Exploring the value of mentorship programmes as a preventative strategy for prenatal alcohol use for at risk women in the South Africa

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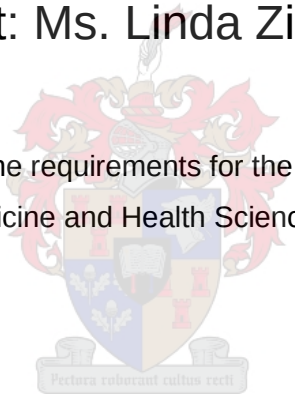

Thesis presented in fulfilment of the requirements for the degree of Master of Occupational Therapy in the Faculty of Medicine and Health Sciences at Stellenbosch University.

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MARCH 2021

Declaration

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March 2021

Abstract

Introduction: The high prevalence rate of FASD is well-known in South Africa, especially in certain areas in the rural Western Cape with an estimation of about 180-260 children in 1000 being affected. Literature confirms that there is poor recognition and response to the epidemic of FASD, and that a response from public health, which could include occupational therapy, could benefit many. Occupational therapy could be a valuable contributor to maternal health during the prenatal stages considering their holistic, client-centered approach. There have been many preventative strategies implemented to lower the prevalence of FASD, and one of them is by the means of mentorship programmes for at-risk mothers in high-risk communities. At-risk women face many barriers in accessing adequate healthcare services and mentorship programmes could potentially provide the necessary care and support at-risk mothers need to improve their maternal health. There is a need for exploring the value of these mentorship programmes to further assist with the development of successful prevention strategies for FASD.

Methodology: A qualitative, explorative case study has been done on community-based mentorship programmes for at-risk mothers in South Africa, with a focus on the Western Cape. The study population has been field experts within the mentorship programmes, as well as mentors and mentees. Data has been collected by the means of an online focus group discussion of field experts (n=4), and SMS-journaling of mentors and mentees over a period of three weeks (n=6). An inductive analysis approach was used. The data was analysed according to themes, sub-themes and codes using content analysis. Ethical clearance has been obtained. Credibility has been ensured by member checking and peer examination. Data triangulation was ensured by using multiple data collection methods. Transferability has been ensured by thick description.

Findings: There were four main themes that emerged from the collected data. These themes were (1) "*It's not just a generic programme"*, (2) "*Our pregnant women are struggling out there"*, (3*) "It has been a wonderful challenge to be a mentor"* and (4) "*What I will say that does not work".*

Discussion: The most valuable components of a mentorship programme as studied is the client-centered, holistic approach while building empathetic, trustworthy relationships and supporting and empowering the at-risk mothers. This relationship between the above-mentioned components is transactional in nature, and one cannot function without the other. It is also

important to consider the contextual challenges that at-risk mothers face in their daily lives, including unemployment, poverty, crime, violence, gangsterism and household abuse which often leads to poor coping mechanisms such alcohol and substance abuse. It is also important for the mentors themselves to feel supported and empowered throughout the mentorship programme to add to the success of a mentorship programme. It also became evident that prevention of FASD should not only start with at-risk mothers, but preventative strategies, such as education for primary school learners, should be implemented. The accessibility of mentorship programmes should also improve to reach more at-risk mothers.

Conclusion: In conclusion, mentorship programmes should include a client-centered, holistic approach while building strong relationships between the mentor and the at-risk mother. It is also important to support and empower the at-risk mother as she experiences a range of adversities and challenges and focus should be given to her mental well-being. This requires a shift from the problems within the person, but rather to that of the environment. Occupational therapy can play a vital role in the fields of maternal health and can assist at-risk mothers to achieve client-centered goals and create supportive environments. This could assist in the success of these programmes, and success of these programme could benefit the public health system in decreasing the prevalence of FASD in those communities.

Opsomming

Inleiding: Die hoë voorkoms van FASV (Fetale Alkohol Spektrum Versteuring) is wel bekend in Suid Afrika, veral in sekere landelike gebiede in die Wes-Kaap met ‘n skatting van omtrent 180-260 kinders in 1000 kinders wat geaffekteer word. Literatuur bevestig dat daar swak erkenning en daarom reaksie is tot hierdie epidemie van FASV, and dat ‘n reaksie daarop van publieke gesondheid, wat arbeidstreapie kan insluit, baie mense kan baat. Arbeidsterapie kan waardevolle bydraes maak tot die veld van moedergesondheid gedurende die voorgeboortelike stadia aangesien hul ‘n holistiese, kliënt-gesentreerde benadering volg. Daar is reeds vele voorkomingsstrategieë geïmplementeer om die voorkoming van FASV te verminder en een daarvan is die gebruik van mentorskapprogramme vir kwesbare ma’s in hoë-risiko gemeenskappe. Kwesbare ma’s staar vele hindernisse in die gesig om toegang tot voldoende gesondheidsorg te bekom en mentorskapprogramme kan potensiëel die nodige sorg en ondersteuning bied vir die kwesbare ma’s om hul moedergesondheid te verbeter. Daar is dus ‘n behoefte om die waarde van die mentorskapprogramme verder te ondersoek om te help met die ontwikkeling van suksesvolle voorkoming strategieë van FASV.

Metodologie: ‘n Kwalitatiewe, ondersoekende gevallestudie was gedoen op gemeenskaps-gebaseerde mentorskapprogramme vir kwesbare ma’s in Suid Afrika, met ‘n fokus op die Wes-Kaap. Die studie populasie was kenners in die veld van die mentorskapprogramme, asook mentors en mentees. Data was ingesamel deur middel van ‘n aanlyn fokusgroepbespreking van kenners van die veld (n=4) en SMS-joernaalinskrywings van die mentors en mentees (n=6) oor ‘n periode van drie weke. ‘n Induktiewe-analise benadering was gebruik. Die data was ge-analiseer volgens tema’s, sub-tema’s en kodes met die gebruik van inhoudsanalise. Etiese goedkeuring was gekry. Geloofwaardigheid was bekom deur deelnemer bekragtiging en portuurondersoek. Datatriangulasie was verseker deur verskeie data-insamelings metodes te gebruik. Oordraagbaarheid is verkry deur ryke beskrywing.

Bevindinge: Daar her vier hoof tema’s aan die lig gekom van die ingesamelde data. Hierdie tema’s was (1) “*Dit is nie net ‘n generiese program nie*”, (2) “*Ons swanger vrouens sukkel daar buite”*, (3) *“Dit is ‘n wonderlike uitdaging om ‘n mentor te wees”* en (4) *“Wat ek sal sê wat nie werk nie”.*

Bespreking: Die mees waardevolle komponente van ‘n mentorskapprogram soos gestudeer is die kliënt-gesentreerde, holistiese benadering wat gevolg word, tesame met die empatiese, betroubare verhoudings wat gebou word en die ondersteuning en bemagting van die kwesbare ma’s. Hierdie verhouding tussen die bogenoemde komponenete is transaksioneel van aard, en die een kan nie sonder die ander een funskioneer nie. Dit is ook belangrik om die kontekstuele uitdagings wat kwesbare ma’s in hul daaglikse lewens teëkom in ag te neem. Hierdie uitdagings sluit in werkloosheid, armoede, misdaad, geweld, bendegeweld en huishoudelike mishandeling wat meestal lei tot die gebruik swak verdedigingsmeganismes soos alkohol- en dwelmmisbruik. Dit is ook belangrik vir die mentors om te voel hulle word ondersteun en bemagtig ten einde tot die sukses van die mentorskapprogram by te dra. Dit het ook duidelik geword dat die voorkoming van FASV nie by die kwesbare ma’s moet begin nie, maar dat voorkomingstrategieë soos opvoeding van laerskool leerlinge, ook geïmplementeer moet word. Die toegangklikheid van die mentorskapprogamme moet ook verbeter om sodoende meer kwesbare ma’s te bereik.

Gevolgtrekking: Ter gevolgtrekking moet mentorskapprogramme ‘n kliënt-gesentreerde, holistiese benadering volg wat sterk verhoudings bou tussen die mentor en kwesbare ma. Dit is ook belangrik vir die kwesbare ma om te voel sy word ondersteun en bemagtig aangesien sy ‘n verskeidenheid van uitdagings en hindernisse ervaar, en daar moet ‘n fokus wees op ‘n geestelike gesondheid. Dit vereis wel ‘n skuif weg van die probleme van die persoon na dié van die omgewing. Arbeidsterapie kan ‘n belangrike rol speel in die veld van moedergesondheid en kan kwesbare ma’s help om hul kliënt-gesentreerde doelwitte te bereik en ondersteunende omgewings te skep. Dit kan help met die sukses van die programme, en daarom die publieke gesondheidsisteem baat deur die vermindering van die voorkoms van FASV in sekere gemeenskappe.

Acknowledgements

I would firstly like to thank both my supervisors, Dr L Cloete and Mr. JP Frederick, for their invaluable time, guidance, and support during the research journey. Thank you for your continuous kind words and encouragement throughout the process.

I would also like to thank my sister and brother-in-law, Alta and Clinton Saunders, for their support, patience, advice, and motivation during this process. They have motivated me to further my studies, and I am grateful for their encouragement. Thank you, Alta, for taking time to edit my work. It is much appreciated.

I would like to thank my mother, Estelle Zietsman, for without her it would not have been possible to complete my studies. Thank you, mom, for your endless patience, grace, and support without falter. Thank you for your continuous motivation and encouragement throughout the process. Thank you, mom, also for editing and correcting my work where necessary. I really do appreciate it.

Thank you to all my colleagues who have supported me at work with the research. Thank you for standing in for me in times when I needed it most and giving me the opportunity to take study leave. Thank you also for all your kind words, motivation, and encouragement throughout the process.

I would also like to thank my friends who have encouraged and motivated me in both the good and stressed times. Thank you for your understanding and support throughout this process. Thank you always listening to me and reassuring me when I needed it most.

I would also like to thank all the participants who kindly agreed to participate in the study. Thank you for your time. This would not have been possible without you.

Table of Contents

List of Figures

List of Tables

Definitions of terms

Term	**Definition**
Prenatal alcohol exposure (PAE)	Exposure of the fetus to alcohol due to mother consuming alcohol during pregnancy (1)
Fetal Alcohol Syndrome/Fetal Alcohol Spectrum Disorder (FAS/FASD)	A syndrome/disorder which includes developmental impairments due to prenatal alcohol exposure (2)
Prevalence	The number or proportion of a population with given condition (3)
Incidence	The initial occurrences (new cases) of a condition within a certain time period (3)
Epidemic	Widespread occurrence of a condition in a population within a certain time period (3)
Community-health workers	In this context, it is paraprofessionals which assists professional health workers in various community-based programmes (4)
High-risk communities	Communities where problem drinking patterns and behaviour due to a range of socio-economic challenges (5)
At-risk mothers	A diverse group of women who are at risk of giving birth to a child with FASD. These women also tend to have problematic drinking behaviour and attend less antenatal classes (5,6)
Parity	Number of pregnancies reaching viable gestational age (7)
Activities of Daily Living (ADL's)	Activities including washing, bowel and bladder management, dressing, eating and feeding, functional mobility, personal device care, personal hygiene and grooming, sexual activity and toilet hygiene (8).
Instrumental Activities of Daily Living (IADL's)	Activities that support daily life within the home and community, which is often more complicated interactions than ADL's such as financial management, community mobility, health management and home management etc. (8).

List of abbreviations

ADHD	Attention-deficit hyperactivity disorder
ADL's	Activities of Daily Living
ARBD	Alcohol-related birth defects
ARND	Alcohol-related neurodevelopment disorder
AUDIT	Alcohol Use Disorder Identification Test
BI	Brief intervention
CHW	Community health worker
CM	Case manager/management
CRA	Community-reinforcement approach
FAS	Fetal alcohol syndrome
FASD	Fetal alcohol spectrum disorder
HIV	Human Immunodeficiency Virus
HREC	Health Research Council
NGO	Non-governmental organisation/s
NHA	National Health Act
PAE	Prenatal alcohol exposure
PEO	Person-Environment-Occupation
PFAS	Partial fetal alcohol syndrome
POPI	Protection of Personal Information
WHO	World Health Organisation

Chapter 1: Introduction

1.1 Background

Jones, Smith, Ulleland and Streissguth (1973) first reported on the association between maternal drinking and the presence of certain physical features and developmental impairments, including cognitive and behavioral impairments. Eight unrelated children with known prenatal alcohol exposure (PAE) were examined, and similar physical features and developmental impairments were observed in all eight children (9). These observations sparked further research of the cause and prevention of such impairments in children. Jones and Smith (1973) were the first to describe these observations in the children as Fetal Alcohol Syndrome (FAS) (10). The first case-specific FAS references in South Africa were made in 1978 by Beyers and Moosa (5). Later, terms such as Fetal Alcohol Spectrum Disorder (FASD) were also introduced and described.

The term FASD is used to describe a range of developmental impairments including physical, cognitive, and behavioral difficulties due to PAE. These conditions are permanent in nature, where FAS is the most severe of these conditions. Other conditions include partial Fetal Alcohol Syndrome (PFAS), alcohol-related neurodevelopment disorder (ARND) and alcohol-related birth defects (ARBD). Alcohol consumed by pregnant women at any stage during the pregnancy dramatically increases the risk of the fetus being affected and resulting in these above-mentioned conditions (2). The conditions include a range of dysmorphic features and other impairments. The physical features include abnormal facial features, visual and hearing difficulties. The cognitive and behavioral impairments include learning difficulties, poor judgment, poor insight and impulsivity, and short attention and concentration span. These conditions can further translate into adulthood with conditions ranging from mental health disorders, difficulties with interrelationship skills and unemployment (2,11). The burden of FASD therefore not only falls on the health economy, but also on the national economy.

1.2 Problem statement

The alarming high prevalence of FASD is well-known in literature, especially in certain rural areas in the Western Cape (2). There is an estimation of 182.7-258.9 in 1000 children being affected with FASD in the Western Cape (12). This indicates that the current strategies and programmes implemented to assist at-risk women as a vulnerable population is not as effective and supporting as one would think. May, de Vries, Marais, Kalberg, Adnams and Hasken et al. (2016) reported on the extreme high prevalence rates of FASD in four rural, low-socio economic status communities in the Western Cape. An active case ascertainment approach was used with a three-tier sampling process of first grade pupils from 53 primary schools between 2009 and 2010 in the four different communities in the Western Cape. Tier one included a study population of 1354 children, tier two 1064 children and tier three 738 children. The first tier consisted of measuring height, weight, and head circumference. Children in the ≤ 25th percentile were advanced to tier two. Thereafter, in tier two, an in-person pediatric dysmorphology exam were done. Tier three consisted of a cognitive test, as well as teacher-reported questionnaire on behavior and attention. These above-mentioned high prevalence of FASD are the highest documented prevalence rates in any studied population in the world (12). These prevalence rates are in strong contrast with the prevalence rates of FASD in four communities in the United States of America (USA) with only 11.2-50 in 1000 children being affected by FASD (13). Another study done in the USA echoes the contrast again. An estimated prevalence rate of an average of eight in 1000 children were found in certain recognised high-risk communities in the USA(14).

May, Blankenship, Marais, Gossage, Kalberg and Barnard et al. (2013) further report on the FASD prevalence in a single study population in the Western Cape. In a population of first grade pupils in a single low socio-economic setting, the prevalence of FASD was between 135.1 and 207.5 in 1000 children (15). These prevalence rates are evidently higher than found in other studies in South Africa, and also other countries (13,16). Although these South African communities represented in these above-mentioned studies are unique in both character and culture such as poor health support and infrastructure not only for at-risk mothers, but also for the general population, it would be difficult to generalise these statistics to a wider, national population due to this uniqueness. However, these prevalence statistics are valuable for advancing further research, especially regarding diagnosing, intervention and especially prevention, as one could start to understand the context and extent of the FASD epidemic (15).

Furthermore, in an active case ascertainment study (n=863 children) by Viljoen, Gossage, Brooke, Adnams and Kenneth et al. (2005), they asserted that the FAS rate of 65-74 in 1000 children was an increase compared to their previous South African study of another cohort born 2-3 years earlier, with a rate of 40.5-46.4 per 1000 children. Both studies were conducted in an anonymous community in the Western Cape. This increase might have been due to increased sensitivity of diagnoses by the physicians; however, this might also be due to liberating social changes and an increase in the supply of commercially available alcohol, either legally or illegally by means of shebeens (17). Shebeens are illegal liquor outlets, mostly in informal settlements. There are an estimated 25 000 shebeens in the Western Cape. Shebeens have largely replaced the illegal practice of the *Dop system*, where wine would be given to farm workers as part of their weekly/monthly remuneration by the farmer, however, the legacy of the system is still very much prevalent, and alcohol is still a favoured commodity among many (18). Viljoen, Gossage, Brooke, Adnams and Kenneth et al. (2005) concludes that comprehensive, community-wide prevention programmes are needed to improve the support at-risk women better. The concerning high prevalence of FASD indicates that effective measures, including effective prevention strategies, should be implemented and evaluated. De Vries and Green (2013) comments that FASD prevention in South Africa is still fragmented, and therefore not effectively addressing the realities of the FASD burden (14).

According to an analysis done by Schneider, Norman, Parry, Bradshaw and Plüddeman (2007), following the World Health Organisation (WHO) comparative risk assessment (CRA) methodology, FAS is ranked fourth (5.5%) with regard to deaths and disability adjusted life years (DALY's) in relation to all alcohol-attributable diseases (n=9) in South Africa. Besides the high ranking of FAS to the DALY's, FAS is ranked third (18.1%) with regard to years of life lived with disabilities (YLD's). The latter high percentage of FAS follows the contribution made by alcohol-use disorders (44.6%) and homicide and violence (23.2%) (19). The alarming high statistics of extensive alcohol use in South Africa suggest a negative impact due to the use of alcohol, especially in relation to pregnancies, in South Africa. De Vries and Green (2013) states that if one should consider the entirety of disorders that may result due to alcohol use during pregnancy, including FASD, stunting and malnourishment, the already significant health problem is even bigger, and therefore effective prevention strategies should be considered even more (14). Literature confirms that there is poor recognition and response to the epidemic of FASD, and that a global response from public health, which could include occupational therapy, could benefit millions (1). These above-mentioned prevalence statistics and risk-assessment statistics of FASD clearly demonstrate that FASD is not only a problem to the individual, but indeed a public health issue.

De Vries and Green (2013) recommend in their recent study that a comprehensive programme, including collaboration and coordination between different role-players, should be implemented to prevention of FASD effectively. These role-players should include the Department of Health, Education and Social Services, non-government organisations (NGO's) and people with lived experiences of FASD. The goal of such a comprehensive programme should not only be to educate, but also to promote a meaningful occupation-based lifestyle as a mother and create a supportive environment which can include addressing maternal drinking behavior patterns before, during and after pregnancy (14). Changes with regard to lifestyle, including drinking behavior, should be implemented in long-term to promote longevity and sustainability of these changes. One such way is creating supportive environments. Creating supportive environments include taking care of one another and taking care of the community (20). This could be achieved by the means of a mentorship programme. Jansen van Vuuren and Learmonth (2013) suggest that rather on focusing on universal, macro-level strategies such as policy and system implementation, prevention strategies should focus on individual, person-centered intervention. A qualitative case study done by Rotherum-Borus, le Roux, Tomlinson, Mbewu, Comulada, le Roux et al. (2011) commented that even though antenatal care in South Africa is freely available, it hardly addresses maternal drinking risks due to restricted face time with the antenatal health care professionals, as well as a lot of additional other antenatal topics that need to be addressed. Therefore, the need to promote additional supportive programmes for the women in high-risk communities are highlighted. Cloete (2018) further suggests that lasting changes in drinking behavior among at-risk mothers can be difficult to attain, and that mentorship can provide the supportive environment in which such changes can be possible.

Additionally, there is also no national strategy or policy for managing and preventing FASD in South Africa, and therefore the onus is on researchers to help develop such strategies (5). Adebiyi, Mukumbang, Cloete, and Beytell (2018) further concludes that local and international research done on FASD and the prevention thereof could assist to develop such policies and strategies in South Africa (21). The different organisations and departments responsible for aiming towards a lower FASD prevalence are working in stratification, and therefore the comprehensive, multifactorial, multidisciplinary approach meant for FASD prevention are not met in South Africa (11).

1.3 Conceptualisation of Study

As mentioned previously, the FASD epidemic is a public health issue. Public health is defined as the "science and art of promoting health, preventing disease and prolonging life through organized efforts of a given society." Health promotion is one focus point of public health (22). Health is seen not only as an objective that needs to be met, but as a resource for everyday living. Health promotion is the process of empowering people to take control and improve their own health, and therefore improving their overall quality of life (20). Health promotion is also defined as "the process of enabling people to increase control over improvements in their health" (23).

The Occupational Therapy Practice Framework: Domain and Process describes health promotion and disability prevention as appropriate intervention approached for the occupational therapy profession. Disability prevention is described as "*an intervention approach that addresses clients with or without a disability who are at risk for occupational performance. This approach is designed to prevent the occurrence or evolution of barriers to perform in context. Interventions may be directed at client, context or occupational level*". It is also the respect and the involvement in decision making, particularly regarding occupational participation, that is a foundation similarity between both health promotion and occupational therapy (8). Therefore, components such as the role of occupational therapy, occupational therapy techniques, meaningful occupation, and occupational engagement have been explored.

The researcher, as an occupational therapist, inherently possesses the skills and knowledge to have a holistic view of a case, whether a person or programme. Also, being in the field of community-based occupational therapy, the researcher is conscious of good and ethical practice within community-based programmes, as well as knowledgeable in continuous qualitative and quantitative monitoring and evaluation of such programmes.

1.4 Rationale of Study

Health promotion has a strong focus on three key strategies: *advocate, enable* and *mediate*. Tucker, Vanderloo, Irwin, Mandich and Bossers (2014) draws on how occupational therapy can directly promote the three key strategies for health promotion. Firstly, occupational therapists can *advocate* for the clients

to improve their occupational engagement. Secondly, occupational therapists can provide supportive environments, training, and skill development to *enable* meaningful occupation. Lastly, occupational therapists can communicate and collaborate with clients, other health care professionals and community organisations to incorporate *mediation* of health promotion (24). Mentorship programmes have been previously, and currently, utilised in South Africa to promote health, including preventing FASD. Mentorship programmes focuses on the individual and is person-centered, as compared to more global prevention strategies which tend to be less effective in prevention of FASD (18). A mentorship programme is described as a mentor, an experienced and/or trusted advisor, giving guidance, direction and support to a mentee, the person being counselled by the mentor (25). One possible outcome of the value of mentorship programmes could be that it enables mentees (at-risk mothers) to engage in a meaningful occupation i.e., being a mentee. The history of occupational therapy is rooted in the understanding of the important influence of occupation on health and well-being (22). Thus, the assumption is that at-risk women who engage in meaningful occupations are healthier; physically, mentally, and emotionally. Moll, Gewurts, Krupa and Law (2013) also explains that one of the three potential contributions that occupational therapy can make towards health promotion is emphasising occupation as an essential element in health promotion. Engaging in meaningful occupation can improve health and well-being throughout the lifespan. The other two potential contributors are promoting healthy lifestyle and giving individual-level intervention (22).

Furthermore, other occupational therapy services also include collaborating and networking with allied health professionals, organisations, communities and policy makers to promote health in communities using a population-based approach and building healthy public policies. Also, occupational therapists can use the skills of networking and lobbying to include government and professional agencies to expand the scope and roles of occupational therapy. Occupational therapists' role in public health are emerging and will continue to grow as evidence grows (26). Hocking (2013) writes that occupational therapists are currently re-engaging their profession with an occupational perspective of health. At the same time, concepts of health promotion are also shifting. Three big shifts towards health promotion include health being primarily determined by social factors, the measure of health being what people do and become and thirdly, that health is a fundamental human right. Again, the issue of how engaging in occupation (what people do) can promote health and well-being is being raised. Hocking specifically pleads that the knowledge of occupational therapy, of meaning of occupation should be brought to issues such as educational under-achievement, binge drinking, isolation, and degradation of environments, to promote public health. She further also explains that one of the key points of promoting health in occupational therapy includes giving an occupational perspective central to public health issues (24).

To be effective in health promotion, however, one must focus on organisation level, community level and governmental levels. Occupational therapy uses the knowledge and perspective of occupational science in these roles and settings. On organisational level interventions may include providing education for staff members, on community level it may include consulting with different role-players in the community and implementing preventative programmes. On governmental level it may include promoting policies, supporting full inclusion of at-risk clients and lobbying and networking to support research and programme development (27). Thus, the importance of occupational therapy being included in community programmes such as mentorships programmes is highlighted. Other contributions of occupational therapy in health promotion is providing education and reducing risk-factors through meaningful occupational engagement (27). Occupational therapy can play a vital role when viewing public health issues such as FASD. The role of occupational therapy within public health issues are mostly highlighted with regards to indirect services, including creating supportive environments, education, promoting occupational engagement, consultation, and networking.

An occupational therapy approach can also assist to help develop the competencies, including knowledge, skills, and attitudes of the role of being a mother for a child, especially for at-risk mothers. This further strengthens the assumption that meaningful occupation, i.e., motherhood, can assist in promoting health and well-being. Assisting and supporting mothers in preparing for motherhood can ensure that the child is in good health; physically and emotionally, as the assumption is that a healthy mother has a healthy baby (28). Furthermore Slootjes, Mckinstry and Kenny (2016) argue that occupational therapists are valuable contributors to maternal health during the prenatal stages, especially considering the holistic, client-centered approach inherent to occupational therapy. Occupational therapists use techniques such as client education, meaningful occupational participation, stress management, group engagement, sleep hygiene and return-to-home routines to improve quality of life and meaningful occupational-involvement. Mindfulness is also another technique used by occupational therapists to support connection between the physiological, emotional, and cognitive changes women experience during the antenatal period. Slootjes, Mckinstry and Kenny (2016) further argue that there is a definite capacity to expand the role of occupational therapy within maternal and child health, especially in prenatal stages (29). Although not all above-mentioned techniques are used in mentorship programmes, some of those techniques play vital roles in mentorship programmes, which will be mentioned later in the literature review. The 2013 South African Child Gauge recommends certain essential services to children within their first thousand days, the day from conception to approximately two years old, for optimisation of child development in the South African context. Within

these recommendations are the support of the mother throughout her pregnancy, including parenting education and support, as well as creating a protective and supporting environment. The article further reports that the well-being of the mother is the single most valuable predictor of good child development outcomes. As brain development occurs most rapidly during the first thousand days, it is therefore of utmost importance to start intervention and support programmes as soon as possible during the pregnancy (30). The need for early occupational therapy during the prenatal stages is highlighted, to support mothers during these early days.

There is thus an opportunity for occupational therapists to determine and establish their role in the antenatal period and maternal health fields. Although there is limited evidence to support the link between occupational therapy and pregnant mothers, occupational therapy can have a powerful impact on the health and occupational performance of this population. It is necessary for mothers to be independent and healthy for them take good care of their children. Law, Cooper, Strong, Stewart, Rigby, and Letts (1996) provide a therapeutic model for a structured, client-centered, holistic approach. This type of model considers the physical, emotional, and spiritual needs of a mother within her specific context. This model addresses performance components of the individual person in terms of their roles and responsibilities (31,32). Engel (1977) proposed a new model that not only looks at the biomedical aspects of someone's life, but also the social, psychological and behavioural aspects. This was termed the biopsychosocial model. This model still remains relevant in the field of occupational therapy, and is also still very much relevant in die field of antenatal care (32,33).

However, little is still known with regard to the contribution occupational therapy can make toward maternal and child health using mentorship programmes. This is mostly due to maternal health being a non-traditional occupational therapy field, as explained by Slootjes, Mckinstry and Kenny (2016), but also because very little research has been done regarding mentorship programmes, the effect thereof and the role of occupational therapy within these programmes especially with regard to FASD prevention (6,29). Rasmussen, Kully-Martens, Denys, Badry, Henneveld, Wyper et al. (2012) argues that FASD prevention programmes, such as mentorship programmes with the aim of decreasing prenatal alcohol exposure, have both personal and public value, and that individual FASD prevention programmes are central in supporting wider FASD prevention. Therefore, not only the gap for research is identified, but also as explained above, the need to understand these programmes and how they fit in with regards to healthy mothers and occupational therapy are identified. It is known that the prevention of FASD requires a multi-faceted approach, and therefore exploring these mentorship

programmes could add value to inform further policies on prevention strategies for FASD. FASD is 100% preventable, however, 100% irreversible.

Chapter 2: Literature Review

2.1 Introduction

The literature review will cover the prevalence of FASD, covering both national and international prevalence studies. Prevention strategies, including case management as a preventative strategy, will be discussed. Mentorship as possible prevention strategy will then be reviewed, also discussing already implemented mentorship programmes. The at-risk women will also be discussed, and their context. Lastly, the methodology and method of inquiry will be reviewed, as well as alternative data collection methods.

2.2 Prevalence of FASD in South Africa

The high prevalence of FASD nationally has been discussed previously, however the diagnosis of FASD in the South African context tends to be more problematic than not, and thus prevalence studies still present with limitations (1,2). The reason is that diagnoses must be made by a highly skilled multidisciplinary team, including a pediatric specialist, which often is either too expensive or inaccessible. In South Africa there is also no national protocol for screening or diagnosis of FASD. This challenge with diagnosing FASD further implicates epidemiological studies and other research done in South Africa regarding FASD (2). Although studies have only been done in areas with an expected high prevalence of FASD due to certain environmental risk factors it does not necessarily skew findings, but rather gives good insight into underlying environmental causes of FASD, risk factors associated with FASD and possible prevention strategies required for the effective prevention of FASD.

There is, however, no national prevalence data of FASD, only of certain communities. Even though FAS, the most severe condition on the continuum of FASD, has high rates in high-risk communities, it is possible that the prevalence rate of milder conditions, including PFAS, could be even higher (17). The magnitude of the FASD burden in South Africa is essentially unknown. Limitations of FASD prevalence studies also include, not excluding above mentioned problems with diagnosing, that studies have only been done in five out of the nine provinces (16). Still, even though studies have been

geographically limited, there is sufficient evidence to confirm that the FASD burden is large in many high-risk communities. It is also unknown to what extent the diagnoses of Attention-Deficit Hyperactivity Disorder (ADHD), learning problems and behavioural difficulties may be masking FASD. It is therefore still unclear what the exact prevalence of FASD in South Africa is, however, one can assume that the burden is large and requires immediate and effective attention (2).

2.3 Effectiveness of FASD prevention efforts

Many efforts have been made to attempt lowering the FASD prevalence rates. FASD is 100% preventable by cessation of alcohol use during pregnancy, and therefore prevention strategies should have a goal of mothers ceasing alcohol use during pregnancy, or even with women of childbearing age, especially in high-risk communities.

McKinstry (2005) suggests that developing and implementing successful FASD prevention programmes in South Africa, including changing drinking behavior in women of childbearing age, may produce public health benefits beyond just purely the prevention of FASD. Interventions aiming at addressing social networks- and community level phenomena, such as the interventions used for reducing other public health-related issues in South Africa i.e. Human Immunodeficiency Virus (HIV) infections, should also be implemented for reducing the prevalence of FASD (34). These interventions can be implemented by including the members of the community, in coordination with allied health professions such as occupational therapists, in programmes such as mentorship programmes (4).

Although no formal policies for FASD prevention have been established, in South Africa certain preventative strategies have been indicated to be effective in lowering FASD incidence rates in selected provinces. In an intervention study, Chersich, Urban, Olivier, Davies, Chetty and Viljoen (2012) concluded that universal prevention strategies were associated with lower FASD prevalence. This study was done in De Aar (2003-2006) and Upington (2005-2010) and included community health workers (CHW's). Three trained CHW's were stationed at each site and were supervised by professional nurses. They distributed pamphlets and posters regarding risks of drinking while pregnant to antenatal clinics, government departments, shops, taverns, and prisons. Regular articles were published in local newspapers, and this was reinforced by local radio stations and drama productions. The CHW's also presented health talks at clinics regarding FASD prevention, as well as training workshops at the

Department of Health and Department of Social Development. There was an overall reduction of FASD incidence, being 8.9% pre-intervention, and being reduced to 5.7% post-intervention. This is the first study that supports the idea that universal prevention can reduce FASD prevalence by more or less 30%. The study further provides evidence that brief interventions and education are effective in reducing risky drinking behavior among women, and consequently reducing FASD prevalence. It is, however, important to note that other concurrent community changes at the time of that study could also have attributed to the reduction in FASD prevalence rates. Other weaknesses of the study include missing data due to incomplete information gathered, especially in two particular cohorts, considering especially selection bias (35).

Furthermore Marais, Jordaan, Viljoen, Olivier, de Waal and Poole (2011) reported on the effect of a series of brief interventions (BI's) on risky drinking behavior of pregnant women in three high-risk rural areas in the Western Cape. The purpose of their study was to assess the impact of these BI's using a pragmatic cluster randomised trail design. The women were recruited at randomised government health clinics in the Western Cape. All women less than 20 weeks pregnant, as well as over the age of 15, were eligible for the study. The BI's, as described by the World Health Organisation (WHO), included counselling strategies on changing drinking behavior, setting goals and re-enforcing safe drinking behavior. These BI's were conducted during clinic visits from March to September 2007 with some visits still in February 2008. A total of 97 participants were included in the intervention group (IG). The IG had one initial assessment, four BI sessions and a final follow-up. The control group (CG) had an end total of 82 participants. The CG only had an initial assessment and a final follow-up. In both the IG and CG, the initial assessment and final follow-up consisted of a personal questionnaire and the Alcohol Use Disorder Identification Test (AUDIT). The AUDIT measures both the quantity and frequency of alcohol use. The participants had a mean age of 25 and were pregnant for an average of 15 weeks. The average parity was 1. Almost all women (72%) in the IG had a reduced score on their AUDIT score, where only 40% of women from the CG had a reduced AUDIT score, and even 10% of the CG had an increased AUDIT score. There was a significant decrease in AUDIT scores when comparing the IG to the CG ($p=0.002$). It was found that 36% participants of the intervention group reported a change after their first brief intervention and that 60% of the same group ceased drinking just before giving birth. Qualitative information gathered showed that most women of the IG made a conscious decision to stop their drinking after their first BI (5).

However, these results do not come without limitations. These limitations include the study being health clinic-based, and therefore pregnant women who do not attend clinics regularly were excluded. A follow-

up study should target heavy drinkers and non-attendees since these women tend to be considered as more at-risk mothers. The women who participated in the study also confirmed their drinking, and therefore their openness towards their drinking behavior could have also contributed to their willingness to be open towards a change in their drinking behavior. The participants were pregnant with an average of 15 weeks, and previous alcohol consumption could have damaged the fetus. However, it is recognised that cessation of alcohol use during any time in the pregnancy is beneficial for the pregnancy and fetus. Even though it is the first randomised-controlled study to be conducted on drinking behaviors of pregnant women and are listed with a range of limitations, it confirms the importance for support of at-risk mothers during pregnancy in a sustainable way (5).

BI's have both differences and similarities to mentorship sessions. Similarities include goal setting and addressing negative behavioural patterns. Differences include BI sessions being time-limited, whereas mentorship sessions tend to be more time-consuming (5). One could therefore argue that these similar qualities of BI sessions and mentorship sessions could be used effectively when developing a model for mentorship programmes.

2.4 Case management as a FASD prevention strategy

Another method of FASD prevention will now be reviewed. Case management is a behavioral intervention with functions such as education, coaching and support with the aim of changing behavior such as the at-risk mother's drinking behavior. An intervention study done by De Vries, Joubert, Cloete, Roux, Baca and Hasken et al. (2015) aimed to reduce the amount of alcohol consumed by pregnant women in South Africa, to reduce the prevalence of FASD. This prospective intervention study was carried out between January 2009 and June 2011 with an 18-month case management (CM) intervention programme. This intervention programme included using proved methods of social work, motivational interviewing (MI) and a community reinforcement approach (CRA). Women who were in their first to third trimester of pregnancy were recruited at health clinics in the Western Cape. These women were then enrolled in the CM programme, and data was collected at different intervals during the CM programme. 67 women were enrolled in the CM programme, however, due to women falling out of the programme, only 50 women completed the CM programme. Screening tests including the AUDIT were used during the intervention. A significant decrease in the mean AUDIT scores were found in women from the baseline assessment to the 18-month assessment, with a decrease of 18.7 to 11.3 scores ($p=0.000$). This is quite significant as it is evident that even though none of these women were

pregnant at the time of the 18-month interval, they still managed to score significantly lower on the AUDIT scores, thus giving an indication that they made long-term changes in their drinking behavior. Furthermore, drinking levels for pregnant women at the six-month follow-up is about half of that which has been reported in pregnant women who have not been enrolled in a CM programme in South Africa (36).

Therefore, there is a need to implement community-based programmes for the reduction of FASD. It is also important to note that the CM programme is designed as only one component of FASD prevention strategies, since FASD prevention, as mentioned earlier, requires a multi-modal strategy. Certain components of CM has also been associated with mentorship programmes including individual support, encouragement of positive lifestyle changes and a person-centered approach (4,36–38). It is such overlapping components that need to be thoroughly explored to determine their value.

2.5 Mentorship programmes as FASD prevention strategy

Mentorship is described as providing guidance, knowledge, support, and opportunities by a more experienced person to an unexperienced person for as long as it is required for the advancement of the inexperienced. Mentors provide emotional support by developing and encouraging their mentees self-esteem and motivation. Mentoring is an extremely powerful, human relationship where trust and commitment are key components (25). Mentoring for at-risk women can therefore provide potential adequate support and guidance for them to overcome their barriers and adversities and be empowered to change their drinking behaviours.

The role of mentorship programmes in FASD prevention is still unclear. A community-based public health intervention mentorship programme, The First Steps Program, launched in 1999 in Alberta, Canada, focused on building positive, empathic relationships between mentors and mentees (at-risk mothers). This programme helped them to identify personal goals and assisted them with support to reduce alcohol and drug use during their pregnancies. The First Steps Program is based on a programme, the Parent-Child Assistance Program (PCAP), which is an intensive three-year advocacy model used with at-risk mothers. This long-term model gives adequate time for realistic and gradual change to take place. Trained and supervised case managers, called mentors, had a maximum case load of 15 families each in the First Steps Program. The study found an overall decrease in needs and

an increase of goals of the mentees after the intervention period. Needs in this context included housing, financial stability, parenting skills, family planning and addiction issues whereas goals were achievable goals that the mentee would like to achieve within a period of six months; either pre-written or own-written goals. FASD is a significant public health issue and mentorship programmes, such as the First Steps Program, have great public and personal benefits. At-risk mothers are a diverse group of women and through participation in programmes these women are afforded the opportunity to improve their and their children's quality of life. Rigorous evaluation of such programmes are critical in order to inform development of such programmes, inspire change and also to demonstrate that public funding of such programmes is money well spent (6).

Non-governmental organisations (NGO) in the Western Cape have dedicated resources to initiatives for the prevention of FASD with the use of mentorship programmes. One of these NGO's implemented a mentor-mentee programme. The aim of this programme is to provide psychosocial support, including education on the dangers of drinking alcohol while pregnant, during and after pregnancy for at-risk mothers (37). Mentors seek out pregnant women in their community and then commence with the mentorship programme, which includes educating the pregnant women on the risk and consequences of antenatal drinking (38). Cloete (2018) concludes that providing *meaningful* mentorships can provide alternative preventative measures for FASD. She further explains that educating, empowerment and enabling pregnant women and their partners is imperative in decreasing FASD prevalence. This is based on the assumption that healthy women, both physically and mentally, have healthy babies, and that this can be achieved by introducing sustainable mentorship programmes within the communities (37).

Another NGO focused on the training of women in low socio-economic status neighbourhoods in the Western Cape as a so-called "Mentor Mother". These Mentor Mothers provide mentorship to pregnant women while simultaneously building a relationship to constructively problem-solve common difficulties that pregnant women from a low socio-economic status face. These Mentor Mothers also educate and support pregnant mothers on a variety of topics, including antenatal drinking. This intervention programme takes place in the form of home visits, thereby already eliminating obstacles pregnant women within low socio-economic areas face, such as accessibility to health care. It is known that developing countries such as South Africa cannot sustainably fund programmes addressing health problems, such as FASD prevention, due to limited national budgets. Preventative strategies employing community health workers, such as the Mentor Mothers, can aid to supplement and support an under-funded, under-resourced health care system in South Africa. One strength that has been identified with

this mentor programme is the use of 'positive peer deviants' as Mentor Mothers are geographically from the same area, usually from the same socio-economic status and therefore the assumptions is that the Mentor Mothers face the same obstacles and challenges that the mentees face. These similarities therefore aim to promote an environment with non-stigmatisation and sustainable support, which presumably supports effectiveness of such programmes (4).

Another NGO has implemented a programme assisting mothers side-by-side during the first 1000 days of their child's life. This programme is based on a social franchise network and aims to support, celebrate, and empower mothers through the first 1000 days of their child's life. These first 1000 days are critical to establish the child's health and general well-being, however, it is also a period of vulnerability during which mothers require support. This programme is made up from weekly visits over a period of 10 weeks with a group of about 10 mothers. These visits are done by a programme franchisee who has been licensed and trained by the NGO to run these visits. A programme franchisee is not just a community worker, but rather a community activist. A range of maternal and health topics are covered, including safe alcohol-free pregnancy (39). However, the emphasis on this programme is not the "do not's", but rather the positive "do's". This positive-outlook approach could be challenging since addressing public health issues tend to be problem-focused, and not solution-focused, as the *Flourish* programme. This positive approach could add to the way we view the value of mentorship programmes and how to approach women in this vulnerable stage in their lives.

These programmes mentioned above have certain components present, which could assist in exploring programme components that needs to be present for success in mentorship programmes. These components include community-based care, i.e. either home visits or using community facilities other than that of the local clinic or hospital, supporting and motivating women throughout their pregnancy, building a trustworthy relationship with the mentee and educating the mentee regarding good maternal health. The mentors have also been specifically trained to offer support and counsel the mentees (4,37,39). Jansen van Vuuren and Learmonth (2013) argue that FASD prevention strategies has previously focused on universal prevention strategies, however, due to their low global success rate of between 5-10%, it is therefore important to focus on person-centered strategies, which has previously been used for increased success, especially with regards to behavioral changes (18).

Rotherum-Borus, le Roux, Tomlinson, Mbewu, Comulada, le Roux et al. (2011) also further conclude that implementing prevention strategies for FASD should include community health workers (CHW's)

(community mentors), as used in above-mentioned programmes. Using CHW's for prevention services might be the only feasible and realistic strategy to scale-up such programmes. Currently, the burden of the range of diseases in developing countries, such as South Africa, cannot be alleviated solely by means of a health care system, and therefore should include other systems, such as mentorship programmes (4).

In conclusion, considering the background and current practice, the need for exploring efficacy and value of mentorship programmes should be considered as to assist to further develop and delve into successful prevention strategies for FASD. It would also further be valuable to ascertain what components, including community-health care workers, are most valuable in these mentorship programmes.

2.6 Describing at-risk mothers

It became evident that it is important to focus on the at-risk mothers when thinking about lowering FASD prevalence rates. It is important to understand the at-risk mother, her risk factors, as well as her environment and context. At-risk mothers are firstly described as women who drink during pregnancy. They are also described as having a risk of having a child with FASD, with highest-risk women described as already having one child with FASD (34). Viljoen, Croxford, Gosagge, Kodituwakku and May (2005) suggests that the contextual characteristics of at-risk mothers in South Africa are women with lower educational attainment from rural areas with families with histories of extensive drinking and alcohol abuse (7).

A detailed presentation of birth mothers of children with FAS, or static encephalopathy, was done by Astley, Bailey, Talbot and Clarren (2000) in Washington, United States of America. 80 high-risk mothers participated in a four-hour structured personal interview to generate a lifetime, comprehensive profile of her socio-demographics, socio-economic status, mental health, support structures, lived experiences, as well as intelligence quotient (IQ). High-risk mothers are also described as mothers who already have one child affected by FASD. Results have shown that 61% of the mothers did not complete high school, 95% had been sexually, emotionally or physically abused and 96% had one to ten mental health disorders with the most prevalent being post-traumatic stress disorder (PTSD) and simple phobia (40). As mentioned, this is a detailed presentation and only represent the demographics of a certain

population. However, it gives good insight into the circumstances of where and how these mothers live and the adversities they are exposed to.

Viljoen, Croxford, Gossage, Kodituwakku and May (2005) did a retrospective case-control study with 31 mothers who had given birth to a child/children with FAS six to nine years previously (case mothers), and a group of 31 matched controls (control mothers). This study was the first of its kind to be done in South Africa, as most studies have been done on women with drinking behavior during pregnancy. However, no studies has been done previously with women who has already given birth to a child/children with FAS. A questionnaire that was developed originally in the USA, and adapted and piloted for the South African context, was used. The 114-item questionnaire included contextual and demographic items, as well as drinking behavior and environmental items. It was found that control mothers had significantly more educational attainment in years ($p=0.027$) and attended church/prayer more often ($p=0.0019$) than the case mothers. This agrees with the study done by Astley, Bailey, Talbot and Clarren (2000) (40). The most significant findings were, however, the drinking environment in which the case mothers lived. It was found that the case mothers reported that they lived in an environment with heavy to problematic drinkers, including brothers, sisters, and best friends. The case mothers attributed their prenatal alcohol drinking to the stressful environment and time and that drinking was a mechanism of coping. Another important finding was that up to 97.7% of alcohol that case mothers consumed during pregnancy were consumed over weekends. This describes the phenomenon of binge drinking, which dramatically increases the risks of the child developing FASD (36). This specific community in the study is known for its high rate of problematic drinking and previous exposure to the *Dop* system due to its agricultural history and geographical location, and therefore one could argue that the findings from the study is specific to the context. However, as context-specific as these findings might be, it is still increasingly valuable to help described at-risk mothers and their environment, as well as provide information for designing further preventative strategies for FASD (7). The small sample may limit statistical power; however, the study suggests that the most valuable characteristics to consider is rather that of the environment in which women live, rather than intrinsic ‘faulty’ characteristics.

Furthermore, discussing the *Dop* system might also provide valuable insight into maternal drinking behavior. Agriculture is an essential component in the economy of South Africa, and as such be, it is the largest source of formal employment for women (41). The *Dop* system was introduced with the colonialization of the Cape colony in early 1700’s, however, has been ruled illegal since 1961 in South Africa. The *Dop* system is typically classified as giving “dop” (wine) as part of the weekly or monthly remuneration for farm workers. This system inevitably promoted a regular, and even binge drinking

behavior among farm workers. A descriptive study by Phillip, Snell, Parry, Marais, Barnard, de Vries et al. (2014) aimed to link this historical perspective to more recent data on alcohol consumption among farm workers and concluded that the historical *Dop* system has contributed to problematic drinking among women from lower socio-economic status (42). The history of alcohol use is further discussed by Christmon (1995). Alcohol, especially rum, was used during the slavery period in the Caribbean from the mid-17th to 19th century. It was specifically used to subdue or control the African-American slaves, and the slaves also had easy access to the alcohol (43). This then raised questions on the long term effect of the alcohol exposure, especially with regard to alcohol-related birth defects, as well as current drinking patterns among African-Americans, and how alcohol is currently viewed (44). It therefore appears thatthe history of alcohol use and the effect thereof is not just subjected to a rural South African context but can be viewed as a global historical problem.

Besides battling against previous practices promoting harmful alcohol use, women in South Africa with children with FASD face a variety of contextual challenges, including stigmatisation, which further leads to barriers in accessing institutionalised treatment (45). These barriers include internal, external, and structural barriers. In a social constructionism study done by Jacobs and Jacobs (2014) they found a compelling association between maternal drinking behavior, stigmatisation and barriers to seeking treatment of women with alcohol dependence, including alcohol dependence during pregnancy. The already poor support and infrastructure to support women who are alcohol dependent also increases these barriers and stigmatisation. Ten alcohol dependent women who were in recovery were interviewed to reflect on their lived experience and the barriers that they faced. These women experienced stigmatisation, as the assumption is that bad mothers drink, and therefore already had feelings of rejection. Other structural barriers included alcohol use as an escape in a world of poverty, powerlessness, patriarchy and where alcohol use is being feminised. Personal barriers that emerged were that of barriers to seek recovery such as shame, guilt, and secrecy. These barriers effectively prevented women from seeking treatment, either for them or for their children (45). McKinstry (2005) further elaborates that the feelings of depression, low self-esteem and low self-efficacy that at-risk mothers struggle with, further creates barriers for these women to seek support and/or treatment (34). Jansen van Vuuren and Learmonth (2013) further discuss that individual psychosocial support is yet to be implemented in South Africa's high-risk communities despite evidence that it may reduce alcohol consumption for at-risk mothers (18).

Furthermore, women from rural communities face greater challenges when it comes to accessing good quality healthcare services, than women from urban communities. Healthcare facilities in rural areas

are often less accessible due to distance and geographical location, are under-resourced and therefore lack essential medicines and services. Not only is it difficult to access transport to get to these mostly under-resourced communities, traveling times are also long. Even though healthcare has been made freely available to all pregnant mothers, affordability of transport still seems to be a problem (46,47). Silal, Penn-Kekana, Harris, Birch and McIntyre (2021) found in their mixed-method study that access to antenatal and obstetric healthcare for women in rural communities were mostly hindered by barriers of affordability, availability, and acceptability. At-risk women faced the biggest barriers to accessing healthcare including longest travel time, highest cost of transport, staff-inattentiveness, shouting at patients and insensitivity. The health outcomes of these mothers were thus poorer, than compared to those from urban areas (46). This clearly illustrates that even though FASD is a recognised as preventable and a recognised health disorder, women still face many obstacles when challenged with their drinking behavior and the effects thereof.

2.7 Qualitative Case Study Methodology

Second to last, the methodology design has been reviewed. A case study design is designed as an intensive study of individual interests, and is an exploratory form of inquiry (48). The case explored could be a person, several people, an institution, an innovation, a service, a program, an event or even an activity. Occupational therapists might study a case as an individual client, an environment or context, and intervention program or even a goal-setting process. The root of case studies lies in social sciences, especially in evaluation research and is not being frequently used in occupational therapy research. Salminen, Harra and Lautamo (2006) did a literature review on the use of case study research in occupational therapy. They mention that of the 50 articles published in the *Australian Journal for Occupational Therap*y during the period of 2000-2003, only five studies used the case study methodology. Even though case studies might not be the most popular research methodology used in occupational therapy research, one can argue that it is the one methodology type that respects occupational therapy principles the most. Occupational therapy considers a person, or a case, holistically, considering both the “case” and environmental context. Case studies are specifically designed to take into consideration both the case as well as the context, which is one of the most-important underlying principles of occupational therapy. Case study methodology provides the opportunity for occupational therapists to study interventions and what these interventions mean to participants, their partners, and the therapists. Case studies also create opportunities for occupational therapists to learn more about their clients, understand practice better and in more detail, as well as to reconceptualise practical problems (49).

Hercegovac, Kernot and Stanley (2019) did a scoping review on how using a qualitative case study methodology (QCSM) can inform occupational therapy practice, knowledge, and skills. They describe QCSM as a comprehensive research approach originating from the health and social sciences. QCSM may be used where a phenomenon needs to be explored in the real-life context. A total of 27 articles were included in their scoping review where the majority were published in occupational therapy journals (n=20). Most studies examined the outcomes of occupational therapy interventions and concepts relating to health care and disability services (n=12). Several studies explored occupational science concepts (n=9). The studies in the scoping review occurred in a variety of settings including mental health, pediatrics, neurological conditions, occupational therapy education, home modifications, hand therapy, driving assessments and older adults. The number of cases studies per article were a mean of 2,96, with a median of 1 (n=17). Most studies also used semi-structured interviews as method of data collection (n=18). The other methods of data collection were individual in-depth interviews, open-ended interviews and focus groups. There were only one study that did not use an interview style for data collection, but used videos (50).

The scoping review demonstrated how widely QCSM can be utilized in occupational therapy research. Researchers can move beyond the perspective of individual clients, but also consider the environment and organisational elements. This may suggest that QCSM may add tothe knowledge occupational therapy. It is however important for the researcher to be aware of how to improve rigor, as case studies are widely criticised for their subjectivity (50).

2.8 Alternative Qualitative Data Collection Methods

Technology has significantly advanced and transformed the way people conduct research, especially in health care (51,52). Options to broaden participant recruitment and data collection methods have become readily available (52). Technology also provides the opportunity to involve participants that otherwise might not have been able to participate in the research. Reasons could include being geographically separated, time constraints and social barriers. The World Health organisation (WHO) declared the Covid-19 outbreak around the world a Public Health Emergency of International Concern on 11 March 2020. South Africa’s president, Mr Ramaphosa, announced a national lockdown on 23 March 2020 which started on 26 March 2020. This national lockdown has since eased, however, strict travel restrictions and restriction in participation in certain economic activities are still in place. Other

regulations, including strict hand hygiene, sanitisation, social distancing and the wearing of masks are still compulsory. These guidelines are defined under the the Disaster Management Act, 2002: Amendment of regulations issued in terms of section 27 (2) issued on 25 March 2020 by the Minister of Co-operative Governance and Traditional Affairs, Dr Nkosozana Dlamini-Zuma (53). In accordance to the national lockdown regulations as mentioned above, Stellenbosch University Postgraduate Office has decided that all postgraduate research activities need to be postponed if it cannot be conducted online/remotely (54). Such regulations provide an opportunity to explore alternative methods of data collection and conducting research, including using everyday technology such as cellphones or video conferencing. Occupational therapists have been dealing with technology in increasing frequency as technology has become an integral part of occupational performance in most individuals' life (55).

Various methods have been previously used for data collection with the means of using day-to-day technology. Cellphones have become widely available and has emerged as a powerful tool for data collection. In 2013, 6.8 billion cellphone subscriptions were active internationally. Furthermore, there are 96.2 cellphone subscriptions per 100 people worldwide, separating it with 126.2 per 100 in developed countries and 89.4 per 100 in developing countries. Cellphone subscriptions exceeded landline telephone connections by a factor of 5.8 (56). Cellphones are even widespread in the rural areas of South Africa (57). One can assume that with cellphones becoming more readily available since 2013 these numbers are even higher currently. Cellphones provide additional advantages other than being so readily available. For instance, the person could be reachable more often, participants could be more easily prompted (reminded) and it could assist in data management through accurate stamping of the data records with a date and time (56). The use of cellphones for data collection, and even in the occupational therapy intervention process, is not a new concept (57). It is also possible to collect data remotely and without contact. There are still also technical challenges with the use of cellphones such as challenges with the cellphone network coverage and speed and the participants' cellphone literacy skills (56). These are however barriers that could be managed.

Another method of collecting qualitative data remotely is with the use of video conferencing. Focus groups are a popular means to collect qualitative data in health care research, and video conferencing has been previously used in health care for conducting small group discussions, teaching, supervising and providing basic health information to underserved populations (52,58). In an article by Glassmeyer and Dibbs (2012) they examined how researchers use live video conferencing software to conduct interviews and focus groups. They found that video conferencing provided a good platform where verbal and nonverbal cues, natural language and immediate feedback can still be present. The participants

are also able to express their personal feelings and emotions. They, however, listed some concerns with the use of video conferencing. Ethical concerns included ensuring that the data does not automatically get stored on the internet without being password protected, ensuring that the participants understand the physical environment of the researcher conducting the interviews/focus groups and ensuring that ‘n do-not-disturb sign is still up at the door of where the researcher is, as well as the participants, to promote privacy. Technological concerns include poor quality of the video conference. This can be improved done by giving enough time before the interview, at least 15 minutes, where participants can sign into the video conference and sort out any technical difficulties with the help of the researcher, who should be familiar with the software program being used (51).

Sedgwick and Spiers (2009) wrote about the experiences from undergraduate nursing students when they used video conferencing for data collection purposes. They started out by explaining that video conferencing does not replicate face-to-face in person interactions. This is because there is deterioration of visual cues, including nods and eye gazes, longer turns between speaker transitions and fewer turns taken by participants. This consequently leads to more formal interactions, making the interview process more unnatural. Also, the sharing of the same physical space promotes a natural flow to the interview process and participants tend to feel more secure, and therefore are more spontaneous and makes more speaking turns. However, after the research study they concluded that none of the participants who participated in the video conferencing interviews verbalised any concern with using video conferencing technology. All though the in-person (n=6) and video conferencing (n=10) interviews were all booked for two hours, there was a concern that the video conferencing interviews might not last that long. The video conferencing interviews, however, all lasted up to two hours, except for one, where some of the in-person interviews only lasted 90 minutes, with some lasting two hours. Still there were some concerns. These concerns included that participants might not have shared all the information they wanted due to lack of physical presence of the researcher and poor quality of the video call. One major advantage is that it provides the researcher with a viable, cost-effective alternative for face-to-face contact (58).

It is therefore evident that, amidst the international pandemic and national lockdown regulations, alternative methods of data collection could still be used. This gives researchers an opportunity to investigate and explore alternative data collections methods, therefore, further promoting research with the use of technology. It might also become evident that alternative methods of data collection might even prove to more effective than the traditional methods. The researcher should, however, be aware of the disadvantages and concerns with using technology for data collection. It is the responsibility of

the researcher to still ensure that all ethical considerations are adhered to, including the safety of the participants, as well as their privacy.

2.9 Research question

Which components of mentorship programmes are considered as the most valuable as a preventative strategy for prenatal alcohol use for at-risk women in the Western Cape.?

2.10 Purpose of the study

The purpose of the study was to explore the value of mentorship programmes for at-risk mothers in high FASD prevalence areas in the Western Cape. FASD is a preventable disorder with cessation of alcohol use during pregnancy. Cessation and/or change in drinking behavior can be achieved with ongoing social and emotional support together with education, as well as engaging in meaningful occupation. This support might be achieved through mentorship programmes in high-risk communities with at-risk mothers. Reducing the prevalence of FASD will positively affect individuals, families, and the wider community. These mentorship programmes therefore have been investigated and explored to further assist with developing effective and sustainable prevention strategies. The valuable components of such a programme have also been explored, including the role of occupational therapy, occupational therapy techniques, meaningful occupation, and occupational engagement, to contribute to a long-lasting change, and to further recommend such programmes to maternal and child health services.

2.11 Aim of the study.

The aim of the study was to explore which components of mentorship programmes assist in preventing prenatal alcohol exposure of at-risk mothers, and the value thereof.

2.12 Objectives

2.12.1 Primary Objective

To explore which components of mentoring programmes utilised for preventative strategies for prenatal alcohol use are valued most by key professionals, mentors and mentees in South Africa.

2.12.2 Secondary Objective

To determine experienced challenges of the mentoring programmes utilised for preventative strategies for prenatal alcohol use by key professionals, mentors and mentees in South Africa

Chapter 3: Methodology

3.1 Introduction

In this chapter the methodology of the research study will be discussed. Firstly, the paradigm in which the study has been done will discussed, as well as the design. Thereafter the sampling process, including the recruitment and selection of participants and the sample size will be discussed. Furthermore, the data collection and analysis process that was taken will be discussed. And then lastly, the trustworthiness and rigor and ethical considerations will be discussed.

3.2 Method of Inquiry and Rationale of Choice of Study

The research has been done within a qualitative paradigm. Qualitative study methods provide alternative methods of investigating and understanding social phenomena, which is harmful drinking during pregnancy, within a specific profession, in this case occupational therapy (3) . Qualitative research is described as studies of people and/or phenomena in their natural setting such as the low socio-economic communities in the Western Cape where unemployment, poverty and crime is rife. This qualitative research world is constructed by attempting to understand the meaning of phenomena as experienced by participants. Participants therefore participated from and within their own contexts, and their own experiences, ideas and opinions has been collected (2).

An explorative case study design, which is an exploratory form of inquiry, has been used to explore and investigate the value of mentorship programmes for FASD prevention within rural areas in the Western Cape (48). A case study design has an underlying belief that experiences of an individual or larger group within a specific context can give insight into other wider, related issues (60). It further explores real life experiences within the context with the use of multiple data collection resources. This enables detailed information to arise from a specific context or complex phenomena which is essential for development and evaluation of community-based programmes such as the context described previously. Stein, Rice and Cutler (2013) explains that the purpose of a case study design is to intensively investigate a certain case. A case study is in an in-depth description and analysis of a case.

The case that has been explored within this study is community-based programmes implemented by NGO's with clients from rural areas in South Africa, with a focus of the Western Cape. These programmes aim at improving prenatal health, including the mother and the baby, using a mentoring approach with a focus on addressing prenatal alcohol exposure (59).

Case studies also have specific features such as being particularistic as it focuses is on a particular situation, event, programme or phenomenon such as, in the case of this study, a mentoring programme addressing prenatal alcohol exposure for at-risk mothers. Case studies are also heuristic as it enlightens the reader's, and researcher's understanding of the case studied and also bring about new meaning to the case (59). A case study design also assists to enable the exploration of occupational therapy contribution in prenatal care and FASD prevention.

3.3 Research context and population

The research context of this study is communities where community-based programmes run that focus on mentoring of pregnant mothers who are at-risk, specifically of drinking while pregnant, and addressing prenatal alcohol exposure. These programmes are developed and implemented by non-government organisations. The specific communities in which these programmes run across South Africa are within low socio-economic communities. These NGO's were part of stage one of the research study which involved a focus group discussion. The first organisation promotes family health, including pregnant mothers, newborn babies and children, disabled people and people affected by HIV (61). They have a program which focusses on home-visit intervention with a mentoring program with at-risk mothers in geographical-defined areas. This intervention focuses on maternal and child health and addresses issues like HIV, alcohol, and mental health. This program runs both in the Western Cape and Eastern Cape (61). Organisation two is an organisation focusing on prevention of stunting of children in the whole of South Africa. They have a programme which focuses on journeying with mothers in their first thousand days of their baby's life by the means of additional antenatal and postnatal classes. This programme is operational in the Western Cape, Eastern Cape, Gauteng, Mpumalanga and Limpopo (39). Organisation three is an NGO which aims to educate the public on the effect of PAE, as well as the effect of FAS on not just the individual, but also the wider community. They have an established mentorship programme for at-risk mothers in the Western Cape and implement this programme by the means of home visits conducted by the mentors (38).

One programme running in the Western Cape was explored in more detail. This organisation was part of organisation of stage two of the research process. The programme in the Western Cape is situated in the Breede Valley district, in the Western Cape of South Africa. The data collection of stage two, which was done with participants from this context, was conducted in Afrikaans as all the participants were Afrikaans-speaking. In terms of educational attainment 32.8% residents reported they have at least matric, with a furthermore of 38.2% reporting to have at least some secondary education (62). This contextual information could be applied to the participants of the stage two, as one could expect that at least 70% of the participants were at least qualified on matric level or higher.

The research population included a total of ten participants, which included professionals, semi-professionals, and experts in the above mentioned programmes, as well as clients and mentors involved in these programmes.

3.4 Sampling

3.4.1 Recruitment of participants

The research process has taken place in two different stages. During stage one a focus group discussion was done, and in stage two the participants participated in journaling.

The recruitment of the participants of both stages has taken place in the following methods. The first step was to determine and select organisations directly involved with mentorship programmes in aim of decreasing the prevalence of FASD in communities where FASD is prevalent. Three organisations were identified for stage one by means of searching for relevance of programmes and discussing with peers and supervisors. These organisations have firstly been contacted via email to explain the purpose of the study and to inquire regarding their willingness to participate in the study. One contact person per organisation has been identified for communication purposes. This contact person was identified as being a staff member who is either directly involved with the respective or the managing/overseeing the programme. This person was selected based on their willingness to be the contact person.

3.4.2 Selection of participants

Purposive sampling has been used for the first stage. Purposive sampling was used in order to demonstrate the experiences within a case, such as the mentorship programmes (63). Therefore a specific, pre-determined study population has been selected to participate in the research study.

An informed consent form has also been emailed to the contact person as this explained the study in greater detail. The contact person inquired within each of their respective organisations whether there were any willing potential participants. Participants included professionals, semi-professionals, or experts in their respective mentorship programmes. Participants varied in terms of their socio-demographics, educational attainment, and geographical sites. The inclusion criteria of the participants were as follows:

Selection criteria
Employees of identified organisations
Professionals, semi-professionals and/or experts in the field of the respective mentorship programmes
Indicated willingness to participate in the research

Table 3.1: Selection criteria for stage one data collection

Potential participants were firstly contacted by the contact person to learn more regarding the research. The contact person only inquired whether the person would like to participate in a research study, indicating to the possible participants that they would be contacted by the researcher. Only after they have indicated to the respective contact person, they have been contacted telephonically or by email by the researcher to inquire regarding their willingness to participate in the research study. After the participants have agreed to participate verbally or via email, a written informed consent form was emailed to each participant. All participants had access to email. See Addendum A. It has been explained to each participant that they have at least one day to read through the form and discuss with peers, relatives, or colleagues. The signed consent formed was emailed back to the researcher. A convenient time for a video conference call was arranged with all participants to conduct the online focus group discussion. All participants had access to video conferencing tools.

One organisation declined to participate in the research study as they did not have the capacity at that moment to participate in a research study. One organisation had only one potential participant and the last organisation had three potential participants. A total of four participants participated in the focus group discussion. Focus groups are typically with four to six participants which lasts about one to two hours (63).

The participants are considered key informants as they were considered influential in their organisation. Key informants are specifically selected based on their expertise in the relevant fields and research. The advantages were that the data collated was information rich. However, a disadvantage is that it was difficult to gain access to them as they were often unavailable, due to their full schedules (63). This was the case in this research study, as some potential participants were not able to participate due to time constraints. See Figure 3-1 for more detail regarding the sampling process.

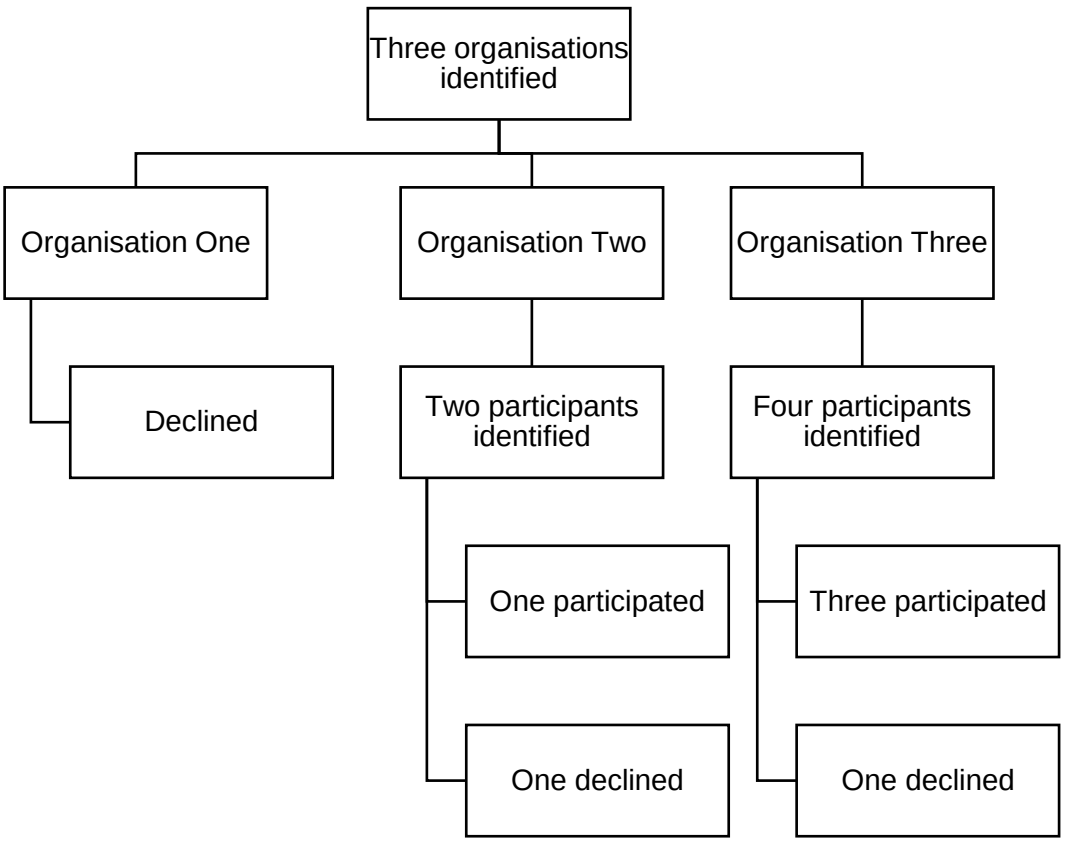

Figure 3.1: Participant selection for the focus group discussion

Participant one (P1) is a community worker who lives in the rural community, in the Western Cape. She is responsible for designing and managing the mentorship programme. Participant two (P2) is a field mentor for a mentorship programme. P2 also lives within the rural community. P3 is also a community worker involved with the mentorship programme, and she also lives in the rural community. P1, P2 and P3 is affiliated with organisation three. P4 is currently a curriculum developer and master trainer for their organisation's programme which focuses on antenatal and postnatal classes. P4 is trained as an occupational therapist. P4 is affiliated with organisation two.

The next part of the sampling process for stage two was to sample participants within one identified organisation also by means of purposive sampling. This organisation was identified as having a community-based mentorship programme with a focus on FASD prevention. The organisation involved is situated in the Breede Valley district, Western Cape.

The potential participants from the organisation included mentees and mentors of the mentorship programme. The inclusion criteria are as follow:

Selection criteria
Mentees/mentors of the mentorship programmes of one identified organisation
Indicated a willingness to participate in the study

Table 3.2: Selection criteria for stage two data collection

A list of potential participants, with telephonic contact details, have been obtained from the organisation via the respective contact persons. The mentors from the organisations have firstly been contacted telephonically to inquire about their willingness to participate in the study. Thereafter, each mentor has also been asked to inquire with their respective mentees whether they are willing participate in the study. The mentors did this by either contacting their mentees telephonically, or by conducting a home visit. A total number of six participants were successfully recruited for stage two. See Figure 3-2 for more detail regarding the recruitment of the participants.

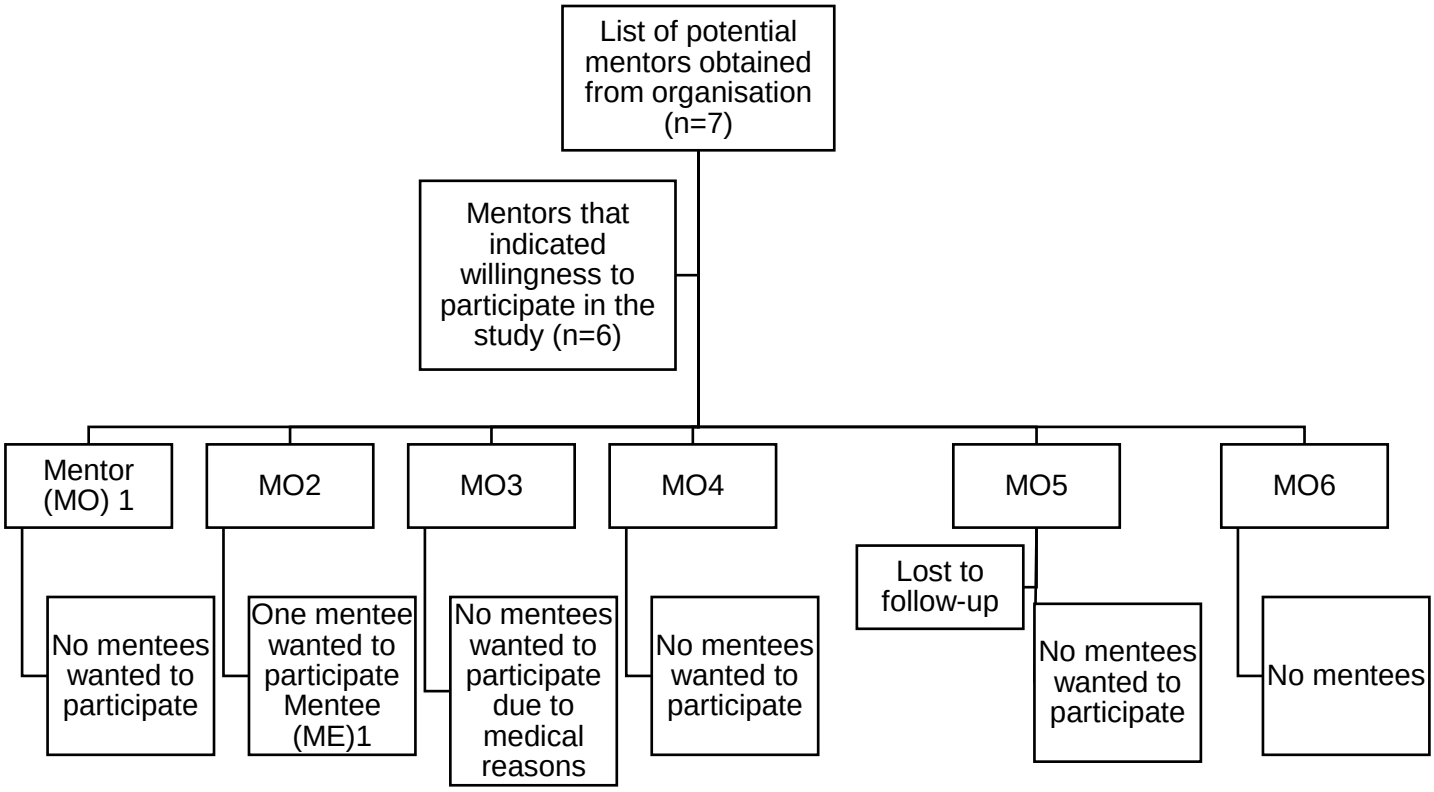

Figure 3.2: Sampling of participants for journaling

The participants were then contacted telephonically. A verbal informed consent phone script was read to all the participants (see Addendum B). Participants were able to verbally withdraw consent to participate in the study at any time during the research process. The process of the telephonic, verbal consent has been documented on a printed document with a table with the date, time, name of caller, name of participant, as well as signature of the caller and the impartial witness (64). See Addendum C. An impartial witness is described as '*a person, who is independent of the study, who cannot be unfairly influenced by people involved with the study, who attends the informed consent process if the research participant or the research participant's legally acceptable representative cannot read, and who reads the informed consent form and any other written information supplied to the research participant*' by the Health Research Ethics Committee of Stellenbosch University (65). The researcher requested participants to use the loudspeaker function on the telephone so that both the caller and witness could hear the conversation clearly. Each participant has been allocated a number, and only the allocated number will be used throughout the data analysis process. The replacement of name by number ensured confidentiality and anonymity to the reader of the participants.

The regulations set out by the Protection of Personal Information (POPI) Act (2013) has been adhered to when dealing with the participant's information, as well as the data gathered by the participants. Firstly, all informed consent has contained the information as set out by Section 18 in the POPI Act. Personal information has only been collected as part of the research study, and therefore all personal information has been collected for a specific, explicitly defined purpose. The personal information gathered has also been disposed of once it was no longer needed (66).

3.4.3 Sample Size

The aim of the sample size was to elicit richness of data regarding a specific experience or phenomena which can be transferrable, rather than generalized (67). Stage one of the studies consisted of four participants of professionals, semi-professionals, and experts. Stage two consisted of six participants. (63,68).

There have been some constraints with regards to recruitment and sampling of participants. These constraints include accessibility to the participants on a remote basis i.e. telephonically and time constraints. This could potentially have impacted on the data saturation, however, the researcher was still able to elicit rich data from the data collected.

3.5 Data Collection

Case studies do not claim specific data collection methods, as any data collection methods can be used (59). Stage one data collection has taken place in the form of an online focus group discussion. Participants have been invited to attend an online video conference call for the focus group discussion. The discussion was conducted in English as all participants agreed that they feel comfortable enough to have the discussion in English. Focus group discussions are used to explore the perceptions and attitudes of the participants regarding topics. The advantages of focus group discussions were that several participants could interact with one another, and this interaction stimulated data that the researcher otherwise might not have been able to collect. This happens when participants modify each other's responses. A disadvantage is that some participants might feel discouraged to disclose their

opinion due to minority feelings and/or feelings of uncertainty (63). The researcher has, however, attempted to minimise the possibility of such incidences by opening the focus group by reassuring all participants of their anonymity to the reader, reflecting on what the participants were saying and creating an environment of openness, transparency, and assurance. Focus groups are increasingly being used to help and develop and evaluate health-related interventions and programmes, and is therefore very relevant (63). The focus group discussion has been recorded on a conference call software. The software that was used was Microsoft Teams. Microsoft Teams requires a two-factor authentication and is well encrypted, therefore safe to use in terms of privacy of information (66,69). The recording of the discussion has then immediately been securely saved separately where only the researcher had access to the data collected. Verbal and non-verbal cues were still present, which one will find in face-to-face focus groups, and participants were still able to express their opinions well and thoroughly. There were, however, at times, some poor quality of the video conferencing and at times the video got delayed. This, luckily, did not happen often and the delay was not long. Considering that videoconferencing has become an often-used tool during the lockdown-period, the participants seemed to be comfortable with it and there were not major issues. Video-conferencing cannot, however, replace face-to-face interviews due to deterioration of visual cues, longer turns between the speaking transitions which consequently creates more formal interactions (58). The video conferencing was still a good alternative considering the lockdown-regulations which included social distancing.

One focus group discussion was done which lasted about 90 minutes. The focus group discussion had an open-ended, unstructured style. The topics discussed have been pre-determined. The focus group discussion has been structured in three phases (See Addendum F). The first phase of the one focus group has been to repeat the purpose of the study and the purpose of the discussion, and to introduce the participants to the researcher and to each other. Opportunity has also been given for any questions or uncertainties. It was reiterated that the participants can withdraw from the discussion at any point during the discussion. The second phase of the discussion has been the body of the discussion, where the researcher had the opportunity to ask questions and the participants had the opportunity to discuss and answer the questions. The researcher was sensitive as to not discuss sensitive topics that the participants might not feel comfortable with discussing. The researcher, as a trained occupational therapist, inherently possesses the necessary skills to determine whether a participant feels uncomfortable with topics discussed, and therefore has been careful to delve into topics that might cause discomfort to the participants. At any time, if the researcher found that a participant should be referred for external services, including counselling, psychology, social work or medical care, the researcher would have taken it upon herself to ensure that the participants received the necessary referral. The referral will be to the nearest community health care facility with the relevant professionals.

However, no external referrals were necessary. The last phase was the concluding phase. The researcher indicated the termination of the discussion to the participants. The participants also had the opportunity to ask any questions. The participants were thanked and reimbursed for their time and inconvenience to participate in the study by means a grocery voucher of R100. These vouchers were sent via SMS.

The phases of the discussion are demonstrated below:

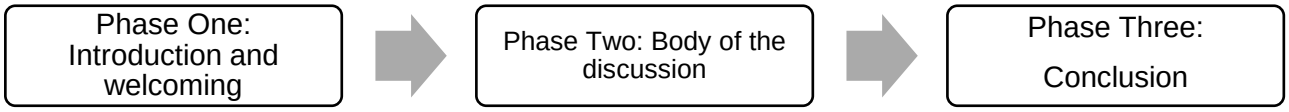

Figure 3.3: Process of focus group discussion

Stage two data has been collected by means journaling using weekly journal logs done by the participants: the mentors and a mentee. Seven participants were recruited to take part in the journaling stage, however before the start of data collection one of the participants, MO5, was lost to follow-up. Only six participants therefore took part in the journaling stage. This is the maximum number of participants that could have been recruited and selected according to the recruiting and sampling process. Three participants responded to all six questions and therefore has a 100% response rate. A response rate of 84% was seen in one participant and a 77% response rate was seen in the two other participants. Overall, there was an average 84% response rate seen across all participants. The participants were instructed to use up to 15 minutes of their time to journal. There was a total of 30 responses. This was done over a period of three weeks with about two journal entries per week. If an average of up to 15 minutes were spent per journal entry, the data collection time would have aggregated to about almost eight hours of journaling time. It is however difficult to estimate accumulated journaling time as participants write a summary of their experiences over a period of time (70).

The structure of the data collection has been explained to the participants beforehand. These messages have been sent via SMS to the researcher. Journaling can be used successfully to explore specific experiences in more natural contexts. The main purpose of journaling is to reflect on personal experiences (71). The participants have each been prompted with questions two times per week for a period of three weeks to send journal logs notes to the researcher. The participants haven been continuously prompted to use up to 15 minutes to write their journal entries. See Addendum G. The specific objectives, purpose and process of the journaling have been explained telephonically first

before commencing with the journaling. Hayman, Wilkes, and Jackson (2012) wrote a methodological paper on some challenges that can affect journaling as a method of data collection, as well as strategies to overcome such challenges. Firstly, journaling generally has a challenge of poor participation. This will be overcome by coaching the participants. Participants have been prompted the days of the journaling by a SMS message from the researcher. These prompts included questions and directions for the journaling. The specific timeline has also been explained to the participants. Limiting the journaling period promotes participation. Timelines are known to encourage participation as participants have a clear expectation of how long it will take. Regular contact has been maintained with the participants by the reminders and the prompts that were sent to the participants each journaling day (71). It was also explained that the researcher can also contact the participant telephonically if the participant has any questions or needs clarification if they were unclear about the process, instructions, or structure of the data collection process. The participants have been reimbursed for their time and expenses to participate in the study by means of a SMS bundle of 50 or 100 units and a grocery voucher of R100. These vouchers have been sent via SMS.

3.6 Data Analysis

Stage One

The voice-recorded data that was collected has first been transcribed by the researcher into text for data analysis purposes. The written data has then been imported into a Qualitative Data Analysis (QDA) software program. QDA Miner Lite has been used for data analysis which is a free and easy-to-use QDA software. It can be used for texts such as interviews, transcripts and open-ended responses (72).

The process of content analysis has been used for data analysis purposes of both stage one and stage two. Content analysis is a systematic method of analysing text data to described phenomena. Content analysis could also be defined as the subjective interpretation of content of data using systematic coding, categorization and classification and identifying themes. The purpose of this type of analysis is to further create inferences from data to further broaden knowledge and categorise data (73,74).

An inductive reasoning approach has been used where categories that were formed were interpreted to form a theory/hypothesis, as shown below:

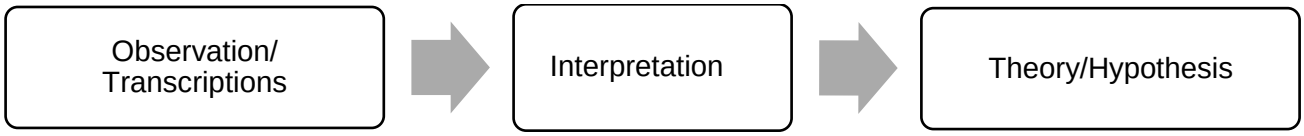

Figure 3.4: Process of inductive reasoning

Inductive content analysis is reported in three main phases, including the preparation phase, the organising phase and the reporting phase. In the preparation phase the units of analysis have been selected. (73). These units are phrases within the data.

The next step was to organise and make sense of the data. Firstly, codes have been assigned to meaningful words, phrases and/or sentences. An open coding method has been used. These codes have then been collated, and sub-themes have been created from these codes. These codes have been categorised into the sub-themes according to a 'belonging' in the same group, based on similarity and relation to each other. The sub-themes have been named according to content characteristics. Thereafter some sub-themes, with similar codes, have been grouped together to form main themes. (73). The process is displayed as such below:

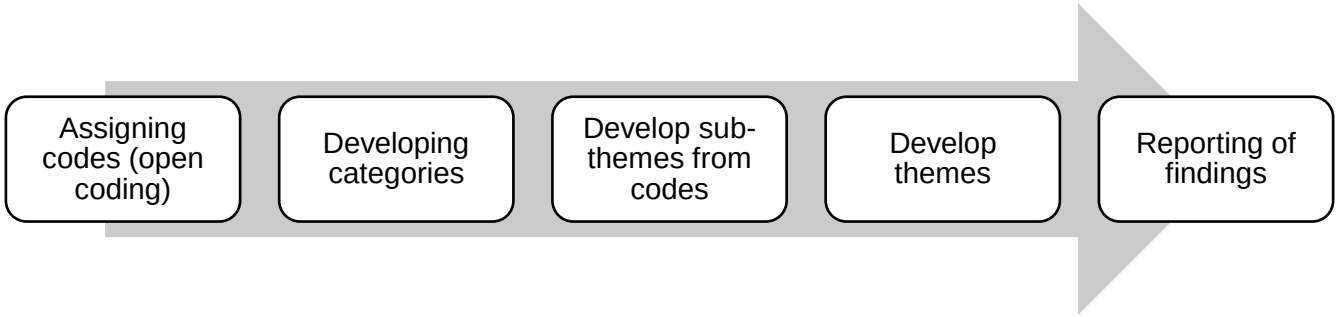

Figure 3.5: Process of content analysis

The codes, sub-themes and themes have been analysed from the different data collection methods i.e.. the transcripts from the FCG and the journaling data. See table below for the counts of the codes, sub-themes, and main themes.

	Stage one data collection	**Stage two data collection**	**Both data collection stages**
Number of codes	161	54	215
Number of sub-themes specific to the data collection stage	4	2	10
Number of themes specific to the data collection stage	n/a	n/a	4

Table 3.3: Table for counts of codes, sub-theme and themes from the collected data.

The data collected have been analysed simultaneously to form sub-themes and themes in order to respond to the objectives of the study. However, four sub-themes emerged with codes only from the first stage of data collection. Two sub-themes emerged solely from the second stage of the data collection process. There have, however, emerged four shared sub-themes from both data collection processes. The codes and sub-themes of both data collection stages were both similar in content and therefore have been analysed simultaneously.

3.7 Trustworthiness and Rigor

Specific strategies has been applied to strengthen the trustworthiness of the qualitative research (75). Firstly, credibility has been addressed. Credibility is the testing of the data to establish how true the findings are based on research design, informants, and context. One strategy to strengthen credibility is by means of member checking. Member checking is a strategy used to check with the participants regarding the data, analytic categories, interpretations, and conclusions. Member checking is a process where the researcher checks whether she has accurately translated the participants' collected data, therefore decreasing the chances of misinterpretation by returning to the participants with the data analysed and therefore checking whether the data is accurately presented (63,75,76). During the process of member checking, the participants from stage one has been emailed the findings of the analysis of their focus group discussion and asked for their comments and opinion on the themes, sub-themes and codes (77,78).

Triangulation of data sources has also been used. This has been done by person triangulation as a variety of people partook in the study and therefore the range of data has been maximised. The research study included key professionals, semi-professionals, and experts in their respective fields with post-matric educational qualifications, as well as middle socio-economic statuses. The participants of stage two consisted of mentors and a mentee who come from a low socio-economic status community, and who has lower educational attainment than the participants from stage one. Data triangulation has also been done as a variety of data collection methods has been used (63). The different data collection methods included a focus group discussion, as well as journal logging via SMS. Peer examination has also been done as the researcher discussed findings with the supervisors and research peers, who both have experience in qualitative research (75). This was done with an online presentation with research peers and reviewing and feedback sessions with supervisors. This allowed the peers to discuss and check emerging themes and look for negative cases.

Krefting (2017) describes transferability as the criterion as to which applicability of qualitative data is measured. Qualitative research fits the criteria when the findings can fit into situations outside of the study context. This can be done by using thick description. Thick description is the providing of dense background information of the participants and the research context as presented in the sampling process. The research context has been provided in the previous chapter. The background from the participants has also been described. Others will now be allowed to assess the transferability of the data (75). Case studies inherently possesses thick description as it is a literal description of a phenomenon (59). Dependability is the strategy that is used to measure whether the same results will be obtained if a similar study design with similar samples and similar context be used, in other words the consistency of the findings. Again, person and data triangulation and peer examination has been used to ensure dependability (75) .

Lastly confirmability has been ensured by means of triangulation, as well as again reflexivity. Confirmability is a strategy to aim for research that has reduced bias from the researchers' perspective. Person and data triangulation have been used, as mentioned previously. Another strategy that was used was discussing the research with two other researchers who are experienced in qualitative methods.

3.8 Ethical Considerations

Firstly, this research study protocol has been reviewed and approved by the Stellenbosch University Health Research Council (HREC). This is in accordance with the National Health Act (NHA) (2003) Section 73. Also, the regulations set out in the NHA (2003) has been adhered to with regards to protect, respect, promote and fulfill the health rights of the participants as set out below (79).

The trustworthiness and rigor of a qualitative study largely depends on the ethics of the investigator (59). The following ethical principles has been maintained during the research study: autonomy, beneficence, non-maleficence, respect, safety and justice.

Autonomy has been supported as the participants have continuously throughout the study had a choice whether they wanted to participate in the study. The participants had the opportunity to withdraw from the study at any point during the research process without any consequences or liability, in respect of self-determination (63). A shortened version of the informed consent form has been sent to each participant via Short Message Service (SMS), and the participants were able to agree via SMS to participate in the study (See Addendum D). This process of the informed consent has also been documented, just as the process of the verbal informed consent (See Addendum E). At least one day was given per participant to read the informed consent form and to discuss with peers or relatives if needed.

The participants on both stages have been asked to give informed consent, verbally and/or written throughout the process of sampling and data collection. It is important to note that informed consent was not a once-off event, but rather a continuum across the duration of the research study (63). The informed consent form was viewed as a legal document that provided information regarding the procedures that occurred, the place, the time required and the risks and benefits involved with participating in the study in a language that was easily understood (63). Information regarding as to whom to address complaints regarding the study with contact details has also been included. Participants have therefore been allowed to withdraw from the study at any stage during the study with absolutely no consequences or questions.

Confidentiality has been maintained by ensuring that personal information gathered has been done voluntarily, and that the above-mentioned information has been always kept confidential. This was done by ensuring the information is kept at a place where only the researcher have been able to access it, thus password protected. Anonymity has been ensured by coding the participants from the beginning of the data analysis process and analysis participant data on the codes. The original data will be retained safely, as mentioned previously, for a reasonable period until the researcher is comfortable that the data will not be required any further. Thereafter the data will be destroyed (66). No personal information has been made known during the writing of the research study, and only the researcher had access to this information. Respect has been maintained by keeping a positive interaction throughout the discussion process. This also entailed being non-judgmental, non-threatening and sensitive (59). Privacy also added to a respectful approach towards participants. Every participant from stage one ensured that they were able to use room that has a door that can close. The focus group discussion has also been a private conference call.

The participants did not directly benefit from the research; however, the findings of the study did assist to further develop and improve prevention strategies for FASD such as mentoring programmes, which will benefit the public, the primary health system and in consequence their community. The participants from stage one has been reimbursed for their time and inconvenience with a grocery voucher of R100. The participants part of stage two has been reimbursed for their SMS charges by means of SMS bundles, and received a grocery voucher of R100. This was to respect their time and effort to participate. The compensation is prorated, and will not be contingent on completion of participation in the study (65). Ethics committees in South Africa recommended R50 per visit, however, recent recommendations from the Medicine Control Council recommended a remuneration of R150 (80). The amount of the grocery voucher thus falls between these recommended amounts. The researcher chose a grocery voucher as she was not able to meet the participants face-to-face to give them the remuneration amount in money. The researcher the also renumerated data costs where necessary.

It has been ensured that a safe environment will be used during the data collection process. The participants of stage one was made known to the other participants taking part in the online focus group discussion.. It was also the concern of the researcher to be sensitive to sensitive topics, such as social and emotional problems, that could have been raised during the discussion process.

The participants have not been prejudiced regarding their demographics, therefore ensuring justice. Also, no pre-judgement has been made by the researcher as to select participants, and the target population had a fair chance to participant in the research study. The informed consent has also been available in the home, or preferred, language of the potential participants to ensure all could participate in the study (65).

These above mentioned considerations were also in line with the regulations of the POPI Act (2013) and supports the protection of personal information (66).

Chapter 4: Findings

4.1 Introduction

The findings chapter will be structured according to the different objectives. In chapter four findings of the objectives will be presented of the primary and secondary objective. These findings will be presented in themes, sub-themes, and categories.

4.2 Findings of the primary objective

Three themes emerged from the data collection for the primary objective. Figure 4-1 shows the three themes that emerged:

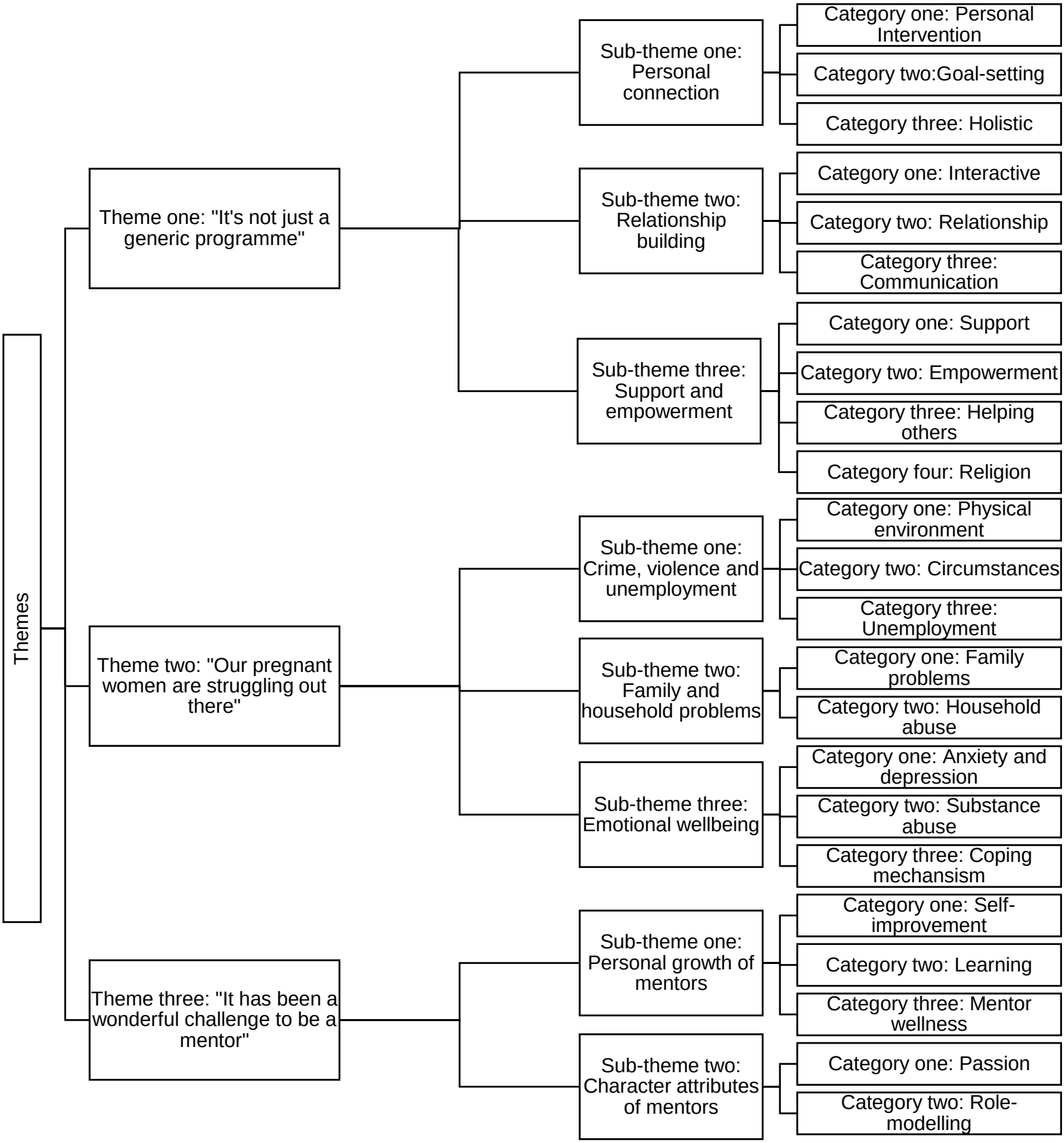

Figure 4.1: Themes, sub-themes, and categories of the primary objective

The different themes that emerged were grouped together according to their similarity and relation to each other. The tree distinct themes that emerged were: (1) "*It's not just a generic programme"*, (2) "*Our pregnant women are struggling out there"* and (3*) "It has been a wonderful challenge to be a mentor"* (see Figure 5-1).

4.2.1 Theme one: "It's not just a generic programme."

The first theme looked at the importance of the individual's needs, of the mentee and relationships built during mentoring programmes. It became evident that it is important to focus on building empathetic relationships that foster and grow personal connections with the clients. The relationships should support and empower the clients. The mentoring programmes pivot around the changes that will occur in the lifestyle of the clients to prevent prenatal alcohol drinking, and therefore it is important to put the client center-stage in such a programme.

4.2.2 Sub-theme one: Personal connection

The first sub-theme that will be discussed is the personal connection that should be cultivated through such a programme. This personal connection is enhanced by creating a personalised, unique intervention by setting specific, personal goals and having a holistic approach to the client. Below are some of the codes that emerged during data collection supporting the sub-theme of personal connection.

P4: "*I think it's more, you're able to personalise their (the client's) intervention more and make it more unique, context specific to the specific need of that person that you are mentoring*."

P4 started to explain how a mentorship programme builds on personal connection. P4 further elaborates that this type of approach could aid in the efficacy of such a programme.

P4: "*So, I imagine it's* (the programme), *yeah. it's more interactive, more personalised, and maybe because of that then it would be more effective than just a generic program, you know, that everybody*

goes to and they all do the same, go to the same talk so, they have the same information, but it doesn't necessarily fit with their, with their life."

P4 specifically mentioned that the deep, personal connection between the mentors and the mentees is important.

P4: "…, *but absolutely the heart the, you know, the trust, the, that deep connection is, is key for us* (programme facilitators)…"

P3 echoed the personal connection that P4 has spoken about.

P3: "*And you know this thing (mentorship programme) is so personal*…"

P4 then went on to explain that the interaction between the mentors and mentees, the mutual goal setting, and addressing of specific needs of each person (client) also adds to the personal connection between them.

P4: "*I would think it's (the programme) more interactive and sort of like a two-way, like it's conversation that you're having in what are your goals, how do you want to reach them, how can we, you know, how can I support you to get there, what do you need from me?"*

4.2.3 Sub-theme two: Relationship building.

The next sub-theme that will be discussed is relationship building. Other than nurturing a personal connection with the clients, it is important that that personal connection roll over into a healthy, trustworthy relationship. This relationship will further promote other lifestyle changes in the clients. These relationships that are being created are some of the first things the mentors speak about when they talk about the programme. These relationships are not only important for the mentees, but also the mentors. MO1 starts by saying that the relationship that is built between the mentor and the mentee is very valuable for a mentorship programme. P3 echoes this.

MO1: *"It is the people relationships between me and my clients (three girls), and our trust in each other. And the respect we have for each other."*

P3 spoke about the journey and unity that the mentors and mentees experience within their relationship with each other.

P3: "*Um, so the mentor is there to stand by the person (client) or even when the person is feeling alone, that she or him knows that there is a mentor coming to, to speak with one another; very close to one another, to journey to be in the kind of oneness in unity*."

P2, P3 and P4 explained that for healthy relationships to be established trust should be built within the relationship. A safe emotional space should also be created, and the relationship should be one where there is no judgement, but rather acceptance of each one involved in the relationship. Relationship building is not a linear process and is unique and specific to each person and should be cared for as such.

P2: "…*and therefore the mentors must be trustworthy and non-judgmental*…"

P3: "*There must be trust, and um, and must have an open heart*,…"

P4: "…*I think, definitely we also talk a lot about non-judgment, and I think there's a lot of overlap there where we need to make sure that the space that we create is safe and moms in that space feel safe and they feel heard. And yeah, that there is definitely no judgment there, and so we build trust*."

4.2.4 Sub-theme three: Support and empowerment

The next sub-theme that will be discussed is the support and empowerment component spoken about in the programme. Both the field experts and mentors mentioned that it is vital for the clients to be supported in whatever way possible. This theme was continuously seen throughout the data collection process. The participants also explained that it is important to support these mothers and empower them with knowledge as much as possible. This support could either be basic emotional support, like listening, showing love and care, or more complex support such as external referrals or training.

It is the view of the participants, however, not only important for the mentees to feel empowered, but also for the mentors. The empowerment of the mentors will, however, only be discussed in theme three. The empowerment and support of the mentees will first be discussed.

P4 mentioned that one of the components of a community-based mentorship programme is support and empowerment that is offered to the women in the programme.

P4: "…*and really understanding you know what are the, what are this person's particular barriers and how, you know, how can, how can they be supported or empowered to, to work around there more, problem solve through them, yeah*."

P1 and P2 specifically mentioned the support that is given. This support may vary in terms of the delivery and landing.

P2: "…*they must feel your support is, your* (mentor's) *support is very important to the ladies* (clients),…"

P1: "*Yeah and the mentors also give a psychosocial support for, for the, for the, for the pregnant women*…"

P1: "*They* (the mentors) *take the women, or the mommies by their hands, and help where they can and, um, support them."*

P2: "*So, we give them lots of love, lots of support, yeah*."

Empowerment of the mothers, however, looks slightly different than supporting. These mothers are empowered by knowledge and education from the mentors.

MO1: "*Being able to empower a mommy with valuable knowledge about what alcohol and substance abuse can do to an unborn baby's brain and his life*."

P4 explained that this empowerment gives the mothers the opportunity to carry on with the mentorship amongst each other. This helps to foster relationships between each other to further carry out the outcomes of the mentorship.

P4: *"And then I think the other thing for us that's really critical in our program is to always see that the woman that we that are in our groups have a lot to offer themselves, that they've got a lot of information. They got a lot of knowledge, they've got a lot of power within themselves that they can use to support one another, and that there isn't this reliance on the host or on programme, but that they end up developing relationships amongst each other as well, so that the, the mentorship can sort of be extended amongst themselves and within their communities as they leave programme and you know, go on*."

The participants mentioned that religious and spiritual activities could also offer some form of support and relief for the mentees. The participants spoke about activities such as discipleship, repentance, believing and prayer which are fundamental religious activities.

P2: "*And religiously, you must talk about Jesus to them, because some of them…they need it, they need it. They need to hear that and that's why, why it's important too*."

P3: "*And the principle of God is to give and forget about yourself. So, for us it is important, because that is a principle of God and like we, like I said, I'm very strong on it because our life is a chaos outside there, but you as a mentor in a community must bring it light, because if we say we are the light, give them the light and bring light into their homes*."

P1: "…*to give their hearts to Jesus so that they can be better mothers, then they can also help their boyfriends or husbands or, or their siblings…"*

MO2: "*I take them to Jesus and encourage them to not get discouraged, there is always hope. Every cloud has its silver lining*."

MO6: "*Prayer is then my key for the road ahead*."

Religious and spiritual activities could offer some support on an emotional level. A religious aspect could add to the improved well-being of the clients; however, care should be taken to deal with it in a sensitive and respective manner. It might be valuable to assert how clients address their religion/spirituality and incorporate that into the programme.

4.2.5 Theme two: "Our pregnant women are struggling out there."

The next theme that will be discussed is the challenge of addressing psychosocial challenges with these community-based programmes. These challenges include crime, violence, unemployment, family problems, household abuse, substance abuse, mental health issues and the poor coping mechanism used by mentees to try and cope with these adversities. These challenges have a direct impact on the mental and psychological well-being of the clients, and as will be discussed, these above-mentioned challenges are often met with unhealthy coping mechanisms.

4.2.6 Sub-theme one: Crime, violence, and unemployment

P1: "…, *you know rural areas, neh, it's like our pregnant woman is very struggling there*…"

The first sub-theme that will be discussed is the presence of crime, violence, and unemployment within the communities these clients live in. As P1 mentioned, these circumstances affect the well-being of the clients, and can lead to clients "struggling". As mentioned previously, these circumstances have a direct impact on the well-being of the clients, and therefore it is important that this should be addressed in these programmes. This could be either with support or building resilience factors, such as relationships.

The participants explain that the context in which these mothers live, and in which these programmes run are met with a set of contextual challenges. As seen below, some of these challenges are gangsterism, crime and violence.

P2: "*And so, it's where we are working, there's a lot of gangsters, there's a lot of gunshots. People living in fear there because every day they shot someone dead there."*

MO2: "…*and we are met with danger, especially in the areas that we stay in. Gangsterism, gun shootings daily*…"

MO4: "…*like when the gangs fight in the area*…"

P1: "*The "skollies"* (gangsters) *or the gangsters there,..."*

P1 also explained that the housing in which these mothers live are not safe.

P1: "*So, we walk even if it, if it is, in, in a, in a hokkie* (shack), *we go in*"

A shack is an informal housing structure that is made from scrap metal, wood, plastic, and other waste materials due to a lack of finances for formal housing. People often live in a shack due to poor household income, which could be due to high rates of unemployment within the community.

The participants also explained that another contextual challenge is unemployment within these rural communities. High numbers of unemployment are usually met with severe poverty and low financial income in the household.

P3: "*And I, like I see in, in our communities when you ride through the areas you see the men, you just see the men is sitting, and you see the women is working*."

P3:" …*but he's looking for a job, but there is no job*."

P3: "*First of all, it starts with the men and there is no job for the men,…"*

The challenges of unemployment could be causal for further challenges that are experienced by the men and women from the rural communities. These contextual challenges create further pressure and burden on the men and women. These challenges mentioned above create psychosocial challenges, as the social and environmental challenges have a direct impact on the psychological well-being of a person.

Furthermore, P4 explained that unemployment, and consequently the inability to financially provide and care, often leads to a lot of pressure that is experienced by men and women.

P4: "*I think, this speaks to the pressures on us, you know, the pressures that society puts on men to be these providers and on women to be the caregivers. And that's a lot you know*."

The mechanisms for coping that are used to try and deal with these pressures will be further explained in a later sub-theme. These poor mechanisms are a consequence of the challenges these men and women are faced with in their everyday life.

4.2.7 Sub-theme two: Family and household problems

The next sub-theme that will be discussed is the family and household problems that are being experienced by the clients. In the previous sub-theme focus was given to the challenges experienced outside their household, albeit it still had an impact within their household. Firstly, the participants explained that these women do not have the support they need to change their drinking practices, in

general and while pregnant, as their own mothers were faced with the same challenges. The participants also mentioned that household abuse is prevalent, which could include physical, verbal, emotional and/or sexual abuse.

P1: "…*and then they have nobody to talk too and their boyfriends is* (are) *very abusive towards them*."

P2: "…,*but like there's* (household) *abuse*."

P3: "…*and then all the* (household) *abuses come into the house, you know, to few children and all that stuff come. So then after all that, we have marriage problems*…"

P1: "*And that is what the reason, why there are always a fight between the men and women and gender-based violence*…"

4.2.8 Sub-theme three: Emotional Wellbeing

The last sub-theme that will be discussed within the second theme is emotional wellbeing. The participants specifically addressed the prevalence of emotional and social challenges that the men and women in the communities are facing. These challenges include drinking excessively and using substance abuse as a coping mechanism to try and deal with the psychosocial challenges they are facing. The participants quite frequently mentioned depression and anxiety when they spoke about the women and men from the communities in which these programmes are running in.

P3: "…*so then depression and stress come*…"

P3: "*So I think that I see more that the husband, you know, the husband feels maybe very depressed, he can't, he can't provide for the family, you know, so that depression comes in*…"

The participants also specifically mentioned substance abuse, either from the women themselves, or from their partners or other family members.

P1: "*They also want to talk to someone because sometimes their own, their mothers or, or grandmothers, they are also victims of, of substance abuse,..*"

P3: "*So, what, what is the first thing, he goes out with his friends and he drink or using alcohol and drugs.*"

The participants further explained that the substance and alcohol abuse is often just a coping mechanism for the pressure and challenges that the women, and men, face in their daily lives. These challenges vary from crime, violence, unemployment, poverty, societal pressure, and household abuse, as mentioned previously.

P2: "*I think when someone is drinking, they don't want to drink every day. You see, um, it's like when people, like our clients, drink because there's a lot of problems they cannot solve exactly*."

P4: "*And if you're not fulfilling those roles in the way that society thinks you should, um, it adds to, to the pressure and it adds to that not desire as you saying, but just adds to that, you know, another reason to just drink and forget, because I'm not, I'm not doing what I'm supposed to be doing,…*"

P4: "*It's not, it's not that somebody wants to drink it, it's um, they just don't see any other way out. You know, it's almost like suicide, you know you just don't see another way out. This is the only way, there is no other way. I don't want to do it, but what, there's nothing else I can do*."

P4 further explained that it would be difficult for the clients of the programme to participate in other meaningful activities if they are continuously just trying to cope with their challenges. However, P4 then further mentioned that meaningful activity engagement could pave a way for these women to improve their coping skills.

P4: "…, *whether it's a mental health issue or something that's, um, weighing on your mind, that does mean from time to time to time you do overindulge, or you, you know, yeah, you, you, you do things that you know are not good for your body or good for the baby if you're pregnant*…"

P4: "…*and we need to look at people's mental health status as well. Do they even have the desire to be engaged in meaningful activity in the first place, because of depression or anxiety or other issues that are clouding, you know, their, their ability to see things clearly*."

P4: "…,*but I would think, I would, I would think that it would you know if, if we are engaged in meaningful activities, whether it's our work or our role in life, as you know, whatever mother, wife or sister, daughter, whatever, I would think that our desire to do something like drinking or substance use or, or self-harm or anything that can hurt us would be less, because we would feel more fulfilled in our life and we would be doing things that mean something to us, and that would take away that desire to forget about, you know. I mean people drink for different reasons. And, but sort of the general term, you know, people drink to forget about the issues or to switch off from the, you know, life because, it's just too much to handle, and then in the end it becomes obviously an addiction. So, then people drink, because they physically, if they don't, they are physically ill. Um, so I would think that if you were feeling, you know, meaningfully engaged in, in life, whatever that was, that you, that need to drink in excess wouldn't be there*."

4.2.9 Theme three: "It has been a wonderful challenge to be a mentor."

The last theme that will be discussed is the importance of the wellness of the mentors themselves. The mentors are ultimately responsible to bring forth change within the communities and the clients, and it is of upmost importance that they are well equipped, both emotionally and physically. Mentors should also grow on personal and professional level, and the importance of the empowerment of the mentors and their characteristics will now be discussed.

4.2.10 Sub-theme one: Personal growth of mentors

The first sub-theme that will be discussed is the importance of the empowerment of the mentors. It is important that the mentors experience a sense of empowerment and achievement in what they are doing for the programme to be more successful. The mentors themselves mentioned that they feel the sense of improvement on personal and professional level. They also mentioned that their sense of empowerment and growth improved.

MO1: "*To also empower myself with information I can transfer to the client*."

MO1: "*I could do something for myself and I could rediscover myself and the qualities which I have within me…sometimes it is difficult, but it is all worth it."*

MO: "*The mentorship changed my life a lot, because before I could be part of the programme, I had to learn more and today it is a bonus, because what I learned helped me a lot personally to understand people better, and to make a difference in my family and wider community*."

MO1 displayed this gaining of knowledge by explaining the impact of prenatal alcohol use.

MO1: "*It is emphasised throughout the program that alcohol and drugs are not good for the unborn baby, because it inhibits the ability of the baby to develop well. It damages all the organs and especially the brain, which develops first, is damaged. A damaged brain cannot be repaired with an operation; thus, your baby is born with FAS. Therefore, it is very important that the client is informed that alcohol and drugs cause permanent damage, and that they shouldn't use any alcohol or other chemical substances during pregnancy. No alcohol=no FAS*."

MO1 and MO2 shared personal stories of how the mentorship programme has impacted their life in a positive way.

MO1: *"From the first day it has been a wonderful challenge to be a mentor. Sometimes it is difficult; the circumstances are very different. Many follows the path quickly; with others you have to push through with prayer and endurance. Sometimes a lot of tears, but sometimes joy when you see someone's (mentees) life turned out for the good, and the most important is that you become part of the client's (mentees) life and birth of the baby. It has changed me, because my life does not just evolve around my family anymore, whom I care for a lot."*

MO2: "*In 2018 the bands of the death surrounded me. I am diabetic and because of my bad eating habits and my lack of knowledge and my own negligence, it was almost the end of me. I had a coronary artery bypass graft, and I am so thankful that God gave me another grace-chance to live fully. I now fully run to make the pregnant mothers aware that there is still hope despite the mistakes they have made with alcohol and different drugs they use and the bad eating habits*."

Two participants mentioned that they grew within their professional capacity and that their work skills such as organisation, time management and listening improved.

MO1: "*In doing so, I also need to be well organised and my timing should be fine so that I can be prepared to convey actual information. To be a good listener, and to be trusted*."

MO6: "T*he mentorship helped me physically a lot in many ways and sharpened my listening skills, to be more set, more tolerant and to tackle life with compassion and learn to debrief when necessary. To be balanced and make time for myself to tackle my tasks refreshingly*."

4.2.11 Sub-theme two: Character attributes of the mentors

The second and last sub-theme that will be discussed is the character of the mentors. The mentors and participants from the focus group discussion mentioned what the qualities and characteristics of mentors should be within a mentorship programme. These qualities include being a leader and a positive role model, as well as having a passion for the job. The qualities of the mentors might be critical

in the success of a mentorship programmes, as the programmes pivot around the daily tasks and doings of the mentors.

P3: "*You must be a leader… because that person is to look up to you…and we have that leadership statements…So, for us, that* (being a good role-model and leader) *is very important to us* (programme facilitators)"

P1: "…*and they need that person to look, to look at, you know, and they needed positive person*."

MO2: "*The most that I learned about the mentorship is the passion that you must have to move around in the field with the different people and their circumstances*."

MO6: "…*and to have compassion…"*

4.3 Findings of the secondary objective

The secondary objective was to determine the challenges experienced by participants of mentoring programmes utilised for prevention of prenatal alcohol use. Below are two distinct sub-themes that emerged.

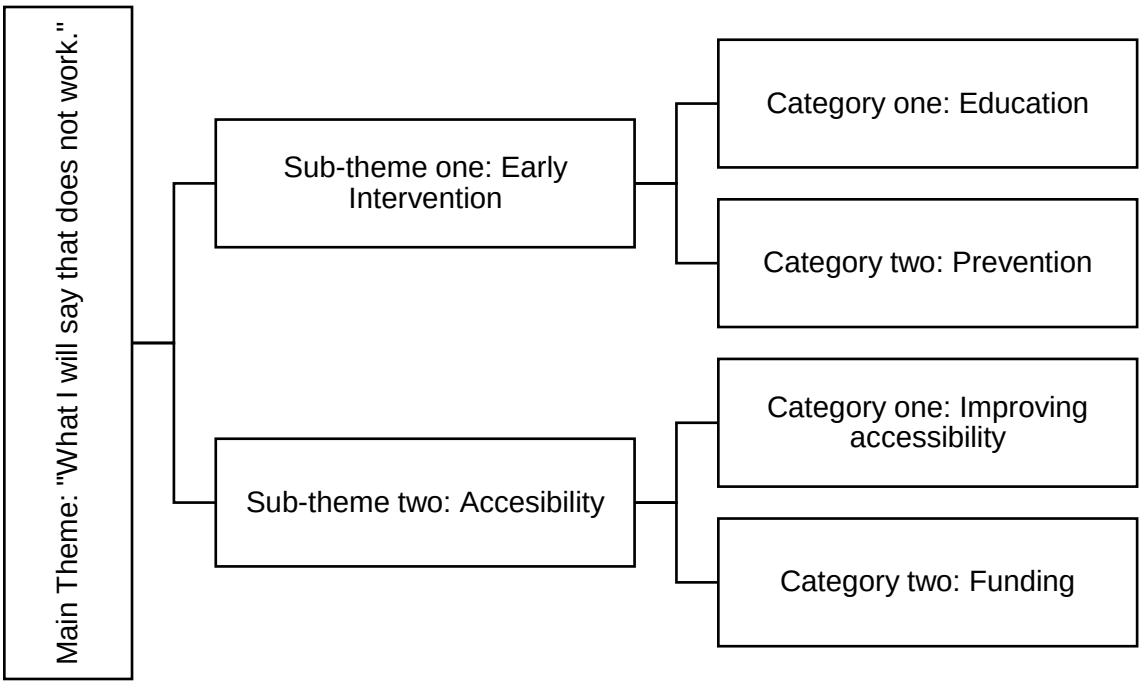

Figure 4.2: Themes, sub-themes, and categories for secondary objective

4.3.1 Sub-theme one: Early intervention

The first sub-theme that will be discussed is the issue of early education and prevention. It is known that prevention is better than a cure. The participants specifically mentioned that early intervention might be able to prevent mothers drinking antenatally. They suggested that intervention should start from an early age, even from as young as primary school, as children are sexually active from an early age, and not only while they are pregnant. This challenge is raised as the current intervention that is offered by the means of the mentorship programmes does not start in person's early years, but only later in life once the at-risk mother is already pregnant. The participants therefore express the need to start earlier with intervention, as compared to what they are currently doing. The terms early intervention and

prevention is used interchangeably in this context. This early intervention is earmarked by educating learners within the schools from a young age.

P2: "*Or from primary school, from Grade Seven. You start from there before they go to high school. Start and, start with the children because if, if, if that is printed in their head, they will know when they are growing up further or later, they must not do that, they must not even look at that, you see. That's what I will say. Start with the young children. Prepare them, prepare them for the future*."

P4: "*You know, you know kids are, we must just admit that they are sexually active from early age and we need to educate them at least on an early age,…"*

P3 mentioned that the schools and relevant departments should provide information regarding FASD in a subject and make it part of the curriculum.

P3: "*And if I can say if we can use this, um, the Education Department maybe, then they can implement it* (education on dangers of prenatal alcohol consumption) *into the curriculum...It's very, very important to make it a subject, and just to teach the kids at school and to make it part of the curriculum. And even we can use it through arts, maybe through drama, maybe through poetry and implement it in on school… So, it's very important. If the Education Department can implement this into the schools, then I think we will make a really a difference*."

4.3.2 Sub-theme two: Accessibility

The second sub-theme that will be discussed is the issue of improving accessibility and funding. The participants mentioned that one limitation of the mentorship programme is that only a limited number of mothers who are at-risk are reached, and that these programmes should be more widely accessible to women.

MO1: "*What I will say that does not work is that only a limited amount clients and areas are reached and that only certain areas are focused on. My opinion is that people who live in affluent neighbourhoods; their babies could also get FAS if they misuse alcohol.*"

MO2: "*If I could bring a change, it would be that every area in* location *has mentors to carry the message and awareness raising, because* location *is a big town*."

The participants mentioned that one way improve the reach and accessibility of the programme is to increase funding. This can help to increase the positive impact of these programmes to more women's' lives.

MO1: "*If there is more funding, more could be achieved*."

MO2: "*If there are maybe more institutions which can get involved to give sponsors, especially where there is a need in households to help pregnant mothers and mentors if they see there is really a big need."*

Chapter 5: Discussion

5.1 Introduction

The research study explored which components of a mentoring programme utilised for prevention for prenatal alcohol use are valued most by .... There has been an exploration of mentoring programmes within South Africa, with a focus of mentoring programmes in the Western Cape. The findings from the case study will be discussed, as they were presented in the findings in chapter four. The first findings that will be discussed are the focus that is put on the mentee, or client, and her well-being. Thereafter, the context and the challenges from the specific situation that the women find themselves in will be discussed, and then the importance of the role of the mentors in the programme will be discussed. The challenges that the participants experienced in the mentorship programmes will then be discussed last.

5.2 Client-centered, holistic approach

The participants mentioned how intervention provided to the mentees should be client-centered, focusing on the needs and goals of the client, and not follow a generic process. They mentioned that the intervention provided by the mentorship programme is personalised according to the needs of everyone with specific goal setting between the mentor and the mentee. The establishment of client-centered goals focuses on the engagement in occupation and activities to support participation in life. These client-centered goals are the reflection of what the client wants to, and will be, accomplishing, and are established in collaboration with the client, in this case the pregnant mothers. The promotion of a client-centered approach and client-centered goals is a central component to the philosophy of occupational therapy . This client-centered approach is highly valued by leaders in the field of the occupational therapy profession. A client-centered approach also requires that the intervention is contextually appropriate and relevant, thus again emphasising that the environment in which the client is living in should not be ignored (8). The client-centered approach has gained much importance over the last 20 years, and occupational therapists consider it imperative to have a partnership (relationship) with the client.

This brings us to the discussion of one of the other sub-themes, *Relationship building*. The relationship and the importance thereof, not only for the mentee, but also the mentor, was continuously highlighted throughout the collected data. These relationships that are being nurtured between the mentee and the mentor promotes trust, which further opens safe spaces for change. Building relationships with the mentees are fundamental in mentoring (81). Prosman, Lo Fo Wong, Römkens and Lagro-Janssen (2014) found that an important factor in mentor-mother support is a good, trusting relationship founded on principals such as empowerment, support, and communication. This relationship then forms the basis for change in lifestyle, such as drinking patterns during pregnancy (82). The empowerment that is being mentioned is generally understood in the field of health promotion and community health as enabling people to gain power in their own lives (83). Empowerment could be achieved through a relationship, or sharing of knowledge, as mentioned previously. The quality of the relationship between the mentee and the mentor lies at the heart of the success of the mentorship programme (84).

The participants also frequently mentioned supporting the mentees. This support could take on a variety of forms. This includes basic emotional support and psychosocial support such as listening and reflecting, as well as building empathetic relationships. The support could also just be to physically be with the mentee, and assisting in whatever capacity, or giving religious support. Religious and spiritual activities could offer some relief from intrusive anxiety, and therefore meditation and spiritual guidance can be important modalities to achieve occupational balance (79). De Vries, Joubert, Cloete, Roux, Baca and Hasken et al. (2015) supports the simple psychosocial support that should be given to these mothers. Their case managers, also called mentors, are often the only one who supports the mother, believes in her, makes her feel worthy and listens to her, and this aspect contributes to the success of the programme (36). The space that the relationship creates also provides opportunity for the mentor to have an improved understanding of the needs, challenges, and is context specific to the mentee. This will then further promote a holistic approach and will be discussed following the discussion of the support.

The participants mentioned that the intervention provided by the mentorship programme is holistic, as it not only looks at physical, or biomedical needs, but the emotional needs as well. Tucker, Vanderloo, Irwin, Mandich and Bossers (2015) explained that a holistic approach is the ability to focus on the client's overall well-being. They further elaborate that the holistic approach is vital for considering the influence of the environment (circumstances) on the individual's life, and that by way of environment and lifestyle

modifications, even occupational therapists can achieve health through fulfillment and purpose by engagement in meaningful activities. The occupational therapist is also able to connect the client with his/her environment that supports empowerment and enablement, in this case the role of a mother, and can be achieved through advocacy, or sharing of skills and knowledge (26,31). The concept of a holistic approach in occupational therapy is another central component of occupational therapy, especially since occupational therapists in the recent years had a shift from a biomedical approach to the emphasis on the individual's whole life, and not just certain parts of it (8,26).

The Person-Environment-Occupation (PEO) model of occupational performance by Law, Cooper, Strong, Stewart, Rigby and Letts (1996) is a popular model of practice for occupational therapy and promotes the idea on focusing not just on the individual, but also on their environment and occupation. This model is a client-centered approach which focuses equally on the environment and occupation as well, which also promotes a holistic approach. See below the illustration demonstrating the relationship between the person, environment, and occupation (see Figure 5-1)

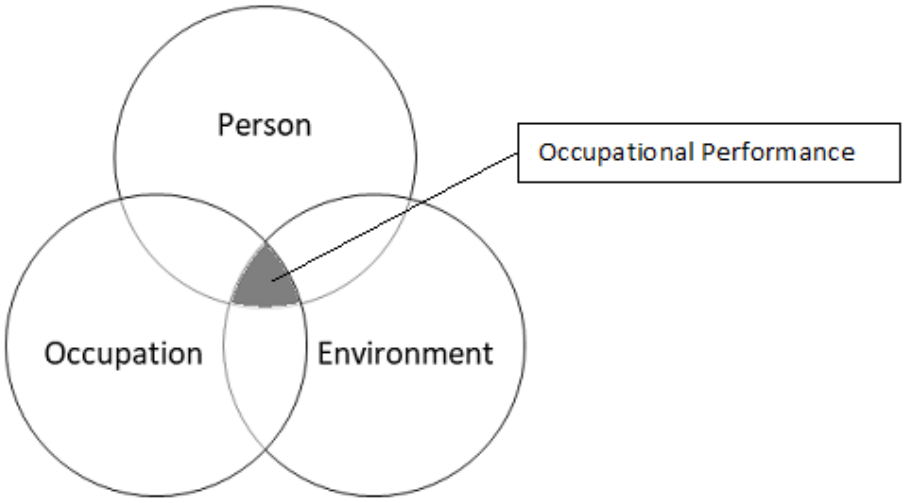

Figure 5.1: Person-Environment-Occupation model of occupational performance

Occupational performance is described as the result of the dynamic transaction between the person, environment, and occupation. Person is described as a unique being and is seen holistically as a composite of mind, body, and soul qualities. Environment includes the cultural, social, physical, and institutional factors, and occupation is considered a component of the person's daily tasks, activities, and professional occupation. Occupation is described activities and/or tasks the person does to meet

his/her daily needs. (8,31). The environment and the occupation of the mentees will be discussed later, however, the concept of the PEO-model will be pulled throughout the discussion, since it has become clear that the focus should not just be on the individual, but their environment and occupation as well. Occupational therapists can facilitate wellness through a holistic and client-centered health promotion practice (8). This model could be used as central philosophy for a mentorship programme.

In summary, the relationships between the client-centered, holistic approach, building relationships and supporting and empowering the at-risk mothers in a mentorship programme is transactional in nature, and that one cannot function without the other. See below illustration of this transactional relationship.

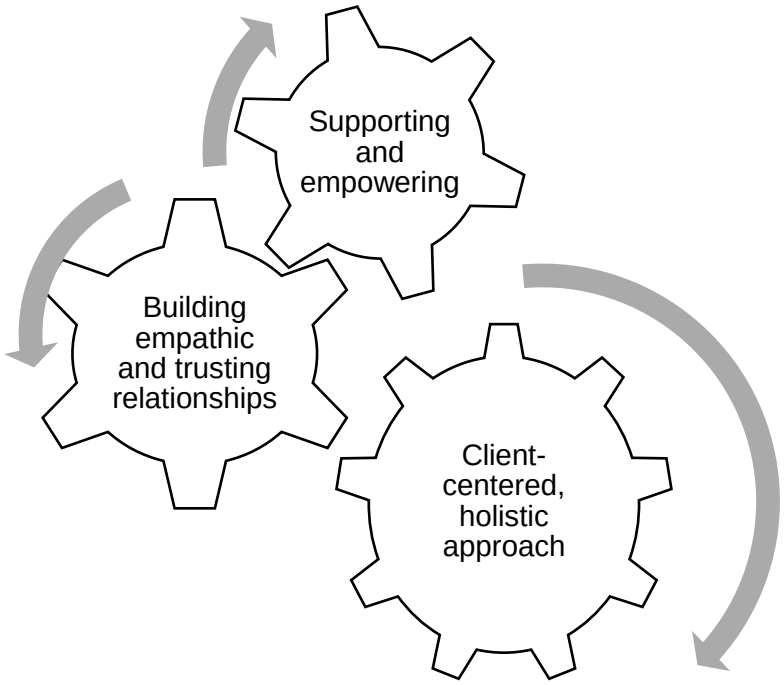

Figure 5.2: Transactional relationship between factors of a mentorship programme

5.3 Addressing contextual challenges

The participants mentioned an array of contextual challenges the mentees are facing in their everyday lives. These challenges include crime, violence, unemployment, and household abuse. In response to these challenges, the men and women in these communities often experience mental health issues such as depression and anxiety and use unhealthy coping mechanisms such as substance and alcohol abuse. These challenges form part of the environment factors from the PEO-model of the mentees. It

is therefore important to acknowledge the challenges these women face in their daily lives and address it in an appropriate manner. These challenges have a direct impact on the emotional wellbeing of the mothers.

Previous studies found that at-risk mothers face many social adversity and contextual challenges in their daily lives including, but not limited to poor to no availability of adequate health care and support structures, financial stress, abuse and trauma, poor interpersonal relationships, and low educational attainment with consequent marginilisation and stigmatisation. These adversities are attributable to the mental health disorders these women are experiencing, and drinking is seen largely as a coping strategy, albeit an unhealthy one. Viljoen, Croxford, Gossage, Kodituwakku and May (2005) describes the context of at-risk mothers. They mention that the most significant finding from their study is that the at-risk mothers lived in an environment consumed with problematic drinkers, including close family and friends. These mothers attributed their drinking behaviour during their pregnancy to the stress they experienced living in such environments, and that drinking was a mechanism for coping.

These findings from the previous studies directly echoes the findings from this study. The challenges and adversities experienced by the mentees are then coped with in unhealthy ways such as misusing of alcohol and/or other substances. The women often do not have access to other support to assist them to cope and overcome these challenges, but also, as seen in the findings, they simply do not see another way of coping other than misusing alcohol and/or substances. It could also be argued that the adversities these women face also create barriers for them to seek support. This is supported by Jacobs and Jacobs (2014) (45). As mentioned previously, the challenges these women face have a direct impact on the emotional wellbeing and mental health of the women.

Astley, Baily, Talbot and Clarren (2000) found that mental health issues are prevalent in at-risk mothers. They found that 96% of at-risk mothers, as described previously, had one to ten mental health disorders. These disorders varied from PTSD, major depressive disorder, phobia, panic disorder, schizophrenia, generalised anxiety disorder and alcohol abuse. This is also in accordance with the findings from this study, as the prevalence of depression and anxiety was often mentioned. However, it has not just been mentioned with regards to the women, but also the men. Astley, Baily, Talbot and Clarren (2000) also found in their study that 84% of at-risk mothers reported that they felt they had a problem with alcohol use, however, 94% reported that they had no desire to change their drinking habits, as it helped them to cope, as 72% reported they were in an abusive relationship and 79% reported that they were feeling

too depressed to do anything about it (40). Again, the use of alcohol as a coping mechanism is highlighted. The participants also mentioned that these mental health issues and unhealthy coping mechanisms could be from pressure society has placed on men and women to fulfill certain roles, and if not fulfilled according to the norms of society, it creates further pressure and emotional burdens on the men and women, who already have feelings of marginalisation and stigmatisation (45).

In conclusion, it is vital for mentorship programmes to have a strong focus on emotional wellbeing and mental health. This could be facilitated by building good, healthy relationships with the clients. Also, practitioners need to be aware about the mental health challenges their clients might be facing, because it is not easy to see such an impairment as it is known as the “invisible illness”. Again, the transactional relationship between the environment, relationships and the individual are highlighted, as demonstrated previously.

5.4 Investing in the mentors

It became evident from the findings that the mentors themselves found that the mentorship programme did not only assist them in helping others, but also had a positive impact in their own lives, whether this was on a personal or professional level. One participant specifically narrated how the mentorship programme personally impacted them, and that they are now able to have an improved life with purpose and meaning. This concept of reciprocal benefits between the mentees and the mentors has been well documented (85,86). Clouder and Adefila (2014) explains this in a ‘gift exchange’ metaphor, that the relationship is dyadic in both receiving and giving ‘gifts’ from all parties involved , and it is within this interactional relationship that the connection is made between the mentor and the mentee (85,86). These gifts could include, but is not limited to sharing of knowledge, insights, and wisdom. Thus, the mentor also benefits from the programme. The benefits that the mentors experience in the programme is of importance, as this impact their job satisfaction and well-being. A satisfied and motivated mentor will be able to provide good support and mentoring, motivation to a mentee, as well as the opposite, where an unsatisfied and unmotivated mentor will not be able to deliver good mentoring and support.

It is also important to delve into the success factors when mentors are building relationships with their mentees. Some of these factors include, but are not limited to, committing to a long-term relationship, living by example, provide support, respect individuality, cultivate independence and hone

communication skills (87). Eller, Lev and Feurer (2014) identified key components of an effective mentoring relationship in an academic setting. Eight themes emerged during their qualitative study. These eight components included (1) open communication and accessibility, (2) goals and challenges, (3) passion and inspiration, (4) caring and personal relationship, (5) mutual respect and trust, (6) exchange of knowledge, (7) independence and collaboration and (8) role-modelling (88). The reason why it is important to delve into these success factors, as some of these success factors were also mentioned by the participants. This included living by example and role-modelling, as well as passion and inspiration. These two factors were specifically mentioned by the participants as attributes that they actively pursue in the mentoring programmes. Relationship building, providing support, honing communication skills, setting goals, respecting, and trusting, and exchange of knowledge has also been mentioned by the participants as factors that they consider important in their mentoring programme. These mentorship programmes are not only meaningful then to the mentee but also the mentor, and meaningful and sustainable mentorship programmes could achieve improved well-being, physically and emotionally, of the at-risk mother.

5.5 Implementing early prevention for prenatal alcohol consumption

As previously mentioned, FASD is 100% preventable, and there should be a collaborative approach to aim at eliminating FASD, even if it means that intervention should be aimed at primary school learners. The participants mentioned that as part of the goal to reduce the prevalence of FASD in the community's education on the dangers and consequences of prenatal alcohol use should start from an early age, as early as primary school, and also be part of the educational curriculum that is being done in the schools. The challenge that these participants experience is that education of the dangers of PAE start too late, and not enough is done to prevent PAE from an early age. This could be done. Participants from the study done by Adebiyi, Mukumbang, Cloete and Beytell (2018) mentioned that they conducted educational programmes in schools aiming at awareness of FASD by means of experiential learning and making children aware of the dangers of drinking while pregnant. The researchers mentioned that they conducted these programmes with Grade 6 -7 learners (11). This just agrees that education for younger learners is possible, and greater effort should be implemented to aim education to younger learners. De Vries and Green (2013) mentions that the Institute of Medicine Model recommends a comprehensive approach for the prevention of FASD, and this includes universal prevention. The universal prevention includes awareness raising, including public education and discussion. Public education is seen as one the most important aspects of universal (early) prevention (14).

Randall-Nkosi, London, Adnams, Morojele, McLoughlin and Goldstone (2008) describe the service providers responsibilities with regards to prevention of FASD in South Africa. He mentioned that the Department of Education is responsible for education of young women on secondary and tertiary level education, as well as implementing education regarding FASD in life skills training on secondary level education (2). Although this coincides with what the participants said, the participants believe that such education should already start on primary level education.

Chapter 6: Conclusion

6.1 Summary of findings

This case study explored the components which are valued most of mentoring programmes in South Africa, with a focus on the Western Cape. The participants included programme facilitators and experts in the field, as well as mentors and mentees. The main findings highlighted the importance of the client-centered, holistic approach. This approach is inherent and fundamental in the science of occupational therapy. This approach gives opportunity to design a unique programme delivery for every mentee which aids to the success of a programme. This approach involves working towards client-centered goals, building healthy and trustworthy relationships with the clients, as well as supporting and empowering the clients. The intervention provided by the mentors should consider the above-mentioned factors, and these factors should be tailored to fit the specific needs and goals of each individual client.

The client-centered, holistic approach entails, as mentioned, a good, trustworthy relationship as well as support from the mentor. This relationship between these factors is, however, transactional in nature with the one not existing without the other. The one factor also feeds from another, and if one is not being attended to, the other cannot exist. It is therefore of absolute importance to incorporate these components within a mentorship programme, as this is what makes it unique, adds value to the programme and is seen as success-factors in the mentorship programme.

It is also of value to continuously take into consideration the context and environment in which at-risk women live, and thus where these programmes are implemented. The programme should then acquaint itself with =these circumstances, which include high violence and crime rates, including gangsterism, as well as unemployment and consequently low household income. Further, at-risk women are often met with household abuse, including emotional, sexual, and physical abuse. These challenges have an impact on the mental wellbeing of these women, as well as their partners, as the prevalence of depression and anxiety has been a prominent finding in the study. Prenatal alcohol use, as well as substance abuse, is thus perceived as a coping mechanism to try and deal with these social and emotional challenges the men and women face living in these circumstances, as mostly, they do not have other forms of healthy coping mechanisms or support.

Lastly, it was found that there is a big need for prevention, and that this could start within primary schools with children from a young age. This prevention could include education on the dangers and consequences of prenatal alcohol use and should be implemented within the educational curriculum of the schools. Also, access to these mentorship programmes is limited, and more funding should be acquired to reach more at-risk women and have a wider impact.

6.2 Limitations of the study

A total of 12 participants were recruited for the research study, however, only 10 were able to participate due to loss during follow-up or participants declining to participate. Data from a bigger sample size would have contributed to better understanding of the case. Also, from the participants, only one mentee was able to participate, and in future it is suggested to include more mentees.

There was also only one FCG discussion and it is therefore suggested that the FCG discussion be repeated with the initial analysis of the first FCG, as well as questions and clarifications from the researcher to further thicken the data collected.

There has also been a challenge to collect data by the means of SMS/WhatsApp messages, as sometimes the participants had to send the same message twice as the researcher did not receive the first message. It is suggested that the researcher enquire per participants what form of messaging they prefer and adapt the data collection method according to that.

6.3 Recommendations

6.3.1 Community-based mentorship programmes for at-risk women

It is recommended that community-based mentorship programmes for at-risks mothers to focus on these components, which were found valuable in this case study. These include following a client-centered, holistic approach focusing on building relationships with the at-risk women and supporting

them and empowering them in any way possible. It is also recommended that the programmes involve a strong focus on the mental wellbeing of the at-risk mother, and not consider their characteristic 'faults' as the reason for alcohol use during pregnancy, but rather considering the barriers and challenges they face as the most challenging 'faults' for reason to drink during pregnancy. This requires a shift from the problems within the person, but rather to that of the environment.

6.3.2 Occupational Therapy

Occupational therapy can play a vital role in the fields of maternal health, and occupational therapists need to claim their role within community-based maternal health. Occupational therapists can assist at-risk mothers to achieve client-centered goals, including change in drinking behaviour during pregnancy, and creating supportive environments within such mentoring programmes. This could assist in the success of these programmes, and success of these programme could benefit the public health system in decreasing the prevalence of FASD in those communities.

6.4 Summary of contributors

The findings of this study contribute to the knowledge of community-based mentorship programmes that is implemented, and highlighted what components are deemed most valuable in these programmes. This could potentially inform other role-players such us other NGO's, Department of Social Development, Depart of Health, Department of Education, and the private sector, when developing strategies for the prevention of FASD. There needs to be a collaborative approach between these role-players when battling against public health issues such as FASD. The findings from the study are valuable indicators into what is experienced as valuable, and what not in these programmes.

Furthermore, the findings contribute to the body of knowledge of what is known about the mentorship programmes, for these programmes to improve in sustainability and longevity, and also to assist in scaling of these programmes to reach a bigger target. Consequently, these findings could potentially be used as motivation for funding for these programmes to be scaled and improve its reach.

6.5 Future research

It is recommended that future research should be done into the role of meaningful occupational engagement and the affect this has on the success of these mentoring programmes. There are currently no available literature published regarding this topic. Meaningful occupational engagement could potentially also play a vital role in the success of these mentorship programmes.

It is also recommended that a longitudinal study be done to determine the success of these mentorship programmes in lowering the prevalence of FASD in high-risk communities. This could either be done on individual level to determine whether mothers from these programme are able to cease drinking while pregnant or determining the FASD prevalence rates over a period in the high-risk communities.

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Addendum A

Informed consent form to participate in the focus group discussion.

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF RESEARCH PROJECT:	
Exploring the value of mentorship programmes as a preventative strategy for prenatal alcohol use for at risk women in the Western Cape	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Ms Linda Zietsman	Ethics reference number: **S20/08/221**
Full postal address: 29 Vrede Estate, Sanddrift street, Paarl, 7646	**PI Contact number: 084 605 2957**

We would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University.** The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

This study investigates the valuable components of mentorship programmes for mothers who are pregnant in rural areas in the Western Cape. It will have a focus on Fetal Alcohol Spectrum Disorder (FASD), as the purpose of

the study will be to determine what it is about mentorship programmes that assist to support mothers or future mothers to stop drinking during pregnancy, and what aspects of such a programme contribute to prevention of FASD. We would like to look how FASD can be prevented and how to reduce the amount of FASD in the communities. The study will take place in rural areas in the Western Cape and a total number of six to nine participants will participate in the first platform of this study.

The different organisations involved with mentorship programmes for pregnant mothers in rural communities have been contacted to inquire regarding their willingness to participate in the study. One contact person per organisation has been identified per organisation for communications purposes. The contact person did identify potential participants within the respective organisation, and firstly informed them about the research study. Only after the potential participants have agreed to be willing to participate in the research stud to the contact persony, they have been contacted to discuss their interest in the study, and whether they would like to participate in the study. Then, the possible participants will be emailed the informed consent forms and they will have to think and discuss whether they would like to go further with the study, and further arrangements for the focus group discussion will then be made.

Why do we invite you to participate?

You have indicated your willingness to participate in the research study as your are part of one of the organisations involved in the study Therefore, you have been contacted to participate in the study.

What will your responsibilities be?

You will have to do a focus group discussion of 60-90 minutes with the researcher online.

Will you benefit from taking part in this research?

You will not benefit directly from the study; however, the results and findings of the study may influence future practice and programmes in order to minimise the amount of FASD in the communities.

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

There are no direct risks involved in participating in the study.

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

You have a free choice whether you want to participate in the study, and you are allowed to withdraw from the study at any time. If you do not wish to participate in the study, your interview will not be used in the study,

Who will have access to your medical records?

No medical records will be accessed.

Even though it is unlikely, what will happen if you get injured somehow because you took part in this research study?

Stellenbosch University has insurance to cover all medical costs of participants in studies approved by the Health Research Ethics Committee. The appropriate external referral will be done by the researcher if she discovers that the participants requires external services.

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

You will be reimbursed for their time and inconvenience to participate in the study by means a grocery voucher of R100. These vouchers will be sent via Whattsapp or SMS.

Is there anything else that you should know or do?

- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study leader has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I ……..…… agree to take part in a research study entitled **Exploring the value of mentorship programmes as a preventative strategy for prenatal alcohol use for at risk women in the Western Cape**

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.

- I understand that taking part in this study is **voluntary,** and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2020.

....

Signature of participant Signature of witness

Declaration by investigator

I *(name)* ……..…… declare that:

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

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2020.

....

Signature of investigator **Signature of witness**

Addendum B

Informed consent phone script to participate in journaling.

PARTICIPANT INFORMATION LEAFLET AND PERMISSION FORM

Title of research project: Explore the value of mentorship programmes as a preventative strategy for prenatal alcohol use for at-risk women in the Western Cape

We would like to invite you to take part in a research project. Please take some time to listen the information presented here, which will explain the details of this project. Please ask me any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary,** and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University.** The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

This study investigates the valuable components of mentorship programmes for mothers who are pregnant in rural areas in the Western Cape. It will have a focus on Fetal Alcohol Spectrum Disorder (FASD), as the purpose of the study will be to determine what it is about mentorship programmes that assist to support mothers or future mothers to stop drinking during pregnancy, and what aspects of such a programme contribute to prevention of FASD. We would like to look how FASD can be prevented and how to reduce the amount of FASD in the communities. The study will take place in rural areas in the Western Cape and a total number of 10 participants will be involved in platform two of the study. The participants will be a variety of mentors and mentees. It will be expected for each participant to do journaling by the means of voicenotes for a period of two weeks with a total of six journaling logs.

The organisation involved with mentorship programmes for pregnant mothers in the community have been contacted to obtain a list of possible participants, including mentee and mentors. Thereafter, the possible participant list has been randomised, and the possible participants have been contacted telephonically to discuss their interest in the study, and whether they would like to participate in the study. Then, the possible participants

will be messaged the informed consent forms, and will also be read a verbal informed consent phone script and they will have to think and discuss whether they would like to go further with the study, and further arrangements for the journaling will then be made.

The organisation involved in the study informed us that you are part of a mentorship programme for mothers in the community, either as a mentor or mentee. Thereafter you have been randomly selected to participate. Therefore, you have been contacted to participate in the study, and you have indicated over the phone that you are interested in participating in the study.

What will your responsibilities be?

You will have to do a journal log for two weeks with six different logs. The journaling will be done by means of messages taking10 minutes per message which will be sent to the researcher three times a week for two weeks.

You will not benefit directly from the study; however, the results and findings of the study may influence future practice and programmes in order to minimise the amount of FASD in the communities.

There are no direct risks involved in participating in the study.

You have a free choice whether you want to participate in the study, and you are allowed to withdraw from the study at any time. If you do not wish to participate in the study, your interview will not be used in the study,

No medical records will be accessed.

Stellenbosch University has insurance to cover all medical costs of participants in studies approved by the Health Researcg Ethics Committee. The appropriate external referral will be done by the researcher if she discovers that the particpants requires external services.

You will be compensated to take part in the study and your expenses will be reimbursed for mobile data expenses with a 200MB data bundle and a SMS bundle of 20 units. You will not have to pay for anything, if you do take part. A R100 Shoprite/Checkers voucher will be given per participant for compensation for your time and inconvenience.

Is there anything else that you should know or do?

- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study leader has not explained to you, or if you have a complaint.
- You will receive a copy of this information and consent form for you to keep safe.

By verbally agreeing to participate in the study, you declare that

- You have read this information and consent form, or it was read to you, and it is written in a language in you are fluent and with which you are comfortable.
- You have had a chance to ask questions and you are satisfied that all your questions have been answered.
- You understand that taking part in this study is **voluntary,** and you have not been pressurised to take part.
- You may choose to leave the study at any time and nothing bad will come of it – You will not be penalised or prejudiced in any way.
- You may be asked to leave the study before it has finished, if the study researcher feels it is in your best interests, or if you do not follow the study plan that we have agreed on.

Please indicate verbally whether you agree to participate in the study or not.

Addendum C

Example of table to document the verbal informed consent process.

Caller	Participant	Date	Time	Verbal informed consent phone script was completed (tick if appropriate)	Participant verbally consented to participate in the study (tick if appropriate)	Signature of caller	Signature of impartial witness

Addendum D

Shortened Informed consent form to participate in journaling.

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

We would like to invite you to take part in a research project.

It is important that you understand the purpose of the research study what it is about. Your participation iscompletely voluntary, and you may withdraw at any time during the study. Nothing bad will come if you refuse or withdraw from the study.

Title of research project: Exploring the value of mentorship programmes as a preventative strategy for prenatal alcohol use for at risk women in the Western Cape.

- This study has been approved by the Health Research Ethics Committee at Stellenbosch University.
- This study investigates the valuable components of mentorship programmes for mothers who are pregnant in rural areas in the Western Cape.
- The organisation involved in the study informed us that you are part of a mentorship programme for mothers in the community. Therefore, you have been contacted to participate in the study, and you have indicated over the phone that you are interested in participating in the study.
- A total number of 10 participants from the Western Cape will be involved in platform two of the study.
- You will have to do a journal log for two weeks with six different logs. The journaling will be done by means of messages taking10 minutes per message which will be sent to the researcher three times aweek for two weeks.
- You will not benefit directly from the study and there are no direct risks involved in participating in the study.
- You will be compensated to take part in the study and your expenses will be reimbursed for mobile data expenses with a 100MB data bundle and a SMS bundle of 20 units. You will not have to pay for anything, if you do take part. A R100 Shoprite/Checkers voucher will be given per participant for compensation for your time and inconvenience.
- You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is somethingthat your study leader has not explained to you, or if you have a complaint.

By sending a message back **"I agree".** I agree to take part in a research study entitled **Exploring the valueof mentorship programmes as a preventative strategy for prenatal alcohol use for at risk women inthe Western Cape**

I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary,** and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is inmy best interests, or if I do not follow the study plan that we have agreed on.

Addendum E

Example of table to document to capture informed consent via SMS.

Participant	Date	Time	Shortened version of informed consent phone script sent via SMS (tick if appropriate)	Participant agreed via SMS to participate in the study (tick if appropriate)	Signature of principal investigator	Signature of impartial witness

Addendum F

Focus group discussion questions.

Introduction	Introduce researcher and participants
	Explain purpose of study and process, as well as informed consent
	Explain recording, confidentiality, and data management
	Explain openness, transparency, and equality
	Familiarise participants with environment and researcher
Questions:	“What is the value of a mentorship programme?”
	“Which components are most valuable for a mentorship programme?”
	“What value does occupational engagement have in mentorship programme?”
Conclusion:	Short summary and review of content
	Explain again purpose of study and data management
	Prepare for termination of interview and thank participants for participation
	Terminate interview

Addendum G

Journaling prompts

Week	**Day**	**Prompt**
1	**1**	What does the mentoring programme mean to you?
	2	What is the most valuable for you about the mentoring programme?
	3	What have you learned through the mentoring programme?
2	**4**	What does not work in the mentoring programme?
	5	What would you change about the mentoring programme?
	6	In conclusion, give a summary about how the mentoring programme has changed your life?