Chapter Five

CONCLUSIONS AND IMPLICATIONS

5.1 CONCLUSIONS ARISING FROM THE STUDY

The present study creates awareness of the broad range of variables likely to be associated with feeding of infants born to mothers living with HIV/AIDS. Although all the participants reported exclusively formula feeding their infants, not all were aware of the fact that breastfeeding could be a route of transmission of HIV/AIDS. Findings suggest that there is insufficient antenatal as well as post-natal counselling of mothers living with the virus. Participants in the study reported that they were not well informed with respect to sterilisation and preparation of formula feeds. The results indicated that the mothers who were interviewed were mainly influenced on how to feed their infants by their culture and their relatives. However, these conclusions need to be viewed critically in terms of the limitations inherent in the research design and methodology of the study.

5.2 LIMITATIONS OF THE STUDY

The results of the present study cannot be generalized to the broader population due to the fact that participants were recruited via a non-probability, convenience sampling procedure. The sample size was also relatively small, and did not contain proportionate numbers of each African group to be able to extrapolate findings to the broader South African population. Furthermore, in view of the fact that the participant sample was recruited from one hospital setting, the
results cannot be generalized to the broader population of mothers attending HIV/AIDS clinics.

The research instrument could have been altered in a number of ways to provide more detailed and accurate information. Firstly, with the closed-ended questions a third possible response option such as ‘maybe’ could have been included and not only ‘yes’ or ‘no’, categories. In hindsight, participants should have been asked if they changed their method of feeding depending on who was present during the feeding. Participants' attitudes and emotional reaction towards their infant should have been included in the schedule (Urban, 2001). A 5-point scale for the interview schedule may have provided more reliable information than the binary yes or no response categories. Furthermore, the ecological validity of the instrument and its appropriateness across cultures was not assessed (Shumaker, Ellis & Naughton, 1997). It is therefore acknowledged that the interview schedule was not ideal and needed further adaptation (Peat, 2002).

Although, an interpreter was available for the study, her services were not utilized for most of the interviews, as all of the participants appeared to be proficient in English. It was felt that the presence of the interpreter may have served as an inhibiting factor in the participants’ responses. The interpreter was from the same culture and community as many of the participants and this factor may have contributed to them not divulging certain information. Moreover, given South Africa’s legacy of Apartheid, the fact that the researcher was a white person who was employed as a health care professional at the hospital may also have influenced the responses of participants, all of whom were black.
Another point to consider was that the participants may have furnished responses in terms of what they felt the researcher wanted to hear, in other words their answers may have reflected social desirability responding. Many studies have had their results swayed by social desirability responding from participants (Kumar, 2005).

5.3 IMPLICATIONS FOR EARLY INTERVENTION AND THE CLINICAL PRACTICE OF SPEECH-LANGUAGE PATHOLOGY

It is also recommended that this theoretical understanding be incorporated, into education and training of speech-language pathologists in order to enhance culturally-sensitive practice and enable speech-language pathologists to be in a position to educate other professionals and the broader community regarding these aspects. Infants born with HIV are at risk for chronic sinusitis and otitis media, which has implications for poor language development and the loss of language milestones (ASHA, 2005). Speech-language pathologists can help by introducing language stimulation programmes for these children, particularly those in community centres, and by introducing a more visual based approach to communication and language learning. The virus can also cause oral lesions which compromise the child’s ability to suck, chew and swallow and thus any oral movement is likely to become painful. The child living with HIV can later present with phonological disorders, central auditory processing deficits and learning disorders. It is then the responsibility of the speech-language pathologist to implement intervention programmes to lessen the severity of the disorder and aid the child by implementing strategies that can help them cope with their disorder (SASHLA, 2005).
Being a child living with HIV is said to carry a triple burden, the burden of poverty, namely being parented by mother or parents who are themselves chronically ill and of having to live themselves with all that the disease entails. There may then be family disruption due to the death of the child’s parents. There is also a burden of secrecy that often surrounds the child’s HIV status (SASHLA, 2005). All of these factors are likely to lead to psychosocial issues that compound the challenges of identification, diagnosis and treatment of the child living with HIV (Kent, 2005), and need to be taken into account in implementing any early intervention programme.

The findings suggested that many of the individuals with HIV/AIDS who were surveyed in this study were likely to be influenced in their decisions to breastfeed or bottle-feed by their cultural beliefs. The findings also suggest that many of the mothers living with HIV/AIDS who were interviewed, appeared not to have had sufficient education and training in the preparation of formula feeds. Many of their reported perceptions and practices are likely to have had an impact on the nutritional intake and the exposure to HIV received by the infant (McIntyre, 2005). These results have clinical implications for speech-language pathologists as well as other health professionals. Speech-language pathologists need to ensure that any feeding information given to mothers living with HIV/AIDS is fully understood. They also need to demonstrate to these mothers the correct way of preparing formula milk.

Research suggests that many infants born to mothers living with HIV/AIDS, are at risk of malnutrition and HIV infection. A dietary history of the infant should therefore be part of every medical
examination. Furthermore, the major goal should be to support the emotional stability and education of the individual living with HIV/AIDS, so that they can maintain control of their own health care and that of their infant. Speech-language pathologists are often consulted by medical personnel because they are viewed as lactation specialists. They are therefore in a position to help in the education of mothers living with HIV, with regard to the feeding of their infants.

Mothers living with HIV also need to be counselled with respect to the importance of infant formula feeding as well as the transmission routes for HIV (Muma, Lyons Borucki & Pollard, 1997). However, it is acknowledged that many mothers living with HIV/AIDS in South Africa are also living below the poverty line and thus do not have access to healthy lifestyles, nutritious foodstuffs or formula for their infants. Furthermore, the argument from some quarters is that to provide free formula to the infants for only six months is an unfair practice and that it would be better to let the mothers breastfeed these infants whilst providing ARVs (Gilbert, Selikow & Walker, 2002).

Hygiene and correct mixing of infant formula is of the utmost importance for infants, especially those born with HIV (Pillay, Colvin, Williams & Coovadia, 2001), especially since poor hygiene and incorrect feed mixing can result in malnutrition (Coovadia, 2002). Thus, counselling and education at hospitals and clinics should aim to establish adequate understanding of hygiene and mixing of infant formula. Hence, professionals need to assume responsibility for adequate education of the person living with HIV and also be aware of the person’s culture. Such education could increase the number of referrals to speech-language pathologists,
who could help with the feeding management and integration of cultural aspects into feeding policies.

The speech-language pathologist is often the first clinician to see an infant that is not feeding well in the neonatal intensive care unit (NICU). The reason for this is that speech-language pathologists are probably the health care professionals who are best trained to understand the intricacies of infant oral anatomy and swallowing function (Davis-McFarland & Layton 2000). Babies born to mothers living with HIV, may have difficulty co-ordinating their suck-swallow-breathe cycles and swallowing, as well as gastrointestinal disorders including reflux (ASHA, 2005), and speech-language pathologists have an important role to play in this regard.

Oral hygiene is of the utmost importance for individuals with weakened immune systems and who may be susceptible to oral thrush, which is usually the case with infants born to mothers living with HIV (Coovadia, 2005). Infants with oral thrush tend to find it uncomfortable and painful to hold milk in the oral cavity and then swallow the milk. The result is that the infant then drinks less milk and then starts to lose weight and become weaker (McIntyre, 2003). Speech-language pathologists have a critical role to play in the area of infant feeding, including modifying the delivery of milk in various ways. For example, they may alter the temperature or viscosity of the milk to suit the infant’s requirements (SASHLA, 2005).

A major disorder that infants living with HIV often suffer from, is gastric reflux, and here again the speech-language pathologist may need to alter the feeding positioning as well as the infant’s resting and sleeping positions in order to minimize the occurrence of reflux
(Arvedson & Brodsky, 1993). In addition, speech-language pathologists may recommend that infants suffering from gastric reflux be given less milk but more frequently.

Many of the emotions expressed by the participants in the study, are ones that other individuals can appreciate. Individuals living with these types of emotions are at risk of struggling to cope with the daily tasks of living. There is a concern that the HIV positive individual who struggles with the myriad of emotions that were reported, could struggle to cope with an infant as well as looking after themselves and the rest of their family. Hence, health care professionals need to provide supportive counselling and arrange support groups for these mothers.

5.4 IMPLICATIONS FOR INFANT FEEDING POLICIES OF HOSPITALS

The present study indicates that Government Hospitals providing care, counselling as well as a free formula programme, need to be made aware of the emotions experienced by HIV positive mothers surrounding infant feeding, the increased need for counselling and the influence of culture on the individual’s decisions regarding feeding. Further information needs to be provided regarding resource and formula availability and feeding options for the mother and infant living with HIV/AIDS.

Coronation hospital, as well as other Government hospitals in South Africa, only provide free formula milk for six months. The argument put forward is that this represents unfair practice by the hospitals, in that many mothers living with HIV are not able to afford to purchase formula milk after the six months have elapsed.
It is therefore recommended that this policy be re-considered and re-evaluated by the South African Dept. of Health (Urban, 2001).

5.5 IMPLICATIONS FOR FUTURE THEORY AND EDUCATION

The present study provided additional knowledge of infant feeding practices among mothers living with HIV/AIDS. Findings demonstrated the complex interaction between variables and thus provided additional support for the influence of culture on breastfeeding practices particularly in the African community. When examining feeding practices in individuals living with HIV/AIDS, the separate dimensions of provision of counseling, access to hygienic preparation methods and the influence of an individual’s family and culture seem to interact and impact on one another. Without a thorough understanding of all these factors and their relationship to one another, management of feeding in infants born to HIV positive mothers is unlikely to be at an optimal level. It is hoped that the results of this study may contribute, in some small way, to enhancing theoretical understanding of infant feeding in the context of HIV/AIDS.

5.6 IMPLICATIONS FOR FUTURE RESEARCH

- In terms of research, the validity and reliability of the interview schedule that was used in the present study needs to be investigated (Nduati, John & Mbori-Ngacha (2000).
- In addition, the nutritional level of infants born to mothers living with HIV/AIDS needs to be further examined, with
particular emphasis directed to ensuring that the correct formula mix is administered. Nutritional status and its effect on immunity (Nduati, et al., 2000), requires further investigation as well.

- Furthermore, the effectiveness of the counselling sessions provided for HIV patients in relation to understanding of HIV transmission routes needs to be subjected to a more controlled study, which could further inform clinical practice, for example measuring knowledge and attitudes before and after a workshop on HIV/AIDS.

- Given the fact that approximately 8 out of every 10 Black South Africans are known to consult with traditional healers in preference to or in conjunction with western health care professionals (Gilbert, Selikow & Walker, 2002), it would also be of interest to conduct research into the role of traditional healers in advising mothers living with HIV/AIDS, regarding infant feeding practices.

- At the time of writing up the study the South African government had endorsed and begun the rollout of anti-retroviral drugs. Although the participants in the present study had access to anti-retroviral treatment, it would be interesting to see the effect this rollout has on the rate of MTCT of the virus as well as effects on feeding and swallowing. The provision of this medication may have profound effects on the aforementioned population (Coovadia, 2005). Anti-retroviral treatment when initiated in all stages of HIV is associated with marked immuno-reconstruction (Maartens, Bekker & Sanne, 2001). However, the side effects
of this treatment are also well documented and may impact on individuals' emotions and their ability to cope with the disease and a new-born infant. Therefore, this area is one that requires examination (Maartens et al., 2001) and it would seem important to conduct a follow up study once anti-retroviral drugs are easily available and more accessible to all patients (Bateman, 2003).

- Finally, it would seem timeous to assess the management of feeding schemes for mothers with HIV and their effectiveness in meeting infant feeding needs (Ndaba & Burns, 2004).

5.7 CONCLUDING COMMENT

In conclusion it would seem that HIV/AIDS is a devastating disease that is “going to fundamentally alter the fabric of South African and Southern African society” (Kallmann, 2003 pg.1). HIV/AIDS impacts on an individual’s entire being, altering physical, emotional, psychological and social functioning and even affects the ‘most natural thing in the world’, to be able to breastfeed your own child (Urban, 2001). It is of utmost importance to develop a better understanding of this disease and its implications and thereby provide improved counselling and education in all aspects of infant feeding, so as to enhance our understanding of the beliefs and practices of different cultural groups within Southern Africa. As the president of the United Nations Kofi Anan said of HIV/AIDS:

“HIV is humanity’s last frontier in the quest for survival”

(Kofi Anan, December, 2004 as cited in Dohrn, 2005 pg 10)