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PREGNANT WOMEN'S PERCEPTIONS AND KNOWLEDGE REGARDING ALCOHOL USE DURING PREGNANCY

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in the field of Genetic Counselling.

Johannesburg, 2013

DECLARATION

I, Chanelle le Roux, declare that this research report is my own work. It is being submitted for the degree of Master of Science (Medicine) in Genetic Counselling in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

_____

_____ day of _____ , 2013.

DEDICATION

To my mom, dad, JW and Jean-Pierre. Your unconditional love and support has carried me through the last two years. You offered your strength when I had none left and you never stopped motivating or believing in me, even when I was on the brink of giving up. I have learned so much from you and am grateful to you for shaping me into the person I am. This work is as much yours as it is mine.

ABSTRACT

The teratogenic effects of prenatal alcohol exposure can significantly influence the development of a child, which may result in a range of structural, cognitive and behavioural abnormalities. The severity of these effects can vary and fall under the fetal alcohol spectrum disorder (FASD). South Africa hosts the highest prevalence rate (12%) of this disorder in the world.

All conditions included in the FASD spectrum are completely preventable through maternal abstinence of alcohol during pregnancy. At present, very limited information is available regarding how much pregnant women in South Africa know about adverse effects caused by prenatal alcohol exposure. This study aimed to determine pregnant women's awareness of alcohol's potential teratogenic effects on pregnancy and their knowledge of the features and characteristics associated with fetal alcohol syndrome (FAS), the most severe of the FASD conditions. Additionally, the study compared the awareness and knowledge of pregnant women attending private antenatal centres, to those attending an antenatal clinic at Charlotte Maxeke Johannesburg Academic Hospital, a state hospital in the Johannesburg area.

Participants (n=211) completed a self-administered questionnaire at their private antenatal class or state clinic. A total of 211 questionnaires were analysed; 107 questionnaires from the state antenatal clinic and 104 from the private antenatal centres. The awareness levels regarding alcohol use in pregnancy were found to be very similar amongst the private (52%) and state (55%) participants. However, results indicated that significantly more private participants (19%), compared to state participants (3%) could be classified as having knowledge of the condition FAS.

Overall, this study found that pregnant women from various backgrounds have limited knowledge of the harms caused by alcohol use during pregnancy. Misconceptions about the acceptable levels of maternal alcohol consumption and the effects thereof were also evident. The results of this research highlights that prevention strategies and awareness campaigns regarding alcohol use during pregnancy should incorporate information on the severity and permanent nature of FAS, as well as highlighting the fact that all types of alcoholic beverages can result in this condition. Also, these campaigns should focus on informing women that no level of alcohol is acceptable during pregnancy, as any amount may have potentially teratogenic effects on the developing fetus.

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ABBREVIATIONS

%	Percentage
AIDS	Acquired immune deficiency syndrome
ARBD	Alcohol-related birth defects
ARND	Alcohol-related neurodevelopmental disorder
CDC	Centre for Disease Control
CEO	Chief Executive Officer
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital
Dr	Doctor
FAS	Fetal alcohol syndrome
FAE	Fetal alcohol effects
FASD	Fetal alcohol spectrum disorder
HIV	Human immunodeficiency virus
IOM	Institute of Medicine
SD	Standard deviation
SES	Socio-economic status
Sr	Sister

1. CHAPTER 1: INTRODUCTION

It has been known since biblical times that alcohol consumption should be avoided during pregnancy as it can be detrimental to the developing baby. Subsequent research has shown that many children exposed to alcohol *in utero* are often born with a similar pattern of malformations (Jones, Smith, Ulleland et al., 1973). At the most severe end of the spectrum, children with significant prenatal alcohol exposure have been shown to be affected with a condition referred to as fetal alcohol syndrome (FAS). Despite the significant amount of research that has been performed to elucidate the specific effects of prenatal alcohol exposure, women seem to only have a vague idea of why alcohol should be avoided and what conditions such as FAS entail (Peadon, Payne, Henley et al., 2010). By increasing women's knowledge and understanding of conditions such as FAS, maternal abstinence of alcohol can be encouraged and the number of at-risk pregnancies could drastically decrease.

The research presented in this report focused on determining pregnant women's knowledge and attitudes regarding the effects of prenatal alcohol exposure. This chapter introduces the research topic by providing background information on the condition caused by prenatal alcohol exposure, fetal alcohol spectrum disorder (FASD). Attention is also given to the prevalence of the conditions that fall under FASD, with particular focus on the South African rates. Maternal risk factors that have been identified in women at increased risk of having an affected child are briefly discussed as are the current levels of alcohol use among women. Literature regarding women's knowledge and perceptions of alcohol use in other parts of the world will be investigated and the effectiveness of preventative strategies mentioned. Genetic counselling and its role in preventing conditions like FAS is discussed, as well as how results of this study may improve how genetic counsellors' approach at-risk pregnant women in a

genetic counselling session. The chapter concludes with motivation for performing the research and the aims and objectives of the study.

1.1. Prenatal alcohol exposure and adverse outcomes

The effect of alcohol consumption during pregnancy on a developing fetus has been investigated for many years. As soon as a pregnant woman consumes alcohol it circulates through the blood and crosses the placenta causing alcohol levels in the fetus and amniotic fluid to rise and reach maternal levels within an hour (Idanpaan-Heikkila, Jouppila, Akerblom et al., 1972). In addition, there are much lower levels of alcohol dehydrogenase present in the fetal liver compared to an adult liver. The fetus is therefore unable to metabolise ethanol as effectively as the mother and is vulnerable to its teratogenic effects (Idanpaan-Heikkila, et al., 1972). Maternal alcohol consumption during pregnancy has therefore been associated with a number of adverse pregnancy outcomes. Risk for stillbirth due to alcohol exposure has been shown to increase in a dose-dependent manner (Kaminski, Rumeau and Schwartz, 1978) and the number of preterm deliveries could decrease by up to 40% simply through maternal abstinence of alcohol (Sokol, Janisse, Louis et al., 2007). Furthermore, previous studies have shown that even mild alcohol consumption during pregnancy may result in miscarriage or spontaneous abortion (Kline, Shrout, Stein et al., 1980), as well as a significant decrease in birth weight (Little, 1977).

Due to a fetus's inability to metabolise alcohol, any child that has been exposed to alcohol *in utero* is at risk of being born with structural abnormalities and neurocognitive or behavioural anomalies. The term assigned to encompass this range of adverse effects is called fetal alcohol spectrum disorder (FASD). It remains unclear whether a safe level of alcohol use during pregnancy exists and as with any teratogenic exposure, factors such as dosage and timing of exposure may influence the severity of the resulting phenotype. Maternal consumption of

alcohol at levels as low as one drink per week have been related to child behavioural problems (Sood, Delaney-Black, Covington et al., 2001), while another study found an association between mild prenatal alcohol exposure and impaired motor function (Mattson and Riley, 1998). However, recent studies have delivered contradictory results showing no difference in the mean IQ or executive functioning of 5-year old children whose mothers consumed low to moderate levels of alcohol during pregnancy (5-8 drinks per week) to those who abstained during pregnancy (Eriksen, Mortensen, Kilburn et al., 2012; Skogerbo, Kesmodel, Wimberley et al., 2012). As no 'safe' level of alcohol use during pregnancy has been established most developed countries recommend complete abstinence (Raymond, Beer, Glazebrook et al., 2009).

1.1.1. Current levels of alcohol use by pregnant women

Reported rates of alcohol use among women of childbearing age may differ slightly in various countries and cultures. However, there is little doubt that the majority of young women consume alcohol, as illustrated by various surveys conducted in a number of countries (Table 1.1). Even in countries such as Korea where traditional social principles allowed only men to consume alcohol in the past, the frequency of alcohol use among women has increased from 32% in the late 1980's to 80% in 2007 (Lee, Shin, Won et al., 2010).

Table 1.1: Reported rates of alcohol consumption among young women (Australian Institute of Health and Welfare, 2005; Canadian Addiction Survey, 2008; Substance Abuse and Mental Health Services Administration, 2008; Office for National Statistics, 2009)

Country	Age group (years)	% of women who consume alcohol
United States	18 – 25	57.1
Australia	20 – 29	86.7
Canada	20 – 24	87.3
United Kingdom	16 – 24	79

Accurate assessments of the use of alcohol among pregnant women pose many challenges, such as differences in methodology of studies and underreporting by participants due to fear of social stigma (Tough, Tofflemire, Clarke et al., 2006). In the United States, a survey by Serdula, Williamson, Kendrick et al. (1991) showed that 25% of women reportedly continued alcohol consumption during their pregnancy, while an alarming rate of 42.8% was reported by pregnant women in certain areas of the Western Cape, South Africa (Croxford and Viljoen, 1999).

Furthermore, studies conducted among young women in America show that young women are increasingly prone to risky or binge drinking patterns (Eaton, Kann, Kinchen et al., 2010) which have been associated with an increased risk of unplanned pregnancies (Walker, Fisher, Sherman et al., 2005). According to an Australian study, up to half of pregnancies are reported as being unplanned (Colvin, Payne, Parsons et al., 2007) and many women do not recognise their pregnancy until after the fourth week of gestation (Floyd, Decoufle and Hungerford, 1999). Consequently, there is an increased risk of unintentional alcohol consumption before pregnancy is even recognised. Results of certain studies show that up to 60% of women continue to consume alcohol before realising they are pregnant. This is extremely concerning since alcohol consumption can be particularly damaging to the developing fetus during the first trimester of the pregnancy, when organogenesis takes place (Floyd et al., 1999).

Although most women instinctively decrease their alcohol intake during pregnancy, habitual heavy drinkers seem much less likely to do so (Waterson and Murray-Lyon, 1989). Research has indicated that mothers of children at the severe end of the FASD spectrum do not typically reduce or abstain from alcohol use once they become pregnant (Viljoen, Gossage, Brooke et al., 2005). A case-control study conducted in one community of the Western Cape of South Africa, found that mothers of affected children reported a consumption of 12.6 drinks per week, compared to 2.4 drinks per week reported by mothers in the control group. More than half of

the mothers with affected children also admitted that their alcohol consumption increased during the pregnancy (May et al., 2000). One drink is equal to one glass (100ml) of wine, 200ml beer or 25ml spirits (Blackhurst and Marais, 2005). Women who decrease their alcohol intake during pregnancy usually have a lower level of alcohol consumption before pregnancy compared to those who do not alter their behaviour (Rosett, Weiner, Lee et al., 1983). Therefore, level of alcohol consumption before pregnancy is a useful predictor of prenatal alcohol consumption (Day, Cottreau and Richardson, 1993).

1.2. Fetal alcohol spectrum disorder (FASD)

Fetal alcohol spectrum disorder (FASD) is the umbrella term used to collectively refer to fetal alcohol syndrome (FAS), which is considered to be the severe end of the spectrum, as well as fetal alcohol effects (FAE), which consists of a less severe phenotype compared to FAS. Fetal alcohol effects include partial FAS, alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorder (ARND) (Jacobson and Jacobson, 2002).

The features and symptoms associated with FASD are irreversible. Importantly, FASD is thought to be the leading cause of non-inherited intellectual disability in the world, despite being 100% preventable through maternal abstinence (Walker et al., 2005). As mentioned previously, various factors may influence the severity of the effects of alcohol on the fetus. Along with timing and amount of alcohol consumed antenatally, the genetic make-up of the fetus and maternal metabolism is also influential (Tough et al., 2006). It has been suggested that some of the more severe physical features associated with a diagnosis of FAS (as described in section 1.2.1) are a result of alcohol exposure during the first three months of gestation, which is considered the critical time of organogenesis, whereas milder symptoms of ARND are caused by maternal alcohol use at later stages of the pregnancy (Gray, Mukherjee and Rutter, 2009). During organogenesis the facial features develop and therefore only interference

during this time will involve abnormalities in facial development. Conversely, the brain and central nervous system continue to develop throughout the pregnancy and will therefore remain vulnerable to interference from alcohol exposure and subsequent neurodevelopmental abnormalities at all times (Sadler, 2010).

1.2.1. Fetal alcohol syndrome (FAS)

In 1973, Jones et al. noted a specific pattern of malformations in eight children born to chronic alcoholic mothers, which was referred to as the "fetal alcohol syndrome" (FAS). Characteristic facial features (Figure 1.1) were found to be associated with FAS, while features of growth retardation and cognitive or behavioural problems (Table 1.2) were also described (Jones and Smith, 1973; Jones et al., 1973).

Subsequent to this description, a number of studies have investigated the features and symptoms associated with prenatal alcohol exposure. Results of further investigations aim to increase the accurate diagnosis of FAS since recognition of the disorder is very difficult, particularly in the first few years of life (Jones, 2003). The diagnostic criteria required to confirm a diagnosis of FAS were originally presented by the Institute of Medicine (IOM) in 1996. Subsequently, these guidelines have been revised and state that in order to diagnose a child with FAS he/she must have the following symptoms: growth deficiency, characteristic FAS facial features (Figure 1.1), dysfunction of the central nervous system and confirmation of prenatal alcohol exposure (Hoyme, May, Kalberg et al., 2005).

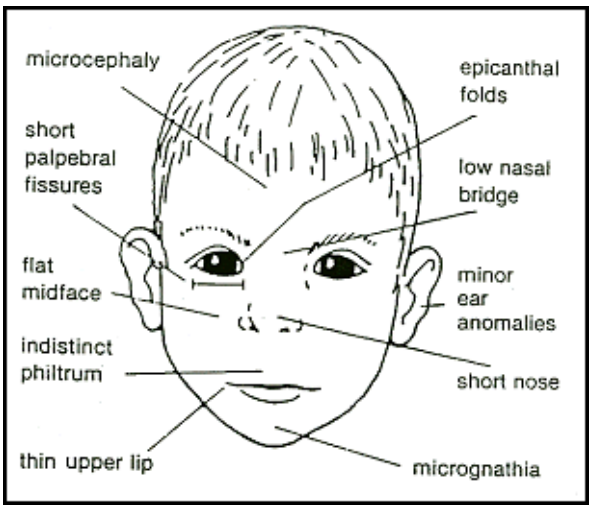


Figure 1.1: Characteristic facial features of fetal alcohol syndrome (Frigaard, 2006).

The development of the brain is most sensitive to prenatal alcohol exposure and many of the functional and structural anomalies associated with FAS, such as microcephaly and neurobehavioural abnormalities, are actually secondary features of damage caused by alcohol on the developing brain. Neurobehavioural dysfunction and behavioural problems (Table 1.2) are commonly seen in children and adults that have been exposed to alcohol *in utero* and could be attributed to various brain abnormalities such as a reduced corpus callosum or basal ganglia (Jones and Smith, 1973).

Table 1.2: Characteristic clinical features associated with FASD (Jones and Smith, 1973)

Facial features	Growth restrictions	Neurobehavioural dysfunction	Other
Short palpebral fissures	Prenatal growth deficiency	Hyperactivity	Developmental delay
Long, smooth philtrum	Postnatal growth deficiency	Tremulousness	Fine-motor dysfunction
Thin vermillion border of upper lip	Microcephaly	Language deficits	Cleft palate
Flat midface		Learning problems	Joint anomalies
Epicanthic folds		Decreased attention	Abnormal palmar creases
Maxillary hypoplasia			Micropthalmia
Micrognathia			Cardiac defects

1.2.2. Fetal alcohol effects (FAE)

Within the FASD continuum, the term "fetal alcohol effects" (FAE) was developed to describe children born to mothers who drank heavily during pregnancy, but who only exhibited some of the features associated with FAS. They therefore did not meet the criteria for a definite diagnosis of FAS (Coles et al., 1997; Jacobson and Jacobson, 2002). The Institute of Medicine decided to further distinguish three forms of FAE, namely "partial FAS", "alcohol-related birth defects (ARBD)" and "alcohol-related neurodevelopmental disorder (ARND)". The features associated with these three forms are described below (Stratton, Howe and Battaglia, 1996; Hoyme et al., 2005).

- **Partial FAS (PFAS)**

  Partial FAS (PFAS) applies to children with substantial prenatal alcohol exposure, some facial features and abnormalities in either the growth or neurodevelopmental categories.

- **Alcohol-related birth defects (ARBD)**

  The term 'ARBD' applies to children with heavy prenatal alcohol exposure, typical facial phenotype, specific structural abnormalities, but with normal growth and development.

- **Alcohol-related neurodevelopmental disorder (ARND)**

  ARND applies to children with prenatal alcohol exposure who exhibit characteristic behavioural or cognitive anomalies, but whose growth and structural development may be considered within the normal range.

1.3. Prevalence rates of FAS

Fetal alcohol syndrome has been identified as a major problem throughout the world with a prevalence of between 0.33 and 2.2 per live births reported in the United States (Abel and

Sokol, 1991; May and Gossage, 2001), 0.06 per 1000 live births reported in Australia (Elliott, Payne, Morris et al., 2008) and up to 7.4 per 1000 live births reported in parts of Italy (May, Fiorentino, Phillip Gossage et al., 2006). An overall estimated prevalence rate of 0.97 per 1000 live births has been established for the developed world (Abel, 1995). Despite these seemingly high numbers, the Western Cape province of South Africa indicates a much larger problem. This is partly explained by the fact that the Western Cape is renowned for its wineland areas and subsequent wine production. It is likely that this has had a major influence on the drinking patterns, particularly among farm workers of these winelands. Individuals in these communities are also faced with poverty, poor nutrition and social problems on a day-to-day basis, factors which are likely to contribute to the high prevalence of FAS.

Historically, farm workers received wine as partial payment for labour under what was known as the "Dop" system and although this has been outlawed, the consequences can still be seen in these communities today (Viljoen, Gossage, Brooke, et al., 2005). Heavy, episodic or binge drinking patterns during weekends are common forms of recreation, particularly among individuals in the wineland area (May, Brooke, Gossage et al., 2000).

A prevalence study performed in the Gauteng Province revealed a FAS prevalence of 19 per 1000 first graders (Viljoen, Craig, Hymbaugh et al., 2003). The Western Cape Province was shown to carry a heavier burden, when research performed in this province revealed that the incidence of FAS alone could be estimated at 40.5 to 46.4 per 1000 first grader school children (May et al., 2000). Similar studies were subsequently performed and results showed rates of 65.2 to 74.2 per 1000 first graders two years later (Viljoen et al., 2005) and 68.0 to 89.2 per 1000 first graders two years following that. (May, Gossage, Marais et al., 2007). However, the most concerning results were found during a study conducted in De Aar, a town situated in the Northern Cape Province. A rate of 119.4 per 1000 (12%) Grade 1 schoolchildren in this town

were affected by FAS (Urban, Chersich, Fourie et al., 2008). It is surprising to find that De Aar, which is predominantly a sheep-farming area has a higher prevalence of FAS than the wine-farming areas of the Western Cape. This suggests that viticulture does not necessarily influence the prevalence of FAS in an area (Urban et al., 2008). A recent study also investigated the prevalence rates of the less severe conditions included in the FASD spectrum, i.e. PFAS, ARND and ARBD among first graders in a specific community of the Western Cape (May, Blankenship, Marais et al., 2012). It was found that 45.3 – 69.6 per 1000 first graders in this community are affected by PFAS, while 30.5 – 46.8 per 1000 were diagnosed with ARND. No participants were diagnosed with ARBD. The high prevalence rates found in different areas of South Africa indicate that not only does this country host the highest incidence rates of FAS reported in the world, but that these rates seem to be increasing.

1.4. Maternal risk factors for prenatal alcohol exposure

Since FAS and other related disorders are 100% preventable if one does not consume alcohol during pregnancy, reasons for the high prevalence rates have been of particular interest, not only in South Africa but throughout the world. A number of maternal risk factors associated with maternal alcohol consumption during pregnancy have consequently been identified. These include increased gravidity and parity as well as partners' and family members' heavy drinking patterns (May, Gossage, Brooke et al., 2005). Importantly, demographic information, particularly low socioeconomic status (SES), which includes rural residence and lower education levels, as well as tobacco use during pregnancy have been identified as significant maternal risk factors for FAS (Viljoen, Croxford, Gossage et al., 2002). An American study reported that mothers of low SES were 45 times more likely to have children with FAS than those of middle and high SES (Bingol, Schuster, Fuchs, et al., 1987). In the Western Cape

Province of South Africa 34% of urban women reported alcohol consumption during pregnancy compared to 51% of rural women (Croxford and Viljoen, 1999).

1.5. Awareness and knowledge of the effects of alcohol on the fetus

A number of studies have been performed to explore women's perceptions of alcohol consumption during pregnancy. The sections below describe these various studies. Two of the studies (Lelong, Kaminski, Chwalow et al., 1995; Raymond et al., 2009) explored pregnant women's beliefs regarding maternal alcohol use and aimed to identify factors which influenced the level of alcohol consumption during pregnancy. Three of the studies (Kesmodel and Kesmodel, 2002; Walker et al., 2005; Peadon et al., 2010) focused on investigating women's knowledge regarding the risks involved with different levels of alcohol intake and thereby evaluated whether educational interventions were needed. No local studies investigating South African women's awareness or knowledge regarding the dangers associated with alcohol use in pregnancy could be found.

1.5.1. Attitudes toward alcohol use during pregnancy

Seventy six percent of pregnant Danish women interviewed at an antenatal clinic considered alcohol intake during pregnancy acceptable (Kesmodel and Kesmodel, 2002). A similar study in France found that while only 6% of pregnant women would not consider drinking even one drink per day, 60% considered two drinks per day reasonable (Lelong et al., 1995). A nationwide cross-sectional survey conducted amongst non-pregnant women in New Zealand revealed that only 44% believed no level of alcohol consumption to be safe during pregnancy (Parackal, Parackal, Harraway et al., 2009). Other studies have shown that some women even consider alcohol consumption beneficial during pregnancy, claiming that since antenatal anxiety has been associated with mental health problems in children (O'Connor, Heron, Golding et al., 2002) some alcohol intake for the purpose of stress relief holds more potential

benefits than risks (Raymond et al., 2009). In addition, inappropriate interpretation of a study conducted in 2008 in the United Kingdom has resulted in the public belief that light drinking in pregnancy could enhance a child's intelligence and behaviour (Kelly, Sacker, Gray et al., 2009; Raymond et al., 2009).

Despite recommended guidelines of abstinence, it is clear that public knowledge regarding the amount of antenatal alcohol intake is somewhat lacking. A recent study has shown that due to conflicting advice from various health organisations, government guidelines and media reports, most women found information regarding safe levels of prenatal alcohol consumption confusing (Raymond et al., 2009). This has been substantiated by results of a survey showing that only 56% of participating couples were aware that no safe level of alcohol use during pregnancy has been established (Chang, McNamara, Orav et al., 2006).

1.5.2. Knowledge of potential adverse effects

On average, women are aware that alcohol use in pregnancy can have adverse effects. This is supported by the results of two studies that indicated 83-85% of women knew that prenatal alcohol consumption could harm an unborn baby (Lelong et al., 1995; Kesmodel and Kesmodel, 2002). Interestingly, results also showed that 70% of women believed that different subtypes of alcohol could cause different adverse effects (Kesmodel and Kesmodel, 2002). Awareness regarding the effects of prenatal alcohol exposure, such as FASD, has been found to vary. According to a Canadian survey conducted in 2006, most women (75%) were aware that any level of prenatal alcohol exposure can potentially harm the fetus and an almost unanimous belief exists that the higher level of alcohol intake, the more severely affected the fetus will be (Public Health Agency of Canada, 2006). Furthermore, this survey indicated that 86% of respondents had heard of FAS or FASD, while a more recent Australian study reported that only about half of participating women had ever heard of FAS (Peadon et al., 2010).

Women seem to only have a vague idea of what the specific symptoms and affects associated with prenatal alcohol exposure and FASD are. Although 42% of Canadian women knew that FAS/FASD generally refers to learning or cognitive disabilities such as lowered IQ, 21% could offer no description of what this disorder entails (Public Health Agency of Canada, 2006). In addition, many of the Australian women who claimed to be aware of some potential dangers could not name any particular effects (Peadon et al., 2010).

Results of such studies described above have shed some light on women's perceptions, knowledge and attitudes regarding alcohol intake during pregnancy and the associated risks. Importantly, many of these studies have indicated that knowledge of potential dangers to a fetus due to prenatal alcohol exposure is not necessarily associated with personal beliefs or level of alcohol use by pregnant women (Lelong et al., 1995; Kesmodel and Kesmodel, 2002). Although most pregnant women seem aware that alcohol can be harmful to their babies, they appear unwilling to heed recommendations of abstinence and many believe that some alcohol intake during pregnancy is considered acceptable (Raymond et al., 2009).

1.5.3. Women's perceptions of the risks associated with prenatal alcohol exposure

Pregnant women's risk perception of the harmful effects of alcohol on a fetus is a particularly important predictor of alcohol consumption during pregnancy. Previous experiences tend to influence how women perceive the dangers of prenatal alcohol exposure and could therefore also explain difference in attitudes between women (Testa and Reifman, 1996; Raymond et al., 2009). For example, it was found that women who experienced previous healthy pregnancies were more likely to report a much lower perception of risk regarding alcohol consumption in pregnancy than those who were expecting their first baby (Testa and Reifman, 1996). Similarly, multiparous women and women aged 30 to 45 years were less likely to be

aware of the dangers associated with alcohol use during pregnancy, such as growth retardation or other lifelong disabilities in children, compared to nulliparous women (Peadon et al., 2010).

1.6. Preventative strategies and awareness campaigns

Considering the high prevalence rates of FASD and apparent deficiency in knowledge of the harmful effects of prenatal alcohol exposure, the need for effective preventative strategies and intense awareness campaigns is imperative.

Three common prevention strategies have been identified; universal, indicated and selected prevention. These strategies have been summarised in Chersich, Urban, Olivier et al. (2012) and are described below:

- **Universal prevention**

  Universal prevention strategies are aimed at increasing the general population's knowledge and awareness regarding the adverse effects caused by alcohol consumption during pregnancy, thereby altering risky drinking patterns in pregnant women.

- **Indicated prevention**

  Indicated prevention targets high-risk individuals such as alcohol dependant women or mothers of children with FASD.

- **Selected intervention**

  Selected intervention provides brief interventions for high-risk individuals identified by screening pregnant women for alcohol use

A recent study conducted in De Aar and Upington, two areas heavily affected by FASD in the Northern Cape Province of South Africa, assessed the effectiveness of intervention strategies aimed at increasing awareness of the harms caused by alcohol consumption during pregnancy. Maternal drinking patterns, prevalence rates of FASD and knowledge regarding alcohol

consumption were assessed before and after universal interventions. These included media coverage of FASD in local newspapers, radio programmes, pamphlets and posters, as well as informative talks by trained community health workers at clinics. According to this study, FASD rates decreased from 8.9% pre-intervention to 5.7% post-intervention, while maternal awareness of harmful alcohol effects increased significantly. Results of this study are therefore very promising, suggesting that universal prevention strategies could reduce the rates of FASD by 30% and thereby supporting the need for community-level interventions (Chersich et al., 2012).

Walker et al. (2005) showed that a simple intervention, in the form of an educational brochure, could significantly and effectively increase women's immediate knowledge regarding FASD (Walker et al., 2005).

Although 70% of women believe information regarding alcohol use during pregnancy should be communicated to them by health professionals, various studies have shown that pregnant women are receiving very limited or inconsistent advice from doctors, nurses and midwives (Lelong et al., 1995; Kesmodel and Kesmodel, 2002; Raymond et al., 2009). It is likely that healthcare professionals fail to discuss alcohol consumption and its adverse effects on fetal development because of their own uncertainty regarding safe levels of alcohol use and whether complete abstinence is necessary (Diekman, Floyd, Decoufle et al., 2000). Considering the significant influence of advice from doctors on their patients, it is essential that healthcare professionals inform their patients about the possible adverse effects of alcohol consumption and recommend abstinence during pregnancy (Walker et al., 2005).

1.7. Genetic counselling

According to the definition approved by the National Society of Genetic Counselors, genetic counselling is "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" (Resta, Biesecker, Bennett et al., 2006). Genetic counsellors see a variety of cases, including mendelian conditions and prenatal teratogen exposure.

Genetic counselling services are usually provided by a team consisting of trained genetic counsellors, clinical geneticists and genetic nurses. Genetics is becoming more relevant to an increasing number of medical areas. Consequently, the contexts in which genetic counselling take place are also increasing. Genetic counsellors may counsel patients that need prenatal screening or diagnosis, have been diagnosed with an adult-onset condition, or have been referred from a paediatric setting. Psychosocial counselling and support, as well as helping patients cope with emotional responses to new information, is an imperative part of the genetic counselling process (Walker, 2009).

In the prenatal setting, counsellors must obtain a family history and gather detailed information regarding maternal health before and during pregnancy. If a patient reveals a history of teratogen exposure during her pregnancy the counsellor is obliged to address the issue by discussing the potential adverse outcomes. Genetic counsellors are frequently required to counsel patients who have consumed various amounts of alcohol during their pregnancies and whose unborn babies are at risk of being affected by FASD (Harper, 2004).

Clinical geneticists examine and assess individuals, particularly children, with various genetic conditions, dysmorphic features or developmental delay (Harper, 2004). Children with features of FASD are often referred to genetic clinics for assessments. Mothers of children with a

confirmed diagnosis of FASD should receive genetic counselling so that the aetiology of the disorder can be discussed with them. In addition, they should be advised to prevent future affected pregnancies by avoiding alcohol consumption when trying to conceive and during pregnancy. .

1.8. Necessity of determining knowledge and awareness in South African populations

Thus far, most studies conducted in South Africa have focussed on the Western and Northern Cape Provinces where the prevalence of alcohol consumption during pregnancy and the subsequent adverse effects have been assessed. Not much information is available on Gauteng, although Viljoen et al. (2003) have investigated the prevalence of FAS in various communities in this province. When considering South Africans' easy access to affordable alcohol at illegal bars (shebeens) (Mager, 2004) and the fact that South Africa hosts the highest prevalence rate of FASD throughout the world, there clearly exists a need for the development of effective FASD preventative measures. The education of women regarding the dangers of alcohol consumption during pregnancy is essential in the prevention of FASD. However, interventions cannot be implemented before we fully understand the perceptions and current levels of knowledge and awareness amongst women regarding the effects of alcohol on their unborn children. A number of studies, as previously discussed, have explored these matters, but the majority have been performed in developed countries and subjects have predominantly been educated women. Therefore, there is reason to conduct a study in South Africa to add to the literature regarding developing countries.

1.8.1. Motivation for conducting research

Information regarding the knowledge and awareness of South African pregnant women regarding alcohol consumption during pregnancy and the associated adverse effects, are

limited, particularly in the Johannesburg area. Considering the vast differences in South African women's cultural and financial backgrounds, as well as disparities in educational and healthcare access, differences in knowledge and awareness among women of varying backgrounds are to be expected. By better understanding where women's misconceptions lie and what the major gaps in their knowledge regarding alcohol use in pregnancy are, appropriate and targeted intervention or preventative strategies can be effectively developed.

1.9. Aims and objectives

The aim of this study was to investigate women's knowledge and perceptions regarding alcohol use and its effects during pregnancy, and compare information obtained from women in the private medical sector to that obtained from women in the state medical sector in Johannesburg. For the purpose of this study, "awareness" can be defined as the realization that alcohol should not be used during pregnancy, because it can be harmful. Whereas being "knowledgeable" refers to knowing specific facts and details regarding FAS, including the cause and features of the condition.

This study had five main objectives.

- To determine whether pregnant women consider alcohol consumption during pregnancy to be safe or harmful to a fetus.
- To ascertain whether pregnant women are knowledgeable regarding the specific effects of alcohol consumption during pregnancy and whether they know about fetal alcohol syndrome.
- To identify sources from which women obtain their information regarding alcohol consumption in pregnancy.

- To investigate whether associations exist between women's knowledge and perceptions regarding alcohol use during pregnancy and their level of education.
- To compare the knowledge and attitudes of pregnant women in the state medical sector to those of women in the private medical sector.

2. CHAPTER 2: METHODOLOGY

This chapter describes the methodology employed for this study including the construction of the questionnaire, the study setting, pilot study, data collection and data analysis.

2.1. Study design

The study was a descriptive, questionnaire-based survey and data analysis was quantitative in nature. Ethics approval was obtained from the Human Research Ethics Committee (Medical), of the Faculty Health Sciences, University of the Witwatersrand. Ethics Clearance Certificate number: M111161 (Appendix A).

An overview of the steps followed during the course of this research, from designing the questionnaire to analysing the data, is summarised in Figure 2.1.

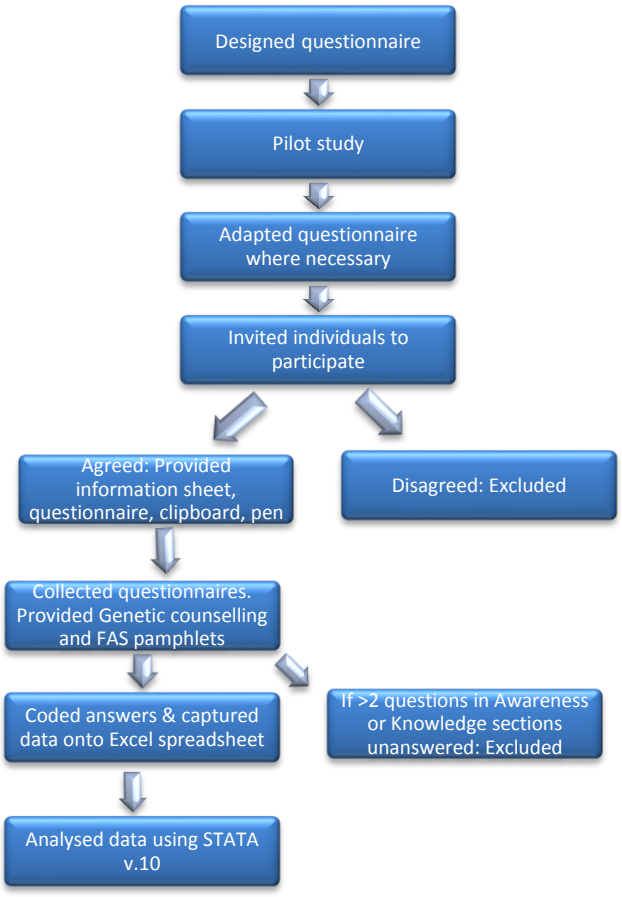


Figure 2.1: Summary of steps followed while conducting the research.

2.2. Study sites

Three study sites were used to recruit participants; one state hospital (Charlotte Maxeke Johannesburg Academic Hospital (CMJAH)) and two private antenatal centres (Tina Otte's Family and Child Centre and the Bryanston Mother and Baby Education Centre). Permission was obtained in writing from Tina Otte (Appendix B) and Nicky Gebka (Appendix C), the owners of the two private antenatal centres, as well as from Dr. Barney Selebano, Chief Executive Officer (CEO) of Charlotte Maxeke Johannesburg Academic Hospital (Appendix D), to perform research at the three sites.

Charlotte Maxeke Johannesburg Academic Hospital is a tertiary hospital situated in Parktown, Johannesburg. The hospital serves patients from across the Gauteng Province as well as neighbouring provinces. Patients are seen at the antenatal clinic every day of the week, with between 60 and 70 pregnant women attending the clinic per day (Sr J. Maredi, personal communication, 6 February 2012). On average, between 1200 and 1400 patients are therefore seen at CMJAH's Antenatal Clinic per month.

Tina Otte's Family and Child Centre is a private antenatal centre, situated in Randburg. Tina Otte is a registered midwife with an international certificate in childbirth education and has been instructing antenatal classes for over 25 years. This antenatal centre offers childbirth education classes, prenatal exercise classes as well as breast feeding and after birth services. Participants for this study were recruited from the childbirth education classes. Approximately 15 – 20 expectant couples attend these classes, which are held for either eight weeks (one class per week) or four weeks (two classes per week).

The Bryanston Mother and Baby Education Centre is run by Nicky Gebka, a registered midwife and certified lactation consultant. This centre offers a number of classes, including a well-

established childbirth education course, which is held for four to six weeks and attended by approximately 10 – 16 expectant couples per course.

2.3. Questionnaire

A structured questionnaire was designed by adapting two validated questionnaires used in previous published studies (Croxford and Viljoen, 1999; Peadon et al., 2010). The questionnaires used in these studies could not be duplicated in this project since the aims, objectives and participants differed to those of the present study. Permission was obtained to use and modify these questionnaires. Also, contrary to the present study, these questionnaires were not self-administered and were therefore constructed for the purpose of personal or telephonic interviews of participants. By keeping the research question, as well as the aims and objectives of this study in mind, appropriate questions were selected from the validated questionnaires and modified to suit the research topic, sampling method and unique South African population. In order to successfully accomplish the aims and objectives of this study, some questions were uniquely developed by the researcher.

Participants were asked to complete the self-administered, structured questionnaire (Appendix E), which consisted of three sections; 1) Demographics and Obstetric History, 2) Awareness and Attitudes, and 3) Knowledge. Questions pertaining to section 1 of the questionnaire included age, ethnicity, religious beliefs, area of residence, education level, occupation and parity. Section 2 of the questionnaire included general questions regarding the safety of alcohol use during pregnancy and the source of participants' awareness, whereas section 3 posed specific questions about FAS and participants' beliefs regarding quantity and level of alcohol use associated with the condition. Section 3 also asked participants to select features associated with FAS from a list of features provided. The features included in this questionnaire were

randomly selected by the researcher to cover the spectrum of severity from brain damage (severe end of the spectrum), to the less common cleft lip and/or palate.

2.4. Pilot study

A pilot study was conducted whereby three state and three private patients were asked to complete the self-administered questionnaire. This was done so as to ensure internal consistency of the questions, to evaluate the data collection method and to identify questions that needed modification. Feedback from the pilot study indicated no major changes to the questionnaire. However, some changes to language were made in order to further clarify questions and to avoid any misunderstandings occurring. In question 17.3, the word "beneficial" was replaced with "good". Also, the word "arise" was replaced with the word "happen" in question 20 (Appendix E).

2.5. Sample size calculation

After consultation with a statistician, the sample size was calculated using the program Statistica (package version 10). Based on an estimated difference of 20% between responses from state versus private patients (estimated 60% of private patients would have accurate information regarding effects of alcohol on pregnancy, compared to 40% in state patients), a sample size of n=97 per group was calculated. This sample size was required in order to achieve a power of 80% and a two-tailed significance level of α=0.05.

Estimations of responses for the private patients were based on results of a previous study (Peadon et al., 2010), whereas the assumptions regarding state patient responses were pure estimates since no research could be found from developing countries.

2.6. Data collection

Individuals at all three study sites were approached in an unsystematic manner and invited to participate in the research. A simple random sampling method was therefore utilised for the purpose of this study. The sampling procedures in the state and private antenatal settings are described in the sections below.

2.6.1. Study participants

Pregnant women between the ages of 18 and 50 years, who were attending one of the three study sites and who resided in the Gauteng area and were able to effectively communicate in English, were deemed eligible for participation in this study. Participants from CMJAH are referred to as "state participants" and those from Tina Otte's Family and Child Centre and the Bryanston Mother and Baby Education Centre are referred to as "private participants".

2.6.2. Sampling conducted at Charlotte Maxeke Johannesburg Academic Hospital

Sampling at CMJAH was conducted between 13 and 17 February 2012. The researcher randomly approached individuals sitting in the queue waiting to be seen at the antenatal clinic. After introductions were performed, the researcher briefly explained that data on women's knowledge of harmful substances during pregnancy was being collected through the completion of questionnaires. Individuals were asked whether they would be willing to complete such a questionnaire and reassured that neither participation nor non-participation would affect future health or pregnancy care in any way. The researcher also emphasised the anonymity of the research and that participants should feel free to respond in any way they saw fit, since the questionnaires would never be traced back to them. Those who agreed to participate were provided with a clipboard, pen, information sheet (Appendix F) and questionnaire (Appendix E). All participants at CMJAH were able to complete the

questionnaire whilst sitting and waiting to be seen by the doctors and therefore never lost their places in the queue. The researcher was always present to clarify any questions the participants might have had regarding the questionnaire. After completion, each participant was given two information pamphlets; one contained information regarding FAS and the other was about genetic counselling and included contact details of the Clinical Unit of the Division of Human Genetics NHLS and the University of the Witwatersrand. Participants were encouraged to contact the Unit and speak to a genetic counsellor if they felt the need to discuss any concerns or questions regarding alcohol use during pregnancy further.

It should be noted that this sampling occurred coincidentally during Pregnancy Education week. During this week women were exposed to educational talks regarding various health aspects of pregnancy. Furthermore, posters in a number of languages, with information regarding the dangers of alcohol use during pregnancy were placed throughout the clinic and hospital (Figure 2.2).

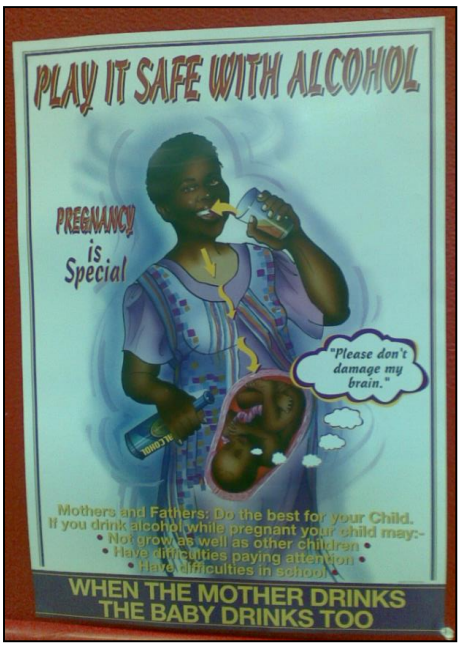


Figure 2.2: An image of a poster displayed at Charlotte Maxeke Johannesburg Academic Hospital during the pregnancy education week.

2.6.3. Sampling conducted at the two private antenatal centres

Sampling at Tina Otte's Family and Child Centre and the Bryanston Mother and Baby Education Centre was conducted between 31 January and 6 June 2012. At each Centre, a group of pregnant women attended a four-to-six week antenatal course. Participants were subsequently approached in each new group at the beginning of their course.

Individuals were approached as they arrived for the class, or at the end of the class. The researcher was not present at four of the classes (two from each study site) and therefore asked the coordinators of the classes to recruit participants and collect questionnaires on her behalf. In these cases, the class coordinators gave individuals a brief overview of the study handed out the information sheets (Appendix F) and invited anyone in the class to participate. The researcher had briefed the coordinators regarding the study overview and instructed them not to discuss any information pertaining to alcohol use in pregnancy in order to ensure the participants completed the questionnaire without any preconceived ideas regarding the correct responses.

All participants who volunteered from the private antenatal centres were provided with a pen, information sheet (Appendix F) and questionnaire (Appendix E). After completing the questionnaire, each participant also received the two information pamphlets regarding FAS and genetic counselling.

The data collected for this study was anonymised, no names or identifiable information was recorded and questionnaires were all coded. Only the researcher had access to the completed questionnaires and subsequent data, none of which had participants names attached.

2.7. Data analysis

Data was captured, cleaned and coded in a Microsoft Excel spread sheet. Data was then imported into STATA version 10 and analysed using descriptive statistics. The Chi-squared test was used to compare two categorical variables. Significance was assumed at a two-tailed p-value <0.05.

A participant was categorised as being "aware" that alcohol is a teratogenic substance if she answered questions 16 to 17.5 of the questionnaire (Appendix E) correctly. A participant was categorised as being "knowledgeable" of the specific adverse effects associated with prenatal alcohol exposure if she correctly identified four or more symptoms of FAS and answered questions 21 and 22 correctly. Statistical analysis using Pearson's chi-squared test was performed to identify associations between participants' responses to different questions, as well as associations between responses and participants' demographic characteristics. The t-test was used to compare the age ranges of the state and private participants. The open question in the questionnaire was analysed by grouping participants' responses into a number of common themes.

Categorical data were presented as frequencies and percentages. Continuous variables that were normally distributed, such as age, were summarised as mean ± Standard deviation (SD). Percentages were rounded to the nearest whole percent and means to the nearest 2 decimal places.

3. CHAPTER 3: RESULTS

This chapter describes the results generated through the analysis of data extracted from the completed questionnaires. This included analysis of the two groups as a whole, as well as comparisons between responses of the state and private participants. The responses of pregnant women from the state antenatal clinic were compared to those from the women at the private antenatal centres. These results and comparisons are presented according to the various sections in which the questionnaire was divided.

3.1. Total sample size

A total of 134 questionnaires were collected from state participants attending the antenatal clinic at CMJAH. Twenty seven participants left out three or more questions in the Awareness or Knowledge sections of the questionnaire and so these questionnaires were therefore regarded as being "partially completed". These partially completed questionnaires were excluded from final analysis. Consequently, a total sample size of 107 was achieved from the state antenatal clinic. In the private antenatal centres, a total of 107 questionnaires were collected. Three participants left out three or more questions and were subsequently excluded from analysis. The private antenatal centres yielded a total size of 104 completed questionnaires. In total, 211 questionnaires (107 from state participants and 104 from private participants) were collected and analysed.

3.1.1. Non-responders and insufficient data

In some sections of the questionnaire, women did not answer all questions, sometimes stating that they left the question out on purpose because they did not know the answer. The majority however, did not indicate the reason behind their lack of response. These participants were coded as "non-responders". Since no assumptions could be made regarding non-responders'

level of awareness or knowledge in the specific questions, results for all questions were only generated after excluding the non-responders.

Questions 4 – 9 (Appendix E) were included with the aim to evaluate the socio-economic status (SES) of participants and to investigate whether associations exist between SES and participants' awareness and knowledge regarding the effects of alcohol consumption during pregnancy. However, upon further analysis, it was found that most participants left out at least one of these questions and that the data obtained was insufficient and unhelpful in determining accurate SES. Consequently, these questions were excluded from the final analysis. Furthermore, question 23 required participants to select the amount of alcohol consumed during pregnancy they believed may result in FAS. However, most participants selected more than one option and since this question does not have a medically accurate answer it was excluded from final analysis.

3.2. Demographic characteristics of the participants

3.2.1. Age of participants

The ages of the participants at CMJAH ranged from 19 to 42 years, with a mean age of 30.04 ± 5.38 years. The age of participants attending the private antenatal centres ranged from 22 to 39 years, with a mean age of 30.2 ± 3.32 years. Overall, the age of all participants in the study ranged from 19 to 42 years, with a mean age of 30.11 ± 4.46 years. No statistical difference was found between the age ranges of the state and private participants (p=0.791).

3.2.2. Ethnicity of participants

Regarding the ethnicity of the total sample (211 participants) 100 (47%) were black, 88 (42%) were white, 15 (7%) were Indian and 7 (3%) were Coloured (Figure 3.1).

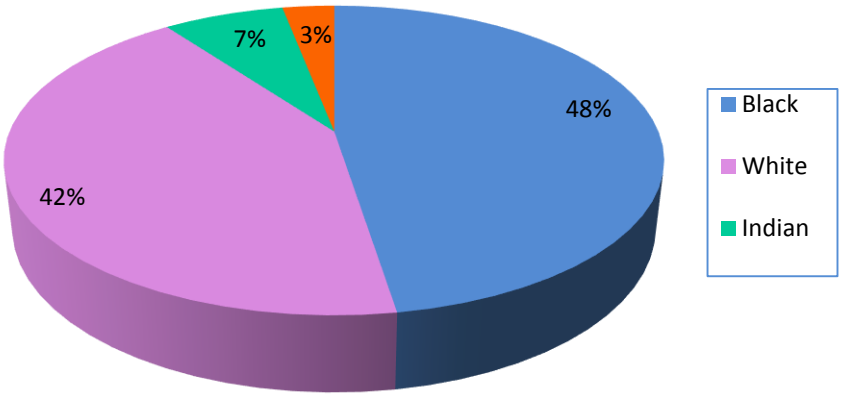


Figure 3.1: Ethnicity of all participants (*n*= 211).

When considering the ethnicity of participants from CMJAH (*n*=107), the large majority (90%, 96/107) of them classified themselves as being black, with only a few being white, Coloured or Indian (Figure 3.2). Conversely, the majority of individuals attending the private antenatal centres were white (82%, 85/104) compared to the three other ethnic groups (Figure 3.2). Overall, a significantly larger number of state participants were black compared to the private participants (p=0.000). Additionally, a significantly larger proportion of participants from the private antenatal centres were white, compared to participants from CMJAH (p=0.000).

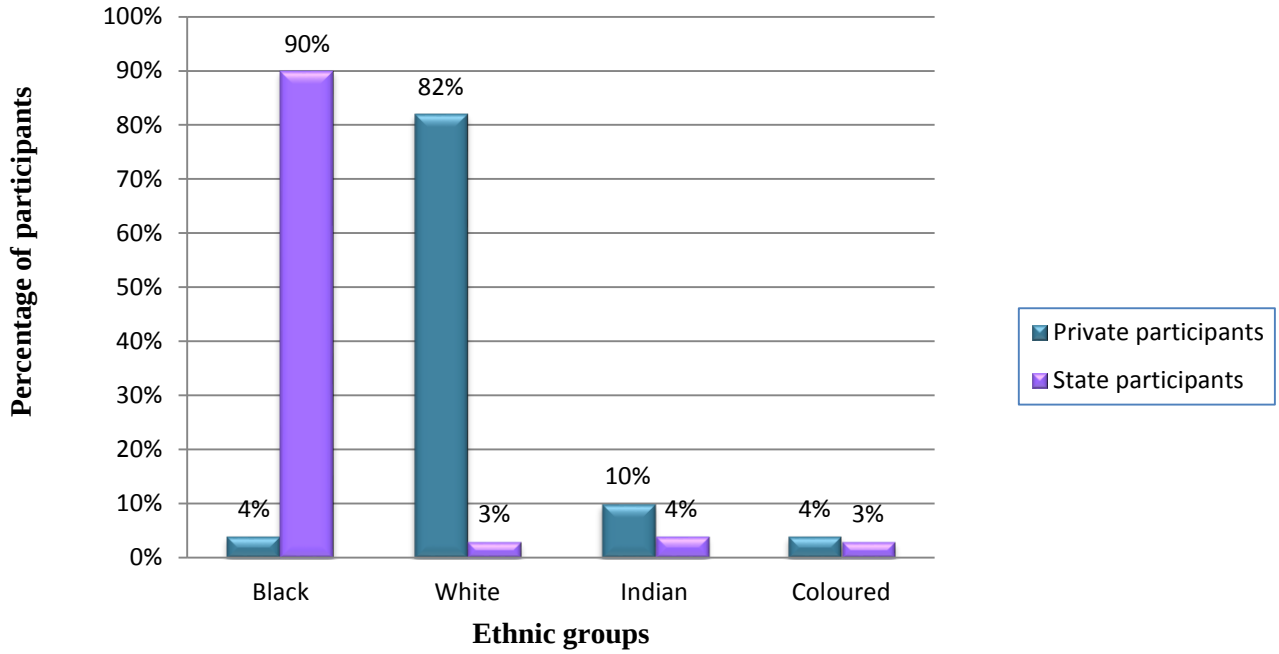


Figure 3.2: Comparison of the ethnic distribution of participants from the private Antenatal Centres (*n*=104) and the state Antenatal Clinic (*n*=107).

3.2.3. Parity

Information regarding participants' obstetric history showed that gravida (number of pregnancies) ranged between one and nine pregnancies in the total group (state plus private participants). Two state participants did not indicate their number of pregnancies and were therefore excluded from analysis of gravida and parity. Over half the women (56%, 117/209) were primigravida (first pregnancy), followed by 17% (36/209) who were carrying their second pregnancy and 15% (31/209) who were pregnant for the third time. Figure 3.3 summarises the number of pregnancies for all participants (*n*=209).

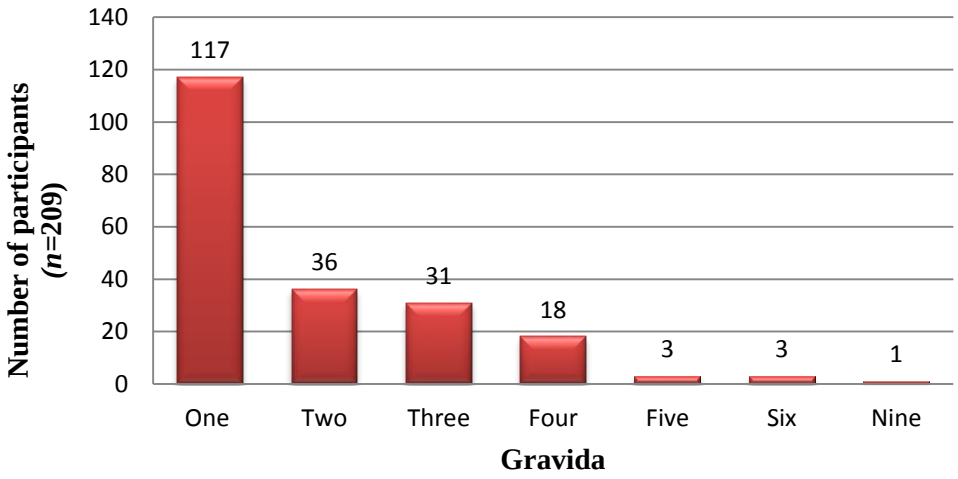


Figure 3.3: Number of pregnancies of all participants (*n*=209).

Participants attending the private antenatal centres had between one and three pregnancies while participants from CMJAH had between one and nine pregnancies, including their current pregnancy (Figure 3.4). As illustrated in Figure 3.4, a significantly larger number of private participants were primigravida compared to state participants (p=0.000).

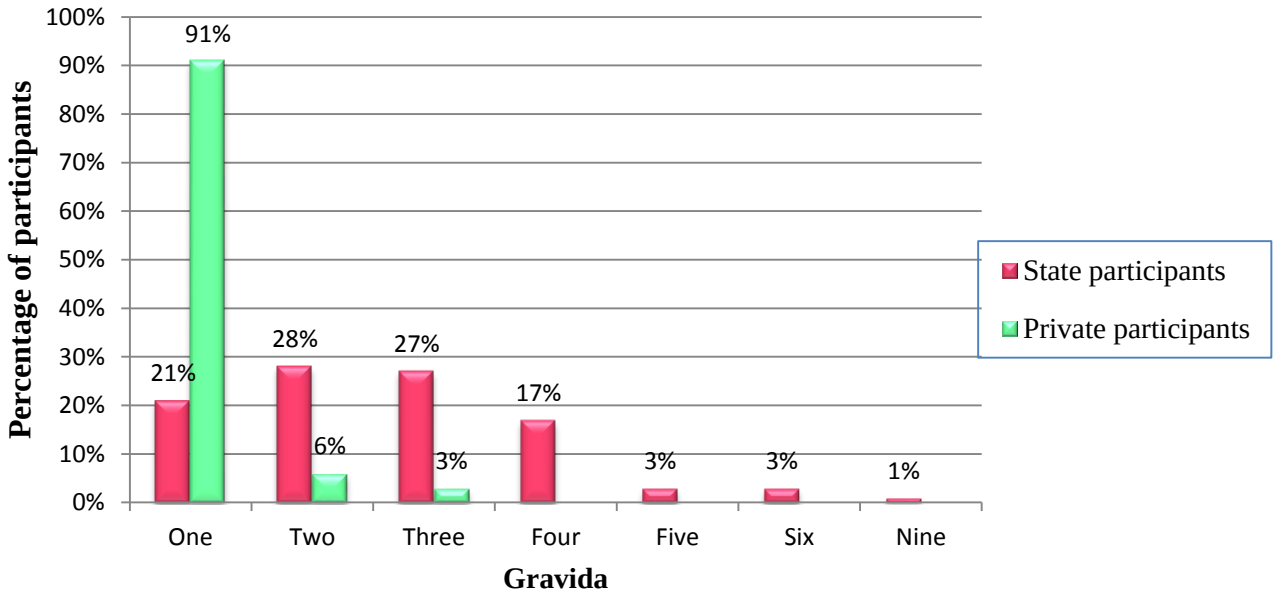


Figure 3.4: Gravida of participants from the two private Antenatal Centres (*n*=104) and Charlotte Maxeke Johannesburg Academic Hospital (*n*=107)

The gestational ages of all participants at the time of completing the questionnaire ranged between nine and 41 weeks, with a mean of 30.07 ± 6.67 weeks. Participants from CMJAH were between nine and 41 weeks pregnant, with a mean gestation of 29.79 ± 8.45 weeks. The gestational ages of participants attending the private antenatal centres ranged between 12 and 38 weeks, with a mean of 30.37 ± 4.14 weeks.

3.2.4. Education and employment

Participants' demographics regarding education and employment differed significantly between those from the state hospital and those from the private antenatal centres (Table 3.1). Some women did not answer all questions pertaining to their education and employment. Results were therefore generated for each question in this section after the non-responders were excluded. Almost all private participants (99%, 103/104) completed Grade 12 in school, however, a significantly lower number of state participants (67%, 69/103) reportedly finished school at the Grade 12 level (p=0.000). Furthermore, although 99% (101/102) of private participants obtained a qualification such as a degree, diploma or certificate after school, less than half (43%, 46/107) of state participants obtained a similar qualification (p=0.000).

Table 3.1: Summary of responses to questions regarding education and employment.

Question No.	Question	State participants			Private participants		
				Total			Total
		n	***%***	***n***	***n***	***%***	***n***
10.	**Completed Grade 12#**	69*	67%	103*	103	99%	104
11.	**Obtained a tertiary qualification#**	46	43%	107	101*	99%	102*
12.	**Currently employed#**	51*	49%	105*	87	84%	104*

***** Non-responders excluded.
# Significant difference between state and private participants.

Regarding employment, only 16% (17/104) of private participants were unemployed at the time of completing the questionnaire, of which 71% (12/17) were not working because of maternity-related reasons or because they chose not to work. Conversely, just over half (51%, 54/105) of state participants were unemployed, of which only 20% (11/54) chose not to work or could not work due to maternity-related reasons. Forty-one percent (22/54) of state participants indicated that they were unemployed because they were unable to find work. As a result, significantly more participants from CMJAH were unemployed, compared to participants from the private antenatal centres (p=0.000).

3.3. Awareness and attitudes toward alcohol use during pregnancy

Participants' awareness of alcohol as a teratogenic agent in pregnancy was determined by evaluating responses to questions 16 and 17 in the Awareness section (section 2) of the questionnaire (Appendix E). Question 16 asked participants to list anything they considered to be harmful to an unborn baby and question 17 (17.1 – 17.5) required participants to state whether they agreed or disagreed with a number of statements regarding alcohol use during pregnancy. Table 3.2 summarises the participants' responses to these questions. Some participants did not answer certain questions; these were coded as non-responders and excluded from analysis.

Participants who responded correctly to the two questions regarding the awareness of alcohol as a teratogenic agent were classified as being "aware" (pg 26, section 2.7). Overall, 54% (113/211) of all participants were found to be aware that alcohol could be harmful during pregnancy (Figure 3.5).

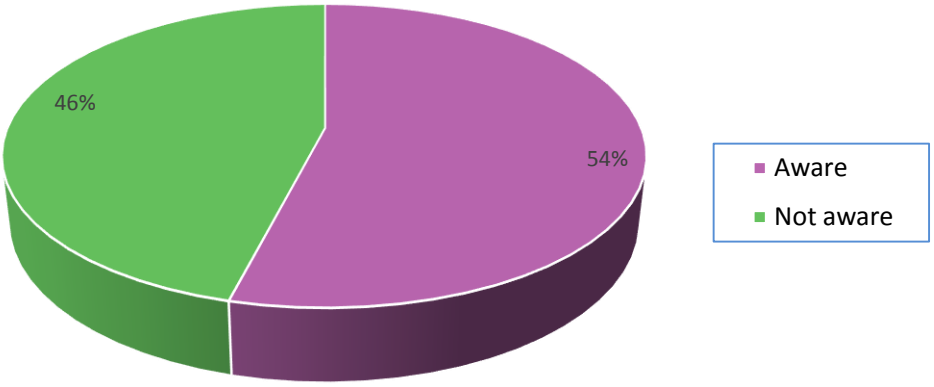


Figure 3.5: Overall distribution of participants' awareness of alcohol use in pregnancy (*n*=211).

Within the two groups, 55% (59/107) of state participants and 52% (54/104) of private participants were classified as being aware that alcohol can be teratogenic and should be completely avoided during pregnancy. There was no significant difference in "awareness" between the two groups (p=0.639).

Table 3.2: Summary of state participants' (n=107) and private participants' (n=104) responses to questions used to assess awareness of alcohol consumption during pregnancy.

Question No.	Question	Correct Answer	State Participants					Private Participants				
			Answered Correctly		Answered Incorrectly		Total	Answered Correctly		Answered Incorrectly		Total
			n	%	*n*	%	*n*	*n*	%	*n*	%	*n*
16.1	List harmful substances during pregnancy	Alcohol	82	77%	25	23%	107	84	81%	20	19%	104
17.1	Alcohol has no effect on baby#	Disagree	82	77%	25	23%	107	101	98%	2	2%	103*
17.2	Alcohol should be stopped completely during pregnancy	Agree	98	92%	9	8%	107	86	84%	16	16%	102*
17.3	Alcohol can be beneficial for pregnancy.	Disagree	96	92%	8	8%	104*	100	98%	2	2%	102*
17.4	Alcohol can be used occasionally during pregnancy#	Disagree	99	93%	7	7%	106*	71	71%	29	29%	100*
17.5	Alcohol can be used after certain gestation#	Disagree	104	97%	3	3%	107	88	88%	12	12%	100*

* Non-responders excluded
# Significant difference between responses of state and private participants.

3.3.1. Substances considered harmful during pregnancy

As part of determining whether pregnant women considered alcohol consumption dangerous during pregnancy, participants were asked to list substances they believed to be harmful to a fetus (Question 16.1). The substances listed by state and private participants are illustrated in Figure 3.6.

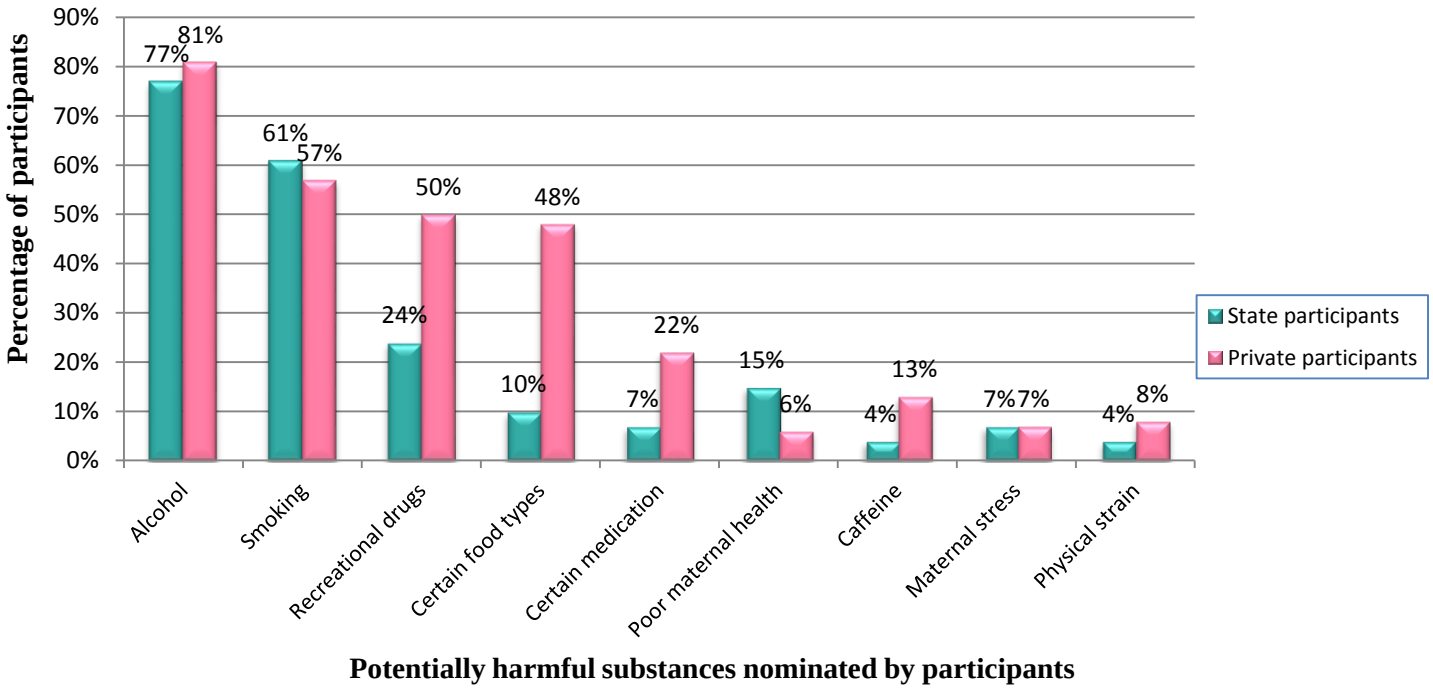


Figure 3.6: Comparison of the percentage of participants from each group who identified certain substances as being harmful to a fetus.

Alcohol was the most commonly nominated substance amongst both the state (82/107) and private (84/104) participants. This was followed by smoking (65/107 (61%) state and 59/104 (57%) private participants). Significantly more private participants (50/104; 48%) named certain food types such as soft cheeses and raw meat as potentially harmful to an unborn baby, compared to state participants (11/107; 10%) ($p=0.000$). While state participants listed maternal health issues, such as hypertension, as being harmful to an unborn baby significantly more often than private participants ($p=0.029$).

3.3.2. Responses to statements regarding the use of alcohol during pregnancy

Participants' responses to statements regarding the use of alcohol during pregnancy provided a more in depth look into their awareness and attitudes towards alcohol use during pregnancy. Table 3.2 represents a summary of the number of participants who correctly responded to five statements in the awareness section of the questionnaire (Appendix E). These statements were that alcohol during pregnancy: "has no effect on the baby" (question 17.1); "should be stopped completely" (question 17.2); "can be good for the pregnancy" (question 17.3); "can be used occasionally" (question 17.4) and "can be used after you are a certain number of months pregnant" (question 17.5). The numbers of state and private participants who correctly responded to each of these statements were compared.

Results showed that a significantly larger number of private participants (98%, 101/103) disagreed with the statement "alcohol has no effect on a baby", compared to 77% (82/107) of state participants (p=0.000). The majority of both private and state participants responded that alcohol consumption should be stopped during pregnancy and that no benefit can be gained by consuming alcohol while pregnant (Table 3.2). However, 29% (29/100) of private participants thought that occasional alcohol consumption was acceptable during pregnancy, while a significantly fewer number of state participants (7%, 7/106) had similar opinions (p=0.000). Twelve private participants (12%, 12/100) agreed with the statement that alcohol use is acceptable after a woman is a certain gestation compared to only 3% (3/107) of state participants. Private participants were significantly more likely to consider alcohol consumption acceptable after a woman has reached a certain gestation (p=0.023).

3.4. Informational resources

Question 18 in the questionnaire (Appendix E) asked whether participants could recall ever having come across information regarding alcohol use during pregnancy. Although many state and private participants claimed to have come across such information, a significantly larger number of private participants (91%, 95/104) had been exposed to information compared to state participants (81%, 87/107) (p=0.034). With reference to Figure 3.7 below, private participants were significantly more likely than state participants to have come across information through the media (p=0.000), books (p=0.041), friends and family (p=0.000) or their studies or work (p=0.0006).

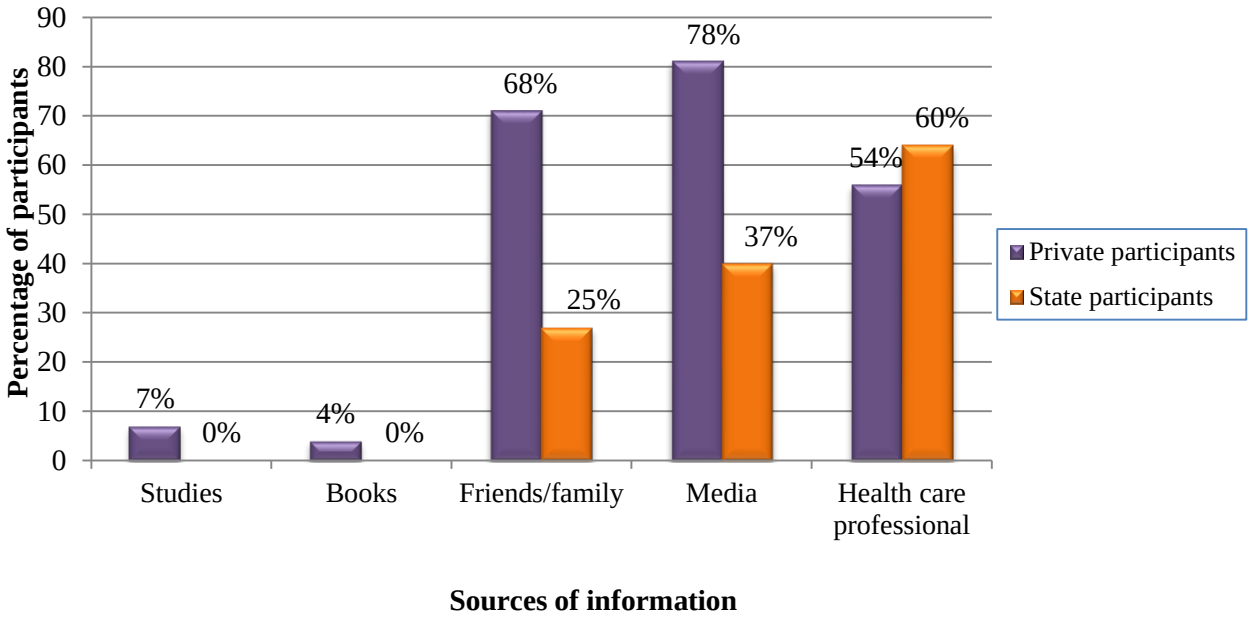


Figure 3.7: Sources of information regarding alcohol use during pregnancy; by state (*n*=107) and private (*n*=104) participants.

Participants were asked whether someone had discussed the topic of alcohol use with them specifically *during* their current pregnancy (Question 19). Significantly more state participants (77%, 82/107) than private participants (61%, 63/104) reported that someone had discussed alcohol consumption with them during their current pregnancy (p=0.012). Table 3.3 illustrates

and compares the percentage of state and private participants who discussed prenatal alcohol use with someone during their current pregnancy.

Table 3.3: Proportion of participants who discussed alcohol use and pregnancy, during their current pregnancy.

Individual(s) with whom discussion was had	State participants (*n*=107)		Private participants (*n*=104)	
	n	**%**	***n***	**%**
Friends/family	6[#]	6%[#]	15[#]	14%[#]
Nurse	42[#]	39%[#]	2[#]	2%[#]
Midwife	11	10%	7	7%
Doctor	41	38%	49	57%

[#] Significant difference between state and private participants

As Table 3.3 illustrates, nurses were shown to be significantly more likely to discuss prenatal alcohol consumption with state participants (39%, 42/107) than private participants (2%, 2/104) (p=0.000). Conversely, private participants were significantly more likely to have discussed the topic of alcohol consumption during pregnancy with individuals, such as friends or family (p=0.032) (Table 3.3).

3.5. Knowledge regarding the effects of alcohol use during pregnancy

To determine the knowledge of participants regarding the adverse effects of prenatal alcohol exposure, specifically FAS, answers to questions 20 – 22 and question 24 in the Knowledge section of the questionnaire (section 3) were analysed (Appendix E). A summary of the questions included in this analysis, as well as the number of state and private participants who answered these questions correctly, is presented in Table 3.4. Some participants did not answer all the questions in this section. These non-responders were excluded from the analysis pertaining to "Knowledge".

Analysis of these "Knowledge" questions revealed that overall, 23 of the 211 participants (11%) could be classified as being knowledgeable regarding FAS (Figure 3.8).

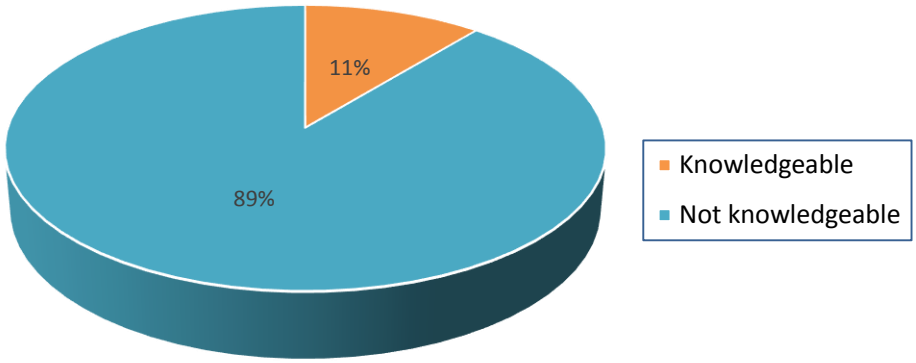


Figure 3.8: Overall distribution of participants' knowledge of fetal alcohol syndrome *(n*=211*)*.

Further analysis of the two groups individually, revealed that only 19% (20/104) of participants attending the private antenatal centres and 3% (3/107) of participants attending CMJAH answered all relevant questions correctly and were therefore classified as having substantial knowledge regarding the effects of alcohol on pregnancy including FAS. A significant difference was observed between state and private participants when comparing the knowledge regarding the effects of prenatal alcohol exposure (p=0.000).

Table 3.4: Answers from the state and private participants to questions assessing their knowledge of adverse effects of alcohol consumption during pregnancy**.**

Question No.	Question	Correct Answer	State Participants					Private Participants				
			Answered Correctly		Answered Incorrectly		Total	Answered Correctly		Answered Incorrectly		Total
			n	%	*n*	%	*n*	*n*	%	*n*	%	*n*
20.	Can alcohol in pregnancy cause problems in a baby?	Yes	106	99%	1	1%	107	104	100%	0	0%	107
20.	If yes, Identify features associated with prenatal alcohol exposure (FAS)[#]	>4 / 7 correct features	9	8%	98	92%	107	25	24%	79	76%	104
21.	Heard of FAS[#]	Yes	49	46%	58	54%	107	98	94%	6	6%	104
21a.	FAS happens when a women uses alcohol during pregnancy	Agree	48	98%	1	2%	49	89	91%	9	9%	98
21b.	Effects of alcohol on baby can be serious	Agree	49	100%	0	0%	49	97*	100%	0*	0%	97*
21c.	FAS can be cured[#]	Disagree	33*	70%	14*	30%	47*	88*	93%	6*	7%	95*
21d.	FAS is population specific[#]	Disagree	38	78%	11	22%	49	92*	98%	2*	2%	94*
22.	Select types of alcohol that cause FAS[#]	All	21*	20%	83*	80%	104*	85*	84%	16*	16%	101*

*Non-responders excluded

Significant difference between state and private participants' responses

Analysis of responses to the first part of question 20 (Appendix E) revealed that essentially all participants of both the state (99%, 106/107) and private (100%, 104/104) were able to recognise that prenatal alcohol exposure may lead to problems in the baby. Assessment of participants' knowledge regarding the specific facts and features associated with FAS provided informative results, which follow in sections 3.5.1 and 3.5.2.

3.5.1. Knowledge regarding the clinical features of prenatal alcohol exposure

Participants were asked to identify the correct features associated with prenatal alcohol exposure from the list of symptoms provided in the questionnaire (question 20, Appendix E). Nine features were provided, of which only seven were correct. The seven correct features were: small eyes; brain damage; lower IQ/intellectual disability; small head; growth problems; baby experiences withdrawal and cleft lip and/ or palate. A comparison of the correct features selected by private and state participants is illustrated in Figure 3.9 and Table 3.4.

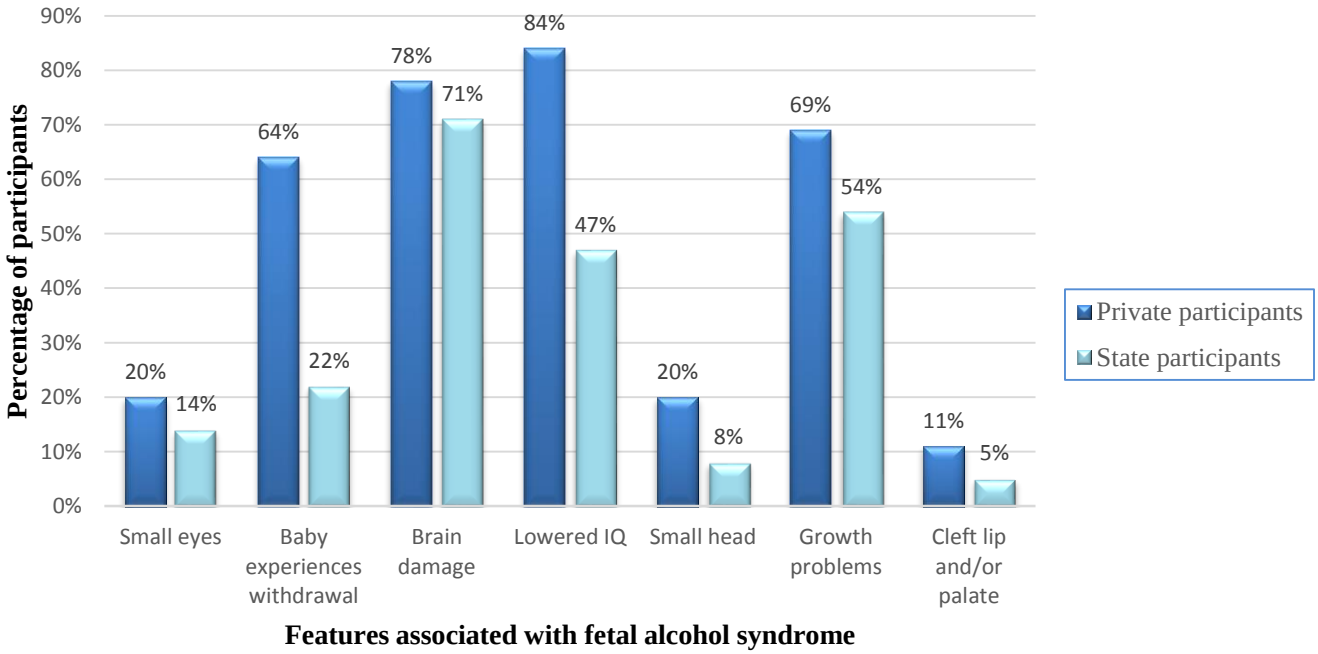


Figure 3.9: Certain features identified by participants as being associated with fetal alcohol syndrome.

Only 8% (9/107) of state participants were able to correctly identify more than four features of FAS, whereas a significantly higher number of private participants (24%, 25/104) correctly identified associated features (p=0.002). Overall, a higher proportion of private participants identified each of the appropriate features. Of the six correct features associated with prenatal alcohol exposure, "brain damage" was the most commonly selected feature by state participants (76/107), while private participants were more likely to select "lowered IQ" as a feature of FAS (87/104). A significantly lower number of state participants (50/107) selected "lowered IQ" as a feature of FAS (p=0.000). Similarly, significantly more private participants (21/104) correctly selected "small head" compared to state participants (9/107) (p=0.014) and significantly more private participants (72/104) knew that "growth problems" may occur in children with FAS compared to state participants (58/104) (p=0.025). Many private participants (67/104) knew that if a fetus is exposed to alcohol during pregnancy the baby could experience withdrawal symptoms at birth. Comparatively, significantly fewer state participants (22/107) considered withdrawal symptoms a feature of prenatal alcohol exposure and FAS (p=0.000). Very few participants from either group were able to identify "cleft lip and/ or palate" as a feature of FAS.

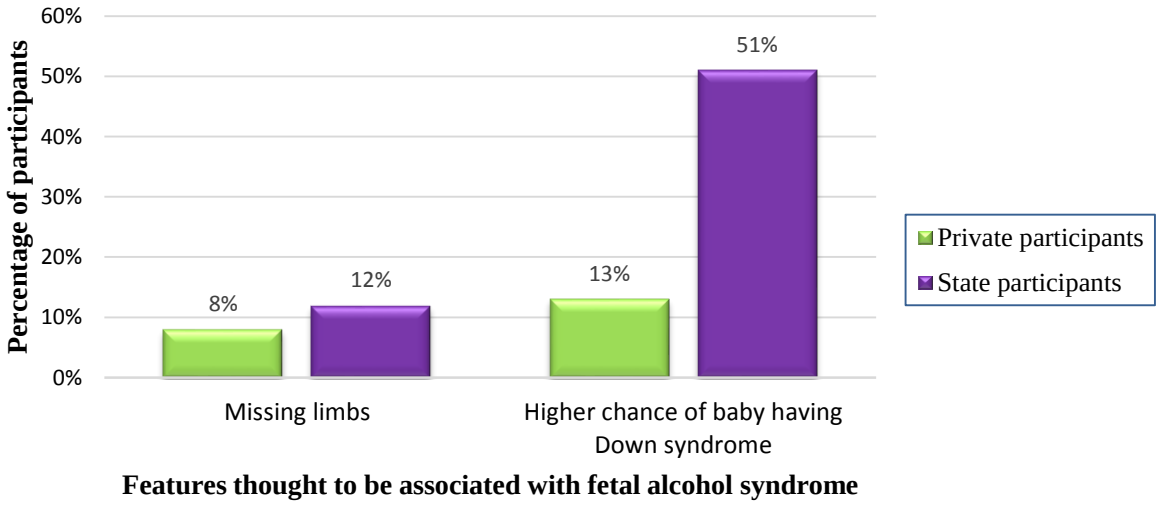


Figure 3.10: Features incorrectly selected by participants as being associated with fetal alcohol syndrome

Despite many correct features being selected, participants also selected some incorrect features when answering this question. Figure 3.10 illustrates the number of participants in both groups who selected features that are not associated with FAS from the list of features provided.

More than half of the state participants (55/107) and 13 of the 104 private participants thought that prenatal alcohol exposure would increase a baby's chance of being born with Down syndrome. The difference in responses regarding the risk of Down syndrome between private and state participants was found to be significant (p=0.000).

3.5.2. Knowledge regarding aspects of fetal alcohol syndrome

As depicted in Table 3.4, although the vast majority of private participants had heard of fetal alcohol syndrome (94%, 98/104), less than half of the state participants (46%, 49/107) claimed to have heard of this condition, resulting in a significant difference between these two groups (p=0.000). Participants who had heard of FAS were asked to respond to four statements regarding the condition (listed in Table 3.4). Of the 49 state participants who had heard of FAS, 98% (48/49) agreed that the condition occurred as a result of maternal alcohol consumption during pregnancy, while 91% (89/98) of private participants who had heard of FAS also agreed with this statement. This difference in responses between the two groups of participants was not significant (p=0.105). Furthermore, all state (100%, 49/49) and private (*n*=97) (1 non-responder) participants who had heard of FAS agreed that the adverse effects of alcohol on a baby can be severe. Responses to other statements regarding FAS differed significantly between state and private participants. Approximately 30% (14/47) of state and 7% (6/95) of private participants who had previously heard of FAS thought that affected individuals could be cured of their symptoms. This indicated that significantly more participants from CMJAH thought that FAS was a curable condition, compared to participants attending the private

antenatal centres (p=0.002). Additionally, 22% (11/49) of state participants thought FAS will only ever occur in specific population groups, whereas a significantly lower number of private participants 2% (2/95) had a similar misconception (p=0.000).

All participants, whether they had indicated previous knowledge of FAS or not, were asked to select the types of alcohol they thought could cause features of FAS. Six participants (three from the state hospital and three from the private antenatal centre) did not answer this question; two said that they did not know the answer whereas the others did not give a reason for not answering. A summary of the percentage of participants from each group (corrected for non-responders), who selected each type of alcohol, is provided in Figure 3.11.

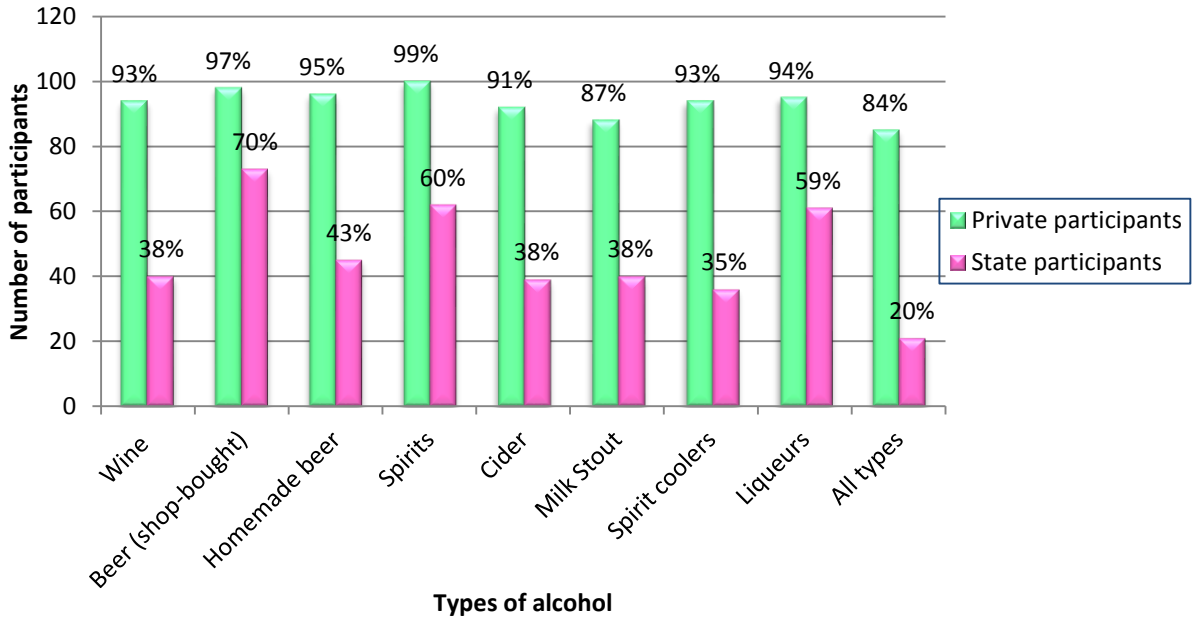


Figure 3.11: Number of participants in the state (*n*=104) and private (*n*=101) who selected specific types of alcoholic beverages as causes of fetal alcohol syndrome

Importantly, only 38% (39/104) of state participants thought milk stout, a popular variation of beer, could cause FAS. Comparatively, a significantly higher number of private participants (87%, 88/101) knew that milk stout was as likely to cause FAS as any other alcoholic beverage (p=0.000). Only 20% (21/104) of state participants and 84% (85/101) of private participants answered correctly by selecting all types of alcoholic beverages. Therefore, private participants were significantly more aware of the types of alcohol that cause FAS than state participants (p=0.000).

Participants were asked to estimate the level of maternal alcohol use that they thought would result in a fetus being affected with FAS. Four of the participants from CMJAH and one participant from a private antenatal centre did not respond and were not included in the final analysis of this question. Of the 205 participants who responded to this question, seven selected all options (3%). The majority of participants (142/205, 69%) selected the option stating that "many drinks every day" will result in FAS, whereas 12% (25/205) of participants thought that "one drink during the whole 9 months" could cause this condition.

3.6. Significant associations in state participants' responses

A significant association was found between state participants whose responses classified them as being "aware" and those that completed Grade 12 (p=0.003). Being aware of alcohol and its effects during pregnancy was therefore found to be associated with completing school.

Knowledge regarding the types of alcohol that can cause FAS was associated with overall awareness regarding maternal alcohol consumption. Of the 21 state participants who knew that any type of alcohol can cause FAS, 18 (86%) were classified as being aware of the dangers associated with maternal alcohol consumption during pregnancy. Of the 59 state participants

who were classified as being "aware" of the dangers of prenatal alcohol exposure 18 (31%) knew that any type of alcohol can cause FAS. Therefore, participants who knew that all alcohol types can cause FAS were more likely to be aware of the danger of consuming alcohol during pregnancy (p=0.005).

3.7. Significant associations in private participants' responses

An association was found between the misconception that occasional alcohol use during pregnancy is acceptable and participants who discussed alcohol use with someone during their pregnancy (p=0.040). Of the 29/104 private participants who approved of occasional alcohol consumption during pregnancy, 23 (79%) reported that someone had discussed the use of alcohol with them during their current pregnancy. These 23 participants who approved of occasional maternal alcohol consumption made up 38% of the 61 private participants with whom alcohol consumption was discussed during pregnancy.

3.8. Interesting comments made by participants

Participants were invited to add any comments at the end of the questionnaire (Question 25, Appendix E). A number of interesting comments were made by participants, some of which reinforced results obtained from previous questions of the questionnaire, while others revealed novel opinions. Relevant comments could generally be grouped into five common themes:

1. **Reason behind women's drinking behaviours**

   A number of comments were made relating to participants' beliefs regarding the reason why people abuse alcohol. The following comments were all made by state participants and eluded to the idea that people see alcohol as a way of dealing with social problems and stress:

- *"Most people think that if they have alcohol they can solve anything they want. They also think it's a solution to everything."*
- *"…most women, they take alcohol because of stress which is not the solution."*
- *"Most people drink because of stress."*

Additionally, three state participants' comments acknowledged that alcohol abuse can lead to an addiction which is difficult to overcome, even in pregnancy:

- *"I think alcohol is not good because it acts like drugs [and] when you're addicted to it, it's very hard for you to leave it."*
- *"Many people are addicted to alcohol, even pregnant women."*
- *"…if it's a habit it is difficult to stop."*

2. Need for information and education regarding the dangers of alcohol use during pregnancy

The most common theme identified from the comments made by both state and private participants related to the importance of educating women regarding the consequences of maternal alcohol consumption during pregnancy. These comments indicated that a large number of participants recognised the need for accessible information and that an increase in knowledge could potentially lead to a decrease in alcohol consumption among pregnant women. The following comments were made by participants attending CMJAH's antenatal clinic:

- *"In my view it's very important to bring information to all the pregnant women, to help them avoid those stuff."*

- *"This can only [be] stopped by educating the people as it can destroy the population of the country…. If the fetus is affected the baby will never be productive and add value to the economy as they are not mentally fit."*
- *"…you must teach people about fetal alcohol [syndrome]"*
- *"Pregnant mothers should be taught about dangers of intake of alcohol, no one must sell alcohol to pregnant women, a strict law must be followed."*
- *"Pregnant women are not educated enough about dangers of alcohol because we turn to it during rejection during pregnancy. It is a very harmful substance and believe a lot of adds, television, radio, post, billboards would help us a lot."*
- *"Many women don't know about the problems alcohol cause when pregnant, because they start attending the clinics late."*

3. Religious and cultural beliefs

Three Islamic participants indicated that their knowledge and responses were limited regarding the topic of this study, since they were not allowed to consume alcohol according to their religious beliefs. These comments were:

- *"I really do not know about alcohol, it's not halal in my religion."*
- *"I am religious and don't drink."*
- *"I am Muslim so we don't drink alcohol. Not something that ever concerned me in pregnancy."*

A comment made by a private participant from Soweto, highlighted the influence of cultural and religious beliefs on individuals' understanding of the cause of conditions such as FAS:

"…most believe that to have a child born with fetal alcohol syndrome is witchcraft or God's will."

4. Acceptability of occasional alcohol consumption during pregnancy

As noted previously, a significant number of private participants considered the occasional use of alcohol during pregnancy acceptable. This belief was further illustrated by two comments made by private participants:

- *"I believe that it is all related to amount consumed and the odd drink shouldn't be a problem."*
- *"Alcohol may be used, but daily consumption (or even weekly) is not good. Only if it is a special occasion."*

Nevertheless, another comment from a private participant captured the reality behind the notion of allowing occasional alcohol consumption during pregnancy:

"They cannot determine exactly how much alcohol can cause FAS in babies and it differs, but the fact is, are you willing to take the risk."

5. Misconceptions

A number of misconceptions were identified amongst participants:

- *"…if you drink too much alcohol [during pregnancy] you must drink water."*
- *"I believe the system of the baby will be alcohol saturated so to cure this in a child is to make him drink at an early age…"*
- *"I have heard that the body needs alcohol, but not sure how much or does it still need a bit of alcohol even when you are pregnant."*

Another comment demonstrated the danger of preconceived beliefs:

- *"Milk stout is good every now and then and can be good for breast milk."*

4. CHAPTER 4: DISCUSSION

Findings of this study have revealed the level of knowledge and awareness regarding alcohol use during pregnancy among participants of various backgrounds in and around the Johannesburg area. Common misconceptions and gaps in knowledge regarding FASD are highlighted. The need for further research and the development of appropriate prevention strategies and awareness campaigns are emphasised.

4.1. Demographics and Obstetric History

Results obtained from this study showed that the ages of participants attending state and private antenatal care services were similar. State participants were between 19 and 42 years old and private participants were between 22 and 39 years old. However, other demographic characteristics differed significantly between these two groups. The vast majority (90%) of state participants attending CMJAH's antenatal clinic were black, which is consistent with results from a previous study which found 94% of pregnant women attending CMJAH's Antenatal Clinic to be black (Basu, Jeketera and Basu, 2010). In terms of obstetric history the state patients had between one and nine pregnancies. Conversely, the majority (82%) of participants attending the private antenatal centres were white and had between one and three pregnancies (Figures 3.2 and 3.4).

Statistics from the year 2011 regarding the demographic distribution of South Africans indicated that 69.7% of individuals who have medical aid coverage are white, while only 8.9% are black (StatsSA, 2011a). Since most women attending state hospital antenatal clinics do not have medical aid, unlike those attending private antenatal centres, results regarding the ethnic distribution of participants in the two groups are not surprising. Women attend the state antenatal clinic for pregnancy management which is equivalent to private participants' visits

to a gynaecologist, whereas the private antenatal classes are not compulsory. Considering the nature of the services provided at the study sites, it is also to be expected that the number of pregnancies differed between state and private participants. These classes are aimed at pregnant women who feel they require guidance and advice regarding the various health and social issues surrounding pregnancy; participants sampled from these centres were mostly (91%) first-time mothers (Figure 3.4). A previous study conducted among Italian women attending antenatal classes similarly found these classes to be aimed at improving women's knowledge and competence regarding childbirth, with the majority of attendees being nulliparous women (Spinelli, Baglio, Donati et al., 2003). Conversely, the antenatal clinic care at CMJAH offers standard health care for all pregnant women, which is equivalent to the care women in the private health sector would receive from their gynaecologists and obstetricians. As a result, participants recruited from the state hospital were therefore more likely to have had more pregnancies than those recruited from the private antenatal centres.

Results from this study also show that participants attending the state hospital were significantly less likely to have completed Grade 12 compared to private participants and were therefore unlikely to have obtained a tertiary qualification. The level of education among both the state and private participants was high in comparison to results of the 2011 South African census which revealed that only 35% of all individuals living in Gauteng completed Grade 12. This study found that 67% of state and 99% of private participants had completed Grade 12. Similarly, the number of state (43%) and private (99%) participants who obtained a tertiary qualification was much higher than the provincial average of 18% (StatsSA, 2011c).

State participants also reported a significantly higher unemployment rate (51%) compared to the private patients (16%) (Table 3.1) The majority of participants from the private antenatal centres were therefore educated (completed Grade 12 in school and obtained a tertiary

qualification) and employed. These results are therefore a realistic reflection of the situation in South Africa; where 29% of black individuals are unemployed, compared to 5.9% of whites (StatsSA, 2011b).

The differences found between state and private participants' demographic characteristics such as ethnicity, level of education and employment status were not only to in line with the available statistics pertaining to such factors in South Africa, but also supported the decision to use the selected study sites. Informative investigations into the knowledge and awareness regarding alcohol and pregnancy were therefore able to be conducted on two distinct groups of pregnant women which could then be compared.

4.2. Participants' awareness of the harmful effects of alcohol use during pregnancy

One of the major aims of this study was to determine whether pregnant women considered alcohol to be safe or harmful to a fetus. This was achieved by evaluating participants' awareness of alcohol as a harmful substance during pregnancy. As discussed previously, "awareness" refers to the general idea that it is not good or healthy to use alcohol during pregnancy, whereas "knowledge" refers to knowing the medical details pertaining to FAS. It is therefore possible to be "aware" but not "knowledgeable" if participants' responses show that they realize alcohol can be harmful in pregnancy, but have not heard of FAS or do not show any knowledge of the condition. Results show that slightly more than half (54%, (113/211)) of all participants answered all "awareness" questions correctly and were therefore classified as being aware that alcohol can be harmful during pregnancy (Figure 3.5).

Considering private participants' increased education levels compared to those of state participants, it would be expected that private participants would be more aware and have more

knowledge regarding the dangers of prenatal alcohol exposure. It was surprising to find that state participants (55%) were similarly aware of alcohol as a teratogenic agent during pregnancy compared to private participants (52%) (Table 3.2).

Participants attending CMJAH's Antenatal Clinic were presented with issues surrounding a healthy pregnancy in the time when sampling was conducted, as this coincided with Pregnancy Education Week. As part of Pregnancy Education Week, a number of posters (Figure 2.2) which focused specifically on informing women of the dangers of drinking alcohol while pregnant were placed throughout the clinic, in various languages. As a consequence of the Pregnancy Education Week and the visible posters, women's awareness regarding alcohol use in pregnancy may have increased. It is possible that a decreased level of awareness may have been obtained if the study had taken place in another week.

This study also aimed to determine whether an association exists between participants' level of education and their awareness of alcohol and pregnancy. An association analysis showed that individuals from the state hospital, who completed school (Grade 12), were more likely to be exposed to information regarding alcohol use during pregnancy which resulted in higher levels of awareness in this regard. Since almost all private participants (99%) completed Grade 12, but only slightly more than half (52%) were classified as being aware that alcohol should be avoided during pregnancy, education was not found to be associated with awareness among private participants. A previous study by Peadon et al. (2010) found that Australian women with higher education levels had increased levels of knowledge regarding the specific effects of alcohol use on pregnancy, however they did not report on awareness. This finding could indicate a difference in the type of information children from different backgrounds are exposed to at school regarding alcohol use during pregnancy. However, no clear conclusions

regarding the link between education received at schools and awareness of prenatal alcohol exposure among state, rather than private participants can be made without further research.

It is concerning that only slightly more than half of both private (52%) and state (55%) participants could be classified as being aware of alcohol being a danger to an unborn baby (Table 3.2). This was in keeping with a study conducted in an American outpatient clinic by Walker et al. (2005), which found that even educated young women were not aware of the risks of alcohol use during pregnancy. This indicates that a lack of awareness is not unique among South Africans, but that first world countries are facing similar challenges and also have a need for awareness campaigns. The following subsections discuss participants' responses to questions used to evaluate their awareness. They also provide insight into where misconceptions regarding acceptability of maternal alcohol consumption may lie.

4.2.1. Awareness of alcohol as a teratogenic substance during pregnancy

Alcohol was the most commonly nominated teratogenic substance by all participants thus indicating that the majority of individuals (77% of state and 81% of private participants), regardless of their background, could identify alcohol as a harmful substance during pregnancy (Figure 3.6). This is a positive finding which suggests that women are effectively receiving the fundamental information that alcohol is a harmful substance when used during pregnancy. The basic knowledge that maternal consumption of alcohol during pregnancy can cause problems in a baby provides a good foundation on which further knowledge regarding FASD (i.e. long term effects of alcohol exposure; symptoms; severity) can be built. Further awareness was demonstrated when most participants from both groups (92% of state and 84% of private participants) were found to be aware that alcohol consumption should be stopped completely (Table 3.2). This is comparable to results found in an Australian study where 80.2% of women

agreed that pregnant women should not consume alcohol at all (Peadon et al., 2010). Conversely, a previous study conducted in France found that most pregnant women (94%) would disagree with this statement, as they considered two or more drinks per day during pregnancy acceptable (Lelong et al., 1995). This might suggest that South African and Australian women show similar awareness levels and that women from both these countries are more aware of the recommended abstinence from alcohol than women in France. These differences may indicate a disparity in the guidelines and advice women receive from their health care professionals or at their various clinics in their respective countries. Additionally, alcohol consumption forms an important part of the culture and traditions in the area of France where the relevant study was conducted. This could therefore also explain why the women from this part of France were found to be so tolerant of alcohol use during pregnancy.

4.2.2. Responses to statements regarding the effect of alcohol on pregnancy

Although results show that state participants (77%) were found to be significantly less aware that alcohol can affect the development of a baby, compared to private participants (98%) (Table 3.2), it is likely that this lowered awareness among state participants was influenced by a misinterpretation of the statement in question 17.1 ("Alcohol during pregnancy has no effect on the baby"). Particularly because almost all state participants (99%) correctly answered "yes" to question 20 ("Do you think problems can happen in the baby if you drink alcohol during pregnancy?"), which is essentially a similar question asked in a different way. The point of question 17.1 might therefore not have been clear to all participants and could have caused confusion. It is possible that some participants' misread the question as whether they thought alcohol during pregnancy "Has an effect on the baby", instead of the actual "Has *no* effect on the baby". Furthermore, responses to another, similar statement indicated that the majority of both private (98%) and state (92%) participants were aware that alcohol could not benefit a

pregnancy (Table 3.2). This was contrary to results of a previous study which found women likely to regard alcohol consumption during pregnancy as positive, due to its ability to relieve stress. According to this study, women considered the risks associated with maternal stress during pregnancy to be higher than that of alcohol exposure (O'Connor et al., 2002).

Further analysis of responses indicated that private participants were significantly less aware that pregnant women should completely avoid alcohol throughout their pregnancy than state participants (Table 3.2). These misconceptions regarding the acceptability of alcohol use during pregnancy is further discussed in section 4.5.

4.3. Knowledge of the adverse effects of prenatal alcohol exposure

Knowledge of the adverse effects of alcohol has been shown to be a strong predictor of behaviour of alcohol consumption during pregnancy (Peadon, Payne, Henley, et al., 2011). A limited number of questions assessed participants' knowledge of the potential adverse effects, particularly FAS, caused by maternal alcohol consumption. These included whether participants thought alcohol use could cause problems in a developing baby, what they thought these problems or features may be, as well as how much they knew about certain aspects of FAS and the types of alcohol that cause this condition. Of all participants (*n*=211), only 11% (23/211) answered these questions sufficiently and could be classified as being knowledgeable regarding FAS (Figure 3.8).

4.3.1. Knowledge of clinical features associated with fetal alcohol exposure

Essentially all participants of both groups who claimed to have heard of FAS (48/49 (98%) of state participants; 89/98 (91%) of private participants), knew that problems can arise in a baby if a woman drinks alcohol during her pregnancy (Table 3.4). However, knowledge regarding

what exactly these "problems" could be was found to be lacking amongst the majority of participants. Only 24% of private participants could correctly identify more than four out of seven features of fetal alcohol exposure (Table 3.4), while a significantly fewer number of state participants (8%) displayed similar knowledge. Of the seven correct features, brain damage, lowered IQ and growth problems were most commonly identified by both private and state participants. Participants of both groups were least likely to identify cleft lip and/ or palate as a feature of prenatal alcohol exposure, followed by a small head (microcephaly) and small eyes (microphthalmia). This could be expected, since the majority of resources aimed at educating and creating awareness of FAS, tend to emphasise the risk of intellectual disability and growth retardation associated with prenatal alcohol exposure, as seen on the posters presented during Pregnancy Education Week at CMJAH (Figure 2.2). An increase in knowledge regarding all the features of fetal alcohol exposure might improve their understanding of how subsequent abnormalities are related. For example, if individuals understood that microcephaly is indicative of a small brain, it might help them understand why intellectual disability is present in affected children.

Previous studies have also investigated women's knowledge of the features of FAS, however direct comparison of the results from the present study to those found in previous studies are hindered by differences in the questions used, data collection methods and study populations. Results from a recent study which also investigated women's knowledge and attitudes regarding alcohol use during pregnancy, found that only 33.9% of Australian women nominated growth problems as an effect of prenatal alcohol exposure and only 15.6% nominated brain damage (Peadon et al., 2010). Compared to the results obtained from the present study, where an average of 75% of all participants were able to identify "brain damage" and 62% of all participants correctly identified "growth problems" as features of prenatal alcohol exposure, South African women seem to have heightened knowledge of these specific

features of FAS than Australian women. Fetal alcohol syndrome is a much less common condition in Australia, with a prevalence rate of only 0.68 per 1000 live births (Harris and Bucens, 2003), compared to the 119 per 1000 first graders found in parts of South Africa (Urban et al., 2008). Consequently, it is possible that the significantly higher incidence rates of FAS in South Africa increases the likelihood of South African women being exposed to affected children in their communities. Additionally, South African media has focused on FAS since the high prevalence rates were revealed and could therefore also be a reason behind why South African women seem to know more about these features than Australian women.

A substantial number of private participants (64%) correctly believed that a baby could experience withdrawal symptoms if exposed to alcohol in utero. In hindsight, the way this feature was listed in the questionnaire was misleading, as it stated "Baby addicted/ experiences withdrawal" as a possible feature of FAS. Although withdrawal can be a feature of FAS, alcohol addiction is not. These two concepts should therefore not have been presented as one feature. The idea that prenatal alcohol exposure may lead to an alcohol addiction in a baby is not uncommon. One participant shared her belief that a baby who was exposed to alcohol prenatally will have a dependency on alcohol and needs to be given alcohol at birth, so as to wean it off the substance. This participant commented by saying that she thought a baby affected by prenatal alcohol exposure will be "alcohol saturated" and that the effects can be cured by "[making] him drink alcohol at an early age." Another study found that almost half (47.8%) of young women thought FAS refers to babies who are addicted to alcohol (MacKinnon, Williams-Avery and Pentz, 1995). Misconceptions such as these are easily spread by word-of-mouth and by beliefs that have been passed on in families and communities for generations.

More than half of the state participants (55/107, 51%) were found to believe that alcohol exposure would increase the baby's chance of having Down syndrome. A plausible explanation for this misconception could be that many individuals are unfamiliar with the clinical features and cause of Down syndrome, even though they are well aware that it is characterised by intellectual disability. Furthermore, Down syndrome is often discussed during pregnancy at the clinic as it is a common condition which is routinely screened for during sonar examinations (Malone and D'Alton, 2003). Participants therefore often hear Down syndrome mentioned while their pregnancy is being managed at clinic and realise that it is a serious condition, causing a child to have certain problems. They may assume that any problems during pregnancy will result in Down syndrome. It is therefore possible to make inaccurate connections between a known feature of FAS (intellectual disability) and a condition which shares this feature.

4.3.2. Knowledge regarding aspects of FAS

In section 4.2 participants were found to be aware that alcohol can be "harmful to an unborn baby", this section discusses participants' knowledge of the details associated with these harms, specifically FAS. Although being generally aware that prenatal alcohol exposure can harm a developing baby is important, having knowledge of a specific syndrome could make the potential problems in an affected child more real. This may encourage behavioural change in pregnant women to abstain from alcohol consumption in order to avoid the possibility of having an affected child. Fetal alcohol syndrome is at the severe end of the FASD spectrum, and is also the most commonly referred to adverse effect of prenatal alcohol exposure, particularly in the media. Although almost all participants (99% of state and 100% of private participants) knew that problems could occur in a baby due to maternal alcohol consumption during pregnancy. Private participants were found to be significantly more knowledgeable regarding a specific condition caused by prenatal alcohol exposure, with less than half of state participants

(49/107, 46%) having any knowledge of FAS (Table 3.4). Of the participants who claimed to have heard of FAS, all were able to successfully recognise the cause of the condition (maternal alcohol consumption) and that the adverse effects can be severe. However, a number of state participants incorrectly responded to statements regarding certain aspects of FAS, i.e. they considered FAS a curable condition (14/47, 30%) and thought it only occurred in certain population groups (11/49, 22%) (Table 3.4). These misconceptions are further discussed in section 4.5.

Any type of beverage containing alcohol and consumed during pregnancy can cause congenital abnormalities. However, results indicated that a number of participants from both groups (80% of state participants and 16% of private participants) considered some types of alcohol to be more likely to cause FAS than others. This is in keeping with results from a previous study which found that the majority (70%) of Danish women considered some types of alcohol more harmful during pregnancy than others (Kesmodel and Kesmodel, 2002). Eight types of alcoholic beverages were nominated in the questionnaire (wine, shop-bought beer, homemade beer, spirits, cider, milk stout, spirit coolers and liqueurs), of which participants could select the ones which they believed could cause FAS. In both groups, beer (shop-bought) (97% of private and 70% of state participants) and spirits (99% of private and 60% of state participants) were considered the beverages most likely to result in FAS, if consumed during pregnancy. These results were once again comparable to those of Kesmodel and Kesmodel (2002), who found that most Danish women (63%) considered spirits a more harmful substance than wine or beer when consumed in pregnancy. Overall, the number of participants (84% private and 20% state participants) who were able to identify all types of alcohol was not as high as expected (Figure 3.11). State participants' responses to this question revealed a sense of confusion regarding which alcohols are considered harmful in a pregnancy, with only 20% having selected "all types of alcohol".

Additionally, only 18 of the 59 state participants (31%) who were classified as being aware of alcohol and pregnancy knew that all types of alcohol could cause FAS. Therefore one could say that even if individuals are appropriately aware that alcohol should be avoided during pregnancy, their understanding that consumption of *any* alcoholic beverages can result in FAS may be lacking. Although concerning, this finding is not unique as there seems to be global confusion among individuals regarding the link between types of alcohol and pregnancy outcomes. Women have previously been found to believe that different types of alcohol (e.g. beer, wine and spirits) can result in different problems in children, if they are exposed prenatally (Kesmodel and Kesmodel, 2002). It is therefore important that pregnant women are made aware of the fact that all types of alcohol can harm a developing fetus. This information should be included in awareness campaigns. An effective approach may be to target companies who produce alcohol, encouraging them to include warning labels with the same message on all their products. Warning labels that state: "Drinking during pregnancy can be harmful to your unborn baby" are predominantly found on certain wine bottles, but should be included on all alcoholic beverages to broaden the target population and thereby increase awareness of the risk associated with maternal alcohol use during pregnancy. In addition, posters, pamphlets and advertisements with information regarding FAS should emphasise that harm to a fetus can be caused by *any* type of alcohol.

As discussed previously, the exact level of alcohol exposure that will adversely affect fetal development is still unknown. However, to determine whether pregnant women had any specific beliefs in this regard, participants were asked to select from a number of options how much alcohol they thought would cause FAS. These options ranged from the conservative, "One drink in the whole 9 months", to the extreme of "many drinks every day." Analysis of this question did not reveal much about women's thoughts on the matter, with many selecting

more than one option and seven of the respondents selecting all options. This illustrates the confusion among the public regarding the level of maternal alcohol use that can be harmful. The majority of participants (69%) felt that if a woman consumed many drinks every day, her child will be affected by FAS. On the other end of the spectrum, 12% of women were very cautious and considered just one drink in the entire pregnancy (nine months) a danger to the developing baby. In hindsight, this was not an effective question to evaluate women's beliefs of an acceptable level of alcohol use in pregnancy. An open-ended question might have provided more insight into women's opinion on the matter.

It should be noted that the question regarding the types of alcohol that can cause FAS (Question 22, Appendix E) was designed to include various types of alcohol frequently enjoyed by all populations, cultures and income groups. However, initial analysis of participants' responses revealed that a number of state participants (61/104, 59%) selected only "liqueurs". Upon further investigation during subsequent sampling, it was revealed that many participants mistook "liqueurs" for "liquor" or "any strong alcohol". This misconception could have influenced the final result obtained from this question, but does not diminish the relevance of the findings.

4.4. Common misconceptions identified among participants regarding the consumption of alcohol during pregnancy

Significant differences between state and private participants' responses to certain statements in the questionnaire have highlighted a few concerning misconceptions regarding alcohol use during pregnancy, particularly among private participants. Significantly more private participants (29%) believed occasional alcohol consumption during pregnancy is acceptable, compared to state participants (7%) (Table 3.2). Although concerning, results from previous

studies conducted among Danish and French women show that this is a much more common misconception in other countries. Kesmodel and Kesmodel (2002) found that 76% of Danish women considered some alcohol consumption during pregnancy acceptable, while 94% of French women allowed at least one drink per day during pregnancy (Lelong et al., 1995). This misconception was further illustrated by comments made in the questionnaire by private participants who stated that "the odd drink shouldn't be a problem" and that on "special occasions" it is acceptable. Of particular concern, was the finding that all of the private participants, who considered occasional alcohol use during pregnancy acceptable, were also educated and had obtained a tertiary qualification (29/29, 100%). This misconception could be explained by a lack of conclusive evidence regarding the effect of low or moderate drinking on fetal development (Peadon et al., 2011).

Significantly more private participants (12%) compared to state participants (3%) also considered alcohol consumption safe after a pregnancy has reached a certain gestational age, (Table 3.2), particularly after three months of pregnancy. Another study found that even healthcare professionals, specifically occupational therapists, thought it is acceptable for pregnant women to increase their alcohol use with one drink or more with each trimester (Rudeen, Cook and Mengel et al., 2007). This is concerning because the brain and central nervous system develop throughout pregnancy and are therefore constantly susceptible to the teratogenic effects of alcohol . Consequently, a fetus who is exposed to alcohol later in pregnancy might not develop FAS, but is still at risk of being born with certain features associated with prenatal alcohol exposure, particularly growth abnormalities (Larkby and Day, 1997). Considering the high level of education of private participants, this increased level of tolerance toward alcohol consumption during pregnancy is concerning and highlights a lack of awareness and knowledge among individuals who attended tertiary institutions. This gap could be addressed by focusing awareness campaigns on universities, colleges and technicons where

women of childbearing age can be exposed to information on FASD and be given guidelines that recommend abstinence from alcohol during pregnancy. This can be done through pamphlets, banners, posters and campaign workers present on campus to approach students and discuss the harms of alcohol use during pregnancy with them.

Myths and prior beliefs about the effects of specific alcoholic beverages on a pregnancy were also revealed when results indicated that 62% of state participants and 13% of private participants did not think that milk stout could result in FAS (Figure 3.11). The name itself could be misleading and cause women to associate milk stout with breast feeding. Indeed, this has been reported as a common belief in various cultures and traditions where women have often been encouraged to consume beer while breastfeeding, in order to stimulate lactation (Mennella and Beauchamp, 1993). Research regarding the legitimacy of these recommendations have nevertheless produced controversial results (Koletzko and Lehner, 2000). This is therefore a problematic misconception, since milk stout is a variation of beer and contains 6% of alcohol.

Traditional beliefs regarding the cause, aetiology and treatment of illnesses or congenital anomalies are common in many cultures. In South Africa, many black individuals still make use of the services of traditional healers. Additionally, they often believe that medical conditions and abnormalities like cleft lip and/ or palate can be attributed to factors such as witchcraft or due to the violation of cultural, traditional or religious norms (Hammond-Tooke, 1989; Dagher and Ross, 2004). A comment made by a private participant touched upon such beliefs, by saying that "older black women…believe that to have a baby born with fetal alcohol syndrome is witchcraft or God's will."

Although traditions and cultural beliefs are important and should be respected, it is important to address beliefs like these by educating women regarding the known medical cause of a condition such as FAS, since education may lead to prevention. A promising approach may be to include traditional healers in the education process, by providing them with the correct medical information regarding the risks associated with alcohol use during pregnancy and the symptoms related to FAS. This concept has been utilised in the fight against HIV and AIDS in South Africa, where formally trained doctors and traditional healers work together in creating awareness of HIV and AIDS (Liverpool, Alexander, Johnson, et al., 2004). Women might be more accepting of information if it comes from a well-known source that they trust and respect.

When assessing participants' knowledge of certain aspects of FAS, a number of misconceptions were identified among state participants. Specifically, a large number of state participants were found to believe that the problems associated with FAS could be cured (30%), or that this condition occurs only in certain population groups (22%). Participants were specifically asked whether they thought of FAS as a population-specific condition, since the majority of research and reports regarding the prevalence of FAS in South Africa have been done in areas of the Western and Northern Cape Provinces, where participants are predominantly from the Coloured population (Viljoen et al., 2002; May et al., 2007). The belief that FAS can be cured is concerning; by failing to grasp the extent and permanent nature of the problems and disabilities in alcohol-exposed children, women may become less concerned about having a child affected by FAS as they believe it can be "fixed".

4.5. Source of information regarding alcohol and pregnancy

Overall, private participants were found to be much more likely than state participants to have come across information regarding alcohol use and pregnancy. Further investigation revealed

that the majority of information obtained by private participants originated from the media (78%) and friends or family (68%) (Figure 3.7). Similarly, a study conducted among a sample of pregnant Danish women also indicated that the media (65%) and relatives (40%) were the most popular sources of information (Kesmodel and Kesmodel, 2002). Coincidentally, FAS was a featured topic on the investigative journalism programme, *Carte Blanche*, on 26 February 2012. Two private participants stated that they learnt about FAS from *Carte Blanche.* These results might suggest that the information currently available is more accessible to private participants, particularly information presented through the media. Newspapers, magazines and certain television channels are only accessible to those who can afford to pay for them.

Significantly fewer state participants could recall having ever come across information related to alcohol use and pregnancy. However, of those state participants who claimed to have come across such information, the majority (60%) received their information from a health care professional (Figure 3.7). This was also the only source from which more state participants received information than their private counterparts, although the difference was not significant. These results may suggest that state participants rely more heavily on their healthcare professionals for information pertaining to their pregnancies. As mentioned previously, all state participants were also exposed to information while attending clinic during Pregnancy Education week. It is therefore likely that even during the data collection process of this study, particularly at CMJAH, these individuals were made more aware of alcohol use during pregnancy through media campaigns.

4.6. Discussions regarding alcohol use during participants' current pregnancies

Considering the serious teratogenic effects alcohol can have on a developing baby, it is pertinent that the topic of maternal alcohol consumption be addressed with expecting mothers. When asked whether anyone had discussed prenatal alcohol consumption with them during their *current* pregnancy, participants' responses delivered interesting results. State participants were significantly more likely to have had a discussion regarding alcohol use than private participants. Furthermore, state participants were much more likely to have discussed this topic with nurses (39%) or medical doctors (38%) than with anyone else (Table 3.3). This is not surprising as pregnant women in the state medical sector are managed by nurses, whereas private patients rarely interact with nurses during their pregnancies. Pregnancy Education week may have influenced these results as doctors or nurses may have been more likely to discuss alcohol with their patients during that particular week. Nevertheless, this is an important result and is consistent with results from a recent study which found nurses to be the most vital sources of information for individuals in the state medical sector (Chersich et al., 2012).

Private participants were more likely to discuss alcohol consumption with friends and family than the state participants were, however the most frequently quoted source of discussion among private participants was a medical doctor (57%) (Table 3.3). It is concerning that despite these discussions with doctors, a large number of private participants still considered occasional alcohol use during pregnancy acceptable. It is therefore important to determine the nature of these discussions and to establish whether they are receiving inaccurate or inappropriate information from their doctors. Advice offered by doctors has often been reported as confusing; with some advising abstinence, while others approving maternal consumption of up to four units a week during pregnancy (Raymond et al., 2009). Some doctors avoid discussing their patients' drinking habits during consultations as their lack of knowledge of

guidelines and a fear of coming across as judgmental make them uncomfortable (Lelong et al., 1995). Consequently, if doctors and other medical professionals are unfamiliar or uncomfortable with guidelines recommending abstinence, pregnant women will not receive accurate information and may assume an attitude of tolerance toward the use of alcohol during pregnancy.

Health care professionals, particularly those who provide care for pregnant women, should therefore be made aware of these guidelines and educated regarding the effects of any alcohol use during pregnancy. This can be achieved by dedicating more time within the curriculum medical school to FAS and developing specific programmes to the education of healthcare professionals regarding prevention, diagnosis and care of FAS, as was done in the United States by the Fetal Alcohol Syndrome Prevention Team at the Centre for Disease Control (CDC) (Sharpe, Alexander, Hutcherson et al., 2004). By having the correct facts themselves, they will be able to share only appropriate information with their patients.

4.7. Limitations

Due to time constraints, this study had some limitations.

- This study originally aimed to determine and compare the level of knowledge and awareness regarding the harmful effects of prenatal alcohol exposure, between individuals from the state and private medical sector, but also between individuals from different socio-economic backgrounds. Questions 4 - 9 were included in the questionnaire with the intent of determining socio-economic status (SES) which could then be used to establish whether associations exist between SES and level of awareness and knowledge regarding alcohol use during pregnancy. However, in retrospect, the type of SES questions that were included in the questionnaire were not sufficient in classifying individuals according to accurate SES statuses and these questions were

consequently excluded from the final analysis. To accurately calculate SES statuses, more in depth questions regarding income and living conditions should have been included.

- Development of the questionnaire used in this study was particularly challenging, since the questions and language used had to be appropriate for participants from various demographic and educational backgrounds. Analyses of responses have indicated that some participants, particularly from the state sector, might have misunderstood certain questions or words, for example "liqueurs" was likely to be mistaken for "liquor". Similarly, participants who were not comfortable with or proficient in English may not have understood what "IQ" referred to and therefore failed to select it as a feature of FAS. This might have been avoided by conducting data collection through interviewer-administered interviews rather than self-administered questionnaires. One of the downfalls of using interviewer-administered interviews is that it may reduce the feeling of anonymity, which could diminish participants' willingness to freely express their opinions and attitudes.

- Participants who did not respond to certain questions were excluded from analysis of those questions. Most non-responders were state participants and excluding them may have negatively affected data analysis and comparisons of knowledge and awareness between the two groups. It is likely that they did not respond because they did not know the answer and could therefore have been included in analysis by being categorised as "unaware" in the specific question. However, it is not accurate to analyse non-responders based on assumptions, as it just as likely that they did not respond because they did not understand the question. In order to avoid this in future, an "unsure" option

should be included in all relevant questions that test awareness and knowledge of alcohol use during pregnancy.

- Since previous studies have found associations between the number of pregnancies women have had and their perception of the risk of adverse pregnancy outcomes due to maternal alcohol consumption (Testa and Reifman, 1996), this study set out to determine whether similar associations could be found among private and state participants in the Johannesburg area. Information was therefore gathered regarding participants' obstetric characteristics. However, due to the nature of the private antenatal classes the overwhelming majority of private participants were primagravidas which consequently may have skewed the distribution of these characteristics and inhibited accurate analysis.

- Although this study investigated the source of information and discussions regarding alcohol use during pregnancy, it did not explore the nature of the information participants received and what they were told during discussions with friends, family or health care professionals.

- Finally, another limitation is that results obtained from this study are specific to individuals in the Johannesburg area and are therefore not representative of pregnant patients attending state hospitals or private antenatal centres throughout South Africa. Recruitment of participants was also limited to those who could read or communicate in English. These selection criteria excluded individuals from certain socio-economic or demographic backgrounds.

4.8. Recommendations and future research

While conducting this research a number of areas were identified where future research is needed so as to improve our understanding of pregnant women's level of knowledge and awareness regarding the dangers of alcohol use during pregnancy.

Previous studies have identified low SES as a risk factor for FAS (Viljoen et al., 2002). It is therefore important for future studies to determine whether individuals from lower SES are at increased risk of FAS, due to a decreased level of awareness and knowledge regarding the dangers associated with maternal alcohol consumption. As mentioned previously, one of the limitations of this study was the fact that SES could not be determined due to a lack of appropriate questions in this regard. Future studies should therefore use more appropriate questions for determining SES, including questions regarding financial status, living conditions and available services. Awareness campaigns can then be customised to suit the informational needs of individuals from specific socio-economic backgrounds.

As mentioned previously, a limitation of this study was the skewed distribution of private participants' obstetric histories, which prevented accurate analysis of associations between number of pregnancies and other characteristics, such as knowledge of FAS. As opposed to sampling from private antenatal centres, participants should perhaps be recruited from Obstetricians or Gynaecologists in private practice antenatal clinics at private hospitals which are attended by all women who have had any number of pregnancies.

Considering the contradictory results found in this study which indicated that despite exposure to information, levels of awareness and accurate knowledge regarding alcohol use in pregnancy remain low as well as the many misconceptions that were identified suggest more comprehensive research is needed in this regard. Future studies need to determine the accuracy,

amount and type of information conveyed to pregnant women by the various sources. This will help identify the source of common misconceptions and misleading information, which can then be targeted for educational programmes.

It is also important that future studies are conducted using samples of participants that are representative of other areas in South Africa. Results of investigations like the present study may differ in other state hospitals and disadvantaged areas. A more comprehensive understanding of South African women's level of knowledge and awareness will enhance the development of appropriate awareness campaigns in the country.

This study assessed knowledge and attitudes of participants, but not their practices. Valuable information can be gained if future studies focus on the association between pregnant women's knowledge or awareness and their practices (whether and how much alcohol they drink during pregnancy). Although this evokes a number of ethical concerns, such as evoking feelings of guilt or stress, it would be valuable to establish the degree to which women's actions are influenced by their knowledge and attitudes.

This study has identified a strong need for the development of effective awareness campaigns that are aimed at increasing pregnant women's awareness and knowledge of the risks associated with maternal alcohol use during pregnancy. As mentioned previously, a number of participants from the private sector have reportedly been exposed to information regarding alcohol and pregnancy through the media. This is an effective means of conveying information which should be utilised more effectively to reach individuals who may not be able to pay for magazines or newspapers, but who still have access to radio and freely available TV channels. It is important to not restrict the presentation of information and awareness campaigns to TV and radio but to make information accessible to all through sources such as posters, billboards

and pamphlets. State participants supported this need for education by stating that "…pregnant women should be taught the importance of not drinking during their pregnancy…", while another thought it "…very important to bring information to all the pregnant women to help them avoid those stuff." These comments emphasised the need for information to be made freely available and highlighted participants' beliefs that an increase in women's awareness of harms associated with maternal alcohol use will ultimately lead to abstinence. It would be ideal if all messages could be adapted for specific target groups by presenting them in the 11 official South African languages. The value of accessible information has been demonstrated by findings from previous studies (Walker et al., 2005), which showed that even a brief intervention in the form of an informational pamphlet or poster may significantly influence a women's awareness of the problems caused by alcohol consumption during pregnancy.

5. CHAPTER 5: CONCLUSION

"They cannot determine exactly how much alcohol can cause FAS in babies and it differs, but the fact is, are you willing to take the risk?"

- Comment from a private participant.

Results obtained from this study have shed some light on pregnant women's level of knowledge and awareness regarding the consequences of prenatal alcohol exposure, as well as how these differ between women from the state and those from the private medical sector.

This research has revealed that slightly more than half of both state and private participants could be classified as being aware that prenatal alcohol exposure can have a deleterious effect on a pregnancy. Nevertheless, it was concerning to find that a large number of private participants consider some alcohol intake during pregnancy acceptable. Results from previous studies have revealed that this is not an uncommon misconception, even amongst educated women from first-world countries such as Denmark and France (Lelong et al., 1995; Kesmodel and Kesmodel, 2002). Consequently, this lack of awareness among private participants can be used as a target for alcohol in pregnancy awareness campaigns

Findings obtained also suggested that although the majority of state and private participants are able to recognise that alcohol consumption during pregnancy can be harmful to a developing baby, their knowledge regarding the specific adverse effects is very poor. Only 3% of state and 19% of private participants displayed sufficient knowledge regarding the features, characteristics and specific aspects of FAS. These results indicate a need for educational and awareness campaigns to focus on the many adverse effects of prenatal alcohol exposure, specifically the various features of FAS and the long-term consequences.

Participants were able to voice their opinions regarding the need to receive more information about the hazards of prenatal alcohol exposure themselves. This indicates that not only are healthcare professionals concerned about the serious lack of knowledge and awareness regarding alcohol use during pregnancy, but that members of the public are eager and willing to be educated on how they can prevent FAS.

"Thanks for this research. I've gained some information and also some research I need to do personally about alcohol intake during pregnancy."

- Comment from a state participant.

Common misconceptions in each of the two groups have been identified. In particular, private participants' misconception that occasional alcohol use during pregnancy is acceptable and the common belief among state participants that FAS is a curable condition which only occurs in certain population groups and that only certain types of alcoholic beverages can harm a baby. Furthermore, areas of knowledge which are often lacking among all participants were identified, including: the features seen in children affected by prenatal alcohol exposure; the characteristics of specific conditions like FAS; and the fact that all types of alcohol can have deleterious effects on a pregnancy, this information can be used to develop effective awareness campaigns and prevention strategies which target these gaps in pregnant women's knowledge. Universal prevention strategies, which aim to increase knowledge at a population-level (Chersich et al., 2011), should address these lapses in knowledge by incorporating the appropriate information. Ideally, women should also be approached in clinics by healthcare professionals and given this information on a personalised level, depending on their level of understanding and their informational needs, however this might not be feasible in our country. Perhaps a more realistic approach would be to identify high risk women by screening them for alcohol use at their clinics and focusing the implementation of the awareness campaign on them. This will then form part of a selective or indicated intervention strategy that focuses on

women who are considered high risk. Intervention in the form of a pamphlet, counselling or general discussion with healthcare worker could be sufficient. It is important to make the information accessible to all individuals, which means it should be available in their own language so that they can easily relate to and understand the information provided to them. Pamphlets and posters with relevant information can be printed and made available in the eleven official languages.

Healthcare workers that have regular contact with women of childbearing age are given valuable opportunities to increase women's awareness on an individual level. As part of the genetic counselling consultation, counsellors have one-on-one discussions with pregnant women in a confidential environment, thereby enabling opportune moments for creating awareness by discussing alcohol use and FAS. It is therefore essential that genetic counsellors know about common misconceptions and how previous exposure to inaccurate information can influence individuals' beliefs and risk perceptions regarding maternal alcohol consumption during pregnancy. If patients convey misconceptions or a lack of awareness regarding alcohol use during pregnancy, genetic counsellors should use the opportunity to address them and educate the individuals.

In conclusion, one would assume that being in private medical care in South Africa is preferable and that those individuals are more likely to be better educated, due to their financial advantages. However, results of this study have shown that individuals from both the state and private sectors lack sufficient knowledge of FAS and both carry certain misconceptions regarding the harmful effects of alcohol use during pregnancy. Fetal alcohol syndrome is a serious health concern in South Africa which needs to be addressed. The findings of this study not only indicates the strong need for effective awareness and tailored preventions strategies, but also identified gaps in individual's awareness and knowledge that can prove useful in the

development of these prevention campaigns. This can ultimately lead to a reduction in the rate of FAS, while also decreasing the economic burden it has on our country.

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APPENDICES

Appendix A: Ethics clearance certificate

0
UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Chanelle le Roux

CLEARANCE CERTIFICATE M111161

PROJECT Pregnant Women's Perceptions and Knowledge regarding Alcohol Use During Pregnancy

INVESTIGATORS Ms Chanelle le Roux.

DEPARTMENT School of Pathology/Human Genetics

DATE CONSIDERED 25/11/2011

M111161DECISION OF THE COMMITTEE* Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 25/11/2011 CHAIRPERSON .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Ms Shelley Macaulay

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Appendix B: Permission to conduct research (Tina Otte)

Tina Otte's Family and Child Centre
Childbirth Education and Support
P.O. Box 1627, Pinegowrie, 2123
4 Jack Street, Jacaranda, Creeta, Randburg, 2194
Telephone. (011) 782-0790 Fax (011) 782-9871
Pr. No. 6829409



18 October 2011

To whom it may concern

I, Tina Otte, hereby grant Chanelle le Roux permission to conduct research for her MSc Med Genetic Counselling degree, entitled: Pregnant women's perceptions and knowledge regarding alcohol use during pregnancy, at the Family and Child Centre during 2012.

Signed: _____

Appendix C: Permission to conduct research (Nicky Gebka)

Nicky Gebka RN,RM
Registered Nurse , Midwife & Childbirth Educator
PR 880000049220

39 Westbourne Rd
Bryanston
2130
e-mail : ngebka@iafrica.com

P.O Box 1116
Sunninghill, 2157
Tel: (011) 463 8393
Cell: 082 411 8038

18 October 2011

To whom it may concern

I, Nicky Gebka, hereby grant Chanelle le Roux permission to conduct research for her MScMed Genetic Counselling degree, entitled: Pregnant women's perceptions and knowledge regarding alcohol use during pregnancy, at the Bryanston Mother and Baby Education Centre during 2012.

Signed: N Gebka RN RM

Appendix D: Permission to conduct research (Charlotte Maxeke Johannesburg Academic Hospital)

health and social development
Department: Health and Social Development
GAUTENG PROVINCE

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Office of the Chief Executive Officer
Charlotte Maxeke Johannesburg Academic Hospital
Tell: 011 488 3792
Fax: 011 488 3753
Email: lindiwe.mngomezulu@gauteng.gov.za
Date: 04th November 2011

Ms. Chanelle le Roux
MSc(Med) Genetic Counselling student
University of the Witwatersrand

Dear Ms. Le Roux

RE: "Pregnant women's in perceptions and knowledge regarding alcohol use during pregnancy"

Please note that your above request is provisionally approved. Your study can only commence once ethics approval is obtained.

Yours sincerely

Dr. Barney Selebano
Chief Executive Officer

Appendix E: Questionnaire

Date:____/____/ 2012

Subject nr:_____

Name of clinic/hospital that you are at:

Charlotte Maxeke Johannesburg Academic Hospital ☐

Bryanston Mother and Baby Education Centre ☐

Tina Otte's Family and Child Centre ☐

DEMOGRAPHICS

Personal Details

1. Age:_____

2. Which race do you identify with?

   a. White ☐

   b. Coloured ☐

   c. Indian ☐

   d. Black ☐

   e. Other: _____

3. What is your religion?_____

4. Where in Johannesburg do you live?

_____

5. What type of housing is most common in your neighbourhood? (Tick appropriate boxes)

   a. Shacks ☐

   b. Government housing ☐

   c. Flats/townhouses ☐

   d. Suburban houses ☐

   e. Other:_____

6. What are the main types of roads found in your neighbourhood? (Tick appropriate box)

   a. No roads ☐

   b. Gravel/dirt roads ☐

   c. Tarred roads ☐

7. Which of the following do you have available (in working order) where you live?

a. Electricity ☐

b. Refrigerator ☐

c. Internet ☐

d. Television ☐

8. Do you have piped (tap) water where you live? Yes | No

8.1 **If YES,** is the tap: (Tick appropriate box)

a. Inside your home ☐

b. On a community stand ☐

9. What type of toilet facility do you have where you live? (Tick appropriate box)

a. Flush toilet inside your home ☐

b. Flush toilet outside your home ☐

c. Pit toilet ☐

d. Other:_____

Education

10. What is the highest grade you completed at school?_____

11. Have you obtained any degrees/ certificates/ diplomas since leaving school? Yes | No

11.1 **If YES**, please specify:_____

Occupation

12. Are you currently employed? Yes | No

12.1 **If YES**, what is your occupation? _____

12.2 **If NO,** what is the reason for your unemployment?

_____

OBSTETRIC HISTORY

13. How many pregnancies have you had, including your current pregnancy? _____

14. How many live children do you have?_____

15. How many weeks or months, are you currently pregnant?

_____weeks **OR** _____ months.

AWARENESS AND ATTITUDES

16. Do you know of anything that could be bad/harmful to an unborn baby during pregnancy? | Yes | No |

16.1 **If YES**, please list some things you think could be bad/harmful to a baby, when used during pregnancy:

_____

_____

_____

17. Do you agree/disagree with the following statements:

Alcohol during pregnancy:

17.1 Has no effect on the baby | Agree | Don't agree |

17.1.1 **If you AGREE,** do you think alcohol has any affect on the mother?

_____

17.2 Should be stopped completely | Agree | Don't agree |

17.2.1 **If you AGREE,** why should alcohol use be stopped completely?

_____

17.3 Can be good for the pregnancy | Agree | Don't agree |

17.3.1 **If you AGREE**, how can it be good for the pregnancy?

_____

17.4 Can be used occasionally | Agree | Don't agree |

17.4.1 **If you AGREE,** when can alcohol be used during pregnancy?

_____

17.5 Can be used after you are a certain number of months pregnant | Agree | Don't agree |

17.5.1 **If you AGREE**, after how many months?_____ months

18. Have you ever come across any information regarding drinking alcohol during pregnancy? | Yes | No |

If YES, where did the information come from? (Tick the boxes)

a. Doctor/health care professional/Clinic ☐
b. Media (e.g. TV/magazine) ☐
c. School ☐
d. Friends/family/word of mouth ☐

e. Cultural/ religious beliefs ☐

f. Cannot remember ☐

g. Other:_____

19. During your current pregnancy, has anyone discussed alcohol consumption with you? | Yes | No |

If YES, who? (Tick the boxes)

a. Doctor ☐

b. Midwife ☐

c. Nurse ☐

d. Other:_____

KNOWLEDGE

20. Do you think problems can arise in the baby if you drink alcohol during pregnancy? | Yes | No |

If YES, which of the following problems in the baby do you think are associated with alcohol use during pregnancy? (Tick the appropriate boxes)

a. Small eyes ☐

b. Baby addicted/ experiences withdrawal ☐

c. Brain damage ☐

d. Lower IQ/ mental disability ☐

e. Missing limbs ☐

f. Small head ☐

g. Growth problems ☐

h. Higher chance of baby having Down syndrome ☐

i. Cleft lip/palate ☐

21. Have you ever heard of Fetal Alcohol Syndrome? | Yes | No |

If YES, do you agree/disagree with the following statements:

a. Fetal alcohol syndrome happens when a women drinks alcohol during her pregnancy.	Agree	Don't agree
b. The effects of alcohol on a baby can be serious.	Agree	Don't agree
c. The problems associated with Fetal alcohol syndrome can be cured.	Agree	Don't agree
d. Fetal alcohol syndrome only happens in certain population groups.	Agree	Don't agree

22. What type of alcohol do you think can cause Fetal alcohol syndrome? (Tick the appropriate boxes)

a. Wine ☐
b. Beer (from the shops) ☐
c. Homemade beer ☐
d. Spirits ☐
e. Cider ☐
f. Milk Stout ☐
g. Spirit coolers (e.g. fruity alcoholic drinks) ☐
h. Liqueurs ☐

23. How much alcohol during pregnancy do you think would cause Fetal alcohol syndrome, where one drink = one glass of wine/ one can of beer/ one spirit cooler? (Tick one appropriate box)

a. One drink during the whole 9months ☐
b. One drink a month ☐
c. One drink a week ☐
d. One drink a day ☐
e. Many drinks on one occasion ☐
f. Many drinks every day ☐

24. Do you think Fetal alcohol syndrome is a problem in South Africa?

Yes	No

25. Please add any other comments:

_____
_____
_____
_____

Appendix F: Information Sheet

NATIONAL HEALTH
LABORATORY SERVICE
University of the Witwatersrand, School of Pathology
Division Of Human Genetics
Practice No.: 0052800295

Hospital Street, Johannesburg, 2001
Telephone: +27-11-489-9224/9223/9211

PO Box 1038, Johannesburg, 2000
Fax: +27-11-489-9226 or +27-11-489-9209

Prof A Christianson 011 489-9211/9239 • Prof A Krause 011 489-9219 • Prof M Ramsay 011 489-9214
Prof H Soodyall 011 489-9208 • Dr T Lane 011 489-9221

Information sheet: Pregnant women's perceptions and knowledge regarding alcohol use during pregnancy.

Investigator: Chanelle le Roux, MSc (Med) Genetic Counselling Student

Good day, my name is Chanelle le Roux and I am a Masters student at the University of the Witwatersrand (Wits), School of Pathology.

For the purpose of my studies, I am doing research on pregnant women and their perceptions and knowledge about alcohol use during pregnancy. In this study I want to learn what women's opinions and ideas are regarding the use and effects of alcohol during pregnancy.

I would like to invite you to take part in this research study by completing a questionnaire consisting of a number of questions related to your knowledge and opinions.

The questionnaire can be completed at your antenatal clinic/class and should not take longer than ten minutes. The questionnaire includes questions regarding your demographic information (e.g. where you live, what work you do, etc.), your current and previous pregnancies, your opinion on alcohol consumption during pregnancy, what you know about the effects of alcohol on pregnancy and how you came about this information.

Results from this study will help us understand South African women's attitudes toward alcohol consumption during pregnancy, what they know about this subject and how they came across their information.

Your participation in this study is voluntary. You have the right to refuse to participate in the study. Also, you have the right to withdraw from the study at any time. Your refusal or withdrawal will not affect present or future management of your pregnancy.

All information will be anonymised. Your name and other identifying information is not required on the questionnaire.

If you have any questions about your participation, please do not hesitate to contact me or my supervisors on the numbers listed below.

Thank you,

Ms. Chanelle le Roux (Principal investigator) – BSc (Med) (Hons) Human Genetics, Genetic Counselling student - 011 489 9223

Ms. Shelley Macaulay (Supervisor) – MSc (Med) Human Genetics, MSc (Med) Genetic Counselling, Genetic Counsellor and lecturer – 011 489 9230

Ms. Tina-Marié Wessels (Supervisor) – MSc (Med) Genetic Counselling, Genetic Counsellor and lecturer – 011 489 9243

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