

**The lived experiences of pregnant women on antiretroviral
treatment (Free State Province, South Africa)**

By

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DECLARATION

I, Mosilo Mina Machere, declare that the Master's degree research dissertation that I herewith submit for the Master's Degree qualification Magister Artium at the University of the Free State is my independent work, and that I have not previously submitted it for a qualification at another institution of higher education.

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SUMMARY

The universal access of antiretroviral treatment (ART) in South Africa has bent the trajectory of the HIV epidemic. The lifelong HIV treatment has moved the disease from a terminal to a chronic and manageable disease. The redefinition has brought hope and normality to many people living with HIV. For HIV-positive women, the prevention of mother-to-child transmission (PMTCT) prophylaxis has influenced their intentions to bear children along with issues related to their reproductive options and prospects. Studies on the influence of HIV on pregnancy have largely been about the baby with limited focus on the lived experiences and perceptions of the expecting mothers. Conceptualising the lived realities of HIV-positive women during pregnancy and motherhood in the context of ART requires a deeper understanding of their experiences. Guided by both descriptive and interpretive lenses of phenomenology, this research approach allowed a more in-depth look into this phenomenon, thereby capturing the complexity of issues women faced from their points of view.

The study aimed to explore the experience of pregnancy from the perspective of HIV-positive women who are on ART. It sought to discover the meanings embedded in their everyday lives. This included, among other things, appreciating what these women regarded as noteworthy in relation to their experiences and learning about the impact that the diagnosis of HIV, and its lifelong treatment had on their lives, both as patients and as care-givers. The objective of the study was thus to understand the experiences of HIV-positive women who were on ART, both their own embodied experiences as well as their experiences in relation to others; how they perceive the

chronic character of HIV; and moreover to explore how they made sense of their experiences of pregnancy and motherhood.

Eight Sesotho speaking participants from the Free State province, South Africa, were recruited. A purposive sampling method was used as only women who were pregnant and on ART were interviewed. The narratives of the lived realities were elicited through in-depth interviews. The face-to-face interviews were digitally recorded and guided by an interview schedule to allow flexibility and engage participants in dialogue while they were narrating their experiences. The data was analysed in the context of HIV diagnosis, pregnancy and ART. This was to elicit what it meant for women to contemplate pregnancy in a context of ubiquitous HIV and new hope in the form of ART; both available for them and their babies. The systematic analysis provided a greater understanding of factors influencing the taken-for-granted experiences of HIV-positive women on ART during pregnancy and motherhood. The content analysis of qualitative data revealed two broad themes related to lived realities of pregnancy on the one hand, and motherhood on the other in the context of ART. Narrating their experiences during pregnancy, sub-themes that emerged were more inclined to point towards the protection of the unborn baby and developing coping mechanisms; while during motherhood there was a shift from the babies' to the mothers' well-being and their life prospects.

Considering the duration of being on ART and the number of pregnancies they have had, the narratives provided a platform to track how experiences such as baby

feeding practices, and coping with stigma and disclosure have ameliorated over time. This indicates how the landscape in which HIV-positive women experience pregnancy and motherhood has changed rather dramatically. The zeal for life displayed by these women bears testimony that HIV diagnosis no longer means that the prospect of death is the sole outlook on their lives and on the lives of their children.

Keywords

HIV and AIDS

Prevention-of-mother-to-child-transmission (PMTCT)

Pregnancy

Antiretroviral treatment (ART)

Motherhood

Stigma

Coping mechanisms

Narrative approach

Lived experiences

Free State Province

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INTRODUCTION

The ability to give birth and to mother is a privilege and an event that leaves an indelible mark on the lives of those women who undergo this experience. For many women, motherhood forms an integral part of who they are and their sense of fulfilment. For women infected with human immunodeficiency virus (HIV), just like for non-infected women, the desire and commitment to bear children are fortified by factors such as the survival of the baby (Smith and Mbakweni, 2007; Myer et al., 2010; King et al., 2011; Erhabor et al., 2012; Schwartz et al., 2012; UNAIDS, 2014). But for HIV-positive women on antiretroviral treatment (ART) the experience of pregnancy is greatly underscored by a cascade of health-related interventions they have to adhere to and follow in order to have an HIV-free baby. From this perspective, and being a mother myself, I have always been intrigued by the negotiation of being HIV-positive, on ART and motherhood. Moreover, my various encounters with HIV-positive women as a research fieldworker in the context of public health¹ facilities motivated me to learn about their experiences. I therefore embarked on this study to understand the women's everyday lived experiences from their own perspectives, taking them as subjects in their own right.

The advent of ART and HIV's subsequent re-definition as a 'chronic illness', have shifted the ways in which HIV (the human immunodeficiency virus) is understood and lived. Like other chronic conditions, HIV has become a condition where its

¹ In South Africa we have a dual health system: public and private. The public sector is free for those who cannot afford the exorbitant costs associated with private medical care and the public sector therefore caters for the majority of South Africans but has far fewer resources available (especially in comparison to the private health sector).

progression and treatment are measured clinically and whereby lived experiences and meanings are excluded, particularly during pregnancy (MacCarthy et al., 2012; Mantell et al., 2014). Hence a plethora of research about HIV and pregnancy has become engrossed with the prevention of mother-to-child transmission (PMTCT) whereby protection of the baby from HIV has become supreme and experiences of HIV-positive mothers have been peripheral (Persson et al., 2003; Long, 2009).

Knowledge and access to PMTCT interventions have led HIV-positive women with children to value their life prospects, including navigating personal aspirations surrounding pregnancy and motherhood. Hence, the women may vary in their desire and plans to have more children (Cooper et al., 2009). In the same breath, little research has considered the lived experiences of HIV-positive women on ART during pregnancy and motherhood (Cotter et al., 2006; Long, 2009; Liamputtong & Haritavorn, 2014; Adam, 2015). Seeking a deeper understanding of pregnancy and motherhood experiences in the context of living with HIV and its lifelong treatment, it is therefore important to delve into the lived experiences of mothers beyond the focus on their children only. Such an approach allowed appreciating and conceptualising the lived realities of women from their points of view.

The primary mode of transmission of HIV in children is from mother-to-child, hence there has been a sense of urgency for babies' survival in a plethora of literature (MacCarthy et al., 2012; Mantell et al., 2014). This urgency is borne out in HIV-positive women as it is given so much importance in official discourses in clinics but also in unofficial discourses among family and friends where the focus on the unborn

baby is often the sole matter of concern. It was therefore interesting to trace these moments in a handful of women's lives: from antenatal care to birth; from birth to motherhood; and from motherhood to subsequent pregnancies, participants' narratives were analysed in order to convey the complex meanings of life and death; stigma and discrimination; blame and regret.

HIV and AIDS has been part of the post-apartheid South African landscape shortly after its inception in 1994 and its own trajectory would have marked plenty of families' lives through single or multiple losses characterised by trauma and setbacks. These losses even include the deaths of babies who were born before the generalised availability of PMTCT interventions. In fact, the first time women are diagnosed with HIV often coincides with pregnancy. However, the landscape in which HIV-positive women experience pregnancy and motherhood has changed dramatically over the years; the most drastic change obviously residing in the fact that they now have the reassurance that MTCT has largely been eliminated and that a host of other interventions in this PMTCT cascade provide additional support to women in looking after the well-being of their children post-partum.

The objective of the study is thus to gain insights into the experiences of HIV positive mothers who are on ART, both their own personal experiences as well as their experiences in relation to others; how they perceive the chronic character of HIV; and moreover to explore how they make sense of their experiences of pregnancy and motherhood.

The dissertation is divided into five chapters. Chapter one sets out the theoretical framework of the study. In chapter two, the literature relevant to HIV, pregnancy, motherhood and ART is reviewed and discussed. Chapter three discusses the chosen methodology and chapter four sets out the findings of the study and the discussion thereof with relevance to the study objectives. The dissertation ends with a conclusion to summarise the main findings of the research.

Chapter 1

THEORETICAL FRAMEWORK

1.1. Introduction

The aim of this chapter is to provide the context within which my research was conceptualised by introducing and describing some theoretical guidelines. The chapter illustrates that a phenomenological approach offers a suitable framework that can guide the investigation of experience under study. For the purposes of this study I have identified and adopted the work of key thinkers to explain this “common-sense” view of everyday life. Within this overarching approach, the study sought relevance for its findings by drawing on a variety of interrelated perspectives. This was achieved by giving a broad overview of phenomenology to uncover the meanings of the everyday life-world in terms of existence and living with others where intersubjectivity is constructed.

1.2. Rationale of the Theoretical Framework

The primary objective of this study is to understand the everyday lived experiences of pregnant women who are on antiretroviral therapy (ART) from their own perspective. To this end, an interpretive phenomenological approach was taken to guide this inquiry because of its emphasis on description and meaning of lived experiences (Creswell, 2007:57; van Manen 1984). In the broadest sense, a phenomenological research study endeavours to describe how participants make sense of or give meaning to their everyday lived experiences. It allows the researcher to interpret the participants’ narratives of various phenomena from a

subjective perspective (Creswell, 2007:54; Hancock et al., 2009:14). It views society as a product of the everyday social interactions of individuals. It also studies the symbolic meanings which arise from these mundane social interactions.

Realising the complexity of human interaction, I then proceeded by expanding the everyday life theoretical perspectives. This was done by outlining the key premises of existentialism and symbolic interactionism. The aim was to tie these diverse but related tenets into a unified approach to the study of social interaction and everyday life.

1.3. Phenomenology of Everyday Life

Everyday life sociology is thought of as an umbrella term embracing a spectrum of theoretical approaches which share the goal of understanding the world of lived experience from the perspective of those who live in it (Adler, et al., 1987). Its key emphasis is to seek to understand the development of individual subjectivity and everyday experiences in a sociological context (Berger & Luckmann, 1967:34; Adler, et al., 1987). It presents itself as a reality from the perspective of those who live and experience it; and who draw subjective meaning from it (Berger & Luckmann, 1967:33). Hence, everyday life sociologists have declared that, in their natural context, people are engaged in an on-going process of making sense of the world in which there is constant interaction with others (Adler, et al., 1987; Overgaard & Zahavi, 2009:98; Inglis and Thorpe:2012:89).

Phenomenology is both a philosophical movement and a research method which has become an important source of reference for the development of different qualitative disciplines; it represents the most radical departure from quantitative methodology. One of the principle founders was Edmund Husserl who developed it as an alternative to natural science methods which he believed, lacked human experience (Fontana, 1984:7; Hitzler & Eberle, 2004:67). The term “phenomenology” is derived from the Greek words *phainomenon* and *logos*. The meaning of *phainomenon* refers to “an observable occurrence”, and *logos* means the “study of something” (Overgaard & Zahavi, 2009:94; Inglis & Thorpe, 2012:86). Although subjected to many interpretations, phenomenology provides insight into the meanings of lived experiences of others through description, understanding and investigation thereof. It lends itself to questions concerned with understanding and eliciting meanings that experiences hold for individuals by focusing on commonplace thoughts and actions and not anything independent thereof (van Manen 1984; Giorgi, 1997; Inglis & Thorpe, 2012:86).

Within this orientation, the study employed a phenomenological approach to elaborate on the experiences of pregnant women while on ART as a lived experience. The approach also holds an explicit advantage in that the experience is captured from the women’s unique perspectives of their everyday lives. Thus, to understand their own sense-making, the study participants gave subjective meanings developed from their individual perceptions and understanding of their spontaneously narrated experiences of everyday life reality (van Manen 1984; Giorgi, 1997; Inglis & Thorpe, 2012:90). From a phenomenological perspective, the study sought to understand the meanings from which social reality is constructed,

with the emphasis on meanings and the social construction of reality effected from the phenomenon under study.

1.4. Intersubjective Life-world

The life-world (Lebenswelt in German) refers to the everyday lived experiences and perceptions thereof that constitute the person's world (Giorgi, 1997). Edmund Husserl introduced the concept of the life-world and Alfred Schutz further developed it to form a social phenomenology where he endeavoured to extend the ideas of human consciousness to social experience (Inglis & Thorpe, 2012:89). In a broad-brush way, Schutz's work advanced phenomenology to examine the life-world. His insights were particularly concerned with how the everyday life is something we tend to take for granted and never question or give reflective attention to (Overgaard & Zahavi, 2009:97). The life-world postulates that the world is experienced and lived and thus provides the foundation for our existence (Inglis & Thorpe, 2012:90). Hence, it is considered a fundamental base concept in phenomenology to uncover the essential invariant features of that experience (Overgaard & Zahavi, 2009:97).

Schutz observed that the world of social interaction with others produces the intersubjectivity of existence and facilitates social understanding (Overgaard & Zahavi, 2009:101; Inglis & Thorpe, 2012:92). In this perspective, he examined how the world is shared with others and how construction of meaning forms the backdrop of our daily actions and interactions (Overgaard & Zahavi, 2009:98; Inglis & Thorpe, 2012:93). In other words, as individuals we exist both through objective and subjective reality and the former is brought about through social interaction thus the

life-world is intersubjective (Berger & Luckmann, 1967:37; Overgaard & Zahavi, 2009:101). The intersubjective character of the life-world also affirms that our experiences and the meanings of our experiences are shared meanings established in social interaction (Fiske, 1992).

For the purposes of the study, the intersubjectivity of the life-world was defined as the capacity of the mothers to experience a sense of “sharing the experiences” through the establishment of relationships with others. For example, the dyadic intersubjectivity during pregnancy between the mother and the unborn baby may reveal the ways in which mothers, situated in a specific context (being pregnant and on ART) reflect upon and understand their life-world. However, in a given life-world, the mother is also faced with dyadic relationships with partners, family and friends who are referred to by Schutz as “consociates” and her community and health care workers who are referred to as “contemporaries”. “Consociates” (also known as significant others), are “those the individual interacts with closely and regularly” and are characterised by “we” relations (Inglis & Thorpe, 2012:92). On the other hand “contemporaries” (also known as generalised others), are “those who share the same life-world as the individual, but whom she does not know personally” and are characterised by “they” relations (Inglis & Thorpe, 2012:92). In dealing with all these people, especially the “consociates”, “typifications” subtly come into play without the individuals realising it, and build our social identity. “Typifications” refer to the process of relying on general knowledge as a way of constructing ideas about people and the social world (Overgaard & Zahavi, 2009:102). This suggests that in all of our encounters with others, we experience and understand the other in terms of presupposed views which make subjective meaning possible (Overgaard & Zahavi, 2009:102). In other words, as we participate in the life-world, most of what we know

of other people does not take the form of direct knowledge, but rather general knowledge from prior experience.

To grasp the social realities and to reach the meaning level of research participants, Schutz makes a distinction between participants' accounts of the lived experience (first-order) and the researcher's account of the participants' account (second-order) (Inglis & Thorpe, 2012:90-91). These first-order interpretations are based on standard assumptions of the life-world (Overgaard & Zahavi, 2009:103). Schutz insists that getting by in life rests upon common-sense knowledge and the existence of shared typifications constructed from our subjective interpretation (Lester, 1984:42). By taking many forms e.g., language, labelling, culture, etc., typifications are not unique to each person but are shared by members of a society. And because they are constructed from the stock of knowledge of any group, they are fluid and constantly modified in the course of human interaction (Overgaard & Zahavi, 2009:102). Our social reality of everyday life is thus apprehended in a continuum of common-sense ways of thinking and reasoning where we employ socially approved typifications and recipes (Inglis & Thorpe, 2012:95).

According to Berger and Luckmann (1967:33), "the world of everyday life is taken for granted as reality by the ordinary members of society in the subjectively meaningful conduct of their lives. It is a world that originates in their thoughts and actions, and is maintained as real by these." When typifications and recipes are experienced as mundane and 'natural' and common-sense notions prevail, the process of 'institutionalisation' occurs, according to the authors of "The Social Construction of Reality" (Inglis & Thorpe, 2012:95). Using our common sense through the process of

communication, experience and interpretation, we typify our world by shaping the patterns of our interactions (Lester, 1984:39). As these interpretations happen within the integrative and stabilising process of institutionalisation, “typifications and recipes become habitual routines of everyday life” (Inglis & Thorpe, 2012:95). Added to this theory of social construction of reality is the idea of alienation. This idea generally posits that individuals as social creations develop social relations and understanding of structures which could be forced upon them. For example, forces such as values and norms may be placed above the personal interests of individuals by being taken as “natural” and accepted ways of social existence (Inglis & Thorpe, 2012:94-95). Berger and Luckmann regard this fundamental integrative mechanism of social systems as becoming “paramount reality” of social existence where people “experience them as real, natural and unavoidable” (Berger & Luckmann, 1967:35; Inglis & Thorpe, 2012:95).

By employing phenomenology as a conceptual framework, the study investigated and described how women combine their subjective (individual) and social (society) experiences into their life-worlds. This theory shows how embedded notions of pregnancy and motherhood manifest in social realities of women. These notions are probably among the areas of life that are most alienating because they have some of the strictest and most intransigent “rules” as to conduct, expectations, and actions. This may leave very little room for women to show and to display individual agency when it comes to their own renditions of pregnancy, especially given their status as HIV-positive and on ART. This reflection draws attention to sociality without modulating the part of individual subjectivity while elaborating on the dual experience of pregnancy and being on ART (Overgaard & Zahavi, 2009:96).

To bring subjectivism and objectivism together, and therefore escape to choose between the two, Pierre Bourdieu applied his concept of habitus (Ritzer, 2012:530). The habitus refers to “internalised, ‘embodied’ social structures” that influence the thoughts and actions of individuals (Ritzer, 2012:531). These dispositions possessed due to life experiences, guide behaviour and thinking in that they are enduring and transferrable from one context to another (Ritzer, 2012:531). In this sense, habitus is manifested by people’s modes of classification, perceptions, choices and behaviour. It is so deeply ingrained in our habits and dispositions that it is confounded by ‘common-sense’.

From a structural perspective, the notions of pregnancy and motherhood leave little room for individual agency. Provided the salience of the phenomenon of pregnancy among the participants in this study, their experiences are overarched by powerful structural forces that greatly shape their meaning-making and perceptions. Socio-structural factors such as the conventions of patriarchy, of marriage or relationship, of gender dominance, of inequalities in health care services, of precarity in general and of self-care and caring for others, are among the factors that shape these women’s experiences and perceptions and influence the event of pregnancy and motherhood in the context of HIV and ART.

1.5. Existentialism

Although distinct from phenomenology in the ways in which it approaches the life-world, it was from this very phenomenological perspective that existentialism

concretised the ways in which human beings share - or fail to share - their universe (Fontana, 1984:7). Deriving its insights from Husserl's descriptive phenomenology, existentialism was developed by Martin Heidegger who was concerned with the deep questions of human existence (Kotarba, 2009:141). It undertakes a close examination of how human beings interact in their natural setting, the everyday world in which they live. In this regard, Heidegger sought to improve the understanding of human interaction by placing emphasis on the subjective and interpretive nature of social reality. With a strong emphasis on these elements, existentialism raises the question of human perceptions of existence, and how the external world appears to, and is experienced by, individuals (Fontana, 1984:7; Kotarba, 2009:141).

With change as its distinctive facet (Kotarba, 2009:140), existentialism is a perspective that is broadly defined in a variety of human action concepts (Fontana, 1984:4). Employing existentialism advocates the view that people are emotional and irrational and that these elements greatly guide how they perceive, interpret and live their lives (Adler et al., 1987; Bendolow & Williams, 1994). It appreciates the ontological and profound aspects of life such as freedom, guilt, choice, and death, which coincide with the varied experiences of the study participants. It also relies on emotions as being central to how people act, as well as the existential dimensions of our existence because these, in turn, determine and influence our affect in everyday life (Adler et al., 1987).

As expounded in the philosophical writings of Arlie Russell Hochschild, emotions are socially and personally embodied experiences (Bendolow & Williams, 1994). They are experienced in and connected to contextual human experiences. This attribute of

embodiment is a primary element for understanding emotions as phenomena within ongoing lived experiences (Bendolow & Williams, 1994). Although they emerge in social contexts, emotions are also personally influenced by social norms and expectations as well as in creating and maintaining our social self or identity (Thoits, 1989; Bendolow & Williams, 1994). Having these subjective and intersubjective attributes, existentialism is well framed to generate understanding about emotions (Adler et al., 1987). With broad dimensions, emotions can possibly be influenced by, among other factors, culture, gender and age to provide contextual and situational perspectives on which our perception of everyday reality depends (Thoits, 1989; Bendolow & Williams, 1994). Feelings such as “love and hate, ecstasy and agony, pleasure and pain, hope and despair, sympathy and spite, comfort and discomfort” and so forth are the core of our existence (Kotarba, 2009:143). These emotions and the intensity thereof greatly determined and influence how reality is constructed in the everyday life of participants (Kotarba, 2009:143).

HIV can bring a certain burden to the existence of the infected person. Physical symptoms, regular medical appointments, medications, unpleasant side-effects, disclosure of HIV status and pregnancy all shape the individual’s worldview and are routine in daily life. These stressors could undermine one’s existing sense of identity. The existential approach posits that certain fundamental challenges are inherent in the human condition, and that these challenges, when encountered, lead to a variety of reactions, ranging from anxiety and despair to creativity and transcendence. In the context of the study, raw emotions evoked during the interviews guided the unpacking and understanding of the participants’ reasons and reasoning with regards to pregnancy while being on ART and the manner in which this reality

influences their everyday lives (Thoits, 1989). The participants' emotions were elaborated on as heuristic elements in attempting to understand experiences that form the context of their actions. Furthermore, it sought to understand and reveal the basic dynamics of emotions interwoven with experiences of pregnancy and being on ART. Through their emotions participants would make sense of themselves and relate to and engage with others and make sense of their social existence (Thoits, 1989). Given their profound quality, participants' identities and emotions were best understood within an existential framework. Through the use of an existential framework, individuals search for their true self and their true personal meaning in life, however fluid and contradictory this may be.

Under the existential sociology rubric, the concept of the "self" is designed to observe the mood and nature of trends occurring in existing routines by focusing on dissatisfaction with the self and social preconceptions of the self (Kotarba, 2009:145). Duly, "existential self refers to an individual's unique experience of being within the context of contemporary social conditions, an experience most notably marked by an incessant sense of becoming and an active participation in social change" (Kotarba, 2009:145). Dealing with the "altered self" manifested by personal and social emotions indicates that people are constantly striving to reinvent and reconstruct their thoughts and feelings about themselves (Kylma et al., 2001; Kotarba, 2009:145). The sense of self is invariably linked to early interactions with others, and their definitions of the social situation exhibiting relative fluidity in the concept of the self (Tiryakian, 1965). To maintain a display of self that conforms to societal norms of emotions, individuals tend to control their emotions (Turner &

Stets, 2008:34). They achieve a sense of self in the course of face-to-face dialogues and interactions, observations, and many indirect contextual factors.

By linking ART and pregnancy, the meanings of motherhood go far beyond the chronic character of ART. A qualitative metasynthesis conducted by Sandelowski and Barroso (2003) reported that for HIV-positive women, motherhood entailed challenges and pleasures. As found in other studies, women were faced with feelings of anxiety, love, ambiguity and confusion in relation to pregnancy and motherhood; and stigma characterised their experience of motherhood after an HIV diagnosis (Wilson, 2007; Sanders, 2008).

Employing existentialism guided the study in exploring the relationships of participants and the way they depend on and make sense of the context of their lives and the environments they inhabit along with others. It sought to understand how participants define their own meanings in life. Therefore, the emphasis was on understanding women's experiences of their existence in the three interwoven dimensions of time: the present, the past, and the future. The study took an existentialist view to emphasise the importance of social interaction and individual existence by focusing on the basic being of participants and their actions on the basis of their feelings (Adler et al., 1987). This theoretical lens served as a guide to discover some self-aspects such as the construction of meaning, decision-making and self-perception without restraining the element of the continued social construction of the life-world (Berger & Luckmann, 1967:194).

Using the existential approach helped me grapple with the world that exists prior to the conceptualisation thereof by investigating participants in their everyday life setting. This was done by concentrating on their existence; and how they choose and decide based on their experiences, beliefs and outlook (Fontana, 1984:4; Kotarba, 2009:142). HIV infection and being on ART herald an adverse change in people's lives. Therefore, the approach also guided this study in revealing how participants view their constantly changing reality of motherhood, more so in the precarious situations of living with HIV and ART. The study therefore drew on an existential perspective to explore various "meaning worlds" of participants and to understand the challenges to their existence brought about by pregnancy, motherhood and ART.

1.6. Symbolic Interactionism

Symbolic interactionism is a theoretical perspective conceptualised by George Herbert Mead who was interested in the results of interaction with others. The theory was further developed and coined by Mead's student, Herbert Blumer, who expounded that symbolic interactionism rests on three basic principles of meaning, language and thought which lead to the development of self from the process of interaction with others in particular contexts (Lester, 1984:23-24; Adler, et al., 1987; Aksan, et al., 2009; Benzies & Allen, 2001; Inglis & Thorpe, 2012:112). In essence, being interested in the results of interaction, interactionism attempts to explain human actions by examining the ways in which people interpret the actions of others, develop a self-concept (self-image) and act in terms of meanings.

Symbolic interactionism postulates that social reality is continually constructed, shaped and redefined through everyday social interactions (Inglis & Thorpe, 2012:107). It focuses on how individuals act according to their interpretation of the meaning of their life-world and how they create and maintain their reality. Because symbolic interactionists believe that society is socially constructed through human interpretation, they analyse society by addressing the subjective meanings that people impose on phenomena through symbols and body language (Blumer, 2012:63). They also hold that meanings are intersubjective and perceived. Hence, the subjective understanding and use of language are critical features for symbolic interactionists (Lester, 1984:23).

Blumer came up with three basic principles that are foundational to his theory and are concerned with meaning, language and thought (Benzies & Allen, 2001; Aksan, et al., 2009). First, the construction of social reality posits that nothing has inherent meaning; rather all meaning is assigned. Second, language is the source of meaning. The meanings assigned to things arise out of social interaction; they are not arbitrary, but are learned. Third, the meanings people attribute to things are handled through an interpretive process of taking the role of the other and the language used by a person in specific situations (Aksan, et al., 2009). These premises are built upon the creation and communication of meaning and lead to conclusions about the creation of self and socialisation into a larger community. Hence, symbolic interactionists do not study individuals; they study the social actions in which individuals engage to grasp the meanings they come to attach to social action as well as how these meanings are constructed (Adler, et al., 1987).

1.6.1. The Construction of Meaning

The construction of meaning implies that “reality” is created through language and, in turn, in order to understand how social reality is created, a great deal of human life exists as it does due to social and interpersonal influences (Inglis & Thorpe, 2012:94). This places language as a critical element of social construction of reality as meaning is given to experience through language.

Language, a fundamental aspect in the process of knowledge production, is not conceived of as describing and representing the world, but rather as a way of constructing it (Inglis & Thorpe, 2012:95). It is the central medium for transmitting meaning. It is a medium regarded by many as an everyday life social element essential to understanding how meanings are developed, maintained and adapted, and hence its importance to the self is paramount (Adler et al., 1987). Gaining its meaning from its use in context and being a social construct, language has an intersubjective character inseparable from the concept of experience (Inglis & Thorpe, 2012:92).

To illuminate both the individual and the social world, Heidegger’s insights echoed the interpretive structure of experience by arguing that human experience is mediated and interpreted through language (Inglis & Thorpe, 2012:101; Andrews, 2012). Language as a human product therefore renders the sense-making process possible by creating perceptions and facilitating the construction of reality. It provides a means of structuring the way the phenomenon is experienced by transmitting thoughts and feelings (Andrews, 2012). This transmission can never be possible without the body of knowledge which is bound by the interactions of individuals

within society and personal beliefs (Berger and Luckmann 1991; Huber & Gillaspy, 1998).

By and large, how knowledge is constructed and understood is guided by everyday life accounts (Inglis & Thorpe, 2012:94). The shared meaning and understanding is so deeply embedded in reality that innovation of knowledge is often perceived to be unnecessary given that reality is mundane and largely taken for granted. The approach of understanding reality through the process of social construction implicates that the world is interpreted through the body of knowledge rooted in language, shared meanings and understanding. Subjective reality encompasses shared meaning and understanding to the degree that it has the potential to free people to engage in the modification of knowledge and drive their everyday actions (Huber & Gillaspy, 1998:194).

Since interactionists are concerned with meanings of actions and self, they are also interested in a theoretical analysis of how language develops and its importance for the self. Within that framework, different contexts could give different meanings to the same experience. In terms of HIV, the body of knowledge and the illness's unique lexicon have developed tremendously since the beginning of the epidemic. The HIV vocabulary does not only include medical terms but also includes everyday parlance and experiences as conceptualised by ordinary lay people affected or infected by the virus. As a result, the body of knowledge of HIV, albeit very complex, is defined pathologically by medical and societal constructs which have produced the epidemic's own language (Huber & Gillaspy, 1998:195). For example, the language of the HIV epidemic embodies cultural tendencies which are socially distributed as

knowledge (Huber & Gillaspay, 1998:195; Overgaard & Zahavi, 2009:106). So, in the context of HIV, ART and pregnancy, language and the body of knowledge inform the construction of concepts such as stigma and motherhood. In essence, the world can only be known in relation to people's experience of it and not independently of that experience. Exhibiting relative fluidity and focusing on "cognitive constructions of definitions of self" (Lester, 1984:29), the study looked at the construction of meaning in the interaction process of stigma and that of motherhood from a symbolic interaction perspective.

The embodied experience of pregnancy is further reflected in the identity of the woman. Blissful or not, pregnancy has a tremendous symbolic significance for women from different cultures. This strong symbolic realm influences personal behaviour, intentions, motivations and relationships. On the other hand, it is also influenced by an array of socio-structural factors such as the need to carry on the family name and the need to secure marriage or relationship (Smith and Mbakweni, 2007; Schwartz, et al., 2012a; King et al., 2011; Myer, et al., 2010). The study attempts to discover the decisive perspectives for the uncovering of the enigma of pregnancy, even in the presence of HIV and ART.

1.6.2. Stigma

Sociologist Erving Goffman approaches stigma as a socially-embedded process mapped onto people while discounting social normality (Goffman, 1963:3). For Goffman, stigma represents a construction of deviation from socially accepted normality. The deviation derives from the culturally embedded meanings of a

particular phenomenon during a particular period. These meanings have a powerful hold on people because they are often based on pre-constructed stereotypes and prejudices (Alonzo & Reynolds, 1995). In trying to comprehend the factors that give rise to the stigmatising attitudes, Goffman identified three types of stigma that often cleave communities along existing social expectations: physical, personal and social (Goffman, 1963:4). At its most basic level, physical stigma, from Goffman's perspective is characterised by overt or external deformations; personal stigma by deviations in individual traits; and social stigma by tribal traits that could be deemed to be a deviation from the normal.

The root of all types of stigma is failing to meet normative expectations by mere possession of the undesired differentness from what others perceive as normal (Goffman, 1963:5). Hence, his framework has been appropriated in much research on HIV stigma which represents a common experience for many people with HIV (Alonzo & Reynolds, 1995; Parker & Aggleton, 2003; Skinner & Mfecane, 2004). This may occur at an individual level, where stigma undermines the person's identity and capacity to cope with the disease. Although a person's perception of stigma may be very individual, to a large extent, this perception is inferred from a multidimensional and socially defined meaning (Parker & Aggleton, 2003).

As a social construct, stigma is not solely about HIV as a disease, but always intersects with existing social prejudices that may have contributed to the social constructions of HIV (Huber & Gillaspay, 1998:200; Parker & Aggleton, 2003). As a result, because it is socially, individually, or culturally patterned, it limits the possibility of disclosure even to potentially important sources of support such as

family and friends (Alonzo & Reynolds, 1995). This multidimensional character manifests overtly and covertly to produce and shape the social trajectory of HIV stigma (Alonzo & Reynolds, 1995). Likewise, mothers' identities may be simultaneously both threatened and reinforced by stigma after the discovery of their HIV status and during disclosure (Wilson, 2007). To curb any form of stigma, public presentations are often adapted to offer the stigmatised people a platform to give a version of their point of view (Goffman, 1963:25). In South Africa, the plight of the stigmatised was embodied through news media taking advantage of the human interest factor in compelling stories. These stories allow us to enter the world of the stigmatised by focussing attention on generating sympathy and compassion (Alonzo & Reynolds, 1995). However, for the stigmatised, these presentations also establish relational boundaries between the deviant and the normal.

For example, Nkosi Johnson was denied school admission, Gugu Dlamini was attacked by a mob and murdered after she had publicly revealed her HIV status, and Lorna Mlofane was raped and then murdered after her three rapists discovered that she was HIV-positive (Skinner & Mfecane 2004). Having an insidious influence, such reports of stigma are pervasive, extending even to the health professions, and are largely influenced by ethical and legal dilemmas, especially around confidentiality (Anderson, 2009; Ullah, 2011; Feyissa et al., 2012; Moodley et al., 2014)

From its beginning, the HIV epidemic has evoked negative and sometimes antagonistic attitudes towards HIV infected people resulting in a pool of metaphors. The use of specific stigmatising terms in daily discourse as a source of metaphor has played, and continues to reveal, the illness in all its complexity (Brandt, 1988; Alonzo

& Reynolds, 1995; Skinner & Mfecane, 2004). Leading to the impediment of treatment and prevention efforts, the social construction of stigma further complicates how people view the disease (Skinner & Mfecane, 2004). In turn, stigma in all its forms has a powerful impact on the choices made in responding to the disease.

The study's focus was greatly influenced by looking at the narratives through the lens of the experiences of stigma from participants and how these experiences have affected their personal and social lives; how they manage resistance to stigma and how they respond to it. The three types of stigma from Goffman's perspective could be identified in the experiences of the study participants. For example, HIV-positive pregnant women could be stigmatised physically because of the mere fact of being pregnant and HIV-positive, while personal stigma can be an attribute of a person's internalised acceptance (or lack of acceptance) of their HIV-positive status. Lastly, social stigma could permeate through accepted and normative community values and perceptions that the HIV-positive pregnant woman, because of her pregnancy, might infringe upon. Generally, mothers could go through instances of overt or covert forms of discrimination. They could bear a stigma or be relatively untouched by it when making reproductive choices while on ART.

1.6.3. Motherhood

Motherhood is an important part of identity construction to many women and this aspect was explored in the study. Although the experience of motherhood is an extremely personal event in a woman's life, the social context in which it occurs

profoundly shapes her experience of everyday life. The phenomenon of motherhood is generally an idealised role that entails a great dimension of sociality wherein the existential self is also accentuated (Ingram & Hutchinson, 2000). Pregnancy is often deemed a cherished form of self-expression and self-worth among many women. The cultural norms and values in most African societies encourage reproduction and emphasise motherhood as a valued role for women; a source of identity. Therefore, fertility is often seen as a necessary reproductive health status in the quest towards achieving social status, and it is not perceived as a social burden (Ingram & Hutchinson, 2000). For women it often symbolises motherhood in the context of social expectations (Harrison & Montgomery, 2001). Moreover, babies symbolise love, approval, and a heritage of affluence and social position, even for a woman without a sense of future for herself (Ingram & Hutchinson, 2000; D'Auria et al., 2006; Kanniappan et al., 2008).

Motherhood presented with HIV and its chronic treatment (ART) could be an existential threat to mothers' identities (Wilson, 2007) as it is central to accounts of their everyday life. Self-perception and societal perceptions of motherhood are subjected to the ideal of a "good mother". HIV often stains this ideal and as it could be perceived to forge a deviation from the inclination of being a good mother given the possibility of vertical infection, subsequent infection as well as the mother's own prospects of her own future and well-being. As a social response, women who deviate from the ideal and accepted norms of motherhood are often subjected to stigma (Ingram & Hutchinson, 2000). The construction of stigma because of this deviation could have huge implications on the health behaviour of women. Among

other factors, it could affect women's health-seeking behaviour and their reproductive choices (Ingram & Hutchinson, 2000).

The overwhelming focus on vertical transmission of HIV from women to their babies reflects the cultural devaluation of women's health. The approach places children's interests before the women's by reinforcing the narratives of "irresponsibility" on the mothers' part (Ingram & Hutchinson, 2000). The determination of establishing and maintaining the ideal of being a good mother somehow dissipates a sense of self from the mothers' point of view. This cultural ideology of motherhood reduces women to their sexual and reproductive capacities. It therefore neglects how motherhood represents a valued role for women, providing an important sense of identity and belonging.

To remedy the attention deflected away from women's own health needs, women's lived experiences should therefore be a focal point of interest. For some HIV positive women who are on ART, motherhood is generally experienced as an intended phenomenon and maintaining the ideal does not prevent them from being pregnant (Craft et al., 2007; MacCarthy et al., 2012). Research has shown that motherhood also seems to provide mothers with a strong sense of self that mitigates their unrelenting desire for the ideal motherhood (Ingram & Hutchinson, 2000; Wilson, 2007). Determination to survive for their children's sake remained a priority in this mothering role despite being on ART with the associated risks posed in treatment adherence, having chronic fatigue and defending their identities as "good" (Ingram & Hutchinson, 2000; Wilson, 2007). On these accounts, questions of how women fulfil the symbolically laden and socially constructed and personal expectations of

motherhood while on chronic medication were grappled with. The study endeavoured to gain insights into how participants experience motherhood as mothers on ART; how they establish and maintain their identities and their perceived understanding of notions of HIV and motherhood. The focus was to examine the social construction of motherhood; how it is influenced by culture, socio-economic factors as well as self-perception and understanding of HIV-positive mothers themselves. These women are pressurised by high expectations which are central to cultural ideals of “proper” or ideal motherhood (Kanniappan et al., 2008; D’Auria et al., 2006). The study explored how these mothers face and resolve challenging issues they experience in their lives; and the extent to which they manage (or do not manage) to negotiate and embrace the lives they want to live as individuals and as mothers.

Drawing on Blumer’s basic principles of symbolic interactionism, the focus was on how participants form meaning as a result of their own experiences. HIV, pregnancy and motherhood are symbolic in so many respects. Symbolic meanings related to these phenomena can change over time and across societies. The study employed symbolic interactionism as a social theory of illness and health care. Some fundamental aspects of the social experience of being pregnant while on ART can be understood through the symbolic interactionist lens looking at patterns created by participants’ interactions and how reality makes up their very existence. Looking at the experiences taking place through a series of communications, social situations and thoughts they have about the phenomena, this enquiry applied a symbolic interactionist perspective to HIV and motherhood. Through this lens the study looked at pregnancy, motherhood and being on ART, and examine how the experiences

and interactions of participants with those of others forms their understanding of reality.

1.7. Conclusion

Although sociological perspectives vary in their approaches, albeit with certain measures of repetitiveness, they share the aim of understanding and explaining the social world. In an attempt to achieve this goal, this chapter combined the insights offered by phenomenology, existentialism and symbolic interactionism. Emphasis was placed on these sociological perspectives and the way in which each approaches the nature of everyday life, the “self” and social interactions. As contexts for these concepts, meanings were placed at the forefront as a frame for the sociological study of human interaction. The construction of meanings via the interaction of people in their various encounters posited that the same phenomenon could result in different self-definitions when employed with reference to a particular area of social life; in this study, being pregnant while on ART.

Chapter 2

LITERATURE REVIEW

2.1. Introduction

Research on the effects of HIV (human immunodeficiency virus) on pregnancy has largely been clinical, focusing almost exclusively on the ability of HIV-positive women to conceive and on pregnancy outcomes (MacCarthy et al., 2012; Mantell et al., 2014). Using mostly quantitative measures and outcomes, this clinically-focused research approach has neglected to consider the lived experiences of women outside of their role as caregivers or as carriers of HIV infection to their babies. The advent of antiretroviral treatment (ART) has transformed HIV from a death sentence to a chronic, manageable condition. In the same breath, the prevention of mother-to-child transmission (PMTCT) prophylaxis has led to women becoming increasingly inclined to reconsider their life prospects, including issues related to their reproductive options and prospects.

Despite the immense health benefits realised by enrolling in the PMTCT programme, women remain faced with challenges in exploring their personal desires and social expectations surrounding pregnancy and motherhood. During pregnancy, HIV-positive mothers grapple with the inevitable health concern of reducing MTCT, the survival of their babies as well as their own well-being. However, their concerns are given little or no regard and are largely taken for granted as the health of their babies takes centre stage. Few research studies have explored the experiences of HIV-positive mothers from their own perspectives and the ways in which their serostatus

and its concomitant treatment impact on pregnancy and childbearing (Persson et al., 2003; Nelms 2005; Pretorius et al., 2005; MacCarthy et al., 2012).

This chapter placed the HIV epidemic in South Africa in its historical context and thereafter introduce pregnancy within the context of HIV. It also provided a summary of literature documenting the experiences of HIV-positive pregnant women around themes relating to pregnancy knowledge and intent as well as specific challenges of motherhood while living with HIV and being on ART.

2.2. Historical Narrative of HIV in South Africa

The first two cases of HIV infection in South Africa were reported in 1982 (Ras et al., 1983). With no treatment, HIV radically altered the patterns of morbidity (disease) and mortality (death), threatened legal rights, and overwhelmed the health system in South Africa (Marks, 2002). The political, social and economic status and state of the country spurred the devastating impact of the HIV epidemic (Karim & Karim, 2002; Marks, 2002). The migrant labour system, an essential element of apartheid design, was a major factor in creating the trellis for transmission of sexually transmitted diseases like syphilis and later the spread of HIV (Karim & Karim, 2002; Fassin & Schneider, 2003).

2.2.1. Lack of Political Leadership

At the dawn of the new dispensation, South Africa's freedom was tailed by the inevitable rise in new HIV infections. The country found itself largely taken over by a

new struggle; the control of HIV and AIDS. The new democratic society struggled to frame HIV and AIDS as a dire health issue (Karim & Karim, 2002) and speculations about what causes AIDS (acquired immuno-deficiency syndrome) were profound (Fassin & Schneider, 2003). Because consensus was lacking on what causes AIDS, public reaction to the epidemic bordered on hysteria. The fear led to an overreaction to the actual problem and diverted attention away from the real public health concern (Fassin & Schneider, 2003). President Thabo Mbeki's government was adamant that ART would cause more harm than good. In their view, ART would be iatrogenic, meaning that the treatment would actually cause more symptoms and side-effects than the original illness (Abbott et al., 2008).

Until now, in the second decade of the 21st century, the former government is largely shadowed by former President Mbeki's obstinacy during his tenure to promote nutritional and other alternatives to clinically tested medicines (Schneider, 2002; Wouters et al., 2011). Also, this dissent shaded the possible free roll-out of HIV treatment in public health facilities (Schneider, 2002; Wouters et al., 2011) not to mention the impact it had on the continued high HIV mortality rate which caused economic, social and personal havoc in the country (Arndt & Lewis, 2000; Smith, 2012).

2.2.2. HIV Activism spawned by the Treatment Action Campaign

As the medical reality of AIDS became clearer all over the globe, the gradual acceptance of the epidemic as a reality also took momentum. Epidemiologists, health care practitioners and activists joined forces to demand an urgent and

concerted response to the epidemic. In South Africa, the treatment procrastination and the infamous era of 'AIDS denialism' led by former President Thabo Mbeki advocated the founding of the Treatment Action Campaign (TAC) in 1998. Among other HIV and AIDS related issues, TAC's activism sensitised the public to a discourse around ART scale-up in South Africa (Grebe, 2011; Colvin, 2013). They dealt with the powerful political gatekeepers who dismissed and refused women's access to PMTCT. Representing the voices of many HIV-positive women, the TAC embarked on a PMTCT campaign which led to the government being compelled by the country's highest court, the constitutional court, to roll-out nevirapine (NVP) in 2002 to prevent the transmission of HIV from pregnant mothers to their unborn babies and this subsequently led to the implementation of a generalised PMTCT programme that saw the light in 2003 (Ford et al., 2011).

Following the constitutional court ruling, the TAC persisted in taking the South African government to task to deal with HIV head on. During the denial era, the TAC galvanised communities through information, education and communication sessions to unmask the myths and to dispel incorrect information from becoming the basis of health policies (TAC, 2013). Due to their diligent activism, the general sense of denial was decreased and the trust in public health was restored after the general public health sector roll-out of ART in 2004. Recently, the roll-out of fixed-dose combination (FDC) ARVs in all public-sector primary health care facilities came as a critical intervention forged resolutely by the TAC's undying treatment activism (TAC, 2012). TAC members' testimonies of living with HIV and 'edutainment' programmes

also played a vital role in showing that with proper treatment and information, the majority of infected people could lead normal and healthy lives (TAC, 2013).

2.2.3. Scale-up of HIV Response

The total number of HIV-positive people in South Africa was estimated at approximately 7 million in 2016; a significant increase from the estimated 4.7 million in 2002 (Statistics South Africa, 2016). On the other hand, the rate at which the population in South Africa is being infected (incidence rate) is declining year on year from 1,77% in 2002 to 1,27% in 2016, while the number of people living with HIV (prevalence rate) is estimated to be at 12.7% in 2016 from 10.3% in 2002. Until today, the development of an HIV vaccine is still a prevention strategy which needs to be realised (Cohen, 2007; Walker & Burton, 2008; Cohen, 2015; Macdonald, 2015). For the time being, ART is an available and the most effective treatment intervention for people living with HIV (PLWH). ART refers to complex drug regimens that slow the replication of HIV in the body. The treatment brings about dramatic reductions in the amount of the virus circulating in the body. Consequently, the decline in the viral load is associated with fewer opportunistic infections and longer life expectancy (Bekker et al., 2014).

ART cannot completely clear the virus from an infected person's body but these clinical indications have resulted in marked reductions in AIDS-related morbidity and mortality; they have given rise to the construction of HIV as a chronic, manageable illness. In retrospect, the current government and the Department of Health under the auspices of Dr Aaron Motsoaledi have learnt from past policy prescriptions and

preconceptions and have changed their approach to HIV care drastically. The country has seen a massive scale-up of its response regarding HIV treatment interventions. For example, HIV patients can now benefit from earlier initiation on ART. Following the 2013 WHO treatment guidelines, the country has increased the threshold of ART initiation to a CD4 count of 500 or less (Department of Health, 2013). As from September 2016 CD4 count eligibility was removed and currently all HIV-positive South Africans qualify for ARVs as soon as they test HIV-positive, irrespective of their CD4 count (Motsoaledi, 2015).

As coverage and access of ART improved, the broader benefits of ART became apparent. New-born babies were the first key population to be successfully protected from contracting HIV with ART. The benefits accrued to give hope to potential parents living with HIV who wanted to have children. HIV-positive mothers transitioned from having no access to NVP for their babies to being offered lifelong ART, including during pregnancy for themselves (Motsoaledi, 2015). As support for combatting MTCT seemed to have plateaued, HIV-positive mothers opened up about their experiences of motherhood and research narratives have turned their attention to the mother as subject (Myer et al., 2010; King et al., 2011; Schwartz et al., 2012).

2.3. Reproductive Choices in the Era of HIV

According to the Executive Director of UNAIDS, Michel Sidibé: “This epidemic unfortunately remains an epidemic of women” (United Nations News Centre, 2010)

as it mostly affects women in their reproductive years. At this stage of sexual development, women face a greater risk of HIV infection with a ratio of three women infected with HIV to two men infected (UNAIDS, 2014). Because physiologically the vagina has a greater surface area for the virus to be passed into the bloodstream, women are especially susceptible to HIV when transmitted sexually (Quinn & Overbaugh, 2005). Socially, women are also more vulnerable to infection as they are often victims of sexual abuse, assault and exploitation. This is frequently due to them being perceived as occupying devalued positions within societies and because of prevalent patriarchal practices in many societies.

The South African medical fraternity reported the first HIV incidence in pregnancy in 1988 at Baragwanath Hospital, Gauteng (McIntyre, 2006). Currently, South African women account for 67% of all national HIV infections and the proportion has increased significantly over the years (UNAIDS, 2014). The prevalence rate has been documented to result from treatment complacency; an increase in sexual debut before the age of 15; young females having sexual partners of at least five years older than themselves; and an increase in multiple sexual partners in males. These factors however do not deter some women living with HIV from having children and these choices are made despite their HIV status (Erhabor et al., 2012; UNAIDS, 2014).

The pleasure and a sense of social and personal fulfilment associated with motherhood, the need to carry on the family name and the need to secure marriage

or significant relationships are some of the factors influencing pregnancy intentions (Smith and Mbakweni, 2007; Myer et al., 2010; King et al., 2011; Schwartz et al., 2012). Also, a lot of pressure is placed on fertility and motherhood for social approval regardless of HIV status (D'Auria et al., 2006; Cooper et al., 2007; Kanniappan et al., 2008; Cooper et al., 2009).

In the beginning of the HIV epidemic, a compromised immune system in pregnancy was thought to render HIV-positive women more susceptible to complications which deterred many from becoming pregnant (Craft et al., 2007). Reports from literature reviews and cohort studies state that decision-making about pregnancy was generally underscored with ambivalence and a lack of information from HIV-positive women and health care workers (Ingram & Hutchinson, 2000; Myer et al., 2010; MacCarthy et al., 2012; Schwartz et al., 2012). Generally, health care information in the context of HIV was centered on pregnancy prevention via coerced sterilisation and abortion (MacCarthy et al., 2012). It was also commonplace for health care workers to seldom or never discuss pregnancy intentions with HIV-positive women (De Bruyn, 2004; Farlane, 2008). Women on ART also expressed a lack of information and fear of becoming pregnant while on ART (Craft et al., 2007; King et al., 2011; Schwartz et al., 2012a).

Today, a turnaround in both attitudes among women and knowledge of health care workers has significantly influenced women to be more confident in the efficacy of risk reduction strategies as well as in determining the ambiguities posed by HIV

infection and motherhood (Sandelowski & Barroso, 2003; Moodley et al., 2014). Women generally narrate stories of adequate care from health care workers but experiences of stigmatisation are still captured in the relationships of patients with health care workers (Sanders, 2008).

The increased survival rate and decline in morbidity amplified by ART has led to renewed hope among women living with HIV intending to have children (Cotter et al., 2006; Long, 2009; Liamputtong & Haritavorn, 2014; Adam, 2015). On the other hand, their decision-making in terms of their sexuality and reproductive health is significantly influenced by socio-economic and biological or physical vulnerability, socio-cultural factors, gender-based violence and other factors (Craft et al., 2007; Schwartz et al., 2012). Yet few studies have focused on mothering within the context of HIV as a maternal chronic illness (Sandelowski & Barroso, 2003). In the midst of all these key challenges, it has been found that HIV diagnosis does not dampen the appeal of motherhood for some women (Ingram & Hutchinson, 2000; Craft et al., 2007).

Recently, several studies concede that HIV infected women are now more likely to desire children (Adam, 2015). There is evidence that births to HIV-infected women have increased, and that fewer women are opting for terminations of pregnancy (Craft et al., 2007; Adam, 2015). These are good clinical stories to tell; however, they leave one with little sense of what the experiences of being an HIV-positive mother on ART must be like. The challenges of meeting these deeply internalised

expectations while grappling with the demands of the illness can be daunting for pregnant women who are living with HIV and who are on ART as they often find themselves in challenging socio-economic positions already.

Pregnancy subsequently represents the opportunity for PMTCT enrolment along a continuum of care. Research studies report that women do continue with childbearing despite their HIV-positive status and being on ART, and this can be strongly attributed to full participation in the PMTCT programme (Myer et al., 2010; Schwartz et al., 2012). The PMTCT programme has been widely researched as being the major enabler of informed decision-making whether to become pregnant or to keep the baby should a pregnancy occur (King et al., 2011; Schwartz et al., 2012; Moodley et al., 2014). Access to PMTCT services has opened the gateway to fulfil the reproductive rights of women to become pregnant without being coerced into sterilisation (MacCarthy et al., 2012). Many studies have shown that irrespective of the intense stigma and discrimination women face upon an HIV-positive diagnosis, they decide to continue with childbearing (Craft et al., 2007; Smith & Mbajweni, 2010; Adam, 2015).

2.4. Prevention of Mother-to-Child Transmission of HIV

The PMTCT programme is an evidence-based package of interventions aimed at reducing the rate of MTCT of HIV (also known as vertical transmission). Without such interventions, up to 30% of infants born to HIV-positive mothers would have acquired the virus during pregnancy or delivery, or through breastfeeding

(Department of Health, 2015). In ideal antenatal care (ANC) settings, effective PMTCT offers immediate health gains in terms of increased life expectancy and reduced mortality of mothers and children (Adam, 2015). The programme is centred on the use of ART, infant feeding counselling and support, and safer delivery practices within a continuum of care (WHO, 2000). It serves as a platform for disclosure of women's reproductive options and of medical, social, and psychological benefits and risks. However, missed opportunities to participate in all PMTCT interventions can severely compromise its efficacy and the ultimate goal towards HIV-free survival of babies as they continue their life trajectories (Cotton et al., 2009; Rispel et al., 2009). For an optimal outcome, pregnant women who are HIV-positive should enrol for a complete PMTCT cascade of interventions: ANC, HIV testing, breastfeeding and ART (Department of Health, 2015). To obtain maximum benefits from the interventions, leakage at any step in the cascade should be prevented.

Since its inception, the PMTCT programme has undergone many evaluation studies which have observed both its successes and challenges in implementation and effectiveness (Cotton et al., 2009). In South Africa, the initial interference and denial from the government of the Mbeki era slowed down access to HIV prophylaxis to pregnant women (Ford et al., 2011). Also documented is a tally of challenges which hamper the prevention intervention, for example, the lack of counselling and testing during ANC and a lack of PMTCT knowledge on the part of mothers and health care workers (Rispel et al., 2009). In addition, other challenges include the lack of HIV test results and NVP prophylaxis received by baby and mother, as well as health-seeking behaviour that is not conducive to receiving the correct care and information

in order to ensure the best health outcomes during and after pregnancy (Delva et al., 2006; Nkonki et al., 2007; Rispel et al., 2009) These impediments unfortunately tarnish the successes of the programme which has already come a long way, and indicate that there is still room for improvement.

Nonetheless, with social activism and changes in the government's stance on the intervention, leaps and bounds were made. Access to ART, improved health facility infrastructure, competent health care workers and policy guidelines are documented among the developments of the programme (Rispel et al., 2009). Successfully, the prevention programme has evolved from no roll-out of ART to single dose NVP; dual drug prophylaxis (zidovudine and NVP) to the availability of FDC (McIntyre, 2006; TAC, 2013; Department of Health, 2015). The achievements in preventing vertical transmission of HIV to the foetus reduced the rate of transmission from about 20% in 2004 to 2.7% in 2011 (De Cock et al., 2000; Department of Health, 2014).

2.4.1. Antenatal Care

ANC is another component of maternal, new-born and child health that promises to potentially save the lives of mothers and babies through a package of evidence-based interventions. By offering integrated care, ANC influences health care-seeking behaviour of mothers during pregnancy. Essential interventions in ANC include preparation for birth and motherhood as well as prevention, detection and management of health problems during pregnancy that affect mothers and babies (Department of Health, 2015). ANC attendance is therefore a possible entry point for women to access timely reproductive health services at primary health care level. It

is also likely to be a good place for health education when women could be receptive to health messages because it links these mothers with the health system. Timely identification of pregnancy is therefore important for initiating ANC among HIV-positive women, moreover for those already on ART (Schwartz et al., 2012a). The national guidelines recommend the first ANC visit at 14 weeks of pregnancy (Department of Health, 2013a). Yet, many pregnant women with an unknown HIV status present late in gestation for ANC, i.e. after 20 weeks (Myer & Harrison, 2003; Craft et al., 2007; Stinson & Myer, 2012). Denial, health systems failure (e.g. lack of stock of HIV test kits and ARVs; long waiting periods), social barriers, and stigma are among the challenges widely reported in qualitative studies for late ANC bookings (Nkonki et al., 2007; Stinson & Myer, 2012).

To encourage early ANC registration and to improve continuity of care to the mothers, a cellphone-based initiative named “MomConnect” was launched in South Africa two years ago. This digital health service requires each pregnant woman to go for her first ANC session at a public health facility and to be registered and provided with personalised free text messages containing ANC information and advice on pregnancy (NGO Pulse, 2014; Department of Health, 2014a). The earlier ANC is accessed, the lower the chances of vertical transmission and the risk of avoidable maternal and infant death may also be more effectively addressed.

2.4.2. HIV Counselling and Testing

HIV counselling and testing (HCT) is central to the prevention and treatment continuum of care. In 2010, the national Department of Health embarked on a

national HCT campaign to encourage people to know their HIV status and to access treatment (Department of Health, 2015). HCT is seen as a gateway into HIV prevention, treatment and care and PMTCT services. For pregnant women who present themselves at ANC facilities, testing for HIV may result in the greatest change of a total reduction in MTCT and conversely, late bookings could be a hindrance to this prevention initiative (Amnesty International, 2014). Various factors have been reported to be barriers to full participation and uptake of HCT interventions. These challenges have been identified as long waiting times at clinics, staff shortages, and the fear of stigma and discrimination (Amnesty International, 2014). Great strides have also been made, as HIV testing of pregnant women is approaching 100% coverage and all pregnant women are considered part of the programme whether they test HIV positive or HIV negative as seroconversions can occur at any point in time, even during pregnancy (Department of Health, 2015).

The effectiveness of PMTCT depends on various factors: the successful linkage of HCT to the continuum of HIV care, and minimal health system leakages resulting in a loss regarding follow-up of patients (Department of Health, 2015). The inclusive approach greatly influences the detection of seroconversions occurring during pregnancy or breastfeeding. It is estimated that 4% of those who initially test HIV-negative in early pregnancy test HIV-positive later in the same pregnancy (Department of Health, 2015). This is a significantly bad outcome for PMTCT because HIV seroconversions present a high risk of vertical transmission due to a high maternal viral load in the absence of prophylaxis treatment (Department of Health, 2015).

2.4.3. Breastfeeding

Infant feeding poses the biggest challenge in the HIV era. Benefits of breastfeeding with or without HIV infection are profound and have been amply described in the literature (Taha et al., 2006; Coovadia et al., 2007; Schack-Nielsen & Michaelsen, 2007). HIV is known to have caused contention and confusion about breastfeeding for HIV-exposed babies (WHO, 2000). For instance, in 2001, the national PMTCT programme recommended formula feeding for infants up to six months of age. This was later withdrawn and replaced by the promotion of exclusive breastfeeding, (i.e. giving only breast milk and no other liquids or solids to babies during their first six months of life) in 2011 (WHO, 2000; Ijumba et al., 2013). The controversy reflected in infant feeding guidelines and policies has had a negative impact on mothers' feeding decisions (Moland et al., 2010). It is well established that breastfeeding is generally one of the most effective strategies to reduce infant mortality.

Infant feeding policies recommend that HIV-positive mothers should breastfeed exclusively unless formula feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) (Moland et al., 2010). Exclusive breastfeeding is hailed the healthiest way to feed any baby irrespective of the mother's HIV status. This feeding option is recommended for the first six months of the baby's life to effectively reduce MTCT and to maintain the overall benefits of breastfeeding (Coutsoudis et al., 1999; Iliff et al., 2005; Alcorn, 2005; Coovadia et al., 2007; Slater et al., 2010); the longer the mother breastfeeds, the greater the risk of vertical transmission (De Cock et al., 2000). Pasteurising breast milk is another appropriate feeding option if there has been a leakage in the PMTCT cascade or in cases where the mother's viral load is

high or ART has not been initiated. Lastly, formula feeding is highly recommended when it adheres to the same AFASS criteria. Mixed feeding is strongly discouraged as it could be the feeding mode associated with the highest rate of MTCT (Coutsoudis et al., 1999).

Infant feeding options are significantly influenced by social and cultural practices rather than informed medical choices (Leshabari et al., 2007; Moland et al., 2010). As a result, HIV transmission via breastfeeding is frequently overlooked by infected mothers and has the potential to undo prevention gains achieved with drugs during birth. Deciding on infant feeding options presents notable challenges for the mothers. The mothers have to make informed decisions which could be difficult to fulfil due to many challenges, including the fear of stigma. Also, not disclosing could lead to a more fractured sense of self where one constantly has to be on guard not to accidentally reveal one's status through chosen feeding options. Each feeding mode is aligned with some kind of stigma and therefore cannot easily be adhered to. In cultures where breastfeeding is a socially constructed norm and a maternal function, formula feeding has been perceived as a marker for mothers' HIV-positive status; likewise, weaning early and not giving water or anything else raises suspicion (Long, 2009:38,137; Leshabari et al., 2007). Framed by women's own stories, not breastfeeding also puts these mothers under cultural criticism as "bad mothers" (Long, 2009:137).

2.5. Pregnancy and HIV in a time of ART

The experience of pregnancy is a personal event in a woman's life which is also characterised by complex and shifting social and medical constructions. Before ART became widely available, many diagnosed HIV-infected women would not have considered parenthood, partly because their reproductive rights were not recognised due to their serostatus (De Bruyn, 2012). Diagnosis and life expectancy were poor, and the risk of a child being infected was around 15-20% in South Africa (De Cock et al., 2000; McIntyre, 2006). HIV diagnosis was associated with a decline in pregnancy incidence and live birth rates, as well as increases in abortion rates (De Bruyn, 2012). The concern about HIV in pregnancy without access to PMTCT prophylaxis and without the generalised availability of ART for pregnant mothers used to be about the progression of maternal disease and MTCT (Craft et al., 2007).

Although the desire for motherhood coupled with an HIV-positive status is fraught with challenges, women have benefitted from the development of ART and care during pregnancy and childbirth (Long, 2009; Salamander Trust, 2009; Liamputtong 2013). A large body of research about women and HIV reflects a broader medical inclination of concern for women's health only in terms of their reproductive roles rather than understanding the women's narratives about their own, personal experiences. Placed in a social context by Marks (2002), the HIV epidemic in South Africa has been shaped not only by powerful medical factors, but by behavioural, social and cultural factors as well.

2.5.1. Adherence to ART

Strict and disciplined adherence to self-administered drugs is never easy. ART drugs must be taken daily for the rest of a person's life in order to prevent potentially dangerous side-effects and resistance. Also, just because patients have been prescribed ART does not mean they are willing to begin lifelong treatment. Disclosure, adherence and retention of patients are among the challenges for HIV prevention interventions as well as in scaling up ART (Nkonki et al., 2007; TAC, 2013). Disclosure has a huge bearing on the ability to adhere to medication and to access support (Campbell, 2004; Skhosana et al., 2006; Greeff et al., 2008). Also, high rates of loss due to follow up (patients who stop taking treatment and cannot be located), "pill burden", and denial (where women have neglected to take NVP prophylaxis because they did not believe they were HIV-positive), are other challenging factors (Nkonki et al., 2007; Nachega et al., 2012; TAC, 2013). Recent studies have reported narratives from PLWH (people living with HIV) of good ART adherence despite initially experiencing side-effects (Wouters & De Wet, 2015).

During pregnancy, poor adherence to ART is associated with an increased risk of MTCT. The introduction of FDC meant a reduction in the "pill burden" for mothers and increased the likelihood of treatment adherence and retention in care (TAC, 2013). Increasingly, studies are showing how the use of digital medical technology can improve ART adherence and ensure full coverage of targeted health interventions. For example, one of the goals of "MomConnect" is to link pregnant women to maternal and child health services using the woman's cell phone as a tool for digital health. In this age, the use of cell phones is nearly universal; hence this tool serves as a good basis for fast-tracking the elimination of MTCT (Department of Health, 2016). Being determined to survive for their children's sake remained a

priority for mothers despite being on ART with associated risks to adherence being posed (Ingram & Hutchinson, 2000; Sandelowski & Barroso, 2003; Wilson, 2007).

2.5.2. Stigma and Disclosure

From the onset of the epidemic, HIV and AIDS have been associated with fear, stigma and discrimination. The epidemic has negatively affected all aspects of prevention, diagnosis, treatment and care - with grave consequences. As a result, the impact of stigma on the lives of those living with HIV has been widely researched (Skhosana et al., 2006; Greeff et al., 2008; Long, 2009; Colombini et al., 2014). In the same line, ART has largely normalised HIV by rendering it a chronic condition and helped bring it out of the proverbial closet. But the epidemic continues to carry considerable stigma which also impacts significantly on people's lives (Lekas et al., 2006). Stigma is omnipresent with HIV and reflects the interrelated issues of fear and disclosure (Greeff et al., 2008). PLWHs are frequently confronted with the important, albeit difficult, decision of whether or not to disclose their HIV status. The choice to disclose reflects the way a person experiences and copes with the illness and her right to privacy and dignity (Greeff et al., 2008). Stigma and disclosure generally have an inversely proportional relationship; the higher the chances of stigma, the lower the likelihood of disclosing.

According to SANAC (2014), "stigma can be directed internally, by a person living with HIV towards themselves (called self-stigma) or externally by people towards a person living with HIV (called external stigma)". Because self-stigma is internalised

and perceived, it impacts on the thoughts and actions of the individual. Some people may perceive HIV as a shameful disease, therefore creating restrictions around their social and interpersonal relationships (Wright & Mwinituo, 2010; Skinner & Mfecane, 2004). There have been anecdotal reports of mothers who have internalised the self-inflicted stigma by peeling the labels off ARV medications so that others would not see the drug names or pretending to take vitamins themselves or give their babies vitamins instead of ARVs.

Although it is the focus of all HIV interventions, stigma deters many members of key populations from learning their HIV status or accessing life-saving interventions. From the onset of the epidemic, the fear of HIV as a killer and an incurable disease was a catalyst of an array of largely detrimental social reactions. The fear and stigma led to a resistance of information and action in relation to HIV. People imagined, without scientific basis, many different ways in which the virus was transmitted. Hence HIV infection is inundated with metaphors of shame, fear and death (Parker & Aggleton, 2002). These myths often gained professional support and therefore led to misguided public policies such as forcing mothers to abort, while scientific evidence of HIV modes of transmission was acknowledged to be secondary.

In South Africa, the erstwhile government's ambivalent response to the epidemic and reports of violence and discrimination against PLWHs fuelled the fear of disclosing one's HIV status. Some reports of stigma have had far-reaching consequences, extending even to health care workers (Anderson, 2009; Ullah, 2011; Feyissa et al.,

2012; Moodley et al., 2014). There have been some instances of reports of health professionals or health facilities that have refused to treat seropositive patients, as well as instances of a breach in health provider-patient confidentiality, thereby challenging the traditional ethical values of the health care profession (Skhosana et al., 2006; Altenroxel, 2001). The anticipation of stigma relating directly to ART adherence, fears associated with premature death and the child's survival, and negotiating safe sex remain obstacles to disclosure (Skhosana et al., 2006; Wouters & De Wet, 2015). As a result, because it is socially, individually or culturally patterned, it limits the possibility of disclosure even to important potential sources of support such as family and friends (Alonzo & Reynolds, 1995).

HIV-positive women are often compelled to decide to disclose their HIV-positive status to their children, partners and relatives (Sandelowski & Barroso, 2003). In a context of continued HIV-related stigma, disclosure of HIV-positive status demands immense confidence and self-determination. The decision-making process is charged with cultural and moral constructions of ideal motherhood. Deviating from so-called "ideal motherhood" presents women with a double bind: a no-win situation (Ingram & Hutchinson, 2000). In these double binds, mothers find themselves in an untenable situation which they cannot exit. They are expected to disclose, but if they do, they subject themselves to stigma. Fear of disclosure and subsequent stigma continue to influence experiences of PLWH even in a time of ART (Ingram & Hutchinson, 2000; Wouters & De Wet, 2015). Narratives about stigma and the fear of HIV still turn PLWH into social outcasts; hence the anticipation of stigma remains an obstacle to disclosure (Ingram & Hutchinson, 2000; Skinner & Mfecane, 2004;

Skhosana et al., 2006; Wouters & De Wet, 2015). Despite the stigma, misconceptions, and cultural influences, mothers are trying to lead fulfilling and meaningful lives. Even when their maternal guilt and fear eclipse their existence, their reproductive decisions are also influenced by positive aspects of motherhood weighed up against these anticipated (or real) negative social pressures.

2.5.3. Motherhood bound to ART

A large body of research concerned with HIV in pregnancy is based on the progression of maternal illness and the transmission of HIV to the child (Myer et al., 2010; Mantell et al., 2014). These studies acknowledge that mothers with HIV face the challenges of incorporating illness into their identity and the possibility of transmitting HIV to their babies, compounded by the dual challenges of caring for themselves and their babies. With the impressive technical advances in medical care and political will, we have witnessed an enormous transformation in the field of HIV infection and reproduction. ART has provided relief from an outlook largely mired in doom and gloom, because despite the side-effects, it has revived hope in parents' and babies' lives (McIntyre, 2006; Kelly, 2007). Mothers living with HIV have hope because ART has brought prospects of a healthy future much closer. Mothers can now imagine a future different from the one previously predisposed to them in an era without ART. However, the experiences of mothers enduring the combination of ART and motherhood are relatively under-researched (Wilson, 2007). Motherhood is often constructed as a function rather than as an experience (Long, 2009) hence in most instances; research depicts the centrality of the child and the marginality of the mother and her experiences. Attention is placed more squarely on the health and

well-being of the baby rather than the mother. Such research fails to view the HIV-positive mother as a subject in her own right.

The dual challenges of being pregnant while on ART and motherhood mean that there are many women who are facing increased psychosocial challenges characterised by feelings of being in a “double bind” (Ingram & Hutchinson, 2000; Sandelowski & Barroso, 2003; Liamputtong & Haritavorn, 2014; Mantell et al., 2014). Presented with ambivalent cultural decisions to live up to the “good mother” ideal, mothers are in constant conflict with that which is inherent in their mothering experiences. This category of mothers continues to shoulder the burden of care and treatment for themselves and their children. They are often the sole providers of care to their children, some of whom are also on ART. Moreover, they are socially and culturally expected to remain in the role of primary child and family caregiver despite their own care and treatment burden (Craft et al., 2007; Schwartz et al., 2012).

Culturally, motherhood gives women on ART a sense of approval (Ingram & Hutchinson, 2000; D’Auria et al. 2006; Kanniappan et al., 2008). It places them in a socially acceptable position wherein they can deflect their energy from themselves to being good mothers; they become oblivious to their own emotions and hardships in order to live “normally”. In a way, motherhood then becomes a type of coping mechanism where mothering is a priority (Ingram & Hutchinson, 2000; Wouters & De Wet, 2015). Even when anxiety and fear permeate women’s lives, the positive shift

brought about by ART enables some women to embrace their experience of living and mothering with HIV.

2.6. Conclusion

I searched and reviewed different studies by accessing different sources to gain an understanding on the lived experiences of pregnant women on ART. The literature review helped me to place my study against the general picture of women, HIV, pregnancy, motherhood and ART. The review also assisted me in the conceptualisation and understanding of concepts related to these topics such as PMTCT, HIV disclosure and stigma, and experiences of mothering with ART. This chapter presented my understanding of these concepts, as well as findings from other studies which were reviewed to provide me with a synthesis of what is known and unknown about the phenomenon under study. To overcome the gap of the unknown I gathered insights into mothers' experiences through a phenomenological methodology which is discussed in the next chapter.

Chapter 3

METHODOLOGY

3.1. Introduction

The aim of this research was to journey with HIV-positive pregnant women on antiretroviral treatment (ART) through their life stories in order to describe and interpret their subjective experiences and perceptions of their lived realities. A combination of different types of qualitative research approaches were appropriate for the purpose of this research in order to uncover the meanings that the participants construct from their own unique perspectives and experiences (Creswell, 2013:44).

In this chapter, I described and justified the research processes I used in the study. The suitability of qualitative inquiry is discussed with reference to the investigation of lived experiences of the study sample. The chapter maps out how the research adhered to strict ethical principles of informed consent, confidentiality and voluntary participation. It describes the process of the research and data collection methods, the sampling decisions, and the type of data analysis. The chapter also presents a brief summary of research participants' demographic and HIV-related profiles and the limitations of the study.

3.2. Methodological Framework

A phenomenological framework, underpinning other qualitative approaches, was applied as it intends to focus on the lived realities of women who share the same

phenomenon of being pregnant while on ART (Creswell, 2007:58). Women shared their narratives focusing on the essence or structure of their experiences of the phenomenon under study. Hence, interpretive frameworks that inform the research study were employed to understand the women's lived realities.

My encounter with HIV-positive women as a fieldworker in several previous studies motivated me to learn more about their experiences. During my previous fieldwork visits at a variety of public health care clinics I would marvel at how easily women who came for their antenatal care (ANC) sessions would relate to one another and how their often spontaneous impulse was to tell their own stories. For most women, recounting narratives about their pregnancy or/and motherhood experiences would be a common thread; a way to find meaning in the experience. This symbolic interaction would afford them an opportunity to be listened to and share their experiences and learn from others. The objective of the study thus developed and materialised in the focus to gain insights into the experiences of HIV-positive women; how they perceive the chronic character of HIV afforded through the availability of ART; and moreover, to explore how they make sense of their experiences of pregnancy and motherhood in light of their infection and its treatment. The study was therefore designed to uncover the meaning of lived experiences by exploring, describing and interpreting the phenomenon of being pregnant while on ART from women's narratives and thereby possibly altering preconceived notions of the phenomenon under study (Starks & Trinidad, 2007).

A qualitative research approach was employed because of its systematic, in-depth manner of capturing people's experiences and their interpretation of events and

circumstances (Katzenellenbogen et al., 1997:181). The study is situated within a qualitative design that incorporates an interpretive framework to make sense of participants' lived experiences. The reliance on qualitative data extracts the descriptive or narrative perspectives which are hidden in quantitative approaches (Katzenellenbogen et al., 1997:181; Wilson, 2007). Following a narrative procedure, discussions with all participants were guided by phenomenological, existentialist and symbolic interactionist perspectives. To attempt to understand the lived realities of participants, the study employed these theoretical perspectives.

As discussed in the literature review chapter, a key tenet of interpretive phenomenology is that it begins in the life-world; the natural world of everyday life. Guided by both descriptive and interpretive lenses of phenomenology, the study seeks to discover the meanings embedded in this everyday life (Creswell, 2007:59). In order to describe and understand experiences that create the day-to-day realities of the everyday life, phenomenology commits itself to descriptions of experiences, not explanations. Motherhood is a crucial part of this study because socially and personally, it is often constructed as a function rather than as an experience. The motherhood experience is not only an extremely personal event in a woman's life, but it is also an event which is marked by complex and shifting social and personal constructions (Long, 2009). Thus, the challenge is to describe things as they are, to understand meanings and essences in the light of intuition and the women's self-reflection.

The experience-centred narrative approach affords participants the opportunity to transform knowing into telling, thereby giving a descriptive account of their lived

experiences (Creswell, 2014:42). The narratives carry content about the participants' lives that I want to understand. It also affords me access into their subjective meaning of the phenomenon that occurs when they are pregnant and on ART. The narrative approach allows me to give the participants the freedom to tell their stories in the manner that makes sense to them; a manner which is not necessarily chronologically prescribed (Creswell, 2007:56). Relying on a combination of the above-mentioned qualitative approaches, I seek to understand the phenomenon under study from the point of view of the participants by situating the narratives within their experiences (Creswell, 2007:56; Hancock et al., 2009). Therefore, I aim to address the meanings HIV-positive women ascribe to being pregnant and on ART.

3.3. Participants

First-person reports of life experiences are what make narrative research valid. Phenomenology refers to a study's focus on the commonalities of participants with regard to a particular phenomenon, as described by those participants (Creswell, 2014:42). Hence the approach is employed as a subjective orientation to reality which rests on first-person experiences as primary data. A prerequisite of participant selection in phenomenological research is to choose participants who have lived through the experience being investigated. Thus, a critical aspect of selecting participants was to locate women among HIV-positive mothers who became pregnant while on ART and who were able and willing to describe their experiences in-depth. As a result, a purposive sampling method was used because participants were selected based on particular criteria which conformed to the research

requirements and to form a reasonably homogenous group (Katzenellenbogen et al., 1997:79; Patton, 2002).

Selecting information-rich participants for in-depth studies is crucial to the logic and the power of purposive sampling (Patton, 2002). Eight HIV-positive women who became pregnant while on ART were invited to take part in the research study precisely because they could offer meaningful insights into the topic of the study; they were not randomly selected. However, with some women it was a challenge to fortify rapport and to obtain rich data even after they agreed to participate. Therefore, three of the initial participants who were on ART at the time of the study, but who were pregnant prior to taking treatment were unable to share their particular knowledge of living with the phenomenon under study and were therefore excluded from the study. Two other women were new moms whom I could not interview because in keeping with customary traditions, I could only see them a month after the birth of their babies. Sadly, one of the willing women was very sick and passed away along with her baby three weeks after giving birth.

Experiencing a form of indifference from some women, I opted rather to focus on the narratives of those participants who showed an interest in the study as an entry point for recruitment. To access additional participants, I used snowball sampling where one woman was recruited who in turn was asked to recommend others to participate in the study (Katzenellenbogen et al., 1997:79; Haralambos & Holborn, 2000:996; Creswell, 2012:146). This sampling strategy, although convenient, may have been limiting in that only a certain section of mothers in the study sites were selected. Participants were related in some way through friendship, kinship ties and

acquaintance from attending the same clinic. The recruitment criteria also meant that all the participants had disclosed their HIV status to someone or were openly living with HIV.

The participants are mothers residing in the Mangaung municipality and the Xhariep district in the Free State province. To consider the need for a variation in the description of a phenomenological study (Creswell, 2007:60), women of different demographic and HIV characteristics were recruited: age, relationship status, number of pregnancies, year of HIV diagnosis, year of ART initiation, etc. were used to include some variety. The overall homogeneity of the group was still valid, however, as they all had to share the fundamental phenomena that underlie the enquiry. Two rounds of in-depth qualitative interviews were conducted with five of the women, while the remaining three were visited once in their natural settings.

Tables One and Two below outline the demographic profile and HIV profile of participants respectively. These individual characteristics are summarised to situate the sample and help provide a context for the research and will thus be reflected on further in Chapter Four.

Table 1: Demographic profile of research participants

Pseudonyms	Age	Children alive	Children dead	Relationship status	Employment status	Highest Education	Number of interviews	Home area
Lethabo	44	3	0	Co-habiting	Unemployed	Grade 10	2	Xhariep
Lerato	29	2	1	In a relationship	Employed	Grade 12	1	Xhariep
Mpho	22	1	0	In a relationship	Unemployed	Grade 11	1	Mangaung
Dimakatso	38	2	1	In a relationship	Unemployed	Grade 10	1	Mangaung
Puleng	34	3	0	In a relationship	Unemployed	Grade 8	2	Mangaung
Matshidiso	34	8	0	Traditionally married	Unemployed	Grade 7	2	Mangaung
Nthabiseng	40	3	1	Co-habiting	Unemployed	Grade 10	2	Xhariep
Rethabile	36	2	1	In a relationship	Unemployed	Grade 9	2	Xhariep

Table One summarises the relevant demographic characteristics of participants. Participants were between the ages of 22 and 44 years at the time of the interviews. The participants had between one and eight children respectively. Although in different relationship statuses, all participants had partners, although these partners were not necessarily the fathers of their children. Only one participant was employed and had completed her secondary education. All the participants were receiving child support grants of R380² per month (about US\$30) per child. One participant was also a recipient of a disability grant. She receives a permanent disability grant of R1250 per month (about US\$90) due to her HIV-status. She is also the only mother who started on ART long before the national roll-out. During her first HIV diagnosis and ART initiation she was living in Cape Town, in the Western Cape Province. This is the only province in South Africa which set a precedent by initiating pregnant women on ART in 1999 and reached 100% roll-out of their PMTCT programme by the year 2003 (Tang, 2010; Cotton et al., 2009; Bateman, 2004; MSF & UCT, 2003).

² A child support grant is money paid to a South African primary care giver of a child until the child is 18 years old. Aimed at lower income households, in order to qualify the applicant has to go through a means test. The test states that the joint income of the applicant should be less than R6 600 (~US\$512) a month if married or less than R3 300 (~US\$256) a month if single. The grant is currently R380 a month per child (~ US\$30).

Table 2: HIV-related profile of research participants

Pseudonyms	HIV diagnosis	ART initiation	Partner's HIV status	Pregnancy intention	Method of baby feeding	Child on ART
Lethabo	2007	2009	Positive (on ART)	Planned	Breastfeeding	2nd born
Lerato	2009	2009	Positive (on ART)	Planned	Formula feeding	none
Mpho	2012	2012	Unknown	Unplanned	Breastfeeding	1st born
Dimakatso	2005	2005	Negative	Planned	Formula feeding	none
Puleng	2011	2011	Positive (not ART)	Unplanned	Breastfeeding	3rd born
Matshidiso	2004	2004	Negative	Unplanned	Breastfeeding	3rd born
Nthabiseng	2003	2003	Unknown	Unplanned	Breastfeeding	none
Rethabile	2005	2007	Unknown	Unplanned	Formula feeding	none

Table Two summarises the HIV-related characteristics of participants as well as whether or not their pregnancies were planned. The participants have been HIV-positive and on ART for between five and 14 years. All participants had received the initial HIV diagnosis during ANC visits in a public-sector primary health care clinic. Moreover, some of the participants had experienced acute illness related to being HIV-positive, including pneumonia, TB, and headaches. One participant also reported managing other health problems in addition to HIV which included epilepsy and high blood pressure. Half of the sample had children on ART and the other half had lost a child due to HIV. The majority of the women chose exclusive breastfeeding as their method of baby feeding. Only one participant has been with the same partner throughout; the partner who is the father of all her children. The others have been with different partners and some have lost partners to HIV. Two participants were aware of their partners' HIV-positive status when they planned to have a child.

3.4. Data Collection

3.4.1. Method

Once approval was granted from the Research Ethics Committee at the Faculty of the Humanities, the fieldwork was launched. I spread the word about my Master's study to family, friends and mothers I met during my fieldwork visits at various clinics. Interested participants were contacted telephonically or visited in person at their homes prior to the interview, partly to build rapport but mainly to ascertain whether or not they qualified to participate in the research study and whether they were interested in participating in the study. They were also informed beforehand as to the type of questions that they would be asked and about the purpose of the study. If they were interested and willing to participate, the date, time and place of the interview were set. Relying on an existential perspective, all interviews were conducted at the participants' homes to ease the participants into the interview in their own familiar day-to-day comfort and space; their natural setting in which they live and interact (Fontana, 1984:4). An assurance of comfort, safety, privacy and freedom from distractions and interruptions was also critical for the setting. Face-to-face interviews were conducted as the vehicle for data generation to gain everyday descriptions of an experience from the participants. The aim was to describe as accurately as possible the phenomenon under study as narrated by participants, refraining from any preconceived interpretations (Starks & Trinidad, 2007).

In addition, personal observations were noted that might have meaningful significance, such as the mood of the participant and non-verbal cues that might have indicated states of discomfort or anxiety, as well as the researcher's personal

impressions of each participant. Consistent with phenomenological methods, open-ended questions were used to initiate the interview and to gain detailed information while the participant put her experiences into context. Participants were given an informed consent form (see Appendix A) describing the study and providing details regarding the study. Informed written consent was obtained from each participant.

3.4.2. Interviews

One of the advantages of qualitative methodology is to extract the perspectives of the individual which are hidden in quantitative approaches. The method provides descriptions and interpretations of subjective experience of research participants. Hence, the first-person narratives of life experiences are the focus of the method. To gain meaningful understanding of the lived experiences from the point of view of participants, I conducted semi-structured interviews with them (Wilson, 2007). The interviews are primary sources of data. Employing semi-structured interviews offered flexibility for the participants to lead the interview in some respects, yet remain guided by the researcher and the initial core themes to be covered during the narratives. To have a guided conversation with participants, an interview protocol (see Appendix B) was developed that resulted in a consistent process of data collection across all interviews. Following the protocol allowed for consistency across all the conversations with all participants about their experiences. The interview schedule was organised around two broad areas of experience: the experience of pregnancy and ART and the experience of motherhood and ART. The broad and general questions were developed to allow participants to construct the meaning of the experience typically transmitted in day-to-day interaction with other people

(Creswell, 2003:8). Supplementing the use of the protocol, I guided the interview in a congenial manner using listening skills through reflections and summarising. The approach enabled the use of prompting and open-ended questions to facilitate the conversation. This characteristic of semi-structured interviews was beneficial because it allowed me to compensate for any weakness in my original interview questions by using the information gained from early interviews to guide later interviews. I also asked additional probing questions to elicit more details from participants when they introduced a relevant topic of interest I had not previously considered (Creswell, 2012:221).

The interviews were between 30 minutes and 60 minutes in duration so as to ensure that I obtained adequate data. In some instances an additional round of follow-up conversations took place to obtain richer data, to get clarifications, and to add on the new topics of interest. Follow-up interviews were between 15 and 20 minutes long and were also recorded. Data was collected in January and April 2016. To facilitate the flow of an open discussion I did not claim expertise on the subject matter but rather assumed a position of being interested in knowing and understanding the participants' experiences (Fontana, 1984:7).

After signing a consent form, a recorded face-to-face interview was conducted. All the participants are Sesotho-speaking. To give a positive countenance that made participants comfortable around me, I conducted all the interviews in Sesotho, my mother tongue. Being a woman with a child of my own gave me insight into their situations, equipping me to illuminate the essence of the lived experience and to set

an ambience for a phenomenologically-orientated interview. Parallel to that, I tried to suspend any presuppositions I may have had about the phenomenon under study, to allow for the collection of a true reflection of the data so that the essence of the data could emerge during analysis. Thus, I was aware that my personal perspectives should be checked so as not to interfere with the collection of the data and of the data analysis, although I am also mindful of the intersubjective nature of building and interpreting meaning. To build rapport, each interview was initiated by collecting demographic data and HIV information, followed by questions about pregnancy and ART. Finally, I asked a series of closing questions about motherhood experiences, and thanked participants for their participation.

The participants' names were changed to protect their identity and to respect notions of confidentiality. All the interviews were transcribed verbatim and translated into English. Recordings were reviewed for accuracy and validated with participants when needed. Additional memos were made regarding key thoughts or interpretations. Most of the data was collected during the initial interviews, but additional very minimal data was also collected when I confirmed the accuracy of my interpretations during the follow-up conversations. Interviews

3.5. Data Analysis

In qualitative research, data analysis is simultaneous with data collection to describe and make sense of the data. This research structure enabled me to make adjustments along the way when new information surfaced. The open-ended

questions generated a set of rich data full of detailed descriptions, providing a strong foundation for intensive qualitative analysis. I familiarised myself with the data collected by means of reading and re-reading it in order to be acquainted with the content of the interviews. I explored the data in detail for common themes which were refined and adjusted as the analysis proceeded to be developed into units of meanings. This was done through writing notes and capturing key ideas and meanings from the data. To complete this procedure, I used a phenomenological lens to elicit description of the essences of the experience as well as heed the existential individual differences in the data.

I analysed the interviews independently, and applied codes to the raw data using key words and phrases. Analysis began during transcription when themes that emerged or issues that were highlighted from the literature were highlighted in bold in the transcript. For each transcript, relevant text was coded as important if it referred to the meaning and sense the participants were making of their experiences. After coding all the relevant text of each individual transcript, code names, which captured the meaning of that part of the text, were ascribed. After this, the code names were clustered across transcripts in order to consider emergent themes. The themes were identified with special reference to the research questions. Names for themes were created and adjusted until they reflected the researcher's interpretation. Themes were divided into sub-themes and meanings were formulated to in an attempt to broadly reflect the shared, albeit unique, experiences of the participants. My supervisor and I discussed individual interpretations, and codes were reviewed, clarified and revised as needed. Based on these discussions, broader concepts were

identified and codes and concepts were organised into two broad themes to finally produce a logical write-up which reflects the content of the narratives.

My intention in the analysis is to illuminate how participants made sense of their lives through the stories they told. I did this to produce meaning from the narrative material around each emergent theme and to support my interpretative assertions. The analysis focused on identifying and describing the women's perspectives, their meanings as well as their subjective views of their pregnancies and motherhood while HIV-positive and on ART. As an iterative process, the focus on the analysis was to present a synthesis of the experience- and subject-centred narratives, as common and as different as they could be.

3.6. Ethical Considerations

During recruitment I provided potential participants with all the necessary information to facilitate their ability to make an informed decision to participate in the research process. This included the stipulation of the expected duration of the interviews and the study, and the voluntary nature of participation as well as my own intentions and identity. The participants were informed verbally of the aims and outcomes of the study prior to them giving their consent to participate. They were told that they had to be HIV-positive and on ART during pregnancy. HIV being a sensitive subject, the researcher was aware that the conversations could lead to emotional distress. As a result, the interview was conducted in such a way that the researcher abstained from putting participants in a therapeutic space in which to be counselled. However, participants were informed that in the event that they found the interviews

emotionally difficult, the researcher would set up appropriate referrals for counselling.

The interviews were meant to probe and explore particular issues around ART, pregnancy and motherhood. No participant was forced to participate; participants were re-informed during the discussion that they could withdraw from the interview at any time. After the purpose of the interview was explained, participants were assured that the information they provided would be treated with the utmost confidentiality. None of the participants expressed that they had found the interviews to be particularly difficult or invasive, nor did any request counselling.

As already mentioned, this study was reviewed for ethical compliance by the Research Ethics Committee at the Faculty of the Humanities at the University of the Free State. Revisions were made to the original ethics application, after which approval was granted. Informed, written consent to participate was obtained from all the participants. The study was deemed to be one of minimal risk to participants and that the probability of harm or discomfort anticipated in the research would not be greater than any ordinarily encountered in the participants' daily life.

3.7. Limitations of the study

As a guided by the descriptive and interpretive lenses of phenomenology, the study is not without limitations. The limitations related to the characteristics of the sample and the sampling strategy. The study may be critiqued in terms of the small sample size which could have implications for the generalizability of the findings. However, it

is acknowledged that generalizability is not necessarily a criterion of a phenomenological study. The study sampling strategy, although convenient, may have also been limiting in that only a certain section of women in the study sites were selected. Participants were related in some way and had to have been pregnant and on ART to qualify for recruitment. The recruitment criteria also meant that all the participants had disclosed their HIV status to someone or were openly living with the HIV virus, thus anonymity was omitted. However, I have respected and treated all their information with the utmost confidentiality. Having done everything in my power to protect their identities, I could not entirely guarantee that their identities would necessarily remain anonymous.

3.8. Conclusion

An interpretive phenomenological framework was used to make sense of participants' lived experiences of being pregnant while on ART. Steps that guided the research process were mapped out to explain the research methodology. Given the potentially sensitive nature of the study, an ongoing concern with regards to the ethics of the research was kept in mind and reflected upon throughout. The design also guided the data analysis and presentation provided in the next chapter.

Chapter 4

THE FINDINGS AND DISCUSSION

4.1. Introduction

To gain more insight into the lived narratives of the participants, this chapter will detail their demographic profiles and unpack and analyse the themes that emerged from the process discussed in Chapter Three. Analysis of the themes will be linked to the study objectives and the literature review (as explained in Chapter Two) to support and/or contradict the findings of this study compared to the literature chapter. The product of qualitative enquiry is firstly to be descriptive. Therefore, this chapter presents the descriptions of the context, study participants and phenomena of interest. Verbatim quotes are included in support of the findings of the study to do justice to the women's lived stories by sharing their words as they were uttered. These excerpts contribute to the descriptive nature of the qualitative research.

As outlined in the previous chapter, the study sample consists of eight HIV-positive pregnant women on antiretroviral treatment (ART). For ethical considerations, pseudonyms have been assigned to ensure confidentiality for the participants. Guided by the interpretive phenomenological framework, the focus of this analysis is on how the participants give meaning to their experiences of being pregnant and on ART. For the purpose of the dissertation, the narratives of the women were translated from Sesotho to English.

The semi-structured interviews that were conducted to obtain detailed narratives generated a set of rich data conducive to detailed descriptions, providing a strong foundation for intensive qualitative analysis. Looking at individual narratives gathered for this study, two broad themes that captured the lived experiences of participants surfaced: the lived reality of pregnancy and ART, and the lived reality of motherhood and ART. These are outlined in Table Three together with sub-themes which characterise the stories told by the women. Overwhelmingly, the HIV pandemic affects women of reproductive age (Cooper et al., 2007; UNAIDS, 2012). As indicated in Table One (in Chapter Three), participants' ages ranged from 22 to 44 years. The oldest, Lethabo, was 44 years old at the time of the study and the youngest participant, Mpho, was 22 years old. Lerato, 29 years old, was the only participant who had completed high school and who was also employed.

Table 3:

Themes	Sub-themes
The lived reality of pregnancy and ART	<i>Protecting the baby</i>
	<i>Disclosure and stigma</i>
	<i>Coping with pregnancy and ART</i>
The lived reality of motherhood and ART	<i>Sources of support</i>
	<i>ART adherence</i>
	<i>Conceptions of the future</i>

4.2. The lived reality of pregnancy and ART

During pregnancy, antenatal care (ANC) presents an opportunity for HIV testing and counselling and enrolment in the prevention of mother to child transmission (PMTCT) programme. The women shared how receiving an HIV-positive diagnosis for the first time during pregnancy forced them to realise the reality of the risks posed to their unborn babies, something which parallels research findings obtained in studies by Long (2009) and Liamputtong (2013). Half of the women received their initial HIV diagnosis during their ANC screening at the clinic; three others while due to give birth at the hospital and one participant while she was admitted to hospital after the birth of her first baby. Four women became pregnant and learnt about their HIV-positive status when ART was relatively new in South Africa as an intervention to prevent MTCT, namely between 2003 and 2005.

Nthabiseng already had two children when she found out she was pregnant with HIV in 2003. She said she cried after being told at the clinic that she was HIV-positive and also later during the same day when she disclosed her status to her brother.

I was hurt. I said, "My brother I am going to tell you that I have come from the sister at the clinic. So, the sister took blood and found that I have HIV" (Nthabiseng).

Matshidiso already had three children when she found out she was pregnant with HIV in 2004. She was initially in denial but later accepted her status.

I did not accept myself but ultimately I did. At the clinic they counselled me and told me I will be fine. And I was fine (Matshidiso).

Lethabo and Rethabile presented themselves late for ART initiation; two years after discovering their HIV diagnosis. All the other women were initiated onto ART in the same month as their HIV diagnosis (see Table Two). Lethabo's second son is HIV-positive because she only discovered her status after giving birth to him in 2007. She says she did not experience any problems with that pregnancy.

I felt fine, I had no problems. The pregnancy was just the same as the first one. Nothing changed (Lethabo).

Rethabile suspects she lost her first baby to HIV in 2004 but the doctors said it was pneumonia. She was diagnosed with HIV during her pregnancy with her second baby in 2004.

I told my family that I believed that I was already LIKE THIS with my first child who died. But doctors...they were hesitant then (Rethabile).

4.2.1. Protecting the baby

After receiving the news about their HIV diagnosis the maternal instinct to protect the unborn baby came strongly to the fore. All the participants presented themselves as knowledgeable about PMTCT. All women but one knew at least one ART regimen by name and how to administer it personally and to their babies.

The pills I used to take were Lamivudine, Stocrin, Stavudine. It was three bottles in all. And I had to breastfeed for six months and not feed the child anything else. They also gave me a pill they called Nevirapine to take when in labour pains (Nthabiseng).

Nthabiseng also had knowledge about the side-effects and what to do when they surfaced.

They made me sick in the beginning. They also told me that I must know that people are not the same. I should know that I may have a headache so when I have that headache I must not sit on it I must quickly come to them to see what is wrong. That headache made me really suffer. But they told me not to stop taking them because of that headache. When I had the headache I went to the clinic and they did lumber puncture in my spine to test for meningitis; TB of the brain (Nthabiseng).

On the other hand, the youngest woman, Mpho, could not remember the treatment's names.

Yes it was a must to take ARVs because I only take one at night. I had to continue taking the treatment to protect the baby. They also injected me with that injection (Mpho).

The common knowledge about available treatment to prevent mother-to-child transmission of HIV (MTCT) among the participants is similar to that found in the

study by Nkonki et al., (2007). Knowledge about treatment to prevent MTCT was coupled with having information about baby feeding options.

When a baby is born she will be given Nevirapine syrup, from then on I will be breastfeeding her for six months without giving her anything else (Nthabiseng).

In South Africa, baby feeding options in the context of HIV are influenced by various perceptions and policies. Lack of understanding of the basis of policy change in 2006 to discontinue free formula left many HIV-positive pregnant women confused (Ijumba et al., 2012). Similar to that study, some participants chose not to breastfeed because they were scared of infecting their babies.

So because I was already scared that the baby may be infected through breastfeeding I requested that I collect baby formula milk at the clinic and not breastfeed. I was given Pelargon for six months (Dimakatso).

To prevent MTCT of HIV, pregnant women put their trust in the health care system to provide the necessary interventions. Whether the pregnancy was planned or unplanned, the women had faith in the health care system. It was painful for Nthabiseng when she found out about her HIV status during pregnancy but she was comforted by knowing about accessible PMTCT services.

It hurt me but I heard that there was a pill they would give me. It will be able to protect the baby that it does not get infected (Nthabiseng).

Other women did not know their partners' (their babies' fathers) HIV status or their partners refused to take ART. The lack of involvement and indifference of male partners in the PMTCT interventions is in line with the findings of Koo et al. (2013).

Their findings highlight the low level of HIV knowledge among male partners.

Nthabiseng's partner refuses to go for HIV testing.

I would say 'but look at yourself you must also go for testing. Do not wait until you are driven there to the clinic in a wheel-chair. When you have been sick for long, ARVs cannot boost your health; you will die because your immune system is already weak' (Nthabiseng).

He also does not believe that Nthabiseng is positive because she looks healthy.

He does not believe me. I would say 'You know my status very well and I never hid it from the beginning'. He would say 'you cannot be this beautiful'. I see I have to be thin as a rake with stuff oozing out of me, I must be skeletal, and then he would believe me (Nthabiseng).

Puleng's partner is HIV-positive but refuses to be initiated onto ART.

He is not taking it at all. And I told him 'It is for your own good, sir.' Even when he comes here and he wants to sleep with me, when I say he must use a condom he refuses. Then I tell him that 'No. I was given hard rules at the clinic. I know I am weak, I get sick easily. If your sperm can enter inside of me and I am taking treatment and you are not, I am the one who is going to be sick again'. So, I want nothing. I got sick and I have had enough (Puleng).

Knowledge about PMTCT had a positive impact on the experiences of women during pregnancy. Unlike some women in the study by Rispel et al. (2009), all the participants knew that they could minimise the risk of infecting their unborn babies through PMTCT interventions. Even for HIV-infected women, pregnancy is arguably the defining moment of motherhood. This was displayed by all the participants expressing their contentment with putting their babies' health before their own. Hence, the women's attention was almost entirely placed on their babies' survival

and their own well-being took second place, as experienced in Liamputtong & Haritavorn (2014) and D'Auria et al. (2006).

They taught us how to take ARVs and the side-effects. They said the baby will be treated but I will remain infected (Matshidiso).

Unfortunately for the women who only knew their HIV status when due for delivery, protecting the baby was not that straightforward. Because they had no knowledge of their HIV status they did not have the required knowledge about ARVs to protect their baby. However, as far as their present knowledge goes, if they were well informed they would have done whatever was necessary to prevent transmission to their baby. Rethabile lost her baby in 2003 when little was known about HIV and when the illness was still shrouded in a lot of mystery and ignorance. She was not tested for HIV and the health professionals could not disclose to her that her baby's pneumonia was HIV related. HIV testing is referred to, by Nkonki et al. (2007) as one of the health system failures that could potentially contribute to missed opportunities in the PMTCT cascade.

They did not test me and one thing I asked myself was that these people did not test me and above all that my baby is sick. Her hands were closed until here (she did not have arms). Her heart was on the right with a lung over it (Rethabile).

Knowing what she knows now about PMTCT, Rethabile reflects on the cause of her baby's death a mere three months after she was born. Back then in 2004, she was not aware of her HIV status and health care professionals did not know how to deal with the HIV disease, let alone how to administer its treatment.

They said it was pneumonia. So, maybe it was that thing of not wanting to tell me straight that "Ma'am your child is positive" (Rethabile).

Similarly, Matshidiso gave birth to a baby boy in 2001 when she also was not told about her HIV status.

Yes the thing is that they (doctors) never explained to me that it was positive or negative at that time (Matshidiso).

Because of lack of PMTCT interventions then, the boy has now been on ART since 2004.

The third born has HIV because treatment was not available then. He was born in 2001 (Matshidiso).

A lack of knowing her own status led to anxiety and confusion for Matshidiso at a later stage, who strongly asserts by shrugging that her partner is still HIV-negative and she does not know where she got it.

Last year (2015) he had TB, but I did not know what was wrong with him. I took him up and down, and they tested him. He still had nothing. I really do not know. As people we walk about. So I will not know where I got it (Matshidiso).

Her first HIV diagnosis was in 2004; three years after the birth of her son and during pregnancy with her fourth child. During her post-natal visit for her fourth child, she took the third born along to be tested as well, just as part of a routine check-up. He was found to be HIV-positive.

I do not know what was happening. But in 2004 I went to the clinic with the one born in 2004, and took along the one born in 2001 to be tested; he was three years, and they found it (Matshidiso).

Although she had done what she could to prevent MTCT and to be a good mother to her child, Puleng's efforts were thwarted by her partner. The couple were engaged to get married when they planned this pregnancy. Puleng was HIV-negative before pregnancy and she knew her partner was HIV-positive. The infection of their baby put a heavy strain on their relationship which resulted in their separation.

They told me not to mix feed the baby; I must just only give him breast milk. Then, why did mine become positive? His father gave him water while I was away (Puleng).

For Nthabiseng, her baby's protection came as an aftermath. Her rejection back then of her PMTCT knowledge led to her baby's death at ten months old because she mixed-fed her. To compensate for her loss she had another baby whom she breastfed for ten months.

So it occurred that I could not breastfeed him exclusively for that long you see? I said, 'no man, what kind of a child is this that is not going to be given water, the one who is not going to be given what what'. I gave him water and bought him Nestum. The child got fat speedily but then he died. But with this second one...to make sure that I did not repeat that thing he was breastfed for the whole ten months (Nthabiseng).

The participants were aware of their reproductive options when it comes to pregnancy prevention. However women should not be forced to terminate their pregnancies (as is sometimes the case) due to their HIV-positive status. Dimakatso contemplated having an abortion at five months to allay the fear of infecting the baby, but her decisions were hindered either by financial constraints or the stage of the pregnancy. She felt that the termination of her unintended pregnancy could reduce her burden.

I thought maybe he won't be born healthy you see. Only to find out that he would not have anything...only to find out he will be healthy. And he is in Grade 4 now (Dimakatso).

She went to a public hospital where she was refused abortion because of her stage of pregnancy. She then decided to make use of the services provided at Marie Stopes, a private abortion facility where she was told of the cost and the risk of performing the procedure in her late stage of pregnancy.

I went to National (Hospital) to request an abortion. When I got there it was found that my stage (5 months) did not allow for an abortion. There is another clinic in town, named Marie Stopes clinic, when I got there they told me that when I am pregnant this far, you are going to pay this much but it is a risk (Dimakatso).

At first when asked if she had planned her pregnancies, Matshidiso's swift response was.

They just keep on coming (Matshidiso).

However, during her interviews she later elaborated about how she suffered from side-effects of birth control and thus could not adhere to it. She stated that she could not prevent her pregnancies because the injectable birth control made her sick. After eight pregnancies, four of them unplanned, had taken a toll on her health, she is now on birth control.

I suffered from painful nerves, I had constant headache. It does not do that anymore though (Matshidiso).

The participants show varying degrees of agency during pregnancy, this important and determining period of their lives. Some participants, like Puleng, now feel that her status and being on treatment have afforded her with another opportunity to be healthy and to be present in the life of her children. That is why she refuses to have sex with her partner whose status is confirmed but who does not take ART. Other participants like Matshidiso seem to vacillate between deciding whether or not to continue with their pregnancies as the combination of pregnancy and being HIV-positive somehow leads to uncertainty as to the outcome of the child's status. Their health statuses in combination with a lot of other hardships therefore somehow taint this valued phase in their lives.

4.2.2. Disclosure and stigma

This sub-theme that deals with disclosure and stigma emerged almost immediately during the analysis when women discussed their experiences during pregnancy. Due to the snow-ball sampling strategy of this study, all the participants had disclosed their HIV status to someone. Participants were related in some way through friendship, kinship ties or as acquaintances, from attending the same clinic which positively influenced their disclosure. Dimakatso and Rethabile are sisters; Puleng and Matshidiso are friends. Mpho was introduced to the study by her HIV-positive mother who did not qualify for recruitment but heard about the study from a friend.

Acceptance about being HIV-positive was a dominant meaning formulated from this sub-theme, rather than being pregnant. Pregnancy entered the picture only where and when the baby was concerned. All women had some knowledge about PMTCT

to help adjust to the diagnosis and deal with the possibility that their unborn babies might be HIV-positive. This is noted in the first sub-theme that deals with experiences of protecting the baby from HIV infection and in some other studies referred to in the literature review as well. Many research studies placed the emphasis of care for newly diagnosed pregnant women on the prevention of MTCT of HIV rather than on the women themselves. Indeed and inevitably, preventing vertical transmission was also central to the women's experiences of pregnancy as they have largely internalised this message (linked to the current discourses related to HIV) but as women they are also expected to put their children's interests first. Controlling information about the diagnosis, and knowing whom, when and how to tell, was the second main condition for living "normally" with HIV.

Defined by individual and social contexts, HIV is laden with associations of stigma (Sandelowski & Barroso, 2003; Long, 2009; Liamputtong 2013). The presence of self-stigma, where a person knows her status but cannot accept that they can live normally after the diagnosis; and thereby postpone access to care, was common for some women. Even after losing a baby and suspecting the cause of death to be HIV related, Rethabile delayed going for ART.

Yes they told me that I should go on a certain date and I did not go. Yes, I was sitting and saying I am not going there. I will see them when I really have to see them. Yes, I ended up going. I got it and became well (Rethabile).

Often and for many people, disclosure could be a double bind process, a no-win situation where if one chooses to disclose, one may be subjected to stigma and if one does not disclose, one may subject others to infection (Ingram & Hutchinson, 2000; Liamputtong & Haritavorn, 2014). Sometimes the reactions they got after

disclosure were hostile. Lerato disclosed life-altering truths herself to a friend and her friend betrayed her trust by telling others. Her wish to have full control over who had knowledge of her HIV status was shattered. However, Lerato now embraces that moment in her life as a symbol of breaking her silence to the public. Before her “public” disclosure, Lerato was the only woman who at some stage sought private health care for ART as a means of avoiding dismissal from work due to absenteeism.

Eish! A friend is a friend neh! (sad voice) You share something with her and...I have a friend whom I disclosed to. Recently, early this year, we had a fight; she stood in the street and insulted me about my status. But it was nothing because I know my status and she does not know hers. Anyway, she helped me a great deal because I did not know how I was going to tell the world (Lerato).

For some women their disclosure was received with love and compassion, especially from their families. Nthabiseng’s brother did not believe her at first. She had to show him the medication to convince him. He was very accepting in the end.

My sister, it is not that you are going to die now. You are still going to live so accept it just as well. Just take your treatment (Nthabiseng).

Rethabile’s sister (Dimakatso) was very compassionate and normalised the situation for her. They both discovered that they were HIV-positive in the same year, 2005. Dimakatso was the first to be diagnosed in April 2005 and Rethabile later during the year.

Agh man! That thing is a small thing (Rethabile).

Her mother was also loving and reassuring about caring for her children.

My mother was first class. She told me that 'do not listen to shit these people are saying. Bring the kids here for me to care for' (Rethabile).

Mpho's mother, who is also HIV-positive, was also loving and reassuring.

I told her that "Mama I am from the clinic and I have tested. They say I am positive". She sat me down and advised me that I should not despair. I must just take my treatment correctly (Mpho).

On the flip side, Puleng's mother is still very upset with her. Puleng's voice was shaking and she was on the brink of crying when she spoke about her mother.

Hell! (Teary)Hell! The person who was very furious was my mother. Even now, she is still very upset. Just when she looks at me (pause) she has not been able to accept. She really has not (Puleng).

She even hid the fact that she was engaged to a HIV-positive man.

Jerrr!, they were mad because I did not tell them that: 'You should know that my plans are to get married to an HIV-positive man.' They were very mad. I do not want to lie. Their spirits were terribly low (Puleng).

The availability of family support influenced how the women coped with the condition. Stigma from family influenced some women tremendously and they chose to isolate themselves because of the experienced rejection.

They (aunts) do not treat me right. I have even stopped going to them. Even when we are all together I can see I am an outcast. They do not appreciate me. My kids also do not go to them. They do not enjoy going there...NEVER (Matshidiso).

Puleng and Matshidiso are cousins and friends. Puleng was at Matshidiso's house during my visit. Matshidiso became HIV-positive and pregnant before Puleng. They draw a lot of strength and support from each other.

We talk about our sickness. Our life is to talk about it. You can see she is weak now. I comfort her 'You will get well. You know, I was also like this. You must just accept yourself' (Matshidiso).

At community level, few of the participants expressed that they experience stigma.

Itjo! Others are disgusted: 'Oh no! AIDS! I do not want them to even give my child anything. She is going to infect our children' (Puleng).

The other woman who had repeat pregnancies while on ART felt she was being discriminated against.

Others, if even when I go ask something from them they say no. They say 'We have nothing. YOU just keep on making children here' (Puleng).

However, at the time of her interview, Puleng was expecting to receive support from her son's school.

He is in school. They recently asked for his clinic card saying they are going to request food for him but I have not heard from them. I will go and ask them (Puleng).

One woman is still wrestling with telling her son who is on ART, that he is positive. Lethabo's son is on ART but he does not know what the medication is for because she chose not to tell him.

John (pseudonym) does not know his status. I told him we have to take the pills for me to be better so that I do not infect him; that I have flu that is very hard to cure (Lethabo).

However, her wish is for him to know his status one day.

But I wish that he grows up taking them so that one day he can know that he has this disease. This disease does not kill people who adhere to treatment and have accepted their status (Lethabo).

Women handled the secrecy surrounding HIV in ways ranging from almost full disclosure to relative silence. Since their first diagnosis years ago, all the women can now talk openly (to some people) about living with HIV.

I am proud even now and I openly speak in public. I speak everywhere. When it is time I say 'now it is time to go take ARVs'. Some of my friends get ashamed. You will find their heads hanging down; those who take them but are hiding (Dimakatso).

Matshidiso whose eight children are all alive is satisfied with her partner's, the father of the children, support.

He was employed then; he took good care of me while in hospital. He supports the children. He really loves his kids. A lot! (Matshidiso).

The increased acceptance of HIV diagnosis and disclosure has led to renewed hopes and courage for all participants. Although it started off as a selective and gradual process for all the participants within the context of relationships, at this stage, disclosure of their status is not a concern as all the participants have duly benefitted by receiving support and care from their significant others. Although

present in some narratives, stigma is not as powerful anymore given that ART has largely normalised HIV and is rendering the illness less “exceptional”.

4.2.3. Coping with pregnancy and ART

Participants had rather similar experiences of coping with pregnancy and HIV which included PMTCT knowledge and treatment adherence. Knowing that regardless of their status, their babies would be born HIV-negative made it easier to cope during pregnancy. During her subsequent pregnancy after John (pseudonym) who is on ART, Lethabo was determined to adhere to PMTCT interventions for the survival of her baby.

I thought nothing about my baby being sick with this disease. I just knew I had to always take what I was given at the clinic (Lethabo).

Matshidiso was also very determined not to pass the HIV onto her babies. She was HIV-positive during her last four pregnancies.

They told me at the clinic that he will be born healthy only if I take my treatment right. Eat well, how to take ARVs, breastfeed for six months and not give any water (Matshidiso).

During these pregnancies she also went for her ANC when she was three months along.

For all pregnancies I started going for my antenatal consultations at three months (Matshidiso).

However, they narrated different approaches in coping with pregnancy and ART. Some of these approaches assisted the women in living with HIV and enabled them not to think about it or to just take it for granted. After disclosing to her sister, Rethabile reckoned that life could still go on and that she did not have to stress the way she was stressing before her disclosure.

I realised that I should not take it to heart because I got it from love this thing. I did not get it from a MISTAKE. I got it from love (Smiling). And it is the truth baby, I am telling you. I got it from love. I do not see why I have to stress because here I am, still okay (Rethabile).

Some women recognised that living openly with HIV may offer them some degree of sanity and protection from the endless pain of isolation (in the event of not disclosing and living with this knowledge on one's own). Initial shock expressed by crying was expressed by Dimakatso as her gateway to coping with her HIV status but after the fact of her infection became more of a reality, she vowed never to cry again.

My problem is that after hearing that I was positive when I left Universitas (hospital), I only cried there. From there on and from the doctor I was feeling okay (Dimakatso).

The majority of the women employed disclosure and openness as a coping mechanism. Some even equated their HIV-status to other illnesses. This subsequently allows them to live openly without fear of stigma and discrimination.

I can even tell other people that this disease lives with us and they must not hide it. Even when you can be insulted with it or be hurt you must adhere to collecting your treatment every month so that you can be well. Even a headache kills; a finger too. A person can have a sore finger and you could hear that he has died because he had a sore finger. It is not that disease that kills. Sugar diabetes also kills (Dimakatso).

For some women, caring for their children was a challenge and they relied on support from family members. Having children from different fathers was common to all the participants except one. Some of these children were sent to live with their paternal families when their fathers were deceased. For those with repeated pregnancies, adhering to the PMTCT cascade and having HIV-negative babies was a buffer against family discrimination (Sandelowski & Barroso, 2003). Nthabiseng decided to get pregnant with her last born after losing a baby due to mixed feeding and this latest pregnancy was decided on primarily to prove that she did not kill her previous baby.

If I have killed him I should have killed Thabo as well (Nthabiseng).

Some participants reported food security as a challenge in coping with pregnancy and ART. They mentioned that the fact that they could not afford a balanced diet impacted negatively on their treatment adherence.

Because I am unemployed; I am not working and I am sick. I cannot afford to eat the food I am supposed to eat (Puleng).

The father of Rethabile's son is a primary school teacher who is married to someone else. He was supportive during the pregnancy but wanted a paternity test after the baby was born when Rethabile wanted him to support the baby.

I filed for child maintenance and he subsequently requested a DNA paternity test. I did not have a problem with that, so we went. This child is his but when we got there the DNA results were negative (Rethabile)

For all the participants, their PMTCT knowledge and ART adherence were the common markers of their babies' survival. Some participants garnered strength to cope from support networks, especially family, like Rethabile who found courage to go on from disclosing to her sister, Dimakatso. On the other hand Dimakatso cried to let go of the pain of her diagnosis at the hospital and decided to live openly with HIV. She copes by equating HIV to other chronic illnesses and advocating disclosure. Other participants like Nthabiseng and Rethabile based their other children with their paternal families for support. Unemployment and food security was a challenge for some participants like Puleng who could not afford to eat a balanced diet.

4.3. The lived reality of motherhood and ART

Although the participants live with constant contradicting experiences of juggling their own interests and desires with those of their children (or their unborn child), many harboured hope for their babies' survival and moreover felt that they would give birth to healthy children. All the participants went through this journey but are at different stages of this trajectory of being HIV-positive, on treatment, and being pregnant. Participants reported that after knowing about their HIV status, they went through a process of accepting their new reality, and integrating having HIV and pregnancy into their sense of self, their daily routines and their plans for their future. Sub-themes that emerged under this theme were: sources of support; ART adherence; and conceptions of the future.

4.3.1. Sources of support

Contrary to studies that indicate that women living with HIV often do not receive sufficient social support from their social networks (Zhou, 2009; Davies et al., 2013), all eight of the participants have experienced a network of caring, non-judgemental support at some stage. Family support was not limited to the domain of HIV, but was also perceived as being instrumental in the broader aspects of life, like providing and caring for children and providing for basic needs.

The aunts assist with caring for the two children who are not staying with me (Puleng).

The majority of the participants indicated that their partners were supportive, while others were more distant in the process of offering support. Although Puleng considers herself to be in a relationship, she left her partner and went to stay with her family when she became very sick.

When I was sick, he never cared for me. He used to leave me alone in the house (Puleng).

Almost all the participants were satisfied with their relationships with health care workers. When Rethabile was delayed going for her ART after her baby's death, she was counselled into treatment initiation by her nurse.

You know Sister. H (pseudonym) counselled me and said 'you know this is not a bad thing that should make you feel otherwise. This is a general phenomenon' (Rethabile).

An encounter with a compassionate health care worker resulted in some women preferring to attend a specific clinic rather than a clinic closer to their homes. Puleng attended a clinic in town, where she used to work, even though she lives quite far from this clinic, in the township. She goes there with her baby who is also on ART because they treat her well.

At Pelonomi (hospital) the doctor then said they must draw blood from his arm, then that sister kept going up and down until we left. The very next day I took money, carried him and went to Bayswater (clinic in another residential area and not in the township). At Bayswater, I do not want to lie; they tested him and gave him treatment immediately (Puleng).

She also drew strength and support from God.

All will be well. I have already accepted I just want to see God, our Father, helping me to get well. All will be well; I have already accepted (Puleng).

Meanwhile, Matshidiso had been to the same clinic for ANC and the same hospital for the birth of all her eight children, who are all still alive. She was HIV-positive for four of these pregnancies.

Only two women expressed dissatisfaction with the service they receive at their health care facilities. Lerato had an encounter with an unsympathetic nurse when she presented herself for her second pregnancy with HIV. The health care worker put undue emphasis on discouraging her from having more children.

I met this "white" sister who asked me if my partner knew about my positive status. I said yes because we both planned this pregnancy. She was rude! She asked if I wanted to kill another baby (Lerato).

Matshidiso wanted to undergo sterilisation as a method of family planning but she was refused this option.

I even asked to be sterilised. "No! It is not possible", they told me. I also want to know why but they never gave me reasons. (Matshidiso).

And Puleng, at four months, was told she presented too early for ANC by her nurse.

You know my status, why are you telling me I came early for ANC. I am supposed to come for you to work with the person inside of me because I know you are giving me treatment (Puleng).

Some women stated that their children assisted them in taking their ARVs and in staying healthy. Nthabiseng describes how her children remind her to take her pills and how this facilitates her adherence to ARVs. Nthabiseng drinks a lot (of alcohol) and is grateful to her support system for making sure that she adheres to treatment.

Even when I would go drinking or wherever, they come running and you will see a child coming with a bottle of water. My first child is 25 followed by this one of 20 years and then Thabo (pseudonym); they bring me water and would say 'Mama here are your pills, take one'. Or I am at the tavern; they do stuff like that for me because they say I will forget (Nthabiseng).

She also considers her mother her friend.

I do not even have friends. My mother is my friend (Nthabiseng).

As mentioned previously, family form a significant support structure for all the participants. Additionally, some participants like Rethabile were satisfied with their relationships with health care workers. However, structural barriers like the health care workers' attitudes were also found to hinder women in expressing satisfaction with the health care set-up (Nkonki et al., 2007; Peltzer et al., 2007). Some

participants encountered negative attitudes from health care workers, like Lerato who was discriminated against for being pregnant and HIV-positive, Puleng who at four months, was chided for presenting too early for ANC, and Matshidiso who was refused sterilisation. Health care workers' PMTCT knowledge, stigma and a lack of support were reported by these participants, echoing the findings in other studies (Nkonki et al., 2007; Peltzer et al., 2007; Wilson, 2007; Sanders, 2008) These barriers remain a challenge in the overall experiences of women who make use of public health care facilities in the South African public health care landscape too.

4.3.2. ART Adherence

All the participants reported a number of factors that contributed to their negative experiences of taking and adhering to their ARVs. These included taking ARVs every day, ART regimens being changed, the size of the ARVs, and dealing with side effects from ARVs which led them to default on their treatment at times. These are in line with several qualitative studies which have identified a number of psychosocial factors associated with poor ART adherence and non-adherence among pregnant women. These factors include stigma, delayed disclosure, depression, and alcohol use (Sandelowski & Barroso, 2003; Long, 2009; Liamputtong 2013). As mentioned previously under the first theme, women took their medication as a symbolic act of protecting their babies. Some also used the ART as proof of being HIV-positive to those who did not believe the news when it was disclosed to them.

'No man. Do not worry. I believe they are just fooling around with you. They are lying'. When he said I was lying, the next day after coming from collecting the treatment from the clinic I showed him the pills (Nthabiseng).

Many had side-effects due to the medication but the side effects were mild and did not cause discomfort sufficient enough for the participants to actually default on treatment.

In 2015 the treatment started making me sick. I constantly had a headache but I am still on it until now (Rethabile).

Puleng was the only woman who expressed dissatisfaction with the new fixed-dose combination regimen.

The problem I have with the treatment is that they make me drunk. If you do not eat you cannot take it because of how dangerous it is. And it makes you drunk. You can feel it when it makes you madly drunk to the point that you do not know yourself. Someone can enter the house and leave, and you will never be able to stand up and see who it was (Puleng).

However she believes she can cope with this side-effect by eating liver as she was informed at the clinic.

That is why at the clinic we are also told to eat too much liver because they say the treatment eats away the liver. They affect the liver. And you do not have to cook it very well, you just rarely cook it (shows with hands) so that it can patch where yours is (Puleng).

However she expressed great confidence in the triple therapy regimen because it treated her very well.

Mosilo: So, you prefer the old triple therapy?

Puleng: Yes those were powerful. I trusted those ones (smiles). This one, even just by looking at me you can see that I am sick. If I was taking the old one, I would be feeling better already. Those had the POWER. Even if they were three of them, they were also strong but they never took something like a week making your drunk. They were very powerful. Those ones I trusted.(smiles) If

they can return them, I would go ask for them. These ones (pause) haai, they are useless.

Mosilo: How often did you take the old ones?

Puleng: I took them only at night, all three of them.

Others were satisfied with the treatment.

They are treating me well; they make me eat a lot (Lethabo).

No it does not give me problems. I have none. It treats me well (Mpho).

On the contrary Puleng was unhappy that the treatment made her eat regularly.

This thick one before I take it, 19h30 I must have something to eat, then take it at 20h00. Around 20h30 I must eat again. Again there around 23h00 I must eat (Puleng).

Some reckoned the treatment was good for them except when they have missed taking it because of not having food to eat.

Other times I did not take my treatment because I did not eat (Dimakatso).

Only when I have not eaten. When there is no food (pause) Eish! They will cause havoc in here (points at tummy) (Matshidiso).

For some it wasn't the absence of food that was the challenge but a lack of appetite.

At the entrance to Puleng's yard there is a neat patch of vegetable garden with fully grown spinach leaves and tomatoes.

I am now sick and have not been eating for a week. I cannot eat. They come back. Even a small portion of soft porridge. My mother makes it and I can only drink a sip. I cannot force it in (Puleng).

For others the HIV medication dictated their decisions regarding employment. Lerato who received ART from the private health care sector (and who therefore had to pay for it whereas it is free at public health care facilities) found it more convenient and less disruptive to her lifestyle. For adherence, she opted to use her own cash for procurement so that she could keep her job.

At work they never allowed sick notes from the clinic. I was a traffic controller then and it was never easy to get someone to stand in for my shift. Then I decided that I will go buy them (Lerato).

Sadly, she then also defaulted when her employment contract ended and when she no longer had money to pay for her medication out of her own pocket. For all the participants, treatment adherence was an issue absolutely fundamental to their health and literally to their life.

During the narratives I observed a sense of determination on the part of mothers not to infect their babies. Women expressed faith and relief during their subsequent pregnancies because of the relative assurance that the PMTCT programme could achieve. They ensured that their unborn babies receive treatment that will help protect them from infection. A high level of determination was observed from Matshidiso during her last four pregnancies. Her visits to the clinic three times a week never deterred her from her goal of protecting her children. At each visit she says she was given a pill and injected.

They injected me and gave me pills. I had them three times a week until I went to give birth. Just after the first ANC session they injected me. They were just very painful. I could not walk. They never made me sick (Matshidiso).

Matshidiso is the only participant who actually experienced stress while pregnant, due to her weekly injections;

They stressed me because I was not even able to sit...They were just very painful. Sometimes I could not walk (Matshidiso).

She also experienced anxiety about the survival of her babies.

I stressed a lot. I was constantly stressing a lot. I asked myself 'Is he going to live or am I going to live?' (Matshidiso).

On the contrary, Rethabile tries to live her life without stressing about her status.

No! All is well. I do not want to stress myself. A person would end up stressful. I also have...if I stress a lot, I collapse. So I do not want to find myself there. I accept all that comes my way and I put it behind me. That is how I am (Rethabile).

Regardless of side-effects or other challenges, all the participants maintained adherence to ART during and after pregnancy. Some like Lethabo, Mpho, Puleng and Matshidiso also maintained their children's treatment compliance and adherence. The survival of their babies was a huge factor in determining how participants coped with the pregnancies as well as their adherence to treatment.

4.3.3. Conceptions of the future

ART has improved the quality of life of many HIV-positive people. The HIV treatment enables them to live healthier and longer lives. Job security was a future prospect for

some women. During the interviews Dimakatso expressed her need to secure a job for herself so as to be able to look after her children.

I want to work and work for my kids. I am also tired of debts. During pay my child's grant ends with the creditors; this also gets me upset. I also have needs. I also have things I feel I must have, my kids as well (Dimakatso).

All the participants, with the exception of one, were unemployed and relied on social support grants (see Table One) which confirms the findings of other studies indicating the employment status of the majority of South African women who find themselves in the position of being HIV positive (Booyesen and Summerton, 2002). This is an indication of the burden of generalised social insecurity against the backdrop of HIV. Four women had children who were also on ART. To cope with this, the children's clinic appointments were scheduled to be on the same day as the women's. In that way they benefitted from saving on transport costs and time. However, the children missed out on school work. In some situations, women had to give up their children to their paternal families for support; and also to give attention to other HIV-positive children.

Puleng's sister died in 2009, leaving behind her son who is on ART. Puleng has taken the responsibility of taking care of her nephew. Together with her son, the three of them attend the clinic on the same day. She carefully organises her clinic appointments to fit in seamlessly with her son's and her nephew's.

We go together. Like this Tuesday we are going. And they are going to take his blood. We go together. Our date is one (Puleng).

She also makes sure that both children take their treatment as prescribed. Her nephew is on pills and her son on syrup.

He takes syrup. It is two bottles which are the same but they make four small ones. He takes 12ml, so that 12ml cannot take a month if they only give him the two bottles (Puleng).

As a mother Matshidiso faces the challenge of caring for herself and her son who sometimes expressed feeling burdened by the daily treatment.

Sometimes he asks me how come he was infected and others are not. I tell him that during that time the treatment was not yet available. You will hear him say 'Jerr! This THING irritates me'. There are times when they make him sick. He says they constipate him (Matshidiso).

Loss of a partner or a child was a common experience in the lives of these women and these losses reinforce the reality often associated with a precarious existence so common in the lives of the participants (Goggin et al., 2001). However, Lerato fell into denial when she lost her baby to HIV. Although she knew then that the child's father died because of HIV, she believed otherwise for her baby.

Her cause of death, I really do not know but according to Black culture it was "mohato"³ (Lerato).

In this instance, Lerato's denial is a form of ignoring the realities of the present and of the future; in this case the lurking reality of AIDS and its ruthless consequences when left unchecked. For others the blame manifested in feelings of despair because partners did not adhere to the baby feeding options and thus infected the baby.

³ *Mohato* is when a person who is using muti (traditional medication) comes near the baby which can affect the baby badly.

When he told me he gave him water I did not take it seriously. I told myself “how do you give water to a small baby like this who has not even finished a month alive” (Puleng).

Clinic visits are commonplace for HIV-positive women during and after pregnancy. Nthabiseng was worried about her son’s weight after birth and took him in and out of the clinic. Her worry was influenced by losing her previous baby whom she intentionally mixed-fed.

I struggled, man. But Thabo was not a sickly person. I could say his problem was not having weight the same as now. Even when I consulted the clinic saying ‘look at how thin this child is’ and they would ask if there was anyone with TB and there was none. Until now he is still thin. I have even found that it is genetic (Nthabiseng).

ART has allowed HIV-positive women to change their expectations about having children (Cooper et al., 2007; Kanniappana et al., 2008). Throughout the interviews, there were great aspirations about motherhood but different factors influenced their intentions. When asked about their desire to have more children, women had mixed feelings about the prospect (Kanniappana et al., 2008). The issue of raising children extends beyond the physical ability of being pregnant to being able to provide for the needs of the child. Matshidiso is an unemployed mother of eight children. She regrets having so many children and does not plan to have more because she cannot even afford to look after the children she has now.

Mosilo: Do you ever regret having these kids?

Matshidiso: Yes I truly regret, really. I even say it that I really should not have had this many children.

Mosilo: Why do you regret?

Matshidiso: Because it is now financially difficult.

Matshidiso is also very determined not to have more children by practicing dual protection. She uses condoms with her partners and she is also on injectable birth control even though it makes her sick.

I am now on injection. Jo!! I never forget the date. Now I have told myself that even if it will make me sick, I will be sick keeping on. We are also using condoms and in case they burst, I also inject. For me, one time only a baby is here. So we must also use condoms as double protection (Matshidiso).

For Dimakatso the determining factor would be the sex of the child.

No. I DO NOT THINK SO. I have a boy and a girl. What else would I want? If I did not have a boy I would say 'Yes I want a boy so because I have both, I am okay' (Dimakatso).

Puleng gave a resounding negative response to express being in control of making that decision.

No. Itjotjotjo!! I pray to Our Father in heaven even now. Even when I am well. Like even if I get back to my old self, I want nothing (Puleng).

She has lost a sister to HIV and was never told of her cause of death.

You see if only they sat me down from the start and told me the cause of her death, I believe I could not have done something like this. So, they did not tell me. They are only talking now: "Your sister died because of this" (Puleng).

And her mother has still not come to terms with her status.

The person who was very furious was my mother. Even now, she is still very upset. Just when she looks at me (pause) she has not been able to accept. She really has not (Puleng).

Rethabile was certain she did not want more children even if it meant losing her partner.

I want NOTHING. I am fine with two children. Even my partner is getting on my nerves because I told him that 'Baby, if the two of us are in love and happy, if you want a baby, my brother me, I will leave you' (Rethabile).

She is currently on birth control which she mentioned first when referring to her visit to the clinic.

Tomorrow on the 9th I am going to the clinic it is my date for birth control, my ARVs collection, and treatment for epilepsy and high blood pressure (Rethabile).

Others had repeated pregnancies as a symbol of their motherhood.

It is hard. When it gets tough that is when you start asking yourself questions 'Why did I have them?' Then I will go back and correct myself, 'I was supposed to have them because I am a mother' (Matshidiso).

This indicates the inevitable fact that so many women tend to associate their identities with motherhood. However, Matshidiso also feels that she has no strength left in her body for more children. Going through eight pregnancies has weakened her immune system and her ability.

*I will really die. I nearly died with this one (points at last born). Now I will die. I will never do it again. NEVER!!! *Joooooh!* I am done....JO JO JO JO. I WILL DIE, MOS. I will really die. I nearly died with this one (points at last born). Now I will die. I will never do it again (Matshidiso).*

Challenging the trajectory of the infection, all the participants who have lost a child to HIV in the past had another baby whom they made sure was protected from the HIV

infection. This was because motherhood was seen as the only way of gaining recognition and integration into family and society after being blamed for the child's death.

My siblings used to say 'yes you killed the child'. I said I did not kill the child it is just that I did not listen to what the doctors told me. I used to get insults for it but now they have stopped it because here is Thabo (pseudonym) (Matshidiso).

Albeit with support from different sources, women continue to bear the bulk of the overall HIV burden. They account for most infections and are greatly responsible for and implicated in the care and the losses of those infected, especially their children. This means that their struggle with HIV continues as before, when ART was not available, even though HIV is now a more manageable and predictable illness. Mpho wants to ameliorate her living conditions despite fears that she would not be able to get a proper job because of her status.

Like when you are not positive...you are able to live for yourself. You can also be able to apply for a job where testing is required. You can get it but when you are positive it will not be easy to get it easily (Mpho).

Most women were struggling financially to make ends meet for their children despite the fact that some of the fathers were still alive. This does not however suggest that fatherhood is merely about financial assistance, but this is one of the critical areas where fathers need to take responsibility. Only one woman mentioned support from her children's father. This raises concerns about the involvement of fathers in the upbringing of their children.

He does support them. He really loves his kids. A lot! (Matshidiso).

Puleng's brother is the breadwinner in her family who also has his own children but financially supports his nephews in the absence of their fathers.

Their father is just a useless piece. My brother works alone and he also has his own two children. The other one stays here with us. She is in high school and often they want this and that (Puleng).

Being separated from her partner during her sickness, Puleng is now staying with her family who are helping to take care of her and her son. Her partner does not support her and the baby; however he still had sexual desires for her.

When he comes here and he wants to sleep with me, when I say he must use a condom he refuses. Then I tell him that "No. I was given hard rules at the clinic. I know I am weak, I get sick easily. If your sperm can enter inside of me and I am taking treatment and you are not, I am the one who is going to be sick again. So, I want nothing. I got sick and I have had enough (Puleng).

Although it was not a common narrative from the women, one woman expressed a fear of death, although her religious belief sustained her.

Will I ever be able to stand? Will I one day wake up dead? Who will take care of my baby? But then again, I accept myself again and say God is here. When this pill enters my body it must work. It must do its job. Life must prevail (Puleng).

Her son on ART has given her hope to go on with life. She was holding him throughout during the interview. She was smiling every time she looked at him. We both laughed when she said this.

I want to live for him and see this silly boy with a runny nose growing up (Puleng).

The findings provide a context for understanding women's experiences of HIV and its treatment beyond lives saved and grief prevented. Women showed a positive view of their future and neither past nor present challenges seem to have had much of an impact on this outlook. Most of the participants actually found hope in their dreams of leading normal lives in the near future because of their abilities having been restored because of ART.

4.4. Conclusion

In this chapter the findings of the research study were presented. Having positioned the research from a phenomenological perspective, explicating meanings was inherent in the research design. The chapter gave insights into how participants, in a given context, made sense of a phenomenon under study. Two themes surrounding the lived experiences of pregnancy and ART; and motherhood and ART emerged and were discussed by meanings formulated from the sub-themes. All the narratives are testimony that death is no longer an inevitable prognosis for HIV-positive women intending to become pregnant. All the participants were concerned about their babies' HIV survival and were determined to protect them. The need to be mothers provided a motivating focus for them. Regardless of having repeated pregnancies while on ART, all the participants have ruled out having more children for different reasons, ranging from finance constraints to having had enough. Beyond their knowledge about pregnancy, HIV and ART, participants developed confidence in their ability to make decisions in the context of sometimes imperfect and incomplete information e.g., baby feeding options or reproductive choices.

CONCLUSION

The reviewed literature indicated that the effectiveness of prevention of mother to child transmission (PMTCT) hinges on the successful HIV counselling and testing (HCT) linkage to antenatal care (ANC) and the prevention of enrolled women and children falling by the wayside during the variety of services on offer to women and their babies in this PMTCT cascade (Department of Health, 2015). HCT is seen as a gateway into the PMTCT cascade which, if women present themselves in time, is highly beneficial in the reduction of MTCT of HIV (Amnesty International, 2014; Department of Health, 2015). Many women in the study went through the events of HIV-diagnosis and pregnancy simultaneously which is a finding that echoes many other similar studies (Long, 2009; Liamputtong & Haritavorn, 2014). Hence, the immediate concern of women, at the time of diagnosis, was the safety of their unborn children.

Maternal responsibilities that carry a tremendous amount of symbolic meaning and normative expectations therefore tended to take precedence over their own emotional needs. This suggests that their adjustment to being HIV-positive became a secondary concern, demonstrating how impending motherhood impacts on their overall HIV diagnosis experience. Just as existentialists posit, when people notice some uncertainty or change which might influence their lives, they are normally prompted to act and do something about their situations. Hence the, the urge to protect the baby was a common theme in various studies. The main theme described by Liamputtong & Haritavorn, (2014) and D'Auria et al. (2006) in their research is 'being there for their babies' coupled with the strong need to protect them from HIV. This was also found in my study as women's narratives also conveyed this

internalised sense of responsibility towards their children, thereby espousing the norms of “ideal” motherhood.

Ideally, women on ART and with babies should be linked into the health care system and therefore should have contraceptive access, however many women in the study had unplanned pregnancies at some stage in their lives. A limited integration of services and a focus on male condoms as a method of HIV prevention may result in inadequate contraceptive provision for HIV-positive women leading to an increased occurrence of unintended pregnancies (Schwartz et al., 2012a). However, these unintended pregnancies were seemingly embraced and welcomed by those participants who experienced it. There did not seem to be a contradiction in the narratives between unplanned pregnancies and normative expectations of good motherhood among those participants who did not plan their pregnancies. These occurrences were seemingly taken in their stride and dealt with, almost in a similar way that those women who actually planned their pregnancies dealt with their pregnancies.

Prior to the availability of PMTCT interventions, women narrated experiences of more generalised incidences that included stigma and discrimination. Yet, with time, the impact of stigma and discrimination seemed to become less because of the normalisation of HIV but also because of their support networks. Sources of support were dominantly from significant others such as mothers, children but in the case of the participants at hand, rarely from partners which corroborates the findings of Koo et al. (2013). Similarly, partners’ involvement in PMTCT was a rare event in the lives

of the participants. Some partners refused to go for HIV testing themselves. Nthabiseng's partner maintained this attitude: 'worry about it when it is time to worry'.

Health care workers, although they were responsible for mostly positive experiences in some instances, were also guilty of harbouring attitudes that were considered to be hostile at times. Few women were challenged by health care workers about their reproductive decisions. However, this attitude was reported to have been encountered during repeat pregnancies. Literature has shown how the lack of information from health care workers could negatively impact on the HIV-positive women's experiences during pregnancy or their intention to become pregnant (Ingram & Hutchinson, 2000; Myer et al., 2010; MacCarthy et al., 2012; Schwartz et al., 2012). The findings indicate a need for health care workers to be better advocates of family planning especially for HIV-positive pregnant women. The findings are related to those by De Bruyn (2004) and Farlane (2008) who found it common for health care workers to rarely discuss reproduction options with HIV-positive women.

On the other hand, from their narratives it can be deduced that their duration on ART and subsequent pregnancies have enabled women to develop skills and confidence to assert their choices with health care workers and to thereby be in control of their reproductive decision-making. This sense of agency and a concomitant reduced sense of shame were also evident in the patterns of disclosure of the participants. All participants have disclosed to significant others for support just after their HIV-diagnosis. Although, for some, their disclosure was received with disbelief, most

received compassion and love. Only a few went through hostile experiences with family, friends or partners. By disclosing women felt encouraged making a contribution to provide support to others when they disclose. Like the sisters, Dimakatso and Rethabile; Dimakatso, who after contemplating abortion, consciously resisted adopting a catastrophic perspective of life with HIV as she felt that her experience was not meaningless as she can now talk about HIV openly. On the other hand she helped Rethabile to view her experience as normal and part and parcel of her being; as she says '*I did not get it from a MISTAKE. I got it from love*'.

Two participants assiduously concealed their status from their children. Lethabo guarded against giving her son John, any reasons that would expose him to stigma but in the process she also confuses him as he asks questions about the compulsory taking of medication. Lerato was acutely aware of her presentation of herself to others and how others would judge her, especially her co-workers. To mitigate or combat stigma she opted to buy her ART from a private doctor rather than to receive these life-saving medication for free at her local primary health care clinic.

Being a mother and responding to the societal expectations to have children serve as strong sources of impetus to keep the baby (and not to abort despite limited planning and means to look after children) and to even have repeat pregnancies despite a positive HIV-status. For these women, becoming a mother highlights the importance of one's personal survival in ways that few if any other life experiences can. ART adherence was therefore pivotal for the HIV-free survival of their children, more so for those of their children who were themselves HIV-infected. Women had

to learn to be strong, to trust themselves and to develop confidence in their ability to fulfil their decision, planned or unplanned, for themselves and their unborn babies. Having developed faith in themselves after each pregnancy, women have shown an increased level in knowledge of PMTCT and how to protect their babies from HIV transmission. For some, the knowledge has enabled women to assert this knowledge in order to get proper care and treatment during pregnancy and thereafter.

What has become clear from the way the women framed their narratives is that having a child after an HIV diagnosis is a reality for many women. ART has greatly extended life expectancies and changed the dynamics associated with living with HIV, especially for women who are the main providers and carers to their children, as was the case with the great majority of these study participants. For many HIV-positive women, one such dynamic is the ability to become pregnant. Over time, all women have managed to put HIV into perspective by developing coping mechanisms to deal with everyday challenges of pregnancy and motherhood in the context of HIV. This has made it important that they also understand the risks involved and precautions to take and not allow HIV to downplay their role of mothering.

As witnessed from the narratives, women viewed their experience of being simultaneously diagnosed pregnant and HIV-positive not as a life sentence but rather a time of hopeful living. Generally challenges that come with HIV and its lifelong treatment such as chronic anxiety, routine medical visits, side-effects and precarity, could not dampen the women's desire to have children. Pregnancy and

giving birth to HIV-free babies has given them ostensible hope and victory over a disease that was once labelled a death sentence. Across the narratives, there is noticeably a shift of preoccupation about protecting the baby from HIV transmission during pregnancy to women's adherence to ART so that she espouses the norms of "ideal" motherhood by being healthy. This extends to children even making sure that their mothers adhere to ART. Their outlook and perspective of life is seemingly one of acceptance, resilience and hope, despite so many setbacks and generalised precarity that characterise their lives. Women modestly relayed their subjective taken-for-granted lived experiences; and hopefully some aspects of their experiences have changed somewhat by being shared.

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APPENDIX A: CONSENT FORMS (ENGLISH AND SESOTHO VERSIONS)

Title of the study: Lived experiences of pregnant women on ART.

2016

Dear Participant

My name is Mosilo Machere. I am a Master's Degree student in "*The Narrative study of lives*" programme: Department of Sociology, University of the Free State. I kindly invite you to voluntarily participate in a research study conducted as part of my degree.

I hope to learn from you about your experiences of pregnancy from the perspective of living with HIV and being on antiretroviral treatment. I would like to hear about your life experiences: the circumstances around your status and pregnancy; the way people reacted and treated you because of your status and being pregnant; and to explore how you make sense of your experiences of pregnancy and motherhood in your everyday life.

Should you agree to participate in the study, I will ask you to take part in an audio-taped interview. The interview will approximately take 1-1½ hours but the interview can be stopped if you feel tired or too emotional to continue. I will visit you a couple of times to talk about these issues and to get to know you better. All information collected from the interview will be used for research purposes only.

Please be advised that you can stop this interview at any time or choose not to answer any questions and that if you do so, there will be no negative consequences. There are no right or wrong answers in this study; what I am interested in are your own life experiences and views. You also have a right to ask any questions regarding the research during the interview or contact me or my supervisor thereafter.

Researcher: Ms. Mosilo Machere

Tel: 072 136 8690

Supervisor: Dr. Katinka de Wet

Tel: 051 401 2918

All the information that you provide will be treated confidentially, in other words, no one will be able to know that you were the one who said something specific. Your identity will remain anonymous, this means that I will not use your real name in my research, but will give you another name and will use that name to tell your story.

This research was approved by the Ethics Board from Faculty of the Humanities in the University of the Free State.

If you agree to participate, please sign this consent form.

[FULL NAMES IN CAPITAL LETTERS]

I fully understand the information in this consent form. I agree to volunteer to participate in this interview. I acknowledge that I have received a copy of this consent form.

Signature of participant

Date

Signature of researcher

Date

SESOTHO VERSION:

2016

Ho wena ya tlang ho nka karolo.

Lebitso la ka ke Mosilo Machere. Ke moithuti wa Master's Degree ka tlasa programo ya "*The Narrative study of lives*": Dipatamenteng tsa Sociology, Yunivesithing ya Foreistata. Ke o kopa ka boikokobeto ho nka karolo ka boithaopo phuphutsong e leng karolo ya dithuto tsa ka.

Ke labalabela ho ithuta ka boiphihlelo ba hao ba ho ima ho ikamahantse le ho phela ha hao le lefu la HIV le ho nwa diARV. Ke tla thabela ho utlwa kaa ha bophelo ba hao: maemo a amanang le boimana ba hao; kamoo batho ba ileng ba amana le wen a ka lebaka la ho ba le tshwaetso ya HIV ebile o le moimana; le ho shebisisa kamoo o utlwisang phihlelo ya hao ya boimana le boMme bophelong ba hao ba letsatsi le letsatsi.

Haeba o dumela ho nka karolo phuphutsong ena, ke tla o kopa hore o nke karolo puisanong eo ke tla e rekota. Puisano e tla nka bonyane dihora tse ka bang 1-1½ empa puisano e ka emiswa haeba o ikutlwa o kgathetse kapa o imelwa moyeng ho ka tswella pele. Ke tla o etela makgetlo a mmalwa ho bua ka dintlha tsena le ho o tseba haholwanyane. Dintlha kaofela tse tla bokellwa hotswa puisanong di tla sebedisetswa feela molemong wa phuphutso.

Ka kopo ela hloko hore o ka emisa puisano nako e ngwee le e ngwee kapa wa kgetha ho se arabe potso efe kapa efe. Le ha o ka etsa jwalo, ha ho naba le letho le tla o ama hampe. Ha hona dikarabo tse fosahetseng kapa tse nepahetseng phuphutsong ena; seo ke se thahasellang ke ho utlwa ka boiphihlelo ba bophelo ba bao le pono ya hao ka ha hona. O na le tokelo ya ho botsa dipotso mabapi le phuphutso ena nakong ya puisano kapa wa ikopanya le nna kapa mookamedi wa ka kamora puisano nomorong tse latelang.

Mofuputsi: Ms. Mosilo Machere

Tel: 072 136 8690

Mookamedi: Dr. Katinka de Wet

Tel: 051 401 2918

Dintlha tsohle tseo o tla fana ka tsona di tla nkwa e le lekunutu. Ho bolelang hore, ha ho motho ya tla tseba seo o se buileng. Lebitso la hao la nnete ha le na ho sebediswa empa ke tla sebedisa lebitso leo e seng la mannete ho bua ka tsa bophelo ba hao.

Phuputso ena e fumane tumello ho tswa ho ba Ethics Board ho tswa Faculty of the Humanities e mane Yunivesithing ya Foreistata.

Haeba o dumela ho nka karolo, ka kopo saena foromo ena ya tumellano.

[MABITSO A HAO KA BOTLALO KA DITHLAKU TSE KGOLO]

Ke utlwisisa ka botlao dintlha tse kahara foromo ena ya tumellano. Ke dumela ho ithaopela ho nka karolo puisanon ena. Ke dumela hore ke fumane khopi ya foromo ena ya tumellano.

Tekeno ya moithaopi

Letsatsi

Tekeno ya mofuputsi

Letsatsi

APPENDIX B: INTERVIEW SCHEDULES (ENGLISH AND SESOTHO VERSIONS)

1. Questions to build initial rapport

Demographic info: Age; Marital status; Employment; Number of children alive and dead

First diagnosis of HIV: What year did you test HIV-positive?

Treatment initiation: What year did you start treatment?

Levels of disclosure and acceptance: Have you disclosed to anyone? Who? What exactly did you tell them? How did they accept it?

Issues with adherence: Are you still on treatment? Any problems with adherence? How do you deal with them? Prompt: Hiding medication?

2. Pregnancy intention and knowledge

Was your pregnancy planned? If yes how did your status influence your decision to fall pregnant? If no how did your status influence the fact that you were pregnant?

Did you have any knowledge about being HIV positive, on treatment and falling pregnant?

If yes please explain. Prompt: PMTCT; ANC

If no, what were your thoughts with regards to being pregnant?

What are the general perceptions among your friends and within your community of being HIV positive, on treatment and pregnancy?

3. Relationships, attitude and discourse

How did people first react to your pregnancy in relation to your HIV status? (Specific focus on health care workers and people who are aware of the woman's status)

Please tell me about your relationship with significant others (children, partner, other family, friends) and other acquaintances (community, health care workers) in relation to your pregnancy?

4. Concluding remarks

Tell me about your experiences of motherhood. Would these experiences have been different if HIV was not present? How does ART impact on these experiences?

Please reflect on any other of your experiences during pregnancy while on ART? (Health related – physical and psychological; relationships; perceptions of the future; perceptions of self). Would you have wanted things to be different?

SESOTHO VERSION:

DIPOTSO TSE AHANG DIKAMANO TSE NANG LE KUTLWISISANO/KUTLWANO

1. Dipotsong tse qalang puisano

Dintlha tsa bophelo: Dilemo; Lenyalo; Mosebetsi; Palo ya bana ba phelang le ba hlokahetseng

Hlahlobo ya pele ya HIV: O testile HIV-positive ka selemo sefe?

Ho qala ho nka meriana: O qadile ho nka treatment neng?

Makgalo a ho ipolela le ho amohela: Na o se o ipoletse ho motho? Mang? O itseng ha e le hantle? Ba ile ba o amohela jwang?

Tsepamelo ya treatment: Na o ntse o nwa treatment? Na o na le mathata ka ho tsepamela hodima yona? O lwantshana le ona jwang? Prompt: Wa e pata?

2. Tsebo le maikemisetso a hoba mmeleng

Na ho ba mmeleng ha hao ho ne ho rerilwe? Ha ho le jwalo, maemo a hao a tshwaetso a bapetse karolo efeng qetong ya hao ya ho ba mmeleng? Ha ho se jwalo, maemo a hao a bapetse karolo efeng tabeng ya ho ba mmeleng ha hao? Na o ne o tseba ho ka ha kokwanahloko ena ya HIV, ka kalafo le ka ho ba mmeleng? **Ha ho le jwalo**, ke kopa o hlalose. Botsa ho ya pele: PMTCT; ANC

Ha ho se jwalo, o ne o nahana eng ka ho ba mmeleng?

Metswalle ya hao le batho ba motseng/sechabeng ba ikutlwa jwang/ba nahanang ka taba ena ya ho ba le kokwanahloko ena ya HIV, ho nwa meriana le ho ba mmeleng?

3. Dikamano, mekgwa le dipuisano

Batho ha ba qala ho utlwa hore o mmeleng maemong a na a hao, ba ile ba ikutlwa jwang/ba etsa eng (haholo basebeletsi ba tsa bophelo bo botle le bao ba tsebang maemo a hao). Ke kopa o mpoelle ka dikamano tsa hao le batho ba haufinyana le wena; ba amanang le wena (bana, molekane, ba bang ba leloko, metswalle) le batho ba bang bao o tsebanang le bona (motseng/sechabeng, basebeletsi ba tsa bophelo bo botle tabeng ya ho ba mmeleng ha hao?

4. Qetelo ya puisano

A ko mpoelle ka tsebo ya hao ya ho ba Mme. A na tsebo ya hao e kabe e fapane ha o ne o sena kokwanahloko ena ya HIV? ART e bapala karolo e kae boitsebelong bona? Ke kopa o nahane morao dinthong tse o fetileng ho tsona nakong eo o ntseng o le mmeleng, o ntseng o le mo ART (Tsa bophelo bo botle-mmeleng, maikutlong/kellelong, dikamanong, pono ya bokamoso, ho ipona/ho itekola). Na o ne o ka thabela dintho ha ne di le ka tsela engwe / e fapaneng?