

Chapter One

INTRODUCTION

1.1 BACKGROUND AND RATIONALE FOR THE STUDY

Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are of major concern in South Africa as the pandemic is now in its fourth decade and millions of people are affected (Dorrington, 2002). It is estimated that more than 60 million people worldwide have lived with HIV/AIDS since the beginning of the pandemic, and 20 million of these people have since died due to the disease (Davis & Pathak, 2001; Moelleken & Kearney, 2003). To date there is no known cure for HIV/AIDS, and the Human Sciences Research Council (HSRC, 2002), reports that the prevalence rates of the disease are increasing rapidly despite advances made in knowledge about HIV prevention. Globally, the fastest growing population of people living with HIV/AIDS comprises women and children, and occurs via the mother-to-child transmission (MTCT) route (World Health Organisation, 2004).

With a total of 5, 3 million infected people, South Africa has one of the largest number of people living with HIV/AIDS, as well as one of the world's fastest growing pandemics (Treatment Action Campaign, 2004). The South African Department of Health (DOH) estimates that of the 5, 3 million people in South Africa living with HIV/AIDS, 2, 95 million are women and 2, 3 million are men. In addition, the Department estimates that 91 271 babies became infected through the mother-to-child transmission route (MTCT), in 2003 alone (DOH, 2003). Evidence suggesting the extent of the HIV

pandemic comes from a variety of sources, but particularly from HIV tests of pregnant women attending public antenatal clinics. The infection rate has increased consistently and dramatically since the start of the antenatal clinic studies (DOH, 2002). Moreover, the MTCT rate appears to have increased despite the provision of education and free formula milk by many South African Government hospitals.

Following diagnosis, the immediate focus is usually on the symptomatic treatment of the disease (Dodel, Berger & Oertel, 2001). There also appears to be little consideration for the affected persons' emotions and their ability to cope with their situations (Ndaba & Burns, 2004). Furthermore, some writers maintain that there appears to be too little information and counselling given to mothers living with HIV (Coovadia, 2005). Treatment is provided for the person's physical symptoms and they are told by clinicians what they need to do in terms of feeding. However, there appears to be a paucity of research being conducted to explore the matter further and enquire if the mothers are able to bottle-feed adequately. There also appears to be a shortage of research in the area of how families and communities' attitudes influence infant feeding practice.

Treatment for people with HIV/AIDS is often limited to medication or providing materials. However, there is literature that acknowledges that with treatment of mothers living with HIV/AIDS, it is important to support the individual's integrity and understanding in the face of the disease (Urban, 2001; Coovadia 2005).

For many individuals and communities, breastfeeding is regarded as a natural activity between a mother and child. Nevertheless, this activity is contraindicated in the event of the mother contracting HIV/AIDS as there is the risk of the disease being transmitted to the infant via the breast milk (McIntyre & Gray, 2002). In order to educate mothers living with HIV/AIDS, with a view to preventing MTCT of the virus, South African Government hospitals have implemented counselling sessions for these mothers. In addition, many Government hospitals have initiated free milk formula programmes to help mothers living with HIV/AIDS prevent the transmission of the virus. While the primary responsibility for educating mothers on the advantages and disadvantages of breast versus bottle-feeding lies with doctors and nurses, the speech-language pathologist has a crucial role to play in assessing and managing swallowing and feeding difficulties associated with infants who are living with HIV/AIDS.

Speech-language pathologists are used as lactation consultants in hospitals as they are often the professionals who are best trained to understand the intricacies of infant oral anatomy and swallowing function (ASHA, 2005). Babies born to mothers living with HIV/AIDS, may have difficulty co-ordinating their suck-swallow-breathe cycles and may present with swallowing as well as gastrointestinal disorders including reflux (McFarland & Layton, 2000).

An important function of the speech-language pathologist is to assess and describe the nature of the infant's feeding. Thereafter appropriate intervention needs to be implemented, based on the assessment and geared towards the infant's needs. The speech-

language pathologist's role also entails counselling for both affected persons and their families. However, despite the plethora of research studies on HIV/AIDS, a significant factor that appears to have been neglected by many investigators is the role of cultural beliefs and practices in the increase of MTCT rates.

This factor takes on particular significance when one considers that HIV/AIDS is a human affliction and what gives people their humanity are their personal and cultural beliefs and practices. In addition to the inability to dissociate people from diseases, it is impossible to dissociate people from the community or society in which they live (Miller, Easley & Zhang, et al., 2001). If speech-language pathologists and other health care professionals are to render culturally-sensitive therapy and counselling interventions, they need to be aware of cultural influences (Ross & Deverell, 2004).

In addition to identifying a need for research on cultural factors influencing breast-feeding, the personal motivation for this study was based on the fact that the researcher was previously employed as a speech-language pathologist at Coronation Hospital. This is a secondary level academic hospital, where the main role of health care professionals is to prevent the spread of mother-to-child transmission of HIV by means of breast milk. The hospital therefore provided the infants with milk formula.

However, once the mother has been given the formula, there is no way of verifying if the formula is given to the baby, whether it is diluted to the correct consistency, whether it is shared amongst other family members, or sold – especially in the case of low

income families. There had been unconfirmed rumours circulating at the Hospital that some of the mothers had been selling this free formula in order to supplement their income.

It was also suspected that the cultural beliefs of the mother would be likely to influence her decision regarding her feeding options. For example, among certain cultural groups especially within African culture, breastfeeding is regarded as a more socially desirable option than bottle-feeding as it provides essential nutrients and antibodies, enhances the mother-infant bond and promotes the contraction of the uterus and return of the mother to her former body shape. Mothers, in the African community who do not breastfeed their infants, risk being identified and labeled as HIV positive.

It came to the attention of the researcher through informal observation that many mothers appeared to display a negative attitude towards bottle-feeding. Furthermore, it became apparent that many of the women attending the hospital tried to conceal the fact that they were receiving free formula for their infants. The question then arose regarding the attitudes that mothers living with HIV/AIDS had towards feeding formula to their infants and why they appeared to give the impression of trying to conceal their bottle feeding practices from other mothers. In view of the fact that the majority of mothers attending the Milk Clinic were black South Africans, the researcher wondered whether African cultural beliefs and practices possibly influenced their feeding choices.

For these reasons, the study aimed to probe whether bottle-feeding practices were perceived to be sufficient to meet the infant's

nutritional needs. The study also attempted to investigate factors such as antenatal education, postnatal support and cultural beliefs, which might be linked to influencing the mothers' perceptions and attitudes towards breastfeeding and bottle-feeding.

1.2 AIMS AND OBJECTIVES OF THE STUDY

The primary aim of the research project was to investigate the beliefs and practices of a sample of mothers living with HIV/AIDS, who were attending an HIV clinic at a Provincial Hospital in the Gauteng area, regarding infant feeding.

Secondary Objectives

In order to address the above aim, the following objectives were formulated:

1. To identify the feeding practices among a group of mothers living with HIV/AIDS and attending an HIV clinic at a Provincial Hospital in the Gauteng area.
2. To determine the mothers' attitudes towards and perceptions of breastfeeding.
3. To elicit information regarding the mothers' views in relation to formula feeding and bottle-feeding.
4. To ascertain participants' knowledge of the manner in which the HIV infection may be transmitted, and if mothers were aware that HIV could be transmitted through breast milk.
5. To probe whether antenatal counselling/information regarding HIV transmission was perceived as adequate.

6. To obtain information on the mothers' feelings regarding their HIV positive status.
7. To explore the mothers' perceptions of the communities' attitudes towards bottle-feeding and whether their communities perceived bottle-feeding as being an indicator of HIV status.
8. To ascertain what happened to the free formula milk that the mothers received.

1.3 METHODOLOGY

In order to investigate the primary aim and secondary objectives of the study, an exploratory-descriptive, cross-sectional survey research design was employed, which incorporated both qualitative and quantitative dimensions. A form of survey, which incorporated a semi-structured interview schedule, was used for data collection (Urban, 2001). The sample was obtained from Coronation Paediatric Hospital, where persons living with HIV/AIDS, who were mothers of infants younger than six months of age, participated in the formula milk scheme.

The interviews were conducted postnatally, when the participants' infants were one month old and feeding patterns had already been established. A total of 42 participants were interviewed, with the assistance of an interpreter. Responses were analysed using descriptive statistics and thematic content analysis (Kerlinger, 2000).

1.4 POTENTIAL SIGNIFICANCE OF THE STUDY

The value of the study appeared to lie in the implications for enhancing knowledge and understanding of health care practitioners, especially speech-language pathologists, regarding beliefs and practices in relation to infant feeding. In terms of the development of theoretical knowledge, it was anticipated that the study might enhance the understanding of the experience of being a mother with HIV and the influence that the African culture plays in feeding.

It was also envisaged that recommendations would be made regarding the education and training of speech-language pathologists in order to better equip them academically as well as foster culturally-sensitive attitudes towards working with mothers and infants living with HIV. In addition, it was felt that findings from the study might enhance the clinical practice of speech-language pathologists with particular reference to early childhood intervention.

In terms of health care personnel, it was hoped that the research project would encourage speech-language pathologists to recognize the need for community education regarding the potential impact of culture on feeding practices of persons with HIV, and the role of the speech-language pathologist in this respect.

It was further envisaged that, knowledge obtained from the study would also be of value to Coronation Paediatric Hospital, as well as other municipal hospitals with regard to the formulation of infant

feeding policies as well as the administration and understanding of their formula milk programmes. It was anticipated that hospitals could gain information that might help them with their counselling of people living with HIV/AIDS. Finally, it was expected that the project would help identify further areas of research within the domain of HIV and feeding.

1.5 ORGANISATION OF THE REPORT

The structure of the report is organized as follows: Chapter One introduced the study, provided a rationale for the research report, and briefly described the aims, methodology and potential significance of the research. Chapter Two discusses the historical backdrop to the study; feeding in the context of HIV as well as general and specific feeding policies, while Chapter Three provides a detailed explication of the research design and data analysis. Chapter Four focuses on the presentation and discussion of the results. Chapter Five draws conclusions and endeavours to highlight implications and make recommendations arising from the findings of the study.