

# The design of clinic-based mother support groups to enhance retention in PMTCT programmes

Formative Research for the Eliminating Paediatric AIDS in Zimbabwe project, Study 2



This is a report of formative research conducted in 2013 as part of the Eliminating Paediatric AIDS in Zimbabwe (EPAZ) project. EPAZ is a four-year (2012-16) implementation research project under the auspices of the World Health Organisation and the Ministry of Health and Child Welfare, Zimbabwe, one of six projects in Zimbabwe, Malawi and Nigeria that are part of the INSPIRE (INtegrating and Scaling up PMTCT through Implementation Research) initiative administered by WHO with support from the Canadian International Development Agency.

Three research studies were conducted as part of the three formative researches conducted by EPAZ project namely;

2. *Assessment of feasibility and acceptability of nurse-led initiation of anti-retroviral therapy*
3. *The design of clinic-based mother support groups to enhance retention in PMTCT programmes*
4. *Unpacking loss to follow-up issues in a rural PMTCT programme context*

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# Acronyms

ANC	Antenatal care
ART	Antiretroviral Therapy
EPAZ	Eliminating Paediatric AIDS in Zimbabwe
HCT	HIV Counselling & Testing
HIV	Human Immunodeficiency Virus
IGP	Income generating project
LTFU	Lost to follow up
MSG(s)	Mother support group(s)
NGO	Non Governmental Organisation
PC	Primary counsellor
PCN	Primary care nurse
PLHA	People living with HIV-AIDS
PMTCT	Prevention of mother-to-child transmission
PNC	Postnatal care
RCT	Randomised Controlled Trial
RGN	State registered nurse

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To the community at large thank you for your time and invaluable responses that are contained in this document. Specific gratefulness goes to HIV+ pregnant mothers and their infant pairs who without hesitation shrugged off fears of stigma and discrimination to attend to interviews. Others welcomed us into their homes with much love and passion risking again questions and potential ridicule from their neighbors for their HIV status.

## Background to the Study

MSGs based at health facilities were initially established to improve ART adherence, provide psychosocial support and increase facility deliveries<sup>1</sup>. Mother mentors link to mothers-to-be after the latter are referred to MSGs by clinic nurses during ANC visits. Mentors help HIV+ pregnant mothers navigate the complicated processes necessary to reduce their risk of PMTCT. Mentors can do this because they have been through these processes before, usually successfully. Mentors can check that mentees attend for ANC and PNC appointments, know about family planning and feeding options, are aware of prophylaxis and that they maintain treatment adherence. If HIV+ mothers default clinic attendance, mentors can contact them, through home visits or by liaison with VHWs. Mentors will also contact mentees using cell phone messaging which when used in PMTCT settings, increased PCR testing and collection of PCR results of infants.<sup>2</sup> In Zimbabwe, 56% of people own a cell phone and the number is surging.<sup>3</sup> Provision of family-centered HIV services increases male partner involvement and uptake of HIV services. Family support groups are easily established in remote rural settings and lead to male partner participation in PMTCT activities.<sup>4</sup> This intervention will build on previous work of its co-investigators that involved establishing HIV-focused facility-based, community-wide care coalitions in the catchment areas of 2 clinics in Zimbabwe.<sup>5</sup> MSGs will be established in rural clinics with strong systems to identify defaulting mothers and increase retention. The groups will also provide psychosocial support.

Though an evolving, some cited in sources above have positioned MSGs as one approach that can be used to curb loss to follow up. Indeed, if successfully implemented, MSGs are bound to promote and improve the health seeking behaviour of mother infant pairs and that of their spouses.

Discussions with HIV+ women respondents in Mutare and Makoni have revealed that mothers do in fact welcome the formation of such support groups. The majority were comfortable with having such groups set up at local clinics and being led by peers

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<sup>1</sup> Intrahealth international (2008) Mothers' Support groups in Ethiopia: A peer support model to address the needs of women living with HIV

<sup>2</sup> Technau KG, K de Tolly, G Sherman, L Kihn, P Benjamin, J Bassett, K Gaddini, A Coovadia(2011), Mobile text messaging improves PMTCT: Folloup in South African public setting. 3<sup>rd</sup> International Workdhop on HIV Paediatrics, Rome

<sup>3</sup> Newsday (2011) Local cell phone ownership surges. May 16

<sup>4</sup> D' mello S, B. Mbatia R , Andrews L, Chen L, Khaflan H, Ramadhani A, Biribonwoha H, Strachan M, Cunningham A(2009) Supporting Comprehensive PMTCT Care in Tanzania through family Support Groups. International HIV/AIDS International Centre for AIDS Care and Treatment Programs. Mailman School of Public Health, Columbia University: Implementers Meeting 12<sup>th</sup> June

<sup>5</sup> Foster G, Maphosa T, Kurebva F. (2012) Faith Untapped: linking commujity level and sectoral health and HIV / AIDS responses. In J Olivier and Q Wodon (eds) Strengthening faith inspired health engagement in Africa. Wasington DC, The World Bank.

# 1. Introduction

There is an urgent need to improve the access that HIV-positive mothers have to services which can prolong their life and reduce the vertical transmission of HIV to their babies. Anti-retroviral treatment started as soon as possible after diagnosis in pregnant mothers and continued for life now forms the standard of care for PMTCT delivery in Zimbabwe and elsewhere. The recognition that many mothers initiated on ART are not retained on treatment by health services has led to the need to establish facility-based mother support groups.

The need to come up with a Mother Support Groups (MSGs) model based at health facilities or in the community is premised upon the following;

- ✓ Recognition that LTFU is a problem and retention is low
- ✓ That facility-based MSGs could have impact on retention rates as well as other important benefits (eg. Male participation, adherence, psycho social support)
- ✓ That to be replicable throughout MOHCW the intervention must be simple and low cost
- ✓ It must be established with limited external assistance
- ✓ That they must support existing MOHCW policies on retention and LTFU
- ✓ That they must have clear entry and exit processes for members if they are to be maintained
- ✓ That as a research intervention, they need to be standardized

It must be noted that current MOHCW policy and actual practice on curbing LTFU and retention is somewhat loosely defined. The system does recognise the challenges linked to LTFU but falls short of practical solutions to curtail such a gap. VHW are one such group that is involved in responding to LTFU issues. Unfortunately, the complexity of the problem at hand renders their assistance less effective.

## 1.1 Statement of Problems

**Low MTCT effectiveness:** Evidence indicates there is drop out from PMTCT programmes at various stages in the cascade<sup>6</sup>. Factors that hamper access to and uptake of services include gender-related barriers; high cost of services; inadequate information; poor provider-patient relationships and quality of services; inconvenient opening hours; concerns about confidentiality and stigma; lack of community support; lack of transport; and shortage of resources<sup>7</sup>.

**Lack of male involvement:** Male partners have considerable impact on women's uptake of HIV testing. Women's perception of their husband's approval of taking an HIV test was the strongest

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<sup>6</sup> Manzi, M. et al., (2005), High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: scaling up requires a different way of acting, *Tropical Medicine and International Health*, Volume 10. 12 pp 1242. 1250, Dec. 2005.

<sup>7</sup> United Nations General Assembly Special Session on HIV/AIDS, Zimbabwe Report, (2010).

predictor of women's willingness to accept a test<sup>8</sup>; opposition from partners was a major factor contributing to low HIV counselling and testing uptake, leading to failure to return for HIV test results<sup>9</sup>. Male involvement in PMTCT is a national and international<sup>10</sup> priority. It includes partner disclosure and partners attending clinics for support or HCT. Male participation is associated with uptake and compliance with prophylaxis, replacement and exclusive breastfeeding<sup>11</sup> and increased infant HIV-free survival<sup>12</sup>. Participation benefits HIV-positive male partners in concordant unions who are less likely to receive ART. Only 37% of adults receiving ART in Zimbabwe were male<sup>13</sup>; in discordant unions, male participation may reduce new infections in pregnant women who are at higher risk than HIV- men; in 19% of HIV-infected couples, only the female is HIV-positive<sup>14</sup>.

**Lack of community engagement with health sector:** Community-based health initiatives are widespread. A WHO study found that health districts in Africa were each home to several hundred initiatives<sup>15</sup>. Community responses have proliferated as result of HIV/AIDS. Three-quarters of community development responses in Zambia involved HIV/AIDS and 65% were faith-based<sup>16</sup>. A review of interventions for neonatal health found that strategies that used community mobilisation reported the highest declines in perinatal and neonatal mortality<sup>17</sup>. Three RCTs of community-based women's groups demonstrated reductions in neonatal mortality<sup>18 19 20</sup>. Yet health sectors are largely disengaged from community health and HIV/AIDS responses.

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<sup>8</sup> Bajunirwe F, Muzoora M. (2005) Barriers to the implementation of programs for the prevention of mother-to-child transmission of HIV: a cross-sectional survey in rural and urban Uganda. *AIDS Research and Therapy*, 2:10

<sup>9</sup> Brusamento, Serena, Elena Ghanotakis Lorainne Tudor Car, Azeem Majeed, Josip Car (2011) Male involvement for increasing the effectiveness of prevention of mother-to-child HIV transmission (PMTCT) programmes. *The Cochrane Library*, 9 Nov

<sup>10</sup> World Health Organization, 2010 .PMTCT Strategic Vision 2010. 2015, WHO, Geneva

<sup>11</sup> Msuya, S.E., et al., *AIDS Care*, 2008.

<sup>12</sup> Aluisio, A, et al. (2009) Male Partner HIV Testing and Antenatal Clinic Attendance Associated with better HIV-free Survival in Infants. Abstract TuAC105, International AIDS Society, Capetown, South Africa, July

<sup>13</sup> Holmes *op. cit*

<sup>14</sup> Lule, Elizabeth, Richard Seifman, Antonio C. David (2009) *The changing HIV/AIDS landscape: selected papers for the World Bank's agenda*. World Bank, Washington

<sup>15</sup> World Health Organisation (1994) *Health development structures in district health systems: a multi-country study of situations, problems, and prospects : summary and analysis of study reports submitted by principal investigators*. Division of Strengthening of Health Services, World Health Organization, Geneva

<sup>16</sup> African Religious Health Assets Program (ARHAP). (2006). *Appreciating Assets: The Contribution of Religion to Universal Access in Africa*. Report for the World Health Organization.

<sup>17</sup> Haws RA, Thomas AL, Bhutta ZA, Darmstadt GL. (2007) Impact of packaged interventions on neonatal health: a review of the evidence. *Health policy and planning*. 22(4): 193-215.

<sup>18</sup> Manandhar DS, Osrin D, Shrestha BP, Mesko N, Morrison J, Tumbahangphe KM, et al. Effect of a participatory intervention with women's groups on birth outcomes in Nepal: cluster-randomised controlled trial. *Lancet*. 2004 Jan 1;364(9438):970-9.

<sup>19</sup> O'Rourke K, Howard-Grabman L, Seoane G. Impact of community organization of women on perinatal outcomes in rural Bolivia. *Rev Panam Salud Publica*. 1998 Jan 1;3(1):9-14.

<sup>20</sup> Tripathy P, Nair N, Barnett S, Mahapatra R, Borghi J, Rath S, et al. Effect of a participatory intervention with women's groups on birth outcomes and maternal depression in Jharkhand and Orissa, India: a cluster-randomised controlled trial. *Lancet*. 2010 Apr 3;375(9721):1182-92.

## 1.2 Mother Support Groups

MSGs based at health facilities were initially established to improve ART adherence, provide psychosocial support and increase facility deliveries<sup>21</sup>. Mother support groups (MSGs) can enhance comprehensive PMTCT services by addressing social norms and beliefs about HIV, stigma and other barriers that cause low uptake and retention. MSGs may also improve ART adherence, and promote diagnosis, treatment and retention of pregnant HIV+ mothers and exposed infants in PMTCT services<sup>22 23 24</sup>.

Some PMTCT support initiatives have involved recruiting “mother mentors” to provide peer counselling to HIV-positive mothers that involve psychosocial support and encourage male participation. Mother support group coordinators will link with mothers-to-be after the latter are referred to MSGs by clinic nurses during ANC visits. Mother Support Group Coordinators will help HIV+ pregnant mothers navigate the complicated processes necessary to reduce their risk of PMTCT. MSG coordinators can do this because they have been through these processes before. Coordinators can check that mothers to be attend ANC and PNC appointments, know about family planning and feeding options, are aware of prophylaxis and that they maintain treatment adherence. If HIV+ mothers default clinic attendance, MSG Coordinators can contact them, through home visits or by liaison with VHWs. MSG coordinators may also contact mothers to be using cell phone messaging which when used in PMTCT settings, increased PCR testing and collection of PCR results of infants.<sup>25</sup>

MSGs may also lead to increased male partner involvement and uptake of HIV services. Mother support groups are easily established in remote rural settings and lead to male partner participation in PMTCT activities<sup>26</sup>.

There are many issues around the functioning of MSGs that require better understanding to inform the design of support groups in Zimbabwe. The lack of scientific literature about the effectiveness of MSGs makes it difficult to formulate strategies based on sound evidence. Some of the issues that are unresolved include:

**Meeting location:** Some MSGs meet at clinics, strengthening links with formal health care systems; others are community based, providing a broader range of interventions

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<sup>21</sup> Intrahealth international (2008) MothersqSupport groups in Ethiopia: A peer support model to address the needs of women living with HIV

<sup>22</sup> Teasdale, Chloe A and Mitchell J Besser. (2008) Enhancing PMTCT programmes through psychosocial support and empowerment of women: the Mothers2Mothers (M2M) model of care. *Southern African Journal of HIV Medicine*, Summer, 60-64

<sup>23</sup> Sequera Dqnello B, Mbatia R, Andrews L, Chen L, Khalfan H, Ramadhani A, Biribonwoha H, Strachan M, Cunningham A. *Supporting Comprehensive PMTCT Care in Tanzania through Family Support Groups*

<sup>24</sup> Long, Siân (2010) *Review of best practices for establishing mother support groups to reduce HIV vertical transmission*, Save the Children, UK, London

<sup>25</sup> Technau KG, K de Tolly, G Sherman, L Kihn, P Benjamin, J Bassett, K Gaddini, A Coovadia(2011), Mobile text messaging improves PMTCT: Folloup in South African public setting. 3<sup>rd</sup> International Workshop on HIV Paediatrics, Rome

<sup>26</sup> Dqnello S., B, Mbatia R, Andrews L, Chen L, Khalfan H, Ramadhani A, Biribonwoha H, Strachan M, Cunningham A (2009) *Supporting Comprehensive PMTCT Care in Tanzania through Family Support*

*Groups*. International 2009 HIV/AIDS International Center for AIDS Care and Treatment Programs, Mailman School of Public Health, Columbia University: Implementers Meeting 12th June

**Establishment:** Some MSGs are established by health or NGO staff. Others are established by HIV positive mothers – the latter may be less effective in meeting PMTCT programme goals

**Mother- or family-focus:** Some support groups that were established for mothers have broadened their scope from infected mothers to affected families<sup>27</sup>

**Community structures:** Most clinic-based MSGs are established and driven with limited involvement of community groups, e.g. churches and community-based organizations affecting their sustainability

**Male involvement:** Some MSGs have promoted partner counselling and testing and male involvement; there is limited data on whether activities are effective and how they should be best implemented, in particular, whether activities should be gender mixed or not<sup>28 29</sup>

### 1.3 Background to EPAZ Study

The EPAZ study is a cluster randomised controlled trial testing the impact of point-of-care early infant virological testing and mother support groups on selected outcomes. The project is being implemented in rural clinics in Makoni and Mutare districts in eastern Zimbabwe and aims to enrol 2,700 HIV-positive mothers and their exposed infants and follow them till twelve months postnatally. The 62 health facilities in the study were grouped into 15 clusters of between 2 and 6 clinics. Five clusters with 21 clinics were randomly selected to test whether MSGs based at health facilities increase retention in postnatal HIV follow-up care twelve months postnatally. Secondary objectives include assessing whether male participation in PMTCT activities is increased at clinics with MSGs and whether antenatal attendance, family planning uptake, nevirapine and co-trimoxazole prophylaxis and postnatal HIV testing are increased at clinics with MSGs.

This formative research project was designed to inform the design of mother support groups prior to their establishment by the EPAZ project. The project had the following objectives:

#### **Broad Objective**

To describe the perceptions and experiences of key stakeholders regarding the acceptability and design of clinic-based MSGs and their relationship to community health structures to promote positive PMTCT outcomes in Manicaland province, Zimbabwe

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<sup>27</sup> Muwa, B., (2007). The role of family support groups in improving male involvement in PMTCT programs, UPHOLD, Uganda.

<sup>28</sup> Aluisio A, Richardson BA, Bosire R, John-Stewart G, Mbori-Ngacha D, Farquhar C. Male antenatal attendance and HIV testing are associated with decreased infant HIV infection and increased HIV-free survival. *J Acquir Immune Defic Syndr*. 2011 Jan 1; 56(1):76-82,

<sup>29</sup> Pride Mucheto, Addmore Chadambuka, Gerald Shambira, Mufuta Tshimanga, Gombe Notion, Wenceslas Nyamayaro (2011), Determinants of nondisclosure of HIV status among women attending the prevention of mother to child transmission programme, Makonde district, Zimbabwe, 2009. *Pan African Medical Journal*, 8:51

### **Specific Objectives**

1. To assess how clinic-based Mother Support Groups can avoid increasing stigma and discrimination against pregnant HIV-positive mothers and their family members.
2. To assess the acceptability of MSG-led activities to reduce loss-to-follow-up of pregnant HIV+ mothers and exposed infants in PMTCT services
3. To assess the acceptability of measures to promote partner disclosure and male participation in PMTCT activities
4. To inform the development of Community Care Coalition structures to support the functioning of clinic-based MSGs

The study aimed to answer the following research questions:

### **Main Research Question**

What are the perceptions and experiences of key stakeholders regarding the acceptability and design of clinic-based MSGs and their relationship to community health structures to promote positive PMTCT outcomes?

### **Secondary Research Questions**

1. How can MSGs function in ways that protect the confidentiality of pregnant HIV-positive mothers and their relatives?
2. How can MSG member activities best increase retention of pregnant HIV+ mothers and exposed infants in PMTCT services?
3. How can activities that promote partner disclosure and male participation in PMTCT activities best be implemented?
4. Which community organisations are present in the catchment areas of clinics that might support MSG functioning?

The study received prior approval from the Medical Research Council of Zimbabwe and the Ethical Review Committee of the World Health Organisation, Geneva.

## 2. Methodology

The research employed a cross sectional study design employing qualitative and quantitative techniques. The study sites included the five central clinics in the five clusters in arm 3 of the study with two additional randomly selected satellite clinics from each of the five clusters. All 15 selected clinics were in arm 3 of the EPAZ study and were planned sites to establish MSGs as one of the interventions in the EPAZ study<sup>30</sup>. The research involved questionnaire study of the following three populations:

1. HIV infected pregnant mothers attending ANC/PNC services at study clinics in the month of data collection.
2. Nurses and primary care counselors working at study clinics
3. Traditional, religious and political leaders and representatives of community organisations with health- related activities living in the catchment areas of clinics

The three semi-structured interview guides were pre-tested on similar populations in clinics outside the study districts leading to modifications to the tools. Data collectors were trained in administering questionnaires and facilitating focus group discussions. Data collection took place in March-April 2013. All FGDs were transcribed.

Analysis of qualitative data from interviews and FGDs was performed using the 'thematic content analysis' framework which consists of reading and re-reading the field notes and transcribed texts, manual coding in the margins and synthesizing and grouping data into relatively exhaustive categories. To ensure integrity of data in qualitative data analysis, we used triangulation, inter-rater reliability, auditability, constant comparison and critical consideration of negative cases.

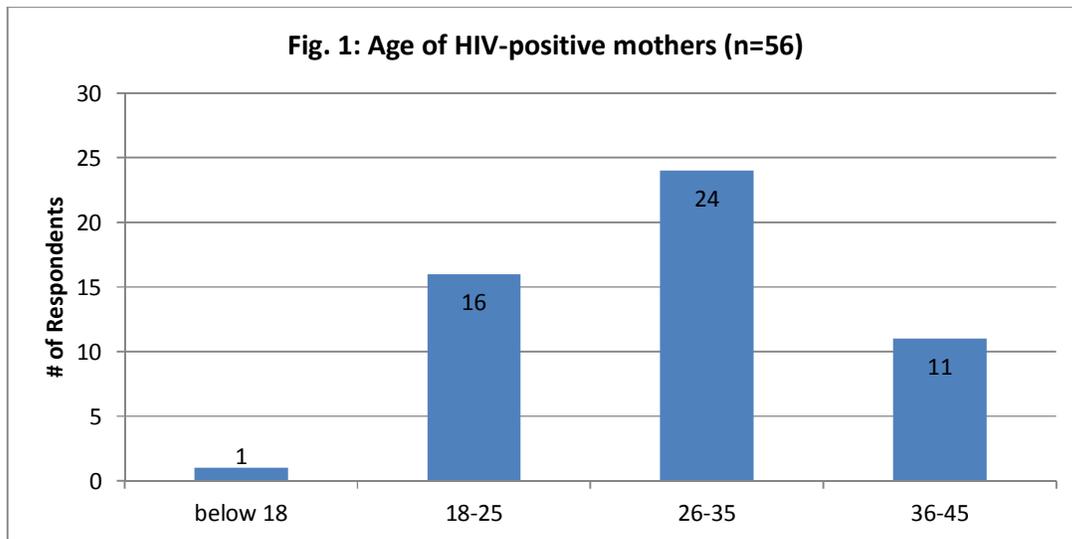
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<sup>30</sup> The fifteen clinics listed according to clusters were (1) Marange Rural Hospital; Bakorenhema & Gwindingwi clinics; (2) Weya clinic; Mayo 1 & Nyamukamani clinics; (3) Chitakatira clinic; Vumba & Burma Valley clinics; (4) St Theresa Mission Hospital; Tandji, & Chiduku clinics; (5) Rukweza clinic; Mukamba & Nyazura clinics

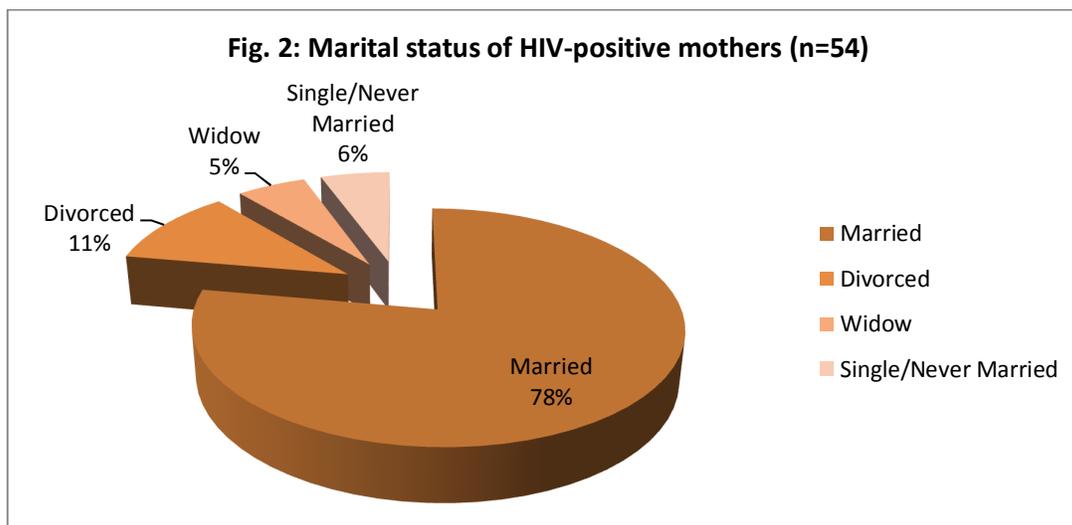
### 3. Study Population

#### 1) HIV-positive mothers

A total of 56 HIV-positive pregnant mothers and mothers with infants were interviewed. Their religious affiliation consisted of the apostolic sect (31%), protestants (31%) and Pentecostal (25%). One respondent followed the Muslim religion. The majority of women interviewed fell under the lower rural class and peasant population generally considered poor and marginalised. The majority were young women aged between 18 to 35 years (Fig. 1).



78% of respondents were married (spousal median age was 36) while 22% were single, widowed or divorced; 36 (78%) of the married women indicated their spouses were full time local residents (Fig. 2).

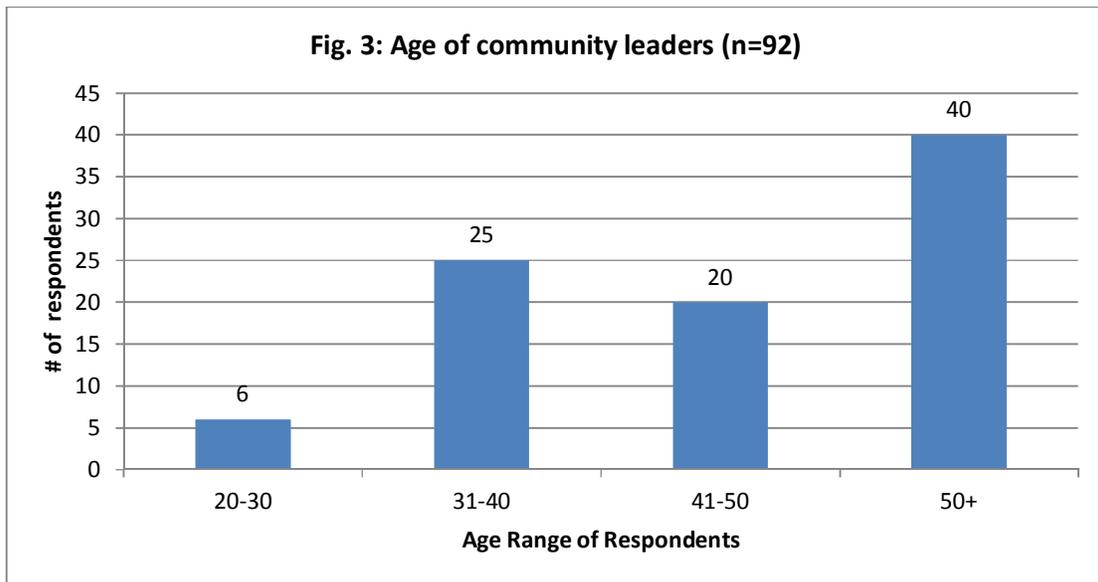


**2) Nurses**

A total of 14 nurses were interviewed from both low- and high- volume rural clinics; 8 were primary care nurses and 6 were state registered nurses; one nurse was male. Twelve nurses indicated that they had been at the particular station for 12 months or longer, a possible indicator that they were probably well versed with issues likely to affect their respective sites.

**3) Community leaders**

A total of 92 community leaders were interviewed. Of these, 67 were males while 25 were females. These belonged to wide spectrum age groups (Fig. 3). The leaders were village health workers, teachers and other civil servants from home affairs, agriculture and health department or belonged to a cross section of groups such as traditional structures, churches and political associations.



## 4. Results and Analysis

### 4.1 Acceptability to Mothers of MSG activities

MSGs were considered acceptable by most HIV+ mothers. HIV+ women stated that they would be attracted to join MSGs because these would provide them with information and emotional support as well as positive health outcomes for their infants. One mother stated “.....we will gain more information and education about HIV. And if we follow the education we will have HIV free children”. She felt that joining the MSG would reduce stress because women can learn from each other how to cope. Some mothers stated that they hoped the groups would provide them with material support in the form of food, clothing and income generating projects.

Some mothers mentioned issues that might make it less likely for them to join MSGs; these included:

- mothers who stay far away from the MSG meeting places might be unable to join
- members of Apostolic Sects that are not allowed to use western medicine might decline MSG membership
- mothers with unsupportive husbands or husbands that lack knowledge on HIV/AIDS and PMTCT may not receive permission in order to join MSGs
- mothers may be required to obtain permission from in-laws which may not be forthcoming
- mothers that have responsibilities for caring for young children may be unable to join
- mothers may decline membership because they fear stigmatization due to their HIV status
- political instability and factional disputes may deter some mothers from joining MSGs

One woman holding a negative viewpoint stated: “...women don’t have authority to join or participate in support groups; even though they are encouraged by other people and want to join; they have to consult their husband or in-laws; if these refuse, they won’t join ....”

Mothers were asked about their views concerning receiving short messages on their cell phones. Overall, 42/54 (78%) were in possession of cell phones and 53/54 (98%) considered it acceptable to receive calls about MSG activities and that their husbands would accept them receiving such calls.

Mothers were positive about the possibility of being visited in their homes by other mothers as a means of offering much needed psychosocial support that was generally lacking during clinic visits. One nurse stated “ ... women will inform each other about the disease and encourage one another to adhere to the PMTCT programmes .Women also get a chance to share experiences and relieve each other’s burden. Team work will also help reduce stigma....” One concern that was raised related to the demeanour of the mentor who might have contact with the mother. Nurses emphasized that the mentor should respect issues of confidentiality and should avoid involvement in private or family issues. Some respondents felt that some mothers would prefer not to receive home visits.

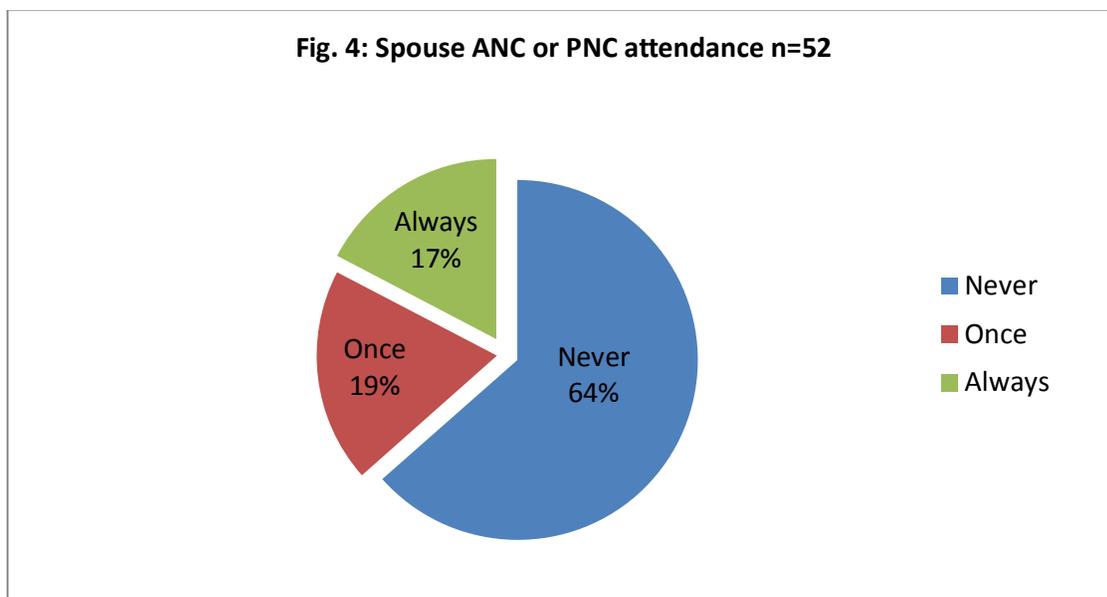
### Conclusion and Recommendations:

1. Thorough training of MSG coordinators and clinic nurses will be necessary
2. There is need to develop client feedback mechanisms to ensure that complaints raised if any by clients against MSG Coordinators are addressed

3. There is need to establish systems to manage and monitor the activities of MSG Coordinators
4. Systems to document complaints and assess whether mentors have acted in accordance with written MSG implementation policies need to be established
5. Community engagement and social mobilization for mentorship activities will be required to reduce stigma and discrimination linked to mentorship visits.

#### 4.2 Disclosure, male participation in PMTCT services and male support for MSGs

Women predominantly stated that their husbands/ spouses were not interested in accompanying them to ANC and PNC appointments. In the sample of HIV-positive women surveyed, 36% had spouses who had accompanied them on a visit (Fig. 4). Men accompanied their wives to provide psychosocial support, for protection or to provide transport.



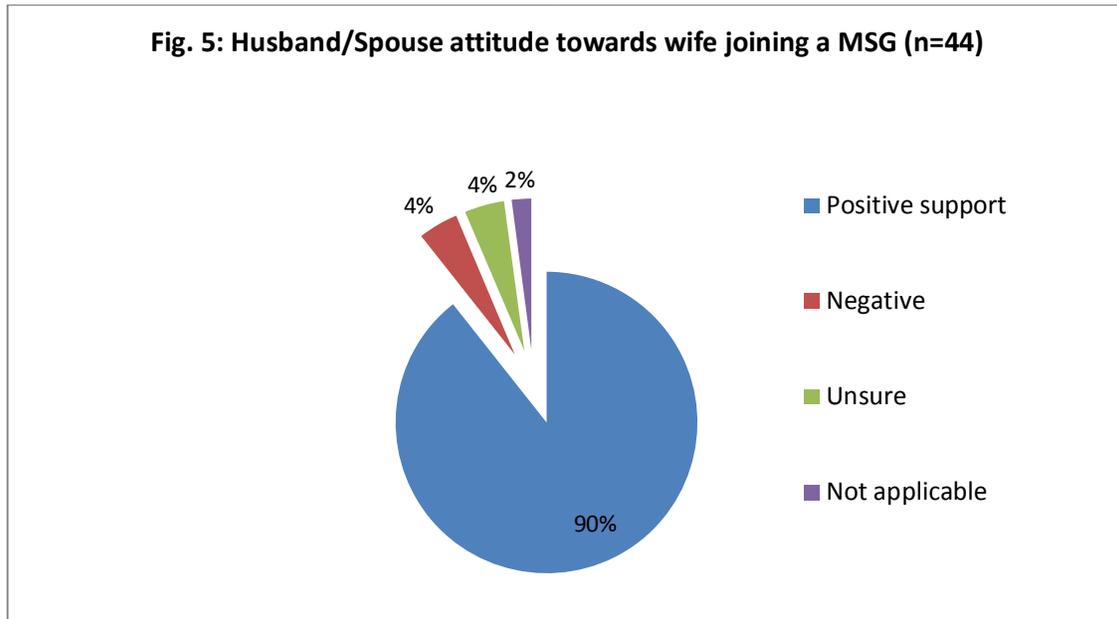
Men over 40 whose spouses had delivered some years before were unlikely to have accompanied their wives to appointments. But younger men often wanted to gain a better understanding of the services being offered their spouse. One man accompanying his wife on a clinic visit stated he was *"... excited about his first child and wanted to know and understand what happens at the clinic..."*

The number of men accompanying their wives on ANC and PNC visits in Makoni district has recently increased. This followed a directive from Chief Makoni who told traditional leaders to instruct husbands to accompany their wives during visits or else face sanctions.

Amongst HIV-positive mothers in the study, some 90% said their husbands/spouses would encourage their participation in MSGs (Fig. 5). Marital status, spousal disclosure and the degree of spousal support emerged as predictors of future MSG participation. For married women, husband support, especially financial support, was viewed as a critical determinant for their participation. Failure of women to receive support was likely to reduce the likelihood that they would participate in MSGs.

Husbands who knew their wives had been tested for HIV and were aware of their HIV status would continue to support their wives by allowing them to join the MSG which would promote positive health outcomes for the mother and baby. Women who had disclosed were more likely to feel free to invite men to MSGs. In contrast, women who had not disclosed their status to their partners

were likely to be equivocal about joining the MSG because of the need to seek approval from their partners. They would not feel comfortable inviting their husbands to the MSGs either.



Women frequently described their spouses as being distant PMTCT promoters who did not wish to have a personal and direct engagement in PMTCT issues. They were projected as being interested in the health of their children but less interested in their own health. Women stated their husbands would accept their wives' involvement in the MSGs provided that they did not insist on their spouse joining the groups. Men interviewed during the study confirmed this perspective.

Men were considered as being instrumental in allowing their wives' participation in the MSGs. Some married women stated they would consult their husband before joining an MSG. Other women expressed that they would join MSGs without consulting their spouse. One respondent concluded *'....the majority of women are free and have the power, ability and authority to join MSGs without restriction even if the husband doesn't want them to, especially those who are positive, because after accepting their HIV status they work closely with health workers adhering to what they are told by the health workers and do not need to consult their spouse.....'*

Men seem to be pulled in different directions between competing societal expectations concerning male participation. The expectation that men should attend PMTCT appointments seemed to be at loggerheads with other community and household expectations of men as breadwinners. Though some religious and traditional leaders encouraged male participation in ANC and PNC, others actively dissuaded men from accompanying their wives on clinic visits with males being severely criticized or in some cases punished by and in a certain religious sect.

Some HIV-positive mothers felt that men should simply provide support to mothers financially and encourage their spouse to adhere to medications and PMTCT schedules. Others thought that men should participate in MSG as leaders, become educated in HIV and PMTCT issues and go on to educate other men. Other mothers thought that there was virtually no role for men in MSGs - this view was more common amongst single women and those who had not disclosed their HIV status.

Though nurses were convinced of the need for greater male involvement in MSGs, many remained sceptical about whether this was possible. Male involvement was thought to consist mostly of peripheral and indirect activities such as financial support to enable women to attend MSGs rather than men actively participating in MSG sessions or actively receiving information. Some nurses doubted the practicality of men attending MSGs; one nurse stated: *“...men are unreliable and have other commitments as breadwinners and so may fail to attend MSGs as expected; this may hinder smooth running of MSGs...”*

More than half of nurse respondents considered that male participation might discourage other women, especially single or divorced women, from attending. But while male involvement with MSGs was considered potentially problematic, their direct participation was viewed as important to improve PMTCT outcomes if men could be successfully integrated into MSGs.

### **Conclusion and Recommendations:**

Men were generally not viewed as a serious hindrance or threat to MSG functioning. What was critical was to encourage men to attend MSGs by ensuring that sessions were at convenient times and of appropriate durations, to address stigma and discrimination and to ensure that groups remain sensitive to the needs of single, divorced and widowed mothers

Since disclosure to spouses is a predictor of participation in MSGs, the project should devise MSG strategies and systems that promote spousal disclosure and male involvement

Since the issue of male involvement in MSGs is contentious in view of the different situations of HIV-positive mothers, it is proposed that no policy be established concerning male involvement in MSGs prior to MSG establishment. After MSGs have been established, those seeking to promote male involvement should be encouraged with the proviso that they seek to be sensitive to the needs of single, divorced, and widowed mothers and those mothers who have not disclosed their HIV status. The project will subsequently document experiences of male involvement in MSGs so that policy guidelines can be developed prior to the conclusion of the EPAZ study.

MSGs should be led by women, with male involvement in MSGs being a women-controlled activity. It will be important to map all community support structures during baseline assessment of clinics prior to enrolment of mothers in the EPAZ study in order to recognise confounders that might influence study outcomes. These community groups might be detrimental to the establishment of MSGs if the existing groups are dominated by men since:

- i. Male leadership of existing groups could be an impediment to the establishment and functioning of MSGs.
- ii. Single, divorced and widowed mothers may feel uncomfortable joining MSGs if these are dominated by men

There will be need for MSGs to engage in intensive public campaigns, community based mobilization and mobilization for support on men and male forums if men are to become involved in MSG activities.

### 4.3 Health Sector Involvement

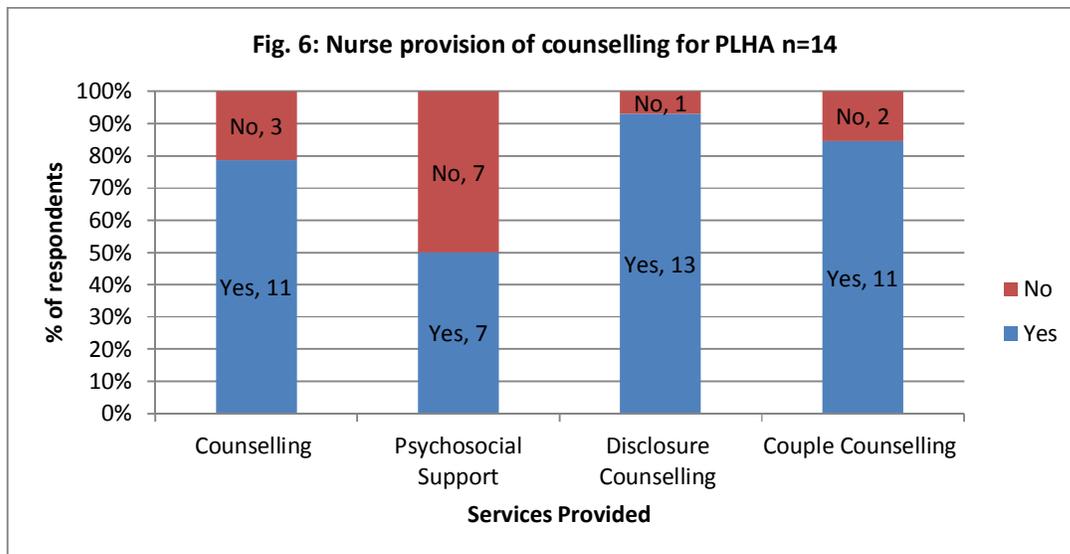
No MSGs or other groups providing PMTCT specific services were identified through the study; some non-facility-based HIV support groups provided services to the general population. Most nurses interviewed stated they were knowledgeable about MSGs, with nine of 14 nurses (64%) responding affirmatively to the question “Do you have any knowledge about MSGs?” But only one nurse had experience of running an MSG. It seems that most nurses were describing support groups for people living with HIV when they affirmed their understanding of MSGs.

Nurses were confident of their ability to provide counselling services to people living with HIV (Fig. 6). But they pointed out the need for additional space, extra skills, time and external support for them to adequately host MSGs in their facilities. The provision of services was determined by client flow patterns; staff establishment; mandate and skills to provide services; and infrastructure.

**Client flow pattern:** Nurse capacity to adequately provide PSS was determined by the rate and pattern of daily client flow. Low volume sites with small staff complements noted that counselling services might need to be terminated prematurely or postponed should nurses deem it necessary to attend patients requiring medical treatment.

**Staff establishment:** Primary Counsellors (PCs) were identified as being the key MOHCW cadre supporting MSG functioning. Clinics with PCs were considered to be better able to offer counselling, disclosure counselling and PSS compared to those with no PC in their establishment. It should be noted that only about 5% of the clinics interviewed had a PC as part of staff establishment.

**Mandate and skills to provide PSS:** Lack of capability of health workers to provide PSS to HIV+ clients was noted in more than half of the sites interviewed. Some nurses considered counselling to be an activity that was beyond the scope of their daily work and not part of their mandate since this was beyond their capacity and training. Exceptions were amongst the few nurses who had had received training from external agents. PSS was sometimes provided by external agents such as NGOs. In most cases, where PSS was provided by someone other than the PC, this was through an NGO such as Family AIDS Caring Trust or the Catholic Diocese (DOMCAPP), or through church organisations such as the Seventh Day Adventist, Anglican and Methodist churches. Fig 6 below outlines interviewed nurse response and therefore capacity to provide various facets of counselling support to the community particularly for PLHA.



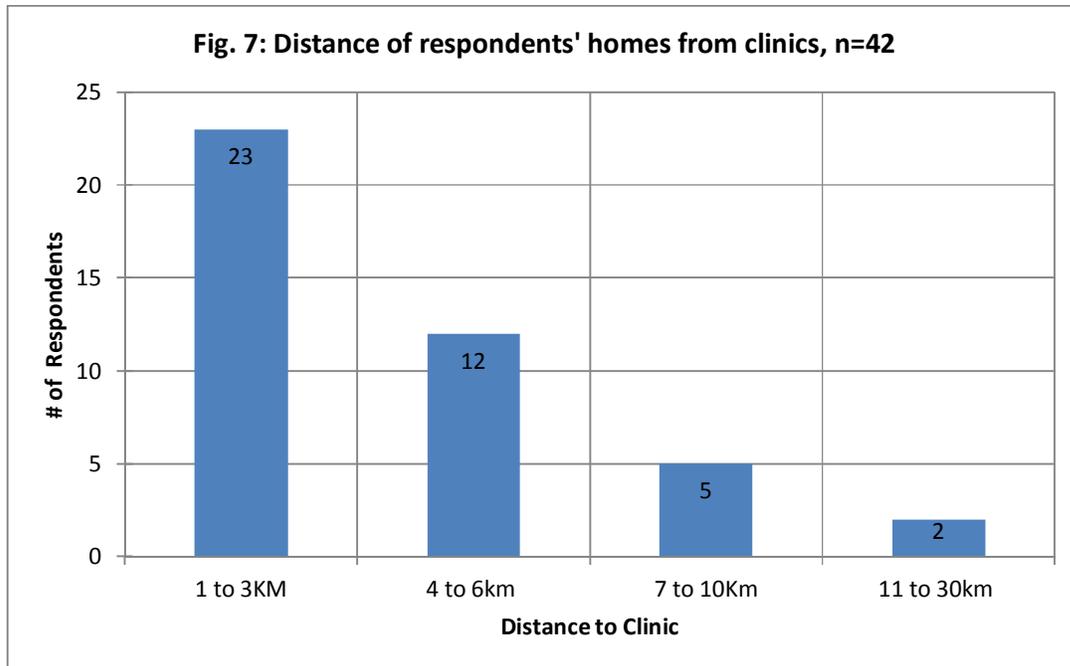
**Infrastructure:** A shortage of accommodation for the provision of counselling was noted. Most high-volume sites sampled lacked space for pre- and post-testing counselling services. Single rooms were used for many functions, such as PSS, counselling, ART adherence, PMTCT record keeping, laboratory and HIV testing and as an office for the counsellor. Disturbances and issues of confidentiality were likely to be compromised under such circumstances forcing the clinics to abandon or skip some of the crucial activities important for support to HIV+ clients. One nurse stated “...the shortage of space and time forces us to relegate psychosocial support to the periphery...”.

#### Location of MSGs

Some 20% of women respondents indicated that they had delivered their last child at home or at another facility other than their local clinic. The median distance of women’s homes to the clinic was about 2.5 kilometres (Fig. 7). Most women stated that the distance was manageable in accessing health services since clinic visits were visited infrequent. The issue of distance from clinics somewhat shaped responses on possible location of MSGs.

The majority of HIV + mothers interviewed approved of MSGs being situated at local clinics. One mother stated “...nurses are not always available to give us information, therefore the mothers would help each other; the nurse can be called to answer any questions the mothers might have”.

Another lady stated, “....it is a good idea to situate the MSG at the local clinic because it is a central point where people conglomerate, hence it is accessible to every mother...” Others added: “... the group will have direct contact with nurses who will be able to help with knowledge on areas they do not understand deal with any misconceptions in the group...”; and, “... Situating the MSG at the clinic has the advantage that new members identified at the clinic can easily join. The clinic also has adequate infrastructure which MSG members will be able to use...”



While locating MSGs at clinics was generally accepted, a few women challenged this idea. One woman complained that, “...Meeting at clinics will increase walking distance of mothers, it is best that mothers meet regularly at their respective villages and then meet at stipulated but less frequent times at the local clinic....”.

**Conclusions and recommendation:**

- i. There is need for awareness-raising of both health workers and community members on the purpose of MSGs. with specific emphasis on the limited objectives of MSGs in relation to PMTCT programming. In particular, PCs should be trained in MSG implementation.
- ii. A manual guiding the operations of MSGs should be produced for the EPAZ study to ensure uniformity of MSG functioning and reduce the likelihood of MSGs functioning outside the intended service delivery model,
- iii. Critical staff and space shortages have a bearing on clinic capacity to provide counselling and PSS. These issues require long term solutions that are beyond the scope of the project. Personnel shortages can be addressed by training MSG Coordinators to offer counseling support to HIV+ mothers, especially in clinics which lack PCs.

#### **4.4 Management of Mother Support Groups (MSGs)**

Nurses were asked their views concerning the management of MSGs within their facilities. Responses varied with some considering MSG management as burdensome while others considered involvement in MSGs as part of their duties. The overall consensus was that nurses identified their core business as attending to patients; MSG management was viewed as being peripheral to their main duties and mandate. Some stated they might consider involvement with MSGs at “convenient times” when their core clinical duties were completed.

One nurse stated that while she had an interest in and capacity to manage MSGs, she would rather *“..... attend to them in the afternoon when all other patients had been attended to or when pressed leave them minding their own business while I attend to patients.....”*. This pointed to the unsystematic nature in which nurses felt they could engage themselves in MSG intervention.

According to 85% (12/14) nurse respondents, outsiders should administer MSGs. Other suggested that the PC or one of the VHWs might be the right people to manage MSGs. There was need to define the extent to which nurses were to be involved with MSGs. Nurses opted for some limited role in the management of MSGs. One nurse envisaged her role to be limited to technical support, explaining matters that non medical staff would have difficulty in providing.

Community leaders concurred that the nurses were not the right personnel to provide day to day leadership of MSGs. since most clinics experienced frequent critical staff shortages. One leader stated: *“...Nurses are overwhelmed. Consequently mothers spend a lot of time in queues....”*. Another noted that, *“.....At times mothers are attended to by unqualified staff when qualified staff are on leave or have attended workshops. At times there is no nurse at the clinic to do the delivery when the qualified staff are not available leading to forced transfers. Mothers at times give birth alone while the nurse is attending other patients.*

Some nurses displayed negative attitudes against patients, and some of these were specifically directed towards HIV positive clients. One community leader complained that, *“... Nurses at times ill treat patients in the way they speak or conduct their duties making mothers afraid to come for ANC and PNC support in PMTCT.”*

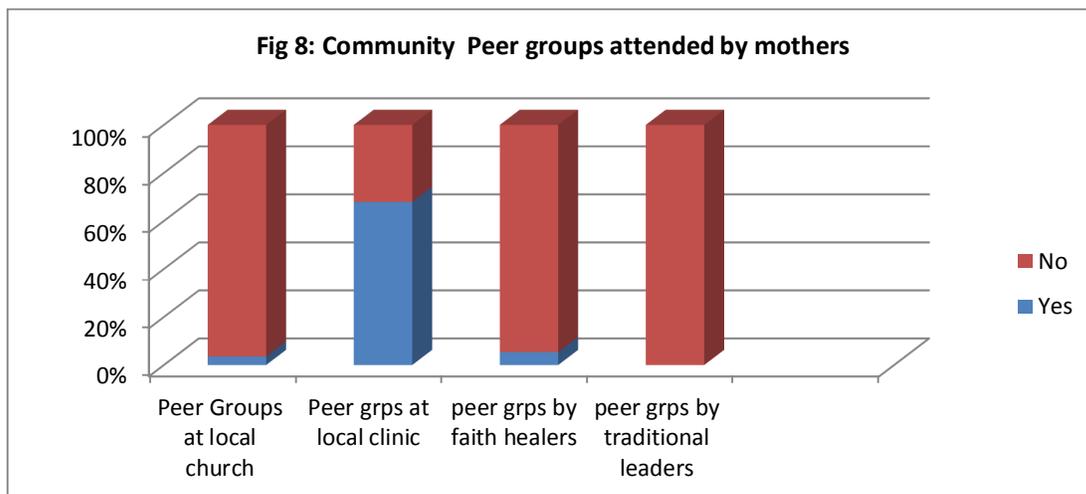
#### **Conclusion and recommendations**

- i. MSGs should be based at clinics to facilitate direct or indirect nurse support
- ii. Where possible, nurses should be given peripheral rather than central management roles in running of MSGs
- iii. There is need to limit the extent to which nurses will be involved in MSGs to critical areas of support such as offering of technical support to MSGs.

#### 4.5 Community Involvement in MSGs

Community leaders and most community members were viewed as being generally supportive towards the implementation of MSGs. Resistance towards groupings of HIV+ women might come from a minority indicating that stigma and discrimination remained an important issue. One woman commented: “...Community discriminates, stigmatizes and gossip about these women laughing at them as people living with HIV and are waiting to die, they discourage such groupings and do not accept them as they regard one’s HIV status as a secret...”

A few community support systems (Church led support and those linked to NGO HIV response) exist outside the formal health sector that HIV + mothers can tap into. These have been initiated by local groups such as churches and NGOs. However these exist in only a few localities and do not systematically provide continuous support to pregnant HIV+ mothers. About 15% of women indicated that they attended such groups for further support related to their HIV+ status. Women respondents stated that they obtained peer support through visits to churches, local clinics and faith healers. Slightly less than half of these women were members of groups set up at church and clinics (Fig. 8 below).



Nurses indicated that churches might compromise MSG activities. Some church sects such as the Vapostori discouraged involvement by their members in formal health sector activities because of their religious beliefs. Consequently, home deliveries were said to be common. Other churches such as Seventh Day Adventist, Methodist and Anglican were identified as already involved in promoting health sector engagement and some were providing education and psychosocial support to people living with HIV.

Most HIV+ women and community leaders stated the need for sustainable livelihood projects to be part of MSG interventions. Suggested activities included sewing, gardening, poultry livestock keeping, soap making, flea markets and dress making.

#### Conclusion and Recommendation

The standard MSG activities that are planned for the EPAZ project focusing on retention, adherence and psychosocial support, does not include other dimensions of what respondents would desire such as income generating projects. It will be important to explore how the planned MSG model may

link with or encourage the development of community-based HIV support services. It will also be important to map all community support structures during baseline assessment of clinics prior to enrolment of mothers in the EPAZ study.

## 5. Conclusion

While there are different types of MSGs that exist, there is a general consensus that MSGs may provide a valuable service to HIV positive mothers and their exposed infants attending antenatal and postnatal PMTCT services. Respondents generally agreed that MSGs may be appropriately established at local clinics and that nurses might play supportive roles in their functioning. Differences in acceptance of and confidence in MSGs seem to be largely the result of concern about inadvertent disclosure by some married women and about male involvement by some single women. On the part of health workers, the key issues related to their ability to provide support to MSGs given their existing responsibilities as health care providers. Overall, nurses welcomed the establishment of facility-based MSGs, viewing them as complementing PMTCT service provision. In addition, many respondents viewed MSGs as presenting opportunities for males to become involved in PMTCT services, though some nurses remained sceptical about the likelihood that MSGs might lead to dramatically increased male involvement. Communities leaders interviewed shared similar sentiments to that of nurses. They looked at MSGs as presenting more opportunities for health support to HIV pregnant positive mothers .

Caution therefore needs to be exercised on the position, role and interaction men will play in MSGs. On the other hand, given the apprehension raised by some nurses on MSG establishment at local clinic and their subsequent role in the newly established MSGs, nurses will need to be taken through a comprehensive MSG induction process so that their concerns can be taken into account and that appropriate activities are established. The prospect of enhanced community involvement in the formal health sector and increased collaboration between health workers and community members is in accord with primary health care principles and represents an exciting possibility, not only for the twenty or so clinics selected for MSG establishment in the EPAZ project, but also for other clinics throughout Zimbabwe if their effectiveness is demonstrated through the EPAZ intervention.