highlighted in a misunderstanding on their behalf that I, the researcher, had a role to play in this, as this was the expectation from the interview sessions. Participant one illustrates this point:

***“No, because she said that one day someone will come to talk to me about him. I am guessing it is today. They only really helped me with telling my husband or the time that I need to control him...”***

(Example 3.6.1.1, participant 1)

In general, there were still uncertainties surrounding the diagnosis, future prognosis of their child, if the symptoms would improve with age or even go away and what could be done in terms of medical management (i.e. could medication be given to combat some of the symptoms). Furthermore, there were concerns around the child’s future in terms of educational needs and employment capability.

In previous literature it has been found that women of children diagnosed with FASD often fear for their child’s future and have several concerns in this regard (Salmon, 2008). This emphasises the great need for ongoing support, advice and post-diagnostic services. Participant seven’s comments illustrate

uncertainties over her child's future as well as her feelings of stress and hopelessness:

***"I still wanted to know about what they said that \*Lewellyn will never go to another grade ... how should you as parent help him or is there a school that he can go to? It won't work if he fails one and then passes another year. At the end of the day what kind of future will that child have. So I would like to know much more about this business. I would like to have a little bit more support with that."***

(Example 3.6.1.2, participant 7)

These uncertainties surrounding the diagnosis and prognosis brought about confusion. There were many unanswered questions and areas which were not well understood, and as a result many women did not accept their child's diagnosis. The gaps in their knowledge (or not being informed) hindered them from progressing through the acceptance stage and in planning for better management of their child in the future, as seen in the following excerpt:

***"The only thing that I have been wondering about is how do you know that it is because of alcohol? ... But it is not that big as some children that have everything maybe. The way I see \*Austin is that he looks exactly like his father because I have been looking at him. Are his eyes smaller? Is there something different in his face? So it is more his brain or what?"***

***"But it isn't that bad. Let me ask you this, if I help him in a certain way will it help \*Austin?"***

***"I don't believe there is any medication for it but what I am trying to say, is there something that I can try to help him to concentrate... but I know not for many hours at once, would that help?"***

(Example 3.6.1.3, participant 1)

As many of the women were shocked and emotionally overwhelmed at the time of the diagnosis, they could not remember a lot of what was discussed during the diagnostic feedback and counselling session. It was evident that these women needed time to adapt to and accept the diagnosis first before obtaining more information and specific details about FASD. Receiving, accepting and managing a diagnosis for their child is a process, and requires more than one session. Time was needed to think about and process what information they had been given and for the women to come with questions

at a more realistic and appropriate time following the diagnosis. The following excerpt illustrates this:

***“No, I wouldn’t know. I have to be honest I was very shocked that day so I didn’t really concentrate on the conversation ... I probably only heard what I wanted to hear at that moment.”***

(Example 3.6.1.4, participant 10)

Overall, there seemed to be confusion over whom to approach if the women need medical help for the child. Furthermore, some of the mothers felt they did not know enough about the condition to know what is normal and what isn’t and when to seek medical help and further support, which would aid in better management of their child. Previous research has reported similar findings where parents of FASD children often felt that they did not know where to seek information and help regarding their child (Snaders & Buck, 2010). Many participants expressed this viewpoint, however an excerpt from the interview with participant one is included here as she communicated this finding best.

***“I am not sure who to ask if I need more support like with health maybe... let me give an example, maybe if I notice something that I don’t like so I don’t know if I should let them know or who I should let know about my concerns... but what I am trying to say is that if I do notice something odd with \*Austin and I am not used to seeing that in him and I don’t know what it is where should I take him then?”***

(Example 3.6.1.5, participant 1)

### *3.6.2 Educational needs and awareness*

In addition to the women requiring more information following the diagnosis for their child, there were needs for both the child diagnosed and the women in terms of education. It was found that the women required additional help and support in terms of a specialised education for their child, which would better suit the child’s educational needs. Furthermore, there was a need for awareness and education in the community in terms of educating and informing about the harmful effects of an alcohol or a drug exposed pregnancy, the risk of substance use and not using contraceptives, with the potential harms which can result. This sub-theme will describe these educational needs, and the need for awareness, in detail.

In general the women expressed a need for special education for their child at school, such as additional support or extra classes to help with the progress of the child. As previously discussed, many children had failed a year or two at school. There was frustration surrounding the child's challenges with homework and learning. The following excerpt demonstrates this:

***“I would like to have him placed in an after school class but I don't think that [school name] have that. I think that he would be better in such a class. Because when he gets home he starts playing and watching TV. I only arrive home at four o'clock and would like to have him in an after school class for two to three hours to help him. He can read a sentence and then a second one and then I would ask him what did he read and he would have already forgotten what he read in the first one.”***

(Example 3.6.2.1, participant 7)

If a child's cognitive development has been affected following an alcohol exposed pregnancy, learning difficulties and intellectual disability in an affected individual commonly result. This directly affects the child's functionality at school and children diagnosed are likely to fail or drop-out of school as a mainstream school structure does not fit their educational needs. The resultant learning problems are challenging and frustrating for parents to deal with (Snaders & Buck, 2010; Granitsas, 2004) as the educational needs of the child are often not met (Whitehurst, 2011). Due to these learning difficulties and consequent struggles at school, parents of FASD children often feel inadequately accommodated at school (Snaders & Buck, 2010). Specialised educational programs and social support services are fundamental in improving the quality of life (and future) of both the child diagnosed and the caregivers (Phung *et al.*, 2011) and a specialised education program is a great need among parents of FASD diagnosed children (Brown & Bednar, 2004). The role of school teachers and professionals can help to support both the child diagnosed with FASD and his or her family (Snaders & Buck, 2010), as discussed in theme two. The findings in this section therefore support previous literature.

As described in detail in theme three, many of the women have a misunderstanding in terms of the amount of alcohol which can cause harm to

the fetus. This, in addition to the misconceptions about drug use during pregnancy, highlights the fact that women need to be educated on the effects and harmful impacts of any consumption of both alcohol and drugs during pregnancy. Ignorance is still rife in this area.

Furthermore, several women described the reason for them drinking was because they did not know they were pregnant, and some mentioned they were still sexually active without use of contraceptives. This emphasises further need for education in dangers of alcohol consumption and unprotected sexual activity. Participant six described the story of how she consumed alcohol on a regular basis as she was not planning to have another child and did not think she was pregnant. She however took no contraceptives at the time and did not think there were any risks associated.

***“You know what happened, after my daughter, I have been using contraceptives for years, the injection. But after that I decided that I am going to stop using the injection. And just after that I was pregnant.”***

(Example 3.6.2.2, participant 6)

Studies have shown that FASD is on the increase in South Africa and unplanned pregnancies and poor education are a major contributing factor to this (FASD prevention symposium, 2008; May *et al.*, 2000; Urban *et al.*, 2015). Alcohol use among women of childbearing age is the most preventable cause of birth defects and intellectual disability (Floyd *et al.*, 2009). Some of the risks associated with woman being susceptible to an alcohol exposed pregnancy include alcohol and substance use, being at reproductive age, not using effective contraceptives and low levels of maternal education (Olivier *et al.*, 2013; Morojele *et al.*, 2010). Social pressures are an additional factor (Urban *et al.*, 2015). In a study conducted by Urban *et al.* (2015), 62% of women studied reported their pregnancy being unplanned, 52% were sexually active and were consuming alcohol and 46% of them were not on any contraceptives. Efforts to address the growing problem of high FASD rates in South Africa need to focus its attention on what the community understands and put interventions into place to address areas of confusion (May *et al.*, 2011a). Currently, efforts to intervene and

provide preventative options are restricted by the lack of knowledge on the effects of alcohol use during pregnancy (Eaton *et al.*, 2012).

From what the women described, the clinic is a good source for support and education. However, education about the effects of drug and alcohol use, as well as information about effective contraceptive use, may come too late when the women are already pregnant when they first attend the clinic. As many women in the community do not listen to the advice given by other women, there is a need for communication and education in the community, through media and local organisations, for greater awareness. Participant seven described how sad and guilty she felt about her child's condition. She wished that someone had told her about the harms of alcohol at the time of her pregnancy. She felt that she has a duty to inform other women in the community as there is very little knowledge about the effects of alcohol during pregnancy where she lives.

***I: "Do you think that it is important that there should be more awareness?"***

***P: "Yes, of course. There should be, yo! It is a big problem with people who drink alcohol. I realise it now."***

***I: "Did you wish that someone had told you before?"***

***P: "Yes."***

***"I would like to know much more about this business to understand what is going on and how to help other people and so on. To help people that I know who are using alcohol."***

(Example 3.6.2.3, participant 7)

Participant eight described that women are sometimes educated about the harmful effects of alcohol by the nursing sister at the clinic, however there is little awareness within the community. Consequently education within the community is needed.

**I: “Do you think that there should be more awareness outside of the clinic to discuss the effects of alcohol?”**

**P: “Yes, maybe the way you put it now, to talk about alcohol. The community hall is there, or a part of it...”**

**I: “Have you had those types of talks there before, has there been something like that?”**

**P: “Not really there no.”**

**I: “And at another place?”**

**P: “No, it’s only the head sister of the hospital that speaks about something like that at the clinic.”**

**I: “Is there a lot of interest there?”**

**P: “Yes.”**

(Example 3.6.2.4, participant 8)

### *3.6.3 Need to change the social context in which these women live*

Theme one described the social context in which these women live, and how the use of alcohol has not only become a way of life but that it is often used as a means to numb the pain and vulnerabilities stemming from a hard life. Lack of male responsibility, illness, death and poverty were found to be contributing factors. The misuse of alcohol as a way to forget about such social problems indicates the need for context-sensitive interventions, especially for these women who find themselves living in a vulnerable population. Although it is not so easy to change the social context, the need for employment, purpose, self-efficacy and worthiness is a start to helping these women rise above their social situation and in helping them to help themselves.

In a common thread mother spoke of a hard life in receiving little support from the father and struggling financially to provide for their child and making ends meet. The women depended on their broader family for financial assistance. They mentioned that although the grant or their income which they receive is small, it contributes toward paying the bills and helps in one way or another. These women did not state outright that they needed financial assistance, although it was evident that financial insecurity was a great burden in their lives. Perhaps they were hopeless and felt that there was little to be done to change their situation, or they were too proud to ask



for any help. Brown & Bednar (2004) also found that parents of FASD affected children require financial assistance. The need for financial stability and support is evident.

Many women were unemployed and it was found that the youth spent most of their time at home and consequently became involved with drugs or alcohol. There is thus a great need for purpose in the lives of the women. Such a purpose may enable them to feel worthy. It may encourage them to not just accept the life that they live but to learn that they have control over the decisions they make and that each decision made can influence their life going forward.

### 3.7 Theme 5. Prevention of FASD

The purpose of this study was to explore the experiences of women who received their child's FASD diagnosis through FARR. Furthermore, the study looked to explore the women's feelings and thoughts in terms of drinking during future pregnancies following the diagnosis. The research findings highlight the value of receiving a FASD diagnosis as many of the women demonstrated an intention to change their drinking behaviour following the diagnosis. The research findings further emphasise the women's key role in spreading community awareness and educating other women within the community about the harms of alcohol consumption during pregnancy. These research findings are valuable for future prevention and intervention programs. The following sub-themes describe this in detail.

#### 3.7.1 *Prevention in future pregnancies*

Overall, most of the women admitted that after receiving their child's diagnosis through FARR, in conjunction with the knowledge gained in the process, they do not plan on having any more children, and if they do, they have the intention to not drink again (or to decrease their alcohol intake) in their next pregnancy. In hindsight, most of the women regretted drinking during their pregnancy with their child, and some discussed how their current drinking habits had changed following the diagnosis through FARR. The community workers further validated this as in their experience they felt that

women who had gone through the feedback process were willing to change their behaviour.

**I: “And your drinking habits now?”**

**P: “If I go to a party. They invite me to parties then I would drink a cider but not really. My children don’t know that I drink so I won’t drink in front of them.”**

**I: “How much did you drink while you were pregnant?”**

**P: “When I was pregnant with \*Ethan I drank crates and crates of beer and then my mom told me to stop drinking.”**

**I: “But you are drinking a lot less?”**

**P: “Yes, a lot. I am rather going to support my children than supporting alcohol.”**

(Example 3.7.1.1, participant 4, child diagnosed with FAS)

These findings are further validated through the comparison of the experiences of the biological mothers to those of the foster mothers whose children had been through the FARR epidemiological study but were not accountable for the problems diagnosed in their foster child. For example, foster mother P5 describes her story of having adopted two of her sister’s children. Her sister is a heavy drinker and cannot care for the children. Social services had taken the children out of her care as a result. This biological mother did not receive her child’s diagnosis through FARR. Consequently she is still uneducated and misinformed about the effects of drinking alcohol during a pregnancy and the harms it can cause in a child. She has yet to change her drinking behaviour or the management of her children and has had little interaction with those of a higher authority to inform her about these harms. She has since fallen pregnant and has continued to drink heavily throughout her next pregnancy. The comparison of this woman, who did not attend the diagnostic and counselling session and who has not changed (or thought about changing) her drinking habits, to those women who did attend the diagnostic and counselling session and who have expressed an intention to change their drinking habits, again emphasises the importance of receiving such a diagnosis through an organisation such as FARR. In this way, the women have been educated about the harmful effects of alcohol and now have the empowered choice to not drink again during a future pregnancy.

This foster mother's story adds further insights into the benefits of receiving such a diagnosis for the potential prevention of FASD.

***“No, she didn't go with [to the FARR diagnostic session] but she was at my house. I told her where I had come from and everything that the woman told us and explained what they explained to me because she had caused all this. She didn't listen to what I was saying though and just carried on the way she does ... with all of them she drank a lot and with this baby. When we were at the school the other day and I showed her what \*Inga was going through. So she just went drinking more ...”***

(Example 3.7.1.2, participant 5, foster mother to her sister's child diagnosed with ARND)

Although these research findings indicate that the women have an intention to change their drinking behaviours, it is difficult to determine if what the women are saying is truthful or if they are just saying what they feel the researcher wanted to hear. Future research should therefore focus on measuring these changes or intentions to change to validate these findings. According to what has been found in the past, fear and knowledge alone does not change a woman's drinking behaviour, however self-efficacy has been found to have a far greater impact (C Lombard 2015, personal communication, July).

### *3.7.2 Encouragement within the community*

A general theme that was identified through the research was that, following the diagnosis of their child, many of the women explained they now encourage other women in their community not to drink. Several women spoke of personal experiences of talking to specific women who were pregnant and were drinking alcohol or using drugs, encouraging them not to do so. While many described this process not to be an easy one, and that many of the women did not listen or take them seriously or had a bad attitude toward them, they still felt it was their duty and responsibility to warn and inform them of the dangers following their experience. The following excerpts illustrate this:

***“So I would advise people even if they get angry with me that they should stop. I would feel that I did my duty. Maybe they get angry with me they will think back and think that that woman was talking the truth.”***

(Example 3.7.2.1, participant 7, age 29)

***“I do tell them a lot that they shouldn't drink because it is bad for the baby and then they would ask me why. They become angry and they would say I have nothing to do with them. Then I would tell them I know I have nothing to do with you but I am worried about your baby because I have experience of it. I know exactly what I am going through but they don't understand that.”***

(Example 3.7.2.2, participant 10, age 42)

***“I would tell her but then you just have to know that the words they say back to you are not going to be very nice. Then they would say but you were a drinker as well and that we will not listen to what you have to say to us. They will stop when they feel like it.”***

(Example 3.7.2.3, participant 11, age 52)

This finding illustrates the fundamental role mothers, who have received their child's FASD diagnosis, play in spreading awareness and encouraging other women in the community not to drink. As many of the women expressed a bad attitude from women in their community towards them, perhaps because they themselves lacked credibility as they had drunk alcohol during their own pregnancy, this may indicate that the women may respect and possibly listen to community leaders and professionals, such as teachers, health care professionals or community workers. More emphasis needs to be placed on prevention than dealing with the problem after the event.

The women expressed that they wished that someone had spoken to them in turn about the effects of alcohol while they were drinking during their pregnancy. They expressed gratitude towards FARR for informing them of the diagnosis and cause, as many of them would not have known if they had not participated in the study. The community workers also mentioned that they felt the women were thankful towards them for giving them their child's diagnosis.

Participant seven even expressed an interest in getting involved in a prevention program to help other women in the community and to contribute towards the prevention of FASD in future pregnancies.

***“But I asked the woman if there’s maybe a possibility of classes or a program that they should phone me about it. I would like to know much more about this business to understand what is going on and how to help other people and so on. To help people that I know who are using alcohol.”***

(Example 3.7.2.4, participant 7, age 29)

This theme illustrates the value and importance of giving families a diagnosis and providing education in the process. This empowerment of knowledge can contribute towards the prevention of future alcohol exposed pregnancies and in raising awareness amongst the community about the harms of an alcohol exposed pregnancy, which could potentially lead to reduced rates of FASD.

Previous literature has reported on how education has led to a reduction in FASD rates. Chersich *et al.* (2012) assessed the effectiveness of the first prevention study for FASD conducted in South Africa. They found that pre-intervention, maternal knowledge about the effects of alcohol was low and the prevalence of FASD was 8.9%. Post-interventions, knowledge levels increased substantially and FASD prevalence dropped to 5.7%. They reported that universal intervention and prevention programs could reduce FASD rates of approximately 30% which will have a great effect on the population. Stade *et al.* (2009) identified four FASD prevention trials which together suggested that a brief psychological (motivational counselling) and educational intervention may reduce alcohol consumption among pregnant women. The current research, as well as findings from previous studies, shows that through education (either through receiving a diagnosis for a child or through a prevention program), prevention of an alcohol exposed pregnancy, or FASD, may result. This is especially important in populations where low levels of awareness and high rates of FASD are reported.

## **Chapter 4: Conclusions, strengths, limitations and recommendations for future research**

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### 4.1 Introduction

This chapter summarises the main research findings and provides suggestions for how some of the issues, highlighted in this research, can be addressed. Furthermore, the strengths and limitations of the study, as well as recommendations for future research, are discussed.

### 4.2 Conclusions

The main aim of the current research project was to explore the experiences of women who have received a FASD diagnosis for their child through the FARR epidemiological study (which determined the prevalence rate of FASD in the West Coast region of South Africa). The comprehension, feelings and needs of women who raise children with FASD and attended a diagnostic feedback and counselling session provided by FARR were explored. It was further investigated if the women's feelings regarding drinking alcohol in their next pregnancy and managing their child currently had changed. Understanding the experiences of parents and caregivers who raise children with FASD, and the psychosocial issues associated, is invaluable in understanding what needs, support, services, education and funding is required (Salmon, 2008). This area in FASD research has been underinvestigated, which directly impacts strategies to support families and address needs (Whitehurst, 2011; Campbell, 2007). The current research is therefore valuable as the results can be used in designing prevention and intervention programs. The research highlights important risk factors for an alcohol exposed pregnancy which may serve as target areas of focus for preventative work in the future. These results provide a true depiction of the environment from which children diagnosed with FASD are raised. This provides great insights into the complex problems of prevention which require urgent attention.

Five main themes were identified through the research study. Theme one included an understanding into the social context in which these women live. Theme two provided an insight into the experiences of living with an FASD

child and the women's struggles, feelings, management, coping mechanisms and support structures in this regard. Theme three identified a mixed understanding in terms of the FASD diagnosis and the effects of alcohol and drug use during pregnancy. Themes four and five identified the needs of these women and further support required, as well as how receiving such a diagnosis has contributed towards future prevention of FASD and an alcohol exposed pregnancy in a positive manner, respectively.

These women have fallen victim to their social circumstances, opening themselves up to vulnerability and disempowerment. The role of the man was found to be very powerful in dictating how relationships and families function and in general there was very little support, involvement, responsibility and leadership from the man. This often contributed towards the drinking habits of the women, either to numb the pain (due to abuse, abandonment and unfaithfulness), to keep their man calm, or to keep up with his lifestyle. This emphasises the great need for male responsibility, support and accountability in the community to reduce the levels of vulnerability and unworthiness felt among these women. It would be worth investigating if male programs could be implemented to encourage male responsibility and self-esteem. Additionally, a study investigating the experiences of males would be needed to know more about their problems and their own perspective. Paternal influence has been identified as a critical yet understudied factor (Eaton *et al.*, 2014) and further research is required in this area.

Furthermore, it was found that drugs, especially methamphetamine („tik“), and alcohol is commonly used in this community. According to the women, these substances are easily accessible and substance abuse has become a way of life over many generations (Salmon, 2008). There was a lack of responsibility among the younger generations. From the experiences told, an impression was given that drugs and alcohol are commonly used among the youth, especially during pregnancy. Furthermore, the use of these substances, coupled with a lack of education and ineffective use of contraceptives, may be significant contributing factors toward the sharp increase in the number of teenage pregnancies in the area. This increases the risk for alcohol exposed pregnancies in the community, leading to increased FASD rates. The effect

of the social environment is significant. Peer pressure, domestic violence, boredom, unemployment, poor education, personal hardships, and feelings of unworthiness and inadequacy were found to be contributing factors towards the high rates of substance use.

The burden of illness and death, and the fear which accompanies this, was also evident in the research. Death and illness are daily realities, which indicate that these women's lives are vulnerable and fragile. Poverty and financial burdens was a pertinent reality as unemployment rates are high, income levels are low and little financial support is received from the man. There was a sense of hopelessness and desperation and life was viewed as a daily struggle for survival.

These findings recognise that there is a great need for context-sensitive interventions, especially for those who reside in the world's most vulnerable populations. Such intervention should aim to address the basic needs in the community, such as employment or financial assistance in terms of medical care for example. This may reduce the vulnerabilities these women face and instill hope, worthiness and purpose into their lives. Intervention work focusing on improving the knowledge, self-respect and self-efficacy (worth) of these women may be an easier and more realistic area of focus in addressing these problems initially.

Many of the women revealed feelings of frustration and high levels of stress in raising a child who has FASD and in dealing with his or her problems. Major problems in the child included developmental, learning, concentration and behavioural difficulties. These findings help to identify the needs of mothers who raise children with FASD and where support can be given in helping the mother deal with these problems (e.g. school involvement, motivational talks, behavioural management and parenting workshops (for children with special needs, etc.)).

It was found that the experiences of receiving their child's FASD diagnosis was emotional, however many women were grateful and benefitted from this as they had a greater awareness for and understanding of the problems in their child which led to a greater tolerance for the child's behaviour. From this



knowledge they felt empowered to manage their child better, which highlights the importance of receiving such a diagnosis. Guilt, shame and anger were dominating emotional reactions experienced by these women. Additionally, some women were in denial over drinking during their pregnancy or that their child had a problem. This may be used as a coping mechanism to numb the feelings of guilt and shame. As a result, these women may not yet have accepted responsibility and simply transferred the blame to numb such feelings of guilt. Feelings of regret, blame, judgment, gossip and distrust in terms of telling other women in the community about their child's diagnosis was found. This inhibits acceptance of the child's condition.

Family members and close friends were found to be a support system for these women. A strong faith assists in dealing with problems and personal hardships. These support networks have been found to help parents raise children with FASD (Brown & Bednar, 2004). These women respected professionals and leaders from within their communities. Most of the participants spoke of the clinic being a valuable resource in terms of education and awareness. It was evident that specific family members, healthcare professionals at the clinics and community workers and teachers at the schools are current areas of support. These resources should be used as a strong foundation to provide communication, education and awareness for greater emphasis to inspire communities to take ownership in instilling a culture of prevention. Broader local institutional interventions and targeted campaigns are necessary to build trust and understanding so the consequences of self-destructive behaviour are understood widely. As the community workers are only employed by FARR in an area for three years and during this process obtain great experience, it is recommended that these individuals be employed by the clinics or schools in the area after their contract with FARR has terminated. These individuals have the necessary skills and are a valuable resource in addressing the needs of the community and training other professionals about FASD.

From the research it was found that there is a basic understanding that alcohol can affect a developing fetus and that this will result in further complications after childbirth. However, there was a lack of understanding in

terms of the amount of alcohol it takes to cause an effect on the unborn fetus. Many women believed that an effect on the fetus may only result in cases where excessive amounts of alcohol on a daily basis takes place, and that low alcohol consumption (such as ciders or beers consumed on a regular basis, but not excessively) would not cause any harm. There was also a lack of understanding in terms of the process in which alcohol causes harm to a fetus (i.e. abstinence by the mother, not the father is imperative). This is a fundamental finding in terms of prevention in a region which is dominated by recreational drinking activities and high rates of FASD, and mothers need to be aware of this. There is thus a great need for enhanced community-level interventions in areas where low levels of education about the harms of maternal drinking during pregnancy are reported (Chersich *et al.*, 2012; Floyd *et al.*, 2009). Population-level knowledge of the extent of the harms of alcohol consumption during pregnancy remains low (Chersich *et al.*, 2012). Efforts to address the growing problem of high FASD rates in South Africa therefore need to focus on what the community understands and put interventions into place to educate individuals about what is unknown (May *et al.*, 2011a). Awareness and education on the effects of any amount of alcohol and the dependency on maternal input for fetal growth is thus essential. Despite activity by FARR, much ignorance and confusion still exists. This indicates that given the size of the problem of FASD in South Africa, more funding needs to be given by the government for education to be effective as clearly statistics show the problem is growing.

Furthermore, it was found that drug use in the community, especially among pregnant women, is a growing concern. There were several misconceptions about the effects of drugs, such as the fact that drugs are better to use during pregnancy than alcohol, which need to be addressed. This illustrated the importance of education and community awareness on both the effects of drugs as well as alcohol. Little is known about the reasons behind the increasing rates of substance abuse during pregnancy. Current research findings indicate certain beliefs about drug use during pregnancy among some communities and highlight a lack of understanding in this area. This could provide insight into one root cause for these increasing statistics.

Future research is thus required in this field to guide targeted prevention and intervention work. This is imperative to attempt to reduce the rates of a substance exposed pregnancy.

Many women were confused around several aspects of their child. It was found that there were uncertainties surrounding the diagnosis, acceptance thereof, future prognosis of their child, if the symptoms would improve with age or even go away and what could be done in terms of medical management. Additionally, there were concerns around the child's future in terms of what the child would be capable of doing and what his or her future entailed surrounding education and employment. There was therefore a great need for further follow-up sessions incorporating additional information, advice and parental guidance. Necessary ongoing support, advice and post-diagnostic services should be provided. Regular follow-up session would be valuable in this regard to monitor the child's medical progress and educate the mother or family in the process as to what to look out for. Ongoing post-birth counselling should be provided to parents of FASD children, as the need for these distinct functions is clearly shown in the interviews conducted in the research. Addressing these aspects of confusion is fundamental in helping with the future management of a child with FASD.

Furthermore, there was a great need for special education and extra school support for their child from the school. The need for financial stability and support was evident. Education amongst the community on alcohol consumption during pregnancy, FASD and substance abuse and unprotected sex and the increased risk for an alcohol exposed pregnancy in this regard is imperative. The clinic is a good source for support and education, however education about the effects of drug and alcohol use, as well as information about effective contraceptive use, may come too late when the women are already pregnant when they first attend the clinic. There is thus a great need for education and awareness within the community outside of the clinic. The potential role of professionals, such as health care professionals or community workers and teachers, as a valuable resource for education, awareness and encouragement, are further highlighted.

Finally, it was found that after these women received their child's diagnosis, a positive influence in terms of the prevention of FASD in the future was observed. Many women said that following the diagnosis they do not plan on having any more children, and if they do, there was an intention to change or reduce their alcohol habits. In hindsight, most of the women regretted drinking during their pregnancy with their child, and some discussed how their current drinking habits had changed following the diagnosis through FARR. Future research needs to be conducted to measure the degree to which these drinking habits may have changed. Additionally, many of the women explained they now encourage other women in their community not to drink and that they felt it was their duty and responsibility to warn and inform women in the community about the risks of an alcohol exposed pregnancy. There is consequently a great value on giving families such a diagnosis and providing education in the process. This empowerment of knowledge can contribute towards the prevention of future alcohol exposed pregnancies and in raising awareness amongst the community, which could potentially lead to reduced rates of FASD where low levels of awareness and high rates of FASD are reported. The research illustrates the fundamental role mothers, who have received their child's FASD diagnosis, play in encouraging other women in the community not to drink and in informing them of the effects of alcohol.

#### 4.3 Strengths of the study:

- The research findings were obtained from many perspectives which accurately depicted and confirmed the results. A combination of the perspectives of the biological and foster mothers, and further insights from the community workers (as well as the FARR perspective) were incorporated to shape the research findings and to obtain a transparent viewpoint to accurately answer the research question.
- All interviews were conducted by an experienced interviewer in the language of the participants' choice. This allowed the participants to best express their experiences and allowed the researcher to observe the non-verbal behaviour of the study participants. The presence of both the researcher and research assistant provided different

perspectives and interpretations of the findings which eliminated any research bias.

- Open-ended questions were utilised with no predetermined answers in mind which allowed women to answer freely.
- All interviews were conducted at a private location (FARR office) which allowed for privacy and confidentiality and illuminated the risk of judgment, labeling or the disclosure of sensitive information within the community.
- The audio recordings provided evidence for the research findings; the researcher's field-notes were valuable in shaping themes and provided further insight in the analysis of these findings and in drawing final conclusions.
- The research findings were valuable and will help in designing prevention and intervention programs in the future. The participants however also benefitted from the research. They received an incentive which helped them financially, they received a therapeutic benefit and they also obtained some information about FASD and the risks of an alcohol exposed pregnancy following the interview.

#### 4.4 Limitations of the study:

- A limitation of the study was that it was trusted and assumed that the participants were being honest and gave a truthful reflection of their experiences, feelings and actions, and that they did not give answers which they felt were socially acceptable or were what they thought the researcher wanted to hear. This could have potentially influenced the credibility of certain results pertaining to the women's claims of a) a change in her feelings regarding not drinking during future pregnancies, b) a change in her current drinking behavior and c) a change in the current management of her child following the diagnosis. Research which aims to quantitatively measure these findings would be required to test the credibility of these claims.
- The researcher and research assistant came from different social and cultural backgrounds to the participants and in this way it may have restricted participants in relating to the researchers and opening up to

them in this regard. It would have therefore been beneficial to have a research assistant who came from a similar background to these participants in addition to being experienced in interviewing and qualitative research.

- Due to time and budget constraints of the project, only two trips were arranged up the West Coast and the interviews were compacted into a tight schedule over several days. Consequently, the researcher did not have a lot of time between the first and second interview to reflect and adjust the research question guide in as thorough way as what she would have liked. In addition, the analysis of the data obtained from the first trip was not completed before the second trip. As a result, some themes had not been analysed yet and the researcher missed some opportunities to probe further with these in the second group of interviews.
- Although the researcher can understand Afrikaans and could follow the interviews, it is acknowledged that Afrikaans is her second language and consequently the researcher had to depend and rely on the skills of the research assistant. For this reason, the researcher may have missed opportunities to probe in certain areas and to explore certain themes further.
- The researcher found that the women studied had an intention to change their drinking behaviours. These are however subjective accounts and behavioural or psychosocial measurements would need to be conducted to validate this finding.
- Due to the time, budget and travel constraints of the project, only a small sample of participants were studied and the researcher could not spend more time in the community to further shape the research findings. This small sample size was a limitation to the study as the findings are not generalisable to other parts of South Africa, however they can be transferred to similar contexts. Qualitative research however looks at individual experiences in depth and is less concerned with generalisability. Additionally, the sample size gave a

good insight into the problems faced in poverty stricken communities and in answering the research question.

#### 4.5 Recommendations for future research

Based on the current research findings, the following recommendations for future research are made and would be of great value:

- It would be beneficial to study and determine how many of the mothers of children diagnosed with FASD have FASD themselves and how this may impact and effect management of an affected child.
- It would be valuable to explore the experiences of women who have an FASD affected child who is at adolescent or adult stage. As these mothers would have gone through different life stages with their child and have more experience with the problems they have faced over the years, they may provide richer information and insights pertaining to the problems, needs, support and management required later on in life.
- A lot of research has been conducted on the effects of alcohol consumption during pregnancy but little research has explored the effects of a drug exposed pregnancy. The current research findings indicated that both drugs and alcohol consumption is prevalent in the community and therefore there is a clear need for substance abuse research. Exploring the communities' beliefs on this topic and identifying factors which may help to better understand the problem and implement prevention studies in this regard would be helpful. Little is known about the nature, extent and impact of drug use among pregnant women, especially in South Africa and therefore research in this area would be of great value.
- Research pertaining to the father's perspective of raising a child with FASD, would be valuable. This may give insights into how he views his role, why there is a lack of support on his behalf and may reveal findings on the mothers which they may not have disclosed.

- Research which aims to quantitatively measure if the drinking behaviours have really changed among women who have received an FASD diagnosis would be beneficial in confirming or validating the findings in the current study.



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**Participant code:** .....

Demographic Data	
<b>Age:</b>	
<b>Number of children:</b>	
<b>Number of children diagnosed by FARR:</b>	
<b>Highest grade completed at school:</b>	
<b>Marital status:</b>	Single / married / divorced / widowed (circle)
<b>Employment status:</b>	Employed / unemployed (circle). Specify work:.....
<b>Place of residence:</b>	Saldanha Bay / Other (circle). Specify other: .....

**Icebreaker (optional)**

- What was your experience like getting to this interview?

**A. Comprehension, feelings and needs of mothers**

- What was it like receiving the diagnosis of FASD for your child?
  - What is your understanding of the diagnosis of FASD?
  - What is your understanding of drinking alcohol during pregnancy?
  - What emotions did you experience during the session with FARR?
  - What do you think was not addressed during the session which would have benefited you?
  - What are your current needs relating to your child e.g. medical care, schooling, prognosis?

**B. Prevention of FASD**

- How do you think FASD could be prevented?
  - What are your feelings with regard to drinking alcohol during your next pregnancy?
  - What did FARR discuss with you with regard to the prevention of FASD in future pregnancies?
  - Would you say that your drinking habits have changed since the FASD diagnosis?

**C. Management of FASD**

- Tell me about what it is like being a mother to a child with FASD?
  - What do you find challenging when managing your child?
  - How do you currently cope when managing your child?
  - What help do you need regarding the management of your child?
  - What advice did FARR give you to help you to stimulate your child and to manage his/ her condition?

Deelnemer kode: .....

Demografiese data	
Ouderdom:	
Aantal kinders:	
Aantal kinders deur FARR gediagnoseer:	
Hoogste graad op skool voltooi:	
Huwelikstatus:	Ongetroud / getroud / geskei / weduwee (sirkel)
Werk status:	Het werk / het nie werk (sirkel) Spesifiseer: .....
Woonplek:	Saldanha Baai / anders (sirkel) Spesifiseer: .....

### Icebreaker (optioneel)

- Hoe was jou ervaring om by die onderhoud uit te kom?

### B. Begrip, gevoelens en behoeftes van moeders

- Hoe het jy gevoel toe jy jou kind se FASD diagnose ontvang het?
  - Wat is jou begrip van FASD as diagnose?
  - Wat is jou begrip van alkohol drink tydens swangerskap?
  - Watter emosies het jy tydens die sessie met FARR ervaar?
  - Wat dink jy is nie aangespreek tydens die sessie nie wat jy voel sou jou dalk gebaat het?
  - Wat is jou huidige behoeftes vir jou kind. bv. mediese sorg, opvoeding, prognose?

### B. Voorkoming van FASD

- Hoe dink jy FASD kan voorkom word?
  - Wat is jou gevoelens oor alkohol tydens jou volgende swangerskap?
  - Wat het FARR met jou bespreek oor die voorkoming van FASD in jou volgende swangerskappe?
  - Sou jy sê dat jou drinkgewoontes verander het sedert die FASD diagnose?

### C. Bestuur van FAS

- Vertel my van jou ervaring van ma wees vir 'n kind met FASD?
  - Wat is die uitdagings teen oor die bestuur van jou kind?
  - Hoe hanteer jy dinge omtrent die bestuur van jou kind?
  - Wat is die tipe hulp wat jy nodig het met die bestuur van jou kind?
  - Watter raad het FARR gegee om jou te hulp om jou kind te stimuleer met haar/ sy toestand te bestuur?

M.Sc. in Genetic counselling Research Project

**Women's experiences of receiving a child's fetal alcohol spectrum disorder diagnosis: A Western Cape study**

**PARTICIPANT INFORMATION SHEET**

STATEMENT BY PARTICIPANT

I, ..... confirm that:

1. I have been invited to be involved in the above mentioned research project which has been initiated through the Foundation for Alcohol Related Research as I was involved in the West Coast Prevalence Study and received a fetal alcohol syndrome diagnosis for my child together with counselling. I understand that 10 – 20 other women will be involved in the study and my name or information discussed in the interview will not be given or discussed with these women or anyone else in the community
2. I understand that the objective of this study is to explore the mother's understanding, feelings and needs after receiving her child's diagnosis
3. I understand that the interview will take place at a private venue close to me (Vredenburg Hospital), at a suitable time and should not take longer than 60 minutes
4. I understand that this is a once off session (after I have received my child's diagnosis) and the interview will take place in 2015
5. I understand that some questions may be sensitive and may cause an emotional reaction, but the risk of harm to me is small. Should I wish to see a counselor, arrangements will be made by the researcher
6. I understand that my involvement in the study may contribute towards further prevention and management studies of fetal alcohol spectrum disorder for the Foundation for Alcohol Related Research
7. I understand that all information discussed will remain confidential. Information gathered will be used for this research project only
8. I understand that the interview will be recorded for research purposes and that information discussed will be accurately translated. These

recordings will be stored in a locked cabinet and downloaded onto a password-protected computer. I understand that only the researcher, her supervisors and the examiners will have access to this raw data. The recordings will be destroyed after the research has been finished. No record of my name will appear anywhere in the thesis

9. I understand that the interview will take place in the language of my choice (English/ Afrikaans). The interviewer and the researcher will attend the interview
10. I understand that I voluntarily choose to participate in this study and that at any stage I may tell the researcher that I no longer want to participate. These decisions will not have any negative effect on my ability to access medical services or those offered by FARR
11. I understand I will be given a R120 voucher to cover some costs I may encounter when attending the interview
12. I understand that this study has been approved by the registered Human Research Ethics Committee at the Faculty of Health Sciences of the University of Cape Town. I have been given contact details should I need to contact the committee about my treatment as a research participant
13. I have the researcher's contact details should I have any further questions about the research
14. .... has explained the information of this study in English/ Afrikaans and I understand this information

**PARTICIPANT CONSENT FORM**

---

**I HEREBY DECLARE THAT I HAVE VOLUNTARILY AGREED TO PARTICIPATE IN THE ABOVE RESEARCH STUDY AND THAT THE INTERVIEW CAN BE AUDIO TAPED**

Signed at:

(*address of venue*).....on.....2015

.....

.....

Participant's name and signature

Witness's name and signature

---

**If you have any questions regarding your rights as a research participant, please contact the Human Research Ethics Committee at the Faculty of Health Sciences of the University of Cape Town at:**

**Professor Marc Blockman (Chairperson of the Human Research Ethics Committee): (021) 406-6496**

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## IMPORTANT INFORMATION

Dear Participant

Thank you for your involvement in this study. If you wish to contact the researcher with regard to questions about the research project or to inform the researcher that you no longer want to be part of the study, please contact me at:

**Tarryn Shaw (Genetic Counselling intern): 084 707 6200**

**Email: [tarrynshaw90@gmail.com](mailto:tarrynshaw90@gmail.com)**

**Dr Tina-Marié Wessels (Supervisor):  [\(021\) 406 6698](tel:(021)4066698) / 6995**

**Email: [tina.wessels@uct.ac.za](mailto:tina.wessels@uct.ac.za)**

If you have any questions regarding your rights as a research participant, please contact the Human Research Ethics Committee at the Faculty of Health Sciences of the University of Cape Town at:

**Professor Marc Blockman (Chairperson of the Human Research Ethics Committee): (021) 406-6496**

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M. Sc. in Genetiese Berading Navorsingsprojek

**Vrouens ervaring teen oor 'n diagnose van fetale alkohol spektrum  
afwykings: 'n Wes Kaapse studie**

**DEELNEMER INLIGTING VORM**

VERKLARING DEUR DEELNEMER

Ek, ..... bevestig dat:

1. Ek genooi is om aan die bogenoemde navorsings projek deel te neem, wat deur die Foundation for Alcohol Related Research (FARR) geïnisieer is as gevolg van my deelname aan die Weskus Voorkoms Studie waar ek berading ontvang het as gevolg van 'n fetale alkohol sindroom diagnose vir my kind. Ek verstaan dat 10 - 20 ander vroue betrokke sal wees in die studie en dat my naam en inligting, bespreek gedurende die onderhoud, nie uitgegee sal word of met hierdie vroue of iemand anders in die gemeenskap bespreek sal word nie.
2. Ek verstaan dat die doel van hierdie projek is om die moeder se begrip, gevoelens en behoeftes na die ontvangs van haar kind se diagnose te verken.
3. Ek verstaan dat hierdie onderhoud op 'n privaat plek naby aan my (Vredenburg Hospitaal), op 'n geskikte tyd sal plaasvind en dat dit nie langer as 60 minute sal neem nie.
4. Ek verstaan dat dit 'n eenmalige sessie is (nadat ek my kind se diagnose ontvang het) en die onderhoud sal plaasvind in 2015.
5. Ek verstaan dat sommige vrae sensitief sal wees en 'n emosionele reaksie kan veroorsaak, maar ten spyte hiervan is die risiko van skade aan my klein. As ek verdere berading benodig, sal reëlings getref word deur die navorser.
6. Ek verstaan dat my deelname in die studie kan bydra tot verdere voorkoming en bestuur studies van fetale alkohol spektrum versteuring vir die Foundation for Alcohol Related Research
7. Ek verstaan dat alle inligting vertroulik sal bly. Inligting versamel sal slegs gebruik word vir hierdie navorsingsprojek



8. Ek verstaan dat die onderhoud vir navorsings doeleindes opgeneem sal word en dat die inligting bespreek akkuraat vertaal sal word. Hierdie opnames sal in 'n geslote kabinet gebêre word en afgelaai word op 'n wagwoord-beskermdre rekenaar. Ek verstaan dat slegs die navorser, haar toesighouer en die eksaminatore toegang sal hê tot hierdie data. Die opnames sal vernietig word nadat die ondersoek klaar is en geen rekord van my naam sal op enige plek in die tesis verskyn nie.
9. Ek verstaan dat die onderhoud sal plaasvind in die taal van my keuse (Afrikaans / Engels). Die onderhoudvoerder en die navorser sal die onderhoud bywoon.
10. Ek verstaan dat ek vrywillig kies om deel te neem aan hierdie studie en ek kan op enige stadium aan die navorser dui dat ek nie meer wil deelneem nie. Hierdie besluite sal nie 'n negatiewe effek hê op my vermoë om mediese dienste te bekom nie, of dienste wat deur FARR aangebied word nie.
11. Ek verstaan dat ek R120 geskenkbewys gegee sal word om sommige van my kostes wat ek aangegaan het geurende die bywoning van die onderhoud te dek.
12. Ek verstaan dat hierdie studie goedgekeur is deur die geregistreerde Menslike Etiekomitee van die Fakulteit Gesondheidswetenskappe van die Universiteit van Kaapstad. Kontakbesonderhede is aan my gegee indien ek nodig het om die komitee te kontak in verband met my behandeling as 'n navorsing deelnemer.
13. Ek het die navorser se kontakbesonderhede indien ek enige verdere vrae oor die navorsing het.
14. .... het die inligting van hierdie studie in Engels / Afrikaans verduidelik en ek het hierdie inligting verstaan.

**DEELNEMER TOESTEMMING VORM**

---

**EK VERKLAAR HIERMEE DAT EK VRYWILLIG AAN DIE BOGENOEMDE  
NARVORSINGS PROJEK DEELNEEM**

Geteken:

(adres).....op.....2015

.....

Deelnemer se naam en handtekening      Getuie se naam en handtekening

**As u enige vrae het in verband met u reg as 'n deelnemer, kontak  
asseblief die Menslike Etiekkomitee van die Fakulteit  
Gesondheidswetenskappe van die Universiteit van Kaapstad by:**

**Professor Marc Blockman (Voorsitter van die Menslike Etiekkomitee):**

**(021) 406-6496**

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## **BELANGRIKE INLIGTING**

Geagte deelnemer

Baie dankie vir u deelname aan hierdie studie. As u die navorser wil kontak in verband met die navorsingsprojek, of die navorser wil inlig dat u nie meer deel wil wees van die studie nie, kontak my gerus by:

**Tarryn Shaw (Genetiese Berading intern): 084 707 6200**  
**E-pos: [tarrynshaw90@gmail.com](mailto:tarrynshaw90@gmail.com)**

**Dr Tina-Marié Wessels (Toesighouer):  [\(021\) 406 6698](tel:(021)4066698)/ 6995**

**E-pos: [tina.wessels@uct.ac.za](mailto:tina.wessels@uct.ac.za)**

As u enige vrae het in verband met u reg as „n deelnemer, kontak assablied die Human Etiekkomitee van die Fakulteit Gesondheidswetenskappe van die Universiteit van Kaapstad by:

**Professor Marc Blockman (Voorsitter van die Menslike Etiekkomitee):**  
**(021) 406-6496**

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Appendix C1. Recruitment Form (English)

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Dear FARR participant,

My name is Tarryn Shaw and I am a Genetic Counselling student at the University of Cape Town. I am doing a small research project and would like to invite you to participate in my study.

The aim of the project is:

*To explore the understanding, feelings and needs of mother's who have children with a diagnosis of a fetal alcohol spectrum disorder.*

Participation in the study is **voluntary** (your own choice) and if you agree to participate, you have the **right** to withdraw from the research at any stage and this will **not disadvantage** you in any way. If you agree to participate in the study, a R120 voucher will be provided to cover costs that you may encounter while being involved in the research.

Your participation in the study would be valuable for this research. **Please note that by signing below this gives FARR permission to give your name and contact details to me.** I will then contact you to explain the study further. Your signature does not mean you agree to participate in the study but only gives permission to FARR to give me your details.

---

I ..... give ..... (FARR member)  
permission to provide the researcher (Tarryn Shaw) my contact details so  
that she can phone me and explain her study to me.

Signed at: (*address of venue*).....*on*.....2014

.....  
Participant's name and signature                      FARR witness's name and signature

.....  
Participants contact details

---

Appendix C2. Recruitment Form (Afrikaans)

---

Aan FARR deelneemer,

My naam is Tarryn Shaw en ek is 'n Genetiese Berading student van die Universiteit van Kaapstad. Ek is besig met „n klein navorsingsprojek en nooi u graag om deel te wees van my studie.

Die doel van hierdie projek is:

*Om die insig, gevoelens en behoeftes van Ma's, wie se kinders met „n fetale alkohol spektrum versteuring gediagnoseer is, te ondersoek.*

Dis is heeltamal **vrywillig** (u eie keuse) om deel te neem aan hierdie study. Indien u instem om deel te neem, het u steeds die **reg** om op enige stadium van die navorsing te ontrek en dit sal u op **geen manier benadeel nie**. Indien u instem om deel te neem aan hierdie projek, sal „n R120 koepon gegee word vir kostes wat u moontlik mag teekom, terwyl u betrokke is by die projek.

U deelname aan die projek sal waardevol wees vir hierdie navorsing. **Neem asseblief kennis dat deur die brief te onderteken, het FARR slegs toestemming om u naam en kontak besonderhede aan my, die navorser, te gee.** Ek sal u dan kontak sodat ek die projek verder aan u kan verduidelik. U handtekening beteken nie dat u instem om deel te neem in die studie nie, maar gee FARR slegs toestemming om u kontak besonderhede aan die navorser te gee.

---

Ek ..... gee hiermee ..... (FARR lid)

toestemming dat my besonderhede aan die navorser (Tarryn Shaw) gegee mag word, sodat sy my kan skakel en haar studie aan my kan verduidelik.

Geteken by:




(adres) ..... op (datum)..... 2014

.....  
Deelnemer se naam en handtekening FARR getuie se naam en handtekening

.....  
Deelnemers kontak besonderhede

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## Appendix D. Ethics Approval Documentation

	<p style="text-align: center;"><b>UNIVERSITY OF CAPE TOWN</b> Faculty of Health Sciences Human Research Ethics Committee</p>	
		<p style="text-align: right;">Room E52-24 Old Main Building Groote Schuur Hospital Observatory 7925 Telephone [021] 406 6492 • Facsimile [021] 406 6411 Email: Sumayah.artefdien@uct.ac.za Website: <a href="http://www.health.uct.ac.za/fhs/research/humanethics/forms">www.health.uct.ac.za/fhs/research/humanethics/forms</a></p>
<hr/>		
<p><b>08 January 2015</b></p>		
<p><b>HREC/REF: 811/2014</b></p>		
<p><b>Dr TM Wessels</b> Clinical Laboratory Sciences Human Genetics Suite 4.13.1 Level 4 Falmouth Building FHS</p>		
<p>Dear Dr Wessels</p>		
<p><b>Project Title: EXPLORING THE COMPREHENSION, FEELINGS AND NEEDS OF MOTHER'S IN AN ALCOHOL PREVENTION PROGRAMME, AND THE DEGREE TO WHICH THIS CONTRIBUTES TOWARD POTENTIAL PREVENTION AND MANAGEMENT OF FETAL ALCOHOL SPECTRUM DISORDERS (MSc-candidate-T Shaw)</b></p>		
<p>Thank you for your response letter dated 17 December 2014, addressing the issues raised by the Human Research Ethics Committee (HREC).</p>		
<p>It is a pleasure to inform you that the HREC has <b>formally approved</b> the above mentioned study.</p>		
<p><b>Approval is granted for one year until the 30 January 2016.</b></p>		
<p>Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.</p>		
<p><b><i>We acknowledge that the following student:-Tarryn Shaw is also involved in this project.</i></b></p>		
<p>Please note that the on-going ethical conduct of the study remains the responsibility of the principal investigator.</p>		
<p><b>Please quote the HREC REF in all your correspondence.</b></p>		
<p>Yours sincerely</p>		
		
<p><b>PROFESSOR M BLOCKMAN</b> CHAIRPERSON, HSF HUMAN ETHICS</p>		
<p style="text-align: right;">Hrec/ref:811/2014</p>		

## Appendix E. Afrikaans Transcripts

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### Example 3.3.1.1

*“Hy gee een maand vir die kinders maar dan weer nie. So ek het gedink ek gaan dit los want ek sal self vir my kinders sorg.”*

### Example 3.3.1.2

*“Nee, ek worry nie van die pa nie. Hy was nege maande toe los ek die pa en sy pa bly daar agter by Seven Eleven hier in die baai in en ek het nog niks vir hom gesê van die goed nie. Maar hy wil, hoe kan ek sê, maar hy wil nie geld gee vir die kind nie. Dis rede ek worry nie meer van hom nie. Ek sal maar my kind self groot maak met die all-pay geld wat hy kry sal ek self vir hom groot maak en my pa en ma help ook saam met hom.”*

### Example 3.3.1.3

*“Ai mense moenie jou laste op iemand sit nie maar ekke... los maar eers [started cring]. Dis hoekom, my lewensmaatjie is mos nou weg en ek dink maar nou ek dink nie aan my nie.”*

### Example 3.3.1.4

*“Waar daar ’n man is dan kan daai kind gebuig raak maar as daar nie ’n man is nie dan kan daai kind doen net wat hulle wil en as hulle voel hulle wil daai ding vir jou gooi dan gooi hulle dit na jou kop maar nou ja.”*

### Example 3.3.1.5

*“Hy het mos nou „n ander meisie gehad. Ek weet nie of hy dalk kinders het by die ander vrou nie maar ek het gevoel ek kan nie verder met hom lewe nie. Jy kan nie al kant jou brood gebotter hê nie.”*

### Example 3.3.1.6

*“Ek het nie eintlik vir my man gesê nie want kyk my man was mos nou lank in die weermag en toe hulle klaar maak toe het hulle mos nie perading gekry nie en sometimes ek het nou nie ’n lekker huwelik nie om nou eerlik te wees. En ek wou hom gaan skei het en ek het die Here toe ingeneem want ons is nou mooi 16 jaar getroud en ek het vir 10 jaar uitgehou met my kinders en ek het die Here vertrou om my man terug te gee. Hy het my geabuse en baie geslaan en is. Hy is ’n different mens as hy nugter is dan sal jy nie sê daar is ’n man in die huis is nie maar as hy dronk is en hy was maar baie bekommerd as hy se... want ek is maar bang vir hom, ek is bang hy verwyf my of want hy sou nie die nuus kon verwerk het nie en hy sal ook nie kan cope nie en ek sal ook nie alleen kan cope nie.”*

### Example 3.3.1.7

*“En sy moet mos altyd so gemaak het, sy moes mos altyd saam met die outjie gedrink het om vir hom rustig te hou gedurende haar swangerskap want hy was mos maar „n baie rowwe man gewees.”*

### Example 3.3.1.8

*“Nee, ek het nie rêrig gedrink nie, met die derde seun. Die eerste drie kinders is van die eerste huwelik se kinders en ek het „n vreeslike man gehad, hy het*

*my geskop en trap en ek moes saam met hom drink ... Toe het ek mos begin bier drink want die lewe wat ek toe gehad het maak mos dat „n mens saam met die stroom gaan want hy is mos nou die wille man en ek het nie wild groot geword nie. En dis danse en al daai plekke en ek moet mos saam want anders pas ek mos nou nie in. Toe het ek ook mos maar later ook maar saam gegaan om in te pas en toe het ook maar later die biertjies gedrink en later is dit na die sterkte toe in. Toe het ek nie omgee nie want toe was my lewe soos wat ek daai tyd gedink het net „n flop en ek het gedrink.”*

Example 3.3.2.1

*“But he is so deep in the drugs I don’t want to talk about it...”*

Example 3.3.2.2

*“Nee mevrou, hoe kan ek dit nou stel. Hulle is meer op die drugs en op die tik afdelings.”*

Example 3.3.2.3

*“Oh, jy moenie eers praat nie... baie van hulle tik... Dit is ’n groot, groot probleem. Want dit is nie net jy wat lei nie maar die baba lei die ergste daar onder want veral as ek sien hoe die mense die goed gebruik is dit nie die moeite werd aan die einde van die dag nie. Veral as jy swanger is want nou is jy swanger en as jy miskien nou nie geweet het in die eerste plek jy is die goede nie. En jy ontdek dit nou agter na miskien is dit nou so maak dit ’n maksimum van twee of drie maande. Jy ontdek nou jy voel nie lekker nie en jou klere word nou so bietjie te styf en dit was nie so en dan gaan jy maar dokter toe om uit te vind wat gaan dan nou hier aan en dan kry jy nou die skok dan moet jy dit onmiddellik staak as jy dan nou probeer om reg te probeer. Maar nou ons kan maar hoor ons is swanger ons gaan maar net aan. So wie se skuld is dit nou as die baba nie gesond is nie. Ek voel dit is die ma se skuld en vandag se ma’s is nie van daai jare nie. Soos die ma’s is nou deesdae so jonk en jonger. Dis gevaarlik wat daar buite aangaan.”*

Example 3.3.2.4

*“Hy sou net stander 10 haal maar toe is hy nou soos die Vredenburg se kindertjies in die tik in.”*

Example 3.3.2.5

*“Maybe it is the life but maybe it is when I have a hard time. When I was a child and I see the way how I was grow up then I think wow why must I do something when I just can go and do nothing with my life. Maar hier is ander gevalle weer dan is jy miskien, dan het jy nou dalk groot geword in ’n huis waar daar alkohol gebruik word, ja maar die ma, jy het ’n nugter ma. Jy het dalk ’n pa wat alkohol gebruik en jou ma wat nugter is groei jy so op dan jy sien wat vir jou die beste is. Jy maak ’n keuse, jy as kind maak vir jousef ’n keuse en dan besluit jy watter keuse jy gaan vat. As jy vir jousef ’n positiewe keuse gaan maak dan eindig jy positief op maar as jy vir jousef ’n negatiewe keuse maak dan eindig jy negatief op. Want wat jy in sit is wat jy uitkry. As jy glo jy is negatief, als wat jy touch is negative then it will be negative but if you have a positive mind then everything is positive for you.”*



#### Example 3.3.3.1

*“..... (silence and crying) ..... Ek het baie gestres. Ek is baie siek en dit maak my om te dink ek sal nie altyd daar kan wees vir haar nie.”*

#### Example 3.3.3.2

*“Se nou maar Ouma dood en my ma dood wat dan. Dan sê ek vir haar dis nog 'n lang tyd en die Here sal sorg vir daai dag. Jy moet nie nou al aan daai dag dink nie. Die Here sal sorg en jy moet nie nou al voorsiening maak vir daai dag nie.”*

#### Example 3.3.3.3

*“Okay toe die neef se pa en se ma ook daar en \*Nellie het toe gewys dat sy 'n dop gevat het. Auntie het toe nog nie gemix nie maar \*Nellie het dit skoon gevat en toe sy weer by kom toe was daai bottel lelik seer gemaak en toe is die griep ook nog in die lug. Baie kinders het toe die griep gekry maar hulle het gesond geraak maar \*Nellie het nie gesond geraak van die griep nie. \*Nellie is nader aan hospitaal toe gestuur en later ook na Groote Schuur toe gestuur. En toe het sy seertjies op haar longe en haar lugpypie is te nou en toe doen hulle 'n operasie op haar lugpyp. En ons het toe vir haar gaan besoek en toe sien ons maar die hart lê daar buite. Okay nou nie daarbuite nie maar dis gekoppel aan die hart maar daar buite lê daar ook iets in die vorm van 'n hart want jy sien hoe haal sy asem en \*Nellie kan nie praat nie want hy het pype deur sy keel toe weet ons nog nie dis cancer nie toe het hy terug gekom en toe gaan ek weer kliniek toe en ek vra wat is dit want \*Nellie pyn dat hy krul en hy hoes en hy braak en hy kan nie rêrig eet en toe sê ek vir hulle kyk hierso sy moet dokter toe en toe draw hy op \*Nellie se longe. Toe sy hy vir my daai een long is vol slym en die een long is vol gate.”*

#### Example 3.3.3.4

*“Ek dink hy was sewe jaar oud, ja, toe sy ma met daai man deurmekaar en hy het sy ma verskriklik geslaan en sy ma was daai tyd siek gewees. En hy was baie oor sy ma... nou ja, daai agtermiddag het daai man die vroultjie geslaat en geskop deur die lig en \*Lial was te klein en hy het natuurlik te klein om te weet.”*

#### Example 3.3.4.1

*“Because somtyds dan vra die skool geld en somtyds is daar nie geld nie. Soos ek moes nou vir haar, haar skool uniform mos gehad het en ek kon toe nie vir haar „n skool uniform koop nie en die skool druk op en ek moet kos koop van my salaris en ek moet vir haar klere koop uit haar grant geld uit en op die ou einde van die dag is daar nie geld nie. Ek het werk nie vir baie geld nie. Ek werk R100 'n dag vir drie dae en dis vir 'n maand.”*

#### Example 3.3.4.2

*“Ek wil hom nie soggens skool toe vat sonder iets op die tafel nie. Dan loop ek maar hier by die kerke dan vra ek maar vir hulle of daar nie rolletjies is of so. Of mense wat ek ken vra ek nou vir hulle... En my seun sê vir my ek moenie vir hom skoene gaan koop nie, koop eerder vir ons krag en koop vir ons iets om te eet. Ek kan maar so loop, sê hy. Maar dan voel ek so seer hier...”*

#### Example 3.3.4.3

*“Want pa wou niks vir ons gesê het nie. En dan moes ek vir hom skoon gemaak het en kimpies aangesit het. Want hy kon nie geloop het nie. En sy kimpies en alles is geld maar pa het dit gekry. En ek sê vir hom dit is beter so want nou is dit ons en jy moet terug skool toe gaan, dit is beter so. En wie gaan vir mammie help hier.”*

#### Example 3.3.4.4

*“Tot die man nou terug kom nie. Dan moet ek nou die baas kontak en dan vir hulle kom verduidelik of kom bring sommer die mense se geld. Dan loop ek maar in ’n kroeg in en dan drink ek maar myself in my glory in en dan kom ek maar weer terug. So tipe, ek wil van niemand hoor nie en niemand sien nie. Nou daai was dit gewees.”*

#### Example 3.4.1.1

*“Kyk hierso, die rede hoekom ek mos nou eintlik gegaan het vir die kaai nie, is omdat hy swak leer by die skool. En hy is nou graad, hy het twee keer graad een oor gemaak. So hy is nou die jaar graad twee toe... want hy leer baie sleg by die skool en hy is baie spelerig.”*

*“Miskien sy skoene, ne, as ek nou my skoene aan hê, dan sê ek vir hom „trek aan jou skoene“ dan trek hy sy skoene verkeerd aan en ek leer hom nou nog. Se „nie so nie, jy is al groot jy moet leer.“ So, ek wil nie stres op hom uit haal nie of kwaad raak of so nie, verstaan? Maar ek het vir hom gesê sy skoolwerk moet hy leer.”*

*“Ek het gister vir hom gesê as hy by die skool uitkom, ne, en nou hy het ’n fiets en nou kom trek hy sy skoolklere uit en dan gooi hy sommer net sy hemp net daar en sy broek net daar en sy skoene lê daar. Ek het vir hom gesê nee, as jy by die skool uitkom, dan trek jy vir jou uit en gooi die goed opmekaar en sit dit op die bed neer. Nie op die vloer nie en nou dit doen hy elke dag en elke dag moet ek gaan praat daaroor. En daai’s nou my probleem, elke dag dieselfde probleem.”*

#### Example 3.4.1.2

*“Daar was toe al by haar skool leerdery ’n probleem en toe vra hulle vir my of die kind reg kan hoor wat dit lyk sy gee nie aandag nie want sy bly nie onthou nie en sy ook nie hoor nie, hulle moet ’n paar maal ’n ding oor sê... Sy kan lees, sy lees nie rêrig nie ... Maar as dit by lees kom dan soek sy nou die moeilike naam en dan lees sy sommer vorentoe. Dan slaan sy die woord sommer oor. Maar sy vorder aan die ander kant.”*

*“En daar het sy ook twee, drie jaar gesit en toe kom sy graad een toe en daar het sy twee jaar gesit en daarna het sy geslaag.”*

#### Example 3.4.1.3

*“Ek is baie eerlik, I will be very honest if I am gonna tell you now. I don’t like them, I am very honest. I don’t like them because their behaviour, oh man. You won’t believe it, I don’t like them. Because you know why, I am the only child of my mom. We was three but the other two passed away. So the words they give to her, say to her, the swearing and the things they do, no man. And my point of view is, she is my mother and I didn’t do that to her. I have*

*five kids and none of them do that to her. See? And my five kids is her only grandchildren and none of them do that to her. Rêrig nee. I don't like them. I will say not really like them but I really don't like them. But no man... Hulle maniere staan my glad nie aan nie. Daar is nie 'n manier nie. So where is the bigger people, where is the elder and where is the child and who is the youngest and who is the elder. You see?"*

#### Example 3.4.2.1

*"So dis hoekom ek voel ek wil vir \*Austin help met ekstra... want om eerlik te wees almal verstaan nie vir hom nie hulle dink hy is stout. En ek het ook altyd so gesê ... En dan verstaan hy nou nie en nou dat ek beter weet, weet ek hoe om hom te help. En ek verstaan hom nou. Miskien iemand anders nie nou nie maar ek weet nou hoe om hom te help en hoe ek met hom moet werk."*

*"Ja, en ek weet nou presies waardeur hy gaan en ek weet wat en hoe om hom te help."*

*"Ja. Want ek sal rêrig nooit geweet het ek doen iets verkeerd nie en ek sal nooit geweet het dit moet nie so wees nie man, wag, nou weet ek, ek moet luister vir wat hy sê en ek weet as hy 'n bietjie aandag wil hê dan weet ek wat om te doen ja. Maar ek sal hom nie bederf in die sin laat, nee. Dit gaan nie so werk nie, ek sal maar net weet hoe ver."*

#### Example 3.4.2.2

*"As ek nou sit en dink na dit wat ek verstaan van die sindroom wat sy meer gebore is, dan lees ek altyd daai briefietjie. Ek het nou vergeet om dit saam te bring maar dit lê altyd in my leertjie. Ek kyk altyd daardeur. En ek laat oefen vir haar haar tensetjies en so haar sokkies en goetjies was. Partykeer dan was ek sommer „n vuil toppie of so, dan vrywe sy dit. So het hulle vir my gesê om haar spiere te ontwikkel."*

#### Example 3.4.3.1

*"Ja, because ek het my dan self verwyf. Ek het gesê ek as ek daaraan dink dan kan ek dit nie vat nie want because is ek was nie 'n drinker nie en dit was so min en ek is nie 'n drinker nie... as my ma nou hoor ek het gedrink dan sal nou dood gaan want dit is eerlik..."*

#### Example 3.4.3.2

*"Die omgewing tel soms weer baie en ek is nou in 'n baie, dis baie anderste... Nooit ek sal nooit. Hulle skinder te veel. Dis beter as, ek het my ma gesê en my suster. Maar nie nog buite mense nie. Because ek wil dan nie eers vir my man sê nie omdat ek nie weet hoe hy gaan reageer nie. Ek vertrou maar my ma en suster. Dis die beste. Want \*Austin is tog deur die dag by hulle so hulle moet ook presies weet en as daar enige iets oorkom dan sal hulle mos vir my kan verslag gee maar hulle sal mos nie vir my kan sê ek het nie geweet hy moet nie so baie loop nie."*

Example 3.4.3.3

*“Omdat die mense nou baie lelik is en hulle is verskriklik op drink en so... Dis maar beter vir my om my eie goed self uit te werk en so want hulle praat verskriklik oor en weer...nee hulle het nou weer dit gesoek en dit gesoek.”*

Example 3.4.3.4

*“Ek het „n bietjie harseer gevoel want dit is mos nou my skuld gewees. Soos ek dit nou kan vat. As ek mos nou nie alkohol gedrink het dan het dit sou dit mos nou nie gebeur het nie. Ek het „n bietjie hartseer gevoel en af gevoel maar ek het gedink ek gaan nie laat daai vir my onder kry nie. Ek gaan probeer vergeet van daai. Nou nie vergeet van daai nie maar probeer om beter te wees. Om te help en so aan te met skoolwerk en of iets waarmee hy sukkel dan probeer ek maar vir hom help.”*

Example 3.4.3.5

*“Maar my babatjie, hy is gesond. Hy is gesond, hy is agt jaar oud en hy is gesond. Dis net hy leer stadig by die skool. En nou weet ek nie, partykeer, sien ek was... hoe oud was ek? Ek is nou 42 years oud en sy pa was 50 jaar oud gewees. Sy pa was 'n groterige man gewees wat ek gevat het en toe raak ek nou swanger van hom. Nou weet nie of dit dalk die rede kon wees nie omdat hy nou baie gedrink het, ek weet nou nie. Want ek het nie gedrink of gerook nie.”*

Example 3.4.3.6

*“Nee, daar’s nie fout met haar nie. Nie fout nie.”*

Example 3.4.3.7

*“Dit was 'n skok vir hom ook want ons het mos gedink dat sy nou soos 'n normale kind.”*

Example 3.4.4.1

*“Want mamma hulle druk nou dis vir haar. Sy moet nou die dokter sien... My suster help maar my ma druk mos nou. Jy moet nie gaan werk nie want die kind moet mos nou by die dokter wees.”*

Example 3.4.4.2

*“Nog altyd. Dit was maar nou sterker as gewoonlik. Ek kan nou nie sê nie ek het nie altyd die Here gedien nie maar kyk hier daar kom soms tye in jou lewe alles opgee as jou lewe so lyk, jou huwelik so lyk... Ek drink nie meer nie want ek is gelowig.”*

Example 3.4.4.3

*“Ek is eintlik fine daarmee. Die Here het maar „n doel met alles. Hy sal vir ons daar deur help, ek weet dit... I ask my Lord every night to help me with than situation and I don’t have a problem with that and I pray to him every day.”*

Example 3.4.5.1

*P: "Ek sal haar aanspreek maar die klinieke sê en wys ook vir hulle goede op die TV..."*

*I: "Dis nou by die kliniek, oor FAS?"*

*P: "Oor swangerskap en alkohol en partykeer van drugs en wat tik veroorsaak en so."*

Example 3.4.5.2

*"Ja want sy is ouer so sy ken die goed. Want as daar praatjies is by die kliniek dan gaan sy gewoonlik en dan luister sy en sy lees wat daar staan teen die mure van al die sindrome en so aan."*

Example 3.4.5.3

*"Ja soos „n ander vroujie wat daar by die skool werk sy kom partykeer daar by my dan vra sy hoe gaan dit met \*Dana of wat maak sy en so. En die kliniek kom so nou en dan vra hulle vir my vrae en dan. Soos \*Brenda by die Hanna Coetzee kliniek sy kom ook gedurig by my in en „n woordjie kom praat soos sterk wees en jy moet kyk na haar en so aan."*

Example 3.4.5.4

*"Dis daai blanke sustertjie. Sy voel, maar sy het vir my gesê die dag wat ek nie meer daar is nie dan kan sy by haar kom bly maar dan moet sy nou al by haar kom kuier. Sy het nou die dag vir my gesê dat sy vir die suster wil gaan kuier. Die suster het gesê sy kan enige middag vir haar gaan kuier maar baie dae dan sê sy vir my „Ouma, pak my sak“, toe sê ek vir hom nee wag."*

Example 3.4.5.5

*"Met sy eerste juffrou, het sy altyd gekommunikeer. Sy het altyd met my daaroor gepraat want ek kan net in pop en dan met haar gesels... En dan skryf sy 'n briefie vir my van wat hy alles verloor het terwyl hy geslaap het. Dan sê sy jy moet dan vir \*Austin verder by die huis leer ek meen nou 'n ander juffrou sal dit mos nou nie doen nie."*

Example 3.4.5.6

*"Net laas jaar se juffrou en die juffrou het hom baie mooi gehelp en dis hoekom hy geslaag het, hy het mos twee jaar in sub A gesit en toe slaag hy nou en toe het die juffrou mos nou geweet hoe om hom te hanteer in die skool. Maar die juffrou sê sy werkies is baie mooi. Maar hulle se somtyds dan is hy nog nie klaar nie dan sê hulle nou kom-kom. Maar hy moet dit nou stadig doen en want die juffrou sê hy moet alles mooi in die lyntjies te skryf en hy probeer om alles daai doen."*

Example 3.4.5.7

*"Hulle bied vir haar boekies aan vir haar en vir die seuns en hulle bied vir my rugsakke aan. Sy het nou die dag „n nuwe rugsak gekry... Ja, en daar werk iemand by die skool wat altyd vir my kom vra of my kinders boeke of liniale nodig en dan gee hulle vir my."*

Example 3.5.1.1

*“Hy het net vir my verduidelik wat is die oorsaak hoekom sy die brein... die ding op haar brein het en dis omdat ek gedrink het. Tydens swangerskap maar kyk ek het mos nie geweet wat die effekte gaan wees nie. En nadat ek met haar gekraam het ook niemand vir my gesê dat daar iets fout is met haar nie. Dis nou 'n jaar terug, nou onlangs, wat ek gehoor het dat sy dit het.”*

Example 3.5.1.2

*“Ek het mos maar nou eers, dis laas jaar wat die ander dametjie vir my daarvan vir my gekom sê het dat hy nou alkohol in hom gevind het.”*

Example 3.5.1.3

*“Hulle het gesê die helfte van \*Lewellyn's se brein is, hoe kan ek nou sê, gedisvorm. Hy het nie sy hele brein nie en dat hy nie eendag, hy sal nooit op die skool kan vorder na „n ander standerd toe nie. Hy sal altyd agter wees en toe vra hulle vir my wat is sy droom wat wil hy graag eendag word. Toe sê ek mos nou vir hulle hy wil „n prokeruer raak. Toe sê hulle vir my hy kan nie want hy sal nooit dat maak nie.”*

Example 3.5.1.4

*“Nou, die rede hoekom ek nou eintlik gekom het, ek wil eintlik weet wat is eintlik die probleem, sien jy nou. Dis nou eintlik die probleem waarmee ek vandag hierna toe gekom het meer.”*

Example 3.5.2.1

*“Ek het nie geweet dis alkohol nie maar mense wat al mekaar elke dag drink. Dan kry jy mos „n alkohol sindroom baba. Maar ek het nou nie geweet dat as jy twee of een biertjies drink elke dag dan sal dit die veroorsaak nie.”*

Example 3.5.2.2

*“Ek was nog nooit 'n drinker nie. Soos in, 'n mens kan sê, jy drink soos in drink. Ek sal net drink by 'n special occasion of en ook nie sommer nie. Net so twee of drie ciders, as ek so twee of drie ciders gedrink het dan is dit genoeg maar wat hulle, die vorige vroujie mos nou kom sê het van die uitslag was vir my baie seer. Die feit dat hier so baie meisies en vroue is wat soos in drink. In die week drink en naweke drink wat ek nou weet van, hulle babas is dan reg.”*

Example 3.5.2.3

*“Ja, seker nie 'n cidertjie nie of so. Ons drink maar net so 'n ligte drankie.”*

Example 3.5.2.4

*“Ek het sleg gevoel maar dit is eintlik die pa se skuld. Hy het te veel gedrink... Hy het te veel gedrink daai tyd tot ons mekaar, hoe kan ek dit nou sê, seksueel gehad het. En so, dis toe hy baie gedrink het...”*

Example 3.5.3.1

*“Hulle sê dit is beter om die drugs te gebruik as om die wyn te gebruik sê hulle ... want die vroumense wat dronk is, wat hulle gatte dronk suip weet niks wat om hulle aangaan nie.”*

Example 3.5.3.2

*“Ek het vir my een tjommie van my, sy het nou nie gedrink nie maar getik en sy was swanger. En hulle sê mos tik eet jou van binne af. Toe het ek mos nou vir haar gesê sy moet die tik los. Dis nie goed nie. Die tik.”*

Example 3.6.1.1

*“Nee, want sy het vir my gesê eendag, dis seker nou vandag, dan sal die persone dit nou verder vat. Hulle het mos nou eintlik vir my net gehelp met hoe ek my man moet sê of die tyd wat ek nou moet control...”*

Example 3.6.1.2

*“Ek wil nog graag geweet het as hulle mos nou so sê, \*Lewellyn sal nie vorder nie. Hoe moet jy as ouer nou maak of is daar ,n sekere skool vir hulle of so wat hulle toe kan gaan of so? Want dit baat nie die kind gaan een jaar sit en die een jaar slaag nie. Op die einde van die dag wat is die kind se toekoms nou eintlik. Tog niks nie. So ek wil graag nog meer oor die besigheid uitvind. Hulp, ek wil eintlik net meer hulp kry.”*

Example 3.6.1.3

*“Al waar ook ek al gewonder het was, hoe weet die mense dit is as gevolg van die alkohol? ... Maar dit is nie so groot soos in party kinders wat nou als dalk het. Nou soos ek nou vir \*Austin sien, hy lyk presies soos die pa. Want ek het hom nou al so sit en kyk. Is die oë klein? Is daar iets in sy gesig wat dit veroorsaak. So dit lê meestal in sy brein of hoe?”*

*“Maar dit sal nou nie so bad... kom ek vra so. As ’n mens vir \*Austin help in die rigting of in die lyn, sal dit hom ’n bietjie afbring van dit?”*

*“Ek glo nie daar is medikasie nie maar wat ek meen die riglyn wat ek nou probeer vir hom om te konsentreer maar ek weet nou nie vir ure aan een nie, sal dit baie help?”*

Example 3.6.1.4

*“Nee, ek sal nie weet nie. Ek moet eerlik wees, ek was daai dag so geskok ek het net die helfte van die gesprek geluister ... Ek het ook seker maar net gehoor wat ek wou gehoor het.”*

Example 3.6.1.5

*“As ek nou hulp nodig het soos in mediese of gesondheid, ek weet nou nie wat hulle daarmee bedoel het nie, ek weet nie vir wie ek daarvoor moet vra nie... kom ek maak maar nou ’n voorbeeld seker nou as ek iets oplet by \*Austin wat ek nou nie van hou of ek nou dink wat dit kan wees. So ek weet nie of ek hulle moet vra of vir hulle laat weet nie... maar ek meen as ek mos nou miskien iets oplet wat mens kan nou noem ’n afwyking is en ek mos nou nie gewoond dat \*Austin dit nie gewoonlik doen nie en ek miskien nou nie weet of kennis dra nie dan waarna toe moet ek gaan?”*

Example 3.6.2.1

*“Ek wil graag vir hom in ,n na klas sit by die skool maar ek weet nie of ek dink nie [school name] bied daai klasse aan nie. Ek weet nou van my selwers wat, as hy in so klas is dan gaan hy beter word. Hy gaan ,n bietjie vorder. Want as hy middag by die huis kom dan is dit speel, TV, speel en agterna as ek*

*miskien so four o'clock by die huis kom dan is hy al by die skool uit dan sal dit vir hom help. Maar ek meen nou vir daai paar, twee ure, van one o'clock tot four o'clock dan kan daar mos „n naklas dan kan hulle mos vir hulle help. Want hy kan ook nie lekker lees nie. Hy kan nou „n sin lees, die tweede sin kan hy lees en as jy weer vir hom vra wat is die eerste sin dan het hy vergeet.”*

#### Example 3.6.2.2

*“Weet jy wat gebeur, na my meisiekind, ek gebruik al die jare die voorbehoed, die inspuiting, ne. Daarna toe besluit ek nou, ewe skielik besluit ek, ek gaan nou nie meer die inspuiting gebruik nie, ek gaan hom los en net daar toe raak ek pregnant.”*

#### Example 3.6.2.3

*I: “[Spoke in English] Do you think it’s important that there should be more awareness?”*

*P: “Yes, of course. There should be yo. It is a big problem with people who drink alcohol. I realise it now.”*

*I: “Did you wish that someone had told you before?”*

*P: “Yes.”*

*“...Ek sal wil graag meer in die besigheid wees. Verstaan wat rêrig aangaan. Hoe om ander mense te help met dit en so. Mense wat ek dalk nou ken wat dalk alkohol gebruik en so.”*

#### Example 3.6.2.4

*I: “Dink jy daar moet meer buite die kliniek moet gepraat word van die effekte wat alkohol kan hê?”*

*P: “Ja miskien soos mevrou dit nou het, miskien om te gesels oor alkohol. Die gemeenskap saal is mos daar, die een gedeelte...”*

*I: “Het julle daai tipe praatjies in die raadsaal gehad, was daar al so?”*

*P: “Nie eintlik daar nie.”*

*I: “En op „n ander plek?”*

*P: “Nee dis mos nou net die hoof suster van die hospitaal of kliniek wat nou dalk by die kliniek wat oor iets wil praat en so.”*

*I: “Is daar baie belangstelling daarvoor?”*

*P: “Ja.”*

#### Example 3.7.1.1

*I: “En jou drink gewoontes nou?”*

*P: “As ek dalk nou na „n partjie toe gaan. Hulle nooi my vir potjies dan sal ek nou „n cidertjie drink maar nie eintlik nie. My kinders weet nie dat ek drink nie. So ek drink nie voor hulle „n cidertjie nie.”*

*I: “Hoeveel het jy gedrink toe jy swanger was?”*



*P: Mevrou, toe ek met \*Ethan swanger was het ek sommer kiste en kiste gedrink en toe sê my ma dis nie hoe ek moet te kere gaan nie.*

*I: "Maar jy drink nou baie minder?"*

*P: "Ja nee baie minder... Laat ek liewer my kinders ondersteun as wat ek die drank ondersteun."*

#### Example 3.7.1.2

*"Nee, sy het nie saam gegaan nie maar sy was by my huis. Toe sê ek nou vir haar waar van daan kom ek en alles wat die vrou vir ons verduidelik het vir haar verduidelik want sy het mos die goed veroorsaak. Maar toe hoor sy dan ook nie en toe gaan sy maar net weer aan... met al drie het sy baie gedrink en met die babatjie. Toe ons nou die dag by die skool was en toe wys ek vir haar kyk nou waardeur gaan \*Inga nou. En toe gaan drink sy net verder..."*

#### Example 3.7.2.1

*"So ek sal mense aanraai, al skel hulle vir my ek worry nie. So lank ek my plig gedoen het. Miskien luister hulle vir my, miskien skel hulle vir my maar agterna gaan hulle terug dink en dink die vrou is reg."*

#### Example 3.7.2.2

*"Ek sê baie vir hulle moenie drink nie want dit benadeel jou baba en dan vra sy vir my hoekom. Hulle raak kwaad en dan sê sy ek het niks met haar te doen nie. En dan sê ek vir haar ek het niks met jou te doen nie maar ek is besorg oor die baba want ek kan so se want ek het ondervinding nou. Ek weet presies waardeur ek gaan maar hulle verstaan dit nie."*

#### Example 3.7.2.3

*"Ek sal vir hulle sê maar dan moet U nou net weet dan kry jy die lelikste woorde want dan word daar net vir jou gesê jy was ook maar net 'n drinker en dan wil jy nou vir my kom staan en sê. Ek sal ophou wanneer ek so voel."*

#### Example 3.7.2.4

*"Maar ek het mos vir die vrou gevra as hulle miskien klasse het of programme het moet hulle vir my bel ek sal wil graag meer in die besigheid wees. Verstaan wat rêrig aangaan. Hoe om ander mense te help met dit en so. Mense wat ek dalk nou ken wat dalk alkohol gebruik en so."*