Mobilizing motherhood: case study of two women's organizations advocating HIV prevention programs in Indonesia

Imelda, J.D.

Citation for published version (APA):
Imelda, J. D. (2011). Mobilizing motherhood: case study of two women's organizations advocating HIV prevention programs in Indonesia

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

UvA-DARE is a service provided by the library of the University of Amsterdam (http://dare.uva.nl)
Mobilizing Motherhood:
A Case Study of Two Women’s Organizations
Advocating HIV Prevention Programs in Indonesia

This PhD project examines the strategy of mobilizing motherhood through two Indonesian women’s organizations – the Pembinaan Kesejahteraan Keluarga (Family Welfare Movement, or PKK) and Tim ODHA Perempuan (Seropositive Women’s Team, or TOP Support) – in the attempt to make prevention of mother-to-child transmission of HIV (PMTCT) programs more socially acceptable. Motherhood and HIV/AIDS are in fact seen as contradictory concepts. However, at a time when PMTCT programs are being promoted, the image of HIV is changing from the disease of ‘women without morals’ to a disease of devoted housewives, which has resulted in the better acceptance of HIV prevention programs in society. The PKK is a formal government led community organization which is socially and politically structured from the very lowest level in the community up to the national level. The involvement of the PKK in maternal and child health programs has contributed to their image of being good housewives and responsible mothers, which has enabled the cadres to gain trust, especially from husbands, to allow them to bring pregnant women to participate in the mobile VCT service. Unfortunately, PMTCT project is not considered of prime importance for the PKK cadres. The notion of ‘sacred motherhood’ enables TOP Support members to project an image of being devoted wives and mothers who were infected by their badly behaved husbands, and who therefore unfortunately (and unknowingly) transmitted the disease to their children. They rework their identity from one of sinful and immoral women to innocent and devoted mothers, and thus generate trust between other seropositive mothers and within the community. The general lack of experience of severe symptoms and ease of access to medical care explain why TOP Support members do not actively champion PMTCT as part of the women’s reproductive health movement. In their involvement in the PMTCT pilot project, the PKK cadres and TOP Support members are able to convert the social capital derived from respected motherhood into social benefits and opportunities to access economic capital. These economic benefits lead the PKK cadres and TOP Support members to regard PMTCT more as an income generating activity rather than a part of the women’s reproductive health movement. This study suggests that there are significant challenges to the promotion of programs such as PMTCT for women through motherist organizations.
Mobilizing Motherhood: A Case Study of Two Women’s Organizations Advocating HIV Prevention Programs in Indonesia
Mobilizing Motherhood:
A Case Study of Two Women’s Organizations
Advocating HIV Prevention Programs
in Indonesia

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. D.C. van den Boom
ten overstaan van een door het college voor promoties
ingestelde commissie,
in het openbaar te verdedigen in de Agnietenkapel
op woensdag 14 september 2011, te 14.00 uur

door

Johanna Debora Imelda

geboren te Jakarta, Indonesie
PROMOTIECOMMISSIE

Promotor:
Prof. dr. A.P. Hardon

Co-promotor:
Prof. dr. B.S. Laksmono

Overige leden:
Prof. dr. J.D.M. van der Geest
Prof. dr. F. Gouda
Dr. E. Moyer
Prof. dr. R. Reis
Dr. P. Wright

Faculteit der Maatschappij- en Gedragswetenschappen
List of Contents

Acknowledgements ix

Chapter 1
Introduction: Mobilizing Motherhood for the Prevention of HIV 1

Chapter 2:
Applying the Concepts 15

Chapter 3
The Emergence of a PMTCT Program in Indonesia: From the Disease of Women without Morals to the Disease of Mothers 24

Chapter 4
The Role of PKK Cadres in PMTCT: Different Job, Same Role 38

Chapter 5
Empowerment of the Domestic Identity 65

Chapter 6
TOP Support Group Members: HIV Trajectories and Interpretations 89

Chapter 7
The Reworking of HIV Positive Identities 132

Chapter 8
Conclusion and Challenges 154

References 168
Summary 182
Samenvatting 187
List of Figures, Graphics, and Tables

Chapter 1
Figure 1 : PMTCT Pilot Project 5
Figure 2 : Cumulative AIDS cases in Jakarta, March 2009 12

Chapter 2
Figure 1 : Mobilizing Motherhood to Prevent HIV 20
Table 1 : Social Capital Mobilized by the PKK 3 and TOP Support to Promote PMTCT 23

Chapter 3
Graphic 1 : Number of AIDS Cases Reported by Year up to December 2010 25
Graphic 2 : Number of Male and Female PLWHA 26
Graphic 3 : Cumulative AIDS Cases among Positive Children in Indonesia up to December 2010 27
Figure 1 : HIV/AIDS Transmission to Low Risk Population 28
Figure 2 : UNICEF PMTCT Public Service Advertisement 34

Chapter 4
Figure 1 : The Formal Structure of the Safe Motherhood Movement (GSI) 43
Figure 2 : Mobile VCT in Jakarta 50
Table 1 : Pre-Test and Post-Test Counselling at the Mobile VCT in Jakarta 51
Figure 3 : Mobile VCT Expansion in Six Provinces 52
Figure 4 : PMTCT Training for PKK Cadres 59
Figure 5 : PMTCT Campaign by PKK Cadres 60

Chapter 5
Figure 1 : The Number of PKK Cadres Engaged in PMTCT in Jakarta 70
Table 1 : The Profile of PKK Cadres 71

Chapter 6
Figure 1 : Support Groups for PLWHA in Indonesia, June 2007 102
Table 1 : TOP SUPPORT MEMBER LIST 124

Chapter 7
Figure 1 : Vina on a Talk Show, 2006 134
Figure 2 : Winta’s Family Tree 141
Figure 3 : Sinta’s Family Tree 143
List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immuno Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Theraphy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>CDC-EH</td>
<td>Centre for Disease Control and Environmental Health</td>
</tr>
<tr>
<td>DFID</td>
<td>Department for International Development</td>
</tr>
<tr>
<td>DKT/KFW</td>
<td>Dharmendra Kumar Tyagi/Kreditanstalt für Wiederaufbau</td>
</tr>
<tr>
<td>FHI</td>
<td>Family Health International</td>
</tr>
<tr>
<td>GFATM</td>
<td>The Global Fund to Fight AIDS, Tuberculosis, and Malaria</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>IDR</td>
<td>Indonesian Rupiah</td>
</tr>
<tr>
<td>IDU</td>
<td>Injecting Drug User</td>
</tr>
<tr>
<td>IEC</td>
<td>Information, Education, and Communication</td>
</tr>
<tr>
<td>IHPCP</td>
<td>Indonesia HIV AIDS Prevention and Care Project</td>
</tr>
<tr>
<td>ILO</td>
<td>International Labour Organization</td>
</tr>
<tr>
<td>IPPA</td>
<td>Indonesian Planned Parenthood Association</td>
</tr>
<tr>
<td>IPPF</td>
<td>International Planned Parenthood Federation</td>
</tr>
<tr>
<td>MDGs</td>
<td>Millennium Development Goals</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NAC</td>
<td>National AIDS Commission</td>
</tr>
<tr>
<td>NGO</td>
<td>Non Governmental Organization</td>
</tr>
<tr>
<td>PCR</td>
<td>Polymerasi Chain Reaction</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living With HIV/AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention Mother-To-Child Transmission</td>
</tr>
<tr>
<td>POSYANDU</td>
<td>Pos Pelayanan Terpadu (Integrated Health Station)</td>
</tr>
<tr>
<td>PUSKESMAS</td>
<td>Pusat Kesehatan Masyarakat (Community Health Centre)</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
</tr>
<tr>
<td>UNESCO</td>
<td>United Nations Educational, Scientific, and Cultural Organization</td>
</tr>
<tr>
<td>UNFPA</td>
<td>United Nations Population Fund</td>
</tr>
</tbody>
</table>
UNGASS  United Nations General Assembly Special Session
UNHCR  United Nations Human Rights Council
UNICEF  United Nations Children’s Fund
UNV  United Nations Volunteers
VCT  Voluntary Counselling and Testing
VOC  Vereenigde Oost-Indische Compagnie (Dutch East India Company)
WHO  World Health Organization
YPI  Yayasan Pelita Ilmu
Acknowledgements

I would like to express my sincere thanks to all of those who supported me in any respect during the completion of my PhD project.

I am thankful to my promoter, Professor Anita Hardon, whose encouragement, supervision, and support from the preliminary to the concluding level enabled me to develop an understanding of the subject. She was always there to listen and to give advice. She showed me different ways to approach a research problem and the need to be persistent to accomplish my goal. A special thank you also goes to my co-promoter, Professor Bambang Shergi Laksmono, for his continuous support. He helped me complete the writing of this dissertation as well as the challenging research that lies behind it. He had confidence in me when I doubted myself, and brought out the good ideas in me.

To all my informants, especially the mothers involved in the PKK and TOP Support, I am sincerely and heartily grateful. Without your cooperation I could not have gotten such relevant data. I have to give a special mention to the support given by the former and current staff of Yayasan Pelita Ilmu (YPI), especially to Dr. Toha Muhaimin and Husein Habsyi, for their various forms of support during my study.

I could never have reached these heights without the help and support from my friend, Valentina Yumi, with whom I forged a very special bond, for her encouragement and helpful advice on my English translation process. I would like to acknowledge and thank my niece, Monica Cravenetya, for the help she has given with the English translation presented in some parts of this dissertation and with other aspects of my research. My sincere thanks go to the editors, Zoe Goldstein and Takeo David Hymans, who have contributed their time and expertise to review the dissertation; Erica van der Sijpt, who gave me her comments on the final version of the dissertation; and Janus Oomen who help me to translate the summary into Dutch. Without them I would not have been able to maintain the necessary quality expected of the writing. Their highly valuable insights and advice have been keys to increasing the quality of my dissertation. My apologies for often insisting on tight deadlines.

I appreciate the financial support from the Dutch Ministry of Foreign Affairs (DGIS), through the Medical Committee Netherlands-Vietnam (MCNV) and Universiteit van Amsterdam (UvA), that funded the research discussed in this dissertation; and the Department of National Education for the Republic of Indonesia, through the University of Indonesia, that financially supported me in the completion of my PhD dissertation. I owe everlasting gratefulness those at the AISSR, especially Nicole
Schulp, for providing me with a good environment and facilities to complete this dissertation.

I am obliged to many of my colleagues and friends, especially to Irwan Hidayana and Amalinda Savirani. Their support and care helped me overcome setbacks and stay focused on my study. I greatly value their friendship and I deeply appreciate their belief in me. Special appreciation is also expressed to Benny Rachmadi and Anna Zuchriana who helped me stay sane through these difficult years.

My immediate family has aided and encouraged me throughout this endeavour. I would like to express my heartfelt gratitude and warm appreciation of the generosity and understanding of my family. Most importantly, none of this would have been possible without the love and patience of my late husband, Taufiq Ishaq. He has been a constant source of love, concern, support, and strength all these years. Lastly, this dissertation is dedicated to my late parents, Salmon Lumbantobing and Tioria Margaretha Paulina Sitompul, who provided me with great support and guidance and showed me the true worth of hard work.

Johanna Debora Imelda
Introduction: Mobilizing Motherhood for the Prevention of HIV

1.A. Research Problem

Women's studies have noted that social movements can capitalize on the symbolic power of motherhood by focusing on women’s roles as devoted mothers who love peace and fight together for the survival of their children and families. Such movements can emerge when emigration or economic crises render men as heads of households and breadwinners absent, or when the role of nurturance assigned to women becomes impossible to fulfil. To distinguish them from feminists, Snitow (1990) classifies women who fight for their families as ‘motherists’. But few studies to date have examined motherist movements.

Motherist movements have demonstrated their power in peaceful action, mobilizing the image of mothers as patient, peace-loving, and devoted to family to challenge existing policies. Most famously, the Mothers of La Plaza de Mayo confronted military dictatorships responsible for the ‘disappearance’ of their children in Latin America (Hernandez, 2002; Trully, 1995). Another example comes from the US, where women successfully used their status as mothers to wage a long, peaceful struggle in Washington DC to reform welfare policies, beginning with the Poor People’s Campaign led by 5,000 African-American women on Mother’s Day in 1968 (Valk, 2000). Woman-to-woman support has been effectively used
within mental and emotional healthcare settings in Australia to support women’s health (Hunt, 1998), while appeals to motherhood have mobilized social support among women who have suffered infant loss (Layne, 2003; Layne, 2006).

In Indonesia, one of the most committed motherist movements is Suara Ibu Peduli (The Voice of Women Who Care). Established in response to the economic crisis in 1988 – which witnessed skyrocketing prices for basic commodities including a 400% rise in the cost of formula milk – its members demanded government action by carrying out peaceful demonstrations, carrying banners, and handing out flowers to passers-by and the police (Arivia, 1999; Doxey, 2007).

The social construction of motherhood not only encourages motherists to fight for the welfare of their families. It also makes all programs which aim to improve the welfare of mothers, children, and families a concern of motherist organizations, even if the program does not easily fit the image of motherhood. Such is the case with the Prevention of Mother-to-Child Transmission of HIV/AIDS (PMTCT) program which is the focus of this study.

The first PMTCT intervention in Indonesia was a pilot project conducted by the NGO Yayasan Pelita Ilmu (Pelita Ilmu Foundation or YPI). Since 1999, YPI has focused its efforts in Jakarta, extending its reach to six other provinces in 2007. Its PMTCT project – which involves two motherist organizations to spearhead implementation – has become a model for other NGOs and a basis for developing PMTCT guidelines by the Indonesian Ministry of Health.

The PMTCT program differs from other women’s health programs. Most HIV prevention programs are aimed at high risk populations such as injecting drug users (IDUs) or sex workers, meaning that they are severely stigmatised; the social stigma surrounding HIV/AIDS in Indonesia also affects the PMTCT program. This PhD project therefore examines the strategy of mobilizing motherhood through two women’s organizations – the Pembinaan Kesejahteraan Keluarga (Family Welfare Movement or PKK) and Tim ODHA Perempuan (Seropositive Women’s Team or Top Support) – to make the PMTCT program more socially acceptable.

Despite the growing number of new cases of HIV/AIDS in Indonesia, the progress of prevention programs has been slow. While there are many policies, there is a lack of actual and sustainable implementation at the national level. Low prevalence is always stated as a reason for delaying HIV prevention programs and to justify slow progress in implementation, even though the government of Indonesia has set itself the target of decreasing the rate of new HIV cases as part of its commitment to
achieving the Millennium Development Goals (MDGs) by 2015. The prevention of mother-to-child transmission of HIV/AIDS has also moved very slowly in Indonesia. As a response to the 2001 UNGASS convention, the National Strategy 2003-2007 prioritized improving PMTCT. This entailed reducing the number of seropositive children by 20% by 2005, and by 50% by 2010, and ensuring that 80% of pregnant women attending antenatal clinics received information, consultation, and services to prevent HIV transmission to their babies (Priohutomo, 2005). Indonesia’s Ministry of Health, however, only launched its national PMTCT guidelines in 2006, and there is still no PMTCT program at the national level.

The PMTCT project is NGO-initiated and donor-driven, with limited government support. Funding depends on foreign donors, in this case the Global Fund, which means that in practice the receipt of money is often erratic. In the midst of government indifference towards HIV prevention, YPI is trying to implement a comprehensive PMTCT program that will deliver a continuum of care, in accordance with the four prongs established by the WHO.

HIV/AIDS prevention is generally not considered a priority by the Indonesian government or the population. In a country with low prevalence and significant stigma surrounding HIV/AIDS, YPI faces an uphill battle in advocating its PMTCT program, particularly for low-risk, respectable groups such as mothers. Motherhood and HIV/AIDS are seen as contradictory concepts. For most Indonesians, motherhood is a woman’s sacred role, while HIV/AIDS is a disease that only affects people who behave ‘badly’. A devoted mother is considered highly unlikely to be infected with HIV. If she is, she will be stigmatized as a prostitute.

Nevertheless, the presence of the word ‘mother’ in PMTCT has allowed YPI to involve two motherist organizations – the PKK and TOP Support – to conduct advocacy for its project. The PKK is socially and politically structured from the very lowest level in the community up to the national level. All married women in Indonesia are automatically members of the PKK. Those who actively involve themselves in its activities are housewives, mostly mothers. The PKK has previously been involved in the development of reproductive health programs through the

---

1 There are eight Millennium Development Goals, which were signed by 185 countries (including Indonesia) in September 2000, to be achieved by 2015. They are: 1) eradicate extreme poverty and hunger; 2) achieve universal primary education; 3) promote gender equality and empower women; 4) reduce child mortality; 5) improve maternal health; 6) combat HIV/AIDS and other infectious diseases; 7) ensure environmental sustainability; and 8) develop a global partnership for development. Prevention of mother-to-child transmission of HIV incorporates targets number 3, 4, 5, and 6.

2 According to the WHO, PMTCT has to be administered as part of a continuum of care based on a four-pronged strategy: 1) preventing HIV infection among women of reproductive age; 2) preventing unwanted pregnancies among HIV positive mothers; 3) preventing mother-to-child HIV transmission; 4) providing psychological and social support and treatment to HIV positive mothers, their babies, and their families.
Safe Motherhood Movement (Gerakan Sayang Ibu – GSI) and the Family Planning Program (Keluarga Berencana – KB). TOP Support is a women’s support group created by YPI that provides psychosocial support to seropositive mothers. Its members are mostly (ex-)injecting drug users or their partners, who typically discovered themselves to be HIV positive after their child or husband had died of AIDS. Among the seropositive women’s support groups in Jakarta, TOP Support is the only one which is an established part of the PMTCT continuum of care.

YPI involves the PKK in its PMTCT project to help prevent perinatal HIV transmission, in line with prong 1 of the PMTCT continuum of care. The role of PKK cadres is to mobilize pregnant women in their locale to attend a mobile voluntary HIV counselling and testing (VCT) service. TOP Support plays an important role in prong 4 of the PMTCT continuum of care: to support seropositive mothers by providing interpersonal psychosocial support.

Members of the PKK and TOP Support use the social capital they gain by being associated with these organizations to promote the PMTCT pilot project, utilizing motherhood to gain trust and build networks among mothers to make issues related to HIV/AIDS more socially acceptable. PKK cadres rely on the community’s trust in their organization and the highly organized PKK network to mobilize pregnant women to access the mobile VCT service, while TOP Support members, through public testimony, invoke the image of the devoted wife and mother infected by her badly-behaved husband to gain support, avoid stigma, and promote PMTCT. In promoting the pilot project, PKK cadres and TOP Support members convert the social capital derived from motherhood into opportunities to access economic capital. Both PKK cadres and TOP Support members receive material rewards, for example in the form of ‘transportation fees’ which can be used to supplement family income. These economic benefits enable women to fulfil their role as mothers responsible for their families, especially when the husband/father cannot satisfy the family’s economic needs.

Unfortunately, PMTCT in Indonesia has remained a YPI project since its inception in 1999. PMTCT is not considered a necessity, either by members of PKK or TOP Support, who tend to see it a means to meet the economic needs of their families. Alongside the stigma attached to HIV prevention, the PKK does not see access to VCT during pregnancy as part of the overall fight for women’s reproductive rights. TOP Support members do not see PMTCT as a means to gain medical access as they already have this through YPI. Most TOP Support members have not experienced full-blown AIDS and do not feel that they have particularly suffered. Furthermore,

---

3 Most of the support groups set up exclusively for seropositive women are not part of the PMTCT program. Women who join mixed support groups, in which most members are injecting drug users, are also not part of the PMTCT program.
Figure 1: PMTCT Pilot Project
Indonesian women are not socialized to make demands for their own needs or to fight for their rights. Motherhood is limited by its domestic social identity, meaning that the activities women can pursue cannot interfere with or violate their domestic role as mothers. Motherhood, as a form of social capital, is thus constrained in fighting for issues outside the domestic sphere. PKK and TOP Support therefore do not feel that it is necessary, or that they are able, to fight for PMTCT as a woman’s right to reproductive healthcare. Following Snitow, I ask: “Is the general marginality of women’s groups a strength or weakness? To what extent is motherhood a powerful identity, a word to conjure with?” (Snitow, 1990, pp. 20-21).

1.B. Research Objectives and Questions

Studies of motherist movements such as the Mothers of La Plaza de Mayo and the Poor People’s Campaign focused on how motherhood was mobilized to achieve common goals based on the domestic responsibilities of women to their families. While motherhood is often seen as a weak and disempowered identity, it can be used to promote women’s programs even when, as described in this study, the program suffers from social stigma.

This study suggests that mobilizing motherhood is an effective means to advocate for PMTCT at both the individual and organizational levels, though influence at the national level remains constrained. The social capital mobilized by women in the PKK and TOP Support derives from their identity as mothers, which is regarded within communities as the ultimate identity of Indonesian women. Motherhood generates identity-based trust which forms the basis for individual mothers to establish social relationships, which can then bind individuals to achieve common goals. Mutual trust is an important precondition for meaningful interaction at the individual level, which later becomes the foundation for positive social relations at the level of organizations and communities (Falk & Kilpatrick, 2000). At the organizational level, motherhood becomes a basic formation to generate support for PMTCT.

The overall objective of this study is to examine the effectiveness of mobilizing motherhood through two women’s organizations – the PKK and TOP Support – in promoting a socially stigmatised HIV prevention program. In particular, this study will answer the following questions:

1. How does motherhood inform social relations among PKK and TOP Support members?
2. How do they make use of the social values and trust surrounding motherhood at the organizational level?
3. How do they mobilize their social and organizational networks to promote PMTCT?
4. How do mothers active in PKK and TOP Support benefit from the PMTCT program and maintain these benefits?
5. How effective was the strategy of mobilizing motherhood to promote PMTCT at the national level?

1.C. Research Significance

Although PMTCT has remained a YPI project, preventing the mother-to-child transmission of HIV has inspired communities and the government to broaden their perspective on HIV/AIDS and start discussing prevention for the general population, not only for high risk groups. Success in raising the issue of PMTCT, as one aspect of HIV/AIDS prevention, cannot be separated from the efforts of senior YPI staff who hold strategic positions in government. YPI’s pilot project was used as a model to develop the PMTCT guidelines issued by the Ministry of Health. Some points within these guidelines are based on lessons learnt from the pilot project, for example that PMTCT should be integrated within maternal and child healthcare services, and that societal mobilization aids implementation. The model of prevention used by the pilot project also receives support from the government (particularly the Ministry of Health) and other donors (particularly the Global Fund), which has allowed it to spread its network to six other provinces in Indonesia.

There are number of reasons to study the PMTCT pilot project in Indonesia. First, because HIV/AIDS prevention programs for women and children hardly exist in Indonesia, this research will provide valuable input for the development of further HIV/AIDS prevention initiatives. This will help the Indonesian government to meet its stated target of achieving the Millennium Development Goals (MDGs) by 2015. Second, it is fascinating to examine how members of the PKK and TOP Support promote PMTCT by uniting the highly respected community symbol of motherhood with the highly stigmatized disease of HIV/AIDS. Finally, this study sheds some light on the importance of motherhood within women’s organizations more generally.

1.D. Methodology

1.D.i. Description of the Project

This PhD project was part of the larger research project ‘Towards a Continuum of Care in Prevention of Mother to Child Transmission Programs: Proposal for Partici-
patory Action Research in Vietnam and Indonesia’, conducted by the Medical Committee Netherlands Vietnam, Hanoi Medical University, the Indonesian NGO Yayasan Pelita Ilmu, the Department of Social Welfare in the Faculty of Social and Political Sciences at the University of Indonesia, and the Medical Anthropology Program at the University of Amsterdam.

My research began with a rapid assessment of PMTCT in Indonesia. The main actors included the Department of Health, the Ministry of Women’s Empowerment, the Indonesian Association of Paediatricians, the Indonesian Breastfeeding Promotion Association, the Family Planning National Coordinating Board, the Indonesian Parenthood Association, the Indonesian Children’s Health Foundation, and the Working Group Study on AIDS (Kelompok Studi Khusus– Pokdisus) at the Faculty of Medicine at the University of Indonesia. Actors also included NGOs such as Yayasan Mitra Indonesia (Mitra Indonesia Foundation) and Yayasan Kusuma Buana (Kusuma Buana Foundation); practitioners including medical doctors, nurses, PMTCT programmers, trainers and counsellors; PMTCT community cadres, seropositive mothers, informal leaders, single and young girls, and pregnant women. Data gathering for the rapid assessment was conducted between May and December 2005. Documentary data on general programs for HIV prevention came from the Community Based Survey, the Behavioural Surveillance Survey, the Human Development Index, the Demographic Health Survey, the National Socio-Economic Survey, PMTCT guidelines, and seminar proceedings on reproductive health. Qualitative data were collected through focus group discussions, semi-structured in-depth interviews, and observation.

The rapid assessment revealed that the only established PMTCT continuum of care program in Indonesia is run by YPI, with the involvement of PKK and TOP Support. Based on this finding, this PhD project pursues an in-depth study of the involvement of the PKK and TOP Support in implementing the PMTCT program. In this, I benefitted from the network and rapport I had built up during the rapid assessment.

YPI conducts a mobile VCT program at the district level involving the PKK as community cadres. I initially interviewed 17 PKK members involved in the mobile VCT program and held focus group discussions with all PKK members involved in the mobile VCT in 11 villages. I visited and interviewed PKK cadres and held focus group discussions during their training. To gain further insight into the VCT program, I interviewed 20 pregnant women who had participated in it and pursued two indepth case studies of pregnant women who were found to be HIV positive through the mobile VCT. I then observed, until 2007, the activities of the mobile VCT, which had been expanded to other provinces. I was involved in several capacity-building trainings of PKK cadres organized by YPI as well as a YPI community rally to prevent HIV transmission to babies. Through these activities I gained the trust of the PKK cadres.
I initially conducted in-depth interviews with 15 TOP Support members and held focus group discussions to gain knowledge about the group. I conducted informal interviews with all TOP Support members. At the time of my fieldwork in 2005-2007, there were 24 seropositive mothers involved in TOP Support. TOP Support members, however, cannot be said to be representative of seropositive mothers in general. It was difficult to interview women found to be HIV positive through the mobile VCT as they refused interviews out of fear of disclosure to the neighbourhood. Most TOP Support members were referred by their medical doctors, hospitals, or NGOs.

YPI counsellors helped me to contact seropositive mothers so that I could regularly visit them. I became closely involved in TOP Support activities, observing the daily activities of members and visiting their homes as part of my data gathering. I held capacity training programs and became involved in income-generating activities, which was also part of the main research project funded by MCNV and the University of Amsterdam. Only by working with them was I able to gain the trust of TOP Support members. I developed very close relationships with some of the women; even now I maintain regular contact, receiving up to date information via telephone, email, and text message. Sadly, some of them have passed away since I conducted my fieldwork.

In collecting field data, I received the informed consent of my informants and assured them that confidentiality would be maintained. For this reason, all informants’ names have been changed to pseudonyms. In total, I conducted 63 in-depth interviews and six focus group discussions among PKK cadres and TOP Support members. To complete my data, I interviewed YPI counsellors and staff as well as medical doctors at the district level.

To gain insight into the many issues surrounding HIV, I held in-depth interviews with policy-makers and studied newspaper articles, policy documents, and statistics. As it is distributed nationwide and is relatively gender sensitive, the national daily newspaper Kompas from 1994-2010 served as my main source of news media. I also looked at other daily newspapers, such as the Jakarta Post, though they rarely report on HIV-related issues. I completed my analysis of policy with statistical reports from the Directorate General CDC and EH, Ministry of Health. In theory, all medical institutions report the number of HIV/AIDS cases they deal with to the Ministry of Health through their Local Health Office; the statistics are then used by other institutions to show the spread of the epidemic in Indonesia.

Browsing the Internet supplemented my knowledge of issues surrounding HIV and AIDS. For example, I joined mailing lists to follow discussions of HIV/AIDS and PMTCT in Indonesia and abroad.

---

4 Centre for Disease Control and Environmental Health.
Documents on HIV/AIDS prevention policies, PMTCT guidelines, newspaper articles, and in-depth interviews with policy-makers provided data on the use of social capital within Indonesian healthcare programs. Quantitative data on VCT uptake, PKK cadres, and seropositive mothers –alongside in-depth interviews with NGO and PMTCT staff – addressed how women’s organizations such as the PKK and TOP Support facilitate the implementation of PMTCT. The roles of the PKK and TOP Support within the PMTCT program, as well as the factors supporting the implementation of PMTCT in Indonesia, were addressed through in-depth interviews.

1.D.ii. Research Site

I conducted my research mainly in Jakarta, with field research focusing on the PMTCT activities of YPI. The reason for this was simply because YPI’s pilot project focuses on Jakarta; the city has the highest prevalence rate of HIV/AIDS in Indonesia, according to data from the Ministry of Health. PKK cadres who became informants in this study lived in Jakarta; so did most TOP Support members, though some lived in adjacent areas, i.e. Bekasi, Depok, and Tangerang.

Jakarta is the capital and largest city of Indonesia. Located on the northwest coast of Java, it has an area of 661 km². Jakarta has been a metropolitan centre since at least the mid-eighteenth century, when it was a Dutch East India Company (Vereenigde Oost-Indische Compagnie, VOC) trading centre for East Asia, and called the ‘queen of the east’ (Kusumawijaya, 2004, pp. 3-12). Like many big cities in developing countries, Jakarta suffers from major urban problems. The population has risen sharply from 2.7 million in 1960 to 8.3 million in 2000 and 8.8 million in 2004, counting only its legal residents. Its population density was 13,826 per km² square in 2010. As Indonesia’s leading economy, Jakarta has attracted workers from surrounding areas. Rapid population growth has outpaced the government’s ability to provide basic needs. Almost every year during the rainy season, Jakarta suffers from flooding due to clogged sewage pipes and waterways. Rainforest depletion due to rapid urbanization on the highland areas south of Jakarta, near Bogor and Depok, has contributed to this flooding. Flooding was a problem during field data collection; most of my informants lived in flood-prone areas. Administrative reforms following the passing of the autonomy law (UU 22/1999) unfortunately did not address the fundamental problems of flooding, poor public transport, and the city’s slums (Kusumawijaya, 2004, pp. 177-179).
Officially, Jakarta is not a city but a province with special status as the capital of Indonesia. It is therefore headed by a governor rather than a mayor. Jakarta is divided into five municipalities (kotamadya) headed by mayors, and one regency (kabupaten) headed by a regent. These are: the municipality of Central Jakarta (Jakarta Pusat), the municipality of East Jakarta (Jakarta Timur), the municipality of North Jakarta (Jakarta Utara), the municipality of South Jakarta (Jakarta Selatan), the municipality of West Jakarta (Jakarta Barat), and the regency of Thousand Islands (Kepulauan Seribu), formerly a sub-district of North Jakarta. Jakarta consists of 44 sub-districts and 268 villages. I interviewed PKK cadres from 11 villages, spread across five municipalities in the Jakarta area.

As a metropolitan city, the health service in Jakarta is enormous. Hundreds of public and private hospitals, puskesmas (community health centres), clinics, alternative health services, and private doctors and midwives can be accessed, though their costs vary.

The incidence of HIV in Jakarta is on the rise. According to the Ministry of Health’s Sero Survey Report 2003-2007, HIV prevalence among Jakarta’s prisoners was 12.63 (per 1,000 population) in 2003 rising to 26.25 in 2007; among commercial sex workers, 7.89 in 2005 rising to 14.63 in 2006; and among injecting drug users, 38.00 in 2003 rising to 69.63 in 20065 (MOH, 2010). As of December 2010, Jakarta counted 3,995 cumulative AIDS cases, resulting in 576 reported deaths. The prevalence of AIDS cases per 100,000 people in Jakarta was 44.74 by December 2010, ranking Jakarta third in terms of cumulative AIDS cases in Indonesia after Papua and Bali (MOH, 2011). In March 2009, there were 337 recorded cases of AIDS in South Jakarta, 127 cases in East Jakarta, 1,298 cases in Central Jakarta, 364 cases in West Jakarta, and 672 cases in North Jakarta6 (MOH, 2009). As a capital city with a multitude of problems, Jakarta is a priority for HIV prevention.

---

5 The HIV prevalence rate in selected populations refers to the percentage of people tested in each group who were found to be infected with HIV.

6 Cumulative AIDS cases based on districts has only been reported by the Ministry of Health up to 31 March 2009.
1.E. Challenges in Research

It was a challenge for me to conduct research on issues related to HIV and AIDS. First, even though I had done a lot of research on women and children, this was the first time I had researched issues around women, children, and HIV/AIDS, which remains a sensitive topic in Indonesia. Collecting data from key informants, mainly HIV positive women, was exceptionally challenging. I needed to be very careful so that they would not feel discriminated against or stigmatized, and had to build up trust and develop a good connection with them.

Second, it was sometimes challenging to separate my role as an activist – who helped some of the key informants gain access to PMTCT – from my role as a researcher. As a researcher, I realized I had to be objective. But I also realized that researching women, let alone through a qualitative anthropological approach, made it tough to be an objective, unbiased researcher.

Finally, English is not my mother tongue. Writing a dissertation in another language has been very challenging for me. I had to read books, articles, journals,
and manuscripts several times before I was able to understand the concepts presented in the materials. This language constraint has also made it tricky for me to translate the expressions of the informants into English. Despite my linguistic abilities, I hope I have been able to make a convincing argument to readers, as well as explain the analysis in this study.

1.F. Structure of the Book

In this introductory chapter, I have explained how the research problem was formulated into questions and discussed my methodology.

In Chapter 2, I assemble the arguments that I use as a basis to analyse the research questions. I explain how the feminine identity of motherhood is highly valued in Indonesia, and has been successfully used by the government to support its policies, and by YPI to promote its PMTCT pilot project. To support my argument, I make use of the concept of social capital, referring to its structural aspects at the individual, organizational and community levels. Both the PKK and TOP Support appeal to the social capital invested in motherhood, not least to women’s biological ability to reproduce. Institutionalization of the identity of motherhood – for example through the activities and structure of the PKK, or the central place of motherhood in PMTCT as expressed by the TOP Support group – gives women affiliated to these institutions access to accumulated social capital. But unfortunately, motherhood is also constrained by its restriction to the domestic sphere, so that it becomes a barrier to women fighting for their rights in public. Motherhood becomes a constraint to influence development priorities at the national level, meaning that PMTCT remains a pilot project. To support this analysis, I compare two motherist organizations – the PKK and TOP Support – and explain how they mobilize motherhood in very different ways, regarding: (1) the function of social support in advocating for PMTCT; (2) mechanisms to generate trust; (3) their social organization and networks; and (4) mechanisms to preserve the benefits of participating in the PMTCT pilot project.

In Chapter 3, I describe how the conflicting concepts of motherhood and HIV/AIDS are brought together in PMTCT. I describe the context of HIV/AIDS in Indonesia – in particular how the image of the disease has changed by penetrating the sphere of mothers and children. This implies that the epidemic has spread to the general population and requires attention from the government. HIV/AIDS has been enshrouded in stigma for Indonesian women as it is considered a disease affecting women with no morals. But with the introduction of PMTCT, government and society have been encouraged to look at the epidemic from another perspective, and have begun thinking about prevention for low risk populations, namely women and children.
In Chapters 4 and 5, I describe the PKK’s involvement in the PMTCT pilot project. Chapter 4 describes how the government mobilized motherhood to create the PKK and how PKK cadres were involved in promoting the Safe Motherhood Movement and the Family Planning Program. I examine how PKK cadres engage in PMTCT outreach, making use of their identities as mothers to access existing networks of trust. The chapter further looks at how PKK cadres as service providers deal with PMTCT being part of a stigmatised HIV prevention program. Chapter 5 describes the social and economic benefits gained by PKK cadres in their involvement with PMTCT. This chapter also describes how PKK cadres maintain their motherly roles and, to maintain their benefits, do not reach beyond the limits of the domestic sphere.

In Chapters 6 and 7, I examine the involvement of TOP Support in the PMTCT pilot project. Chapter 6 describes how seropositive mothers became members and how TOP Support as an NGO-driven organization supports them. I examine how members interpret and respond to HIV/AIDS as women, in light of the fact that most of them have not experienced full-blown AIDS. Chapter 7 examines how TOP Support members construct their identities as devoted and innocent housewives and mothers to gain trust when promoting PMTCT, thereby allowing them to access economic benefits. I also explain how they preserve these benefits by maintaining their role as mothers who always put their families first, by restricting their activities, and by not publicly disclosing their HIV status if this may jeopardize their family’s welfare.

Finally, in Chapter 8, I analyse the PKK and TOP Support as two different kinds of motherist organizations involved in the PMTCT pilot project and examine how they make use of motherhood for their own interests, as organizations and as individual members. This chapter also addresses future challenges that need to be considered when implementing similar programs elsewhere.
Chapter 2: Applying the Concepts

2.A. Motherhood in Indonesia: An Esteemed Biosocial Identity

Rose and Novas in their article on biological citizenship argue that individuals are identified by their biological traits that differentiate them from other individuals, while collective identities often form around biological conceptions of shared identity (Rose & Novas, 2005). But, identity is more than the innate characteristics of a person that reflects differences in personality and behaviour – it is a socially constructed meaning that emerges from the productive power of discourse, continuously (re)created through social interaction (Maguire, Philips, & Hardy, 2001).

The physical bodies of women with their biological ability to reproduce give rise to their identity as mothers. In Indonesia, the bio-social identity of motherhood is constructed to mean a woman who is devoted to the welfare of her family and innocent by being socially restricted to the domestic sphere. Marriage and motherhood are the key signifiers of a woman’s social identity and are constructed as natural. Married women enjoy higher status than unmarried women, while mothers enjoy higher status than childless women. Married women are referred to as *ibu* or *nyonya*[^7], respectful titles that are also used to address

[^7]: Nyonya means housewife. A housewife can also be called *ibu rumah tangga*, or mother of the household. A housewife conjures more the identity of a mother than a wife.
older women and women of social standing (Bennet, 2005). *ibu* (literally, mother) is the most respectful term of address for a woman. There is an expression ‘heaven is at your mother’s feet’. It means a child is not allowed to oppose her mother’s will if she wants to be happy and successful in life.

An Indonesian saying has it that a wife’s territory is the kitchen, the well, and the bed – alluding to cooking in the kitchen, washing clothes by the well, and making love in bed. Similarly, the Javanese saying *yen awan dadi theklek, yen bengi dadi lemek* means “during the day slippers, during the night a blanket”. In other words, the wife is a domesticated partner who must anticipate her husband’s needs, without asking (Kroeger, 2000, p. 171). As a predominantly Muslim country, many Indonesians believe that wives must obey husbands in all cases that do not contradict the will of Allah, as revealed in the Quran.

Indonesian mothers have the exclusive task of bringing up their children. In Indonesian culture, children not only have biological or psychological value, but also economic value for the family. Children are investments for the future. Producing offspring is therefore an obligation (Sidharta, 1987, p. 65) and there is great social pressure for married couples to have children. Indonesian mothers are expected to be caring, loving, nurturing and devoted, and the proper upbringing of children is considered part of their loyalty to their husbands and in-laws. According to Djajaningrat-Niewenhuis (1987, pp. 43-44), an Indonesian woman – as a good *ibu* – is responsible for nurturing the nation without demanding power or prestige in return. Motherhood is an esteemed identity that every Indonesian woman should aspire to.

Motherhood in Indonesia has been politicized by the state to control the activities of women. In the colonial period, the government confined women to the domestic sphere in order to reduce their economic and political activities, which could potentially contribute to the struggle for independence (Gouda, 1998). In the New Order era, the government institutionalized motherhood within women’s organizations to impose its gender ideology, which sought to limit women to their roles as wives and mothers in accordance to their *kodrat*, or destiny. Appeals to motherhood were used to mobilize society through the state-run women’s organizations *Dharma Wanita, Dharma Pertiwi*, and *Pembinaan Kesejahteraan Keluarga* (PKK), reaching from top government offices all the way down to the grassroots (Sunindyo, 1996, pp. 124-125). Women were encouraged to be devoted mothers, sexually passive, and obedient and caring wives, as well as the gatekeepers of family morality and orderliness –which was deemed instrumental in guaranteeing the morality and orderliness of society as a whole. The role of women was codified in the *Panca Dharma Wanita* (Five Responsibilities of Women) as: appendages and companions for their husbands, as procreators of the nation, as mothers and educators of children, as housekeepers, and as members of Indonesian
society (Suryakusuma, 1996, pp. 101-102). To guide women’s activity, the New Order regime established the State Ministry of Women and Empowerment, which again reinforced the role of motherhood within the domestic sphere.

The fall of the New Order regime did not free women from their imposed domesticity. Even when Indonesia had a woman president in 1999, President Megawati cast herself in the role of a mother – when campaigning, when in power, and eventually in defeat (Rochayah, 2001, p. 13). The reformed government of President Yudhoyono has subsequently reinforced the role of the motherly woman by reactivating Posyandu (Pos Pelayanan Terpadu or Community Service Post) activities under the PKK – activities that had been discontinued after the fall of the New Order government. The institutionalization of motherhood has created extensive, well-organized networks of mothers reaching deep into communities – networks that can be used by the government and NGOs to promote programs for women.

The social construction of the domestic sphere leaves women in charge of its daily functioning, responsible for maintaining family harmony. If the husband as the head of the family cannot perform his role as breadwinner, the wife must take over. Nevertheless, women are not expected to oppose their husbands’ will or to have any power in the public sphere. They can only fight for their rights if these are related to their domestic roles as mothers, and if they receive permission from their husbands to do so. So despite having powerful, well-structured organizations, motherists in Indonesia cannot leave their domestic roles behind and still be considered good mothers. These are the constraints on women entering the public sphere and fighting for their rights as women. As a result, their struggle only focuses on improving the welfare of their own families and does not extend to publicly defending the rights of fellow women.

The empirical chapters of this dissertation examine how the two women’s organizations PKK and TOP Support mobilize the esteemed role of motherhood to promote the PMTCT program.

2.B. Motherhood as Social Capital

Previous studies have examined the mobilization of motherhood by women’s organizations and collectivities to advocate woman-to-woman social support (Layne, 2003; Layne, 2006); to promote women’s health and welfare (Hunt, 1998); and to criticize policies detrimental to the well-being of families (Hernandez, 2002; Trully, 1995; Arivia, 1999; Doxey, 2007; Valk, 2000; Hardon A., Contesting Contraceptive Innovation – Reinventing The Script, 2006). The current study examines the strategy of mobilizing motherhood as social capital to implement a stigmatised HIV
The concept of social capital was first coined by Hanifan in 1916 to focus attention on the importance of community participation in society (Woolcock & Narayan, 2000; Harriss, 2001). Portes (1998, pp. 5-15) defines social capital as the ability of actors to secure benefits by virtue of their membership in social networks or other social structures through value introjections, bounded solidarity, reciprocal exchange and enforceable trust. Portes explains that to possess social capital, a person must enter into relationships with others, and that it is these others who are the actual source of his/her advantage. Social capital thus inheres within the structure of relationships. As a form of capital, the mobilization of social capital can be understood as a strategy for achieving specific ends. Uphoff (2000), for example, shows that investing in social capital can increase efficiency and probability of success within development initiatives.

Structuralists have examined social capital at the micro-level of individuals, the meso-level of organizations and communities, and at the macro-level of societies. Social capital at the micro-level infuses face-to-face interactions between individuals in daily life; scholars have also studied social relations at the individual level by referring to status and roles (Lawang, 2004); trust, skills, identity, and knowledge (Falk & Kilpatrick, 2000); expectations and obligations (Coleman, 2000); values, attitudes, norms, beliefs, and cooperation with others (Krishna, 2000; Uphoff, 2000). Social capital at the meso-level informs social relations within or between institutions and organizations; scholars have also examined social relations at this level by referring to social networks (Coleman, 2000; Lawang, 2004), collective action decision-making, resource mobilization and management, communication, conflict resolution (Falk & Kilpatrick, 2000; Uphoff, 2000); and roles, rules, and procedures (Krishna, 2000). Social capital at the macro-level can be observed in social relations between parties, often with unequal power, and infuses notions of national development (Turner, 2000), social order (Falk & Kilpatrick, 2000), contracts and legal coercion (Nootebboom, 2007).

This study examines the mobilization of micro-level social capital in the interactions between individual members of the PKK and TOP Support, and the mobilization of meso-level social capital in how these two motherist organizations implement the YPI pilot program to prevent mother-to-child transmission of HIV. Falk and Kilpatrick (2000) argue that trust in social interactions at the individual level is a necessary foundation to build meaningful and positive social relations at the organizational level. The latter, in turn, are necessary to affect developments at the level of society. Loyalty and cohesion within organizations largely stem from identity-based trust among their individual members, while social capital at the
meso and macro levels largely depend on groups sharing social values. For Falk and Kilpatrick, the generation of social capital depends on the frequency and quality of social interactions. The latter is facilitated by shared knowledge (of internal and external networks, precedents, procedures, and rules) and identity (norms, values, attitudes, vision, trust, and commitment to community).

Coleman (2000) likewise points to the importance of trust and norms at the level of individual interaction to sustain social capital at higher levels of aggregation. Applied to our case, the social capital mobilized by women in the PMTCT pilot project derives from motherhood, which allows individual women to form relationships of trust – which can then be used by organizations to pursue collective goals. Maguire, Philips, and Hardy (2001) argue that such identity-based trust within organizations not only fosters goodwill among their members but perceptions of organizational reliability and predictability. This generates trust in institutions, increasing the level of social capital at their disposal (Nooteboom, 2007, p. 30). In a parallel argument, Krishna argues that to reach coordinated and goal oriented behaviour, people need not only mutual trust and good-will, but also clear roles within established structures (Krishna, 2000, p. 77).

The empirical chapters of this study show that investing in motherhood as a form of social capital has been a reasonably effective strategy at the micro and meso-levels in circumventing the social stigma attached to HIV/AIDS prevention work. But, while the media focus on motherhood has had some effect in changing the image of HIV/AIDS from a disease that only strikes immoral women to one that can also affect respectable people, the strategy of mobilizing motherhood has had no impact at the level of national policy.

Motherhood, as a form of social capital for promoting PMTCT, has serious constraints. Crucially, motherist organizations cannot go beyond the normative boundaries that arise from their very identities. Indonesian women are not socialized to make demands for their own needs or to fight for their rights, but to respect the differences between male and female roles. Thus the ideal of motherhood becomes a barrier to women fighting for goals outside of the domestic sphere. The involvement of motherist organizations has not helped YPI to frame PMTCT as a woman’s right to reproductive health care.

My findings thus seem to corroborate Turner’s finding that micro and meso-level social capital can be successfully mobilized to improve living standards, so long as goals remain modest and uncontroversial (Turner, 2000). Real change at the level of national policy would require the government’s commitment to implement a national program on HIV prevention, which to date has not happened in Indonesia.
Figure 1: Mobilizing Motherhood to Prevent HIV

Society (macro) level social capital
Motherist movement for HIV prevention

Constraints:
- Gender construction of motherhood
- Lack of government commitment

Organizational (meso) level social capital

- Social values
- Social relations (network, support, integration)

PKK (government-led)  TOP Support (NGO-driven)

Formal bonding relationship  Informal bridging relationship

Community cadres  Seropositive mothers

- Trust
- Obligation
- Expectation

Individual (micro) level social capital

Knowledge resource (motherist organization)

Identity resource (motherhood)
2.C. The PKK and TOP Support: Individual and Organizational Investment in Motherhood

The word “mother” within PMTCT enables YPI to implement its pilot project by involving the two motherist organizations PKK and TOP Support. As these two organizations are very different in nature, we need to examine how they mobilize motherhood in very different ways.

1. Function of social support

YPI views PKK participation as valuable social capital that can be used to support its PMTCT program. YPI depends on PKK cadres to mobilize pregnant women in their districts to access its mobile VCT service, in line with prong 1 of the PMTCT continuum of care – to prevent HIV among women of child-bearing age. Unfortunately, the social support provided by PKK exclusively targets mothers, in this case pregnant women, and excludes other women of reproductive age.

YPI created TOP Support to help seropositive mothers and their children in line with prong 4 of the PMTCT continuum of care – to provide emotional and psycho-social support to people living with HIV/AIDS. TOP Support members, who are themselves seropositive mothers, visit hospitals and homes and organize gatherings to support fellow seropositive mothers. They provide emotional and informational support on how to live positively with HIV/AIDS, including how to support HIV positive husbands and children. As part of their advocacy work, TOP Support members are expected to educate communities about HIV/AIDS through public testimonials.

2. Mechanism to generate social trust

In advocating PMTCT, PKK and TOP Support members present themselves as devoted mothers and innocent, sexually passive women, whose concerns are limited to the domestic sphere. Their self-presentation is accepted and respected by Indonesian people, both men and women, and generates trust and solidarity.

The government-led PKK identifies itself as an organization of good housewives and responsible mothers. Its previous involvement in the national Family Planning Program and the Safe Motherhood Movement means that it is trusted as an organization that promotes maternal and child health. Crucially, this trust extends to women’s husbands, who must give permission to their pregnant wives to make use of the mobile VCT service. Husbands will only allow their wives out of the house with people whom they trust. And while the husband may not know the PKK cadres personally, the PKK is a known and trusted
institution that is “safe” for their wives. By emphasizing values that reinforce the domestic role of women, the PKK gains trust from society, especially from husbands.

In contrast, appealing to motherhood enables members of TOP Support to re-work their identities as immoral women into that of innocent and devoted mothers who were infected with HIV by their depraved husbands. TOP Support members also make use of their collective identity as sick people to speak for others who suffer, to bear testimony and to contribute to community wisdom. But unlike PKK cadres whose identities as responsible mothers are beyond question, TOP Support members need to continually work on their identities as innocent and devoted mothers through their appearance and testimony.

3. Form of organization and social network

Studies of organizational structure have differentiated between bonding, bridging, and linking networks. Bonding networks develop among peers, for example neighbours and colleagues; they tend to be exclusive and inward looking, and are characterized by trust, reciprocal support, and a common identity among their members. Bridging networks are likewise generally horizontal, but are much more loosely organized. They arise among socially diverse groups that come together to promote their members’ common or overlapping interests. In contrast, linking networks are vertical and generally more complex, involving hierarchical relationships between individuals and groups with differential status and power (Woolcock, 2001; Campbell, 2003, pp. 56-58; Evans & Syrett, 2007, p. 59).

The PKK, as a government-led community organization, is structured from the highest national level down to individual neighbourhoods. YPI involves the PKK because its formal organization allows its cadres to reach out to all pregnant women in their neighbourhoods. In the PMTCT pilot project, PKK housewives relate hierarchically to each other as service providers (cadres) and beneficiaries (pregnant women). Social relationships within the PKK can be seen as a formal bonding network.

TOP Support is an informal support group established by YPI. Its members are all sero-positive married women or mothers. Ties among TOP Support members can be seen as informal bridging relationships that connect seropositive women living in different areas of Jakarta. Members of TOP support interact with each other horizontally, as both service providers and beneficiaries.

Mechanism to preserve benefits

Participating in the PMTCT pilot project brings PKK cadres and TOP Support members direct financial benefits (“transportation fees” and honorariums) as well as access to social and professional networks to improve their prospects for
further employment. The sums they receive are significant additions to family income – especially when husbands are unavailable or unable to provide for the family’s needs – and are used to support not only their own nuclear families but their extended families and in-laws. For those members of TOP Support who are divorced or widowed, participation in the PMTCT program is also a way to find new partners. The financial compensation the women receive strengthens their role as mothers responsible for the well-being of their households.

PKK cadres and TOP Support members preserve these benefits by safeguarding their social identity as devoted mothers. This allows them to maintain the trust of the program’s beneficiaries, and crucially, that of their husbands. The latter entails putting the interests of one’s own family first and receiving permission from husbands to participate in the PMTCT project. For TOP Support members, it entails reworking their public appearance (for example by wearing a hijab and talking demurely in public), and for some, remarrying to maintain their public image as married mothers.

### Table 1: Social Capital Mobilized by the PKK and TOP Support to Promote PMTCT

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>PKK (Family Welfare Movement)</th>
<th>TOP Support (Seropositive Women’s Support Group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function of social support</td>
<td>Instrumental support to mobilize pregnant women to access mobile VCT services</td>
<td>Emotional, informational, and psychological support through supportive peer relationships</td>
</tr>
<tr>
<td>Mechanism to generate social trust</td>
<td>Channel of dominant culture by the state that sees women as housewives and traditionally powerful community members; maintain identity of devoted housewives and promote values of responsible motherhood</td>
<td>Rights and autonomy approach that sees women as central agents in development but powerless and stigmatized by HIV/AIDS; promote identity as innocent wives and victims of husband behaviour to gain trust and expand networks</td>
</tr>
<tr>
<td>Form of organization and social network</td>
<td>Government-led, value-oriented, national organization; highly organised and structured network of formal bonds reach into communities</td>
<td>Informal NGO initiative funded by foreign donors; informal bridging network based on mutual interests</td>
</tr>
<tr>
<td>Mechanism to preserve benefits</td>
<td>Put the interests of the family above all; preserve the identity of the good mother by obeying the husband</td>
<td>Maintain the image of innocent housewives in appearance and behaviour; maintain the role of the good mother within marriage</td>
</tr>
</tbody>
</table>
The understanding of HIV/AIDS in Indonesia is based on a high risk group paradigm, with a dominant contextualization of the virus as a ‘hooker’s disease’. Since the beginning, HIV prevention programs have primarily targeted female sex workers, as they have been seen as being responsible for the spread of the virus. At a time when prevention of mother to child transmission (PMTCT) programs are being promoted, the image of HIV is changing from the disease of *wanita tuna susila* – women without morals – to the disease of *ibu rumah tangga baik-baik* – devoted housewives. The word ‘mother’ in PMTCT has had a significant role in this change, as an image that destigmatizes HIV, and which has resulted in HIV prevention programs being better accepted in society.

In this chapter I describe the problem of HIV/AIDS among women in Indonesia, to show that the issue is a significant one to be tackled, despite low government commitment. Then I describe how PMTCT has helped to destigmatize HIV/AIDS by changing the notion of a disease of women without morals to the disease of innocent mothers.

### 3.A. HIV/AIDS and Women

The issue of HIV/AIDS, especially among women and children, is hidden behind a very low prevalence rate that is considered
insignificant and therefore not a priority to overcome. Yet, as is the case with HIV/AIDS in general, new cases are increasing very significantly, both among women and children.

The Ministry of Health has reported that the cumulative HIV and AIDS cases from July 1987 to December 2010 were 24,131, of whom 4,539 have died (MOH, 2011). HIV prevalence in Indonesia has been at a ‘concentrated’ stage since 2000, indicating high risk groups such as intravenous drug users, transsexuals, and female commercial sex workers, where infection rates for each group are over five percent. However, the prevalence rate is still low; the prevalence estimation among those of reproductive age between 15-49 years was 0.2% in the year 2010. Considering the low prevalence, HIV/AIDS is not seen as a crucial matter that needs to be prioritized over other infectious disease. However, Indonesia now has the fastest growing epidemic in Asia, while elsewhere in the world HIV/AIDS has shown signs of stabilizing (Kompas, 2008a). In 2007, Indonesia was placed in the rank of 99th highest prevalence in the world, from its previous rank of 154 in 2003 (the World Factbook, 2009).

---

**Graphic 1:**

Number of AIDS Cases Reported by Year up to December 2010

![Chart showing number of AIDS cases reported by year up to December 2010](source: MOH, 2011)
The epidemic was initially centred among injecting drug users (IDUs) in Bali, Jakarta, and West Java, and among the extra-marital sexual relations of men in Papua. Now, however, the epidemic encompasses many of their non-injecting sexual partners, as well as prisoners, sex workers and their clients, and has spread throughout the archipelago (Riono & Jazant, 2004, p. 79). Yet, the statistics show that the number of infections among women is insignificant. Out of the 24,131 cumulative HIV and AIDS cases reported in December 2010, 17,626 cases (73%) were men, and only 6,416 cases (26.6%) were women.

Increase in the cases of HIV among women is, however, evidenced by the significant increase in HIV cases among children. In December 2010 the Ministry of Health reported 217 AIDS cases among children under one year of age, 265 cases among children aged between 1-4 years, and 193 cases among children aged between 5-14 years (MOH, 2011). The number of cases is increasing significantly from year to year, from only a single case found in 1995 to eight cases in 2000; then ten years later, in December 2010, the number of cases increased by 800% to 675 cases.
It is unfortunate that the number of seropositive women and children being reported by the mass media is much higher than the number provided by the Ministry of Health. The newspaper Kompas Daily, for example, frequently reports on HIV/AIDS cases among children in some areas. On July 19 2008 the paper reported that in the previous five years, 62 children under the age of five in West Java had been identified as having HIV (Kompas, 2008c), and between the years 2006 and 2007 there were 101 children under the age of five living with HIV/AIDS in Jakarta (Kompas, 2008b). In contrast, in the year 2007, Surabaya Health Office reported only eleven HIV cases among children aged 0-4 years, while in the year 2006 there were no cases reported. In January 2008, Dr Soetomo Hospital, Surabaya, had handled 40 new HIV cases among children and babies; in total there were 64 patients, three times more than the number of cases in 2007 (Kompas, 2008d). In Bekasi, between January and December 2007, there were 9 children under one year of age and 3 children under the age of five known to be infected with HIV, and 25 cases among housewives (Kompas, 2008e). More recently, in 2010, Kompas reported that in December 2009, the highest reported number of HIV/AIDS cases was among housewives, with 1,970 cases, while the reported cases among commercial sex workers was only 604 (Kompas, 2010).
When harm reduction programs do not work, it is women who suffer most. Either they are infected through unclean needles or from unsafe sexual intercourse with their partners who are IDUs or clients of sex workers. They may then transmit the disease to their children. In addition to biological vulnerability, caused by a woman’s reproductive anatomy, women’s vulnerability to HIV/AIDS is also caused by their weak social, economic, and cultural position, and their generally weaker bargaining position as they are constructed as unequal in relation to men (Aditya, 2005). Continuation of the family lineage is considered extremely important in Indonesian families. Giving birth and producing offspring are compulsory, and thus women are usually considered incomplete if they have not produced a child. Furthermore, fertility is considered as belonging only to a woman. An infertile woman, a woman without child(ren), or a woman considered as being unable to nurture children well must accept either being divorced by her husband or the fact that he will take concubines (Sidharta, 1987, p. 65). Grandparents want a grandchild before they die, and it is the woman who is responsible to provide healthy children. Considering also the high social stigma towards widows, Indonesian women will have a child at any cost to protect their marriage and their economic dependence on their husbands and husbands’ family, even when they or their husbands are HIV positive.

The findings of the Behavioural Surveillance Survey (BSS) in 2004-2005 describe how and why women are vulnerable to HIV transmission, and how subsequently their babies are also at risk (see Figure 1 below).

Figure 1:
HIV/AIDS Transmission to Low Risk Population

Source: Extracted from BSS Report 2004-2005, MOH.
Considering the facts behind the statistical data, a comprehensive and intensive HIV prevention program for women and children needs to be implemented forthwith. HIV prevention among women of reproductive age is the first step that the government must take. Failure to administer this primary prevention will cause an increase in the number of HIV cases among mothers and children.

3.B. Slow Progress and Low Commitment

Unfortunately, the progress of HIV prevention programs for woman and children, as with all other HIV prevention programs, is very slow due to limited political commitment. The Indonesian government seems to be uncommitted to overcome the HIV epidemic. Despite the fact that there are many policies on HIV prevention, there is a lack of actual and sustainable implementation programs at the national level.

The first National Strategy for AIDS Prevention was only formulated in 1994, seven years after the first AIDS case was reported in 1987. This was based on the Presidential Decree No. 36/1994, on the forming of an AIDS Prevention Commission, in which the President gave an order to immediately create HIV/AIDS prevention programs. One of the important aspects of this first National Strategy was the acknowledgement that society itself plays a major role in dealing with HIV/AIDS prevention, and also of the importance of NGOs as partners in nationwide HIV/AIDS prevention in Indonesia. However, there was neither community representative nor NGO involvement in the National AIDS Committee (NAC), nor any contribution by either to the formulation of the National Strategy.

Following the National Strategy, in July 1994 the government set up a special AIDS facility in North Jakarta, in Koja General Hospital, which was originally set up to specialize in treating highly communicable diseases such as cholera and smallpox (Post, 1994). In 1995, the government launched a campaign for ‘HIV/AIDS family awareness’, to protect people with low risk from HIV infection. However, the campaign was only administered by spreading the campaign materials to between 5,000 and 10,000 families over the whole of Indonesia (Kompas, 1995b). In 1997, Pokdisus FKUI (an AIDS study group at the medical faculty at the University of Indonesia) received a permit to obtain AIDS medicines from Dirjen Pengawasan Obat dan Makanan (the Medicine and Food Control Section, Ministry of Health) in order to treat people living with HIV/AIDS (PLWHA). However, it was only in August 2001 that the cheap AIDS medicines from India came regularly (Kompas, 2002e).
It was only after the passing of laws on regional autonomy – Law No. 22/1999 and Law No. 25/1999\(^8\) – that local governments and NGOs seemed to be more critical and tactful about the AIDS problem. In 2001, Indonesia signed the agreement of the UN General Assembly Special Session on HIV/AIDS (UNGASS), held in Brunei Darussalam. After UNGASS, the Indonesian government held a special session on HIV/AIDS prevention in Indonesia in a cabinet assembly, to increase the commitment of national leaders in preventing HIV/AIDS and perfecting and deciding upon strategic policies against the HIV/AIDS threat. The assembly produced some drafts for an HIV/AIDS prevention program; one of them was the *Gerakan Nasional Stop HIV/AIDS* (Stop HIV/AIDS National Movement), which was intended to be administered until 2010 under the Ministry for People's Welfare and the Ministry of Health, supported by the Global Fund for AIDS, Tuberculosis, and Malaria (Kompas, 2002f). The notion of women's empowerment and gender equality started to be a concern in the UNGASS declaration ‘Global Crisis – Global Action’, which has also acted as a reminder of HIV/AIDS issues for the Indonesian government (Kompas, 2001b).

The recent development and changes in the Indonesian epidemic have forced the government to renew its National Strategy for HIV/AIDS Prevention. The National Strategy 2003-2007 has been a reflection of the commitment of the Indonesian government to reach the goals of the UNGASS declaration in 2001. It was administered according to the identified target groups, i.e. vulnerable groups (such as youth, women, pregnant women, etc.), high risk of infection groups (IDUs, sex workers, etc.), and infected groups (PLWHA).

The commitment to improve PMTCT as one of the priority programs of HIV/AIDS intervention, as stated in the National Strategy 2003-2007, is a response to the UNGASS convention, which included the aim of reducing the number of sero positive children by 20% in 2005 and 50% in 2010, and to ensuring that 80% of pregnant women who attend an antenatal clinic (ANC) receive information, a consultation, and services to prevent HIV transmission to the baby (Priohutomo, 2005). Since 2004, the Indonesian government has subsidized ARVs, so that people can obtain them easily and freely. Access to free ARVs, however, has not proven easy to guarantee. It may be easy for those living in the cities, such as Jakarta, to gain

---

\(^8\) Law No. 22/1999 grants significant regional autonomy as the answer to a long period of growing distrust and antagonism from the peripheral provinces. Law No. 25/1999, concerning fiscal arrangements between the centre and regional governments, arranges the total General Allocation Funds distribution. It is stated that only ten percent is to be used by the provincial government, with the rest intended for use by *kabupaten* (regency) and *kota* (city/town) levels of governments. Laws No. 22/1999 and 25/1999 provide the *kabupaten* and *kota* in Indonesia with significant autonomy to govern and administer to their populations and manage local problems. By applying these laws, local governments become more empowered than before because they have their own local budget to tackle their local problems. These laws have brought significant changes in the governmental system, bringing about more local and regional autonomy, although the real impact of the laws came some years after implementation.
access, because they can get free generic ARVs at referral hospitals. For those living in rural areas, services provided are far from ideal. To access ARVs people must wait a long time and pay high administration costs, in addition to transportation fees to and from the clinics.

The NAC renews the National Strategy regularly every five years. Yet progress in implementation seems very slow. The first national PMTCT guidelines were only launched by the Ministry of Health in 2006, twelve years after the first National Strategy in 1994 and nineteen years after the first AIDS case in 1987. A PMTCT pilot project by the Yayasan Pelita Ilmu (YPI) has become the basic example for the Ministry of Health in formulating guidelines for PMTCT. Some YPI administrators who were involved in the PMTCT pilot project have also been involved in the formulation of the PMTCT guidelines issued by the Ministry of Health. However, up to now there are no PMTCT programs at the national level. The HIV/AIDS program evaluation in Jakarta, 2006, also shows that PMTCT sites (in hospitals and community health centres) and the Suku Dinas Kesehatan DKI Jakarta (Provincial Health Offices) have not optimally engaged in PMTCT activities.

3.C. A Disease of Women without Morals

There is another reason besides low prevalence which has resulted in minimal commitment from the government to tackle the HIV problem. HIV prevention programs which concentrate extensively on high risk groups have created a stigma for the programs. In the minds of people, HIV/AIDS is associated with criminal behaviour and a hopeless life. Added to the general lack of knowledge about the virus, this creates an atmosphere of fear and accusation around infected and affected persons. There is a social stigma that HIV/AIDS will only infect ‘badly behaved’ people who have sex with many partners, or it is regarded as a disease of IDUs. People who test positive for HIV face stigma and discrimination; society looks down upon them. There are also some forms of discrimination, including the refusal to treat HIV positive persons, differential treatment for PLWHA, the disclosure of an individual’s status to others without their consent, and the physical isolation of PLWHA (Merati, Supriyadi, & Yuliana, 2005).

In the beginning, HIV/AIDS was considered a ‘foreign’ disease, and was initially believed to have been imported by western foreigners. Later on, female sex workers were the ones seen to be responsible for the spread of HIV. The first HIV/AIDS case was found in Indonesia in 1987, when a Dutch homosexual tourist died in Bali. HIV/AIDS was then perceived not as an ‘original disease’ from Indonesia but a disease of foreigners (westerners) and of homosexuals (Sciortino, 2007, pp. 181-191). This view created a stigma against western foreigners. For example, UU Keimigrasian No. 9/1992
Pasal 8 (Immigration Law No. 9/1992 Article 8) states that the immigration officer can refuse foreigners entry to Indonesian territory if s/he has an infectious disease that can be a threat to public health in the country (Kompas, 1996). Furthermore, the HIV national prevention approach has always emphasized a fear of western intervention; for example, the promotion of condoms is considered a campaign to promote men having extra-marital sex, which is seen as an imposition of negative western moral values. However, in 1991 the Indonesian government, with the help of American researchers, started conducting HIV tests to observe the spread of the disease. They found two sex workers in a brothel in Surabaya who tested HIV positive. Since then, Indonesian society has begun to view HIV differently, from a disease of foreign tourists and homosexuals to a disease of female sex workers, literally known as ‘women without morals’ (wanita tuna susila) (Kroeger K. A., 2000, pp. 4,25; Sciortino, 2007, p. 192).

There have been some discussions to counter this notion. In a seminar entitled ‘The HIV/AIDS Problem and Gender’ on June 2 1999, it was said that the training and identification of HIV/AIDS cases was still too focused on sex workers, and was not being accelerated with training for the identification of HIV cases among men (Kompas, 1999). On International AIDS Day in 1995, Nafsiah Mboi9, then a representative of the House of Representatives (also known as the People’s Consultative Assembly), said that HIV/AIDS prevention, which mostly prioritizes high risk groups, has made the community less alert of it. At the same time, this statement was also echoed by Adi Sasongko, an AIDS activist, when emphasizing that HIV/AIDS prevention has to be more strategic by not only handling either general or specific groups, but both groups at the same time, in an accelerated, systematic, and objective fashion, and by doing the action. Slogans, however, are not enough; there must be real action and big campaigns (Kompas, 1995). In 2001, Endang R Sedyaningsih-Mamahit10, an official of the Ministry of Health, said that the materials used for HIV campaigning were ambiguous as they were covered by a moral issue; the IEC (Information, Education, and Communication) program is still limited to sex workers as the main target group; the potential groups, i.e. the male clients of sex workers, migrant workers, and IDUs, are still not being reached (Kompas, 2001). Unfortunately, the discussion about this has not prompted many reactions. HIV/AIDS prevention programs still target (mostly) sex workers. Since 1991, the government has been testing sex workers for HIV; Family Health International (FHI), together with researchers from the University of Indonesia, have conducted a risk behaviour survey each year since 1996 among sex workers. Although, there have been tests for IDUs since 2000, and it has been

9 She is now Secretary of the NAC.
10 She is now the Minister of Health (2009-2014)
found that HIV/AIDS prevalence among this group is increasing much higher than among sex workers and their clients, until now people still view HIV as a disease of ‘women without morals’ (Pisani, 2008, pp. 44-46).

Kroeger (2003), in her study on HIV/AIDS in Indonesia, argues that the stigma and discrimination related to the HIV/AIDS epidemic has worsened the position of HIV positive women. In Indonesia, according to Kroeger, the situation is compounded by the existence of power and control from the government towards the political body of individuals, particularly women. Indonesian women have become very helpless individually, socially, and politically. The role of women, which is constructed as obedient, passive, patient, and loyal, increases vulnerability to harassment, sexual violence, and economic dependence, and reduces access to education and health services. This constitutes a double burden for HIV positive women: of being both HIV positive, having to deal with the disease and the associated social stigma, and the human rights violations faced by women in general (Aditya, 2005; Subiyantoro, 2005; Hanifah & Kumala, 2005). The stigma of HIV/AIDS as a disease of women without morals becomes a challenge to a woman’s maternal and nurturing role in Indonesia. Consequently, HIV prevention programs for women who are not categorized as high risk groups become difficult to implement.

3.D. PMTCT: Connecting Motherhood with Stigmatized HIV/AIDS

When people started to know about PMTCT programs, there began to be a change in the views of society, whereby people started to realize that HIV/AIDS had spread among housewives. The word ‘mother’ in PMTCT has a symbolic power that has had a significant influence.

The mass media has played a very important role in constructing the perception of the community regarding HIV/AIDS. The role of the media in reporting on HIV/AIDS has changed over time, and has brought about a positive impact on PMTCT. Since 1991, the media in Indonesia has learned that news about HIV/AIDS is worthy to be told and sold, and results in good media circulation and increased ratings. News on HIV/AIDS has caused a sensation because of the high incidence of discrimination against PLWHA and also because people forget the rights of PLWHA. Media reporting shows that the number of news items that contain violence, discrimination, and the sensational in relation to HIV/AIDS has much reduced, though coverage has not shifted much from the classic three topics each year, i.e. the shift/increase in number of cases, ceremonials of AIDS days, and description of moral and normative policies of the clerics, such as their normative policy regarding condom use (Luviana, 2005). Media coverage on HIV/AIDS also shows a positive trend in exposing the
transmission of HIV to low risk populations, such as mothers and children. The image thus spread by the media is that HIV can also infect innocent housewives. For example, Kompas Daily (Kompas, 2002d) reported that Nesim Tumkaya, the head representative of UNFPA, said in May 2002 that “the HIV spread these days had been to family level. Housewives who were infected by their husbands who had sex with different partners would eventually infect their babies during delivery”. Coverage like this is not only in the print media, such as daily newspapers, but also in audiovisual media like television. Some public service advertisements for HIV/AIDS prevention tell the story of how an innocent housewife is infected with HIV by her intravenous drug using husband. Usually, advertisements on HIV/AIDS prevention are displayed alongside condom promotion. An example comes from public service advertisements produced by UNICEF, in which it is said that “Every child is entitled to a chance to make her dreams come true. What happens if HIV/AIDS becomes a part of her life, if her father infects her mother or the child becomes an orphan? Prevent HIV transmission by asking your health consultant and realize our dreams, a world free of HIV/AIDS” (Unicef, 2008).

Figure 2:
UNICEF PMTCT Public Service Advertisement

PMTCT is about the prevention of mother to child transmission, and hence acknowledges that mothers in the general population are at risk. An interview with a staff member of the NAC at the women’s division suggests that this is viewed as a positive thing, because through PMTCT, HIV can be destigmatized so that it can be more easily accepted in society. She said:
CHAPTER 3

...PMTCT has the least discrimination of them all, because it’s all about mothers, who are innocent... Most pregnant women find out their status either after knowing that their child has HIV, or after their husband is sick when the doctor tells them to have VCT. What I notice from the testimonials, it has been the same until now. They don’t think this way: ‘I have high risk behaviour, I have to have a check because I want to get pregnant...’; but it always goes like: ‘My husband is sick and is (HIV) positive, it means...’. It’s always like that, the same story... I think PMTCT is the easiest to sell (HIV testing) without discrimination, without leaving the patient behind. The high risk group (sex workers) is an easy target, they have a special place (brothel)... But their clients... When they leave the brothel, we don’t know where they are. It means PMTCT has a more difficult target because it has a broader range. There’s no other choice, we have to put it in an existing system on the national level. I think the well established system, antenatal care, it belongs to the public, right? It means the target is also regular mothers. I think all pregnant women should be asked to have VCT. (Wenita, Women’s Department, NAC)

The word ‘mother’ in PMTCT has not only changed society’s view, towards a destigmatization of HIV as a disease that can infect ‘regular’ people, but has also brought administrative consequences in a formal institution. The institution which actively promotes PMTCT is the Ministry of Health, through the Sub-Directorate Mother and Child Health, under the Directorate of Family Health. However, there is as yet no national PMTCT program. There are guidelines, but no implementation guidance. The National AIDS Committee has not even performed or coordinated any programs related to PMTCT. The Sub-Directorate for AIDS and STIs, under the Directorate of the Centre for Disease Control (CDC), does not do PMTCT, even though they engage in other HIV prevention programs like harm reduction. Actually, the units of the Ministry of Health involved in HIV/AIDS prevention are the Directorate of Family Health, the Directorate of CDC, and the Directorate of Medical Services; each directorate has different interests. The program related to PMTCT is considered as more related to mother and child health than to the prevention of infectious diseases. One of the PMTCT task force members, who also works for the Directorate of CDC, said:

Because it’s related to pregnant women, to babies, to children, we have to work together with the other team (Directorate of Family Health), Directorate of Mother... It’s called Directorate of Mother and Child now. Actually we were...we were like, ‘Just let the Directorate of Family Health do it’, because it’s very related to it although it is actually HIV/AIDS prevention.
But, they also had problems with that, it's very difficult. That's why we finally work together. (Endang, Sub-Directorate AIDS and STIs)

The Directorate of Family Health, through the Directorate of Mother and Child Health, has conducted trainings for medical staff and midwives and formulated guidelines. Regularly, the directorate administers national PMTCT training for its local medical staff at the provincial level. In the beginning, only one hundred medical staff from six provinces were trained, in DKI Jakarta, West Java, East Java, Riau Island, Bali, and Papua. After the training activities, the trained medical staff were supposed to administer PMTCT knowledge and activities in their own local areas, including training to protect field health workers against HIV infection through contact with their clients. Besides the trainings, the Ministry of Health has also published other guidelines related to PMTCT, such as VCT guidelines, ARV guidelines, universal precaution guidelines, and opportunistic infection treatment, and has established a PMTCT task force. From an interview with one of the staff of the Directorate of Family Health, I came to know that they have their own interest in doing the PMTCT related training program:

Actually, there's no PMTCT program in Indonesia until now. There is an HIV/AIDS prevention program now which is managed by the Sub-Directorate of AIDS Prevention, and one of its activities is the VCT process. Coincidentally, the VCT process is related to women. Women, pregnant, having children, they all are said to be PMTCT because if these matters are not solved, there will be main victims: number one is midwives, medical staffs who are not aware, in villages, midwife private practices, midwives in central public health services, or at the village health post. The next victims are children. We cannot refuse a child from a sero positive mother. He was born, right? It's the responsibility of the Family Health Division, so the most suitable division is the Directorate of Family Health. That's why PMTCT is our task. (Ilhami, Sub-Directorate Mother and Child Health)

It is difficult to promote PMTCT on a national level if it is only performed by the Directorate of Family Health. The only PMTCT related product created by the Directorate of Family Health and which is nationally accepted is the PMTCT guideline, launched in 2006, which has been the main set of guidelines for every program on HIV/AIDS and for training medical staff who provide obstetrical and neonatal services.

However, on the other hand, the word ‘mother’ in PMTCT also has a negative influence. PMTCT has created another point of view about how HIV prevention should be done – i.e. prevention should happen in households. The HIV problem
has become simplified as a problem of housewives, through isolating it as a mother and child issue, so that its handling has been limited to institutions related to the health of mother and child. As a result, PMTCT cannot be accessed by other groups of women, like sex workers or unmarried women, and thus its programs cannot fulfill the PMTCT continuum of care as stated by the WHO. Moreover, the administration of PMTCT can be misinterpreted as a program that aims to curtail the HIV epidemic by advising pregnant sero positive women not to have their child; a view that is against the actual nature of PMTCT which is to promote women’s reproductive rights to have a healthy baby.
Chapter 4

The Role of PKK Cadres in PMTCT: Different Job, Same Role

The PKK (Pemberdayaan Kesejahteraan Keluarga) or the Family Empowerment and Welfare Movement is a government-led mothers’ organization. The PKK has been proven to be an essential government vehicle in support of the Safe Motherhood Movement and the Family Planning Program. Through its well-organized network and identity as an organization whose members are normative mothers, PKK cadres have won trust within communities as Family Planning Program Fieldworkers (Petugas Lapangan Keluarga Berencana, PLKB). The role of PKK cadres has been to persuasively approach housewives to participate in and accept family planning, and to mobilize young mothers to bring their babies to the integrated health station or Posyandu (Pos Pelayanan Terpadu) for monthly medical check-ups. In its PMTCT pilot project, the NGO YPI (Yayasan Pelita Ilmu, Jakarta) made use of the existing network of and trust in the PKK cadres to reach pregnant women at the district level, since the PKK is able to mobilize pregnant women to come to mobile VCT locations.

In this chapter I will describe how PKK cadres have been involved in the government-led women’s health movement, through the Safe Motherhood Movement and Family Planning Program, by promoting their identity as mothers. I then examine how they have made use of their existing position of trust and
their networks to engage themselves in promoting the prevention of mother to child transmission of HIV (PMTCT); furthermore, I examine whether the PKK cadres view the tasks that they have been invited to do, for such a highly stigmatized program as PMTCT, in the same way as they view the Safe Motherhood Movement and Family Planning Program.

4.A. The Involvement of the PKK in the Women’s Health Movement

Grootaert (1999, p. 29), quoting Werner, classifies the PKK as a state led social organization present in every level of the community in Indonesia, which provides assistance and services to community members in education, health, pest management, and security. Guidelines for State Policy (Garis-garis Besar Haluan Negara, GBHN), written on TAP MPR11 No. IV/MPR/1983, state that the PKK was one of the tools used to increase women’s participation in creating a prosperous family. Described as a movement to promote community wellbeing, the PKK program should be in line with the Panca Darma or Five Responsibilities of Women: i.e. a wife is to (1) support her husband’s career and duties; (2) provide offspring; (3) care for and rear the children; (4) be a good housekeeper; and (5) be a guardian of the community (Sunindyo, 1996, p. 124). These concepts have been adopted by the major women’s organizations and enjoy government endorsement (Suryakusuma, 1996, p. 101).

The PKK is a national movement which has its roots in the community, and in which women are the prime motivators. It started with the seminar ‘Home Economic’ in Bogor in 1957, and was then followed up by the Department of Education in 1961 with the formation of PKK cadres at all levels, based on Ministerial Decree No. 27/1961. In the beginning, PKK membership was voluntary, and consisted of female society leaders such as the wives of local officials (Kepala Dinas/Jawatan) and of County Heads (Kepala Daerah), up to the kampong (Desa) and district or sub-district (Kelurahan) levels. The PKK then became a passive regime institution, whereby every Indonesian woman automatically becomes a member as soon as they get married and gain the status of housewife. Married women or housewives are also referred to as mothers. In the Indonesian language, a housewife means “a mother of the household”. Therefore, the bio-social identity of a woman as a mother is the significant marker for involvement in PKK activity.

11 The Decree of the Provisional People’s Consultative Assembly. The role of the Assembly was very significant during the New Order era.
Each PKK member is both a provider and a beneficiary of all PKK activities. The PKK was aimed originally at organizing women in their roles as caretakers of the household and the family, and was used to control women’s movements. By developing its identity as a caretaker of the family, the PKK is not supposed to speak out for women’s rights (Wieringa, 1998, p. 37).

In 1964, the PKK received financial support from UNICEF to arrange their operational planning, but this could only be implemented in 1967, when the New Order (Orde Baru) era took over the government. In the early 1970s, the PKK was piloted in Central Java by Kardinah Soepardjo Roestam, wife of the then governor of Central Java, who was in 1983 promoted to Minister of Home Affairs (Marcoes, 2002, pp. 187-191). The PKK has continued to be internationally recognized and supported, for example when UNICEF awarded them with the Maurice Pate Award in 1988.

Initially, the PKK was financed by the national government through the Ministry of Home Affairs. After the new laws on regional autonomy passed in 1999, PKK activities were financed by the Provincial Fund (Anggaran Pendapatan dan Belanja Daerah). The Minister of Home Affairs gave an order for all governors in Indonesia to administer funds to the PKK movement, and named December 27 as the PKK Movement Day.

PKK cadres are formed at the national (nasional), provincial (propinsi), municipality (kotamadya), district (kabupaten), sub district (kecamatan), and village (kelurahan) levels, using a network which is consultative, coordinative, and hierarchical. To help the PKK in guiding and facilitating society at the village level, there are PKK groups formed based on the regional area and activities. Based in these regional areas, there are PKK groups at the Community Association (Rukun Warga, RW) level, as well at the Neighbourhood Association (Rukun Tetangga, RT) level and Dasawisma groups. Based on their activities, groups are formed to administer them, such as organizing activities at the mosque (Majelis Taklim), providing support for mourners (Rukun Kematian), literacy education (Kejar Paket A/B), income generating activities (Pokpel UP2K), facilitating work at integrated health stations (Posyandu), and community credit programs (Arisan), among others.

12 Rukun Warga (RW – Community Association) is a community division that is not included in the government administration. It is established by community consultation in order to provide services which have been decided upon earlier by the sub-district authority (kelurahan). An RW consists of a number of Neighbourhood Associations (Rukun Tetangga, RT), which consist of a number of households.

13 Dasawisma means ‘ten households’. It is a community group which is established by the government, formed for every ten households. It means that in every ten households there is one coordinator who should organize their daily community development activities.

14 Arisan is a rotating saving system where a group of women will gather at a certain time, weekly or monthly, and contribute a certain amount of money, which is already agreed upon by the members. Upon gathering it, each of the participants’ names are written on a piece of paper which is rolled up and put in
The administration of the PKK is influenced by government structure. The wife of the chairman of each council, whether a district, sub-district, or village, automatically becomes a chairperson of the PKK, without any consideration of whether she is capable of handling the task or not. For example, the wife of a Sub-District Head (Camat) becomes a PKK chairperson at the sub district level. A woman also does not have any choice about becoming a PKK leader (Wieringa, 1998, p. 38; Sciortino, 2007, p. 118). During the reformation era, after the downfall of the New Order government, this situation changed slightly. Nowadays, a chairperson of the PKK is not necessarily the wife of the head of the district or sub-district; rather, she should be elected according to her competence. However, in practice, people still respect the tradition that the wives of local elites should be chairpersons.

A PKK chairperson and other women whose husbands have positions in governmental institutions are called PKK board members. Their involvement in the PKK does not have a real standard since they are elected based on their social status in society. It also means that their involvement depends on how much free time they have, and the quality of the service they provide to the community depends on their capability. The real implementers of PKK activities are those who join the PKK Task Force (Pokja/Kelompok Kerja). These are called the PKK cadres, and they are generally those who have more time for community service. Other women in the community are the targets and beneficiaries of all PKK activities. Through the PKK, housewives are socialized with an ideology that a woman’s task is to serve her husband and family, so housewives will only actively participate in the PKK when they feel that the activities will not disturb their household chores.

In relation to local autonomy policies in 1999, the national PKK cadre team has made some adjustments. The PKK is expected to increase family welfare through their roles as women and mothers, and to help people deal with national economic problems, both financially and mentally. Since this time the PKK has also been called the Family Empowerment and Welfare Movement.

Because of its well organized structure, the PKK as a community organization is a very effective vehicle for implementing the government’s social service programs, as long as these programs do not contradict a woman’s role as a housewife and caretaker of the family. Although the PKK was established in 1950, only under
the New Order regime with President Soeharto was the PKK used as a vehicle to promote the Safe Motherhood Movement and Family Planning Program. These two programs were the successes of the Soeharto regime, and were later integrated into posyandu in 1980.

Posyandu activities are administered by the PKK through POKJA IV, whose task is to administer activities related to the health program. Posyandu is a health service facility for the community at the kampong and sub-district levels. This facility provides services for people living far from a hospital or health clinic. Posyandu was established in 1986, based on a mutual agreement between the Minister of Domestic Affairs, the Minister of Health, Chairman of the National Coordinating Board for Family Planning (BKKBN), and the PKK chairperson. Later on, due to the financial crisis in 1990s, posyandu services were unavailable for quite a long period of time, but it was reactivated on 13 June 2001 by the Ministry of State and Regional Autonomy. Posyandu was intended to support an immunization program and a weighing and measuring program for infants and toddlers under five, as well as to provide health services to the elderly; its main goal, however, is to reduce infant mortality. As the activities of posyandu are very much related to mother and child care, most PKK cadres who are actively involved in posyandu are mothers with babies or under-five toddlers.

Infant and maternal mortality has been a problem in Indonesia since the time of Dutch colonialism. In 1852, the Dutch colonial government established an indigenous midwife school named Sekolah Bidan Pribumi to reduce infant and maternal mortality rates. These indigenous midwives received western education to replace the position of traditionally trained midwives, who were regarded as bio-medically incompatible and dangerous to the lives of the mother and baby. After independence in 1945, the focus of healthcare services was placed on rural areas, with special attention to infant and maternal mortality. In 1952, every county/regency (kabupaten) had established a Centre for Mother and Child Welfare called the BKIA (Balai Kesejahteraan Ibu dan Anak) that provided services for pregnant women, children, and babies by conducting health campaigns and counselling, vaccination, and general medical care. In the period of the New Order led by President Soeharto, BKIA and the institutions for disease prevention and control together with a polyclinic were integrated into a community health centre called a puskesmas (Pusat Kesehatan Masyarakat) which also functioned as a first level health referral system in the sub-district (kecamatan).

In the second development plan, Repelita II in 1975-80, the government set the target that every puskesmas should be equipped with at least one trained midwife and one medical doctor. In Repelita III in 1980-85, the role of the community was noted as key to improving healthcare programs, and for that purpose the government created a posyandu at the district level with five priorities: nutrition,
care for diarrhoea, family planning, vaccination, and mother and child health. The responsibility to implement these activities was placed on indigenous healthcare cadres, under the supervision of trained midwives. To formulate his political commitment, in June 1988 the President promoted the reduction of the maternal mortality rate by 50%, from the then current rate of 450 deaths per 100,000 live births, by announcing a Safe Motherhood Initiative through the strategy “60-60-60%”, that represented 60% of health centres in every county/regency providing essential basic maternal care, 60% of deliveries to be assisted by trained healthcare personnel, and 60% of high risk cases supported in referral hospitals.

In December 1996, President Soeharto formally announced the Safe Motherhood Movement, which was to be conducted by the community in collaboration with the government to improve the quality of life of women, especially by reducing the maternal mortality rate, to enhance the development of human capital. The movement was institutionally well structured in the community as well as in the government. The leading institution for the movement was the Ministry of Women’s Empowerment (formally the State Ministry of Women’s Role) in cooperation with the Ministry of Health, the National Coordinating Board for Family Planning (BKKBN), the Department of Domestic Affairs, and included the participation of NGOs and the PKK as key partners.

**Figure 1:**
The Formal Structure of the Safe Motherhood Movement (GSI)

Source: (Cholil, Iskandar, & Sciortino, 1999)
Unlike the Mother and Child Health Program, the Family Planning Program in Indonesia was not developed before the 1970s because it did not receive any political support from the government. The family planning movement itself, however, began in Indonesia in 1957, initiated by the Indonesian Planned Parenthood Association (IPPA) or Persatuan Keluarga Berencana Indonesia (PKBI), and affiliated with International Planned Parenthood Federation (IPPF). The objective was to provide birth control advice and maternal as well as child care, especially in the case of high risk pregnancies. The family planning movement was not, however, seriously supported by the Indonesian Old Order government, as then President Soekarno, like many other post colonial leaders of newly independent countries, was a pro-natalist (Samosir, 1993, p. 27). According to Soekarno, contraceptives would be detrimental to Indonesian sexual morality (Kroeger, 2000, p. 125). Due to the lack of political support from the government, funding agencies through the PKBI and some NGOs took a ‘silent’ approach, by sending intellectuals to study family planning abroad (Adrina, Purwandari, Triwijati, & Sabaroedin, 1998, p. 74).

The Family Planning Program in Indonesia was influenced by the New Order government of Soeharto, who was convinced that high population growth leads to developmental problems. The objectives of the first twenty-five year long-term plan, called the PJP-I (1969-1993), mentioned that economic development and welfare can be improved by a reduction in population growth through family planning. Influenced by western educated technocrats sent abroad during the Old Order era and the World Population Declaration 1967, Soeharto’s government brought about a shift in Indonesian population policy, from pro-natalist to anti-natalist, introduced a population control philosophy to overcome the population problem in the country, and made strong commitments by signing the Declaration of World Leaders in 1969. The first step taken in 1969 was to limit the population by controlling birth rates (Samosir, 1993, p. 27). A year later, Soeharto launched the Family Planning Program and set up the National Board of Family Planning (Badan Koordinasi Keluarga Berencana National, BKKBN) in 1970 (Niehof, 1994, p. 15). This approach to population control has influenced Indonesia’s fully established state led population policies and was used as a basic principle for fertility regulation. The previous slogan of “The more the children, the more happy and prosperous the family” was intentionally changed to slogans such as “Two children are enough”.

In the first Five Year Development Plan, called Repelita-I (1969-1973), family planning was still at the stage of preparing the foundations for implementation. At that time, it was part of the overall health program and was being executed by a private organization, though gradually it became a government program and has ever since constituted an integral part of national development. The main focus of the program was to bring down population growth by reducing the birth rate in order to increase the standard of living for people and the standards of health and
welfare for mother and children. At the time of the *Repelita*-I, the idea of fertility control was, however, still very sensitive, especially from a religious point of view, hence a clinical approach was the best way to make population control, the strong ambition of the government, acceptable. From *Repelita*-II up to IV, the government’s ambition to achieve the target of reducing population growth became stronger and more explicit. Family Planning Program implementation focussed upon reduction of the total fertility rate by up to 50% (Adrina, Purwandari, Triwijati, & Sabaroedin, 1998, pp. 75-76). The main objectives of the Family Planning Program in *Repelita*-II were intensification of the program in order to increase family planning acceptors and maintain their continuation through co-ordination with other development programs. In *Repelita*-III (1978-1983), population policy began to be more clearly outlined. In it, the long term objectives of family planning were to reduce the fertility rate, increase life expectancy at birth, and reduce the mortality rate. For short term objectives, the program activities aimed at improving the standard of living for those who accepted family planning. Implicitly, it implies that those who did not accept family planning were excluded from certain benefits.

In *Repelita*-IV (1983-1988), the concept of ‘Family Planning Program Management by the Community’ was introduced. The objectives of family planning policy were specified in more detail. A low birth rate was targeted and the norm of a small family was institutionalized. At this stage, the role of community based movements, as agreed during the World Population Conferences in Bucharest 1974 and Mexico City 1984, was acknowledged. Even though the main goal still was to reduce the fertility rate, in order to achieve the population growth targets the family planning objectives in *Repelita*-V and VI acknowledged the importance of considering human resource development. This is how the Family Planning Program became a community movement. During this period, coverage of the Family Planning Program was increased and reached out to even remote areas and new settlements, with the objective of increasing demand for long term contraceptive methods and improving the quality of family planning and contraceptive services, including health services. For this purpose, one of the main policies was to increase participation of the local community, such as social organizations and businesses, in the management of the Family Planning Program.

For implementation of Family Planning Program activities, the National Board of Family Planning worked in collaboration with other ministries and institutions, such as the Ministries of Health and Home Affairs. The Family Planning Program encourages community participation as a program strategy by acknowledging community based movements in family planning objectives. Thus, Village Community Development Institutes (*Lembaga Keamanan Masyarakat Desa* or LKMD) have been set up at district and sub-district levels, under the Directorate of Rural Development, Ministry of Home Affairs, responsible for promoting community
participation in the planning and implementation of development programs, including family planning (World, 1990, p. 121). The LKMD is led by the Head of the Kampong/County (Kepala Desa), and in health related programs it is supported by the PKK, led by the wife of the Kepala Desa (Sciortino, 2007, p. 114). To achieve family planning targets, the National Board of Family Planning created a formal institution known as Family Planning Program Fieldworkers (Petugas Lapangan Keluarga Berencana, PLKB) under the LKMD, which mostly consisted of housewives from the villages who were also members of the PKK. In the community, these fieldworkers were also known as family planning cadres (Kader KB).

By 1996, there were more than 20,000 trained fieldworkers throughout the country. Their tasks included motivation of the local community and assisting them by providing contraceptives, simple training, and family planning literature. To accomplish their task the fieldworkers get support from another institution known as Village Family Planning Management Assistance (Petugas Pembantu Keluarga Berencana Desa, PPKBD). The PPKBD is a voluntary institution, which assists the village chiefs in family planning related activities. At its peak there were about 76,000 village distribution centres and 315,000 sub-village distribution centres contributing to the Family Planning Program. However, these formal institutions are generally more engaged in their own hierarchical institutional snares rather than disseminating family planning information and materials (Samosir, 1993, p. 44).

To achieve the target numbers for those accepting family planning, the Family Planning Station (Pos KB) and Acceptor Groups (Kelompok Akseptor) have been created by the PKK, responsible to the Ministries of Home Affairs and Women’s Affairs. These ‘acceptor groups’ are lead by the fieldworkers to promote family planning services in the community. Acceptor groups usually comprise of between 15 to 30 female family planning acceptors. In regards to the Family Planning Program, the PKK is responsible for designing and managing the local initiatives, such as distributing contraceptives, motivating potential acceptors, and consulting new acceptors. The National Board of Family Planning uses the PKK to monitor birth rates and to increase the number of acceptors (United Nation Population Policies and Programmes, 1993, p. 134). A community pressure strategy, as applied through the PKK, was indeed a very successful way of achieving target numbers for family planning acceptors. For example, a woman would be embarrassed if she did not join the Family Planning Program while most of the women in her environment use contraceptives. She would also not be able to avoid family planning if a PKK cadre or fieldworker visits her almost every day asking her to join the program (Adrina, Purwandari, Triwijati, & Sabaroedin, 1998, pp. 97-100).

The PKK was thus an integral part of the overall government movement to reduce infant mortality, maternal mortality, and population growth through the Safe Motherhood Movement and Family Planning Program, as community health
workers; i.e. local inhabitants selected by the community, mostly working as part
time volunteers, given a limited amount of training to provide basic health and
nutrition services, and working in close relationship with the healthcare system. In
the 1980s there was an attempt to convert community health workers into large scale
programs; however, this often resulted in some loss of flexibility and commitment
at the local level, which then led to a narrow and less idealistic definition of the
concept (Walt, 1988, pp. 4-5).

The PKK’s contribution has been very important in promoting family planning
in society. PKK cadres actively involved as posyandu cadres or fieldworkers have an
important role in mobilizing the community, especially housewives. However, as
stated by Shiffman (2004), strong government support and political will for the Safe
Motherhood Movement and Family Planning Program was the key factor for the
success of the programs.

The Safe Motherhood Movement and Family Planning Program show that the
government of Indonesia is capable of making a program work, i.e. bringing family
planning technology to the people, with support from the community through the
PKK. These two programs are considered to be very relevant in terms of women’s
roles as wives and mothers. Unfortunately, the programs have also had a negative
impact, in terms of muffling women’s voices to fight for their rights (as they were
used during the previous President Soekarno era) (Katjasungkana & Wieringa, 2003;
Wieringa, 1992; Wieringa, 1998). Indonesian women have no longer been able
to voice their rights and they have had a tendency to support the programs only
because they feel they have to, because of their duty as a wife and mother.

4.B. Engaging in PMTCT

During the New Order regime, PKK members as family planning fieldworkers
used to receive a regular salary out of the National Budget Plan for Income and
Expenses (Anggaran Pendapatan dan Belanja Negara, APBN). However, when the
economic crisis hit Indonesia in the 1990s, PKK activities could no longer be funded
automatically by the government. Since the crisis, things have changed. Subsidy
for the Family Planning Program is has reduced due to the limited national budget.
The fieldworkers no longer receive a regular salary from the government. Without
funding, the activities are not being done effectively, and the regular PKK activities
have almost disappeared. Those that remain are only non-routine activities which
do not cost a lot, and the cadres only receive reimbursement for transportation.
However, the well organized structure of the PKK has still been an effective vehicle
for mobilizing the community and for supporting the programs of the government
or NGOs. YPI has seen this opportunity and has included the PKK in their PMTCT
program, especially the mobile VCT program that aims to identify and prevent HIV among pregnant women in certain districts.

In an interview with a PMTCT program manager from YPI, I learned that the involvement of PKK cadres in the PMTCT program has proved very helpful. The role of the PKK cadres is to mobilize pregnant women to access HIV testing through the mobile VCT service. Before commencing their activities, PKK cadres are asked to participate in at least a basic training program on HIV/AIDS and its spread, as well as on the mobile VCT activity itself. It is then hoped that the cadres can explain these issues to pregnant women and encourage them to access the mobile VCT activities.

YPI decided to work together with the PKK in running mobile VCT at the village (Kelurahan) level, because women who are involved in the PKK are familiar with their community. They have a list of pregnant women at the Neighbourhood Association and Community Association levels, and are considered very successful at persuading women to engage in activities. Typically, YPI writes to the Lurah (Head of the village, usually a man, thus also called Bapak Lurah) to invite PKK members and cadres to join PMTCT training at the YPI secretariat. The Lurah, usually helped by the local head of the PKK (often his wife), recommends two or three PKK members or cadres who will participate in the training. YPI has definitely enjoyed the benefits of having PKK members involved in their activities. On the one hand, it is not an easy task to reach pregnant women in the community without the help of the PKK. On the other hand, PMTCT is also seen as providing benefits for PKK members, e.g. to increase their knowledge about HIV/AIDS and PMTCT, to improve their organizational skills, to enhance PKK activities in the health service, and to intensify the relationship between PKK members in different villages (Husein Habysyi, PMTCT Program Manager).

VCT is the entry point to the PMTCT continuum of care. To conduct the mobile VCT, the YPI team might, for example, predict a potentially high risk location, suspected of having a high number of injecting drug users (IDUs). The team then goes to the community and introduces the program through the informal community leaders. Meanwhile, the team contacts the PKK and looks for its members who are willing to participate in the program as cadres and provides trainings on HIV/AIDS and antenatal care for them. The cadres are the spearhead of this program because they are involved as community health workers who have direct contact with the community.

The task of the PKK cadres is to invite pregnant women to come to a meeting of the mobile VCT, usually conducted in the community meeting place. The cadres
receive a transportation fee based on the number of pregnant women they bring along (I will describe the benefits they get in the next chapter); thus the more women they bring along the more money they may get. About 20-30 women attend the meeting where the YPI counsellor introduces HIV/AIDS and antenatal care. Afterwards, the pregnant women have a pre-test face-to-face counselling session in a small individual booth where the counsellors motivate them to do an HIV test. The mobile VCT administered by YPI is not provider driven since there is a pre-test counselling step in which the counsellor has to ask for informed consent from the pregnant women before they have their blood tested. If the women agree, a well trained nurse draws their blood to be examined. All the women who come to the meeting receive a vitamin supplement to prevent anaemia during pregnancy and snacks, but those who do the blood test also get a transportation reimbursement fee of about 15,000 IDR\textsuperscript{15}.

A week after the meeting, only the women who had the test are invited back for post-test counselling with the same counsellor, who will inform them about the result of their test in a closed envelope. If the result is negative, the mother is asked to maintain her HIV status, and if needed to change her behaviour, for example engage in safe sex. If a women tests HIV positive, YPI asks her to join the TOP Support group for the PMTCT continuum of care, where will be able to access free ARV prophylaxis, a caesarean delivery, a PCR (Polymerasi Chain Reaction)\textsuperscript{16} test, formula milk for her newborn baby, and other forms of psychosocial support. At post-test counselling, all women get another transportation fee reimbursement of 15,000 IDR. However, the mobile VCT service can only be accessed by a woman once. If a woman needs to go for re-testing, she may have to go to a clinic or referral hospital and pay a fee for the VCT service.

In the first phase of the YPI mobile VCT program in 1999-2000, funded by Becton Dickinson, 574 pregnant women were reached in five slum areas in Jakarta, short of the target of 1000. Six of those who accessed the mobile VCT in this first phase tested positive. In October 2003 YPI continued their second phase with a similar format and aimed to reach 2000 pregnant women in Jakarta. This time it was funded by the Global Fund. They conducted mobile VCT services in 18 locations, which included 12 villages, 2 clinics, 2 NGO sites, and 2 community health centres (puskesmas).

\textsuperscript{15} Equivalent to US$ 1.7 (as US$/IDR = 8,800 IDR in January 2011)

\textsuperscript{16} A PCR Test is an HIV test that detects the genetic material of HIV itself, rather than antibodies or antigens. This test is a fairly recent development in DNA testing and the results are relatively quick to determine, usually within 3 days to a week.
In the period of October 2003 to December 2006, YPI, with the support of the PKK, motivated 2,771 pregnant women to access the pre-test counselling service at the mobile VCT; 2,458 of these women had an HIV test, but only 2,113 came back for post-test counselling and got the result of the test. Eight women were confirmed HIV positive.

Considering the amount of money spent on carrying out the mobile VCT program, only a small number of sero positive pregnant women have been found through mobile VCT. This does not mean, however, that YPI has been wrong in choosing the target areas for its program. The low number of women testing positive is more likely due to the relatively low prevalence of HIV/AIDS in Indonesia. The success of YPI and the PKK should not determined by how many sero positive pregnant women have been found by the program, but by looking at the number of pregnant women who have been motivated to undergo both the pre-test and post-test counselling. The PKK has had a great role in mobilizing the community to test and know their status.
Table 1: Pre-Test and Post-Test Counselling at the Mobile VCT in Jakarta

<table>
<thead>
<tr>
<th>Locations</th>
<th>Pre-Test Counselling</th>
<th>HIV Test</th>
<th>Post-Test Counselling</th>
<th>HIV Positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>BC Bonzie</td>
<td>43</td>
<td>40</td>
<td>38</td>
<td>.</td>
</tr>
<tr>
<td>Bukit Duri</td>
<td>129</td>
<td>110</td>
<td>91</td>
<td>.</td>
</tr>
<tr>
<td>Ciracas</td>
<td>103</td>
<td>98</td>
<td>79</td>
<td>.</td>
</tr>
<tr>
<td>Jati Bunder</td>
<td>1042</td>
<td>919</td>
<td>803</td>
<td>4</td>
</tr>
<tr>
<td>Johar Baru</td>
<td>174</td>
<td>163</td>
<td>144</td>
<td>.</td>
</tr>
<tr>
<td>Kampung Bali</td>
<td>48</td>
<td>46</td>
<td>37</td>
<td>2</td>
</tr>
<tr>
<td>Klinik Mandiri</td>
<td>139</td>
<td>112</td>
<td>96</td>
<td>.</td>
</tr>
<tr>
<td>Klinik Remaja</td>
<td>25</td>
<td>23</td>
<td>23</td>
<td>.</td>
</tr>
<tr>
<td>Krukut</td>
<td>67</td>
<td>62</td>
<td>52</td>
<td>.</td>
</tr>
<tr>
<td>Manggarai</td>
<td>27</td>
<td>26</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>Pademangan</td>
<td>52</td>
<td>51</td>
<td>49</td>
<td>.</td>
</tr>
<tr>
<td>Pademangan Barat</td>
<td>26</td>
<td>24</td>
<td>12</td>
<td>.</td>
</tr>
<tr>
<td>Pasar Minggu</td>
<td>26</td>
<td>24</td>
<td>21</td>
<td>.</td>
</tr>
<tr>
<td>Petamburan</td>
<td>140</td>
<td>136</td>
<td>123</td>
<td>.</td>
</tr>
<tr>
<td>Puskesmas Johar</td>
<td>26</td>
<td>24</td>
<td>19</td>
<td>.</td>
</tr>
<tr>
<td>Puskesmas Tebet</td>
<td>113</td>
<td>86</td>
<td>44</td>
<td>.</td>
</tr>
<tr>
<td>Rawa Bunga</td>
<td>571</td>
<td>497</td>
<td>441</td>
<td>1</td>
</tr>
<tr>
<td>Sanggar Kerja</td>
<td>20</td>
<td>17</td>
<td>17</td>
<td>.</td>
</tr>
<tr>
<td>Total</td>
<td>2771</td>
<td>2458</td>
<td>2113</td>
<td>8</td>
</tr>
</tbody>
</table>

Source: extracted from YPI Documents

Since its beginnings in 1999, the PMTCT program has not run continuously, as its dependence on funding agencies is very high. When the funding agency stops financing the program, it cannot be continued further. In 2002-2003, the program was disturbed because there were no funds. Even though they wanted to continue the program in 2006, they had to pause again because they were waiting for funds from the Global Fund. Based on the request of the Global Fund, YPI expanded their
activities to six provinces beyond Jakarta – Banten, West Java, Central Java, East Java, South Sulawesi, and Papua – though this caused the activities in Jakarta to stop because of lack of budget. The project was postponed in 2007 but was continued in 2008 with funds from the Global Fund.

**Figure 3:**
Mobile VCT Expansion in Six Provinces

As mentioned earlier, the PKK functions in the mobile VCT program through its POKJA IV, which in turn uses Posyandu activity. The population targets of Posyandu are those who do not have (good) access to hospitals and health clinics, either because they find the hospitals and clinics expensive or they live in a remote area that is far from the hospitals and clinics. This unfortunately means, however, that people who are able to access health services at hospitals and clinics cannot be reached by the Posyandu network to participate in the mobile VCT program. VCT programs are not available at every hospital or clinic, and even where they are provided, they are not always free.

### 4.C. Existing Trust and Networks Versus Clients’ Privacy

YPI makes use of the existing trust in and network of the PKK to promote PMTCT. Good trust and networks enable PKK cadres to do their job effectively in promoting mobile VCT in the community. The trust built up by PKK is based on their identity as
members, which is related to their identity as responsible mothers. This kind of trust is called ‘identity-based trust’ or ‘relational trust’; and it arises from an intersubjective social reality based on shared meaning between trusting partners. It is generated in conjunction with normative social control through the construction of a particular identity that leads actors to exhibit goodwill and to tolerate a situation of exposure to risk, harm, and opportunism (Maguire, Philips, & Hardy, 2001). Because of their identity, PKK cadres can easily persuade pregnant women to visit the mobile VCT location. Interviews with pregnant women who came to the location have shown that these women trust the cadres, even when they have not received clear information about the program. These women’s husbands also trust PKK cadres. Ibu Suryati from Cileduk said:

I told my husband I was asked by a PKK cadre. ‘Go ahead!’ he said. ‘If a cadre asks you, you go ahead. They will never give you any bad service, never.’ (Ibu Suryati, 32 years, pregnant, Cileduk)

It is very possible that the cadre who asked Ibu Suryati to attend the mobile VCT program had not been involved in the Safe Motherhood Movement and Family Planning Program at the Posyandu, considering that these PKK activities had been more or less abandoned for the last ten years. Yet, as the PKK has maintained its good identity as an institution, a PKK cadre also has a good identity as a person; it is the identity of a responsible mother as well as a woman who helps promote women’s health. Nooteboom (2007, p. 30) argues that trust may be built on a personal basis within relationships; it may also arise more impersonally on the basis of institutions outside relationships. To the extent that there are no institutions that support trust, trust must be built entirely from relationships; but, without institutional support, that can be laborious and such trust can prove fragile. Nooteboom further added that to form institutionally based trust as the basis for trust in people, one must have trust in those institutions. Without such trust, it would be almost impossible for pregnant women to go out of their domestic sphere, as explained by one of the cadres in an FGD:

If it’s not us looking for them in their own neihbourhood, they’d be unsure. But because they know us from the PKK at the RW (Community Association), they believe us. If not, they’d be confused and scared. (PKK cadre in an FGD)

Aside from trust, the other main form of social capital of the PKK is their social network. The network is clearly visible when PKK cadres look for data regarding pregnant women, who are the main target for accessing mobile VCT. Without a good
network, it would be very difficult for the cadres to know the number of pregnant women in their district and where they live, considering that the district coverage is generally quite wide. Some different networking mechanisms were applied in the districts to find the pregnant women.

At Rawabunga village, they have the ‘pregnant mother post’ that registers the number of pregnant women in their district. This registry is present in every Community Association. Pregnant women’s data are collected by the local PKK cadres at the Community Association level by visiting each family. So, in order to get data on pregnant women, PKK cadres can be contacted. Invitations to join the mobile VCT activities are also distributed by the PKK cadres at the Community Association level, who later visit the pregnant women door to door.

Because of lack of budget, there are only two cadres at the sub-district level at Rawabunga who have become the brokers between YPI and pregnant women. They are Ibu Jubaedah and Ibu Ucum. In practice, they are in turn supported by three cadres at the Community Association level. With the ‘pregnant mother post’, the cadres’ work-load is reduced.

Just ask the cadres: ‘How many people from the RW (Community Association) 09 will come?’ We just need to write down their names until we get 30. There is data on pregnant women, just like the Family Planning Program. They have to report to us every month: how many women are pregnant, how many have delivered babies. They all happen at the ‘pregnant woman post’. We just go there, the jumantik day’s on Friday, and we just bring our note and check it. So, we’re looking for the jentik (mosquito spawn), as well as pregnant women. (Ibu Jubaedah, a PKK cadre at Rawabunga)

YPI just asks for three cadres. They can work in turn; anyone who can help to find the pregnant women is accepted. These women are from the whole RW, the RT (Neighbourhood Association) 01 until 09. I was just looking for them from the kelurahan (village) area, at Rawa Bunga. But Rawa Bunga didn’t have any, I then moved to Pulo sometimes or Bukit Duri. I just needed to call and ask, ‘Do you have any pregnant women? You can let them come here because there will be a free blood test... Oh, OK’. The ‘pregnant woman post’ began in 2005, actually in 2004 it started already, but in 2005 it was smooth. (Ibu Ucum, a PKK cadre at Rawabunga)

At Pasar Minggu village, PKK cadres use the existing network in the existing system, such as the data from the Community Association office, posyandu, puskesmas, or arisan at the Neighbourhood Association level. So, the cadres contact the Community Association office to get the data on pregnant women. If the data is not available at the Community Association office, the cadres contact Posyandu. The
information on the mobile VCT is also spread during the women’s gathering which is regularly held once a month. After the data on pregnant women is collected, the cadres will visit them at home one by one and explain the goal of this activity, as explained by the cadres below:

Let me explain: there are ten RWs (Community Associations) in a kelurahan (village). Within those ten RWs, it’s not always the case that there are a lot of pregnant women in each RW. That’s why we list them all… We visit them again, explain again as best as possible so that they want to join, hopefully with pleasure. (Ibu Slamet, a PKK cadre at Pasar Minggu)

There are, for example, ten pregnant women from our RW; I would call to ask how many women are pregnant in the RW 01, then the next RW, etc. I would tell them about the PMTCT and whether they are interested. Usually they would say yes. ‘I’m looking for thirty people, together with Bu Slamet.’ I, sometimes together with Bu Slamet, was looking for them door to door, I would come to their houses and ask them about their pregnancy and ask, ‘Do you want to join us madam?’ I’d call the RW, letting them know how many pregnant women I’ve got. At the RW level sometimes they didn’t know and had to call Posyandu first. The Posyandu includes three RTs (Neighbourhood Associations). If there’s an arisan here, I’ll tell them the news from kelurahan (village). Usually the gathering is on the 6th of every month. During the gathering, I’ll tell them any problem we’ve got. So, I expect that all the women in our RT come to the gathering, I mean PKK cadres at the RT level. The secretary is ok, the treasurer is also ok. If there’s anything I have to say from YPI, for example, I’ll tell them in the gathering. YPI, for example, has asked for the list of the pregnant women in my RT. I’ll collect the data from my RT and visit them. (Ibu Suciasih, a PKK cadre at Pasar Minggu)

Just like the cadres at Pasar Minggu village, Johar Baru village also has an advantage by getting the data on pregnant women from posyandu.

We don’t invite them directly. We ask the Posyandu workers first, usually we tell them we need some pregnant women, we ask for their data. After getting the data, we visit them. Usually they’re okay with that. We give them the date. If they don’t show up in the meeting, we visit them, come to their houses. (Ibu Fitri Handayani, a PKK cadre at Johar Baru)

At Kampung Bali village, however, cadres would contact other cadres directly during their activities at the POKJA. After collecting the data, the cadres contact the pregnant women one by one to explain the goal of the mobile VCT activity.
I informed the other PKK cadres and said, ‘Please get the data of the pregnant women and give it to me’. Because I’m the member of POKJA, they can give the data to me. I go with Bu Titin to visit and see people. Other PKK cadres are also involved and if we’ve got the budget, we give them some transportation fee. There are ten RWs (Community Associations) and each is taken care of by a cadre. The RW 01 by Bu Nurhayati, RW 02 by Bu Elly, 03 also by Bu Elly, 04 by Ms Iistiqomah, 05 by Bu Nursamin, Bu Leha, etc. We try to make a connection. We get the data from them, they’ll show us who are pregnant…and so forth. So, it’s not really an individual work. Especially Ms Titin, she has to visit them, I usually only call. When we meet, we’ll talk and plan to visit them. They usually come on the day of the meeting. If they don’t come, we call the cadre and ask why they don’t come, so that we don’t have to wait only for them. (Ibu Supriati, a PKK cadre at Kampung Bali)

Trust and good networking are the social capital owned by the PKK that make it possible to provide a more effective mobile VCT service. Unfortunately, however, when the pregnant women are found through the mobile VCT to have HIV, the good relationship and network may have a boomerang effect. As already mentioned above, an HIV test result is given to a pregnant woman in a sealed envelope during the post-test counselling. Theoretically, PKK cadres should never find out the test results of the women, unless told by the woman personally. However, this does not mean that the PKK cadres have no suspicions of who has been found HIV positive. When YPI staff visit those who are infected or when the pregnant women who are infected come to YPI for a further consultation, PKK cadres will easily recognize them and this information is passed on to other people throughout the network. Confidentiality for the women is not an issue for the cadres. This, in addition to the community stigma, is probably the reason why pregnant women are reluctant to follow the further activities at YPI once they find out they are HIV positive.

I once met the husband of one of the woman who had been found to be HIV positive through a mobile VCT. At that time, I was visiting her at home with a YPI staff member. Her husband clearly said that he forbade his wife to join any follow-up programs at YPI because their family had suffered from societal stigma as soon as it was found out that she had gone to YPI after participating in the mobile VCT program.

In an in-depth interview with Ibu Mumun, a cadre from Jatibunder, she admitted that she knows who among the tested women have HIV, although she also mentions that this information is only for her and not to be told further:

In my neighbourhood, there are few of them. I know that, but it is a secret. I can tell you who have it and who do not. Take Haris Masdi, I took his
wife to a mobile VCT location. Yuni (his wife) uses syringes (drugs). Haris and his wife. Then she gets pregnant. I asked her, ‘How far along are you, Yun?’ ‘three months, Mpok (Sis) Mumun.’ ‘Do you want to join my program?’ ‘What kind of program?’ ‘The one for HIV because I’m concerned for the baby. You use syringes (drugs), don’t you?’ ‘Yes, Mpok Mumun, I want to.’ ‘You will be given medicines, the medicines are expensive you know!’ ‘Yes Mpok Mumun, it’s free of charge. How do you know that I’m using drugs?’ ‘From your face, from your scars.’ ‘Please don’t tell anyone!’ Leli, her husband, died of HIV. I met him for the last time at Cipto (hospital). At YPI he didn’t get many medicines. He should have been taken to Dharmais instead of Cipto. He finally died. The medicines didn’t work. I don’t tell anybody, no I don’t! (Ibu Mumun, a PKK cadre, Jatibunder)

It is therefore not surprising that those who are found HIV positive through the mobile VCT are reluctant to join the support group and follow-up program. Those who do join are mostly referred by hospitals or clinics.

4.D. Keep Her Away to Keep Me Clean

As explained earlier, YPI uses the PKK as a vehicle to promote PMTCT, similar to how the PKK was used to promote the Safe Motherhood Movement and Family Planning Program. YPI hopes that the PKK will not only participate in mobilizing pregnant women to take part in the mobile VCT program, but also in distributing knowledge about HIV/AIDS to the community in order to make PMTCT successful. Unfortunately, in doing their tasks as community brokers for the mobile VCT, PKK cadres are faced with a dilemma. Fear and shame of the disease is a big obstacle faced by the cadres in doing their job, but social obligation makes them join anyway. As human beings, PKK cadres are afraid of the disease; additionally, they feel it is also shameful to be involved in the program due to the social stigma attached to HIV/AIDS.

Once, I was asking Mumun, a PKK cadre at Jatibunder, what she felt about HIV. She did not say how she really felt about it; rather, she told me about other cadres’ experiences in dealing with PLWHA. She said she was able to handle her feelings, but that some of the cadres were still afraid of the ‘dirty’ illness. She told me about her conversation with Ucum, a PKK cadre at Rawabunga who she had known since 1999, when they both joined the mobile VCT activities. Considering what she told me, I got the impression that Mumun had the same fears about the disease as Ucum did. From her explanation, I saw that it was also a dilemma for her. On the one hand, Mumun feels that as a PKK cadre who has participated in a PMTCT program for quite a long time and has participated in HIV/AIDS training, she should not stigmatize...
PLWHA. Yet, as a part of society, Mumun has a negative perception of HIV/AIDS and PLWHA.

I’m ok with that, others are afraid, just like Bu Ucum. I had a training on PMTCT in Puncak. Yanti, a PLWHA, joined it. When she was washing before praying, I said to Bu Ucum, ‘Bu, there is a PLWHA here.’ Are you kidding?’ ‘You don’t know? You look for people right, I know which one is infected or not, I do.’ ‘How do you know?’ ‘I know that Bu Ucum only does her job to look for pregnant women, but actually she is afraid of HIV. ’No, I just want to know which one.’ ‘Do you want to know which one is a PLWHA?’ ‘What is PLWHA?’ ‘You don’t know!! People who get infected with HIV, just the symptoms, not yet really positive, just the beginning.’ ‘I see, that’s PLWHA.’ ‘Don’t you know?’ ‘I don’t.’ Later on, Yanti sat down, Yanti has just got infected, not yet AIDS, just the virus. ‘Which one?’ ‘This one.’ ‘I see, she’s thin.’ ‘These people are thin, if she still continues she’ll die, but if she doesn’t she can be fat again, don’t tell other people.’ ‘I won’t. But Bu Ucum didn’t want to get close to Yanti. She ran away. ‘I want to go, Yanti is there!!!’ I’m handling the PLWHA differently. There’s one at Kebon Jeruk, very beautiful, but she is HIV infected. Bu Ucum would run away, ‘No, dirty, afraid.’ She doesn’t want to touch or even sit near her… (Ibu Mumun, a PKK cadre Jatibunder)

It is not only Ibu Mumun and Ibu Ucum who fear the disease but almost all of the PKK cadres who are involved in the mobile VCT. In an FGD, the cadres told me that even though they know about HIV from the training, they are still unsure about it, as exemplified by the statement below:

When I went to a villa of paralyzed people, the place for PLWHA, I was afraid that the water, I was afraid I drank the wrong one. The normal PLWHA and the PLWHA who are sick are in the same place, I was a bit scared. She asked, ‘It’s ok to touch.’ She shared the room with one of the women with HIV, but she locked her out. She thought that HIV people should get some scratches because it is related to the blood. But, hmm… One of them sat next to her… (PKK cadre, FGD)

As an effort to deal with fear and shame of the disease, as well as to minimize the stigma and discrimination against PLWHA, YPI regularly provides training for the cadres. The stigma of HIV/AIDS can be minimized by enhancing knowledge about the disease and how it can be prevented. However, enhancing knowledge on HIV/AIDS is not enough. Lack of knowledge may be one of the factors that makes the cadres worried, but training will not necessarily change the way they
behave towards PLWHA. Furthermore, the cadres who have been involved in the activities and trainings since the beginning still do not necessarily have enough and proper knowledge regarding HIV/AIDS, due to their limited capacity to absorb new knowledge. Training on HIV/AIDS offers no guarantee that they will not discriminate against PLWHA.

There is another fundamental obstacle hindering PKK cadres from actively promoting PMTCT into a full movement. Most still consider HIV to be a dirty and shameful disease that only infects bad women; therefore, HIV/AIDS represents values that go against their role as good and devoted mothers and housewives. Keeping the disease and those infected with it away from them is considered the only way to keep themselves clean. No matter how much training has been provided for the PKK cadres, they still attach a stigma to HIV/AIDS and to PLWHA.

Figure 4:
PMTCT Training for PKK Cadres

An example of how the PKK cadres do not fully engage themselves in PMTCT activities lies in their use of information, education, and communication (IEC) materials. In capacity building training, PKK cadres are provided with brochures and posters on HIV prevention and PMTCT to take away with them. Aside from allowing the cadres to read the materials in depth at home, having possession of these materials makes it easier for them to disseminate the information to the community. However, they never use the materials. Another example is that on one occasion the cadres were asked to demonstrate for PMTCT, together with members of TOP Support, in a rally on National AIDS Day. They did come with their children, but after that the activity stopped without any further actions.
Lack of government support, together with fear and shame of the disease, hampers the cadres in fully promoting PMTCT as a movement. In this case, YPI cannot expect that the cadres will promote PMTCT as they did for the Safe Motherhood Movement and Family Planning Program.

4.E. Discussion

The evolution of women’s organizations usually occurs along a continuum, from a social movement that mobilizes social forces for morality issues, into a formal organization that is sometimes used by political authorities to achieve certain goals or implement government programs (Saptari & Holzner, Perempuan Kerja dan Perubahan Sosial: Sebuah Pengantar Studi Perempuan, 1997, pp. 404-406). Like other women’s organizations in general, the PKK evolved from a movement for family empowerment with a focus on women’s welfare and healthcare into a politically well structured organization. Unfortunately, in its evolution, the PKK has lost its moral spirit as a social movement and rather has become a means for the government to restore and bolster the domestic role of women, and which only
aims at meeting practical gender needs\textsuperscript{17}. However, the PKK is still an effective vehicle for the government and NGOs to implement their programs.

The PKK's role in PMTCT programs is not very different from their role in the Safe Motherhood Movement and Family Planning Program. With all its limitations, the PKK can only function as an extension of the program provider. Soetomo (2008) cites Glassner & Freedman when they say that social services efforts by the nation will require interaction and mutual relationships between agencies, which function to prepare, organize, and deliver services; workers are very important in delivering and connecting services to clients; and clients' roles are to respond to and utilize the services (Soetomo, 2008, p. 257). In supporting the Safe Motherhood Movement and Family Planning Program, as well as the PMTCT program through the mobile VCT service, PKK cadres only play a role as workers that deliver the service to pregnant women. In this sense, the PKK can be seen as community health workers. While in the Safe Motherhood Movement and Family Planning Program it is the government that takes the role of the agency that provides the service, in PMTCT, the agency that designs and prepares the program is YPI. PKK cadres view PMTCT as work, similar to how they view the Safe Motherhood Movement and Family Planning Program. For them, success is when they are able to mobilize pregnant women, because they feel that they have helped other women by doing so.

However, it does not mean that the role of the PKK as a mediator or as workers is not important. There are supportive conditions that YPI benefits from through involving the PKK to promote PMTCT. Firstly, the PKK is an effective vehicle for reaching housewives. Using the formal power that it already had as a structured institution in society, the PKK has the ability to approach people, especially housewives. This is an important matter for supporting the PMTCT program considering that HIV/AIDS is a highly stigmatized disease. Pregnant women need an assistant that they can trust to bring them to VCT services; the PKK cadres' position as trusted members of an established organization will therefore support success in VCT programs.

Secondly, the PKK has social capital in the form of a social network, which can support the cadres in promoting PMTCT. According to Putnam (1993), networks, norms, and trust in the community are the social capital resources that can give personal strength to members and cumulatively become social assets, for they facilitate coordination and cooperation for mutual benefit. In this case, the active PKK cadres become an asset in supporting pregnant women to access mobile VCT.

\textsuperscript{17} Practical gender needs are the immediate needs that reduce women's burden, but do not mention gender inequalities such as the sexual division of labour or unequal access to services. Strategic gender needs are long term needs that eliminate gender imbalances within and outside the household, and ensure women's rights and opportunities to express their needs (Saptari & Holzner, Perempuan Kerja dan Perubahan Sosial: Sebuah Pengantar Studi Perempuan, 1997, p. 157).
The PKK has a special mechanism to get information about pregnant women in their own district. This makes it easier to reach pregnant women, even the ones living in more remote areas. Beyond facilitating access to VCT, in the long run the PKK may become a useful vehicle for setting up community support groups to support housewives in accessing HIV information or to support sero positive mothers in accessing ART. In addition, the formal network mechanism in the PKK’s organizational structure means that it has good and regular management, from the central to the district level. Thus, if the PMTCT program were to be administered at the national level in the future, PKK involvement might help simplify the activities, including monitoring and evaluating.

Unfortunately, however, despite their activities to support PMTCT through encouraging pregnant women to access to mobile VCT, the PKK as a social organization is still not able to create mutually beneficial collective action. Through its well organized and well structured organization, the PKK should have generated a movement to promote PMTCT in the community through collective action, as they did for the Safe Motherhood Movement and Family Planning Program. As Uphoff (2000, p. 228) has said, social organization should be able to make collective decisions, mobilize and manage resources, and disseminate information to create mutually beneficial collective action. As things stand, however, the PMTCT program cannot be expected to become a movement like the Safe Motherhood Movement and Family Planning Program. As far as I am concerned, there are some serious unsupportive conditions that distinguish the success of the PKK in supporting the Safe Motherhood Movement and Family Planning Program and in its support for PMTCT.

First, both the Safe Motherhood Movement and Family Planning Program have government support, as the government has paid great attention to mother and child health and stated its obligation to reduce population growth. The PMTCT program is an NGO initiative; it is not a government driven program. Neither the government nor society view HIV/AIDS as an emergency situation, as HIV prevalence is regarded as low. The government also does not recognize it as a social problem. Lack of government support is an obstacle for PMTCT programs being promoted in the wider community. Peter Piot, Director of UNAIDS, on his visit to Indonesia in 2005, said that lack of leadership and political will are the main obstacles to preventing HIV/AIDS transmission in Indonesia (Kompas, Tingkatkan Koordinasi, 2005a). PMTCT may not receive political support from the government because it is not triggered by a critical situation, and thus PKK cadres do not receive any government funds to conduct mobile VCT; in addition, the sustainability of NGO funding for PMTCT cannot be guaranteed. As a consequence, unlike the Safe Motherhood Movement and Family Planning Program, PMTCT may never become a nationally successful program, even though it has used the same existing social capital of the PKK.
Second, unlike the Safe Motherhood Movement and Family Planning Program programs that support the domestic roles of housewives in PKK activities, PMTCT is seen as a ‘dirty’ activity that threatens the image of the mother, who is portrayed as innocent and loyal to her husband and family. PMTCT, as an HIV prevention program, is still regarded as shameful and stigmatized, even by the cadres who have been trained and provided with information to combat such stigma. PMTCT does not fit into their role as a good mother and devoted wife. This may hamper them in promoting PMTCT into a national movement.

Third, like mother and child health and family planning services, PMTCT can only be accessed by married women. It is almost impossible for other groups of women, such as unmarried women and girls, to access the service. Family Planning Program propaganda has always be translated as “meant for married people only and not for virgin girls” (Pausacker, 2001, pp. 106-109). As a consequence, PMTCT will not be accessed by all women equally.

In addition to the above stated barriers, there are some internal obstacles within the PKK that have made it harder for the cadres to promote PMTCT. First of all, the PKK has not had any capacity to voice women’s rights since the New Order regime tried to suppress them and emphasized the domestic roles of women. The cadres have limited experience in promoting women’s reproductive rights, as they were only allowed to promote reproductive health and were strictly forbidden to talk about women’s or even citizens’ rights. The PKK is known as an institution that does not let women talk and that creates households as the only places for women. This can go against the aims of PMTCT, which is known as a program that supports women’s reproductive rights. Through PMTCT, pregnant women can apply their rights to prevent HIV/AIDS for the sake of their own reproductive health and the health of their babies. However, the PKK can only be used to mobilize people, not to fight for their rights. In other words, the PKK is not the right institution to empower pregnant women and to limit transmission of HIV in Indonesia. PMTCT may enhance the power and resources of the PKK in a specific domain, i.e. the reproductive sphere as mothers, but not to empower them to fight for their reproductive rights.

Second, the strong PKK networks mean that pregnant women who are found HIV positive through mobile VCT are reluctant to join the follow-up programs due to the social stigma spread about by the PKK cadres themselves. Although there is a special mechanism within mobile VCT to protect the confidentiality of all women’s HIV status, PKK cadres always find a way to know the results of the test. They do not really realize the importance of confidentiality and pass the confidential news around to the whole community.

Third, in finding the pregnant women, PKK cadres are using the existing networks of mother and child health and family planning, in collaboration with the government pregnancy clinics posyandu and puskesmas. These are designed for
Other women who face exposure to HIV, such as sex workers, will not be registered or found through this network (Pisani, The Wisdom of Whores: Bureaucrats, Brothels, and the Business of AIDS, 2008, p. 36). In this case, the mobile VCT may not be able to reach those women and is only being directed towards ‘good housewives’. It is therefore no wonder that most women are found HIV negative.

Furthermore, women attend the antenatal clinics for the wellbeing of themselves and their babies, so they cannot be regarded as volunteers for the initiative to combat HIV/AIDS. Considering the obstacles mentioned above, YPI cannot expect the PKK as an institution as well as individuals to be able to promote PMTCT as effectively as they did the Safe Motherhood Movement and Family Planning Program. However, in general, the involvement of the PKK in mobile VCT has been considered successful and therefore YPI has maintained the same format in running PMTCT in six other provinces. Considering the remuneration given to PKK cadres and the transportation fees given to the pregnant women, I worry that the PKK cadres, as well as the pregnant women, see PMTCT as just another type of income, instead of as a part of HIV prevention. Therefore, it is also worth discussing further why the PKK cadres like to join in this activity. I will go into this in the following chapter.
Empowerment of the Domestic Identity

Yayasan Pelita Ilmu, through its PMTCT program, has involved the PKK in order to help facilitate community prevention of HIV/AIDS. Unfortunately, due to the PKK’s limitations and lack of government support, as well as the ongoing stigma against HIV/AIDS as a dirty and dreadful disease, PKK cadres have only been able to function as community workers. They have not had much success in promoting HIV/AIDS prevention. For most PKK cadres, the PMTCT program is seen only as another type of work, a source of extra income; which is actually similar to how they viewed the Safe Motherhood Movement and the Family Planning Program.

In this chapter I examine how the PKK cadres make use of the identity of motherhood to grant them access to economic benefits through the PMTCT program; and further look at the extent to which motherhood, which gives access to economic benefits, empowers or disempowers PKK cadres.

5.A. Remuneration for PMTCT

Mobile VCT, administered by YPI, not only brings benefits for the pregnant women but also remuneration for PKK cadres. In each mobile VCT program, YPI has a special budget for those who are involved in this activity, including the cleaning service team and
security staff. They call the money offered a ‘transportation fee’, although it is not necessarily used for transportation per se. The money is not only for PKK personnel but is also distributed for regional benefit, i.e. to the Community Association, or for renting a room. The money is given to one or two key cadres who will divide it as they see fit. Every district has its own way of distributing the money.

At Rawabunga village, YPI gives some money to the two key cadres, who distribute the money as ‘transportation fees’ between themselves and some other accomplice cadres who help them. All the cadres receive 5,000 rupiah for each pregnant woman they approach. For example, a cadre can bring three pregnant women to join the mobile VCT. She will get 15,000 rupiah. The money given by the YPI is also used to pay fees for the Community Association’s petty cash, for renting a room and for a cleaning service, as explained by Ibu Jubaedah, one of the key cadres in Rawabunga:

About the transportation, for me, if I say (need to get) twenty-five (pregnant women), I give (the fees to) twenty-five (cadres). I also get some fees from YPI for being a coordinator, also for the RW’s (Community Association’s) petty cash and cleaning service, they (YPI) have a separate budget. It’s up to the RW whether he wants to give some (money) to PKK (as petty cash). We still give it, for example a hundred thousand rupiah (for the RW). For the cleaning service, we give it directly to the cleaners. If we get it from Ai (YPI coordinator), we give it directly to the cleaners. I think it’s enough… for people like us… better than if we don’t join… as long as we enjoy. I’ve got a lot of advantages, giving the society information about women’s health. I’m also grateful that the society gets involved, so those are the advantages. I am known by people. (Ibu Jubaedah, PKK cadre at Rawabunga)

When I discussed this with another key cadre, Ibu Ucum, I found that she also had a similar arrangement:

A person is 5,000 (IDR, which they get for each pregnant woman they invite to the VCT location). The cadres also get paid. So, there’s money for the cadres and pregnant women. So, it is informed directly to the cadre: ‘If you get pregnant women you will get this much/Oh, ok’. Ai (from YPI) would say, ‘This is for Bu Cum, for Bu Narti, Bu Pepen’, etc. Besides that, (there is) also some budget for cleaning service and room rent. Just give it (as one package) for the RW’s (Community Association’s) petty cash… (Ibu Ucum, PKK cadre at Rawabunga)
At Pasar Minggu village, there are only two key cadres who approach pregnant women one by one. YPI gives an amount of money according to the number of pregnant women they are able to bring to the mobile VCT. YPI also gives money for room rent and cleaning services. The cadres feel, however, that the money is not enough, as they are not helped by other accomplice cadres and sometimes have to find the pregnant women from other Community Associations which are located far away from their house.

I like joining the PMTCT, I get knowledge about the disease, I get money, tips. That’s what I want. I say I like being involved in PMTCT and getting money at the same time, I love it!! The budget is shared differently. For example, a room rent: last time when we rented the Abror mosque, we received 100,000 (IDR) and I got money as a cadre who guides. I don’t remember how much, I had to share the amount for the three of us. If we invite the Lurah (head of the village) and other PKK cadres, I asked that the cadres should get a little souvenir, as a sign of respect, so they know it is from YPI. They didn’t ask actually, but I feel like… If we use a mosque, the money goes to the mosque but not as a donation. I gave them 100,000 (IDR) for cleaning service. Actually, if using the mosque, it’s not a must to pay a certain amount of money. We can just use it, as long as you clean it afterwards, we can even borrow chairs because we get permission from the wife of the Lurah. At that time ‘…Can we borrow it?’ They didn’t ask for a certain amount. But I understand. Mul, the office boy, I gave him 50,000 (IDR). ‘This is for you/Thanks madam!’ The janitors were given money, but not the security. The security was not really involved so…we just rented the room. For me as a cadre coordinator, for each pregnant woman I get 5,000 (IDR). I get 30 pregnant women, so 30 x 5,000 is what I get. That’s what I know. ‘You get 30 pregnant women, for each you get 5,000 (IDR) times 30/For whom is this?/For you.’ You know, I like it if PMTCT can hopefully give more money, will love it. If I get more transportation fee, you know it’s not only for paying the transportation cost, I need to go to the RW 10 as well, that’s far and costs a lot to pay for the ojek (motorcycle taxi). I don’t want to spend my time to search for pregnant women and spend money too, I don’t want it. They have to give my efforts a price, too, I have to get something… We get paid based on the activities! If there’s not any activity, we don’t get anything… That’s why I said if there’s an activity, it’s positive, if not… I have a lot of contacts… I’ll say who will pay me? …. Especially when we have to search for pregnant women. ‘Bu Slamet, let’s go to the RW 09?/I don’t want to, I want to ride an ojek!!’ So we have to
ride ojek to get there. ‘How much?/10,000/Are you kidding me? It’s 10,000 (IDR) just to get there. If it costs 10,000 (IDR) per day who can afford it? (Ibu Suciasih, PKK cadre at Pasar Minggu)

At the Johar Baru village, there is even a special amount of money for the Lurah (head of the village), aside from the money for the PKK cadres and cleaning service. Use of the room is free of charge because it is usually held at the Village Office, but they give money to the Lurah as usually he gives an opening speech at each mobile VCT. If the village office is occupied, they have to rent a room at a school. The money is given to the key cadres to be shared according to their needs. In Johar Baru there are three key cadres helped by two accomplice cadres, who mobilize the pregnant women to go to the mobile VCT location.

It’s not bad for getting extra money, sometimes the Lurah says that. He calls it Uang Pembuka (an opening speech fee). They’ve asked for a specific amount of money. Not too much…including the cleaning service. But not including the security, only cleaning service. But not at the Kelurahan (village office), it’s included already… The last time when it was held here (at the school), we had to pay for the rent. We rented it, but the amount is up to us. It’s 2.5 (250,000 IDR) or what…if I’m not mistaken…it’s a long time ago. Here (at the village office), it costs a hundred. At YPI it’s 150 (150,000 IDR) or something like that, I forget. The money is given first to us, we count it first and share the money, and then we pay them after the meeting. Usually we, PMTCT cadres, get some money from YPI. It’s not bad. It doesn’t cost a lot from my place to Kampung Rawa…we still get some. Sometimes the half of our fee is taken to give some to the cadres who have helped. It’s also from us. We get it from YPI, then the money from YPI we share with the three of us. For example, the three of us are PMTCT cadres, we collect the money from us, and then we give it to the cadres who have helped us. Without them we cannot succeed… (Ibu Fitri Handayani, PKK cadre at Johar Baru)

At Kampung Bali village, the mobile VCT location keeps moving from one Community Association Post to another. YPI gives the rent payment to the PKK cadres at the Community Association level who are responsible for the place, usually to the wife of the Community Association Head, who is the local head of the PKK.
The cleaning service fee is paid directly to the janitors. There are two key cadres helped by some accomplice cadres involved in the mobile VCT. The accomplice cadres, through the key cadre, get a certain amount of money depending on how many women they can approach. The key cadre gets a special payment.

If a room is used, we give it to the wife of the RW (Community Association Head), who is responsible for the activity. For example, I use the community post at RW 04, we tell the PKK it’s the RW 04, we have to know who is responsible, as well as the cleaning service payment, which is given directly to the cleaners. Cadres also get some. For example, the one responsible for RW 01 is Ibu Nurhayati, (she) gets two, we give her 5,000 (IDR), times two people, is equal to 10,000 (IDR). It works like that, we share the money. So, YPI gives the money to us. There is also some amount for us, 75,000 (IDR) for the two of us. I think there’s no money for the security... You know, cleaning service, room, like room rent…. Everything is paid by YPI, that’s all. For each pregnant woman, we get 5,000 (IDR), so it depends on the number of pregnant women, if we get many, just multiply it by 5,000 (IDR). Just like at the RW 07, 08, 09, 10, we’ve asked the cadres to get the data on pregnant women, we’ve asked them to search for the pregnant women and they’ll get money in return. But if it’s possible, don’t give us only 5,000 (IDR), if it’s possible a little bit more than that, so that the cadres are more enthusiastic. You know, looking for pregnant women is not a simple job. Some of the pregnant women don’t want to tell us that they’re pregnant because they’re afraid to get tested. ‘Maybe I have HIV, maybe I’m ….’ That’s what they’re afraid of. But we have to be patient with the women. ‘Come on, sit down.’ If nobody comes, we try to find more: ‘Join us, sit down.’ That’s the risk, we have to be patient. (Ibu Supriati, PKK cadre at Kampung Bali)

5.B. Profile of the Cadres

As mentioned in the previous chapters, the PKK cadres are referred to YPI by the head of the village. From 1999 until the end of 2006 when the data was collected, YPI trained seventy-three PKK cadres from eighteen villages in Jakarta to support the mobile VCT service, part of their PMTCT pilot project, as shown below.
Figure 1:
The Number of PKK Cadres Engaged in PMTCT in Jakarta

<table>
<thead>
<tr>
<th>CODE</th>
<th>Districts</th>
<th>no of PKK cadres</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Jakarta</td>
<td>Pademangan Barat</td>
<td>3</td>
</tr>
<tr>
<td>Central Jakarta</td>
<td>Karang Anyar</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Tanah Tinggi</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Johar Bari</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Kg Bali</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Jati Bunder</td>
<td>6</td>
</tr>
<tr>
<td>West Jakarta</td>
<td>Krukut</td>
<td>3</td>
</tr>
<tr>
<td>East Jakarta</td>
<td>Matraman</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Cipinang</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Kg Melayu</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Klender</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Rawa Bunga</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Kali Malang</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Ciracas</td>
<td>3</td>
</tr>
<tr>
<td>South Jakarta</td>
<td>Manggarai</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Bukit Duri</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Gandaria Utara</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Pasar Minggu</td>
<td>3</td>
</tr>
</tbody>
</table>

Source: Extracted from YPI Documents

The profile of the PKK cadres participating in the mobile VCT service varies. The data taken from the period 2004-2006 shows that most of them were middle aged (older than fourthy years), though some were older than sixty years. At these ages, most women in Indonesia do not take care of babies or children anymore, so their free time can be used to join social activities. Almost all PKK cadres involved in the VCT activities were in the POKJA (Task Force) IV, which is related to health, and were also active in Posyandu activities. Their involvement in the PKK had been fairly long term; some of them had even been active for decades. Usually, women first become active when their children are under five years old, when they join the Posyandu as beneficiaries. As their children grow up and they are not working, they start to be involved in the PKK as providers.

As an Indonesian woman, one must prioritize one’s husband’s and family’s needs above all else. Therefore, the women can only join in voluntary activities when they feel that the activities will not disturb their household chores. This is not only in line with the socialized role of Indonesian women, but is also written in the basic rules of the PKK, in the form of Panca Dharma Wanita, or the Five Responsibilities of Women, that define women as appendages and companions to their husbands, as procreators of the nation, as mothers and educators of children, as housekeepers, and as members of Indonesian society (Sunindyo, 1996, p. 124; Suryakusuma, 1996, pp. 101-102).
Many PKK cadres involved in the mobile VCT were those with little education, generally not beyond high school, and were mostly stay-at-home mothers and housewives. With limited education, knowledge, and skills, PKK cadres cannot be expected to effectively spread information about HIV/AIDS throughout the community, although they have had some training beforehand.

**Table 1:**
The Profile of PKK Cadres

<table>
<thead>
<tr>
<th>Education</th>
<th>Occupation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Housewife/Not working</td>
<td>Working</td>
</tr>
<tr>
<td>No answer</td>
<td>29</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>39.7%</td>
<td>1.4%</td>
</tr>
<tr>
<td>SD (Primary School)</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>1.4%</td>
<td>0.0%</td>
</tr>
<tr>
<td>SMP (Junior High School)</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>15.1%</td>
<td>1.4%</td>
</tr>
<tr>
<td>SMA (Senior High School)</td>
<td>20</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>27.4%</td>
<td>9.6%</td>
</tr>
<tr>
<td>Diploma (Bachelor)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>2.7%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Total</td>
<td>63</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>86.3%</td>
<td>13.7%</td>
</tr>
</tbody>
</table>

Although it is not considered as work, PKK cadres often receive an honorarium when they are involved in PKK activities. As already mentioned in the previous chapter, the government used to provide funds for the PKK. However, during the economic crisis of the 1990s, the PKK’s activities could no longer be automatically funded by the government. As a result, the regular PKK activities have almost disappeared. Those remaining are the non-routine activities which do not cost a lot, and for which the cadres only get a transportation fee. A PKK cadre talked about this matter in an FGD. She participates in a dengue fever prevention program, and for doing so she used to get a salary as a worker. But now, PKK cadres who participate in this program do not get any salary as they used to but only a limited transportation fee, even though they have to do the same tasks as before.
I used to work at *Puskesmas* as a *jumantik*\(^{18}\), the salary was the regional minimum wage, and we went from one RT (Neighbourhood Association) to another. So every month we made a report to the RW (Community Association). But now, *jumantik* doesn't exist; it is now called a cadre. A cadre doesn't get any salary, only tips. We function as a cadre, as well as a *jumantik*, but now the salary (is), a hundred thousand rupiah for five of us. (PKK cadre, FGD)

Most PKK cadres involved in the PMTCT program used to be active as Family Planning Program Fieldworkers (*Petugas Lapangan Keluarga Berencana*, PLKB). During the New Order era, PKK members who were also fieldworkers received a regular salary taken from the National Budget Plan for Income and Expenses. After the crisis, things have changed. Fieldworkers no longer receive a regular salary from the government, and as a result the role and function of the fieldworkers in society are not very clear.

At PPKB (Village Family Planning Management Assistance) I get 15,000 (IDR) from the RW (Community Association), I think the RW is very kind; I used to get 15,000 (IDR), now I get 50,000 (IDR)... It depends on the RW, there are no rules. I don't get it from *kelurahan* (village office)... From them I used to get 3,000 (IDR) a month, now I get 10,000 (IDR). Ha ha... If you get it at once for a year is not bad. Usually I get it every six months, sometimes two months, sometimes three months. But I don't get it regularly every month... Sometimes I don't mind not being paid, as long as my husband allows me. PPKB has its own budget from the government by the way. (PKK cadre, FGD)

*Posyandu* activities are one of few areas to have survived the national crisis. There was a time when it could not be as active as it used to be, but *posyandu* is now back on track. In the reformation era, *posyandu* activities under the PKK were brought to life again using government funds. The government planned that on the 27\(^{th}\) of every month, every district office should hold a *Posyandu* activity. Although *posyandu* is still alive, the budget provided by the government for its activities is not as much as in the past before the crisis.

---

\(^{18}\) *Jumantik* is *Juru Pengamat Jentik* (mosquito spawn inspectors). This role was formed to tackle the dengue epidemic in Indonesia. Every Friday, the PKK cadres should walk around the village to do an inspection of the environment in the neighbourhood. In particular, they check the bathrooms and water reservations for mosquito spawn.
Especially now that we get the fund for posyandu, we have more responsibilities to give the service, if there is funding; we are responsible because the fund is from the government. Now that we've got the fund we need to think about the cadres, the posyandu... Lurah (head of the village) can be responsible, we get 450 (450,000 IDR), because I have three groups, a group gets 150 (150,000 IDR) per month for the operational expenses, the food supplement program for children under five years old. Last time on the 27th, I cooked chicken soup because we're responsible for the fund. I made the report with a signature and list of expenses. The recent program since there is PPMK (Program Pengembangan Masyarakat Kota - Community Development Program in the City) is handled by kelurahan (village office). PPMK is now a program of kelurahan, but not PKK, but Posyandu is ok. So every month two hundred, depending on the Lurah. (PKK cadre, FGD)

Posyandu has got attention, we have got funds and every month, we really get attention. There is an improvement from the government. Better, even for a health problem we can get it for free. Now it's easier, the government pays attention to posyandu. Every month we get money, subsidy, and funds for food supplement from kelurahan. Each month we get 50,000, a year long. Posyandu is on every 27th, also for pregnant women. (Ibu Fitri Handayani, PKK cadre at Johar Baru)

Voluntary work that earns some money is very suitable for PKK cadres, because not only can it help support their households, but this kind of activity also does not consume too much time, meaning that it is possible for them to still take care of their husbands and children. However, because of the very limited budget available, PKK cadres earn less money than before for regular PKK activities. The money provided by YPI when they participate in the PMTCT program can therefore be a good alternative source of extra income.

5.C. Benefits of Caring

Walt (1988, pp. 5-7) said that while volunteers aim at helping or benefiting others, there is an assumed self interest in voluntarism to benefit oneself. Volunteering is often seen as a venue for paid work and as leading to future employment, especially in less developed countries where job opportunities are lacking. In more religious countries, voluntarism may have a positive impact on one's social status. For women, who are in general heavily burdened with daily tasks, reciprocity between neighbours and families at certain times may become the reason to do voluntary
work. In Indonesia, cultural respect for and compliance with authority may lead to voluntarism.

As mentioned above, knowing that PKK cadres’ socioeconomic condition is generally below average, i.e. they have a minimal educational background, no formal job with a regular salary, have unemployed husbands, etc., the money they get from PMTCT activities is significant. Ibu Mumun, a key PKK cadre from Jati Bunder village who has been involved in the mobile VCT activity since 1999, tells how the material advantages she gets has had a big influence on her life. PMTCT was her first experience in voluntary work. She had not been involved in any PKK activities before joining the PMTCT program. She began as an accomplice cadre, who got less money than the key cadre. Yet, she was happy with the money. She gets a lot of money now since she is the only key cadre responsible for the mobile VCT service in Jatibunder.

At that time of our discussion, we were on our way to the YPI secretariat to deliver an invitation from Ibu Mumun, who was going to have a party to celebrate her son’s religious circumcision. Ibu Mumun told us proudly that she would hire a dangdut music band to entertain the guests at the party as a request from her son. To be able to have a party to celebrate a male’s religious circumcision, let alone to hire a music band, is a luxury for families like hers. She told us that this luxury is as a result of her hard work participating in the PMTCT program. Below is what she told us:

I used to get 7,500 (IDR) for thirty people (as an accomplice cadre). The cadre gave me that much and I was very happy. But Tante Nia (a YPI volunteer) said, ‘Don’t just take it’. She said, ‘How much did you get to have brought so many people? 7,500, for two times is 15,000/Don’t take it, stupid!!/Why not? Is it too expensive?/You’re stupid, I’ll talk to Pak Samsu (YPI director), don’t take it if it’s too little/I was given that much, I just accepted it!!/Ok, I’ll introduce you to Jajang (VCT coordinator) so that you can be a cadre, something like that, I’ll ask him to take you’. Alhamdullilah I know more about being a cadre. Sometimes I get 150,000 (IDR), not including the rent payment for the chairs, how much do I get? YPI spends a lot if I look back… Since 1999 there has been almost 800 (800,000 IDR) that I have brought, there’s been a lot. In a month, sometimes I get 200 (200.000 IDR), 650 (650,000 IDR). That’s

19 Male circumcision is among the rites of Islam and is part of the fitrah (in Arabic), or the innate disposition and natural character and instinct of the human creation. For Betawi people, an indigenous tribe from Jakarta, to have a celebration after the circumcision of a son brings them pride, even though it is costly. People will look up to them.

20 Dangdut is a genre of popular music that is partly derived from Malay, Arabic, and Hindustani music. It developed in the 1970s, but beginning in the late 1990s reached a broader following in Indonesia. Instruments usually include a tabla, mandolin, guitars, and synthesizers.
my income in a month, not to mention the other income, thirty people per month, I can bring them two times, three time. For example, the 27th, they’ll get the result on the 1st. If there’s no YPI, I might still have difficulty. Before YPI, I was very miserable. After YPI, with their activities, people respect me. Nobody cared about me, my child was in trouble, my husband didn’t have any job. After working for YPI, my youngest child can have a circumcision. With the money I bought a television. I didn’t have a TV when Aul (her child) was smaller, I wanted to buy a TV, I wanted to have my own clean water supply, electricity. I didn’t have them all. After joining YPI, I can!! I can be independent. I say to myself how lucky I am. When Aul was a baby, 9 months old, I left him and went looking for pregnant women. In the past, even to get 50 IDR was very hard, but now if there’s work, it’s ok. It was very hard even to earn just 100 IDR. I didn’t have any ojek (motorcycle taxi) business, now I’m an ojek boss, people rent motorcycles from me. I save the money from YPI every month, I can buy a TV, build a house; I never imagined it in the past. At First, I asked the pregnant women, ‘Do you want to join our program?’ I just tell them the truth!! ‘Then you will be tested whether you have a disease. If there’s a disease and you are pregnant, you will be cured!! If there’s a disease, we take care of it/Oh I see, I want to try because I easily get sick!’ They all know me. From the first alley, hmm….for example in the market, when I walk, whether they’re pregnant or not, they still know me. People say walking with me is busy, Ibu Ucum (cadre from Rawabunga) was surprised. ‘All the way, they know you’. I am now joining activities in the kelurahan (village), also at the kecamatan (sub-district) as a PKK cadre. They say, ‘Mumun will know, she has ability, everything is easy with Mumun’. I join MOP (Metode Operasi Pria – Men Surgery Method) and MOW (Metode Operasi Wanita – Women Surgery Method) program (for family planning)…. For a vasectomy, I join the vasectomy program at the kecamatan (sub-district), together with Ibu Pri. (Ibu Mumun, PKK cadre at Jatibunder)

As the only key cadre who works independently without help from other cadres, Ibu Mumun can definitely earn enough income from the PMTCT program, which she can use to support her family and even to provide some capital for her husband to start another business as a juragan ojek21 which, it is hoped, will bring better income for the family. It is fascinating that not only can Ibu Mumun afford to buy household items with her income, but she can also prove to the community that a poor family with nothing is able to upgrade their status to one that is able to fulfil

21 An ojek is a motorbike taxi and a juragan ojek is one who owns a few or many motorbike taxis and rents them to the ojek driver.
their household needs such as water supply, electricity, a television, and even to hire a music band to celebrate a religious circumcision. The voluntary work she does certainly influences the social status of her family, from being helpless to respected and well known.

PKK cadres not only consider PMTCT as a community activity but also as an activity that brings some money home. When YPI continued its PMTCT program in an additional six provinces in 2006, Jakarta province was not included in the program because of lack of funds. The cadres felt like they had lost their job. Ibu Mumun kept asking me about this matter since she had contacted a number of pregnant women. At that moment, they were waiting for PMTCT and they had been promised to receive some money if they participated in the program. Ibu Mumun explained her disappointment that her community was no longer involved in the PMTCT program, which meant that she would lose some income:

I wonder why we don’t have it anymore (mobile VCT activity). I don’t understand. Does it still exist? Many pregnant women have asked me about that. ‘Why haven’t you invited us? You said it would be last December, the 23rd. Now it’s the 1st, but we still haven’t had it yet’, they said. I haven’t heard anything yet. What can I say, you know? If I had the money, I would do it for sure. But, I don’t. I heard about it from Mbak Ai and she got (the money) from another person. It’s hard (the money matter) and there have been a lot of them (pregnant women). We have achieved the target, which is fifty (women), but I heard Mbak Ai has moved to Banten. Mama Nia said, ‘Why didn’t she take you with her? You are the one who has been looking for these women. Why is she like that?’ I’ve got fifty (women) with me and she hasn’t said anything. (Ibu Mumun, PKK cadre from Jatibunder)

It is not only Ibu Mumun; Ibu Ucum from Rawabunga felt the same way, too. Both of them regularly go to the YPI secretariat asking for the PMTCT program to return.

I would like to have it every month, but it stopped. Ibu Mumun (from Jatibunder) called me again and again and asked, ‘Do you have any job already? If so, please tell me. I really need one’. I said, ‘No, not yet, just relax and pray’. Ibu Mumun said, ‘It’s been a long time, would you call them?’ One morning, Ibu Mumun said, ‘Ibu Ucum, why don’t we go to YPI, I’ll wait for you there (at YPI secretariat)’. We go (to the secretariat) frequently by a taxi though it is costly, me and Mumun. (Ibu Ucum, PKK cadre at Rawabunga)
Ibu Mumum is a special case. As the only key cadre in her area, she can get a significant amount of remuneration for her voluntary work. The other PKK cadres who have to share the money with accomplice cadres do not get as much remuneration as her. Still, the remuneration they gain is an additional income for their pocket. They usually use the money to buy snacks for their children or grandchildren or just to go out with friends.

PMTCT causes PKK cadres to be known by people in the community as persons who have skills or who are close to a money source. Ibu Ucum from Rawabunga is not only known in her own community, but also in other communities.

I become famous in lots of places. One day, a washing machine technician, I called him just saying, ‘Ibu Ucum’ (he told me) ‘Yes, I went there yesterday, if I’m not mistaken RW 04? I was looking for the house, nobody knew, then I told them ‘Ibu Ucum’, they told me right away, easy. Last time I was looking for another house I couldn’t find it, I asked them ‘Pak RT16’ (but) nobody knew. I asked them then where Ibu Ucum’s house is, they could tell me where it is. (Ibu Ucum, PKK cadre at Rawabunga)

A similar experience was told by Ibu Jubaedah. Aside from getting additional knowledge from the PMTCT program, she believes she has had many other advantages from being known by people in the community (as seen in her quote at the beginning of this chapter).

For some people, being well known by the people in the community is not crucial; but for PKK cadres, being well known is important because it means that they have a better chance of participating in similar activities. Ibu Supriati says that participating in the PMTCT program has improved her knowledge; the community knows her as a person who has knowledge about mothers’ health, and as a result it is easier for her to follow similar activities in her community.

...The advantage (is) a lot, indirectly we learn. If I want to get involved in an activity it’s easier, having that kind of activity is not easy, everything has to be prepared, including how the people work in the field, it has to be prepared. About PMTCT, what we know is about pregnant women, (we get) training, so we know the techniques. I have been trained in those techniques. By having the technique...it’s like...it’s how YPI does it... Of course our relationship with society is better. People say, ‘Madam, is there anything else? Is there any test for pregnant women?’ People will come to you. First of all, this is the advantage, firstly, we get information, secondly, we can know directly the characters of the pregnant women: some are afraid to be open, some are not; if one is pregnant, she’ll be, ‘I want to get tested...
even if I'm not pregnant or I don't want to get tested’… Something like that. I understand people better. It’s also easier if we involve other information. (Ibu Supriati, PKK cadre at Kampung Bali)

Access to other activities or programs means access to more work that can bring financial benefits, as Ibu Mumun said above. As a person who is considered to have good knowledge about health, she is also involved in activities for a vasectomy program at the sub-district level, as well as an HIV/AIDS training program. Aside from Ibu Mumun, Ibu Ucum from Rawabunga is also involved in an HIV/AIDS training program administered by the D Plus Foundation that mobilizes commercial sex workers.

I didn’t know anything about pregnant women, I didn’t, but now I know. ‘It is money, a lucrative project. Don’t let them give you little money’, Pak RW (the head of the Community Association) said. Sometimes from D Plus, D Plus Foundation. The other time we had to collect PSK (sex workers). They asked for fifty commercial sex workers, there are around thirty of them. They get some transportation cost and an HIV test. They know that my work always has something to do with HIV. (Ibu Ucum, PKK cadre at Rawabunga)

Ibu Rimayati from Johar Baru village has even become a well known person in DKI Jakarta province after she participated as a representative for Johar Baru village in a national meeting in Surabaya. Ibu Rimayati shared her experience as a cadre that has helped YPI with its PMTCT program. Below is what she shared with other PKK cadres:

I would like to thank Yayasan Pelita Ilmu (YPI) that chose me as their representative in Surabaya. The head of PKK cadres in DKI Jakarta was present. I was not so confident because I had never flown before. The flight was at 10:15 and I was brought to Hotel Shangrila. I was a representative and spoke there, other speakers were from Sidoarjo, another one from Tulung Agung, another one from Surabaya, from Tulung Agung. The head of the PKK from Tulung Agung, from Surabaya, the wife of the governor (were there). I wasn’t so confident about it. I even had a toothache and couldn’t talk. I was the first speaker. I only talked casually, but the wives of the governors were keen and they would like to know about my activities. I talked about my experiences in DKI (Jakarta province) and they were enthusiastic. I talked about the HIV problem, I thought I was only a cadre and wouldn’t get any response because the other speakers were governors, good looking people with nice clothes, they came by cars and I was just…different. But, there was
a response from the Minister of Women’s Empowerment. They asked for my phone number and the phone number of the PKK of East Jakarta. She asked me to be a speaker at the Ministry of Women’s Empowerment. I’m not sure because I am facing important people who have a higher power. I’m just a cadre, you know. I just go from one place to another. They sometimes tell us that PKK means Perempuan Kurang Kerjaan (women with more free time). Also, there was somebody from KPA (Komisi Penanggulangan AIDS - the National AIDS Commission) at the national level. She asked us to come, especially at the national level because PKK cadres can socialize HIV/AIDS and tell people the danger of it. So, she planned to talk to the head of the National PKK about this PKK program to be able to socialize HIV prevention. (Ibu Rimayati, PKK cadre at Johar Baru)

The above story describes how the PMTCT program can change the life of a PKK cadre, from a helpless person to be a person who is empowered both in family life and in society. Yet, voluntarism is not only undertaken for empowerment reasons. As Walt says (1988), for women it can also be an excuse to take a break from domestic chores and the routines of being a housewife. It is important for PKK cadres to have social activities outside their domestic activities, and in the process they can also gain social prestige from the community, as mentioned in the following quotes from PKK cadres in an FGD:

I think if we are committed, although I have a lot of chores to do at home, I still come when I am asked. I don’t think anymore whether it costs me or not.

I just like it, being together, sharing each other’s stories. It’s better than talking about other people. For me I’m taking an hour break from the kitchen… My life is just around the kitchen, my children, and husband.

We get it when there is training, the transportation fee. But sometimes we don’t think about it, as long as we are happy and can make friends, we don’t think about the money. I think we have a high social treasure. If we’re outside home, we can meet friends, get refreshed.

Ibu Suciasih admits that a social activity like the PMTCT program has had a very positive impact for her, because not only does she gain experiences from outside her home where she usually does her domestic routines, but these different activities have given her a positive spirit to take care of her health.
I’m now fifty. If I do nothing, just stay at home and don’t move, I won’t be healthy. I’m getting older so I have to keep healthy. How? By following different activities. It will improve my knowledge and encourage relationships with other people. If I do nothing I know nothing. That’s why I keep myself busy with this kind of activity. (Ibu Suciasih, PKK cadre at Pasar Minggu)

Community work in PMTCT does not only bring material benefits for PKK members as individuals and to the PKK as an institution because of the voluntarism of PKK cadres, furthermore these activities have an empowering influence on the cares’ personal lives. However, the cadres feel that the activities are more for filling their leisure time with other women who are in the same boat, than to enable them to fulfil their desire to be a volunteer.

5.D. Preserving the Benefits

It is not a simple task for PKK cadres to be able to preserve the benefits they get from PMTCT activities. PKK cadres must able to maintain their social status as housewives, and cannot neglect their domestic jobs. It is very important for them to maintain their image as devoted mothers. For this reason, PKK cadres normally become active as voluntary providers only once their children reach school age, which means that there is less demand for childcare at home. Here is what one mother said:

I followed the PKK cadres who also went to weigh, I was called a non-active PKK member. It’s because sometimes I joined, sometimes not, I didn’t fully give 100% service because my children were small. I have become very active since 2000, since I have been free, my children work already. The oldest graduated in 2000. I am active until now. (Ibu Suciasih, PKK cadre at Pasarminggu)

In addition, PKK cadres also have to get permission from their husbands to go out of the house to do voluntary work. Therefore, they must ensure that the domestic work is done before leaving home.

Thank God, my husband (gives permission). Right before that we ask for permission first, ‘Can I do this activity?’ Then he supports me. (Ibu Fitri Handayani, PKK cadre at Johar Baru)
Still, support. The important thing is I am not leaving the household chores. My husband comes home in the afternoon. When he comes home, I am at home. The kids are at home. Sometimes I go in the afternoon, sometimes in the morning. (Ibu Ramli, PKK cadre at Cileduk)

When I have to go in the morning, I have to cook before leaving. After everything is ready, I can go out. (Ibu Ucum, PKK cadre at Rawa Bunga)

PKK cadres have to be capable of describing PMTCT in language that the pregnant women can understand, so that the women will voluntarily want to visit the mobile VCT. While doing so, the PKK cadres must also maintain their image as devoted mothers. If a PKK cadre fails to explain the mobile VCT well, the pregnant women may not want to participate. As a result, the cadre will not get any money, as the money received depends on the number of pregnant women they bring to the mobile VCT. Considering this, it is fascinating to see how PKK cadres, by using the existing network and trust in the organization, can persuasively approach and explain to the pregnant women why they should voluntarily join the mobile VCT. It is clear that the women have to go voluntarily and without force. This is really a challenge for the PKK cadres.

Barnett and Whiteside (2002b, pp. 7-8) state that one of the limitations of household studies on HIV/AIDS is that communities and households may not have the same perception as the researchers of the importance of HIV/AIDS studies. They cite one research study in Zambia as an example: in an area with high HIV prevalence (14.8%), there was still almost no link in people’s minds between HIV/AIDS and child mortality, nor with the value of children or fertility; HIV/AIDS was not seen as a major problem by the majority of people, despite a general recognition of it as a worrying disease. If in a country with high HIV prevalence such as Zambia people do not feel it to be a problem, it is hard to imagine why people would feel differently in a low HIV prevalence country such as Indonesia. Unlike Zambia, HIV prevalence in Indonesia is only 0.2% among the reproductive age population. In the Indonesian context, HIV/AIDS is not an emergency situation, and the government has not recognized it as a major problem. The majority of people do not even have any knowledge about HIV/AIDS. In fact, it is seen as a highly stigmatized and embarrassing disease whose existence is feared. This matter has a big influence on PKK cadres when they introduce PMTCT to pregnant women.

Most of the time, PKK cadres do not place HIV/AIDS at the fore when they approach the pregnant women. Usually, they treat mobile VCT as a part of mother and child health, and leave the information dissemination about HIV/AIDS to YPI counsellors, who are considered more competent in explaining it. This is the easiest
and the most frequently used method, because the roles of the PKK cadres in *posyandu* are very much related to mother and child health. In an FGD, the cadres told me:

I just told her that her health and her baby's would be checked, whether they’re healthy or not. If you want to continue, just go ahead, you can later register with this person, at a certain time. Maybe it's better to let them know. The decision is the counsellor’s…

I made it clear, it's to prevent, but I didn't tell about HIV right away, only (that it is) to see whether she has a disease and it has to be done by having a blood sample test. So, if your blood sample is taken, it depends on you. You have come already and to know whether you are healthy or not, you can talk to the counsellor...

I would just tell them, but don’t tell them about the blood sample test, don’t tell them either whether they can or can’t. ‘You will get information on pregnant women, the Family Planning Program service, so you are invited to come to the RW 09 on the 22nd. Yes madam, I want to come’, and they really came. After being explained about HIV, they would be called one by one by the counsellor...

Some hardly even tell the pregnant women that there will be a blood sample taken for an HIV test. This method includes a little manipulation, because if they did tell upfront about the HIV test, much fewer pregnant women would voluntarily participate in the mobile VCT. One of the PKK cadres from *Pasar Minggu*, Ibu Suciasih, said that she never informs the women that there is an HIV test because then the pregnant women would refuse the invitation to come to the mobile VCT:

I told them like that but I didn't tell them their blood samples would be taken. I don’t because they might refuse. I told them, ‘So, there will be an HIV test. There will be somebody asking you, just listen to me, you will be called one by one, your baby will be checked whether he is healthy or not.’ So, I told them it’s a test for mother and baby's health, I didn’t tell them their blood samples would be taken. I’m afraid they would refuse. Later on, when there were people from the district area giving the training, one of them said, ‘Could I take your blood sample? It’s up to you whether you want to or not, it’s ok’. But most of them would refuse. The first time with the PMTCT all of the thirty people wanted to get their blood sample taken. The second time the training was slightly different, as if the women were afraid and said,
'My blood sample was taken last time, the other person told me it’s ok if I don’t want to get my blood sample taken. So, with the second one, there were a lot who didn’t want it, only some wanted to. I even had to tell them to let their babies be checked, so if they have diseases, it can be treated. They refused by saying ‘I’m healthy, my blood sample was taken.’ (Ibu Suciasih, PKK cadre at Pasar Minggu)

Some cadres lure the pregnant women with promises of free medication, food, or transportation fees as a benefit of attending the mobile VCT service. It turns out that free medication interests the pregnant women due to the high price of medication for pregnant women. In this case, they do not mention HIV either.

If we invite her just like that, she has to consider it first. But, if we ask her softly, you know a little bit luring, we lure them to make them come, especially if there’s milk. The blood test is free. They may be interested because firstly it’s free, secondly they don’t have to pay anything, and they get milk when they come back home. They should get transportation fee so that they don’t have to think twice. (Ibu Slamet, PKK cadre at Pasar Minggu)

It is not only a free pregnancy check but also a free caesarean section that is offered if a woman is found HIV positive. Caesarean sections are quite expensive in Indonesia, costing between 5-20 million rupiah. Nevertheless, there is a growing trend for caesarean sections as it is considered easy and painless. One of the PMTCT counsellors has said that some of the pregnant women participating in the mobile VCT hope that the test will be positive so that they will get a free caesarean section. To attract the women’s attention, Ibu Suciasih sometimes uses this approach:

I told her she didn’t need to pay. If you go to a midwife, your husband has to pay. With this, you will be tested whether you have a disease and if it’s so the baby has to be born with a C-section, it’s free. But I hope all the women tested are healthy. I told them so. If they’re sick, it’s also a scary thing. ‘I want to go then…I get transportation fee, right?’ I told them they get it, there would be snacks too. They just need to sit down. They wanted to go. In my opinion, you have to tell them like that. Even some of them would ask me later ‘Why don’t you ask me to go now?’ (Ibu Suciasih, PKK cadre at Pasar Minggu)

Sometimes the cadres have to discuss the HIV test when the pregnant women want more explanation about the purpose of the invitation. However, they do not treat HIV/AIDS as a dangerous disease but as a disease whereby further care is
guaranteed, as if it will not be a big problem if the woman has HIV. This is how Ramli from Cileduk explained it to one of the pregnant women:

About this HIV, if you have your blood tested, you will be given counselling with a counsellor, you will be tested. Whether the result is positive or not, it's only you who will know it, not anybody else, except the tester and you. Then, when it's known that you're positive, the treatment will be taken care of by the YPI Foundation. So, you won't be left alone. You will be taken care of and assisted. If you deliver the baby, the YPI Foundation will help. If you need a C-section, you will be helped as well, at all, until your baby is not infected. For a year, you will get formula milk. For those infected… Just come, you get a snack, transportation fee. When you have your blood sample test, the result, you will get another transportation fee. (Ibu Ramli, PKK cadre at Cileduk)

A similar opinion emerged in a discussion among PKK cadres in an FGD:

When I was looking for the pregnant women, I would tell them that we would like to have a training for pregnant women, to take care of their health, but also tell them about HIV/AIDS… So, I was informed before, but we gave the information about the training and automatically they wanted to know more. They were also told there would be a blood sample test and counselling. ‘So, they won’t force you, if you want to get a test, go ahead, as long as you have had counselling before that, have had your questions answered.’ Whether these pregnant women want this or not, we can’t force them… But the HIV/AIDS matter is still informed. If I didn’t tell them beforehand, I’m afraid they would be disappointed when they come, they would be unsure and take a step back. It’s better to be firm, direct, so when they come, they’re ready to follow the HIV training. So, I’ve got a different method.

It is interesting to see that the cadres also treat HIV/AIDS as a disease of depraved husbands as a means to approach the pregnant women. By using this approach, they try to emphasize the domestic roles of the pregnant women as devoted wives who have husbands who are cheating on them. They approach the pregnant women by treating them as innocent victims, telling them that HIV can be caught from their partner. By doing this, the pregnant women may feel that if they are infected, it does not mean that they are bad, but merely it is because of their partner’s behaviour. The cadres do not acknowledge that the women might be pregnant because of their own high risk behaviours. Ibu Mumun from Jati Bunder and Ibu Supriati from Kampung Bali told me what they usually say to the pregnant women.
I usually explain like this: ‘About HIV, we’re concerned about the baby. So, before the baby is checked, it’s better if the mother is checked, maybe you get infected from your husband.’ We never know if her husband is infected, so we should prevent it. ‘Oh OK,’ she said. ‘You don’t know from the appearance, inside he may have bacteria or viruses that we don’t know? Maybe you’re right. I want to join then!’ It’s appeared that these women want this. It’s never difficult to convince them. There will always be a lot of them because there are a lot of IDUs there; especially the target location is the slum area. If we tell them about HIV in the first place, they may be reluctant, so it should be explained later in the training. It will be explained later anyway, I’m not a doctor. I’m no expert. I just have to search for the pregnant women. If they want to ask further, there’s a doctor, a midwife. (Ibu Mumun, PKK cadre at Jati Bunder)

At Kampung Bali, everybody knows that Kampung Bali is famous for its drugs... First of all, the training for the pregnant women. If later on people ask what it is for, we can deal with it face to face. We talk carefully, confidentially, because these people are, in my opinion, they have a risk to their confidentiality. About their behaviours, you know... Kampung Bali used to be a ‘drug’ area, there are also a few people who have died here, they may have the ‘history’. ‘Maybe your husband is like one of them, your child has to be healthy’. (Ibu Supriati, PKK cadre at Kampung Bali)

The strategy to blame the husband seems to be an effective one. The pregnant women often confirm the possibility that their sexual partner may be infected with HIV, knowing that sexual relationships outside marriage are much more permitted for husbands, but not for wives, as told by Linda from Ciledug and Hafizah from Tajur. Linda also wanted her husband to be tested.

If possible, my husband is also checked because he’s the one who likes to flirt. (Ibu Linda, pregnant woman at Ciledug)

I’m worried whether the result is negative or positive. Alhamdulilah it’s negative. But just because it’s negative, doesn’t mean we have to ignore it, we have to be careful. You never know, maybe from our husbands. (Ibu Hafizah, pregnant woman at Puskesmas Tajur)

It is interesting that almost all the women in the PKK agreed on the mother’s role as a ‘good woman’, revealing the positive power which the domestic identity of a mother gives for women.
5.E. Discussion

Although some references say that volunteers are the ideal to which most community health workers aspire, the reality is that most governments or NGOs give rewards to the community workers, either as a salary or an honorarium. Programs that work on a completely voluntarily basis or on community financing show high attrition rates (Walt, 1988). In YPI’s PMTCT program, PKK cadres do not work on a completely voluntary basis; YPI provides some money to attract cadres and pregnant women to participate in this activity. PMTCT can in fact bring quite a significant remuneration for the PKK, not only as individuals but also for the benefit of the PKK as an institution. This remuneration has made the mobile VCT possible. However, the remuneration can only be accessible to the cadres if they are involved in the PKK organization; and as a mothers’ organization, the PKK requires of the cadres the bi-social identity as mothers. Thus the motherhood identity is important for the PKK cadres in order to get the remuneration from the PMTCT project.

As most of the cadres have no job and limited education to find decent work, the remuneration becomes a good income that may increase their status in the family and the community, especially for those with more limited education or jobless husbands. The involvement of the cadres in the PMTCT program activities may also lead them to have access to other jobs that will bring further economic benefits. PMTCT may not actually empower the PKK cadres in terms of being able to prevent HIV/AIDS in their community, especially as the epidemic is not significant enough to be considered a collective social problem in Indonesia. However, to some extent PMTCT may domestically empower the PKK cadres.

Empowerment is seen as a process of helping disadvantaged groups and individuals to compete more effectively with other interests, by helping them to learn and use their skills (Ife & Tesoriero, 2006, pp. 85-86). Mikkelsen (2005, p. 243) states that a source of women’s empowerment is her participation in the modern sector and her lifetime exposure to employment. The empowerment of women is usually achieved by getting women out of their domestic domain and placing them in the public domain so that they can attain equal rights as men. The public domain is very much related to the economy, and economic empowerment can only be reached by having a good education and a decent job, which certainly can only be obtained outside the domestic domain.

In PMTCT, the empowerment brought to the PKK cadres exists in the domestic domain. The involvement of the PKK cadres in the PMTCT program does not place them outside of their domestic domain; indeed, the remuneration they get from involvement may increase their motherly role, as one who is responsible for her family’s welfare. Aside from access to resources, PMTCT also brings access to economic activities. Through the mobile VCT training and activities held by YPI, the
CHAPTER 5

cadres become known in the wider community as persons who have knowledge of maternal and child health, including knowledge of HIV/AIDS. Their participation in the training gives them good access and a channel to participate in similar activities, even outside of their own community, although they still perform as community workers. They can also benefit from these extra activities financially. With the extra income they are able to support their family better. PMTCT has given the PKK cadres social, economic, and identity empowerment in their domestic domain, as devoted wives and protective mothers.

Access to resources and economic activities does not necessarily mean that one has power over those resources or economic activities. Power over resources includes the effective control of their use and distribution (Ife & Tesoriero, 2006, p. 72). PKK cadres admit that the money has significantly influenced their economic life. A woman’s work is often invisible in society since women are usually involved in work which does not make money and/or is not done outside the home (Saptari & Holzner, Perempuan Kerja dan Perubahan Sosial: Sebuah Pengantar Studi Perempuan, 1997, pp. 14-20). Even when they bring home money which is quite significant, women’s work might still not be appreciated. Maria Mies, as quoted by Suryakusuma (1996, pp. 101-102), argues that married women in Indonesia are socially defined as housewives, dependent for their sustenance on the income of their husbands, regardless of their actual contribution to their family. In other words, as housewives, women provide free domestic labour, and are assumed to provide their labour without expectation of prestige, power, or remuneration (Parker, 2001, p. 57; Suryakusuma, 1996, pp. 101-102). Mostly, the money is used simply to add to their pocket money for buying snacks or to go for outings with friends. In the case of Ibu Mumun, the money was used as capital for her husband to start a motorcycle taxi business, and not for her to start her own business. In so doing, she loses some power over the use of the resources she has earned. PKK cadres have access to more economic activities due to their participation in PMTCT, as they become familiar to a wider circle, and thus they have a chance to do other activities that generate money. Yet, they do not have control over the mechanisms for these activities since the ‘work’ they do is regarded as voluntary.

Access to resources and economic activities has already proved significant for the PKK cadres and therefore needs to be maintained. The PKK cadres have to maintain their bio-social identity as devoted mothers because it gives them access to resources and economic activities through the PKK. However, this identity can be destroyed by their engagement in PMTCT activities as it is part of an HIV prevention program; for a shameful, dirty disease that is regarded as affecting badly behaved people. The PKK cadres must therefore maintain their identity as ‘decent mothers’ as part of their role in PMTCT. Thus, in introducing PMTCT to pregnant women, they have a tendency to blame high risk sexual behaviours on husbands rather
than explaining the HIV risks during the pregnancy. Aside from having limited HIV knowledge and social skills when approaching the pregnant women about PMTCT, I also saw that the PKK cadres believe that they have to maintain their PKK identity. The trust the PKK cadres have from the pregnant women is based on their identity as devoted wives and responsible mothers. This identity has been socialized very effectively in society. Considering that the pregnant women are also themselves PKK members, though not actively involved as community cadres, both the women and the PKK cadres have to respect each other’s image and identity. Thus both blame husbands for their high risk sexual behaviours, while at the same time placing the responsibility for the health of their unborn babies onto the women. This permissiveness towards men leads them to be considered as the main cause of HIV/AIDS infection among housewives, the latter of whom are regarded as innocent.
Chapter 6

TOP Support Group Members: HIV Trajectories and Interpretations

It is interesting to see how the HIV positive women I met with who were involved in the TOP Support group understood HIV/AIDS. They were socially and economically vulnerable, both in their families and the community. They were poor and powerless, and lived in an environment which made them peculiarly vulnerable to HIV infection. Most of them found out their status when their child or husband had become sick or died, yet when they found out almost none of the women had yet reached the stage of suffering from full-blown AIDS. Consequently, they did not respond to HIV as a disease; rather, their response was strongly influenced by their bio-social identity as mothers.

In this chapter I describe how the seropositive women engaged in TOP Support; how TOP Support as an organization supports its member; how the women responded to HIV; and what kind of treatment they chose to live with HIV/AIDS.

6.A Getting into the Support Group

Almost all of the TOP Support members were referred by the referral hospitals or by NGOs; only one or two members were found through the mobile VCT service run by YPI in the community. This shows that it is not easy to get people who
have been diagnosed with HIV through the mobile VCT service to become involved in a support group. This is mostly because of stigma and discrimination. If a woman is found to have HIV during the mobile VCT program in her community and she comes regularly to the support group, even though the location is quite far from her neighbourhood, the neighbours will be suspicious. In Indonesian communities, the interpersonal bonds at the neighbourhood level are still relatively high. Thus neighbours may recognize if a woman has been detected as HIV positive, and not only she but also her family will be stigmatized. Additionally, of course, few HIV positive women are found through the mobile VCT service because HIV prevalence is still relatively low.

Members who participate in TOP Support join after finding out that they are HIV positive. Some people had the test at a VCT clinic at a referral hospital. The hospital then referred them to YPI, which not only has a PMTCT program for pregnant women, but also a referral clinic appointed to distribute antiretroviral medications (ARVs) and other programs for people living with HIV/AIDS (PLWHA), including (free) CD4 testing for viral load, PCR tests for babies (also for viral load), etc. Through the PMTCT program, YPI provides recommendations for pregnant seropositive women to deliver by caesarean section at the referral hospitals, an assistant who can remind them to take their medicines, and formula milk for babies for one year.

It is interesting to know that most of the HIV positive women did not know about their husbands’ high risk behaviours and health condition until they found out their own status. This fits with the picture of Indonesian women as being passive and inactive in relationships with their spouse. Although premarital medical check-ups are encouraged for couples, and should ideally be done six months before the wedding, premarital counselling and HIV testing are not mandatory due to a lack of public awareness about the importance of such check-ups, cultural influences, and religious dogma that the choice of a spouse should be left in God’s hands; going for premarital health screenings questions God’s omniscience (Kompas, 2002a; Kompas, 2002b). In addition, a premarital test, including a rapid test for HIV, is relatively expensive; from approximately 800,000 IDR up to 1.5 million IDR\(^2\). A survey administered by drug addiction clinics in 2002 found that injecting drug users (IDUs) who have HIV/AIDS have a tendency to keep their status secret and do not dare tell the result of the test to their spouse, even though they still have a sexual relationship with them without using protection (Kompas, 2002c).

The majority of the women in TOP Support who found out that they were infected with HIV after their child or husband became ill or died had not, at the time of this study, yet reached the stage of AIDS. Thus, they had not yet experienced

\[^{22}\] Equivalent to US$ 91.20-171 (as US$/IDR= 8,800 IDR in January 2011)
serious symptoms. They were participating in TOP Support because they had been referred by the doctor who handled their ill husband or child. In general, they felt healthy and did not have any health problems.

Wiwid is the eldest among three siblings. She is a little bit shy. She was dating a boy, though because he was living outside of town, so she fell in love with his best friend, who then became her husband. Her husband was an IDU, but Wiwid had no clue about his background when they got married. Two years of marriage passed, and Wiwid happily gave birth to a son. Within one month, however, her son fell ill. The first symptom was fungus in his mouth, then an unstoppable cough. After a few medications, his condition was worsened by chronic diarrhoea. He kept losing weight. At that point he was referred to one of the referral hospitals where he got tested. Wiwid was shocked when she was told that her baby was infected with HIV. The doctor suggested that she and her husband should be tested. The result showed that both of them were infected. Four months later, in August 2006, her son died.

Wiwid started to investigate her husband’s background, and discovered that he was an IDU who had been expelled from his family a long time ago. Some of his friends had already known that he was HIV positive. According to Wiwid, his family would not admit it, though they had also known about the situation. Just before they got married, her husband worked in a factory for Susu Bendera (Frisian Flag Milk). One day, the factory conducted a medical check-up for workers, after which he was sacked. Wiwid did not know the reason why; she guessed that it was because of his chronic coughing, caused by too much smoking. This was early in their first year of marriage.

Wiwid met YPI staff during their hospital visit, where she was introduced to TOP Support. A few months after her son died, Wiwid joined the group. At the time of interview, Wiwid was not on treatment, though in 2008 she did start antiretroviral treatment (ART) after she got a severe infection in her womb.

I first got to know Mbak Sun and Mbak Ati (YPI staff) at Pasar Rebo Hospital (the hospital where her son had been treated). I’ve just been active (at TOP Support) for a couple of months, after my child died at the end of July or beginning of August (2006). I just knew about my HIV status a couple of months ago, three months ago, in May 2006. It began from my child, my child was diagnosed positive. My husband and I were also tested last May. The symptoms were diarrhoea, he (wiwid’s child) was hospitalized almost every week, until he was almost four months old, but before four months he had coughed continuously. I took him to tumbu kembang (paediatrician), the one they say is the most expensive, but still he was not cured. The cough’s gone, the diarrhoea comes. Within a week, he lost around 800 grams
to one kg. I was so concerned what kind of disease he had since he got thinner and thinner. He was one and a half month in the hospital before he died. He was beautiful and active; the nurses said he’s got a very high spirit of life. He was not in the coma at that time. I felt so pity about him. That’s why we, the family, prayed to God that if he was to be cured, please cure him fast; if not, we let him go. He was 3.3 (kg) when he was born, healthy, his body was normal. I never imagined after a few months he died. Maybe it was my fault. Actually if a child’s positive, he can’t be breastfed, can’t be mixed, if you want to give breast milk, give only breast milk. I gave both breast and formula milk, I didn’t know, because all my mother’s children got them and because I was working. I didn’t know why my breast milk was very little but as a mother I wanted to give the best for him. I thought he would get the body immunity from the breast milk and food from the formula milk. In the beginning, my nipples were wounded, very much until they bled, my child sucked very hard, he was very strong. That’s why I thought it’s from the breast milk because my nipples were badly wounded and bled and he had fungus in his mouth when he was a month old. There were a lot, until before he died he was resistant to the medicine. Just before starting with the second line whose medicines we don’t have here, he died. Moreover, I didn’t know about that, usually when a baby gets mixed milk, he’ll get solid food by four months, I did that too, that was wrong, I shouldn’t have given solid food (for an HIV positive baby). I was stupid; I want to make it better. I know now. I am a hundred times more careful. I’m angry with the one who has infected us. He didn’t tell me about that, if he did I could have prepared. (Wiwid, 29 years, married)

Viona too only realized that she had been infected by her husband when her first child was ill. At that time, she was pregnant with their second child. They used to live in Papua where there is no proper medical service, especially for children with HIV. As her son needed medication, she had to move to Jakarta to live with her in-laws while her husband stayed in Papua. The paediatrician was suspicious that she or her husband was an IDU. Her husband, then, admitted that he was an ex-IDU; he may have infected her and the baby. As soon as she knew that she had HIV, Viona followed the PMTCT program at YPI as advised by the paediatrician who treated her first child. Her second child was healthy and free of HIV; she got a free caesarean section and free formula milk from the PMTCT program. Not long after her third baby was born, her husband died.

I got married when I was twenty-one; I got my first pregnancy eight months after our marriage and then I (was) pregnant continuously till I have
been sterilized after giving birth to the third child. There was a problem when I was pregnant with Daud (the first child); at that time we were still in Sorong (Papua). The doctor said, ‘If it stays like this, it will be bad for the baby’, because the foetus is under the normal weight, I had to vomit every day, that’s why I had to go to the doctor every day. The doctor told us we’d better go to Jakarta because there are more doctors and the facilities are good. In Sorong it is limited, there’s only one gynaecologist, the vitamins and food supplements are rare. That’s why we came here in the beginning of 2003, when Daud was two months old. His father was in Sorong when he was born, he only took us to Jakarta and came back to Sorong. When Daud was four months, he was ill. It all started there. He was given the first medicine, blue pills. There was no paediatrician, there is one so-called paediatrician, but actually he’s not. When he had been ill for almost a month, there was a paediatrician who came to Sorong and he said, ‘It’s fungus already, not only mouth ulcer’, and he was given medicines. He could not eat, only vomited. This doctor is also stupid. You know Candistatin, the medicine for children against fungus, it’s normally given in a bottle and if the child is not cured after consuming a bottle, he should have questioned it. In Daud’s case, he had to take even more antibiotic. Luckily, when Daud was ill, I always kept the copy of the prescriptions. I kept them. When it was getting worse, he could not drink from the bottle but from the pipette. It took a lot of efforts to feed him, even using a pipette; he still had to throw up. Finally we came back here to Jakarta. When we just arrived at night I had to cry. The doctor at Bekasi was also confused and he said, ‘I’ve tried my best, but it doesn’t show any progress but gets worse’. His weight was 6kg when he came to hospital, and became 5.6kg. His condition’s worse. Then, with the paediatrician, we had a counselling, then he said, ‘I (know) you are an ex-IDU, he maybe (has) HIV infection’. We were messed up at that time. At that time I didn’t know that I was pregnant (with the second child). I was very emotional. I had a fight with my husband who must have been infected. ‘I wouldn’t get infected if it’s not from you’, I said. I went to Doctor Evy (a paediatrician). My husband told me he used to use drugs, but never as detailed as during the counselling, never. I was crying when I was listening to it, but what can I do now? I was depressed and had a mental breakdown. (Viona, 27 years, widow)

Winta did not know about her husband’s HIV status until he was in poor health. Winta dated her husband-to-be for four years before becoming pregnant at fifteen. She never knew he was an IDU, though her family never approved of her relationship with him because they thought he had a bad attitude. Her school performance was worsening, and she dropped out soon after graduating from junior high when
she became pregnant. Winta never told me in detail what she had done in her life, though once she told me that she was about to be trafficked by her neighbour who worked as a prostitute, and later on I knew from her friends that she used to work as a call girl.

Winta knew about her status when her husband became very sick. Doctors suggested to her to get examined. At the time she found out about her HIV status, she was eight months pregnant, and then one month later her husband passed away. She was introduced to the PMTCT program at YPI, though unfortunately, according to Winta, there was no intervention given for her pregnancy. She was not given ARV prophylaxis, support for a caesarean section, or formula milk. It may have been considered too late in her pregnancy. When he was examined, her son was also found to be HIV positive.

At the time when I met her, Winta had a second child from her second husband. For her second child she got a free caesarean section and free formula milk from YPI.

We had been married for a month when my husband was ill in 2004. He was ill for three months but his HIV (status) was unknown yet, I don’t know, in my family there’s nobody who has this kind of illness, it’s from him. I wanted to ask my parents, but I don’t talk to them; I wanted to ask the neighbours, but they would talk rubbish; I wanted to ask my husband’s family, but they don’t care. My family and his family do not care. We were just hugging each other. We had a relationship before getting married for four years, but I never knew he used drugs. When it was getting worse, actually I got recommendation to go for a further check-up, but I never did that, I didn’t have money and my husband was only selling mineral water on the street. With our income it’s not enough, even for food it’s not much, not to mention to pay for the rent. He was ill and couldn’t work and I was six months pregnant. When he was ill, I took care of him until it got very much worse. He was ill for one and a half month, I was six months pregnant… The worst was when I was 7-8 months pregnant… The worst was when I was 7-8 months pregnant… The worst was when I was 7-8 months pregnant… The worst was when I was 7-8 months pregnant…
knew he had been drinking and taking soft drugs, that's what I knew. 'We can see the result if you don't believe it'. When we saw the result it was really AIDS positive. I was out of breath, unconscious, panic, I don't know who took me, but finally I found myself on the bed in the hospital. My husband was also unconscious; he couldn't do anything else besides lie down. When I was awake around midnight, I tried to accept it. I thought he might have had free sex because I didn't know he did drugs, didn't know about AIDS. Maybe he's had free sex, doing drugs is impossible. I have proof that he's had free sex because when we're dating he taught me many dirty things; that is what I thought. If he's HIV infected, I can accept it, but of course if he's positive, I must be positive and people with AIDS cannot live longer than 2-3 months, I thought about that continuously when I was in the hospital. But life's not your decision, it's God's and I didn't know yet about HIV/AIDS. After two days of being hospitalized, I was examined by the doctor who took care of him. I'm positive, I got even more confused. After thirteen days in the hospital, he was home again and after four days, he passed away. (Winta, 18 years, remarried)

Tiara also came to know her HIV status when her husband was very ill. She had never realized before that her husband had been an IDU long before they were married. After knowing that her husband had AIDS, Tiara and their son, Keenan, were also tested and both of them were infected. When our interview took place, Tiara was living alone with three year old Keenan after her husband had passed away. Shortly before, her CD4 count had dropped very low, but she was refusing to start ART as she was afraid that the side effects of the medication would make her ugly.

My husband usually came to Tangerang because his grandmother's sister lives not far from my house. He came there very often because of his grandmother, he came here very often. I usually left my house for fitness, for class, for college. When I went to fitness, he usually waited for me and asked me to go together, that's the beginning, and we just talked. Until he died, he never knew that he's positive. I told his family and other people not to tell him. Four days before his death, he wasn't allowed to drink, not even a drop of water. They said he couldn't because his stomach was having a problem. He was bleeding when he vomited. He was not given any drink or food. The first time he was hospitalized at the neurology department because he had cramps. We went to neurology. The wife of the neurologist is an internist. She's also there, at Sulianti Saroso (referral hospital). He couldn't be given ARVs even though he was ill. Under his lips there was a lot of white stuff. If
I cleaned it in the morning, it came back in the afternoon. In the afternoon when I cleaned him, I cleaned his lips until they were red, not long after that the white colour came back. The CD4 level was twelve. After five days, he got a CT scan. Two days after that, after the CT scan, he seemed to be out of breath, he had another CT scan two days later. It appeared that one of his lungs was broken already. Not good. Only within those eleven days, everything was acute. There wasn’t anything in the lungs before, but at that time there was. He even threw up blood. His stomach used to be normal, at that time he had a stomach infection. I was immediately examined, the result was ready in two hours and I was told I was positive. I called my mom. ‘Mom, I this, this, and this...etc.’ That’s it. In August 2005 he died, and during the funeral, I told my Mom, ‘Mom, I’m positive, blah, blah, blah. What can I do?’ My mom said... ‘I told you that: But she’s not angry, I mean knowing the condition, she’s not angry. Then she asked, ‘Is Keenan tested?’ She took him right away to Budi Asih (hospital). He’s also positive. (Tiara, 22 years, widow)

The cases above are fairly representative of the TOP Support members. Another intriguing story was told by Titi who, together with her husband, found out her status after his third time donating blood to Palang Merah Indonesia (PMI - Indonesian Red Cross). Titi’s husband was an IDU, but neither Titi nor her husband had ever been seriously ill. Fortunately, their only son is HIV negative.

So, my husband had an itching problem. He thought he had eczema although my parents thought it was influenced by our unborn child. At that time I was pregnant. Then, he went several times to the hospital to see a dermatologist, but it couldn’t get better. We thought when the medicine was finished it could get better. Finally, he decided to donate his blood because he’s an IDU, he thought he could get rid of the dirty blood by donating it to PMI. We didn’t know his status yet. He had been donating three times, and before donating for the fourth time we got a letter from PMI that my husband’s blood couldn’t be accepted. That was actually the third notice already, but we had only received the letter once. After that he stopped. Then, PMI told us that it was only a screening test. Not..., not everything, not accurate. So in order to get accuracy we were referred to Prof. Zubairi. Finally Prof. Zubairi referred us to Prodia (clinic laboratory) for a full HIV test. That’s it. After the delivery I was tested. Just after knowing that my husband’s positive, at that time I was at Bunda Hospital, I was crying like crazy. And then the Prof. advised me to see Mbak Tika, who later gave me counselling. So I had the counselling right away at the same place. But, at that time I had not dared to have a test. Four months later I had the test. When I knew
that I was positive, I was ok actually. I was ok, I accepted it, I thought there's nothing I could do. Only when I knew for the first time that my husband was positive, I was hysterical. We were both also not ready to let Yanto have the test (at that time). We were finally ready that he could have the test when he was two years old. (Titi, 24 years, married)

Not all of the seropositive women involved in TOP Support were definitely infected by their spouses. Some had been IDUs themselves, and some were still actively taking drugs when I met them; although some were taking only oral rather than intravenous drugs. These women were often not really sure when and how they had contracted HIV; it may have come from the needle they shared with their husbands or friends who were mostly IDUs, but it may also have come from unprotected sexual intercourse they had when drunk.

Asti was an active girl, and had used drugs from an early age. Her first husband was the best friend of her then boyfriend. Asti did not know that he was an IDU, and she fell in love with him because her then boyfriend, who was of a different religion, dumped her to get married to another girl. Her husband worked as a band member after he quit his previous job as a Blue Bird taxi driver for health reasons. When her husband fell ill, the doctor recommended taking an HIV test, which was how they came to know about his status. Asti wondered whether she had been infected by her husband or the other way around, since both of them used to be IDUs. Asti had a terrible illness just before she had the HIV test, and had begun to suspect that she was infected because her illness was as bad as her husband’s. She went to Puskesmas Tebet which provides services for IDUs, and from there was referred to YPI.

I started taking pills when I was in Senior High School, then we shared needles. It didn’t last a very long time, only for a year and I wasn’t addicted, just occasionally. If there was some, I used it, if not, I didn’t. My husband didn’t know about that, he was shocked. He used drugs occasionally too, but I never saw him taking them. I noticed the difference when he worked as a security guard; he often had fever and muscle pain. I once saw him with a big school bag full of drugs. He had been ill for a long time, at the clinic they always told him he had typhus; I didn’t believe he always had typhus, the longer, the worse. We went to a professor; he was advised to eat a lot of *pisang batu* (a special sort of banana) and coffee. I didn’t believe it, I told him we’d better go to the hospital. His condition was worse... He ate but was getting weaker; he was shaking when he walked... His body was trembling... Finally I told him to go to the hospital because he’s trembling. His mouth was full of fungi. He was hospitalized for twenty-one days and had a therapy in Indramayu in his hometown, the traditional massage in his
hometown. He could walk again; he could even drive, his body was heavier. But I don’t believe that. He still consumed ARVs; I took them from the RSPI (referral hospital). Also the traditional medication. He used to weigh 45-65kg; it reached 20kg within seven months. You can imagine…only bones…

I wanted to cry seeing him like that. Although he was shaking when he walked, his weight was ok when he died, I was shocked… He was about to have a job promotion. The symptoms were like having a heavy chest and he could not breathe, very heavy. So, when he died he got tuberculosis, was operated. He used drugs, but he was not honest to me, until the end. So, I didn’t hate it very much because he knew I was a drug user. I didn’t think that way. He was infected by me? Or I was by him? (Asti, 30 years, remarried)

Strikingly, although many women realized that being an IDU made them vulnerable to HIV infection, some still believed that they got the disease from their husbands rather than because of their own risky behaviour. One reason behind this way of thinking could be the fact that these women had never been seriously ill.

Lina’s experience with drugs was not very different from Asti. Lina was also an IDU, but she still felt that her husband had infected her because, according to her, her experiences with drugs would not infect her with HIV. Sadly, Lina passed away in May 2009.

I’ve used it, only three times. Well, actually I just wanted to try it, but maybe I was infected from it. It was only three times in a year. I shared it with my husband. So at that time I only wanted to try it. Just to try it. Actually, with him was twice and with his friend once without him knowing. He actually didn’t allow me because he told me that I could get addicted. But I said, ‘If you can, why can’t I?’ I just wanted to feel how it’s like, that’s why. I used something, what was the name again? For him who was used to having it, it might feel good, but for me I felt different, I felt dizzy, nauseous, light headache, I wanted just to sleep. That’s it. It’s not that I didn’t want to try it anymore but I thought it only felt like this. That’s it, maybe I was infected from that because we were married maybe only for a year. If I knew that the needles had that effect, I wouldn’t dare to try it. Also with my husband; if he had known, he wouldn’t have done it. Only us, it is enough. We’ve done it, so we deserve it, but why our child is also becoming a victim - that makes me sad. (Lina, 22 years, remarried, passed away in May 2009)

In addition to being referred to TOP Support by the hospital or doctor treating their ill husbands or children, some women found out about the support group when they were hospitalized themselves due to an HIV/AIDS related illness, and
other TOP Support members made visits to the hospital, as in Wanda's case.

Wanda is the second of four children in the family. She was known as the rebel in her family, and had a very bad relationship with her father. Wanda said that there were no members of her family that she could talk to. Her father was a civil servant who earned an extra income by renting houses, which meant that her family was quite prosperous. When her father retired from his job, he began to focus every day on his hobby, fishing, from the evening to late at night. He said it was best to catch fish in the dark, but Wanda thought it was just a good reason to escape from the boredom atmosphere at home. According to Wanda, her father loved her brother and sisters more, especially since her sisters were quiet and obedient. In high school, Wanda started to have a relationship, though she got pregnant by someone else while drunk. She married the father of the child, but then divorced soon after she gave birth. Her first child was not infected with HIV and until today lives with her parents in Pasar Minggu. Wanda married for the second time with her boyfriend. She gave birth to her second child who was luckily also not to be infected.

Wanda told her family that she had been infected with HIV by her husband. None of her family members knew that she used to be an IDU, or that she occasionally smoked marijuana, used heroin, and drank alcohol with friends; though she did stop using drugs when she was carrying her first child. Her husband, on the other hand, was using drugs up until he died, even when he was ill. Wanda had lost hope after she had been in hospital for one year, at which point she met the TOP Support staff who made a hospital visit.

Since the first year of junior high school I have started with smoking weed, I got it from friends. Nobody knew at home. I once got home with red eyes after smoking weed, but because it was at night, my father didn’t really notice. That’s the only time, usually I didn’t do that, and I didn’t dare to get home like that and never took the stuff home. I once took the aluminium foil (for heroin) home and put it in my purse; my sister found it and asked, ‘What is it for?’ ‘It’s nothing’, I said. I had used it together with my husband, but we didn’t know, we thought if we washed it, it would be clean. But actually, it’s not simple to clean it, you have to use a bleaching if I’m not mistaken. Three times washing and then with water, that’s how you wash it. We used to think to clean it with warm water, but it’s wrong, it should be cleaned with cold water, that’s why some junkies are dead. Actually, before doing drugs, I knew that I got HIV. Because the doctor told me that my husband was probably HIV positive, I thought I had to be positive too! The doctor told me, told me to check it just in case. But I was scared, impossible, and impossible. I was then hospitalized for the first time, I had feelings already, but I didn’t want to admit it. I was healthy again, and then sick again, and was hospitalized
again and again. They said that it might be typhus. The second time I was diagnosed as having typhus. I even took traditional medication, I ate worms which have been first cooked and grilled and chopped. It should be cured, but not in my case. I still had fever, fourty degrees, I had feelings already. Finally I went to GMC (hospital) at Buncit, I made a confession to a doctor, not to my family; but I told him not to tell my family since it’s one’s right to have this matter confidential. ‘Go ahead tell me,’ he said. I was crying, scared, I just knew that it’s a serious disease, the second killing disease in the world. I thought there’s no medicine at all. The doctor told me, there’s no medicine for HIV yet, but there’s an antivirus to prevent the virus from growing. I was referred by GMC to IRNA RSCM (referral hospital). I was the only female. At RSCM at IRNA I knew I was positive. I think YPI means a lot to me, that (first) visit. When I was found to be HIV positive, I was referred to RSCM. Every time I woke up at that time I was like dreaming whether I was still alive or not. There was a hospital visit. Mbak Yuna, together with Mbak Lina and Mbak Sundari (YPI staff) visited me. My mother didn’t want to talk to them. Mbak Sundari said, ‘We are friends. These are your friends and I am too’. In the beginning I was wondering what these people were doing since they didn’t know me but they visited me. Later they explained to me that they were members of YPI, Yayasan Pelita Ilmu. They asked for my phone number. I asked for their name card. From then on I knew that I’m not alone. One who looks very healthy can have it (HIV) too. Then I asked Lina, ‘Where were you treated?’ ‘Alhamdulillah I’ve never been ill,’ she said. I made up my mind I have to be cured. TOP Support means a lot to me. When when I was finished with the treatment, I joined YPI. (Wanda, 27 years, widow)

Dina’s story is unique among the women of the support group. She became infected with HIV because she was a drug user, yet her first husband had never been tested. She had three unhealthy children from her first husband; her first and second child had never been tested until they died. After delivering her third child, she became so ill that the doctor advised her to get an HIV test, but when she found out that she was infected, her husband left her. Now, Dina was remarried to another PLWHA who pumps up her life spirit and supports her to continue taking ARVs and together they had another child who luckily was not infected. Unfortunately, Dina passed away in 2010, not long after her second husband died.
I knew I was positive in July 2004, at RSPI (referral hospital), with a counsellor. I was asked to have a blood sample test and three days after that I had another counselling. I didn’t know that it was HIV, but my father knew. After delivering my third child, I was sick. Since her birth until the fourth month, I was never healthy, sick, thin, having fever, and my hair fell out. I thought I had a hernia. I got a massage and went to the doctor, but I wasn’t getting better. My father asked his friend who worked at the clinic of the office where he worked at and also at the RSPI. He said to him, ‘My child’s been ill for four months but why is she not getting better? Her first child died, the second child’s also ill, both of them have a lung disease/What are the symptoms of her illness?/Fever, her body’s very thin, her hair’s falling out/Did she use (drugs)?/Yes, she used injection drugs/Let her have a blood test done, maybe she has HIV’. Father said to me, ‘Go get a blood test done’. When I was checked I was asked what the symptoms were. I said, ‘I’m ill, coughing’. The doctor said, ‘Oh ok, do you want to have a blood test? You’ll talk to the counsellor’. He meant that I should have the counselling first and then followed by a test. (Dina, 23 years, remarried, passed away in 2010)

6.B. Advantages of Being a Member of TOP Support

Nowadays, there are more people with HIV/AIDS getting actively involved in HIV prevention programs. It reflects what Nguyen has classified as the second flow of HIV intervention programs, that sees the involvement of affected communities and local forms of solidarity, with the concepts of buddies, self-help, and empowerment (Nguyen, 2005, p. 127). The GIPA (Greater Involvement of People Living with HIV/AIDS) spirit has influenced them. The number of support groups is increasing all over Indonesia. In 2006, there were ninety peer support groups for PLWHA located in fifty districts and cities in twenty-six provinces across the country. In June 2007, according to data collected by Yayasan Spiritia (Spritia Foundation - an NGO which is actively involved in HIV prevention programs), there were 161 peer support groups spread all over Indonesia, most of them located in Java Island. Those groups supported specific target groups including transvestites, homosexuals, methadone consumers, injecting drug users, women, uninfected partners of PLWHA, families, and outreach workers. Of the 161 support groups, the majority targeted IDUs, and there were only ten which especially targeted female PLWHA.
In Jakarta, there are twenty-seven known support groups, only two of which are specifically for women, including TOP Support created by YPI. This low number is understandable as not many seropositive women are registered or recognized by NGOs or the government. According to the National Coordinator of Ikatan Perempuan Positif Indonesia, the Indonesian Positive Women Affiliation, they supported 250 seropositive women in 2008; those women were IDUs or partners of IDUs, sex workers, or partner of sex workers’ clients. Although the number of seropositive women does not seem like much according to the statistical data, it has been increasing significantly in recent years.

YPI has been running a program of care and support for PLWHA in Jakarta since 1994. Up to December 2003, YPI had provided care and support for 669 PLWHA. However, to strengthen their HIV/AIDS prevention efforts, and due to the increasing number of PLWHA and the expression of the GIPA (Greater Involvement of PLWHA) spirit, the support group Pelita Plus was set up in September 2002, whose objective was to increase PLWHA’s quality of life. Pelita Plus was a mixed support group open to seropositive men and women. YPI supported them with a room for an office and equipment, and at the beginning also empowered the group with organizational skills and self esteem; Pelita Plus, however, conducted its own activities. These activities included a monthly meeting for PLWHA, home visits, hospital visits, public awareness and community campaigns, and income generating activities such as creating products for sale (t-shirts, postcards, red ribbons, dolls, etc.). One of the public activities of Pelita Plus was to advocate for the government to provide ART
access in Indonesia. *Pelita Plus* organized a street rally with 200 participants and declared the need for ARVs in 2004 (Habsyi, Yogatama, & Muhaimin, 2004). Due to a mismanagement matter, *Pelita Plus* is now inactive.

As a sub-group of *Pelita Plus*, YPI established a support group especially for seropositive mothers in Jakarta as part of their PMTCT continuum of care program to provide psychosocial support for seropositive mothers, their babies, and their families as written in the prong 4, that is to provide psychological and social support and treatment to HIV positive mothers, their babies, and their families. It started with six seropositive mothers in August 2005. The group, called TOP Support, derives its name from the abbreviation of *Tim ODHA Perempuan*, which means ‘seropositive women’s support group’. From its small beginnings it grew to fifty women in 2009. The role of TOP Support is to provide psychosocial support to seropositive women and to advocate for PMTCT to the wider community. As a support group, it provides a comfortable space to make it easier for seropositive mothers to disclose their HIV status and share their problems with other women like themselves. The bio-social identity of motherhood is very significant for TOP Support members. TOP Support also has a role as an advocacy and interest group that consists of women who have a condition and who have something to gain or lose from the group’s actions (Kitsuse & Spector, 1995).

Using the funds from Global Fund in 1999-2001 for the PMTCT program, YPI supported seropositive mothers mainly by providing a service for caesarean sections in conjunction with some referral hospitals in Jakarta, offering recommendations to get ARVs, and providing formula milk for newborn babies in their first year. During the first years of the PMTCT program in 1999-2001, YPI provided a caesarean service for eleven mothers, nine received ARV treatment, and six babies were provided with formula milk. Between 2003 and December 2005, YPI continued its PMTCT program using money from the Global Fund. Twenty-eight women had assistance for a caesarean section to deliver their babies.

The PMTCT program performed by YPI has depended much on donor support. As a result, not all seropositive mothers who join TOP Support can access the caesarean service, and some activities can only be carried out irregularly when YPI manages to get extra funds, for example PCR (Polymerasi Chain Reaction) tests for babies, CD4 tests, and income generating activities. Through TOP Support, YPI has provided HIV positive mothers and babies with psychosocial support from buddies, hospital visits, and home visits. YPI allows TOP Support to use one of their office rooms for their secretariat and weekly meetings. Two days per week, either on Wednesday or Friday, two people are in charge of the secretariat. They receive money to distribute

---

23 Without a recommendation letter from a doctor, clinic, or NGO, it is impossible for a PLWHA to get ARVs for free.
as a transportation fee of up to 25,000 IDR to each woman who attends the group meetings, with an additional allowance if they go for home or hospital visits.

The help provided by YPI through its PMTCT program, especially the medical help which would otherwise be costly for TOP Support members, has been very useful for the seropositive mothers, as described by Lina below:

...(it was) from the PMTCT program, so every woman who gathered there got the CD4 test for free. There was a program (free test from the YPI), everybody was asked to have the test done, but every six months. I used to have the test done myself. In the beginning I had the test done every six months, and then I got it free from here. If it’s free, it’s only once a year here, and only at the end of December. It’s been four times. In February 2005 was the first time, the second one was three months after that. The first one was 260, at that first time CD4 count was tested. The second one was 337 or something like that, oh yes 337, two months after the first test, no, no, three months. Then, the 400-something was in the month, the month before this, before the 146 one. In March 2006 it was 146 and I was put on medicine. In December, if I’m not mistaken, it was 438, it was from YPI (her CD4 count increased after the medication). I paid the tests myself, twice, eh once in April. The rest was from YPI. In February, the first time, was from Kampung Bali. In December was also from YPI. In March it was from the PMTCT program. The ones from YPI were free. Only once, the one whose result was 300-something, 337, that’s the one I paid, 110,000 IDR, at the Dharmais. I get the Duviral from a clinic, the Remaja Clinic, I only paid for the doctor, (which) cost 15,000 (IDR). The ART is free of charge, from YPI. (Lina, 22 years, remarried, passed away in May 2009)

Because a caesarean section is costly and the funds are limited, YPI can only provide three per month, and a limit is set to only one caesarean section per woman. Thus YPI states that they will not provide a caesarean section for a woman if she has had the service before. However, they do make exceptions in some cases, and YPI has helped women with their second caesarean section, as Viona discusses below. She received a free caesarean for her second child and had to pay only fifty percent of the cost of the caesarean for her third child.

Doctor Evi called and asked me to come to have the test at Cipto (referral hospital). There was a representative from YPI, it was Mbak Tia. I had a (free) c-section with my second child, and with Joshua (the third child) I got help for half of it, I paid the other half because his father had a job at that time. And (formula) milk. But I had to pay for the prophylaxis. Now I have to buy
one kind of ARV. For Daud (her first child, HIV positive) I have to buy one kind too. Only Reviral, he only has to take one kind (of medicine), I have to pay 200 (200,000 IDR). A counselling costs 40,000 (IDR), I have to pay by myself. (Viona, 27 years, widow)

When the funds provided are not enough, YPI refer patients to get treatment at a hospital or clinic that has similar facilities and services. For example, Dina was referred for a free caesarean section from RSCM Hospital and a free check-up from Dharmais Hospital. Actually, Dina was under medication by the RSPI Hospital and referred to YPI to get the caesarean through their PMTCT program, which is when she was registered as a TOP Support member. She gets free ARVs from RSPI hospital but for her opportunistic infections she has to pay for the medicine herself, which is relatively expensive.

In total, it costs 6,700,000 (IDR). YPI provided 5,000,000 (IDR). I delivered the baby at RSCM. Before giving birth, I got a training from YPI, the PMTCT program. Babies born to mothers who have HIV get ARVs until six months of age in RSCM while it is given only for a week in RSPI as stated in the national guidelines. So, I went to RSCM as well as my baby. It was in December. I was checked two times, the first one at Dharmais (referral hospital), it was free of charge. When I had the CD4 test on June 13, it was free of charge, at Dharmais, as well as the one I had in July, also at Dharmais. It actually costs 110,000 (IDR for the CD4 test), but I didn’t pay anything. It (the test) is also free of charge for my child. (Dina, 23 years, remarried, passed away in 2010)

As mentioned above, aside from the medical service, TOP Support members also receive a transportation fee of as much as 25,000 IDR each time they come to YPI to do administration work or for hospital/home visits. The amount may not be much, but it can help their financial situation since most of them do not have a regular income. The most significant benefit of their participation in TOP Support, however, is that they realize that they can again function socially like other women who are not HIV positive. By taking ARVs, they hope to live longer, as explained by Tiara below.

Luckily it exists, so I know, I’m not as afraid as in the past, like I thought I would just die. Now, I’m like, ‘Hmm, why should I be afraid, there’s ARVs…’ That’s it, maybe not as long as other people, but hmm… It’s ok. The (weekly) meeting, it makes us understand more, to learn, a lot of benefits… (Tiara, 22 years, widow)
Their involvement in TOP Support enables them to have a chance to have contact with other people, to learn from their peers, and to support each other. Sometimes TOP Support has a gathering activity where they also invite members of other support groups. Through this, the women have a chance to get remarried and still have healthy children. Most of the seropositive women I interviewed were still sexually active with their partners; some of them were unmarried and had multiple partners. In most cases, they had met their new partner(s) at the TOP Support activities in which they mixed with people from other support groups. Although those who have had experience with an infected child are usually afraid to have more children, the chance to have a healthy child makes them feel like normal women again. This motivates most of the women to want to have children. Having a child is also a support for them to stay positive about the future.

Dina’s story below shows how she got a new spirit of hope after she remarried and delivered a healthy child with the assistance of the PMTCT program. Dina and her first husband had three children who all died when they were still babies. When the third child was ill at the age of four months, Dina and the child were tested. The results showed that they were both positive. Dina was at that time very sick, but the child passed away when she was only ten months old. Dina has since met her second husband, who has given her a spirit to live. They now have a healthy baby. She even wants to have another baby after giving birth to her healthy fourth child.

I took Neviral Duviral in 2004, I quit for a while because I was lazy. My child passed away. After she passed away, my husband wanted a divorce, and then I got HIV, I didn’t know if I had friends. I thought I just wanted to die. Luckily I’m not dead yet. If I were not visited (by her second husband) maybe if it was later, a month later, and a week later, I would have been dead. Worse, got mouth ulcers, couldn’t talk, my mouth was dry. I went back to the doctor and told him, ‘Doc, I want to take medicine again/ Are you serious now because if later the drug regimen has to be changed, it’s not available yet in Indonesia,’ he said. ‘Yes, I’m now serious, I’ll be obedient, I used to have many things in my mind’. And then I was given it, I should try Neviral Duviral first. I started again in May 2005. Yes, if we have the spirit. The PLWHA also need the spirit besides ARVs. If I fall in love, it increases, I gain weight. Feeling good, happy feeling, having a lot of friends. My second child died four months old; the third died at the age of ten months. I didn’t know it by the first child, the status of the third child was known. The second child died earlier before having the test. The third child was tested when she was four months old, positive, always sick. The fourth one has been tested, negative. If I knew, I would have already cured it. I breastfed, had a normal delivery. Her food was like the normal babies. When she was 4 months old she was sick, I’m too, and
that’s it. I didn’t understand. All of them were born normally, only the last one with c-section. After knowing it, I want to be pregnant again, to have offspring. (Dina, 23 years, remarried, passed away in 2010)

Dina is not the only member who has found her partner at the activities of different support groups. Lina, Yuna, Asti, Vina, Tiara, and Wiwid have all had relationships with other PLWHA. Some eventually married. By functioning socially by getting married and having children as most mothers do, the members of TOP Support can minimize the stigma and discrimination against them.

6.C. Who are the Members?

TOP Support members are young HIV positive mothers. When the data was collected in 2005-2006, the youngest TOP Support member was eighteen and the oldest thirty-six, though most members were between 22-29 years. Most are referred by referral hospitals and NGO clinics. They are living in different places in Jakarta, and 6 members come from outside Jakarta in Bekasi, Depok, Tangerang. Some of them, especially those living further away, complained about the transportation cost to come to the weekly meeting, which is quite expensive.

The members of the support group have many things in common. At the weekly meetings, they discuss their common problems, such as getting infected by their husbands, pregnancy and labour problems, being widows, having children with no fathers, etc. Some of them had HIV positive children and husbands who had passed away at the time of data collecting. Female PLWHA have more problems than just HIV/AIDS and their general health. They have economic problems; some because their husbands are jobless and spend their little money to have sex with other women or buy drugs; some do not have good relationships with their families or in-laws; some are married without permission from their parents so they do not have access to financial help from them; some come from very poor families. Although the cost of ARVs is not one of the problems (because they can get them for free from the referral hospital), the transport costs to collect the medication is an unsolved problem.

Most TOP Support members do not have a good enough educational background to get a decent job; only some could continue their education to get a diploma, and while most of them had been to senior high school, not all were able finish their education due to problems related to drug use or teenage pregnancies. Some did not even finish junior high school. For those who were using intravenous drugs during school time, they did not study seriously.

Wanda moved schools a lot when she was in elementary school because she
was badly behaved and often missed classes. She was not allowed to hang around and play with friends at home so she skipped school to play with her friends. She started smoking when she was in the third grade of elementary school and started using drugs in high school. Currently, Wanda is unemployed.

I changed junior high school three times because I was naughty. At home, my dad always controlled what I did, even when it was right, let alone when it was wrong. For example, I had to be home by 1pm after school. We never know sometimes you have to stay at school for extra lessons or extracurricular activities, he doesn’t care, I had to be home at 1pm and I had to stay at home, could not go anywhere else. That’s why the time to go to school was used to play; I skipped school often and moved to another school. First, I moved to a public SMP (junior high school) at Srengseng Sawah, then to Islamic pubic school SMP Tsanawiyah Negeri. Later on, because I skipped school very often, I moved to SMP Pasar Minggu, close to Ramayana department store Pasar Minggu, but my habit didn’t change. Then I moved to Kalibata, next to the army cemetery. I was dropped out of school and asked to find another school. They couldn’t accept me at school if I kept continuing skipping classes and getting bad grades as a result. That was my last school, SMP Kalibata, a private school. After that I really wanted to get into a SMIP (Senior High School for Tourism), wanted to take a hotel school, I wasn’t allowed, I even had two tests. At SMIP, I passed the test for the height and weight, I just needed to do another test, but I wasn’t allowed. It’s a waste of money to have bought the application form. I looked for another SMA (senior high school) and found an SMA at Borobudur, Cilandak. The school began in the afternoon that made me even worse. I was very bad if it came to school. It’s because my father didn’t want to understand what I wanted, never on the same page, also the other family members didn’t care what I wanted. For example when I wanted to join the basketball extracurricular activity, my father thought it’s strange, what I should do with a ball? Another example, if I entered SMIP, I would continue my study at Sahid University (a well-known university for tourism), but I wasn’t allowed!! See what happened, I moved from Borobudur to a SMEA (Senior High School for Economy) at Tanjung Barat area, I didn’t finish it, I paid to get the illegal diploma. I started with it (drugs), I tried it since SMP. I was depressed, nobody understood me at home. At home they were all silent. (Wanda, 27 years, widow)

Asti’s story is not much different from Wanda’s. Asti became an IDU in senior high school. She moved from one school to another as she was expelled; she was even moved to another province where she went to a Catholic school. After four years
of her relationship, she had to marry her boyfriend when she was seven months pregnant.

My primary school was in Jakarta. But because of my attitude, since I was at the primary school in South Jakarta I was known as naughty because I smoked, was boyish, didn’t like girl’s stuff, I played cards, skipping ropes, flies, and I did fight with other schools. That made my mother worried. When I finished my primary school, my mom sent me to the village to continue my junior high school. A Catholic school in Boyolali. When I was in junior high school, I still used to fight, very often. My weight was only 20 kg or something like that, very small, that’s why I used to be called ‘tiny Asti’. I used to come home late, my aunt found it difficult to take care of me. I used to date a Christian guy for six years, until we went to senior high school. He’s a motor racer. He was alone there. His parents were in Kediri. I almost got married to this boy, but my mom didn’t agree because we had different religions. I chose my parents of course. I went back to my mom and did my senior high school at SMEA (Senior High School for Economy) YPK in Jakarta, at South Manggarai. I dated another boy for four years, then got married, at the age of twenty-two, eight years ago, I got married by accident (because she got pregnant before she was married). I delivered just two months after our wedding. (Asti, 30 years, remarried)

Those who were not IDUs usually dropped out of school in order to get married, as they had become pregnant out of marriage. In Indonesia, women who are pregnant cannot get access to continue their studies, even at the basic or high school level. However, very few Indonesian women who are married and have children want to continue their studies at the university level because they lack the time, on account of being mothers and housewives. Winta told her story about her problems related to her teenage pregnancy.

My primary school was at Bukit Duri, I always had good grades from my first until sixth year, was the second or third rank (in the class). My father was very happy to see his child doing well at school; I was very much loved by my family. When I entered junior high school, the first year, I started to date. At fifteen I was pregnant, but at that time I entered the first year of senior high school already and I stopped. I wasn’t expelled from school, I just stopped. In my first year of junior high school, I started dating my husband who died lately. I dated him. I was twelve; he had finished his senior high school. I didn’t want to listen to my parents that I must not date him. I just said yes. We lived in the same neighbourhood, so my father knew his daily life and he didn’t
like him. But we still dated that my father had to slap me. He had never done it before; he slapped me with his hands, later on with things, broom, and stick. Even the stick didn’t make me scared. Then sapu lidi (another form of broom to clean usually hard surfaces, contains of a lot of pieces, each piece is made of thin wood), but it still didn’t make me stop. Then with rubber, he slapped me with rubber, finally he used electric wires when we had dated for three years, at that time I was in the third year of my junior high school. At that time I was still a virgin; when I graduated from junior high school my boyfriend took my virginity. My father became angrier…!! When I was pregnant my father was even angrier. I was fifteen years, got married to my husband. After getting married my husband was ill and my family didn’t want to accept it and we ran away. (Winta, 18 years, remarried)

From the above descriptions, one can see that the school environment does not always have a positive influence on students. These women did not go to school for the sake of schooling, but because it is the norm. They did not study or take the lessons seriously. The school was even in some cases the location where they were introduced to high risk behaviours for HIV, such as sex and drugs use.

With limited education, many of these women have limited work chances as well. Most of them are unemployed. Even those who continued their studies to a higher level do not have jobs. However, as women, they are not regarded as the main earner in the family, and therefore they do not have an obligation to get or maintain a stable job, even though there may be no fixed income in the family if their husbands are also jobless or have passed away. Even if they do have jobs, they only have limited choices, such as unsecured jobs that do not require special skills, and they may change jobs frequently.

While waiting for her high school certificate to be given, Asti got a job as a sales promotion girl, but she quit since she was bullied by her seniors. Then she got a job at California Fried Chicken. She had problems with the manager who did not give her a free day to hold a birthday party for her first daughter. Asti quit the job and has not had another job since. Instead, she helps with her mother-in-law’s house renting business, and she and her friends try to run a beauty salon, whose customers are dangdut singers (local performers) and prostitutes at Tanjung Priok, North Jakarta. Right now, she works as a peer educator in one of the NGOs concerned with HIV/AIDS.

I started to work as soon as I finished high school. I hadn’t had the diploma yet when I applied at Matahari (a department store) at Jatinegara Plaza (a shopping mall in Jakarta), as a sales assistant, (it was) only for a month, because there was a problem... I was new. I think it was because of
the old sales assistant ... She let me take care of the counter while I was still having my probation period, I didn’t understand yet. There was a problem at the cashier desk; the customer was angry because the alarm on the port went on and that the security guard had to come, while the customer had paid for the purchase, I didn’t understand yet. That was it. Instantly there was a problem. So, my uncle had a job for me at a cooperation, a credit cooperation, bookkeeping, it was ok. I worked there...for seven months. In short, I finished my high school, a month at Matahari (department store), then seven months at the credit cooperation, and then at California Fried Chicken for two years at Tebet, then changed to Mc Donald’s for two years. I keep changing (jobs). I used to be a dancer, a modern band, when the Batavia dance was in I used to dance at hotels, it’s not bad. I used to work at California (Fried Chicken) as a cashier, a door girl, cook; I have done all of them. But, I had a problem with the manager. It was because I couldn’t get a free day for my daughter’s birthday. I now work in a salon, it belongs to my friend. Most of them (the customers) are the girls (prostitutes), they have (hair) bonding treatment. (Asti, 30 years, remarried)

Wiwid used to have a successful tailoring business. But then she ran out of capital when she used it all to pay for her baby’s medication, which was quite expensive. Her employees resigned, one by one. Now, Wiwid is trying to build up her future again, and received quite a few orders for the last Eid at the time I spoke with her.

I still have my own business; I have to keep good relations… Now, my business is getting better, when they knew I had started again, they were interested to contact me. Actually, it was not really bankrupt, it was just because I couldn’t handle it, and without me they couldn’t make any move. Automatically, there were no orders because we were not available; I had to stop (working) because I took care of my children. I was pregnant, so I had to take it easy; some of the employees got married. Only one stays with me, she’s like a family member, her house is also close. Some other employees just quit. (Wiwid, 29 years, married)

Without a proper education that would enable them to get decent jobs, these women’s lives rely very much on their families, especially to cover their medication expenses and childcare. Most TOP Support members live with their parents or parents-in-law, and thus their expenses are the burden of their extended families. Naisbitt (1996) points out that in a country lacking a formal social security system such as Indonesia, the extended family is an alternative safety net for people. Vina told me that her life is at the expense of her extended family.
My mother told me that she used to take care of me the first time they knew that I was sick. She used to remind me whether I had taken my medicine or not. I am worried that I’ll be tired of taking medicines. I also have difficult problems that I cannot solve. My brother is now working, (but) I’m afraid that he cannot work anymore. He gives money to us every month. If he doesn’t work, how can I get money for daily expenses? I don’t want to use my parents’ money. As long as I am a PLWHA, as long as I have hopes, I still want to use my own money. *Alhamdullilah*, I can pay for my child’s education and other expenses. I also don’t ask for transportation costs from my parents. My brother works at Garuda (an Indonesian airline). (Vina, 29 years, widow)

Asti and Viona told me that their in-laws financially support them with their living expenses. Their in-laws support them because they realize that it was their sons – the women’s husbands – who brought the infection upon them, and therefore the in-laws should be responsible for them.

When my husband was sick, it was only my parents-in-law who knew about it. Also the first time we got a test, I only told my in-laws. So, my parents didn’t know about that. They didn’t know about it until I was sick. First, I went to Cipto (HIV referral hospital), to *Pokdisus* (HIV Integrated Post) precisely, so my mother knew that I got this disease. Now she can accept it. The support, any kind of help I need to get cured, I get it from my mother-in-law. Even for our business, like to lend some stuff (some credit), as long as we can have a job. For the rent, we’re also given (that). I now live in a rent house; it belongs to my parents-in-law. My family doesn’t know about it, but my parents-in-law do. I don’t talk too much to my own mother, the reason is because my mother thinks too much about her own children, and she takes care of her grandchildren, so it’s impossible to tell her. She knows that my disease will get worse, but she only gives me (mental) support. My younger brother knows more than her. My younger sister just knew about it from my mother because there was a problem when I was taking Neviral. About my child, I rely on my mother and mother-in-law; they know better. Right now I’m living the rest of my life positively. (Asti, 30 years, remarried)

My daily expenses and those of my children are taken care of by my parents-in-law, fully. For the medication, my parents-in-law pay. My parents don’t know, because my mom, she had a stroke, I’m afraid she’ll get worse. (Viona, 27 years, widow)
Because many of the women do not feel that their behaviour might also have put them at risk for contracting HIV/AIDS, most feel that their parents and in-laws should support them if their husband infected them.


People are often blamed and stigmatized for their illness and it is a common assumption that individuals are responsible for their own health. When an individual develops AIDS, people assume that he or she was/is either promiscuous, drug addict, or homosexual; and the stigmatization lead others to reject him/her and hold him/her responsible not only for not seeking care but also for becoming ill (Levin, Innis, Carroll, & Bourne, 2000, pp. 278-279). In the minds of many people in Indonesia, HIV/AIDS is associated with criminal behaviour and a hopeless life. Added to the general lack of knowledge about HIV/AIDS, which makes people afraid to be close to an infected person, this creates an atmosphere of fear and accusation around infected and affected persons. There is a social stigma, for example, that HIV/AIDS will only infect ‘badly behaved’ people. Seropositive women are confronted with multiple stigmas, for not only are they discriminated against as women, but additionally they must face a society that is ignorant and fearful of HIV/AIDS, that looks down upon them because HIV is considered to be the disease of commercial sex workers (Sciortino, 2007), and because they are often the widows of PLWHA. To make it worse, women are sometimes stigmatized and discriminated against by their own families. To avoid this, some seropositive women are not willing to disclose their status, especially to their families. This may become a dilemma for them as disclosure is often required to gain access to treatment and therapy (Waddell & Messri, 2006). It was revealed in an FGD with TOP Support members how even close family members distance themselves from the women since they are afraid to be infected.

My own cousin is even worse, if I walk in front of her, she closes her nose, as if I’m a virus, and my own sister, my own sister, she walks like this...turns around, to avoid me. There’s a virus, so she has to turn around. I’m mad at her, I really want to punch the people. I even had fights. That’s my own cousin! (Wanda, 27 years, widow)

Indeed, the discrimination comes from the family first. The neighbours aren’t that bad. The family is stronger. At first, I was crying when my sister-in-law did that, it’s not a nice feeling. But later on I can accept it. I don’t want to care. I let it be, because I get this disease, I have to be more careful.
consequence is when she visits our home. She’s very careful with food. She brings plates from home, to our home. I must tell her like this, ‘There’s only one thing you can’t bring here, the gas cooker.’ I tell her that. So, she brings all the utensils, from spoon to Tupperware. She even washes them separately; also she places them separately for her child and for mine... But sometimes I do it too after washing the dishes. But it’s not really a problem. I don’t care. If I have to think about a small thing, I’ll get sicker. It’s miserable to have this kind of disease, I’ll get more hurt. Later on, when they come home, I try to understand more, I tell them this is mine, this is hers, etc. I just explain it; it’s not really a problem. But until now, my sister-in-law still acts the same. Later on, my sister-in-law tries not to hurt my feeling. At first, it was not nice when she started separating things. (Vina, 29 years, widow)

Being unwanted women, seropositive mothers are also vulnerable to being neglected and abused. One of the members, Sinta, had to accept it when her husband beat her up because she thought she did not have another choice and did not dare to save herself. Luckily, Sinta decided to move out and live separately from her first husband when she received some income from YPI. Yet, although they no longer lived together, she did not dare to divorce him, and he continued to bother her and take money from her for his drugs. After the death of her first husband, Sinta married a PLWHA whom she met in a support group meeting.

Dina’s case is also interesting. Her husband wanted to have a divorce when he knew her HIV status. He did not want to have the test himself but blamed Dina as she used to be an IDU, and accused her of carrying the virus and transmitting it to their children.

Oh, after knowing the status, he moved out right away. He just left me like that, my body hurt, I was hurt, my world collapsed. A divorce because of HIV. (Dina, 23 years, remarried, passed away in 2010)

Seropositive mothers experience discrimination, not only in the neighbourhood or family, but also in society and from medical staff. A study from 2005 in Jakarta and Bali found that in practice, healthcare staff discriminated against PLWHA and did not adhere strictly to rules or regulations on non-discrimination. Forms of discrimination included refusal to treat HIV positive persons, providing differential treatment, disclosing their status to others, and physical isolation (Merati, Supriyadi, & Yuliana, 2005). In the experiences of TOP Support members, the women were usually suggested not to have children once their HIV status became known, although this is against the written rules of the PMTCT guidelines.
It was suggested if my CD4 level is under 200, I shouldn't get pregnant. But I just took the risk, I wanted to prove to my friends, to a lot of people, that PLWHA can have a child. We only heard from other friends in Jakarta, ‘Oh, her child’s negative,’ but we haven’t experienced it ourselves. If we see the proof from the pregnancy and birth, we’ll have more courage! (Dina, 23 years, remarried, passed away in 2010)

In addition, for those women who get a caesarean section, they soon find out that it is often followed by a sterilization/tubectomy. Viona, Winta, and Maria were all sterilized after having a caesarean section. Their husbands were asked to sign the agreement letter for the sterilization procedure just moments before the caesarean without any chance to refuse it. It was therefore done without the consent of the women. Furthermore, the doctors said they would refuse to give the Caesarean if parents, especially the father, refused to sign a sterilization agreement. Viona was warned not to have anymore children by the doctor who performed the caesarean section of her second child. However, when she gave birth to her third child, the doctor would only do the caesarean after he got the agreement letter for a sterilization signed by her husband.

I was advised not to have children by doctor Evi (who treated her second child): ‘You shouldn’t have more children,’ she said. After giving birth she said if you want to have another one, better not right away. If you want to have another one, you should join PMTCT, you must! So, before giving a caesarean delivery to Joshua (her third child), Doctor Bowo told me, ‘Is there any agreement letter for a sterilization yet?/Yes, my husband has signed it.’ When I met him at Bunda (maternity ward), he told me to have a sterilization, that’s why he asked, ‘Is there any (letter) for c-section and sterilization?/Yes, doctor’/It is a must.’ So I said yes; I was sterilized after Joshua’s birth. (Viona, 27 years, widow)

There’s an operation right away. I was sterilized, by Doctor Evi. A direct operation, the letter for the operation was made, given to my husband. He agreed, I could not refuse it; I had no choice. This husband (he is her fourth husband) has not had any child (Maria, apprx 40 yeras, remarried)

It would seem that there are efforts being made to prevent children being born from seropositive mothers. This may relate to the government’s efforts to control population growth through the Family Planning Program. It may also relate to the perceived cost burden to the government of babies who are born infected, or who are just feared will be infected, with HIV. The medical interventions to prevent
transmission from mother to child, such as sperm washing, insemination, etc., are also expensive. It is intriguing that the women in these cases above defencelessly accepted a sterilization procedure, although it is understandable remembering that they are in a difficult position. A sterilization is done right after the caesarean section and the agreement is mostly signed just before by the husband, not by the woman. In this way, the reproductive rights of the woman are ignored, and the husband, who is regarded as the head of the family, can decide what is best. Additionally, because they receive help to pay for the caesarean section, they have very little bargaining power. As written in the PMTCT guidelines, a caesarean delivery for seropositive pregnant women is actually a must to prevent the transmission through delivery. It may bring a problem for those who cannot afford to do the costly caesarean section. However, the doctors may threaten to refuse to treat the woman if she does not want to go for a caesarean followed by sterilization. In most cases, the women agree to get themselves sterilized. Considering that the relationship between patients and health providers is usually not equal and is dominated by the health providers, such as surgeons and nurses, it is understandable that even TOP Support members cannot avoid the pressure for a caesarean section followed by sterilization.

Lina was the only woman who refused to get the caesarean service from YPI. However, she did it secretly because she would have lost other services. In order to avoid a caesarean section, Lina took a risk and used a traditional method whose safety is questionable. Her first child had been HIV positive and died at the age of three. Later on, Lina married another PLWHA and they had two daughters. According to Lina’s mother, Lina took some traditional medicines in order to deliver her babies prematurely. Her second child was born at seven months and her third child at six months. Both of them were born without a caesarean. Lina confessed to her mother that she had intentionally delivered the babies before the due date because if her pregnancies had reached nine months, she would have been registered to have a caesarean without her consent. Lina did not want this because she was scared of an operation, and furthermore, if she had refused it, she would have lost the other benefits from YPI, such as ARV medicines and free formula milk. Lina passed away in May 2009 and never told me the story personally.

6.E. Response to HIV/AIDS

It is fascinating to reveal that based on my observations and analysis of FGD data, the HIV positive women with whom I spoke showed differences in their ways of interpreting HIV. Those who had never had any severe sickness and who typically had little knowledge about the disease identified HIV as a curse caused by their actions, which were considered to go against social norms, i.e. to be passive and
sexually inactive before marriage. They blamed themselves and thought that HIV was a punishment and a sign that now they should live better lives according to the norms of women. In an FGD, most of the seropositive women said that they believed there was a very powerful energy reminding them of their so-called ‘misbehaviours’ as Indonesian women. Most of these women got married without consent from their parent(s). In this case, they mean their male parent (father) or any male representative of their (extended) family. A marriage without parental consent is considered illegal and a sin. As a result, sexual activities in an illegal marriage are also forbidden. Maintaining virginity is an obligation and a very important matter in a girl’s life (Niehof, Madurese Women as Brides and Wives, 1987, p. 174; Sidharta, 1987, p. 64), and a girl should be a virgin and sexually inexperienced before a legal marriage (Kroeger, 2000, p. 176). Being pregnant out of marriage is a big sin that cannot be tolerated. For this reason, it is understandable that they feel they have committed a serious sin in their life.

By having HIV, they say they now realize what they have done and that they must do better in order to get back on the ‘right path’. HIV is considered as an illness to forgive their sins after having done actions which were against their norms and religion, such as consuming drugs or having unprotected sex.

Firstly, I was pregnant, seven months pregnant. Secondly, my husband was sick.... The illness comes not because we asked for it, it comes from God. We should learn from it. (Winta, 18 years, remarried)

I feel guilty towards my parents; it’s karma because I didn’t listen to them. My parents were on my side actually, my husband’s a junky. I didn’t use to steal, but later on I stole for him. My parents advised me. Just like normal parents, they were angry with me and said they wished no happiness for me. It happened what they said. Their curse became a reality. My parents cursed me. They said I’d never be happy, if I’d have a child my child would be sick, that’s true! This is what I experience now. What parents say is magic. If I can I want to kiss their feet. I didn’t realize what I did was wrong. Having a disease now I can learn something. God gives us temptations, for each one of us. We shouldn’t be naïve. If we’re dating junkies, they always think of sex. You don’t realize you’re doing adultery. God gives me punishment because I’ve been adulterous. He gives me the disease. God may have said that from above. We don’t have to be a hypocrite as a PLWHA, people who date PLWHA must have sex. I’m not a hypocrite, I feel it. I’ve done a sin. Allah knows the

24 In Javanese tradition, kissing parents’ feet symbolizes respect when asking for forgiveness.
sins. I get a warning, the HIV. The sin is that I’ve had sex before marriage. My parents are angry; we don’t realize we’ve hurt their feelings by rebelling and not listening maybe. There’s something to learn, I think so. We get closer to God. Usually we forget the prayers, but not now. I pray more often. (Vina, 29 years, widow)

Yes, it’s true. It is the curse, I mean, it is not for me or you, but to your husband and mine. They’ve done a sin. We were cursed. It’s a curse from God... you know. I’m a victim. Back to God, He gives everything to us, He must help too. As a victim, it doesn’t mean that I’ll get the disease forever. I believe one day, I keep praying and taking medicine regularly, I may suddenly not be sick anymore, I believe that. I believe it will be gone. (Asti, 30 years, remarried)

Sometimes HIV’s not a curse, I emphasize it, HIV is not a curse. But sometimes we feel that way. If we don’t listen to our parents, we’ll get punishment. I’ve done a sin when I was still a virgin. With this warning, I’m better, I ask for forgiveness. (Sinta, 26 years, remarried)

Every action has a consequence. Not from God, actually. From ourselves, but we don’t realize it. Only God allows it to happen so that we can realize it. As a human, we don’t realize what we’re doing, we think we’re right. But, it’s not always right. People make mistakes, even though it’s a simple sin, or big sin; for God it’s a sin. God allows it to happen. But everything’s God’s will. I didn’t use to give donations, now I do. Death is in God’s hands, but at least we’re ready, we’re ready. Especially after knowing my status, I have to be closer to God, I really have to be closer to God because this illness is strange, it is strange in my opinion. What’s strange is the ones who have high risks and are not infected, and that those who are not at risk at all, who never have any idea about it, are infected. And then we see, mothers who are in a very bad condition, but the children are not infected. On the other hand, the mothers seem healthy, yet the children may be infected since their birth. If we think logically, it’s difficult to understand, maybe it’s like this, maybe it’s like that. It all comes back to Allah. I wear a veil (the Moslem hijab), just lately... It’s been a year after giving birth to my child. Especially after knowing my status, I have to get closer to God, I really have to get closer to God because this illness is strange in my opinion. When I knew it for the first time I had mixed feelings, all the feelings became one. Have you ever imagined if a durian (large thorny-skinned fruit) falls on your head? I think that’s what I felt... (Wiwid, 29 years, married)
Those who had experienced severe illness due to HIV/AIDS exhibited a better understanding of the fact that they got infected because of their so-called risky behaviour, not because of a curse or punishment from God. Nevertheless, their behaviour was still considered a sin and HIV the punishment for having committed the sin. Lina and Wanda replied cynically at the FGD when they were asked to comment on their peers’ answers.

That’s a sin of both of us, husband and wife. We dated and made love a lot. (Lina, 22 years, remarried, passed away in May 2009)

Only Malin Kundang was cursed\(^\text{25}\). It’s not a curse, it’s a disease. Actually, it’s a blessing that I get HIV. Alhamdullilah. Because I do remember God now. I realize it now, I ask for forgiveness. I used to pray once a day, now all of them (all five times, Moslems pray five times a day). At least we’ve got something to be taken to another world (when we die). (Wanda, 27 years, widow)

It appeared that the HIV positive women felt particularly guilty when their children had to pay for their so-called sins, as described by Wiwid and Vina below.

It’s not a burden for me, what bothers me is that my child is also infected. I feel guilty. If (my health) gets worse, but my child is healthy, I can accept it. Allah decides your fortune. I don’t know how but there must be a way. What I’m concerned (about), what makes it worse, is when I die and my child is also sick. That’s my concern. Who will take care of him? (Wiwid, 29 years, married)

When I knew that she’s positive (her only daughter) I was very sad, I feel like I’ve done the sin. I try to pay for it. I give her medicines regularly, I give her healthy food. If I can make her happy from my own income, I try to buy anything she wants. That’s what I do. (Vina, 29 years, widow)

Many of the women do not regard HIV/AIDS as a disease but rather as a punishment for their sins, given by God in accordance with the prevailing religious norms. Religion not only provides them with an answer to the question ‘why me?’ but also provides them with a way to deal with the curse, i.e. they can cleanse themselves and wear a veil.

\(^\text{25}\) Wanda is referring to a famous Indonesian fable in which Malin Kundang, the son, is cursed by his mother.
Because these women did not feel that they had HIV, they did not feel the importance of taking ARVs and visiting the doctor regularly. Discontinuance and non-compliance was not an unusual thing among them. For Dina, Winta, and Lina, although they received ARVs free of charge, they still did not attend the clinic regularly to get the medicine. I think this was because they did not feel ill. For most people, doctors and medicine are related to the condition of being ill. One does not go to see the doctor or take medicine if one does not feel like one is sick. Asymptomatic people may refuse medical treatment even though physical abnormalities of the body are found (Helman, 2001, p. 104). This happens also among TOP Support members; even if they feel some symptoms they do not regard them as symptoms of HIV but of the opportunistic infections or of the medications themselves. When they have an opportunistic infection, the doctors will suggest that they buy medicine to treat it; medicine which is, however, relatively expensive. Then, usually for economic reasons, they become demotivated even to get the free ARVs from the referral hospital or to attend health check-ups.

The side effects of ARVs were stated as another reason why they do not take them regularly. The side effects are even considered to be more of a disease than the HIV itself. Tiara refused to start ART even though her CD4 count was very low (at 97), as she was afraid that the side effects would have a negative impact on her appearance, such as producing dull skin, a fatty body, or a pimpled face.

Asti shared with me her experiences of taking ARVs. Before ART, Asti had been on TBC treatment for tuberculosis. Both medications, the TBC treatment and the ART, caused serious side effects for her body. She later tried a different type of ARV, but it did not help. Eventually she has found an ARV type which has the least side effects.

I got TBC, very bad, very ill, seriously ill. I took some medicine, but the medicine had ‘burned’ me, made me weak, and (I was) totally ill. As if I was literally burned, I was black as if I would die anytime soon, it’s so scary to have a look at myself, I swear…! I was given the medicine for a week, and then I stopped and had a consultation with *Puskesmas*. Then I was given the same medicine by the doctor. The medicine costs 200,000 ( IDR). Later I was tested at Dharmais (hospital). That’s right, I got ARVs. I quit taking ARVs because of nausea, itchiness. I took Duvinevin, now I take Duviral Evaviren. Evaviren sometimes makes me dizzy and I hallucinate, about half an hour to an hour. (Asti, 30 years, remarried)

Titi and Wanda place no importance on consulting their doctor with their complaints. Whenever they pick up their ARVs at the referral hospital, they also have an obligation to consult the doctors about their health problems, in order to
detect opportunistic infections as early as possible. However, medication for the opportunistic infections is costly. Titi and Wanda shared their stories below.

If, for example I’ve got complaints…such as my liver hurts or this hurts that hurts, Prof. will give me extra medicine. This extra medicine costs already around 400 (400,000 IDR), only if I’m very ill will I be given. The capsule which costs fifty thousand each, a capsule, and I have to take 150mg, three capsules. But sometimes I am reluctant to tell the Prof... hmm... if I have a certain complaint. I’m afraid of the medicine (because it’s expensive). So, before seeing him I will do ‘it’ myself first (self-medication). Such as taking much juice, you know, taking juice or buying vitamins myself. If I get better, I won’t see the Prof. But if I can’t help it, if I’ve done everything, I have to see the Prof. (Titi, 24 years, married)

I never talk to the doctor about that because if I do I must get medicine from him. He must give medicine if we have complaints, I don’t feel like taking it. I don’t tell anything. The doctor only asks me if I have complaints or not. If he asks and I don’t have any complaint, he gives only the prescription of Nuviral Deviral. (Wanda, 27 years, Widow)

6.F. Discussion

Glick (1998) argues that there are three dimensions of a diagnosis statement: (1) evidence, the empirical indication which can be proved by signs and symptoms; (2) the process, which describes what actually happens to produce the evidence; and (3) the cause or agents, who/which in some ways bring their powers to bear against their victims. I have noticed that in the TOP Support group, most members never feel that their symptoms are evidence of HIV. In fact, anybody who has HIV will eventually develop AIDS, at which time symptoms of opportunistic infections will appear. However, being HIV positive does not always mean that an illness exists or that there is any change in one’s health condition. Many of the support group members did see evidence in the fact that their children and husbands have died, but they did not experience the symptoms themselves.

The distinction between a disease and an illness refers to the different symbolic perception and explanation between doctors and patients about the sickness (van der Geest, 1987, p. 31). A disease is a clinical fact, and refers to something related to an organ which is based on scientific rationality and the objective observations of doctors. A symptom of the disease can only have meaning when it is explained by objective and physical changes. In contrast, an illness refers to the subjective
response of an individual and the people around him regarding his ill health, which includes his experiences and the meaning he gives to these experiences (Helman, 2001, pp. 79-84). Semiotically, an individual will interpret his illness based on the symptoms he experiences. Cultural background and personal experience have an influence on a person’s thoughts about certain symptoms, which eventually help decide upon the meaning of the illness to that person (Frake, 1998; Glick, 1998; Good, 1998).

It is possible that someone who has HIV has not had any related health complaints, since they have not yet reached the stage of AIDS. Thus, even if a person has experienced some physical symptoms, if these symptoms are not severe they might not consider themselves to have a health problem (Kaplan, Sallis Jr, & Patterson, 1993, p. 278). Without symptoms, one cannot actually diagnose one’s illness (Frake, 1998; Glick, 1998; Good, 1998). This is the reason why it is hard for TOP Support to emphasize to the seropositive women that HIV is a disease. For most TOP Support members, having HIV is rather the consequence of having committed a sin that goes against their bio-social identity as a woman and as a mother.

It is interesting to know that without symptoms which function as evidence of HIV, the HIV positive women in TOP Support can explain the process and cause of the disease. The ‘agent’ which caused the disease was the woman herself (perhaps because she was an IDU) together with her (IDU) partner, and what really happened was the sin of losing her virginity as a result of improper sexual relations. Interestingly, the women blame the risky behaviour of their partners, instead of their own behaviour, as the cause of HIV, even though some of them were still sexually active with multiple partners and/or active IDUs. It is a defence mechanism of the seropositive women to define themselves as innocent and devoted women, even though they were aware of their own risky behaviour. Emphasis on men’s sexual permissiveness enables the women to take an on innocent and devoted motherly role as a mechanism to rid themselves of the stigma of HIV.

Their bio-social identity as mothers also means that they display more concern about the health of their husbands and children than for their own. Because the ART causes some side effects, they think that the symptoms of the disease can be cured by not taking ARVs. In addition, though many of them receive ARVs for free, to collect the medication requires money for transportation; money which they feel they need more to feed their family. Their ignorance regarding taking ARVs regularly and treating opportunistic infections are evidence that they do not consider HIV as a worrying disease.

In my opinion, their response has also been influenced by their (socialized) feminine characteristics. They have a passive response to the stigma and discrimination against them, and avoid conflict or discriminatory treatment. For example, if there is a family member who discriminates against them, they might
choose to avoid contact with the family. Another example is when the women face a caesarean section followed by a mandatory sterilization; they either accept the decision made for them or secretly engage in other risky practices, which actually put them and their babies in danger. The case of Lina, who twice took traditional medicines to prematurely induce labour in order to avoid a caesarean section, provides a vivid example of this.

Even though they face a dilemma because they know that their children have to pay for their sins by having HIV at birth, the women are still very eager to create a family and have children as they have to keep up their motherly role. In Indonesia, a woman’s identity is always related to fertility, and giving birth and producing offspring are compulsory in order to give a woman stronger status in the community (Bergink, 1987; Bringgreve, 1987; Jordaan, 1987; Sidharta, 1987). According to Ulanowsky and Almond (1996, p. 38), seropositive women may decide to remain childless, but “knowing that her prognosis is bad, or even anticipating a short life expectancy may provide a very strong reason for a woman to seek fulfilment in motherhood”. Furthermore, a sense of insecurity and a lack of social security mean that the women may try to have as many children as possible, as this will guarantee them a comfortable retirement in their old age. PMTCT provides the promise of giving birth to HIV negative children as social insurance; and since the women do not have symptoms they do not see any good reasons for not having a child.

A marriage also brings an advantage for them economically. Women are socially defined as housewives who are dependent on their husbands’ income, regardless of their actual contribution to their families (Suryakusuma, 1996, pp. 101-102). Being a secondary earner, a woman is never considered by others (nor herself) as a breadwinner. The TOP Support members also reflect on this idea. They do not have any confidence that they could earn money to take care of their children alone, and they very much depend on the (extended) family to take care of them and their children. Instead of having a secure job, which most of them cannot get because they do not have good educational backgrounds, they prefer to seek a partner who can financially support them and their children. TOP Support becomes a place where they can meet their future partner.

In the next chapter, I will explain how the women pragmatically use their HIV positive status to access individual benefits.
Table 1:  
TOP SUPPORT MEMBER LIST

<table>
<thead>
<tr>
<th>No</th>
<th>NAME</th>
<th>MARITAL /SEXUAL RELATIONSHIP (PAST/PRESENT)</th>
<th>HIV TRAJECTORY</th>
<th>TREATMENT TRAJECTORY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Vina</td>
<td>She is now in a relationship with an HIV positive man and sexually active</td>
<td>She was referred by the hospital that was taking care of her severely sick daughter. She believes that her husband infected her and her only daughter. Her IDU husband died in 2003. He knew his positive status but refused to take ARVs until he died. Her daughter tested positive at the age of 3 months in March 2002 and has been on ART since.</td>
<td>She started ART in October 2002. Because of the side effects from Lamifudin, in 2005 she started line 2 ARVs with Kaletra. She routinely checks her CD4 count and viral load. In 2006, her CD4 count was 172. She has never experienced any severe opportunistic infections.</td>
</tr>
<tr>
<td></td>
<td>29</td>
<td>Widow</td>
<td>Senior high school, graduated with secretariat vocational training</td>
<td>Moslem</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Moslem</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Yuna</td>
<td>She is now in a relationship with a man and is sexually active. She has 2 un infected boys.</td>
<td>She tested positive after her HIV positive IDU husband died in 2004 from severe typhus.</td>
<td>She has been on medication (Zidovudine, Nevirapine, Lamifudin) since April 2004 as her CD4 count was 169 and she was 8 months pregnant. As she got anaemia, she changed Zidovudine to Stavudine. She has never experienced any severe opportunistic infections since she tested positive.</td>
</tr>
<tr>
<td></td>
<td>32</td>
<td>Widow</td>
<td>Senior high school, graduate</td>
<td>Moslem</td>
</tr>
</tbody>
</table>

26 The condition of the informants are continuously being updated through unconditionally meetings, emails, telephones, or test messagings since the field research was conducted in 2006 up to 2010.
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital Status</th>
<th>Education, age and religion: no record</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Willy</td>
<td>25</td>
<td>Separated</td>
<td>Senior high school, graduate Catholic</td>
<td>She lives separately from her husband who has recently remarried to another woman. She got tested after her husband tested positive, but both of them have been IDUs. She recently stopped taking the drugs as her best friend passed away from an overdose. Her husband is still actively using drugs. She has been on ARV medication since 2006 as her CD4 count dropped, but has never experienced severe opportunistic infections. Her husband stopped ART. He was in jail and never shows up anymore.</td>
</tr>
<tr>
<td>Dini</td>
<td></td>
<td>Married</td>
<td>Passed away in 2007 Education, age and religion: no record</td>
<td>She was married to an IDU. She took VCT after her husband was severely sick. Both of them have now passed away. They had two uninfected children. Before she died, she was on ARV medication as her CD4 count had been low since 2006, a year before she passed away in 2007</td>
</tr>
<tr>
<td>Lina</td>
<td></td>
<td>Passed away at the age of 25 in 2009 Remarried to a PLWHA</td>
<td>Junior high school, graduate</td>
<td>She was married to her first husband, who died of AIDS in 2005. She had 1 son with her first husband, who died of AIDS at the age of 3 years in 2007. Her son had never been medicated. She was sexually active with some boyfriends before she remarried to another PLWHA. She had 2 uninfected daughters from her 2nd husband. Both girls were born prematurely. She found out her status after her baby boy was severely ill. She thought that she was infected by her first husband. She was on ARV medication since March 2006 and died of Tuberculosis. She stopped ART several times, even though she got it for free at the referral hospital.</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Marital Status</td>
<td>Education</td>
<td>Religion</td>
</tr>
<tr>
<td>--------</td>
<td>-----</td>
<td>---------------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Winta</td>
<td>18</td>
<td>Remarried</td>
<td>Junior high school, graduate</td>
<td>Moslem</td>
</tr>
<tr>
<td>Wanda</td>
<td>27</td>
<td>Widow</td>
<td>Senior high school, graduate with illegal diploma</td>
<td>Moslem</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Marital Status</td>
<td>Education</td>
<td>Religion</td>
</tr>
<tr>
<td>-------</td>
<td>-----</td>
<td>----------------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Wiwid</td>
<td>29</td>
<td>Married</td>
<td>Senior high school, graduate</td>
<td>Moslem</td>
</tr>
<tr>
<td>Sinta</td>
<td>26</td>
<td>Remarried to a PLWHA</td>
<td>Senior high school, graduate</td>
<td></td>
</tr>
<tr>
<td>Asti</td>
<td>Remarried to a PLWHA</td>
<td>Senior high school, graduate</td>
<td>Moslem</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Status</td>
<td>Education</td>
<td>Religion</td>
</tr>
<tr>
<td>------</td>
<td>-----</td>
<td>--------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Tiara</td>
<td>22</td>
<td>Widow</td>
<td>Bachelor diploma degree, graduated Moslem</td>
<td></td>
</tr>
<tr>
<td>Netty</td>
<td>23</td>
<td>Married</td>
<td>Senior high school, graduate</td>
<td></td>
</tr>
<tr>
<td>Dina</td>
<td></td>
<td>Passed away in 2010 at the age of 25 year Remarried</td>
<td>Senior high school, graduate Moslem</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Marital Status</td>
<td>Education</td>
<td>Religion</td>
</tr>
<tr>
<td>-------</td>
<td>-----</td>
<td>----------------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Ika</td>
<td>32</td>
<td>Married</td>
<td>Senior high school, graduate</td>
<td>Moslem</td>
</tr>
<tr>
<td>Titi</td>
<td>24</td>
<td>Married</td>
<td>Diploma III school, graduate</td>
<td>Moslem</td>
</tr>
<tr>
<td>Irene</td>
<td>23</td>
<td>Married</td>
<td>Senior high school, graduate</td>
<td>No record</td>
</tr>
<tr>
<td>Ade</td>
<td>22</td>
<td>Married</td>
<td>Junior high school, graduate</td>
<td>No record</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Status</td>
<td>Education</td>
<td>Religion</td>
</tr>
<tr>
<td>-------</td>
<td>-----</td>
<td>---------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Evi</td>
<td>23</td>
<td>Widow</td>
<td>Senior high school, graduate</td>
<td>no record</td>
</tr>
<tr>
<td>Viona</td>
<td>27</td>
<td>Widow</td>
<td>Diploma I school, graduate</td>
<td>Christian</td>
</tr>
<tr>
<td>Atik</td>
<td>29</td>
<td>Divorced</td>
<td>Diploma III school, graduate</td>
<td></td>
</tr>
<tr>
<td>Siti</td>
<td>26</td>
<td>Married</td>
<td>Senior high school, graduate</td>
<td>Moslem</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Marital Status</td>
<td>Education</td>
<td>Religion</td>
</tr>
<tr>
<td>---------</td>
<td>--------------</td>
<td>----------------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>Ruminta</td>
<td>36</td>
<td>Remarried</td>
<td>Senior high school, graduate</td>
<td>Christian</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maria</td>
<td>Remarried</td>
<td>Moslem</td>
<td>Age and Education: no record</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dessy</td>
<td>Age: no record</td>
<td>Married</td>
<td>Senior high school, graduate</td>
<td>Moslem</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Chapter 7

The Reworking of HIV Positive Identities

Many articles have shown that people are stigmatized and discriminated against for having HIV/AIDS. However, some people are able to benefit from HIV/AIDS programs through their therapeutic identity as a PLWHA. A story from a ‘friendship centre’ created by Jeunes sans Frontières (Youth without Borders) in Ouagadougou, Burkina Faso, shows how people there made use of a local tactic for mobilizing resources through proximal networks of social relations (Nguyen, 2005). As part of their advocacy work and efforts to reduce HIV/AIDS related distress amongst themselves, the members of the friendship centre created a self-help group called a ‘talking group’, where they shared stories to cope with their experiences of HIV/AIDS. They came up with the concepts of ‘living positively’, ‘taking responsibility’, and ‘caring for others’, through testimonials and confessionals. This confessional technique is advocated by the global AIDS movement. The key to survival is the ability to tell your story to the people. Nguyen, describing the talking groups in Ouagadougou, shows how this ability to tell their story enabled some of the active members who regularly came to the group to receive medical benefits. More than that, some of them were able to migrate to European countries following seminars and conferences, or to obtain sponsorship from their fellow European activists. These individuals live as therapeutic migrants who gain a decent job, usually at an NGO working in the field of HIV/AIDS, and receive free medical treatments assured by the government, leaving their unlucky fellow patients behind in their hometown. In his article, Nguyen shows
how some members of the friendship centre use their therapeutic identity as a way to legally migrate to a better-off country, and live as therapeutic citizens (Nguyen, 2005, p. 142).

Similar to the members in the friendship centre, some TOP Support members use their biomedical condition to construct a therapeutic identity through testimonials and confessionalis at seminars and conferences in order to gain material benefits. Instead of identifying themselves as PLWHA first and foremost, they make use of their bio-social identity as innocent and victimized housewives and devoted mothers, who were infected by their ‘badly behaved’ husbands, and in some case unfortunately transmitted the disease to their offspring. This identity is locally constructed through the image of PMTCT as a part of women’s reproductive health, and disregards the question of an individual’s risk behaviour. This identity is collectively shared among the members of the support group.

TOP Support members face stigma and discrimination for having a ‘whores’ disease’. However, PMTCT helps change that, by shifting the image of HIV/AIDS as a disease of badly behaved people to a disease of innocent and devoted housewives and mothers. Given this, it is interesting to examine to what extent the construction of a collective social identity by TOP Support members, based on their therapeutic identity, has generated a bio-social grouping; and how this collective social identity benefits TOP Support members, as individuals and as members of the support group.

First of all, I discuss how the TOP Support members construct the image of good housewives and devoted mothers and how they get benefits by ‘playing the victim’. I also describe how some individuals’ use of the group for their own interest has changed the role and focus of the group from one of social support to one with commercial interests. Finally, I describe the dynamic of deciding to disclose or not to disclose their HIV status for the sake of their family’s welfare.

7.A. Being Innocent and Having HIV: Identity Shifts

This was part of Vina’s story that was broadcasted on one of Indonesia’s cable TV channels in 2006. The program was highlighting the discrimination against people with HIV/AIDS in accessing medical services and getting a job. Vina was one of the guests. I watched the rerun a few days later. Vina was sobbing as she was telling the audience her touching story on the live talk show, especially when she was talking about Uti, her daughter. The audience felt sympathy for Vina, an ‘innocent’ housewife who got HIV from her husband, a drug user. After her husband left her, she had to struggle on her own to make a living for her HIV positive daughter and herself. Vina told the audience how hard it was for a seropositive woman like herself to get a
It seemed to her that most employers did not want her. However, Vina never told the audience about her poor educational background or the fact that she lacks skills, both of which have also made it difficult for her to get a job. She also never shared her risky behaviour in the past which took her to her IDU husband. Rather, she was repeating the same touching story of an innocent and unlucky housewife, which she had told in many seminars and conferences, even some international ones. Vina is one of the TOP Support members who has disclosed her HIV status to the public. This was not her only TV appearance; she also shared her story on a news program on another cable TV channel in 2005.

Vina is not the only TOP Support member who has been invited onto a live talk show. Recently, another TOP support member, Lina, was also invited to the same show in 2008. Here is the story that Lina shared on the program:

Lina, who was pregnant with her second baby when she was interviewed, got HIV from her husband. She did not have any suspicion about his illness although he was having a health problem at that time and got hospitalized because of it. The doctor then suggested to her to let his blood (be) tested. She found out that her husband was HIV infected. Later on, she found out that she got infected as well. Her first baby boy also got infected and died at the age of three (Kick Andi, 2008).

On the program, Lina appeared with Ben, her second husband whom she had recently married. Just before this TV appearance, Lina and Ben were also
interviewed on another TV channel. They were interviewed at Ben’s parents’ house and were showing their harmonious relationship as husband and wife. Lina did not tell the audience that Ben was her second husband who had three children from his previous marriage. Ben’s ex-wife is not HIV positive, nor are his three children. Ben and Lina got married because she became pregnant, though at the time Lina also had another boyfriend. Lina’s first son from her late husband passed away in 2007 at the age of three after treatment was sought too late when he was sick. By that time, Lina was so in love with Ben that she neglected her son, who was taken care of by her mother instead. Ben is a drug user and has relapsed several times. Lina has told me that she also still uses drugs occasionally. Lina and Ben have two daughters together. Their second daughter was born prematurely due to an opportunistic infection which Lina contracted during her pregnancy. During the TV interviews, Lina mentions her late husband and son only occasionally, and she gives only very brief explanation so no one actually notices this part of the story. Instead, she puts herself in the position of an unlucky wife who had surrendered herself to be infected by her late husband and therefore unfortunately infected her baby.

The TOP Support members do not only appear on TV; their stories are also frequently written about in magazines and newspapers. Yuna is one of the members whose story appeared on an online magazine in December 2008. Yuna presented an image which is not much different from her two fellow members above, i.e. the image of a wife who has devoted her life to taking care of her HIV positive husband from whom she contracted the disease. Luckily, in Yuna’s case her baby is HIV negative.

**I got infected by my beloved husband.**

Everything started when my husband had typhus symptoms. Confusingly, after more than a month, he was not getting better. The doctor advised us to visit Persahabatan Hospital to have a blood test done. The result was really shocking. My husband is HIV/AIDS positive!

**My husband is an ex-IDU.**

The blood test said that I was also infected. I was devastated. During six years of our marriage, as far as I remember, he never acted or showed any strange behaviour. Finally he confessed that he used to be a drug user but had never used drugs since four years ago.

**The virus attacked my body immune system.**

I had quit working as I was too busy taking care of him; I didn’t even pay attention to my unborn child. A doctor had reminded me that the HIV/AIDS virus could infect the innocent child in my womb. A month after my husband
died, I decided to join *Medicine sans Frontières* (MSF), an NGO from France. I was given further information on HIV/AIDS completely so that I understand more about the virus which has no medicines yet. Then, a doctor advised me to have a CD4 test done. As I expected before, my CD4 level was 169; it should be between 500-1000. My body is very fragile to infection.

**God has given me help.**

Praise the Lord, there are actually people who want to help me. At the beginning, I felt insecure because I knew it would cost a lot, from the ARV medicine therapy to the caesarean section that I needed. My baby had to be born with a c-section to minimize the risk. When I was seven months pregnant, I was appointed to *Yayasan Pelita Ilmu* (YPI) which has a PMTCT program. YPI has given me such enormous help. They paid all the birth expenses; they even gave a subsidy for the formula milk for a period of a year’s time.

**My child is HIV negative.**

I am very thankful my baby was born safely. When he was eight months old, he had the HIV/AIDS test done and the result was negative! For all the mothers-to-be living with HIV/AIDS, don’t give up. Remember that your children need you. That’s why you should get as much information as you can on HIV/AIDS so that your children can be saved (Mother and Baby, 2008).

Almost all of the TOP Support members have given testimonials, including Vina, Lina, Yuna, Winta, Sinta, Wanda, and others. The interesting point is how they disclose their HIV status and create an image of themselves, reconstructing their identity as victims and implicitly blaming their husbands who had wicked behaviour. They choose a role as innocent and passive housewives who are powerless. This role is accepted well in the public eye. Indonesian women are socialized as domestic partners who have to listen to and obey their husbands, are not allowed to ask questions, and have to anticipate what their husbands needs are without asking (Kroeger, 2000). On one hand, this is a shortfall for women, but in the case of the seropositive women at TOP Support, they have occupied this role to manipulate their image to their benefit. People will not have sympathy for an HIV positive woman who was infected because of her own risky behaviour; however, they will have sympathy for the never-ask-questions housewife who was being responsible for her family, and faithful and obedient to her husband.

In order to emphasize their image as innocent women, they also change their appearance. Many of them wear a *hijab* (see Vina’s picture above), the traditional
covering for the hair and neck that is worn by Moslem women. Moslems make up the majority in Indonesia, thus the hijab is a common thing to wear in Indonesia. Lately, many Indonesian (Moslem) women wear the hijab to present themselves as fine and religious women. Research conducted by Smith-Hefner in Yogyakarta mentions that between 1999 and 2002, the number of women wearing a hijab increased by more than 60% (Smith-Hefner, 2007). According to Wikipedia, in popular use, hijab means head cover and modest dress for women among Moslems, which most Islamic legal systems define as covering everything except the face and hands in public. However, many Indonesian Moslem women wear a hijab to cover only their neck, hair, and ears.

Based on my observation, I noticed that TOP Support members wear the hijab in order to present themselves as good women. These members also believe in the stereotype that HIV is a cursed illness which only infects badly behaved people. From their point of view, it is clear that some people therefore believe that they are the ones who have behaved badly. Indonesian women are socialized and expected by society to identify themselves as religious, innocent, and virginal, until they become mothers and housewives, and caregivers who serve and nurture. By wearing a hijab, the women in TOP Support hope to present this image expected of women by society. In other words, they wear the hijab because they do not want to be seen as people with bad behaviour. Some of the women told me that they started wearing the hijab when they knew they were HIV positive, in order to hide their so-called bad behaviour which was considered shameful and inappropriate.

Research by Lindquist (2001) conducted among female migrant workers in Batam found that the women wear a hijab during the day, but take it off at night when they work as prostitutes. Why is wearing a hijab and appearing as pure and religious so important? If women fail to appear this way, they cannot get access to certain facilities as they are regarded as ‘bad’ women. Lindquist’s study shows that female migrant workers in Batam wear the hijab in order to break from their prostitution identity or to get rid of sexual harassment during the day when they do a regular job, which they need in order to financially support their families in the villages. But the money they earn is not enough, so at night they have to take over their husbands’ role as the breadwinner and work as prostitutes. Working as a prostitute for them is shameful, since by doing so they cannot function as the ‘expected Indonesian women’. TOP Support members also wear the hijab to cover their shame. They are ashamed of themselves and they understand that they have (and perhaps still do) engaged in high risk behaviour. The shame, then, creates a feeling of guilt, as admitted by Wiwid. She became a religious person as soon as she found out about her HIV status. She feels and believes that wearing the hijab can bring her closer to God. It also makes her more relaxed and lessens her shame.

For these TOP Support members, the hijab is worn to get attention and to
support their collective identity as innocent housewives and proper Indonesian
women. Some of them wear the hijab when they go out of their home, in accordance
with Moslem rules, however, some of them wear the hijab only occasionally when
they have to give testimonials at seminars, to meet the community doing advocacy
work, or to welcome the ‘guests’ at YPI who come to visit TOP Support, especially the
guests who are offering assistance or funds for them.

If we talk to the guests, for example to the women, I can’t say the
word gue (a slang word for ‘I’, usually used by young people in big cities in
Indonesia) because it doesn’t really show respect. Sometimes I wear... for the
Ngobras (Ngobrol santai informal chat, a weekly meeting program), because
there are a lot of people coming, I wear hijab so that they can’t see the real
me, I’m actually bad (I have bad behaviour). But I’m confident to talk. (Asti,
30 years, remarried)

Asti is an ex-drug user, but she found out that she was HIV positive when her
husband, who was also an IDU, got severely ill and passed away soon afterwards.
She feels that her extrovert attitude brought her to bad environments, and therefore
she got the disease as a curse for being a bad girl.

The advocacy work of TOP Support not only gives the participants a degree of
celebrity status in Indonesia, it also brings them to places they never thought they
could ever visit, or to meet very important people whom they would otherwise
never have met. For example, Vina was able to participate in AIDS International
conferences as a representative of seropositive young women from Indonesia. Last
year, she participated as a Unilever ambassador for HIV/AIDS. In 2007, Vina went to
Canada. This is her comment on it in an FGD:

Maybe, getting the disease can have a positive effect. This is like what
my sister told me. When I was about to go to Canada, my sister told me, ‘If
you weren’t sick, it would be impossible for you to go abroad.’ It might be
true. It means there’s an advantage of being a PLWA. I can make others
happy. Even if I’m sick, I don’t bother others. For sure, I can be independent
and can still earn money by myself. (Vina, 29 years, widow)

According to Winta, aside from having participated in an international seminar,
her identity as a seropositive mother allowed her to meet the President of Indo-
nesia. As Winta told me in an FGD:

... (I) can go abroad, I can meet SBY (Susilo Bambang Yudoyono - the
president). If I didn’t get the disease, it wouldn’t be possible to know a lot of
people. It means I take the positive side of having this disease. If I wasn’t sick, I wouldn’t know people from abroad... If I kept being angry at my husband, I would only focus on him. If my husband was alive, he would say, ‘It is because I infected you that you can go to another country’. I can meet a lot of people. That’s why this accident brings a positive side, I focus now on my child, and I take care of him. (Winta, 18 years, remarried)

7.B. Economic Benefits

Nguyen (2005) shows how in the friendship centre in Burkina Faso, the members of the talking group use a confessional technology to get access to medical treatment. TOP Support members, by contrast, use testimonials and confessionals to get an income rather than to gain access to treatment. In their case, free treatment is provided by YPI, therefore collective action for treatment is not necessary.

As an NGO, YPI has very much depended on international funding agencies. Unfortunately, the international support is not always available. Whenever there is a shortage in the budget, YPI will cut the expenses for transportation fees for the members who work at the secretariat or do home or hospital visits. From 2007 onwards, due to limited funds, they hardly do any hospital or home visits. Furthermore, meetings are only conducted when needed. YPI has also rearranged the routine secretarial activity in order to be able to save the remaining budget for transportation fees, because without the transportation fee, usually no one comes.

The TOP Support group functions as an access to charity for these women, an information centre about ‘jobs’ on seminars and in the mass media. Almost every time I visited the TOP Support secretariat where they usually have their meeting every Wednesday, I saw TV crews filming the activities of the TOP Support members, capturing their daily activities there. Unfortunately, the crews did not capture any other parts of their lives, for example the struggle the group members have to face in supporting themselves and their families.

It is not only being able to go abroad and meeting important people that brings benefits; more importantly, the advocacy work gives them an opportunity to earn money, especially when they are invited to either local or international seminars or talk shows. One of the YPI staff, Sundari, functions as a coordinator. She is the one who takes orders from other institutions or the media for giving testimonials and distributes them among the TOP Support members. According to Vina, she received 2 million IDR (US$200) for one appearance on a talk show. Sinta and Wanda have had similar experiences. In addition to getting acknowledgment, they usually get some amount of money for sharing their experiences as seropositive mothers. In almost all appearances, they present themselves as innocent housewives, the
identity they have received from the PMTCT program. Because of the money they get, they consider it as working and call it a ‘job’.

I don’t get any regular salary; the transportation fee is only 25,000 (IDR) each time (she comes to YPI). But I depend on another job besides it (the support group), for example by being a speaker. We get 500 (500,000 IDR). I even received 1 million because it’s a foreigner who invited me. I only depend on it, so I never have a target for a month. Sometimes, I get nothing for a month. Only 50,000 of the transportation cost. That’s it. (Sinta, 26 years, remarried)

Sometimes I join the training, just like the other day, not bad, I got 50 (50,000 IDR) per day. There’s not always the chance to give a testimonial. In November, December, I got a lot; I don’t know in January or in the future... If we’re not active (regularly coming to the secretariat), we can’t be invited as a speaker etc... The other day I bought my kids Pampers (diapers), the money’s from the testimonial. It’s not bad for a week. All my life, I’ve never worked. I never felt the joy of earning money. I feel pity towards my parents; they’ve paid so much for my sickness and for my children. (Wanda, 27 years, widow)

Note how Sinta points to the larger fee given by foreign donors. Foreign donors are vital for HIV prevention programs in developing countries such as Indonesia. Although the government budget for HIV/AIDS intervention rose from US$6.3 million in 2003 to US$10.6 million in 2004 and then to US$13 million in 2005, the budget only covers thirty percent of the total budget used for the national HIV/AIDS program. The other seventy percent comes from foreign donations, as much as US$19.5 million in 2003 and US$22.8 million in 2004. During 2003-2005, in addition to the government budget of US$30.9 million (25% of national spending on HIV/AIDS), the national AIDS prevention program received funds from several sources, such as bilateral donations of as much as US$80.8 million (66%), UN core funds of US$10 million (8%), and from international NGOs US$1 million (1%). The sources of the bilateral donations are IHPCP (Australia), FHI (USA), DFID (United Kingdom), GFATM, DKT/KFW (Germany); the UN core funds came from UNICEF, UNFPA, UNDP, WHO, ILO, UNESCO, UNV, World Bank, UNHCR, and UNAIDS; the fund sources of the international NGOs were Save the Children, Cordaid, MSF Belgium, and Church World Service (National AIDS Commission Republic Indonesia, 2005). Foreign donors usually come in with several programmed activities and will only give funds to the activities that have coherence with their programs.

Wanda’s story above shows how proud she was when she, a woman who never had had a job before, was able to buy diapers for her daughter. The money could be used to fulfil her family’s needs and it made her feel that she had value for herself
and for her daughter. Winta shared a similar story. According to Winta, she is the backbone of her family, and her mother frequently asks her for money after finding out that she has had a ‘job’. Winta lives in a five square metre sub-standard house in a crowded slum area with her husband, daughter, mother, and siblings. Her father was a *tukang parkir* before he died and earned 1000 to 2000 IDR for every car he helped. Since her father’s death, her mother has had to do many different kinds of work to make a living, including doing laundry for other households. Winta thinks that she owes her family a lot. She is now married again, to a driver. Her husband has never been tested, so they do not know if he has been infected with HIV or not. They have a daughter who does not have HIV. Since getting married, however, her financial condition has not improved. She has still been helping her family (including her mother and siblings) with the money she gets from the public testimonials.

![Winta’s Family Tree](image)

Mbak Ati (a YPI staff) also said, ‘Winta, if you become a speaker or get money from YPI, save the money, don’t be too open to your mother’. My mother, she’s happy if I go to YPI, she thinks I always get money from YPI, because last year I became the speaker too often, maybe because my story’s the most unique one, that’s why I am always invited. My mother thinks if I go

---

27 *A tukang parkir* is someone who helps car drivers park their cars by using his hands to give signs as to which parking spaces are free and by giving signs to the cars on the street when a car is leaving the parking lot.

28 Laundry is done manually by Winta’s mother at her clients’ homes.
with Mbak Ati, I always get money. The other day when I had an interview with a magazine, I didn’t get a lot of money, I didn’t ask for it either. If I become a speaker, I expect to get a lot of money, but for the interview I don’t really. I think for them it is good to get the info from us. My mother thought I was a speaker, like the other day at the Grand Hotel, my mother thought I brought money home. ‘I didn’t get money, I haven’t been paid. Are you sure they haven’t paid, are you lying?’ My mother didn’t believe me, so when I got the money from my husband, I gave it to her and said, ‘This is the money from yesterday, I just received it this afternoon.’ I put it in an envelope with a note written by my neighbour, ‘Your fee as a speaker, 100 thousand’. If I come home today, if I don’t get money, she’d ask, ‘Don’t you get any money?’

(Winta, 18 years, remarried)

In Sinta’s case, the money she receives is more than enough to fulfil her daily needs. It even saved her from her abusive husband. A few years ago, Sinta decided to leave her prosperous life with her parents. She preferred to marry her boyfriend instead of continuing with her studies by going to a university in Singapore. She is the only child of a well off family. Her father is a Singaporean who lives in Singapore and her mother is a Chinese Indonesian who lives in Batam. Sinta is closer to her mother than to her father, as she always lived separately from her father. Her mother did not allow Sinta to have a (serious) relationship, especially to an Indonesian. As a Chinese, her mother believes in the stereotype that Indonesians have bad behaviour and are lazy.

Sinta met her husband, Arjuna, when she was in high school. They met through a friend when there was a band performance in Batam in which he was one of the performers. They started to have a secret relationship since it was forbidden by Sinta’s mother. After she graduated from high school, Sinta ran away with Arjuna and lived in Jakarta with his family. Later on, they got married and she was converted to a Moslem. Arjuna did not come from a well off family. His father was a construction worker who worked by order, which only came once a year or once in six months. The family always had some debt in order to survive. Arjuna had a lot of siblings, so they always lived jostling in a house which was shared by fifteen people. Nevertheless, Arjuna’s mother often wasted money without thinking of saving. When Sinta had some money, she had to ‘deposit’ it to her mother-in-law or else the in-laws would say something cruel.

At the beginning, the marriage went well. But after their first child was born, eight years ago, Arjuna started to become rude. Sinta was frequently beaten and yelled at in abusive language. Then she found out that Arjuna was a drug user and had many sexual affairs. Sinta had to accept it when her husband abused her and she did not dare to save herself. She did not have any legal documents; she had left
her identity card, her school diploma, and her birth certificate in Batam. She did not dare to go back home to get those documents and never had enough money to get legal documents from the local government in Jakarta. Later, she unexpectedly had a second child. She had tried a few times to get rid of the baby when she was pregnant but it did not work. Luckily, in spite of this, the baby was born safely; furthermore, both of her children are HIV negative.

Sinta decided to move out when she received some income from the ‘job’. Through the TOP Support network, Sinta now has a more stable job as the coordinator of *Ikatan Perempuan Positif Indonesia* (Indonesian Seropositive Women Affiliation). Arjuna passed away and Sinta remarried another PLWHA whom she met in a support group meeting. She has also been able to get her children from her ex-mother-in-law and take them to live with her; previously, her ex-mother-in-law had kept her children in order to get money from her. Now, even though her ex-mother-in-law still calls her by phone almost every day in order to get more money, she is quite happy living with her new husband and children.

**Figure 3:**
Sinta’s Family Tree

At eighteen I ran away, at nineteen I was pregnant. The first and second year was fine. Our family was ok. Since five years ago, things have gotten worse. One day I got...received a letter from his office, from a woman, his lover. Of course I was angry. I thought that’s what he did after everything I did. From then on, things were getting worse. He kept saying there’s nothing between them, at least they didn’t have sex. He’s got a belief that if one cares about him, loves him, she should know what he likes and what he doesn’t
like. But I said if he tried to hide it, there must have been something wrong. He kept it secret. Later on he told me they were only friends and he only used her money. It’s always been his reason, but I can’t accept the reason. It creates revenge. I did also have a relation with a man, but only friendship. But, he was so angry by then. I didn’t have anybody there, I had a dead card, and I could do nothing. I couldn’t say no, couldn’t ask for a divorce. I had to listen to what they said. Then, we found out about the disease. I still took care of him. At that time I was pregnant with my second child. That was actually an unwanted pregnancy. I didn’t have money; I couldn’t have protected sex. Arjuna absolutely didn’t want the pregnancy since he was not sure whether it was his child or not. I told him, ‘In the name of Allah it’s your child’. My stomach was kicked, beaten, he asked me to have an abortion, I was told to take medicines to kill the baby. I took the most expensive medicines from the pharmacists; they said the medicines from abroad, hundreds of thousands we spent. But, this child wanted to live. I took a decision, I didn’t care whether he could accept the child or not. I didn’t want to die taking the medicines on and on, I said it’s easy for him he could marry again. After that we had a fight. I kept the child. Luckily, the child is ok. No defects or anything. I was often beaten by him and abused by him. His parents put me in a home to stay together with my children because they couldn’t stand it anymore witnessing me being abused. He kept promising me to change, but he never did. He still has a free sex life, but every time he comes and apologizes, I can’t resist him. I wanted to come to my parents’ home, but I couldn’t because I would have to leave my children. I wanted to rent a house, I didn’t have money. I had nowhere to go. I was their backbone meaning that I did all chores at home. I washed the dishes every day as if they were having a party. His mother used to have a nice life with servants, so her children are not used to work. If I get money, his mother always asks, I always give. If she doesn’t get money, she’ll be very angry. Since knowing YPI, his mother sees only my money. My father-in-law works, but how dare her ask money from me who earns only that little. I’m not stingy. I’m easygoing, but she always asks and always says, ‘Don’t forget to give me 200 (200,000 IDR)’. She also likes to borrow money. ‘I want also to borrow extra money, I’ll pay you later’. Usually what she borrows is paid back. But then all my money is in her hands, I have to give to her and to lend to her. I don’t keep the money, my God! Sometimes I try to be patient. So, every time I get a job, my husband wants something, my mother-in-law wants another thing; I don’t get anything for my children. I’m stressed out; my husband depends on me, as well as my mother-in-law. (Sinta, 26 years, remarried)
In contrast to Winta, it is interesting to see that in Sinta’s case, instead of her own mother it was her then mother-in-law who demanded money. This is because she used to live with her. At that time her own mother did not know she was infected with HIV. Both these women were expected not only to be good housewives, but also to earn money for their own and/or their husband’s parents. The money earned from giving testimonials is a valued economic resource for the infected women, as well as their extended family. In addition to the fact that most TOP Support members do not have adequate educational backgrounds or skills to get a decent job, they usually come from families with low socioeconomic backgrounds; then to make it worse. PLWHA are discriminated against when it comes to applying for a job. It is then understandable that whenever they have a chance to earn some money, they will prioritize how they spend it according to what they consider as important. In Wanda’s and Winta’s cases, the money was used for fulfilling daily needs. In Sinta’s case, the money was used for her family and parents-in-law. That is why there was no money left for Sinta to take care of the documents she needed to free herself from her abusive husband before he died.

In my opinion, Sinta’s case is a complicated one. She could have used her money to get away from her abusive in-laws, but she did not do that because as a good daughter-in-law and devoted wife she believed she had to serve them. Sinta could only eventually free herself from her parents-in-law after Arjuna passed away. She could finally use the money she earned to take care of her documents and marry her current husband. As far as I am concerned, none of the women considered using the money they made to treat their illness or to save it for their children’s future, although they know they will not live for a very long time because of their illness. The reason behind them not using the money to treat themselves is possibly because of the norms dictating that women should put their families first before themselves.

On one occasion, Vina sent me a text message to ask whether she and the other TOP Support members would receive some transportation fee if they participated in an income generating activity. I was part of a research team at the university that supported the members to develop empowerment activities. For the activity, we provided some funds to buy sequins to be applied to hijabs. To welcome Eid ul-Fitr we thought that the hijabs would sell well, and even better if the sequins were applied. Tasks were then divided. Some of them would buy the sequins and decorating beads, some would learn how to stick the sequins to the hijabs, and the rest had the task to sell the decorated hijabs. The idea was that this collective activity

---

29 Eid ul-Fitr or Id-ul-Fitr (Arabic: إِيَادُلْ-عِلْ-فَيْتِر), often abbreviated to Eid, is a Moslem holiday that marks the end of Ramadan, the Islamic holy month of fasting. It is celebrated starting on the first day of the Islamic month of Shawwal.
would generate income for the group. However, what happened in practice was that the women sold the *hijabs* individually and used the money for their individual needs.

TOP Support is seen mainly as a source of income. However, as the ‘jobs’ are not always available for everyone, it can trigger conflict among the members. Not everyone can get the chance to do them. Those who have an extrovert personality, who dare to disclose their status and have a unique background, are the favoured ones. Vina and Winta are the members most frequently asked to give testimonials in seminars, and have been invited several times to international HIV/AIDS conferences. They were among the first six participants of TOP Support to disclose publicly, long before the other members dared to do so. Moreover, Winta’s unique background as a teenage mother with HIV has led her to be a representative at the Youth International Conference, regardless of her risky behaviour, while Vina is invited as a leader of a seropositive women’s group. Both of them were promoted by YPI through its network and are used as icons for the PMTCT project. This is the reason why the media and the public know them better than the others.

The members only get ‘jobs’ when they regularly come to the secretariat and actively involve themselves in the group’s activities, as already mentioned by Wanda. At the friendship centre in Burkina Faso, the group applies a triage system, whereby members who are active and regularly come to meetings are able to get better access to treatment than other members who are not active and do not regularly come to meetings. The reason behind this triage system is the idea that these active members can help others better than those who are not active (Nguyen, 2005, p. 132). The system is more or less the same in TOP Support. In fact, it is clear from what I observed that in most cases, the decision about who gets the ‘job’ depends very much on the content of their story; the more dramatic the story, the higher the chance they have of being selected to give testimonials. In Vina’s case, she was one of the first to disclose her HIV status, and in Winta’s it is her being a teenage mother. However, they have to come regularly to the secretariat to get invited to give testimonials, even though, it is not a guarantee that they will get the ‘job’, as the jobs are not always available.

Instead of mobilizing resources and disseminating information to create mutually beneficial collective action, the members of TOP Support compete against each other. A simple matter can trigger a conflict among them, as Wanda describes below:

> I was close to Vina, but she is not professional in my opinion. Sometimes private problems between us can influence our professional relationship. Actually, Unilever offered a position for both of us (Vina is also a part time volunteer for Unilever – she does the same advocacy work by giving
testimonials whenever Unilever offers the ‘job,’ which also means that she gets an additional income from Unilever), but she kicked me out without any confirmation. I was mad at her, but she told others that I was angry because she had a relation with my ex-boyfriend. Dr Joni from Unilever contacted her but she never told me about it. What I know then is that she works for Unilever and I do not get the job. It is not clear to me. She should have told me what Dr Joni had told her, even if it is not good news for me. I met the director of Unilever in Cikarang, and Dr Joni always asks for Vina and me whenever there’s training for their staff, but when we had to discuss about the contract the other day, Vina did not tell me because we had a fight about my ex-boyfriend. From now on, I won’t tell her anything about me. Some members share their stories, Lina, Sinta, Yuna, but they do not tell Vina, because their stories will be passed on to everyone when they have a fight with her. Sometimes, I think it is because Vina is the senior among us. (Wanda, 27 years, widow)

Sinta had this to say on the same conflict:

None of us agrees to have Vina as the leader. But she always feels like she is our leader, so she becomes the leader. We, then, tell her our objections… Yesterday, Mbak Sundari (YPI staff) said that there’s a cut on the TOP Support transportation fee; it will no longer be given. They used to allow each person to come three times a week but now they cut it to twice a week, it means each person will only get 50,000 (IDR) a week. Vina told me, ‘I may not be too active and to participate because they no longer give me money. It costs me a lot to come here.’ It makes sense to me since she lives quite far from here. But, she still wants to be the leader because she counts on the job, just like we had yesterday at the hotel. That’s what she’s counting on. Vina has no skills. She counts every cent she’s got and we should report all the events we have joined or will be joining. She’ll get mad if we don’t tell her though we’re the ones who are being appointed. However, she never tells us if she’s being appointed. She wants to take all the jobs offered. I told her to share the jobs. I said, ‘You’re not the only person who needs it.’ I feel sorry for the other members because Vina is too greedy. They are mad at her. I told them not to be too hard with her, so I should text Vina tonight and tell her that I’m invited to Trans TV. Otherwise, there will be another conflict and then she has a reason to get mad again. (Sinta, 26 years, remarried)

What has happened at TOP Support brings about a negative impact on group solidarity, whereby the success of one member of the group weakens the solidarity
among the members as they do not feel on the same level (Portes A., 1998, p. 15). As a result, the group can only remain as an information channel for commercial interests, and used for individual benefit. The collective identity given by TOP Support as a biosocial group is only used pragmatically by the individuals. TOP Support is seen mainly as a source of income:

There will be no use to stay at YPI. I want to leave YPI and get a job at the (shopping) mall; I’ll work to make a living. I really need it to survive. In my calculation, transportation fee (to come to TOP Support) is 25 (25,000 IDR) a week, my household expense is more than that, also for my mom and my brothers... more than 25 (25,000 IDR) ... It was hard when I was single. I was short of money badly, but I was patient and waited for the interview (for which she gets paid), wanted to be the speaker for YPI. What you get is what you spend. (Winta, 18 years, remarried)

Furthermore, the network developed by YPI only benefits the members as individuals and not as a group. Considering this, it may be difficult to encourage TOP Support to engage in collective action for a social movement that fights for the needs of its members. As a group they could fight for better medical treatment, for example free ARVs for all seropositive mothers and babies, or free PCR tests for newborn babies. The findings presented here, however, suggest that their primary concern is everyday survival, i.e. having a job and avoiding the stigma attached to HIV.

7.C. Back to Family Life

In Indonesia, there is a decline in trust, altruism, mutual reciprocity, social solidarity, and tolerance at the community level (Hasbullah, 2006; Suwardiman, 2008). Those factors are perhaps reflected in the weak solidarity among the members of TOP Support. Additionally, as women, they are not used to working in a group, fighting for their rights, or fighting for others outside their (extended) family. Like many Indonesian women, their lives are dedicated to their husbands and families (Kroeger, 2000). This may result in a lack of solidarity among them. Though some of the TOP Support members do engage in the testimonial activities, these activists stop their activities when confronted with stigma and when they find out that disclosing their HIV status may harm the lives of their husband and family. If their involvement in TOP Support stigmatizes their spouse and family, for example, they leave the group peacefully, without considering the impact on, or importance of, the group. Avoiding the risk of having their family discriminated against is a greater
concern. For Indonesian women, a family’s dignity and prestige come first before material benefit. Some are willing to lose the access that membership to the group gives them in terms of material benefit as long as their family is saved from the stigma of HIV.

Especially for those who have been remarried, a harmonious life with their new husband and in-laws is their main concern. They usually feel angry and resentful towards their ex-husbands because they infected them with HIV, and that is why they usually think that the marriage with their new husband has set them free. In addition to being taught to serve her (extended) family, an Indonesian woman is also taught to believe that her life is only complete once she gets married. To be loved by her parents-in-law is a plus. Being a woman with a so-called ‘cursed illness’, many fear that they will never be a complete woman because no man will want to marry a ‘badly behaved woman’ with HIV. When there is a man who will accept her the way she is, she will do anything for him and his family.

After getting remarried to her second husband, who was himself HIV positive, Sinta preferred to focus on her work as the coordinator for the Indonesian Sero-positive Women Affiliation. She still works for the TOP Support secretariat and is able to do advocacy work, but does fewer confessionals. She gets less income and sometimes she does not get the payment for several months, but she considers it a better job since her new husband, who works as a civil servant at a District Office in the area where they now live, is not involved. Once she appeared on a talk show and one of her neighbours recognized her. After this her mother-in-law asked her not to appear on talk shows anymore, because she did not want the neighbours to know about the status of her son. Sinta’s own mother, soon after finding out about her status, also requested her not to appear on talk shows. Sinta has to respect her mother and parents-in-laws, although she says that it is against her own will.

The other day I was on TV. My neighbour recognized me on TV. My (new) husband was angry. His mother also says I shouldn’t do it again because he hasn’t disclosed his status. My family doesn’t approve of it either, my mother is afraid my aunts will find out about it (that she has HIV). This is actually not what I want because I actually want to let others know more about HIV in relation to IPPI (Ikatan Perempuan Positif Indonesia- Indonesian Seropositive Women Affiliation). I can still do seminars. Most seminars are usually about presentation and to let them know about PLWHA, but no testimonials. The other day, I was at a seminar at the cabinet secretariat with the officers.
(Sinta, 26 years, remarried)

Similar to Sinta, Winta never refused to be interviewed and did not mind people taking her picture whenever she was interviewed. But now, she refuses to show her
face in public, as requested by her new husband. Winta tells me that she is afraid that her new husband and her newborn baby will be stigmatized if she dares to show herself in public. Her first son is stigmatized because she used to be open about her status. Winta does not do any testimonial ‘jobs’ now and her family depends only on her husband’s income. In an FGD Winta spoke about this:

I was on a talk show on Trans TV, all my neighbours knew about that, almost all of them knew it from —, even though I was covered with a hijab (on TV), they still knew it was me and started to discriminate me. I’m sad every time my child wants to play. My parents were told by Pak RT (neighbourhood association leader) that my child shouldn’t play outside for a while. He told my mother, but didn’t directly tell me. My sister, the one who took me to YPI the first time I took an HIV test - she took me to YPI - I mean she’s my own sister. She should know more than my parents who are sort of short minded, she should understand more. She still discriminates my child! For example, if my child shares a drink with her child, she’d say, ‘No, no, don’t do that.’ She says my child has a lung disease. That’s what she tells her child. Even the neighbours know that my child has a lung disease; I tell them intentionally that my child has a lung disease so that they won’t discriminate him because he actually has HIV. I hide my child’s status from that sister. We have different spoons. She should know better. So, if she wants to ask for food, I finish the food fast. If not, I don’t eat in front of her child because she’ll ask for food. If I don’t give it, it’s not nice, if I eat and she’s there I’ll tell her not to disturb me. So, I try to ignore her, but actually my heart hurts. If she wears my towel, I’d say, ‘Don’t do that, you can get infected, the saliva can do this blah blah blah’. The one who is not smart is the one who acts exaggerated. Actually, it’s not infected through sweat, so many times Mbak Atik (YPI staff) has told us it’s not infected through sweat, but my sister tells my mother it can be infected through sweat. (Winta, 18 years, remarried)

Yuna was asked by her in-laws not to give any more testimonials after her story appeared in an online magazine (as shown at the beginning of the chapter). Yuna does not agree with this, for she needs the money she gets from giving testimonials. However, Yuna did decide in the end not to give any more testimonials and instead works as a voluntarily peer educator for another NGO and she has opened a small grocery store.

The TOP Support members who have stopped giving testimonials and confessinals, including Sinta, Winta, and Yuna, because they want to protect their family from stigma and discrimination, reveal a complicated situation. They can get good money from such activities, which can in turn be an opening door for them
to get access to a decent job. As far as I am concerned, the material benefits are not unimportant for them. However, they do not want to publicly expose themselves further as they are worried about the harm it could bring to their family. Sometimes they have no other choice and must take such ‘jobs’, but only because of the money they can get. As soon as they can find another source of income, they will stop altogether. Other sources of income are, for example, their (new) husband’s income or income from a less well paid but more secluded job. However, as soon as they realize that the financial support from their husbands or salary cannot support their family, they have to start again giving testimonials and confessionals, despite the concern about the stigma and discrimination their family will face.

I asked for a confirmation from Sundari, a staff member from YPI, whether it was true that some TOP Support members have refused the testimonial ‘jobs’ because they are afraid of stigma affecting their families. According to Sundari, some of them have in fact refused to give testimonials in the public media, such as talk shows on TV. However, there are not fewer members who ask for ‘jobs’ from YPI. Even Winta has been back to YPI lately and has asked for a ‘job’.

Of course they still want the job. The other day, Winta came here and asked me whether there’s a job available or not. I heard her husband is now in jail. (Sundari, YPI staff)

According to Sinta, there must be another reason behind their refusal to give testimonials on talk shows. According to her, they refuse not because they are afraid of the stigma, but most likely because they are offered just a small amount of money.

If they refuse, you should ask why. Maybe it’s because they don’t get much money or because they don’t get paid at all. If the money is ok, they usually won’t refuse. Just ask them. (Sinta, 26 years, remarried)

I find it interesting to know from the cases mentioned above that the decision to disclose or not to disclose their status is based on their concern for their family’s safety and comfort rather than their concern about themselves or about the support group. On the one hand, they disclose their status to earn some money from the testimonials, which is certainly useful to support their family. On the other hand, they hide their status if they feel that their openness is harming their family. This behaviour illustrates the ideal of ‘a real Indonesian woman’. Women are never taught to work or speak for themselves or their group, but for their family.
7.D. Discussion

In this paper I have shown how members of TOP Support have reconstructed their bio-social identity based on their HIV status in order to get some material benefit through giving testimonials and confessions in public. As HIV is stigmatized as a disease of whores, the seropositive women involved in the group adopt the safer identity as innocent housewives, who may be powerless but inherently have a power to destigmatize HIV/AIDS. TOP Support was set up as part of the PMTCT program of YPI, which focuses on mother’s health and is automatically considered a program for women. Seropositive women can benefit from this, as women and mothers who take on the identity of innocent housewives. Being part of the PMTCT program enables TOP Support members to shift their identity from being a ‘bad woman’ who contracts HIV because of her ‘immoral behaviour’, to an innocent housewife who gets infected by her husband whom she respects and obeys even though he has an ‘improper attitude’.

The image of PMTCT as being for mothers and housewives contributes to these seropositive women’s identity reconstruction, and the network provided by YPI enables them to make use of this bio-social identity. However, there is very little collective action, and the resources are used for individual gain. The collective identity given by TOP Support to its members, and supported by the network provided by YPI, is used pragmatically to fulfil individual needs. They do not use their identity to access treatment, as in Nguyen’s case from Burkina Faso. They do not become therapeutic citizens. Rather, they use the group to rework their bio-social identity and play the role of victim – not women with ‘bad morals’ – to access income generating activities, which is a priority need for them.

PMTCT may not result in collective action or a social movement since TOP Support is only used for individual, commercial goals. There is even competition between those who give more testimonials and those who do not have as many chances to give testimonials. They do in fact fight collectively to diminish stigma by promoting their bio-social identity as innocent and devoted mothers through their testimonials. However, there is a lack of core activities at TOP Support, as well as alliance building in their system, that could lead to real collective action. Everyone has their own interest. Dissemination of information based on interpersonal communication is used as the tool to spread the information about the availability of testimonial work to the members of TOP Support. If there are no offers for testimonials, they do not feel there is any importance in attending the group.

Diani says that mutual trust and mutual recognition, which are the indicators of social capital owned by the actors involved in a relationship, an organization, or group, do not necessarily imply the presence of a collective identity (Diani, 1997, p. 129). In the TOP Support case, it happens the other way around; a collective
identity drawn from the image of PMTCT is used by the members of TOP Support. The women’s presentation of themselves as victims is their collective identity, and is used to gain trust and recognition from other people in order to individually access economic benefits. Thus, the word ‘mother’ in ‘Prevention of Mother to Child Transmission’ has been very significant since it gives a positive image to the members of TOP Support. Motherhood is a socially strong and respected identity for Indonesian women (Sidharta, 1987). It is believed that a mother does not have a bad attitude, and even if she has HIV, it is most likely that she is innocent and contracted the virus from her husband.

However, the image of caring, loving, and nurturing mothers who always put their families before themselves and who do not demand anything in return, is also reflected in TOP Support. Therefore, when confronted with stigma, or when there is a risk of negatively involving their husbands and families, they turn back to their family life and seek other means of income and choose not to be too open in public. Their bio-social identity as mothers can give access to testimonial work, but it also means that they have to quit the job when it harms the family they are supposed to serve. Moreover, their bio-social identity as mothers prevents them from fighting collectively for the group as they are supposed to be passive and not supposed to demand their rights, since the family comes first. Yet, when they know that any other source of income available to them is not enough to make a living, they are not reluctant to go back to giving testimonials in public. They do not care about the stigma or discrimination they have to face as long as they have considered both the benefits and the risks.
Chapter 8

Conclusion and Challenges

The motherist movement has received scant attention in women’s studies. There are, however, numerous examples of women successfully asserting their claims through movements that mobilize on the basis of motherhood. This study has examined how two women’s organizations in Jakarta have appealed to the social capital inherent in motherhood to promote HIV prevention programs for women. The empirical chapters of this study suggested that mobilizing motherhood – at the individual and organizational levels –is an effective means to promote women’s participation in HIV prevention programs, programs which would otherwise suffer from severe social stigma. Nevertheless, mobilizing motherhood was not found to be an effective strategy for influencing policy-making at the national level.

Field data collection began with a rapid assessment to gain an overview of PMTCT and other HIV prevention programs in Indonesia. Data collection was completed with the support of YPI, the NGO responsible for the first PMTCT pilot project in Indonesia. Following the rapid assessment, primary data for this study was collected, starting in 2005, using ethnographic methods in Jakarta and its surrounding areas. Jakarta was the primary site of research as the PMTCT pilot project was initiated in Jakarta, before expanding to six other provinces. Jakarta also has one of the highest recorded prevalence rates of HIV in Indonesia.
Primary data were collected through in-depth interviews and focus group discussions with: 1) PKK cadres involved in the mobile VCT services in 11 villages throughout Jakarta province, not including the Thousand Islands area; 2) pregnant women, the target group of the mobile VCT services; 3) seropositive mothers active in TOP Support, some of whom lived outside the Jakarta area; and 4) policy-makers related to the PMTCT program. The primary data were supported by secondary data drawn from Indonesian demographic surveys, documents and data from the Ministry of Health and the National AIDS Commission, discussions on HIV/AIDS mailing lists, and newspaper clippings reporting on HIV/AIDS and PMTCT.

8.A. General Description of PMTCT

Though new cases of HIV are increasing rapidly in Indonesia, HIV prevalence among the general population is still regarded as low. While many policies addressing HIV/AIDS have been announced, commitment to implementation lags behind. This is also the case for prevention programs: while there are many policies, there is a lack of actual and sustainable implementation at the national level. Low HIV prevalence is always given as the reason to delay prevention programs and to justify the slow progress in implementation, even though the government of Indonesia is aiming to decrease the rate of new HIV cases as part of its commitment to achieving the Millennium Development Goals (MDGs) by 2015. Prevention programs are moreover based on a high-risk group paradigm. They focus on female sex workers as responsible for the spread of HIV, leading to its stigmatization as a hooker’s disease. HIV, in Indonesian parlance, is a disease of women without morals.

The prevention of mother-to-child transmission of HIV/AIDS, known as PMTCT, has also moved very slowly in Indonesia. The first national PMTCT guidelines were only launched in 2006 by the Ministry of Health, and to date there is no PMTCT program at the national level. Nevertheless, the word ‘mother’ in PMTCT has had the power to begin destigmatizing HIV/AIDS, from a disease of prostitutes to an affliction of housewives. The media has also played an important role in spreading news related to HIV/AIDS, and has increasingly reported on its rising prevalence among low-risk groups such as housewives and children. The HIV/AIDS epidemic is thus no longer viewed as an exclusive affliction of badly-behaved people, but a disease that threatens the balance of the domestic sphere and the fate of future generations.

Involving PMTCT in maternal and child health and family planning services, as advocated by the Ministry of Health, has brought subtle changes to the image of HIV/AIDS. But the Ministry – through the sub-directorate of Mother and Child Health under the Directorate of Family Health – actively promotes PMTCT only for
the benefit of its own medical staff, to prevent them from contracting HIV through contact with pregnant women. While the Ministry of Health has not made PMTCT services available to the wider community, the steps it has taken have provided a basis for community awareness that HIV/AIDS not only affects stigmatized groups, but can also be transmitted to mothers and children.

The first and only PMTCT intervention in Indonesia has been a pilot project conducted by the NGO, Yayasan Pelita Ilmu (YPI), which has concentrated its efforts in Jakarta since 1999, extending them to six other provinces in 2007. The NGO-initiated pilot project is donor-driven, with limited government support. Funding depends on foreign donors, in this case the Global Fund, which means that in practice the receipt of money is often erratic. In the midst of government indifference towards HIV prevention, YPI is trying to implement a comprehensive PMTCT program based on the principle of a continuum of care, in accordance with the four prongs established by the WHO. As HIV prevalence in Indonesia is still considered low and social stigma surrounds the illness, YPI faces an uphill battle in promoting its PMTCT program, particularly for low-risk, respectable groups such as mothers.

Motherhood and HIV/AIDS are in fact seen as contradictory concepts. For most Indonesians, motherhood is a woman’s sacred role, while HIV/AIDS is a disease that only affects people who behave ‘badly’. A devoted mother is considered highly unlikely to be infected with HIV as the virus is believed to be confined to prostitutes. If a mother is found to be HIV positive, she will therefore be stigmatized as a prostitute. But by appearing as a devoted wife and mother, an HIV positive woman can blame her husband’s behaviour, playing the role of innocent victim to avoid social stigma.

8.B. Motherhood as a Source of Social Capital

Women’s biological ability to reproduce gives rise to their social identity as mothers. While Indonesian women may seem weak and subordinate in many respects, mothers play an important and powerful role in society. Mobilizing motherhood enables PKK cadres and TOP Support members to access accumulated social capital in the form of trust and social networks among women.

The social capital that accrues to motherhood can be mobilized at both the individual and organizational level. Shared motherhood creates trust among individual mothers while their networks of trust become ready resources for mobilization at the organizational level. Trust is crucial in building social relations and networks. PKK cadres rely on the community’s trust in their organization as well as its extensive neighbourhood networks to mobilize pregnant women to access the mobile VCT service. TOP Support members project the image of the devoted
wife and mother – infected by her badly-behaved husband – to gain support, avoid stigma, and promote PMTCT.

In their involvement in the PMTCT pilot project, PKK cadres and TOP Support members are able to convert the social capital derived from respected motherhood into opportunities to access economic capital. Both PKK cadres and TOP Support members receive rewards, for example in the form of ‘transportation fees’ which can be used to supplement family incomes. These economic benefits enable the women to fulfil their roles as mothers responsible for their families, especially when the husband/father cannot satisfy the family’s economic needs.

Unfortunately, the strategy of mobilizing motherhood has made no inroads into the arena of national policy-making. Motherhood is limited by its very identity, meaning that the activities the women can pursue cannot interfere with or violate their domestic roles as mothers. Through socialization, women not only learn to take full responsibility for their families, but to respect the differences between male and female roles – both of which impose limitations on their individual power and social space. Thus the ideal of motherhood, as a source of social capital, becomes a barrier to women fighting for goals outside of the domestic sphere.

8.C. PKK and TOP Support: Motherist Organizations in PMTCT

This project examined how motherhood has been mobilized by the PKK and TOP Support in very different ways to promote PMTCT.

8.C.1. Social Support for HIV Prevention

YPI views PKK participation as valuable social capital that can be used to support its PMTCT program. YPI encourages PKK cadres to mobilize pregnant women in their districts to access the mobile VCT in line with prong 1 of the PMTCT continuum of care – to prevent HIV among women of child-bearing age. Involving the PKK is an effective strategy: one of its goals is the promotion of women’s health, while the organization has experience promoting the Safe Motherhood Movement which aimed to reduce maternal mortality in Indonesia. Unfortunately, the social support provided by PKK exclusively targets mothers, in this case pregnant women, and excludes other women of reproductive age. PMTCT is also not a priority for the PKK as HIV prevalence among women – though growing – is still considered low. The mobile VCT service rarely finds new cases.

YPI created TOP Support to help seropositive mothers and their children in line with prong 4 of the PMTCT continuum of care. TOP Support provides emotional and
psycho-social support within the PMTCT pilot project. It facilitates the provision of emotional support by and to seropositive women, bringing them together to face their illness and engage in positive living. Emotional support is needed to counter threats to self-esteem that an HIV positive diagnosis can bring. Having someone to confide in can make a big difference; self-esteem is enhanced by acceptance and approval from significant others with whom there is a mutually respectful relationship (Wills, 1985, pp. 67-68).

Unfortunately, PMTCT is not a priority for TOP Support members. They already receive free medical care from YPI, while many members are ill-informed about their illness. Some women had already experienced severe illnesses caused by HIV but defined their ill health by the symptoms they experienced, revealing that they did not really feel as if they were living with HIV/AIDS. Despite the fact that some members had died due to AIDS, many still could not believe that they were suffering from HIV/AIDS or that their illnesses were caused by it; rather, their symptoms were of other diseases such as diarrhoea, tuberculosis, or hepatitis. And though they realized that their past (or present) behaviours put them at risk, they maintained that they were victims who had contracted the disease from their promiscuous or drug-injecting husbands. Even when they did admit that their own behaviour had something to do with it, they did not consider HIV/AIDS as a disease but a curse from God, a punishment for their immoral behaviour. Since membership in TOP Support provided them with access to medical care – including ARVs, viral load tests, c-section services, and formula milk for infants – and additionally gave them opportunities to generate income, they felt no need to push for change.

This study has shown that the involvement of the motherist organizations PKK and TOP Support did not succeed in establishing the PMTCT continuum of care. Pregnant women found to be HIV positive through the mobile VCT service very rarely participated in TOP Support activities, due to stigma spread by community gossip. TOP Support members were mostly referred by hospitals or clinics, and often lived further away from YPI, thus allowing them a measure of anonymity.

8.C.2. The Role of Social Values in Generating Trust

Women in PKK and TOP Support draw upon their bio-social identities as mothers who are sexually passive and limited to the domestic sphere. This identity provides PKK members a sense of solidarity with a group of good housewives and responsible mothers. Its value for TOP Support members is that, through their collective identity as innocent wives and mothers who contracted HIV from their ‘irresponsible’ husbands (and thus perhaps inadvertently transmitted the virus to their children), they can counteract the stigma attached to HIV/AIDS. The identity of loyal, passive,
and innocent mothers is accepted and respected by women in Indonesia. The bi-social identity of motherhood therefore has extraordinary power in advocating for PMTCT as it helps to destigmatize HIV/AIDS in the community. It is a central notion that enables PKK cadres and TOP Support members to generate trust and perform their advocacy tasks.

The PKK as an establishment keeps women’s voices under control by strengthening the traditional role of women as housewives and mothers, while the state uses the organization to reinforce the dominant patriarchal culture that emphasizes the domestic role of women. The PKK’s emphasis on the domestic role of women informs its involvement in activities that promote mother and child care. Its involvement in the Safe Motherhood Movement and the Family Planning Program, for instance, made the organization synonymous with mothers’ responsibility for their families. PKK cadres thus have a highly valued bio-social identity through which they reinforce women’s domestic roles, thereby gaining trust in society.

This strongly gendered identity is a powerful form of social capital, upon which PKK cadres draw when mobilizing pregnant women to attend the mobile VCT service. Pregnant women are generally reluctant to go for VCT due to the stigma it could carry for them and their families. When PKK cadres persuade pregnant women to go to the mobile VCT service, they do not necessarily tell them that it involves an HIV test. They instead claim that the mobile VCT provides medical exams for pregnant women which are good for the baby’s health. If they do talk about HIV, PKK cadres utilize the image of the devoted mother concerned about her child’s welfare (who is, by implication, also passive and loyal to her husband) to place blame for possible HIV infection on the husband. By portraying pregnant women as innocent, PKK cadres manage to bring them to the mobile VCT.

A major challenge for YPI in involving the PKK in its outreach is that many of the cadres, due to their limited education and knowledge, still fear HIV/AIDS. PKK cadres do not want their bio-social identity as devoted mothers to be contaminated by the stigma of HIV/AIDS, which they still consider a disease of women without morals. As individuals, PKK cadres are reluctant to promote PMTCT in the public domain more than they already do, despite the fact that YPI has conducted capacity trainings. PKK cadres are thus limited in their abilities to challenge the stigma surrounding HIV/AIDS, or to seriously advocate for PMTCT.

As an organization, TOP Support has developed an image of itself as a group of women who are the innocent victims of HIV/AIDS. Its members, like PKK cadres, appeal to their bio-social identity as mothers. Motherhood allows TOP Support members to rework their stigmatized identity as seropositive women and to develop a collective identity as innocent wives victimized by depraved husbands. This new identity is derived from the common interests, experiences, and solidarity of the group members. Nevertheless, TOP Support members still struggle to reinforce
the image of their maternal role in society – through testimonials in seminars and workshops, by reworking their appearance (such as by wearing a hijab), or by exhibiting passive and introverted behaviour in front of others, as is expected by society. The media and the government also help to shape the image of innocent motherhood in the face of HIV/AIDS.

Exploiting their innocent identities as mothers, TOP Support members gain confidence to campaign against HIV/AIDS-related stigma through testimonial activities in the community, in seminars, and in the media.

8.C.3. Mobilization of Social Networks

Social support is delivered through the organizational networks of the PKK and TOP Support. The two motherist organizations have their own specific functions within the PMTCT pilot project.

PKK is a formal women’s organization created by the government. Its members are housewives; all Indonesian women automatically become members when they marry. The chairperson of the local PKK is usually the wife of the chairman of the local government institution, while PKK board members are married to men of position in the community. Women who are actively involved in PKK activities are called PKK cadres and act as service providers within its programs. The PKK is highly-structured, from the national level down to individual neighbourhoods. In previous times, the organization’s activities were financially supported by the government. Today, the state no longer aims to control the voices of women as it once did; the government has thus reduced its funding, bringing most PKK activities to a standstill. Nowadays, the PKK only provides Posyandu (integrated health station) services to mothers and children on a regular basis, supported by local governments.

The involvement of the PKK in PMTCT advocacy was highly strategic. The organization had accumulated social capital through its previous involvement in the Safe Motherhood Movement and the Family Planning Program. The public trust in PKK cadres, especially among mothers, made the PMTCT program more socially acceptable. Not only mothers but also husbands trusted the cadres, who then permitted their wives to participate in PKK activities. For Indonesian women, the husband’s permission is essential for participation in the public arena. YPI thus makes use of the formal networks and official status of the PKK to invite women to access mobile VCT services. PKK cadres, for instance, have privileged access to data on pregnant women in their areas, including those in remote districts.

In the Safe Motherhood Movement and the Family Planning Program, PKK cadres as service providers and PKK members as beneficiaries established bonding relationships through their shared identity as mothers. But in the PMTCT pilot
project, women relate hierarchically to each other as providers (PKK cadres) and as beneficiaries (pregnant women). PKK cadres and pregnant women may share a common bio-social identity as mothers, but they do not share an identity as beneficiaries, i.e. as mothers who may be HIV positive. Suspicion can enter their inter-personal relationships, making it much harder to create networks of trust, let alone the effective organizational ties needed to function as an effective advocacy group. Then again, the PMTCT pilot project is seen as top-down NGO program that is of scant interest to the motherist PKK.

TOP Support is an informal support group established by YPI catering to seropositive mothers. Within it, informal bridging relationships connect seropositive women from various areas in Jakarta. Members interact with each other horizontally as both providers and beneficiaries of services. They regularly conduct home or hospital visits to support their peers, provide information through hotlines, organize peer education activities, and hold monthly meetings; in all of these activities, they promote positive living to other seropositive mothers. As seropositive mothers themselves, members of TOP Support provide interpersonal resources, such as the feeling of being accepted and valued by others.

TOP Support often organizes gatherings with other support groups, creating opportunities for their members to meet and network. These gatherings also offer opportunities for TOP Support members to find new partners. Following divorce or widowhood, finding a husband is one of the primary concerns of TOP Support members. As with most women in Indonesia, they economically depend on men and feel pressure from the community to remarry. TOP Support members are stigmatized both for being widows and for being seropositive; marriage is one way to rid themselves of some of the stigma. But, finding a spouse as an HIV positive woman can prove daunting – hence, the value of a network of people living with HIV/AIDS.

TOP Support members can also use YPI’s network to gain access to HIV/AIDS-related medical services from other institutions and hospitals, making it easy to access the medical help they need. YPI also provides facilities for TOP Support activities, while membership provides access to employment through YPI’s social network.

Established by YPI as part of its envisioned PMTCT continuum of care, TOP Support is well-connected to other institutions. As a motherist organization that supports women’s reproductive health, one might expect TOP Support to be actively promoting PMTCT within the wider community. Unfortunately, it has become an exclusive organization limited to seropositive mothers. TOP Support members face a double burden as subordinated women who only have power in the domestic sphere and as people living with HIV/AIDS who face stigma as immoral women. Moreover, their biological ability to reproduce also means that they are

TOP Support is an informal support group established by YPI catering to seropositive mothers. Within it, informal bridging relationships connect seropositive women from various areas in Jakarta. Members interact with each other horizontally as both providers and beneficiaries of services. They regularly conduct home or hospital visits to support their peers, provide information through hotlines, organize peer education activities, and hold monthly meetings; in all of these activities, they promote positive living to other seropositive mothers. As seropositive mothers themselves, members of TOP Support provide interpersonal resources, such as the feeling of being accepted and valued by others.

TOP Support often organizes gatherings with other support groups, creating opportunities for their members to meet and network. These gatherings also offer opportunities for TOP Support members to find new partners. Following divorce or widowhood, finding a husband is one of the primary concerns of TOP Support members. As with most women in Indonesia, they economically depend on men and feel pressure from the community to remarry. TOP Support members are stigmatized both for being widows and for being seropositive; marriage is one way to rid themselves of some of the stigma. But, finding a spouse as an HIV positive woman can prove daunting – hence, the value of a network of people living with HIV/AIDS.

TOP Support members can also use YPI’s network to gain access to HIV/AIDS-related medical services from other institutions and hospitals, making it easy to access the medical help they need. YPI also provides facilities for TOP Support activities, while membership provides access to employment through YPI’s social network.

Established by YPI as part of its envisioned PMTCT continuum of care, TOP Support is well-connected to other institutions. As a motherist organization that supports women’s reproductive health, one might expect TOP Support to be actively promoting PMTCT within the wider community. Unfortunately, it has become an exclusive organization limited to seropositive mothers. TOP Support members face a double burden as subordinated women who only have power in the domestic sphere and as people living with HIV/AIDS who face stigma as immoral women. Moreover, their biological ability to reproduce also means that they are
biologically ‘able’ to transmit HIV to their unborn children. The relatively powerless and stigmatized position of TOP Support members makes them poor advocates. Easy access to medical services through YPI, coupled with their ignorance of the illness in general, explains why TOP Support members do not champion PMTCT as part of the women’s reproductive health movement. The organization supports its members’ individual and collective bio-social identity as mothers, and is used pragmatically by its members to deliver economic benefits.

TOP Support’s external networks are not supported by strong internal relationships among its members, which are characterized by jealousy and competition over opportunities to gain economic benefit. Internal relations are marked by conflicts of interest, as seen in the frequent changes of personnel. Without a strong internal organizational structure, TOP Support cannot be expected to serve as an interest group to fight for the reproductive rights of seropositive women.

8.C.4. Benefiting from Motherhood

Most Indonesians still see motherhood and PMTCT as contradictory concepts. The respected feminine identity of motherhood demands that women behave according to existing norms to be devoted, sexually inactive, and responsible for family and children. PMTCT, on the other hand, is seen as part of a stigmatised HIV prevention program for badly-behaved people. As participation delivers benefits to individual members of PKK and TOP Support, PMTCT is seen as more of an income-generating scheme than a women’s health program.

The PMTCT program provides tangible benefits to individual PKK cadres and TOP Support members who assist in its implementation and promotion. By participating in the mobile VCT program, they receive reimbursements in the form of transportation fees, which they can use to augment family incomes. This economic benefit strengthens women’s position in the domestic sphere, especially when their husbands’ incomes are insufficient. The PMTCT project also brings recreational and relational rewards. Participating in its activities means that one becomes known in the wider community. Wider networks open doors to further employment, while participating in mobile VCT activity is also an opportunity to leave the household and its domestic work and to connect with others.

TOP Support members receive a transportation fee when providing social support to other seropositive mothers. Members use this money to support their immediate as well as their extended families and in-laws, which empowers them domestically. Participation in seminars and workshops also means that they become known by the public and by members of other networks, increasing their chances of finding more stable employment.
In their advocacy of PMTCT, the PKK and TOP Support operate as different groups, though in practice they both consist of mothers earning a living. As most PKK cadres and TOP Support members involved in the PMTCT program come from lower-middle class households with limited socio-economic resources, their priority is to fulfil their material needs—which are considered more important than access to medical care. As housewives, they are responsible for their household finances, particularly if their husbands do not function as breadwinners. While the husband-breadwinner is the cultural ideal, in reality many women, especially TOP Support members, are on their own. By participating in the PMTCT program and strategically mobilizing the concept of motherhood, they can access extra income to meet their financial needs.

The significant economic benefits resulting from their activities empower PKK cadres and TOP Support members in the domestic sphere. By bringing additional income to their families, women improve their bargaining positions, gaining greater say in determining household expenditures. Some women even become the main breadwinners. While the women maintain the ideology of being mothers and being dependent, in practice they have the economic responsibility of women who earn a living.

The benefits gained through involvement in the PMTCT program are very important for PKK cadres and TOP Support members and must therefore be maintained. To preserve their benefits, they must maintain their status as mothers. PKK cadres do this by obeying their husbands and placing the interests of their families first. They will not participate in the PMTCT program without their husband’s permission, or if its activities interfere with the welfare of the family and children. Likewise, TOP Support members safeguard their benefits by maintaining their image of innocent housewives in appearance and behaviour, and their roles as mothers within marriage.

8.E. Can Motherhood Promote PMTCT as a National Program?

Considering the bio-social capital commanded by the PKK and TOP Support, these two organizations should be effective in promoting PMTCT. But PMTCT remains on the margins of public awareness and has yet to be institutionalized nationally. Alongside the internal constraints mentioned above, the very factor that brought the PKK and TOP Support some success in promoting PMTCT—the bio-social identity of motherhood—prevents inroads being made at the level of national policy.

Although PKK and TOP Support can provide social support through their social networks, the two organizations have hardly integrated PMTCT into their daily lives.
functioning. Nor have the goals of HIV/AIDS prevention been integrated socially among their members. Lack of such social integration renders activities ineffective for achieving common goals, and militates against PMTCT advocacy making any inroads into the domain of national policy-making.

Another challenge is that the PMTCT program is not government-led, as was the Safe Motherhood Movement and the Family Planning Program. PMTCT remains a YPI project supported by a donor agency. This means that funds are not always available and PMTCT activities do not always run smoothly, while they remain limited in their coverage area. As with other HIV prevention programs, government support and commitment to PMTCT is lacking. The support provided by the PKK and TOP Support can, thus, only has limited impact. Limited financial support means that the PMTCT program is unable to involve all PKK cadres, or to involve cadres at the higher district, city, or provincial levels. This is unfortunate as PKK cadres at higher levels have greater opportunities to influence policy through the power of their husbands, who occupy high positions in government. But those involved in the PMTCT pilot project are full-time housewives and only have influence at the neighbourhood, village, or district levels, for example to provide facilities and permits for mobile VCT services through the power of their husbands. If the PKK could involve women married to men in higher positions, it would be able to exercise more influence over PMTCT policy and other HIV prevention programs.

The word ‘mother’ in PMTCT has been fortuitous. Due to it, PMTCT has been able to contribute to the destigmatization of HIV, from a disease of women without morals to a disease affecting devoted and innocent housewives. But there is a negative side to this focus on mothers. HIV/AIDS is now perceived as a problem for housewives in the domestic sphere; prevention efforts should thus take place within households, not in the public sphere. This, alongside the argument that prevalence is still low, gives the government excuse for inaction. Though the epidemic needs to be tackled nationally, it has been isolated as an illness to be handled within institutions related to mother and child health. To date, only the Sub-Directorate of Mother and Child Health, under the Directorate of Family and Health, is active in promoting PMTCT.

The construction of gender in Indonesia encourages women to be passive and focused on domestic affairs and for men to control public space. Women as mothers are restricted by and to the domestic domain when it comes to fighting for their rights. But even in the domestic sphere, it is the husband who makes the final decisions. Women thus cannot work to promote PMTCT if their husbands do not give them permission to do so. On top of this, the time and energy women have for advocacy is simply limited by the household and care tasks they must perform. When their spouses cannot fulfil the family’s financial needs, it is also their responsibility to get a job and bring money home. It means that women have limited time for social activities.
Trainings held by YPI for PKK cadres and TOP Support members do not effectively promote gender empowerment. The trainings usually focus on capacity-building and awareness-raising but recipients are not provided with the skills to fight for their rights. So while involvement in the PMTCT pilot project may further individual women’s financial interests, sense of motherhood, and bargaining power within families, any wider social purpose for Indonesian women is ill-served.

8.F. Future Challenges

YPI’s strategy of involving the PKK and TOP Support to promote PMTCT has worked well—to an extent. This study has shown that the bio-social capital of motherhood can be effectively utilized to promote programs for women. First, motherhood as a bio-social identity has the power to generate trust and facilitate support and networking among women, uniting them through shared values, feelings, and experiences. In contexts of meagre government support, mobilizing social capital can become the primary means to promote community programs. This study showed that PKK cadres were able to use their formal networks to support pregnant women in accessing the mobile VCT service by focusing on their role as devoted and responsible mothers. Motherhood also facilitated TOP Support members to form a bio-social group to deliver psychosocial support to other seropositive women, and to transform their identity from one of sin and immorality to one of innocence.

Second, the emphasis on motherhood can empower women by strengthening their role in the family. By mobilizing their bio-social identity as mothers, women can convert social capital into economic benefits, which can be used to support their families. As they contribute to family income, their domestic bargaining position in the family improves.

Third, a motherist identity makes it easier for women’s organizations to gain trust from the public in general, and especially from women’s husbands. This would most likely not be achieved by promoting a feminist identity. Motherist values are not considered threatening to husbands in patriarchal societies and are therefore very useful in promoting women’s programs in the community, given the importance of husbands’ involvement in their wives’ activities outside the domestic sphere.

Fourth, as a highly respected bio-social role, motherhood can be used to place blame on husbands’ sexual promiscuity. Motherhood can thus help to destigmatize sexually transmitted disease prevention programs for women, making them more acceptable in society.

Finally, motherhood can be used to informally affect policy. In Indonesia, the wife of a man with a high position in society automatically has a correspondingly respected position, which provides her with an opportunity to influence policy. For
example, the wife of a head of a district automatically becomes the head of the PKK at the district level, which gives her the power to make or influence policies or take important decisions regarding programs for women at the district level. Moreover, the wife can use her domestic power to influence decisions made by her husband. If a man has a high position in the government bureaucracy, his wife can enjoy significant influence to advocate policies that support programs for women.

Nevertheless, there are significant challenges to promoting programs such as PMTCT for women through motherist organizations such as the PKK and TOP Support. First, the potential social capital of motherist organizations can only be drawn on effectively if individuals involved in the group are empowered. This study has shown that members of the PKK and TOP Support, to be able to more effectively champion PMTCT, are in need of gender empowerment training. Without it, PMTCT will only meet women's practical needs and strengthen their domestic roles. The socialization of Indonesian women to be passive limits the PKK and TOP Support's ability to champion women's rights; their members are more concerned with their own families than advocacy.

Second, motherist organizations only empower women within the cultural boundaries that state what roles women can play. This raises questions about women who do not benefit from the program – those who do not present themselves as mothers, including prostitutes, sexually active girls, and unmarried women. The integration of PMTCT into mother and child health services, directed at mothers and pregnant women, restricts services to these groups. This means teenagers, young and unmarried women, and women who are not pregnant – as well as their male spouses or partners – have no access to PMTCT or HIV prevention services. Furthermore, according to Pisani, (2008, p. 36), those women who are most likely to have HIV – including sex workers – do not go to government pregnancy clinics as these are only for 'nice' women. These women may be HIV positive but cannot benefit from the programs because they cannot present themselves as 'respectable mothers'. And even if they can access other HIV prevention programs, they will be stigmatized as badly behaved, immoral women.

How to reach such excluded women is one of the challenges in promoting the PMTCT continuum of care as outlined by the WHO. There are two extremes in HIV prevention programs for women in Indonesia: 1) PMTCT, exclusively devoted to mothers, cannot be accessed by women who do not have this bio-social symbolic identity; and 2) harm reduction programs, usually aimed at sex workers, which stigmatize users as immoral women. Neither program is able to reach all women because many women fall outside both categories.

Third, housewives are still not defined as a risk group. To prevent HIV transmission to babies and to protect women from infection, PMTCT has to address the issue of housewives being at risk. In the current study, women have found a neutral way
of engaging in support by presenting themselves as ordinary housewives and mothers. But raising awareness that they are at risk is necessary. This, however, would be highly controversial. Accepting the idea that housewives are at risk means that PMTCT programs must address the role of men in transmitting the disease. The notion of motherhood works well in PMTCT and enables fulfilment of the third prong of the WHO’s four-prong continuum of care (identifying women and helping those who are positive), but engaging in awareness and activities to prevent women from infection in the first place (as stated in the first prong) is much more threatening to the cultural order. To prevent HIV/AIDS, one has to directly address the men who have unprotected or extramarital sex and infect their wives and partners.

Finally, a PMTCT program’s sustainability is always a challenge. Considering the experiences of the Safe Motherhood Movement and the Family Planning Program, PMTCT, to be sustainable, needs to be funded and supported by the government. But despite its rising prevalence in Indonesia, HIV/AIDS is still not considered a priority, by the government or by society at large. PMTCT thus rarely receives formal attention. This study has shown that the identity of motherhood – without appropriate social support and networks – is not enough to promote PMTCT or the idea that HIV/AIDS is a wider social problem. Creating informal bonding networks between providers and beneficiaries – as value oriented or interest advocacy groups – to support PMTCT is one of the main challenges to maintaining the program’s sustainability.


REFERENCES


Women’s studies scholars have noted the presence of social movements around the world that focus on women’s roles as devoted mothers who love peace and fight together for the survival of their children and families. Such movements have demonstrated their power in peaceful action, mobilizing the image of mothers as patient, peace loving, and devoted to family, in order to challenge existing policies. Women who fight for their families are classified as ‘motherists,’ to distinguish them from feminists. The social construction of motherhood not only encourages motherists to fight for the welfare of their families, but also makes all programs which aim to improve the welfare of mothers, children, and families a concern of motherist organizations.

This PhD project examines the strategy of mobilizing motherhood through two Indonesian women’s organizations – the Pembinaan Kesejahteraan Keluarga (Family Welfare Movement, or PKK) and Tim ODHA Perempuan (Seropositive Women’s Team, or TOP Support) – in the attempt to make prevention of mother-to-child transmission of HIV (PMTCT) programs more socially acceptable; even though, as part of a stigmatised HIV prevention program, PMTCT does not fit the image of motherhood. The first and only PMTCT intervention in Indonesia was a pilot project conducted by the NGO Yayasan Pelita Ilmu (Pelita Ilmu Foundation, or YPI), which from 1999 initially concentrated its efforts in Jakarta, then expanded to six other provinces in 2007. The PMTCT project is NGO initiated and donor driven, with limited government support due to the low national HIV/AIDS prevalence rate and stigmatization of the disease, despite the fact that the government of Indonesia has stated its aim to decrease the rate of new HIV cases as part of its commitment to achieving the Millennium Development Goals (MDGs) by 2015. In the midst of government indifference towards HIV prevention, YPI is trying to implement a comprehensive PMTCT program that will deliver a continuum of care in accordance with the four pronged strategy established by the WHO of: 1) preventing HIV infection among women of reproductive age; 2) preventing unwanted pregnancies among HIV positive mothers; 3) preventing mother-to-child HIV transmission; and 4)
providing psychological and social support and treatment to HIV positive mothers, their babies, and their families.

Using ethnographic methods, field data collection began in 2005 with the support of YPI. Primary data for this study was collected in Jakarta and its surrounding areas through in-depth interviews and focus group discussions, supported by secondary data drawn from significant documents, discussions on HIV/AIDS mailing lists, and newspaper clippings reporting on HIV/AIDS and PMTCT.

Motherhood and HIV/AIDS are in fact seen as contradictory concepts. For Indonesians, motherhood is a woman’s sacred role; thus a devoted mother is considered a highly unlikely candidate to be infected with HIV, as the virus is believed to be confined to people who behave ‘badly’, such as prostitutes and injecting drug users. However, involving PMTCT in maternal and child health and family planning services, as advocated by the Ministry of Health, has brought subtle changes to the image of HIV/AIDS. It has provided a basis for community awareness that HIV/AIDS not only affects stigmatized groups, but can also be transmitted to mothers and children. The media has also played an important role in spreading news related to HIV/AIDS, and has increasingly reported on its rising prevalence among low risk groups such as housewives and children. Indeed, the word ‘mother’ in PMTCT has had a significant role in this change. At a time when PMTCT programs are being promoted, the image of HIV is changing from the disease of ‘women without morals’ to a disease of devoted housewives, which has resulted in the better acceptance of HIV prevention programs in society.

Mobilizing the image of motherhood enables PKK cadres and TOP Support members to access accumulated social capital in the form of trust and social networks among women. The social capital of motherhood can be mobilized at both the individual and organizational level. Trust is crucial in building social relations and networks; a shared motherhood identity creates trust among individual mothers, while their networks of trust become ready resources for mobilization at the organizational level.

The PKK is a formal government led community organization which is socially and politically structured from the very lowest level in the community up to the national level. The state uses the PKK to reinforce the dominant patriarchal culture by persuasively strengthening the traditional role of women as housewives and community members. In previous times, the PKK were involved in the Safe Motherhood Movement and Family Planning Program, which broadened its community networking base. The formal, well structured social network of the PKK is thus a very powerful resource for use in approaching women to access PMTCT, as the foundation for a formal bonding relationship between the PKK cadres and pregnant women already exists. YPI has encouraged PKK cadres to engage in mobilizing pregnant women at the village level to access the mobile VCT services,
for the purpose of preventing HIV among women of reproductive age.

The involvement of the PKK in maternal and child health programs has contributed to their image of being good housewives and responsible mothers, which has enabled the cadres to gain trust, especially from husbands, to allow them to bring pregnant women to participate in the mobile VCT service. This trust is important as Indonesian women will engage in activities outside of their domestic sphere only when granted permission by their husband.

Unfortunately, as the PMTCT project is seen more as a program of YPI, it is not considered of prime importance for the PKK cadres. The PKK has managed to mobilize pregnant women to attend the mobile VCT services, as evidenced by the numbers participating in pre- and post-test counselling, but the cadres never had a sense of being integrated into the program due to lack of knowledge and advocacy skills and personal fear of the disease. As a result, the PKK cadres merely performed the same role as they used to do within the Safe Motherhood Movement and Family Planning Program. Furthermore, almost all of the women with HIV detected by the mobile VCT program were unwilling to engage in follow-up activities with YPI due to persistent community stigma against HIV/AIDS. As a result, PMTCT activities that should function as a continuum of care as stated by the WHO cannot reach their goals.

Furthermore, there is a degree of imbalance and suspicion between the PKK cadres and the pregnant women in their interpersonal relationships, since the cadres see the pregnant women as mothers who may be HIV positive and therefore may harm their common biosocial identity as devoted mothers. It is thus much harder to create networks of trust and the effective organizational ties needed to function as an effective advocacy group.

To help seropositive mothers overcome their problems as individuals and as mothers, YPI created the seropositive women’s support group TOP Support, to provide psychosocial support for HIV positive women, their children, and their families. The group facilitates an informal bridging relationship among its members, who come from various areas in Jakarta. Aside from mutual emotional support, members of TOP Support also provide informational support to the community through testimonials in public seminars and the media as a part of their advocacy activities.

The notion of ‘sacred motherhood’ enables TOP Support members to project an image of being devoted wives and mothers who were infected by their badly behaved husbands, and who therefore unfortunately (and unknowingly) transmitted the disease to their children. They utilize this image to gain support, avoid stigma, and promote PMTCT. They rework their identity from one of sinful and immoral women to innocent and devoted mothers, and thus generate trust between other seropositive mothers and within the community, which enables them to access
psychosocial support and to advocate PMTCT through public testimonials.

Fortunately, very few of the TOP Support members who took part in this study had reached the severe stages of AIDS. Those who had suffered from AIDS felt that the disease was a curse from God as punishment for their (past) behaviour, which harmed their identity as devoted women (as expected of them by the community). Because the majority had not experienced the severity of AIDS illness, few of them fully recognised the potential severity of the disease with which they were infected. YPI also provides access to medical services, so that TOP Support members do not have problems of medical accessibility. These two factors combined – the general lack of experience of severe symptoms and ease of access to medical care – explains why TOP Support members do not actively champion PMTCT as part of the women's reproductive health movement.

In their involvement in the PMTCT pilot project, the PKK cadres and TOP Support members are able to convert the social capital derived from respected motherhood into social benefits and opportunities to access economic capital. Both PKK cadres and TOP Support members receive rewards, for example in the form of ‘transportation fees’, which can be used to supplement family incomes and thus strengthen their domestic roles as mothers who are responsible for their families, especially when the husband/father cannot satisfy the family's economic needs. These economic benefits lead the PKK cadres and TOP Support members to regard PMTCT more as an income generating activity rather than a part of the women’s reproductive health movement.

The financial incentive is quite significant for the PKK cadres and TOP Support members, and they access this by maintaining their social identity as ‘decent’ women and devoted mothers and wives. One of the ways in which they maintain their identity as devoted mothers is to obey their husbands and not neglect their family. Many of the TOP Support members, whose partners have absconded or died, seek out new marital partners in order to maintain this image. The women also rework their appearance, for example by wearing the Muslim hijab and talking politely in public, in order to appear and be perceived as ‘proper’ women.

Considering the social capital commanded by both the PKK and TOP Support, these two organizations should be effective in promoting PMTCT. Unfortunately, the utility of the image of motherhood is limited in that mothers cannot, by definition, interfere with or violate their domestic roles. A woman's domestic sphere shapes the essential characteristics of passivity and non-aggression, and establishes a social space for a mother as the person in charge of the domestic sphere – but not beyond. Women are socialized to respect the differences between male and female roles, which impose limitations on their individual power and social space. The role of motherhood, as a source of social capital, thus becomes a barrier for women fighting for goals outside of the domestic sphere. This is why the strategy
of mobilizing motherhood has made few inroads into the arena of national policy making.

This study suggests that there are significant challenges to the promotion of programs such as PMTCT for women through motherist organizations. Firstly, in order to be able to more effectively champion PMTCT, motherist organizations are in need of gender empowerment training. Secondly, motherist approaches exclude women such as teenagers, young and unmarried women, and women who are not pregnant; this is one of the main challenges in promoting the PMTCT continuum of care as outlined by the WHO. Thirdly, to prevent HIV transmission to babies and to protect women from infection, PMTCT has to address the issue of housewives being at risk, which means that PMTCT programs must address the role of men in transmitting the disease. Fourthly, to maintain the sustainability of the program, PMTCT needs to be funded and supported through formal attention by the government or by society at large.
Samenvatting

Onderzoekers op het gebied van vrouwenstudies hebben gewezen op de aanwezigheid van sociale bewegingen over de hele wereld die zich richten op de rol van vrouwen als toegewijde moeders die samen strijden voor de rust en het overleven van hun kinderen en families. Dergelijke bewegingen hebben hun kracht getoond in vreedzame acties waarmee zij middels het mobiliseren van de beeldvorming van vrouwen als geduldige, vredelievende en aan hun familie toegewijde moeders, het huidige beleid betwisten. Vrouwen die voor de rechten van hun families strijden worden geclassificeerd als ‘motherist’ om een onderscheid te maken met feministes. De sociale constructie van moederschap stimuleert niet alleen dat ‘motherists’ voor het welzijn van hun families vechten, maar bovendien dat alle programma’s die zich ten doel stellen om het welzijn van moeders, kinderen en families te verbeteren voor ‘motherist’ organisaties van belang zijn.

Dit proefschrift onderzoekt de strategie van het mobiliseren van moederschap door analyse van twee Indonesische organisaties –de Pembinaan Kesejahteraan Keluarga (Familie Welzijn Beweging, ofwel PKK) en Tim ODHA Perempuan (Seropositief Vrouwen Team, ofwel TOP Support) – die zich beide ten doel stellen om programma’s ter preventie van moeder-naar-kind overdracht (Prevention of Mother-to-Child Transmission; PMTCT) van HIV/AIDS sociaal acceptabeler te maken. Dit ondanks het feit dat PMTCT, als onderdeel van een gestigmatiseerd HIV preventie programma, niet goed past bij het beeld van moederschap. De eerste en enige PMTCT interventie in Indonesië was een pilot studie uitgevoerd door de NGO Yayasan Pelita Ilmu (Pelita Ilmu Foundation, of YPI) die vanaf 1999 haar inspanningen in eerste instantie concentreerde op Jakarta en daarna heeft uitgebreid naar zes andere provincies in 2007. Het PMTCT project is NGO geïnitieerd en door donoren aangedreven met geringe ondersteuning van de overheid vanwege de lage nationale HIV/AIDS besmettingsgraad en stigmatisering van de ziekte. Dit ondanks het feit dat de Indonesische regering zich wel ten doel heeft gesteld om het percentage van nieuwe besmettingen te verminderen in het kader van het bereiken

In 2005 is met steun van YPI het verzamelen van de veldwerk gegevens begonnen via etnografische methoden. De primaire data voor dit onderzoek zijn verzameld in Jakarta en omstreken middels diepte interviews en focus groep discussies. Deze gegevens zijn aangevuld met secundaire data die verkregen zijn uit belangrijke documenten, discussies op HIV/AIDS fora en krantenartikelen op het gebied van HIV/AIDS en PMTCT.

Moederschap en HIV/AIDS worden gezien als tegengestelde concepten. Voor Indonésiërs is het moederschap de heilige rol van de vrouw waardoor een toegewijde moeder als een hoogst onwaarschijnlijke kandidaat wordt gezien om met HIV besmet te zijn, het virus zou alleen betrekking hebben op mensen die zich ‘slecht’ gedragen zoals prostituées en injectorende drugsgebruikers. Toch heeft de opname van PMTCT in moeder- en kindzorg en gezinsplanning services, zoals bepleit door het Indonésische ministerie van gezondheidszorg, geleid tot subtiele veranderingen van het imago van HIV/AIDS. Dit heeft erin geresulteerd dat binnen de gemeenschap meer bewustzijn is ontstaan dat HIV/AIDS niet alleen gestigmatiseerde groepen raakt, maar tevens overgedragen kan worden naar moeders en kinderen. De media hebben ook een belangrijke rol gespeeld in het verspreiden van HIV/AIDS gerelateerd nieuws. Zij hebben steeds meer aandacht besteed aan de oplopende HIV besmettingsniveaus bij lage risico groepen zoals huismoeders en kinderen. Het woord moeder (Mother) in PMTCT heeft ook een belangrijke rol gespeeld in deze verandering. In een tijdsgewricht waarin PMTCT programma’s worden gepromoot is er een verandering in de beeldvorming van HIV waar te nemen van een ziekte voor ‘immorele vrouwen’ naar een ziekte die ook toegewijde huismoeders treft. Dit heeft geresulteerd in meer acceptatie van HIV preventie programma’s binnen de samenleving.

Door het beeld van moederschap te mobiliseren kunnen PKK kaders en TOP Support leden toegang krijgen tot het verzamelde sociale kapitaal in de vorm van vertrouwen en sociale vrouwennetwerken. Het sociale kapitaal van moederschap kan gemobiliseerd worden op individueel niveau en organisatie niveau. Vertrouwen is cruciaal in het opbouwen van sociale relaties en netwerken; de gedeelde identiteit
van het moeder-zijn schept vertrouwen op individueel niveau, terwijl deze vertrouwensnetwerken ook benut kunnen worden op organisatorisch niveau.

De PKK is een formele overheidsgeleide gemeenschapsorganisatie die sociaal en politiek dusdanig is georganiseerd dat zij het hele spectrum van het laagste niveau in de gemeenschap tot het hoogste nationale niveau beslaat. De staat gebruikt de PKK om de dominante patriarchale cultuur te versterken door op overtuigende wijze de traditionele rol van vrouwen als huisvrouwen en gemeenschapsleden te benadrukken. Vroeger was de PKK betrokken bij de Safe Motherhood Movement en het Family Planning Program (Veilig Moederschap en Gezinsplanning Programma) waardoor zij toegang hebben tot een brede basis van bestaande gemeenschapsnetwerken. Het formele en goed georganiseerde sociale netwerk van de PKK is dus een krachtig middel om vrouwen te benaderen om gebruik te maken van PMTCT diensten aangezien er al een formele band tussen de PKK kaders en zwangere vrouwen bestaat. YPI heeft de PKK kaders gestimuleerd om zwangere vrouwen op dorpsniveau zich er toe te laten bewegen om van de mobiele VCT (Voluntary Counseling and Testing – Vrijwillige Test en Zorg) diensten gebruik te maken ten einde HIV te voorkomen binnen de groep vruchtbare vrouwen.

Het betrekken van de PKK kaders bij gezondheidszorgprogramma’s voor moeder en kind heeft bijgedragen tot het beeld van hen als goede huisvrouwen en verantwoordelijke moeders. Dit heeft geleid tot meer vertrouwen in de kaders, in het bijzonder bij de echtgenoten, die nu eerder toestaan dat hun zwangere vrouwen van mobiele VCT diensten gebruik maken. Dit vertrouwen is van groot belang aangezien Indonesische vrouwen alleen externe activiteiten buiten het huishouden ondernemen als de echtgenoot hiervoor zijn toestemming heeft verleend.

Aangezien het PMTCT project binnen de rangen van het PKK meer gezien wordt als een programma van het YPI wordt de waarde van dit project helaas niet als cruciaal gezien door PKK kaders. De PKK heeft wel bereikt dat meer zwangere vrouwen zich van de mobiele VCT diensten bedienden, zoals blijkt uit de data van pre –en post-test zorg, maar de PKK kaders hebben echter nooit het gevoel gehad deel uit te maken van het programma door een gebrek aan kennis en persoonlijke angst voor de ziekte. Dit heeft erin geresulteerd dat de PKK kaders louter dezelfde rol speelden als binnen de Safe Motherhood Movement en het Family Planning Program. Bovendien hebben bijna alle vrouwen die tijdens het mobiele VCT programma met HIV gediagnosticeerd werden de vervolgactiviteiten van YPI geweigerd wegens aanhoudende stigma binnen de lokale gemeenschap met betrekking tot HIV/AIDS. Hierdoor is het onmogelijk gebleken voor YPI om deze vrouwen het volledige PMTCT pakket aan zorg, zoals beschreven door het WHO, aan te bieden.
Tevens bestaat er wantrouwen en een gebrek aan evenwicht in de relatie tussen PKK staf en zwangere vrouwen, aangezien PKK stafleden de zwangere vrouwen zien als moeders die HIV positief kunnen zijn en hierdoor de gemeenschappelijke biosociale identiteit van vrouwen als toegewijde moeders kunnen verstoren. Hierdoor is het veel lastiger om vertrouwensnetwerken en effectieve organisatorische samenwerkingsverbanden op te zetten om effectieve belangenbehartiging van deze groep te volbrengen.

Opdat seropositieve moeders hun individuele problemen en hun problemen als moeder tegemoet kunnen treden heeft YPI de seropositieve vrouwenhulpgroep TOP Support opgericht om psychosociale hulp voor moeders, hun kinderen en families te kunnen verzekeren. Deze groepen stimuleren informele relaties tussen haar leden die uit verschillende delen van Jakarta komen. Behalve de wederzijdse emotionele steun verlenen de leden van de TOP Support groepen ook informatieve steun aan de gemeenschap door hun getuigenissen in het openbaar en in de media.

De notie van ‘heilig moederschap’ verleent de TOP Support leden de mogelijkheid om een imago uit te stralen van toegewijde moeders en vrouwen die met HIV zijn geïnfecteerd door het ‘slechte’ gedrag van hun mannen en die hierdoor buiten hun schuld en medeweten om de ziekte op hun kinderen hebben overgedragen. TOP Support gebruikt dit imago om draagvlak te verkrijgen, stigmatisering te vermijden en PMTCT te promoten. Zij herdefiniëren de identiteit van deze vrouwen van zondige en immorele vrouwen naar onschuldige en toegewijde moeders waardoor vertrouwen wordt gegendereerd in de groep van seropositieve vrouwen en ten opzichte van de gemeenschap, waardoor deze vrouwen toegang krijgen tot psychosociale hulp en zij zelf PMTCT propageren via publieke getuigenissen.

Gelukkig hebben slecht zeer weinigen van de TOP Support leden die aan dit onderzoek hebben meegewerkt de ernstige fases van AIDS bereikt. Diegenen die aan AIDS lijden hebben het gevoel dat de ziekte een vloek van God is als straf voor hun gedrag wat haaks staat op hun identiteit als toegewijde vrouw (zoals die van hun door de gemeenschap verwacht wordt). Aangezien in de meeste gevallen de vrouwen nog niet geconfronteerd werden met het volledige pakket aan symptomen behorend bij de ziekte AIDS was er slechts een enkeling zich ten volle bewust van de mogelijke gevolgen van de ziekte. YPI zorgt ook voor toegang tot medische voorzieningen, zodat TOP Support leden geen problemen ondervinden met beschikbaarheid van medische zorg. De combinatie van deze twee factoren, de afwezigheid van ernstige symptomen bij de doelgroep en de toegankelijkheid van medische zorg, verklaart waarom TOP Support leden niet actief PMTCT voorstaan als integraal deel van de vrouwenbeweging voor reproductieve gezondheidszorg.

Door hun betrokkenheid bij het PMTCT proefproject zijn de PKK kaders en TOP Support leden in staat om het sociale kapitaal ontleend aan het respect voor
moederschap om te zetten in sociale en economische mogelijkheden. PKK stafleden en TOP Support leden ontvangen beide vergoedingen, bijvoorbeeld in de vorm van reiskosten compensatie, die gebruikt kunnen worden ter aanvulling van het familie-inkomen en hiermee wordt de rol die moeders hebben als verantwoordelijke voor het welzijn van hun familie versterkt, des te meer als de man des huizes financieel niet in staat is om in alle benodigdheden voor het gezin te voorzien. Door deze financiële uitkeringen zien de PKK kaders en TOP Support leden PMTCT meer als inkomensbron dan als deel van de vrouwenbeweging voor reproductieve gezondheidszorg.

De financiële stimulans is tamelijk relevant voor de PKK en TOP Support leden, en de laatste groep kan hier van profiteren zonder dat dit schade berokkent aan hun sociale identiteit als fatsoenlijke vrouwen en toegewijde moeders. Één van de manieren waarop hun identiteit als toegewijde moeders gehandhaafd kan worden is door gehoorzaam te zijn aan hun mannen en hun familie niet te verwaarlozen. Van de TOP Support leden waarvan de partners zijn overleden of verdwenen gaan er veel op zoek naar een nieuwe huwelijkspartner om toch dit imago te behouden. Veel vrouwen veranderen ook hun publieke verschijning, bijvoorbeeld door het dragen van de islamitische hijab en door op een nette manier te praten in het openbaar, om toch maar gezien te worden als een ‘nette’ vrouw.

Gegeven de beschikbaarheid van het sociale kapitaal binnen de PKK en Top Support mag men verwachten dat deze organisaties effectief zijn in het promoten van PMTCT. Helaas is de bruikbaarheid van het beeld van moederschap gelimiteerd in de zin dat moeders zich per definitie niet kunnen bemoeien met of zich kunnen onttrekken aan hun huishoudelijke rol. De huiselijke omgeving rondom de vrouw geeft gestalte aan de typische kenmerken van passiviteit en non-agressie en bieden haar de sociale ruimte om als hoofdverantwoordelijke binnen de huiselijke kring, maar niet daar buiten, op te treden. Van vrouwen wordt verwacht dat zij de rolverdeling tussen mannen en vrouwen respecteren, terwijl dit rollenpatroon voor de vrouw ook een obstakel vormt voor haar individuele macht en sociale ruimte. De rol van het moederschap, als bron voor sociaal kapitaal, vormt als zodanig ook een barrière voor vrouwen die voor meer rechten buitenshuis strijden. Hierdoor heeft de strategie om moederschap te mobiliseren weinig weerslag gevonden op het gebied van nationale beleidsvorming.

Dit onderzoek geeft aan dat er nog aanzienlijke uitdagingen bestaan om gebruik te maken van ‘motherist’ organisaties om programma’s zoals PMTCT voor vrouwen te promoten. Ten eerste hebben ‘motherist’ organisaties behoefte aan gender empowerment training om PMTCT programma’s effectiever te kunnen promoten. Ten tweede sluit de benadering vanuit ‘motherist’ perspectief groepen vrouwen uit zoals tieners, jonge ongetrouwde vrouwen en vrouwen die niet zwanger zijn; dit
blijft één van de grote uitdagingen wat betreft de stimulering van allesomvattende PMTCT zorg zoals de WHO adviseert. Ten derde zal PMTCT, om HIV infectie van huisvrouwen en overdracht naar baby’s te voorkomen, rekening dienen te houden met de rol die mannen spelen in de verspreiding van HIV/AIDS. Ten vierde is het noodzakelijk voor het voortbestaan en succes van het PMTCT programma dat de overheid en de samenleving ondersteuning bieden en fondsen beschikbaar stellen voor PMTCT.