CHAPTER 2

PROJECT DESCRIPTION

2.1 Rational

The incidence of HIV infections in women has been growing at an alarming rate representing over 14,800,000 women worldwide (UNAIDS, 1999). Approximately 80% of these women are in their childbearing (15-44) years (Berger & Ray , 1993; Gibbs & Zeeman, 1993). Thailand follows the same trend. The number of HIV positive women has increased rapidly from 3 cases (in 1989) to 1,745 cases (in 1994) and to 6,546 (in 1998). The HIV infection rate among pregnant women has increased from 0.6% in 1991 to 2% in 1999 (Department of Epidemiology, 1995,1999). As the incidence of HIV infection in women rises, so does the number of HIV infected infants. In Thailand, the vertical transmission rate has been reported at 15-35% (Department of Mental Health, 1998). More than 80% of the children infected with HIV through vertical transmission will develop AIDS and die in 3-5 years (Berer & Ray, 1993; and Mauskopf et al 1996). Children who are not infected are left parentless as their parents die of AIDS.

The overall impact of HIV infection on women's health and psychosocial well being is disastrous. These women are confronted with a number of health problems that will progressively result in deaths. HIV positive pregnant women are also confronted by a number of psychosocial problems related to stigmatisation, problems disclosing their status, uncertainty and guilt about the risk of infection to the child, feelings of anger toward their husband who may have

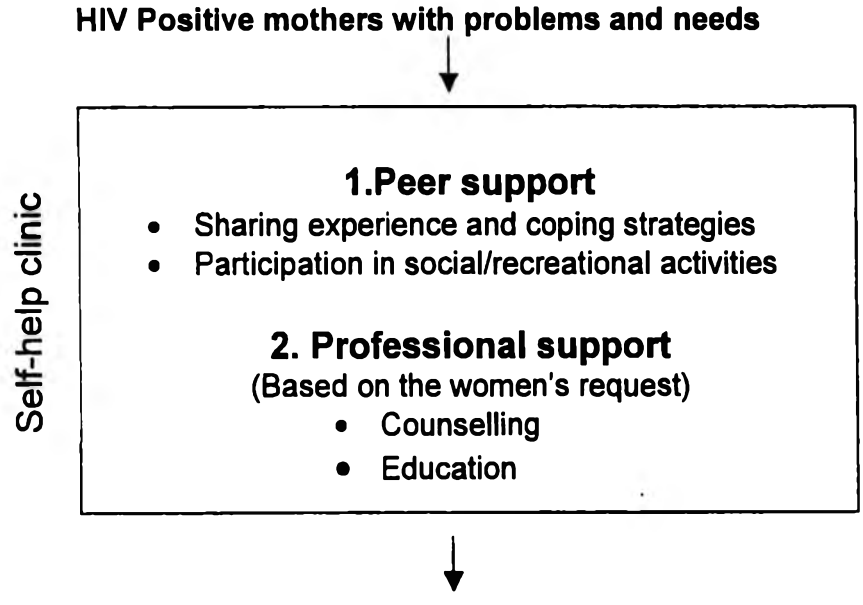
infected them, fear of dying, concern for their child 's future as well as concern about husband's HIV status (Berer & Ray, 1993; Chaiprasit, 1994; Gibbs & Zeeman, 1993; Kongsakorn,1995; Kraisurawong, 1996; and Kuropakornpong & chaichana, 1996,). Living with HIV confronts infected women with the need to juggle multiple roles. The HIV positive family woman remains both mother and wife, cares for an ill partner and/or child as well as being 'sick' herself. Women in society are traditionally "nurturers" caring for others and when confronted with illness themselves find it hard to be cared for (Bennett, et al.,1996) It is for this reason women support groups may offer more to a woman than traditional clinical health system approaches. Peer support allows women to continue the nurturer role and at the same time allows themselves to be cared for.

A concern of this problem has led health care decision makers and health care providers to develop strategies to reduce the infection rate and to support HIV positive women and their children. These include the provision of pregnancy termination, antiretroviral and prophylactic medication, caesarean section birth and counselling services. However, due to the excessive demand on services caused by an increased number of HIV positive mothers, the chronic and terminal nature of the disease and the sophistication of psychosocial problems confronted by these women, professional services alone cannot adequately address the issue. In Bamrasnaradura Hospital, staffing levels in Antenatal Care unit are limited to a ratio of staff 10: 23,766 occasions of service per year (Bamrasnaradura, 1999). However it is the lack of shared experience of the health workers that perhaps detracts most from the support offered by clinical personnel. As many women feel bordered with maintaining the "secret" of the HIV

status this leads to social and emotional isolation. Likewise discrimination of HIV positive women within communities can also isolate a woman. Professional support no matter how good cannot break down a sense of soul isolation alienation.

There is a need to establish a self-help clinic to respond to the need of HIV positive mothers. This clinic, comprising both peer and professional support, will enable HIV positive mothers to adopt adaptive ways of thinking about and coping with their problems and needs. Peer support will provide an opportunity to share experience and participate in social activities. Adaptation to a life with HIV will be developed through a variety of process including modelling, reinforcement, encouragement and peer influence (Bishop, 1994, Kaplan et al 1993, Leethongin, 1992, Nitipong, 1992, Sariyaporn et al 1995 and Posthuma, 1996). Professional support will provide additional knowledge and skills which are not fulfilled by peer support . Education and counselling has been proved to play a significant role in caring of HIV positive people (Department of Mental Health, 1998; Posthuma, 1996; Sariyaporn, 1996). Figure 1 presents the conceptual framework of self help clinic.

Figure 1: Self-help Clinic Conceptual Framework



2.2 The Project Aim and Objective

This one year pilot project being conducted in Bamrasnaradura Hospital with the aim of providing peer and professional support to HIV positive pregnant women through participation of group activities. HIV positive mother who have delivered a child within 2 years were also allowed to participate.

Objective of the project:

- To improve amongst HIV positive pregnant women and mothers adaptive ways of coping with the multiple stressors of living with HIV.

Indicators used in the project are improved:

- HIV knowledge level

- confidence in self care and baby care
- positive attitude toward living within their society
- self esteem in social functioning
- coping strategies and adjustment
- level of psychosocial well-being

Expected outcome

It is anticipated that the project will lead to:

- Strengthened health, social and psychological support systems for HIV positive mothers and their children.
- Reduction in the burden of professional care and health care cost over the longer term.
- A more effective and clients centred approach to the treatment, care and support of HIV positive mothers and their children in the hospital setting, and
- Reduction in the risk of drug resistance caused by non compliance.

2.3 Project Limitation

It is recognised that the process of self help may be inhibited by the clinical setting and the amount of professional involvement. However, these women are not ready to set up a self help group in a community due to the lack of skills and experience and problems of stigmatisation. Once these women have developed capacity and network, it is expected that they can expand their self help system to the community setting where the feeling of ownership is optimal and enhanced.

2.4 Approaches

2.4.1 Hospital Preparation

Before the project was started, notification was given to the hospital director, the head of medical counselling & social welfare unit, and the head of Antenatal & Postnatal care unit. Written approvals were obtained with establishment of project co-ordinating committee, project co-ordinator and project implementation staff (a nurse, a counsellor and a trained volunteer). The purpose of the project, the methods and the concern for and protection of the participants was explained together with distribution of curriculum and intervention program.

2.4.2 Self-help Clinic Setting

A large counselling room in Antenatal Care Unit was selected as a setting for the self-help Clinic as it provides a secure and private discussion area with sufficient space for running activities for a group of up to 20 people. This area is also convenient for pregnant women who come for ANC visit at the hospital who were our main target group as these women are confronted with several issues related to both pregnancy and HIV.

2.4.3 Recruitment of Participants

Recruitment was conducted prior to the commencement of the project and is an ongoing process to allow new members opportunity to participate in the project activities. Participants were recruited on a voluntary basis by the project co-ordinator with assistance from the project staff mainly from antenatal care, postnatal and outpatient. Inclusion criteria for recruitment include:

- HIV positive
- Pregnant women or mothers who have just delivered a child within 2 years.
- Able to communicate in Thai language
- Receive pre and post HIV test counselling or individual counselling prior to participation
- Consent to participate is freely given.

Although HIV positive pregnant women were our target group, the recruitment criteria was open to mothers who had delivered a baby within the last 2 years. This was to provide an opportunity for women who have to bring their babies back for HIV follow up testing until they are 2 years old. It also useful for experience sharing between pregnant women and mothers who already have experienced a delivery. During the recruitment process, the project co-ordinator met the participants individually in a private counselling room to explain verbally and provide written advice about the objectives of the project, how activities would be run and what would be expected from the participants. Then application and consent forms were obtained from all participants who wished to join the project. (see Appendix B for application and consent form)

During the first 3 months of the project's implementation, there were 10 HIV positive pregnant women and one HIV positive mother enrolled in the project. Eight participants were involved from the beginning of the project, the other three started later during the project implementation. Characteristics of participants are illustrated in Table 1.

Table 1: Characteristics of project participants

Variables	Variable Classification	Number	% (N=11)
Age	< 25 25-30 ≥ 31	7 3 1	63.6 27.3 9.1
Occupation	Housewife Blue collar worker Company employee	6 4 1	54.5 36.4 9.1
Income	< 5000 Baht 5000-10000 Baht Missing Data	7 3 1	63.6 27.3 9.1
Number of children	None/ currently pregnant 1 2 ≥ 3	6 3 1 1	54.5 27.3 9.1 9.1
Known to have HIV infection	< 1 month 1-2 month 3-4 month 5-6 month ≥ 7 month	4 3 1 1 2	36.4 27.3 9.1 9.1 18.2
Relationship with partner	Not in a relationship Excellent Satisfactory unsatisfactory	1 3 5 2	9.1 27.3 45.4 18.2
HIV disclosure	To: Husband Parents Siblings relative Friends (*response more than one answer)	 9* 2* 2* 2* 1*	 81.8* 18.2* 18.2* 18.2* 9.1*
Previous experience with self-help group	None < 10 times ≥ 10 times	9 1 1	81.8 9.1 9.1
HIV service awareness	Not aware Know < 5 agencies Know 5- 10 agencies	7 3 1	63.6 27.3 9.1
Previous access to welfare/support service for HIV+ people	None Less than 5 occasions	10 1	90.9 9.1

2.4.4 Intervention Plan

In this project, participants are encouraged to meet at the self-help clinic twice a month for peer support activity and professional support activity.

During peer support activity, a group discussion session (the 'self -help discussion' in this project) is run by a group leader who is a counsellor and a co-leader who is a volunteer from the participants. Participants are encouraged to share experience among themselves during discussion sessions. Experience sharing helps participants to learn and provide help to others in the group. After a group discussion session, participants will have a tea break together . This is designed to help participants further develop their relationship in a less formal atmosphere.

Professional support activity has been planed to provide additional knowledge and skills which are not fulfilled by peer support. Speakers are invited from inside and outside of the hospital to provide education sessions on topics relevant to the HIV positive pregnant women and mothers. These topics may include HIV and pregnancy, nutrition, exercise, stress management, communication and negotiation, problem solving skill, family planning, and taking pride in being a women. Table 2 outlines an intervention session plan for self- help clinic activities identifying the responsible person and time spent in each period.

Table 2: Self- help clinic activities session plan

Activity	Objectives	Duration (minute)	Participant	Responsible Person
Peer Support Activity 1. Introduction/ opening of meeting	Develop • Cohesion • Sense of belonging • Feeling of trust	15	HIV+ mother	Group leader
2. Self-help discussion	Share experience & coping strategies	45	HIV+ mother	Group leader
3. Debrief	Summary key discussion issues and Provide emotional support/ encouragement	15	HIV+ mother	Group leader
Tea Break	Develop social relationship in a less formal atmosphere	15	HIV+ mother	Group leader
Professional Support Activity 1. Education/counselling	Provide counselling/ education as indicated or requested by participants.	30	HIV+ mother	Counsellor/ Invited speakers
Total hour		2 hr		

The above intervention is designed for the whole one year. However, its operation has evolved slightly to be different from the initial stage to the end of the project. Intervention is divided into 4 phases as followings. Each phase has a three month duration.

Phase 1 (initial phase): *"Unstructured peer and professional support"*

This phase is the most flexible stage, peer and professional support activities are combined into one session and duration time is reduced according to the needs of the participants. A counsellor runs the group activity with assistance from a co-leader who is a volunteer from the participants. This is designed to familiar participants with each other and become familiar with the activity. Education

provided by the counsellor during this phase will be general and relate to HIV and pregnancy, HIV and children and other relevant issues as raised by the participants .

Phase 2: *"Unstructured peer support and structured professional support"*:
This phase separates peer support activity from education activity by tea break. Food is provided during the brake for all participants. For professional support, a speaker is invited to provide education on a topic relevant to the participants. Participants are encouraged to identify their needs so that professional support can be planned based on these needs.

Phase 3: *"Structured peer support and structured professional support"*:
This phase is similar to phase 2 except that peer support activity is more structured by setting up group programs in advance. These structured group programmes are designed to facilitate and enhance participants' skills in experience sharing on a particular topic . Participants will get to learn as well as provide advice to others in the topic most relevant to their needs. This will enable participants to get the most value out of peer support discussion. Structured group programmes may include self-esteem development, HIV disclosure and living in society (See Table 3 for list of structured group programmes and education topics).

Phase 4: *"Structured peer support, structured professional support and outdoor activity"*:

This phase comprises peer support activity, professional support activity and an outdoor activity. During this phase participants have the opportunity to go out twice in the community to observe or participate in social activities related to HIV. This outdoor activity will expose participant to a broader picture of HIV in Thailand and help them to further develop networking with agencies or groups working with HIV.

Table 3: List of education topics and group programmes for structured peer and professional support activities

Education Topics (For Phase 2, 3 and 4)	Structured Group Programmes (For Phase 3 & 4)
Include: 1. HIV &pregnancy 2. Self-care for baby & mother 3. Anti-retroviral Medications 4. Nutrition 5. Exercise 6. Stress management skills 7. Communication & negotiation 8. Problem solving skill 9. Sexually transmitted diseases & Family Planning 10. Agencies & Services available for HIV positive mothers and their children 11. Proud to be a woman	Include: 1. Self-esteem development 2. HIV disclosure 3. Living in society 4. Coping with stress 5. Relationship development 6. Increasing self value

Throughout the project, participants are encouraged to make decisions and plan for activities conducted in each session in order to enhance the feeling of ownership and to ensure that their needs are met. Professionals will provide assistance and support based on the participants' needs.

2.5 Implementation during the first 3 months (Phase 1)

During the first 3 months of the implementation, a total of 6 meetings were held on Wednesday afternoons of every second week. Each meeting comprising of , peer support activity and profession support activity conducted for approximately one to one and a half hours. Participants were encouraged to come to meetings however attendance always was not convenient to them. Therefor, the number of participants in each meeting vary ranging from a minimum of 2 to a maximum of 9. Issues discussed in each meeting are summarised as following (see Appendix F for complete meeting records).

Meeting 1:

- Introduction about the project, project's aims and activities.
- Experience sharing among participants on HIV disclosure to partner.
- Education from an ante-natal care nurse counsellor on HIV disclosure and preparation for delivery.
- Atmosphere: only a few participants talked, others were quiet and talked only when the group leader asked.
- Activity closing with informing about next meeting

Meeting 2:

- Brief introduction about the project, project's aims and activities.
- Experience sharing among participants on HIV knowledge and HIV disclosure to relatives.
- Education from an Ante-natal care (ANC) nurse counsellor on HIV, transmission and disease progression and Hepatitis B which can be used

to explain to relatives about their illness and treatment instead of telling them the women is HIV positive.

- Participants expressed concerns and anxiety about HIV disease progression, symptoms which may develop in the future and risks of infection to their baby. The ANC nurse counsellor (after giving information on HIV) reassured the participants on the low rate of vertical transmission and ways to stay healthy and emphasised on the importance of focusing on current issues not future issues.
- Atmosphere: all participants were actively involved in the discussion. One new participant was introduced to the group with warm welcoming atmosphere.
- Activity closing with information about the next meeting and that a document on Hepatitis B would be given to participants as requested at.

Meeting 3:

- Brief review about the project's aims and activities.
- Experience sharing among participants on HIV disclosure to partner as new participant joined in and how to prepare for relatives visiting after delivery. Also some education and feedback from an Ante-natal care nurse counsellor on HIV disclosure and preparation for visiting after delivery.
- Atmosphere: all participants were actively involved in the discussion. At the end of the meeting, a participant had to go to the delivery room due to a feeling that her baby was about to come premature. Other participants were positively excited with the colleague having the baby and showed great emotional support. Many participants stated their willingness to come

and visit the fellow participant after delivery in order to keep the woman in touch with the project activity.

- Closing with informing about the next meeting and provision of document on Hepatitis B.

Meeting 4:

- Brief review about the project's aims and activities.
- Experience sharing among participants on AZT medication and its effect on HIV positive women. One participant read a newsletter on AZT. One participant saw a news report on late stage HIV positive people living in a temple in a province of Thailand.
- Education from a nurse on AZT and its use in reducing vertical transmission
- Atmosphere: Not much discussion as only a few participants came to the session. Participants who saw or read the news article provided their information on what they had seen and asked the nurse for comments as other participants did not have much input. Didactic style was mainly adopted in the session.
- Closing with informing about next meeting.

Meeting 5:

- Brief review about the project's aims and activities.
- Experience sharing among participants on drug trial involving HIV positive women.

- Education from an ANC nurse on a drug trial currently available for HIV positive pregnant women discussing its pros and cons.
- Atmosphere: Two new participants were introduced to the group. Participants were quiet at the beginning after new participants joined in. After the beginning, all participants were actively involved in the discussion. They showed great interest in the discussion topic. As most drug trial need to have the women's partner to consent to the trial, participants who have not disclosed their HIV status to their partners were concerned. Other participants encouraged the participants to disclose to partners as the other women all had positive experiences in disclosing their status to their partner
- Closing with informing about the next meeting.

Meeting 6:

- Brief review about the project's aims and activities.
- Experience sharing on how to keep a secret form others so they do not know about HIV status. The topic was raised by a participant who has a friend who is also pregnant and had come for antenatal care at the same hospital.
- No formal education as the experience sharing took a very long time and there was no need identified by the participants.
- Atmosphere: A large number of participants joined the session. All were very actively involved asking questions as well as answering questions from the others. All participants seem to feel comfortable talking to each

other as they all seemed to provide their ideas, experience on the issues discussed during the session with very little probing from the group leader.

- Closing with informing about the next meeting.

2.6 Problems, conflicts and means for resolution

During the first 3 months of the implementation, many pregnant women participated in the project when they were 8 or 9 months pregnant (See Chapter 3 for demographic data on the participants). This led to a problem of dis-consistency when these women had a delivery and could not come to a meeting. The problem also occurred after the delivery as these women had to look after their baby at home. To help keep these women in touch with the project activity, the project coordinator, with prior permission from the participants, decided to follow up these women by phone. A volunteer from the participants was also used for making such contacts. When necessary, some contacts were scheduled on their baby's appointment with doctors at the hospital.

Ethical Issues

It is recognised that whilst participants were assured of privacy and confidentiality and that participation was voluntary, there may be participants who would hold a belief that their ongoing care and management at the hospital may be adversely affected. Every attempt adopted for addressing this issue and for reassuring the prospective participants was clearly stated verbally during recruitment and included in the consent form (See Appendix B: Application and consent form).