

CHAPTER 4

RESULTS AND DISCUSSION

This chapter consists of three sections: demographic characteristics, the qualitative findings based on the research questions, and discussion of the findings.

Results

Demographic characteristics

- Caregiver

The participants in this study were 74 primary caregivers of HIV infected children, under the age of fourteen receiving highly active antiretroviral treatment at the pediatric infectious disease clinic, Maharaj Nakorn Chiang Mai hospital. Demographic information about the caregivers who participated in this study is shown in Table 1. The majority of the caregivers were female (77.03%) who ranged in age from 25 to 72 years with a mean age of 43.91 years. Moreover, most (33.78%) of the caregivers were the child's mother, 17.57% the father, and the remaining number consisted of other relationships. The majority (74.32%) had been the primary caregiver for over 5 years (mean 7.79, range 1-14), over half (54%) were married, with a primary education (51.35%), and employed (78.38%). Numbers in the household ranged from 2 to 10 persons with a mean of 4.05 persons, and the majority (37.84%) had a monthly income of between 5,001 and 11,000 Baht. Almost half of

the caregivers were HIV infected (n=34; 45.95%) and of that thirty four, 79.41% were receiving ART. Most of the caregivers reported their health as fair (51.36%) or excellent (47.30%).

Table 1
Demographic characteristics of the primary caregivers

Categories	Total: n=74	
	Number (n)	Percentage (%)
Gender		
Female	57	77.03
Male	17	22.97
Age		
Range: 25 – 72yrs		
Mean: 43.91yrs		
≤ 30 years	13	17.57
≤ 50 years	38	51.35
≥ 51 years	23	31.08
Relationship to child		
Mother	25	33.78
Father	13	17.57
Maternal grandparent	13	17.57
Step-parent/other relative	12	16.22
Paternal grandparent	6	8.11
*Other	5	6.76
Duration as primary caregiver		
Range: 1 – 14yrs		
Mean: 7.79yrs		
< 5 years	19	25.68
≥ 5 years	55	74.32
Marital Status		
Married	40	54.05
Widowed	19	25.68
Separated/divorced	10	13.51
Single	5	6.76
Education level		
No formal education	7	9.46
Primary education	38	51.35

Categories	Total: n=74	
	Number (n)	Percentage (%)
Secondary education	18	24.32
Bachelor degree	11	14.86
Employment status		
Employed full-time	21	28.38
Seasonally employed	19	25.68
Self-employed	18	24.32
Homemaker	10	13.51
Unemployed/retired	5	6.76
Employed part-time	1	1.35
Number in household		
Range: 2 – 10		
Mean: 4.05		
1 – 2	10	13.51
3 – 4	40	54.05
5 – 6	16	21.62
≥7	8	10.81
Monthly household income		
< 2,000	8	10.81
2,001 - 5,000	22	29.73
5,001 - 11,000	28	37.84
>11,001	16	21.62
HIV status		
Don't know	3	4.05
Negative	37	50.00
Positive	34	45.95
On ART		
(n=34)		
Yes	27	79.41
No	7	20.59
General health		
Excellent	35	47.30
Fair	38	51.35
Poor	1	1.35

(* other includes teachers and workers in a children's home)

- Children

Regarding the demographic data of the children, the children of the caregivers were mostly male (59.46%), with a mean age of 9.39 years (range 1.4 - 13.9 years) with an average duration of 48.36 months on HAART. Regarding type of medication, all children were taking tablets while 9 children were taking tablets and syrup (see Table 2).

Table 2
Demographic information of the children

Categories	Total: n=74	
	Number (n)	Percentage (%)
Gender		
Female	30	40.54
Male	44	59.46
Age		
Range: 1.4 – 13.9yrs		
Mean: 9.39yrs		
< 4 years	7	9.46
4 – 9 years	21	28.38
> 9 – 14 years	46	62.16
Length of time on HAART		
Range: 1 – 72 months		
Mean: 48.36 months		
≤ 12 months	8	10.81
13 – 36 months	11	14.86
37 – 60 months	28	37.84
> 60 months	27	36.49
Type of medication		
Tablets	74	100.0
Syrup	9*	12.16

(* Taking both tablets and syrup)

*Qualitative findings***Prevalence of adherence**

Prevalence of adherence to highly active antiretroviral treatment was measured using 4 markers namely caregiver reported missed doses, pill count, last CD4 count, and last viral load, the results are shown in Table 3. According to the caregiver reported missed doses 95.94% of the participants had an adherence rate of $\geq 95\%$ (classified as adherent if they have missed less than 3 doses within the last 30 days), adherence rate using pill count method was 78.38%, using CD4 count was 89.19% and viral load was 93.24%. Using these 4 markers, the average HAART adherence measured as $\geq 95\%$ in children in this study was 89.19%.

Table 3

HAART adherence of the children

Method of measurement	Total: n=74 Prevalence ($\geq 95\%$)	
	Number (n)	Percentage (%)
Caregiver self report	71	95.94
Viral load (≤ 400 copies/ml)	69	93.24
CD4 ($\geq 15\%$)	66	89.19
Pill count	58	78.38

Knowledge and understanding of caregivers

- Medication identification

Table 4 shows the number and percentage of the caregivers who could correctly identify their child's medication including pills each dose and dose per day. Over half (52.70%) could identify exactly all aspects of the medication including the name, colour, size, shape, medication schedule and dose and special instructions, 37.84% could identify partly, they could describe the medication and the schedule and dose, whereas 9.46% could not identify or describe the prescribed medication. Moreover, almost all caregivers (91.89%) reported always following the specific medication schedule, where as 16.22% reported not always following the special instructions.

Table 4

Medication information

Medication identification	Total: n=74	
	Number (n)	Percentage (%)
Identify:		
• Exactly; medication type and regimen	39	52.70
• Partly; medication type and regimen partly (dosing times only)	28	37.84
Always follow:		
• specific medication schedule	68	91.89
• specific medication special instructions	62	83.78

- Knowledge

Participants were asked nine general questions about HIV answering either yes, no or don't know/not sure. Table 5 provides the responses of the caregivers to the knowledge and understanding questions. When asked whether the caregivers knew why their child was taking the medication, all (100%) responded that they knew why their child was taking the HAART medication. The majority of caregivers responded correctly to all questions (75.38%). Over half (51.35%) of the caregivers correctly answered that taking ARV medication could not cure HIV. Moreover, most knew that the AIDS virus develops resistance to some ARV medications if they are not taken as prescribed (91.89%), that the CD4 count measures the changing number of white blood cells in the immune system (86.49%), and that CD4 count increases when the HIV condition improves (86.49%). However, when asked whether the drugs were still effective if the virus develops resistance, almost half of the caregivers (40.54%) could not answer correctly or were not sure of the answer. Moreover, 9 caregivers (12.16%) reported that it was not worth taking the ARV medicine even when there are serious side effects.

Table 5

Knowledge and understanding of caregivers n=74 (%)

Item/statement	Total: n=74 (%)		
	Yes	No	Don't know
1. Taking ARV medication can cure HIV	25 (33.78)	38* (51.35)	11 (14.89)
2. The AIDS virus develops resistance to some ARV medications if they are not taken as prescribed	68* (91.89)	2 (2.70)	4 (5.40)
3. The drugs are still effective if the virus develops resistance	10 (13.51)	44* (59.46)	20 (27.03)
4. The CD4 count measures the changing number of white blood cells in the immune system	64* (86.49)	1 (1.35)	9 (12.16)
5. The CD4 count increases when the HIV condition improves	64* (86.49)	3 (4.05)	7 (9.46)
6. After taking the ARV medicine the CD4 count stays the same	13 (17.57)	49* (66.22)	12 (16.22)
7. It is worth taking the ARV medicine even when there are serious side effects	55* (74.32)	9 (12.16)	10 (13.51)
8. Currently, we know the long-term effects of the ARV medicine on health	53* (71.62)	2 (2.70)	19 (25.68)
9. Taking ARV medication can extend a person's life	67* (90.54)	2 (2.70)	5 (6.76)

(* denotes correct response)

- Practices

Caregivers were asked whether they had utilized specific tools to help them remember to correctly administer the child's medication. As shown in Table 6 the most common aids used by caregivers to assist in reminding them included the timer/clock (68.92%) followed by pill boxes (43.24%) and beeper/mobile phone (35.14%). Whereas the least common reminder tools used were radio (13.51%) and diary (8.11%).

Table 6
Most common reminder tools used by caregivers

Tool used	Total: n=74	
	Number (n)	Percentage (%)
Timer/clock	51	68.92
Pill boxes	32	43.24
Beeper or mobile phone	26	35.14
Programmable wrist watch	17	22.97
TV program	16	21.62
Song (eg National Anthem at 8.00am and 6.00pm)	14	18.92
Calendars/daily planner	11	14.86
Label/stickers	11	14.86
Radio	10	13.51
Diary	6	8.11

(some caregivers reported using more than one tool)

The participants were asked what type of medication was more convenient for them to administer (Table 7). Most participants (85.14%) reported pills (tablets) as the most convenient followed by capsules (68.92%) with powder being the least convenient (13.51%).

Table 7

Medication convenience

Medication type	Total: n=74	
	Number (n)	Percentage (%)
Pills (tablets)	63	85.14
Capsules	51	68.92
Syrup	23	31.08
Powder	10	13.51

The caregivers also reported the medication preference of the children with the majority (85.14%) reporting pills (tablets) as the preference of their children, followed by capsules (50.00%), syrup (41.89%), and powder (8.11%) as seen in Table 8.

Table 8

Medication preference of children

Medication type	Total: n=74	
	Number (n)	Percentage (%)
Pills (tablets)	63	85.14
Capsules	37	50.00
Syrup	31	41.89
Powder	6	8.11

Other factors of adherence

- Attitudes

Caregivers were asked to rate their level of agreement/disagreement to ten statements regarding their attitude and self-efficacy, the results are seen in Table 9. All participants (100%) were confident that the ARV medicine would help their child, all believed that they could follow all the proper instructions necessary, and that they could manage their child's illness well. However some (14.86%) participants disagreed or strongly disagreed that they had no fear of giving their child the medicine in public. Almost all caregivers agreed and strongly agreed (94.59%) that if their child got sick, they would be able to take care of him/her with no problems. Moreover, almost half (47.30%) of participants reported that they were the only capable person in the household able to give the ARV medicine to their child, and almost all reported that they were confident that they could still give the ARV even though their child was suffering from side effects (91.89%), they were confident that they could still give ARV even when they were sick/tired/depressed/busy (98.65%) and that they believed that they knew what was best for their child and would act accordingly (98.65%).

Table 9

Attitude and self-efficacy of caregivers

Item/statement	Total: n=74 (%)	
	Strongly agree/ agree	Disagree/ strongly disagree
1. Confident that the ARV medicine will help my child	74 (100)	0 (0.00)
2. Believe that I can follow all the proper instructions necessary	74 (100)	0 (0.00)
3. Manage my child's illness well	74 (100)	0 (0.00)
4. Have no fear of giving my child the medicine in public	63 (85.14)	11 (14.86)
5. If my child gets sick, I will be able to take care of him/her with no problems	70 (94.59)	4 (5.41)
6. Taking ARV correctly will have no impact on my child's health	11 (14.86)	63 (85.14)
7. In my household I am the only capable person able to give the ARV medicine to my child	35 (47.30)	39 (52.70)
8. Confident that I can still give the ARV even though my child is suffering from side effects	68 (91.89)	6 (8.11)
9. Confident that I can still give ARV even when I am sick/tired/depressed/busy	72 (98.65)	1 (1.35)
10. Believe that I know what is best for my child and I will act accordingly	72 (98.65)	1 (1.35)

- Difficulties

The study participants were asked whether they had ever experienced specific problems or difficulties administering the medication to their child. The results are shown in Table 10. The majority of the caregivers never experienced any of the problems or difficulties, however the most common difficulty experienced in the last seven days to three months previously was that a lot of people looked after their child/not always with him/her at the correct time, experienced by 28.38% of the participants. Almost all participants never ran out of medicine before the next

scheduled appointment (86.46%), moreover, over one quarter (25.68%) of caregivers reported the difficulty of not being with the child every time he/she needs to take the medicine. Almost one fifth (18.92%) reported that at some point in the 3 months previously their child was playing and didn't take the medicine on time.

Table 10

Experience of problems or difficulties

Item Problem/difficulty	Total: n=74 (%)		
	Never	Last 7 days to 3 months	Don't remember
1. Ran out of medicine before next appointment	64 (86.49)	5 (6.76)	5 (6.76)
2. Didn't come for medicine	70 (94.59)	2 (2.70)	2 (2.70)
3. The medicine tastes bad	59 (79.73)	9 (12.16)	6 (8.11)
4. Forgot to give it	66 (89.19)	6 (8.11)	2 (2.70)
5. Worried about the side effects	51 (68.92)	14 (18.92)	9 (12.16)
6. Change in daily routine	64 (86.49)	8 (10.81)	2 (2.70)
7. Too busy with the child	64 (86.49)	8 (10.81)	2 (2.70)
8. Child refused to take the medicine/spat out	69 (93.24)	3 (4.05)	2 (2.70)
9. A lot of people look after the child/not always with him/her at the correct time	45 (60.81)	21 (28.38)	8 (10.81)
10. Not with the child every time he/she needs to take the medicine	48 (64.86)	19 (25.68)	7 (9.46)
11. Don't want others to notice giving the medication	53 (71.62)	10 (13.51)	11 (14.86)
12. Child was ill so didn't give the medicine	72 (97.30)	1 (1.35)	1 (1.35)
13. Don't think the child needs it	67 (90.54)	6 (8.11)	1 (1.35)
14. Family/someone told me not to give it anymore	72 (97.30)	2 (2.70)	0 (0.00)
15. Was ill	70 (94.59)	2 (2.70)	2 (2.70)
16. Felt the medicine might be harmful	67 (90.54)	5 (6.76)	2 (2.70)
17. Child was not staying in the house where the medicine was kept	73 (98.65)	1 (1.35)	0 (0.00)

Item Problem/difficulty	Total: n=74 (%)		
	Never	Last 7 days to 3 months	Don't remember
18. Felt depressed	58 (78.38)	8 (10.81)	8 (10.81)
19. Child was well, no need for the pills	66 (89.19)	6 (8.11)	2 (2.70)
20. Child was away from home without his/her medicine	68 (91.89)	5 (6.76)	1 (1.35)
21. Felt there was too much medicine to give	68 (91.89)	5 (6.76)	1 (1.35)
22. I was away from home	63 (85.14)	8 (10.81)	3 (4.05)
23. Too busy with other things	67 (90.54)	5 (6.76)	2 (2.70)
24. Didn't understand the instructions clearly	72 (97.30)	1 (1.35)	1 (1.35)
25. Think I gave too much medicine	71 (95.95)	3 (4.05)	0 (0.00)
26. Don't think I gave enough medicine	73 (98.65)	1 (1.35)	0 (0.00)
27. Had a task at work so I could not give the medicine	65 (87.84)	8 (10.81)	1 (1.35)
28. Child was playing and didn't take the medicine on time	51 (68.92)	14 (18.92)	9 (12.16)

- Clinical setting and support

Participants were asked to rate their level of agreement/disagreement to thirteen statements regarding the clinical setting and the results are seen in Table 11.

All or almost all participants strongly agreed/agreed that the doctor or support nurse gives them the necessary information about the ARV medicine, they also felt comfortable discussing the ARV medicine with their doctor, they believed that they understood very well about ARV medication and when they have problems about ARV medication they can get advice from staff straight away. All caregivers (100%) were satisfied with the advice given related to ARV and almost all believed that they could ask anything about ARV medication with the doctor or nurse. In addition, almost all participants agreed/strongly agreed that they were very satisfied with the

service they receive at the clinic (98.65%), they felt the clinic ensures their confidentiality (91.89%), and they felt safe and comfortable discussing any problems at the clinic (97.30%). Moreover, the majority (93.24%) were happy with the clinic's environment. However almost one half (43.24%) reported that they often felt embarrassed or reluctant to approach a doctor/nurse about any problems they may have and over a third (36.49%) agreed/strongly agreed that it was not convenient for them to bring the medical bottles/bags to the clinic every time.

Table 11

Experience of clinical setting

Item/statement	Total: n=74 (%)	
	Strongly agree/agree	Disagree/strongly disagree
1. Doctor or support nurse gives me the necessary information about the ARV medicine	73 (98.65)	1 (1.35)
2. Feel comfortable discussing the ARV medicine with my doctor	74 (100)	0 (0.00)
3. Often feel embarrassed or reluctant to approach a doctor/nurse about any problems I may have	32 (43.24)	42 (56.76)
4. Understand very well about ARV medication (from doctor/nurse)	72 (97.30)	2 (2.70)
5. When I have problems about ARV medication or anything, I can get advice from staff straight away	73 (98.65)	1 (1.35)
6. Satisfied about the advice given related to ARV	74 (100)	0 (0.00)
7. Can ask anything about ARV medication with the doctor/nurse	73 (98.65)	1 (1.35)
8. It's not convenient for me to bring the medical bottles/bags to the clinic every time	27 (36.49)	47 (63.51)
9. Very satisfied with the service I receive at the clinic	73 (98.65)	1 (1.35)
10. Unhappy with the clinic's environment	5 (6.76)	69 (93.24)
11. Feel the clinic ensures my confidentiality	68 (91.89)	6 (8.11)
12. Feel the appointment times are not convenient for	27 (36.49)	47 (63.51)

Item/statement	Total: n=74 (%)	
	Strongly agree/agree	Disagree/strongly disagree
me		
13. Feel safe and comfortable discussing any problems at the clinic	72 (97.30)	2 (2.70)

For support, participants were asked questions related to financial and emotional support that they received along with support received giving ARV correctly from 4 groups of people; their partner/spouse, doctor/health worker, support group, and family members, as in Table 12. Regarding financial support over half (51.35%) of the caregivers received no financial support from their partner or spouse, however over two thirds (74/33%) received financial support from other family members. In addition, most (70.27%) stated that they received some or a lot of financial support from their doctor or health worker. Regarding emotional support, caregivers experienced the most support from their doctor or health worker (98.65%) followed by family members (89.19%), partner or spouse (66.22%), and support group (63.51%). When mentioning support administering ARV correctly, caregivers received the most support from their doctor or health worker (94.59%) followed by family members (82.43%), partner or spouse (56.76%), and support group (47.30%).

Table 12

Caregiver support received n=74 (%)

Item/statement	Not at all	A little/some	A lot
Financial support			
Partner/spouse	38 (51.35)	12 (16.22)	24 (32.43)
Doctor/health worker	22 (29.73)	33 (44.59)	19 (25.68)
Support group	51 (68.92)	20 (27.03)	3 (4.05)
Family members	19 (25.68)	33 (44.59)	22 (29.73)
Emotional support			
Partner/spouse	25 (33.78)	9 (12.16)	40 (54.05)
Doctor/health worker	1 (1.35)	16 (21.62)	57 (77.03)
Support group	27 (36.49)	15 (20.27)	32 (43.24)
Family members	8 (10.81)	17 (22.98)	49 (66.22)
Support giving ARV correctly			
Partner/spouse	32 (43.24)	6 (8.11)	36 (48.65)
Doctor/health worker	4 (5.41)	3 (4.05)	67 (90.54)
Support group	39 (52.70)	14 (18.92)	21 (28.38)
Family members	13 (17.57)	13 (17.57)	48 (64.86)

Discussion

The purposes of this study were to study the prevalence of HAART adherence among HIV infected children who receive 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 HIV as reported by caregivers.

Prevalence of HAART adherence

Although effective adherence levels for HAART have not been defined in concrete, levels of adherence below 95% have been associated with poor virological and immunological response (Paterson, Swindells & Mohr, 2000), other data suggest that levels of 100% achieve even greater benefit than adherence below 100% (Mannheimer, Friedland, Matts, 2002). In this study the prevalence of adherence to HAART 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. The results of the prevalence of adherence in this study were not congruent to previous studies where prevalence rates were much lower. The prevalence in this study was relatively high (almost 90%) and this may be because of several factors. Thirty four out of 74 caregivers ($\approx 46\%$) who were HIV infected, almost 80% were also on HAART, this may have made them better at adhering to the child's medication as they also needed to administer their own. In addition, participation in this study was voluntary, some caregivers were perhaps aware of the child's poor adherence and therefore did not

elect to participate in the study. In addition, in this study, according to the caregiver reported missed doses, 95.94% of the participants had an adherence rate of $\geq 95\%$ (classified as adherent if they have missed less than 3 doses within the last 30 days). As other studies have identified, patient or caregivers self reports of adherence tend to be exaggerated and caregivers generally overestimated adherence compared with other methods (Naar-King et al., 2005; Steele et al., 2001; Gao et al., 2000).

As mentioned, the prevalence of adherence in this study was relatively high compared to the findings of Mills' study in developed countries, where adherence was 55% (Mills et al., 2006). Also DiMatteo and colleagues highlighted that non-adherence to medication is very common and that typical adherence rates for medications prescribed over long periods of time are around 50-75% (DiMatteo, Giordani, Lepper, & Croghan, 2002). Moreover, in a paper reviewing the pediatric HIV literature on adherence, Steele and Grauer (2002) describe 13 studies addressing the rates and predictors of adherence. Mean adherence rates described in these studies identified by Steele and Grauer are suboptimal, typically ranging from $<50\%$ to $>95\%$, depending on the method of assessment. Measuring adherence is problematic as there is no single method to assess adherence accurately (Horizons and Population Council, 2004), in this study according to the caregiver reported missed doses 95.94% of the participants had an adherence rate of $\geq 95\%$ (classified as adherent if they have missed less than 3 doses within the last 30 days), adherence rate using pill count method was 78.38%, using CD₄ count was 89.19% and viral load was 93.24%. Similar to the current study where some discrepancies were found between adherence rates depending on the measurement, by analysing studies measuring adherence, Gill and colleagues found large discrepancies between the different methods used on the

same groups (Gill et al., 2005). With this information they constructed a relative hierarchy of adherence measurement methods, with physician assessment and self-report being the least accurate, pill counts intermediate, and electronic drug monitoring the most accurate surrogate adherence marker (Gill et al., 2005).

Evidence of drug resistance, increasing viral load and decreasing CD4 count are commonly considered signs of nonadherence (Simoni, Montgomery, Martin, New, Demas, & Rana, 2007), and Turner (2002) interestingly mentions that every available tool either over or underestimates adherence, so in order to compensate it is advisable to use a combined approach (Turner, 2002). Therefore the results of adherence prevalence in the current studies are still relevant and appropriate, even though there are some discrepancies in the rates depending on the measurement used.

Caregivers' knowledge and understanding regarding HAART

Relatively few studies have covered the area of caregivers' knowledge in relation to HAART adherence and this current study did not statistically evaluate the relationship between caregivers' knowledge and understanding regarding HAART and prevalence of adherence, but aimed to explore only their knowledge and understanding. As Marhefka and colleagues (2004) suggest regimen knowledge assessment and may be one of the best methods available for adherence assessment within the clinical setting.

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. 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%). 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.

These results are similar to the results found by Katko et al., (2001) whose study supports the use of knowledge assessment as an indicator of adherence. Katko et al., asked 35 caregivers to name or describe their children's ART medication and corresponding doses and dosing frequencies, only 54% of the caregivers were able to provide accurate medication information. Similarly, Nicholson, Mellins, Dolezal, Brackis-Cott & Abrams (2006) examined whether caregivers' treatment related knowledge and self-efficacy was associated with better clinical outcomes and ART adherence among HIV infected children. The results suggested that both knowledge and self-efficacy are important for empowering caregivers and both treatment-related knowledge and adherence self-efficacy were associated with better clinical outcomes, as measured by either CD4 count or viral load. However, in this study, neither were directly associated with caregiver reports of child's ART adherence.

Caregivers in the current study seemed to understand the importance of optimal adherence and were asked whether they had utilized specific tools to help them remember to correctly administer the child's medication. The most common aids used by caregivers to assist in reminding them included the timer/clock, used by almost three quarters of the sample followed by pill boxes and beeper/mobile phone.

Wang and Wu (2007) in their study of adherence in a Chinese rural population also found that adherence was associated with, among other things, using reminder tools.

Other factors of adherence

Identification of adherence factors is important for the development of effective interventions to improve adherence to HIV treatments (Ickovics & Meade, 2002). Williams and colleagues (2006) note that adherence to medication in children with HIV infection is a complex process that is influenced by multiple factors, including demographic, health, medication characteristics, and psychological characteristics of the child and family. This study was guided by the Ickovics and Meade's (2002) Determinants of Adherence Model, which has 5 main concepts, patient/caregiver characteristics (socio-demographic and psychosocial factors), treatment regimen, patient-provider relationship, clinical setting and disease characteristics (which are not included in this study).

Patient/caregiver characteristics: A number of psychosocial factors have found to impact adherence including depression and other psychiatric illnesses (Gifford, et al., 2000: Gordillo et al.,1999), social support (Ickovic & Meade, 2002: Eldred et al., 1998), attitudes and mood (Remien et al., 2003), knowledge, (Williams, 1997) and self efficacy (Chesney, 2000: Eldred et al., 1998: Gifford, et al., 2000). Moreover, Chesney (2000) stated that a person's knowledge of the medication regimen and understanding of the relationship between non-adherence and build-up of resistance to medication can also predict better adherence. Simoni et al., (2007) also mentioned that children's adherence to treatment is largely guided by the resources and efficacy of their caregivers.

In the current study caregivers were asked to rate their level of agreement/disagreement to statements regarding their attitude and self-efficacy. All participants were confident that the ARV medicine would help their child, all believed that they could follow all the proper instructions necessary, and that they could manage their child's illness well. These results are inline with Simoni et al., (2007) who concluded that, parents of adherent children report higher perceptions of their ability to administer the prescribed doses and medication efficacy.

In the present study almost all caregivers agreed that if their child got sick, they would be able to take care of him/her with no problems, however almost half of the caregivers reported that they were the only capable person in the household able to give the ARV medicine to their child and felt an element of burden. Similar to the results of the current study, Reddington et al., (2000) identified caregiver perception of medication efficacy and dosing self-efficacy as significant predictors of child adherence.

Caregiver support has also been identified as a factor of adherence (Ickovic & Meade, 2002; Eldred et al., 1998). In this study, the caregivers were asked questions related to financial and emotional support that they received along with support received giving ARV correctly from 4 groups of people; their partner/spouse, doctor/health worker, support group, and family members. Regarding financial support most received financial support from family members other than their partner or spouse, moreover surprisingly they stated that they received some or a lot of financial support from their doctor or health worker. The researcher believes that the caregivers did not have a clear understanding of the question or the question was not asked clearly as the caregivers do not receive financial support from the

doctors/health workers at the clinic. The caregivers do receive monthly financial support from the Thai government if they have declared the HIV status and they receive free medication, perhaps this is where the confusion lies. Regarding emotional support, caregivers reported receiving the most support from their doctor or health worker likewise when mentioning support administering ARV correctly, caregivers received the most support from their doctor or health worker. Power and colleagues found in their study a relationship between social support by a partner and adherence, however support from a family or friend did not have the same influence on adherence behaviour (Power et al., 2003).

Caregivers reported barriers to adherence can include difficulties with the medication itself (e.g., number of pills, difficulty swallowing medication, bad taste) as well as environmental problems (e.g., taking medication outside the home), and individual child behaviors (e.g., child refusal) Boni, Pontali, De Gol, Pedemonte, and Bassetti (2000). However in the current study, the majority of the caregivers never experienced any of the problems or difficulties listed in the questionnaire. Nevertheless the most common difficulty experienced (by nearly 30% of the caregivers) was that a lot of people looked after their child/not always with him/her at the correct time and almost one fifth reported that at some point in the 3 month previously their child was playing and didn't take the medicine on time.

Treatment regimen: One of the main challenges of HAART is that it involves a complex treatment regimen that may include more than 20 pills a day, with multiple daily dosing and specific dietary restrictions (Horizon and Population Council, 2004; Ickovic & Meade, 2002). In addition, medication related side-effects (Gao et al., 2000) and palatability (Albano et al., 1999) have been found to have a

negative impact on adherence behaviour (Gao et al., 2000), and early toxicity contributes to lower adherence (Horizon and Population Council, 2004). In the current study, the caregivers were asked what type of medication was more convenient for them to administer and which medication their child preferred, for both questions most answered pills (tablets) followed by capsules. In this study, all children received their medication in tablet form, where as only 12% received syrup. Surprisingly, syrup was not the most preferred medicine, and some caregivers mentioned that ‘the child can’t take it (syrup) because it tastes too bitter’. When asked to expand on their answers, some caregivers felt that the size of the pills and frequency of dosage were a hindrance however this did not stop them administering the medication correctly. The caregivers in the current study did not report any major problems or difficulties with the medication itself, which is inline with the findings by Wagner (2002) who found that the number of pills per day, length of time of current treatment and regimen complexity were not associated with the degree of adherence.

Patient-provider relationship: The patient-provider relationship plays an important role in improving adherence to medication and it is believed to be a motivating factor of adherence to HAART (Hall, et al., 1988: Ickovic & Meade, 2002). Ickovic & Meade (2002) identified specific aspects of the relationship that may be influential including: tone of the relationship, trust, open communication, cooperation, and overall satisfaction.

In the current study, the majority of the caregivers were satisfied with their health care provider through their responses to statements posed to them. They believed that the doctor or support nurse gives them the necessary information about the medicine and they felt comfortable discussing the medicine with their doctor. All

caregivers were satisfied with the advice given related to ARV however almost half reported that they often felt embarrassed or reluctant to approach a doctor/nurse about any problems they may have. The study by Russell and colleagues (2004) also suggests that adherence to HAART is influenced by the quality of the relationship between the health care provider and the client. Russell and colleagues highlight that their research, similar to this current study, shows that consistent with the model suggested by Ickovic & Meade (2002), adherence relies on a complex set of factors that include, but are not limited to, the nature and quality of the relationship between client and provider (Russell et al., 2004). The study conducted by Williams (1997) also identified that patients who have been able to establish an ongoing relationship with a single primary care provider may find it easier to adhere to difficult regimens. Moreover when a health care provider is consistently available to answer questions, reinforce recommendations, and provide positive feedback, the patient's chances of success are enhanced (Davis, Canniff, Andradas, Cohen, & Hellinger, 1997 as cited in Williams, 1997).

Clinical setting: Existing data is limited in this area (Horizon and Population Council, 2004), however aspects of the clinical setting may be associated with improved adherence. Bangsberg and colleagues (2000) identified aspects of the clinical setting that may be associated with improved adherence namely: availability of transportation and childcare, pleasantness of the clinical environment, convenience in scheduling appointments, and confidentiality. In the current study, almost all the caregivers were very satisfied with the service they received at the clinic, they felt the clinic ensured their confidentiality and they felt safe and comfortable discussing issues at the clinic. However almost 40% felt the appointment times were not

convenient and it was not convenient for them to bring the medical bottles/bags to the clinic every visit.

In summary, it is well established in the literature that adherence is critical to optimum clinical outcomes, but also well documented that near-perfect adherence to complex antiretroviral regimens is rare (Turner, 2002). Williams and colleagues (2006) note that adherence to medication in children with HIV infection is a complex process that is influenced by multiple factors, including demographic, medication characteristics, and psychological characteristics of the child and family. This chapter showed the prevalence of HAART in HIV infected children, caregivers' knowledge and understanding, and concluding with other factors of adherence found in the study.