

Mother support groups



A manual for health workers and coordinators

Family AIDS Caring Trust

Eliminating Paediatric AIDS in Zimbabwe project



Acknowledgements

The Eliminating Paediatric AIDS Project (EPAZ) was established by Family AIDS Caring Trust (FACT) in 2012 in collaboration with the Ministry of Health and Child Welfare (MOHCW) and the Africa University Clinical Research Centre.

The EPAZ project is a four year implementation research project that aims to assess whether clinic-based mother support groups (MSGs) increase retention rates of HIV-positive mothers and their exposed infants in prevention of mother-to-child transmission (PMTCT) services. It also aims to assess whether point-of-care virological testing on infants increases anti-retroviral treatment (ART) initiation rates in rural clinics in Manicaland in eastern Zimbabwe.

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We hope this manual will help health workers and MSG coordinators to educate and empower mothers attending support groups based at health facilities.



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**To support, educate, and empower mothers living with HIV
about their health and their babies' health**

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Mother Support Group Information Sessions

The manual describes the functioning of mother support groups. It provides detailed information that will be provided to HIV-positive mothers during MSG sessions. The manual provides guidance to health workers and MSG coordinators who facilitate the mother support groups and who present the topics during the information sections of the meetings.

Information is presented to MSG members over a 16-week period in eight sessions. Mothers cover the whole curriculum during this time. Mothers attend the group from enrolment and graduate at six months postnatal. Mothers who attend the group regularly may repeat some information sessions. Mothers can join the MSG at any time during the 16-week cycle.

The MSG Coordinator will facilitate each meeting (Appendices 1 and 2). A health worker from the clinic will present information during part of the meeting, followed by questions and answers. The coordinator will close each session at an appropriate time.

Information sessions include the following topics and key information:

Nb	Topic	Key information
1	Mother-to-child transmission (MTCT)	<ol style="list-style-type: none"> 1. Likelihood and timing of MTCT. 2. Reducing the risk of MTCT.
2	Anti-retroviral treatment (ART)	<ol style="list-style-type: none"> 1. Why lifelong ART? 2. Adherence. 3. Monitoring. 4. Side effects.
3	Infant delivery, testing and treatment	<ol style="list-style-type: none"> 1. Delivery in health facilities 2. Infant testing. 3. Infant treatment.
4	Disclosure	<ol style="list-style-type: none"> 1. Pros and cons of disclosure. 2. Informing your partner of your HIV status
5	Positive living	<ol style="list-style-type: none"> 1. Healthy living 2. Psychosocial support 3. Prevention of transmission to partners
6	Family planning and sexually transmitted infections (STIs)	<ol style="list-style-type: none"> 1. Why family planning is important 2. Family planning products. 3. Prevention and treatment of STIs.
7	Infant nutrition and health	<ol style="list-style-type: none"> 1. Breastfeeding. 2. Artificial feeding 3. Growth monitoring and child health
8	Male participation	<ol style="list-style-type: none"> 1. Male attendance. 2. Male testing. 3. When your partner is HIV-negative. 4. Male participation in MSGs.

Session 1: Mother-to-child transmission (MTCT)

1.1 Likelihood and timing of MTCT

1.1.1 *Spread of HIV takes place during pregnancy, delivery and through breastfeeding*

1.1.2 *Most babies born to HIV-infected mothers are born free of HIV-infection*

1.1.3 *Breastfeeding is now the commonest cause of HIV infection in babies in Zimbabwe*

Without use of anti-retroviral (ARV) medicine in mothers and babies, slightly less than one quarter of babies born to HIV-positive mothers will have HIV infection soon after birth; nearly as many babies become infected after two years of breastfeeding without ARVs.

Breastfeeding is now the commonest route of transmission of HIV to babies in Zimbabwe. Pregnant mothers should be started on anti-retroviral treatment (ART) as soon as possible and continued on ART for at least the duration of breastfeeding to prevent spread of HIV.

1.2 Reducing the risk of MTCT

1.2.1 *It is possible to virtually eliminate the spread of HIV from mothers to babies.*

1.2.2 *Establishing a mother on ART soon after diagnosis reduces the risk of spreading HIV to her baby*

1.2.3 *Exclusive breastfeeding by a mother during the first six months of life reduces the spread of HIV to her baby.*

HIV-positive mothers who are taking ART at the time of conception have a lower rate of HIV transmission than mothers who start ART during pregnancy. Mothers starting ART in pregnancy preferably should continue this for life. As well as reducing the risk of HIV transmission to her baby, ART also improves the mother's health. Lifelong ART taken by the mother means more effective prevention of HIV transmission during the next pregnancy.

If mothers decide to breast feed their baby, exclusive breastfeeding reduces the risk of HIV transmission in the first six months of life. It is no longer recommended that mothers stop breastfeeding at six months. Breastfeeding may continue throughout the second year of life though there is increased risk of HIV transmission with prolonged breastfeeding.

[N.B. duration of breastfeeding is discussed in Session 7, *Infant nutrition and child health*].

DISCUSSION STARTER

Some mothers stop taking ART after stopping breastfeeding, perhaps because they consider their baby is no longer at risk and because they have no symptoms. Should mothers be encouraged to continue taking ART if they are not convinced of whether this is necessary?

Session 2: Anti-retroviral treatment (ART)

2.1 . Why lifelong ART?

2.1.1 *ART is started before people develop symptoms of HIV infection and should be continued for life*

2.1.2 *Take your ART every day. Anti-retrovirals (ARVs) frequently cease to be effective in people who do not take their ARVs every day*

By the time a person develops HIV-related symptoms, their immune system (their body's defences against illnesses) may be damaged. Therefore, ART is usually started before people develop HIV-related symptoms.

Pregnant mothers who start on ARVs should continue taking the medicine for life. HIV infection is a *chronic* disease. Diabetes is another chronic disease. ARVs and diabetes medicines that are given for chronic diseases do not cure patients of their disease. But even though the medicines do not cure patients from their disease, they do help to control the disease. If people with a chronic disease stop taking their medicine, their disease may get worse. In addition, if people with HIV don't take ARVs properly, the ARV medicines may stop working. If ARVs are then restarted, the virus may now be resistant. So the ARVs no longer work to control their HIV disease. Many people with HIV disease are now ill even though they are taking ARVs because the ARVs no longer work to control their disease.

2.2. Adherence

2.2.1 *If you forget to take your daily ART medicine, take it as soon as you remember; Make sure that you always have at least one week's supply of ARVs in stock*

The ARVs that you take each day fight against the HIV in your body. If you forget to take your ARVs and go for more than 24 hours without taking once daily ART medicine, you will not feel any different straight away. But the HIV in your body will get stronger as it starts to develop resistance against the ARV medicine. After a time, the ARVs will no longer prevent the virus from multiplying in your body because they will no longer work. But it may take several months until you start to feel ill. That's why it is important to take ARVs every day.

2.3. Monitoring

2.3.1 *Checking your CD4 count (or viral load) enables you to know that your ART is working*

Usually before you start treatment, a health worker will request a CD4 test. Your CD4 count is a measure of your body's immune functioning. The normal CD4 test level in adults is 500-1500/mm³. If it is low, this may be because your immune system is weak or damaged.

Usually, a health worker checks your CD4 count every six months. If your CD4 count falls while you are taking ARVs, this may be because you have not been taking ARVs properly, or because the ARVs are no longer effective. Viral load tests are also used for monitoring ART; if you have taken ART for longer than six months, your viral load should be less than 1000 copies/ml.

2.4. Side effects

2.4.1 ART rarely causes serious side effects; common side effects include nausea, vomiting, tiredness or skin rashes and are usually mild and get better in 1-2 weeks.

If you develop new symptoms, you should mention this to your health worker. If the symptoms are severe or if your next appointment is still several weeks away, return to the clinic early since the symptoms may be a side effect of your ARVs.

Since efavirenz can cause dizziness, it is best taken before sleep. Abdominal pain, general body weakness and difficulty breathing may be associated with tenofovir and lamivudine toxicity.

DISCUSSION STARTER

Do mothers have any experiences of how they make sure they remember to take anti-retroviral medicine every day?

Session 3: Infant delivery, testing and treatment

3.1 Delivery in health facilities

3.1.1 Deliveries performed at Ministry of Health-approved facilities by trained health workers are safer for mothers and babies than home deliveries

Adherence to PMTCT programmes includes delivery in a health facility. Worldwide, nearly half of all women who die due to pregnancy-related causes were from sub-Saharan Africa which has only 13% of world population. The main factor contributing to maternal death was failure to receive treatment by trained health workers. Maternal deaths can be prevented by performing deliveries in health facilities attended by skilled health workers.

3.2 Infant testing.

3.2.1 It is not possible to confirm HIV infection in infants under 18 months old using standard rapid testing

3.2.2 To confirm HIV infection in infants from six weeks old, blood is sent for virological testing to a laboratory in Harare. Results may take up to three months to be returned

3.2.3 Same-day HIV results may now be obtained at nearby clinics through point-of-care virological testing in babies from six weeks old (State the name of the nearby clinic).

3.2.4 Babies are at risk of HIV infection throughout breastfeeding; they should receive rapid antibody tests at nine and 18 months old

Infant testing allows infected babies to be started on ART as early as possible. Infants with HIV not started on ART have high rates of serious illness and death. Infants who are negative on testing and are still breastfeeding are at risk of being infected with HIV. They must be followed up and retested until three months after cessation of breastfeeding.

3.3 Infant treatment.

3.3.1 Babies confirmed to have HIV infection should be started on ART as soon as possible

Infants can be started on ART by health workers based at clinics with PoC testing. The medicines used in infants are either liquids or sprinkles (dispersible tablets). They are usually given twice daily. As babies get bigger, the amount of medicine must be increased.

DISCUSSION STARTER

Do waiting mothers' shelters increase the likelihood of delivery in a health facility? How can mothers wanting to deliver in health facilities do so despite pressure from relatives?

Session 4: Disclosure

3.1 'Pros' of disclosure

- 4.1.1 *If a mother discloses her HIV status to her partner can, he can be encouraged to find out his status by obtaining an HIV test.*
- 4.1.2 *Many partners who discover their wife is HIV-positive become more supportive to her*
- 4.1.3 *If a partner discovers he is HIV-positive, he can be started on ART; when husbands and wives both receive ART, they are more likely to adhere to treatment*
- 4.1.4 *The partner who finds out he is HIV-negative can take measures to prevent himself becoming HIV-infected*

Most women are positive about their course of action after disclosing their HIV status to their partner. As a result of disclosure, many women have fewer symptoms of anxiety and depression and are better able to join support groups and obtain more psychosocial support.

4.2 'Cons' of disclosure

- 4.2.1 *After disclosure, the partner may accuse his wife of marital infidelity, leading to domestic violence, increased extra-marital sexual partners, separation and divorce*
- 4.2.2 *The partner who finds out he is HIV-negative and is in a discordant union may decide to separate from or divorce his HIV-positive wife leading to loss of economic support*
- 4.2.3 *The mother who discloses her status may be rejected by the husband's family*

Some women experience negative outcomes after disclosure to their partner of their HIV status, including blame, anger, stigma, depression, violence, and abandonment.

4.3 Informing your partner of your HIV status

- 4.3.1 *Mothers wishing to disclose their HIV status to their partner can be helped to do so in ways that reduce the likelihood of discrimination, separation or violence*

Some mothers disclose their HIV status to their husband in the presence of a friend or relative (e.g. a sister or mother), a health worker or member of a support group. The fear of disclosing is real but the experience of many mothers is that though they expected a negative reaction from their husband or partner, they experienced positive support as a result of disclosure with little subsequent blame or quarrelling.

DISCUSSION STARTER

How do different mothers disclose their HIV status to their partner, relatives or friends?

Session 5: Positive living

4.1 Healthy living

5.1.1 The way we live influences our health both positively and negatively.

5.1.2 Healthy living for mothers with HIV involves good nutrition, getting enough exercise and rest, avoiding harmful substances and seeking early medical attention if you develop new or severe symptoms

Positive living involves a healthy lifestyle to assist your body's immune system to fight against HIV infection. Good nutrition involves eating additional food (by increasing size per helping and adding snacks between meals), a balanced diet including carbohydrates (e.g. sadza, bread, rice), proteins (e.g. beans, eggs, meat, fish, nuts) and fats (e.g. margarine, oil, avocado) together with 3 or more daily servings of fruit or vegetables.

Avoid any alcohol during pregnancy and excessive alcohol thereafter; avoid smoking cigarettes or mbanje

5.2 Psychosocial support

5.2.1 It often helps to talk to others who are knowledgeable and that you can trust about your concerns

Depression and excessive anxiety have negative impacts on our ability to function and can be reduced through talking about concerns either as a group or with trusted individuals. Psychosocial support addresses the ongoing psychological and social concerns and needs of HIV-positive mothers, their partner and their family. Mother support groups provide an opportunity for HIV-positive mothers to learn, ask questions and share their experiences concerning HIV infection.

5.3 Prevention of transmission to partners

5.3.1 Avoid sex with anyone other than your regular partner; if you have sex with someone else, use a condom and ensure your partner knows your HIV status

Disclosure remains one of the most effective preventive measures against the spread of HIV infection. It is important that HIV-positive people who have sexual contact with HIV-negative people are receiving ART as treatment is an effective form of HIV prevention.

DISCUSSION STARTER

What are mothers in the group most worried about regarding their HIV infection?

Session 6: Family planning and sexually transmitted infections

6.1 Why family planning (FP) is important

Preventing HIV infections in children also involves preventing unintended pregnancies in HIV-positive women; this involves counselling couples and enabling access to FP products

6.1.1 *Breastfeeding reduces the likelihood of a mother becoming pregnant but is not a completely reliable method of family planning especially after six months postnatal*

6.1.2 *An alternative method of FP is not necessary until six months postnatal provided:*

- a. *the mother has not had return of menstruation,*
- b. *she exclusively breastfeeds and*
- c. *she does not have prolonged periods of not breastfeeding at night or by day*

6.1.3 *From six months old (or before in some cases, see 6.1.2), a reliable modern method of family planning should be established*

6.2 Family planning products.

6.2.1 *Modern family planning methods are preferred for breastfeeding mothers*

- a. *daily progestin only contraceptive pill*
- b. *monthly injectable progestin*
- c. *two small 'Jadelle' rods containing progestin implanted in the arm*
- d. *condoms – these have the advantage of also preventing the spread of STIs*

6.3 Prevention and treatment of sexually transmitted infections (STIs)

6.3.1 *STIs are more common in partners of pregnant and breastfeeding mothers*

6.3.2 *Genital discharge, ulcers and pain on passing urine may indicate STIs in the mother or her partner requiring them both to receive antibiotic treatment*

STI's are more common in pregnant and breastfeeding mothers. If your partner has an STI, you need to be screened and/or treated for the STI even if you have no symptoms.

Discussion starter

What can pregnant or breastfeeding women do to reduce their risk of acquiring sexually transmitted infections as a result of their husband's sexual behaviour?

Session 7: Infant nutrition and child health

7.1 Breastfeeding

Most HIV+ mothers in Zimbabwe choose to breastfeed their babies in view of the expense of formula feeds and the complications associated with artificial feeding such as diarrhoeal disease, malnutrition and pneumonia.

- 7.1.1 *Mothers who decide to breastfeed should start as soon as possible after delivery*
- 7.1.2 *Exclusive breastfeeding involves no sweet drinks, porridge or other solids until six months old and leads to reduced HIV and other infections in babies*
- 7.1.3 *Breastfeeding should continue into the second year of life and only stop once a nutritionally adequate and safe diet, without breast milk, can be provided*

7.2 Artificial feeding

- 7.2.1 *Replacement feeding with formula prevents HIV transmission but is associated with unacceptably high sickness and death rates for most babies in Zimbabwe*
- 7.2.2 *Porridge should be started at six months old; the amount should gradually increase and the frequency up to 3-4 times per day with high energy supplements such as margarine, oil or peanut butter being introduced*

7.3 Growth monitoring and child health

- 7.3.1 *Infants under one year should be weighed each month; for the first six months of life, infants' weights should increase each month by between 500 and 1000 gram.*
- 7.3.2 *HIV-exposed babies who become ill should be taken to a clinic for assessment by a health worker early during the course of the illness in view of the possibility of complications*
- 7.3.3 *Infants should receive a full course of immunisations in the first year of life, including BCG soon after birth, oral polio, pneumococcus and pentavalent vaccine (diphtheria, tetanus, pertussis, hepatitis and hemophilus) at 6 weeks, 3 months and 4 months and measles vaccine at 9 months old.*

Discussion starter

Breastfeeding in the second year of life carries a continued risk of HIV transmission; how should mothers decide that it is safe to stop breastfeeding to reduce the risk of HIV transmission yet ensure that their infant continues to grow well?

Session 8: Male participation

8.1 Male attendance.

- 8.1.1 *Male partners should be encouraged to attend antenatal and postnatal appointments with their wives*

Some men who physically accompany their wives to clinics then fail to accompany them during their wife's PMTCT appointments. Partners need to be encouraged to attend appointments with their wives so they can understand HIV- and pregnancy-related issues.

8.2 Male testing

- 8.2.1 *Male partners should be tested for HIV. If the partner is HIV+, he should also start ART; husbands and wives who are both on ART are more likely to remember to take their medicines*

8.3 When your partner is HIV-negative.

On testing, some men are found to be HIV-negative even though their wife is HIV-positive.

- 8.3.1 *HIV-negative men should take measures prevent himself becoming HIV-infected*
- a) *by using condoms during sexual intercourse with his wife*
 - b) *by avoiding contracting sexually transmitted infections*
 - c) *by obtaining male circumcision that reduces the risk of HIV transmission.*
 - d) *by ensuring that his wife consistently takes ART;*
 - e) *the exposed partner should check his HIV status every six months*

8.4 Male participation in MSGs.

- 8.4.1 *Couples attending ANC/PNC appointments may wish to establish couples support groups for HIV-affected couples.*

Discussion starter

Do you think men should attend mother support groups? Or should a separate couples' support group be established at this clinic so that husbands and wives can attend together?

APPENDIX 1: Format of mother support group meetings

Meetings are usually led by the MSG coordinator. A health worker will usually provide information to group members. The following activities take place each MSG meetings

No	Activity	Description of activity
1	Start with prayer	A member of the group will be asked beforehand to lead the prayer.
2	Welcome new members	Introduce mothers who have joined the group for the first time
3	Outline the aims of the group (Appendix 3)	<ol style="list-style-type: none"> 1. To promote attendance at antenatal and postnatal appointments 2. To encourage adherence to ART by mothers 3. To promote male partner disclosure, testing and treatment 4. To empower HIV+ mothers health and their baby's health
4	Reinforce confidentiality	Remind members of the group that personal information shared by members during the meeting should not be repeated outside the group. This allows members to share openly, knowing that confidentiality will be respected and reduces discrimination against people living with HIV.
5	Explain retention activities (Appendix 2)	<ol style="list-style-type: none"> 1. A reminder is sent to members before each MSG meeting 2. Non-attending members receive a reminder message or call 3. Persistent non-attending members may receive a home visit 4. Mothers unable to attend are asked to inform the MSG coordinator
6	Celebrate members' new babies	Babies recently born to members (present or absent) should be acknowledged and new babies present in the group welcomed. Reinforce the need to obtain PoC testing at 6 weeks at a nearby clinic.
7	Acknowledge HIV results of babies.	Invite mothers who are willing to share the HIV result of their baby. Most babies will be HIV-negative – sharing this result reinforces the elimination goal of the PMTCT programme. Mothers whose babies are HIV-infected should be supported
8	Celebrate graduations; remind members of graduation policy	Mothers who are 6 months postnatal and about to leave the group should be recognised. Those completing 8 sessions receive a graduation certificate. Those completing less than 8 sessions receive an attendance certificate. (Appendix 3). At graduation ceremonies, reinforce the “mothers graduate from MSGs at 6 months postnatally” message.
9	Introduce the information topic	The information section may be facilitated by a health worker who is able to answer questions on the topic by group members.
10	Next MSG meeting	Remind members of the date, time and subject of the next meeting.
11	Close with prayer	A member of the group will be asked beforehand to lead the prayer.

APPENDIX 2: Retention activities

Retention means keeping (or “retaining”) HIV-positive women and their exposed babies in monthly antenatal and postnatal appointments for elimination of mother-to-child prevention programmes.

- A. For pregnant women, this means that they stay in care during pregnancy and throughout the duration of breastfeeding (or at least until 12 months postnatal).
- B. For HIV-exposed babies, this means staying in care until at least three months after stopping breastfeeding and their final infection status can be determined (or until at least 12 months postnatal).

Mother support group coordinators will be responsible for carrying out a standard set of retention activities to maintain mothers and exposed infants in PMTCT follow-up by health workers at clinics.

Table 3: Retention messages and calls by MSG Coordinator to MSG members

No	Message recipient	Title of message	Message / Phone Call	When message sent
1	All members of MSG	Reminder	<i>“The next meeting of the mothers’ group is on (day) (date) at (name of clinic)”</i>	Weekly (e.g. each Sunday)
2	Mothers missing one group meeting	One missed attendance	<i>“We missed you yesterday at the mothers’ group. Please visit the clinic this week if you also missed your antenatal / postnatal appointment”</i>	Day after missed attendance #1
3a	Mothers missing more than one group meeting	Several missed attendances	<i>“We missed you again at the mothers’ group. Please visit the clinic this week if you also missed your antenatal / postnatal appointment”</i>	Day after missed attendance #2 or more
3b			Phone call to find out reason for non-attendance and to encourage retention in support group and continued ante- / post-natal attendance	

1. The MSG Coordinator sends each mother who is a member of the MSG an SMS (text message) reminder before each support group meeting (Table 3)

2. A member who does not attend a support group meeting will be sent a subsequent SMS reminder usually on the day after the missed meeting
3. If a mother repeatedly fails to attend support group meetings she will be sent repeated SMS reminders. In addition, the MSG Coordinator will attempt to contact her by phone. She will inform the sister-in-charge of repeated non-attendance. The MSG coordinator, another member of the MSG or a village health worker may conduct a home visit.,
4. A mother who is unable to attend an MSG meeting or scheduled ANC/PNC appointment is asked to communicate this information by SMS to the MSG coordinator
5. No message or communication will enable a mother to be identified as being HIV-positive. When a phone call is made, the Coordinator should first confirm that the client in question is the person speaking on the phone.
6. If a mother does not have a cell phone, she will be asked to provide a contact number of a friend or relative that can be used to send reminders and make calls
7. If no contact number is provided, follow-up activities will consist of home visits by a village health worker, the MSG coordinator or another member of the MSG.

The MSG Coordinator will meet regularly with the Sister-in-Charge who will provide support in retention activities (see chart below).

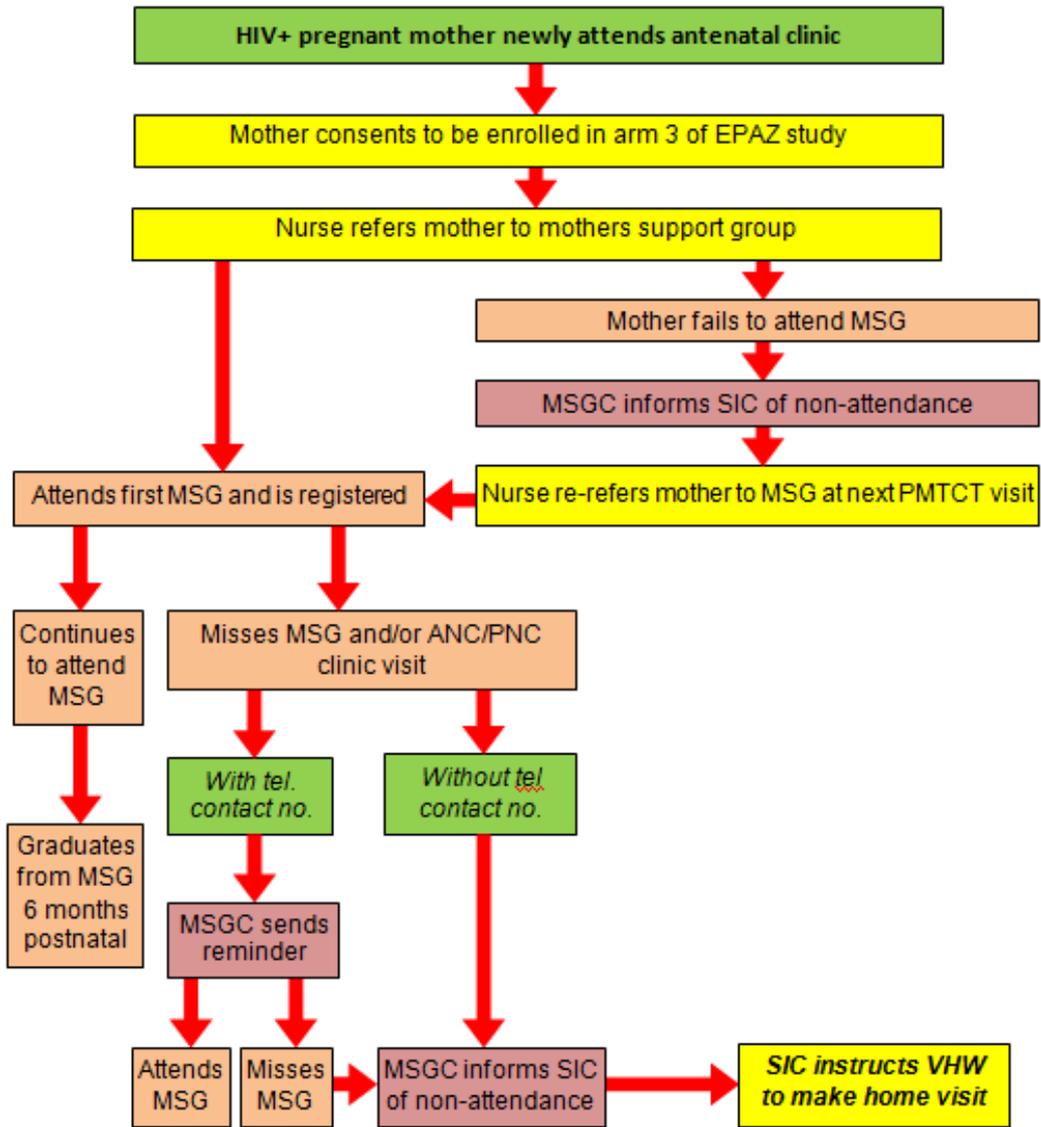


Chart 1: Retention activities of MSG Coordinator and the Sister-in-Charge

Appendix 3: Aims, membership and graduation from mother support groups

1. Aims of mother support groups

Mother support groups have the following aims:

- A. **Retention** : To promote attendance at antenatal and postnatal appointments
- B. **Adherence**: To encourage adherence to ART by mothers
- C. **Disclosure and male participation**: To promote male partner disclosure, testing and treatment
- D. **Psychosocial support**: To empower mothers to make decisions that improve their own and their baby's health
- E. **Feeding support**: To support feeding decisions that mothers make that maintain the health and nutrition and that prevent HIV transmission to their babies
- F. **Family planning uptake**: To encourage access of mothers to modern family planning products

2. Joining mother support groups

HIV-positive mothers who are pregnant or breastfeeding are invited to join the support group. They may be identified as being HIV-positive during pregnancy or breastfeeding. They may initially decline to join the group and then later change their mind and decide to join the group later.

Mothers whose HIV status is unknown and who decline testing may wish to join the group. Mothers who know they are HIV-negative may request to join the group. Though the group is predominantly for mothers who know they are HIV-positive, other mothers may exceptionally join the support group.

3. Leaving mother support groups

Mothers will normally graduate from the group when baby turns six months old. This is necessary to enable new mothers to join the group. It may be difficult for mothers to leave the support group after attending every two weeks for perhaps a year. The following measures may assist mothers to leave the group:

A. Graduation

At each meeting, the coordinator reiterates the fact that mothers will graduate from the support group when their baby is six months old. When a mother's baby is six months old, she should graduate. This involves the coordinator giving the mother a certificate in front of other group members.

- I. If the mother has attended at least eight sessions, she receives a graduation certificate
- II. If the mother has attended fewer than eight sessions, she receives an attendance certificate (see below)

B. Transfer to community support group

In some cases, mothers graduating from MSGs may join community-based support groups for people living with HIV or for economic empowerment or a faith-based support initiative.

Examples of certificates of graduation and attendance



Appendix 4: Responsibilities of coordinators and health workers

A. MSG Coordinator

Attributes

1. HIV-positive mother
2. Recent PMTCT experience (6 months – 3 years)
3. Literate, numerate and mature (e.g. >30 yrs),
4. Has disclosed HIV status to partner or to one or more persons in household
5. Allows phone records to be monitored

Responsibilities

A. Group meeting responsibilities

1. Sets dates for meetings
2. Attends each meeting
3. Welcomes new members
4. Outlines aims and rules of MSGs, including retention actions
5. Celebrates new births, infant HIV results and member graduations
6. Records details of new members
7. Keeps attendance register
8. Meets with sister-in-charge each two weeks
9. Obtains list of mothers agreeing to join MSG from SIC

B. Retention responsibilities

1. Sends a weekly reminder of the support group to all members
2. Sends a reminder to attend to all mothers missing an MSG meeting within 24 hours
3. Makes a phone call to mothers repeatedly missing an MSG within 24 hours
4. Informs SIC of non-attendance at MSG of mothers repeatedly missing MSG meetings
5. Conducts or facilitates visits to non-attender homes

C. Monitoring responsibilities (Appendix 5)

1. Maintains membership register (at time of registration)
2. Maintains attendance register (at each meeting, after delivery testing and graduation)

B. Sister-in-charge

1. Keeps record of PMTCT appointments of HIV+ mothers
2. Instructs village health worker to follow up non-attending mothers
3. Registers mothers into EPAZ study and provides list to MSGC
4. Meets with MSGC every two weeks
5. Attends MSG meetings to provide technical information
6. Supervises MSGC
7. Countersigns MSGC record book each month
8. Receives complaints against MSGC or MSG members and reports

Appendix 5: Data monitoring

A. Membership register

Name of member	date of first meeting	address	Telephone access			contact tel no.	disclosure of HIV status to partner and date	Baby place of birth * (see key below)							d.o.b of baby	baby HIV status	expected month of graduation	actual date of graduation
			own	other	none			1	2	3	4	5	6	7				
Mother 1							Y / N date:								pos / neg			
Mother 2							Y / N date:								pos / neg			

B. Attendance register

name of member	date of MSG meeting	attended		action taken for non-attendance						
		Yes	No	sent SMS reminder	MSG member home visit	inform SIC of non-attendance	VHW home visit	mother died	no action taken	
Mother 1										
Mother 2										

* KEY: 1 This clinic 2 District hospital 3. Another clinic in this district 4. Provincial hospital
 5. Health facility in another district 6 Home delivery 7 Unknown