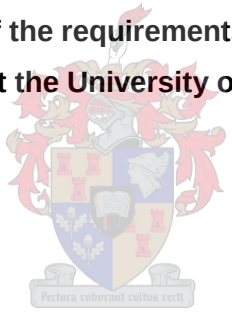
PERCEPTION OF PERSONAL AND GENERAL RISK OF ALCOHOL USE DURING PREGNANCY AMONG WOMEN IN A HIGH RISK COMMUNITY IN THE NORTHERN CAPE PROVINCE, SOUTH AFRICA

JACOBUS GIDION LOUW

Thesis presented in fulfillment of the requirements for the degree in Master of Arts (Psychology) at the University of Stellenbosch.



Supervisor: Prof. Mark Tomlinson

December 2014

DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment/thesis/dissertation is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

…… 26-11-2014……..

Signature Date

SUMMARY

Maternal drinking during pregnancy and its consequences are a growing health concern worldwide. It has also been identified as a significant problem in South African communities with some of the highest prevalence rates of Fetal Alcohol Spectrum Disorder (FASD) reported in South Africa. The primary aim of this study was to explore how women in a South African community in the Northern Cape Province perceive the personal and general risk of drinking during pregnancy. The secondary aims were to ascertain whether there was evidence of unrealistic optimism, to examine whether there were personal characteristics that are associated with high or low risk perception, and to examine women's knowledge of FASD. A total of 128 women from De Aar in the Northern Cape, an area with a high prevalence of FASD, and therefore drinking during pregnancy, were recruited to take part in the study. Participants had previously taken part in a FASD prevention programme. Questionnaires were administered assessing the perception of the risk posed to a participant's own child should she drink during pregnancy, and the risk posed to others' children should they drink during pregnancy. The questionnaire also contained questions on FASD knowledge and demographic variables. Participants were between 18 and 44 years of age and reported high rates of unemployment. Most women had more than one child and 7.8% had a child diagnosed with FASD. No evidence for unrealistic optimism was found. Multiple regression analyses revealed both FASD knowledge, and the perception of how easy it would be for oneself to stop drinking, were significant predictors for both personal and general risk. A model including the perception of general risk, FASD knowledge and the perception of how easily one could stop drinking accounted for the most variance in the perception of personal risk (66.4%). Perception of personal risk on its own was the strongest predictor of the perception of general risk accounting for 56.1% of variance. There was no significant correlation between passage of time and FASD knowledge, but possible gaps in FASD knowledge were identified. The study provides an overview of the perception of the risk of drinking during pregnancy in the target population. It also suggests improvements to the research design and materials for further research.

OPSOMMING

Moederlike drankgebruik gedurende swangerskap en die gevolge daarvan word wêreldwyd met groeiende kommer beskou. Dit is ook as ’n wesenlike probleem in Suid-Afrika geïdentifiseer, met van die hoogste voorkomssyfers van Fetale Alkohol Spektrumafwykings (FASA) wat in Suid-Afrika aangeteken is. Die primêre doel van hierdie studie was om, in ’n Suid-Afrikaanse gemeenskap in die Noord Kaap provinsie, die persepsie van persoonlike en algemene risiko van drink tydens swangerskap onder vrouens, te ondersoek. Die sekondêre doelstellings was om vas te stel of daar bewyse van onrealistiese optimisme is; te bepaal of daar persoonlike eienskappe is wat korreleer met ’n hoë of lae risiko-persepsie, en om ook die vroue se kennis van Fetale Alkohol Spektrumafwykings (FASA) te ondersoek. 128 vroue van De Aar in die Noord-Kaap is gewerf om aan die studie deel te neem. Die gebied het 'n hoë FASA voorkoms, en dus ook alkoholgebruik tydens swangerskap. Deelnemers het voorheen deelgeneem aan 'n FASA voorkomingsprogram. Vraelyste is voltooi rakende die persepsie van die risiko vir 'n deelnemer se eie kind sou sy tydens swangerskap drink, en die risiko vir ander se kinders, sou hulle tydens swangerskap drink. Die vraelys het ook vrae oor FASA kennis en demografiese veranderlikes ingesluit. Deelnemers was tussen 18 en 44 jaar oud en het hoë vlakke van werkloosheid gerapporteer. Meeste vrouens het meer as een kind gehad en 7.8% het ’n kind wat met FASA gediagnoseer is gehad. Geen bewyse vir onrealistiese optimisme is gevind nie. Meervoudige regressie-ontleding het bevind dat beide FASA-kennis en die persepsie van hoe maklik dit vir ’n deelnemer self sou wees om op te hou drink, beduidende voorspellers vir beide persoonlike en algemene risiko is. 'n Model wat die persepsie van algemene risiko, FASA-kennis en die persepsie van hoe maklik 'n deelnemer self kan ophou drink, het die grootste variansie in die persepsie van persoonlike risiko verduidelik (66,4 %). Persepsie van persoonlike risiko op sy eie, was die sterkste voorspeller van die persepsie van algemene risiko, opsigself verantwoordelik vir 56,1% van die variansie. Daar was geen beduidende korrelasie tussen die verloop van tyd en FASA kennis nie, maar moontlike gapings in die kennis van FASA is geïdentifiseer. Die studie bied 'n oorsig van die persepsie van die risiko van drankgebruik tydens swangerskap in die teikenbevolking. Dit stel ook verbeteringe vir die navorsingsmetodiek voor vir toekomstige navorsing.

ACKNOWLEDGEMENTS

Thank you to Prof. Mark Tomlinson, for your support and guidance. It was a privilege to work with you.

At the Foundation for Alcohol Related Research, I would like to thank Leana Olivier and Prof. Dennis Viljoen for giving me the opportunity to work in their programme. Thank you to Lian Drotsky as well for her assistance in De Aar.

A big thank you to the FARR community workers in De Aar: Anneline Jonas, Annelize Esau and Lena Rooi who administered the questionnaires, recruited the participants and dealt with my inevitable follow up questions. Without you my study would have been impossible.

Thank you to my family, my family-in-law and friends.

For financial support, thank you to Johann Louw, John Cowlin and Flip Nel.

A special word of thanks to Shaun Helders for years of support

Finally, thank you to Narina Nel. You are the best.

TABLE OF CONTENTS

DECLARATION i

SUMMARY ii

OPSOMMING iii

ACKNOWLEDGEMENTS iv

TABLE OF CONTENTS v

LIST OF FIGURES x

LIST OF TABLES xi

CHAPTER 1: Introduction 1

CHAPTER 2: Literature Review 3

2.1 Alcohol use and the global health burden 3

2.2 Distribution of the burden of injury and disease attributable to alcohol 3

2.3 Alcohol use in South Africa 4

2.4 Alcohol exposed pregnancies 5

2.5 Alcohol use among women in South Africa and adverse birth outcomes 5

2.5.1 Alcohol consumption among women in South Africa 5

2.5.2 Contraceptive use among women in South Africa 6

2.5.3 Late recognition of pregnancy 6

2.6 Fetal Alcohol Spectrum Disorder 7

2.6.1 FASD: Features and diagnosis 7

2.6.2 Determining the prevalence of FASD 8

2.6.2.1 Passive surveillance methods 8

2.6.2.2 Clinic based studies 9

2.6.2.3 Active case ascertainment methods 10

2.6.3 Estimating the prevalence of FASD 11

2.6.3.1 Global prevalence of FASD 11

2.6.3.2 Prevalence of FASD in South Africa 12

2.7 Spectrum of damage associated with FASD 13

2.7.1 Birth defects and dysmorphology 13

2.7.2 Growth deficits 13

2.7.3 Neurocognitive deficits 13

2.7.4 Secondary disabilities associated with FASD 14

2.7.5 Societal impact of FASD 15

2.7.6 FASD risk factors 15

2.8 FASD prevention 16

2.8.1 Selective prevention interventions 17

2.8.2 Indicated prevention interventions 17

2.8.3 Universal prevention interventions 17

2.9 Risk perception 18

2.9.1 Perceived risk and health behaviour 18

2.9.2 Obstacles to accurate risk perception 18

2.9.2.1 Measurement of risk perception 19

2.10 Unrealistic optimism 20

2.10.1 Unrealistic optimism and smoking during pregnancy 21

2.11 Risk perception, unrealistic optimism and FASD 21

2.12 Theoretical framework 22

2.12.1 Extended Health Belief Model 22

2.12.2 Risk perception theory 22

2.13 Rationale for the study 23

2.14 Research aims 24

CHAPTER 3: Method 25

3.1 Study design 25

3.2 Study setting 25

3.2.1 Healthy Mother Healthy Baby© programme 25

3.3 Study population 26

3.4 Sampling 26

3.4.1 Inclusion criteria 27

3.4.2 Exclusion criteria 27

3.5 Data collection 27

3.5.1 Existing records 28

3.5.2 Questionnaire 28

3.5.2.1 Demographic questions 28

3.5.2.2 Risk perception questions 28

3.5.2.3 FASD knowledge questions 29

3.5.3 Ethical considerations 29

3.5.3.1 Participant incentives 29

3.5.3.2 Informed consent 29

3.6 Data analysis 30

3.6.1 Demographic variables 30

3.6.2 FASD knowledge 30

3.6.3 Perception of personal and general risk 31

3.6.3.1 Unrealistic optimism 31

3.6.3.2 Predictors of high or low perception of risk 31

CHAPTER 4: Results and Data Analysis 33

4.1 Sample characteristics 33

4.2 Demographic variables 33

4.3 Pregnancy outcomes 35

4.4 FASD knowledge 36

4.4.1 Effect of time on FASD knowledge 36

4.5 Perceptions of personal and general risk 36

4.5.1 Unrealistic optimism 36

4.5.1.1 Student's t-test for related samples 36

4.5.1.2 Wilcoxon's matched-pairs signed-ranks test 37

4.6 Predictors of high or low perception of risk 37

4.6.1 Linear regression with perception of personal risk as dependent variable 37

4.6.2 Linear regression with perception of general risk as dependent variable 38

4.6.3 Multiple regression analysis with perception of personal risk as dependent variable 40

4.6.4 Multiple regression analysis with perception of general risk as dependent variable 41

CHAPTER 5: Discussion 43

5.1 Demographic variables 43

5.2 FASD knowledge 44

5.3 Unrealistic optimism 46

5.4 Predictors of high or low perception of risk 47

5.4.1 Predictors of personal risk 47

5.4.2 Predictors of general risk 48

5.5 Strengths and limitations 48

5.6 Suggestions for further research 50

CHAPTER 6: Conclusion 52

REFERENCES 54

APPENDICES 69

Appendix A: Images of dysmorphological features 69

Appendix B: Questionnaire 71

Appendix C: Ethical approval 77

Appendix D: Informed Consent 79

LIST OF FIGURES

Figure A1. Flattened Philtrum associated with FASD 69

Figure A2. Epicanthal fold and short palpebral fissure associated with FASD 69

Figure A3. “Railroad track” ear associated with FASD 70

Figure A4. “Hockey stick” palmar crease abnormality associated with FASD 70

LIST OF TABLES

Table 4.1. Sample characteristics 33

Table 4.2. Summary of demographic variables 34

Table 4.3. Healthy Mother Healthy Baby© risk group data 35

Table 4.4. Women who have experienced negative pregnancy outcomes 35

Table 4.5. Summary of linear regression analyses with perception of personal risk as dependent variable 38

Table 4.6. Summary of linear regression analyses with perception of general risk as dependent variable 39

Table 4.7. Significant predictors of perception of personal risk 40

Table 4.8. Significant predictors of perception of personal risk with perception of general risk included as predictor 41

Table 4.9. Significant predictors of perception of general risk 42

Table 4.10. Significant predictors of perception of general risk with perception of personal risk included as predictor 42

CHAPTER 1

Introduction

The harmful use of alcohol is recognised as one of the leading health risks worldwide, implicated in more than 2.5 million deaths per year (World Health Organization [WHO], 2011). Measured in disability-adjusted life years (DALYs), alcohol use also accounts for approximately 4.5% of the global burden of injury and disease each year (WHO, 2011). In 2000 alcohol use accounted for 7.1% of all deaths and 7.0% of all DALYs in South Africa (Marais, Jordaan, Olivier, & Viljoen, 2012).

In South Africa, when the 65% of the population who abstain from the consumption of alcohol are excluded, roughly 35 litres of alcohol are consumed per capita each year (WHO, 2011). Globally women tend to be less at risk of alcohol-attributable harm than men, and they are also less likely exhibit high-risk drinking behaviours. In South Africa however the prevalence of high risk drinking behaviours is similar among female drinkers and male drinkers, with 41.2% of women who drink engaging in heavy episodic drinking compared to 48.1% of men (WHO, 2011).

Women in South Africa are more at risk of alcohol-attributable harm than the global average. Furthermore between 13% and 43% of women report drinking while pregnant (Croxford & Viljoen, 1999; Marais et al., 2012), putting them at risk of Alcohol Exposed Pregnancies (AEPs). This is reflected in the prevalence of Fetal Alcohol Spectrum Disorders (FASDs)[1] in South Africa, which is the highest reported in the world (Chersich et al., 2012; May et al., 2007; Urban et al., 2008).

There are three major strategies for preventing AEPs and thereby preventing FASD. These strategies are universal prevention interventions, selective prevention interventions and indicated prevention interventions. Of the three types of intervention, universal interventions are the least resource intensive and can reach entire populations through, for example, media campaigns (Stratton, Howe, & Battaglia, 1996). This is important in resource constrained contexts characterising much of the world (Rosenthal, Christianson, & Cordero, 2005).

The aim of universal prevention interventions is to raise awareness about the risks of drinking during pregnancy. The effectiveness of these interventions is however contested and their impact on behaviour is not clear (Őosterberg, 2004). However perception of risk does influence health behaviour (Brewer et al., 2007) and universal prevention interventions

[1] I will be following convention and using the American spelling of Foetal in this study

have the potential to change societal norms and educate the public, indirectly leading to behaviour change (Rosenthal et al., 2005). Further research is needed to improve the impact of universal prevention interventions aimed at preventing drinking during pregnancy.

To improve universal prevention interventions it is important to establish what the current perception of the risk of drinking during pregnancy is. This knowledge can serve to guide future interventions by identifying obstacles to accurate risk perception, which can then be addressed. This leads to the research question: What is the perception of the risk of alcohol use during pregnancy among women in a high risk community in South Africa?

This chapter has given a broad background for this study. Chapter two will consist of a literature review that will explore the adverse effect of alcohol on birth outcomes as well as elaborating on the issue of FASD in South Africa. It will also examine the importance of, and obstacles to, risk perception and provide a rationale for the present study.

Chapter Three will cover the method used in this study, including the population selection, sampling, questionnaire construction and proposed analysis. Chapter Four will consist of the results and data analysis. Chapter Five will discuss the results, including strengths and limitations, and make suggestions for further research. Finally, Chapter Six will be the conclusion of the thesis.

CHAPTER 2

Literature Review

2.1 Alcohol use and the global health burden

The harmful use of alcohol has been recognised as one of the leading health risks worldwide, implicated in more than 2.5 million deaths per year (WHO, 2011). It is one of five risk factors (including childhood underweight, unsafe water and sanitation, unsafe sex and high blood pressure) responsible for one quarter of deaths globally (WHO, 2009). Harmful use of alcohol by itself accounts for approximately 4% of deaths worldwide each year, which is more than HIV/AIDS or tuberculosis (WHO, 2011). It is estimated that among drinkers 1.2 deaths per 1000 are attributable to alcohol (Anthony, 2009) with the leading causes of alcohol-attributable deaths being unintentional injuries, cancer, liver cirrhosis, cardiovascular diseases and diabetes mellitus, intentional injuries and neuropsychiatric disorders (WHO, 2011).

Measured in DALYs, harmful alcohol use accounts for approximately 4.5% of the global burden of injury and disease each year, and is the third leading risk factor for injury and disease (WHO, 2009, 2011). The major causes of alcohol-attributable DALYs are neuropsychiatric disorders, unintentional injuries, intentional injuries, liver cirrhosis, cardiovascular diseases, diabetes mellitus and cancer (WHO, 2011). Alcohol use is also listed as a necessary cause for over 30 diseases in the International Classification of Diseases (ICD) manual, and it is listed as sufficient cause for more than 200 diseases (Rehm et al., 2010).

2.2 Distribution of the burden of injury and disease attributable to alcohol

The global average consumption of alcohol per capita is approximately 6.13 litres of pure alcohol per person over the age of 15. The levels of consumption vary from country to country with high-income countries generally having the highest per capita consumption (WHO, 2011). Countries with high consumption levels do not necessarily have a higher than average burden of injury and disease attributable to alcohol. Low and middle income countries (LMIC) however tend to have a disproportionately high levels of injury and disease attributable to alcohol (WHO, 2010). Rather than per capita consumption, the burden of disease attributable to alcohol is linked to the volume and quality of alcohol consumed, as well as drinking patterns (Rehm et al., 2010).

Not all alcohol consumed comes from government controlled sources. As much as 30% of estimated global alcohol consumption is accounted for by consumption of unrecorded

alcohol[2], which can be homemade alcohol, smuggled alcohol or alcohol not intended for consumption. The quality of this kind of alcohol cannot be controlled and can lead to an increase in the burden of disease through, for example, methanol or lead poisoning (Rehm et al., 2010; WHO, 2011). In LMIC unrecorded alcohol tends to account for a larger portion of total per capita consumption (WHO, 2011).

How people drink, as opposed to how much they drink, is strongly associated with the burden of disease and injury. The WHO patterns of drinking score (PDS) is based on a range of drinking attributes and gives an indication of prevailing drinking behaviours in a country on a scale of 1 (lowest risk) to 5 (highest risk). Countries may have a high rate of per capita alcohol consumption, but the prevailing patterns of drinking can be low risk with few alcohol attributable deaths and DALYs (WHO, 2011).

Heavy episodic drinking, drinking 60 grams or more of pure alcohol on one occasion, is a pattern of drinking that predicts acute consequences of alcohol use. It amounts to approximately five standard drinks per occasion (as defined by most countries) and has been found to increase the risk of disease and death more than the risk caused by alcohol consumption by itself. The presence of heavy episodic drinking can also negate the positive effects of low to moderate alcohol consumption (Rehm et al., 2010). There is no consistent relation between country income and the presence of heavy episodic drinking and it is also not necessarily linked to high per capita alcohol consumption (WHO, 2011).

2.3 Alcohol use in South Africa

The per capita annual alcohol consumption in South Africa has remained relatively stable around 9.5 litres, but with 65.2% of the population abstaining, the per capita consumption of alcohol for drinkers only is roughly 34.91 litres (WHO, 2011). In 2000 alcohol use accounted for 7.1% of all deaths and 7.0% of all DALYs in South Africa (Marais et al., 2012).

Globally, the harmful use of alcohol has less of an impact on women, with only 1.1% of deaths and 1.4% of the burden of disease among women being attributable to alcohol, compared to 6.2% of deaths and 7.4% of the burden of disease among men. Women are also less likely to engage in heavy episodic drinking by a ratio of four to one (WHO, 2011). Amongst drinkers in South Africa however, 41.2% of female drinkers engage in heavy episodic drinking, compared to 48.1% of men (WHO, 2011). This means that women in South Africa are more at risk of alcohol-attributable harm than the global average. Between 13% and 43% of women also report drinking while pregnant (Marais et al., 2012), which

[2] The World Health Organisation refers to alcohol that is not subject to governmental control and taxation as “unrecorded alcohol” (WHO, 2011).

means that a large segment of the population is at risk of having Alcohol Exposed Pregnancies (AEPs). This is reflected in the high prevalence of Fetal Alcohol Spectrum Disorders (FASDs) in South Africa (Chersich et al., 2012; May et al., 2007; Urban et al., 2008).

2.4 Alcohol exposed pregnancies

Due to the teratogenic properties of alcohol, drinking during pregnancy is a contributing factor to numerous adverse birth outcomes. AEPs have been linked to increased mortality due to Sudden Infant Death Syndrome (SIDS), stillbirths and spontaneous abortions (Grinfeld, 2009; Odendaal, Steyn, Elliott, & Burd, 2009). AEPs are implicated in birth complications like anal atresia, preterm labour and placental abruption (Odendaal et al., 2009). The effects of drinking during pregnancy can have a lifelong impact as it is associated with increased risk of being born with orofacial clefts, renal abnormalities and cardiac problems (Odendaal et al., 2009; Ornoy & Ergaz, 2010). AEPs are further implicated in psychological disorders, including ADHD, somatoform disorders, substance dependence and other personality disorders later in life (Ornoy & Ergaz, 2010). Drinking during pregnancy is also the causal factor of FASD (Manning & Hoyme, 2007).

2.5 Alcohol use among women in South Africa and adverse birth outcomes

There are three criteria that need to be met to identify a woman as at risk of an AEP. The woman must (a) be fertile and of childbearing age, (b) drink alcohol, and (c) not use contraception or use contraception ineffectively (Morojele et al., 2010). An additional risk factor that must be considered is late recognition of pregnancy. Even with the intention of not drinking during pregnancy it is possible that the foetus will be exposed to alcohol because the mother is unaware that she is pregnant (O'Connor et al., 2011).

2.5.1 Alcohol consumption among women in South Africa

Nationwide it is estimated that 15.4% of women drink alcohol (WHO, 2011), but this figure varies with population group (Parry et al., 2005). The areas where the most women report current drinking are the Western Cape (24.2%), Northern Cape (23.1%) and Free State (24,5%; Parry et al., 2005). Among the female drinking population the prevalence of binge drinking is similar to men with 41.2 % of women reporting heavy episodic drinking (WHO, 2011). The majority of heavy episodic drinking (also referred to as binge drinking) happens over weekends (95%) for both men and women (Parry et al., 2005), with individuals in rural communities being more likely to binge drink (Morojele et al., 2010; Peltzer & Ramlagan, 2009).

What is of particular concern is that women continue to drink even after pregnancy recognition. In a sample of 635 women in the Western Cape 42.8% admitted to drinking during pregnancy (Croxford & Viljoen, 1999). In a survey of 893 women visiting drinking establishments in the Western Cape 13% were pregnant and only 10% of the pregnant women reported abstaining (Eaton et al., 2012).

Recently a study in the Western Cape investigated why women continued drinking after pregnancy recognition (Watt et al., 2014). The reasons given included alcohol addiction, having a lack of attachment to the pregnancy (or the pregnancy being unwanted), and drinking to cope with stress and negative emotions. In some areas women also saw drinking during pregnancy as the norm. What the study however did not examine was the women's awareness of the risks of drinking during pregnancy (Watt et al., 2014).

2.5.2 Contraceptive use among women in South Africa

Regardless of the amount of alcohol a woman drinks, effective contraceptive use significantly lowers the possibility of an AEP (Morojele et al., 2010). Among women aged between 15 and 49 in South Africa, 60% use modern contraceptives, which is substantially more than the average 20% in sub-Saharan Africa (United Nations Fund for Population Activities [UNFPA], 2013). Even though birth control methods, including emergency contraceptives, are provided free of charge by the Department of Health, 20% of pregnancies are unwanted and a further 36% unplanned (Morroni, Tibazarwa, & Myer, 2006), although in some cases this can increase to 75% (Myer, Mlobeli, Cooper, Smit, & Morroni, 2007). These unplanned pregnancies may be due to incorrect or inconsistent use of contraceptives or the result of sexual assault (Harries, Orner, Gabriel, & Mitchell, 2007; Morroni et al., 2006; Myer et al., 2007).

2.5.3 Late recognition of pregnancy

A complicating factor in the cessation of drinking during pregnancy is that pregnancy recognition does not happen immediately after conception (Abrahams, Jewkes, & Mvo, 2001; Myer & Harrison, 2003). Women do not necessarily relate symptoms like tender breasts, food cravings, nausea or even a missed menstrual period to pregnancy (Abrahams et al., 2001; Harries et al., 2007; Myer & Harrison, 2003; O'Connor et al., 2011). By the time pregnancy is recognised a woman may be well into the first trimester and serious damage to the foetus may already have occurred (O'Connor et al., 2011).

2.6 Fetal Alcohol Spectrum Disorder

Although drinking during pregnancy is a contributing cause to a number of adverse birth outcomes (Grinfeld, 2009; Odendaal et al., 2009), this study will focus on FASD. Alcohol is the causal factor in FASD (Manning & Hoyme, 2007), and as any woman can theoretically have a child with FASD it can be argued that all women in a community are at equal risk of having a child with a FASD, should they drink during pregnancy. Unlike most other adverse birth outcomes associated with AEPs, FASD is entirely preventable and it can be prevented through behaviour change (Hankin, 2002).

2.6.1 FASD: Features and diagnosis

FASD is an umbrella term for a range of alcohol-attributable adverse birth outcomes manifesting as distinctive patterns of physical and neurodevelopmental disabilities. To diagnose FASD individuals are examined according to a set of criteria in three categories. These categories are growth retardation, characteristic facial abnormalities and central nervous system (CNS) anomalies or dysfunction (Manning & Hoyme, 2007; O'Leary, 2004).

Growth retardation is defined as low pre- and\or postnatal weight and length (equal to, or lower than the 10th percentile of published normative values for the child's age[3]). The characteristic facial abnormalities are short palpebral fissures[4], a flattened or smooth philtrum[5] and an upper lip with a thin vermilion border. CNS abnormalities representing structural or functional damage include microcephaly, motor deficits, tremors, neurosensory hearing loss, visual anomalies, abnormal muscle tone and structural brain abnormalities. There are also additional minor malformations that can strengthen the diagnosis even though they are not sufficient for a diagnosis on their own. These include palmar crease abnormalities, epicanthal folds and "railroad track" ears (Manning & Hoyme, 2007; Wattendorf & Muenke, 2005). See Appendix A for examples of some of the dysmorphological features.

There are other malformation syndromes that can have similar characteristics to FASD. De Lange syndrome also features a thin vermilion border of upper lip, depressed nasal bridge, and microcephaly; while Noonan syndrome features epicanthal folds and wide spaced eyes (Manning & Hoyme, 2007). If there is evidence of abnormality in all three categories however (facial abnormalities, growth retardation and CNS abnormalities\dysfunction) most other birth defects and syndromes are eliminated from a diagnosis (O'Leary, 2004). Due to the

[3] Measurements are compared to the Centers for Disease Control and Prevention's growth charts for example.
[4] The distance between the inner and outer corners of the eye (Astley & Clarren, 1996)
[5] The vertical groove that extends from the nose to the upper lip (Astley & Clarren, 1996)

complexity of the diagnosis, it is important to have a multidisciplinary team evaluate suspected FASD cases. The team should ideally include a dysmorphologist (or a physician experienced in evaluating developmental disabilities), a psychologist, an educational specialist and trained interviewer (Manning & Hoyme, 2007; Marais et al., 2012).

There is some dispute over the preferred terminology with regards to less severe forms of FASD (Banakar, Kudlur, & George, 2009). In this study I will be referring to the diagnostic criteria and terminology as used by the updated version of the Institute of Medicine (IOM) categories. According to these criteria there are six categories making up FASD which lie on a continuum based on the severity of the disabilities and on clinically detectable features (Hoyme et al., 2005). These categories are Fetal Alcohol Syndrome (FAS) with confirmed maternal alcohol exposure, FAS without confirmed maternal alcohol exposure, Partial Fetal Alcohol Syndrome (PFAS) with confirmed maternal alcohol exposure, PFAS without confirmed maternal alcohol exposure, Alcohol Related Neurological Disorder (ARND) and Alcohol Related Birth Defects (ARBD; Hoyme et al., 2005). ARND and ARBD cannot be diagnosed without confirmed maternal alcohol exposure. See Manning and Hoyme (2007) for details on IOM criteria.

2.6.2 Determining the prevalence of FASD

Determining the prevalence of FASD is complicated by the lack of standard diagnostic criteria and the use of different methods of determining prevalence (Marais et al., 2012; May et al., 2009). Although the diagnostic features for FASD are well established, there is some controversy about which assessment techniques and statistical measurements to use (Astley, 2006; Hoyme & May, 2007; May et al., 2009). There are three main methods used to determine FASD prevalence, passive surveillance systems, clinic based studies, and active case ascertainment methods[6] (May & Gossage, 2001).

2.6.2.1 Passive surveillance methods

Passive surveillance methods use existing records in a specific catchment area to estimate the prevalence of FASD. The records used are birth certificates, medical records and birth defect registries (May et al., 2009). Because of the overlap with other malformation syndromes, and with CNS and behavioural abnormalities not being readily apparent at birth, it is difficult to reliably diagnose FASD (especially ARND) from birth up to 3 years of age. The records used in the passive surveillance method are normally created in this period where signs of FASD may easily be missed (Chudley, 2008; May & Gossage, 2001; May et

[6] In keeping with the latest literature I will be using “case ascertainment” rather than “case detection” (May et al., 2009, 2013; Petković & Barisić, 2010)

al., 2009). It is usually only by the age of 6 to 7 years that all the features of FASD are evident and amenable to testing (May et al., 2009).

The records are also not usually completed by specialists, but rather by physicians and nurses. Due to the complexity of the diagnosis physicians and nurses may not easily recognise the signs of FASD (May et al., 2009). Medical professionals also do not treat FASD with the same concern worldwide and, especially in Europe, they are less likely to give a diagnosis of FASD (May et al., 2009; Stratton et al., 1996). Some physicians may be hesitant to diagnose FASD for fear of stigmatising the mother as well (Stratton et al., 1996). Passive surveillance systems therefore lack rigour and combined with the difficulty of diagnosing FASD at an early age, this means that these methods underestimate the prevalence of FASD, especially the less severe forms ARBD and ARND (May & Gossage, 2001; May et al., 2009).

2.6.2.2 Clinic based studies

The prospective nature of clinic based studies lends itself to more rigorous design and can eliminate some of the problems encountered with passive surveillance systems (May & Gossage, 2001; May et al., 2009). Clinic based studies are usually conducted in antenatal clinics but can also be completed at primary health care facilities. Data are gathered from prospective mothers on diet, health behaviours, and alcohol use. At birth, and generally for some months postpartum, babies can be examined to determine if they have a FASD (May et al., 2009).

Because data on alcohol use are gathered it makes diagnoses where confirmed maternal alcohol use is required possible. Passive surveillance methods on the other hand, usually do not have access to data on maternal alcohol use (Manning & Hoyme, 2007). The studies are also conducted in a context where health services can be offered during pregnancy to women identified as at high risk of having a child with FASD (May & Gossage, 2001). Unfortunately the diagnosis of FASD remains complicated as children are seen at a time (birth to 3 years of age), where only the severest forms of FASD are diagnosable (May et al., 2009). In addition, the participants in these studies are often self-selected, with the result that women at the highest risk of AEPs might be underrepresented as they may not attend antenatal clinics regularly (May et al., 2009). Finally, the studies are usually conducted in public-funded or state clinics\hospitals, so middle and upper class populations will be underrepresented (May et al., 2009).

Clinic based studies could give accurate estimates for FAS prevalence in low socioeconomic status (SES) communities that depend on public health facilities, but it might overestimate

population wide prevalence with the lack of data for middle and upper class populations (May & Gossage, 2001; May et al., 2009). The full spectrum of FASD will likely be underestimated due to the difficulty diagnosing PFAS, ARBD and ARND. It is estimated that for every FAS case in a population there will be 3 to 4 cases of ARND which is the most difficult to diagnose and will most likely be unreported (Chudley, 2008).

2.6.2.3 Active case ascertainment methods

Active case ascertainment relies on an aggressive search for FASD cases in a community (May et al., 2009). Entire populations are screened for characteristics associated with FASD and those children meeting the criteria are then examined, ideally by a team of specialists, to confirm whether they can be diagnosed with a FASD (May et al., 2009; Stratton et al., 1996). There is some selection bias in these studies as not all parties who are approached will agree to participate, but as entire populations are studied results are more generalisable (Clarren, Randels, Sanderson, & Fineman, 2001; May & Gossage, 2001; May et al., 2009). Active case ascertainment is likely to uncover more cases along the full spectrum of FASD. As a multidisciplinary team is involved in the diagnosis, and because diagnosis is usually done at a later age where features of FASD are more fully developed and therefore more amenable to measurement and testing, the chances that less severe forms of FASD will be picked up are greatly improved and the validity of the diagnoses increased (May et al., 2009; Stratton et al., 1996).

Conducting these studies is however time consuming, labour intensive and requires the cooperation of various parties not involved in the research such as community leaders and political and health officials. This makes conducting these studies more logistically, administratively and financially complicated than passive and clinic based studies, (May & Gossage, 2001; May et al., 2009). These studies may also overestimate the prevalence of FASD as they are generally conducted among high risk communities, but they do uncover more cases of FASD even among populations previously screened (Clarren et al., 2001; May et al., 2009).

In-school active case ascertainment minimises the complications associated with active case ascertainment (May et al., 2009). In these studies all children in a particular grade are screened using standardised diagnostic criteria for dysmorphology (Clarren et al., 2001; May et al., 2000, 2007; Petković & Barisić, 2010; Viljoen et al., 2005). The testing is conducted around 6 to 7 years of age (May et al., 2009), and those children meeting the criteria are given a full dysmorphology exam and a psychological\developmental assessment before a diagnosis is made. This approach increases the sensitivity of the diagnosis (Viljoen et al.,

2005). In the majority of cases, in-school studies give higher FAS and FASD prevalence estimates than any other studies (May et al., 2009)

In-school populations are generally representative of entire populations (May et al., 2009), although not all schools necessarily agree to take part (Clarren et al., 2001; May et al., 2000). As the logistical complications of finding and screening children are reduced more children are screened and more cases are identified (May et al., 2009). However some children might be overlooked if they do not attend school during the screening process (May et al., 2000). Working in collaboration with the schools also lends credibility to the process, and the psychological\developmental testing is of benefit to parents, schools and the affected children (May et al., 2009). These studies are however mostly conducted among high risk communities (May et al., 2000, 2007; Urban et al., 2008; Viljoen et al., 2005), so will overestimate the overall prevalence of FASD (May et al., 2009).

2.6.3 Estimating the prevalence of FASD

Diagnosing FASD is important in itself as it enables affected individuals to access appropriate medical or psychological aid (Stratton et al., 1996), and can lead to the development of effective strategies to assist affected children (May et al., 2009). From a research perspective identifying cases of FASD helps gain an understanding of its etiology, and helps refine the diagnostic criteria (May et al., 2000, 2009; Stratton et al., 1996). Estimating the prevalence of FASD is crucial for determining the impact of FASD on society, guiding resource allocation (Stratton et al., 1996), evaluation of interventions using before and after figures (Chersich et al., 2012), and for determining risk factors for FASD (May et al., 2009).

2.6.3.1 Global prevalence of FASD

Estimates of global prevalence vary due to the above methodological differences, but also due to the fact that low SES communities have significantly higher prevalence rates of FASD (Abel, 1995). In Western Australia a prevalence of 0.02/1000 births for non-Aboriginal children and rates of 2.76/1000 for Aboriginal children were found (Bower, Silva, Henderson, Ryan, & Rudy, 2000). In the Northern Territories in Australia rates of between 1.87-4.7/1000 births were found for Aboriginal children and 0.68-1.7/1000 births for the entire population (Harris & Bucens, 2003). The nationwide prevalence of FAS in the USA has been estimated between 0.5 and 2 per 1000 births, and the prevalence of FASD could be as high as 10 per 1000 births. Prevalence rates in the USA are however also higher in low SES populations (May & Gossage, 2001)

In-school and other active case ascertainment studies are rare in Europe. Studies have been conducted in Italy (May et al., 2006), Croatia (Petković & Barisić, 2010), in orphanages in Russia (Miller et al., 2006) and Sweden (May et al., 2009). There is to my knowledge no data available on the FASD prevalence in countries such as Ireland and Austria that have a high prevalence of risky drinking patterns (WHO, 2011). Neither is there data for countries in central Europe, Poland and the Ukraine for example, where the per-capita alcohol consumption is higher than countries for which we have prevalence data such as South Africa and the USA (May et al., 2009; WHO, 2011). The result is significant gaps in our knowledge of FASD prevalence, making an accurate estimate of global FASD prevalence impossible. Based on the limited data that are available however, global FASD prevalence has been estimated to be 15.6/1000 (May et al., 2009).

2.6.3.2 Prevalence of FASD in South Africa

There have been three in-school studies amongst first grade pupils in the Western Cape (May et al., 2000; May et al., 2007; Viljoen et al., 2005), and one among children in Gauteng (Viljoen, Craig, Hymbaugh, Boyle, & Blount, 2003). More recently an in-school study amongst first grade pupils, as well as a longitudinal active case ascertainment study among infants in the Northern Cape (Chersich et al., 2012; Urban et al., 2008) has been conducted. The FAS prevalence rates in the Western Cape of 40.5-46.4/1000 births (May et al., 2000), 65.2-74.2/1000 births (Viljoen et al., 2005) and 68-89.2/1000 births (May et al., 2007)(May et al., 2009). Subsequently prevalence of FAS\PFAS of 119.4/1000 was found in De Aar and 74.7/1000 in Upington in the Northern Cape surpassing the prevalence in the Western Cape (Urban et al., 2008).

A recent study assessing the efficacy of universal prevention efforts found FASD prevalence of 89/1000 births pre-intervention and 49/1000 births post-intervention among infants in De Aar and Upington (Chersich et al., 2012). These studies have focused on high-risk and high-prevalence areas, so it is likely that the nationwide rate of FASD might be overestimated. The study in Gauteng was conducted on a population representative of the Gauteng province and not on a high risk population. Nevertheless, the rates of 19-26.5/1000 births are high compared to the global estimate of 15.6/1000 births (May et al., 2009; Viljoen et al., 2003). The studies in the Northern Cape and Gauteng also showed that the problem of FASD is not localised to wine growing areas or ethnic group (Marais et al., 2012). Until a screening system for FASD births is put in place countrywide, the actual prevalence of FASD will remain uncertain (Marais et al., 2012), but the FASD prevalence in South African communities is still the highest recorded in the world.

2.7 Spectrum of damage associated with FASD

The teratogenic effects of alcohol interfere with foetal development during all three trimesters. DNA synthesis, cell migration and development as well as cell division are affected which causes the various primary and secondary disabilities associated with FASD (Clarke & Gibbard, 2003). The impact of alcohol on the foetus is influenced by various factors, including frequency and level of exposure to alcohol, as well as at what time during gestation the exposure occurred, therefore the pattern of disabilities can vary greatly (Clarke & Gibbard, 2003; Mukherjee, Hollins, & Turk, 2006).

2.7.1 Birth defects and dysmorphology

In addition to the characteristic facial abnormalities associated with FASD, namely short palpebral fissures, thin vermilion border of the upper lip and smooth philtrum, prenatal alcohol exposure is also associated with other birth defects (Hoyme et al., 2005). Roughly one third of children affected by alcohol in utero will suffer from cardiac abnormalities (Ornoy & Ergaz, 2010) especially septal defects (Clarke & Gibbard, 2003). Other organ systems affected include the renal, ocular and auditory systems. Alcohol exposure also affects skeletal development leading to defects like clinodactyly and hypoplastic nails, the presence of which can be used to strengthen a diagnosis of FASD (Clarke & Gibbard, 2003). Not all of these features persist into adulthood (Stratton et al., 1996).

2.7.2 Growth deficits

One of the earliest indicators of FASD is low birth weight for gestational age (Hoyme et al., 2005). This growth deficit persists as the child grows older and manifests as fluctuations in the expected growth curve (Clarke & Gibbard, 2003). Growth deficits, like birth defects, do not necessarily persist into adulthood (Stratton et al., 1996).

2.7.3 Neurocognitive deficits

Unlike growth deficits and some of the birth defects associated with FASD, the neurocognitive deficits associated with prenatal alcohol exposure do not improve over time. The extent of these deficits is also not predicted by the presence and severity of the characteristic facial abnormalities (Mukherjee et al., 2006). Neurocognitive deficits manifest along a continuum of severity from structural CNS abnormalities to patterns of cognitive or behavioural abnormalities. These cognitive and behavioural abnormalities cannot be explained by environment or familial background and are not consistent with developmental level (Clarke & Gibbard, 2003). These deficits are thought to underlie the various secondary

disabilities associated with FASD (Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998).

CNS abnormalities include decreased cranial size at birth, microcephaly, impaired fine motor skills as well as visual and hearing problems (Clarke & Gibbard, 2003; Stratton et al., 1996). The primary cognitive and behavioural deficits associated with FASD are in the areas of adaptive functioning, language and learning, attention, reasoning and memory (Clarke & Gibbard, 2003). These deficits mean that people with FASD often struggle to learn from past experience, have trouble understanding complex language and frequently have difficulties with attention (Clarke & Gibbard, 2003; Olson et al., 1998). They also have difficulty in the realm of socioemotional functioning partly due to a lack of consideration of the consequences of actions, lack of response to social cues and poor interpersonal relationships in general. The specific pattern of neurocognitive deficits can vary however, presumably because of differences in the timing of the alcohol exposure (Jacobson & Jacobson, 2002).

2.7.4 Secondary disabilities associated with FASD

FASD is associated with a number of adverse life outcomes as a result of the interaction between the physical, neurological and behavioural deficits and the adverse environmental conditions frequently associated with the high prevalence of FASD (Abel, 1995; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; May et al., 2008). Individuals with FASD often exhibit inappropriate sexual behaviour, have disrupted school experiences (due to expulsion, suspension or dropping out) and problems with employment. These individuals are also frequently confined for inpatient treatment of drug abuse or mental health problems, and often have trouble with the law leading to incarceration (Clark et al., 2004; Clarke & Gibbard, 2003; Streissguth et al., 2004). People with FASD are over-represented in the criminal justice system (Mitten, 2004).

Possibly the most serious sequelae of FASD are mental health problems. They occur more frequently in patients with FASD than in comparable populations of intellectually disabled people. Frequently occurring mental health problems are ADHD, depression, suicidal ideation and panic disorder (Clark et al., 2004; Clarke & Gibbard, 2003). Interventions could possibly reduce the occurrence of other secondary disabilities, especially when diagnosis happens before six years of age (Clark et al., 2004; Clarke & Gibbard, 2003), but mental health disorders do not seem amenable to change through these interventions (Clarke & Gibbard, 2003).

2.7.5 Societal impact of FASD

FASD and its sequelae have an economic impact on families, caregivers and society, not only because of medical costs, but also costs associated with education (special schooling), social services (foster care), the cost to law enforcement and welfare payments. This list is by no means exhaustive and currently there are no reliable estimates of the societal costs of FASD. The annual cost of FASD has been estimated as high as 5.3 billion Canadian dollars in 2007 for Canada and 6.5 billion US dollars in 2010 for the United States (Popova, Stade, Bekmuradov, Lange, & Rehm, 2011).

The only study on the cost of FASD in South Africa has focused exclusively on medical costs, based on a small sample of children with FAS\PFAS in the Western Cape and it was estimated that 5% of the Western Cape's health budget for 2010/11 was used to care for children with FAS and PFAS. This figure excludes the various surgical procedures that are frequently required to correct birth defects and dysmorphology, and it also excludes institutionalisation. Furthermore children in children's homes were excluded from the sample and the costs are only calculated for children up to 12 years of age (Credé, Sinanovic, Adnams, & London, 2011). There are no estimates for the lifetime costs of FASD in South Africa which has been estimated as high as 2 million USD per FASD birth in the US (Popova et al., 2011).

2.7.6 FASD risk factors

FASD can only be caused by drinking during pregnancy, but although this is a necessary factor it is not sufficient. A significant proportion of heavy-drinkers (two or more standard drinks a day, more than five per week or more than five per occasion) have no incidences of FASD births (Abel, 1995). FASD is rather the result of a complex interplay between biological, psychological and social factors. Risk factors can vary between different populations (May et al., 2004; Morojele et al., 2010) but I will focus on risk factors identified in South African populations with high prevalence rates of FASD (Chersich et al., 2012; May et al., 2000, 2004, 2005, 2007; Urban et al., 2008; Viljoen et al., 2005).

Higher risk of FASD births is associated with advanced maternal age, low-SES and unemployment. Women at risk tend to be single or co-habitating with partners and\or close family members who drink heavily (Chersich et al., 2012; May et al., 2005; Viljoen et al., 2005). Mothers of children with FASD are more likely to be from rural communities, work on farms (if employed) and are more likely to be smokers than women in control groups (May et al., 2000; Urban et al., 2008; Viljoen et al., 2005). Women at risk tend to report poor lifelong and current nutrition as well as frequent hunger during pregnancy (May et al., 2005).

Women who give birth to children with FASD tend to have higher gravidity and parity (Chersich et al., 2012; May et al., 2005; Urban et al., 2008), more living children and the child with FASD tends to be higher in birth order than controls (May et al., 2005). They also tend to report fewer social resources, more stressful life events (May et al., 2005) and frequently suffer from depression (Chersich et al., 2012). Another risk factor is low body weight (BMI) and head circumference, possibly linked to chronic under-nutrition and generations of alcohol abuse (May et al., 2005; Urban et al., 2008). Women at risk of FASD births usually have a longer drinking career and consume more alcohol than controls (May et al., 2000, 2005, 2007; Viljoen et al., 2005).

Alcohol consumption is the most important risk factor, but there is clear evidence of a dose-response effect with peak blood alcohol concentration playing a major role (Abel & Hannigan, 1995; May et al., 2005). The riskiest pattern of drinking is therefore episodic binge drinking during pregnancy (May et al., 2004). In rural populations in the Western Cape, the bulk of alcohol consumption (about 90%) happens over weekends in a binge drinking pattern (May et al., 2005) and the pattern of binge drinking is similar in the Northern Cape (Peltzer & Ramlagan, 2009). There is no consensus on whether there is a 'safe amount' of drinking during pregnancy, therefore complete abstinence is still considered the only safe option (Day, 2012).

2.8 FASD prevention

Prevention of FASD is a social and public health issue that requires a multifaceted approach to intervention (Marais et al., 2012; Rosenthal et al., 2005). FASD is disproportionately prevalent among low-SES communities (Abel, 1995), therefore prevention efforts should include a social improvement component. The targets of interventions should not only be women of childbearing age but communities as a whole (Rosenthal et al., 2005). It is important that interventions are evidence based and continuously evaluated and refined to achieve the maximum impact (Barry et al., 2009).

At present interventions can be organised into three overlapping categories namely, universal, selective and indicated. The different types of intervention lie on a continuum and are used depending on the risk profile of the intervention's target population. Universal interventions are aimed at entire populations regardless of individual risk status. Selective interventions are aimed at women at greater risk of AEPs than the general population and indicated interventions aimed at populations with the highest risk of AEPs (Barry et al., 2009; Hankin, 2002; Stratton et al., 1996)

2.8.1 Selective prevention interventions

Selective prevention interventions are targeted at groups or individuals who are at higher risk of having FASD births than the average population, which means all women of reproductive age who use alcohol (Hankin, 2002; Stratton et al., 1996). These interventions have shown success through the routine screening for alcohol misuse or abuse of women at risk in primary health care settings, followed by brief interventions (Anderson, Chisholm, & Fuhr, 2009; Marais et al., 2011).

2.8.2 Indicated prevention interventions

Women with the greatest risk of FASD births, namely those who are alcohol dependent or who have already had a child with a FASD, are harder to assist and the necessary treatment is complex (Barry et al., 2009; Hankin, 2002). Brief interventions in isolation do not seem to be effective in this population and a more holistic approach, including treatment of alcoholism or encouraging prevention of pregnancy, is required (Anderson et al., 2009; Barry et al., 2009; Hankin, McCaul, & Heussner, 2000).

2.8.3 Universal prevention interventions

Universal prevention interventions aim to raise awareness about the risks associated with drinking during pregnancy at a population level (Barry et al., 2009; Hankin, 2002). Using mass media, education campaigns and beverage warning labels has been associated with an increase in awareness about the consequences of drinking during pregnancy (Barry et al., 2009), but that this has a significant impact on drinking during pregnancy is unclear, and further studies are required (Anderson et al., 2009; Ayers & Myers, 2012; Barry et al., 2009; Őosterberg, 2004). Where a change in drinking behaviour has been found, for example due to warning labels, the effects disappeared over time and drinking returned to pre-intervention levels (Hankin et al., 1996; Hankin, Sloan, & Sokol, 1998). A multifaceted universal prevention intervention in South Africa has however shown significant results, with a 30% reduction in FASD prevalence, but a follow up study is needed to confirm the lasting impact (Chersich et al., 2012).

Regardless of the lack of data validating the use of universal prevention interventions to reduce rates of drinking during pregnancy, population wide awareness of risk is an important part of combating FASD and high-risk drinking in general (Barry et al., 2009; Rosenthal et al., 2005; WHO, 2010). It has been argued that community wide awareness can have a trickle-down effect and, may change the behaviour of higher risk individuals without selective

interventions (Bateman, 2010; Stratton et al., 1996). The underlying assumption of these interventions is that risk perception influences health behaviours.

2.9 Risk perception

Universal prevention interventions aimed at reducing AEPs are based on the assumption that because very few mothers would knowingly harm their babies, making them aware of the risk of drinking during pregnancy will motivate them to stop drinking if pregnant, and when attempting to conceive (Bateman, 2010). These efforts also assume that health decisions are taken based on a expectancy-value model, that people act based on a combination of judgement of the probability of positive\negative consequences and the expected utility of the action they perform (Van der Pligt, 1994). Ensuring mothers, who drink during pregnancy, have an accurate perception of their risk status is therefore an important part of universal interventions.

There are both cognitive and affective components to risk perception, and they seem to be separate constructs (Zajac, Klein, & McCaul, 2006). The way these components interact is unclear. Currently, risk perception is predominantly conceptualised as a cognitive\rational process (Janssen, Van Osch, Lechner, Candel, & De Vries, 2012), and rational risk perception has been shown to impact risk behaviour (Brewer et al., 2007). In this study I will be focusing on the cognitive component of risk perception as the consequences of drinking during pregnancy are not immediate and less likely to elicit an affective response (Leppin & Aro, 2009)

2.9.1 Perceived risk and health behaviour

Perception of risk plays a role in shaping health behaviour, but what this role is and how important it is still unclear (Brewer et al., 2007; Brewer, Weinstein, Cuite, & Herrington, 2004; Van der Pligt, 1994; Weinstein et al., 2007). There is however evidence of a significant impact of risk perception on health behaviour (Brewer et al., 2007; Weinstein et al., 2007). It is likely that even if perception of risk is not sufficient for behaviour change it is necessary (Van der Pligt, 1996), and that perception of risk may be amenable to change (Ayers & Myers, 2012).

2.9.2 Obstacles to accurate risk perception

The perception of risk is not based on an appraisal of relevant information alone. Estimates of risk are based on the interaction of numerous factors, including, the context of the risk information, personal characteristics and message framing (Van der Pligt, 1996; Yu, Ahern, Connolly-Ahern, & Shen, 2010). How individuals estimate levels of risk is still unclear. It is

thought that this estimate is based on comparison of the self to an "other" (Thornton, Gibbons, & Gerrard, 2002). For universal prevention interventions to be effective, the information provided must encourage an accurate perception of personal risk.

A number of factors have an impact on the accuracy of risk perception, including a number of biases and heuristics like regressive bias (small probabilities of risk over estimated and large probabilities underestimated), egocentric bias, the availability heuristic, defensive denial and stereotyped beliefs (Hilbert, 2012; Van der Pligt, 1994, 1996). These inaccuracies have variously been attributed to our biologically limited cognitive capacity (we cannot consider a sufficiently large amount of data to make accurate decisions), social influences, biased perception of control as well as emotional motivations, like avoidance of distress and the need to maintain self-esteem (Hilbert, 2012; Hoorens, 1994; Van der Pligt, 1994). There are also personal characteristics that impact on perceived risk, like perceived personal control over the risk behaviour (Klein & Helweg-Larsen, 2002; Roberts & Kennedy, 2006; Sjöberg, 2000; Van der Pligt, 1994), attitude towards the consequences of the risk behaviour (Roberts & Kennedy, 2006; Sjöberg, 2000), perception of the severity of negative consequences (Taylor & Shepperd, 1998) and previous experience, or lack thereof, of negative consequences of the risk behaviour (Hoorens, 1994; Van der Pligt, 1994; Van der Velde & Hooykaas, 1992).

2.9.2.1 Measurement of risk perception

The way that the perception of risk is measured can also influence estimates, especially as these estimates do not necessarily remain constant (Brewer et al., 2004; Taylor & Shepperd, 1998). Important factors are how the risk is described (Yu et al., 2010), the context of the risk message (Van der Pligt, 1996), and how the questions regarding the risk estimate are asked (Brewer et al., 2004). Risk perception questions should refer to specific risks and contain information about risk target, time frame and must be stated in terms of performance or non-performance of the behaviour of interest (Brewer et al., 2007, 2004; Sjöberg, 2000).

Questions about an unspecified risk ("I will become ill") are less likely to predict behaviour than questions about a specific risk ("I will get the flu") as some participants may, for example, regard getting a cold as becoming ill while others do not. The same can be said about a time frame. The question "What are the chances of you getting the flu?" may elicit different responses than "What are the chances of you getting the flu this winter?" as some participants may interpret the first question as implying "this winter" while others may not (Brewer et al., 2007). What is often overlooked is that a person's behaviour or behavioural intentions can influence their perception of risk (Brewer et al., 2004). An individual who has been vaccinated for influenza will likely give different estimates of risk if asked "what are

your chances of getting the flu" than if they were asked "what are your chances of getting the flu if you are not vaccinated". To minimise the impact of this, it is important that risk perception questions must be stated in terms of the performance or non-performance of behaviours of interest (Brewer et al., 2007). In terms of the present study it is likely that the questions "what are the chances of your baby being born healthy" and "what are the chances of your baby being born healthy *should you drink during pregnancy*" will elicit different answers, especially from women who do not drink.

Risk perception questions must also specify a target, as there is a difference in how people perceive their own risk (personal risk) and the risk to others (general risk). The perception of personal risk is a stronger predictor of behaviour than the perception of general risk (Brewer & Hallman, 2006; Sjöberg, 2003). When no risk target is specified risk estimates are closer to estimates of general risk than to those of personal risk (Sjöberg, 2000). Most people estimate their personal risk to be lower than the general risk for most adverse life events. It is statistically impossible for the majority of people to be at below average risk and this mistaken belief has been termed unrealistic optimism or risk denial (Weinstein, 1980).

2.10 Unrealistic optimism

Unrealistic optimism is a robust phenomenon in health psychology (Dillard, Midboe, & Klein, 2009; Sharot, Korn, & Dolan, 2011; Sjöberg, 1998, 2000; Van der Pligt, 1994), and has been shown to exist for numerous risks, for example the risk of negative effects of alcohol use, smoking and pollution (Sjöberg, 2000), the risk of contracting sexually transmitted diseases (Roberts & Kennedy, 2006) and adverse birth outcomes due to smoking during pregnancy (Tombor, Urbán, Berkes, & Demetrovics, 2010). Even if individuals correctly assign themselves to a high-, low- or medium-risk group, for a particular negative outcome they still judge themselves less at risk than the others in that group (Van der Pligt, 1996). It has been argued that this hinders change in health behaviours and impacts on the efficacy of universal prevention interventions (Hilbert, 2012; Hoorens, 1994; Van der Pligt, 1994, 1996; Weinstein & Klein, 1995). When individuals are aware of the risk of a harmful behaviour they tend to associate that knowledge with the risk to other people and do not necessarily see it as applying to them personally (Sjöberg, 2003). This is especially true for 'lifestyle risks' like smoking, drinking and drug use (Sjöberg, 2000, 2003).

There are both cognitive and motivational\affective explanations for the existence of unrealistic optimism. Some cognitive explanations are selective attention to information, biased perception of control (people believe they have more control over the risk than others) and comparison to prototypical victims. Motivational or affective explanations include the need to maintain self esteem, the use of defensive denial as coping mechanism and the

need to reduce anxiety (Hoorens, 1994). Factors that moderate unrealistic optimism are similar to those that impact on risk perception in general and include proximity of feedback, perceived control, prior experience and perception of the severity of consequences (Helweg-Larsen & Shepperd, 2001).

It can be argued that unrealistic optimism may be psychologically adaptive and can improve the ability to cope with stressful life events (Dillard et al., 2009; Van der Pligt, 1994), but it is associated with increased risk behaviours and adverse health outcomes (Brewer & Hallman, 2006; Dillard et al., 2009; Roberts & Kennedy, 2006; Tombor et al., 2010). Unrealistic optimism is resistant to change (Weinstein & Klein, 1995) but it can be influenced leading to more accurate perception of personal risk and to less risky behaviour, or adoption of healthy behaviour (Ayers & Myers, 2012).

2.10.1 Unrealistic optimism and smoking during pregnancy

To the best of my knowledge there are no studies investigating unrealistic optimism and drinking during pregnancy, and there is also scant research about unrealistic optimism in pregnant women in general. Unrealistic optimism has however been found in relation to smoking during pregnancy (Tombor et al., 2010). The risk factors for smoking during pregnancy closely resemble those for drinking during pregnancy. Both smoking and drinking are more common in women with high gravidity and parity, low SES, lower education, with a partner who smokes\drinks and women with a history of smoking\drinking, especially during a previous pregnancy (May et al., 2005; Tombor et al., 2010). Smoking has also been found to be a predictor of alcohol exposed pregnancy risk (Morojele et al., 2010).

Similar levels of unrealistic optimism have been found for smoking and drinking, which can partly be attributed to high levels of perceived control over both actions (Sjöberg, 2000). As evidence of unrealistic optimism was found for women who smoke during pregnancy (Tombor et al., 2010), and because of the similarities between these risks in terms of perceived risk and risk factors, it is likely that it will also exist among women who drink during pregnancy.

2.11 Risk perception, unrealistic optimism and FASD

Large scale universal prevention interventions to combat FASD in South Africa have shown some success. In the Northern Cape intensive awareness programmes making use of media campaigns, health talks at clinics, distribution of literature and posters as well as training workshops proved effective (Chersich et al., 2012). Post intervention the prevalence of FASD had decreased and knowledge about the harms of drinking during pregnancy had

significantly increased among the population. The prevalence of FASD post-intervention was however still among the highest reported in the world (Chersich et al., 2012).

Using universal interventions to make women aware of the risk of drinking during pregnancy had an effect on their health behaviours as predicted, but there is an apparent limit to what can be accomplished through these interventions, especially when women who have sound knowledge of the risk of drinking during pregnancy still drink (Chersich et al., 2012; Croxford & Viljoen, 1999). Risk perception research however, raises the question of whether the women are aware of their *personal* risk, or if the universal prevention interventions mainly made them aware of the general risk, which does not predict behaviour change (Brewer et al., 2007). Should the women show unrealistic optimism, universal prevention interventions can be made more effective as risk perception is amenable to change (Ayers & Myers, 2012).

2.12 Theoretical framework

2.12.1 Extended Health Belief Model

The Health Belief Model (HBM) was developed to explain why people were not utilizing public health departments in the USA in the 1950s. Interventions promoting healthy behaviours based on the HBM have shown significant results (Glanz & Bishop, 2010) and the model has been applied to a large range of behaviours including, sexual risk taking, practicing safer sex, healthy eating, breast self examination and adherence to long-term medication regimens (Abood, Black, & Feral, 2003; Boone & Lefkowitz, 2004; Downing-Matibag & Geisinger, 2009; Munro, Lewin, Swart, & Volmink, 2007; Norman & Brain, 2005).

The Extended Health Belief Model (EHBM) states that whether a person will perform, or abstain from, a health behaviour depends on a) a cognitive evaluation of the risk of, and severity of the condition the behaviour can cause or protect against, b) the perceived effectiveness of performing or abstaining from the behaviour with regards to avoiding negative outcomes and c) perceived self efficacy with regards to performing of, or abstaining from, the behaviour (Munro et al., 2007; Webb, Sniehotta, & Michie, 2010). The EHBM also specifies the need for a ‘cue to action’, whether internal (e.g. recognition of symptoms) or external (e.g. media campaigns), to initiate the evaluation of the health behaviour (Glanz & Bishop, 2010; Webb et al., 2010).

2.12.2 Risk perception theory

To fit with the cognitive basis of the EHBM, risk perception will be defined, in this study, as a cognitive evaluation of possible negative events. This fits with the cognitive theories

regarding the mechanisms of unrealistic optimism\risk denial which include selective attention to information, biased perceptions of control and the use of prototypes in social comparison (Hoorens, 1994; Van der Pligt, 1994). Unrealistic optimism is therefore seen as a consequence of lack of access to relevant information and limitations due to limited cognitive resources (Hoorens, 1994).

Conceptualising optimism bias as a purely cognitive phenomenon is limiting, as there are definitely other factors at work as well. Affect and social influences, for example, play a major role in optimism bias (Loewenstein, Weber, Hsee, & Welch, 2001; Yechiam, Druyan, & Ert, 2008), but the underlying mechanisms of unrealistic optimism are not of paramount importance to this study as the risk questions used will be framed in terms of cognitive evaluations.

2.13 Rationale for the study

Even though some studies cast doubt on the assertion that no amount of alcohol consumption during pregnancy is safe (Falgreen Eriksen et al., 2012; Henderson, Gray, & Brocklehurst, 2007; Underbjerg et al., 2012), a threshold for safe drinking has not been found. The policy in many countries, including South Africa, is that no amount of drinking is safe, and pregnant women should avoid alcohol (Ntsabula, 2001; O'Leary, Heuzenroeder, Elliott, & Bower, 2007). Universal prevention interventions are therefore aimed at increasing the public's perception of the risk associated with drinking during pregnancy to encourage abstinence among pregnant women. Based on health psychology theories the perception of the risk of drinking during pregnancy has an impact on risk behaviour, and this has received support in the literature (Testa & Reifman, 1996), but universal prevention interventions have only been partially successful (Chersich et al., 2012; Hankin, 2002). This is not unexpected as there are risk factors that are not amenable to change through universal prevention interventions, but these interventions may still be improved.

At present there are no studies on how women in South Africa perceive the risk of drinking during pregnancy, there are also, to my knowledge, no studies worldwide on unrealistic optimism in terms of alcohol use during pregnancy. This study will help expand the literature about unrealistic optimism in pregnant women (Tombor et al., 2010) and it will examine how women in a high risk South African community perceive both the personal and general risk of drinking during pregnancy. Additionally if drinking during pregnancy, like smoking during pregnancy, is subject to unrealistic optimism then universal prevention interventions need to be tailored to increase the perception of personal risk as general risk does not necessarily predict health behaviour (Brewer & Hallman, 2006; Brewer et al., 2007).

2.14 Research aims

The primary aim of this study was to explore how women in South Africa perceive the personal (subjective) and general (objective) risk of drinking during pregnancy. Secondary aims included ascertaining whether there was evidence of unrealistic optimism, and to examine whether there were personal characteristics that correlated with high or low perception of risk. Women's FASD knowledge was also examined, focusing on whether it remained stable over time, and whether there were any significant gaps in their knowledge.

CHAPTER 3

Method

3.1 Study design

This is a quantitative study of prospective and descriptive design. Data were gathered by questionnaire during personal interviews (see Appendix B) and from existing records.

3.2 Study setting

This study was conducted with the assistance of the Foundation for Alcohol Related Research (FARR) in De Aar in the Northern Cape. High prevalence rates for FASD have been found in this area (Chersich et al., 2012; Urban et al., 2008). This can be partly explained by high levels of drinking, specifically binge drinking and poor socioeconomic conditions (Parry et al., 2005). The unemployment rate in the Emthanjeni municipality (the head office of which is in De Aar), is 28% overall and 37.2% among individuals between 15 and 34 years of age. Only 24% of inhabitants have completed secondary education and 11% have received no schooling at all (Statistics South Africa, 2012). As part of their prevention efforts FARR runs the Healthy Mother Healthy Baby© programme in De Aar.

3.2.1 Healthy Mother Healthy Baby© programme

The Healthy Mother Healthy Baby© (HMHB) programme is both a selected and indicated prevention intervention, and is aimed at women in high risk communities. Women who are at high risk (who report drinking heavily, or who are alcohol dependent) take part in a more intensive targeted intervention than women who are at low risk (who do not report drinking). Women at low risk are however not excluded from the programme to avoid stigmatising participants as “mothers who drink”, and because, in the low-SES communities where the programme is usually implemented, there is a general need for antenatal support and guidance with regards to healthy habits during pregnancy.

Participants in the HMHB© programme are recruited from primary health care clinics in their community. During an antenatal clinic visit the clinic sister will obtain informed consent to disclose a client’s pregnancy status to the FARR community worker. The community worker from FARR then explains the programme to the client and, providing their pregnancy is at or below 20 weeks, asks if they want to participate. In this process it is made clear that participation is voluntary and that the client can leave the programme at any stage. Some women are not recruited through the clinics, but rather go to the FARR centre directly to take

part. These women may have been encouraged by others who attended the program or have taken part in the program during a previous pregnancy.

If the mother-to-be wishes to take part in the programme, an Alcohol Use Disorders Identification Test (AUDIT; Babor, Higgins-Biddle, Saunders, & Monteiro, 2001) is administered. Based on the results participants are placed into one of four risk groups, with group one (participant does not drink at all) being the lowest risk group and group four (participant engages in heavy drinking and is alcohol dependent) the highest. All participants take part in brief motivational interviews, with those in the highest risk groups receiving additional interviews, and home visits. Additionally all participants, regardless of risk group, are invited to frequent health talks and other events.

The women who remain in the programme are followed throughout their pregnancy and they are encouraged to participate in events and talks even after they have given birth. When their children are nine months old, they are encouraged to attend a clinic where the babies' health is examined and they are screened for FASD. High risk women are encouraged to use family planning and to consider sterilisation if they cannot stop drinking to prevent further FASD births.

3.3 Study population

All women in this study came from previously disadvantaged areas in De Aar. Local residents distinguish between 16 smaller "communities" and there is some variation in living standards and SES between them. It was not recorded in which of the smaller communities participants lived, but the overall community is still similar enough that this is unlikely to be a confounding factor. Afrikaans is the main language in the area, spoken by 68,9% of the population, followed by IsiXhosa (23,4%) and English (2,3%; "Emthanjeni," n.d.). Data on race were not recorded. The HMHB© programme is however predominantly attended by women of African or Mixed descent. All participants in this study have taken part in the HMHB© programme.

3.4 Sampling

For ease of access to eligible participants, convenience sampling was used. All women who had taken part in the HMHB© programme in De Aar between 2009 and 2012 were eligible for participation in the study. At the start of the study no new women were being recruited to the HMHB© programme as funding for it had not been secured. Thus all participants had completed the HMHB© programme at least 12 months before the date of their interview for the current study.

All women in the study had previously voluntarily participated in the HMHB© programme and were therefore self-selected. The women approached by the community workers were those that were easily reachable, therefore some sampling bias existed. The population of interest is however fairly homogenous, so the results should be meaningful in terms of the rest of the population (other women who took part in the HMHB© programme) and to a large extent to women in the De Aar area

3.4.1 Inclusion criteria

Participants had to be older than 18 to participate in the study. Participants had to have previously completed the HMHB© programme and have been assigned to a risk group based on an AUDIT. They must also have been assigned a client number by FARR for data recording purposes.

3.4.2 Exclusion criteria

Women who were not English or Afrikaans capable, defined as women who were not able to understand conversational English or Afrikaans, were not included in the sample. There were however no women in the study population who were not English or Afrikaans capable as the HMHB© programme is only offered in Afrikaans and English. The study materials were also only in Afrikaans and English.

3.5 Data collection

FARR community workers approached eligible women and inquired if they were willing to participate in the study. If they were willing a meeting was scheduled when the questionnaire would be administered. Before the interview the women's date of birth, date when they finished the HMHB© programme, and risk group were recorded on the questionnaire.

Data were gathered from existing records and by questionnaire (see Appendix B). The questionnaires were administered by three community workers form FARR who all had extensive experience in administering questionnaires. Data gathering took place over a four month period between March and June 2013. After ethical clearance was obtained, a three day training program was held with the FARR field workers to familiarise them with the questionnaire. The questionnaires were administered at the FARR office in De Aar, which is easily accessible to the participants as it is in located in their community. This also meant that there was no transport cost involved. I was present for the first interviews to ensure that any unforeseen difficulties regarding the interviews could be dealt with immediately. Recordings were made of some of the interviews for quality control purposes.

3.5.1 Existing records

As all participants were part of the HMHB© programme the results of an AUDIT they completed when joining the program was available. FARR uses the AUDIT results to place women into one of four groups based on their risk of having an AEP. Data on risk group was used in this study as a proxy for drinking habits. In addition the period when participants were part of the programme was drawn from their files to examine whether FASD knowledge decreases over time (with the assumption that the HMHB© programme is the main source of their FASD knowledge).

3.5.2 Questionnaire

Data were collected using a pen and paper questionnaire. The questionnaire gathered demographical data and data on the perception of personal and general risk of alcohol consumption during pregnancy. Data on participants' knowledge about FASD was also collected (see Appendix B).

3.5.2.1 Demographic questions

The biographical questions as well as questions regarding smoking, religiosity, pregnancy (including gravidity and parity) and contraceptive use were adapted from the "Maternal Risk Factors" interview compiled and administered by the FARR. It has been used in both the Northern Cape and Western Cape for studies on FASD, including epidemiological studies (Urban et al., 2008; Viljoen et al., 2005). There were additional questions regarding birth outcomes to ascertain whether positive or negative birth outcomes have an effect on risk perception. It has, for example, been suggested parity can be a proxy for healthy birth outcomes (Testa & Reifman, 1996).

3.5.2.2 Risk perception questions

The questions on risk perception were extracted from a much larger questionnaire on health beliefs (Testa & Reifman, 1996). The questions were adapted to specify risk target so personal and general risk could be compared. Each question was asked twice, once in terms of the participants' own risk, and once in terms of other women in their communities' risk. For ease of administration the response scale was changed from numerical to verbal and the response items were changed from seven to five. All questions were asked in such a way that women who did not drink were still required to give an indication of their risk should they drink. The time frame of the risk was also made explicit as questions referred to "during pregnancy" throughout (see Appendix B).

3.5.2.3 FASD knowledge questions

The questions gauging the participant's knowledge about FASD were drawn from various online resources as well as doctor- and patient information resources (Best Start Resource Centre, 2005; "Fact Sheet," n.d.; National Institutes of Health, 2006). The questions require a "true or false" answer, but the correct answer for all questions was true. This was to ensure that women who completed the questionnaire were not exposed to conflicting or confusing messages (see Appendix B). It has been shown that statements may be misremembered as true even if it is subsequently made clear that they are in fact false (Skurnik, Yoon, Park, & Schwarz, 2005).

3.5.3 Ethical considerations

Ethical approval was obtained from Stellenbosch University (Reference #: S12/11/274; see Appendix C). Participation in the study was voluntary and the women who chose to participate were free to withdraw at any stage (see Appendix D). All data were treated as confidential and were only accessible to FARR fieldworkers and the parties involved in this research. All FARR employees have confidentiality clauses their contracts to assure the protection of all women in the HMHB© programme and it applied to all data gathered by this study as well. All data were de-identified while being captured electronically.

3.5.3.1 Participant incentives

Even though incentives can serve as an acknowledgment of time and effort invested by participants and may increase enrolment (Groth, 2010) no incentives were given for participation in this study. FARR requested that no incentives be given as it may impact on women's participation in the HMHB program (L. Olivier, personal communication, 13 September, 2012) and as the participants were drawn from a low-SES community monetary incentives may have exerted undue influence on their decision to participate in the study (Grant & Sugarman, 2004).

3.5.3.2 Informed consent

Informed consent was obtained before the interviews commenced, emphasising that participation was voluntary and that participants could withdraw at any time without affecting their participation in the HMHB© program. Participants were also made aware that no payment or incentives would be received for participation. Informed consent was also obtained to access the information on FARR's records regarding participants risk category based on the AUDIT test (see Appendix D).

3.6 Data analysis

Data capturing was done concurrently with data collection and the data were entered into IBM SPSS Statistics 20. Data on FASD knowledge was subsequently entered into PQStat version 1.4.6 to perform a post-hoc analysis not available in SPSS.

3.6.1 Demographic variables

Descriptive statistics were calculated for all demographic variables. As no data were gathered on participants' current drinking behaviour, the risk group the women belonged to when they participated in the HMHB© programme was used as a proxy. Women in risk group one were treated as non drinkers, risk group two as casual drinkers, risk group three as binge\heavy drinkers and risk group four were treated as alcohol dependent. Risk group data were treated as ordinal for the purposes of analysis. Although risk group data was the only estimate of drinking available in this study, its reliability is questionable as women's drinking habits could have changed in the time since they were in the programme.

A one way ANOVA was done to determine if women in the different risk groups differed significantly in terms of age, years of schooling, gravidity or the time elapsed since attending the HMHB© programme. The time elapsed was recorded in months based on the date on which the participant completed the HMHB© programme, and the date of the interview. If the result gave a fraction of a month under fifteen days it was rounded down and if it was fifteen days or more it was rounded up. For example 30 months and 13 days would be recorded as 30 months, and 30 months and 16 days would be recorded as 30.5 months.

3.6.2 FASD knowledge

Cochran's Q was calculated to test whether the FASD facts selected for this study were all equally well known in the sample. The data are dichotomous and it was assumed that the correlations between pairs of responses were the same in the population (Myers, Well, & Lorch, 2010). A post-hoc Dunn test was conducted to find which items were more likely to be incorrect. To test whether passage of time had an effect on participants' knowledge of FASD a Pearson correlation (two tailed) was also conducted. Participants total score on the knowledge questions was compared to the time elapsed since their participation in the HMHB© programme.

3.6.3 Perception of personal and general risk

Cronbach's Alpha was calculated separately for questions regarding personal risk, and questions regarding general risk as a measure of internal reliability. Results of $\alpha > .7$ were treated as reliable (Bland & Altman, 1997).

3.6.3.1 Unrealistic optimism

To determine if there was any evidence of unrealistic optimism in the sample, the mean score for perception of personal risk and perception of general risk were compared. For the first analysis, a Student's t-test for related samples, it was assumed that personal risk perception and general risk perception scores were normally distributed in the population (Sheskin, 2000). Although convenience sampling was used, the data were treated as if participants were randomly selected for the analysis. Homogeneity of variance was also assumed (Sheskin, 2000).

As there is some dispute as to whether a Student's t-test is applicable to Likert items, a Wilcoxon's matched-pairs signed-ranks test was also conducted (De Winter & Dodou, 2010). For this analysis the selection of participants was once again treated as if it were random. It was also assumed that the difference scores in the population were symmetrically distributed around the median (Sheskin, 2000).

3.6.3.2 Predictors of high or low perception of risk

Simple linear regression analyses were performed on variables that theoretically have an impact on risk perception, and on variables included in the risk profile of mothers who are at risk of having children with FASD. These included

- participant age,
- HMHB© risk group as proxy for drinking behaviour,
- time elapsed since participant attended the HMHB© programme,
- years of schooling,
- the perception of how easy it would be to stop drinking for the participant,
- the perception of how easy it would be to stop drinking for others,
- gravidity,
- parity,
- number of planned pregnancies,
- number of unplanned pregnancies, and
- total score on FASD knowledge questions.

The first analysis had perception of personal risk as the dependent variable and included the perception of general risk as predictor variable. The second analysis had perception of general risk as dependent variable and included perception of personal risk as a predictor. Variables that were significant predictors of the perception of personal risk were then entered into a multiple regression analysis with perception of personal risk as dependent variable. Significant predictors of the perception of general risk were entered into a multiple regression analysis with perception of general risk as dependent variable.

As perception of personal risk was expected to be a highly significant predictor of perception of general risk and vice versa, these variables were not entered into the initial multiple regression analyses. Using stepwise multiple regression analysis, including these variables may have hidden small, yet significant, effects (Field, 2009). Two subsequent multiple regression analyses were however conducted, with the variables included to examine whether any predictors found remained significant. For all regression analyses it was assumed that predictor variables were not correlated with external variables, and that there was no perfect multicollinearity. Homoscedasticity was assumed as well as independence of errors.

CHAPTER 4

Results and Data Analysis

4.1 Sample characteristics

A total of 129 women consented to be part of the study, but one withdrew during the interview for a final sample of 128 women. The mean age of the participants was 29.09 years (*SD* = 6.45), and most (*n* = 125) had received some years of schooling (*M* = 9.4, *SD* = 2.62). The mean gravidity was 2.92 (*SD* = 1.83) and for parity it was 2.64 (*SD* = 1.60). All participants had finished the HMHB© programme at least 14 months prior to the interviews (*M* = 31.66, *SD* = 11.20). See Table 4.1 for a summary.

Table 4.1

Sample characteristics

Variable	*M* (*SD*)	Range
Age	29.09 (6.45)	18-44
Years of schooling	9.4 (2.62)	0-13
Gravidity	2.92 (1.83)	1-10
Parity	2.64 (1.60)	1-9
Months since HMHB attended	31.66 (11.20)	14-54.5

Note. *N* = 128

4.2 Demographic variables

A summary of the demographic variables is given in Table 4.2. There was a high level of unemployment (82%) and a high percentage of women have never been married (76.2%). Looking at protective factors, 96.9% of women report being a member of a religious group and 64.6% of women use some form of contraception.

Table 4.2

Summary of demographic variables

Variable	Yes (%)	No (%)
Currently employed	18	82
Married[a]	23.0	76.2
Smoker (lifetime)	43.3	56.7
Smoker (current)	32.8	67.2
Use contraceptives	64.6	35.4
Member of religious group	96.9	3.1

Note. N = 128

[a] Includes women who are currently married, have been married previously and who have been married more than once

Of the women in the sample 61.4% reported using contraceptive injections, 2.4% used oral contraceptives, and 0.8% (one woman) had undergone sterilisation. There was no report of condom use for contraception and 35.4% reported using no contraceptive methods. Data on drinking behaviour was not gathered directly, but the HMHB© risk group of the participants was used as a proxy (see Table 4.3). Women assigned to risk group one were of lowest risk of an AEP and those assigned to group four were at highest risk. The majority of women (66.9%) were in risk group one and did not drink at all. Only 19.7% of women drank at hazardous levels (risk groups three and four combined). A one way ANOVA did not find any significant difference between women in the different risk groups based on age, years of schooling, gravidity or the time elapsed between the date of the interview and when the woman attended the HMHB© programme.

Table 4.3

Healthy Mother Healthy Baby© risk group data

HMHB© Group	*no*	%
Risk Group 1	85	66.9
Risk Group 2	17	13.4
Risk Group 3	10	7.9
Risk Group 4	15	11.8

Note. N = 127

4.3 Pregnancy outcomes

In addition to gravidity (*M* = 2.92, *SD* = 1.83) and parity (*M* = 2.64, *SD* = 1.60), data were gathered on pregnancy outcomes (see Table 4.4). In this sample at least 25.2% of women have experienced some form of negative pregnancy outcome (this includes having a child diagnosed with FASD).

Table 4.4

Women who have experienced negative pregnancy outcomes

Pregnancy outcome	*no*	%
Miscarriage	25	19.7
Still birth	6	4.7
Child with FASD	10	7.8
Total[a]	32	25.2

Note. N = 128.

[a] Percentages will not add up as some women experienced more than one negative pregnancy outcome

4.4 FASD knowledge

The mean score on the FASD knowledge questions was 8.75 (*SD* = 1.72). Responses to the questions testing participants' knowledge of FASD (see Appendix B), were used to test whether some facts about FASD are less well known among the population. The results were statistically significant (Cochran's *Q* = 109.33, *df* = 9, *p* <.001) and the null hypothesis that the probability of errors were the same for all items could be rejected. Based on a post-hoc Dunn test it was determined that item 1 (If I have had a healthy baby even though I drank during pregnancy, it does not mean that I cannot have a child with FAS) and item 9 (A Fathers drinking cannot give a baby FAS) of the FASD knowledge questions were more likely to be incorrect (*p* <.05). In total 86.7% of participants agreed that no amount of alcohol is safe during pregnancy.

4.4.1 Effect of time on FASD knowledge

A Pearson correlation (two-tailed) was used to assess whether knowledge of FASD decreases over time. Participants' total score on the FASD knowledge questions (*M* = 8.75, *SD* = 1.72) and the time elapsed (in months) since the participant was part of the HMHB© program (*M* = 31.66, *SD* = 11.20) were not significantly correlated (*r*(124) = .048, *p* = .593).

4.5 Perceptions of personal and general risk

4.5.1 Unrealistic optimism

To determine whether women in the sample showed evidence of unrealistic optimism, the means of the items measuring personal and general risk were compared. The perception of personal risk and the perception of general risk were highly correlated (*r*(126) = .743, *p* < .001). Cronbach's alpha was calculated separately for the items measuring the perception of personal risk which consisted of 10 items (α = .871) and for the perception of general risk which also consisted of 10 items (α = .841).

4.5.1.1 Student's t-test for related samples

The Student's T test was used to compare the mean of participants' responses to questions about personal risk and the mean of their responses to general risk (see Appendix B). The difference between the perception of personal risk (*M* = 4.42, *SD* = 0.751) and the perception of general risk (*M* = 4.51, *SD* = 0.630) was significant (*t*(127) = -2.018, *p* = .046). The difference in means was however small (-0.09).

4.5.1.2 Wilcoxon's matched-pairs signed-ranks test

When the medians of the perception of personal and perception of general risk questions were compared, using the Wilcoxon's matched-pairs signed-ranks test, the results were not significant (z = -1.542, p = .123). The mean rank for perception of general risk less that perception of personal risk was 36.2. The mean rank for perception of general risk greater than perception of personal risk was 41.01.

4.6 Predictors of high or low perception of risk

4.6.1 Linear regression with perception of personal risk as dependent variable

With the perception of personal risk as dependent variable, the perception of how easy it would be for oneself to stop drinking and how easy it would be for others to stop drinking, were both significant predictors. FASD knowledge and perception of general risk were also significant predictors. The perception of how easy it is to stop drinking was used as a proxy for perceived control over drinking. The four significant variables were selected for the further multiple regression analysis with perception of personal risk as dependent variable. Please see Table 4.5 for a summary of all variables tested.

Table 4.5

Summary of linear regression analyses with perception of personal risk as dependent variable

Predictor variable	B	SE B	B
Participant age	.016	.010	.140
HMHB© risk group	-.025	.064	-.384
Time since HMHB© attended	-.004	.006	-.053
Years of schooling	-.016	.026	-.056
Ease of quitting (self)	.303	.054	.448**
Ease of quitting (other)	.111	.052	.190*
Gravidity	.042	.036	.102
Parity	.049	.042	.105
Number of planned pregnancies	.057	.047	.110
Number of unplanned pregnancies	-.005	.041	-.012
FASD Knowledge total	.246	.033	.561**
Perception of general risk	.886	.071	.743**

Note. $N = 128$.

* $p < .05$. ** $p < .001$

4.6.2 Linear regression with perception of general risk as dependent variable

With the perception of general risk as dependent variable, the perception of how easy it would be for oneself to stop drinking and how easy it would be for others to stop drinking, were again both significant predictors. FASD knowledge and perception of personal risk

were also significant. These variables were therefore selected for the subsequent multiple regression analyses with perception of general risk as dependent variable. Please see Table 4.6 for a summary of all variables tested.

Table 4.6

Summary of linear regression analyses with perception of general risk as dependent variable

Predictor variable	B	SE B	B
Participant age	.013	.009	.131
HMHB© risk group	-.035	.054	-.059
Time since HMHB© attended	-.008	.005	-.137
Years of schooling	-.011	.022	-.044
Ease of quitting (self)	.188	.048	.330**
Ease of quitting (other)	.113	.043	.229*
Gravidity	.029	.030	.084
Parity	.046	.035	.117
Number of planned pregnancies	.083	.038	.191
Number of unplanned pregnancies	-.035	.034	-.091
FASD Knowledge total	.148	.030	.401**
Perception of general risk	.624	.050	.743**

Note. $N = 128$.

* $p < .05$. ** $p < .001$

4.6.3 Multiple regression analysis with perception of personal risk as dependent variable

Stepwise multiple regression analysis showed that both FASD knowledge and the perception of how easy it would be for oneself to stop drinking, predicted the perception of personal risk. The perception of how easy it would be for others to stop drinking during pregnancy was excluded by the stepwise analysis. The results are summarised in Table 4.7.

Knowledge of FASD alone accounted for 31.3% of the variance in the perception of personal risk. Combined with perceived control over own drinking, the two variables accounted for 38.4 percent of the variance. A positive correlation with perception of personal risk was found for both FASD knowledge ($r(120) = .563$, $p < .001$) and perceived control over drinking ($r(120) = .455$, $p < .001$).

Table 4.7

Significant predictors of perception of personal risk

Variable	R	R^2	B	SE B	B
FASD Knowledge total	.559	.313	.198	.034	.450*
Ease of quitting (self)	.620	.384	.196	.053	.289*

Note. $N = 122$.

* $p < 0.001$

A final stepwise analysis was performed with the significant predictors with the perception of general risk, which is highly correlated with the perception of personal risk ($r(126) = .743$, $p < .001$), included as a predictor variable. A summary of the results are given in Table 4.8. The perception of general risk was the strongest predictor of the perception of personal risk, explaining 56.1% of variance on its own. Knowledge of FASD and the perceived control over drinking accounted for an additional 10.3% of variance.

Table 4.8

Significant predictors of perception of personal risk with perception of general risk included as predictor

Variable	R	R^2	B	SE B	B
Perception of general risk	.749	.561	.701	.070	.589*
FASD Knowledge total	.801	.642	.116	.026	.264*
Ease of quitting (self)	.815	.664	.111	.039	.164*

Note. N = 125.

* *p < 0.001*

4.6.4 Multiple regression analysis with perception of general risk as dependent variable

The first stepwise multiple regression analysis with perception of general risk as dependent variable, indicated that both FASD knowledge and the perception of how easy it would be for oneself to stop drinking predicted the perception of general risk. The perception of how easy it would be for others to stop drinking during pregnancy was excluded by the stepwise analysis. The results are summarised in Table 4.9.

The correlation with perception of general risk was positive for both FASD knowledge ($r(120) = .402$ $p < .001$) and perceived control over drinking ($r(120) = .326$, $p < .001$). FASD knowledge and perception of how easy it would be for oneself to stop drinking accounted for 19.7% of the variance.

Table 4.9

Significant predictors of perception of general risk

Variable	R	R^2	B	SE B	B
FASD Knowledge total	.402	.162	.120	.033	.325**
Ease of quitting (self)	.444	.197	.116	.051	.204*

Note. $N = 122$.

* $p < 0.05$. ** $p < 0.001$

A final stepwise analysis was completed on significant predictors with the perception of personal risk included. With the inclusion of the perception of personal risk in the model, none of the other predictors remained significant. Only perception of personal risk was entered into the analysis and accounted for 56.1% of total variance (see Table 4.10).

Table 4.10

Significant predictors of perception of general risk with perception of personal risk included as predictor

Variable	R	R^2	B	SE B	B
Perception of personal risk	.749	.561	.624	.051	.749*

Note. $N = 125$.

* $p < .001$

CHAPTER 5

Discussion

The discussion of the results of the data analysis will first look at demographic and lifestyle variables, to give an overview of the study sample. Thereafter it will look at the participants' knowledge of FASD as it is an important factor in both risk perception and unrealistic optimism. The next section will look at whether there is any support for the existence of unrealistic optimism, followed by an overview of the predictors of high or low perception of risk. The strengths and limitations will then be discussed, and the final section of this chapter will give suggestions for further research.

5.1 Demographic variables

Women were between 18 and 44 years of age, a third of all women reported smoking, three-quarters of women were unmarried and only 18% were employed. About two-thirds of women reported contraceptive use, which is higher than the most recent estimates (36%) for the Northern Cape (National Statistics System, 2010). The majority of women in the sample were multiparous, and 7.8% have already had a child diagnosed with FASD, which could be expected based on the prevalence data for this area (Urban et al., 2008).

The characteristics of the sample fit the profile of high risk mothers and communities identified in earlier studies. In studies examining risk factors for FASD births, participants were on average between 25 and 29 years old (May et al., 2004, 2008; Viljoen, Croxford, Gossage, Kodituwakku, & May, 2002). The average age of women in this study (29.09) was also similar to a study conducted on universal interventions in the same area in the Northern Cape, where the average age of participants was 27.2 years before and 27.4 after the intervention (Chersich et al., 2012). This study therefore adds to the knowledge we have of the profile of women in high risk communities.

What is of concern however is that there is a gap in knowledge about younger women. Women under the age of 18 were excluded from this study for practical reasons, and looking at the average age and age range of participants in prevalence studies and studies on risk profiles among South African communities it appears that teenage women are underrepresented (May et al., 2004, 2008; Morojele et al., 2010; Viljoen et al., 2002). In the De Aar area 41.3% of the population are younger than 19 ("Emthanjeni," n.d.). Furthermore in a general household survey 5.4% percent of all women between 14 and 19 years country wide reported being pregnant during the previous 12 months. Teenage pregnancy is of great concern in South Africa (Statistics South Africa, 2014) and it is important that younger

women are also targeted in universal interventions and that research is conducted to examine their beliefs about drinking during pregnancy.

Examining other demographic variables, unemployment is much higher than expected based on census data. The De Aar area has an unemployment rate of 28% (“Emthanjeni,” n.d.), and in this study’s sample 82% of women reported being unemployed. Unemployment has been found to be a risk factor for AEPs in high risk South African communities (Chersich et al., 2012; May et al., 2005; Viljoen et al., 2005). This seems to support that women in this study are from a high risk community, but there may be some bias involved. As the interviews were completed during the day, and community workers recruited women who were available and accessible, unemployed women were more likely to be recruited.

Being unmarried or co-habiting has also been found to be a risk factor. In this sample 23% of women are married, which is similar to the census figures of 21.5% (“Emthanjeni,” n.d.). No data were gathered on drinking so participants’ HMHB© risk group was used a proxy, but it is not ideal. The AUDITs used to assign participants to groups were completed at least one year before the interview. There is no guarantee that the data is still the same as women may have stopped or started drinking in the interim. According to these data only 19.7% of women are at high risk of having an AEP, but this figure should be treated with caution.

5.2 FASD knowledge

The level of FASD knowledge was high in this sample with a mean score of 8.75 out of a possible 10 for the questions (*SD* = 1.72). Knowledge about FASD is therefore quite high. A previous study in the Northern Cape also examined FASD knowledge in this area, albeit in a shorter format. In that study 92% of participants stated that one drink during pregnancy harms the foetus compared to the 87% of participants in the present study who stated that no amount of alcohol is safe during pregnancy (Chersich et al., 2012). The aforementioned study focused on De Aar and Upington making it impossible to extrapolate what the level of knowledge was in De Aar alone. It still indicates that although this study was conducted in a high risk area, it was also an area where a relatively high level of knowledge about FASD has been documented.

Of interest is the finding that knowledge of FASD did not correlate with time elapsed since HMHB© programme attendance. It was expected that knowledge deteriorates over time as with the studies on beverage warning labels (Hankin et al., 1996, 1998). This could be attributed to the information being made more memorable and salient through interpersonal contact sessions than through images and media messages. It is also possible that message recall was facilitated by the context of the interviews. The interviewer was a FARR

community worker and the interviews were held at the FARR offices where there are posters and other material about drinking during pregnancy

The high scores may also be due to a response set as the correct answer for the true\false questions, was always “true”. As the study was conducted in a high risk community, it was deemed more important to ensure that no confusing information was given to the participants than to eliminate the possibility of a response set. The answers were always “true” to ensure that women were only exposed to the correct information. Unfortunately no current data are available on the level FASD knowledge in the general population who have not been part of the HMHB© programme. This limits the conclusions that can be drawn from this data.

There were gaps identified in FASD knowledge among participants. The finding that the statements “If I have had a healthy baby even though I drank during pregnancy, it does not mean that I cannot have a child with FAS” and “a Fathers drinking cannot give a baby FAS” (see Appendix B), were significantly more likely to be incorrectly identified as false suggest that these two facts must be reinforced in universal prevention interventions. Based on reports from the community workers who administered the questionnaire, the first statement was however sometimes found confusing by participants[7]. It may therefore not be a true gap in the knowledge about FASD in this population.

An alternative interpretation of the high levels of FASD knowledge among participants is that the HMHB© programme effectively increases awareness and knowledge about FASD and that the increase in knowledge remains stable over time. It is important to remember that the HMHB© programme is not the only avenue of raising awareness in this area, and no data are available about FASD knowledge before the intervention. An increase in knowledge is also no guarantee of behaviour change (Van der Pligt, 1996).

The HMHB© programme is part of a comprehensive approach to prevention but it is important to note that the HMHB© programme is not a universal intervention. It is aimed at women in high risk communities and contains both selective and targeted interventions. These results can therefore not determine if it was the universal interventions in the community or the HMHB© programme that increased FASD knowledge in this study’s sample. To determine if the HMHB© programme is independently successful at increasing knowledge and awareness, it would be necessary to include a sample where the coverage of universal prevention interventions has not been as widespread and the interviews should be held outside of the context of FARR, i.e. by someone not affiliated with FARR somewhere

[7] This was only reported during debriefing sessions after the majority of interviews had been done. At that stage it was too late to amend the questionnaire.

other than FARR premises. The questionnaire could also be administered to a control group to see if their level of FASD knowledge compares.

5.3 Unrealistic optimism

Against expectations, no evidence of unrealistic optimism was found. Even though the Student's t-test showed a significant difference between the means of perception of personal and general risk, the difference was too small to infer a meaningful difference on a five point Likert scale. It is also possible that the assumption of normality was violated, as the perception of risk may be negatively skewed in a population that has taken part in a prevention intervention. The lack of evidence is surprising, given the robustness of the phenomenon in other settings and across various fields (Dillard et al., 2009; Sharot et al., 2011; Sjöberg, 1998, 2000; Van der Pligt, 1994).

There could be a number of explanations for the lack of evidence, the simplest being that the participants are not unrealistically optimistic. Given the reduction in FASD prevalence in this area (Chersich et al., 2012), it is possible that this change in health behaviour has been coupled with an increase in the perception of personal risk. Based on the data gathered it is however not possible to conclude that no unrealistic optimism exists in the sample. It is also possible that the lack of a significant result may be due to inadequacies in the measurement instrument.

Likert items have been found to be problematic in certain populations. Variables like age and level of education can have an impact on responses to Likert items. Participants may not fully understand the graded response format, and social desirability bias may play a role as well (D'Alonzo, 2011). It is possible that participants in this study are not used to Likert items, they may not be test-wise and unfamiliar with the response format. Level of education most likely also played a role as participants on average had only 9 years of schooling (*SD* = 2.62).

When examining the data there were indications of a possible response set, as frequently only the highest value on the Likert items was selected for all questions, even for the questions that were reverse scored (there were two such questions, one for perception of personal risk and one for perception of general risk). This could be due to social desirability bias as the respondents may have said what they expected the FARR fieldworkers would want them to say. There was also the possibility that the interviewers lead the participants to the correct answers inadvertently through the way questions were asked or how they responded to participants' answers. While listening to the interviews recorded for quality control I did not find any indication that interviewers influenced participants.

5.4 Predictors of high or low perception of risk

5.4.1 Predictors of personal risk

Both FASD knowledge and the perception of control over own drinking predicted the perception of personal risk. To perceive drinking during pregnancy as risky it is of course necessary to know what risks are associated with it. It is therefore to be expected that FASD knowledge would be a strong predictor of the perception of personal risk. It has after all been found to be a protective factor predicting less risk of having an AEP (Morojele et al., 2010), and been associated with a decrease in FASD prevalence (Chersich et al., 2012). FASD knowledge only predicted 31.3% of variance in the first analysis, where the perception of general risk was excluded, which once again suggests that knowledge is not enough to ensure an accurate perception of risk.

What is however surprising is that the perception of control over drinking is positively correlated with risk perception, as according to the literature high perceived control should lead to increased optimism bias (Klein & Helweg-Larsen, 2002; Roberts & Kennedy, 2006; Sjöberg, 2000; Van der Pligt, 1994). A possible reason for this is that the majority of women in the sample did not drink regularly (only 19.7% were considered at risk and 66.9% did not drink at all). The question that gauged perceived control over drinking was “I feel confident that I could stop drinking totally if I became pregnant” (see Appendix B). A woman who does not drink or who is a casual drinker is likely to strongly agree with that statement. A woman who does not drink *can* be confident that she will “stop” drinking during pregnancy.

The mean score for the perception of personal risk was (M = 4,42, SD = 0.751), which means that women on average agreed that drinking during pregnancy poses a risk to themselves and their pregnancies. Combined with the fact that two-thirds of participants could realistically say they could stop drinking during pregnancy it could explain why high perceived control is predicts high perception of personal risk. Women are aware of the risks of drinking during pregnancy, but as they do not drink they can rightly believe they could control their drinking during pregnancy.

Perception of general risk was included in the analyses as it was highly correlated with perception of personal risk. This was to be expected based on the literature, and it explained the most of the variance in the dependent variable. FASD knowledge still explained a significant amount of the variance, as did the perception of control over drinking. As discussed earlier the impact of the perception of control over drinking should however be treated with caution. The final model suggests that FASD knowledge is not enough on its own to increase the perception of risk.

5.4.2 Predictors of general risk

To estimate the perception of general risk, women in this study were asked to think of the average woman in their community. This makes drawing conclusions from these estimates more challenging as, most likely, no two women will picture the average woman in their community the same (Van der Pligt, 1996). Bearing that in mind, FASD knowledge and the participants' perception of control over their own drinking predicted the perception of general risk. It is also to be expected that FASD knowledge would be a strong predictor of the perception of general risk. Regardless of unrealistic optimism personal and general risk perception are still generally correlated (Sjöberg, 2000).

The correlation between the perception of general risk and the perception of control was once again positive against expectations, and this may be for the same reasons discussed previously in terms of predicting the perception of personal risk. A confounding factor in this instance could however be that all women do not have the same "average woman" in mind as previously mentioned. Depending on whether they perceive the average woman in their community as someone who drinks or who does not drink, their responses could differ.

It is also not clear how the perception of how much control they have over their own drinking would influence how at risk other women are if they drink during pregnancy. Once again this could be due to different conceptualisations of the average woman. It may also be due to the fact that women are aware of the high general risk of drinking during pregnancy, and they themselves do not drink so they can be sure they will be able to "stop" drinking during pregnancy. This could lead to the positive correlation.

In the final analysis FASD knowledge, perception of control and the perception of personal risk were entered. Only the perception of personal risk remained significant. This raises some questions about the questionnaire and how well it measured the perception of general risk. Based on the EHBM and the literature on risk perception, one would have expected at least FASD knowledge to remain a significant predictor.

5.5 Strengths and limitations

The main strength of this study is that it adds a new dimension to the body of knowledge already available on this population (Chersich et al., 2012; Urban et al., 2008). Although it is not a randomly selected sample from the community, it offers an opportunity to examine the community from a different perspective as no research on how women perceive the risk of drinking has previously been conducted in this area. Furthermore it examined FASD knowledge in more depth than previous studies (Chersich et al., 2012).

This study's sample likely differs from the general De Aar community, due to the fact that all participants had participated in a FASD prevention programme. Due to this difference no clear conclusions can be drawn about risk perception and the knowledge of FASD in the broader community. Taking into account that knowledge about the risks of drinking was expected to deteriorate and did not (Hankin et al., 1996; Hankin et al., 1998), and that there have been comprehensive universal interventions in the area (Chersich et al., 2012), the findings suggest that knowledge of FASD and the perception of the risk of drinking during pregnancy in the community may be relatively high as well. This would be a fruitful avenue of further investigation. The present study also adds to the body of knowledge regarding risk perception and risk denial in terms of health behaviours during pregnancy (Haslam & Draper, 2000; Tombor et al., 2010).

A major strength of this study is that it gathers in depth information on participants' knowledge of FASD. Rather than just examining whether participants are aware that drinking can harm a foetus it also explores whether participants are aware of certain key facts about FASD, for example that it cannot be cured and that a fathers drinking cannot cause FASD. The fact that some of the questions were more likely to be answered incorrect shows that there is a benefit associated with a more comprehensive inquiry into individuals' knowledge of the risks of drinking during pregnancy. Focusing on more than whether people are aware of the impact of the timing and amount of alcohol consumed can identifying gaps in FASD knowledge. Based on this universal interventions can be improved or tailored to specific communities.

A limitation of this study is the population the sample was drawn from. There is a high level of awareness regarding the risk of drinking during pregnancy in the study sample. Combined with the fact that the study was done in the context of a indicated intervention aimed at preventing FASD the results in terms of the lack of unrealistic optimism can most likely not be generalised to the community at large, only to other women who have participated in the HMHB© programme. The wider communities' knowledge of FASD may also be high, but it based on the risk perception literature unrealistic optimism would likely still be present. Further research would be required to determine the level of FASD knowledge and whether unrealistic optimism exists in the community at large.

The risk perception questions in this study are more in line with current risk perception research than the questionnaire they are based on (Testa & Reifman, 1996). With the addition of a time frame (during pregnancy), by making the target of the risk explicit (personal risk or general risk) and by asking participants to estimate risk *should* they drink a clearer picture of their perception of the risk of drinking during pregnancy may be gained.

The way the questions are asked in this study should eliminate some common causes of inaccurate measurement of risk perception (Brewer et al., 2004, 2007; Sjöberg, 2000).

There were however severe limitations to the questionnaire which unfortunately only came to light during data analysis. All women in this population may not be accustomed to Likert items and may have had difficulty in estimating the probability of hypothetical events (D'Alonzo, 2011). Recordings made of the interviews seemed to support this possibility. The questionnaire should have contained practice examples and it may be useful to have pictographic representations of the response scale (Price, Pentecost, & Voth, 2002). As there was indications that there may have been a response set, more items should have been reverse scored to control for this. Furthermore the fact that the interviews were done in the context of FARR it may have increased social desirability bias. Participants may have responded as they expected the interviewer to want them to.

The wording on some of the questionnaire items was problematic, for example the statement "If I have had a healthy baby even though I drank during pregnancy, it does not mean that I cannot have a child with FASD" was found confusing by participants. This needs to be reworded without the double-negative. At present it is not possible to say with confidence that the response to the above statement indicates a true gap in FASD knowledge. The data gathered on drinking behaviour was also inadequate. The use of HMHB© risk group as proxy ignores the fact that drinking behaviour may have changed.

5.6 Suggestions for further research

Due to the shortcomings of the present study and questionnaire, the research question of how women in high risk communities in South Africa perceive the risks of drinking during pregnancy has not been satisfactorily answered. To answer this question it would be necessary to review the questionnaire and to select a more suitable population for sampling. As mentioned previously practice items should be added to familiarise participants with the response format, and more reverse scored questions should be included. The context of the research should also be carefully considered. If the same research is conducted in primary health care facilities for example, it is still likely that this will increase social desirability bias. The benefit of ease of access to eligible women must be weighed against this confounding factor.

The FASD knowledge questions are also a fruitful avenue for further investigation. Using the short ten item test one can compare FASD knowledge in different populations. In terms of the present study, it would be informative to ask these questions of women in the same community who have not been part of the HMHB© programme. This would provide valuable

information on the efficacy of the programme in increasing FASD knowledge. The same questions can also be asked of men to see if universal interventions reach them as well.

If more information is gathered on current drinking behaviour in a future study, it would be useful to examine the impact thereof on risk perception. The present study did include question regarding different amounts and types of alcohol, but no significant differences could be detected in how it influenced risk perception. In a different population and in a different context it might be possible to investigate this. Are different kinds of alcohol perceived as more or less risky to pregnant women? A similar qualitative study has been conducted in the USA which suggest this will be a useful avenue if inquiry (Branco & Kaskutas, 2001).

An additional question that is raised is why there was a positive correlation between perceived control and perceived risk? More questions on perceived control would be required and also more women who drink. As perceived control was only based on one question in this study no conclusion can be drawn from the current data. As this result was unexpected it would also be worth examining (Sjöberg, 2000)

In terms of evaluating the efficacy of the HMHB© programme in increasing FASD knowledge over an extended period of time, it would be necessary to have a control group of women who have not participated in the programme. It would also be better if future studies were done in an area where FARR is active, but the same level of universal awareness has not been established (Chersich et al., 2012).

CHAPTER 6

Conclusion

This study set out to examine how women in a high risk South African community perceive the risk of drinking during pregnancy, both subjectively and objectively. The study investigated whether there was any evidence of unrealistic optimism in the sample. Additionally it investigated whether there were any variables that significantly predicted high or low risk perception. The women's knowledge of FASD was also examined to see whether it stayed stable over time and if there were any significant gaps in their knowledge.

The sample drawn from the HMHB© programme showed the characteristics expected of a high risk group in terms of demographic variables. As the sample was drawn from a population that had been part of an intervention programme, it is however unclear how representative they are of women in the rest of the community. Bearing this in mind the study did provide useful information about how women in the De Aar community perceive the risk of drinking during pregnancy.

There was a high level of FASD knowledge in this sample, even though some possible gaps in knowledge were identified. Regardless of whether the level of knowledge remains stable due to the HMHB© programme or due to other interventions, the findings are contrary to what has been reported in the literature about how knowledge and impact or warning messages decrease over time (Hankin et al., 1998). Since there has been a decrease in FASD prevalence (Chersich et al., 2012) in this area, the De Aar community offers rich opportunities to investigate what leads to successful FASD prevention interventions.

Women in the sample seem to be aware of their personal risk in terms of drinking during pregnancy, and awareness of personal risk is the best predictor of health behaviours (Brewer et al., 2007; Weinstein et al., 2007). No evidence of unrealistic optimism was found when comparing the perception of personal and general risk. Due to the robustness of this phenomenon in the literature however, this result seems suspect. It is also plausible that the large proportion of participants who were abstainers could have influenced the results. A reworked questionnaire with more women who drink in the sample would shed more light on whether there is in fact no unrealistic optimism or if the result was due to an inaccurate measuring instrument.

Only perceived control over drinking, FASD knowledge and the perception of general risk predicted the perception of personal risk, and only FASD knowledge and perception of personal risk predicted the perception of general risk. It was surprising that the major risk

factors for AEPS, such as high gravidity and parity, advanced maternal age and smoking for example, did not predict higher or lower risk perception. This seems to contradict the risk perception literature and warrants further investigation with a reworked questionnaire as well.

As an exploratory study this thesis has succeeded in giving a basic overview of the perception of the risk of drinking during pregnancy among women in a high risk South African community. It has also raised interesting questions regarding the effectiveness of the HMHB© programme and has shown some support for it.

REFERENCES

Abel, E. L. (1995). An update on incidence of FAS: FAS is not an equal opportunity birth defect. *Neurotoxicology and Teratology*, *17*(4), 437–443. doi:10.1016/0892-0362(95)00005-C

Abel, E. L., & Hannigan, J. H. (1995). Maternal risk factors in fetal alcohol syndrome: Provocative and permissive influences. *Neurotoxicology and Teratology*, *17*(4), 445–462. doi:10.1016/0892-0362(95)98055-6

Abood, D. A., Black, D. R., & Feral, D. (2003). Nutrition education worksite intervention for university staff: Application of the health belief model. *Journal of Nutrition Education and Behavior*, *35*(5), 260–267.

Abrahams, N., Jewkes, R., & Mvo, Z. (2001). Health care-seeking practices of pregnant women and the role of the midwife in Cape Town, South Africa. *Journal of Midwifery & Women's Health*, *46*(4), 240–247.

Anderson, P., Chisholm, D., & Fuhr, D. C. (2009). Effectiveness and cost-effectiveness of policies and programmes to reduce the harm caused by alcohol. *Lancet*, *373*(9682), 2234–2246. doi:10.1016/S0140-6736(09)60744-3

Anthony, J. C. (2009). Harmful alcohol consumption: World epidemiological data. In A. G. De Andrade, J. C. Anthony, & C. M. Silveira (Eds.), *Alcohol and its consequences: dealing with multiple concepts* (pp. 1–34). Retrieved from http://www.epi.msu.edu/janthony/EPI495/Anthony.alcohol.pdf

Astley, S. J. (2006). Comparison of the 4-digit diagnostic code and the Hoyme diagnostic guidelines for fetal alcohol spectrum disorders. *Pediatrics*, *118*(4), 1532–1545. doi:10.1542/peds.2006-0577

Astley, S. J., & Clarren, S. K. (1996). A case definition and photographic screening tool for the facial phenotype of fetal alcohol syndrome. *The Journal of Pediatrics*, *129*(1), 33–41.

Ayers, B., & Myers, L. B. (2012). Do media messages change people's risk perceptions for binge drinking? *Alcohol and Alcoholism*, *47*(1), 52–56. doi:10.1093/alcalc/agr052

Babor, T. F., Higgins-Biddle, J. C., Saunders, J. B., & Monteiro, M. G. (2001). *The Alcohol use disorders identification tests - guidelines for use in primary care* (2nd ed.). Retrieved from http://whqlibdoc.who.int/hq/2001/who_msd_msb_01.6a.pdf

Banakar, M. K., Kudlur, N. S., & George, S. (2009). Fetal alcohol spectrum disorder (FASD). *Indian Journal of Pediatrics*, *76*(11), 1173–1175. doi:10.1007/s12098-009-0239-2

Barry, K. L., Caetano, R., Chang, G., DeJoseph, M. C., Miller, L. A., O'Connor, M. J., … Leeks, K. (2009). *Reducing alcohol-exposed pregnancies: A report of the national task force on fetal alcohol syndrome and fetal alcohol effect*. Retrieved from Centers for Disease Control and Prevention website: http://www.cdc.gov/ncbddd/fasd/documents/redalcohpreg.pdf

Bateman, C. (2010). FASD - De Aar mums get beyond the "tippling point." *South African Medical Journal*, *100*(11), 706–708.

Best Start Resource Centre. (2005). *Participant Handbook: Supporting Change, Preventing and Addressing Alcohol Use in Pregnancy*. Retrieved from http://www.beststart.org/resources/alc_reduction/pdf/participant_hndbk_june05.pdf

Bland, J. M., & Altman, D. G. (1997). Statistics notes: Cronbach's alpha. *British Medical Journal*, *314*(7080), 572–572. doi:10.1136/bmj.314.7080.572

Boone, T. L., & Lefkowitz, E. S. (2004). Safer sex and the Health Belief Model. *Journal of Psychology & Human Sexuality*, *16*(1), 51–68. doi:10.1300/J056v16n01_04

Bower, C., Silva, D., Henderson, T. R., Ryan, A., & Rudy, E. (2000). Ascertainment of birth defects: The effect on completeness of adding a new source of data. *Journal of Paediatrics and Child Health*, *36*(6), 574–576. doi:10.1046/j.1440-1754.2000.00575.x

Branco, E. I., & Kaskutas, L. A. (2001). "If it burns going down... ": How focus groups can shape fetal alcohol syndrome (FAS) prevention. *Substance Use & Misuse*, *36*(3), 333–345.

Brewer, N. T., Chapman, G. B., Gibbons, F. X., Gerrard, M., McCaul, K. D., & Weinstein, N. D. (2007). Meta-analysis of the relationship between risk perception and health behavior: The example of vaccination. *Health Psychology*, *26*(2), 136–145. doi:10.1037/0278-6133.26.2.136

Brewer, N. T., & Hallman, W. K. (2006). Subjective and objective risk as predictors of influenza vaccination during the vaccine shortage of 2004-2005. *Clinical Infectious Diseases*, *43*(11), 1379–1386. doi:10.1086/508466

Brewer, N. T., Weinstein, N. D., Cuite, C. L., & Herrington, J. E. (2004). Risk perceptions and their relation to risk behavior. *Annals of Behavioral Medicine*, *27*(2), 125–130. doi:10.1207/s15324796abm2702_7

Chersich, M. F., Urban, M., Olivier, L., Davies, L.-A., Chetty, C., & Viljoen, D. (2012). Universal prevention is associated with lower prevalence of fetal alcohol spectrum disorders in Northern Cape, South Africa: A multicentre before-after study. *Alcohol and Alcoholism*, *47*(1), 67–74. doi:10.1093/alcalc/agr145

Chudley, A. E. (2008). Fetal alcohol spectrum disorder: Counting the invisible - mission impossible? *Archives of Disease in Childhood*, *93*(9), 721–722. doi:10.1136/adc.2008.137109

Clark, E., Lutke, J., Minnes, P., & Ouellette-Kuntz, H. (2004). Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia. *Journal of FAS International*, *2*, 1–12.

Clarke, M. E., & Gibbard, W. B. (2003). Overview of fetal alcohol spectrum disorders for mental health professionals. *The Canadian Child and Adolescent Psychiatry Review*, *12*(3), 57–63.

Clarren, S. K., Randels, S. P., Sanderson, M., & Fineman, R. M. (2001). Screening for fetal alcohol syndrome in primary schools: A feasibility study. *Teratology*, *63*(1), 3–10.

Credé, S., Sinanovic, E., Adnams, C., & London, L. (2011). The utilization of health care services by children with Foetal Alcohol Syndrome in the Western Cape, South Africa. *Drug and Alcohol Dependence*, *115*(3), 175–182. doi:10.1016/j.drugalcdep.2010.10.019

Croxford, J., & Viljoen, D. (1999). Alcohol consumption by pregnant women in the Western Cape. *South African Medical Journal*, *89*(9), 962–965.

D'Alonzo, K. T. (2011). Evaluation and revision of questionnaires for use among low-literacy immigrant Latinos. *Revista Latino-Americana de Enfermagem*, *19*(5), 1255–1264.

Day, S. M. (2012). Alcohol consumption during pregnancy: the growing evidence. *Developmental Medicine & Child Neurology*, *54*(3), 200. doi:10.1111/j.1469-8749.2011.04207.x

De Winter, J. C. F., & Dodou, D. (2010). Five-Point Likert Items: t test versus Mann-Whitney-Wilcoxon. *Practical Assessment, Research & Evaluation*, *15*(11), 1–12.

Dillard, A. J., Midboe, A. M., & Klein, W. M. P. (2009). The dark side of optimism: Unrealistic optimism about problems with alcohol predicts subsequent negative event experiences. *Personality and Social Psychology Bulletin*, *35*(11), 1540–1550. doi:10.1177/0146167209343124

Downing-Matibag, T. M., & Geisinger, B. (2009). Hooking up and sexual risk taking among college students: A health belief model perspective. *Qualitative Health Research*, *19*(9), 1196–1209. doi:10.1177/1049732309344206

Eaton, L. A., Kalichman, S. C., Sikkema, K. J., Skinner, D., Watt, M. H., Pieterse, D., & Pitpitan, E. V. (2012). Pregnancy, alcohol intake, and intimate partner violence among men and women attending drinking establishments in a Cape Town, South Africa township. *Journal of Community Health*, *37*(1), 208–216. doi:10.1007/s10900-011-9438-7

Emthanjeni. (n.d.). Retrieved February 06, 2014, from http://beta2.statssa.gov.za/?page_id=993&id=emthanjeni-municipality

Fact Sheet. (n.d.). Retrieved from http://www.fasd-fl.org/faq/fact-sheet/

Falgreen Eriksen, H.-L., Mortensen, E., Kilburn, T., Underbjerg, M., Bertrand, J., Støvring, H., … Kesmodel, U. (2012). The effects of low to moderate prenatal alcohol exposure in early pregnancy on IQ in 5-year-old children. *BJOG*, 1–10. doi:10.1111/j.1471-0528.2012.03394.x

Field, A. P. (2009). *Discovering statistics using SPSS* (3rd ed.). London: SAGE.

Glanz, K., & Bishop, D. B. (2010). The role of behavioral science theory in development and implementation of public health interventions. *Annual Review of Public Health*, *31*, 399–418. doi:10.1146/annurev.publhealth.012809.103604

Grant, R. W., & Sugarman, J. (2004). Ethics in human subjects research: Do incentives matter? *The Journal of Medicine and Philosophy*, *29*(6), 717–738. doi:10.1080/03605310490883046

Grinfeld, H. (2009). Alcohol abuse in pregnancy. In A. G. De Andrade, J. C. Anthony, & C. M. Silveira (Eds.), *Alcohol and its consequences: dealing with multiple concepts* (pp. 179–200). Retrieved from http://orig.cisa.org.br/UserFiles/File/alcoolesuasconsequencias-en-cap9.pdf

Groth, S. W. (2010). Honorarium or coercion: Use of incentives for participants in clinical research. *The Journal of the New York State Nurses' Association*, *41*(1), 11–13.

Hankin, J. R. (2002). Fetal alcohol syndrome prevention research. *Alcohol Research & Health*, *26*(1), 58–65.

Hankin, J. R., Firestone, I. J., Sloan, J. J., Ager, J. W., Sokol, R. J., & Martier, S. S. (1996). Heeding the alcoholic beverage warning label during pregnancy: multiparae versus nulliparae. *Journal of Studies on Alcohol*, *57*(2), 171–177.

Hankin, J. R., McCaul, M. E., & Heussner, J. (2000). Pregnant, alcohol-abusing women. *Alcoholism: Clinical and Experimental Research*, *24*(8), 1276–1286.

Hankin, J. R., Sloan, J. J., & Sokol, R. J. (1998). The modest impact of the alcohol beverage warning label on drinking during pregnancy among a sample of African-American women. *Journal of Public Policy & Marketing*, *17*(1), 61–69.

Harries, J., Orner, P., Gabriel, M., & Mitchell, E. (2007). Delays in seeking an abortion until the second trimester: A qualitative study in South Africa. *Reproductive Health*, *4*(7). doi:10.1186/1742-4755-4-7

Harris, K. R., & Bucens, I. K. (2003). Prevalence of fetal alcohol syndrome in the Top End of the Northern Territory. *Journal of Paediatrics and Child Health*, *39*(7), 528–533.

Haslam, C., & Draper, E. (2000). Stage of change is associated with assessment of the health risks of maternal smoking among pregnant women. *Social Science & Medicine*, *51*(8), 1189–1196.

Helweg-Larsen, M., & Shepperd, J. A. (2001). Do moderators of the optimistic bias affect personal or target risk estimates? A review of the literature. *Personality and Social Psychology Review*, *5*(1), 74–95. doi:10.1207/S15327957PSPR0501_5

Henderson, J., Gray, R., & Brocklehurst, P. (2007). Systematic review of effects of low-moderate prenatal alcohol exposure on pregnancy outcome. *BJOG*, *114*(3), 243–252. doi:10.1111/j.1471-0528.2006.01163.x

Hilbert, M. (2012). Toward a synthesis of cognitive biases: How noisy information processing can bias human decision making. *Psychological Bulletin*, *138*(2), 211–237. doi:10.1037/a0025940

Hoorens, V. (1994). Unrealistic optimism in health and safety risks. In D. R. Rutter & L. Quine (Eds.), *Social psychology and health: European perspectives* (pp. 153–174). Brookfield, VT, US: Avebury/Ashgate Publishing Co.

Hoyme, H. E., & May, P. A. (2007). Response to criticisms raised by Astley to clarifications of the IOM diagnostic criteria for FASD [Peer commentary on the paper " Comparison of the 4-digit diagnostic code and the Hoyme diagnostic guidelines for fetal alcohol spectrum disorders" by S. J. Astley]. Retrieved from http://www.pediatricsdigest.mobi/content/118/4/1532.short/reply#pediatrics_el_5934

Hoyme, H. E., May, P. A., Kalberg, W. O., Kodituwakku, P., Gossage, J. P., Trujillo, P. M., … Robinson, L. K. (2005). A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 institute of medicine criteria. *Pediatrics*, *115*(1), 39–47. doi:10.1542/peds.2004-0259

Jacobson, J. L., & Jacobson, S. W. (2002). Effects of prenatal alcohol exposure on child development. *Alcohol Research & Health*, *26*(4), 282–286.

Janssen, E., Van Osch, L., Lechner, L., Candel, M., & De Vries, H. (2012). Thinking versus feeling: Differentiating between cognitive and affective components of perceived cancer risk. *Psychology & Health*, *27*(7), 768-783. doi:10.1080/08870446.2011.580846

Klein, C. T. F., & Helweg-Larsen, M. (2002). Perceived control and the optimistic bias: A meta-analytic review. *Psychology and Health*, *17*(4), 437–446.

Leppin, A., & Aro, A. R. (2009). Risk perceptions related to SARS and avian influenza: Theoretical foundations of current empirical research. *International Journal of Behavioral Medicine*, *16*(1), 7–29. doi:10.1007/s12529-008-9002-8

Loewenstein, G. F., Weber, E. U., Hsee, C. K., & Welch, N. (2001). Risk as feelings. *Psychological Bulletin*, *127*(2), 267–286.

Manning, M. A., & Hoyme, H. E. (2007). Fetal alcohol spectrum disorders: A practical clinical approach to diagnosis. *Neuroscience and Biobehavioral Reviews*, *31*(2), 230–238. doi:10.1016/j.neubiorev.2006.06.016

Marais, S., Jordaan, E., Olivier, L., & Viljoen, D. L. (2012). Fetal Alcohol spectrum Disorders. In A. Van Niekerk, S. Suffla, & M. Seedat (Eds.), *Crime, Violence and Injury in South Africa: 21st Century Solutions for Child Safety* (pp. 214–228). Retrieved from http://www.mrc.ac.za/crime/Chapter15.pdf

Marais, S., Jordaan, E., Viljoen, D., Olivier, L., De Waal, J., & Poole, C. (2011). The effect of brief interventions on the drinking behaviour of pregnant women in a high-risk rural South African community: a cluster randomised trial. *Early Child Development and Care*, *181*(4), 463–474. doi:10.1080/03004430903450392

May, P. A., Blankenship, J., Marais, A.-S., Gossage, J. P., Kalberg, W. O., Barnard, R., … Seedat, S. (2013). Approaching the prevalence of the full spectrum of fetal alcohol spectrum disorders in a South African population-based study. *Alcoholism: Clinical and Experimental Research*, *37*(5), 818–830. doi:10.1111/acer.12033

May, P. A., Brooke, L., Gossage, J. P., Croxford, J., Adnams, C., Jones, K. L., … Viljoen, D. (2000). Epidemiology of fetal alcohol syndrome in a South African community in the Western Cape Province. *American Journal of Public Health*, *90*(12), 1905–1912.

May, P. A., Fiorentino, D., Gossage, J. P., Kalberg, W. O., Hoyme, H. E., Robinson, L. K., … Ceccanti, M. (2006). Epidemiology of FASD in a province in Italy: Prevalence and characteristics of children in a random sample of schools. *Alcoholism: Clinical and Experimental Research*, *30*(9), 1562–1575. doi:10.1111/j.1530-0277.2006.00188.x

May, P. A., & Gossage, J. P. (2001). Estimating the prevalence of fetal alcohol syndrome. A summary. *Alcohol Research & Health*, *25*(3), 159–167.

May, P. A., Gossage, J. P., Brooke, L. E., Snell, C. L., Marais, A.-S., Hendricks, L. S., … Viljoen, D. L. (2005). Maternal risk factors for fetal alcohol syndrome in the Western Cape province of South Africa: A population-based study. *American Journal of Public Health*, *95*(7), 1190–1199. doi:10.2105/AJPH.2003.037093

May, P. A., Gossage, J. P., Kalberg, W. O., Robinson, L. K., Buckley, D., Manning, M., & Hoyme, H. E. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews*, *15*(3), 176–192. doi:10.1002/ddrr.68

May, P. A., Gossage, J. P., Marais, A.-S., Adnams, C. M., Hoyme, H. E., Jones, K. L., … Viljoen, D. L. (2007). The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug and Alcohol Dependence*, *88*(2-3), 259–271. doi:10.1016/j.drugalcdep.2006.11.007

May, P. A., Gossage, J. P., Marais, A.-S., Hendricks, L. S., Snell, C. L., Tabachnick, B. G., … Viljoen, D. L. (2008). Maternal risk factors for fetal alcohol syndrome and partial fetal alcohol syndrome in South Africa: A third study. *Alcoholism: Clinical and Experimental Research*, *32*(5), 738–753. doi:10.1111/j.1530-0277.2008.00634.x

May, P. A., Gossage, J. P., White-Country, M., Goodhart, K., Decoteau, S., Trujillo, P. M., … Hoyme, H. E. (2004). Alcohol consumption and other maternal risk factors for fetal alcohol syndrome among three distinct samples of women before, during, and after pregnancy: the risk is relative. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *127C*(1), 10–20. doi:10.1002/ajmg.c.30011

Miller, L. C., Chan, W., Litvinova, A., Rubin, A., Comfort, K., Tirella, L., … Kovalev, I. (2006). Fetal alcohol spectrum disorders in children residing in Russian orphanages: A phenotypic survey. *Alcoholism: Clinical and Experimental Research*, *30*(3), 531–538. doi:10.1111/j.1530-0277.2006.00059.x

Mitten, H. R. (2004). Section 9: Fetal alcohol spectrum disorders and the justice system. *Commission on First Nations and Métis Peoples and Justice Reform Final Report - Volume II*. Retrieved from http://www.justice.gov.sk.ca/justicereform/volume2/12section9.pdf

Morojele, N. K., London, L., Olorunju, S. A., Matjila, M. J., Davids, A. S., & Rendall-Mkosi, K. M. (2010). Predictors of risk of alcohol-exposed pregnancies among women in an urban

and a rural area of South Africa. *Social Science & Medicine*, *70*(4), 534–542. doi:10.1016/j.socscimed.2009.10.040

Morroni, C., Tibazarwa, K., & Myer, L. (2006). Combined condom and contraceptive use among South African women. *South African Medical Journal*, *96*(7), 620–622.

Mukherjee, R. A. S., Hollins, S., & Turk, J. (2006). Fetal alcohol spectrum disorder: An overview. *Journal of the Royal Society of Medicine*, *99*(6), 298–302. doi:10.1258/jrsm.99.6.298

Munro, S., Lewin, S., Swart, T., & Volmink, J. (2007). A review of health behaviour theories: How useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*, *7*(104). doi:10.1186/1471-2458-7-104

Myer, L., & Harrison, A. (2003). Why do women seek antenatal care late? Perspectives from rural South Africa. *Journal of Midwifery & Women's Health*, *48*(4), 268–272. doi:10.1016/S1526-9523(02)00421-X

Myer, L., Mlobeli, R., Cooper, D., Smit, J., & Morroni, C. (2007). Knowledge and use of emergency contraception among women in the Western Cape province of South Africa: A cross-sectional study. *BMC Women's Health*, *7*(14). doi:10.1186/1472-6874-7-14

Myers, J. L., Well, A. D., & Lorch, R. F. (2010). *Research design and statistical analysis* (3rd ed.). New York: Routledge.

National Institutes of Health. (2006). *Drinking and your pregnancy*. Retrieved from http://pubs.niaaa.nih.gov/publications/DrinkingPregnancy_HTML/pregnancy.pdf

National Statistics System. (2010). *Goal 5 - Improve maternal health*. Retrieved from http://www.statssa.gov.za/nss/Goal_Reports/GOAL 5-IMPROVE MATERNAL HEALTH.pdf

Norman, P., & Brain, K. (2005). An application of an extended health belief model to the prediction of breast self-examination among women with a family history of breast cancer. *British Journal of Health Psychology*, *10*(1), 1–16. doi:10.1348/135910704X24752

Ntsabula, A. (2001). *Human genetics policy guidelines for the management and prevention of genetic disorders, birth defects and disabilities*. Retrieved from http://www.doh.gov.za/docs/policy/humangenetics.pdf

O'Connor, M. J., Tomlinson, M., Leroux, I. M., Stewart, J., Greco, E., & Rotheram-Borus, M. J. (2011). Predictors of alcohol use prior to pregnancy recognition among township women in Cape Town, South Africa. *Social Science & Medicine*, *72*(1), 83–90. doi:10.1016/j.socscimed.2010.09.049

Odendaal, H. J., Steyn, D. W., Elliott, A., & Burd, L. (2009). Combined effects of cigarette smoking and alcohol consumption on perinatal outcome. *Gynecologic and Obstetric Investigation*, *67*(1), 1–8. doi:10.1159/000150597

O'Leary, C. M. (2004). Fetal alcohol syndrome: Diagnosis, epidemiology, and developmental outcomes. *Journal of Paediatrics and Child Health*, *40*(1-2), 2–7. doi:10.1111/j.1440-1754.2004.00280.x

O'Leary, C. M., Heuzenroeder, L., Elliott, E. J., & Bower, C. (2007). A review of policies on alcohol use during pregnancy in Australia and other English-speaking countries, 2006. *The Medical Journal of Australia*, *186*(9), 466–471.

Olson, H. C., Feldman, J. J., Streissguth, A. P., Sampson, P. D., & Bookstein, F. L. (1998). Neuropsychological deficits in adolescents with fetal alcohol syndrome: Clinical findings. *Alcoholism: Clinical and Experimental Research*, *22*(9), 1998–2012.

Ornoy, A., & Ergaz, Z. (2010). Alcohol abuse in pregnant women: effects on the fetus and newborn, mode of action and maternal treatment. *International Journal of Environmental Research and Public Health*, *7*(2), 364–379. doi:10.3390/ijerph7020364

Ősterberg, E. (2004). *What are the most effective and cost-effective interventions in alcohol control?* Retrieved from http://www.euro.who.int/document/E82969.pdf

Parry, C. D. H., Plüddemann, A., Steyn, K., Bradshaw, D., Norman, R., & Laubshcer, R. (2005). Alcohol use in South Africa: Findings from the first Demographic and Health Survey (1998). *Journal of Studies on Alcohol*, *66*(1), 91–97.

Peltzer, K., & Ramlagan, S. (2009). Alcohol use trends in South Africa. *Journal of Social Sciences*, *18*(1), 1–12.

Petković, G., & Barisić, I. (2010). FAS prevalence in a sample of urban schoolchildren in Croatia. *Reproductive Toxicology*, *29*(2), 237–241. doi:10.1016/j.reprotox.2009.11.006

Popova, S., Stade, B., Bekmuradov, D., Lange, S., & Rehm, J. (2011). What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. *Alcohol and Alcoholism*, *46*(4), 490–497. doi:10.1093/alcalc/agr029

Price, P. C., Pentecost, H. C., & Voth, R. D. (2002). Perceived event frequency and the optimistic bias: Evidence for a two-process model of personal risk judgments. *Journal of Experimental Social Psychology*, *38*(3), 242–252. doi:10.1006/jesp.2001.1509

Rehm, J., Baliunas, D., Borges, G. L. G., Graham, K., Irving, H., Kehoe, T., … Taylor, B. (2010). The relation between different dimensions of alcohol consumption and burden of disease: An overview. *Addiction*, *105*(5), 817–843. doi:10.1111/j.1360-0443.2010.02899.x.

Roberts, S. T., & Kennedy, B. L. (2006). Why are young college women not using condoms? Their perceived risk, drug use, and developmental vulnerability may provide important clues to sexual risk. *Archives of Psychiatric Nursing*, *20*(1), 32–40. doi:10.1016/j.apnu.2005.08.008

Rosenthal, J., Christianson, A., & Cordero, J. (2005). Fetal alcohol syndrome prevention in South Africa and other low-resource countries. *American Journal of Public Health*, *95*(7), 1099–1101.

Sharot, T., Korn, C. W., & Dolan, R. J. (2011). How unrealistic optimism is maintained in the face of reality. *Nature Neuroscience*, *14*(11), 1475–1479. doi:10.1038/nn.2949

Sheskin, D. (2000). *Handbook of parametric and nonparametric statistical procedures* (2nd ed.). Boca Raton, Florida: Chapman & Hall/CRC Press.

Sjöberg, L. (1998). Risk perception of alcohol consumption. *Alcoholism: Clinical and Experimental Research*, *22*(7), 277–284. doi:10.1111/j.1530-0277.1998.tb04380.x

Sjöberg, L. (2000). Factors in risk perception. *Risk Analysis*, *20*(1), 85–93. doi:10.1111/0272-4332.00001

Sjöberg, L. (2003). The different dynamics of personal and general risk. *Risk Management*, *5*(3), 19–34. doi:10.1057/palgrave.rm.8240154

Skurnik, I., Yoon, C., Park, D. C., & Schwarz, N. (2005). How warnings about false claims become recommendations. *Journal of Consumer Research*, *31*(4), 713–724. doi:10.1086/426605

Statistics South Africa. (2012). *Census 2011 Municipal fact sheet*. Retrieved from http://www.statssa.gov.za/Census2011/Products/Census_2011_Municipal_fact_sheet.pdf

Statistics South Africa. (2014). *General household survey 2013*. Retrieved from http://beta2.statssa.gov.za/publications/P0318/P03182013.pdf

Stratton, K. R., Howe, C. J., & Battaglia, F. C. (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment*. Washington D.C.: National Academy Press.

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*, *25*(4), 228–238.

Taylor, K. M., & Shepperd, J. A. (1998). Bracing for the worst: severity, testing, and feedback timing as moderators of the optimistic bias. *Personality and Social Psychology Bulletin*, *24*(9), 915–926. doi:10.1177/0146167298249001

Testa, M., & Reifman, A. (1996). Individual differences in perceived riskiness of drinking in pregnancy: antecedents and consequences. *Journal of Studies on Alcohol*, *57*(4), 360–367.

Thornton, B., Gibbons, F. X., & Gerrard, M. (2002). Risk perception and prototype perception: Independent processes predicting risk behavior. *Personality and Social Psychology Bulletin*, *28*(7), 986–999. doi:10.1177/014616720202800711

Tombor, I., Urbán, R., Berkes, T., & Demetrovics, Z. (2010). Denial of smoking-related risk among pregnant smokers. *Acta Obstetricia et Gynecologica Scandinavica*, *89*(4), 524–530. doi:10.3109/00016341003678427

Underbjerg, M., Kesmodel, U., Landrø, N., Bakketeig, L., Grove, J., Wimberley, T., … Mortensen, E. (2012). The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on selective and sustained attention in 5-year-old children. *BJOG*, *119*(10), 1211–1121. doi:10.1111/j.1471-0528.2012.03396.x

United Nations Fund for Population Activities. (2013). *The state of world population 2012: By choice, not by chance - family planning, human rights and development*. Retrieved from http://www.unfpa.org/webdav/site/global/shared/swp/2012/EN_SWOP2012_Report.pdf

Urban, M., Chersich, M. F., Fourie, L.-A., Chetty, C., Olivier, L., & Viljoen, D. (2008). Fetal alcohol syndrome among grade 1 schoolchildren in Northern Cape Province: prevalence and risk factors. *South African Medical Journal*, *98*(11), 877–882.

Van der Pligt, J. (1994). Risk appraisal and health behaviour. In D. R. Rutter & L. Quine (Eds.), *Social Psychology and Health: European Perspectives.* (pp. 131–151). Brookfield, VT, US: Avebury/Ashgate Publishing Co.

Van der Pligt, J. (1996). Risk perception and self-protective behavior. *European Psychologist*, *1*(1), 34–43. doi:10.1027/1016-9040.1.1.34

Van der Velde, F. W., & Hooykaas, C. (1992). Risk perception and behavior: Pessimism, realism, and optimism about AIDS-related health behavior. *Psychology and Health*, *6*, 23–38.

Viljoen, D., Croxford, J., Gossage, J. P., Kodituwakku, P. W., & May, P. A. (2002). Characteristics of mothers of children with fetal alcohol syndrome in the Western Cape Province of South Africa: A case control study. *Journal of Studies on Alcohol*, *63*(1), 6–17.

Viljoen, D. L., Craig, P., Hymbaugh, K., Boyle, C., & Blount, S. (2003). Fetal Alcohol Syndrome - South Africa, 2001. *Morbidity and Mortality Weekly Report*, *52*(28), 660–662.

Viljoen, D. L., Gossage, J. P., Brooke, L., Adnams, C. M., Jones, K. L., Robinson, L. K., … May, P. A. (2005). Fetal alcohol syndrome epidemiology in a South African community: A second study of a very high prevalence area. *Journal of Studies on Alcohol*, *66*(5), 593–604.

Watt, M. H., Eaton, L. A, Choi, K. W., Velloza, J., Kalichman, S. C., Skinner, D., & Sikkema, K. J. (2014). “It’s better for me to drink, at least the stress is going away”: Perspectives on alcohol use during pregnancy among South African women attending drinking establishments. *Social Science & Medicine*, *116*, 119–125. doi:10.1016/j.socscimed.2014.06.048

Wattendorf, D. J., & Muenke, M. (2005). Fetal alcohol spectrum disorders. *American Family Physician*, *72*(2), 279–285.

Webb, T. L., Sniehotta, F. F., & Michie, S. (2010). Using theories of behaviour change to inform interventions for addictive behaviours. *Addiction*, *105*(11), 1879–1892. doi:10.1111/j.1360-0443.2010.03028.x

Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology*, *39*(5), 806–820. doi:10.1037//0022-3514.39.5.806

Weinstein, N. D., & Klein, W. M. (1995). Resistance of personal risk perceptions to debiasing interventions. *Health Psychology*, *14*(2), 132–140.

Weinstein, N. D., Kwitel, A., McCaul, K. D., Magnan, R. E., Gerrard, M., & Gibbons, F. X. (2007). Risk perceptions: Assessment and relationship to influenza vaccination. *Health Psychology*, *26*(2), 146–151. doi:10.1037/0278-6133.26.2.146

World Health Organization. (2009). *Global health risks: Mortality and burden of disease attributable to selected major risks.* Retrieved from http://www.who.int/healthinfo/global_burden_disease/GlobalHealthRisks_report_full.pdf

World Health Organization. (2010). *Global strategy to reduce the harmful use of alcohol*. Retrieved from http://www.who.int/substance_abuse/alcstratenglishfinal.pdf

World Health Organization. (2011). *Global status report on alcohol and health*. Retrieved from http://www.who.int/substance_abuse/publications/global_alcohol_report/msbgsruprofiles.pdf

Yechiam, E., Druyan, M., & Ert, E. (2008). Observing others' behavior and risk taking in decisions from experience. *Judgment and Decision Making*, *3*(7), 493–500.

Yu, N., Ahern, L. A., Connolly-Ahern, C., & Shen, F. (2010). Communicating the risks of fetal alcohol spectrum disorder: Effects of message framing and exemplification. *Health Communication*, *25*(8), 692–699. doi:10.1080/10410236.2010.521910

Zajac, L. E., Klein, W. M. P., & McCaul, K. D. (2006). Absolute and comparative risk perceptions as predictors of cancer worry: Moderating effects of gender and

psychological distress. *Journal of Health Communication*, *11*, 37–49. doi:10.1080/10810730600637301

APPENDICES

Appendix A: Images of dysmorphological features

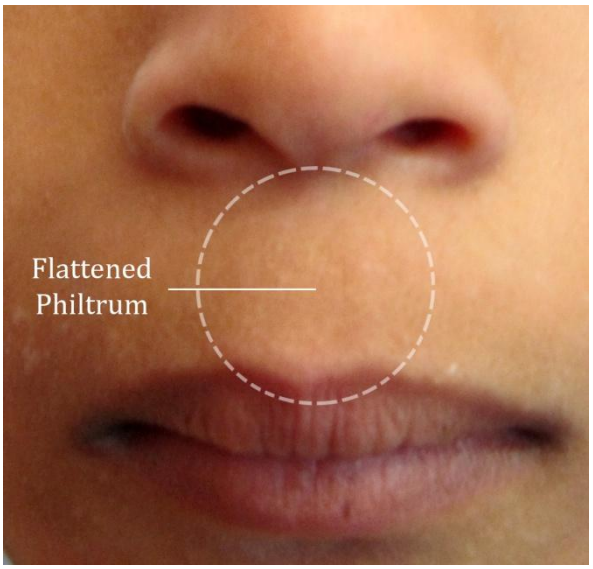


Figure A1. Flattened Philtrum associated with FASD. Copyright 2013 by Foundation for Alcohol Related Research.

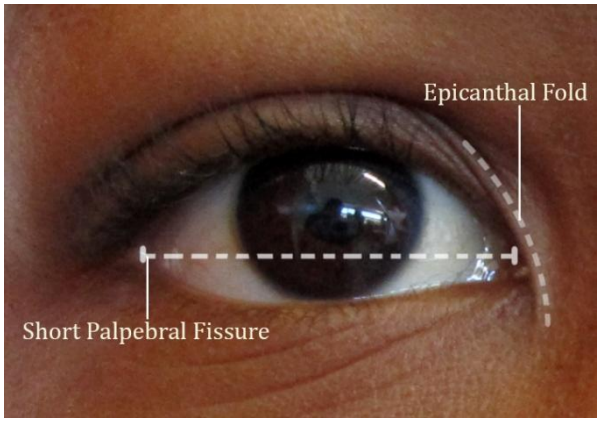


Figure A2. Epicanthal fold and short palpebral fissure associated with FASD. Copyright 2013 by Foundation for Alcohol Related Research.

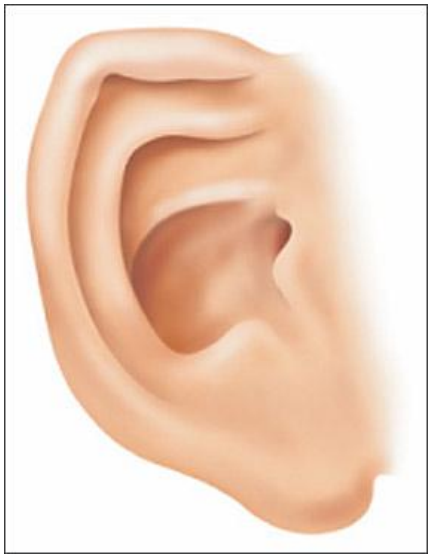


Figure A3. “Railroad track” ear associated with FASD. From “Fetal alcohol spectrum disorders,” by D. J. Wattendorf and M. Muenke, 2005, *American Family Physician*, *72*(2), p. 281. Reprinted with permission

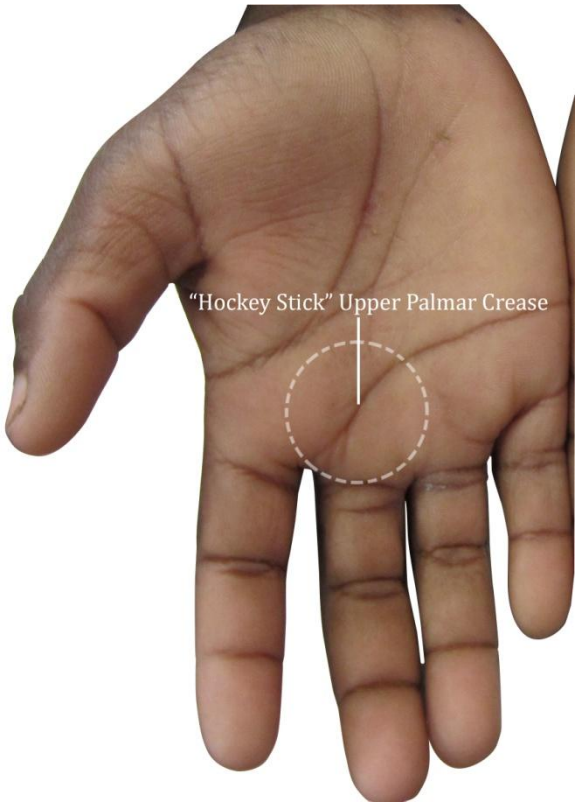


Figure A4. “Hockey stick” palmar crease abnormality associated with FASD. Copyright 2013 by Foundation for Alcohol Related Research.

Appendix B: Questionnaire

Questionnaire:

Perception of risk regarding drinking during pregnancy

Name of interviewer: _____

Date of interview:_____

HMHB Risk Group_____ [*To be completed after interview*]

Instructions:

1. Please complete the informed consent form first. If the participant is not able to read, please ensure that a (preferably impartial) third party is available to serve as witness.
2. Please complete the questionnaire in pen. If a mistake is made please draw only one line through the answer and write the correct answer next to it.
3. Where questions have more than one answer, please circle the applicable **number**. Where the question has only two choices (Yes \ No : True \ False) please circle the correct answer. If a mistake is made by one of these questions please draw an X through the incorrect circle and circle the correct answer.
4. Please read the entire scale from Definitely no to Definitely yes for each question

Introduction:

Thank you very much for your willingness to participate in this study. I would just like to remind you that you can stop at any time if you are not comfortable with the questions or if you do not want to continue. It will have no impact on your participation in FARR's Healthy Mother Healthy Baby© programme.

I also want to remind you that your answers will not be shared with anyone except FARR employees and the individuals conducting this study. Everything will remain highly confidential

1. Biographical Questions:

1. Name and Surname of person being interviewed: _____
2. HMHB Number:_____
3. When were you born?
   Day_____ Month _____ Year_____
4. For how many years did you attend school? _____
5. What was the highest grade\standard you passed? _____
6. Do you belong to a church or religious group? Yes \ No (If no skip to Question 8)
7. Does the church\religious group expect you to attend services\meetings, and if yes how often to you attend?
   1. Never
   2. Not very often (once a month)
   3. Often (twice a month)
   4. Very often\Always (Every week)
   5. Unsure

8. Are you currently employed? Yes \ No
9. How many times have you been legally married? _____

2. Perception of personal risk regarding drinking during pregnancy

The following section consists of different statements about drinking during pregnancy. I would like to know if you agree with the statements or disagree. There are no right or wrong answers. Please take a moment to think about each of the statements and then say if you agree or disagree. The options are:

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

*[To the interviewer: Please stress the words on **bold** to ensure the participant is aware the statements are applicable to her personally]*

1. If **I** drink spirits (like brandy, rum, whiskey, gin) while I'm pregnant, **my** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

2. An occasional drink (one glass of wine or equivalent once or twice a week) would be a good way for me to relax if **I** was pregnant, as long as **I** don't overdo it. [*Reverse Scored*]

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

3. If **I** am pregnant and **I** drink heavily (two or more drinks a day, or more than five per week) it increases my chances of having a baby with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

4. If **I** drink wine while I'm pregnant, **my** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

5. If **I** drink one drink (glass of wine or equivalent) **per week** while **I'm** pregnant, **my** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

6. If **I** drink one drink (glass of wine or equivalent) **every day** while **I'm** pregnant, **my** baby is more likely to have mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

7. **I** feel confident that I could stop drinking totally if **I** became pregnant.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

8. If **I** drink beer while **I'm** pregnant, my baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

9. Even if it's hard for **me** to avoid drinking while **I'm** pregnant, **I** know that it is worth it.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

10. Not drinking while **I'm** pregnant means **I'll** have a healthy baby.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

11. Not drinking while **I'm** pregnant means **my** baby cannot be born with Foetal Alcohol Syndrome

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

12. If **I** am pregnant and **I** binge drink (more than 5 drinks per occasion) it increases **my** chances of having a baby with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

13. If **I** drink coolers (Bacardi Breezers, Smirnoff Spins, Hunters etc.) while **I'm** pregnant, **my** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

3. Questions about smoking habits:

1. Have you smoked cigarettes, or used tobacco at any stage of your life? Yes \ No (if no skip to next section)
2. Do you currently smoke? Yes \ No
3. If you have stopped smoking, when did you stop? _____

4. Questions regarding pregnancy:

1. How many times have you been pregnant? ____
2. How many children were born full-term (at 9 months)? ____
3. How many were born prematurely? ____
4. Have you ever had a miscarriage? Yes \ No
5. Have you ever had a still-birth? Yes \ No
6. Have you ever had a child diagnosed with FASD? Yes \ No
7. Have you had a planned abortion? Yes \ No
8. How many of your pregnancies were planned? ____
9. How many were unplanned? ____
10. Have you ever had a child pass away younger than 1 month old? Yes \ No
    If yes: Age____ Cause____
11. Have you ever had a child pass away younger than 1 year old? Yes \ No
    If yes: Age____ Cause____
12. Do you usually use birth control to prevent pregnancy? Yes \ No
13. If yes what method do you use? _____

5. Perception of general risk associated with drinking during pregnancy

The following section consists of different statements about drinking during pregnancy. The statements are about “a woman in my community”. Please try not to think of a specific person, but rather think of the average woman in your community. I would like to know if you agree with the statements or disagree. There are no right or wrong answers. Please take a moment to think about each of the statements and then if you agree or disagree. The options are:

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

*[To the interviewer: Please stress the words on **bold** to ensure the participant is aware the statements are applicable to an average woman in her community]*

1. If **a woman in my community** drinks spirits (like brandy, rum, whiskey, gin) while pregnant, **her** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

2. An occasional drink (one glass of wine or equivalent once or twice a week) would be a good way for **a woman in my community** to relax while pregnant, as long as she doesn't overdo it. [*Reverse scored*]

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

3. If **a woman in this community** drinks while pregnant (two or more drinks a day, or more than five per week) it increases **her** chances of having a baby with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

4. If **a woman in this community** drinks wine while, **her** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

5. If **a woman in my community** drinks one drink (glass of wine or equivalent) **per week** while she’s pregnant, **her** baby is more likely to have mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

6. If **a woman in my community** drinks one drink (glass of wine or equivalent) **every day** while she is pregnant, **her** baby is more likely to have mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

7. Most **women in this community** can stop drinking totally if they become pregnant.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

8. If **a woman in this community** drinks beer while she is pregnant, **her** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

9. Even if it's hard for **a woman in this community** to avoid drinking while she is pregnant, it is worth it.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

10. If **a woman in this community** does not drink while pregnant she'll have a healthy baby.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

11. If **a woman in this community** does not drink while pregnant her baby cannot be born with Foetal Alcohol Syndrome.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

12. A pregnant **woman in this community** who binge drinks (more than 5 drinks per occasion) increases **her** chances of having a baby with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

13. If **a woman in this community** drinks coolers (Bacardi Breezers, Smirnoff Spins, Hunters etc.) while she is pregnant, **her** baby is more likely to be born with mental or physical problems.

1	2	3	4	5
Definitely not	Maybe not	Neutral	Maybe yes	Definitely yes

6. FASD Knowledge Questions

Please answer the following questions true or false

1. No kind of alcohol is safe to drink while pregnant True / False
2. The problems caused by FASD last for a lifetime True / False
3. If I have had a healthy baby even though I drank during pregnancy, it does not mean that I cannot have a child with FASD. True / False
4. There is no safe time to drink during pregnancy True / False
5. There is no known safe amount to drink during pregnancy True / False
6. Anyone can have a baby with FASD if they drink during pregnancy True / False
7. FASD is a 100% (completely) preventable True / False
8. FASD cannot be cured True / False
9. A Fathers drinking cannot give a baby FASD True / False
10. A child with FASD may need medical care (doctors) all their life True / False

All the statements we just went through are in fact true *[To the interviewer: Please read the statements again]*

1. No kind of alcohol is safe to drink while pregnant
2. The problems caused by FASD last for a lifetime
3. If I have had a healthy baby even though I drank during pregnancy, it does not mean that I cannot have a child with FASD.
4. There is no safe time to drink during pregnancy
5. There is no known safe amount to drink during pregnancy
6. Anyone can have a baby with FASD if they drink during pregnancy
7. FASD is a 100% (completely) preventable
8. FASD cannot be cured
9. A Fathers drinking cannot give a baby FASD
10. A child with FASD may need medical care (doctors) all their life

That is the end of the questionnaire. Thank you very much for your participation, it is greatly appreciated.

Appendix C: Ethical approval

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Notice
Response to Modifications- (New Application)

28-Jan-2013
Louw, Jacobus G
Victoria Street
Stellenbosch
Stellenbosch, WC

Ethics Refernce #: S12/11/274
Title: Perception of the personal and general risk of alcohol use during pregnancy among women in a South African community

Dear Mr Jacobus Louw,

The **Response to Modifications** - ***(New Application)*** received on **22-Jan-2013**, was reviewed by Health Research Ethics Committee 2 via Committee Review procedures on **28-Jan-2013** and has been approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **28-Jan-2013 -28-Jan-2014**

Present Committee Members:
Davids, Mertrude MA
Fernandez, Pedro PW
Kruger, Mariana M
Blaauw, Renee R
Bardien-Kruger, Soraya S
Barsdorf, Nicola
De Roubaix, Malcolm JAM
Engelbrecht, Susan S
Willett, David DWE
Verster, Gerrit GC
Edwards, C E
Rohland, Elvira EL
Botha, Matthys MH

Please remember to use your **protocol number** (**S12/11/274**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired.
The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.
Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 0219389207.

Included Documents:
Checklist
Consent Form
Synopsis
Investigators declaration
Application Form
Protocol

Sincerely,

Mertrude Davids
HREC Coordinator
Health Research Ethics Committee 2

Appendix D: Informed Consent

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Perception of the personal and general risk of alcohol use during pregnancy among women in a South African community

REFERENCE NUMBER: S12/11/274

PRINCIPAL INVESTIGATOR: Jaco Louw

ADDRESS: **Saxenburg Crescent 1**
Strand
7140

CONTACT NUMBER: 072 342 8234

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study is being done among women who participate in FARR's Healthy Mother Healthy Baby program in De Aar and there will be about a hundred women in total taking part.

This study wants to see how risky women in this community think it is to drink during pregnancy in terms of having a child with Fetal Alcohol Syndrome (FAS). In other words what do women in this community think that the chances of having a child with FAS are if alcohol is used during pregnancy.

If you take part in the study you will be interviewed by one of FARR's field workers who will go through a questionnaire\list of questions with you. The process will take about one hour. We will then use the answers you give and the AUDIT test on drinking behaviour that FARR completed with you, to explore how women in this community see the risk of drinking during pregnancy.

Why have you been invited to participate?

You have been chosen to participate because you are part of the Healthy Mother Healthy Baby© programme and you already completed an AUDIT test about drinking behaviour for FARR so we will not have to do another one.

What will your responsibilities be?

If you participate in this research you must complete the interview with the field worker and you must be willing for us to use the results of the AUDIT test that FARR has on file for you.

Will you benefit from taking part in this research?

You do not stand to benefit directly from this research, but your assistance will help us learn more about how women think about drinking during pregnancy and the risk of FAS. Based on this we can develop new ways to inform the public about FAS to try and prevent children being born with FAS.

Are there in risks involved in your taking part in this research?

There are no foreseeable risks associated with taking part in this study, but if participating causes you any discomfort or distress the FARR staff will be able to assist you.

If you do not agree to take part, what alternatives do you have?

If you choose not to take part it will not count against you at all. It will not impact on your participation in the Healthy Mother Healthy Baby© programme at all.

Who will have access to your medical records?

We will not have access to your medical records, but we will have access to the results of your AUDIT test. Only the FARR field worker conducting the interview, those directly involved with this study and, in the event of an audit, the Research Ethics Committee (REC) at Stellenbosch University will have access to the answers on your questionnaire. The questionnaire will be kept in a locked office, and upon completion of the study it will be stored in a locked archive at FARR's offices in Cape Town. When the data is captured and analysed your name will be replaced with a code so your answers will remain anonymous.

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

There are no foreseeable risks associated with taking part in this study, but if participating causes you any discomfort or distress the FARR staff will be able to assist you.

Will you be paid to take part in this study and are there any costs involved?

You will not be paid to take part in this study. Taking part in this study will not cost you anything

Is there any thing else that you should know or do?

- You can contact Lian Drotsky at tel: 053 631-1922 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

➢

Declaration by participant

By signing below, I ……..…….. agree to take part in a research study entitled: Perception of the personal and general risk of alcohol use during pregnancy among women in a South African community

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2005.

....

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2005.

....

Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* ……..…… declare that:

- I assisted the investigator (*name*) …… to explain the information in this document to (*name of participant*) ……..…….. using the language medium of Afrikaans/Xhosa.

- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) .....….....…….. on (*date*) ……...……..

....

Signature of interpreter **Signature of witness**

DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK:

Persepsie van die persoonlike en algemene risiko van alkohol gebruik tydens swangerskap onder vrouens in ’n Suid Afrikaanse gemeenskap

VERWYSINGSNOMMER: S12/11/274

HOOFNAVORSER: Jaco Louw

ADRES: **Saxenburg Crescent 1**
Strand
7140

KONTAKNOMMER: 072 342 8234

U word genooi om deel te neem aan ’n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek?

Hierdie studie word uitgevoer onder vroue wat in De Aar aan FARR se “Healthy Mother Healthy Baby©” program deelneem. In totaal gaan daar ’n honderd vroue deelneem

Hierdie studie wil vasstel hoe vroue, van hierdie gemeenskap dink oor die gevare van alkohol gebruik tydens swangerskap, terme van Fetale Alkohol Sindroom (FAS). Met ander woorde, wat dink vroue in die gemeenskap is die kans om geboorte te skenk aan ’n kind met FAS as drank tydens swangerskap gebruik word.

As u deelneem aan die studie sal een van FARR se veldwerkers ’n onderhoud met u voer en deur ’n vraelys gaan. Die proses sal ongeveer een uur neem. Ons gaan dan u antwoorde op die vraelys na, asook die AUDIT toets oor drankgebruik wat FARR met u gedoen het. Ons gebruik dan alle inligting om vas te stel hoe vrouens die gevaar van drink tydens swangerskap sien

Waarom is u genooi om deel te neem?

U is gekies om deel te neem omdat u deel is van FARR se “Healthy Mother Healthy Baby©” program en omdat u reeds ’n AUDIT toets oor drankgebruik voltooi het, so ons hoef nie weer een te doen nie.

Wat sal u verantwoordelikhede wees?

As u deelneem in die studie moet u die onderhoud met die FARR veldwerker voltooi. U moet ook bereid wees dat ons die resultate van die AUDIT toets wat u reeds voltooi het gebruik.

Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

U gaan nie direk bevoordeel word deur hierdie studie nie, maar u hulp sal ons in staat stel om te leer hoe vroue dink, oor drink tydens swangerskap en die risiko van FAS. Ons kan dan, gebaseer op hierdie inligting, nuwe maniere ontwikkel om die samelewing bewus te maak oor FAS en daardeur poog om te keer dat kinders met FAS gebore word

Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

Daar is geen voorsienbare risiko's verbonde aan deelname in hierdie studie nie, maar sou u deelname enige ongemak of ontsteltenis veroorsaak, sal die FARR werkers u kan bystaan

Watter alternatiewe is daar indien u nie instem om deel te neem nie?

As u besluit om nie deel te neem nie, sal dit geen impak hê op u deelname aan die “Healthy Mother Healthy Baby©” program nie

Wie sal toegang hê tot u mediese rekords?

Ons gaan nie toegang hê tot u mediese rekords nie, maar ons sal toegang hê tot die AUDIT toets wat u by FARR gedoen het. Slegs die FARR veldwerker wat die onderhoud voer, diegene wat direk by die studie betrokke is en, in geval van ‘n oudit, die Gesondheidsnavorsingsetiekkomitee (GNEK) van Universiteit Stellenbosch sal toegang hê tot u antwoorde op die vraelys. Die vraelys sal in ‘n geslote kantoor gehou word, en nadat die studie voltooi is sal dit in ‘n geslote argief by FARR in Kaapstad geberg word. Waneer die data ge-analiseer word sal u naam met ‘n kode vervang word so u antwoorde sal anoniem bly.

Wat sal gebeur in die onwaarskynlike geval van ’n besering wat mag voorkom as gevolg van u deelname aan hierdie navorsingsprojek?

Daar is geen voorsienbare risiko's verbonde aan deelname in hierdie studie nie, maar sou u deelname enige ongemak of ontsteltenis veroorsaak sal die FARR werkers u kan bystaan

Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

U sal nie betaal word vir deelname aan die navorsingsprojek nie. Deelname aan die navorsingsprojek sal u niks kos nie.

Is daar enigiets anders wat u moet weet of doen?

- U kan Lian Drotsky kontak by tel 053 631-1922 indien u enige verdere vrae het of enige probleme ondervind.
- U kan die **Gesondheidsnavorsingsetiek administrasie** kontak by 021-938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur u studiedokter hanteer is nie.
- U sal ’n afskrif van hierdie inligting- en toestemmingsvorm ontvang vir u eie rekords.

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek, ……..……..……..……., om deel te neem aan ’n navorsingsprojek getiteld: Persepsie van die persoonlike en algemene risiko van alkohol gebruik tydens swangerskap onder vrouens in ’n Suid Afrikaanse gemeenskap

Ek verklaar dat:

- Ek hierdie inligting- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in ’n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te *(plek)* ..... op *(datum)* ……..…….. 2012.

....

Handtekening van deelnemer **Handtekening van getuie**

Verklaring deur navorser

Ek *(naam)* ……..…… verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan

  …….....…….

- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek ’n tolk gebruik het/nie ’n tolk gebruik het nie. (*Indien ’n tolk gebruik is, moet die tolk die onderstaande verklaring teken.)*

Geteken te *(plek)* ..... op *(datum)* ……..…….. 2012.

....

Handtekening van navorser **Handtekening van getuie**

Verklaring deur tolk

Ek *(naam)* ……..…… verklaar dat:

- Ek die navorser *(naam*) …….....…….. bygestaan het om die inligting in hierdie dokument in Afrikaans/Xhosa aan *(naam van deelnemer)* ……..... te verduidelik.
- Ons hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek ’n feitelik korrekte weergawe oorgedra het van wat aan my vertel is.
- Ek tevrede is dat die deelnemer die inhoud van hierdie dokument ten volle verstaan en dat al sy/haar vrae bevredigend beantwoord is.

Geteken te *(plek*) .....…….. op *(datum*) ……...…….. 2012.

....

Handtekening van tolk **Handtekening van getuie**