CHAPTER 5

CONCLUSIONS, DISCUSSIONS AND SUGGESTIONS

5.1 Conclusions and Discussions

This study consisted of three phases. In phase I, a qualitative study was used to understand the attitudes and beliefs about disease and medicine among ALWHs. In phase II, results from Phase I and literature review were used to develop a questionnaire acquiring information about factors affecting adherence with ART for ALWHs. In phase III, predicting factors gained from phase II were put together with the individual patient’s contexts to develop a tailored intervention for enhancing ART adherence of adolescents infected with HIV. Finally, the researcher evaluated the program for its effectiveness in improving adherence, knowledge and CD4 cell count.

Results of Phase I study reveal that ALWHs with different age had diverse level of knowledge and understanding of their disease conditions. By classify the participants into two group, early ALWHs (10 – 15 years) and middle ALWHs (16 – 18 years), we could understand their perceptions, clearly. The middle adolescents were able to explain their answers in details while most of the early adolescents had unclear and basic answers. On the other hand, the early adolescents need further knowledge about routes of transmission and the difference between AIDS and HIV-infected persons.

This could be explained by the fact that the early adolescents have a limitation of their age potential. Similarly, in non-HIV/AIDS Nepalese adolescents, they also had moderate level of overall HIV/AIDS knowledge, but a lack of knowledge in the areas of mode of transmission and prevention of HIV/AIDS (Mahat & Scoloveno, 2006). In Pakistan, non-HIV/AIDS adolescents had partial knowledge about AIDS and its related issues (Arsalan, 2010).

Their perceptions in susceptibility, severity and benefit according to HBM were in the high level. This finding is in consensus with other studies on non-HIV adolescents in South Carolina (Petosa & Wessinger, 1990), New York (Koopman et al., 1990) and Malaysia (Zulkifli & Wong, 2002). This result might be explained that ALWHs received enough information about disease and medicines from the healthcare team in Thai public hospitals. The practice guideline is clearly states that every patient has to attend series of counseling sessions by a multidisciplinary team and to attend educational interventions for assuring the correct knowledge about HIV/AIDS and the importance of their adherence.

Finally, Most of them told that they needed their family members to encourage them to adhere with their treatment and enhance their desire to take antiretroviral drugs. These qualitative data referred to the importance of caregivers and family role in ART adherence.

By surveying ALWHs in the North and North-Eastern regions of Thailand, results from phase II study, showed that having caregiver was an important factor associated to ART adherence. This contributed to phase I results, ALWHs still need assistant and support from caregiver and their family member. This finding was in consensus with a previous study in North-Eastern, Thailand that reported a positive role of caregiver to children and adolescents with HIV/AIDS in supporting higher adherence (Udompanich et al., 2008) and other countries (Santer et al., 2014; Sivapalasingam et al., 2014; Usitalo et al., 2014; Ugwu & Eneh, 2013; Azmeraw & Wasie, 2012).

Other factors that significantly related to compliance were female gender, studying status and convenient transportation to the hospital. In the Northern region and middle ALWHs, studying status was a significant factor associated to ART adherence. In the North-Eastern region, female gender was a significant factor. Having caregiver was a significant factor for respondents in North-Eastern region and early ALWHs. Convenient transportation was a significant factor for HIV DR group. These contributed to previous studies that note demographic and psychosocial factors were associated with ART adherence (Barclay et al., 2007; Castro et al., 2015; Dahab et al., 2008; Denison et al., 2015; Hammami et al., 2004; Hudelson&Cluver, 2015; Karl Peltzer et al., 2010; Katz et al., 2013; Kip et al., 2009; Li et al., 2011; Lowenthal et al., 2014; Mellins et al., 2004; Mills et al., 2006; Mutwa et al., 2013; Peltzer & Pengpid, 2013; Rachlis et al., 2011; Sanjobo et al., 2008; Sayles et al., 2009; Udompanich et al., 2008; Vreeman et al., 2009; Vreeman et al., 2008). These findings highlight many factors that would assist the ALWHs in their medicine taking behavior. With the help of a caregiver, they can take their medicines regularly. With the change of living such as quitting school and starting to work, these could be change their available time to take ARVs and would affect their adherence, too (which supports by the findings from phase III).

Majority of them had low to moderate level of knowledge about disease and medicine (78.15%). It might be that disclosure processes were done at early age and no test repeated over period later (Oberdorfer, 2006). Therefore, they had a gap of knowledge required from their perspective. Health care providers should be paying more attention to explore what they want to know. This was not consistent with the study among adolescents and young adults attending an adolescent in Ghana which stated high level of knowledge (Kenu et al, 2014). Otherwise, in their perspective, they assessed their knowledge in moderate level (51.41%) and prioritized necessity of knowledge of disease and medicine in their life in most level (57.58%).

Knowledge, attitudes and their perception according to HBM were not associated with ART adherence. These results might be explained that it is possible that ALWHs had similar knowledge about disease and medicines, thus we found no difference among them. Since only general knowledge was asked in the questionnaire, therefore the items were not fit for specific conditions of each individual to classify their levels and perceptions.

Our study findings highlight the constructs of the HBM that the ALWHs had high perceived benefit from ART. For example, they completely agreed that ART was the only one method of treatment for HIV/AIDS. However, there were several perceived barriers to ART adherence. The size and side-effects of antiretroviral drugs were the first concerned when they had the HIV-drug resistance. Barriers to taking antiretroviral drugs regularly were transportation to the hospital, physical properties of antiretroviral drugs, their daily activities and unavailability of adherence aids.

Most of self-efficacy of the participants was low to moderate level, but not significantly associated with ART adherence, this contrast with previous studies (Tuldra et al., 2000; Judith et al., 2010; Li et al., 2011). It could be explained that this study was focused only adolescents group, but other studies had higher mean ages, therefore the different age might be affect to self-efficacy. However, it might be because of Thai culture that they did not want to show their capabilities or their power to other people. The questions asked may need further clarification. We need further studies to clear this suggestion.

Stigma and discrimination were not highlighted in these results. Most of ALWHs disclosed their disease status to their friends and communities, but they didn't have problems from this situation compared with other studies (Li Li et al., 2010; Mills et al., 2006; Birbeck et al., 2009; Dahab et al., 2008; Kip et al., 2009; Murray et al., 2009; Sanjobo et al., 2008). It is possible that they were too shy to show off their emotion on stigma and discrimination which is also cultural limitation for this study.

Regarding to the TPB, data indicated that their family has the most influential on their normative belief. Participants expressed a need for family support. They stated that their family members helped preparing their medicines, reminding them to take medicines, supporting them in treatment adherence and understand their conditions.

The ALWHs' daily activities were an important barrier. They were busy playing with friends, doing homework or going outside when their guardians called for medicines. This presented consensus with the result from the United States which stated that "child was away from home" was common barriers to medication adherence in HIV-infected children and youth (Buchanan et al., 2012). This finding may be due to their increase in maturity in their late childhood and adolescence (Murphy et al., 2001). Lifestyle change was also highlighted in study Phase III where a home visit allowed the researcher to get deeper explanation about the barriers to ART adherence.

The most reported problem related to medicines was noted that adherence would increase by the hope that their disease would be cured; they would be more motivated to take the medicines. They felt bored to take medicine and it was even worst when they realized that their disease could not be cured. Additionally, they reported that they were sometimes late for taking the medicines (but not more than 10 minutes) and they would be happy if someone helped remind them to take their medicines and to prepare their medicines. It was contributed to the low to moderate level in cue to action. This situation can occur normally in other chronic disease patients that take lifelong medication (James et al., 1985; Kalyango et al., 2008; Gossell et al., 2014). Therefore, finding a trigger to action or something to remind them to take medicines would be a key to help with adherence problem among these adolescents.

Moreover, in the findings we found that they still wanted to have a caregiver or someone to remind them to take ARVs on time, which might cause them to get used to it. As a result, caregivers need to gradually alternate their responsibility from just preparing the medications to understanding their limitations and encouraging them to take medications regularly. This contributed the important role from family members that influencing adherence (Denison et al., 2015; Vissman et al., 2011).

Good adherence (≥ 95%) found in this study was 79.18%. The rate was similar to a study in the same age group from Brazil that was found at 79% (L F B Filho et al., 2008), but higher than the adherence rate of patients living with HIV/ AIDS and receiving ART aged 23 – 64 years living in the North and North-Eastern region, Thailand (Li Li et al., 2010) which was reported at 69%.

Regarding to regression analysis, for others demographic characteristic, although previous studies have found that gender (Berg et al., 2004; Kempf et al., 2009) financial (Mills et al., 2006; Dahab et al., 2008) and transportation costs (Birbeck et al., 2009) were associated with ART adherence, but not in this study. We found that these factors (gender and the convenience of transportation) were significantly related to adherence only in subgroup analysis. It could be explained that these female participants were younger and had less impacted from hormonal induced depressive symptom which led to non-adherence than previous study (Berg et al., 2004; Kempf et al., 2009). Otherwise, most of participants had convenient transportation to the hospital (70.44%). They had no problem with transportation costs and medical free for ARVs since it was supported by the NAPHA in Thailand since 2001 (Chasombat et al., 2006). This might be assumed that these factors not significant association with ART adherence.

Phase III study showed that home visit was an effective method to investigate and assess individualized ART adherences' problems. Specific interventions on individual and caregiver played important role to improve ART adherence. Supporting from caregivers could improved ART adherence, this finding consensus to the qualitative findings in Phase I and Phase II that noted a requirement for caregivers from family members to enhance ART adherence.

For the root cause problems related to ART adherence, their other daily activities during the time taking ARVs were common problems lead to non-adherence. This finding was in consensus with results from phase I and a study from Africa that noted children with disrupted routines were at risk for treatment failure (Jessica et al., 2011). In the U.S., literature found that forgot to take medicines, taste of medicines, being away from home, refusing to take medicine, and not-feeling well were barriers to medication adherence in HIV-infected children and youth (Buchanan et al., 2012). Additionally, changes in routine schedule and being too busy were individual barriers associated with non-adherence (Marhefka et al, 2008), which were similar to the findings found in this study.

Common causes of barriers in this study were playing outside with their friends, transferring to a new school, getting a new job and changing of working time. These changes in life schedule are sometime overlooked by healthcare personnel or the ALWHs might think that it is a little problem to tell the healthcare team. In this study, with only an assisting in adjusting their medicine time schedule to the most convenient time for them and advising them to set an alarm clock are very effective interventions used for ALWHs who had inappropriate time taking ARVs from lifestyle changed.

This finding in phase III made a clearer explanation for the findings from phase II that studying in school was a factor affecting their adherence. In reality, studying status was associated with ART adherence by the fact that lifestyle change affected to the time to take ARVs. ALWHs did not know how to deal with it since they were asked to restrict with their medicine taking time. Finally, non-adherence occurred.

Healthcare team needs to spend more time with the ALWHs, to assess their living schedule, and to help them adjust their appropriate medical taking schedule that fit to their life schedule, especially when they change their lifestyle e.g. move to work in other place or other school, etc. These seem to be a little problem, but obviously the results from phase I and phase III of this study highlight that this can lead to ART non-adherence among ALWHs.

Caregiver’s help, especially with an ability to identify ARVs correctly was very important for ALWHs who could not organize the medicines by themselves (Azmeraw & Wasie, 2012). Findings from Phase III of this study supported this recommendation, where a pharmacist could help assist a caregiver or patient to be able to remember and manage his medicine, correctly. Making a one day medicines’ example set is very helpful for participant or caregiver who has memory limitations. Afterwards, they could easily manage their medicines according to the sample for every meal. When, they could easily manage their medicine, their self-efficacy improves. This could be explained that high self-efficacy is important for medication adherence (Li et al., 2011) and taking self-efficacy scale is an effectively intervention to promote ART adherence (Judith et al., 2010)

This study highlights the importance of caregiver that most of non-adherence cases did not have a caregiver. The findings from every phase showed that ALWHs still needed caregiver supports and caregivers played important role to ART adherence. From the interview, their caregivers thought that ALWHs were already grown up and should take responsibility by themselves. In fact, some ALWHs could not completely do it by themselves. With the support of caregiver to assist their medicine taking schedule they could better adhere to their medicines (Denison et al., 2015; Hammami et al., 2004; Mellins et al., 2004; Udompanich et al., 2008; Vreeman et al., 2009).

Regarding living status, this study’s results revealed that orphan ALWHs had lower adherence than ALWHs that still got their fathers or mothers. Family members were important groups influencing adherence (Vissman et al., 2011). Moreover, this study found that orphan ALWHs who lived with their grandparents had better adherence than those who lived with other relatives. It was possible that other relatives e.g. uncle, aunt were not so close that they could not pay attention to them. Some ALWHs might reject their relatives, that lead them to stop ARVs.

Families and home environments help supporting ALWHs' adherence to ART and life skills. This results supports the previous studies in Zambia where adult caregivers for HIV helped support the patients' self-management (Denison et al., 2015). By having a guardian presented at each clinical encounter, comforting with asking questions to health providers and participating in group sessions were all significantly associated with excellent adherence in Zimbabwe (Gross et al., 2014). The guardian helped taking care of the HIV infected children and adolescents in Brazil (Maria et al., 2014). Previous studies suggested that a clinician should explore caregivers' views of their children's futures and empower their ability to overcome adherence barriers in Rural Uganda (Olds et al., 2014). Therefore, HIV programs should stimulate caregivers of HIV-infected adolescents to join them for their clinic visits and involve both child and caregiver in the tasks of remembering when to administer the medications, sustaining adherence, and appropriately transitioning medication responsibility to the youth (Mutwa et al., 2013, Buchanan et al., 2012). In conclusion, caregivers are still in need for adolescents, but in the role of mentoring, not to a medicine managing as they were childhood, except for those who have memory's problem or physical limitations.

In addition, this study findings showed that for some adolescents who already had a partner or lover, their partner could play an important role in ART adherence. In this study we found that some ALWHs tried to conceal their disease status and avoided to take ARVs in the time that they stayed together with their lover. As a result, they might stop their ARVs. Our study suggests that ALWH's partner can be a good caregiver that helps to promote their adherence. Therefore, life skills or life-steps intervention is necessary for both ALWHs and their partners (Steven A Safren et al., 2001).

Improving ART adherence after the intervention was confirmed the effective of specific individual intervention. This contributed the individual intervention in the self-management group was potentially useful model for improve adherence (Scott et al., 2003). In this study the most frequent used interventions were providing knowledge and assisting with medicine management. Although the results from phase II showed knowledge was not associated with ART adherence and most of them had moderate to high score level of knowledge, but in phase III, we found that some ALWHs still needed some specific knowledge that helped fill the gap of their problem.

No significant relationship between knowledge and adherence could be explained by the fact that the questionnaire in phase II study developed from researcher's perspective, therefore it might be not represented the specific knowledge requirement from the participants. Phase III results showed that they still needed knowledge, but in the different topics such as how to live with their partner, how to get a HIV negative child in their family life, and how they should disclose about their disease to their lover, friends or others. Pharmacists and healthcare team should pay more attention to assessing individual needs and helping them to fulfill the gap of their knowledge. It might be suggested that their knowledge about disease and medicine that they gain while healthcare team disclosed their disease was not enough. Additionally it was provided when they were too young. Therefore, they didn't perceive that they got HIV and did not realize that their disease was important to their life in the future (Sudjaritrak and Oberdorfer, 2011; HIV guideline, 2011). When they grow up to be older teenager, their lifestyles have changed. They may need additional information that fit to their new way of living.

Spending enough time for each case is also an important key to get effective counseling session with the patients since overall context of the individual is assessed and specific information is slowly and clearly explained. In real life practice, the time that healthcare team spends with ALWHs is less than that they previously received as they were younger children. This studying suggests a long time spend in each counseling session with ALWHs. This is consistent with previous studies showing that HIV disclosure was an important factor associated to ART adherence (Ncama et al., 2008; Li Li et al., 2010), beliefs in the value of treatment was the key facilitator that decreased barriers to ART adherence (Dahab et al., 2008), and lack of adherence was linked primarily to psychosocial factors such as assigning treatment responsibilities to the child without taking into account his/her psychological maturity (Castro et al., 2015).

From Phase III of the study, participants' knowledge significantly improved after intervention, this might suggest that a tailored and individualized intervention where a healthcare worker visit a patient at their home and provide specific information to adjust patient’s or cargiver’s misunderstanding is effective for ALWHs. Tailor-made investigation by in-depth interview is more useful for the difficult to assess groups as the ALWHs. At their home, they attentively and freely give feedback to healthcare workers because it is at a private condition and they don’t need to worry about their shyness, their work or school schedule, or transportation time, or other barriers. As the result, there are more willing to receive knowledge information than when they are at a counseling unit at the hospital.

Home visit is an effective tool that it allows healthcare workers to understand the true reasons behind the patient’s non-adherence behavior that they cannot get in hospital setting e.g. living environment, psychosocial factors and other limitations. Moreover, they can meet with the key informants who generally do not go to the hospital with the ALWHs. They can gain deeper and get more important information that will assist them to select the most appropriate solution that fit for each individual patient later on.

Moreover, this study results showed that volunteers or healthcare workers could screen patient’s living environment and problems because they live closely with the patients. However, they could not resolve a complex problem or give deep and clear information to the patients and their family. A pharmacist is very important personnel who can help analyze and resolve the problems related to ART adherence. Additionally, a psychologist is needed for a patient who has psychological problem.

This study findings was consensus to a study from South Africa (Nachega et al., 2006) and from African American that noted interventions focusing on caregivers and their interactions with the individual youth and extra familial system should be prioritized for prevention and treatment efforts to address non adherence during the transition into adolescents (Naar-King et al., 2013). However, there is no intervention that we can use as one “model” fit for all, because they had individualized problems. Health care professionals are important source of adherence support for their families and caregivers.

CD4 cell had not changed after the participants receiving the individual intervention. This might suggest that to have immunological impact (WHO, 2010), a longer following up time may need in order to monitor of the changes (Sungkanuparph et al., 2010; Kaufmann et al., 2003). The two months following-up period in this study was too short to detect the immunological change. In addition, the wide range of CD4 cell count before the intervention (11 – 850 cell/ml.) from various conditions of participants might influence the mean of CD4 cell count (WHO, 2010). Together with a small sample size, it might not be able to make a significant change.

5.2 The strength and limitation of study

The strength of this study lines in the fact that it focuses on ALWHs which are difficult to access and the large number of participants from multi-sites study (30 hospital sites) and medical data records of this target group are complete and available to collect. It highlights the need of individualized counseling for both ALWHs and their important caregiver at their house. However, the main limitations of the study were:

1. The findings might not be able to generalize to the situations in other regions of Thailand, since the data was collected from the North and North-Eastern of Thailand. The participants in the North-Eastern region for phase II study was conducted in only from three provinces (Surin, Buriram and Roiet) and all are in lower North-Eastern region. The results might only be generalized to patients of similar demographic profiles of other North-Eastern provinces. Because of the limitation of study period and financial support, the researcher could not collect data for other long distance areas. Therefore, future research should conduct with other provinces in the North-Eastern regions to achieve more representative results.

2. This study focused on ALWHs' perspectives, it lacked of perspectives from peers, communities or others that might relate to ALWHs' ART adherence behavior.

3. Although the result from univariate regression analysis in phase II study noted that ALWHs who were still studying in school were more likely, than those who dropped out, to adhere to ART medicines and who had a caregiver were more likely to adhere to the ART medicines, compared to those who take care of their own medicines,

but only having a caregiver was associated with ART adherence after multivariate regression analysis. In real situation we found that there were many other factors lead to non-adherence in phase III study that we did not include into the survey in Phase II. It could be explained that the data collection method in phase II study, using a questionnaire and clinical data collection form, might have a limitation. Additionally, since it was a self-administered questionnaire, it might be a bias where the respondents did not tell the truth and the researcher could not ask for any further explanations for their answer. As the results, we could not explore their reasons or other behaviors that might affect their adherence.

4. With a quasi-experimental study, one group pre- and post-intervention in phase III study, there is a limitation due to lack of true control group to ensure the study results from the intervention program. Therefore, a future research should conduct an experimental study where a study group iscompared with a control group to confirm the results of intervention program.

5. The two months following-up period for evaluating a pre- and post-intervention program was too short for monitoring a change in CD4 cell count. In Thailand, the price of one test for CD4 cell count is around 500 baht (15.17 USD), total number of before and after CD4 cell count test were 34 tests, total cost around 17,000 baht (515.78 USD). Therefore, this study was designed to collect this clinical outcome between the time of routine laboratory tests, which occurs twice a year, by collecting CD4 cell count before intervention at the second times of fiscal year 2014 (July, 2014) and after intervention at the first time of fiscal year 2015 (November, 2014). Therefore, a future research should monitor with longer following-up period which my need more financial support.

5.3 Suggestions

Findings of this study could provide recommendations for decision makers, healthcare team, family caregivers and society.

5.3.1 Decision makers: To gain a better ART adherence among ALWHs, it is recommended that:

1. A home visit should be implemented. Healthcare team together with a pharmacist should work together to have a home visit to gain better and deeper understanding to their individual patient's conditions and contexts. Later, the healthcare team can provide an assistance which is appropriate to the patient to decrease non-adherence in ALWHs at least once a year.

2. Health volunteer should be included into healthcare team. In caring for ALWHs, health volunteers could help for ART adherence surveillance screening, because they have close contact and have been entrusted from the ALWHs, which can fulfill the gap of relationship and patient access to the healthcare team. Collaboration of volunteers and healthcare team can improve service system to enhance patient's adherence.

5.3.2 Healthcare team: Healthcare team is crucial for ART adherence among ALWHs.

1. There is a wide range of disclosure protocols found across the hospitals. Disclosure is crucial for ALWHs' care. Thus, there should be a standardized disclosure technique and methods to assess for readiness with their family/caregiver before disclosed.

2. Healthcare team should closely monitor the high risk group of non-adherence and spend longer time with their counseling session. The ALWHs with one or more these following characteristics are at high risk for non-compliance; not having caregiver, male and quitting from school.

3. Healthcare team should re-checking ALWHs' lifestyle change in every follow-up visits. More important, they should check how their new life schedule affects their medicine taking period. If necessary, they could help the ALWHs arranging their medicine taking schedule to fit with their new living activities.

4. Healthcare team should re-check ALWHs' understanding about disease and medicine after the disclosure, especially when they change from early adolescents to middle adolescents. We should provide appropriate information that fits to their situations change when they get older.

5. Life skills or life-steps intervention is necessary for ALWHs, especially on how to interact with their boyfriend/girlfriend and how to disclose their disease status to them. This study presented an important role of their partner to become ART non-adherence.

5.3.3 Their family: Family support as caregivers is crucial for ALWHs.

1. Their family’s members should be encouraged to support ALWHs in treatment adherence and understanding their conditions. To gain their help, the healthcare providers need to identify the right one and understand the living circumstance of the caregiver as well.

2. Changing responsibility of ARVs management from caregiver to ALWHs is very important process. Caregivers need to carefully plan and understand the ALWHs’ limitations before gradually shift a medicine taking responsibility to the ALWHs. Healthcare team could help assessing their readiness and preparing for the change.

3. Caregivers have limitations and needs for the support, too. In order to help their love one, they need to be able to have an understanding about disease and medicines. Healthcare providers should help assisting with the medicine preparations and assuring that their help is important for the ALWHs.

5.3.4 Society: Society could help supporting the caring for ALWHs

A society should give opportunities for ALWHs to understand their disease and to recognize that they can live as normal. Moreover, they can have a family with their boyfriend/girlfriend with appropriate care. These openness of the society may let the ALWHs to open their mind to disclose their disease status to their love one that their boyfriend/girlfriend or their child can still live together with different HIV status. This will lead to “decrease to zero new HIV infection” as a social prevention in overview.