

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

This chapter is divided into four parts: findings, implications of findings, limitations, and recommendations for further research.

Conclusion of Findings

This study was a cross – sectional descriptive research aimed to examine the prevalence of HAART adherence among HIV infected children receiving treatment at Maharaj Nakorn Chiang Mai Hospital, to study the caregivers' knowledge and understanding regarding HAART and to explore other factors of adherence in children with Human Immunodeficiency Virus (HIV) as reported by caregivers. The study was guided by Ickovics and Meade's (2002) Determinants of Adherence Model. The target population for this study consisted of caregivers of HIV infected children under the age of 14 years, who received treatment at the pediatric infectious disease clinic at Maharaj Nakorn Chiang Mai hospital and the final sample included 74 caregivers of children under 14 years who received treatment at the pediatric infectious disease clinic and volunteered to participate in the study. The instruments used for data collection included a five part questionnaire and a data extraction form including the child's demographic data and medical information. The questionnaire was developed by the researcher using a modified version of the Treatment Interview Protocol (TIP) by Marhefka et al., 2004 and the Pediatric

Adherence Questionnaires by the Pediatric AIDS Clinical Trials Group (PACTG, 2004).

The main findings of the study are summarized as follows:

A high level of medication adherence is necessary for viral suppression and reductions in HIV related morbidity and mortality (Paterson et al., 2000) and Simoni and colleagues (2007) highlighted that family/caregiver factors are crucial to pediatric adherence, because infants and younger children depend almost entirely on a caregiver to administer medications. Adherence was measured using 4 markers namely caregiver reported missed doses, pill count, last CD4 count, and last viral load. Using these 4 markers, the average HAART adherence was 89.19%, measured as $\geq 95\%$, meaning that nearly 90% of the children had $\geq 95\%$ adherence to their HAART medication.

Regarding medication identification knowledge of the caregivers in the current study, over half could identify exactly all aspects of the medication including the name, colour, size, shape, medication schedule and dose and special instructions and almost 40% could identify partly, they could describe the medication and the schedule and dose. Moreover, almost all the caregivers reported always following the specific medication schedule. Therefore even though only half could correctly identify their child's medication, the majority of the children (89.19%) had $\geq 95\%$ adherence to their HAART. In addition, the current study showed that when the caregivers were asked nine general questions on HIV, the majority responded correctly to all questions (75.38%).

Williams and colleagues (2006) note that adherence to medication in children with HIV infection is a complex process that is influenced by multiple

factors and this study identified factors that may influence adherence to medication. Such factors include patient/caregiver characteristics (socio-demographic and psychosocial factors), treatment regimen, patient-provider relationship, and clinical setting.

Implications of Findings

What can be taken from this and similar studies, is that adherence is a complex behavior that is impacted by a variety of different factors. While generalization from such studies is not appropriate, they do provide insight into experiences.

The information gleaned from this study can be used for the health care providers at the pediatric infectious disease clinic at Maharaj Nakorn Chiang Mai hospital to be aware of the situation at the clinic and to better understand factors of adherence experienced by the caregivers of HIV infected children. The health care providers can use the information to assist in developing intervention strategies to improve adherence for HIV infected children and their caregivers. In addition, health care providers at the clinic will be more aware of the caregivers' situations and can prepare them of the possible challenges of adherence before they commence HAART medication, which can be cost effective. The results of the level of caregiver's knowledge can be used to plan education programs for caregivers to help increase their HAART knowledge moreover the general results can be used as background information for further research on drug adherence in HIV infected children in Chiang Mai.

Limitations of the Study

There are several limitations of the study that must be acknowledged. As a qualitative study with 74 participants, the findings cannot be generalized and are limited to describing adherence, knowledge and understanding, and other factors from the experiences of the caregivers. As this study was solely an exploratory study no statistical correlation between factors of adherence and adherence levels was conducted. In addition, there was also a possibility of selection bias as caregivers who did not agree to participate may have been aware of adherence difficulties of their child or did not feel comfortable discussing why medication was not administered correctly. Moreover, data collection was carried out in the clinical setting (pediatric infectious disease clinic), and the researcher believes that this location was not the most productive location to conduct the study, especially since there were questions in the questionnaire related patient-provider setting and experience of clinical setting. The caregivers perhaps felt uneasy and uncomfortable to answer honestly and fully.

Recommendations for Further Research

As evidenced by the experiences of the caregivers in this study as well as the body of literature, adherence behavior is an experience that suggests an individualized approach to the assessment of the patients' situation as well as the development of interventions to help identify sources of and overcome challenges to adherence behavior. Even though the prevalence of adherence in this study was relatively high (89.19% with $\geq 95\%$), this could decrease if constant monitoring and encouragement is not offered. A person who is categorized as adherent may not be far

from becoming non-adherent and individuals who are adherent may be struggling with the same issues that non-adherent individuals encounter, therefore the researcher recommends a longitudinal study measuring the prevalence of adherence over a one or two year period. Ongoing adherence research is needed to further identify factors that can help individuals deal with the effort of incorporating a medication regime into daily routines and to support successful maintenance of that behavior, therefore further research is needed to further explore the concept of adherence as a process as a phased process could be supported by various interventions depending on the task associated with each phase. Retrospective studies are needed in the context of caregivers and their children to examine the adherence process of currently adherent individuals, such studies can help to further define the adherence process and identify barriers and facilitators of the process over time. The researcher suggests future research using a variety of sampling schemes to capture information about the experiences of the range of individuals impacted by HIV, and specifically further studies should include child-caregiver relationships and data collection within their households, not the clinical setting.