What can PACT do more to empower the HIV infected women, involved in their support groups, so that they can live more independently from the help of NGO's?

Jesus therefore said to them, “Children, have you anything to eat?” They answered him, “No.” He said to them, “Cast the net on the right side of the boat, and you will find some.” They cast it therefore, and now they weren’t able to draw it in for the multitude of fish.

John 21 : 5 - 6
Summary

The topic of bachelor thesis Social work is the empowerment of HIV infected women involved in support groups of PACT. PACT (Project Aids Through Care and Training) is a Christian NGO, which started in 1997, as one of the first NGO's in Chennai (India), helping HIV infected persons. HIV infected people in India face stigma and discrimination. Their economic status is usually low, their health status is unstable and the future for these people and their children is usually bleak. PACT raised 11 support groups throughout the city with almost 250 women visiting these groups. PACT workers meet every month with the groups to educate and encourage them and to share the gospel. Many NGO's helped HIV infected women through the years causing HIV infected people to become dependent on the help of NGO’s, financially and emotionally. Now that their health is better because of the availability of medication which slows down the virus, they have more opportunities to build up their life. However they still withdraw from society, not knowing what to do to improve their life. Many women are widowed and have to now work outside the home to generate income and take care of them selves. However these women have never learned or developed such life skills, which poses a problem. PACT wants to empower these women so they can live independently from the help of NGO’s.

There’s a Chinese proverb which summarizes the concept of empowerment and what PACT wants to do very clearly. It also summarizes the aim of this research: “Give a man a fish and you feed him for a day. Teach a man to fish and you feed him for a lifetime”. The goal of this research was to find out what the PACT staff can do to teach the women involved in the support group “fishing.” To obtain this we visited many support group meetings, we interviewed the PACT workers, other NGO’s in the city, we searched for literature about empowering HIV infected women, did a questionnaire and interviews with the women involved.

Through the questionnaire we came to know about the inabilities of women to build up their life when infected. Some of the major issues are a lack of education, an inability to take care of themselves and financial marginalization. This makes them dependant on the NGO’s. The PACT workers told us that Indian women don’t learn to take care of themselves, that it is hard to be widowed in India even more so when they lack skills and education. We came to know about the desire of the workers to empower women and the problems they face due to cultural and financial obstacles. Literature told us about the importance but also the difficulties of empowerment. It made us understand that empowerment (improvement of the physical, economical, political and social-well being of women) will not be sustainable unless there are changes on individual, structural and relational levels. There are many interventions done by different NGO’s creating a lot of new ideas that can be used in empowering the women from the support groups.

Knowing these things, we wrote recommendations for the PACT workers that will enhance their resolve to empower women. It is imperative that the women gain self confidence. The support groups are safe places to challenge the women in taking responsibility and to come out of their isolation. Also the groups help them to develop communication skills. We recommend that the workers maximize these opportunities. We also recommend peer education as a way to value the experience of the women and to reduce the working stress of the PACT workers.

We recommend that the PACT workers pursue ongoing training to enhance their effectiveness. Additionally we suggest they utilize relevant tool kits and training manuals developed by similar NGO’s in order to reduce their work load. We think that PACT should fight against duplication between NGO’s, and hope that they will take the first step by setting up a data base with names of people involved. We advice PACT to overcome their financial obstacles by working together with companies and business men and to go on with encouraging women to join self help groups and to reconsider giving travel money to all women.
4. Interviews with employees  
   1.1 Venister  
   1.2 Isaac  
   1.3 Suresh  
   99  
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5. Interviews other organisations  
   5.1 Interview World Vision  
   120  
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Preface

Before you lies the final thesis about empowerment of HIV infected women involved in PACT support groups. We decided to go to India in the summer of 2010 and then started searching for an organization with a research question. When we came in contact with PACT and heard about the work they do and the research question they had, we quickly agreed on going there. A decision we’ll never regret.

Doing our final thesis at PACT gave us the opportunity to see the Indian culture from inside out. It was hard for us to understand how everything works in such a different culture than our own, but it enriched our perspective enormously. We never had to face the impact of HIV before, and we were shocked when we heard about the difficulties this people go through. Meeting the HIV infected women, drinking tea with them, making jokes and hearing their stories really touched our heart. They taught us important life lessons about holding on to hope and being strong in hard times. PACT is doing a great job working with these women. They bring hope and relief in accepting them, appreciating them and giving them opportunities to come up in life. PACT workers showed us what it is to obey to your calling, to dedicate yourself to Jesus and how to make an impact with sharing the good news of Jesus. It’s been wonderful and encouraging for us to have seen and tasted the fullness of life in the midst of a world full of fear, pain and suffering.

We really value the work PACT is doing and we hope that the work will continue for many more years. The women really need people who believe in them the way PACT workers do! PACT is already doing a great job in empowering women, and we hope that they will expand their empowering capacities. We hope that this research will contribute to the continuation and development of the work of PACT.

Acknowledgements

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We also want to thank the women of the support groups for sharing their time and stories with us and for filling in the questionnaire. We’ll never forget the time spend with them, and the lessons they learned. Thanks to Lakshmi for translating the questionnaire from English to Tamil. Thanks to Wilma, Francis and Joanna for putting this thesis into correct English. Thanks to Arend ten Brinke, our professor, for his feedback and support.

Heidi Roest & Roos Muilwijk

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Introduction

India’s socio-economic status, traditions, cultural myths on sex and a huge population of marginalized people makes India extreme vulnerable to the HIV/AIDS epidemic. In India, HIV/AIDS has already been prevalent for two decades. How many people exactly are infected is unclear. NACO (National Aids Control Organization from the Indian government) says in their report of 2010 that 1.8-2.9 million people are infected, UNAIDS estimated in 2006 already that there were 5.9 million people infected. Anyhow, the impact of the epidemic in India is enormous and hard to control.

The South-East Indian state of Tamil Nadu, is known as one of the most conservative states of India but it has the nation’s second highest rate of HIV/AIDS infected people. Due to societal change and shifting cultural norms, a lot of men having extra marital sex pass the virus on to their wife and children. Since the first HIV-infection was reported in Chennai, the capital of Tamil Nadu, HIV spread rapidly from the city to the rural areas and from high-risk groups (sex workers, men having sex with men, drug users) to the general population. HIV/AIDS not only affects individuals and families but also the social, economic, health and moral fabric of Tamil Nadu and India in the future. AIDS renders people in their prime, sick and incapacitated. They cannot take care of and support their family. Therefore the impact on families with one or more HIV-infected members is devastating. The HIV/AIDS epidemic results in direct and indirect economic costs. Because of the epidemic there is a loss of productivity and investment in all societal sectors. Furthermore the costs of health care increase¹.

There is ample evidence that the high and increasing vulnerability of women to HIV is due to gender-based social and economic inequalities. These inequalities consist of violence against women including sexual violence; and inequity in access to prevention, education, training and care. The difference in socio-economic and political power between men and women and a lack of respect for women’s rights increase women’s vulnerability to HIV infection. That is why it is increasingly important to ensure that new policies have a special focus on gender equality and empowerment of women as a critical element in combating HIV².

Those who have become a victim of HIV/AIDS not only suffer from physical pain (due to weakening of immune system) but also undergo various types of stigma and discrimination at work, in their families and in society. Caring for HIV/AIDS patients involves an approach that must focus on their physical, mental, emotional and spiritual needs.

PACT’s purpose is to reach out to HIV positive people with compassion by meeting their heartfelt needs through a holistic approach and reconcile them to their spouse, family members, friends, relatives and most important to bring them to a relationship with Jesus Christ.

Over the last eleven years PACT has touched about 40000 HIV infected people in counseling and meeting their needs.

When Anti Retroviral Drugs (ARD) became available, and because of the government that provides in the costs for it, the situation of HIV infected people in Chennai changed. When PACT started in 1997 with helping HIV-infected people, almost all of them were really sick and in desperate need of care. Now the situation is different, people are less sick and most of them are able to live a quite normal life because of the availability of ARD. During the time PACT has worked with HIV infected people in

¹ Saravana Kumar, S. (2008); A study on social security measures for the people infected with HIV/AIDS in Chennai, Department of social work, Bharathidhasan University (autonomous) Tiruchirappalli
² Hope, Ruth (2007); ‘Women’s empowerment and HIV prevention –donor experience’, research report from DAC Network on Gender Equality, Paris
Chennai, they have noticed that most of those who come for help become very dependent on the help of NGO’s. People can collect everything they need at different NGO’s, this keeps them from holding a job and it makes them unable to live independently from NGO’s.

Since the Western world is in an economical crisis, there is less money available for organizations like PACT. There are many NGO’s involved in taking care of HIV infected people in Chennai. They all have spent lots of money in the care of these infected people for years. Many NGO’s provided financial support, food provisions, medical care etc. The women went from organization to organization to collect everything they needed. Therefore they have developed a habit of receiving (or they have become comfortable with being recipients). Last year many NGO’s had to halt much of these services due to financial shortages causing many NGO’s to stop existing. This left the women helpless and abandoned once again. They are unable to take care of themselves because they have always been dependant; therefore they never learned to generate their own income. To break this pattern of dependency, PACT is focusing on empowering women.

PACT asked us to help them in searching for ways to further empower HIV infected women. This research hopefully answers the question as to what are effective ways to empower these women so that they can face the future without help from NGO’s. We try to find out what PACT can use of what’s already been written in literature about empowerment. Furthermore we try to find what information and methodologies PACT can utilize from organizations also involved in the empowerment of HIV infected women. There is a future for women living with HIV, but they have a long way to go with lots of cultural and gender barriers to still overcome. We want to point out what obstacles there are in empowering women and what can be done to overcome these obstacles. In the end we hope to offer PACT some recommendations to improve the great work they are already doing, and a toolbox in which we will gather relevant training manuals and information about empowering HIV infected women.
Chapter 1 Relevance and purpose of this research

This chapter is about the relevance and purpose of this research. We describe here why, how and what we want to find out by doing this research.

1.1 Problem description

PACT started in 1997 as one of the first NGO’s in Chennai helping HIV infected persons. Later on they saw many more NGO’s coming up with programs to offer help to HIV infected people. PACT saw the situation of infected people change, because of the availability of ART, and because of all the help that was offered by NGO’s. Still the situation of HIV infected people in Chennai is difficult, they face discrimination, their economic status is usually low, their health status is unstable and the future for these people and their children is usually bleak. Help is still required, but a lot of the programs run by NGO’s are not working towards a sustainable situation in which people can live independently from their help. Many help-organizations want to be needed and they are sincere in the help they offer, but giving money and provisions are only short term solutions. PACT facilitates support groups for at least 250 women each month. In these support groups they give the women a chance to share their stories and the difficulties they face. Moreover they train the women in several skills so that they can face the future with less fear. PACT is already empowering the women involved in the support groups but they want to do more. This means that they are searching for opportunities and work towards sustainable changes, so that the women can gain increasing independence because they can take care of themselves. PACT wants to know what they can do to make this happen and wants to expand their empowering capacities.

Empowerment is a long term solution and tries to enable women in several ways so that they gain control over their lives.

1.2 Research question

In this research we want to answer the following question:

What can PACT do (more) to empower the HIV infected women (involved in their support groups), so that they can live independently from the help of NGO’s.

In order to be able to answer our research question, we need to answer the following sub questions:

- What keeps the HIV-infected women involved in the support groups of PACT, dependent from NGO’s?
- What have similar organizations/projects done to empower HIV-infected women?
- Which approaches and methodologies from organizations who do similar projects can PACT use?
- What conclusions can be made out of relevant literature about empowering HIV-infected women that are useful for PACT?
- What is the situation of the women involved in the support groups and what do they want/need to be empowered?
- What are the strengths, weaknesses, opportunities and threats that PACT as an organization faces working with HIV infected people?
- What do the staff of PACT want/need to empower these women so that they are less dependent on the NGO’s?
1.3 Aim of the research
In the following statements we describe the aim of this research.

- Figuring out what it is that keeps HIV infected women dependent on the help of NGO’s, so that PACT knows where to empower these women in so that they become less dependent on NGO’s.
- Bringing knowledge, insight, and ideas out of relevant literature, from other organizations and our experiences, about empowerment of HIV infected women together in recommendations. These will help the PACT staff improve their empowering activities/capacities which will result in less dependency of the women from NGO’s.
- Making a toolbox with relevant information (training manuals, useful approaches and methodologies) which can help and inspire trainers of the PACT project in preparing the support groups.

There’s a Chinese verb which summarizes the concept of empowerment and what PACT wants to do very clearly, it also summarizes the aim of this research: “Give a man a fish and you feed him for a day. Teach a man to fish and you feed him for a lifetime”. The aim is that the PACT staff teaches fishing to HIV-infected women so that they can feed themselves for a lifetime.

1.4 Method
This research has an exploring aspect, and the findings have been consolidated into a constructive form. We started by exploring literature on the topic of empowerment of HIV infected women around the globe, in India, Tamil Nadu and Chennai. We distilled all relevant information which would be applicable and useful to PACT. We also wanted to find out what methodologies and approaches have already been developed. Furthermore we tried to find out what the women involved in support groups and the staff training these women, see as difficulties and opportunities in empowerment. We used all relevant information we found for writing constructive recommendations for the PACT staff. We put practical information (methodologies, manuals etc) together in a toolbox, which can function as an inspirational guide in preparing support group meetings.

1.5 Data collection
This research contains qualitative and quantitative data collection methods.

Structured Questionnaire (quantitative)
We interviewed the women involved in the support groups through a structured questionnaire. During support group visits we spread the questionnaires at random. The aim of this questionnaire was to come to know more about the background of the women (family, education, financial and social status) participating in the support groups and to obtain information about where they want to be empowered, what they see as empowerment and what are obstacles in attaining empowerment.

Participation observation (qualitative)
We visited many support groups and took notes while observing the behavior of the PACT trainer leading the group. We focused on the empowerment topic and what we saw of it in the support groups.

Experience based stories (qualitative)
The PACT trainers choose some women involved in support groups at random and asked them to tell us their stories. We did not ask many questions because we wanted them to tell us what they think is important. In this way we found out more about how the women live, and we got to know the women behind the questionnaire.
Individual Questioning
This was composed of informal and unstructured interviews. These conversations were mostly with staff members at the office and women involved in support groups, all to get a better understanding of HIV and empowerment. We will interview the director of PACT to get a better understanding of the organization structure. We want to gather the results into a SWOT analysis.

Interviews with organizations like PACT
To get to know about the possibilities there are for HIV infected women in Chennai and what other organizations do, focus on and invest in, we interviewed organizations working with HIV infected women in Chennai. We also asked what they think and do about the empowerment of HIV infected women and we asked if they have any modules or approaches which are possibly useful for PACT.

Half Structured Interview (qualitative and quantitative)
We have a list of questions prepared for the interviews with the PACT trainers to give our interview direction and to keep it focused on the topic of empowerment, but we will leave space for personal opinions and the experiences of the women.

Literature analyses (qualitative)
A lot has been written on the topic of empowerment of HIV infected women around the globe, and in India. We distilled the information that may be relevant for PACT. This includes information that leads to a greater understanding of all that is seen as empowerment and information about basic conditions to empower effectively. We also gathered information about approaches and methodologies to empower, and analyze which parts may be useful for PACT to implement.

1.6 Abbreviations
Here you can find the meaning of abbreviations used in this research.

AIDS: Acquired Immune Deficiency Syndrome
ART: Anti Retroviral Treatment/Therapy
ARD: Anti Retroviral Drugs
FSW: Female Sex Workers
HIV: Human Immunodeficiency Virus
HIV+: HIV positive (infected with the virus)
IDU: Injecting Drug Users
INP+: Indian Network Positive people
MSM: Men having Sex with Men
NCP+: Network Chennai Positive people
NACO: National AIDS Control Organization from the Indian Government
NGO: Non Governmental Organization
PACT: Project Aids through Care and Training
PLWH: People Living With HIV
PWN+: Positive Women Network
STI: Sexual Transmitted Infection
SW: Sex Workers
UNAIDS: United Nations AIDS (special department of the UN in combating AIDS worldwide)
WV: World Vision
YWAM: Youth With A Mission
Chapter 2 Who is PACT?

In this chapter you can read about the history and organizational structure of the PACT project. We will also look at the strengths, weaknesses, opportunities and threats of the PACT organization.

2.1 PACT part of YWAM

Project AIDS Through Care & Training (PACT) is a project of Youth With A Mission (YWAM) Chennai. YWAM is an international, interdenominational, nonprofit Christian missionary organization. Founded by Loren Cunningham in 1960, YWAM’s stated purpose is to ‘Know God and to make Him known’. In the nearly 50 years since its inception, YWAM’s activities have expanded from youth focused short term evangelistic missionary journeys to include educational training, church planting, business as a mission, and relief and development services. Today, YWAM involves people of every age group. YWAM includes people from over 150 countries and a large number of Christian denominations, with over half of the organization’s staff coming from ‘non-western’ countries. YWAM currently has over 16,049 full-time volunteer workers in nearly 1,100 operating locations in 171 nations and trains 25,000 short term mission volunteers annually. YWAM India was registered in the year 1985 in Chennai. Today they work in about 110 locations in India. YWAM India is mainly involved in holistic development projects and programs in urban centers sharing the love of Jesus through compassionate love and care.

2.2 Structure of the PACT ministry

Mission Statement of the PACT ministry
Pact’s purpose is to reach out to HIV positive people with compassion by meeting their heartfelt needs through a holistic approach and to reconcile them to their spouses, family members and friends and most importantly to bring them into a relationship with Jesus Christ.

The essential objectives of the PACT ministry
a. To provide adequate nutrition and medical care
b. To provide counseling to the infected and their families.
c. Empower men and women with skill training
d. To share the love of Jesus in a practical way
2.3 PACT Services

Hospital visits
PACT staff regularly visits HIV/AIDS patients in three hospitals in Chennai. One of these is an 800 bed Government hospital for people with HIV/AIDS and TB co-infection. This hospital receives patients from urban and rural areas of Tamil Nadu, and even from other states.

Home Based Care
PACT staff visits 250 patients in their homes. They provide counseling, material needs and occasionally financial needs, as the budget allows. PACT also helps them with any other assistance they might need. These visits from the staff create an atmosphere of love and care through which they encourage the family members to reciprocate. This encourages the family members to accept their sick loved ones wholeheartedly.

Educational Sponsorship
In 2003 many HIV positive children were dropping out of school due to financial distress. So, for the last eight years PACT has been financing the education of children from low income HIV positive families. For Government school students, all expenses such as school fees, uniform and books are paid for. For students from English medium private schools, PACT takes care of 50 percent of admission fees, books and uniforms, but not the monthly fees. This support extends till high school, and beyond for deserving students. About 20 children have finished their education under this program.

PACT Children’s Home
HIV/AIDS has robbed a large number of children of their families. PACT provides a home for such children and currently cares for 13 kids who are all HIV positive. Except for two, all have lost both parents and come from poverty stricken families. The home has a nurse, cook and housemother who take care of them. The children attend a government funded; privately managed school and go through monthly check ups at the Government hospital. The home provides ART, nutritional supplements such as protein powder, and a planned diet including eggs and milk every day. According to J.D Wilson director of the PACT ministry:

“We want to give them the best we can, just as we would for our own children. We do not want to run a typical orphanage with 100 kids stuffed inside a small place run by only two staff. We want to multiply smaller units providing, personal care and a, family like environment.”

In Chennai, a city with 10 million, there are only three homes taking care of HIV positive children. PACT is planning for a larger facility on the outskirts of Chennai, which would have different homes within a campus.

Support and Self Help Groups
PACT has established 11 groups of HIV positive people in Chennai and in Kanchipuram districts. These groups meet once a month for instruction and fellowship. Each group consists of 25 members and a few groups have doubled in attendance. Within the support groups they have started eight women and one men’s self help groups. These groups meet regularly on their own initiative, with each group having 12 to 15 members. They collect and save money from their own income, to set up a business or pay the school fee of their children. Some have taken a small loan already from their SHG account to start a business. Looking at the need, the target is to start another 25 SHG in Tamil Nadu by 2016 and a vocational training center to help them produce something marketable.
2.4 Strengths
From the research we have done it has showed that there are multiple factors that indicate that the PACT project is a strong organization. The organization is accessible to the needy and there is little bureaucracy, so much work can be done by few people. Workers have the ability to make decisions regarding their responsibilities. Workers said that they experience freedom in their work, such as determining which patients need immediate assistance or when appointments take place. Each morning, the team comes together to worship God and ask him for his guidance. Christian identity is the foundation of the team. Many of the workers feel called to do this work and to be fully involved in the kingdom of God. This means that everyone feels responsible to be totally committed and to perform the job well.

The Pact office is conveniently located just behind the TB hospital, where many HIV infected people come for treatment and checkups. Through the years of experience and many contacts within the hospital there are short lines between the hospital staff and the team, so PACT has become a link between hospital staff and patients. PACT also has extensive experience in the psychological support of HIV infected patients. In summary, PACT does much work with a relatively small team, while patients are still satisfied with the help that the team gives them. This shows that the organization has great potential to continue the project.

2.5 Weaknesses
As you can see above, the mission statement of YWAM is ‘To know God and make him known.’ This means that in practice the PACT team consists mainly of missionaries. While bringing the gospel, especially to HIV infected people gives salvation and acceptance of their illness, the team said that they do not always feel well equipped. Finding the right way to lead a support group and getting appropriate educational materials is one of the concerns. In addition, the personal appreciation of intense mental work and involvement in each other’s work is minimal. This is partly because employees work individually and are personally responsible for the results. The women in support groups are often demanding, which costs a lot of energy. Despite the demanding nature of the work, the staff is available at any time of the day for questions and emergencies. Workers at PACT are supported through fundraising which often falls short resulting in frustration and a lack of motivation.

Aside from a manual of rules, mission statements and administration, there are few records. This creates a problem because the results and progress of the project can not be verified. Following the recession in the West it has becoming increasingly difficult to acquire funds. Without charted proof of the progress and results of the work, including a good overview of the financial spending it is even harder to raise funds. This project may soon be removed if no financial resources are made available.

2.6 Opportunities
AIDS is a pressing issue not only in India but worldwide. The government pays attention to curbing the epidemic and empowering affected women. The government focus is on good healthcare and providing loans, so that HIV infected women can function independently. The government offers free
medication (antiretroviral medic station) for people with AIDS resulting in a longer lifespan. Therefore banks are increasingly willing to provide loans for small businesses to HIV infected self help groups. The government has many advantages through the presence of PACT, because they are a charity that costs the government nothing. PACT has a hard working team and they mean a lot to HIV infected people in Chennai which does not make obtaining government funds impossible. For fundraising in Europe it is advantageous that PACT is part of YWAM, a renowned international organization.

In addition, World Vision will stop this summer with their support groups, because this project is not funded any more. Fortunately women are no longer able to switch to another Christian support group, so PACT has the opportunity to stimulate more and more independence. In the future, it is an opportunity for the PACT project to serve in places where they are most needed such as the countryside. In these places barely any organizations are active and HIV infected people have limited access to proper medical facilities.

2.7 Threats
As described above, dependency on Western funding continues to be a challenge to the ongoing work. There are more and more procedures associated with the acquisition of money. Funding, if made available, usually goes towards short-term, specific projects rather than to sustaining long-term work such as PACT. This in turn makes it almost impossible to plan ahead. It is also difficult to obtain government funds, because of the organization’s Christian character. In recent years the national and state governments have been increasingly opposed to any form of Christian mission endeavors.

Chennai has various organizations which are active among HIV infected people. What one sees now is that women ‘shop around’ between organizations to see where they can get the greatest benefits. New organizations set up by Westerners are especially popular because there is something to get. Initiatives such as monetary handouts have often proven to be counter-productive and result in women who are demanding and lazy. Employees indicate that duplication is one of the biggest external threats. Although the team wants to expand the work and start a new project in the countryside, it is difficult to find skilled workers willing to work in rural areas for little money. It is not attractive to be financially dependent on relatives and other benefactors. In addition, people with AIDS are stigmatized, even by people from within the Christian community. The fear and the risk of getting AIDS itself, makes the occupation unattractive.

Our research in the context
Over the last eleven years PACT has touched about 40.000 HIV infected people through counseling and meeting their needs. During this time PACT has noticed that most of those who came for help became very dependent on the NGOs and end up unable to provide for themselves and their families. The self help project would help them to raise their quality of living and to integrate into society and not be dependent on NGOs. Our research is done to support the self help project of the PACT ministry. J.D. Wilson asked us to research what PACT can do to empower the women visiting the support groups.
Chapter 3 What is AIDS?

This chapter summarizes what AIDS is and how it developed. Firstly the history and the origin of AIDS will be described, subsequently characteristics and the process of AIDS will be defined. Detailed information about AIDS worldwide and Indian policy can be found in the appendix.

3.1 General definition

Acquired Immuno Deficiency Syndrome, AIDS, is a disease of the human immune system caused by the human immunodeficiency virus HIV. This condition reduces the effectiveness of the immune system and leaves individuals susceptible to infections and tumors. HIV is transmitted through direct contact of a mucous membrane or the bloodstream with a bodily fluid containing HIV, such as blood, semen, vaginal fluid, preseminal fluid, and breast milk. This transmission can involve anal, vaginal or oral sex, blood transfusion, contaminated hypodermic needles, exchange between mother and baby during pregnancy, childbirth, breastfeeding or other exposure to one of the above bodily fluids.3

3.2 History of HIV / AIDS

The earliest known positive identification of the HIV virus comes from Congo in 1959 and 1960 though genetic studies indicate that it passed into the human population from chimpanzees about fifty years earlier. A recent study states that a strain of HIV probably moved from Africa to Haiti and then entered the United States around 1969.4

The HIV virus descends from the related and the similar immunodeficiency virus (SIV), which infects apes and monkeys in Africa. There is evidence that humans who participate in bush meat activities, either as hunters or as bush meat vendors, commonly acquire SIV. However, only a few of these infections were able to cause epidemics in humans, and it did so in the late 19th—early 20th century.

To explain why HIV became epidemic only by that time, there are several theories, each invoking specific driving factors that may have promoted SIV adaptation to humans, or initial spread: social changes following colonialism, rapid transmission of SIV through unsafe or unsterile injections, colonial abuses and unsafe smallpox vaccinations or injections, or prostitution and the concomitant high frequency of genital ulcer diseases in nascent colonial cities.

AIDS was first reported June 5, 1981, when the U.S. Centers for Disease Control recorded a cluster of Pneumocystis Carinii Pneumonia in five homosexual men in Los Angeles.5 In the beginning, the CDC did not have an official name for the disease, therefore the term GRID, which stood for Gay Related Immune Deficiency, had been coined. However, after determining that AIDS was not isolated to the homosexual community, the term GRID became misleading and AIDS was introduced at a meeting in July 1982.6 By September 1982 the CDC started using the name AIDS, and properly defined the illness.

3.3 Development of HIV / AIDS

AIDS is the ultimate clinical consequence of infection with HIV. HIV is a retrovirus that primarily infects vital organs of the human immune system such as CD4+ T cells, macrophages and dendritic cells. The HIV virus directly and indirectly destroys CD4+ T cells. Once HIV has killed so many CD4+ T

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3 Kamaraj Prof. Dr., Dr. K.S. Jeyarani Kamaraj (2007); 'Aids and other sexually transmitted diseases, Prevention and Care', New World Publications, Chennai, p 37-53
6 Unmesh Kerh (2003); '80 days that change the world - A name for the plague', found on 18-2-2011 at http://www.time.com/time/80days/820727.html
cells that there are fewer than 200 of these cells per micro liter (µL) of blood, cellular immunity is lost. Acute HIV infection usually progresses over time to clinical latent HIV infection and then to early symptomatic HIV infection and later to AIDS. AIDS is identified either on the basis of the amount of CD4+ T cells remaining in the blood, or the presence of certain infections. In 1993, the CDC expanded their definition of AIDS to include all HIV positive people with a CD4+ T cell count below 200 per µL of blood or 14% of all lymphocytes.

In the absence of antiretroviral therapy, the median time of progression from HIV infection to AIDS is nine to ten years, and the median survival time after developing AIDS is only 9.2 months. However, the rate of clinical disease progression varies widely between individuals, from two weeks up to 20 years. Many factors affect the rate of progression. These include factors that influence the body’s ability to defend against HIV such as the infected person’s general immune function. Older people have weaker immune systems, and therefore have a greater risk of fast disease progression than younger people. Poor access to health care and the existence of coexisting infections such as tuberculosis also may predispose people to faster disease progression. The infected person’s genetic inheritance plays an important role and some people are resistant to certain strains of HIV.  

3.4 Recognition of HIV/AIDS
In 1990, the World Health Organization (WHO) grouped these infections and conditions together by introducing a staging system for patients infected with HIV. An update took place in September 2005. Most of these conditions are opportunistic infections that are easily treatable in healthy people.

- **Stage I:** HIV infection is asymptomatic and not categorized as AIDS
  
  In the first stage when the infection has just occurred does the blood identify the virus as foreign material and starts to fight against them. In turn, the virus start to enter the body cells for their own multiplication and subsequent destruction of cells. This can extend up to one year, but none of this is manifested in any way of a symptom. The infected person looks healthy and normal.

- **Stage II:** includes minor mucocutaneous manifestations and recurrent upper respiratory tract infections
  
  In the second stage the body’s defense is high against the infection and slowly symptoms start to appear. They will not always be recognized as specific symptoms of AIDS, but those of the opportunistic infections that invade the body. Flu, fever, swelling of the lymph glands, red boils all over the body which last for several days are some of the often seen symptoms. Headache, nausea, malaise, stiffness in the neck, muscle stiffness are also associated symptoms. Very often the symptoms will disappear after some time and the infected person still looks healthy.

- **Stage III:** includes unexplained chronic diarrhea for longer than a month, severe bacterial infections and pulmonary tuberculosis

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2. World Health Organization (1990); ‘Interim proposal for a WHO staging system for HIV infection and disease’, *WHO Wkly Epidem, Volume* 65
At this stage the virus has gained over the body defense cells and established themselves. And can be identified even by skin tests. The manifestation of the infection can be seen as soon as CD4+ T cells are destroyed. There will appear candidiasis, a fungal infection which manifests as blisters all over the body. It first attacks the mucosal membrane of the throat and the tongue. They appear white with a coating inside which red clusters develop. These make swallowing even bland foods difficult.

Following candidiasis, herpes simplex infection takes place which gets manifested especially in anal and genital regions.

- **Stage IV**: includes toxoplasmosis of the brain, candidiasis of the esophagus, trachea, bronchi or lungs and Kaposi’s sarcoma; these diseases are indicators of AIDS.

Body’s resistance level is extremely low or totally nil. Opportunistic infections of the mucus membrane spread throughout the body. HIV alone cannot be said to be totally responsible for pushing an infected person to the AIDS stage. Bacteria, other viruses, fungus and other parasites invade the body simultaneously which intensifies the disease progression. Since the body is unable to tackle the infections, death becomes inevitable.
Chapter 4 Situation of Indians living with HIV

In this chapter you can read about the current situation of HIV infected people in India and the problems they experience. After the current situation has been discussed we look at the people who are HIV infected and how they got infected. Finally, we shortly view the response of the environment of HIV infected people. An overview of the Indian policy concerning AIDS can be found in the appendix

4.1 Aids in India

At the beginning of 1986, despite over 20,000 reported AIDS cases worldwide, India had no reported cases of HIV or AIDS. There was recognition, though, that this would not be the case for long, and concerns were raised about how India would cope once HIV and AIDS cases started to emerge. One report, published in a medical journal in January 1986, stated:

“Unlike developed countries, India lacks the scientific laboratories, research facilities, equipment, and medical personnel to deal with an AIDS epidemic. In addition, factors such as cultural taboos against discussion of sexual practices, poor coordination between local health authorities and their communities, widespread poverty and malnutrition, and a lack of capacity to test and store blood would severely hinder the ability of the Government to control AIDS if the disease did become widespread.”

Later in the year, India’s first cases of HIV were diagnosed among sex workers in Chennai, Tamil Nadu. It was noted that contact with foreign visitors had played a role in initial infections among sex workers, and as HIV screening centers were set up across the country there were calls for visitors to be screened for HIV. Gradually, these calls subsided as more attention was paid to ensuring that HIV screening was carried out in blood banks.

4.2 Current estimates

In 2006 UNAIDS estimated that there were 5.6 million people living with HIV in India, which indicated that there were more people with HIV in India than in any other country in the world. In 2007, following the first survey of HIV among the general population, UNAIDS and NACO agreed on a new estimate between 2 million and 3.1 million people living with HIV. In 2008 the figure was estimated to be 2.31 million. In 2009 it was estimated that 2.4 million people were living with HIV in India, which equates to a prevalence of 0.3%. While this may seem low, because India’s population is so large, it is third in the world in terms of greatest number of people living with HIV. With a population of around a billion, a mere 0.1% increase in HIV prevalence would increase the estimated number of people living with HIV by over half a million.

Tamil Nadu

With a population of over 66 million, Tamil Nadu is the seventh most populous state in India. Between 1995 and 1997 HIV prevalence among pregnant women tripled to around 1.25%. The State Government subsequently set up an AIDS society, which aimed to focus on HIV prevention initiatives. A safe-sex campaign was launched, encouraging condom use and attacking the stigma and
ignorance associated with HIV. Between 1996 and 1998 a survey showed that the number of men reporting high-risk sexual behavior had decreased. In 2007 HIV prevalence among antenatal clinic attendees was 0.25%. HIV prevalence among injecting drug users was 16.8%, third highest out of all reporting states. HIV prevalence among men who have sex with men and female sex workers was 6.6% and 4.68% respectively.  

4.3 Affected groups in India

People living with HIV in India come from incredibly diverse cultures and backgrounds. The vast majority of infections occurs through heterosexual sex (80%), and is concentrated among high risk groups including sex workers, men who have sex with men, and injecting drug users as well as truck drivers and migrant workers.

A general problem

In contrast to the common perception that HIV is transmitted predominantly through injecting drug use and sex between men, the overwhelming majority of infections in India occur through heterosexual sex. Women now account for around 39% of adult infections. In many cases married men have acted as 'bridge populations' between vulnerable populations and general populations; women who believe they are in monogamous relationships are becoming infected because their husbands have had multiple sexual partners. Often social norms restrict women from making decisions about their sexual relations, contributing to their vulnerability to HIV. Studies have shown that intimate sexual partner violence is also a risk factor for women. Another significant trend is that most of the people becoming infected are in the sexually active and economically productive 15 to 44 age group. This means that most people living with HIV are in the prime of their working lives. Many are supporting families.

Sex workers

Women often get involved in sex work as a result of poverty, marital break-up, or because they are forced into it. Although sex work is not strictly illegal in India, associated activities, such as running a brothel, are illegal. This means that police hostility and brothel raids can be justified by the authorities. Stigma and discrimination against sex workers also means that they can find it difficult to access healthcare, even if they actively seek it. In southern India, around a quarter of sex workers are infected with HIV. This situation is not surprising given that in one study only 20 percent of sex workers had always used condoms with commercial clients in the past month. India’s National AIDS Control Organisation’s (NACO) 2008-2009 report showed that female sex worker sites in the three large cities Mumbai, Pune and Thane had an HIV prevalence of more than 30%.

Truck drivers

India has one of the largest road networks in the world, involving millions of drivers and helpers. Truck drivers spend long periods of time away from home, and it is common practice for them to have relations with sex workers while on the road. A 2008 study showed that nearly a third of the long-distance truckers had paid for sex in the past twelve months. Sometimes, relations with sex workers occur at roadside ‘dhabas’, which act as both brothels and hotels for truck drivers. In other cases, drivers stop to pick up women by the side of the road, and

16 NACO (2007); ‘HIV sentinel surveillance and HIV estimation in India 2007: A technical brief’, p 6  
18 Silverman J. G. (2008); ‘Intimate Partner Violence and HIV Infection Among Married Indian Women’  
19 Shetty, Priya (2010); ‘Meena Saraswathi Seshu: tackling HIV for India’s sex workers’, The Lancet Volume, Issue 9734, p. 17  
transport them to another area after they have had sex with them. Both truck drivers and sex workers move from area to area, often unaware that they are infected with HIV. There are signs that some efforts to prevent HIV among truck drivers have been successful. For example, a recent survey of truck drivers in Tamil Nadu found that the proportion of drivers who reported engaging in commercial sex declined from 14% in 1996 to 2% in 2003. Of those who did report having commercial sex, the proportion that had not used a condom the last time they did so fell from 45% to 9%.  

“About seven years ago my husband got sick and died, my son was only 55 days old then. My husband was a truck driver and he didn’t know about his HIV+ status before he died. After his death I also got sick and went to the hospital, then they found out that me and my son are HIV positive. I cried and cried for days and felt very depressed. My body condition was very low and my weight was only 28 kilo’s”.

Chandracala, support group member

Drugs users
Nationally, HIV prevalence among injecting users declined slightly to 7% in 2006 but has since risen to 9.2%. Transmission through injecting drug use is a major driving factor in the spread of HIV in India. The alarming levels of infection occurring through needle-sharing have implications which extend beyond networks of drug users. Some of those who inject drugs are also sex workers or truck drivers, and many are sexually active, which can result in infection being passed on to their partners. NACO has linked an increase in HIV prevalence among sex workers in the North East, for example, with the high HIV prevalence among injecting drug users in the region. In the majority of Indian states, though, tough regulations on drug users make it hard to reach this group with HIV messages, and to survey how they are being affected by the epidemic.

Man who have sex with man
Sex between men is highly stigmatized in India and is not openly talked about, making it easy for people to underestimate how commonly it occurs. The estimated HIV prevalence among MSM in India is 7.3 % but difficulties in surveying this stigmatized group mean prevalence could be much higher. In India, many men who have sex with men (MSM) do not consider themselves homosexual, and many have female partners. A large study in Andhra Pradesh found that 42% of MSM in the sample were married, that 50% had had sexual relations with a woman within the past three months and that just under half had not used a condom. As such, unprotected sex between men can also present a risk to any women that they may subsequently have sex with. Since conditions are so restrictive, there is little information available to MSM in India. Because so many MSM also have heterosexual relationships, there is a high chance that rising levels of infection among MSM in India will aggravate the epidemic among the general population. It is hoped that since the law that criminalizes homosexuality was abolished in July 2009, MSM will be easier to reach with HIV prevention, treatment and care services.

25 NACO (2010); ‘Department of AIDS Control, Annual Report 2009-2010’, p. 4
26 Dandona L., Dandona R. (2005); ‘Sex behavior of men who have sex with men and risk of HIV in Andhra Pradesh, India’, Volume 19, Issue 611, p19
28 UNAIDS (2009); ‘Landmark Delhi High Court decision recognizes inappropriate criminalization as a barrier to health, human rights and dignity’, found on 27-3-2011 at http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2806%2968319-0/fulltext
Migrant workers
A large number of people move around India for work; it is estimated that 258 million adults in India are migrants, the majority are men migrating for employment. Studies from across the world have linked migration to multiple sexual partners and increased HIV transmission. It has been said that migrants and other mobile individuals are bridge populations for HIV transmission from urban to rural areas and between high-risk and low-risk groups. Long working hours, isolation from their family and movement between areas may increase the likelihood that an individual will become involved in casual sexual relationships, which in turn may increase the risk of HIV transmission. In many cases, migration does not change an individual’s sexual behavior, but leads them to take their established sexual behavior to areas where there is a higher prevalence of HIV. Therefore not all migrants are at equal risk of HIV.

4.4 Stigma and discrimination
In India, as elsewhere, AIDS is often seen as “someone else’s problem” – as something that affects people living on the margins of society, whose lifestyles are considered immoral. Even as it moves into the general population, the HIV epidemic is still misunderstood among the Indian public. People living with HIV have faced violent attacks, been rejected by families, spouses and communities, been refused medical treatment, and even, in some reported cases, denied the last rites before they die. As well as adding to the suffering of people living with HIV, this discrimination is hindering efforts to prevent new infections. While such strong reactions to HIV and AIDS exist, it is difficult to educate people about how they can avoid infection. AIDS outreach workers and peer-educators have reported harassment, and in schools, teachers sometimes face negative reactions from the parents of children that they teach about AIDS.

Discrimination is also alarmingly common in the health care sector. Negative attitudes from health care staff have generated anxiety and fear among many people living with HIV and AIDS. As a result, many keep their status secret. It is not surprising that for many HIV positive people, AIDS-related fear and anxiety, and at times denial of their HIV status, can be traced to traumatic experiences in health care settings. A 2006 study found that 25% of people living with HIV in India had been refused medical treatment on the basis of their HIV-positive status. It also found strong evidence of stigma in the workplace, with 74% of employees not disclosing their status to their employees for fear of discrimination. Of the 26% who did disclose their status, 10% reported having faced prejudice as a result. People in marginalized groups - female sex workers, transgender and gay men - are often

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30 NACO (2007); 'Targeted interventions under NACP III: Operational guidelines'. Volume II: Migrants and truckers’
stigmatized not only because of their HIV status, but also because they belong to socially excluded groups.  

Impact
Indians who have contracted AIDS often suffer in several ways. Firstly, family members often reject the members with AIDS due to the social stigma it brings and fear of contracting the disease. Secondly, one who has contracted AIDS will often lose her job if co-workers come to know of it. Thirdly, many private health care professionals refuse to treat or see AIDS patients due to their own ignorance of the disease and fear of contracting it. The entire scenario leaves the AIDS patient rejected, ignorant of his or her disease, destitute, and unable to meet even their basic needs.

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Chapter 5 What does ‘empowering’ women mean?

PACT, and various similar organizations, have the goal to empower women who are HIV infected. 

But what is empowerment? How do we recognize it? How can we evaluate it?

The term empowerment is used in several disciplines, and a lot has been written about it. Empowerment became a popular term in recent years and almost everyone knows about it, but to define it clearly isn’t that easy at all.

5.1 General Definition

At the core of the concept of empowerment is the idea of power. The possibility of empowerment depends on two things. First, empowerment requires that power can change. If power cannot change, if it is inherent in positions or people, then empowerment is not possible. Empowerment is only possible, when power can change. Second, empowerment depends on the idea that power can expand.34

To make these statements count, we have to define power. Power is a word we often relate to influence and control; it often reminds us of people around that do what they want, regardless of the wishes and interests of others. You can have negative experiences with power on different levels, from political dictators, to dominant parents. The key to understand power is to recognise that it only exists in relationship between people or things.35 Power does not exist in isolation nor is it inherent in individuals. Since power is created in relationship, power and power relationships can change. Empowerment as a part of this process makes the meaning of empowerment clearer.

Understanding power as absolute, as something that you get at any expense, cuts most of us off from power. Absolute power means that power will remain in the hands of the powerful unless they give it up. Power was and is often experienced in this way, in many different levels of life, and it knocked down many people, mentally and physically in many ways.

Grounded in an understanding that power will be seen and understood differently by people who have various positions in power structures, contemporary research on power has opened new perspectives that reflect aspects of power that are not absolute, but shared.36 Feminists, racial and ethnic groups and even individuals in families bring into focus another aspect of power, one that is characterized by collaboration, sharing and mutuality. Researchers call this relational power, or integrative power.37 It means that gaining power, strengthens the power of others rather than diminishing it such as occurs with domination/power. It’s about people uniting, joining hands and fighting together. It is this development that that gives the possibility of empowerment (Kreigsberg, 1992).

Empowerment is a shared term in many disciplines: in community development, psychology, education, economics and studies of social movements and organizations. How empowerment is understood varies among these disciplines but a common understanding of empowerment is necessary to see if people with whom we are working are empowered and to evaluate programmes of social services. How we define it precisely depends on the specific people and context involved.

N. Page and C.E. Czuba (1999), define empowerment as follows: Empowerment is a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power in people, for use in their own lives, their communities, and in their society, by acting

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34 Page, N. & Czuba, C.E. (1999); ‘Empowerment: What is it?’ Journal Editorial Office of People Empowering People (PEP), Volume 37, Number 5
35 Lips, H. (1991); ‘Women, men and power’, Mountain view, Mayfeld, California
on issues that they define as important. To understand this definition you need to know what they mean with multi-dimensional the sociological, political, psychological, economic and other dimensions. Empowerment also occurs at various levels, such as individual, group and community. One of the most important implications of this definition is that individual and community are fundamentally connected.

More and more researchers, politicians and employers recognize that individual change is a priority for community and social change and empowerment. Changes in these aspects are necessary to fight HIV/AIDS. To create change, people must change individually to enable to become partners in facing and solving difficulties. Wilson (1996) says that in collaborations based on mutual respect, diverse perspectives, and a developing vision, people work toward creative and realistic solutions. He sees this inclusive individual and collective understanding of empowerment as crucial in programs with empowerment as a goal.

You cannot give people power, and you cannot make them “empowered”, but as a social worker you can provide the opportunities, resources and support, so that people gain experiences, knowledge and skills to expand their power and gain more control over their lives. Teaching people skills and knowledge will motivate them to take steps in gaining control over their lives.

5.2 Definition of Women’s empowerment

Women’s empowerment generally refers to the recognition that women legitimately have the ability to and should, individually and collectively, participate effectively in decision-making processes that shape their societies and their own lives. This is the definition of women’s empowerment, mostly used in research of women’s empowerment and HIV. Women’s empowerment in sexual and reproductive health matters is greatly influenced by women’s ability to exercise and enjoy human rights, prevailing concepts of gender and gender roles and their own re-socialisation. To achieve women’s empowerment and gender equality, both men and women need to be allies and partners in reform. Both men and women must support changes to behaviours to reduce the transmission of HIV. Empowerment can lead to improved health outcomes; it is a valuable (do you mean valuable or viable?) public health strategy.

CARE, an international help organization since 1946, which did field research in four countries on the impact on women’s empowerment, found out what the participants own definition of an empowered woman is. In four countries where the research was done, four elements were common to participant’s definitions. According to the respondents in India, Ecuador, Yemen and Bangladesh, an empowered woman has:

- Notions of self-worth and dignity
- Bodily integrity; freedom from coercive forces over a women’s very control and influence over household and public resources.
- Experience with or appreciation of the value of collective effort and solidarity among women.

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Wilson, P. (1996); ‘Empowerment: Community economic development from the inside out’, Urban studies, p.33
Hope, R. (2007); ‘Women’s empowerment and HIV prevention –donor experience’, research report from DAC Network on Gender Equality, Paris
Chapter 6 Key Interventions and approaches in empowering HIV infected women

This chapter contains important information we found in literature about empowering HIV infected women, in order to answer our research questions. In this chapter we pay attention to interventions, visions and knowledge from important NGO’s or scientists who are specialists in working with HIV infected women.

6.1 Empowerment in the context
Since HIV affects all sectors of the life of women who are infected, lots of different initiatives and approaches have been developed to help them. In the eighties and nineties, a lot of people became very sick and died because of their HIV infection. No specific medication had been developed yet and the life expectancy of HIV positive people was very low at that time. Subsequently only care was provided and little attention was given to sustainable projects to empower HIV infected people. The last ten years things have changed, because medication became available the life expectancy increased. Right now 33 million people are living with HIV/AIDS worldwide, 33 million people who are needed in their community and family. It is time for action, sustainable interventions are needed and empowering is seen as a sustainable intervention for people living with HIV facing the future.

HIV is affecting increasing numbers of women and girls. Women now make up 50% of the people currently infected worldwide (41% in 1997 and 35% in 1985)\(^4\). The link between many women’s powerlessness to avoid high risk and the spread of HIV is now widely recognized and accepted. There is ample evidence that the high and increasing vulnerability of women to HIV is due to social, economic and political inequalities between women and men, which results in (sexual) violence against women, and inequity in access to prevention, education and training and care. A lack of respect for women’s rights fuels the epidemic and increases the impact of the epidemic\(^4\). That’s why it is increasingly important to ensure that new policies have a special focus on gender equality and empowerment of women as a critical element in combating HIV\(^4\).

Lots of literature is available on the topic of empowerment of HIV infected women. They all display the vulnerability of women infected with HIV in many different ways. All research that has been done to effective ways of empowering women conclude that interventions to empower women integrated with the economic, educational and political sectors have shown the greatest impact of women’s quality of life.

6.2 General Approaches and Interventions in Empowering (HIV-infected) Women

**CARE**

Empowering women is fundamental to ending poverty and protection of human rights and dignity, says CARE. CARE is an international help organization since 1946, committed to addressing the underlying causes of poverty and social injustice. This organization set out on a global journey to explore the relationship between women’s empowerment and vulnerability to HIV through a multi-country, comparative research study in Africa, Asia and Latin-America, from June 2007 to December 2008\(^4\).

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\(^4\) Hope, R. (2007); ‘Women’s empowerment and HIV prevention –donor experience’, research report from DAC Network on Gender Equality, Paris

\(^4\) CARE (2009); ‘Gender, sex and the power of solidarity- the implications of empowering women at risk of HIV’, Cooperative for assistance and relief everywhere Inc. Atlanta
Despite the diversity of contexts, similar patterns emerged. It became clear that bringing groups of women together to collectively address problems in their lives is beneficial. They also found out how they can foster the solidarity in these groups more effectively and that there were many improvements in the lives of women who participated in peer groups. Members of peer groups reported higher utilization of STI and HIV testing and services compared to peers who did not participate in these groups. They tended to carry less self-stigmatizing views of their social position in their communities, had higher self-esteem, had better knowledge of HIV, and reported being able to address powerful stakeholders through their group leadership.

The most important outcomes of the research that leads to the approach of CARE in empowering women are summarized in the following recommendations written as a conclusion of the research:

1. Design projects with a comprehensive approach to empowering women. Projects should aim to increase women’s agency, help them engage more effectively with power holders and support them in challenging structures that make them vulnerable. A well designed project can strengthen women as collective actors to challenge structural forces and ultimately create sustainable change.

2. Ensure that project design takes into account the diversity of relationships in women’s lives. Implementers should avoid the tendency to categorize women in simplistic terms as sex workers or injecting drug users, that might lead to a blind spot in the design of a project. These women are also mothers, wives, daughters-in-law, and sisters. The categorization may initially serve as an entry point but must eventually expand to a holistic view of the multiple identities of women. A thorough mapping and social analysis that explores women’s roles and relationships as well as the many power holders in their lives is essential to the project design process. This process can be deeply personal and requires trust with communities; in these cases, this type of mapping may take place mid-way through a project.

3. Engage men as part of the solution. In all research sites, women’s relationships with men were instrumental in influencing women’s sexual relations and HIV-prevention behaviors. With regard to men, women cited fear of violence or abandonment; elimination of needed resources; a desire for maintaining love, trust and familiarity; men’s lack of information on HIV; and traditional gender roles as key factors that influence their decisions in regard to HIV prevention. Research from all six countries indicated that women’s risk of HIV remained high despite their correct knowledge because their male sexual partners were neither involved in HIV interventions nor willing to adopt safer sex methods. It is unrealistic and short-sighted to put the onus of safer sexual practices solely on women. Their sexual partners need to be engaged as well.

4. Design flexible long-term funding cycles. Implicit in implementing these program recommendations is the need to address donor flexibility. Implementers need to ensure that donor education is not only focused on the issues, but also the processes needed to best meet shared goals. Current program funding, specifically U.S. government funds for HIV and AIDS, places heavy emphasis on narrow and specific project results without investments in broader programming that will make the results more sustainable and wide-reaching. A flexible program design allows for communities to identify programming priorities and interventions, thus engendering a sense of ownership and commitment from communities.

CARE is leading the way with their understanding of empowerment that combines theory and practice to promote sustainable change. CARE is using their understanding of empowerment to improve their work and to assess the impact of their programs. Built upon the social theory that recognizes the power of individuals (sociologists call this “agency”) and structures, CARE’s view is unique, because they also incorporate human relationships, which, research and experience indicate,
are key factors in effective empowerment. Their understanding is that empowerment (improvement of the physical, economical, political and social- well being of women) will not be sustainable unless there are changes on individual, structural and relationship level. Many colleagues in the international development field joined and supported them in this approach such as the United Nations and many NGO’s.

**Structures change:** Women and men, individually and collectively, challenge the routines, conventions, laws, family forms, kinship structures and taken-for-granted behaviors that

**Individuals change:** Poor women become actors for change, able to analyze their own lives, make their own decisions and take their own actions. Women (and men) gain ability to act by building

**Relations change:** Women and men form new relations with other social actors, form coalitions and develop mutual support in order to negotiate, be agents of change, alter structures and so realize rights, dignity and livelihood security
The United Nations

UNAIDS, Nations the Joint United Nations Programme on HIV/AIDS, is an innovative partnership that leads and inspires the world in achieving universal access to HIV prevention, treatment, care and support. UNAIDS sees empowerment of women as the most effective approach to tackle the increasing impact of the HIV epidemic. Their main focus in empowering women is to tackle gender inequality. UNAIDS says the following things about the gender issue on their web site: “Gender equity is the process of being fair to women and men. To ensure fairness, strategies and measures must often be available to compensate for women’s historical and social disadvantages that prevent women and men from otherwise operating on a level playing field. Equity leads to equality. Gender equality requires equal enjoyment by women and men of socially valued goods, opportunities, resources and rewards. Where gender inequality exists, it is generally women who are excluded or disadvantaged in relation to decision-making and access to economic and social resources. Therefore a critical aspect of promoting gender equality is the empowerment of women, with a focus on identifying and readdressing power imbalances and giving women more autonomy to manage their own lives.”

More power to women does not translate into less power for men. Empowering women, strengthening their agency as actors and decision-makers in their own lives, and guaranteeing their rights increase the power of women, as well that of households, communities, and entire economies. To know how to empower women requires deconstructing the sources or components of power that are amenable to project or policy intervention. From the research the UN has done they conduct that they can identify six sources of power: information and education; skills; access to services and technologies; access to economic resources; social capital; and the opportunity to have a voice in decision-making at all levels.

They conclude that the following actions are needed to empower HIV infected women in an effective and sustainable way. Most of their actions will also lead to gender equality:

- Educate women. Give them the information they need about their bodies and sex. Information is power and women have the right to receive it.
- Give women the skills they need to use a condom. Make them condom literate. Provide skills training on communication about sex and foster inter partner communication.
- Improve women’s access to economic resources. Ensure that they have property and inheritance rights, have access to credit, receive equal pay for equal work, have the financial, marketing and business skills necessary to help their businesses grow, have access to the agricultural extension services to ensure the highest yield from their land, have access to formal sector employment, and are protected in the informal sector from exploitation and abuse.
- Ensure that women have access to health services and that they have HIV and STI prevention technologies that they can control, such as the female condom and microbicides. And support the development of an AIDS vaccine that is safe, effective, and accessible to women and young girls.
- Increase social support for women who are struggling to change existing gender norms by giving them opportunities to meet in groups resulting in visibly in communities; by strengthening local women’s organizations and providing them with adequate resources; and by promoting sexual and family responsibility among boys and men.

• Move the topic of violence against women from the private sphere to the public sphere. This is not a personal issue it is a gross violation of women’s rights and is has significant negative implications for the health of communities and for economic development.
• And, to give women a voice, provide them with the opportunity to create a group identity separate from that of the family because for many women the family is often the social institution that enforces strict adherence to traditional gender norms; and promote women’s decision-making at the household, community, and national level by promoting women’s leadership and participation.

**UNICEF and UNAIDS**

UNICEF and UNAIDS also say that women and girls in Asia face an increasing vulnerability to HIV/AIDS due to the gender discrimination and abuse throughout their lives, discrimination circumscribes their power to exercise choice in many critical areas including education, marriage, reproduction and employment. Coupled with high rates of domestic violence and abuse, this discrimination translates into high levels of vulnerability to HIV infection among women and girls. Violence undermines the ability of women to access HIV/AIDS prevention, care, support, and treatment programs and HIV/AIDS, in turn, contributes to an increased risk of violence because of the stigma and discrimination experienced by those who are infected or affected by the disease.

UNICEF and UNAIDS end their paper about the role of gender relations and violence on the impact of the AIDS epidemic, with lessons they have learned from initiatives during that time (2003 and earlier). Although these conclusions are made years ago, they still seem to be useful.

They conclude that to enable women and girls to protect themselves in the HIV/AIDS epidemic and to eliminate gender-based violence in all its forms, it requires:

1. Quality, sex-disaggregated data on violence against women and children and HIV/AIDS;
2. Policies and interventions that empower girls and women and reduce gender inequalities;
3. Normative changes in the definition of gender relations and the acceptability of violence against women and children; and
4. Political commitment and leadership.

Point 1 is necessary because it is difficult to establish accountability or carry out assessments of the impact of policies and programs without reliable data. Reliable data are needed to evaluate and monitor the benefits of changing policies and programs.

Point 2. Reducing vulnerability to violence and HIV requires the empowerment of girls and women. Basic education, information about their legal rights, available services, their bodies, sexuality, disease, and reproduction is essential if women and girls are to protect themselves from violence and HIV/AIDS. To improve girls’ and women’s economic status to protect them from abuse, exploitation, and HIV/AIDS access to economic resources and assets must be ensured and it’s necessary to:

• Invest in Girls Education;
• Ensure implementation and protection of women’s property and inheritance rights;
• Ensure access to formal sources of credit;
• Ensure equal pay for equal work;
• Ensure the provision of business, financial and marketing skills necessary for the success of their enterprises;

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Let’s Go Fishing
Research among HIV+ women in India

- Ensure provision of access to agricultural extension services;
- Ensure access to formal sector employment.

These actions don’t work without increasing the social support to women and girls who are struggling to change existing gender norms. Support expansion of social networks by providing them opportunities for sharing experiences and join efforts for raising awareness in communities. Also providing in leadership opportunities for women is seen as necessary. They say that women are empowered if they have the political agency to make decisions that shape their own destinies.

State and national-level policies to increase women’s and girls’ access to key resources are:
- Decrease the gender gap in education,
- Improve women’s access to economic resources,
- Increase women’s civic and political participation,
- Protect women from violence are key to empowering women.

Point 3: Challenge the acceptability of cultural practices and norms that disadvantage women and promote a culture of silence around HIV/AIDS and violence is critical for prevention Community advocates and peer educators can serve to foster such dialogue. Schools and the media have a particularly important role to play in challenging existing norms and actively promoting new roles and responsibilities for women and men, girls and boys. Education and media policies can support such efforts by creating an enabling cultural environment for healthy sexuality and gender equitable relationships.

Point 4: Political will and determination is needed at the national and regional levels. Dedication and credible champions at the national level are required to call for zero-tolerance for violence against women and the necessary resources to address the gender-related vulnerabilities that fuel the HIV/AIDS epidemic. Leaders of political parties, faith-based organizations and communities, need to advocate for the empowerment of women and the transformation of gender norms and practices as pivotal to a new strategy for addressing HIV/AIDS and violence against women and children.

“At UNAIDS, we firmly believe that respect and concern for human rights, including the rights of the child as well as equality between men and women, must be at core of a collective response to this disease...to end violence against women, we must help make the voices of millions of vulnerable women heard. If we are to empower women and enhance their protection, we must especially make those heard who are living in the shadow of violence and AIDS.”

Dr. Peter Piot, Executive Director, UNAIDS Commission on the Status of Women, Forty-third Session, Panel on Women and Health: HIV/AIDS and Violence against Women

Naila Kabeer
Naila Kabeer, professor at the University of Sussex and social economist specialized in poverty, social exclusion and gender in South and South-East Asia, sees two structures that block the empowerment of women:
- Ideology: norms, values and traditions that places men higher than women on every level, in media, education and policy.
- Economics: different roles between men and women. Men as primary breadwinner and the one taking decisions. Women working in the house and taking care of the family or working in underpaid sectors. This leads to unbalanced divide of resources, and unbalanced access to for example labor and governmental programs.

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Kabeer says that it is time for women to reconsider and renegotiate the already existing relations in their life. Kabeer sees now as the right time for women to take back their rights, since their rights have been stolen ages ago. She says that the beginning of a change, starts with yourself but she recognizes the importance of global change in policies and strategies as necessary. Examples she gives for these changes are:

1. Educating growing children, reconsider the relations the way they are and how they can be. Undo stereotyping, and raise your kids with renewing ideas of gender equality to guarantee the change for the next generation.
2. Focus on property rights through social movements of women who stand up for their rights.
3. Stimulate women in doing business (by micro-crediting) to assure them of financial security is to make them more powerful in decision making in case they have to leave their family because of violence and abuse. Financial independence makes decision making easier.
4. Stimulate women to raise their voice and to get involved in politics.
5. United, you are strong. Invest in women groups, they need each others support in taking the risk and chances to stand up for their rights.

**NACO - Approaches and interventions in empowering women in India**

The Indian government’s policy on HIV/AIDS, managed by and implemented through the National AIDS Control Organization (NACO) recognizes the complexity of the HIV problem the country faces and the need for large scale action that targets structural barriers as well as individual behavior. In 1992 the Indian Government launched the first National Aids Control Program (NACP-I). This program was implemented during 1992-1999 with an objective to slow down the spread of HIV infections so as to reduce the morbidity, mortality and impact of the HIV epidemic in the country. NACP-II (1999-2007) was launched, based on the experience gained in Tamil Nadu. The focus shifted from raising awareness to changing behavior. NACP III has the overall goal to halt and reverse the epidemic in India over the five years period from 2007-2012. NACPIII hopes to achieve this through a four pronged strategy:

- Prevent infection through saturation of coverage of high-risk groups with Targeted Interventions (TI), and scaled up interventions for the general population.
- Provide greater care, support and treatment to a larger number of people living with HIV/AIDS (PLHA). Address human rights and ethics issues with focus on fundamental rights of the PLHA and their active involvement.
- Strengthen the infrastructure systems and human resources in prevention, care, support and treatment at the district, state and national levels.
- Strengthen the nationwide Strategic Information Management System, to help track the epidemic, identify pockets of infection.

Concrete interventions NACO took to achieve these goals are:

1. Treatment for sexually transmitted infections (more test centers)
   Condom provision (ensure safe practices by providing choices and options of easy accessibility, availability and acceptability. The condoms are supplied through peers, outreach workers and social marketing. Also by placing more condom vending machines and free pick-up condom boxes at strategic locations, they want to promote condom use).
2. Behavior change communication (involves understanding and assessment of individual and group practices/behavior which can pose risk to HIV infection, and development of context specific strategies/activities to address the risk of infection through peer counseling, counseling through counselors, creating enabling environment to reinforce safe practices. The Peers, Outreach workers lead the activities through one to one sessions and group

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sessions among the community. Group issue specific Information Education and Communication (IEC) materials are developed to further augment behavior change.

3. Creating an enabling environment with community involvement and participation (NACP envisages identification of power structures and their influence on the access and control over resources for sustaining safe behavior and practices. There are provisions for building the capacity of HRGs to advocate for themselves in creating an enabling environment as well as control of requisite resources to address the issues of stigma and discrimination).

4. Linkages to care and support services (ICTC, ART, Community Care Centre, RNTCP Program, and Detox Centre) are meant to reduce vulnerability. NACP-III has envisaged building the capacity of the counselors and health care providers at care and support institutions relating to perspectives and sensitivity.

5. Strengthening enabling environment for targeted interventions

6. Community organization and ownership. (NACP envisages engaging Community-Based Organizations (CBOs) in program management through developing their capacity and ownership for steering of community agenda).

6.3 What is the key?

In this part we summarize all the interventions from the literature we used before. These include interventions both globally and in India, that brought changes to individuals, structures and relationships and resulted in the empowerment of women.

We cannot separate different interventions to individual, structural or relationship level, because most interventions deal with all three levels.

**Innovations in Education**

All countries and leading developmental institutions have agreed on Millenium Development Goal 3, Target 4: eliminate gender disparity in primary and secondary education, preferably by 2005, and in all levels of education no later than 2015. This goal is also important for women’s empowerment and HIV.

School fees and other formal and informal costs reduce the number of children who can stay in school. Girls are less likely to receive family financing for educational costs than boys. Girls have a greater responsibility for caring for sick parents and siblings than boys. AIDS-related illnesses have increased this burden. Girls are more likely to be kept home from school to help with household chores.

“**Awareness and education are very much important to make a difference in our society. As we as women only stay at the house, we only depend on our men and our husband. We have to get out of our box of fear and embarrassment, because that leads us to insecurity. We need to realize that life after marriage isn’t ending and we learn this in the support groups.**”

Surya Prabha, support group leader

Education helps girls and women achieve greater control over their lives. Information is power, and women have the right to receive it. It is a weapon against poverty and discrimination, a weapon to face the future. Providing school fees can make the future of HIV infected girls better. However to make this work, we have to overcome the cultural barriers to girls’ school attendance. These barriers have everything to do with gender based issues.
Innovations in gender based issues

Without gender equality, women will remain disadvantaged economically and in access to services. This disadvantage contributes to continued poverty, lower status and to vulnerability to HIV and its impact. It is urgent that the relations between men and women at the individual, family and community level changes, to assure a safer future for women infected with HIV. There are a few examples of different approaches and methodologies that seek to reduce gender based violence, coerced sex and to increase male involvement in reproductive health and HIV prevention. These approaches address gender socialisation of children and the construction of masculinity and femininity.

One approach is called: “Engaging men in gender equality: positive strategies and approaches’. It discusses vulnerabilities and powerlessness including the fact that men may be prone to such feelings. For example in situations where there are social hierarchies, men may be forced into dominant masculine norms through peer pressure. This approach seeks dialogue between men and women in search for gender equality and justice.

CARE USA and the International Centre for Research on Women (ICRW) developed a gender and sexuality initiative called: ‘Inner spaces, outer faces (ISOFI)’. CARE implemented this method in India. The ISOFI methodology has been tested in India and Vietnam and knows 5 intervention modules: portfolio review and assessment of needs; gender and sexuality training; reflective dialogues (collective reflection); personal learning narratives (individual reflection and participatory learning and action.

Stepping Stones is a methodology for addressing gender, HIV, communication and relationship to communities. It takes communities through a series of facilitated focus group discussions where men and women of various age groups have a space and private time with their own self-defined age and gender peers to address gender and relationship issues together. Drama and role-plays are used to help people communicate about subjects that are not normally spoken about openly. This training package promotes gender equity, inter-generational respect and solidarity with HIV positive people, in a human rights framework. It is an important resource for those seeking to transform gender roles, create a more gender-equitable society to reduce the spread of HIV. This methodology has been used by NGO’s all over the world and there is a special version developed for countries in Central Asia.

Change to support gender equity, includes changes in the legal framework to reduce discrimination against women. Changes in the legal code must ensure married women and girls to know their rights for example to divorce from a violent, abusive husband; rights to own land and property; to be able to inherit property and land from their husbands, and not themselves be inherited by a dead husband’s brother or other male relative, and that women’s legal rights are respected.

Economic development interventions

Since HIV infected women suffer from stigma and discrimination, local money lenders, as well as friends and family, refuse many times to lend money to women who are known to be HIV positive. To improve girls’ and women’s economic status to protect them from abuse and exploitation, we must ensure access to economic resources and assets. Many HIV infected women are economically marginalized, because of their low immune system they get sick often, they lose their job because of this and are unable to generate their own income. Providing micro-loans is the best way to get positive women out or their marginalized position.

Sisters for Life is a methodology that combines a micro financing programme with gender and HIV training. This combination of social and economic development decreased the intimate-partner violence and led to great changes in the future plans of HIV infected women.
Innovations in stigma and discrimination issues

There are different approaches to reduce stigma and discrimination. Using the media to undo wrong assumptions about HIV is a good opportunity to reach a lot of people. Also awareness campaigns schools help debunk myths about HIV/AIDS and other sexual transmitted diseases. Other possibilities that can strengthen the women themselves include:

Drop-in Centres:

Part II (Pages 36-71) from the original document.

Drop-in Centres:
Multi-purpose safe spaces that allow the community to think, act and lead processes. These spaces create an enabling, non-judgemental environment which encourages communities to collectivize, mobilize and advocate from the front. It’s beneficial for women (but also men), that their individual silences have a collective voice. Those who have suffered in obscurity and silence can find a safe community where they share experiences, successes, and woes. It should also be a place where education, counselling and training takes place, empowering women to move on with their lives.

Advocacy

Leaders of political parties, faith-based organisations and communities, need to advocate for the empowerment of women and the transformation of gender norms. Public figures should maximize their chance to influence public opinion and correct wrong notions about HIV. They should advocate for people living with HIV by giving proper education, and people living with HIV should unite and stand up for themselves. Hiding and being ashamed is not the way to go to create a better future to their children who are probably infected with HIV too. Challenge the acceptability of cultural practices and norms that disadvantage women and promote a culture of silence around HIV/AIDS and violence is critical, Community Advocates and peer educators can serve to foster such dialogue.

(Peer) education about positive living

People living with HIV often feel abandoned by their community and family. Loss of self-esteem and a sense of victimization is a major issue especially for women, who most of the time didn’t cause their infection themselves. Most of them have a fatalistic worldview, they live without hope for the future and feel overwhelmed by the prospects they face. Peer education can help people living with HIV. Sharing your experiences, stories and heart can help others and yourself in the area of self-esteem. Leadership opportunities and chances to help others, can give people living with HIV a sense of being useful and needed.

“Now, almost 10 years after discovering that I am HIV positive, I face a lot of trouble because of my low immune system, but Jesus helps me out every time. I brought lots of people who’re also HIV infected and desperate to the Lord. I talk with them, educate them about HIV and pray with them.”

Sujatha, support group member

Innovations in health, sexual and reproductive health issues

Education about health issues is necessary. Eating properly is necessary when you’re using Anti-Retroviral Drugs and a good health is necessary to work. Education on health issues such as hygiene and nutrition are the basics in care of HIV infected people. A lot of information about HIV and healthy living is available.
Anti Retroviral Drugs have many side-effects. Education about dealing with these side-effects is crucial as well as the necessity to take their medicines properly.

Education about sexuality and reproductive health is needed. Many women don’t understand the consequences of their HIV infection on their sexual and reproductive health behaviour. More education is needed, worldwide to avoid mother child transmission and a further spread of HIV.

Decision making is an important term according to innovations in sexual and reproductive health issues. Many women in high prevalence countries (including India) don’t have the right in decision making about their own body. They are not the ones making the choices with who she’s having intimate relationships, and if and when to have children. Many women only gain access to health care when permission of their husband or mothers in law is given. CARE tries to intervene in this decision making process to ensure women receive health care. CARE also promotes dialogue within families to give women a voice.
Chapter 7 Gaps in knowledge and programming

The key interventions written about in the chapter before may give you the impression that empowering women is a well known process that only needs the right conditions to make it happen. In reality it is much more complicated. This chapter shows the issues which make empowerment complicated, and the gaps there are in knowledge and programming.

7.1 Cultural obstacles

Evidence from UNICEF and UNAIDS studies done in India indicate that young women who are being infected with HIV are mainly, those within the context of a monogamous relationship. This is a clear outcome of the gender inequality women in India face today. From denial of life at birth to differential access to nutrition, health care and education in childhood and from restricted mobility and economic opportunity and early marriage in adolescence, to lack of voice or decision making in adulthood, women rarely realize the principle of equality that is enshrined in the constitution of every country. Socially and culturally determined gender norms that are embedded in the institutions of family, community and society perpetuate gender hierarchies alive and drive this unequal balance between men and women, boys and girls.\(^{50}\)

Empowerment programmes don’t make a chance changing all this in just a few years, there should be a long-term focus in which all who are involved in the programme (donors, trainers, women) should be happy with every little step. It isn’t working like that unfortunately. Donors, mostly from the west, want to see results of their investments, they want to see the Millenium Goals they set achieved but striving to gender equality is dangerous with an outside-in approach and with a short-term vision. Empowering women only can endanger the stability of a society. Empowerment should start at the very beginning of the household. Because in India, husbands and their mothers typically exercise great power over wives and daughters-in-law, CARE developed a strategy in which they bring mothers-in-law, husbands and daughters-in-law together for a facilitated discussion on their shared goal of healthy pregnancies and healthy babies. With this common interest in the center of the discussion, all parties usually can agree that a pregnant woman must have the autonomy to seek health care and spend household resources to get it. In this way, women cease to be pawns in others’ often-arbitrary use of power, and exercise their right to basic health care.

In this way men and women can learn to discuss, and are working towards working together.\(^{51}\) Too often people who invest in women’s empowerment are so focussed on the women, that they forget to think about the fact that a woman in India can’t function by herself and involvement of family and spouse is needed. They should be seen as part of the solution, not as the problem.

Another disturbing factor in empowerment programmes is stereotyping men as bossy and overbearing and women as weak and passive victims of male power and dominance. Lots of government agencies and NGO’s feel good by spreading as much condoms as they can and see it as a way to protect women from men. By doing this they encourage violence against women and avoid a sustainable situation in which responsibility and respect are keywords which may lead to consensual and mutual satisfying sex. Promoting the use of condoms is only a short term solution, bigger changes are needed. Failing to focus on the family as a unit has proven to be counter productive in empowerment efforts.

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\(^{51}\) CARE (2009); ‘Gender, sex and the power of solidarity- the implications of empowering women at risk of HIV’, Cooperative for assistance and relief everywhere Inc. Atlanta
7.2 Community empowerment

To empower women in a sustainable way it is important to connect with the family but also with the community. It should come to a win-win situation for the women and the community to pay attention to women’s empowerment. If women are trained to gain self confidence and independence but if they have to pay for this in the context of their marriage it is not a workable solution. In such situations women are in fact left more vulnerable, they are at risk of even more violence and discrimination.

Perhaps the most common undesirable consequences result from fear that empowerment is a zero-sum game; that for one person to gain, another must lose. CARE saw this happen during a micro crediting programme they set up:

- Cases where emergency response prioritized women and children, whose needs were greatest, but left the women at greater risk of attack from men who would steal food and other aid items.
- Instances around the world in which women suffered abuse from husbands who feared that their participation in a project of any stripe would alter the status quo.

Most people live within social structures so deeply normalized that they are seen as the natural way of things. An individual who benefits from some change in status or wealth may use that change not to alter structures, but to gain power within the very system that restricts her. For example:

- A woman in India may use increased income to purchase fetal screening and, per cultural preferences for sons over daughters, abort a female fetus.
- Some women whose social status grows from improved financial security may use her new position to abuse the only socially-sanctioned power relation available to her: control over her daughter-in-law.

Transforming gender roles

Programmes that seek to transform gender roles and create more gender equitable relationships are more advanced than gender-sensitive approaches because they seek to change the underlying conditions that cause gender inequities within the context of HIV/AIDS programmes. They also transform HIV/AIDS initiatives by reaching both women and men and recognizing both genders as critical players in ensuring the effectiveness of HIV/AIDS programming. Stepping Stones is such a programme. Since every country has its own male/female roles, it is hard to develop a programme which is applicable to different countries. In fact the initiative for women’s empowerment should start with the women themselves. Men need women, so when women unite and grow firm in standing up for their rights, then they will achieve it though it will take time. Changing roles, takes time, a lot of time because it affects all individuals, relations, structures and systems it is a long process. An inside-out method is the strongest. Women who are able to fight for their rights in their own marriage and society are needed to work towards gender equality. Outside help seeking to change communities, particularly Western approaches do not help women in fighting their battles. Understanding male/female roles in another culture is difficult; it takes a lot of historical, religious and cultural knowledge. Obtaining such understanding is almost impossible without immersing oneself in the culture over a long period of time. The biggest gap in knowledge and programming is an outside-in programming with the ideology that men and women should be totally equal. This is a bridge too far in many cultures, it’s not even a desirable situation, it keeps men from taking their responsibility and it doesn’t help women feel secure. It all starts with meeting women in the situation they are and with seeing the opportunities they see. The only thing organizations should do to empower; is to provide training and care so that women can get the skills and encouragement to make it happen. In the end they need to do it themselves, it is their life, their family, their future.
7.3 Best practices

There’s no widely accepted method for measuring and tracking changes in women’s empowerment. Methods written about in the chapter “Key interventions and approaches in empowering HIV infected women”, all promote the empowerment of women and have the goal to reduce their vulnerability to the HIV epidemic and its impact. However all of them have only been implemented on pilot basis or at small scale. It’s not known yet whether they can be used in other countries or on a bigger scale. It’s difficult to see the results of empowerment programmes, changes in gender roles, chances for women to rise up and influence society and structures all take years. Fact is that empowerment programmes written about in the last chapter, brought changes for women. We have read and heard stories from women who have greatly benefitted by empowerment interventions. It started with individuals who are living the change. They will influence other women around them, and that’s how sustainable change to empower women will become a reality.

“From the moment we carried money in our hands, men started to respect us. But we still commit to our responsibilities towards our husbands. I believe that respecting our husbands makes life more worth it.”

Surya Prabha, support group leader
Chapter 8 What is the current situation of women involved in PACT support groups?

For a better understanding of the HIV infected women, we created a questionnaire containing questions about their life situation. In addition to our research we also asked what they think is important in development towards greater independence. The questions in the questionnaire have been related to the questions from the PACT team and is an answer to the following sub question; ‘What is the situation of the women involved in the support groups and what do they want/need in order to be empowered?’ The questionnaires were translated into the local Tamil language so women could fill it out without help. Out of 75 questionnaires we conducted, we could only use 50, mostly because of illiteracy and incomplete answering of the questionnaires.

Diagram 1

8.1 Gender and age
The first question is about the gender of the respondents. Even though the majority of participants in the support groups are women, we wanted to know the needs of men as well. Previous literature showed that women empowerment only works when men are involved; therefore we have chosen to involve men in this study, to get an impression about their needs. In total we used 50 questionnaires of 37 women and 13 men. With these details in mind it is clear that the data of men are less reliable than those of the women.

Diagram 1 shows that most women participating in support groups are younger than the average man. These data are consistent with national data that show that more men than women become infected. Infected men who transmit their disease to their younger spouse is one of the most common transmission of AIDS.
8.2 Educational status

There are several reasons for the low levels of literacy in India, not the least of which is the high level of poverty. Over one-third of the population is estimated to be living below the poverty line. Although school attendance is free, the costs of books, uniforms, and transportation to school can be too much for poor families. Poor families are also more likely to keep girls at home to care for younger siblings or to work in family enterprises. If a family has to choose between educating a son or a daughter because of financial restrictions, typically the son will be chosen.

Negative parental attitudes toward educating daughters can also be a barrier to a girl’s education. Many parents view educating sons as an investment because the sons will be responsible for caring for aging parents. On the other hand, parents may see the education of daughters a waste of money because daughters will eventually live with their husbands’ families, and the parents will not benefit directly from their education. Also, daughters with higher levels of education will likely have higher dowry expenses as they will want a comparably educated husband. However, education sometimes lowers the dowry for a girl because it is viewed as an asset by the husband’s family.

Interesting to note in diagram 2 is that men and women are almost equal when it comes to education. This does not comply with what we have been told about the education level of man and women. It could be that men with higher education have no need or are ashamed to visit a support group. Another reason could be that men with lower education are more likely to get HIV infected. However, it’s clear that three fourths of the participants have not passed the tenth grade. This group probably consists of more than three fourths, because people who did not fully complete their questionnaire mainly couldn’t read or write. So these questionnaires are not included in our research. The knowledge that the educational level of the participants is relatively low can be used in the selection of teaching materials of the PACT staff.
8.3 Caste category

Nowhere is caste better exemplified by degree of complexity and systematic operation than in India. In ancient India a social system developed in which people were divided into separate close communities. These communities are known in English as castes. The origin of the caste system is in Hinduism, but it affected the entire Indian society. The caste system in the religious form is basically a simple division of society in which there are four castes arranged in a hierarchy and below them the so-called outcast. But socially the caste system was far more complicated, with many more castes and sub-castes and other divisions. Legally the government prohibits the practice of caste system but has a policy of affirmative discrimination of the backward classes.

FC = The Brahmans, the priestly and learned class
BC = The Kshatriyas, the warriors and rulers
MBC = The Vaisyas, farmers and merchants
SC = The Sudras, peasants and laborers
ST = Untouchables/outcaste, tribal people

The occupational barriers among Indian castes have been breaking down slowly under economic pressures since the 19th century, but social distinctions have been more persistent. Attitudes toward the untouchables only began to change in 1930 under the influence of Mohandas Gandhi’s teachings. Although untouchability was declared illegal in 1949, resistance to change has remained strong, especially in rural areas. As increased industrialization produced new occupations and new social and political functions evolved, the caste system adapted and thus far has not been destroyed.

As shown in diagram 3, about half of the participants are from the BC caste. This is relatively similar to the national average where 52% of the population is from the BC or MBC caste. Remarkable is that no people marked that they belong to the untouchables. Before we conducted the questionnaires PACT staff told us that this question would be a sensitive question. People do not talk openly about their caste category. This is shown by the fact that some people deliberately did not say what caste they come from. The outcome that all castes are represented in the support groups confirmed the fact that AIDS is not related to one particular caste.
8.4 Martial status

In the preceding diagram you can see the percentage of men and women who are married, single, widowed or separated. We have chosen to process this information, because the importance for women to be married in India is significant. Of the entire population of India is only 4.3% of men and 1.8% of women are widowed. This diagram shows that the support groups are 46% percent of men and 38% of women who are widowed. Widowhood especially for women in India has huge consequences.

The following data is from a study which was published by the National Council of Applied Economic Research (NCAER), with the collaboration of the National AIDS Control Organization (NACO) and supported by the UN Development Programme (UNDP).

“The economic and social situation of HIV-positive widows was particularly dire. According to the study report, they face a double burden, as a widow and an HIV-positive, of stigma and suffer discrimination from the family and society in which they live. The study shows that hardly 10% of widows are living with their husband’s family and out of the others, more than 90% had stopped living in their marital homes after the death of their husband. Only 9% of widows reported getting financial support from their in-laws.... 79% of the widows complained that they were denied a share in their husband’s property”.

In many families, women living with HIV face more discrimination than men. Married women testify that they may not disclose their HIV positive status to their husbands for fear of being victimized and deserted. Women are often blamed by their family in law when husbands are infected with HIV. They are seen as vector of the infection even if the family has knowledge that the husband had visited sex workers. This blame is made in the belief that the wife was unable to satisfy her husband sexually resulting in his seeking sex workers. Ironically, the wives are still expected to provide care for husbands living with HIV/AIDS. After the husbands death, however, the usefulness of the wife will have ended. This is demonstrated by the family in law denying the wife a share of her husbands property or pension.
Diagrams 5 shows clearly that all men who work, work for an NGO. Probably this is not reliable, but it is clear that there are men who work alongside NGOs to join a support group. Diagram 7 shows that it is probably because men want to get a loan at the bank and join together for that purpose. It is alarming that only 32% of the women’s individual work, without being dependent on NGOs. Apparently it’s attractive to work for NGOs and people take the opportunity to use it.

The shame and discrimination attached to HIV/AIDS is at times harder to cope with than HIV itself. In an ILO study conducted in four Indian states, undertaken by the Networks of People Living With HIV/AIDS (PLWHA)

“About 70% respondents had faced discrimination at work. Maximum prejudice was reported from within the family (33.33%), followed by health care settings (32.5%). Nearly 18.3% people faced prejudice from neighbours and 9% from community, educational institutes or relatives. Discrimination at the workplace could be higher than the reported 6.1% considering that many PLWHA do not disclose their status fearing losing the job. Positive people are compelled to leave their job on account of harassment such as denial of promotion, being forced to take voluntary retirement or being ostracised by co-workers.”

According to employees of the PACT project this is the problem when it comes to empowering women. As long as women work for NGO’s and NGO’s continue to provide jobs, without guiding women to a permanent job, women will remain dependent. Moreover, NGO’s are often no stable factor, because they can be lifted once the money runs out. In the future PACT wants to put more effort in helping women learn skills or a trade to be able to acquire employment.

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8.6 Monthly income
The common international poverty line had in the past been roughly 1 dollar a day. In 2008, the world bank came out with a revised figure of 1.25 dollar a day. If we continue this information, it means that about 40% of respondents are living below the international poverty line. The fact that these people live below the poverty line is not entirely objective data. In studies of living conditions data showed that only 24% of women live independently and 15% of men. This could mean that the remaining 76% of women are not the only breadwinner in the household. However, it is clear that none of the support group participants earn a high income.

Poverty is widespread in India, with the nation estimated to have a third of the world's poor. According to a 2005 World Bank estimate, 41.6% of the total Indian population falls below the international poverty line of 1.25 dollar a day. Since the 1950s, the Indian government and non-governmental organizations have initiated several programs to alleviate poverty. These efforts include subsidizing food and other necessities, increased access to loans, improving agricultural techniques and price supports, and promoting education and family planning. These measures have helped eliminate famines, cut absolute poverty levels by more than half, and reduced illiteracy and malnutrition. Although the Indian economy has grown steadily over the last two decades, its growth has been uneven when comparing different social groups, economic groups, geographic regions, and rural and urban areas.

Eradication of poverty in India is generally only considered to be a long-term goal. Poverty alleviation is expected to make greater progress in the next 50 years than in the past, as a trickle-down effect of the growing middle class. Increasing stress on education, reservation of seats in government jobs and the increasing empowerment of women and the economically weaker sections of society, are also expected to contribute to the alleviation of poverty. It is incorrect to say that all poverty reduction programmes have failed. The growth of the middle class (which was virtually non-existent when India became a free nation in August 1947) indicates that economic prosperity has indeed been impressive in India, but the distribution of wealth is not at all even.

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8.7 My support group helped me the most with

Diagram 7 shows that the needs of men are different than the needs of women in support groups. Men expect to receive a loan, while women benefit from education and being part of a caring community. To conclude that for men materialistic status is more important than for women, is premature. However it becomes clear that the establishment of self-help groups to obtain a loan has positive effect. A good question to ask would be; where do the needs of men and women touch each other when it comes to designing a support group meeting? This we also see in diagram 9. Another question to ask would be how can the men help the women obtain a loan?

At the PACT project, Self Help Groups represent a unique approach to financial intermediation. The approach combines access to low-cost financial services with a process of self management and development for men and women who are self help group members. These groups are formed and supported by PACT. Self help groups are seen to confer many benefits, both economic and social. Self help groups enable women to grow their savings and to access the credit which banks are increasingly willing to lend.

“To be a member of the support group makes me feel like a valued person and I can share my heart with others who understand and accept me they way I am. I really enjoy the friendship with other members, it gives me energy”.

Chandracala, support group member

Self help groups for women represent an opportunity for social action and empowerment through women’s involvement in considering, addressing and participating in issues that affect their members and their communities, including exclusive women’s issues. The extent to which this is happening is perhaps less than hoped for, although a beginning has been made. One reason is the huge challenge involved in women finding the right to speak out and taking a stand in a still very traditional, patriarchal society. The related reason is that social objectives require a strategic approach, persistence and follow-up.
8.8 I prefer in the support group
More than half of male respondents in diagram 8 show that they want more education done by women. This result seems to go completely against the idea that women do not get the chance to stand up for their rights in India. Apparently the support group is a safe place for men and women to be open to the opinions and views of the opposite sex. Nearly one quarter of women would like more games and activities and 20% would like to hear more mean sharing their experience.

“If you know the way to be more independent, you should share your knowledge with other women. Teaching is very important, because empowerment is also about sharing with others. We go from house to house and share our experience. We try to convince people to join our support group.”

Surya Prabha, support group leader
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<td>Building self/confidence, standing up for yourself</td>
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Diagram 9
8.9 Topics I want to see mentioned in the support groups

In response to the quest of the PACT team to find out, what should be done to further empower women, we asked the support group members what they wanted to be educated about? The results can be found in diagram 9. As shown, many women chose, "building self/confidence" and almost half of men would like to learn more about it. Both men and women find it important to know how they can stand up for their rights. We also see that women are more concerned how they can set up their own business. While men want to learn about hygiene.

The results of this question we have used in the development of toolboxes, we purposed to give the PACT staff. At the end of our stay we gave the toolboxes about different current topics.

“"I became a member of this support group one year ago. A friend who was involved in the support group invited me to join the group. I feel that this group helps me to reduce my burden.""

Thenmohli, support group member
Chapter 9 Interviews with support group trainers

In this chapter we describe the most important outcomes of the interviews with trainers of the support groups. You can find the description of who they are and what they exactly said, in the attachments of this research document. Isaac, Suresh and Venister are the trainers we interviewed, we joined them many times to support group meetings and learned a lot from them. We made a list of questions to interview them to come to know what their vision, mission and opinion is about empowerment of the women involved in their support group. You can find this list with questions in the attachments too. In this chapter we describe the highlights of these interviews with the trainers of the support groups, which may contribute in answering our research question. We subdivided the important things they said in headlines.

9.1 Empowerment

All trainers are very conscious of the impact and effect of empowerment and their role in this process. They’re all very much willing to pay attention to women’s empowerment but the Indian culture and finances are the biggest barriers in working towards a situation where the women are financially and emotionally independent. The trainers see empowerment as a multi dimensional process, and are trying to balance between emotional, physical, spiritual, financial, educational care. They see an empowered woman as an independent woman who can take care of herself and her family in all areas of her life.

What makes the women dependent?

The position of women in India is quiet complex, the trainers told us. Most families have a traditional view on gender roles, women stay in the house and take care of the family, the man is the breadwinner. This is no problem, till HIV enters the family, then the roles have to change. Most women were used to the fact that the men cared for them, they are not used to take charge and stand up for themselves. That makes it difficult for them to live without a husband (many women are widowed) in society. The women can be very demanding to the trainers, they want them to take responsibility for them. The women want these men to take care of them because they feel so vulnerable. Many women have a low self esteem and think that they can not do anything about their situation, they feel helpless and abandoned. They’re unable to make decisions about their own life, what they want and how, they never learned to track their own path. It is new for them that the trainers point them to their own responsibility to get a job and to stand up for themselves.

The trainers told stories about women who carry a lot of shame and fear because of their HIV+ status. They face a lot of stigma and discrimination. Many Indian people condemn and humiliate them. HIV positive women are ostracized due to cultural taboos and myths about HIV/AIDS. Many women got upset about the discrimination and it makes them numb. Most women feel ashamed, powerless and insecure as a result they withdraw from society. The trainers are trying to put them into an empowerment process by giving them opportunities to develop skills like leadership, communication, running business. It helps them to come out of their confinement to discover that they’re able to do something with their life.

It is not only their HIV+ status and culture that hinders them from being independent, the trainers say. Many NGO’s originating from the Western world lavished money to help the people. They were sincere in their motivation to help, but did not adequately consider the dynamics involved. As a result the women have become passive recipients. In the words of the trainers: they have become kind of lazy and spoiled.
9.2 Finances
All trainers are very clear about the fact that the greatest need is improvement of the financial situation of the HIV infected women involved in the support group. They have different ideas as to how to go about this. Advocate for jobs at companies, skill training, focus on self help groups, are the most important of these ideas. It’s hard to have a regular job for HIV+ women, HIV+ people have a low immune system, they get sick often and are not able to go to work. It’s hard to get or keep a job because of this but also because of discrimination due to their HIV+ status.

Self help groups, which are groups where women save money together so that they can help each other financially in an emergency. Involvement in these groups also serve to prove that they are able to save regularly, which may lead to getting a loan from a bank. Women who get to know each other at a support group, form a self help group. Many self help groups already got loans and set up their own businesses with this money. Owning a business is the best solution for HIV infected people because they can arrange their own working hours.

9.3 Situation of PACT trainers
PACT is already working for years in the field of HIV+ people. They don’t do just a job for an income. They have a mission, a vision and they have a sense of calling. This makes PACT special, the women also experience this as they see their faithfulness and love. The PACT trainers have lots of experience in dealing with the problems HIV+ women face. PACT does not rely on the government for finances so they are quite flexible in charting their own course. However PACT is responsible for fund raising efforts for the support of the work they do and the financial income for each of the staff. This is extremely challenging as they don’t get a lot of reward financially for the demanding work they do. Lack of finances also puts pressure on the families of each of the PACT workers, sometimes they are not able to cover even their basic expenses. Also the funding for the project is unsure, this puts pressure on the team, because they can’t make long term plans although they have vision for growth and expansion of the work. This financial situation puts them under a lot of stress and frustration.

9.4 Future of PACT and the support groups
The trainers see a lot of challenges for empowering the women involved in the support groups. There are a lot of differences between the groups, some are really depending on the leadership of the trainer and other groups lead themselves. All trainers try to work towards a situation in which the support group functions independently. They hope and expect the groups to go on, also when PACT stops existing. They want to give the women more ownership of the support groups by giving them responsibility and accountability. Doing this is one of the most important things for them at this point, the women should correct and help each other and function as a family, the trainers say. They want the women to run the groups themselves, in leadership and organization and all. In this way the PACT workers would only fulfil and advisory role and share the gospel. They don’t want the women to rely on them, but as written before, this is kind of complicated in the Indian culture.

The trainers say that they need more money to invest in educational materials and for their continued education. The trainers say it is difficult to come up with new ideas for support group meetings all the time. Sometimes they don’t really know what to do with the group, they don’t have a plan set up for the meetings. Everyday they have to think about something new, or they repeat what they did before, or they just see what pops up during the meeting. All trainers are men, they say that it is difficult to talk about certain topics as men, they want more women to educate each other. They also want to invite more experts to teach the women about setting up a business or to
give financial advice. Empowerment is a multi-dimensional process, one man is not able to cover all the dimensions.
Chapter 10 What is the strategy of similar organisations?

All organizations we interviewed are working with HIV infected people in Chennai and all of them are already working in this field for many years. PWN+ mainly focus on women; NCP+ (part of INP+) welcomes all HIV positive people in the city but especially reaches out to high risk groups (MSM, IDU, FSW), World Vision reaches out to everyone. Though they all work with HIV infected people, they all have a different vision, mission and way of working. They focus on different topics in empowerment and all have a different way of seeing the problems of HIV infected people. In this part we describe the highlights from the interviews that may contribute in answering our research question. We asked in particular about the situation of women because we focus our research on empowerment of women. All the people we interviewed agreed on the fact that women are extra vulnerable to the HIV epidemic because of their sex.

10.1 Differences and similarities

Mission and Vision
We interviewed all the persons in the drop-in centres they run. In these drop in centres, big plates were hanging on the wall with their mission and vision statement and organization structures in just a few lines. This was helpful in interviewing the organizations because we came to know about their core values very soon, and the persons we interviewed referred to their mission and vision during their explanation about their organization.

Funding
All of the organizations we interviewed get government support. The government is supporting NGO’s who strive to realize the NACO policies written. Governments on national, state and district level contribute financially to realize the policies written. The organizations we interviewed also get funding from abroad; the European Union and the United Nations for example invest in combating the HIV epidemic in order to achieve the Millennium Goals they set up. The organizations also receive funding from individuals all over the world including Indians.

Different starting points
NCP+ and PWN+ were started by persons who were infected themselves; still almost all of the leaders who are running the organizations right now are HIV positive themselves. These networks were formed because the positive people needed each other, they were sick and suffered from stigma, they needed company and had the belief that uniting was their only hope. World Vision is established from another point of view, they wanted to help people who were HIV infected because of their faith in Jesus Christ who says that you must help the poor, widows and orphans.

World Vision started with a budget and a plan already set up before they started, the networks started with meetings and grew into an organization with a budget and a plan. World Vision came outside-in, the networks came inside-out.

(Peer) Education and leadership
Peer education became a big theme in NCP+ and PWN+. In the beginning (it was not called a network by then) they just came together to encourage each other and to educate each other about how to do deal with health issues, stigma and discrimination. At that time they didn’t call it peer education yet, now they do. Peer education is still a big drive in the networks. They use their drop in centres for peer education and counselling. In this way they give positive people a chance to develop leadership skills and they use each others experiences to find hope and courage in life. They also build the network in this way so that it becomes a caring community. The leaders of the networks are mostly infected them selves. In the process of developing networks these leaders grew and developed in
their interpersonal and leadership skills. The networks elect their own leaders (president, secretary etc).

10.2 Empowerment in action
The organizations offer a lot of different programmes to HIV infected people to overcome their difficulties. This is a list of the empowering activities offered:
- Counselling (WV, PWN+, NCP+)
- Peer education and counselling (PWN+, NCP+)
- Education about service access (WV, PWN+, NCP+)
- Micro Crediting (WV)
- Support groups (WV, PWN+)
- Facilitating self help groups (WV, PWN+, NCP+)
- Treatment counselling (NCP+)
- Mother Child Transmission Care (PWN+)
- Milk powder provision (PWN+)
- Hospital Advocacy (PWN+)
- Nutrition provision (at least 2 meals a day for everyone) (WV)
- Advocacy at government, community, hospitals etc. (WV, PWN+, NCP+)
- Prevention programmes (WV, PWN+, NCP+)
- Community outreach programme to reduce discrimination (WV)
- Legislative help (mediation, help at the court, advocating for changes in legal framework) PWN+
- Drop in Centres (WV, PWN+, NCP+)
- Education about health issues (nutrition, hygiene, safe sex) (WV, PWN+, NCP+)
- Providing condoms (NCP+)
- Paying school fees (WV)

Organizations offer a lot of the same help, that is to be expected as almost all HIV infected people face similar difficulties in getting/keeping a job and because of stigma/discrimination. The list of programmes and help the organizations offer is probably useful for PACT in referring people to experts and to avoid duplication.

All organizations see empowerment as necessary to work towards a sustainable situation in the future in which women can take care (of each other) financially but also mentally, so that they won’t depend on the help of help organizations anymore. Financial problems are seen as the most difficult problems to deal with, by the organizations we interviewed. Most women who are infected are already from lower social/economical classes and being HIV positive brings sickness and discrimination which causes them to be further marginalized. All the organizations are still searching for the best way to deal with this problem. Self help groups proved themselves as helpful in every organization.

PWN+ became a close partner of the government in helping HIV infected women especially. PWN+ sees making women aware of the opportunities they have at the government, NGO’s etc to get help as very important. They take part in meetings to discuss the future for HIV infected women and try to create opportunities for women. Their wish is to canalize all the facilities available for women, and to have a committee with the government, NGO’s, companies etc. who’re involved in empowering women, so that they can maximize the programme. PWN+ offers a unique programme of legislative help in which they help women to stand up for their rights, they mediate about inheritances, and give help in going to the court.

World Vision has the finances to give people loans and to provide in goods to help people start businesses; they also give money for nutrition and children’s school fees. World Vision has a community approach in prevention and reducing discrimination.

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The organizations are not really working together; they don’t refer people to each other for specific help, mainly because they offer the same sort of help facilities and because they want people to connect with their organization.
Chapter 11 Analysis of the results

This chapter contains analysis of the results we reported in the chapters before. We’ve been collecting data and knowledge in different ways, we observed the support groups, we interviewed women, trainers, NGO’s etc. We want to connect all the information we have collected to get an overview on micro, meso and macro level. Micro level means the personal life of the women involved in the support groups, meso level means PACT as the bridge between the women and society, and society on the macro level. In this chapter we describe the highlights we found on all the different levels that will help to answer our research questions. We point out these highlights with different headlines.

11.1 Micro level: Personal life of the women

Social network

We already found out the first week of our stay that the Indian culture is very much family oriented. Honourable behaviour and a good family reputation are immensely important. When HIV enters a family, a lot of anger, shame and fear comes up. There’s the fear of the family to get infected themselves, the disappointment of an husband who cheated, the anger of the family because of damage to the family reputation, the fear for curses of the Hindu gods etc. When women get HIV+ their whole social status and network turns upside down. We heard awful stories, these women have been going through enormous hardships. They faced discrimination in many ways, expressed in violence, exclusion of every social activity, humiliation and abuse. Many women hide away in shame and fear and are totally isolated. We saw women ‘coming back to life’ during the support groups, they still had the pain in their eyes, but they came out of their cocoon of isolation. They felt needed in the group, they had a voice again, friends to live for and rediscovered purpose. What also came up during the interviews with other NGO’s, is that women and especially these women, want to be needed. When their social network decided to ban them, the women lost their purpose. Literature says that support groups are one of the basics of an empowerment process. A support group is like a mini society, women decide together what the rules are, they need each other to run the mini-society, they get a family back and are part of a system again which asks from to be accountable and responsible. It can help them to achieve competencies and confidence to claim back their place in society. People get meaning in relation with others.

Health

Since HIV is a virus that attacks your immune system, HIV+ people are frequently ill. Eating properly and taking the medication regularly can help to slow down the virus. However many HIV+ haven’t learned to make the best nutritional choices within their budget. Health is the basic of life, without health everything is difficult. We discovered during the support group visits that many women don’t have enough knowledge about medication, hygiene, healthy food etc. The trainers said that they themselves need to be better equipped to educate the women in some of those areas. During our literature study we found out that there is a lot of information available on topics of healthy living.

Work

Many HIV+ people are marginalized. Due to their health status it is hard to hold a regular job. Many bosses fire someone when an employee’s HIV+ status is discovered, and many bosses won’t employ those who are known to be HIV+. When they have a job it’s hard for them to keep it because they can’t go to work all the time when they feel ill. Due to ART, which helps to slow down the virus, it is possible to have a somewhat normal life although HIV+ people get sick frequently. It doesn’t mean that they can’t work at all, but they need to do at their own pace. The self help group/saving groups help people save money and obtain loans to set up a small business, so they can plan their own working hours. This is the most ideal situation for HIV+ people. There’s a lot of work to do for NGO’s in advocacy for HIV+ people. There is still a lot of stigma and fear attached to the idea of normally
relating to HIV+ people. Common place awareness needs to be raised that the virus is not transmissible easily. Furthermore that these people can do a job just like anyone else in fact they may excel at it, knowing how few chances they have.

**Finance**

As said many HIV+ are marginalized financially. Because of loss of family support and jobs, life sustenance has become very difficult. Some women we spoke were really needy, they could not even eat twice a day or pay the school fees for their children. Others were doing well they had set up their own business. In some groups the women help each other financially, although hardly anyone can really afford to give money to others. The HIV+ women developed ‘a habit of receiving’, as Suresh called it. Just because NGO’s from the West gave money for years, the women got used to care coming their way quite easily. Now that the West is in an economical crisis, not as much money as before is available. The money there is, is spend now in sustainable projects in which they teach people fishing so they are not hungry for a lifetime. Instead of giving them a fish so they are not hungry for a day. Some HIV+ women involved in the support group are sick and unable to work, they really need support, but there are also women who are quiet healthy. Since ART is available their health status is much more stable, so they are able to work. Financial development is most needed, the trainers of PACT say. If they’re able to manage their life financially, the rest of their life will also be easier. They can afford a healthier lifestyle, they can face the future with less fear. A big obstacle for HIV+ people to make money independent from NGO’s, is that they’re not educated. Jobs for uneducated people are mostly physical heavy jobs, those kind of jobs are hard to sustain as people’s health is unstable. HIV+ people from higher casts were mostly depending on family money, when they get kicked out of the family because of their infection, they have to make their own money. They are educated most of the time, but never worked and are somewhat reluctant to work. Fortunately, India’s economy is growing, this creates jobs. When HIV is more commonly known, the discrimination will decrease, this will also create job opportunities. Still micro-crediting and saving programmes are the best way for HIV+ people to provide in their livelihood, small scale businesses provide flexible working hours.

**Low self esteem**

It did not surprise us that one of the outcomes of the questionnaires is that they want help in building self-esteem. These women lost all faith in them selves and in others. This explains their tendency to be passive recipients and their dependency. If society puts you down and makes you believe that you’re no good, than everything that comes from outside is better than what you can do yourself. The exclusion and discrimination made them numb and totally unaware of the knowledge that they’re somebody who can make good and bad choices. They have lost all sense of responsibility for their own life and destiny. This leaves them very dependent on the very few people who do care about them.

Empowerment is a multi dimensional process. As you see in literature is it is necessary to bring changes in structures, relations and on individual level to make empowerment work. Because of their low self esteem the women expect everything from outside, but if they don’t gain any self confidence they will not be able to embrace changes on the other levels and make them work. Literature says that support groups are enormously important in making women capable to get into action and change. A support group can offer a place to have a voice again, it gives learning possibilities in leadership, sharing and educating. Coming out of the cage is necessary to get into the world again. The sense of unity makes the women feel stronger, the knowledge that they’re not the only one suffering helps them to carry on. A support group offers a lot of chances for women to overcome a low self esteem.
11.2 Meso level: PACT as organisation

PACT vs other NGO’s

We have seen the work of PACT from different angles, from the women’s perspective, the trainers, the director, other NGO’s. PACT has something unique compared to other NGO’s. They work in the field for so many years, many NGO’s came and went over the time that PACT has been in existence. PACT has never been an organisation with lots of money. The people working for PACT don’t do a job just to get an income, they have a mission and a calling. (or, the PACT staff don’t view the work they do like any other job, they consider their work a ministry. In other words they believe they serve God by serving the poorest of the poor) They can go further and deeper than most other NGO’s because the women can rely on them, they are faithful and committed to demonstrate the living hope that the Gospel of Jesus Christ presents to all people. Somehow that makes an immense difference, the women and other NGO’s really appreciate the spiritual care and many receive Jesus, who sets them free and give them hope. PACT has a different starting point, they started at the ground, with nothing, no experience, they really grew into the situation now. They were always flexible, wanted to to see the need. This is the same with the positive networks, they started with HIV+ people coming together and grew into an organisation, they came from inside out. Many NGO’s just get funding for 4 years, set up something and leave when there’s no money left. PACT is also an organisation which came from ‘outside-in’, but want to make it increasingly ‘inside-out’, they want the women to have a sense of ownership of their groups. Empowerment is a process what will lead towards this.

Documentation

Workers of PACT have lots of experience; they all have worked with HIV+ people for such a long time. They know how it all works and have a lot of knowledge, but this is not translated into documentation. As an outsider it is hard to understand how PACT works, there’s no documentation about the way of working, structures and future planning. We know and have seen that the workers of PACT are really working hard, but it’s hard to trace what they are exactly working at. The women are willing to prepare activities for the support groups but don’t have access to any documentation. This makes it hard to train them in taking up responsibilities.

In conversation with other NGO’s working with HIV+ people we came to know that they developed methodologies, approaches, toolkits and educational materials. They also put on paper their mission statement, goals and objectives. They are required to show their donors what they are doing and their plan of action.

Financial situation

The financial situation of PACT is very threatening. Chances are that they may run out of funding from December. In one way this may work out positively, the trainers of the support groups are trying to pass on responsibilities in case they won’t be able to continue the work themselves. However besides thriving support groups there is continued funding needed to do sustainable investments to empower women. It’s hard to set goals when funding is not in place. The workers also have to raise their own support from family and friends, they have difficulty reaching their target support level. The lack of finances puts pressure on the project and the workers. The lack of documentation is affecting their prospects of raising more funds from the West. They need to lay out clear goals and measurable objectives to be considered as viable partners in relief and development.

Appreciation of the work

It is really hard to work with the HIV+ women in the support groups as we came to know about during our support group visits and as we also heard from the workers. The women can be very demanding, have a habit of receiving and some always ask for money. This frustrates the workers of PACT, they don’t have lots of money themselves either. It’s hard not to get the financial reward you deserve for doing this tough job. This works affects the motivation and the hope workers have for
doing the job. The workers are all leading the support groups in their own way, they have their own talents and approaches. It would be nice if they received more appreciation from the women but the women are very focused on their own needs and problems. It would be desirable that the workers give more appreciation to each other in order to motivate and encourage each other.

Evangelism vs Empowerment?
During our research we found out that evangelism and empowerment contradict each other in many cases. The foundational value of PACT is to bring Jesus to HIV+ people and to be like Jesus to them. Empowerment has a mission to bring change at different levels so that women can live independently. Empowerment is about standing up for yourself, it’s about being your own leader and making your own decisions, it’s about taking responsibility. The Bible tells us a different story, it’s about having mercy for everybody, it’s about embracing everybody with love no matter what, it’s about caring for the widows, poor and orphans. These contradictions form a dilemma for PACT, because they want to respect and care for people the way they are yet push people to move forward in life. It is also hard to find the balance between preaching the gospel and education and empowering. The women need both. The other issue is that PACTs main mission is to bring people to Jesus that means that empowering is takes second place. In this way the women can manipulate the empowering process and the trainers, they can claim to be cared for, to stay the same and receive. The PACT workers want to reach as many women as possible with the gospel. The question often is, will the women seek Jesus or the benefits they can receive from those who seek to care in Jesus’ Name? Jesus is stronger than human desire and can break this cycle, but considering the history of these women it’s hard to break this cycle. Empowerment should become a right for women, something they want to reach and embrace, but right now they don’t see enough hope to look beyond their problems. They live day by day, they don’t necessarily look for a sustainable solution yet, the task for the workers is to motivate them and to use the knowledge of women who are already empowered.

11.3 Marco level: Indian Society
Caste system
The Indian caste system is a system of social stratification and social restrictions. To a great extent your caste defines who you are, what your chances are and what your future will be like. It was so hard for us to find out how the caste system works, we read and talked a lot about it but we will never be able to understand it fully because we are from such a different society. What we found out is that the caste you belong to will determine who you are, the people don’t fight this, they accept it. Indian people don’t think in individuals, they think in groups/clans. Women involved in the support group are mostly from low castes. The fact that they belong to a low caste determines their perspectives, being HIV+ makes it even harder to have hope to come up in life at all. The caste system blocks the empowerment process. Every caste has a maximum in what they can reach or influence, as said being HIV+ puts you down even harder. Many people don’t have the hope that they will reach a higher status in this life and if you’re HIV+ you way is even more blocked. Society will define the opportunities there are for people, it doesn’t depend on the help organisations and the chances they will offer to the HIV+ people, they can fight and stimulate but there is a ceiling that is usually ‘lower’ than especially western organisation hope for. In the end, the whole society decides, it’s impossible to empower only individuals in India, just an individual can’t do anything. Succesful empowerment can only be sustainable if they embrace and focus on the whole living environment of the women. It’s not only about what the women can do or be but also about the chances the society gives them. This makes advocacy for HIV+ people and awareness programmes even more important.
Gender balance

“More power to women does not translate into less power for men. Empowering women, strengthening their agency as actors and decision-makers in their own lives, and guaranteeing their rights increase the power of women, as well that of households, communities, and entire economies. Promoting Gender-equality, renegotiate men-women relations, stimulate men to be part of the solution (Gupta G.R. 2000)”. The power balance between men and women involved in the support groups are mostly quiet traditional. When HIV enters the family, the roles are disturbed. This is difficult for men and women, we have heard and seen this from women while visiting support groups. Only empowering women will even more disturb the relations between men and women. The literature tells us that’s it is essential to involve men as part of the solution. This is hard because many women are really hurt by men, they ruined their whole life. Since the culture in India is quiet conservative, divorce is not an option for most women. The situation is that they live with their husband in a house, they’re both infected, both get discriminated and have fear for the future. They need each other to face their challenges it is therefore imperative to pay attention to the husband/wife relationship in teaching them to talk about issues like sex and problems.

Discrimination

We were totally perplexed when we heard the stories from workers and the women themselves about the discrimination they face. Women thrown out of their families, hospitals refuse to treat them, they are denied jobs, rejected by all. The discrimination takes its emotional toll on the women, but also socially and financially. The discrimination has different reasons, people don’t want HIV+ people to take part in society and taboos surrounding transmission. HIV+ people also face discrimination inside the (in law) family for causing what is called shame to the family name. The impact of the rejection of your family is enormous in India, family is your social security and support system.

Overload of NGO’s

Due to the plight of HIV+ people, many NGO’s came to the rescue. We already wrote about the reason of women who depend on NGO’s. Some women literally move from NGO to NGO to collect enough money and provisions for living. They really use the NGO’s. Many NGO’s keep on doing the work anyway. They wrote a 2,3 or 4 year plan, and received funding for these years. They have to hold on to the project, and are responsible spending the money right and have to tell the donors about this. This is the reason that they do not want to lose involvement of women in their NGO, they get funding for every women involved. In fact they’re doing the right thing by helping them, but if help is limited to mere financial hand outs, the women are not served in the long term. Most NGO’s recognize that the need of the hour is working towards a susainable situation in which women can earn their own money and take care of themselves.

Duplication

The overload of NGO’s causes a lot of duplication. NGO’s don’t want to work together, because they need every women involved to get their funding. This causes that many women get financial support from different organisations. This makes them really dependent, if you can get everything for free, why should you work for it? The problem is that the NGO’s quit their programme after they run out of money, and leave the women empty handed. NGO’s can spoil the women, but let them down even harder when they leave. PACT tried to discuss with other NGO’s about who is doing what, to offer HIV+ women a complete package of help, unfortunately few NGO’s are open for such cooperation.

11.4 Limitations of the study

Cultural limitations

We faced a lot of obstacles during our research. First of all the big difference between the Dutch and the Indian culture. Almost everything is different in India. The first weeks we struggled to understand a thing, but just because we had nothing to hold on to from our own culture, we learned how things
work quiet easily. Though we know that things as the caste system and the marriage traditions will never be understood by people grown up in the West. There’s a difference between knowing how things work and understanding them. Europe has such a different history than India, with a different political, social and economical system. We have been very open to learning as we have asked questions and listened to the things people wanted to tell yet India is still a mystery to us. People don’t speak so directly and it is really rude to ask things very directly. We sought to be culturally sensitive which at the same time seemed to hinder us from entering the mysteries about how marriage, sex, addiction etc. work in India.

Language problem
The other big limitation of this study was that we don’t speak Tamil, the native language of most of the women involved in the support groups. This language barrier made it difficult to do the research. The PACT workers translated everything for us, they really did a good job, but we could never talk spontaneously with the women and sometimes we missed out on parts because of translation.

We wrote this whole thesis in English, which is not our mother tongue. Speaking English is ok for us, but writing is quite difficult. Indian people have a very nice English accent, real soft and easy to understand, but they talk very fast this added to the difficulty.

Illiteracy
Because we could not really talk with the women, we thought that it would be easy to hand out a questionnaire about their life, health, working and financial situations. When we asked them to fill it out, many couldn’t because they are illiterate. They needed help of others who could read and write. The PACT workers gave clear instructions to the women how to fill it out, but things such as how long they have been infected etc, can be corrupted because they couldn’t be honest with the person who helped them fill the questionnaire.
Chapter 12 Conclusions

In this chapter we go back to where it all started, the main and the sub questions that came up when we came to know about PACT, their desire to empower women and the problems they faced in doing that. It is hard to put all we learned and experienced in answering these questions. The women involved in the support groups, the PACT workers, Indian culture and its secrets, it brought us much more than these answers, yet these questions led us into a totally different world, we will never regret the experience even though we ended up with more questions than answers.

1. What keeps the HIV-infected women involved in the support groups of PACT, dependent upon NGO’s?

We can conclude that there are a number of reasons why the women involved in the support groups remain dependent on NGO’s. First there are cultural obstacles. Girls in India are disadvantaged compared to boys in many ways, they receive less education and less respect. Some families see girls as a burden because they have to pay a dowry for them. Girls always stay with the family, they stay under guidance of the men in the house. When HIV enters the family, the roles in the family change. Many women in support groups are widowed, or their husbands are very sick. They have to take care of the family now but they have never learned the skills to do that. They never went out of the house much and are ill equipped to function independently. This makes them dependent on NGO’s, they’re not used to be in charge in their own life and want the NGO to take over the responsibility. Due to a lack of education and skills, many women are financially marginalized. Because of discrimination on the workplace, and a low immune system that makes them frequently ill, it’s hard to find a regular job. No job, means no money, NGO’s who provide in the financial needs help the women, but it keeps them dependent as well.

2. What have similar organizations/projects done to empower HIV-infected women?

There are many NGO’s like PACT in Chennai to help HIV+ women. Some have a long history, some came out of networks of HIV+ people, others were set up by people who saw the need of the HIV+ people in the city. There is a lot of expertise in Chennai about empowering HIV+ infected women. Since Chennai is the capital of the conservative state of Tamil Nadu, empowering is difficult because of cultural barriers, like the caste system, male/female relationships and because issues like sex and addiction are really hidden. Empowerment is a multi dimensional process which requires changes on structural, relational and individual level, it is hard for organisations to cover all these dimensions. You can find a list of interventions from different NGO’s in the chapter “Key interventions to empower HIV+ women”. This is an overview of all the things done. We can conclude that NGO’s are more and more focused on empowering women, since the economical crisis in the West results in less funding. NGO’s are more focused on stimulating women through training and education to do things them selves, instead of fixing everything for them.

3. Which approaches and methodologies from organizations who do similar projects, can PACT use?

There’s no widely accepted method for empowering women. Methods written about in the chapter “Key interventions and approaches in empowering HIV infected women”, all promote the empowerment of women and have the goal to reduce their vulnerability to the HIV epidemic and its impact but all off them have only been implemented on pilot basis or at small scale. It is not known yet whether they can be used in other countries or on a bigger scale. It is difficult to see the results of empowerment programmes, changes in gender roles, chances for women to rise up and influence society and structures, changing these things take years. There are some toolkits developed to empower women by organizations we visited and interviewed. PWN+ has the money to invest in research and is busy developing a series of trainings for women. These trainings will be very useful for PACT, since PWN+ is also located in Chennai. Also INP+ has some training manuals. We also found manuals and trainings from Stop AIDS Now, International Centre for Research on Women, CARE and
USAID. We expected more evidence based trainings, manuals, methodologies and approaches in empowering women. This proves that there is a long way to go in empowerment of HIV+ women.

4. Which conclusions can be made out of relevant literature about empowering HIV-infected women that are useful for PACT?

One of the most important lessons that gave us an overview of the important issue, comes out of a CARE research report. This tells us that empowerment built upon the social theory recognizes the power of individuals (sociologists call this “agency”) and structures. CARE’s view is unique, because they also incorporate human relationships, which research and experience indicate, are key factors in effective empowerment. Their understanding is that empowerment (improvement of the physical, economical, political and social- well being of women) will not be sustainable unless there are changes on individual, structural and relational level. This makes us understand of the importance of interventions at different levels, and makes us aware of the risk of investing in only one level.

Another important conclusion that can be made out of the literature is that it is necessary to involve the whole society in empowerment over HIV+ women. Interventions done to empower HIV+ women can be summarized in interventions on education level, economical level, stigma and discrimination issues and gender based issues. Many interventions will not be specifically focused on HIV+ women, but on women in general, because it ha got to do with the position of women in general. Specific interventions that are necessary for HIV+ women are advocacy at public places (because of stigma and discrimination). Another needed intervention is intentional efforts to build the women’s self esteem which is most of the time very low because of all their condition and position in society. It also becomes very clear that uniting in groups will help HIV+ women to improve their self esteem and helps them come out of their isolation and stigma. Peer education and ownership of the group are keys to successful groups. Another important aspect we learned from literature is that men should be part of the solution, even though they caused the women a lot of pain, they are needed in the process of empowerment since men and women together are the future for their families and society.

5. What is the situation of the women involved in the support groups and what do they want/need to be empowered?

While conducting the questionnaires, we learned that many women are illiterate. Because they wanted to fill the questionnaires they were helped by other women. Unfortunately we cannot use the questionnaires, but it does give a picture of the women who come to the support group. In addition, the average concentration of women was not long enough to complete the questionnaire form. We concluded that we should shorten the questionnaire to twenty basic questions. The results tell us that women involved in support groups suffer in several ways due to multiple problems. The financial situation of women is alarming when we see that 40% of them live below the poverty line and can’t take care of their family. Furthermore, 38% of the women are widowed and a quarter of them have no jobs.

We asked women what they need to be educated about in support group meetings another question was what do they need for everyday life. 76% noted that they like to work on their self-confidence. We can conclude that there is a big gap between what women want and what society expects. Women need more self confidence if they want to make progress and succeed in efforts such as setting up their own business and standing up for their rights. But society won’t expect HIV women to be assertive. Expectations of society will form a major barrier in the expression of empowerment. 38% of the women said that the support group help her the most by accepting herself the way she is and by being part of a caring community. We believe that the setting of a support group is an ideal place to work on the self confidence of HIV infected women. Only self confident women can continue working on goals they want to realize.
6. What are the strengths, weaknesses, opportunities and threats that PACT as an organization faces working with HIV infected people?

In regards to strengths; one of the most important factors that make PACT a strong organization is that they are all united in Christ. Christ is the foundation of their desire to work for the poorest of the poor and share the Gospel with them. The workers are called to do the work and even if it is hard, they find peace in God. Besides that, it is incredible how many people the PACT project reaches through such a small team. The location of the office and the contacts with the TB hospital makes the PACT project an accessible organisation.

In regards to weaknesses; the stress level of the workers is high, because they work individually and are personally responsible for the results. As mentioned before the PACT staff faces financial stresses at both personal and organizational level, as they continue to struggle with a lack of funding. On an administrative level, the PACT project is poorly organized, there is little or no documentation of results of the past years, that makes it hard to obtain funding from the West.

An opportunity for PACT presents itself as banks are increasingly willing to give self help groups a loan for the empowering of women. And as more and more media attention gets to micro credits, PACT may in the future function as a link between the banks and support groups. In addition, World Vision will discontinue their support groups this summer due to lack of funding. Fortunately women are no longer able to switch to another Christian support group, so PACT has the opportunity to stimulate more and more independence.

Several threats are facing further continuation of the PACT project namely; duplication between local NGO’s makes it difficult to see where the biggest need is for help. Women get spoiled as NGO’s give money unconditionally. However the biggest threat remains lack of funding. At this rate the project may have to be discontinued in December if they fail to see sufficient funds raised.

7. What do the staff of PACT want/need to empower these women so that they get less dependent upon NGO’s?

The PACT workers are trying to put the HIV+ women involved in the support groups into an empowerment process by challenging them to develop skills like leadership, talking about emotions, running business etc. They help them to become more self reliant and pro-active. The PACT workers challenge women to develop new skills in giving them responsibilities in support groups. As written before, this is difficult because of cultural obstacles. All trainers are men, this is strengthening the cultural obstacles. We can conclude that there are also women needed to put the empowerment process to work. Women should be an example for each other, they have to activate each other in making steps towards a more independent situation where they can generate their own income, stand up for themselves etc. The PACT workers need more money, for themselves to do their work without stress, but also for the women. They want and need to invest in skill training and education material to speed up the empowerment process. This is the biggest need since financial problems are blocking the empowerment process enormously. At present many NGO’s quit their projects due to a shortage of money, it is urgent to work towards financial independency. Financial independency will provide the way and give rest and freedom to work towards other empowerment issues.
Chapter 13 Recommendations

In this chapter we want to sum up what we think is necessary for PACT to do, to stimulate the empowerment process. During the research we found out how things worked, or didn’t work. We analysed the situation of PACT and the women involved in the support group in Indian society and Chennai. We drew conclusions from them and out of these conclusions we want to give some practical recommendations to make the empowerment process work even better.

2. **Overcome duplication, by installation of a safe online database of different local organizations where names of participants and the support they receive can be checked**

During interviews and discussions with PACT workers and other NGO’s it became clear that other NGO’s are not always willing to work with a shared database. Their fundraising is based on the number of people involved in their NGO, who have been registered, therefore other organizations are not given access to their data. Since this aspect is no reason for PACT (their donors are not funding on those grounds), they can provide insight into their participant lists, PACT can ask cooperation from other organizations to see if some support group members are already registered elsewhere, without interfering with other policies. We can’t change the problem of duplication at local level, as long as the problem remains at the level of our own organization.

3. **Government funds, try to get funding at the government as long as the government benefits from the work PACT does.**

In previous discussions it was indicated that the financial involvement of the government could interfere with the mission and vision of the ministry of PACT. The government would likely want to be involved in the decision-making, which means less freedom to do whatever needs to be done. This is a difficult situation the PACT ministry is facing, because the previous funding from the West becomes less due to the economical recession. If the PACT ministry wants to continue, there needs to be cooperation and support in some way to get the needed financing. The government, who benefits by PACT’s ministry, should be the first one to want to invest in the ministry. It is recommended that PACT reach an agreement with the government to show them that PACT is working with them in realizing their goals to reduce the impact of the AIDS epidemic while at the same time staying close to their Christian identity and vision. The identity, vision and way of working of PACT contribute to reach the goals the government has set.

4. **Professional growth, motivate employees to do part time studies, so funding will be easier and professionalism is increased.**

Relevant knowledge is needed about a specific subject in order to teach it to others. In addition, knowledge about a subject should be reliable for everyone. Discussions revealed that staff do not always know what they should teach the support groups and that the information passed to the support groups is based on things that staff has heard from others or learned through a course. This does not imply that staff is inexperienced and doesn’t know where they are talking about, but it is uncomfortable for staff when they get sometimes corrected by group members. A part-time study would contribute to the confidence of staff, reliability of the transferred knowledge, professionalism of the organization and the opportunities to find long term funding. In addition, to run a vocational training center to teach SHG members to produce something marketable within five years,

5. **Establish and collect evidence based training manuals to base the work on professional methods to be used in fundraising and as a resource for workers.**

Staff indicates the benefits of having a toolbox for support group meetings. It will help them to prepare themselves for the support groups more easily and information will not get lost. Recognizing the growing evidence of the increasing feminization of the AIDS epidemic and a lack of a uniform,
coordinated strategy in implementation of education in support groups at the PACT project, makes our research valuable. Information, education and counseling are vital elements to support women in decision making and carrying them out safely and voluntarily. A recent study in India articulated that lack of appropriate education and counseling curtail reproductive choice of women. It is necessary to invest more in education, the PACT workers have the skills and possibility to enhance their knowledge by using materials from NGO’s working towards empowering HIV+ women.

There are a lot of training manuals, toolkits etc. available. It is necessary to acquaint themselves with these, to find out what works. When PACT workers will evaluate every support group, they will come to know more about what works in these support groups and what the needs are of the women. This will help to professionalize the PACT ministry.

6. **Optimize and renew the way of teaching.**

It is scientifically proven that people, especially illiterate people, remember things better if they live through it or see it portrayed. During our support group visits we noticed that the PACT workers put a lot of energy in their teaching. They teach real interesting material and the women are listening carefully but the workers also told us that the women forget everything easily. Using games, visualize the problem with images, photo’s, movies etc, will help the women to connect more with the information that has been told.

6. **Ownership of the support groups.**

During our support group visits we mentioned that some women have a very submissive, subservient attitude. Some women come to the support group, and sit and wait for the leaders to take their place, without doing anything themselves. It is part of Indian culture that women act like this around men and leadership. However the PACT workers want the women to take more responsibility, they want the women to be the owners of the support group. Literature taught us that support groups are hugely beneficial for HIV+ women. They can share their heart in a safe environment and get encouraged by each other. We recommend that the PACT trainers take (more) time to let the women share their stories. Literature also tells us that support groups can be a playground to practice new skills, like speaking in public, leading a group, standing up for yourself in a group. We recommend to challenge the women involved in the support groups to give them more responsibility. It is their group, give them the opportunity to choose the topics, let them organize the snacks and drinks, let them share their knowledge about specific topics. It can be really beneficial for the women to practice certain skills in a safe group, so that they get more confident to take their place in society. They will also have the sense of being needed and desired, this will increase their self esteem, which is one of their biggest problems. One of the outcomes of the questionnaires is that they’re really willing to prepare things and to share their knowledge, the cultural issue probably is that someone has to tell them what to do exactly. To let the women do more themselves will also reduce the stress on the trainers. To invest in the ownership of the group by the women themselves connects with the desire of the trainers to work towards independency of the women at every level.

7. **Peer education**

We have come to know about the importance of peer education during our visits to other organizations and while reading literature. These women know the best themselves, what they feel, need, want etc. Sharing their knowledge in educating, helping and supporting others will help them see the importance of their life and experience, and it will help others to deal with their life. Uniting is enormously important for these women who carry so much shame and fear. It will help to reduce

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54 IISnVhezhan Dr. T; Mahalingam Dr. P; Pratheeba, Dr; APAC (2010); ‘Reproductive, child and sexual health needs of women living with HIV/AIDS, a situational analysis 2010’, PWV+, Chennai, p. 5-6
their burden. If women can use their experience to help others, their perspective on everything they have gone through can change into something positive, something useful for others.

8. Money issues
The self help groups function very well. The PACT workers really stimulate and encourage the women in doing this, and it is working out well. It helps the women in taking responsibility, being accountable and work towards a goal. Literature says that self help groups are one of the best ways for HIV+ infected women to rise up. We also heard stories about self help groups falling apart because women are not faithful in saving, and that it takes a very long time to get a loan sometimes.

The West is in an economical crisis which has resulted in less funding for developing countries. The economical crisis doesn’t mean that there is no money at all. The governments can’t give money away while their own people are in crisis, but there are companies in the West who are doing well during the crisis. They are willing to make investments which will pay them selves back when the economy is getting up again. Since India is one of the largest rising economies, there are probably companies who are able to make investments. We have read about such initiatives and it is working out well. The women have to pay back in time, but this is part of the empowerment process in which they take personal responsibility, not merely wait for hand outs. Since starting is the hardest part in building a business due to a lack of money to set it up, this may be an option to overcome this problem. A small business enables HIV+ people to have flexible work hours and generate their own income. A regular job may be hard to sustain for HIV+ people because of their low immune system that makes them frequently ill. We recommend to do research and find out what companies in the West, but also in India, can give micro-loans. Use the knowledge of experts and use the contacts there are with (business) people (in churches for example) and other NGO’s.

Another thing we want to recommend is to stop giving 50Rupees travel money (to get to the support groups) to everybody. 40% of the women involved in the support groups lives under the poverty line. This means that 60% isn’t. Now everybody gets the money, while some are able to pay it themselves. We recommend to give a certain amount of money for travelling, an amount that the women have to divide themselves. In this way the women will learn to take care of each other and stimulate them to think and assess their own financial situation. The PACT workers want the women to function like a family, who take care of each other in giving and taking. This is a way to stimulate the women to grow into such relationships with each other. We heard that the financial situation of PACT is not so stable, we uggest that the money spent on travel money for women can better be invested in sustainable innovations like skill training for PACT workers or educational material. Giving money can block the empowerment process. It causes women to depend on NGO’s because it compounds their sense of helplessness. At the same time it could make women lazy because it is less tiring to receive money than to work for it.

9. Involve men as part of the solution
We recommend the PACT workers to involve men in the empowerment process. The power balance and relation between men and women involved in the support groups is mostly quiet traditional. When HIV enters the family, the roles are disturbed, men get sick and are at home all day, women have to go out to work, or they become widows at a young age. The disturbing of the gender roles is difficult for men and women, we have heard and seen this in women while visiting support groups. A lot of women have real bad experiences with men, they cheated on them, used and abused them. But empowering women only, will even more disturb the relations between men and women. Literature tells us that’s it is essential to involve men as part of the solution. Men are needed to combat the AIDS epidemic, and to keep the families in shape. Men are leading the Indian society, so they are needed to make the empowerment of women work. They have to give and take, just as the
women, to make it better together. The first step is to make men and women conscious of their role, a lot of time roles are determined by traditions. It is important to bring men and women together in a re-negotiation process of the roles, with the eye on the future of their children, their marriage, themselves. Also talking about difficult issues like sex, violence, addiction etc. is necessary in creating a better future for the next generation and for themselves. PACT values family life, as written in their mission statement they want to “reach out to HIV/AIDS victims with compassion, by meeting their felt needs through a holistic approach and reconcile them to their Spouse, Family and Relatives”. Involving men as part of the solution will help to make this mission statement become a reality.
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<td>Product capacity of employees is unclear, no reports of work what has been done</td>
<td>Tamil Nadu is getting an example for the whole nation</td>
<td>Stigmatization makes that not many people want to do this work</td>
</tr>
<tr>
<td>The team get trained every six months on different topics</td>
<td>Part of an international organization is a disadvantage for local funding</td>
<td>Media and government pay attention to the topic of empowering HIV+ women</td>
<td>It is hard to get good professionals to do this work for so less money</td>
</tr>
<tr>
<td>Money use is transparent</td>
<td>Not able to do sustainable investments because of limited budget</td>
<td>International attention and involvement to stop the AIDS pandemic and give care to the victims</td>
<td>The level of people HIV+ infected is getting lower, there is a change that the government will cut the finances down</td>
</tr>
<tr>
<td>Ethical community between employees</td>
<td>No fixed data storage, so that data can get lost</td>
<td>Part of an international organization, with a good name who are seen as professionals</td>
<td>Money only will be available as the government report the right thing to international organizations</td>
</tr>
<tr>
<td>Employees feel to be called to do this job in Gods kingdom</td>
<td>Motivation and stress level can influence employees by being uncertain about their financial rewards</td>
<td>The PACT office is located near the TB hospital were many HIV+ people get treatment</td>
<td>Less financial resources because of the economical recession in the west</td>
</tr>
<tr>
<td>Employees have a wide experience to do the job</td>
<td>Leak of marketing experience and professional organization skills</td>
<td>The banks are getting more willing to give loans to HIV+ people</td>
<td>New organizations without experience come and spoil the needed by giving money</td>
</tr>
<tr>
<td>The team is flexible on delivering various services depending on the needs</td>
<td>Not much professional care for the mental ballast of the work</td>
<td>World Vision, who does similar work as PACT is leaving the field</td>
<td>For funding the employees need to be educational qualified</td>
</tr>
<tr>
<td>The employees are able to maintain short lines between the people they work with and themselves</td>
<td>Short term and undetailed planning</td>
<td>There is enough need to expand the work</td>
<td>Short term finances make long term planning imposable</td>
</tr>
<tr>
<td>Employees take time</td>
<td>Insufficient systematic</td>
<td>The government is</td>
<td>Distends, some HIV+</td>
</tr>
</tbody>
</table>

**Analysis inventory**
| to share their thoughts and experiences every day | evaluation of the work | helping the self-help groups more and more | people live on the other site of the city |
| Employees are given freedom to make their own decisions | No long term sustainability of local funding | From the government there is more attention for children education | There is concurrence of organizations who do similar things as PACT does |
| Job description is going to be developed for each worker | Not enough manpower compared to the amount of work | The government has benefits by the PACT ministry, it doesn’t cost them much | Duplication, participants going to different organizations to get benefits |
| The employees are accountable | PACT depending people on them by giving money | The ownership of support groups are within themselves | |
| The PACT project moves a lot of work with a small team | The organization depends on some team members | | |
| The PACT ministry owns property | Insufficient clarity about employees responsibilities | | |
| Supporting and reaching out to many HIV+ children and adults | Staff has no professional education to counsel participants | | |
| PACT works inside out, depending on the needs of participants | No established manuals employees can use for their work | | |
| The management has the desire to expand the work and see enough need | | | |
| Cooperation with organizations doing the same work | | | |
| Checks with World Vision that participants won’t abuse the services | | | |
| Positive relation with the local police | | | |
| Good and short connection with medical resources | | | |
### Confrontation Matrix

<table>
<thead>
<tr>
<th>Opportunities</th>
<th>Treats</th>
</tr>
</thead>
<tbody>
<tr>
<td>World Vision, leaves the field of HIV+ women</td>
<td>Banks are willing to give HIV+ a loan nowadays</td>
</tr>
<tr>
<td></td>
<td>Government has benefits by the PACT ministry, it doesn’t cost much</td>
</tr>
<tr>
<td></td>
<td>HIV+ people depend on PACT and get lazy</td>
</tr>
<tr>
<td></td>
<td>Concurrence of other organizations</td>
</tr>
<tr>
<td></td>
<td>No long-term funding form abroad</td>
</tr>
</tbody>
</table>

#### Strength

- **Committed and experienced team**: 5
- **Good relationship and contacts with local services**: 3
- **Reaching out to many HIV+ people who need support**: 5

#### Weakness

- **No professional education to counsel participants**: 3
- **Stress because of uncertain financial rewards**: 1
- **No database of professional established working manuals**: 1

The matrix shows the balance between opportunities and challenges, with a focus on the strengths and weaknesses of the approach.
<table>
<thead>
<tr>
<th><strong>Strategy questions</strong></th>
<th><strong>Opportunities</strong></th>
<th><strong>Treats</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>World Vision, leaves the field of HIV+ women</strong></td>
<td>Banks are willing to give HIV+ a loan nowadays</td>
<td>Government has benefits by the PACT ministry, it doesn’t cost much</td>
</tr>
<tr>
<td><strong>HIV+ people depend on PACT and get lazy</strong></td>
<td><strong>Concurrence of other organizations funding from abroad</strong></td>
<td><strong>No long-term funding</strong></td>
</tr>
</tbody>
</table>

**Strength**
- Committed and experienced team
- Good relationship and contacts with local services
- Reaching out to many HIV+ people who need support

How can we strengthen our opportunities?
- Coordination with World Vision and plan in advance what PACT can take over of World Vision’s work field
- Ask the government for material support, so no money get involved
- Work on the relationship with the banks, so banks will give loans to support groups without PACT’s involvement.
- Try to get support of local companies by standing gerent for the loans of support groups, micro credit

How can we use our strength to reduce our treats?
- Being an example as a team for participants, by working hard and living in faith
- A save online database of different local organizations where names and support can be checked and participants know about

**Weakness**
- No professional education to counsel participants
- Stress because of uncertain financial rewards
- No database of professional established working manuals

How can we use our opportunities to overcome our weaknesses?
- Coordination with World Vision about taking over materials (and professional employees?), so information and knowledge won’t get lost
- Try to get funding at the government as long as the government has benefits by the work PACT does

How can we strengthen our weaknesses by resisting our treats?
- Establish or collect working manuals so work will be based on professional methods, it can be showed to funders and is easy for workers.
- Give working manuals to participants and ask them to educate themselves by reading and telling others
- Motivate employees to do part time studies, so funding will be easier and professional knowledge grows
- One employee who helps other employees by getting funding and write policy about how personal funding can be divide honestly
2. Extra information about AIDS

2.1 AIDS world wide

As of 2009, AVERT estimated that there are 33.3 million people worldwide living with HIV/AIDS, with 2.6 million new HIV infections per year and 1.8 million annual deaths due to AIDS. In 2007, UNAIDS estimated: 33.2 million people worldwide had AIDS that year; AIDS killed 2.1 million people in the course of that year, including 330,000 children, and 76% of those deaths occurred in sub-Saharan Africa. According to UNAIDS 2009 report, worldwide some 60 million people have been infected, with some 25 million deaths, and 14 million orphaned children in southern Africa alone since the epidemic began. In 2008, US$ 15.6 billion was estimated to be available from all sources for HIV.


<table>
<thead>
<tr>
<th>Region</th>
<th>Living with HIV</th>
<th>Newly infected with HIV in 2007</th>
<th>Died of AIDS in 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>North America</td>
<td>1.3 million (480 000–1.9 million)</td>
<td>46 000 (38 000–68 000)</td>
<td>21 000 (18 000–31 000)</td>
</tr>
<tr>
<td>Caribbean</td>
<td>230 000 (210 000–270 000)</td>
<td>17 000 (15 000–23 000)</td>
<td>11 000 (9800–18 000)</td>
</tr>
<tr>
<td>Latin America</td>
<td>1.6 million (1.4–1.9 million)</td>
<td>100 000 (47 000–220 000)</td>
<td>58 000 (49 000–91 000)</td>
</tr>
<tr>
<td>Western and Central Europe</td>
<td>760 000 (600 000–1.1 million)</td>
<td>31 000 (19 000–86 000)</td>
<td>12 000 (&lt;15 000)</td>
</tr>
<tr>
<td>Middle East and North Africa</td>
<td>380 000 (270 000–500 000)</td>
<td>35 000 (16 000–65 000)</td>
<td>25 000 (20 000–34 000)</td>
</tr>
<tr>
<td>Sub-Saharan Africa</td>
<td>22.5 million (20.9–24.3 million)</td>
<td>1.7 million (1.4–2.4 million)</td>
<td>1.6 million (1.5–2.0 million)</td>
</tr>
<tr>
<td>Eastern Europe and central Asia</td>
<td>1.6 million (1.2–2.1 million)</td>
<td>150 000 (70 000–290 000)</td>
<td>55 000 (42 000–88 000)</td>
</tr>
<tr>
<td>East Asia</td>
<td>800 000 (620 000–960 000)</td>
<td>92 000 (21 000–220 000)</td>
<td>32 000 (28 000–49 000)</td>
</tr>
<tr>
<td>South and south-east Asia</td>
<td>4.0 million (3.3–5.1 million)</td>
<td>340 000 (180 000–740 000)</td>
<td>270 000 (230 000–380 000)</td>
</tr>
<tr>
<td>Oceania</td>
<td>75 000 (53 000–14 000 (11 000–1200 (&lt;500–2700)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: UNAIDS ‘AIDS epidemic 2007’
.2 Policy in India

In 1987 a National AIDS Control Program was launched to co-ordinate national responses. Its activities covered surveillance, blood screening, and health education. By the end of 1987, out of 52,907 who had been tested, around 135 people were found to be HIV positive and 14 had AIDS. Most of these initial cases had occurred through heterosexual sex, but at the end of the 1980s a rapid spread of HIV was observed among injecting drug users (IDUs) in Manipur, Mizoram and Nagaland - three north-eastern states of India bordering Myanmar (Burma). At the beginning of the 1990s, as infection rates continued to rise, responses were strengthened. In 1992 the government set up NACO (the National AIDS Control Organization), to oversee the formulation of policies, prevention work and control programs relating to HIV and AIDS. In the same year, the government launched a Strategic Plan for HIV prevention. This plan established the administrative and technical basis for program management and also set up State AIDS Control Societies (SACS) in 25 states and 7 union territories. It was able to make a number of important improvements in HIV prevention such as improving blood safety.

By this stage, cases of HIV infection had been reported in every state of the country. Throughout the 1990s, it was clear that although individual states and cities had separate epidemics, HIV had spread to the general population. Increasingly, cases of infection were observed among people that had previously been seen as ‘low-risk’, such as housewives and richer members of society.

In 1998, M.L. Nath wrote:

“HIV infection is now common in India; exactly what the prevalence is, is not really known, but it can be stated without any fear of being wrong that infection is widespread... it is spreading rapidly into those segments that society in India does not recognize as being at risk. AIDS is coming out of the closet.”

In 1999, the second phase of the National AIDS Control Program (NACP II) came into effect with the stated aim of reducing the spread of HIV through promoting behavior change. During this time, the prevention of mother-to-child transmission (PMTCT) program and the provision of free antiretroviral treatment were implemented for the first time. In 2001, the government adopted the National AIDS Prevention and Control Policy and former Prime Minister Atal Bihari Vajpayee referred to HIV/AIDS as one of the most serious health challenges facing the country when he addressed parliament. Vajpayee also met the chief ministers of the six high-prevalence states to plan the implementation of strategies for HIV/AIDS prevention.

The third phase (NACP III) began in 2007, with the highest priority placed on reaching 80 percent of high-risk groups including sex workers, men who have sex with men, and injecting drug users with targeted interventions. Targeted interventions are generally carried out by civil society or community organizations in partnership with the State AIDS Control Societies. They include outreach programs focused on behavior change through peer education, distribution of condoms and other risk reduction materials, treatment of sexually transmitted diseases, linkages to health services, as well as

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advocacy and training of local groups. The NACP III also seeks to decentralize the HIV effort to the most local level, i.e. districts, and engage more non-governmental organizations in providing welfare services to those living with HIV/AIDS.  

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http://india.gov.in/spotlight/spotlight_archive.php?id=34
3. Questionnaire support group members

The following results from the questionnaires informed us about the background and situation of the women involved in the support groups, but didn’t contribute to the answer of the main and sub-questions directly. That’s the reason why we decided to put them in the attachments of our research report. The information these results show us are interesting and important anyway. They can probably help the PACT workers to get more useful information about the women involved in their support groups. This can probably lead to a more focused and specific approach of their work.

3.1 Remaining results

![Gender Distribution](chart1.png)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>13</td>
</tr>
<tr>
<td>Women</td>
<td>37</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
</tr>
</tbody>
</table>

![Living Status Distribution](chart2.png)

<table>
<thead>
<tr>
<th>Living Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>15%</td>
</tr>
<tr>
<td>Living with family</td>
<td>46%</td>
</tr>
<tr>
<td>Living with family in law</td>
<td>38%</td>
</tr>
<tr>
<td>Men %</td>
<td>24%</td>
</tr>
<tr>
<td>Women %</td>
<td>59%</td>
</tr>
<tr>
<td>Total</td>
<td>16%</td>
</tr>
</tbody>
</table>
Research among HIV+ women in India

**Religion**

<table>
<thead>
<tr>
<th>Religion</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hindu</td>
<td>62%</td>
</tr>
<tr>
<td>Christian</td>
<td>38%</td>
</tr>
<tr>
<td>Moslim</td>
<td>0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Hindu</th>
<th>Christian</th>
<th>Moslim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men %</td>
<td>65%</td>
<td>35%</td>
<td>0%</td>
</tr>
<tr>
<td>Women %</td>
<td>62%</td>
<td>38%</td>
<td>0%</td>
</tr>
</tbody>
</table>

**Discovering the HIV status**

<table>
<thead>
<tr>
<th>Event</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>After death of the spouse</td>
<td>8%</td>
</tr>
<tr>
<td>Blood testing after frequent illness</td>
<td>46%</td>
</tr>
<tr>
<td>Blood testing during pregnancy</td>
<td>31%</td>
</tr>
<tr>
<td>Others</td>
<td>15%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>After death of the spouse</th>
<th>Blood testing after frequent illness</th>
<th>Blood testing during pregnancy</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men %</td>
<td>8%</td>
<td>46%</td>
<td>31%</td>
<td>15%</td>
</tr>
<tr>
<td>Women %</td>
<td>16%</td>
<td>54%</td>
<td>24%</td>
<td>5%</td>
</tr>
</tbody>
</table>
LET'S GO FISHING

Research among HIV+ women in India

### Years after discovering status

<table>
<thead>
<tr>
<th>Years after discovering status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 3 Years</td>
<td>23%</td>
</tr>
<tr>
<td>3 - 6 Years</td>
<td>31%</td>
</tr>
<tr>
<td>6 - 9 Years</td>
<td>15%</td>
</tr>
<tr>
<td>9 - 12 Years</td>
<td>23%</td>
</tr>
<tr>
<td>12 - 15 Years</td>
<td>8%</td>
</tr>
<tr>
<td>16 Years &gt;</td>
<td>0%</td>
</tr>
</tbody>
</table>

- **Men %**: 23%, 31%, 15%, 23%, 8%, 0%
- **Women %**: 19%, 24%, 30%, 22%, 3%, 3%

### Moment of disclosing HIV status

<table>
<thead>
<tr>
<th>Moment of disclosing HIV status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately after knowing</td>
<td>69.23%</td>
</tr>
<tr>
<td>Within a year</td>
<td>0.00%</td>
</tr>
<tr>
<td>After re/confirming with next test</td>
<td>15.38%</td>
</tr>
<tr>
<td>Disclosed when unable to work and earn</td>
<td>0.00%</td>
</tr>
<tr>
<td>Not disclosed yet</td>
<td>15.38%</td>
</tr>
</tbody>
</table>

- **Men %**: 69.23%, 0.00%, 15.38%, 0.00%, 15.38%
- **Women %**: 56.76%, 24.32%, 10.81%, 2.70%, 5.41%
Research among HIV+ women in India

### Using ART medicine

<table>
<thead>
<tr>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men %</td>
<td>85%</td>
<td>15%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women %</td>
<td>65%</td>
<td>35%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Start of taking ART medicine

<table>
<thead>
<tr>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 - 1.5 years ago</td>
<td>1.5 - 3 years ago</td>
<td>3 - 6 years ago</td>
<td>6 - 9 years ago</td>
<td>More than 9 years ago</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men %</td>
<td>73%</td>
<td>9%</td>
<td>0%</td>
<td>18%</td>
<td>0%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women %</td>
<td>54%</td>
<td>13%</td>
<td>8%</td>
<td>25%</td>
<td>0%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**LET’S GO FISHING**
3.2 Questionnaire English version

Profile of study participants

1. Gender
   - Male
   - Female
   - Transgender

2. What is your age?

3. Respondent’s living status
   - Living with family
   - Living with family in law
   - Living in commune/cluster/Group
   - Living alone
   - Others ______________

4. Educational status
   - Never attended school
   - Class 1-5
   - Class 6-10
   - Class 11-12
   - College degree
   - Post graduate course

5. Religion
   - Hindu
   - Christian
   - Muslim
   - Other ______________

6. Caste Category
   - SC
   - ST
   - MBC
   - BC
   - FC
   - No Response

7. Martial Status
   - Unmarried/single
   - Married
   - Widowed
   - Divorced/separated
   - Others ______________

8. Occupation
   - House wife
   - Permanent job
   - Working for a NGO
   - Self employed
   - Please specify ______________
9. Income
   - $<1000
   - $1000 - 2000
   - $2000 - 3000
   - $3000 - 4000
   - $4000 - 5000
   - $5000+

10. How did you discover your HIV status
    - After death of the spouse
    - Blood testing during pregnancy
    - Blood testing after frequent illness
    - Others _______________________

11. When was it discovered? How many years ago?

12. When did you disclose your status of HIV infection to your family/partner/other
    - Immediately after knowing
    - Within a year
    - Disclosed when unable to work and earn
    - After re/confirming with next test
    - Not disclosed yet

13. Do you use the ART medicine?
    - Yes
    - No
    If yes, for how long have you been taking the medicine?
    - 0 - 1,5 years
    - 1,5 - 3 years
    - 3 - 6 years
    - 6 - 9 years
    - 9 - 12 years
    - Longer than 12 years

**Knowledge about HIV**

14. Are you aware about transmission of HIV / AIDS?
    - Yes
    - No

15. Have you ever been educated about:
    - Personal / menstrual hygiene
    - Yes
    - No
    - Nutrition safety
    - Yes
    - No
    - Sexually Transmitted Infection
    - Yes
    - No
    - Contraception
    - Yes
    - No
    - Treatment Availability
    - Yes
    - No
    - Sex and Sexuality issues
    - Yes
    - No
16. Who informed you about:
   Personal / menstrual hygiene  □ Hospital  □ Support group
   □ Family/friends  □ Others
   Nutrition safety  □ Hospital  □ Support group
   □ Family/friends  □ Others
   Sexually Transmitted Infection  □ Hospital  □ Support group
   □ Family/friends  □ Others
   Contraception  □ Hospital  □ Support group
   □ Family/friends  □ Others
   Treatment Availability  □ Hospital  □ Support group
   □ Family/friends  □ Others
   Sex and Sexuality issues  □ Hospital  □ Support group
   □ Family/friends  □ Others

17. Do you have any children?
   □ Yes  □ No
   If yes, do you have enough knowledge and skills to educate your child about:
   Personal / menstrual hygiene  □ Yes  □ No
   Nutrition Safety  □ Yes  □ No
   Sexually Transmitted Infection  □ Yes  □ No
   Contraception  □ Yes  □ No
   Treatment Availability  □ Yes  □ No
   Sex and Sexuality issues  □ Yes  □ No

18. If you need medical care, do you know where to get the right treatment?
   □ Yes  □ No

19. Would you tell the hospital about your HIV+ status?
   □ Yes  □ No
   If not, please explain__________________________________________________________

20. What is the attitude of spouse/family members towards you after knowing your HIV+ status?
   □ Very supportive
   □ Only spouse is supportive
   □ Spouse is not supportive
   □ Some family members are supportive
   □ No support at all

*Stigma and discrimination*
21. If you do face any discrimination by spouse/family members, what type of discrimination do you face?
   - Physically harassed, please specify:
   - Deprived from property, please specify:
   - Neglected / Isolated, please specify:
   - Deprived of using basic amenities at home, please specify:
   - Asked to leave home, please specify:
   - Verbally harassed, please specify:
   - Others, ____________________________

22. Has there been any change over time in their behavior?
   - Yes
   - No
   If Yes, what was the reason for change in their attitude?
   ________________________________

23. Are you employed?
   - Yes
   - No
   If no, what is the reason for not having a job?
   ________________________________

24. Have you disclosed your HIV status to your employer?
   - Yes
   - No
   If Yes, what is the attitude of your co-workers at the work place?
   - Supportive
   - Physically harassed
   - Verbally harassed
   - Avoid sitting in close proximity
   - Neglected / Isolated
   - Labeling and name calling
   - Deprived of using shared amenities
   - Asked to resign
   - Other, specify____________________

25. If people know that you are HIV+, do they stigmatize you on religious grounds?
   - Yes
   - No

Recourses and support

26. What have you done to avoid discrimination?
   - Migrated to unknown place and kept the HIV status secret
   - Avoided participation and communication with community and neighbours
   - Victimized suffering from exclusion
   - Taking support of law/NGO’s for equality
   - Joined support groups (network of positive people)
   - Other, specify____________________
27. What have you done to overcome financial stress?
- Dept from relatives, friends and other institutions
- Mortgage property
- Sale of assets
- Liquidation of bank savings/bonds
- Cutting down cost on quality of live; moving to a smaller place, use low cost transport, shifting children to low cost institutions for education etc.
- Stop children’s education
- Spouse takes up responsibility of household earning
- Children working for household income
- Mortgage of jewels
- Other, specify____________________

28. Do you avail any social insurance schemes?
- Yes
- No
If Yes, have you claimed any insurance so far?
- Yes
- No

29. Do you avail any of the following pension?
- Old age pension scheme
- Destitute widow pension scheme
- Destitute/deserted wives pension scheme

30. Do you feel that people infected HIV+ must be provided with monthly pension?
- Yes
- No
If Yes, how will it help you and your family?
- Buying medicines
- Buying nutrition
- Paying the house rent
- Paying children education
- Other, specify____________________

31. Do you make any financial savings towards the network to get a loan in the future?
- Yes
- No
If yes, how much Rupees monthly ____________

**Empowerment**

32. What do you understand by empowerment?
Please give three examples
____________________________________
____________________________________
____________________________________
33. Do you or your group in any way demanded for your rights to the Government?
   □ Yes  □ No
   If yes, where about did you demand your rights?
   Please specify__________________________________________________

34. What are the special services and support you need the most?
   Please number the services from first priority to less priority
   (example: 1 Nutrition provision, 2 Family care and support etc.)

<table>
<thead>
<tr>
<th>Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling</td>
</tr>
<tr>
<td>Health testing</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Medicines Proper</td>
</tr>
<tr>
<td>Nutrition provision</td>
</tr>
<tr>
<td>Family care and support</td>
</tr>
<tr>
<td>HIV / AIDS monthly pension</td>
</tr>
<tr>
<td>Others ____________________________</td>
</tr>
</tbody>
</table>

35. My Support Group helped me the most with (choose one)
   □ Giving finances
   □ Getting a loan
   □ Education about ________________________
   □ Accepting me the way I am
   □ Being part of a caring community

36. What would you prefer as a member of a support/ self help group?
   Some education done by women □ Yes □ No
   More games and activities □ Yes □ No
   A group without men participating □ Yes □ No
   More men sharing their experience □ Yes □ No

37. As a member of a support/ self help group I want to participate in:
   Preparing games and activities □ Yes □ No
   Sharing knowledge about a topic □ Yes □ No
   Sharing experiences about a topic □ Yes □ No
   Providing snack and share at the support group □ Yes □ No
   Collecting and registration of money □ Yes □ No
   Opening my house for meetings □ Yes □ No
   Finding good healthcare excess and share it □ Yes □ No
   Helping others with getting a job □ Yes □ No
   Read a book and share the education □ Yes □ No
   Leading a support group □ Yes □ No
38. Which topics would you like to see mentioned in the support groups (choose five)

- Women rights and the law
- Hygiene
- Domestic violence and abuse
- Information about organizations that can do something for
- Building self/confidence, standing up for yourself
- Good Parenting
- How to deal with trauma´s, fear
- Kids and HIV
- Financial advise
- How to deal with discrimination and stigma
- Sexual education
- How to deal with anger
- Who is Jesus
- How to disclose my HIV status
- Financial education and advise
- How to deal with sex after infection
- How to deal with depression
- Pregnancy and being HIV positive
- Food education, how to avoid risks to get sick and building up immune system
- Medical education about antiretroviral drugs and how to deal with side effects
- How to read the bible
- How to set up a own business
- Nutrition advices
3.3 Questionnaire Tamil version, completed

1. இராண

☐ மறை
☐ வேலை
☐ குறிப்பிட்டுக்கொள்ள

2. நான் எதைச் செய்து வேண்டும்? தெரியுமா? 38

3. நான் தமிழ் கூறினாம்

☐ பெண்களின் உயிரிற்குரிய
☐ வேலையாளர்கள் உயிரிற்குரிய
☐ குழந்தைகள் உயிரிற்குரிய
☐ மற்றும் _ ___________ 

4. பண்டைப்பேச்சு

☐ மாதம் இல்லாமல் இராணுணர்வு
☐ அக்டோபர் 1-5
☐ அக்டோபர் 6-10
☐ அக்டோபர் 11-12
☐ நவம்பர் பாரம்பரிய
☐ செப்டம்பர் பாரம்பரிய

5. குறிப்பிட்டு

☐ குறிப்பிட்டு
☐ பதில் செய்யப்படாது
☐ மற்றும் _ ___________ 

6. குறிப்பிட்டு

☐ SC ☐ ST ☐ MBC ☐ BC ☐ FC ☐ குறிப்பிட்டு மிக் ஸ்பார்டிகர்கள்

7. குறிப்பிட்டு

☐ குறிப்பிட்டு மலர்சுகாலன்கள்/சுருக்காலன்கள்
☐ குறிப்பிட்டு மலர்சுகாலன்
☐ சுருக்காலன்
☐ மலர்சுகாலன் புகைத்துல்ல
☐ மற்றும் _ ___________ 

8. குறிப்பிட்டு

☐ குறிப்பிட்டு
☐ பதில் செய்யப்படாது
☐ இணையத்துடன் இணைந்து பெரும் நேரலை
☐ மற்றும் _ ___________

I work in the positive network office.
LET'S GO FISHING
Research among HIV+ women in India

9. Age distribution
- □ <1000
- □ 1000 - 2000
- □ 2000 - 3000
- □ 3000 - 4000
- □ >4000

10. Reasons for not going fishing today:
- □ Bad weather
- □ Not enough time
- □ Lack of fishing equipment
- □ Other

11. How often do you go fishing?
- □ 1-2 times a month
- □ 3-4 times a month
- □ 5-6 times a month
- □ 7-8 times a month
- □ >8 times a month

12. What is the relationship between fish caught and daily food intake?
- □ Direct correlation
- □ No correlation
- □ Indirect correlation

13. How do you prepare the fish you catch?
- □ Roast
- □ Fry
- □ Boil
- □ Other

14. What are the benefits of fishing for HIV+ women?
- □ Improved nutrition
- □ Increased income
- □ Social interaction
- □ Other

15. Possible challenges in fishing:
- □ Weather conditions
- □ Equipment failures
- □ Access to markets
- □ Other

16. What are your suggestions for improving fishing?
- □ Better equipment
- □ Training in fishing techniques
- □ Access to markets
- □ Other
Research among HIV+ women in India
LET'S GO FISHING
Research among HIV+ women in India

20. Have you ever been tested for HIV (+ve)? If yes, do you have confidence that the test result is accurate and reliable?

☐ Yes
☐ No
☐ Don’t know

21. Do you think research among HIV+ women in India is important? Why or why not?

☐ Yes
☐ No
☐ Don’t know

22. Are you allowed to have a close relationship with me, my husband's younger brothers, children are not allowed to talk

☐ Yes
☐ No
☐ Don’t know

23. Do you think women should be involved in research?

☐ Yes
☐ No
☐ Don’t know

24. Do you think researchers should be allowed to conduct research on women's health?

☐ Yes
☐ No
☐ Don’t know

Confidentiality

☐ Yes
☐ No
☐ Don’t know

95
25. Does your partner have HIV+ status? Did you have sex with your partner when you knew he/she had HIV? 
   [ ] Yes
   [ ] No

2. Let’s go fishing

26. Have you taken any measures to prevent the spread of HIV? 
   [ ] Yes
   [ ] No

27. What are the measures you take to prevent the spread of HIV? 
   [ ] Teach your children
   [ ] Educate your family
   [ ] Use condoms
   [ ] Avoid sharing needles
   [ ] Avoid sexual contact

28. How do you go to work? 
   [ ] On foot
   [ ] By bicycle
   [ ] By bus
   [ ] By car
   [ ] By motorcycle

29. Do you/have you had any support from your community? 
   [ ] Yes
   [ ] No

30. In the event of an HIV+ diagnosis, what measures have you taken to care for your children? 
   [ ] Yes
   [ ] No

Infected affected children can be taken care more...
LET'S GO FISHING
Research among HIV+ women in India

31. I have a plan to go fishing. I... (continued...)

☐ Yes ☐ No

32. The savings from the... (continued...)

☐ Yes ☐ No

33. The type of job I... (continued...)

☐ Yes ☐ No

34. The type of... (continued...)

☐ Yes ☐ No

35. The... (continued...)

☐ Yes ☐ No
36. What are the common symptoms experienced by women with advanced HIV in India? ( tick the correct answer(s))

- Fever
- Fatigue
- Weight loss
- Night sweats
- Cough
- crushed bones
- Increased appetite
- Cold body
- Headache

37. Research among HIV+ women in India

- Education level
- Income level
- Employment status
- Sexual orientation
- Marital status
- Sexual practices
- Substance use

38. What factors influence the decision to seek medical care for HIV? ( tick the correct answer(s))

- Access to care
- Cost of care
- Distance to health facilities
- Social stigma
- Cultural beliefs
- Personal health beliefs
- Family support
- Government policies

LET’S GO FISHING
Research among HIV+ women in India
4. Interviews with employees

4.1 Venister
Name: Venister Thomas
Sex: Man
Education: Sociology
Function in PACT: Support group trainer, hospital counsellor, AIDS awareness programme
Marital status: Married, 2 kids
Age: 37

Empowerment

1. How would you define empowerment and is it needed?
Empowerment should lead to a situation where women can stand on their own, not dependent from help of others because they can do some work and earn their own money. Empowerment is really needed. HIV infected women have a habit of hiding and being ashamed, they sit in their house thinking that nothing can change. They should come out of their house, claim their rights and live life. They shouldn’t have a complex because of their infection, and hide away. They should be a part of society, they are like everybody else only with a disease, but everybody got something. They shouldn’t focus on their HIV positive status all the time, they are like everyone else.

2. What do you think that the women see as empowerment?
Women see having a job mainly as empowerment, that will help them the most to live in less fear for the future.

3. Where do you want to educate the women more about?
That they should stand on themselves and not be dependent on NGO’s. So I teach them how to generate their own income, give them advice for opportunities they have to start small businesses.

4. What have you done to empower women?
Most of the women feel rejected, they are hating themselves. I try to get them out of their shame, that they see their importance, I try to build their self esteem so that they come out and live their life. They scare people off when they act so scared themselves, people should see that they just live a normal life with friends and work and all.

5. What do you think that PACT can do more to empower women?
There are enough chances in Chennai city for women to get empowered. In the rural areas around Chennai, the people are in a big need. People suffer real badly there. It’s a real short time ago that the first HIV infection is discovered, lots infections followed. There are a lot of orphans because of HIV, and nobody cares for them. Also a lot of women are infected, but they don’t have any help, no education, no food. There’s only one NGO working there, CARE, but there is way to much work for one NGO. The hospital refuses to help women with delivery of babies because of their HIV status, even people at the hospital are too scared to help them. The situation of these women is shocking compared to women in Chennai. There is a big chance for PACT to expand their work to rural areas.

Definition of dependency

6. What keeps HIV infected women dependent upon NGO’s?
The NGO’s make the women dependent upon their organization. A lot of NGO’s get money for the people involved in their organization, they don’t mind if people also go to other organizations. They want to keep helping them because they get money for every person involved. In this way HIV infected people can go from NGO to NGO to get money, food, clothing, everything. The women can
Research among HIV+ women in India

get everything, this isn’t motivating them to do something themselves, it made them lazy and dependent.

7. What do ‘you’ think that the biggest obstacle is in empowering women?
So many organizations who are giving hand outs keep women from being empowered. The women are not motivated to do something themselves because they can get everything they need from NGO’s. So the biggest obstacle is that there are too many NGO’s working for HIV infected women and that the women are spoiled because of all the things they receive. Another obstacle is that the women get sick often because of their low immune system, at those times they are unable to work. This is a real difficult problem because it keeps them from getting/keeping a regular job with regular working times.

8. How can you overcome this barrier?
Stop giving. This can be hard because the people are still in need, but they will be in need the rest of their life if they don’t learn to stand up for themselves and keep on receiving. NGO’s need to work together to avoid that people get spoiled. They should only get what is needed. Only the people in real need should get money, the people in rural areas. I like it more to lead the support groups in Salem (in the rural area) than in Chennai. It’s hard to be motivated sometimes for support groups in Chennai because the people are spoiled. It’s easier to be motivated for support groups in Salem, because I know and see the need, I can do there more to help people.

9. Are you working towards a situation that they function independent from YWAM?
Yes, by training and education in opportunities. I want to support groups to function on their own. The people need to unite, and function like a family, they should take care of each other. Self help groups will make them independent in the future, now they save money later on they will get loans and be able to set up a own business. I really support women to get involved in self help groups. Maybe there will be a vaccine against AIDS in the future, that will save the children from an unsure future. It’s not good that children feel different than other children who are not infected and that their on pictures on websites of NGO’s. Maybe in the future they can marry, and if people remind them of photo’s of NGO’s somewhere on the internet than it can ruin their future.

10. If YWAM doesn’t support the groups financially, will the groups continue?
The groups will continue when YWAM isn’t supporting them anymore. The leaders will go on organizing the meetings. I only support 2 women in the Pallavaram support group, the rest of them is coming without getting any money, they come because they want to come. Also when people don’t get any money anymore for transportation, the relations the women have with each other will make them come, most of them are really faithful to come to the meetings.

11. Do they have enough skills to function independent?
Everybody can do something for work. I believe that they have enough education and skills but it’s hard to get a chance to show it. Creating jobs for them would be a good solution to make them independent.

What can PACT do?

12. What makes PACT different from other organizations?
Not much, PACT is doing a lot of the same things other organizations are also doing. We have a holistic approach in which spirituality is important, we preach Jesus, that makes a difference.

13. What do support group participants see as the strength of PACT?
The support group gives them a reason to come out of their house and it makes them meet new people. The support groups gives women an opportunity to learn. Last Christmas there was a celebration where one women told about her life and her experiences and what she learned. She
never spoke in public before, but now she discovered that she can do that. Support groups are challenging them, they discover and learn new things about themselves, they don’t keep everything inside anymore.

14. What does the support group see as a weakness of the program?
Sometimes I hear people complaining, and then they say that PACT should give rice and all and not only teaching. They’re not satisfied with only teaching, they have a habit of receiving and they are unsatisfied if I don’t give anything. Its not nice to hear all these complains when I do my best, but it’s good for the empowering that they don’t receive. It iss not really a serious weakness of the programme, it’s more a weakness of the women.

15. What obstacles do you face with the support groups?
I don’t know. The elections can change a lot in the way HIV infected people can get help from government instances. Also getting loans at the banks is an obstacle. This is hard, because the women try their best to save and then the banks are not willing. That’s difficult to deal with.

Need of staff members

16. Do you have resources or tools do you have access to as a leader, to prepare the support groups?
We have resources and tools to prepare the support groups but we need more. We need more money to buy materials where women can make some things from to sell, in this way we can create jobs. In this way they work for their money. We are already busy creating jobs with companies, they place orders. We can use some new ideas, pictures and materials to run the support groups better.

17. How do you prepare the support group meeting?
I take some actual things out of the news and connect that with the situation the women are in, or what influences them of what they can influence. I say the things that come up in my head, and I connect it with the Bible. If there would be manuals available I would use them for ideas.

18. Do you have enough support (financially but also mentally) to do your work well?
I don’t have enough support. Financially it’s really hard. I can’t pay my sons school fees. I get some money from PACT but it’s not enough to pay the rent. It brings me stress and it influences my work in that way that stress has it’s effects on the body. Sometimes I panic, than I’m down because of the stress my financial status brings me and my family. I don’t feel a lot of support of the team in these moments.

19. What do you need more to empower the support group members?
We need somebody who brings us some new knowledge and inspiration that we can pass on to our support groups. Especially more information about self earning possibilities will help to empower the women in giving them advice, possibilities and chances to expand their opportunities for developing their own business.

Future plans

20. What responsibilities could members take over in the support group?
They should take over everything in time and lead the group by themselves.

21. What is your dream for the women involved in the support groups?
My heart is to be there for the people who really need it. There’s work to do in the rural areas. For the women I hope that they have self confidence, they can get up in life.
22. How do you see PACT in 5 years in addition to empowering women?
There will be more groups, at least 3 new ones. The groups will be led by their own leaders, YWAM staff will only come to visit them, they will not prepare the groups. They will be self supportive.
4.2 Isaac

Name: Isaac
Sex: Man
Education: Finished high school, 10 standard
Function: PACT Project manager
Marital status: Married, one boy
Age: 34

**Empowerment**

1. **How do you define empowerment and is it needed?**

   We work a lot among women, especially HIV positive women. Empowering the women means, basically we want to see women who are in a lower state, social and spiritual and emotional lower state and come in their lives to help them and increased them with in a holistic approach to come up in life. For example many of the ladies where we are working with who are economical in a low position, we look at that area, how we can empower that area and empower them to get to a higher economical level.

   That is also why we have these self help groups, where we encourage them to save money, take loans, start some small businesses for themselves and make money. Empowerment is getting women from a lower level to a higher level. We can help them at first, but we can’t keep helping them. We can help them to start, not for a long time, but then they have to pick it up themselves. It is like the phrase about the fisherman, we learn to make them fish. We as an organization we are not able to help the women for a long time, because than we get frustrated. We want the women to stand on their own by training them and we do that on different levels. Emotional level, economical level and physical areas or if there health is down and they want to see a doctor, we will show them the directions. We aren’t doctors, but at least we can do that. We channelize the women and encourage them to have a healthier live and a better emotional status. We know that they can do a lot better. Empowering means to encourage women in all different areas through a holistic approach. In our society the HIV infected people are not treated with dignity, they get are not viewed the same as other people. People look down upon them, HIV women get rejected and discouraged. So they are lonely as a person and have fear. Then when you come along as a person and encourage them, that’s all of their need, especially to feel more confided and face life. We try to build confidence in many ways as we come along and encourage them that they are able to change things. We bring positive ideas and let them see the possibilities. That encouragement is needed, sometimes in the way of counseling or financial help, they may need groceries or education about their children. Most of the HIV infected women think that their live is gone, as they know about their infection. They lose their confidence, get depressed and will not take care of themselves after all. What we tell the ladies that everything they hear, they should teach to others, so they encourage each other.

2. **What do you think that the women see as empowerment?**

   Many times we see in our society that women only want to receive 80% of the time. We want to change their attitude, there thinking style, that they can’t depend on others all the time. Women depend on others because our society is like that. The parents, even if the women is married, tell them that they are depending on their father. They don’t let you go anywhere on your own. Parents really care about their children, they think that they have to teach them everything. Our system works well because the family is very close, but on the other hand the system makes everybody very depending on each other. Nobody encourage the other to do things on their own. Only man work and the women stays at home. Off course women want to be independent, but as they lose their husband or their family, they are used to be taken care of. Most women don’t tell their status to the family, because they are depended on them and don’t want to be rejected.
We don’t explain empowerment to the women, but the things which are in empowerment we speak to them. We won’t say that the women need to be empowered, but because of the way of working, they slowly understand and want to be self supported or stand on their own. It’s a big struggle, because it isn’t just a matter of one or two days. Sometimes even the women are demanding and telling that we have to give money to them. Because many NGO’s are giving money if women demand, they keep giving and keep doing the things the women asks for. So they say that YWAM should do that as well. Sometimes we give money if the women really need it, but many times women are upset also when we stop the regular monthly support.

We teach them to be self supported and that’s why many ladies are joining a self help group. The approach has changed as the ART is free from the government now. It changed their thinking, but still women do struggle with lack of understanding. They struggle with thoughts that they don’t have a future and need counseling how to live a life being infected. Especially when women go through a sickness and think that their live will be ending soon. But then we are telling them that they shouldn’t worry, take their ART on time and eat healthy food. Supporting your own body system with good food will help you to overcome the sickness we will tell. I know a lady who eats only one meal a day, because she doesn’t have the money and she is dependent on her father who is an alcoholic and in his house she only eats dinner. But even if she eats this food she has to listen to abusing words of her father, so she tried to commit suicide several times. Once she took a box of tablets but somebody found out and took her to the hospital. And another time she putted kerosene on her to get burned, but as people see that she was on fire, they stopped her. But then we decided to give her provision for a period of time and we encourage her to get a job. This provision was just for a year and she knew that. Also her son got paid for his school fees. She got a job and from that time she could care about herself and her father. HIV positive people have so many things to manage and deal with so many practical issues. So much assistance is needed. The income system here in Tamil Nadu is also very low. You need to work ten hours a day and get less paid, that also really doesn’t help our people, while the living cost is going up like anything. Even ladies who have work find it really hard to manage their income. Imagine where these people go through. Sometimes it is heartbreaking when you realize what these people go through. We can’t do as much as we want to do.

Even if we got the money we only could help them to get to another state and then encourage them to stand on their own. The help we give helps at least for some people for some extend, but the need is much more. Many people aren’t able to rent a house or get enough food. Sometimes if I see the need, I will give some money of my own. Especially if I know that they have children.

3. **What do you want to educate the women more about and what have you done to empower women?**

I want to give more education about their status, on HIV, related to sickness, how they can live a better life and handle their emotions. Education on that level is really needed. On the second level we try to help them to come up in life. It can be on the area of making money or how to get housing, the economical level. Through their economical level we have to see their possibilities and help to improve their life, maybe to educate them, but also to encourage them to work instead of sitting at home, being depressed. That is kind of education, it seems like a small encouragement, but it is also a way to teach them to come out of their comfort zone and try different things, facing the challenges. For example one lady her husband is very sick and demanding her to do things all the time. Then I’m encouraging her to find a job. So she can setup everything for her husband before she is leaving for work. And if she left at least he can take care of himself a little bit. If she makes the food ready he can take it. And if the bathroom is very close to him, he can help himself by touching the walls. By that he is helping himself also, by exercising. By explaining that to the women I tell her that she should get a job near to her place, so there is an income. Of course it isn’t easy, but I am encouraging her, because if there is no income it is hard to live at all. Her husband doesn’t really want her to leave, because there are also two children. The women also feels guilty when she leaves the home, because she is scared that something will go wrong in the house. We will try to overlook
their future, because what will happen when she again doesn’t pay the house rent. And it will improve her economical status.

4. What do you think that PACT can do more to empower women?
I think that whatever we are doing and we keep ourselves at the strategy we got we will do good. But we can improve ourselves at the economical level to give women job opportunities. We just started to give women job opportunities, training them. We don’t want to give so much help to the people anymore financially, but it would be nice if we could increase the support to the home based care, that are mostly the needed people who really need help or assistance. But for that it may not be, by saying ‘helping more’ it should empower women more. But for some extend we need to help them so they will have hope again.

Some women are connected to other organizations as well, other than YWAM and get financial support. In that case, if they get support from three other organizations we don’t want to help that person financially. Because I have a relationship with the people, I will personally ask the women; ‘Aren’t you getting help from this or that organization?’ Sometimes they are honest and sometimes they may not tell. But I definitely will find out. Somehow we have relationships with other organizations, some day or the other it will come to my notice. If I come to know I will tell them that I know about their financial support of other organizations and ask why they don’t let other people have their support who really need it. But off course it is not easy, because they are not happy when you find out. I will confront them in a nice way, but in some cases I will let them and encourage them to get help there. Their need depends on the economical situation and the living cost. Considering their situation they may not be able to earn that much for their living state, because their health is in a bad condition. Some women are expecting more help from us, but we are not able to do that, in that case I will also tell them, why don’t you take from these people. Or when we can’t give help we are telling them to get to other places. So in that line we can’t also blame the other organization. If people need help we can tell about resources of other organizations who are offering the service and be helped.

Definition of dependency
5. What keeps HIV infected women dependent from NGO’s?
Contact between other organizations is needed and working together as a network is needed. But many organizations don’t want to this, they sort of have their own networks. Within these networks they try to avoid duplication. They try to overcome that many women are asking help from different organizations. Some of the women are very good in asking and get money from all the organizations. (Is it right that you are saying that organizations are not willing to work together?) Sometimes, the organizations have their own set of goals, their own targets and funds to do certain things. For example we wanted and NGO coordination meeting organized, with some NGO’s, I used to organize these meetings. So we will talk about different things. At one meeting we talked about education support, so we found out that different organizations gave the support to the same persons. Why don’t we think of some ways to avoid this duplication, we say. Finally we only talked about it and people agreed that it should be nice when we avoid duplication, but nothing really happened. If only I go to them and go through their list and if I am willing to make some changes, only I have to do that. Actually we have to create a random system to overcome the duplication, but we need to get assistance. But even if we got the system, how many NGO’s are willing to adapt the system, because they may have some good relationships with patients and they still want to stick to these people. They don’t want to lose the people, because they get fund for as many people they work with. For example, you get help from World Vision and they find out that you get financial support of YWAM. If World Vision says to you I don’t support you anymore, you will stop going to their support meetings and stop entertaining me. If I do that to hundred people, they will lose funding of the hundred
people for my programs. So, my reports will show differently, that will affect my job and the organization, that also will effect my good reports to the donors.

Our YWAM organization is different from other organizations. We as an organization have freedom to do whatever is needed. Sometimes in our organization, so far, we may not look for this many numbers, we base our work on the need of the people. We only work with people who are really in need, we don’t look for the numbers and want to stick to our own style. And if we want to see changes, we need to work on that as we already do. For example, we stopped many people’s monthly support. There were families were we gave monthly support for their groceries, already for many years, we stopped that. Now we have a different system which says that we only support for one year. If we identify a person who needs help, we will say; ‘Ok, only for one year we will support you’. Then you keep your word and stop the support after a year. We got this system for more than one and a half year now and see that people are preparing themselves for self support. But still many more challenges are there, education, fundraising, and the contacts with family of the children in the children’s home. We initially used to help for example to pay all the school fees for the children. But nowadays we are only giving the half amount of the fees and the rest they need to pay themselves. There are so many children we support now that we also didn’t have a choice to do else. Instead of helping less people, we help more now. People can only accept, because they want all the support they can get. So in that case, if people are taking money from another organization for the child’s fees, we have more power. For example, nowadays the school fees for children is getting very costly, one child has to pay 10000 RP. And monthly fees are also there. If they can’t pay the costs of the private schools, we tell them to put the children in a government school, which fees are much lower. We also take care of the initial expenses, like school uniforms. We encourage people many times that it doesn’t matter where your child is studying, it matters how your child is studying. I studied in a government Tamil school and paid only 200 Rp a month and I came up in live. Many leaders in the country came up in live and studied in a government school. So sometimes we tell, if you can, put your child in a private school, if not, enter a government school. Even some government schools are run by catholic institutes, who give better education and ask less fees. Some ladies are stubborn and put their children in a private school and struggle with paying the fees. But we figured out a system which works although some people will always be upset when changes are made. But if we really want to make a difference we have to get through changes.

6. **What do ‘you’ think is the highest barrier in empowering women?**

Their mindset and the society system and the family who are rejecting them. And they are not able to do a regular jobs like healthy people. Sometimes they get sick and can’t work for a day or so. Children are also a difficulty if we talk about work. Women have to leave the house in the early morning, but when they also have children, where they have to care about, it is hard. This is a reason that we are telling the ladies to join a self help group and get a loan to setup their own business. Work and an income will make women less dependend.

7. **How can you overcome this barrier?**

If the ladies have their own business they are more flexible with working hours. We tell them; ‘Be convenient and find an opportunity to get some money as an income.’ That is why we want them to join a self help group. But still we need to give them some possibilities to work, so they can choose what fits them the best. Options are very important for the women, because they are not use o make their own decisions. We need leaders of the support groups and we train the leaders. So they can train others and look for job opportunities.
8. Are you working towards a situation that they function independent from YWAM?
Yes we are working towards that and we think about it a lot. We will work towards a situation where women can live independently, through involvement in self help groups. We encourage the support group members to be part of a self help group, because that will help them in the future also.

9. If YWAM doesn’t support the groups financially, will the groups continue?
This self help group was established to be functioning on their own. So if they are already self supported they don’t need help, we don’t need to give money, nothing. The only thing we have to do is facilitate them, bring them together, encourage them, and give some help to get the group grow. Alongside we will give them moral support. And help them with some bank people of some other areas.
Even not all other organizations will help them for a long time. For example World Visions will help them for 6 or 3 months, give groceries and pay their house rent and then stop. Afterwards they will offer loans to start their own business. This is an whole other type of help than we do, so I don’t think that women will leave the support group as they don’t get money any more. Some organizations help in another way, they don’t give money but give material to run a business, like selling sarees. They have to give money for every sold saree. Some women are really interested in offers like this. We should show the women the options of jobs they can do. Sometimes we invite women to show the options and some pick it up, some women don’t. They think that they need all lot of money to start a business, but you can start a business with only 500 Rp. If you keep working with the 500 Rp you will get more profit every time. Than it is up to them to take it or leave it, some are very lazy.

10. Do they have enough skills to function independent?
The options we show as a job, it are always options they can do. Or if they haven’t the skills yet, we give training to them, skill training. We have to recognize more skills and more training. How to improve their economical level. Going to the bank and doing the regular account, they do it already on their own. But getting a loan can be difficult, so they want us as YWAM to help them. They are sometimes not used to get things from formal organizations, but if we go with them, they can learn to talk to authorities like we do and next time they may be doing it on their own. In that line, we educate the women to talk for themselves. When they don’t have education women won’t get into job where they require high education, because most of the women didn’t graduate the 12 standard, but there still is an opportunity to get other job, which may not give them a great income. But doing some small business will give self-confidence and make people coming up in live. But they have the infirmity of lower education, but that doesn’t mean that they can’t do such jobs.

What can PACT do?
11. What makes PACT different from other organizations?
The spiritual aspect in our lives is a difference from other organizations. We won’t force people to believe in Christ, but we share and encourage people with spiritual aspects, because our people and society is very religious, basically. They believe in God, so the believing system is already there. We believe in Christianity and we use that aspect to help people. That aspect, really build so much important strength for the people and gives confidence, because it is beyond the intellectual level, it is the power of God penetrating their harts through the spiritual aspects. We don’t only stick to spirituality, but also through other social activities, where we try to connect with people. That is all part of our holistic approach. We bring in the spiritual aspect. And we have seen that this really changes people’s lives. So that also brings satisfaction in their lives as it brings it in ours. It is a breakthrough in their lives. I can really talk about it with Hindu people as well, because we got a
12. What do support group participants see as the strength of YWAM? 
If people approach to us in that line, the spiritual aspects line, they won’t go to another organization. Anyhow there are Christian organizations. But I experienced that we are close to the people. For example, one lady was calling me and asked, can you please pray for my daughter, she has exams today. So women do know other organizations, because this lady works for another organization, but she called me. They know that we really hold our word as it comes to living with Christ. Another lady just calls me and asks me to pray for her. When they are responding like that I do believe that is something where we are different than other organizations. NCP asked us to do their support group at their organization, because they realize that they needed more spiritual aspects in their meetings. Then I started that group.

13. What does the support group see as a weakness of the program? 
Woman can complain about the support we give them. But I have not noticed that people will complain at other organizations that there is something wrong with the PACT ministry. I’ll tell you, if we don’t give people what they want, they will talk so bad about you. That part happened with us, but that I won’t see as a weakness. It is their disappointment, not our weakness. Other organizations may see it as a weakness, but that will not affect us. We like to have Government funding like other organizations, but at the moment we can use the money for the purpose we want to use it for. We are on the field for many years and we have seen the needs of the people we work with. So we should have freedom to do whatever is needed and the women appreciate that. We are called by God and want to give our live for the kingdom of God, so we want to have the freedom to do right. The government may not like that our vision is build on spiritual aspects. But if a possibility comes along we would like to have the funding, we are searching for opportunities, because we are not against government funding. Even corruption is a problem. We may have to give money back to the government before you even get it. But materials, we love to get that from the government.

14. What obstacles do you face with the support group? 
Maybe I can say that there are challenges. We want to see that the groups function by themselves and help each other. Sometimes women come to the meetings for us as staffs. When you say that the PACT ministry will stop soon, they say that they will show up, but we are not sure. Nowadays we are helping the support group members by giving some money if they come from a far distance. We may stop doing that, in the meantime. Without the travel money, snacks and tea we provide, they still need to be willing to still meet. We want to see that happen, but that will be a real challenge for us. If we stop the benefits for them we have to see if women will keep meeting. We want to see that happening. Even if there is no money anymore, we as staffs want to continue meeting the support groups, because we want to encourage them and want to share the gospel with them. We don’t want to start something and just leave after awhile. We have done some talking about a plan, but we don’t have a target plan how we are working towards self depending support groups. But we are already thinking about it and have to make our plans.

Need of staff members

15. What resources or tools do you have access to as a leader? 
What do you need more to empower the support group members? 
We have had some trainings about different topics, so we improve our knowledge to share with the support groups. We try to get trainings about topics which our related to the need of our support group members. And we also have ways to hire people. Initially, we used to have women talking every month, now we don’t have the fund for that anymore, but we can ask women from one or
another support group to talk about different topics ones in a while. We need still to work on new teachings for the staff. We like to have modules to run the support groups. I’m still breaking my head about the topics I should teach the women about in the support groups. I supposed to ask people around me how they run their support groups. Sometime collecting topics to tell something else every month, it was hard. We would have liked to have some modules, even now. Methods to run the support groups effectively. For the other staff we also need to organize trainings to help them run their support groups. Than we can improve the support group meetings. We don’t have setup manuals, but it will be very helpful. That will give us ideas. Even now I am asking the support group members to give me topics they want to be taught about, sometimes they will give me ideas. Because I am not a proper social worker I haven’t had all the knowledge what I should tell them. Only through experience we notice what the people need. Even now I want to organize a support group leader meeting en I am thinking of the topic I should talk about. It is also hard to manage HIV positive people, because they are not in a very good social network.

16. How do you prepare the support group meeting?
My support group is depending on the support group local leaders. We want to see that leaders are really leading the group, but it isn’t always happening. I need to prepare myself. Basically what we do as a support group is having a time of fellowship and sharing our thoughts and giving practical advises to the members. When they come to the groups they are damaged in some ways, so I will plan in those lines and talk about their troubles in life. Sometimes I manage the local support group leaders to do some activities and actions. But at NCP last time I told the local leaders to organize some games, but when I got there, nobody had done anything. Than I have to change my plan. Sometimes things are very organized, when I am planning to teach on some topic, I prepare myself. Also when I invited a person to share their knowledge, apart from that I hear some people. Sometimes I don’t really prepare anything for the support groups, because I want to be open to listen to their needs and give them a chance to talk about what they want to talk about. As I talk to the people I get to know what they want to talk about. Women will never say that the support group wasn’t helping for them, but if so, I can see it on their faces. Some women will say that it wasn’t really helpful, but I won’t happen often, they don’t want to confront me.

17. Do you have enough support (financially but also mentally) to do your work well?
Yes I have. Yes, the team is supporting me. We believe that as God calls us, He also will provide. I have experienced Gods blessing over the years. (No more comments)

Future plans
18. What is your dream for the women involved in the support groups?
We want to see as many people live on their own, have their own income and place to live. The self help groups are the way to go, so we want to see that developed. And at least 10 groups are our aim to be formed by August. There are in Tamil Nadu no other self help groups run by government money from the bank of HIV positive women, except for the PACT run self help groups. It’s hard because many women think that they can’t do better and can’t save money, because of their health and small income. Then I give an example of my own life and tell them how they can do it.

19. What are the good opportunities facing the support groups in the future?
As the women get in that system of saving and pay their amount properly, then they will be able to get a loan at the bank for the purpose they choose. That’s the way they can start small businesses. We want to see more self supported positive women, who are independent, standing on their own. We want the women to take care of themselves, their family and help other individuals through the self help groups.
20. How do you see PACT in 5 years in addition to empowering women?
The past three years we had the aim that coming August we will have 10 self help groups out of the support groups. Now have 8 proper ones and there is one group coming up. Now we hope to have 13 groups at that time. And many people from the self help groups became self supported. That is what I want for the groups and for the members.

21. How do you face the future to be the leader of PACT Chennai?
I am doing this work for seven years now. And I know about the process already for a long time now. And I have been praying and we believe that God want to put me on the second level, because recently the answer of God came, that I should take this position. Personally I didn’t really want this position, because there are a lot of responsibilities and challenges. But because Jesus is with us, He will strengthen us in the challenges we are facing.
4.3 Suresh
Name: Suresh
Sex: Male
Education: Bachelor theology, dts, evangelism training, pastors training
Function in PACT: Counselling at the hospitals & support group manager
Marital status: Married, two children
Age: 37

Empowerment

1. How would you define empowerment and is it needed?
I’m working for 10 years with HIV infected people. Last ten years the empowerment of HIV infected women in Tamil Nadu increased 20 to 40% that means that they were really dependent on husbands and parents before but not anymore. Now women work, able to live alone, they don’t stay in the house anymore. Nowadays 80% of women is working in Chennai. I see empowerment as being independent. It’s needed, because of economic reasons. Economic status of the people in Chennai is low, everything is very expensive nowadays, prices have increased. In HIV field, men are not working because they’re too sick, women work. I encourage women to get to work because when you stay at home you get discouraged, you feel more sick when you think to much, it’s better to work. Women have to be empowered because their husband is not there anymore, they have to take care of themselves and because it will help them to feel better. HIV infected women can do the work now because of the medication which is available for almost everyone, they can live a normal life now with work and all so they should not rely on NGO’s.

2. What do you think that the women see as empowerment?
A woman came to me, her husband died because of HIV, and she herself was also infected. She never get out of the house during her marriage, she was supposed to run the household and to stay at home all the time. She asked me what to do, since her family wasn’t able to support her because they were poor she had no food. I told her to get outside, to search for a job so that she could feed herself and her family. That was really hard for her to hear, in Indian culture women don’t go outside and she was scared to go but she was forced to do it because she wanted her kids to have a future. Finally she went outside, took a job and she told me that it was really good to earn her own money, also for the kids. She met some HIV infected women who always stayed at the house, she told them about her adventure of getting a job and getting into action and that it really helped her to go on with life and to come up in life. She helped the women in encouraging them. Women see being able to take care of yourself and family and friends as empowerment. Women can really help each other in the empowerment process, when they get along as a family they can take care and encourage each other. It helps women to encourage others, to be able to take care of each other, to share their life.

3. What do you want to educated the women more about?
Indian women are always fearing for family and culture, they won’t come forth when they keep fearing everybody. They have to learn to communicate. Men always doubt about their wife and women are most of the time very depending on their husbands. It’s needed to change roles, that there’s interaction. Women and men have to be educated in communicating, it’s important for the future that things between men and women change so that women will be able to get a job and all. It is new for people to talk about these communication issues between men and women but it’s helping them to discuss. One woman told that her husband came to ask for forgiveness after they discussed about their communication habits and relationship.
4. **What have you done to empower women?**

Education about gender issues, husband/wife relations. Getting loans for them, encouraging them, counseling them.

5. **What do you think that PACT can do more to empower women?**

I’m 80% satisfied with how the support groups function. Not 100% because women sometimes don’t come on the right time, or people are too sick too attend. The culture is pushing back the women, husband don’t allow their women to go and don’t want their women to change. Another thing is that it’s tiring that women always want money. I say straightforward that I can’t, but it’s hard that some women keep on asking. Slowly this is changing, they come forward in life and they don’t only think about themselves anymore, last time they celebrated my birthday and bought me a cake. Normally I take everything, but now they arrange things them selves more and more, also for other people.

PACT is doing a good job, they should offer more training for the women to teach them skills, we should develop trainings and be in contact with NGO’s and companies for jobs. PACT only give ideas and teaching, we can do more in the future, for example tailor training, jewellery making, embroidery, make plates from leaves and all. Other NGO’s are already giving such trainings, but we can also do it on our own way.

**Definition of dependency**

6. **What keeps HIV infected women dependent from NGO’s?**

Women go to NGO’s because everybody is discriminating them because of HIV, now it’s changing. First they were not able to work because they were really sick, they really needed the NGO’s to take care of them because they had no money to buy food and nobody took care of them. They were deserted by family and friends. Some people still really need help because of this reason, but only 5-10 percent are only depending and not doing anything themselves. The others take care of themselves, sometimes with support, but at least they do something for it. He tells them not to depend on NGO because NGO’s can quit and then they don’t have anything. NGO’s should only give limited amounts of money, only the really needy women should get something, other women should take their own responsibility. HIV infected people can have a future right now, awareness programmes from the government work well, the stigma gets less during the years. It’s still there, but people now know better how HIV works and get less fear, so they can offer them jobs. Women in my support group don’t depend on NGO’s, I educated them in grabbing their chances to get jobs.

There are some women fully depending on NGO’s, but most of them are working for their money and take care of themselves or each other.

7. **What do ‘you’ think is the highest barrier in empowering women?**

Cultural barriers are the biggest obstacle in empowering women. High caste people were never used to working, low caste people are. In the HIV community is no classification, outside there is. High caste people often had some education but are not used to hard working, low caste people are used to hard work but they don’t have any education so they can’t get a very good job. Education is needed for a good job, so it is an obstacle if you didn’t have any education.

8. **How can you overcome this barrier?**

For the next generation it will be better, for now it will be a big problem. It’s not possible to overcome in one generation. It’s good when NGO’s educate them in training specific skills. People want training, but afterwards some of the high caste women say ‘no sir this is not my culture, i won’t go out to work’. It’s pride that’s blocking them, it’s impossible to overcome this. The caste problem is impossible to solve, I’m from a low caste, high caste people don’t even allow me to come into their house. I can’t do anything about it, it’s hard to accept it, but it’s like this for such a long time, it won’t change in a short time.
9. Are you working towards a situation that they function independent from YWAM?
I’m working towards a situation that my support groups function independent. I told my support group that I possibly won’t come next month because I won’t be in the city because I want to visit my hometown. I told them to run the group when I’m not there, and they said no problem, we run it. The leaders take their responsibility. I also try to make them accountable and responsible by giving the leaders the money that they have to share with others, and they do. I appreciate them for sharing it so well, it gives them a good feeling. I think that giving them responsibility gives them the opportunity to try new things. It builds trust.

10. If YWAM doesn’t support the groups financially, will the groups continue?
Everybody gets travel money, 50 Rs each person. I teach them to go on with the meetings, even when they don’t get any money. My groups already get loans and all, they can do it on their own, they will go on with the support groups, they need it. The support groups are really developing very well, also financially because of the loans. They are willing and able to support each other when they have financial problems. A few women who were not able to pay the school fees for their kids, the group collected money to pay it.

11. Do they have enough skills to function independent?
My support group has the skills, they can take the responsibility. I train them in teaching so that they can pass on their knowledge and skills. I teach them how to teach, how to prepare yourself for teaching others in searching on internet for information etc.

What can PACT do?
12. What makes PACT different from other organizations?
PACT is different, PACT is a ministry not an organization who wants to do some work. We’re sharing the gospel, and that’s very important. The Bible is also telling about empowered women, I can give examples of empowered women in the Bible. We as PACT are already on the field for so many years, others come just 2 or 3 years. People can rely on us, we’re faithful and not depending on government money and others. The people know that we’re trusting God and God provided already for so many years.

13. What do support group participants see as the strength of YWAM?
They see that we bring Jesus and Jesus is changing lives. Many women were sex workers, not anymore, they came to know Jesus and He accepted them and now their life is changed, they are not sex workers anymore. We try to offer them training so that they can change jobs. We train them in other things in tailoring, sari selling etc. Most women in the support group had and still have a difficult life, they’ve been going through a lot of heavy things. Only Jesus can save them and he does. He uses PACT for that.

14. What does the support group see as a weakness of the program?
One girl does sex work because she needs more sex than her husband is giving and he’s also not giving her enough money to raise her kids. We can only give them counselling and tell them it’s sin, but then they go their way and do it again just because they have to do it. PACT is not giving enough money as they want and it’s hard not to have enough money to make them stop with doing such things. Before I was really angry on the people doing this work, I couldn’t accept, but now I know them in person and I have to accept, but I still want and hope they can change their ways. I try my best to help them to change their ways but sex workers are hard to work with.
15. What obstacles do you face with the support groups?
One support group just opened a bank account, but now they’re not faithful in saving. They couldn’t find a bank first, now they have but the women live in different areas so it’s hard to collect the money every time. Sometimes people are too sick to come to the support group or they don’t have money to come. These are though obstacles, they have to solve it themselves. I support them to take their responsibility.

Need of staff members

16. What resources or tools do you have access to as a leader?
I want some training from other people in leadership. I want some nice leadership books to inspire me. I need some more inspiration of topics to teach about. PACT gives ideas and information and I know some people my self who can give me some more information. I enjoy being a leader, but I want to become better in it. Sometimes it’s good when women teach, I try to arrange women leaders to teach, I want them to share and lead, they should be an example for the other women.

17. How do you prepare the support group meeting?
Tomorrow is a support group, I will prepare it tonight out of books and the Bible.

18. What should you as a person avoid in your work?
We are working very hard, we teach how to come up help people in so many ways, and when they keep on living the way they do, involve in sex work and drinking, makes me feel discouraged and very bad. I feel bad about it that they keep on living the life they do, I don’t know why they don’t come up in life, why they stay like that. It’s hard to talk about sex with women, as a man. I should avoid that, women will feel shy and uncomfortable. I invite women to talk about it with the women and leave then with the men, to teach them about family life and to tell them that it’s not only about sex.

19. Do you have enough support (financially but also mentally) to do your work well?
Financially not enough support, life is becoming more expensive in Chennai, it’s hard to get enough funding.

20. What do you need more to empower the support group members?
I want to educate them more. So many people are waiting and raise questions. I have to give a lot of suggestions, sometimes I don’t know what to answer to all these questions. Our culture is different, different people, different teaching. We need culturally specified education, not European education.

Future plans

21. What responsibilities could members take over in the support group?
I already pass on responsibilities. I encourage them that they can do it themselves, that I’m just a dummy. I’m responsible for the loans, that they will pay it back, I worry about their sickness sometimes it can make it impossible to pay back. The government will come to me if the women don’t pay back, that makes me worried sometimes. The women can’t take over these worries, one way I’m happy about getting the loan for them because the life of 16 women and their families will change, but on the other hand, for myself it’s hard, it’s a heavy burden and responsibility. It makes my life stressful sometimes, but God is good, He will take care of me.

22. What is your dream for the women involved in the support groups?
That people live independent, that they do their own job, earn their own money and that they’ll have a peaceful family life.
23. What are the good opportunities facing the support groups in the future?
My support group is the first HIV infected group who got a government loan ever, in the whole of India. That’s really special and I’m proud of it. Probably more money is on the way for the women. Loans can change the life of families, and give a future to the kids.

24. How do you see PACT in 5 years in addition to empowering women?
There should be more support groups outside of Chennai, the existing groups will raise new groups and educate them. Support group members should pass on the things they learned to new people.
5. Interviews with other organizations

5.1 Interview World Vision

About World Vision:
World Vision India is a Christian humanitarian organization working to create lasting change in the lives of children, families and communities living in poverty and injustice. World Vision serves all people regardless of religion, caste, race, ethnicity or gender. Spread across 174 locations in India, World Vision works through long-term sustainable community development programmes and immediate disaster relief assistance.

Three basics of the work of World Vision:
- Focus on Children: All development work we carry out is focused on building the community around children so that they have the opportunity to reach for a better future.
- Grass root Based: World Vision’s relief and development is community based. Our staff lives with the communities at the grass roots, living with them, learning from them and working along with them to find solutions to issues of poverty.
- Partnering for Change: We partner with the people in their development, work with the Government and civil society to usher in a better and brighter future for India.

World Vision is an international partnership of Christians whose mission is to follow the Lord and Savior Jesus Christ in working with the poor and oppressed. To promote human transformation, seek justice, and bear witness to the good news of the kingdom of God.
They formulate their core values as followed: We are Christians, we are committed to the poor, we value people, we are stewards, we are partners, we are responsive.

World Vision India has been responding to HIV and AIDS since 1991. Presently, there are fourteen special projects on HIV and AIDS, located in high-prevalence states and districts, while many of their Area Development Programmes (ADPs) provide care services to people living with HIV. World vision in all its HIV programs works to advocate for and ensure the rights of children affected by HIV and AIDS as well as those marginalized due to HIV and AIDS.

Since 1999 World Vision India - Grace Program Chennai (Grass root response To AIDS through Care and Education support) has been addressing the issues of HIV/AIDS in Chennai city. Their response to HIV AIDS focuses on prevention, care, support and advocacy. The overarching goal is to reduce transmission of infection and improve quality of lives of children and adults, affected by HIV AIDS. They (the GRACE project in Chennai) formulate their mission as followed: Children, women and families affected by HIV/AIDS and those at risk for HIV infection leading a life free of discrimination and sharing equal opportunities with fellow citizens.

The basics of the HIV/AIDS-Care projects of World Vision:
- Long term sustainable community development programmes
- All projects based on children so that they may have a better future
- Staff living with them, learning from them, working along with them to find solutions for poverty.
- Responding on medical, emotional, nutritional, educational, economical and social needs of adults and children effected by HIV and AIDS.

The GRACE project gets money in blocks of 5 years. There’s money to run the project in the contemporary situation till the end of 2012. They don’t know what happens after that, the organization on higher level is trying to get funding for 5 more years, but the future of the project is unclear today.
Who we interviewed:
Mr. Veeraraghavan Jayaraj, director of the GRACE project, working for the GRACE project since the start, works for World Vision for 20 years now.

Context
We interviewed Mr. Jayarai in the drop in centre of World Visions GRACE project, just after a support group took place. Mr. Jayarai leaded the support group himself, but he also invited some people to speak about different subjects. One women told her testimony. She really felt forsaken and angry when she got cancer. She thought her life was over, but then she felt the power of Jesus. It gave her a reason to live, and it gave her power to face life the way it was and it made her going on. Now she’s cured and tells everybody of what Jesus did for her. She encouraged the women to seek Jesus, and not to give up. She said that God made every women for a special reason and unique, women should find out what their talents are and share their talents and personality. She told the women not to hide away because of their health status, but to be bold and show their power and to stand for their rights.

Another women who spoke about protecting your health and about the power of sharing their stories with each other. She also gave some education about schemes the government is offering to sick and widowed women. She is HIV+ herself and told her that there’s still a lot possible if you are HIV infected. She told the women to stand up for their rights and to unite, because together you stand strong. She said that women should hold on to their rights and shouldn’t think low of themselves because of their HIV status. She said that there’s still a lot to live for and that they shouldn’t allow people to steal their joy in life.

The women in this support group are from all over the city. The building where the meeting took place is a drop in centre. It’s always opened, so that women can always drop in with their questions and concerns. There are always people to talk with them, their work people who’re infected themselves that understand the problems of the women very well. Peer counseling is taking place. Once a month support groups take place.

World Vision is working with and for HIV-infected people. They have prevention programs in different neighborhoods. They reach the people by mobilizing the community leaders. They invest in the relationships with these leaders first and educate them about HIV/AIDS. They make the leaders share their knowledge about HIV/AIDS with the community. They create awareness and sensitize the community with clear information about the risks and prevention of HIV/AIDS and how important it is to care for people who’re infected. World Vision has vision for community based care because of the sustainability. In the end the people in the communities should take care of each other, because they can’t be sure that World Vision can keep giving care and support all the time. In this way they try to make HIV/AIDS infected people less dependent from their help.

They also have an advocacy programme. They have contact with different organizations in different levels of society and advocate the rights of HIV/AIDS infected people. World Vision is known by many NGO’s and governmental organizations because of representing them. They fight for the rights of people who can’t stand up for themselves and create the conditions (by helping them with filling in forms, and education) to have fair access to insurances, banks, hospitals etc. They help people in finding the right access to their rights. The other programme which is part of the GRACE project is the ‘care and training’ programme. World Vision has a drop in centre, is doing home visits, encourage peer education, gives counseling and treatment support, gives lessons in healthy living and educates the people involved in the support groups about different relevant subjects by inviting experts.
Finance
World Vision helps HIV/AIDS infected people financially. They provide micro credits to encourage the economical development of them. They invest about 5000-10000 Rs. People who want to start up a business. They don’t give it cash, but provide in the materials to start up the business. Families with children who’re in a difficult financial situation can get financial support of 700 Rs. Monthly for each child. They also pay the school fees for the kids. It’s part of World Vision mission to take care of the kids first because they are the future of the communities. That’s why they invest in education of the children. They also provide nutrition supplements for the kids. Before providing in anything (money of goods), a employee of the project is making a home visit to check the need. There want to share the money they have properly, so they check where the need is the most high and give it to these people.

Medical Health
World Vision educates HIV/AIDS infected people in healthy living by giving workshops about nutrition, hygiene etc. Often they invite experts to tell about different health issues. They pay attention to health education to the people who drop in at the drop in centre, but also in support groups and during home visits. They encourage the women in passing on the knowledge they’ve learned to others. They give women training in peer counseling.

Religion
World Vision has a clear mission: World Vision is an international partnership of Christians whose mission is to follow the Lord and Saviour Jesus Christ in working with the poor and oppressed. To promote human transformation, seek justice, and bear witness to the good news of the kingdom of God. Core values: We are Christians, we are committed to the poor, we value people, we are stewards, we are partners, we are responsive.
Mission of the GRACE project in Chennai: Children, women and families affected by HIV/AIDS and those at risk for HIV infection leading a life free of discrimination and sharing equal opportunities with fellow citizens. Everybody, from every religion is welcome at World Vision. The main focus is to serve the people, not to evangelize even though they are very clear about being a Christian organization with Christian values. They say that their actions should say enough. They pray for people if they want to, and start their meetings with prayer.

Empowerment
World Vision is empowering the women by providing them different services. One of the most important things in empowering of women for them is to join the women in facing their negative thoughts, to give them the feeling not to be alone in it and to start at this point to look forward. Before the women can move forward they need basic education about accessing services, health issues and help in their financial situation to secure their family of at least 2 meals a day. If these basics are present, the women can get empowered in being self confident, standing up for their rights and passing on their unique talents and knowledge (in peer counseling). Summarized World Vision is empowering women through prevention programmes, through care and training and through advocacy. They don’t use a specific methodology, but they work through community building, by reaching out to leaders.

The biggest barrier in empowering women is the financial situation of the infected women, says Mr. Jayarai. Because of their HIV infection their immune system is low. They get sick too much to have a regular job. World Vision isn’t able to sponsor every women, but they make sure that every child is going to school to be sure that the future of these kids is safe, because they already suffer immensely because of growing up in a family affected with HIV/AIDS.
YWAM and World Vision
Some people who’re involved in support groups of YWAM go to World Vision for financial support. World Vision and YWAM are in contact to know which help and how much money visiting people get, so that they don’t get it twice. YWAM and World Vision are partners, they share the same belief and have the same core values. They help each other in referring people to each other for support groups, financial support etc.
5.2 Interview Positive Women Network (PWN+)

About PWN+

PWN+ was founded in 1997 by four women who came to know that they’re HIV infected. All of the women had different stories, but they all faced stigma, discrimination and harassment because of their HIV status. They met each other at a National AIDS Control Organization (NACO) meeting in Chennai, and realized that they needed each other in care and support in living positively also with HIV. That’s why they joined hands and set up PWN+ by raising their voice. Their vision was and still is: Empowering women living with HIV and infected/affected children, to live a life of dignity and equality, free from stigma and discrimination. Their mission: To change the existing situation of all women living with HIV/AIDS, and infected/affected children in India. Building capacities, increase access to rights, develop partnerships and advocate for programme and policy change.

With having a positive attitude and passion to fight for their rights and dignity, PWN+ became an all-Indian Network of HIV infected Women, all focused on improving the quality of life of women and children living with HIV/AIDS by supporting each other, fighting for their rights and sensitizing society about their needs. Right now the Positive Women Network is functioning in 13 states of India, with networks in 65 districts. With support from organizations like UNICEF, UNAIDS, NACO, the European Commission and others, the network has lots of challenging chances to develop and already has influence on different levels in society61.

The five core strategies of PWN+ are:

- Strengthen community outreach systems to identify and enhance the greater involvement and participation of women living with HIV/AIDS (WLHA)
- Scale up advocacy initiatives based on the experiences of WLHA, and the innovative strategies and interventions undertaken by the Positive Women Network and each of the state chapters
- Network with like-minded, supportive and influential institutions, stakeholders and groups that can address the concerns of WLHA
- Improve delivery mechanisms and modalities of all types of services for women vulnerable to, and living with HIV/AIDS
- Expand capacity building programmes and to work through WLHA wherever possible

Work outs from this strategies are support groups, self-help groups, projects to increase the mother-child transmission of HIV, counseling, projects to educate women about their rights etc.

We had the interviews in the headquarter of PWN+ in Chennai. This headquarter also contains a Drop-In centre where women can come to ask for advice or just to tell their stories.

Who we interviewed:

Ms. Kousalya, president and founder of PWN+
Ms. Anbu, coordinator Support Groups and Drop-In centre
Mr. Dr. L. Ramakrishnan, director project property ownership and legal literacy
Ms. Bhattacharjya, coordinator project reducing mother-child transmission HIV

Context

Ms. Kousalya: Most of the women involved in the projects are vulnerable in many ways, they can’t stand up for their rights because they never learned that as a women, some get abused, some are lonely because their family rejected them and because their husband died, most of the time their infected by an unfaithful husband, they’re out of money and they suffer from stigma and discrimination. For example: hospitals don’t want to take care of HIV-infected women in their hospitals, they look for excuses to send them to other hospitals.

61 www.pwnplus.org
The social economic status of women, especially in rural areas, is bad. Some families feed their girls less than their boys, they don’t send them to school or to a bad school. That’s why girls already get used to struggling and by that reason they can handle HIV better than men. Just because they already got used to struggling and humiliating situations.

Tamil Nadu is a high prevalence district. That means that 60 to 70% of the women infected with HIV is widowed. HIV came into Tamil Nadu quiet early compared to other states in India, that’s why more people are infected and why there already died a lot of people because of it, and that’s why there are already a lot of widows.

Ms. Anbu: A lot of women who come to the drop-in centre are really in need of a place where they can be open about their health-status and the difficulties they face. In their communities they can’t be open about their situation. Some haven’t disclosed their HIV-status to the people around them, they carry a big secret, they use the drop in centre as a save place to tell their stories and get some relief. Disclosing their HIV-status probably makes their life even more complicated, they probably lose their jobs, family and respect in the community. They spend a lot of time on family issues in support group meetings.

Mr. Ramakrishnan: We offer HIV-infected women help in standing up for their rights. It happens often that when their husband dies (because of HIV), the in-law family is throwing them out of the house without giving them anything from the family property. They say that the HIV-infected women has bring a shame and a curse on their family, and say that it’s her fault that her husband, and their son died. Other women they try to educate on standing up for their rights are women involved in domestic violence cases. Some women are stuck in a marriage where they get abused in many ways. They can’t leave their husband because of the dowry that’s been paid and because it’s hard to live as a women alone in India. So they stay at their husband (and his family), PWN+ tries to mediate between widows and the families in law, after the death of their husband about property rights. They also help women involved in violent relations with forcing their husband and his family to stop the violence by educating them about the law and the consequences of not keeping the law.

Ms. Bhattacharjya: Some women come to know about their HIV-status while doing a blood test because of their pregnancy (which is must in Tamil Nadu). They’re going through a heavy time by then, accepting that they have HIV and why and to set a child in the world with an unsure future. There’s a lot to do to increase mother child transmitting of HIV, so that brings relief.

Finance
Ms. Kousalya: In the Indian culture are women are women depending on the men in many ways. Also financially. It’s usual that men earn the money with a job and that women are housewives, taking care of the household and the children. When this gets disturbed by HIV, because the man of the wife gets to ill to do the work, or dies, big financial problems come up. Women were never used to working, and often they’re not educated enough to get a good job. This causes a lot of trouble and makes the disaster of HIV even bigger, especially for the children growing up in a family affected by HIV. PWN+ tries to educate women in setting up own businesses, trying to connect women in self-help groups and get loans for them.

Ms. Anbu: Lots of women lose their husband because of HIV (men are mostly longer infected than the women, so dies earlier). Financial problems come up then, and many women are in panic because of that. Some get help from their family. Sometimes the children can’t go to school anymore.
because there’s no money to pay the school fees. A lot of women in this situation come up to the drop-in centre to ask for advice and to find relief of peers.

Mr. Ramakrishnan: Troubles with finances is one of the most important reason why PWN+ set up a program to advocate the rights of women on property. When the husband dies and the women get kicked out of the family in law, they don’t have anything, and they don’t know how to work. There are laws to protect these women and the law says that the wife of a husband who died, gets also parts of his property. Financial security is necessary to offer the kids a better future and to live a healthy life. The program is offering women help with getting to the court to claim their money or they help in mediation with the family in law to make appointments about the money and other property.

Ms. Bhattacharjya: A lot of women don’t have the money to deliver babies in a private clinic so they have to go to a government hospital. Government hospitals have to accept women with HIV, but often they have excuses to send them away, just because they’re not willing. Women also do not have women for milk powder, which gives risks, cause mother can transmit HIV by giving breast feeding. PWN+ provides help in giving milk powder, transport to hospitals and advocating their rights at hospitals.

Medical Health
Ms. Kousalya: Not all the women involved in the programmes are taking medicines. Only when their immune system gets under a set level they get medicines. When you start with the medicines, you have to take them your whole life. The medicines the government provides are not always good, you can get better medicines at private clinics but they’re most of the time to expensive for the women. They get a medicine check up every month, if the medicines you get are not working properly, they switch to another one, if that one’s also not working well, than there’s a problem, cause they can’t give any other medicines.
PWN+ gives education on nutrition, hygiene and health issues, all to expand the ability of the women to create a safer and healthier environment around them so that they get less sick.
PWN+ believes that spirituality can be used as a healing method for trauma’s and depression that understanding your body (by education) will lead to inner healing of health and mind.

Ms. Anbu: A lot of women are unknowing about hygiene and nutrition and the influence it has on their health. Education about that is necessary and they provide that in support groups and in the drop in centre.

Mr. Ramakrishnan: Because of their HIV-status, many women got the feeling that they’ll die soon. That makes them uncaring about their future and that’s why they don’t stand up for their rights. Now everybody has access to medication this changes, there’s a future for the women and their children which are infected with HIV.

Ms. Bhattacharjya: Women who discover to have HIV while they’re pregnant are often scared about what will happen with their health in the future and how that’s going to affect their child and family. Education is a key intervention in helping these women and (unborn) children. They also give a lot of education about safe sex while infected and how to get pregnant while infected. They counsel people who go for a child in doing each step as safe as possible.

Religion
Ms. Kousalya: PWN+ sees spirituality as a key to rehabilitation. PWN+ is open for every religion and encourages women with the same religion to celebrate their faith with each other, with celebrating the feasts and sharing and helping each other in trying to find an answer to the big questions in life. Inner healing will provide a better health of body and mind. Religion is a chance to build up the
communities, these women need a feeling of belonging so much because sharing is important and knowing that you belong to a community, while your own family rejected you, gives strength and hope for the future.

Ms. Anbu: There are working people from different religions at PWN+, and the network is open for women from every religion, so that there’s always somebody to connect with on a spiritual level.

Empowerment
Ms. Kousalya: the activities from PWN+ to empower women are various. From standing up for women rights to support group meetings to meet their physical and mental needs. Ms. Kousalya set up PWN+, and is personally involved (she has HIV), she’s been busy for a long time empowering women with HIV. She says that education on health and family issues is first important and then economic empowerment to grant a future, also for the children. They set up self-help groups with women with ambition and help them with getting loans. Some have real good businesses running now. Sometimes they arrange marriages between infected men/women, so that they can live a normal life.

Another important thing is that PWN+ empowers the women indirectly by lobbying at the government to tell them about the needs of the women, to get money so they can empower the position of the women. PWN+ provides in work for HIV-infected women. The biggest goal they set is that they want the women to help each other. It started with four and now many women (almost all infected) work for PWN+. They spread their experiences and knowledge. Women on all levels in the organization, from the president to the volunteers who visit women in hospitals, all of them are convinced from the fact that together they can make a change.

Ms. Anbu: One of the most important things in empowerment of women is making them aware of the opportunities they have at the government, NGO’s etc to get help. They want to canalize the facilities available and make them known for the women. In the future they want to set up a committee with people from the government, NGO’s, and middle level services so that they can optimize the help for women infected/affected with HIV.

Another important thing in empowerment are the support and self help groups where the women can share, help each other, join hands to set up things and to motivate them for standing up for their rights. They developed 7 modules for the support groups, with topics they talk about in the groups. From practical things like hygiene, and nutrition to talking with your children about your/their infection with HIV.

Mr. Ramakrishnan: If women learn to stand up their rights, they can protect their own future and the future of their children. It’s hard for women in India, cause they are thought not to stand up for themselves. With giving them counseling, motivating them to hold on to their rights although it’s hard because of the resistance from the court that works slow and their families, and to educate them about what the law can do in different situation, they try to empower the women.

Ms. Bhattacharyya: Our programme advocates for the women at hospitals to claim their rights to deliver the baby and for medication and good care. We also empower them in connecting them to the services they need and we counsel the women and their husband in making choices in getting pregnant, in dealing with pregnancy and in giving advice to raise the child while you’re infected.

Wishes
Ms. Kousalya: The biggest wish from the PWN+ is that all the women they reach with education and training, will pass on what they learned to women who now get infected, so that women with HIV
can keep their dignity and live free from stigma and discrimination. Another goal is that the government comes to know about the needs and difficult situation of the women with HIV, who aren’t involved in programs for sex workers and human trafficking, simply because they are not out of this group. PWN+ goes on with advocating the women at governmental levels, by telling their stories at public meetings, bringing out brochures etc.

Ms. Anbu: Having a committee with members from NGO’s, governmental organizations and also commercial organizations who meet regularly to let each other know about the plans and chances they have for HIV infected women so that the services Fit together. Canalizing all the services to one point so that the women can find their way to a new and better future for themselves and their children.

Mr. Ramakrishnan: The dream for this programme is to help women standing up for their rights by encouraging them to hold on to their rights, cause they often give up because of the difficult court system but also because they have the fatalistic thought that they’ll never make it. Women in India should stand up for their rights, gender equality is on her way, but it has a lot of barriers to pass. The dream is that this programme works with the women to equality of men and women.

Ms. Bhattacharjya: The goal is that every HIV infected women is informed about the risks and chances of getting a baby while infected. By counseling and training, the people will get to know that there’s a normal future for their families. The wish is that less babies get infected with HIV by safe deliveries. Another goal and wish is that HIV infected women get a proper treatment, just because they deserve that as any other women.

Your organization/YWAM
Ms. Kousalya:YWAM and PWN+ don’t work together. Some women are involved in both organization, some join a support group from YWAM, some get some advocacy from PWN+. Ms. Anbu: PWN+ developed 7 modules with topics to discuss in support group meetings. YWAM can use parts of that.

Mr. Ramakrishnan: YWAM can refer women with property issues and domestic violence issues to the programme PWN+ is running.

Ms. Bhattacharjya: YWAM can refer women who need specialized advice in pregnancy and HIV, or who are in need of counseling because of a pregnancy.

HIV/AIDS brings with it a fear of rejection, stigma, discrimination and harassment. Women living with the virus have described a sense of fatalism that sets in and a darkness that descends on their lives. The Positive Women Network encourages women to joint their programma Living Positive which means converting a life filled with fear and fatalism into one of hope and meaning. It involves knowing that something can be done to make your life better, and that there are people who can walk with you on your journey.
5.3 Interview NCP+ (Network Chennai Positive)

About NCP+

NCP+ is a district level organization affiliated to national level Indian Network for People living with HIV/AIDS (INP+) through state level Tamil Nadu Networking people with HIV/AIDS (TNNP+). The idea of forming an association of PLHIV was born in 1994 and after several informal meetings. The 12 men and women living with HIV converged in Chennai on February 20, 1997 to form the Indian Network for People Living with HIV/AIDS.

INP+ is a social movement by and for People Living with HIV/AIDS (PLHIV) in enforcing the recognition for Human Rights of PLHIV in India. INP+ has waged a long and intensive struggle against fear, ignorance, prejudice and despair born out of the epidemic and stood to represent courage, insight, acceptance and hope to hundreds and thousands of People Living with HIV/AIDS.

Our members include besides PLHIV, people from diverse orientation and marginalized sections of the society – MSM (Men having Sex with Men), IDU (Injecting Drug Users), Sex workers etc. The membership is open to all Indians living with HIV irrespective of gender, caste, religion etc.

All the activities of the network are focused on a triangular approach covering the components of Advocacy, Network Building and Service Delivery.

The triangle reflects the strong connectivity among these three components - each component can only be strengthened when the other 2 are strengthened.

**Advocacy**

This focuses on addressing the ardent issues of PLHIV like human rights, access to information, treatment, GIPA, Positive Prevention at regional, national and international forums. In the beginning, the focus was on visibility, but as the course of the epidemic changed, there has been a shift in focus for policy change.

**Network Building**

This focuses on the formation and strengthening of the network at state, district and Taluk/Block level.

It also aims to provide technical assistance to the networks in capacity building of its members at state and district level in Program and Finance Management, Service Delivery, Leadership and governance through appropriate trainings.

**Service Delivery**

This focuses on the models of care and support services such as Drop-in-Centres, Life Focus Centre, Family Counseling Centre, Positive Living Centre Treatment Counseling Centre to the PLHIV irrespective of age and gender.
Who we interviewed:
Mr. Gnana Sekar, Social Worker in the drop in centre in Villawakkam.

Context
NCP+ has 5 drop in centers in different parts of Chennai. They work on street level, which means that every positive man or women can drop into the centre. They can expect to meet people who’re accepting them the way they are. Peer counseling is one of the basics of the help NCP+ offers, so if you drop in you may expect a peer to share their story with. NCP+ believes in the power of experience. Everybody learned something he/she can pass on, Mr. Gnana Sekar Gave the example of a men who was a drug addict for 10 years. People may look down on him, but he knows things nobody else knows. NCP+ is challenging people to share their stories and to help each other through telling their experiences.

Some people who drop in are scared to have HIV and want advice about testing, others are rejected because of their HIV status and need people to talk with, some need just company, others need information about different topics like medicines or treatment availabilities. NCP+ can give them advise in these things. They refer people to the right organization to get the right help, NCP+ only offer basic services like counseling, education and a meeting point.

NCP+ is doing outreaches to testing centers and government hospitals to meet the HIV infected people there in their needs and to bring them in contact with the network. So they meet a lot of different people, but most of the infected people have lower incomes and are from a lower caste. The rich people mostly don’t disclose their status, they get their medicines via private clinics and you won’t see them in the government services. People connected to the network are in different levels of experiencing HIV, some people involved in the NCP+ are already infected for many years and set up their own businesses, others just discovered their HIV status and are dealing with totally different issues like disclosing their status and losing their job because of their status. These people help each other in the network.

Finance
Most HIV infected people have to deal with difficulties in earning money because they lose their job because their boss is not accepting their status or because they often get sick. Also the people connected to NCP+ have these problem. NCP+ refers them to governmental services to get money, but still it’s difficult. Some have successfully started own businesses. They had a self help group together, have been saving money together for a long time and got a loan from the bank because they were stable in saving the money. People connected to the network give each other advices in dealing with money. NCP+ in Chennai has 9 self help groups. 6 of them started the last 6 months and are getting steady right now, others already got a loan. Every member of the network has to pay 5 Rs. A month, so that they the network keeps going and to make people accountable to their membership.

Medical Health
The health of people connected to the network is varied. Some don’t get ART (anti retroviral treatment) yet because their immune system is strong enough. Some already get ART for many years. Some are really sick, other function really well. The network wants people to support each other. To give what you have. If you’re sick you can at least help others by listening, if you’re quiet healthy you can do some practical things for the sick people. The network is supposed to function like a community. They educate people about safe sex, condom use etc. They counsel people in living a healthy life by nutrition and sex education.
Religion
The network is not bound to any religion. The mission is to let HIV infected people live in dignity, without stigma and discrimination. They want to improve the quality of life of HIV infected people. NCP+ is welcoming to people from any religion. The people themselves can support each other in their spiritual development, if they want. NCP+ is not offering specific help in religious/spiritual activities.

Empowerment
N. says that unemployment is the biggest problem in empowerment of women. It’s not easy to get a job, and if you have one, it’s not easy to keep it because the immune system of people with HIV is low, so they get sick often. Setting up a own business will help them lots, but they lack the credit to start something. NCP+ refers people who want to set up a own business to World Vision who’s offering a micro-financing programme. Another thing they do is to educate the people from the network about service accesses from the government and other NGO’s, to get help in paying school fees, providing food etc.

They empower women by counseling. Some people can get a paid job at NCP+. The network chooses its own leaders and is a democratic organization. So the members chose the board members themselves. In this way they learn to participate in official systems and they get stimulated in decision making and responsibility.

NCP+ and YWAM
NCP+ and YWAM are working together. YWAM is having a support group meeting in the drop in centre of NCP+. In this way visitors of NCP+ can get involved in support groups of YWAM. NCP+ is part of INP+ (the all Indian network of positive people living with HIV). INP+ developed many modules and trainings to empower women. NCP+ can refer Christians who’re infected to YWAM so that they can get support in religious ways, but also other people who’ve big questions in life about the reason for living and suffering. They appreciate YWAM in offering spiritual care, but also because of organizing support groups and other care. NCP+ asked YWAM a few years ago to have their support group in their drop-in centre, when they hadn’t any money to do.

NCP can help YWAM in bringing things on a higher level; they are part of a big organization with all sorts of contacts, also contact with the government, on local, district, state and national level. They can help to make YWAM’s voice heard. INP+ invested in lots of researches, some researches took place in Chennai and are relevant for PACT. They also developed some training on different topics of empowerment, these are probably useful for the support group meetings. ...
6. Interviews support group members

Story’s support group members:

Zion church, Suresh group 9-03-2011

Jayalakschmi found out that she was HIV infected when she was pregnant of her second child. She got infected through her husband, who had other relationships while he was married to her. Her first child, a girl, is not infected, the second baby is infected. She comes from a big family, she was the oldest of 7 children. She always was the sweet girl, that is why she was scared to tell anyone about her infection. When she and the baby became really sick, they went to the hospital in Tambaram. The doctor told her parents there that she was HIV infected. The family took her husband outside and told him to leave her. They took care of her, and told her that she would be cured. When her mother died, she returned to her husband. She still thought that HIV was curable. When she and her husband found out it was not they were really shocked. They started ART, and that worked. Now she has got a job at a NGO called WEcare. Her husband has TB and is too sick to work, he is not doing anything at all. She has to take care of the family. She’s worried about her son who is also HIV positive, he is often sick. She’s getting financial support for her kids from YWAM so that the kids can go to school and eat healthy.

She joined the support group because she and one of the leaders of the support group became friends. She never talked to people around her before joining the support group. In the support group she learned to speak and to connect with others. Her husband doesn’t like that, he is very jealous and thinks that she talks to other men, he controls her a lot. That is difficult for her. But she learned to care for herself, to share her feelings and while the others cared for her in first instance, she now learned to care for others around her. She is supporting people around her now in working for that NGO and in talking to others. It is comforting her knowing that she is not the only one with HIV, and to share her life with the other women from the support group.

She is not having any future plans anymore. She hopes that her children develop well but worries about her son who is also infected and about her husband who is not trusting her. She is not having any contact with her relatives at the moment; she hopes that this will improve in the future.
Sumathi told us the tragic story about her life. Her husband got an accident in the company he worked. He hurt his hand really badly and lost a lot of blood. His company brought him to a government hospital for treatment. He needed a blood transfusion and by this transfusion he got infected. He infected her afterwards, not knowing that he was infected. Before the accident happened her husband earned 18500 Rs a month, which is really a lot here. They had a good life, they build a big house and everything was going well. Now her husband isn’t having any work and is doing nothing all day. He drinks a lot now, he is still very angry with the company that they took him to such a bad hospital while it is a rich company. He got back to the company to get another job, but then he became so angry and said such bad things that they do not care for him right now.

Her family and neighbors are treating her well. They all feel sorry for her. Her kids, two girls are not infected, she worries about their future. The support group is helping her to escape the situation at home sometimes. It helps her to have fun with the other women and to share stories. She is not using ART yet, only vitamins and minerals. She is scared of the future. Once they all had it sorted out, they had lots of money, a big house, a happy family, and now they are empty handed. She’s feeling down sometimes, but the support group helps her to go on.
Chandrakala is telling her story about losing her husband and her health. About seven years ago her husband got sick and died when her son was only 55 days old. Her husband was a truck driver and she didn’t know about his HIV+ status before he died. After his death she became sick and went to the hospital where they found out that she and her son were both HIV+. She cried and cried for days and felt very depressed. Her body condition was very low and her weight was only 28 kilo’s. Suresh, one of the PACT crew members got in contact with her at that difficult time and encouraged her to fight for her life. He told her that she had a purpose in life, because God gave it to her. Seven years after this all happened we talk to her, now she looks healthy and strong. She shares with us that she is positive about life. She is working for an export company, sells flowers one day a week and does tailoring work in her free time. Her son is HIV+ but healthy and one of the best students of his class. Her family in law denied that she got HIV from her husband, who already died. They were angry that she wanted to accuse him and decided that they didn’t want contact any more. Now she is living with her mother, sister and son Canelesh, in one house.

Canelesh’s health and education is one of Chandrakala biggest worry for the future. If she gets sick there will be no money for his education. She didn’t make any plans for the future and lives day by day. At the moment she has enough money to support her family, because she got widow support what is 300 RP a month and she gets money for Canelesh’s nutrition and school fees. The nutrition and school fees are supported by YWAM. To be a member of the support group makes her feel like a valued person and she can share her heart with others who understand her. She really enjoys the friendship with other members, it gives her energy.
Thenmolhi tells about her husband who didn’t tell her about his HIV+ status. Her husband got a fever and went to a private hospital without telling her or his family about it. In this hospital he found out that he was HIV infected. He didn’t want to tell Thenmolhi what happened, because he was scared that she should leave him and be rejected. But after some strange visitors from the TB hospital came at her home, there were raising more and more questions.

Rhenmolhi convinced her husband to tell her what was going on and he did. Her family in law didn’t respond very helpful by ignoring and avoiding the whole situation. But her sister and brother in law sacrificed everything to take care of their two daughters, while Thenmolhi took care of her husband in the hospital. At that time Thenmolhi went through a hard time when found out about her own HIV+ status. Thanmolhi still didn’t want to leave her husband, because she loved him so much and he helped her also as she went through hard times before. But she feared the stigma and discrimination they would face in the future. She made plans with her husband to commit suicide with both of their daughters, who aren’t HIV+. The oldest daughter didn’t agree with the plans and told their parents; “We are going to live, my sister and I still have a life. We can’t do this. Don’t be so scared. We are going to move to another place and start again!” This all happened in 2008.

Thenmolhi is proud of her daughters who help them and take care of them. Her daughters are good students in ninth and eleventh grade and her husband is still a driver, while she runs the household. One year ago Thenmolhi became member of this support group. A friend who was involved in the support group invited her to join. She tells about the group; “I feel that this group helps me to reduce my burden”. If there is a need she wants to continue the support group by leading. She wants to encourage people and help them like her daughters do to her.

Thenmolhi has worries about her future, as she thinks of her daughters. What will happen when she and her husband pass away, who is taking care of them than? She also is scared to lose her husband, so if he is late from work she is worried. Even if her husband doesn’t feel well it is affecting her health.
Sujatha, now 28, told us the tragic story of her life. When 18, she got married with her uncle, which is something common here because of religion. After 1,5 year marriage she got pregnant. The baby, a girl, got very sick after she was born. She went to the hospital with the baby, where they found out that her baby had a brain tumor and was HIV positive. In this way she found out that she was infected herself. She cried and was so shocked that she had to be in the hospital for three days. During these days the doctor told her husband that his wife and child were both HIV positive and that he needed to test himself too. Her husband went to the mom of his wife Sujatha (his sister), and told her to take care of Sujatha and the kid. Then he left and committed suicide. The same day the baby died also because of the brain tumor. Sujatha lost everything in one day and didn’t know how to get on with her life. The family got in a big fight because of all that happened. They were arguing about whose fault the HIV infection was and whose responsibility it was to take care of Sujatha. Sujatha saw no way out of all the difficulties and decided to kill herself. She wanted to commit suicide by hanging herself, but her mother heard the noise of her bangles and saved her from committing suicide. Then a pastor came to her in the hospital and told her about Jesus. She got some Christian counseling and found out that God promised her life. While crying, Sujatha told us that Jesus taught her to live again.

Now, almost 10 years later, she still faces a lot of trouble because of her low immune system, but Jesus helps her out every time. She brought lots of people who are also HIV infected and desperate to the Lord. She talks with them, educates them about HIV and prays with them. She told an HIV infected women she met about the possibility of medicines that avoid the HIV transmission from mother to child during pregnancy. Now this woman has 3 healthy children. Right now she is still staying with her family, but maybe in the future she wants get married again. Suresh wants to find a good husband for her, something she really deserves after so many hardships in her life.
7. Support group reports

Reporting Support Group  
Meeting 1  
6-2-2011

Support Group leader: Izaac  
Location: Hospital near beach station  
Number of people: about 30 women, 5 men, 5 children  
Translator: Raja

Context
A lot of women who visited the Support Group were married. They wore golden necklaces which mean that they are married. Some of them were widows, some men joined their women to the support group, some of the visitors were family members of HIV-infected women. Izaac gave a lecture about good parenting. The uniqueness of every child, the 5 love languages, not comparing your child with others, not hitting your child but telling their boundaries, effective punishment rules etc. Women were really interesting. Some asked questions, some told they stopped hitting their children after they paid attention to that in a Support Group meeting earlier.

Finances
Before the Support Group meeting started the women already gathered together to collect money. One of the leaders from the group administrates the money they collect, everybody has to sign for the money they insert, afterwards the leaders bring the money to the bank to deposit it on the joint bank account they have. They save money with the Support Group members, so that they can give each other loans to start businesses. These loans are about 3000 to 5.000 rupees. The groups mostly starts with collecting and saving money after 10 months since the group started. Before they are willing or able to do so, they have to trust each other. Accountability is one of the keys to a successful saving/loans programme. Most of the members are accountable and drop every meeting about 100 rupees. If they do this for a longer time, the bank will see that they are trustable and stable in saving the money, so they will consider giving them loans. These loans give them the ability to make bigger investments for their businesses.

Work
Some women brought the sari’s they embroiled. That’s a business they started with a loan from the Support Group savings. Others sell snacks. Izaac and the leaders told about the opportunity to take part of a tailoring learning programme YWAM is offering to the groups. They found someone who wants to give workshops for tailoring. If you want to join this course you have to be very dedicated and We didn’t really talked about work furthermore.

Health situation
Izaac started the meeting with the question how everybody felt. A lot of them were doing well. Everyone has access to medication (antiretroviral drugs). One women told that she wasn’t feeling well because she switched medicines and faced a lot of problems because her husband was to sick to work so that they didn’t have enough money. Another lady had the same problem, her husband used to be a carrier of goods but now he had terrible back pains. They hadn’t enough money to feed their children. Most of the women looked very well, they looked well fed and laughed a lot.
Religion
During the lecture about parenting Isaac referred to some bible passages about how God treats his children, and some proverbs about parenting and punishing children. Everybody seemed to be very interested. At first Isaac started the meeting with prayer, also the ladies with a bindi (the Hindu stain between the eyes) took a veil over their head and prayed with him. Also the Muslim women (recognised by their handcrafts) closed their eyes, so everybody was praying altogether. Isaac is says that they don’t push women to pray or to convert to Christianity, but many feel the power of Christ during the meetings, and some convert to Christianity.

Wishes
This group is already meeting for a long time. They discussed the possibilities of getting a loan from the bank. What they need for that and who should lead in this process.

YWAM
YWAM has arranged a course by and expert who’s willing to offer his corporation in educating the women in tailoring. Before telling this in the groups they talked with the leaders of the group about what they expect from the women, dedication and initiative, so that the leaders can screen the people who want to attend. YWAM offers the women the money they need to travel to the Support Group. After the meeting some women came to Isaac to ask for some more money. Only in extreme situations YWAM can offer some money to these people, they have funding problems themselves so it isn’t easy to just give money. In the future they hope that the group is helping each other out in times of trouble. Community building is really important.
Context
We were invited at one of the ladies house to join the meeting. Her husband died of HIV. We got into a living/bedroom of ten square meter. We had to sit on chairs and children wanted to shake hands with us. We had a little chat before the meeting started. After a while there were about 20 people in the room and ten sitting in the hallway. There were four man who sat on the bed. Three of them brought their wife’s with them. Even one of the couples had adopted a child three hours after her birth and seemed to be very happy with her. The man made a lot of jokes while Isaac was talking to the ladies. The two local leaders of the group collected the money from everyone who got involved in the loan project. It was the hostess daughter’s birthday and Isaac bought a cake for her to celebrate. Instead of blowing the candles out, it is the tradition to fire the candles.

Finances
The two lady leaders of the group collected the money for saving. There was a lady who write everything in a book and the other counted the money again. If I see the people there is a difference between there background in wealth. Some of the ladies have lots of gold and others don’t have any. One of the ladies cried when we were praying. She later told that her daughter will marry soon, but she doesn’t have money to support her.

Work
Some of the ladies worked as a tailor and celled there goods for money. There is a man who works as an auto driver and one of them works at the police office. Isaac tells the ladies about a free tailoring course. He is asking the ladies to think about getting involved and participate in this group. But he warned them that he really want committed ladies to join the group. The course will only be given when the ladies show up three evenings a week and that for about three months. Isaac emphasized that the ladies shouldn’t make a dissension right away. When Isaac was talking the man made jokes, but we couldn’t understand about what.

Health situation
We don’t know much about the health of these people. Isaac tells about a liquid what will help to built their health system and support the working of medicine. It cost a lot of money, but his wife and a other lady is also taking it and they feel the benefits. One of the man he tells that he couldn’t visit the support group last time, because he got sick of the side effects the contains progression medicine he takes. He asked at the hospital to change the prescription, but they haven’t done it yet. He prayed for him.

Religion
Some of the ladies asked to be prayed for. You can see the difference between Christian and Hindu by the paint between their eyes. Isaac is preaching the gospel to the ladies and we pray together. Some of the ladies cover their heads with a scarf.

YWAM
Isaac gave a training about how to breed children in a right way. He is telling the people to give children compliments. They shouldn’t compare their children with others and tell the children. This training is the same as in the first group we got to with Isaac.
REPORTING SUPPORT GROUP

Meeting 1
13-2-2011

Support Group leader: Suresh
Location: Pre-Natal Hospital, 1h by bus
Number of people: 20 women, 3 men, 3 children
Translator: Suresh

Context
We met this group in a pre-natal hospital. The group gathered in the lecture room of this hospital. Some people weren’t there, they were at a wedding. A lot of people wore the golden necklaces, so they were married. There were also 2 men, not connected with visiting women.

Finances
All the ladies were very clear about the fact that it wasn’t easy to live from the money they earned with their jobs. Because of their HIV-infection their immune system is low so that they are often sick. Then they can’t work, and don’t earn any money. Most of them are unable to take good care of their kids financially. YWAM gives these families 300 rupees per month for food for the kids and provides in the costs for schooling for the kids.

Work
All the ladies told what they did for living. Some were working at the hospital, some sold flowers and other things, some were housewives, embroidering saris or tailoring.

Health situation
Some of the ladies looked very sick, they were really skinny and you saw that they were out of energy. Some looked worried.

Religion
Suresh preached a bit, all were reacting very well on that. They lifted their hands in prayer, also the ones having a bindi.

Wishes
They wish to have enough money to start their own businesses so that they can run it in their own way. Then they can afford to be sick some times. Right now their financial situation is unstable and hard to bear because of all the uncertainties it brings.

One women asked us to take her child with us to Holland. That shocked us, but it declares the worries of some parents about their children.
### Reporting Support Group

<table>
<thead>
<tr>
<th>Support Group leader:</th>
<th>Venister</th>
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<tbody>
<tr>
<td>Location:</td>
<td>Church near St. Thomas Mount</td>
</tr>
<tr>
<td>Number of people:</td>
<td>20 women, 7 kids, 1 men</td>
</tr>
<tr>
<td>Translator:</td>
<td>Venister</td>
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</tbody>
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### Context

Venister said that the group already meets for 6/7 years. You saw that the people were close to each other. Venister encouraged that with saying that they should take care of each other. That if one another is sick they have to call them, and visit them. When sick, you shouldn’t hide in your house, then everybody will think there’s nobody who wants to take care of you, or that you’re disease is so badly that it’s dangerous. As a support group you should function as a family who’s taking care of each other. He empowered the women not to be down because of their stigma, but to be in action in the society, just because they are just as worthy and clever as anyone else. When HIV just came India, the government told that when you’re infected you’d die soon, right now the situation is different. You do have a future, and you do have abilities to just live life like anyone else, so act like that en take your place in society. Venister tells that they shouldn’t confront their children with their HIV-status if they’re infected, because then the kid is probably going to believe that he/she is different and not good enough. He/she is going to bear the stigma by then. You should avoid that, probably in 5 or 10 years there will be a medicine to cure HIV, so by then, they should know how to live as an ordinary boy/girl in society.

### Finances

Also these women have financial problems. Although many have jobs, what they earn is not enough to live properly. They get provisions from other NGO’s like World Vision. YWAM is not taking care in a way of giving provisions. They focus on teaching, they give only money for taking care of the kids, and for school fees. So, some women are involved in different NGO’s. He’s encouraging them not to be dependent on NGO’s. He said that after every election, the policy on NGO’s can change, so they better be able to take care of themselves by running businesses than to be dependent on the money of NGO’s. Women were not saving money altogether, only some do that together, but not during the support groups.

### Work

Many women work at NGO’s. Venister encourages them to set up own businesses; so that they’re not dependent of NGO’s, just in case the government policies for NGO’s changes (see finances). Women make flower things, candles and things like that at NGO’s. Also many are housewife, Venister says that women who say that are scared to say that they are unemployed.

### Health situation

Venister says that a lot of the women of this group are kind of healthy and that they’re able to work. One boy, who’s also infected, had to vomit while the meeting. He looked very sick, his mother looked very worried.

### Religion

Most of the women of this group came to believe in Jesus. Some of them are Hindu. One of the women said that one of the most important things in being part of the support group for her is that Christians, Muslims and Hindus can share, pray and take care together.
Wishes
They want a good future for their kids, they’re longing for loans to set up own businesses, but for now that’s not going to happen because the bank’s not working with them.

YWAM
On the question what the most important thing is for them in being a support group, they answered that it was important for them to have a place where they can be open about their HIV-status and worries and pains and share this with others. Another important thing for them is that they don’t hide in their houses, scared of all that people may think of them, but that they can go to the support group, showing them that they have a normal life with friends.
Many of them have friends now in different areas in the city, they met at the support group. This is important for them, a network, where they can share joy and pain with.
Context
We started the support group with some games like telling a story which all people have to tell to their neighbour. In the end you heard back a total different incomplete story. The meaning: if you want to know something about anybody, ask it yourself, don’t trust all the talking of the people around you, their stories may be incomplete and not totally true.
The reaction of the women on the games was nice. It broke the tension from the beginning and the women connected with each other, they laughed and joked with each other.
One man and a women were in big trouble. She discovered that she had cancer and they can’t pay the medicines for the treatment. They are both infected with HIV, and already have enough worries. They came to realise that they need Jesus in their life. They confessed their sins and came to the Lord. Izaac prayed with them after the meeting.

Finances
Some people weren’t faithful in the saving programme. They weren’t able, or they weren’t motivated enough to save money anymore. Saving for making a chance for a loan, takes many months. Before the bank will consider to give loans, the amount of saving must be stable for months. There were 3 groups saving money, but a lot of people were not joining the group regularly anymore, NCP+ and YWAM discussed this with the leaders, they decided to split up the groups. So now the people who were stable in their savings come in the same group, the others get their money back and leave the group. So a new group, out of the 3 groups comes together now. All of these people are really motivated and faithful in their contribution to the saving programme, so probably it will work out better than before. It was disappointing that it didn’t work out well and that not all of the three groups were stable. Having patience with saving money and getting a loan is hard when you need the money right now.

Religion
Everybody joined in the prayer. No matter what religion they have, they put the veil over their head and pray altogether. One women and man came to Jesus this meeting. This happened outside of the meeting. NCP+ isn’t a Christian organization but is open minded to Christians like YWAM. They gave Izaak the opportunity to pray with the couple in one of their rooms.

Wishes
Some people really want to continue with the savings.
The good parenting course worked out well. All of the women were listening very carefully. They really want a good future for their kids, but they realize that it’s going to be hard with parents who’re HIV infected and some of the kids are infected themselves.
Context
We met again in the church. All the women sitting on the ground, talking, joking and laughing really loud. It’s great to see them enjoying the time together. They always have lots to talk about, Suresh gave them the time to share stories with each other. He gave us the opportunity to hear some stories of the women. The women told us really tragic stories. A lot of women filled in the questionnaire.

Work
One couple started a lunch business with a loan from a self help group. The business is going very good. They earn lots of money. The men and women shared their story about how they started up the business and how they keep it running. It was inspiring the other women, they realised that there are opportunities in life for everybody.

Religion
Suresh prayed with the women, they all prayed with him.

Wishes
While filling in the questionnaire the thing that came out the most is that most of them don’t have any income at all. They’re struggling every day to have enough money for food and other necessary things. They’re depending on government services for provision and schemes.
Context
All the women of this group were married. Suresh talked about the marriage, about men/women relationships, the responsibilities etc. The women laughed but were also serious. Suresh prayed for wisdom in relationships. These women weren’t meeting for a long time.

Health situation
A husband of a women visiting the Support Group became blind by the anti retroviral drugs to slow down the HIV infection because he didn’t take the drugs properly. It was sad to see that his women had to lead him everywhere, and that he could only sit, and not see his little child playing around him.

Religion
Everybody prayed with Suresh. No Muslims here. Some women really prayed out loud.
Context

We met again in the blue house of Ruth Mary in Perambur. The women filled in our questionnaire really seriously. All the women were very talkative. They invited two women of a NGO (one of them we knew from a support group of World Vision, were she spoke also) who talked about the opportunities and potential the women have, and how to come up in life. Because it was women’s day this week, and because women rights are still denied, the women of the support group wanted something special for this meeting. They invited two women to speak, women who’re infected themselves, but have a great story to share. They told the women not to think low of themselves cause there are many things the women still can do. She talked about women like Indira Ghandi and Mother Teresa, women who stood up for their rights and for the rights of people around them. They believed in their actions, cause they knew it was right what they were doing and that’s why they were confident and had courage. Women should unite, cause together you are strong. Isaac added to this that the support group should function like a family in that way that you use each other’s capacities, so that you can build up a future together in helping each other. The leaders of the support group should see the power and talents of the women in the support group and bring these powers and talents together, so that they can grow in many ways.

Many women shared about the difficulties they face. One women had no money for the wedding of her daughter, and her brother who should pay is now in jail in Malaysia because of an expired visa, one women had skin itches because of an allergy, one women just lost her job, some kids of the women had important exams. We all prayed for these things, the Christian women laid there hands on the sick and prayed for them, and they discussed about the best way to deal with difficulties they face.

Finances

The saving programme isn’t going so well. Some women are not faithful in bringing the money and are not accountable. The leader of the group was worried about this and wants to arrange a meeting to discuss about the future of their saving programme. She was disappointed and some women were angry about it.

Work

The women who were invited to speak didn’t only talk about potential, they also gave the women some opportunities to get up in life. They offer trainings themselves, which they can offer if there are more than 10 people together who want to learn something like making purses, bags or you want to be good in make-up and beauty issues. They know people who can give trainings in these topics. They also gave them the advice to go to the libraries, just to get to know more about several subjects. That may be useful info for the community, and for the self esteem of the women. They said to the women that they shouldn’t waste their time in thinking low about themselves, and with useless talking, they challenged them to good time management. To use their time efficient, so that they build op themselves. Help each other with your knowledge!! One of the women who spoke told that first she was a house lady for 250 rupees a month, then a tailor for 2500 a month and now she’s working for a NGO for 6000 a month and almost a bachelors grade in the pocket. There are opportunities to come up in life, be smart, just start somewhere, challenge yourself in getting more knowledge about different subjects.
Health situation
We didn’t talk a lot about health this support group. We prayed for some women who weren’t feeling well.

Religion
Isaac shared the story of Mary who took the time to sit near Jesus. He shared this story to tell the women that they should tell their worries to Jesus, and not to be busy with only worrying, and work. Jesus wants to be involved in your life, so he wants to know your troubles and fears. Share it with him, and find peace in his presence.

Wishes
A lot of women struggle with finding a job. Today some opportunities were showed to them, it’s up to them to grab their chances.

YWAM
YWAM tries to facilitate jobs for the women. Probably they got some new work next month, Wilson is busy with a new project. Hopefully is the tailor workshop going to start soon, as soon as the man who gives the workshop is ready for it, it starts.
REPORTING SUPPORT GROUP

Support Group leader: Suresh
Location: Perambur, on the roof of South Indian Positive Network
Number of people: 30 women, 11 men.
Translation: Suresh

Context
We met this big group on the roof of the building of SIPN+. People were really close with each other, they’re laughing and talking. The men sat separately from the women, and both have their own saving groups. These groups are already saving money for a real long time. They already have had loans for 2,2 Lakh, which is really a lot. Suresh had a lot of interaction with the group, everybody was listening intensely. We also shared some things or our life and experiences here in India, we have tried to encourage them with going on with saving money, coming together and keeping hope and faith. Suresh talked about poverty, we don’t know exactly what he said, but he interacted with the very group very much. He asked to the people to give the definition of poverty and talked about the different views on that.

He also talked about gender issues. He asked who’s the boss in the house? Men, women or both. Most women said both. Then he asked to the women if they trust their husband, almost no women really trusted her husband, so Suresh asked them why they don’t trust their husband and why they let her husband be bossy if he’s not one to trust. There were also some student finishing their field work at SIPN+ today. They said goodbye and received a recommendation letter for their University.

Finances and Work
Also out of the questionnaires we can conclude that this group is doing quiet good financially. Almost everybody has a job. 8 women are running their own business and others just work in the private sector. The women who’s leading the saving group was really strict and though to ladies who didn’t bring the money or came too late. Suresh said that she’s a real good leader, she makes the group work, with result: big loans. These loans gave women the opportunity to start their own business, so that they’re free to decide how long and when and in which conditions they work. It gives them enough money to take good care of themselves in buying good food and taking enough rest.

Health situation
Many people of the group weren’t there because they were too sick to come. Suresh says that this mostly comes because of taking ART while not eating properly. We prayed for them. The people who were there looked very lively.

Religion
There are a lot of Christians in this group. They prayed altogether.

Wishes
They continue saving, they know that they can do it.

YWAM
The people really like Suresh as a leader. They all respect him very much and they are very opened to him about their situation. ...
8. Presentation

LET’S GO FISHING
Empowerment of HIV+ women

Research done by:
Roos Muilwijk & Heidi Roest
OVERVIEW OF THE PRESENTATION

- Personal experience
- Research question
- PACT in action
- What is empowerment
- Circle of sustainable empowerment
- Seen at other organizations
- Discussion: What women want
- Manuals
- Recommendations so far
PERSONAL EXPERIENCES
What can PACT do more to empower the HIV infected women (involved in their support groups) so that they can live more independently from NGO’s

Data collection:
• Literature research
• Support group visits
• Personal stories of HIV+ women
• Questionnaires of HIV+ women
• Interviews with support group managers
• Interviews and visits to other organizations
• Participation in team for a SWOT analyses
VIEW OF A SUPPORT GROUP VISIT
PACT IN ACTION

- Compassioned
- Courageous
- Responsible
- Committed
- Flexible
WHAT IS EMPOWERMENT?

- Literature
  
  Definition: Empowerment is a multi-dimensional (sociological, economical, political, psychological) social process that helps people to gain control over their life. It is a process that fosters power in people, for use in their own lives, their communities, and their society, by acting on issues that they define as important.

- Women

- Support group managers

Quote: *Give a men a fish and he will eat for a day, teach him fishing and you feed him for a lifetime*
CIRCLE OF SUSTAINABLE EMPOWERMENT

- Individual
- Structural
- Relational
SEEN AT OTHER ORGANIZATIONS

- Peer education
- Education done by women
- The habit of receiving
- Working structure
- Government funding
75 Questionnaires
- Only used 50 Questionnaires
- 13 men and 37 women participated
- Between 25 and 45 years old
- 34% Christian, 66% Hindu
INTERACTION AND WOMEN

More games and activities during the support group will enlarge the involvement of women in the support group.

What would you prefer as a member of a support/ self help group?

Women teaching women will help in talking about taboos and overcome shame and ignorance.
IT'S ALL ABOUT THE MONEY ...

Stop giving 50Rp travel money to every support group member because they can pay it themselves if they really want to come.
Building self confidence should be the main focus in support groups.

Women want education about:

- Nutrition advice
- How to set up a own business
- Medical education about antiretroviral drugs and side effects
- Food education, how to avoid risks, building immune system
- Pregnancy and being HIV positive
- How to deal with depression
- How to deal with sex after infection
- How to disclose my HIV status
- Who is Jesus
- How to deal with anger
- Sexual education
- How to deal with discrimination and stigma
- Financial advise
- Kids and HIV
- How to deal with trauma’s, fear
- Good Parenting
- Building self/confidence, standing up for yourself
- Information about what organizations can do for you
- Domestic violence and abuse
- Hygiene
- Women rights and the law
New ideas and inspiration
Enlarge self-esteem, knowledge and skills
Helpful for preparing
Tools to challenge the interaction
RECOMMENDATIONS SO FAR

- More responsibility to women in support groups
- Stop giving travel money to ‘everyone’
- Let the main focus be education on building self-esteem
ANY QUESTIONS?
Participants ACT

To the PACT team