THE EXPERIENCES OF MOTHERS WHO RAISE CHILDREN WITH FETAL ALCOHOL SYNDROME: A COLLECTIVE CASE STUDY

By

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Thesis submitted in partial fulfillment of the requirements for the degree of

Master of Education in Educational Psychology (MEdPsych)

at the

Stellenbosch University

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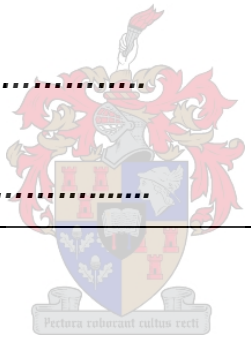
March 2007

DECLARATION

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

Signature: ***……***

Date: ***……***



SUMMARY

Fetal Alcohol Syndrome (FAS) is an ongoing problem in the Western Cape. Marginalised and poverty-stricken communities use alcohol as a method of entertainment because it is freely available and relatively inexpensive. Due to a cycle of ongoing poverty and lack of education, many women drink large quantities of alcohol when they are pregnant or before they know they are pregnant. This causes the unborn baby to be severely at risk for FAS. There has been much research done in academic and social environments on the presentation and symptoms of FAS and of behaviour. Less research has been done surrounding the mother's experience of her FAS child, it is therefore my aim to research this gap in the research.

This research study investigated the experience of mothers who raised children with FAS. Many mothers of children with prenatal exposure to alcohol feel conflict and guilt regarding their children and I attempted to find out what their general experience surrounding this was. Within this research topic I aimed to investigate the mothers' attitudes, their behaviour towards and their general perceptions of their developing child with FAS. This was viewed from an eco-systemic framework in which the mother is an integral part of different systems impacting and working together, that influence her maternal functioning. Finally, the aim of this research study was to ascertain how best mothers of FAS children could be supported. In this same process, I hoped, the mothers could learn to feel empowered to help and support their child, and in the process attempt to shift ongoing cycles of negative behaviour patterns to more positive outcomes.

The over-riding method for the research was an interpretive qualitative and collective case study, using an interpretivist paradigm. The subjective experiences of the mothers who rear FAS children were collected as data.

Interviews, observations and information gathered from medical files was my main method of data collection**.** The participants were three biological mothers from an urban area in Cape Town whose children had been clinically diagnosed as having FAS. Themes that emerged from the data have been recorded and repeated patterns finally viewed from an eco-systemic framework will be discussed. The research findings will be also be discussed and presented.

OPSOMMING

Fetale Alkohol Sindroom (FAS) kan beskou word as 'n voortgaande probleem in die Wes-Kaap. Gemarginaliseerde en arm gemeenskappe gebruik alkohol as deel van hul ontspanning aangesien dit betreklik goedkoop en vrylik beskikbaar is. Weens 'n kringloop van armoede en gebrekkige kennis, drink baie vroue groot hoeveelhede alkohol terwyl hulle verwagtend is of onbewus is van hul swangerskap. Hierdie lewensstyl kan geweldige groot risiko's inhou vir die ontwikkeling van FAS by ongebore babas. Daar is reeds baie navorsing gedoen in akademiese en sosiale omgewings oor die voorkoms en simptome van FAS en die gedragspatrone wat daarmee gepaardgaan. Minder navorsing is uitgevoer aangaande moeders se belewenisse van hul kinders met FAS en derhalwe is dit my doelwit om navorsing te doen in hierdie veld.

Hierdie navorsingstudie ondersoek die belewenisse van moeders wat kinders met FAS grootmaak. Talle moeders van kinders met voorgeboortelike blootstelling aan alkohol, ervaar konflik en skuldgevoelens aangaande hul kinders en ek het probeer om vas te stel wat hul algemene ervarings is. Binne hierdie navorsingsonderwerp is dit my doel om benewens hul algemene persepsies en perspektiewe rondom hul kind, ondersoek in te stel aangaande moeders se houdings en gedragsoptrede teenoor hul kinders met FAS. Die ondersoek is benader in die lig van 'n eko-sistemiese raamwerk waar die moeder 'n integrale deel vorm van onderskeie interaktiewe en samewerkende sisteme. Hierdie sisteme affekteer en beïnvloed haar funksionering as moeder. Ten slotte was die doel van hierdie studie ook om vas te stel op watter wyses daar ondersteuning aan moeders van FAS kinders gebied kan word. Terselfdertyd was dit my strewe om die moeders te laat leer en te bemagtig oor hoe om hul kinders te help en te ondersteun. Hiermee word gepoog om die voorgaande siklusse van negatiewe gedrag te omskep in meer positiewe uitkomste.

Die oorhoofse navorsingsmetode was 'n interpretiewe, kwalitatiewe en kollektiewe gevallestudie wat vanuit 'n interpretivistiewe paradigma gebruik is. Die subjektiewe ervaringe van moeders wat kinders grootmaak is versamel as datagegewens. Onderhoude, observasies en inligting wat versamel is vanuit mediese lêers was my hoofbronne van data wat geraadpleeg kon word. Die deelnemers het bestaan uit die biologiese moeders wie se kinders klinies gediagnoseer is met FAS, woonagtig in 'n stedelike gebied in Kaapstad. Temas wat voortspruit uit die data sal aangeteken word en herhaalde tendense wat finaal vanuit 'n ekosistemiese verwysingsraamwerk gesien kan word, sal bespreek word. Die navorsingsbevindinge sal ook bespreek en voorgelê word.

ACKNOWLEDGEMENTS

I would like to thank the following people for assisting and supporting me on this journey:

- My mother, Sarah, for her constant enthusiasm and interest in my studies and in particular, this research process.
- My teenage son, Tom, for his patience and level headed nature, for always allowing me the freedom I needed to study, and for never complaining during this seemingly endless process.
- Richard, for constantly being there, and always encouraging me to go further, to see things from a different perspective, and to keep pushing the boundaries.
- The Foundation for Alcohol related research, especially Mrs. A. Marais who were always supportive and incredibly helpful in making the connections with the participants that made this study possible.
- My supervisor, Mariechen Perold, for her continued guidance, support and encouragement, especially when the going got tough.
- The participants in this study, the three mothers whom I interviewed. I feel humbled and honoured to have had the opportunity to briefly see the world through their eyes.

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CHAPTER 1

CONTEXTUALISATION AND ORIENTATION OF THE STUDY

1.1 INTRODUCTION

According to Olson, O''Connor and Fitzgerald (2001:271), ""alcohol interferes with the developing brain at multiple levels and alters the coordinated developmental schedule of the central nervous system. Thus prenatal alcohol exposure can adversely impact the child''s neurobehavioral functioning, with lifelong implications for development ranging from subtle functional compromise to diagnosable disabilities"". Mothers who consume alcohol when they are pregnant can cause their children to be affected in the way described above, which is known as Fetal Alcohol Syndrome (FAS). Olson et al*.et al.* (2001:275) describe how this syndrome creates ""lifelong implications for development"" of the child born with FAS. Children born with FAS are severely at risk of having learning and behaviour problems.

The consumption of alcohol and its misuse in some subcultures of the population in the Western Cape of South Africa is socially accepted according to Viljoen, Croxford, Gossage, Kodituwaku and May (2002:7): ""… drinking during pregnancy has been reported to be frequent in parts of the Western Cape, even among prenatal clinic patients"".

Although there is much information on the clinical presentation and behaviour manifestations of FAS, there is very little research regarding the biological parents'' experience of rearing children with FAS.

The reason that I chose to research a study on FAS is largely a matter of coincidence. The road that I travelled during the year that I spent driving to Stellenbosch to complete my Master''s degree took me through exquisite vineyards. Dotted amongst these grape vines were cottages which housed underprivileged families. I often wondered about them and the life they led, knowing that although they are in such beautiful surroundings they live in abject poverty.

Coincidently, my community service during my year of study took me to a farm school in the midst of the above-mentioned context. I was involved with the language enrichment of grade 1 learners whose home language was not the same as the language of instruction at their school. These learners struggled to understand what the teacher was telling them to do in the classroom situation. I took small groups at a time and used various reading approaches and interventions to increase their vocabularies and enrich their understanding of English.

The vast majority of these learners came from farming communities in and around the area. Most of them were thin, untidy and clothed in anything that could be found for them to wear, often not appropriate to the season. Most of the children somehow managed to follow the instructions given by the educator either through understanding or watching what others were doing at the work table. However a handful of children in each of the junior primary phase classes did not follow the teacher''s instructions, and were clearly at a constant loss of what to do, often confused and uncertain of how to work at all. They appeared out of place and isolated, certainly not engaging in the educational process. These children, according to their teacher, were the children with ""FAS"", and as an educator of special needs learners, they tugged at my heart strings.

As I have researched FAS, it is only now, on reflection, that I understand what those learners may have been experiencing. Not only the neurological and biological implications of the FAS diagnosis, but also the emotional component of being raised by mothers/fathers who abuse and consume alcohol. I started to think about the various contextual components, influences, and realities in these children''s lives. As there has been much researched and recorded regarding FAS academic and behavioural presentation, I started to feel curious and concerned about their mothers reality and unique life perspective. In addition, I have come to realize how little research there is regarding a mother's' experience in rearing her child with FAS.

Streissguth, Bookstein, Barr, Sampson, O''Malley and Kogan Young (2004:230) make the telling comment that ""[t]here are almost no studies of the psychosocial milieu into which children with FAS are born, or of how this might affect their lives at different stages of development. Each person with FAS has a mother who abused alcohol to some extent"". This was the motivation for my study. Another insight provided by Streissguth et al.*et al.* (2004:230) was:

> Among the environmental circumstances frequently found in association with prenatal alcohol damage are early maternal death, living with an alcoholic parent, child abuse and neglect, being removed from the home by authorities, experiencing repetitive periods of foster carse and other transient home placements, and being raised by adoptive or foster families.

I felt that the learners with FAS are burdened indeed. But then the question presented itself: what about his/her mother in this scenario, what does she experience as a parent? I felt urged and committed to commence this research study. As an educational psychologist, I also felt that this topic of research was relevant within our society at this time. If viewed from an eco-systemic framework, the mother has a critically important role in influencing the potential of her child. Schools and professionals cannot work in isolation. The role of the mother is extremely valuable and we need to have her “"on board”" in the child''s education.

1.2 THE ROLE OF THE RESEARCHER

Denzin and Lincoln (2005:4) liken the qualitative researcher to a quilt maker, ""as he stitches, edits and puts slices of reality together"". This process creates and brings psychological and emotional unity – a pattern – to an interpretive experience. My role as researcher in this study will be one of immense responsibility to explain the plight and narratives of mothers of children born with FAS. My sense of social responsibility has influenced my choice of topic for the study and I think, also, my experience of being a mother. I have therefore combined different issues together, the product of which has been this research document.

Denzin and Lincoln (2005:6) continue by stating that the researcher understands ""that research is an interactive process shaped by his or her own personal history, biography, gender, social class, race and ethnicity, and by those of the people in the setting"". The researcher brings to the study many aspects of her/his own life experience and reality and weaves together the multi aspects of another''s life experience.

1.2.1 Researcher bias

According to Bless and Higson-Smith (1995:146), ""As human beings, researchers can never be completely neutral"". I attempted to remain as unbiased as possible in this research study as it was the mother''s experience that I was investigating. Bless

and Higson-Smith (1995:146) continue that ""throughout the research process the beliefs of the researchers, their political, religious and racial attitudes and other convictions play an underlying role"". In my attempt to investigate the participants ""experience"" of the phenomena of raising a child with FAS, I made sure at all times that my researcher bias aimed for what Patton (2002:49) described as ""empathic neutrality"". This is the ""middle ground between becoming too involved which could cloud judgment and remaining too distant, which could reduce understanding"". So the challenge for me as a researcher was to attempt to simply report on the data that I collected and analysed in a neutral manner. Usefully, Patton (2002:57) argues that neutrality ""does not mean detachment. Qualitative inquiry depends on, uses and enhances the researchers direct experiences in the world and insights about these experiences. This includes learning through empathy"".

This enabled me to attempt to give the inquiry credibility at the same time because as Patton (2002:51) states, ""qualitative inquiry seek honest, meaningful, credible and empirically supported findings"".

1.3 PROBLEM STATEMENT

The problem statement regards the experience of mothers who rear children with FAS. Very little research has been done regarding the families or in this case the mothers of children with FAS. If we are to target FAS as a problem to be prevented, we need to target the grass roots of the situation ""healthcare providers at all levels should be trained to screen for, diagnose, prevent and treat an alcohol exposed pregnancy"" (Rosental, Christianson and Cordero, 2005:1099). In addition ""because FAS is preventable through behavioural change, more research is needed on ways to change the drinking patterns of pregnant women"" (Baxter, Hirokawa, Lowe, Nathan and Pearce, 2004:225).

It is important to view the child with FAS in his systemic context and ask why it is still so prevalent. According to Baxter et al.*et al.* (2004:226), ""some populations appear to be at substantially greater risk for FAS and related alcohol induced disorders"". This statement is especially appropriate when bearing in mind mothers in the Western Cape of South Africa who give birth to children with FAS. Baxter et al.*et al.* (2004:226) continue that FAS appears to be negatively related to socio economic status.

What is still needed, according to Rosental et al.*et al.* (2005), is risk factor intervention techniques and long term planning in which education and support are provided in group settings which can promote and reinforce safer behaviours and behaviour change.

In addition to the above-mentioned factors, my motivation for pursuing this research study included the adversity that children with FAS experience in childhood. They are affected not only because their mothers'' misused alcohol while they were in utero but they are also at risk because of lack of adequate parenting practices.

The Addiction and Family Research Group (www.addictionandfamily.org:parenting) states that alcoholic parents'' offspring often manifest significant emotional, behavioural and social problems. In addition, parental substance abuse has a negative impact on parenting behaviours displayed toward children. Inadequate and punitive parenting practices play a critical role in the development and maintenance of child problems. Mayes and Bornstein (1997) state that different types of negative parenting practices have been closely associated with the development of childhood problems.

There is substantial evidence that there is increased risk of adverse outcomes for children of substance-abusing parents. It is therefore critically important that parental intervention is carefully structured to alleviate this problem. In addition, according to Olson et al.*et al.* (2001:271) ""environmental influences may mediate or moderate the relations between prenatal alcohol exposure and developmental outcome"". Olson et al.*et al.* (2001:271) continue by stating that women who consumed more alcohol during pregnancy had infants with higher levels of negative affect and insecure attachments.

The research question that serves as the guideline for this study is:

""What are the experiences of mothers who rear children with fetal alcohol syndrome?""

I will constantly refer to this question throughout the research study.

1.4 AIM OF THE RESEARCH

The main aim of the research was to find out what the unique experiences were of mothers who rear children with FAS. It was hoped, that patterns that emerged from

the data would offer a different perspective on children who were born with FAS, namely the mothers'' unique experience. As a secondary aim, it might be possible to look for ways of supporting mothers who rear children with fetal alcohol syndrome. Rosental et al.*et al.* (2005:1099) argue that ""we need to better understand the many social and psychological processes that contribute to risky drinking and sexual activities in the environments in which these mothers live and we must seek to delineate personal and social interventions that are both acceptable and realisable"".

Through the findings of the research, it was hoped that new insights might be gained into how best to support mothers of children who have FAS. Another very important aim of this research study would be to contribute to the process of educating mothers who abuse alcohol. A related aim would be to contribute to a FAS prevention programme within specific communities where inhabitants are particularly at risk here in the Western Cape.

It is hoped that the research will contribute to a greater understanding of FAS and the implications for education within larger and across different communities. As Rosental et al.*et al.* (2005) argue, for communities, changes in attitudes, norms and practices can be brought about through health communication, social marketing, community mobilisation and organisation.

1.4.1 Context

I selected to interview biological mothers of children with FAS who live in the Cape Town Metropolitan area. The suburbs that they come from are poverty stricken areas on the Cape Flats, an urban area around Cape Town. Each of the mothers had children who had been formally and clinically diagnosed as having FAS. This process is lengthy and complex. It must be performed by a dysmorphologist as they are testing and diagnosing for four specific criteria or ""a distinctly recognizable pattern of malformations associated with maternal alcohol abuse"" (Hoyme, May, Kalberg, Kodituwakku, Gossage, Trujillo, Buckley, Miller, Aragon, Khaole, Viljoen, Lyons Jones and Robinson, 2005:39). Diagnosis of FAS will be discussed in detail in Chapter two. Addendum C can be consulted regarding the criteria for diagnosing FAS.

I was allocated three biological mothers by the Foundation for Alcohol Related Research (FARR). While these mothers were pregnant, they were tested and examined at the maternal obstetric unit in a suburb, Cape Town. They became part of a research study, namely ""Fetal Alcohol Syndrome: Pre-natal assessment of the foetus at high risk"" being carried out by Louise Matthews for an MD in medicine.

Each of the mothers reported alcohol consumption during pregnancy. In addition they all resided in under-privileged urban suburbs on the Cape Flats.

1.5 RESEARCH PARADIGM

The framework that I used for this study was that of a constructivist interpretive paradigm. According to Mertens (20041:169), ""in qualitative research, the investigator usually works with a wealth of rich descriptive data, collected through methods such as participant observation, in depth interviewing and document analysis"". She further defines this process by stating that ""the constructivist researcher must provide information about the backgrounds of the participants and the contexts in which they are being studied"". Merriam (2002:5), states that in this process the researcher will ""strive to understand the meaning people have constructed about their world and their experiences"" (in this case, the experience of the mother in raising her child with FAS).

Merriam (2002:4) contends that the researcher in an interpretive qualitative study is interested in understanding how participants make meaning of a situation or phenomenon. This meaning is then mediated through the researcher. In this process the researcher seeks to discover and understand a phenomenon, a process, the perspectives and worldviews of the people involved.

Flick (1998:19) discusses how ""the concentration on the participants'' points of view and on the meaning they attribute to experiences and events, as well as the orientation towards the meaning of activities and events, informs a large part of qualitative research"". Merriam (2002), states that the process is about showing how complex meanings are built out of simple units of direct experience. Therefore this form of research is an attempt to investigate inner experiences un-probed in everyday life. In this particular study, the focus is on the experiences of mothers who rear children with FAS.

In order to understand the essence or structure of an experience the researcher should put aside attitudes and beliefs that are held in order to have a clearer picture of what the essence of the phenomenon is.

1.6 RESEARCH DESIGN

The research design supplies the framework for my study. This framework guides and gives structure to the study and to the research process. Qualitative research, according to Denzin and Lincoln (2005) is inherently multi-method in focus. I therefore made use of various methods in order to give my study credibility.

I have chosen to do a collective case study for the research design of this research study. According to Merriam (2002:8), the case study is an intensive description of a social unit such as, in this case, three individual mothers. ""The case is a bounded integrated system. By concentrating on a single phenomenon this approach seeks to describe the phenomenon in depth. The unit of analysis, (mothers rearing their children with FAS) and not the topic of investigation, characterizes a case study"". Stake (2005:444) continues by saying that ""case study concentrates on experiential knowledge of the case and close attention to the influence of its social, political, and other contexts"".

1.7 RESEARCH METHODOLOGY

Merriam (2002:97) talks about description (interviews), reduction (thematisations) and finally interpretation (hermeneutic reflection), during the methodology process. Mertens (20041:69) argues ""the perceptions of a variety of types of persons must be sought"" during the methodological process.

The interviews that took place during the fieldwork and data gathering were conducted in poverty-stricken urban suburbs on the Cape Flats. Through purposive sampling, I was able to isolate mothers who had clinically diagnosed children with FAS. The mothers whom I interviewed signed an informed consent form (see Addendum B) and were willing to participate in the interviewing process. The mothers were also given the opportunity to decide whether they wanted to participate in the study or not. In addition information regarding the research process and what it would entail was given to them, which they signed (see Addendum B).

The three mothers became the collective cases in question in this study. They were interviewed using open-ended questions (see Addendum D). These were semi-structured interviews conducted with the help of a carefully prepared interview schedule. These were also depth interviews that were made use of in order to elicit

as much in depth information as possible. In addition, I made use of a relatively informal approach to the interviewing, which I hoped, would put the participants that I interviewed at ease.

I also gathered information from the members of the FARR team regarding these mothers who comprised the collective case study. I used audio-cassette tape-recordings to store the information and these were used in order to transcribe the information and answers to the questions verbatim.

Babbie and Mouton (2001:282) report ""using multiple sources of data is important in case studies … this involves using more than one method, multiple interview or observation occasions and a variety of informants. The product of such a research process would be a thickly described life history from the point of view of the subject"". Based on what Babbie and Mouton advise, the third source of data that was made use of was that of community context observation of the mothers and their children with FAS. According to Denzin and Lincoln (2005:643), ""there is no pure, objective, detached observation; the effects of the observer''s presence can never be erased … observers now function as collaborative participants in action inquiry settings"". In addition to these two sources of information, I received generalised information regarding the participants from the FARR representative. She had had extensive dealings with each of the mothers who took part in this study.

Once the data had been transcribed I commenced the analysis of this. I used codes to isolate and designate themes at first, which emerged out of the data analysis process. I then looked at patterns emerging from the themes. These were then viewed through the ecosystemic framework. In case studies, according to Babbie and Mouton (2001:283), ""research reports must account for the multidimensionality of the findings which is done by presenting the multiple patterns of phenomena and by describing the context and conditions under which the patterns appear"". Finally, once all of the above had taken place, I started to formulate further research recommendations. I also identified the limitations of the research process.

1.7.1 Trustworthiness, credibility, dependability and confirmability

In order to ensure verification of data and data analysis, the trustworthiness of the research study must be ensured. This includes such aspects of the research process as credibility, dependability, transferability and confirmability. Trustworthiness and

dependability have taken the place of reliability and validity in quantitative research. In order to attain the above-mentioned factors in any research study, Babbie and Mouton (2001:278) state that an ""inquiry audit"" should be put in place. In this inquiry audit, processes undertaken during the data collection and analysis phase should be meticulously recorded and maintained and carefully managed. In addition to this, triangulation (multiple methods of data collection) is made use of and is undertaken to establish the validity of a study (Babbie and Mouton, 2001:278). This particularly makes the study dependable. An audit properly managed, can be used to determine dependability and confirmability simultaneously. In addition the process of triangulation is also used in order to reduce the likelihood of misinterpretation. According to Denzin and Lincoln (2005:454), triangulation has been generally considered a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation"". Triangulation will be discussed in depth in Chapter Three.

1.8 ETHICAL CONSIDERATIONS

Ethical considerations of all research participants is an important aspect of the research process and should not be overlooked. I received the permission from the Ethics Committee at the University of Stellenbosch in order to commence the research (see Addendum A). The informed consent form was read to the participants and they agreed with it and signed it. Additional ethical guidelines were adhered to regarding informed consent, confidentiality and according to Terreblanche, Durrheim and Painter (2006:241) ""four widely accepted philosophical principles that are applied in various ways to determine whether research is ethical"", namely autonomy and respect, non maleficence, beneficence and justice.

The ethical considerations for mothers who raise children with FAS should be respected and honoured during any research study. If this process is strictly adhered to and carefully managed, the mother, her child and the researcher are all protected.

1.9 CLARIFICATION OF TERMINOLOGY

***Dysmorphology*:** A term coined by Dr David W. Smith to describe the study of birth malformations, particularly those affecting the morphology (the anatomy) of the individual. It means ""the study of abnormal form"" (www.medicineNet.com).

***Ecosystemic framework*:** Donald, Lazarus and Lolwana (2004:375) describe this as ""the view of human interactions between individuals and between different levels of the social context"". This term is discussed in more detail in Chapter 2.

Experience: According to the Oxford Dictionary: CD ROM version (1998), the word experience can be described as follows: 1) As a noun: involvement in, practice, participation in, contact with, familiarity with, acquaintance with exposure to, observation of, understanding of, impression of 2) As a verb: an individual could have experience of, undergo, encounter, meet, feel, know, become familiar with, come into contact with, face, participate in, live/go through, sustain and suffer. The actual dictionary definition of this word is as follows: ""The actual observation of or practical acquaintances with facts or events, considered as a source of knowledge"".

***Fetal alcohol syndrome (FAS)*:** When the four diagnostic criteria have been confirmed by a dysmorphologist, namely growth retardation, structural abnormalities, behavioural/cognitive abnormalities and confirmation that the mother consumed alcohol when pregnant.

Fetal alcohol spectrum disorder (FASD): This terminology is used to denote the full range of foetal alcohol spectrum disorders associated with prenatal alcohol exposure. The characteristics range from mild to severe, and differentially impact language/communication, social/behavioural, academic/cognitive, and adaptive functioning (Olson et al.*et al.*, 2001:275).

Teratogen: Any substance, organism or process (for the purposes of this research study, reference is made to alcohol) that causes or increases the probability of congenital disorder or birth defect in a baby (Coleman, 2006:576).

***Pattern*:** an arrangement or sequence regularly found in comparable objects or events (South African Concise Oxford Dictionary, 2002).

Phenotype: The characteristics of an organism determined jointly by its genetic constitution and its environment (ColemanOxford Dictionary of Psychology, 2006).

Syndrome: ""A group of symptoms which consistently occur together"" (South African Concise Oxford Dictionary, 2002).

1.10 STRUCTURE OF PRESENTATION

Chapter 1 introduces the nature of the research study to be done. It contextualises and discusses how the research will be carried out.

Chapter 2 discusses in detail a review of the literature that has been recorded and written about FAS. The literature review seeks to capture and discuss the salient information relating to the research question.

Chapter 3 looks at the design methodology of the study and explains in detail the specific processes that were carried out in order to give the study credibility and rigour.

Chapter 4 records the capturing of the data, recording and then the process of transcription and analysis, including the patterns that emerged. The patterns are be synthesised and then discussed. This is done within an ecosystemic paradigm. The reflections of the researcher are also presented here.

Chapter 5 examines the discussion of the research and implications of the study. These inform and influence the recommendations for the future regarding FASD. Limitations of the study are also discussed.

1.11 REFLECTION AND CONCLUSION

This chapter is the introduction to the study and gives a brief overview of the process of the research process and maps out the various facets of the research. It also serves to encapsulate and integrate the various facets of FAS, which are to be investigated – in this case, the mothers'' experience of raising a child with FAS with the research methodology and design. The context of the mothers and the reason for their selection, and some ethical considerations were also briefly discussed. In addition, the layout of the chapters was presented and the terminology used in this study was defined. In the following chapter I will discuss the literature pertaining to fetal alcohol syndrome in detail. I will also look at the circumstances underlying the pastime of parental alcohol consumption here in the Western Cape. The mother of a child with FAS will be viewed from an ecosystemic framework.

The reflection in this chapter served as a spring-board for me, enabling me to become immersed in this research study. It served as a framework for the entire study and it gave me bearings and direction. It also allowed me an opportunity to contemplate the layout and structure of the research document as a whole, which was an important requirement because a study of this nature is a large undertaking.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 was an introduction to this research study and gave the broad framework of the research process from commencement to its end. This chapter discusses the many issues surrounding Fetal Alcohol Syndrome (FAS). FAS is common around the world, but in South Africa and specifically the Western Cape, FAS comprises a complex interaction of historical, political, economical, and societal issues. The child with FAS finds himself in the midst of this complex interaction. He in turn experiences a complexity of anomalies, which are psychological, physical, neurological, biological and educational in nature. According to Miller (2006:13) the characteristics associated with fetal alcohol exposure range from mild to severe, and differentially impact language/communication, social/behavioral, academic/cognitive and adaptive functioning.

It is the experience of the child"s mother, however, which I will be focusing on in this research document. There are very few studies on the psychosocial environment into which children with FAS are born. Neither the experience of the mother from her unique perspective nor the family system in which she lives has been researched in any depth. ""Pitifully, little research has been done where the proverbial rubber meets the proverbial road – at the level of the family and the community"" (Devries and Waller, 2004:119).

In this chapter, I will initially look at the mother and her child born with FAS within an ecosystemic framework. The ecosystemic perspective of the community in which both mother and child with FAS live is critically important and will be discussed. As the mother forms part of the micro-system of the child, the various systems interacting with each other will also be analysed. This will attempt to put into some perspective the experience of a mother rearing a child with FAS.

It is also important to look at the manifestations, symptoms and presentation of FAS in the child and in different contexts, and how this impacts upon his functioning. This will weave together the myriad difficulties experienced by any mother rearing a child

with FAS. As there is very little specific literature pertaining to this aspect, namely the mothers'' experience of rearing a child with FAS, I will discuss mothers'' experiences of other similar problems. According to Nansen and Hiscock (1990:656), ""prenatal exposure to ethanol is now recognized as a frequent cause of mental retardation, borderline intellectual development and hyperactivity in children"". I will therefore include Attention Deficit Hyperactivity Disorder (ADHD), a behaviour pattern closely linked to FAS, and will briefly touch on intellectual difficulties which are typically manifested in children born with FAS.

In addition, in this chapter I will discuss the historical background surrounding societal and historical issues linked to FAS. I will also incorporate the risk factors of these mothers and why they are particularly vulnerable, in their unique context here in the Western Cape. There has been much research done regarding fetal alcohol syndrome and how it presents and manifests in children. Behavioural studies, historical contexts and educational interventions, etc. have been looked at, but there is little or no research done which looks at the biological mother''s experience regarding the upbringing of their child born with FAS.

There is a clear gap regarding this type of research and information. It is of importance that in our attempt to help support and prevent alcohol consumption when the mother is pregnant, or after the child has been born, that we look closely at the mother and her experiences of bringing up a child who has FAS.

In the Western Cape many mothers'' of children with FAS are marginalized, impoverished and are remain part of a social system, which does not empower or attempt to break the cycle of alcohol dependence and misuse. According to Viljoen et al.*et al.* (2002:7) ""it is still apparent that alcohol is a favoured, valued and expected commodity among many of the local population of workers, who receive low pay and live in very humble circumstances"". Many of these mothers are not well educated and therefore are unaware of the dangers of abusing alcohol while pregnant.

FAS is the most common preventable form of mental retardation world wide (Viljoen, 2005). The Western Cape has one of the highest prevalence rates in the world, and in 2000 it was estimated that there were up to 46 per 1000 learners between ages 5 to 9 years old. In 2000, these statistics were 18 to 141 times higher than in the

United States (May, Brookes, Gossage, Croxford, Adams, Jones, Robinson and Viljoen, 2000:1905). By 2005, the statistics were found to be much higher, and in particular pockets of the population 60 to 70 per 1000 children suffered from FAS. The rate of FAS found in this study was the highest yet reported in any overall community in the world. These rates were 33 148 times greater than United States estimates and higher than in a previous cohort study in the same community, in the Western Cape, South Africa (Viljoen, Gossage, Brooks and Adams, 2005:595).

2.2 EMERGENCE OF AN ECOSYSTEMIC MODEL

As the global paradigm shift started to become more focused on human rights issues, new philosophies and models began to emerge internationally. A paradigm is described as ""a shared pattern of basic beliefs and assumptions about the nature of the world and how it works. These assumptions tell us what is real and what is not; they shape our cultural identity and guide and justify our institutional practices"" (Skrtic, 1995 in Swart, 2005:4). Mertens (20045:7) states a paradigm is a ""worldview that includes certain philosophical assumptions about the nature of knowledge"". The need to view human beings and their varying and unique realities from a more systemic perspective began to have meaning as the medical model lost credence.

Individuals started being seen as integral participants within the context of their unique cultural environment with their unique and often varying traditions or rituals. In addition, these individuals were now seen as influenced and affected by these cultural and contextual norms. This way of thinking was based upon the ecological theory in which each organism or animal is important within their unique micro-system: ""Every part is as important as another in sustaining the cycle of birth, death and regeneration, which together ensure the survival of the whole system"" (Donald et al.*et al.*, 2002:45). These unique micro systems are seen everywhere in nature.

The ecosystemic perspective has evolved from a ""blend of ecological and systems theories. This perspective shows how individuals and groups at different levels of the social context are linked in dynamic, interdependent, and interacting relationships"" (Donald et al.*et al.*, 2002:44). Uri Bronfenbrenner, in his ecosystemic model pointed out that individuals, adults and children alike are part of various levels of systems,

which are dynamic and interacting constantly. Each of the different levels or systems influences the individual, and thus he is viewed as part of a bigger system.

For the purposes of this study, the participants (the mothers) will be viewed from this ecosystemic framework. This is important because they are an integral part of the context and culture in which they live. The influences of the social context in which the mothers live are ""dynamic"" which, according to Donald et al.*et al.* (2002:44) means ""continually moving, shifting and interacting"".

2.3 THE MOTHER OF A CHILD BORN WITH FAS WITHIN THE ECOSYSTEMIC MODEL

If one were to look at the ecosystemic model of child development, we would view the mother and her developing child born with FAS, as part of a critical and important interaction of nested systems. Donald et al.*et al.* (2002:51) discuss the following four sets of systems, namely the *micro-system*, the *meso-system*, the *exo-system* and the *macro system*. These all interact with the *crono-system*:

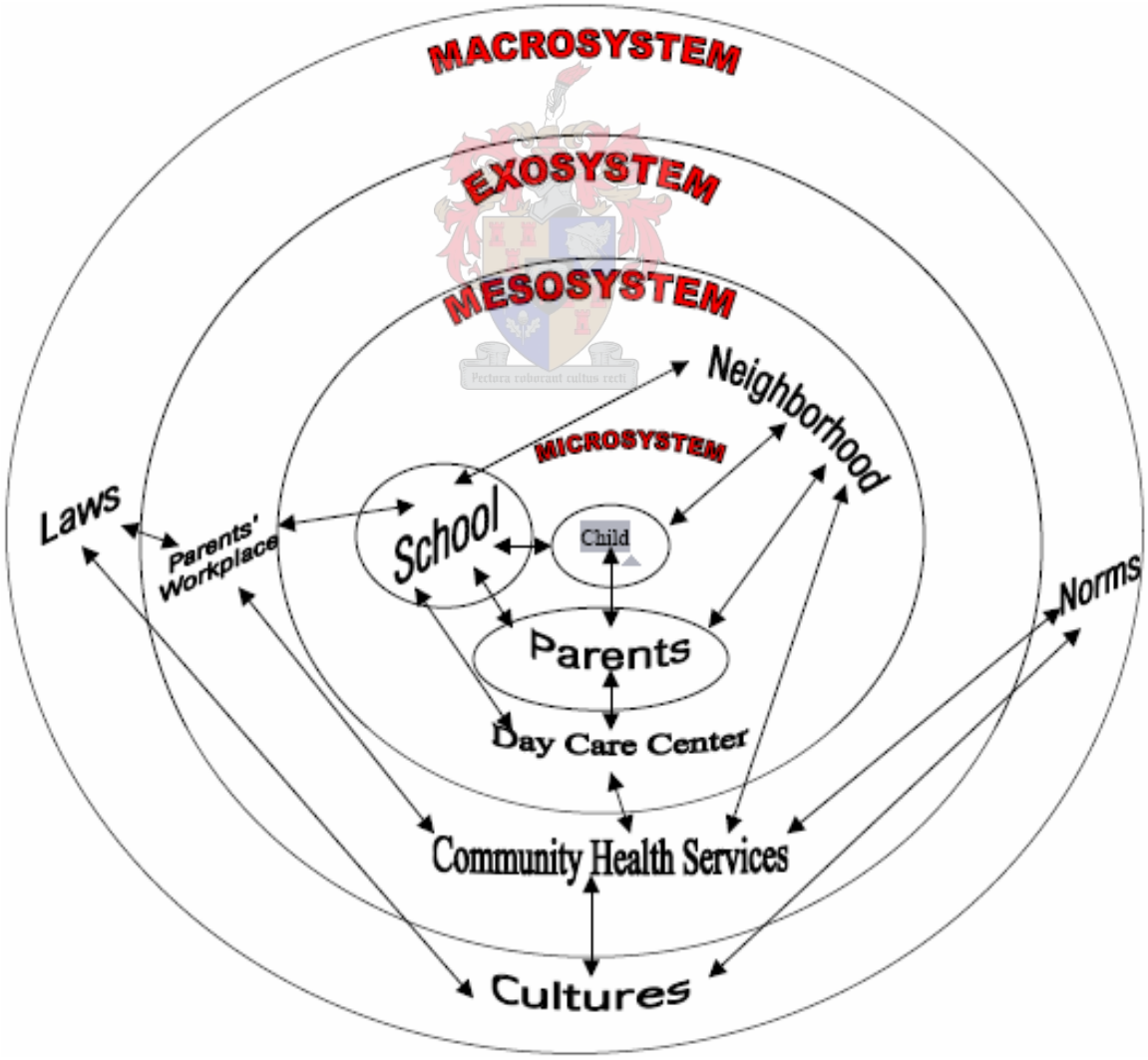
- The *Micro-system* involves the individual child as central to this system. It is the immediate environment of the child incorporating the family, the school or the peer group in which children or individuals are closely involved in the continuous ""face to face"" interaction with other familiar people. Such systems involve patterns of daily activities, roles, and relationships. ""The parents, teachers and anyone in a close relationship for a substantial amount of time with the child are in that first ripple and have the most immediate effect on the child (Boemmel and Briscoe, 2001).

- The next level is the *Meso-system*, which can be seen as a set of micro systems, which interact with one another. It refers to the child''s neighbourhood or the local community, and it reflects the interactions of the previous level of school, peer group, and family interaction.

- The *Exo-system* comprises other systems which influence the child but which the child may not be directly involved, an example could be the child''s parents work situation. Although the child does not experience his mother''s work situation it can influence his reality.

- The *Macro-system* involves dominant social structures, and norms which influence society as a whole and has an impact upon the reality of the individual.
- The final and most encompassing level is the broadest of them all and is referred to as the *Chrono-system*. This refers to ""developmental time frames"" and the child"s ""progressive stages of development"" (Donald et al.*et al.*, 2002:53). It is on this level that the child changes and matures over time, as he moves through the different developmental phases of his life. According to Boemmel and Briscoe (2001), these conditions can be internal or external environmental influences, which affect the child"s development.

HUITT, W. (1999). SYSTEMS MODEL OF HUMAN BEHAVIOR: THE CONTEXT OF DEVELOPMENT (http://chiron.valdosta.edu/whuitt/materials/sysmdlc.html)



Huitt, W. (1999) (http://chiron.valdosta.edu/whuitt/materials/sysmdlc.html)

In viewing the mother of a child with FAS within the context of a community in the Western Cape it is critically important to view her within the ecosystemic model. According to McKinstry (2005:1097), research shows that mothers of children with FAS often come from parents who were heavy drinkers themselves. This points to a familial pattern of binge drinking, which is passed from one generation to the next. McKinstry continues that ""there is strong evidence that children in the region, who are often malnourished or suffering from FAS, grow up to be low-skilled, malnourished adult workers"".

Most mothers of children with FAS come from families with a history of generations of alcohol abuse and heavy drinking (McKinstry, 2005:1909), so there is little escape from this type of system in which the mothers find themselves.

It is a difficult cycle to break, and ""children with FAS born into impoverished conditions will be hard pressed not to perpetuate the cycle"" (McKinstry, 2005:1098). This example of the *chrono system* within the ecosystemic model exemplifies the type of cycle, in which the mother of a child born with FAS finds herself.

Mothers of children with FAS come from a social system that supports such behaviours and from which there appears to be little or no escape. Because the families are often marginalized workers, there is little option but to join in with social patterns of behaviour, which in this case is excessive binge drinking at weekends or on holidays. In addition alcohol is seen as a favoured, valued and expected commodity among many of the local population workers (McKinstry, 2005:1098).

It may be interesting to see how any member of this system may become part of this cycle, especially when it is viewed from the ecosystemic perspective. Because there are few other forms of entertainment in impoverished communities and because there are very few resources or opportunities to do anything else, the only form of entertainment within the community is alcohol consumption, and in many cases, binge drinking. According to May et al.*et al.* (2000:1911), this happens for a number of reasons. The following are part of the *macro system* in which the mother of a child with FAS finds herself:

The country is in early stages of economic development

The mother has achieved a low educational attainment

The mother is from a low socio-economic environment

There is increased and easy access to alcohol

There has been a loss of folk and traditional culture

The larger community and social system from which the mother comes should also be taken into consideration, namely the *macro system*. The socio economic conditions that labourers find themselves in also influence and may even determine their life style choices. Workers, who have no opportunities for empowerment or improvement of their working conditions, are likely to remain dependent upon those who employ them for their existence.

Seedat (2003:58) stated that ""the psychological consequences of the deprivation caused by poverty which is the condition the majority of South Africans find themselves still find themselves in are endless"". Many workers battle to make ends meet and this has repercussions as described by Seedat (2003:58) ""these include the mental and physical developmental impact of poor nutrition on children and the anxiety, depression, and stress related conditions caused by poor living conditions and occupational circumstances"".

In addition, Abel discusses (1998:127) ""whatever impact prenatal alcohol exposure may have, that impact cannot be separated from developmental processes that go on prior to or after birth"". Unless the care-taking conditions into which children with FAS are born are taken into account, the relationship between prenatal alcohol exposure and subsequent behaviour will continue to be problematic.

2.4 HISTORICAL CONTEXT AND BACKGROUND TO FAS

The Western Cape in South Africa has one of the highest prevalence rates of FAS disorder in the world (Viljoen, 2005). Many thousands of tourists visit the wine lands of Stellenbosch in the Cape during the summer and winter months. Wine making and export is one of the biggest and economically viable sectors of the economy in South Africa. During the 1700s European colonialists capitalised on the fertile land and climate of South Africa to create an agricultural economy of grape and wine production in the Cape (McKinstry, 2005:1098). The farmers have labourers working on the farms who have been part of a system of marginalized and often disempowered workforce for many decades.

During colonisation and during the apartheid years, a system of payment for labour with alcohol became known as the ""dop-system'' in the Western Cape. The ""dop or tot"" system is the part payment of workers wages in the form of alcohol (McKinstry, 2005:1098). This custom was introduced from European countries more than 200 years ago and continues to be used today. Problem drinking practices and patterns have existed among the agriculture labourers for multiple generations according to Viljoen et al.*et al.* (2002:7).

McKinstry (2005) states that this system promoted and sustained a cycle of alcohol intake that not only ensured that local communities stayed impoverished but also had negative biological, psychological and social consequences for the farm workers. This historical background forms part of the *macro system,* which the mothers in this research study find themselves.

These long-term effects of the ""dop system"" have aided in encouraging a custom of abusive drinking among farm workers who became ''dependent'' upon the employer. Although this system has been outlawed in many areas it is still being used in some farms in the Western Cape. In addition, it is still apparent that alcohol is a commodity which is anticipated and welcomed among many of the local population of workers who receive low pay and who live in very humble circumstances (Viljoen et al.*et al.*, 2002). Each of the mothers in this research process had been brought up in poverty-stricken contexts.

The legacy left by this system means that many of these farm labourers continue to abuse alcohol. This is usually done over week ends and takes the form of binge drinking. Alcohol is cheap and easily available for these workers to purchase (Viljoen, 2002:7). In addition, because they are disempowered and receive extremely low wages there is no other entertainment or incentive to do anything else. The above-mentioned factors place many of the female labourers, or those married or partnered with heavy drinkers, at risk (Wilsnack in Viljoen et al.*et al.*, 2002:7). The risk situations include falling pregnant while abusing alcohol. Many of these mothers have little or no education regarding the hazards of abusing alcohol when pregnant and therefore they do not take adequate precautions against it. The mothers in this research study had little or no formal education and each one left school at about the age of 13. No further opportunity for education was available to them and they

therefore had no knowledge that consuming alcohol while pregnant may have detrimental effects on their developing baby.

According to Viljoen et al.*et al.* (2002:7), ""influences on maternal drinking are complex and originate from a combination of factors: biological, familial, social and psychological"". Mothers of children who have FAS find themselves in a complex interplay between poverty, social habits and norms and inadequate education (Donald et al.*et al.*, 2002:45).

2.5 MATERNAL RISK FACTORS

In order to understand why mothers are at risk of having children with FAS, it is important to understand and examine the social conditions in which the women in the Cape Province, in South Africa live. ""Women constitute 30% of the commercial agriculture workforce and are 2 to 3 times more likely to be hired as casual labourers. More than two thirds of farm workers live in waged poverty with a household income of less than R700.00 per month. Mothers face a difficult challenge as both mothers and workers dealing with waged poverty"" (McKinstry, 2005:1097).

Risk factors for mothers producing offspring with FAS are external experiences such as binge drinking during pregnancy, maternal age, poor education, poor nutrition, genetic influences, gravidity, and poor socio-economic environment are a starting point for identifying women at risk according to Rosental et al.*et al.* (2005:1099). Internal experiences also play a role in increasing the risk of having a child with FAS, according to Viljoen et al.*et al.* (2002:7): ""women who misuse alcohol report multiple social and psychological risk factors, particularly low self-efficacy, low purpose in life, depression and feelings of powerlessness"".

Many of these mothers understandably experience depression and low self esteem as a result of alcoholism. ""With alcoholism so entrenched in the culture, both at work and at home, it is likely difficult for mothers attempting to maintain sobriety to get support"" (McKinstry, 2005:1908). It is thus also evident from these types of references that there is little support for these mothers. In addition they bear the burden of bringing up one or more children with FAS.

2.6 ALCOHOL USE/ABUSE

Alcohol is a form of entertainment in many communities in the Western Cape of South Africa. Almost 50% of pregnant mothers in the Western Cape misuse alcohol according to McKinstry (2005:1109). Although it is widely condoned within these communities, the adverse effects of alcohol abuse are well documented and recorded. According to Olson et al.*et al.* (2001:274), ""women in their peak childbearing years (age 18-34) are two to four times more likely to have a Diagnostic and Statistical Manual for Mental Disorders (DSM-IV) alcohol dependence diagnosis than are individuals in other age ranges"".

The individuals described in this research study misuse alcohol for a number of different and complex reasons. Psychological, cultural, and social factors definitely play a role. Kelly (2001) contends that ""the alcoholic appears to be using alcohol to solve his problems. His drinking appears to be an effort to drown his depression, forget work or marriage difficulties, and obliterate loneliness and insecurities and ease mounting tensions"". The participants described in this case study appear to need to consume alcohol for many complex reasons, some of which are described earlier.

According to the DSM-IV (2004:214), alcohol abuse falls under the category of a substance abuse disorder and it interferes with the individuals normal functioning. In the case of an adult, alcohol abuse may interfere with the following:

- Job performance may suffer from the after effects of drinking or from actual intoxication on the job
- Child care or household responsibilities may be neglected
- Alcohol-related absences may occur from their place of work

Individuals who abuse alcohol may continue to consume it despite the knowledge that continued consumption poses significant social or interpersonal problems for themselves. In addition according to the DSM-IV (2004:214), alcohol intoxication is the ""presence of significant maladaptive behavioural or psychological changes (inappropriate sexual or aggressive behaviour, mood lability, impaired judgment, impaired social or occupational functioning) that develop during or shortly after the ingestion of alcohol"". These changes are accompanied by evidence of slurred speech, in-coordination, unsteady gait, impairment in attention or memory, or stupor

or coma. It would appear that any mother experiencing these symptoms of alcohol abuse may struggle with parenting on various levels.

2.7 HOME ENVIRONMENT OF MOTHERS OF CHILDREN WITH FAS

The home environment for children with FAS is often chaotic - ""for most children the kind of continuity that a child with FAS can expect from their biological mother whose alcoholism is un-arrested is often nightmarish. Child neglect or abuse is common"" (Streissguth, 1991 cited in Abel, 1998:137).

Children with FAS who remain with their biological mothers are burdened with significant influences from both pre- and postnatal alcoholism. Abel (1998:138) states that prenatal influences are largely neurological and biological in nature, whereas postnatal influences are mostly emotional, regarding lack of support or where alcoholic parents are abusive in nature. Children raised in such an environment can only exacerbate underlying biological problems. ""FAS is not just the result of being born to an alcoholic mother, it is also the result of being raised by an alcoholic mother, and it is especially the result of being born and raised by a poverty-stricken alcoholic mother"" (Abel, 1998:138).

Many mothers who drink during pregnancy have partners or husbands who are also substance abusers. According to Aronson (1997:24) "children prenatally exposed to alcohol who remain in biological families with continued alcohol problems appear to be doubly handicapped. In addition to their prenatal and primary damage, the continued risk of experiencing psychosocial problems is present". This can be very damaging for the growing child with FAS. Home environments would be extremely unstable with both parents being alcoholics. ""Growing up in an alcoholic environment in which a child has no opportunity to become socialized, results in many of the same conduct disorders currently associated with FAS. Such children do not form intimate lasting relationships and do not develop a sense of remorse"" (Streissguth, 1991 cited in Abel, 1998:137).

Further research surrounding children of alcoholic parents indicates that their offspring often manifest significant emotional, behavioural and social problems. According to Mayes and Bornstein (1997), parental substance abuse use has a negative impact on parenting behaviours displayed toward children. In addition, inadequate and punitive parenting practices play a critical role in the development

and maintenance of child problems. Types of parenting practices that have been closely associated with the development of child problems include:

- Inconsistent discipline
- Irritable explosive discipline
- Low supervision and involvement
- Inflexible and rigid discipline
- Poor nurturing

Children with FAS are exposed to parenting by their mothers who abuse alcohol that may be dysfunctional in nature. This would in turn exacerbate difficult behaviours caused by FAS.

2.8 WHAT IS FETAL ALCOHOL SYNDROME (FAS)?

FAS was formulated by Kenneth L. Jones and David Smith who first described it in 1973 as a pattern of anomalies and deficits in children prenatally exposed to large amounts of alcohol. Since that time, substantial progress has been made in developing specific criteria for defining and diagnosing this condition according to Hoyme et al.*et al.* (2005:39).

""The adverse effects of alcohol on the developing human represent a spectrum of structural anomalies and behavioural and neuro-cognitive disabilities, most accurately termed *fetal alcohol spectrum disorders (FASD) …* children at the severe end of the spectrum, with the complete phenotype have been diagnosed as having fetal alcohol syndrome (FAS). The children whose mothers have been interviewed for the purposes of this research study have been clinically diagnosed as having FAS"" (see Addendum B).

""Children on the FASD have characteristic facial and body dysmorphology (see Addendum E), a pattern of delayed physical growth and development and mental and behavioural deficits"" (May et al.*et al.*, 2000:906).

According to Astley and Sterling (2000:147), the 4-Digit diagnostic code reflects the magnitude of the four key diagnostic features of FAS in the following order:

1) Growth deficiency

2) The FAS facial phenotype (facial dysmorphology)

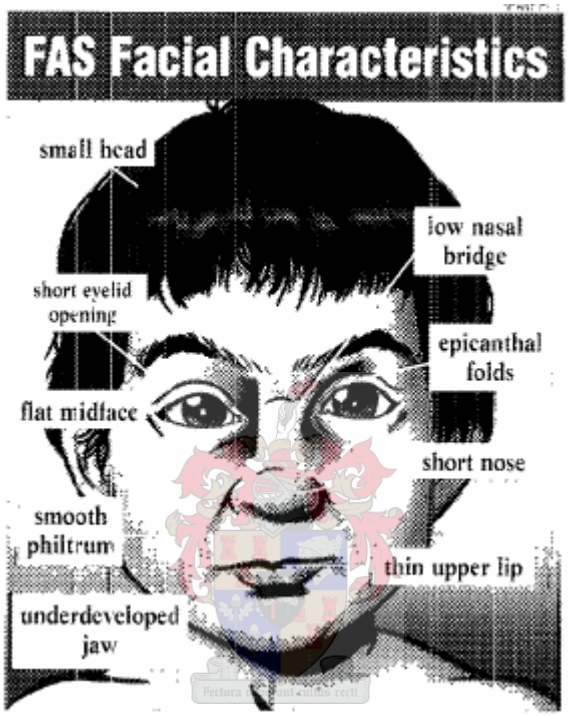
3) Brain damage/dysfunction

4) Gestational alcohol exposure.

2.8.1 Facial Features and dysmorphology

According to (Viljoen 2005), the midface is hypoplastic in children with FAS. The facial dysmorphology includes shortened papebral fissures, flattened nasal bridge, shortened nose with upturned nares, a long smooth upper lip with thin vermilion border and micrognathia.

FAS FACIAL CHARACTERISTICS TAKEN FROM McLEAN



(2000:35, in Viljoen, 2005)

FAS Facial Characteristics taken from McLean (2000:35) in Viljoen (2005)

2.8.2 Growth deficiency

Viljoen (2005) points to significant physical effects. All the body measurements in children with FAS may be affected both prenatally and postnatally. In many cases, the measurements are usually all less than average for age and sex and display either a reduction in head circumference or a reduction in weight or height together. These measurements remain deficient throughout life.

2.8.3 Central Nervous System

The growth of the brain, especially the frontal lobes, is deficient in FAS. Microcephaly, partial or complete agenesis of the corpus callosum and cerebellar hypoplasia are structural anomalies often encountered. The child with FAS also exhibits impaired fine motor skills, neurosensory hearing loss and poor hand-eye co-ordination. The average IQ is 63 with a wide range, from profound mental retardation to a level where individuals can function adequately in mainstream schools (Viljoen 2005).

2.9 BEHAVIOUR PRESENTATION OF DIFFERENT DEVELOPMENTAL STAGES OF CHILDREN WITH FAS

There has been much research done surrounding the presentation and manifestation of FAS symptoms in children. FAS behaviour has been well documented by neurologists, psychologists and paediatricians. It is especially important to view the adverse effects of alcohol on the developing brain in the fetus. While the baby is developing in the uterus, harmful teratogens (harmful chemicals – in this case alcohol – which can cause deformities in the developing embryo) make their way via the mothers'' bloodstream into the placenta (Golden, 2005:3). There the fetus absorbs the alcohol and this has a devastating and irreversible effect on the child''s neurological and biological development.

The effects of alcohol absorbed during pregnancy produces a recognizable characteristic behavioural and physical phenotype in the child with FAS. The width and breadth of the clinical spectrum are understandable in view of the expected variability imposed by teratogens, based on dose, time, duration of exposure and genetic susceptibility. These ranges of behavioural disabilities include poor habit formation in infancy, poor cause and effect reasoning and attention deficit hyperactivity disorder in childhood, maladaptive behaviours in adolescents and poor life adaptation as adults (Streissguth, 1997 cited in Abel, 1998:139).

2.9.1 Five distinctive behavioral phenotypes

- In addition to the mother of a child with FAS dealing with her own alcohol addiction, and the neurological impact of prenatal alcohol exposure on her child, she also has to deal with behavioural implications. Research done in the USA by the FAS Family Resource Centre indicates that a behavioural phenotype has been identified as a result of information supplied by parents: individual is not even aware of the difference.

Devries and Waller (2004:121) note that the second feature of the phenotype is:

- They exhibit behavioural volatility. This means that the child with FAS''s behaviour can be out of proportion with environmental stressors. This means that major crises can pass without much notice of them, but minor inconveniences or misunderstandings can cause huge behavioural outbursts

and over reactions. The magnitude of the event and the response to it often do not match.

- The third phenotype according to Devries and Waller (2004) is impairment in the understanding of the need for social rules and cooperative living. Thus many children with FAS are summed up that ""they just don"t get it"". They may be able to read and remember rules for instance, but they just as quickly then turn around and break them. This is due to many factors, possibly because they do not understand them, or they do not understand the consequences of them, or they cannot generalize the application of these rules.
- The fourth behavioural phenotype, De Vries and Waller (2004:122) is a child-like innocence that is clearly a precocious trait. The parents are constantly involved with professionals while the child with FAS presents as vulnerable, even into adolescence and early adulthood. If this syndrome is left undiagnosed their innocence can be abused which in turn results in the person with FAS becoming angry, aggressive or self abusive.
- The fifth phenotype is the exaggerated need for immediate gratification. The ability to choose or even consider delayed gratification in almost impossible for the FAS individual. They are consistently considered irresponsible in sexual activity; they continue stealing from and lying to family members, regardless of consistent love and discipline (De Vries and Waller, 2004:122).

2.10 FAS – SYMPTOMS AND MANIFESTATIONS

Although very little is recorded regarding the mothers" experiences of their child born with FAS, much is known about the presentation of the baby presenting with these features and behaviours.

> In the first few days postpartum, decreased arousal and slower habituation to stimuli may be seen in infants prenatally exposed to alcohol. In addition studies have also found that these infants may show unusual reflexive responses and slower information processing as compared with infants not prenatally exposed to alcohol. This includes fine-motor dysfunction, irritability, sleep problems, feeding difficulties and a quick startle response. (Zevenbergen and Ferraro 2001:124).

TABLE 1: IMPACT OF FETAL ALCOHOL SYNDROME CHARACTERISTICS ON FUNCTIONAL DOMAINS (Adapted by Miller, 2006:13)

Characteristic	Language/ Communication	Social/ Behavoiral	Academic/ Cognitive	Adaptive Behavior
Social communication/ Language difficulties	Interprets cues incorrectly; difficulty with nonverbal communication	Interpersonal and peer Problems; social skills Difficulties (e.g., lacks Skills in sharing, cooperating		Doesn"t follow or Understand rules in Social games in sports Difficulty communicating Needs and wants
Conceptual reasoning/ Thinking skills	Doesn"t use language To reason and analyse; Understands at literal Level	Lacks understanding of Consequences of Behavior; attention Difficulties; hyperactive	Difficulty understanding Abstract concepts; lack Of judgment and Reasoning skills; Difficulty understanding time And sequence; challenged by Meaning of cause and effect.	Doesn"t understand time- Sensitive tasks; Difficulty with decision Making skills in home and Community; difficulty Following directions And problem-solving Around functional issues.
Emotional/social	May be chatty, talkative, With adequate or above vocabulary	Temper tantrums and angry Outbursts; impulsive; Unpredictable behaviour and/or moods, mood swings, Depression; poor self esteem Aggression; noncompliant	Unmotivated; Unorganized	Immature behavior
Independence/ Self-sufficiency	Expressive or receptive Language deficits	Difficulty regulating behavior	Deficits in short/long-term Memory	Lacks independent Living skills; problems With age-appropriate Hygiene skills

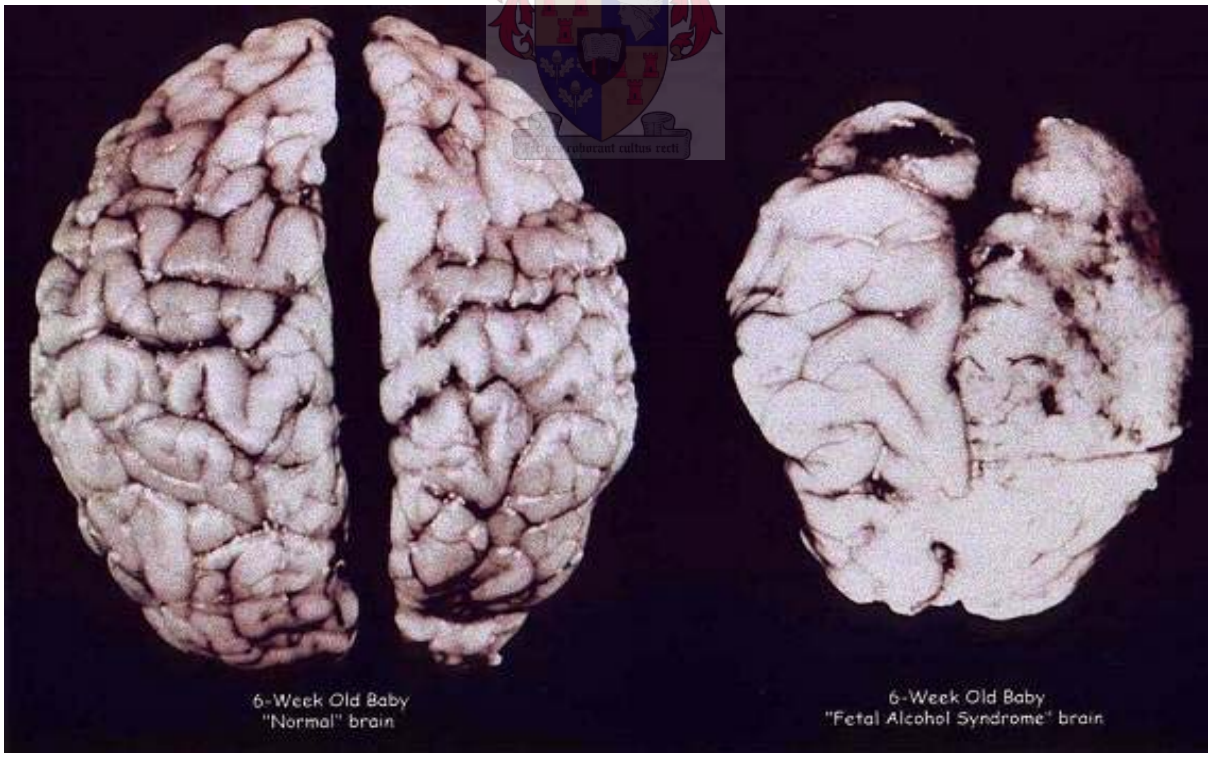
The above described scenario begins to beg questions around how mothers actually cope with their children born with FAS. Any ""new"" mother dealing with a newborn baby experiences challenges as she becomes used to the demands made on her. A baby with any or all of the above mentioned problems would create definite challenges for the mother. Setting this against the contextual backdrop and reality in which this new mother finds herself, a bleak picture emerges.

As the baby with FAS matures and grows into a toddler, the picture does not get any brighter. Speech and language delays are noted, especially once the child starts to attend preschool. ""Socially, FASD preschoolers show a lack of stranger anxiety, poor attention and hyperactivity are also usually first identified"" (Zevenbergen and Ferraro, 2001:125).

2.10.1 Manifestations of children diagnosed with FAS

The presentation of FAS including manifestations and characteristics have been well researched. ""Prenatal exposure to alcohol results in the disruption of how brain cells develop as well as how these cells migrate during development. In addition, prenatal alcohol affects the neural circuitry of the brain, resulting in an imbalance in both electrophysiological and neuro-chemical functions, thereby resulting in inadequate and dysfunction message transmission within the brain"" (Zevenbergen and Ferraro, 2001:127). Therefore it can be deduced that vast structural and functional damage results from prenatal alcohol exposure.

PICTURE OF A FAS BRAIN (ON THE RIGHT) COMPARED TO A NORMAL 6 WEEK OLD BABY'S BRAIN (ON THE LEFT)



Picture of a FAS brain (on the right) compared to a normal 6 week old baby's brain (on the left).
(From the clinic of Dr Sterling Clarron, University of Washington, Seattle.)

Pectora roborant cultus recti

Early on in the baby''s life, FAS features are not as easily recognisable, and mothers of these children may not be aware of problems, especially if the baby is the first-born and they do not have another child to measure it against. However, there are problems experienced by babies with FAS.

Zevenbergen and Ferraro (2001:128) explain that ""characteristics of FAS related to central nervous system abnormalities are frequently referred to as neurobehavioral deficits"". These vary according to levels of impairment which in turn is relative to the amount of alcohol consumed by the mother during her pregnancy and at what stage the alcohol was consumed. According to Viljoen et al.*et al.* (2002:6) ""alcohol in a dose response effect, is likely not only to produce FAS, but such individual features as growth and developmental delay, neurobehavioral deficits, microcephaly, and craniofacial anomalies in children"".

Zevenbergen and Ferraro (2001) cite studies that show infants prenatally exposed to alcohol may show unusual reflexive responses and slower information processing. Fine motor dysfunction, irritability, sleep problems, feeding difficulties, restlessness, and quick startle response are some of the results.

All of the above mentioned factors could influence the mothers'' relationship with her child and create an even more stressful situation. This would appear to be especially so when the mother is already dealing with significant life stressors such as low socio economic status, alcohol abuse and lack of support. Lack of support may take the form of emotional support or she may experience some stigmatisation within her social group.

2.11 THE EXPERIENCES OF MOTHERS OF CHILDREN WITH FAS

Very little research has been done surrounding the experiences of mothers who rear FASD children. I am particularly interested in various aspects of the mothers'' experience of rearing her child born with FAS. Through listening to the unique experiences and needs of these mothers, this may ultimately help to inform professionals of ways in which prevention can be put in place. As Baxter et al.*et al.* (2004:224) rightly argue, ""[b]ecause FAS is preventable through behaviour change, more research is needed in ways to change the drinking patterns of pregnant women"".

Teresa Kellerman (cited in McLean, 2000:33), the adoptive mother of a child with FAS, describes her son John as having ""a hang over that never leaves ... when he''s not on medication, its just like he''s drunk – part of the brain has been so damaged so he has no impulse control, no judgement, he acts silly. But he''s one of the fortunate ones who respond to medication; after he takes it, it''s like watching someone sober up"". She continues by using the metaphor of ""broken beaks and wobbly wings"" in an essay written to describe him, and her experiences in rearing him. The following is an excerpt:

> During the early years of my parenting John, there was not much information available on what to expect for his future. I had to ""wing it"", so to speak, and had to rely on basic good parenting and my own maternal instincts. There is so much more known today about what intervention strategies work best. Even though we can''t change the primary disabilities of impaired neurological function that stunt social development, we can learn how to parent in ways that minimize some of the more avoidable pitfalls, and increase the chances of success in school and on the job, with relationships and with life in general.
>
> We might not be able to strengthen those wings but we can strengthen the safety nets, and we can encourage our young to fly tandem, with mentors and coaches, who can accompany them as they discover all that life''s expansive horizons have to offer.

The mother''s drinking habits are often stigmatised. In many cases drinking during pregnancy is ""under-reported because of feelings of guilt, knowledge of wrong-doing, fear of retribution from the father of the child, and possible exposure to litigation in some instances"" (Viljoen, 2005).

Many children with FAS are fostered because their parents are unable to care adequately for them. (Streissguth et al.*et al.*, (2004) discuss how children with FAS experience repeated periods in foster care and other transient home placements, and are often raised by adoptive or foster families. Timler and Olswang (2001:51) record how Brenda, the foster mother of Ian who has FAS, shares her perceptions of Ian at home:

> I just assume one day he may know it, but another he may not and that''s ok …I think you can only be wilfully disobedient if you understand what your doing … but he''s not making the choice. I mean he gets mixed up or distracted.

Timler and Olswang (2001) explain that at home, Brenda often struggled to help Ian follow directions and household rules. Every direction given to Ian had to be repeated by Brenda. In addition to difficulty following directions, Brenda noted that Ian had difficulty answering her questions as she attempted to piece together previous events that happened to Ian at school or at home. Brenda found Ian''s need for concrete directions and explanations frustrating, and she wondered whether, if she punished him, he would really understand why he was receiving the punishment. She struggled with how to teach Ian the consequences of his actions when *'"'he does not understand what he is doing wrong'"'*:

> ""I am on him all the time. The neighbors must think I''m a bad mommy because sometimes I just lose it with him"".

2.12 PROBLEMS PRESENT IN CHILDREN WITH FAS AT SCHOOL

As the child matures, and progresses through toddler-hood and into pre-school, problems in the manifestations of symptoms of FAS become exacerbated.

Phelps (1995:200) provides evidence that learners with FAS have been found to experience impairments in executive functioning and perceptual processing in such areas as:

- Short-term memory deficits in verbal and visual material
- auditory memory, spatial ability, spatial learning, auditory recall, design copying
- Inadequate processing of information, reflected by sparse integration of information and poor quality of responses.
- Inflexible approaches to problem solving and difficulties in mathematical computations.

2.12.1 Attention Deficit with Hyperactivity Disorder (ADHD) manifestations

Zevenberg and Ferraro (2001:127) identify poor attention and hyperactivity as being the first behavioural problem to be identified in children with FAS. These behaviours continue to cause significant problems for these children and are regularly recorded as being co-morbid symptoms with FAS. According to Miller (2006:14), students with FAS frequently have problems controlling their anger, aggression and impulses, which contribute to other social difficulties. These students often demonstrate

attention problems and many are diagnosed with Attention Deficit Hyperactivity Disorder (ADHD).

According to Carpenter (1999), the outward manifestations of ADHD in children most often include the following criteria in varying degrees; learning disability, poor attention, impulsivity, poor coordination, restlessness, memory problems and peer relationship problems. These symptoms often have a lifelong effect on the person with ADHD. Hence ADHD is a disorder that has the potential for socially disabling a person throughout life. Significantly, it seems that ""there are behavioural similarities between children who have FAS and children with Attention Deficit Disorder (ADD). Children in these groups have been described as hyperactive, impulsive and distractible"" (Kaemingk and Paquette, 2000:122).

Children who display this type of behaviour can be very challenging for parents and teachers alike. Characteristics include trouble sustaining attention, hyperactivity, impulsivity, and failure to plan behaviours.

2.12.2 Experiences of mothers with children with ADHD

Cronin (2004) found that mothers of children with ADHD reported little family support, high perception of child-related demands, and less confidence in their success in mothering these children. In describing their daily routines, these mothers often stated that there was no such thing as a ""normal"" day. They felt constantly ""on alert"" and did not feel that they had ""normal"" routines. Cronin (2004) describes how mothers of children with ADHD felt distress because their child did not easily conform to social standards, and they were likely to express exhaustion in their role as ""mother"".

According to Carpenter (1999), ""It is the disabling effect on a woman of mothering a child with ADHD that leads to her identification as being different which in turn has an additional disabling effect on her as a person"". The above mentioned experiences are from mothers whose culture differs from the female laborers of the Western Cape, South Africa. They are typically from more elite, wealthy westernized cultures. Although the patterns and experiences of mothering differ across cultures, when looking at rearing a child with FAS who also displays ADHD type of behaviour, there are clearly significant similarities.

According to Carpenter (1999), ADHD has a disabling effect on some mothers. This occurs because some mothers of children with ADHD appear different from the mythical image of a "good" mother constructed by society. Mothers of children with ADHD clearly battle in their role and feel blamed for not being a ""good enough mother"".

Mothers'' experiences of rearing children with ADHD are captured below (www.schwablearning.org):

> It was 9 o''clock on Wednesday evening. I had barely managed to get my 7 year old into bed. I collapsed into a chair, exhausted, with a nagging feeling that something was wrong. How could a simple maths worksheet take three hours of work with my child?

Another mother describes an incident with her son''s teacher:

> ""I had just returned from a parent-teacher conference for my 10 year old. The teacher suggested that he may need testing and special help at school. His reading scores were really low, and he had fallen behind his classmates. In the pit of my stomach I was afraid, but I had suspected this for some time now. I was not really surprised by what his teacher said, just found it hard to hear it spoken aloud"".

It appears in the research that many mothers of children with ADHD experienced a sense of grief when the diagnosis was initially made. ""Whenever there is a loss of hopes and dreams, whenever they confront the reality that something is different, something is wrong with their child, they naturally experience grief"", according to Christen (2001). Feelings of shock, grief, anger, depression, blame and denial are common to the experience of having a child with learning disabilities in the home. In addition feelings of guilt and denial are also experienced.

2.12.3 Intellectual difficulties and learning problems: Mothers'' experiences of rearing a child with an intellectual disability

Prenatal exposure to alcohol causes brain damage, which in turn causes intellectual functioning difficulties: ""Patients with FAS are often clinically characterised by behaviours resembling those for patients diagnosed with frontal lobe lesions"" (Connor, Sampson, Bookstein, Barr and Streissguth, 2000:332). In addition to ADHD being present in children with FAS, there is also strong evidence of learning disabilities. According to Zevenbergen and Ferraro (2001:125), both syndromes are

characterized by learning problems, low academic motivation and academic difficulties.

Many children with FAS have similar disabilities to those children who present with an intellectual disability of some sort. According to Ebner and Rema (1999:351), ""numerous brain anomalies have been described following moderate levels of alcohol exposure to the fetal brain"". FAS is also one of the ""leading causes of mental retardation in the Western world"" (Kaemingk and Paquette, 2000:115). In addition it is well documented that in order to diagnose FAS a child must present with cognitive and neurological abnormalities.

According to Sands, Kozelski and French (2000:84), ""there is little doubt that the birth or subsequent identification of a child with disabilities creates challenges, demands, stresses and issues that the family must deal with day in and day out. The lives of families change when a child is born, particularly one with disabilities"". Parents'' reactions differ depending on stages of the child''s life, and it seems that the mothers react differently from the fathers. Blacher (cited in Sands et al, 2000:85), describes three stages of adjustment on hearing the news that a child has a disability of some type: 1) ""an emotional crisis characterised by shock, denial, and disbelief 2) a period of alternating feelings of anger, guilt, depression, grief, lowered self-esteem, rejection of child and over protectiveness, and 3) acceptance"". This is a type of mourning process which assists parents in moving beyond the initial trauma.

> Juanita was 16 when she had Tanya. She described feelings of guilt, bewilderment, and sadness, which she experienced to be overwhelming. On some days she was too tired to drive the 70 miles to see Tanya in the hospital yet she felt guilty on the days she could not be there. She often thought ""why me?"" and ""what did I do to make this happen?""

Some families, according to Sands et al.*et al.* (2000) first learn that their child has a disability when the child begins school. In some cases school professionals identify issues and through special educational process a label is applied to the child for the first time. They point out that though ""mothers may feel frustrated and confused by the discovery of a disability"" (Sands et al.*et al.*, 2000:87), it is sometimes a relief to them to find out that there is something indeed wrong with their child.

Many of the mothers documented in the research found discriminatory remarks regarding their child the most offensive and hurtful. Even health care workers such as doctors would make disparaging comments regarding their intellectually impaired child (www.learningaboutintellectualdifficultiesandhealth). A mother describes her experience of rearing her daughter who has Down syndrome:

> Teaching her how to adapt to the world is ongoing. Life gets more complex and it all needs explaining. But now I have less fear and more trust. I am trying to find that balance to help her develop hers, but not lose herself. Not an easy job for any parent (Yaron-Field, 2006).

The mother continues:

> The first year was fuelled by fear. I was very manic, constantly at an appointment, I imagined that if I worked hard enough I could change and shape Ophir. And that constant notion of ""developing potential"" led me to physiotherapists, developmental checks, a portage specialist, therapeutic playgroups, homeopaths, cranial osteopaths … She was never left to discover the world by herself. She was woken from naps to attend groups. I regret this, I was frightened and lacked trust in her natural ability. I believed I had to control.

Mothers described how hard it is to raise a child with intellectual disabilities. Many describe how they felt ""out of control"". However, it should be noted too that the presence of a child with a disability may also strengthen families. According to Sands et al.*et al.* (2000:84), ""there is emerging recognition that the presence of a child with a disability may also strengthen families … recognition that there are both positive and negative aspects of raising children with disabilities creates a more accurate picture of the range of families" experiences"".

2.13 PSYCHOLOGICAL DIFFICULTIES MANIFESTING IN FAS WHICH PRESENT IN ADOLESCENCE AND ADULTHOOD

Steinhausen et al.*et al.* (1982) in Zevenbergen and Ferraro (2001:132), found that children with FAS were more likely than children without FAS to show eating and sleeping problems, stereotyped habits, dependency, toileting problems and phobias. It is estimated that 50% of adolescents with FAS showed significant conduct problems such as bullying, lying, stealing or cheating. School problems such as

suspension from attending school and drop-out are also common in adolescents with FAS.

Abel (1998) continues by describing the clinical description of FAS adolescents as irresponsible, impulsive, having poor judgment, lacking in inhibition and remorse and unable to appreciate the consequences of their actions. As individuals with FAS experience lowered executive functioning abilities, their ability to perform complex and abstract tasks is diminished according to Kodituwakku, May, Ballinger, Harris, Aase and Aragon (1997), and this has life-long implications.

According to Connor et al.*et al.* (2000:333), behaviourally and socially, FAS adults have difficulty maintaining employment because of poor judgment and inability to stay focused on tasks, and require assistance with many daily living skills including hygiene, structuring leisure time, and managing finances. They also experience difficulty with relationships due to poor impulse control and decision-making skills. Adults with FAS are unable to work steadily; unable to live independently and must instead live with family or in group homes. They are unable to manage money, have few friends and often become isolated and some have a high incidence of psychosocial problems (Abel, 1998:134).

2.14 REFLECTION AND CONCLUSION

This chapter has presented an overview of the literature on a combination of facts regarding the manifestation of FAS, some experiences of mothers of children with parallel abnormalities to FAS and the contextual factors influencing mothers drinking habits, here in the Western Cape. The contextual factors were discussed first, then a discussion of the presentation of FAS and finally some anecdotal evidence of mothers'' experiences of their children with disabilities. The contextual factors were seen through the ecosystemic model.

I found the picture that emerged devastating. I have found that the more research I have done regarding this literature review, the more engrossed and involved I have become regarding FAS and all its complex facets. The circumstances surrounding FAS and the life-long implications for the individual child are tragic. FAS is irreversible, but it is the most preventable of all the intellectual disabilities. Tragically it remains rife here in the Western Cape and in different societies around the world.

Research in the area of the family system is needed urgently in order to strengthen prevention programmes, and to help stop mothers drinking while they are pregnant.

A child with FAS would be difficult for any parent to handle but a parent who is inclined to abuse alcohol may find dealing with the situation especially challenging. In some cases it may exacerbate the need to abuse alcohol even more on the part of one or both parents. It is very likely that the mother of a child with FAS may become part of a vicious cycle in which she needs to continue misusing alcohol in order to attempt to escape the many pressures and stresses that she experiences.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

This chapter discusses the research design, which I will use as the framework for this research document. Bless and Higson-Smith (1995:63) describes a research design as the ""planning of any scientific research from the first to the last step"" and ""a programme to guide the researcher in collecting, analysing and interpreting observed facts"".

The research design and methodology are therefore an important aspect of this thesis, as they map out the designated plan from the beginning to the end of the process. Qualitative research, however, allows for flexibility within the research process. This chapter, therefore, acts as a guide or a framework within which changes may occur as the process progresses.

The main method of analysis of this study will be that of a collective case study. A case study, per se, is difficult to define and means different things to different people. According to Merriam (2005:179), ""the process of conducting a case study … a bounded system, allows for any number of qualitative strategies to be combined with the case"". I will combine various methods to create a collective case study. Stake (2005:444) describes a case study as ""not a methodological choice but instead a choice of what is to be studied"". However, it is important that various methods are employed in order for the case study to be viewed as credible and valid.

3.2 THE RESEARCH QUESTION

Research problems are often formulated in the form of questions as a way of focusing the research problem, Mouton (20014:53). My research problem discusses the experiences of mothers who raise children with FAS.

- What are the experiences of mothers who raise children with fetal alcohol syndrome?

It is this problem that I plan to investigate during the research process.

3.3 AIM OF THE RESEARCH

The aim of the research is directly connected to the conclusion that I will draw up about the phenomenon that I have chosen to investigate. In this case it explores the experiences of mothers who raise children with FAS. According the Oxford Dictionary (1998), the word experience is defined as ""to undergo, encounter, meet, feel, know, become familiar with, come into contact with, face, participate in, live/go through, sustain, suffer"". The aim of this research study is to investigate this umbrella term ""experience"" from the perspective of a mother raising a child with FAS. In addition the aim of the research study is to gain understanding and insight into these mothers'' experiences.

Once this has been clearly understood, it may be possible to look at what could ultimately be done to support mothers of children with FAS. The study may also lead to deeper understanding of and insight into these mothers'' needs, and thus preventative measures could evolve.

3.4 CONTEXT

There were three mothers whom I interviewed and talked to regarding the rearing of their children with FAS. They were the biological mothers of children who had been diagnosed with FAS, and they all came from an urban setting, which is also an under privileged area in the Cape Town metropolitan area.

The environmental context of these mothers is important, as it constituted the observation section of the data collection. Babbie and Mouton (2001:282) explain that ""to understand and interpret case studies, researchers describe the context in detail. The surrounding environment with its notions of multiple, interacting, and contextualised systems helps conceptualise the context in which the units of analysis are embedded"".

The mothers were carefully selected because their children had been clinically classified, and diagnosed as having FAS. This test would have been done by a dysmorphologist who would have used an internationally recognised set of criteria to diagnose their child as having FAS (see Addendum C).

All the mothers were from underprivileged and poverty-stricken environments, financial pressures lead to overcrowding in homes. Each of the mothers started consuming alcohol at relatively young ages, and consumed significant amounts of alcohol while they were pregnant. In addition, these mothers continue to misuse alcohol on a regular basis.

3.5 THE RESEARCH PARADIGM

In this research study, a constructivist interpretive paradigm was adopted. Mertens (20045:12) argues ""the basic assumptions guiding the constructivist paradigm are that knowledge is socially constructed by people active in the research process"". In this particular study, since I was attempting to understand the experiences of mothers who raise children with FAS, I adopted a combination of a constructivist and interpretive paradigm. According to Merriam (2002), learning how individuals experience and interact with their social world, the meaning it has for them, is considered an interpretive qualitative approach. Merriam (2002:5) notes that there are several key characteristics in all interpretive qualitative research designs:

- The first characteristic is that researchers strive to understand the meaning people have constructed about their world and their experiences.
- The second characteristic is that the researcher is the primary instrument for data collection and data analysis.

The results of this process mean that the researcher comes to conclusions based upon what she has found. ""Thus the researcher has to interact with the participants to get to know the particular social setting, share in the feelings and interpretations of the people being studied and see things through their eyes. Knowledge is concerned not with generalisations, prediction, and control but with interpretation, meaning and illumination"" (Seedat, 20031:143).

In addition the focus of the research was on the meaning that people attach to their lives and experiences. Merriam (2002) sums it up by saying that the product of a qualitative inquiry is richly descriptive. Words and pictures rather than numbers are used to convey what the researcher has learned about a phenomenon.

Thus data was ""mediated through human instruments instead of questionnaires or tests"" states Seedat et al.*et al.* (2001:143). Qualitative methods allowed the

researcher to study selected issues in depth, openness and detail. The researcher, according to Merriam (1998), is the primary instrument for gathering and analysing data and, as such, can respond to the situation by maximising the opportunities for collecting and producing meaningful information.

3.6 RESEARCH DESIGN

""The research design is the blueprint upon which the research process is based"" (Mouton, 2001:55). Although this takes the form of a set design at the outset, there is flexibility once the data gathering process begins. There is a certain amount of flexibility, which is required even though the research design has been planned according to a particular method. Rubin and Rubin (1995) cited in Mouton (2001:195) explain this in the following way:

> You cannot plan the entire design for a qualitative project in advance, because the design changes as you learn from the interviewing. But you can begin the work with a rough and tentative design, talk with potential interviewees, sort out initial ideas, refocus the research, and decide with whom else to talk and about what … you can write a research proposal describing the object of the research, explaining its importance.

I have used a basic interpretive qualitative study, which, according to Merriam (2002:6) exemplifies all the characteristics of qualitative research in that ""the researcher is interested in understanding how participants make meaning of a situation or phenomenon, this meaning is mediated through the researcher as instrument, the strategy is inductive and the outcome is descriptive"". Since I worked in an interpretivist interpretive paradigm, I focussed on attempting to understand the phenomenon or in this case the experience of mothers raising children with FAS. Merriam (2002:7), states that ""the world is not the fixed, single, agreed upon or measurable phenomenon … instead there are multiple constructions and interpretations of reality that are in flux and that change over time"". In this case study, the essence of raising a child with FAS, from his mother''s perspective is probed and investigated. Merriam (20202:4) continues that ""learning how individuals experience and interact with their social world, the meaning it has for them is considered an interpretive, qualitative approach"".

3.6.1 The Case Study

I used a collective case study for this research process. Stake (2005:445) states that a collective case study is when ""a number of cases are studied jointly in order to investigate a phenomenon, population or general condition"". In this research study, three cases were researched, and it evolved into a collective case study. Stake (2005:446) continues by describing that the individual cases within the study ""may be similar or dissimilar … and they are chosen because it is believed that understanding them will lead to better understanding, and perhaps better theorising about a still larger collection of cases"". According to Babbie and Mouton (2001:281) ""most case studies involve the examination of multiple variables. The interaction of the unit of study with its context, is a significant part of the investigation.""

Merriam (2002) describes a case study as a search for meaning and understanding, the researcher is the primary instrument of data collection and analysis, it is an inductive investigative strategy and the end product is richly descriptive.

Stake (2005:447), states that case researchers seek out both what is common and what is particular about the case, but the end product of the research portrays more of the uncommon, drawing from

- the nature of the case, particularly its activity and functioning
- its historical background
- its physical setting
- other contexts such as economic political legal and aesthetic
- other cases through which this case is recognised and
- those informants through whom the case can be known.

Finally the methods for case work are to learn enough about the case to ""encapsulate complex meanings into a finite report and to describe the case in sufficient descriptive narrative so that readers can experience these happenings vicariously and draw their own conclusions"" (Stake, 2005:4).

3.6.2 Drawbacks Disadvantages of a Case Study

According to Baxter, Hughes and Tight (2001:73), there are drawbacks to case study research. When dealing with a case study in particular ""the very complexity of a

case can make analysis difficult. This is particularly so because of the holistic nature of a case study means that the researcher is often very aware of the connections between various events, variables and outcomes"" At the end of the data gathering process, the researcher will have a large amount of information to organise and analyse. Baxter et al.*et al.* (2001:73) continue that ""accordingly everything appears relevant"". This large amount of information should be carefully analysed in order for the researcher to see that it is all relevant. The data should be seen by the researcher ""in terms of the Russian doll metaphor, where each piece of data rests inside another, separate but related. The researcher needs to show the connections but not lose sight of the whole"" (Baxter, 2001:73).

3.7 RESEARCH METHODOLOGY

In a qualitative approach, the researcher works inductively. According to Terre Blanche and Durrheim (20061999:43), inductive themes imply ""immersion in the details and specifics of the data to discover important categories, dimensions and interrelationships; this begins by exploring genuinely open questions rather than testing theoretically derived hypothesis"".

In a qualitative paradigm of research, therefore, researchers are primarily concerned with the process rather than the outcome. This research process is more descriptive and adequately represents meaning and the understanding of data.

3.7.1 Methods of data production

3.7.1.1 Sampling

According to Bless and Higson-Smith (1995:85) ""sampling is a technical accounting device to rationalise the collection of information, to choose in an appropriate way the restricted set of objects, persons, events and so forth from which the actual information will be drawn"". Similarly, Merriam (2002:20) argues that ""a sample is selected on purpose to yield the most information about the phenomenon of interest"".

This study makes use of purposive sampling. Bless and Higson-Smith (1995), explain that the purposive sampling method is based on the judgement of the researcher, regarding the characteristics of representative participants. In the case of this study, I selected three mothers whose children had been clinically diagnosed

with FAS. This diagnostic criteria is critical for the importance of my study and therefore only mothers meeting this criteria were selected.

The population from which I have selected my participants, that is mothers whose children have been clinically diagnosed with FAS, were from an urban environment. This is a sample from which the most can be learnt. Patton (1991) cited in Merriam (2002:12) states that it is important to select ""information-rich cases from which one can learn a great deal about the issues of central importance for the purpose of the research"".

Research population, according to Bless and Higson-Smith (1995) in this case, is the entire set of objects and events or group of people, which is the object of research and about which the researcher wants to determine some characteristics. Specific criteria are made use of in the selecting of a purposive sample.

3.7.1.2 Data Production

Data production are the techniques used in order to gather the data for the research study. In this research study, a collective case study, three main techniques were used to produce data according to the research question. Merriam (2002:12) reports that there are ""three major sources of data for a qualitative research study – interviews, observations and documents"". For the purposes of this study, all these three sources were made use of, namely open-ended interviews combined with an informal conversational approach. In addition to this, my observations and field work were recorded and made use of. Then, information gathered from the medical files of each of the mothers was gathered.

A plan was essential for data gathering and according to Stake (2005) caseworkers should also seek what is ordinary in happenings, and in settings. Recording things that are unusual but also ordinary takes a lot of time – for planning, gaining access, data gathering, analysis and writing up.

In addition, the representative from FARR provided me with some background and medical information regarding the cases before I started with the observations and interviews. This gave me some contextual background and history regarding the lives of the mothers. Merriam (2002:14) reports that in qualitative research, ""data analysis is simultaneous with data collection. That is, one begins analysing data with the first interview, the first observation, the first document accessed in the study …

this allows the researcher to make adjustments along the way … and to test emerging concepts, themes and categories against subsequent data"".

The following techniques were used in order to begin the data production process:

3.7.1.23 Depth Interviewing combined with informal conversational approach using an interview schedule

Patton (2002:341) points out that the ""quality of the information obtained during an interview is largely dependent on the interviewer"". As this data held the most informative and important of the data collected for this study the interviewing process was carefully researched before being implemented.

Interviewing, and in the case of this study, depth interviewing, with an interview schedule was made use of Minichiello et al.*et al.* (1990) in Merriam (2002:272) describes depth interviewing as ""conversation with a specific purpose – a conversation between researcher and informant focusing on the self, life, and experience, and expressed in his or her own words. It is the means by which the researcher gains access to and subsequently understands, the private interpretations of social reality that individuals hold"". In the case of this study, the experiences of mothers raising children with FAS was to be investigated. This required a method of interviewing that would probe this phenomenon.

The data that I planned to collect was through in-depth, semi-structured interviews, combined with an informal conversational approach. According to Merriam (2002:166) ""the central purpose of the interviews is to engage in dialogue with participants to elicit their descriptions and perceptions"". The interviewees needed to be guided as to what to say, but not influenced in their answering (see the interview schedule in Addendum D).

The Informal Conversational Interview was to be used when first meeting the participants and in the gathering of the biographical and demographic information. This was the main method of building rapport with the participants. In addition to this I attempted to feel empathy towards them. Merriam (2001:23) states that ""empathy is the foundation of rapport. A researcher is better able to have a conversation with a purpose – an interview, in other words – in an atmosphere of trust"". If the respondent found that some of the information imparted was of a private and delicate nature, then it was important to have developed a sense of trust. This required that

the researcher should be a skilled listener and be aware of and sensitive to subject matter which may provoke emotion.

""The strength of the informal conversational approach to interviewing is that it allows the interviewer to be highly responsive to individual differences … questions can be individualised to establish in-depth communication with the person being interviewed and to make use of the immediate surroundings and situation to increase the concreteness and immediacy of the interview questions and responses"" (Patton, 1987:110).

The semi-structured interview, according to Bless and Higson-Smith (1995:110), ""allows for the discovery of new aspects of the problem by investigating in detail some explanations given by the participants"". For them, ""the wealth and quality of the data gathered are strongly dependent on the skill of the interviewer, the confidence they are able to awaken in the participants, the type of questions which are asked, and the encouraging comments which are made at the correct moment"". The whole purpose of qualitative interviewing is to capture the complexities of the participants" individual perceptions and experiences.

Viljoen (2005) states that alcohol exposure during pregnancy is ""universally under-reported due to the stigmatisation of the drinking mother and her guilt, knowledge of wrong-doing, fear of retribution of the father of the child, and possible exposure to litigation in some instances"". It is therefore important, Viljoen (2005) continues that the interviewer be ""skilled and well trained in extracting valid information … the interview should be conducted in a non-threatening and quiet environment. The woman undergoing evaluation should be assured of anonymity, total confidentiality, help to overcome her problem, and the empathy and interest of the interviewer"". Each of the mothers was given a pseudonym in order to protect her true identity (see the terms and conditions as set out and agreed upon by the Ethics Committee at Stellenbosch University in Addendum B).

The above mentioned excerpt drew my attention and thoughts to the following question, posed by Fontana and Frey (2005:707) ""How do I present myself"" during an in depth interview with a mother who is raising a child with FAS? In order to attempt to build up trust, I needed to think carefully about how I would present myself, because I did not want any of the participants to feel that I as the researcher

was in any way superior to them. As Fontana and Frey (2005:707) urge, ""this is very important because once the interviewers'' presentation of self is ''cast'', it leaves a profound impression on the respondent and has a great influence in the success of the study, or lack thereof"".

During the interview process the following should be kept in mind, according to Patton (1987:123):

1. The wording of the questions: this should be in a language that is understood easily by the participants; in addition the wording should be easily interpreted, free of complicated jargon. The language preference for this study was Afrikaans.
2. The questions should be open-ended: Because the nature of qualitative interviewing is to ""maximise the imposition of predetermined responses when gathering data"" (Patton 1987:123). It also means that the interviewee should be able to respond to the questions on his own terms.
3. The questions should be clear: The interviewer must make it clear to the respondent what is being asked. This is part of building rapport with the interviewee; the questions should also be focused.
4. Use of language: The interviewer should find out before the time what language but also what type of language the participants use when giving data, in the case of this study, the language was Afrikaans.
5. Questions should communicate neutrality: The researcher needs to convey to the respondent that he is only interested in what that persons experience has really been like.
6. Sensitivity should be conveyed: It is the responsibility of the interviewer to convey that some questions or discussion may cause sensitivity in the participants.
7. The interviewer must build rapport with the respondent before and during the interview. If this is not done the respondent may experience discomfort, hostility or negativity. This would influence the spontaneity of the answers and could influence the honesty of answers.

Interviews were conducted with each of the three participants. Biographical and demographical information was gathered from the participants at the beginning of the interview and formed part of the rapport building effort. Following this, semi-structured interviews with open-ended questions were made use of.

3.7.1.43 Observations and field notes

Observation was another method of data collection that was made use of for the purposes of this research study. According to Denzin and Lincoln (2005:643), ""going into a social situation and looking is another important way of gathering materials about the social world"". This was done on the initial visit to the participant''s homes. The visits were relatively brief, but a short tour of the home gave valuable insight into the contextual environment of mother and her child with FAS. According to Babbie and Mouton (2001:282) ""the unit of analysis in case study research is rarely isolated from and unaffected by factors in the environment in which it is embedded"".

According to Patton (2002:260) Observation in social inquiry requires disciplined training and rigorous preparation. Training to become a skilled observer includes: ""learning to pay attention, see what there is to be seen, and hear what there is to be heard. Practice writing descriptively, acquiring discipline in recording field notes and knowing how to separate detail from trivia"". I found this statement to be particularly true with regard to the observations made for this study. Denzin and Lincoln (2005:643) explain that since ""there is no pure, objective, detached observation; the effects of the observer''s presence can never be erased … [so the] observers now function as collaborative participants in action inquiry settings"".

Field notes were recorded throughout the observation period. I was cautious however, not to write down information while I was in the observation venue. It would have been inappropriate to be obviously recording data while I was attempting to build up rapport and trust, having just met the participants for the first time. In addition, I was a guest in their home, and for that reason I did not wish to be note taking while talking to them. However, as soon as I was able I made use of field notes to record environmental data.

3.7.1.54 Information from documents (medical files) gathered from FARR

A third method of gathering data on the participant mothers and their children who have FAS was that of their medical files. Merriam (2002:13) states that ""the strength of documents as a data source lies with the fact that they already exist in the situation; they do not intrude upon or alter the setting in ways that the presence of the investigator might"". Although I did not have access to any of the information personally, I was able to gather this information from the FARR representative. This data was of a medical nature and had recorded the participants'' child''s prenatal and ante-natal progress. Information regarding the mothers'' drinking and smoking habits were given to me from these files/documents.

3.7.1.65 Data Analysis

Merriam (2002:179) states ""qualitative case study researchers proceed with data collection and data analysis like other qualitative researchers. The findings of the investigation are written up as a comprehensive description of the case"". Data analysis is essentially an inductive strategy, which compares units of data to other units of data all the while looking for common patterns to emerge. Therefore before the latter could be done, the raw data gathered was put through a progressive process in order to validate it. Many researchers, once they have gathered the data for their research study, do not know what to do with it. The organisational process differs from person to person. Merriam (2002:396) speaks of ""immersing yourself in your data; listen to it, read it, touch it, play with it, copy it, write on it, colour code it, over and over again!""

According to Mouton (20014:108), ""Analysis involves breaking up the data into manageable themes, patterns, trends and relationships. The aim of analysis is to understand the various constitutive elements of one''s data through an inspection to see if there are any patterns or trends that can be identified or isolated and to establish themes in the data"". It is vital that all the data are put together to form a coherent whole.

According to Strauss and Corbin (1990:144) ""The process of analysis and interpretation involves disciplined study, creative insight and careful attention to the purposes of the evaluation"" he continues by saying that ""when data collection has ended and it is time to begin the formal analysis, the evaluator has two primary sources to draw from in organising the analysis:

> The evaluation questions that were generated during the conceptual and design phases of the project and the analytic insights and interpretations that emerged during data collection.

For the purposes of this research study, I made use of coding, and I identified themes and patterns that emerged from this. The method was inductive in the beginning of the data analysis process. It is of importance that an open mind is kept throughout the process. ""The process"" at this stage was about data reduction. According to Merriam (2005), the data should be reduced to key themes. It is also of importance that an open mind regarding making new meanings and generating new knowledge is kept. Researcher biases must be ignored at this stage. At this stage just the transcript is read through.

Patterns and themes, which emerge from the data analysis should be linked to the research question.

In the processing of my data, I made use of a thematic approach first. After discussing the observations and the information gathered from the medical files and completing the interviews, I looked at themes that emerged from this information. From this, I grouped the repeated themes together creating a cluster of patterns. Next, I discussed the repeated patterns collectively from an ecosystemic framework. Finally, I drew the repeated patterns from the information gathered from each of the three participants together. I viewed this information from an ecosystemic framework. This formed the beginning of the research discussion.

According to Babbie and Mouton (2001:283) research study reports should use multiple sources of evidence and represent dimensions of thick description. I analysed the data collected in this study according to what Yin (1994) cited in Babbie and Mouton (2001:283) described as the modes of case study analysis to include:

1. Pattern matching: Pattern emerging from the data are matched with patterns in the theory or in alternative predictions.
2. Explanation building: This is a specific kind of pattern-building, where the idea is to generate explanations about your case.

The patterns that emerge are given names (codes) and are refined and adjusted as the analysis proceeds. The codes are names, which according to Merriam

(2002:148), are ""discrete incidents, ideas or events taken from an observation or interview procedure"".

Finally the case study researcher ends up ""describing the case in sufficient descriptive narrative so that readers can experience these happenings vicariously and draw their own conclusions"" (Stake, 2002:450).

3.7.2 Constant Comparative Method

The constant comparative method involves, according to Merriam (2002:8) ""continually comparing one unit of data with another in order to derive conceptual elements of the theory."" She continues to describe this method of data analysis in which ""units of data deemed meaningful by the researcher are compared with each other in order to generate tentative categories and properties … through constantly comparing incident with incident, comparing incidents with emerging conceptual categories, and reducing similar categories … an overall framework begins to develop"".

I made use of this strategy when analysing the data gathered during the field work stage. I initially worked with themes that clearly emerged from the data and then compared them to each of the other themes that emerged from the three mother''s data. I was finally able to isolate these themes and put them together in the form of collective patterns because they were repeated in each of the data gathering processes.

3.7.3 Study Implementation

In this section, I will explain the process that was used in conducting this research study.

The first step of the process was to have the research plan approved by the Ethics Committee at the University of Stellenbosch (Please see Addendum A). While that was being processed, I had to find the biological mothers of clinically diagnosed children with FAS. It was important that the children had been officially diagnosed as having FAS, as I knew that this would add to the credibility of the study. I was able to do this through the co-operation of The Foundation for Alcohol Related Research (FARR). The participants were mothers living in the Cape Town metropolitan area. In addition to the above I also needed their informed consent and permission, so that

they had a clear idea of what the interviewing and the research would entail (see Addendum B).

Initially, I met the representative from FARR and discussed my needs for this particular research study. SheThey waswere willing to co-operate and the three mothers were contacted via FARR and asked if they would be willing to participate. They agreed. The next step was to go and meet the mothers myself, along with the representative from FARR in order to set up interview times and allow them to read and sign the informed consent papers.

Interview times were set up and then conducted the following morning. These occurred in a church hall that was close to where the participants resided. The interviews were done over a time period of a few hours. All data was carefully recorded on an audio tape and then transcribed by myself.

In addition, I also spoke into the tape recorder while I was at the interviewing venue, recording ideas and observations that I did not want to forget regarding the participants, the venue and the atmosphere in which I found myself. A tape recorder is part of the indispensable equipment of evaluators using qualitative methods (Patton, 1985:137). ""It all comes to naught if the interviewer fails to capture the actual words of the person being interviewed, the raw data of interviews are the actual words spoken by interviewees. There is no substitute for these data"".

The period of time directly after the interview took place, should not be ignored. According to Patton (2002:383), this period is a critical time of reflection and elaboration. ""It is a time of quality control to guarantee that the data obtained will be useful, reliable and authentic."" Some pointers are given by Patton for what to do immediately after the interview has occurred:

- Check that the audio cassette tape-recorded the interview and if there was some malfunctioning, then immediately make extensive notes of everything that can be remembered.
- The interviewer should go over the interview notes to make certain that they make sense, to uncover areas of ambiguity.
- Listen to the start, middle and end of the tape.
- Obtain clarification if there is uncertainty.

In addition to the above mentioned factors, I also obtained information regarding each of the mothers from the representative from FARR. This was given with the permission of each of the mothers, via the informed consent paper (Addendum BA). The information given to me was verbal, and I was in a position to take notes as I had not requested personal access to their medical files.

Once the data was collected via field work, it was then transcribed, coded and the themes generated from the data were analysed inductively.

3.7.4 Data Verification

To make empirical data more objective and less subjective, the researcher used replicative, falsification and triangulation methods. ""Good case study research follows disciplined practices of analysis and triangulation to tease out what deserves to be called experiential knowledge from what is opinion and preference"" (Stake, 2005:455). I made use of a combination of methods to verify the data that I collected and then started to analyse.

3.7.5 Trustworthiness, credibility, dependability and confirmability

Merriam (2002:422) states that a major consideration in research is its trustworthiness, or the authenticity of the study. Trustworthiness and dependability are an alternative to validity and reliability, as they are known in quantitative research. Lincoln and Guba (1985) in Hoepfl (1997), ask the question ""How can an inquirer persuade her audience that the research findings of an inquiry are worth paying attention to?"". As the central aim of a research design is to ""establish a relationship between the independent and dependent variables with a high degree of certainty"" (Bless et al.*et al.*, 1995:82), creating trustworthiness is an important factor in the research process.

This aspect of the research process is of critical importance and various methods were made use of in this study to safeguard the findings. Triangulation (to be discussed in the next section), ethics and keeping researcher bias to a minimum were applied in the study. I also took into account the argument presented by Denzin and Lincoln (2005:5) that ""the combination of multiple methodological practices, empirical materials, perspectives and observers in a single study is best understood as a strategy that adds rigor, breadth, complexity, richness and depth to any inquiry"".

According to Lincoln and Guba (1985) cited in Flick 1998:232, the criteria of trustworthiness, confirmability, and dependability are used to assess and increase the credibility of qualitative research. Procedural dependability is checked through the following procedures (Flick 1998:232):

- the raw data, their collection and recording,
- data reduction and results of synthesis by summarising, theoretical notes etc summaries and short descriptions of cases,
- reconstructions of data and results of synthesis according to the structure of developed and used categories (themes, definitions, relationships), findings (interpretations and inferences) and the reports produced with their integration of concepts and links to the existing literature,
- process notes, i.e. methodological notes and decisions concerning the production of trustworthiness and credibility of findings,
- materials concerning intentions and dispositions like the concepts of research, personal notes and expectations of the participants,
- information about the development of the instruments.

Babbie and Mouton (2001:278) argue that an inquiry audit incorporating all of the above mentioned factors, should be put in place and properly managed. This can then be used to determine dependability and confirmability simultaneously. In this study, careful attention was paid to each of these factors. Confirmability, according to Babbie and Mouton is ""the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher"". An audit trail ensures confirmability.

In this study, my bias as a researcher had to be kept to a minimum and I aimed for what Patton (2002:49) describes as ""empathic neutrality"". I did this by conscious awareness of the fact that as the researcher in this inquiry I needed to remain neutral at all times. According to Patton (2002:51), ""the neutral investigator''s commitment is to understand the world as it unfolds, to be true to complexities, multiple perspectives as they emerge and be balanced in reporting both confirmatory and disconfirmatory evidence with regards to any conclusion found"". I continually urged myself to keep an open mind and that my role was only to observe, record and

investigate and then discuss my findings. In addition, all tape recordings, transcriptions and notes were kept so that if needs be an audit trail can be put in place. As agreed with the participants, however, once this thesis was handed in, all information pertaining to the participants was destroyed (see Addendum B).

""Credibility depends less on sample size than on the richness of the information gathered and on the analytical abilities of the researcher"" (Patton, 1990 in Hoepfl, 1997). Credibility can be further strengthened via triangulation methods, which will be discussed in the next section.

3.7.6 Triangulation

This term was first conceptualised as a strategy for validating results obtained with the individual methods. Triangulation in a qualitative case study according to Stake (2005:454), means to ""reduce the likelihood of misinterpretation"". He continues that ""triangulation has been generally considered a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation. Triangulation helps to identify different realities"".

Denzin and Lincoln (2005:5), state that the use of multiple methods, or triangulation reflects an attempt to secure an in-depth understanding of the phenomenon in question … triangulation is not a tool or a strategy of validation but an alternative to validation. The combination of multiple methods in a single study is used as a strategy that adds rigor, breadth, complexity, richness and depth to any inquiry.

In this case study, triangulation was made use of to verify my findings. I cross checked my perceptions of the case findings through talking with members of FARR who had similar or alternative perceptions of my findings. In addition, I combined observation of living conditions with information from FARR and the interviews conducted in order to create triangulation in this research study.

Denzin and Lincoln (2005:6), continue by stating that ""triangulation is the simultaneous display of multiple, refracted realities and each of the metaphors ""works"" to create simultaneity rather than the sequential or linear. Readers are then invited to explore competing visions of the context, to become immersed in and merge with new realities to comprehend"". This description is relevant to this particular research study in that my goal in part, was to draw the reader into the unique experience of the mothers who raise children with FAS. I planned to do this

by drawing together the threads of information that initially created themes, then via the emergence of patterns from repetitions of the themes.

Babbie and Mouton (2001:278) state that ""overlap methods represent triangulation, which is typically undertaken to establish validity"".

3.8 ETHICAL CONSIDERATIONS

Ethical considerations have long been overlooked in research studies, but as the human rights of individuals are gaining greater acknowledgement and respect, more attention is being paid to this.

As Mertens (20045:53) rightly argues, ""ethics in research should be an integral part of the research planning and implementation process, not viewed as an afterthought or a burden"". No information regarding another individual should be written about, recorded or printed without their permission and consent.

In addition, ethics in research should be regarded with vigilance. It is imperative that consent should be sought from the individual being interviewed. The researcher in his capacity as summariser of information should report and record everything honestly and with integrity.

Christians (2005:144) discuss four major guidelines for directing codes of ethics:

- **INFORMED CONSENT**: participants have the right to be informed about the nature and consequences of experiments in which they are involved. Proper respect for human freedom generally includes two necessary conditions. First, participants must agree voluntarily to participate and secondly their agreement should be based on full and open information. These include the duration, the methods possible risks and the purpose or aim.
- **DECEPTION**: In emphasising informed consent, social science codes of ethics uniformly oppose deception.
- **PRIVACY AND CONFIDENTIALITY**: codes of ethics insist on safeguards to protect people''s identities and those of the research locations. Confidentiality must be assured as the primary safeguard against unwanted exposure.

- **ACCURACY**: Ensuring that data are accurate is a cardinal principle in social science codes. Fabrications, fraudulent materials, omissions, and contrivances are both non-scientific and unethical.

Terre Blanche et al.*et al.* (2006:241) describe that the following points should also be taken into account when determining whether research is ethical:

- **AUTONOMY AND RESPECT**: The protection of the individual and institutional confidentiality is an important expression of this principle.
- **NONMALEFICENCE**: The researcher must ensure that no harm befalls the research participant as a dire or indirect consequence of the research.
- **BENEFICENCE**: The researcher is obliged to attempt to maximise the benefits that the research will afford to the participant in the research study.
- **JUSTICE**: This implies that people get what is due to them. Researchers should treat research participants with fairness and equity at all stages of the research process.

Confidentiality is another aspect of the research process that should be taken into account during data gathering. Mertens (20045:333) states that ""confidentiality means that the privacy of individuals will be protected in that the data they provide will be handled and reported in such as way that they cannot be associated with them personally"".

Ethical procedures entered into for this case study:

A research plan was submitted to the Ethics committee at the University of Stellenbosch. This was checked at their general meeting and then taken to a smaller committee for discussion. At the same time a form requesting informed consent by the participants was formulated (see Addendum B). This was also authorised by the ethics committee at the Stellenbosch University.

Once I received this permission from the ethics committee (see Addendum A), I submitted this to FARR who then arranged three mothers of children with FAS for me to interview. The mothers were then given the informed consent form to fill in and sign (see Addendum B). A representative from FARR who knew the mothers from previous interaction, showed them the consent form, read it to them and witnessed the signing.

It was only after this procedure had been completed that I was able to commence the data collection process. At the end of the interviews each mother was given R50 as a token of appreciation for their participation in the study. I also gave them sandwiches, coke and chips for their children.

THE ROLE OF THE RESEARCHER

Denzin and Lincoln (2005:4) liken the qualitative researcher to a quilt maker, ""as he stitches, edits and puts slices of reality together"". This process creates and brings psychological and emotional unity – a pattern – to an interpretive experience. My role as researcher in this study will be one of immense responsibility to explain the plight and narratives of mothers of children born with FAS. My sense of social responsibility has influenced my choice of topic for the study and I think, also, my experience of being a mother. I have therefore combined different issues together, the product of which has been this research document.

Denzin and Lincoln (2005:6) continue by stating that the researcher understands ""that research is an interactive process shaped by his or her own personal history, biography, gender, social class, race and ethnicity, and by those of the people in the setting"". The researcher brings to the study many aspects of her/his own life experience and reality and weaves together the multi aspects of another''s life experience.

3.9 REFLECTION AND CONCLUSION

This chapter has guided the reader through the blueprint of the research design. It presented the research paradigm, the purpose of the study, the context of the study and the methods used to produce the data. The interpretive research design focused on the mothers'' experiences of raising children with FAS.

This framework not only guided the research process but it also guided the researcher who often finds herself on a long, hard journey with many challenges along the way (Brott in Merriam, 2002:422). Personally, I feel that this was an exploratory experience, one which presented me, the researcher, with twists and turns, some easy and rewarding and others challenging, but nevertheless a journey of discovery. The following chapter discusses the analysis of the research data that

was gathered for the purposes of this study. In reflection, this chapter gave me important guidelines and a blueprint which I found to be helpful during the data gathering and analysis phase. As each research study is unique it helped me to conceptualise this particular research process.

CHAPTER 4

IMPLEMENTATION OF THE STUDY

4.1 INTRODUCTION

This chapter begins with a discussion of the research process during the production of the data. The previous chapter construed the process of how the data gathering and analysis would be carried out. In the following sections the data produced from the interviews and the observations of the living environments as well as data collected from the FARR representative and from the medical files of the mothers whom I interviewed is presented. Although this is classified a collective case study, I will present each of the three mothers as cases, individually. I will end each of the three studies in this chapter by reflecting on each one. All the first names used in this research document are pseudonyms, chosen by myself the researcher. After that I will look for corresponding patterns in all three cases.

4.2 RESEARCH PROCESS

After permission was obtained from the Ethics committee at the University of Stellenbosch to conduct the research study, I contacted Anneline, the FARR representative. She became the link between the FAS mothers and myself. As soon as I received the permission from the University, Anneline drove to the homes of the mothers that I intended to interview and arranged for me to meet them. Each of the three mothers was poverty stricken and lived in an underprivileged area, so arrangements could not be made over the telephone.

The three participants had been purposively identified and selected to be in this collective case study. The criterion for this was that they were mothers who had clinically diagnosed children with FAS. Anneline arranged a day and a time for me to meet with them and this initial meeting was scheduled to take place at their homes.

I initially met each of the three mothers separately, during the first part of the morning, and all on the same day. This was a ""safe"" time in the dangerous area

within the Cape Flats in Cape Town, where unemployment and gang activities are rife. Domestic and organised crime areis common occurrences. During my initial encounter with each of the mothers, I was able to observe their living environments. This observation opportunity was an important part of the data gathering process and was to be one of the three points in the triangulation process within this research study.

Each of the mothers had the informed consent papers read to them and once this was done and it had been explained in their language of preference (Afrikaans), they each signed the document. At this point they were also given the opportunity to ask any questions. Ensuring that they understood exactly what was expected of them during the data collection phase was a very important part of the research process.

We then arranged a time that was convenient for them to be interviewed. I obtained the permission of a local minister to conduct the interviews in the safety of his church hall. The context of the participants" homes would not have been an appropriate venue for the interviews as they live in overcrowded dwellings. In addition, the interviewing venue needed to be a quiet, safe, neutral environment where rapport could be established between researcher and participant, away from the scrutiny of fellow inhabitants and interested neighbours.

I returned on the allocated days and conducted the interviews. First, I collected Elsabé from her home and drove her to the interview site. The interview took approximately 80 minutes. I then drove Elsabé back to her home. On my return to the church office, Karien arrived independently, but with her six-year-old son, Eddy, at the allocated time at the venue. This interview took 35 minutes to complete. I then drove Karien back to her home. I interviewed Sara the following week as she had work commitments until 3 pm on three days a week, namely Monday, Wednesday and Friday. I fetched her from her place of work, and the interview took place in my car as the church hall was not available in the afternoons. This took about 45 minutes.

The interviews were in-depth and semi-structured. An interview guide was used (see Addendum C). The questions were predominantly open ended. The interviews were tape recorded with the consent of the participants and then transcribed verbatim onto a computer for data analysis. The language medium was Afrikaans. After the

interviews, I coded the themes that emerged from them. Following this procedure, I isolated themes from each of the data gathering processes. Repeated themes from each case study were then clustered together to form patterns.

In addition to the observations of the mothers'' living environments, which was done prior to the interviews, detailed case information were obtained from the medical files from Anneline, the FARR representative, which contributed to triangulation. Babbie and Mouton (2001:281) state that ""thickly described case studies take multiple perspectives into account and attempt to understand the influences of multilevel social systems on participants'' perspectives and behaviours"". This has been a critically important aspect of this research study, namely the experience of mothers who raise children with FAS. It would have been an impossible task to separate the mothers and their experience of raising a child with FAS from the multilevel social system and context in which they live.

4.3 ELSABÉIE

4.3.1 Phase One: Observations – entry into the community: The context of Elsabé and Saartjie

I immediately noticed that the context in which Elsabé lived was poverty stricken and overcrowded. This particular suburb is one of the most vulnerable areas in Cape Town due to its high levels of poverty and unemployment. In addition, there are many gangs that operate in the area where organised and opportunistic crime is a normal and everyday occurrence. Shebeens are easily accessible and many inhabitants buy liquor from them, as there is very little else to do. High levels of unemployment are an everyday reality in this under privileged area of Cape Town.

On the morning that I first met Elsabé in early September there was no indication of spring having arrived in this area of Cape Town. The colours of buildings had faded and the paint was peeling off the walls. The atmosphere as well as the aesthetics of the area was bland. There were no flowers and very few trees. What I did observe was many scruffy dogs sniffing around and some children, too young to be at school, tottering around outside gates and inside gardens. It was a bleak and cold environment.

The home that Elsabé emerged from was made of bricks and mortar but the back room which she inhabited with her six year old daughter, and three others was a

""lean to"" made from corrugated iron joined on to the wall in a make-shift manner. Her living quarters were cold, cramped and dark.

As I entered the house, there were some inhabitants sitting in a tiny square of mudded ""garden"". The owner was sitting on an upturned box. She greeted us, as did everyone else who was standing around. Some appeared to be unemployed men, some young children. I gained a general impression of untidiness and lack of hygiene. The living area smelt of very stale cigarette smoke. The living room was very cramped with two or three couches and chairs. The house did, however, have running water and electricity.

We made our way through the house, past the kitchen and into the back room that Elsabé inhabited. The smell of tobacco smoke and stale kitchen smoke created an acrid smell throughout the house. I entered Elsabé''s living quarters, which was just one small room. Here I observed large open vents between the walls and the corrugated iron roof, which were visible, above the double bed that Elsabé shared with her daughter, Saartjie and one other person. From these vents a cold draft blew into the room. I shuddered to imagine the conditions there when lashing rain and storms occurred as they do in Cape Town in winter. In addition to the double bed, there were two other single beds in the room. The air was grey and dark, and a sleeping body stirred in the double bed, another inhabitant in Elsabé''s already overcrowded ""living"" quarters. I did not notice any toys, pictures or clothing, which may have belonged to Saartjie or to any child living there. There were no objects which may have been a source of enjoyment or entertainment for a six-year-old little girl.

Elsabé presented as an extremely thin and petite woman. She was clothed in jeans and a jersey and she looked as though she had made an effort to look neat and well presented for the interview. Her short hair was neatly brushed backwards and she was on time for the interview, which she appeared to consider important.

4.3.1.1 Themes which emerged from this observation

The first theme that struck me regarding Elsabé''s experience of being a mother of a child with FAS was that of poverty. Lack of income and resources led her to living with many other people in the home, which she inhabited, in squalid conditions. The

second theme that emanated from this observation was that of lack of hygiene in the home and lack of healthy standards of living.

A further theme that emerged was that there were many other people living in close proximity to Elsabé and Saartjie, forming a type of extended family system. The impact of this would have allowed Elsabé to be absent from the home in the evenings, in order to go to work or to go or to consume alcohol as a form of recreation with her friends. This would allow her to ignore Saartjie"s demands and needs.

4.3.2 Phase Two: Information gathered from Elsabé"s medical file

Elsabé was forty-five years old at the time of the interview. She was born in a small village in the Western Cape. She attended the local school until she left after standard four (grade six). She came to Cape Town at the age of twenty to look for work.

At the time of the interview, her daughter, Saartjie was six years and six months and she had been clinically diagnosed as having FAS. Prenatal history indicated that Saartjie had experienced intra uterine growth retardation. Saartjie was born prematurely, and because of fetal distress she was delivered via an emergency caesarean section. Saartjie weighed 1.5 kilograms at birth. At her six week check up she was diagnosed as having FAS. This diagnosis was confirmed at thirteen months of age. Saartjie met three of the diagnostic criteria for FAS, namely growth retardation, structural abnormalities, and cognitive/behavioural abnormalities. Since Elsabé confirmed that she had consumed alcohol while she was pregnant with Saartjie, the fourth criterion was also met.

According to Elsabé"s case history, she had started drinking at 10 years of age in the village where she was born. Elsabé drank wine daily throughout her pregnancy – up to three litres of wine per day. She did not eat while she was drinking, only afterwards. In addition she smoked five to ten cigarettes per day.

4.3.2.1 Themes that emerged from the information gathered from the medical files belonging to the FARR representative

The first theme that emerged from the information gathered from Elsabé"s medical files was that she had been drinking alcohol since she was pre- adolescent (the age varies). In addition to this, her education ended at an early age, so she had no

education after grade six (standard four), which affected her experience of bringing up her daughter. In addition, she continued drinking while she was pregnant with Saartjie. Elsabé abused alcohol and tobacco during her pregnancy with Saartjie. Another pattern was that Saartjie was diagnosed as having FAS on all four of the diagnostic criteria. Saartjie also experienced low birth weight, and was a premature baby.

4.3.3 Phase Three: Interview with Elsabé

4.3.3.1 Initial encounter with the text

Elsabé was interviewed in the local church office near to her home. She had been interviewed before on a few occasions, so this was not a new experience for her. She was able to answer most of the questions put to her. Elsabé, however, did not often elaborate on answers put to her, and some of her answers were monosyllabic. In addition some of the interview was not audible, as she spoke very quickly sometimes using colloquial language.

4.3.3.2 Identification of themes from the interviews

- Elsabé originated from a large family with five brothers and one sister.
- Elsabé"s biological family members drank alcohol including her mother and her father.
- Elsabé"s started abusing alcohol when she was pre adolescent (twelve years old).
- Elsabé"s peers also consumed alcohol while they were still at school (up to Grade six).
- Elsabé"s education was prematurely ended (Standard four).
- There appeared to be conflict in Elsabé"s family of origin (""Ek was maar gruwelik gewees"").
- Elsabé was born outside Cape Town and spent her early years growing up in a small village in the Western Cape. She came to find work in Cape Town at the age twenty, by which time she had a three year old child whom she abandoned in her village of origin.

- Elsabé had no current contact with immediate family members from her family of origin. Therefore Elsabé had no support at that time from family members (""ek en Saartjie is alleen"").
- There were manifestations of effect of alcohol on developing baby in utero (""die baba was te klein"").
- Elsabé worked long hours as a domestic worker (""ek werk tot 10 uur in die aand"").
- Elsabé acknowledged that alcohol abuse while pregnant caused FAS in Saartjie (""sy is die kleinste onder hulle"" [Saartjie se vriendinne]).
- Elsabé''s current family system has broken down (""die oudste een, suster, wanneer ek Kaap toe kom was sy drie jaar, wanneer ek haar gelos het. Die ander een was een jaar wanneer die social werker haar geneem het"").
- Elsabé spoke of difficult experiences of Saartjie, her child with FAS (""sy maak my baie kwaad"").
- Elsabé was often absent from the house where she and Saartjie lived (""ek is min by die huis ek kom van werk 10 uur in die aand"").
- Elsabé and Saartjie lived in an over-crowded dwelling (""baie mense woon daar"").
- Saartjie did not tell Elsabé that she had homework to do at home (""In die oggend sê die ander kind by die huis dat Sara huiswerk gekry het, maar sy net skool toe gaan"").
- According to Elsabé, Saartjie enjoyed playing when she should be learning (""sy moet leer, sy is spelerig"").
- The teacher at school indicated that Saartjie liked to play (""sy is spelerig"").
- There were conflicting reports of Elsabé''s experience of Saartjie''s behaviour (""sy is nie ''n moelike kind nie"", ""sy gee my geen probleme nie"", ""sy maak my baie kwaad"", ""ek praat saam met haar maar sy luister nie"").
- Elsabé experienced anger toward Saartjie (""ek sê vir haar sy moet kom"", ""sy moet leer maar sy is stubborn"", en ""sy wil nie, loop hulle weg, met haar vriende"").

- Elsabé experienced high levels of frustration with Saartjie (""in die oggend sê die ander een dat sy het huiswerk gekry, maar sy het skool toe gaan, dan kan ek help nie"" en ""sy maak my elke dag kwaad"").
- Saartjie did not want to do homework (""die ander kind wat in die huis bly sy het huiswerk"").
- Saartjie listened to other adults in the house but not to Elsabé (""sy luister vir Margaret die huisvrou se dogter"").
- Saartjie talked a lot and was active (""sy is baie besig"").
- Elsabé experienced Saartjie as needing aid with some self-help skills (""sy kan self uit trek maar ek moet haar in die oggend aan trek"").
- Elsabé experienced negative emotions when hearing the news that Saartjie had FAS (""ek voel anderste"" ""dat ek is ''n alkoholiek, ''n alkoholiek se kind"").
- Elsabé continued experiencing the same negative emotion now (""dis altyd met my, ek het ''n alkoholiek kind"").
- Elsabé disagreed with the diagnosis that Saartjie had FAS (""Ek stem nie saam nie"" en ""ek hou nie van wat hulle sê nie, dat sy is ''n alkoholiek se kind"").
- Elsabé experienced social isolation at times as a result of having a child with FAS. She argued with her friends about this fact (""somtyds strike ons, die een is maak hulle my kwaad wanneer hulle so praat, sy is kwaad vir my want ek slat vir Saartjie"").
- The most painful experience for Elsabé was with her friends rather than Saartjie''s behaviour (""Wanneer hulle sê sy''s ''n kind van alkohol, sy kan dit nie help dat sy ''n kind van alkohol is nie"").
- Elsabé was aware that she could have prevented the FAS by not drinking.
- Elsabé''s experienced discipline as difficult (""Ek wil wegloop want die mense skel vir my as ek haar baie slat"").
- Elsabé wished for good outcomes (""ek wil ''n lewe vir my kry"").
- Elsabé drank every night of the week and each day of the week end.
- Elsabé smacked Saartjie when she felt she had been naughty (""Ek slat haar"").

4.3.4 Clustering of patterns

The clustering of patterns which emerged from the interview with Elsabé were as follows:

- Elsabé"s biological family system and its historical context – that of poverty, parental drinking habits, and community consumption of alcohol. Alcohol abuse was common practice.
- Elsabé started consuming alcohol at early age and still abuses alcohol today.
- Elsabé stopped her education process prematurely.
- Elsabé"s experience of Saartjie indicated high levels of frustration, and anger and annoyance at times.
- There was a lack of a functional nuclear family structure, but she had some support in the form of fellow house inhabitants. Elsabé reported that Saartjie listened to one of the other mothers in the house, but not to Elsabé herself.
- Elsabé lived in poverty-stricken circumstances; there was evidence of over crowding and lack of hygiene in the home.
- Elsabé felt guilt and anger when her friends called Saartjie ""a child of alcohol"".
- Saartjie was diagnosed with FAS on all four of the diagnostic criteria. Some physical manifestations apparent in Saartjie.
- Elsabé was consuming alcohol daily and over the week ends.
- Elsabé"s friends had created a support network for her.

4.3.5 Discussion of the ecosystemic perspective of clustering of patterns

Within Elsabé"s ***micro system*** we need to view the effect that her family of origin had upon her. Elsabé was exposed to alcohol from an early age because her parents and others in her environment drank alcohol regularly. She started drinking alcohol herself when she was 10 or 12 years old. Therefore alcohol had played a significant role in her life, stemming from her biological family system. It was still playing a significant role in her unique reality at the time of the interview. Being a mother and an alcoholic mother would impact on her experience of raising Saartjie.

Within Elsabé''s ***meso system*** the fact that she ended her education in grade six (Standard four then), also impacted upon her experience of raising Saartjie. Elsabé may not have learnt some fundamental basics of how to raise a child and this lack of knowledge could transfer into forms of neglect at times. When this is coupled with Elsabé''s need to abuse alcohol, this could significantly impact upon Saartjie''s behaviour presentation, especially if Elsabé was often absent while working or consuming alcohol with her friends. In addition to the fact that Saartjie had been clinically diagnosed as having FAS, Elsabé''s experience of raising her was influenced by factors other than FAS. Elsabé experienced anger and frustration toward Saartjie when she did not listen to her requests. When this became extreme, Elsabé walked away from the situation indicating that she was unable to cope with or deal with Saartjie''s behaviour.

The poverty that is experienced in Elsabé''s ***macro system*** is being kept in place by policies and laws which impact upon her existence. An example of this is that there might not be adequate facilities for her to attempt to go into a rehabilitation centre where she could try to stop drinking alcohol where she lives. In addition, shabeens operate and it is easy for Elsabé to purchase inexpensive alcohol.

Within Elsabé''s ***micro system*** and her ***meso system***, there is evidence of many people living in overcrowded conditions close to her and Saartjie. This could be both positive and negative in nature. The many other people living in the same house as Elsabé were able lighten her burden of having sole responsibility for raising Saartjie. She worked until 10 pm on many evenings of the week, leaving ""friends"" in the house to tend to Saartjies needs. This indicated that Elsabé was regularly absent in the afternoons or evenings. This emanates from within Elsabé''s ***exo system*** which makes her work place inadvertently impact upon Saartjie which in turn impacts upon Elsabé''s experience of raising her.

Within Elsabé''s ***chrono system,*** which is viewed as her development over time, we see that her family of origin has shaped her in addition to her consuming alcohol over her life span. Choices that she had made during her life were affecting her and her life with Saartjie. The fact that she abandoned her first born daughter, her family of origin and her home town to come to live in the city to find work has impacted on her life now. The implications of this are that she and Saartjie had no biological family to interact with. The co-inhabitants at the house where they stayed had

become a surrogate family for her and especially Saartjie as Elsabé was out of the house often.

4.3.6 Reflections by the researcher on Elsabé

The experience of meeting Elsabé stayed with me for many days and weeks after I had met with her. I found going into her living space and for a brief moment seeing the world through her lenses an arresting experience. This was not an existence to be relished. Hardship was evident in every aspect of her reality. I could not imagine that her experience of raising a child with FAS was an easy one. Elsabé presented in many ways as a tough, street-wise woman, but my overall picture of her is very different.

When I first fetched her up from her home, Elsabé was slightly embarrassed and giggled a little, obviously feeling a little uncomfortable. But when we got to the church hall, and we had got into the swing of the interview, I sat with her and spoke as a fellow mother about very real, shared issues pertaining to child rearing, regardless of the difference in our contexts. I felt a connection with her which I had not expected. I felt deeply empathic towards her as some of her streetwise layers fell away and she spoke honestly about her experiences of raising Saartjie. Elsabé spoke candidly about her pain and hurt when her friends (a family system for her) called Saartjie a ""child of alcohol"" (""kind van alkohol""). This reaction seemed such a normal one, and yet her context seemed so harsh, I did not expect her to experience their taunts in this way.

4.4 KARIEN

4.4.1 Phase One: Observations – entry into the community: The context of Karien and Eddy

The area in which Karien lived was overpopulated and the roads leading there were narrow and litter lay strewn around. My initial impression of the environment was that it was overcrowded. Rows of washing hung between dwellings and some unemployed residents loitered on street corners, while pensioners stood at their gates, observing the goings-on of the morning. The houses appeared to be double-storey ""town houses"" and Karien and her family inhabited the top storey of the building, living in a flat on the top floor.

We parked outside on the verge and immediately half a dozen men gathered in a group next to the car to observe our arrival. I felt somewhat uncomfortable as we opened the small gate and went up the steps on the outside of the building, into Karien''s living space.

Karien''s small son, Eddy, was at home, too young to attend school yet. In the corner of the sitting room, her crippled father was sitting in a chair. Karien and her family lived in this particular flat, namely her husband, three children, father, and her two brothers.

Karien, Anneline, the representative from FARR and I moved through the dwelling into the kitchen and sat on a make-shift bench. Karien then talked animatedly to me and Anneline. The kitchen was filthy. A double hot-plate was thick with blackened oil, appearing not to have ever been cleaned. Cigarette butts lay on the kitchen floor. The smell of stale cigarette smoke was very strong. Karien chatted animatedly while I read and explained the informed consent paper to her. She was in agreement with all aspects of it and did not have any questions regarding it. We arranged a follow up session to complete the interview for the following morning. Karien explained that she had to take her father to fetch his pension pay out but would make her way to the church office by 10.30 am.

Eddy and his younger sister played in the lounge while Anneline and I spoke to their mother. The lounge had too much furniture in it, including a large, old television set in the corner. This flat appeared to be a more established dwelling, than that of Elsabie''s. Karien explained that her husband had a job and that he did not want her to work, but rather stay at home to look after the children.

4.4.1.1 Themes which emerged from this observation

The initial theme that emerged from this observation experience was that of general poverty. The second theme that I observed was lack of hygiene in Karien''s living space, and overcrowding in the flat that she lived in. Although her husband brought in an income, Karien and her family lived in a poverty stricken environment, which appeared to be untidy and chaotic. She did not appear to have cleaned the house for a long time. There was evidence of dirt in the home, which in many respects was mirrored in the community in which they lived.

Another theme that emerged from the observation was that the community lived in extremely close proximity. This allowed Karien to drink alcohol and not to worry about Eddy. There were many other people in the flat or in the neighbourhood who could keep an eye on him while she consumed alcohol.

A further theme that emerged from the observation was that Eddy appeared scruffy and unkempt.

4.4.2 Phase Two: Information gathered from Karien''s medical file

Karien was forty years old at the time of the interview. She was born in Athlone in Cape Town where she was brought up. She attended school until standard 5 (grade 7). She left formal education because she had to help her mother in the house that they lived in.

At the time of the interview Karien''s son was 5 years 7 months and he had been clinically diagnosed as having FAS. Prenatal history indicated that Eddy had experienced intra uterine growth retardation. Karien attended the local clinic and became part of the FARR study, which was ""Fetal Alcohol Syndrome: Pre-natal assessment of the foetus at high risk"" done by Dr Louise Matthews.

Eddy met three of the four diagnostic criteria for FAS, namely growth retardation, structural abnormalities and Karien''s confirmation that she had consumed alcohol during the pregnancy. Eddy weighed 2.1 kilograms at birth.

Eddy''s FAS was diagnosed at the age of 4 weeks.

During the recording of Karien''s history, she stated that she had started drinking at 14 years of age. She participated in binge drinking during the first trimester of her pregnancy, but on Fridays and Saturdays only. During this time she drank predominantly beer but she drank whiskey on average twice per month. She reported that she stopped drinking the whiskey when the pregnancy was confirmed. Karien only ate food after she had consumed alcohol. She smoked up to 20 cigarettes per day.

4.4.2.1 Themes that emerged from the information gathered from the medical files belonging to the FARR representative

The theme that emanated from this aspect of information was that Karien began drinking alcohol at the age of fourteen. In addition she drank on and off throughout

her life, and misused alcohol and tobacco in the form of binge drinking while she was pregnant with Eddy. Another theme was that she stopped formal education at a young age (Grade 6) because she had to go and help her mother in their house. A final theme that emerged was that Eddy had been diagnosed as having FAS and he met with three of the four criteria for diagnosis.

4.4.3 Phase Three: Interview with Karien

4.4.3.1 Initial encounter with the text

Karien appeared to be in a hurry and although she said that she had been interviewed before, I was uncertain as to the genuineness of some of her answers. She arrived at the interview venue with Eddy who sat in the church office throughout the interview. Karien appeared to rush through the answers during the interview. Eddy her son, had to stay in the room with us as there was no other place for him to go, while we discussed issues around raising him. He sat very quietly at the other end of the room while we completed the interviewing. I had brought him some coke and chips and that diverted his attention and kept him happy throughout the duration of our meeting. When I expressed concern about his presence in the room while we were clearly discussing him and using his name in the conversation Karien repeatedly assured me that it did not matter and that he would not realise that he was being discussed. My instinct and respect for children made me feel extremely uncomfortable with Eddy in the room.

4.4.3.2 Identification of themes from the interviews

The themes which emanated from the interviews were taken from the transcriptions, as they were discussed in the interviews:

- Karien was born locally, and has lived in Cape Town all her life.
- Karien was from a family whose members also abused alcohol.
- Her biological family of origin was large: 7 brothers and 1 sister.
- Karien started drinking in early adolescence.
- Karien consumed alcohol while pregnant, in the form of binge drinking.
- She received financial support from her husband who is a bread winner in the home.

- Karien did not think that her child with FAS is difficult, just sometimes (""dis net sommige tyd wat hy onbeskof is, gaat, baklei"") Karien does not think he is different to other children (""nee, glad nie hy is net soos die ander kinders"") Karien thought Eddy was the same as her three other children (""soos enige ander ouers wat ons groot gemaak so is hy"").
- There was not yet enough money for Eddy to attend school yet.
- Even though she consumed alcohol during pregnancy Karien experienced Eddy as normal (""Hy is normal kind, ek het gedrink maar hy is die selfde as die ander wat ek gehad het""), and she felt that Eddy was developing all right (""Hy vorder alright""). Karien does not think Eddy is a difficult child (""Nee hy is nie moelik nie"").
- Karien did not often get cross with Eddy (""Partykeer dan slat ek hom"").
- Karien experienced Eddy as active (""Baie besig"").
- Karien knew Eddy sometimes did not understand why she smacked him (""Ek slat hom maar hy weet nie wat hy doen nie, dan slat ek hom sommer"").
- Karien experienced Eddy as talkative (""praat baie soos "n papagaai, in die aand baie babble voor hy gaan slap dan praat hy heel aand"").
- Eddy''s sleeping routines were not age-appropriate (""Hy gaan bed toe 10 uur en slaap tot 10 uur in die oggend"").
- Karien did not think that Eddy needed any additional help (""Nee, hy het nie baie help nodig"").
- Eddy was independent as far as self-help skills are concerned.
- Eddy interacted and mixed with other children in the community.
- When she was told that her son had FAS she did not feel anything (""want al die mense doen dit ook"" – [drink]).
- Karien felt exactly the same at the time of the interview as she did with her other children, no different now with her child with FAS (""ek voel net soos ek het met my ander kinders groot gemaak, net soos ek nou is"").

- Karien did not feel any different now as she did before she knew that he had FAS (""geen verskil"").
- Karien would like to meet with other FAS mothers.
- Karien did not worry about him because he was the same everyday (""elke dag dieselfde"").

4.4.3.3 Clustering of patterns

- Karien''s biological family system and its historical context – that of poverty, parental drinking habits, and community consumption of alcohol. This appeared to be an acceptable pastime in her reality.
- Karien''s started consuming alcohol at an early age and still was still abusing alcohol and tobacco.
- Karien''s education processes were prematurely terminated.
- Karien''s sometimes became angry with Eddy, and she did not accept Eddy''s FAS diagnosis.
- Karien experienced Eddy as being no different to any of her other children.
- The environment and neighbourhood were supportive and accepting of Karien and Eddy.
- Karien and her family lived in a poverty stricken area.
- Karien had an extended family who lived with her and gave her support.
- Eddy was a very active child with bad sleeping habits.

4.4.3.4 Discussion of the ecosystemic perspective of clustering of patterns

Within Karien''s ***micro system,*** we need to view the effect that her biological family had on her. Her parents and friends also consumed alcohol. In addition, her siblings and those friends at her school and in her community also drank alcohol therefore it was an activity that was done naturally and regularly around her. In addition within her current family system, there were some who also consumed alcohol in the same quantities. The community in which Karien lived did support her and Eddy.

Within Karien''s ***meso system*** the community in which she lived offered support to her and Eddy. He was often invited to play with other children who also lived in the

area. In addition, many people lived together within the same dwelling. Karien stopped her formal schooling at a young age and had had no further formal education. This might have impacted upon her raising Eddy as she might not have had the knowledge of some basic aspects of parenting.

Within Karien"s ***exo system*** there are some community health services which support her and Eddy. It was in the local clinic that Eddy was diagnosed as having FAS. There are not enough community health centres, however, available to support Karien in helping her to stop the consumption alcohol.

The ***macro system*** impacted upon Karien by creating laws and norms which keep her in an existence of poverty. There are shebeens which allow individuals to purchase alcohol inexpensively. These are not policed as they should be. It appears to be all too easy for Karien to continue with the misuse of alcohol. Community education of the effects of alcohol during pregnancy or thereafter appear to be lacking. It appears to me, the researcher, that nobody appears to care that she continues to consume alcohol. Dominant social structures are in place which allow her to continue with this pastime.

Within Karien"s ***chrono system,*** a significant factor is her decision to continue misusing alcohol has implications for Eddy"s future. Over time Karien has become a woman and mother who abuses and misuses alcohol.

4.4.3.5 Reflections by the researcher of Karien

Karien presented as rushed and in a hurry to do the interview. I did not get a sense of her being involved in the process or her intending to share her experience of raising Eddy. Karien spoke very fast and her body language suggested that she was not entirely comfortable or interested in answering the questions that we discussed. After a while I began to get the impression that she wanted the interview to be over as quickly as possible. There were times when I was able to smell alcohol on her breath during the interview. Many of her responses were impulsive and in a way they appeared to be superficial. In addition it worried me that she had brought Eddy along with her to the interviewing venue. It seemed to me that she did not care that he was hearing us discuss him.

I found it more difficult to connect with Karien in the same way that I did with Elsabé. I felt strongly that Karien was in denial regarding Eddy having FAS. She appeared to be out of touch with her experience as a mother.

4.5 SARA

4.5.1 Phase One: Observations - entry into the community: The context of Sara and Kenneth

Sara and Kenneth lived in an informal settlement (squatter camp). Although the greater environment was not a poverty-stricken one, the squatter camp was walled off and people walked or drove in and out. The land is owned by a farmer and the inhabitants who lived there pay R25 rent per month. The atmosphere outside the informal settlement was pleasant: there was a feeling of spaciousness and freedom. The area that was walled off was on a large piece of open land. The road leading there was tarred but once it became gravel, it deteriorated and it became bumpy and pot-holed.

On the day that I interviewed Sara, I was alone and I felt uncomfortable going into the squatter camp on my own. Going into the informal settlement alone would have been an irresponsible decision. I therefore arranged to return with Anneline, the FARR representative who knew the mothers from previous studies. The day that we returned, we were unannounced, and Sara did not know that we were coming. As we entered into the informal settlement, we were met by two ""gate keepers"" at the entrance of the settlement. We had to inform them of who we wanted to see, and they asked if we were there to test for Tuberculosis (TB). One of them showed us where to walk, on a dusty road, in between shacks made from corrugated iron. There was evidence of unemployment as many residents, young and old, were sitting outside their dwellings.

The homes that we passed were a mixture of corrugated iron sheeting, wooden planks and glass or plastic windows. Some female residents were sweeping and cleaning their homes and one cleaned out a toilet. There is no formal sanitation in this squatter camp, family members have to go and collect water from central taps placed within the walled area. Sanitation in the form of single-standing units which house toilets have been delivered and placed strategically, servicing up to around ten families.

We saw Sara and waved in greeting. It was a warm, sunny day so the dusty road was dry. In torrential rain, which we get in winter, this road would surely be muddy and unpleasant to walk along. After greeting Sara and some of her friends standing outside her house, we went into the enclosure that she shares with her cousin and her cousin''s husband. Their living quarter was on the right hand side and Sara''s shack was behind this. Their area was walled off with wooden fencing, creating an enclosed area. The smell emanating from her cousin''s house was clearly that of dagga (marijuana). A group of young and healthy looking men sat inside participating in this activity.

Sara''s shack was small, just one room with a bed, a cupboard on one side and the kitchen area at the other. All three inhabitants share the bed, namely Sara her older son and Kenneth. The first thing that struck me about her dwelling was that it was immaculately clean and tidy. The bed was neatly made and the floor swept clean. There were cups and saucers on shelving next to another few cupboards. A large bucket with a lid on it contained fresh water for Kenneth to drink from. Everything was neat and ordered. This was in stark contrast to Elsabé and Karien''s living areas. Kenneth arrived and immediately went to drink water from the bucket. He used a plastic cup for this purpose and he scooped the water out of the bucket and into his cup to drink. I saw no toys or objects that could enrich or educate two small boys, aged four and nine.

4.5.1.1 Themes that emerged from this observation

The initial theme that emerged from the observation of Sara was that of poverty stricken existence as she lived in a squatter camp. Although Sara is employed doing char work three days a week, she lives in a corrugated iron shack with Kenneth and her older son, and other members of her extended family, namely her cousin and his husband.

In addition the theme of over crowding and many people living together in close proximity to her and Kenneth indicated that she had a form of support from these people. Lack of hygiene and squalor emanated from the informal settlement. In addition, although the inhabitants from the informal settlement lived in close proximity together there is a sense of lawlessness there. According to Anneline the

subculture within the squatter camp tend to do as they wish and often a breakdown in laws, values and principles occurs. Anneline reported that ""any thing goes"" there.

4.5.2 Phase Two: Information gathered from Sara''s medical file

At the time of the interview, Sara was thirty one years old. She was born in a small village in the Karoo. She attended school until she reached Standard four (Grade six) after which she then left school. She came to Cape Town because her father used to hit her (""my pa het my baie geslaan""). When she came to Cape Town she looked for work.

At the time of the interview, her son Kenneth was four years and four months. He had been clinically diagnosed as having FAS at four weeks of age. At the prenatal clinic where she met Anneline, Sara became part of the FARR study. Prenatal history indicated that was Eddy born at full term and weighed 2,6 kilograms at birth. He conformed to all four of the diagnostic criteria for FAS, namely growth deficiency, structural deficiency, and cognitive/behavioural abnormalities. The fourth criteria for FAS, namely drinking during pregnancy was confirmed during an interview by Sara at the clinic in Hanover Park.

Sara started drinking at twenty two years of age. She reported that she participated in binge drinking over weekends and she drank beer. In addition to drinking alcohol while she was pregnant, she smoked hand rolled cigarettes. She reported that although she consumed some food during binge drinking sessions, she usually ate food afterwards.

4.5.2.1 Themes which emerged from the information gathered from the medical files belonging to the FARR representative

Sara started drinking at a young age twenty two. Her formal education process was stopped after she completed Grade six (Standard four). She grew up in a small village in the Karroo.

She consumed alcohol during the first trimester of her pregnancy with Kenneth. Kenneth was diagnosed with all four of the diagnostic criteria for FAS at 4 weeks of age. Karien participated in binge drinking over week ends when she was pregnant. She also smoked cigarettes.

4.5.3 Phase Three: The interview with Sara

4.5.3.1 Initial encounter with the text

Sara had been interviewed before so she was able to answer the questions with ease. The interview took place in my car as it was not appropriate for me to interview her in the dwelling she inhabited in the informal settlement (squatter camp). She appeared to be a little apprehensive and she presented as quiet and reserved in many respects a shy person.

4.5.3.2 Identification of themes from the interviews

- Sara''s schooling was stopped after she completed Grade 6 (""die geld was te veel"").
- Sara reported conflict in her family of origin (""my pa het my baie geslaan"").
- She started abusing alcohol when she was twenty two years old, a year after she left her town of origin in the Karoo.
- Sara came from a large family of origin comprising two brothers and four sisters, many of whom also abused alcohol.
- Sara appeared not to know that Kenneth had FAS.
- Sara experienced Kenneth''s behaviour as naughty (""hy is stout"").
- Sara gave Kenneth a hiding at times when she became very angry with him, then she calmed down (""ek gee hom pak"", ""dan koel ek af"").
- Sara experienced economic hardship (""woon saam met my niggie"").
- Sara worked to support her two children.
- Kenneth experienced eating problems (""hy wil nie sy kos eet nie, net brood).
- According to Sara, Kenneth presents with some physical manifestations of FAS, i.e. growth retardation (""hy is te klein"").
- Sara reported that there were distinct differences between Kenneth who has FAS and his older sibling (""hy was anders as sy"").
- Kenneth''s behaviour was difficult (""hy huil baie, gooi klippe, hy is bakleierig en hy slat vir ander kinders"" en ""hy slaap baie"").

- Kenneth talked too much (""praat te veel"", ""speel baie"").
- Kenneth needed some self help aid (""kan nie self kos gee nie"").
- Sara experienced remorse and guilt (""ek wil nie meer nie (drink), ek wil ''n goeie ma wees vir my kinders"" en ""ja, wou nie gedrink het nie"").
- Kenneth demanded his own way (""hy is woelig en soek net chips en lekkers"").
- Sara desired to stop drinking and for positive outcomes (""as ek mooi vir hom kyk dan voel ek gelukkig"").
- Sara was experiencing guilt after drinking now (""ek voel baie bekommerd"" en ""ek voel nie lekker nie"" en ""ek voel hartseer"").
- Sara experienced criticism of her drinking from family members whom she lived with (""my niggie word kwaad met my … sy drink niks nie"").
- Sara got angry with child (""ek word kwaad, dan koel ek af"").
- Kenneth could not go to shops with his mother (""ek bring hom nie saam nie want hy wil iets vat en dan is daar nie genoeg geld nie, dan huil hy"").
- Sara desired an external ""support"" to help her in her life (""ek wil die here in my lewe neem"").
- Sara desired support.

4.5.3.3 Clustering of Patterns

- Sara''s biological family of origin and its historical context manifested aspects of poverty, parental drinking habits and community consumption of alcohol.
- Sara''s started consuming alcohol after she came to Cape Town and still abuses alcohol now.
- Sara''s formal education was prematurely terminated.
- Sara and Kenneth were living in poverty-stricken conditions.
- Sara''s experience of her child with FAS was that she got angry. He demanded his own way, talked too much, was active, had eating problems, and generally difficult behaviour.
- The environment that Sara lived in is an informal settlement.

- She got some support from extended family members, her community and the clinic where Kenneth was diagnosed as having FAS.

4.5.3.4 Discussion of the ecosystemic perspective of clustering of patterns

Within Sara''s ***micro system***, her original biological family would have influenced her and had an impact upon her consumption of alcohol. Her parents, other family members and her friends all consumed alcohol on a regular basis. Her father hit her regularly whilst he was under the influence of alcohol. It was for this reason that she moved to Cape Town in search of work. She reported that she started drinking after this.

Within her ***meso system,*** Sara had to terminate her formal education process. This lack of education would impact upon her mothering skills when raising Kenneth. Sara comes from a family where there were many siblings.

Within Sara''s ***exo system,*** her place of work, and the hours she worked could be of influence regarding the parenting of Kenneth. He was not yet at school and she worked until 3 o''clock three times a week. Sara did not mention who she left him with, but he remained at the house where they lived while she worked.

If we view Sara from within the ***macro system*** we see that laws, norms and the culture in which she lives influences her experience of raising a child with FAS.

The informal settlement that Sara lived in was an indication that there was not enough housing for her to have her own. Informal settlements are also legal, and the landowner received a payment of R25 for them to live there. There were also not enough facilities for her to be supported in stopping drinking alcohol.

The ***chrono system*** from within which we view Sara, indicates that the decisions she had made in her life time were affecting her and her children. After she had made the decision to leave her home town, to come to Cape Town to search for work, she started abusing and misusing alcohol and tobacco. The implication of this decision was that Kenneth was being raised by a mother who abused alcohol.

4.5.3.5 Reflections by the researcher on Sara

My encounter with Sara was brief. I found her to be very fragile and not tough or street wise like the other two mothers that I interviewed. She was gentle and very reserved. I also found her to be a private person. Sara presented as a gentle victim in a larger system, which she had no control over, influence in or ability to change. She seemed more vulnerable that either Elsabé who was older and more mature in

many ways, or Karien who just wanted to get what she could out of the process and go. I sensed that if only she could access it, she could reach a brighter future and be experience positive outcomes for herself and her two young sons. This is not what I experienced with either Elsabé or Karien.

4.5.3.6 Discussion of the collective patterns viewed according to the ecosystemic framework

Initially, themes that emanated from the data analysis of each of the three participants were put into categories. Finally, repeated patterns that emerged and appeared to be common with the three mothers were put together. In the discussion of the clustering of patterns according to the ecosystemic framework, I would like to quote Donald et al.*et al.* (2002:47) who state that this theory ""sees different levels and groupings of the social context as systems where the functioning of the whole is dependent on the interaction between all its parts"". Babbie and Mouton (2001:281) state that ""thickly described case studies … attempt to understand the influences of multilevel social systems on participants'' perspectives and behaviours"".

The first system to be observed when viewing the collective patterns that emerged from the data analysis according to the ecosystemic framework is that of the ***micro system***. Within the ***micro system*** the individuals who interact with the child have the most immediate effect on him. According to Boemel and Briscoe (2001) ""Bronfenbrenner uses the term bi-directional to describe the influential interactions that take place between mother and child, child and father, child and teachers, understanding that the influences go both directions"". For the purposes of this research study, we can apply this system to each of the mothers'' biological family of origin and its effects and influence on her as a child. In addition we can apply the system to each mother''s current unique family structure. The fact that the mothers'' were alcoholics influenced their parenting abilities, this then influenced the way the children with FAS respond to their mothers. I have attempted to capture this bi-directional process as part of the participants ""experience"" of raising their child.

The fact that Elsabé, Karien and Sara came from families where consumption of alcohol was routine and accepted may have influenced their perception of this practice. Each of the mothers started consuming alcohol at a young age. Sara left her home of origin because her father became very abusive when he was under the

influence of alcohol. The consumption of alcohol therefore has become a crystallised theme in their realities.

The next system to be viewed is that of the ***meso system***. At this level, according to Donald et al.*et al.* (2004:52) ""peer group, school, and family systems interact with one another … the meso system is very similar to what some call the neighbourhood and … the community"". The pervasive theme of poverty permeates all aspects of this research study. Elsabé, Karien and Sara were brought up in under-privileged conditions and now live in poverty-stricken homes. However, the fact that there is evidence of overcrowding in their homes is not always negative. This sense of community also created a type of support system for Saartjie, Eddy and Kenneth, especially when their mothers are at work or absent from the home because they are drinking alcohol.

The ***exo system*** is the next system to be viewed. According to Donald et al.*et al.* (2004:52) ""this level includes other systems in which a child is not directly involved, but which may influence or be influenced by, the people who have proximal relationships with the individual in the micro system"", for example the mothers'' place of work. Elsabé works until 10 pm on some evenings, and in addition she reported that she consumes alcohol every evening, leaving her six year old daughter with the other inhabitants in the house. Elsabé is absent for the important routine times in the evening i.e. evening meal, bathing, homework and preparation for school the following day. Sara is away at work three days per week and Kenneth is left behind at home to be cared for by members of the community. in Freedom Park. The implications of this are that Elsabé''s and Sara''s relationship with Saartjie and Kenneth respectively could be impacted upon. The effect of this is that the experience of raising their child with FAS may be influenced by these factors.

The ***macro system*** could be described as the ""outer most layer which envelopes the micro system, mesosystem and exosystem … it consists of things that influence and sometimes support the child within the environment such as cultures, norms and laws"" (Boemel and Briscoe, 2001). In viewing the mothers within this particular system, it may be observed that their unique realities have been influenced and affected by the societies in which they live and have lived in. The social structures that were in place during the apartheid years aided in keeping many communities like these disempowered. Cultural minorities during the apartheid years were

marginalized and given very few opportunities for cultural enrichment. ""Institutionalised fragmentation, like apartheid, that is too singular, lasting and absolute interferes with the necessary evolution of patterns in the domains of living and work. Our options become reduced, and in our ensuing alienation and helplessness is a profound sense of crisis"" (Seedat et al.*et al.*, 2003:120). This would may have exacerbated have encouraged a forum for consumption of alcohol. In addition the regular consumption of alcohol is an accepted, valued and enjoyed form of entertainment in many marginalized communities in the Cape Province (Viljoen et al.*et al.*, 2002:7). The norms and policies which occurred during the apartheid years may also have influenced the lives of Elsabé, Karien and Sara by maintaining marginalisation.

The last of the systems is that of the ***chrono system***. ""The interactions between these systems and their influences on individual development are all crossed by developmental time frames"" (Donald et al.*et al.*, 2004:53). The influence of all the above-mentioned systems, interact with the mothers over time. According to Donald et al.*et al.* (2004), the child, but in this case the mother, is an active participant in her own development. Elsabé, Karien and Sara had all made choices in their lives that affected the outcome of their current unique life experience and reality. ""In a child''s life, there will be events … that can change the conditions of that child''s life"" (Boemel and Briscoe, 2001). New conditions can affect an individual''s development, such as Elsabé''s decision to leave her town of origin and abandon her three year old child. Sara''s decision to leave her family because of her father''s abuse towards her had repercussions for her and Kenneth, her commencement of drinking alcohol when she came to Cape Town. Sara did not have a home of her own, but lived in an informal settlement, with other family members. Elsabé lived in a ""lean-to at the back of someone else''s house. Both Elsabé and Sara were dependant upon either members of their extended family or members of the community in order to live and upon whom they remain dependant.

4.6 CONCLUSION

This chapter looked initially looked at the themes that emerged from the data that was collected. Themes that came out of the observation, the information from the medical files and the interviews were identified. Finally, the repeated patterns that

emerged out of the themes were clustered together. These were then viewed from an ecosystemic paradigm.

The findings which I discuss in chapter five are more complex than I anticipated. A broad range of additional factors influence the experience of mothers who raise children with FAS. It is almost impossible to gauge the impact of the FAS alone. This will be discussed in detail in the next chapter.

The experience of data analysis has been a challenging one. The information gained from the mothers via the interviews was conflicting and sometimes confusing. This made the process more difficult to present in this report. However, I gained insight into the mothers" unique realities, which I experienced as a privilege. I would not have had the opportunity to do this if it were not for this research study.

CHAPTER 5

DISCUSSION, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

5.1 INTRODUCTION

The purpose of the research study is to find out what the experiences of mothers who raise FAS children are. In this concluding chapter, the research findings presented in Chapter 4 will be discussed. The findings will be related to the research question. The limitations of the research will be outlined, followed by recommendations for future research. Finally, my reflection on the research process as a whole and my conclusion will be presented.

According to Babbie and Mouton (2001:283) ""research study reports should use multiple sources of evidence and represent dimensions of thick description"". In this chapter, I have attempted to create for the reader a thick description of the multiple case studies that I researched.

5.2 DISCUSSION OF FINDINGS

Before I reflected on the discussion of the findings, I was reminded by Patton (1987) in Merriam (2002:5) that the process of qualitative research:

> *… is an effort to understand situations in their uniqueness as part of a particular context and the interactions there. This understanding is an end in itself, so that it is not attempting to predict what may happen … but to understand the nature of that setting – what it means for participants to be in that setting, what their lives are like, what"s going on for them, what their meanings are … the analysis strives for understanding.*

This statement summarises the discussion that follows, and encapsulates the process of the research study in this case. The question posed in this research study was: ""What are the experiences of mothers who rear children with Fetal Alcohol Syndrome?"" The main aim was to gain a deeper understanding of their of the mothers'' experiences. The secondary aim of the research was to find

ways in which to support the mothers. These will be discussed in the recommendations. Through the research process, I have blended together the ***experiences relating to the participants external contexts*** (i.e. poverty, life long consumption and misuse of alcohol and tobacco, lack of formal school education, living in unhygienic conditions) with ***the participants experience relating to their internal world*** of raising a child with FAS (i.e. shame, guilt, anguish, frustration, anger, depression). It has been an impossible task to completely separate these two issues when researching the experience of the mothers'' in raising their child with FAS.

5.3 EXPERIENCES RELATING TO PARTICIPANTS EXTERNAL CONTEXTS

Poverty was a pervasive theme throughout this research document and so I have viewed it as the most important and influential of the experiences relating to the participants'' external contexts. Following on from this was the fact that the environments in which the participants live are overcrowded and often unhygienic. The mothers have had very little formal education and mothers live in conditions that view alcohol consumption and smoking as normal practice. This was observed in the participant''s family of origin and also in those living in close proximity to them. The participants are still misusing and abusing alcohol and tobacco. The implications of raising a child under these circumstances will be discussed in the next section of this chapter.

5.4 EXPERIENCES RELATING TO PARTICIPANTS INTERNAL WORLD

The experiences relating to the participants internal world include feelings of anger and frustration toward their child with FAS. In addition, guilt, regret and shame are experienced. Some of the participants experience some degree of denial that their child has FAS, contesting the diagnosis of the doctors at the clinic.

I have found it difficult throughout to separate the experience of the mothers in raising their child with FAS clearly from other influences and life stressors. Since there are many other external factors that could influence the behaviour their children exhibit, it seems that other influences may negatively affect the experience the mothers have of their child. It is therefore not clear what plays the biggest role in influencing this maternal ""experience"". What is certain is that FAS cannot be viewed in isolation and it is only one part of the broader canvass of the mothers''

lives. As Abel (1998:138) points out, ""FAS is not just the result of being born to an alcoholic mother, it is also the result of being raised by an alcoholic mother, and it is especially the result of being born and raised by a poverty-stricken alcoholic mother"".

Golden (2005:162) argues that ""epidemiological studies suggest that many, if not most individuals exposed to high doses of alcohol prenatally, were also affected by maternal malnutrition, exposure to tobacco, the effects of maternal stress, obstetric complications, and low birth weight"". This is applies to each of the children with FAS whose mothers I interviewed. The results show that the mothers'' experience of raising a child with FAS does not seem to be distinct because there are so many other life stressors impacting negatively upon their lives.

As ""an active participant"" (Merriam, 2005:148) in the research process, I found it impossible to accurately separate the influence of the FAS ""condition"" from the other multiple and complex influences which affected the mother''s unique experience in raising her child. In referring to the above-mentioned conditions, i.e. maternal malnutrition, exposure to tobacco, effects of maternal stress, obstetric complications and low birth weight, Golden (2005:162) suggests their interrelatedness: each of the them has ""been shown to have behavioural effects, making it nearly impossible to tease out the precise contribution of the alcohol"". This statement is congruent with the research findings.

5.5 EXTERNAL EXPERIENCES IMPACTING UPON THE MOTHERS EXPERIENCE OF RAISING HER CHILD WITH FAS

5.5.1 The influence of poverty in the experience of the mother and raising her child with FAS

The first major pattern that recurred throughout the research study was that each one of the participants lives in poverty-stricken conditions. Poverty was a pervasive theme throughout this research study. There was very little financial income, although two of the mothers had ""char"" jobs. There were also very few resources available to the mothers whom I interviewed. There was not enough money for Karien to send Eddy to school or enough for Sara to take Kenneth to the shops when she went as he always wanted things which she could not purchase for him. This was also evidenced by the dwellings in which the mothers'' lived. As Golden

(2005:162) argues, ""… environmental factors such as poverty, abuse, neglect, and family disruption as well as genetics, play key roles in shaping behaviour"". The reciprocal nature of interaction between mother and her child with FAS forms the major part of my research discussion and argument. Boemel and Briscoe (2001) explain that ""Bronfennbrenner called this bi-directional"" because the mothers'' interaction shapes the child''s responsive behaviour toward her and the child''s behaviour influences her experience of him. This is an ongoing process and it forms the major part of my research discussion and argument.

Clearly, poverty can have severe physical and cognitive impact on the normal development of a child. Poverty stricken families endure great hardship since it ""is known to affect and inhibit the quality of parenting that children receive"" (Seedat et al.*et al.*, 2001:90). In the case of Elsabé, Karien and Sara, poverty certainly influenced their experience of raising a child with FAS. I observed that there were no toys or items that might interest, educate or enrich a child in any of the home settings that I visited. In addition, both Elsabé''s and Karien''s babies suffered from intra uterine growth deficiency and Elsabé and Sara both describe their children as small for their ages. As Seedat et al.*et al.* (2001:90) points out, ""ten percent of pre-school children are underweight, and twenty five percent show growth stunting due to nutritional deficiency … many of these children manifest either mental retardation or specific learning disabilities"". The children that are affected by poverty appear to manifest similar features to children with FAS. For this reason it is difficult to distinguish the effects of FAS from the effects of poverty on the child.

> *The psychological consequences of the deprivation caused by poverty are endless. These include the mental and physical developmental impact of poor nutrition on children and the anxiety, depression and stress-related conditions caused by poor living conditions and occupational circumstances* (Seedat, 2001:58).

5.5.2 Mothers still currently consuming and abusing alcohol

Each of the three mothers, namely Elsabé, Karien and Sara, still consume alcohol regularly and in large quantities. Elsabé reported that she drinks every night and over week ends during the day. The implications of this are that Saartjie, Eddy and Kenneth are in effect, being brought up by mothers who regularly abuse and misuse alcohol. Research findings show that children of alcoholic mothers ""are at a higher

risk for externalising and internalising disorders, particularly manifested in impulsivity and neurotisism"" (Olson et al.*et al.*, 2001:271). This indicates that there may be additional negative influences on the child with FAS in this type of family system.

According to Olson et al.*et al.* (2001:277) ""there are life-long developmental repercussions of children of heavy parental drinking through the heritability of substance abuse and/or because of possible psychological compromise via dysfunctional life experiences of drinking parent"". The behaviour manifestations of children with FAS could therefore be exacerbated by being brought up by an "alcoholic" mother. Olson (2001:280) states that mothers who consume alcohol ""interacted in ways that were less responsive and developmentally stimulating to their babies and their children displayed higher levels of insecure attachments"". This suggests that Saartjie, Eddy and Kenneth"s behaviour presentation may be because their mothers still significantly abuse alcohol and so are not very responsive to their needs. Elsabé reported that Saartjie often does not listen to her when she tells her to do things. Saartjie will, however, listen to Mary, another co-inhabitant in their house.

5.5.3 The effect of Elsabé, Karien and Sara"s biological family system on their experience of raising a child with FAS

It is impossible to isolate the mothers and their children born with FAS from the systems in which they interact and exist. The mothers" families of origin may have had a strong influence in their patterns of behaviour, in this case the consumption of alcohol. Donald et al.*et al.* (2002:47) state that ""a family tends to function in ways that preserve its own characteristic patterns. Individual members within the family shape and are shaped by these patterns in a continuous process of dynamic tension and adjustment"". Each of the mothers continued a pattern of alcohol abuse as those members of their family of origin and local community had done. Alcohol abuse was all around them since it is acceptable practice in their communities. According to McKinstry (2005:1097), research shows that mothers of children with FAS often come from parents who were heavy drinkers themselves thus indicating a familial pattern of drinking, which is passed from one generation to the next. A similar view is taken by Viljoen et al.*et al.* (2002:7) who cite ""studies of alcohol dependence and alcohol misuse [that] have reported that these behaviours do run in families, therefore implying heritability or a genetic influence in susceptibility"". Each of the

participants stated that members of their immediate biological families had also consumed alcohol.

5.6 EXPERIENCES RELATING TO PARTICIPANTS INTERNAL WORLD

5.6.1 The mother''s experience of their child with FAS: Frustration and anger

Two of the three mothers interviewed for the purposes of this research study expressed the view that their children could be difficult at times. Both Elsabé and Sara described how Saartjie and Kenneth would often not listen to them when they were given instructions or when they were asked to perform a task. In this research study Elsabé and Karien reported challenging relationships between their child with FAS and themselves. Olson et al.*et al.* (2001:280) notes that clinicians working in this field have ""speculated that what are called ""attachment disorders"" may occur at elevated rates among alcohol-affected children, in part due to abuse and neglect and in part because of alcohol-related deficits in cognitive and social-emotional functioning that lead to less resilience"". It would appear therefore as though the participants in this study experience this because the children appear to be less responsive and less willing to comply with their mothers'' attempts at parenting. Elsabé discussed how Saartjie made her angry all the time. Karien stated that Eddy was difficult at times and Sara talked about Kenneth being very naughty and that she got angry with him.

The relationship between Elsabé and Sara and their children with FAS could be at risk from an early age, thus affecting their current experience of mothering. Olson et al.*et al.* (2001:280) continue that ""relationship difficulties in the critical early years of life can undermine a child''s later socio-emotional development, and it seems likely that an alcohol-affected child''s emerging cognitive and neurobehavioral deficits can compound these problems over time"". In addition Rover and Leadbeater (1999:524) report that ""feelings of competence or inadequacy in the maternal role may be magnified in conditions of socio economic hardship"".

Olson et al.*et al.* (2001:280) also point out that ""attachment theory has documented that a disordered parent-child attachment lays the groundwork for disruption in a child''s later behaviour and relationships"". Both Sara and Elsabé reported that they found behaviour management difficult to cope with. Mother and child interaction is a reciprocal phenomena and Lang, Perham, Atkeson and Murphy (1999:187) report

that ""not only do parents affect children but children also have the potential to exert powerful influences on the parents through their personal attributes and behaviours"". The behaviour presentation of children with FAS clearly influences the way Elsabé and Sara experiences this. Each of the mothers report smacking their children. Elsabé reported this (""Ek slat haar""), Karien stated that she gave Eddy smacks (""ek slat hom sommer"") and Sara described that she sometimes gave Kenneth a hiding (""pak gee"").

In addition Saartjie and Kenneth were described as being ""very busy"" which could indicate hyperactivity, a comorbid behavioural phenotype often attributed to FAS. According to Connor and Streissguth (1996:4) in a description of the effects of FAS argue that ""infants reveal tremors, difficulty ""tuning out"" redundant sensory stimuli and a weak suckle. Infants and toddlers may be developmentally delayed and often hyperactive"". In addition Sara reported that Kenneth was very active. It has been clearly documented that ""children exhibiting ADHD behaviours evoke significant distress and coping efforts from adults charged with their care"" (Lang et al.*et al.*, 1999:177).

Saartjie did not like doing homework and so would not tell Elsabé that she had homework that had to be completed. Connor and Streissguth (1996:4) argue that ""neuropsychological tests show that people with FAS often have a hard time focusing their attention"". Sara reported that Kenneth did not eat or sleep properly. Saartjie did not like waking up in the mornings. Olson et al.*et al.* (2001:271), describe that ""irritability and difficulties in behavioural regulation, activity, feeding and sleeping among infants affected by prenatal alcohol exposure may impair the process of mutual regulation and attachment between mother and child"" this may influence the mothers experience of her child with FAS, because it may be challenging to foster a close bond. This may in turn cause the child with FAS to act out because his emotional needs are not being met.

Steinhausen et al.*et al.* (1982) in Zevenbergen and Ferraro (2001:132) found that children with FAS were more likely than children without FAS to exhibit eating and sleeping problems, stereotyped habits, dependency, toileting problems and phobias. Elsabé and Karien described how Eddy and Saartjie had sleeping problems. Sara reported that Kenneth would not eat a variety of foods (net brood).

5.6.2 Mothers experience of their child with FAS: feelings of guilt, shame and unhappiness

Two of the three mothers reported that they experienced strong feelings of guilt and shame around raising children with FAS. Elsabé, especially commented on how bad she felt when she heard the news that Saartjie had FAS, she reported feeling ""different"" and ""bad"". She knew that she was responsible for this, because she had consumed alcohol while she was pregnant. Many of Elsabé"s friends call Saartjie a ""child of alcohol"" and this upsets Elsabé deeply. She reported that this was more painful and difficult for her than Saartjie"s often challenging behaviour. Elsabé clearly stated that it was not Saartjie"s fault that she has FAS, but hers. Sara reported that she wanted the best for Kenneth, and in addition wanted to be a good mother to him. She stated that she felt happy when she could care for him, but unhappy after she had had a ""drinking session"". She reported that she felt ""heart sore"" that she had drunk alcohol while pregnant. In addition, she stated that she did not wish to drink, but that she wanted to be a good mother to her child. When she drank alcohol, she stayed at home with Kenneth.

5.6.3 Mothers denial of FAS and their disagreement that their child has FAS

Elsabé and Sara stated that they did not agree with the diagnosis that their children, Elsabé and Kenneth had FAS. Elsabé stated clearly that she did not agree that her daughter had FAS (Ek stem nie saam nie, and ek hou nie van wat hulle sê nie, dat sy is "n alkoholiek kind); and Sara answered in the negative when interviewed about Kenneth having FAS (Het hulle vir jou gesê dat Kenneth FAS het? Nee. Ken jy die word FAS? Nee).

Christen (2001) argues that when parents, or in this case mothers, received the news that there was something ""wrong"" with their child they experienced negative emotions. ""Whenever there is a loss of hopes and dreams, whenever they confront the reality that something is different, something is wrong with their child, they naturally experience grief"". This grief could manifest in the form of denial as in the case of Karien who repeatedly stated that Eddy was normal and just like her other children, or exactly the same as any other child in the neighbourhood. Karien might be experiencing some denial that Eddy has FAS. Anneline reported that each of the three mothers had been told that their children had FAS.

5.6.4 Mothers wish for support and help

Two of the three mothers felt that they would like some support from: A FAS mother''s support group, a social worker or from the clinic. Karien stated that she would like to be part of a support group for mothers of children with FAS. Sara also stated that she would like this. Elsabé, however, stated that she did not want to be a part of a group, and was not interested in this, and she wished to stay close to home. Another indication of a need for help and support is that Sara reported that she felt better when she had been to church. She also stated that she wanted God in her life. The mothers interviewed clearly wish for some type of support to help them in coping with their lives, their children with FAS and their drinking problems.

5.7 LIMITATIONS OF THE STUDY

The limitations of the study encompass issues that emerged in conjunction with the reflective process that I describe at the end of this chapter.

- The children of the mothers interviewed were too young. I think that it may have been more beneficial to have children who were already at school. This is because the children whose mothers I interviewed were too young to really present with ""problems"". According to Streissguth (1990) cited in Phelps (1995:8), ""the evidence of these problems may not become apparent until the child enters school"". Early on in the baby''s life, FAS features are not as easily recognisible, and mothers of these children may not be aware of problems.
- It should have been very clear that the mothers'' other children were definitely NOT children with FAS. It may have been useful to compare their child with FAS with a sibling who did not have a formal FAS diagnosis.
- The mothers whom I interviewed could have been older. It may have been more useful to talk with mothers whose experience of raising a child with FAS was a retrospective and reflective one.
- The term ""experience"" in the title, I found to be very broad. In terms of researcher bias, I expected the experience to be from an internal perspective i.e. the feeling of anger, frustration, guilt, and shame. In reality, additional other influences impact upon the mothers experience of raising a child with FAS i.e.

poverty, lack of formal education, living in overcrowded and unhygienic conditions, still consuming large amounts of alcohol on a regular basis.

- According to Patton (2002:260) when reporting on the limitations of the researcher''s own perspective both ""self-knowledge and self disclosure should be called upon"". I found the realities of the participants very different from my own and this perception may have affected the general integration of this study.

5.8 RECOMMENDATIONS FOR FUTURE RESEARCH

According to Bless and Higson-Smith (1995:147), ""research is mainly relevant if it has implications for the improvement of the human condition"" therefore recommendations are an important aspect of the outcome of this research study. The recommendations for future research should be linked to the problem statement of this research study.

- As stated therein, very little research has been done regarding the parenting milieu into which children with FAS are born. I feel that this could be researched in detail. It may be interesting to learn what exacerbates the manifestations and presentation of FAS and what conditions ameliorate them.
- Further research could be done to find out what factors increase resilience in the mothers of children who have FAS. In addition it may be interesting to find out if mothers who abused alcohol in the form of regular or binge type drinking when they were pregnant have subsequently stopped this pastime.
- It may be of interest to find out to what extent overcrowding and living in dwellings with many other people supports drinking habits or enables parents of children with FAS to find the courage to stop this habit.
- I feel that there should be stricter policing to eradicate shebeens and alcohol outlets. Research into finding out whether or not this would have an impact upon those who abuse alcohol could be carried out.
- Pilot studies for the effectiveness of local rehabilitation centres for mothers of children with FAS could be set up.
- Education programs should be set up in order to address the detrimental effects of alcohol abuse not only while pregnant but also after birth and as the child

grows up and develops. Ways of teaching mothers who continue to abuse alcohol to interact with their child in a supportive and constructive manner should be explored. This could be done in the form of a support group.

5.9 CONCLUSION AND REFLECTION

In this chapter, I have discussed the research findings as presented in Chapter 4. To use the words of Stake (2002:450), ""the case study researcher ends up describing the case in sufficient descriptive narrative so that readers can experience these happenings vicariously and draw their own conclusions"". In Chapter 4 and in this chapter I have attempted to do this. I have also discussed the short comings of the research and made recommendations.

In conclusion, I have reflected upon the research process and the study as a whole and in addition, the process of coming closer to understanding the experiences of mothers who raise children with FAS. I started out on this journey, thinking that the participants would clearly describe only the manifestations of FAS. Although many apparent FAS manifestations of this syndrome were discussed, when viewing all of the additional influences in these mother''s lives it seemed that any one of these (poverty, lack of adequate nutrition, being brought up by an alcoholic mother) could have caused a similar type of manifestation. The long term outcomes for Saartjie, Eddy and Kenneth do not appear to be positive, and I now know that they represent thousands of children with FAS throughout the Western Cape. My empathy still remains with Elsabé, Karien and Sara, however.

The research process has been an enlightening one and I have been affected by it. In reflecting on my position as researcher before beginning the study, however, I decided to adopt the advice given by Patton (2002:575): in order for trustworthiness and authenticity to be developed, I had to be ""balanced, fair and conscientious in taking account of multiple perspectives, multiple interests and multiple realities"", and put to one side any preconceived judgments that I may have had.

There were many moments when I knew I had to push my emotions to one side and continue with this research process as an academic student. However, if for a moment now I allow my emotions to come to the fore, it is easy to feel deeply for both mother and child. These are not so much feelings of sympathy, but feelings of frustration, knowing that the outcomes for them are bleak. Elsabé, Karien and Sara

are attempting against all odds to bring up Saartjie, Eddy and Kenneth. My sense is that others in the community sustain them. Overcrowding, although difficult for me to accept, may for them be a saving grace. It gives support for their children and allows for a sense of unity of being a part of a group.

In addition, as an educational psychologist, researching the experience of the mother has been an important one. No child can be viewed in isolation. The maternal role remains an important and valuable contributor to the unfolding and reaching of potential. It will be an important part of my role, to draw all mothers into this process. This journey has certainly not just been an academic exercise. My gratitude for my existence and life style, opportunities to study further and my health and that of my immediate family has deepened. My experiences of being a mother have been deepened through this study as I have reviewed and reflected on the role of a mother.

> *"It is mother, complete or incomplete, who now is destined to be judged on the innate qualities of her natural reproductive fate; a mother who fails defies the natural inclinations of her sex, subverts the God-given order of the family; for she will live for others … and not for herself … She must love and give birth, that is her sacred duty. It is mother alone who also bears responsibility for the flowering or deformation of her offspring, or in the language of the twentieth century, for the health or pathology of her child"* (Polakow cited in Montague 2006:8).

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ADDENDUM A

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

Tel.: 808-4623
Enquiries: Maryke Hunter-Hüsselmann

1 November 2006

Ms. T Campbell
Department of Educational Psychology
STELLENBOSCH UNIVERSITY
7600

Dear ms Campbell

APPLICATION FOR ETHICAL APPROVAL

With regard to your application for ethical approval, it is with great pleasure that we inform you that your project *The experiences of mothers who rear children with fetal alcohol sindrome* have been approved by Subcommittee A, with the understanding that:

1. Your research will be conducted within the procedures and protocols that you have indicated in your proposal; and
2. You will conduct the research within the guidelines of national law, institutional guidelines en standards of scientific conduct within your particular research field.

We would like to wish you success with your research activities.

Best regards

MS. M. HUNTER-HüSSELMANN
SECRETARIAT: SUBCOMMITTEE A

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ADDENDUM B

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

"THE EXPERIENCES OF MOTHERS WHO REAR CHILDREN WITH FETAL ALCOHOL SYNDROME (FAS)"

You are asked to participate in a research study conducted by Theresa Campbell, from the Department of Educational Psychology at Stellenbosch University. The results will be contributed to a research thesis. You were selected as a possible participant in this study because you have a child who has been diagnosed as having fetal alcohol syndrome. I wish to find out about mothers experiences regarding the rearing of their FAS child.

1. PURPOSE OF THE STUDY

The purpose of the study is to find out what the experiences are regarding mothers who rear FAS children. I hope that this information will aid in formulating recommendations which may aid in supporting mothers of FAS children.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

For you to give permission for me (the researcher) to interview you at your home. This will take about an hour of your time. This appointed time will be arranged by yourself and will be at a time that is convenient to you. The representative from the Foundation for Alcohol Related Research (FARR), will arrange this with you before the time. If it is not convenient for me to come to your home then an alternative arrangement will be made.

3. POTENTIAL RISKS AND DISCOMFORTS

It is possible that some of the questions that I ask you MAY make you feel a little uncomfortable. At no time will you be put into a situation that will make you feel threatened or confronted.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

You will receive R50.00 as a token of appreciation for your participation in this study.

In addition, I hope that your participation in the study will help other mothers who have FAS children, and be of support and comfort to you to know that others are also having similar experiences.

5. CONFIDENTIALITY

All the information (audio-tapes) i.e. the conversations held between the researcher and yourself (the respondent) that is obtained in connection with this study will be strictly kept confidential at all times. In addition this information from you will be kept and remain anonymous at all times. It will only be disclosed with your permission or as required by law. Confidentiality will be maintained by means of keeping the information you give me on the said audio-cassette. Later the information will be transferred on to my computer, which will be locked away.

I will use a tape recorder so that I can listen to what you have told me afterwards. You have the right to listen to what we have talked about. You can change any of the information that you want to afterwards. I am the only person who will have access to these tapes. I will erase the information (from the audio-cassette and on my computer) as soon as the thesis is written (December 2006).

If extracts from our conversations are used in the research report your name will not be used and thus the information will be kept anonymous. The information, however, will be available to my supervisor and the examiners. It will also be used for educational purposes.

6. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

7. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Theresa Campbell (principal investigator) on 021 – 6865448 or 083 3029062, or Mariechen Perold (Supervisor) 021 – 8082307.

8. CONSENT AND RELATIONSHIP WITH FARR

8.1 We hereby put it on record that you have been identified by FARR as a possible participant in this study, and that you have given your consent to them in this regard.

8.2 We also put it on record that the researcher will have an interview with the representative from FARR, (Mrs Marais), in which information will by shared about yourself and your FAS child, and that you have given your consent to this, with the understanding that the researcher will not have access to your files as such.

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms M. Hunter-Husselman ph: 021-8084623 at the Unit for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me the participant by Theresa Campbell in Afrikaans and I, the participant is in command of this language or it was satisfactorily translated to me, the participant. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____ _____

Signature of Subject/Participant or Legal Representative
Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant]* and/or [his/her] representative _____ [*name of the representative]. [H*e/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/*English/*Xhosa/*Other*] and [*no translator was used/this conversation was translated into* _____ by _____].

_____ _____

Signature of Investigator Date

ADDENDUM C

PHYSICAL EXAMINATION

NAME: _____ NUMBER: O2C

NAME OF SCHOOL: _____ EXAMINER: _____

DATE OF EXAMINATION: ____/____/____

DATE OF BIRTH: ____/____/____ SEX:____ AGE:____years____months

Ht	_____ cm	Ht %	_____	☐	EXAMHT
Wt.	_____ kg	Wt %	_____	☐	EXAMWT
OFC	_____ cm	OFC %	_____	☐	EXAMOFC
ICD	_____ cm	ICD %	_____	☐	EXAMICD
PFL	_____ cm	PFL %	_____	☐	EXAMPFL
IPD.	_____ cm	IPD %	_____	☐	EXAMIPD
OCD.	_____ cm	OCD %	_____		
Philtrum:	_____			☐	OTHMEAS
Mental status / behaviour	_____			☐	HYPERACT
Neurological	_____			☐	FINEMOTOR
Cranium	_____				
Face: General	_____			☐	HYPOFACE
Ears	_____			☐	RREARS
Eyes	_____			☐	PALPFISS
Nose	_____			☐	STRABISM
Mouth	_____			☐	PTOSIS
Neck	_____			☐	EPICANTH
Thorax	_____			☐	NALSBRDG
Heart	_____			☐	ANTENARE
Abdomen	_____				
Arms	_____			☐	LONGPHIL
Hands General	_____			☐	SMTHPHIL
Creases	_____			☐	NRRWVRML
Dermal patterns	_____			☐	PROGNATH
Legs	_____			☐	HEARTMUR

Feet _____ ☐ SUPINATE

Skin _____ ☐ CLINDACT

Hair _____ ☐ CAMPDACT

Other / Comments _____ ☐ PALMCR

_____ ☐ OTHFEAT

Asymmetry: No / Yes (specify): _____

_____

Mother's Name: _____

Address: _____

_____

Telephone No: _____

DIAGNOSIS

Abnormalities compatible with FAS (circle ALL that apply)

☐ **1 = Growth deficiency**

☐ **2 = Structural abnormality**

☐ **3 = Cognitive / behavioural abnormalities**

☐ **4 = No abnormalities compatible with FAS observed**

☐ **5 = No significant abnormalities of any kind observed**

Does child have FAS?

☐ **1 = No**

☐ **2 = Yes**

☐ **3 = Deferred**

Does the Child have another diagnoses?

☐ **1. No**

☐ **2. Yes (please specify)**

a. _____

b. _____

c. _____

d. _____

Is special follow-up or testing recommended?

□ **1. No**

□ **2. Yes (please specify)**

_____

_____

_____

_____

NOTES:

_____

_____

_____

_____

ADDENDUM D

INTERVIEW SCHEDULE

1. Vertel vir my ‘n bietjie van jouself
2. Waar was jy gebore?
3. Vertel vir my van jou geboorte gesin
4. Waar het jy gewoon wanneer jy groot geword het?
5. Het jy broers en susters
6. Het jou ma of pa alkohol gedrink?
7. Hoe veel het hulle gedrink?
8. Het jou ma alkohol gedrink wanneer sy swanger met jou was?
9. Enige ander mense…soos jou susters of broers alkohol ook gedrink het?
10. Het enige iemand anders in jou gesin alkohol gedrink?
11. Mense in die omgewing waar jy groot geword het?
12. Waar was jy op skool?
13. Wat was die laaste graad/standard wat jy geslaag het?
14. Was daar ander kinders in jou skool wat alkolhol gedrink het op die stadium?
15. Hoe oud was hulle op die tyd?
16. Het jy so ‘n bietjie by die skool gedrink?
17. Vertel vir my wat jy gedoen het nadat jy skool verlaat het.
18. Hoe oud was jy wanneer jy _____ verlaat het?
19. Vertel vir my van jou werk
20. Watter werk het jy vroeër gedoen?
21. Waarom het jy opgehou met jou werk op die tyd?
22. Vertel vir my van jou gesin nou
23. Wie woon in jou huis
24. Wanneer jy swanger was, hoe het jy van Anneline by die kliniek gehoor?
25. Hoe veel kinders het jy?
26. Woon hulle saam met jou?
27. Vertel vir my van _____
28. Hoe vorder hy by die skool?
29. Vertel vir my hoe hy anders is as:
    - jou ander kinders
    - ander kinders wie jy weet
    - Hoe is hy anders? Verduidelik
30. Is _____ ‘n moelike kind?
31. Wat maak hom so?
32. Wat se gedrag maak _____ moelik?
    Is hy : baie besig,
    praat baie,
    slaap baie,
    eet baie,
    speel baie?
33. Kry _____baie ekstra hulp? Het hy ekstra hulp nodig?
    - met self hulp? Kan hy aantrek en klere aftrek? Self kos gee?

- met huiswerk? Van die skool af?

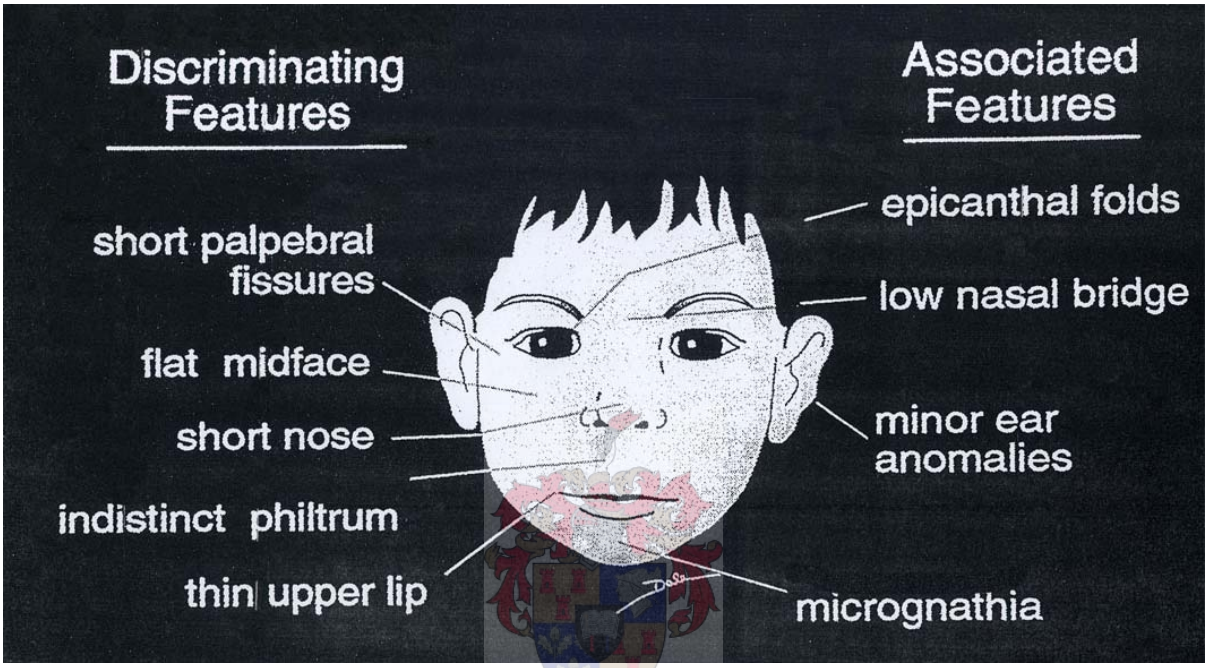
34. Wie het vir jou vertel dat jou kind FAS gehad het? (van die alkohol gedeurende die swangerskap).
35. Hoe het jy gevoel wanneer jy hierdie nuus uitgevind het?vertel vir my
36. Hoe voel jy nou, as ‘n ma van ‘n kind met FAS?
37. Verduidelik
38. Voel jy ongelukkig, bly, kwaad, frustreed?
39. Voel jy anders nou as jy gevoel het voor die nuus?
40. Wat is die moelikste ding om ‘n ma van _____ te wees?
41. Is jou gedrag anders met _____ as jou ander kinders?
42. Hoe is jou gedrag anders? Vertel vir my.
43. Dink jy dat daar iets verkeerd met _____is? as gevolg van die alkohol? In watter manier?
44. Wat dink jy?
45. Dink jy dat daar was iets wat jy kon gedoen het om die FAS te stop?
46. Hoe disiplineer jy jou kind? Vertel vir my
47. Is dit moelik?
48. Luister hy as jy praat? Doen hy wat jy se?
49. Hoe voel jy wanneer hy nie luister nie?
50. As jy ‘n keurse het wat wou jy

- Anders dan gedoen het?
- Wat wou jy nou verander?

51. Wat is moelik vir jou van _____ se gedrag?
52. Hoe is sy fiesiese vordering?
53. Watter sort van ondersteuning het jy nodig om _____ groot te maak?
    Skool?
    Finansies?
    Maatskaplike werker
54. Watter help het jy nodig nou?

ADDENDUM E

FAS FEATURES



Source: Streissguth and Little, 1994. Reproduced from Alcohol Health and Research World, National Institutes of Health, USA