

The role of family support groups in improving male involvement in PMTCT programs

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Abstract

Involvement of spouses and families is crucial for compliance to HIV interventions including prevention of mother-to-child transmission (PMTCT), as men wield financial and social power for their families. JSI/UPHOLD, a USAID-funded program working in 28 districts of Uganda, supports Family Support Groups (FSGs) to enhance male involvement in PMTCT. Through FSGs, HIV positive pregnant mothers are supported to cope with their status and disclosure to their spouses and children. 18 Focus Group Discussions (FGDs) were held with clients enrolled with FSGs to explore members' knowledge and spouses' attitudes. Reported achievements of the initiative were: more support from men who joined FSG to their pregnant spouses; increased communication and cooperation between the spouses; better birth planning; and improved adherence to Nevirapine and infant feeding options. FSGs are a good approach for targeting couples before and after pregnancy, and women who come for antenatal care visits should be encouraged to come with their spouses.

Background

Too often in the past, men were presented as an obstacle and not as part of the solution. The majority of interventions and services to promote sexual and reproductive health, including care during pregnancy and childbirth, have been exclusively focused on women. Yet, men and women living in the same society are influenced by the same beliefs about the roles and responsibilities that are appropriate for each gender (Ntabona, 2002). During the past several years, especially since the 1994 International Conference on Population and Development (ICPD), there has been increased attention around the world on constructive male involvement in reproductive health. Reproductive health practitioners have recognized that the failure to target men in programmes has weakened the impact of reproductive health programmes since men can significantly influence their partners' reproductive health decision-making and use of health resources (Metha, 2002) it is important to understand men's behavior and their point of view because, given the gender asymmetry prevalent in most societies, they still have a dominant role in reproductive health-related decisions and outcomes (Pantelides, 2002). Men have a strong influence on women's health and their access to care (Young and Kols, 2002), male behavior is critical to preventing the transmission of HIV/AIDS and other STDs, programmes also encourage men to adopt positive behaviors such as consistent condom use and remaining faithful to a single partner.

Moreover, studies have shown that men who are educated about reproductive health issues are more likely to support their partners in contraceptive use, use contraception themselves, and demonstrate greater responsibility for their children (Grady et al., 1996). More importantly, women express great interest in wanting their partners to be involved in joint reproductive health decision-making. For example, a study in Ecuador surprisingly showed that 89% of women wanted their partner to accompany them on their next family planning visit and 94% would have liked their partner to be present during their family planning session (Roy & de Vargas Pinto, 1999; Mehta, 2002).

The need for male involvement in reproductive health is clear and male involvement is becoming even more critical in the delivery and uptake of HIV/AIDS services, including the Prevention of Mother to Child Transmission of HIV/AIDS (PMTCT).

Description of project intervention

UPHOLD is a bilateral project designed by the Government of Uganda and the United States Agency for International Development (USAID) to improve the quality and utilization of primary education, health and HIV/AIDS services in 34 districts of Uganda. for HIV/AIDS service and HIV. Under the HIV/AIDS sector, the interventions supported include: HIV Counseling and Testing (HCT), Youth and Adolescent Health, Abstinence, Faithfulness and Other prevention interventions, prevention of gender based violence, palliative care, HIV + Tuberculosis and PMTCT. The experiences drawn from the last four years emphasize the need for male involvement in the delivery of reproductive health and HIV services in general and PMTCT services in particular.

Reasons for low male involvement

Supervision reports reveal various reasons for low male involvement. Part of the reason for the low male involvement has come a long way with the traditional attitude of health workers, coupled with notices in the health care premises, for example; “Men are not allowed in the labor ward” which discourage the men from giving support to their wives while in ANC and labor.

Further, some men feel it is a duty which needs facilitation in terms of a ride, so when they do not have bicycles, they see no point in escorting their wives, both of them walking. In some instances, men who have bicycles probably as the only asset fear to leave them in unsafe places in order to be there for their wives. In this case, a safe custody for bicycles go a long way in convincing men to accompany their wives to health care facilities.

Sometimes couple dialogue may be the problem; once there is communication breakdown for one reason or the other, the whole family function fails. As well, alcohol plays an important role in keeping men away from involvement in the family affairs as most of the time they may be drunk, leaving little or no money to facilitate the needed care.

Using Family Support Groups to increase male involvement in PMTCT programs

Objectives of Family Groups

FSGs are intended to enable members to:

1. Build a personal support system through disclosure to each other, friends, relatives and partners.
2. Learn to accept and understand one's sero status and how to live life positively.
3. Make informed decisions about Antenatal Care (ANC), swallowing niverapine, birth plan and safe delivery, infant feeding and PostNatal care (PNC) and Family Planning (FP).
4. Learn how to access Anti Retroviral Therapy (ART) and help those on ART to adhere to the treatment.
5. Live positively by learning and getting linked to where to find Income Generating Activities (IGAs), food support and home care services.
6. Encourage partners to get tested for HIV and support each other in accepting and understanding one's sero status.

The process of forming FSGs

District Sensitisation

200 district health workers-who manage the public health facilities, were oriented on the concept of FSGs in 8 districts to expedite mobilization

Health Facility Mobilizes women/men for PSS Groups

In all the 8 districts, health workers and counsellors organised meetings for Ante Natal Care, HCT and PMTCT clients to create awareness about FSGs. During these meetings, participants also discussed resources needed for meetings and ways of generating them. As well, agreed on meeting frequency, days and venues.

Supervision by District PSS Coordinator

In addition to the regular FSG meetings, health workers and counsellors are involved in home visits to follow-up members that have delivered; and those that need niverapine, ART, and any other support

Mother Father/Mentor's selection and training

FSG members select peers who are trained as mentors. 48 mentors were trained-6 from each of the 8 districts. Mentors are trained to provide supportive counselling and to coordinate activities for psychosocial and material support for the members. Mentors also support health workers in conducting home visits.

A summery of steps

1. District Sensitisation.
2. Health Facility Sensitisation and Introduction.
3. Health Facility Mobilizes women/men for PSS Groups.
4. Resource mapping
5. Preparation Meeting to start PSS Group.
6. Supervision by District PSS Coordinator
7. Involvement of PSS Members.
8. Mother Father Mentor's selection and training.

FSG Discussion Guidelines

One of the objectives of FSGs is to provide information for members to make informed decisions. Six topics have been identified as essential

a) Topics

1. Review of HIV/AIDS Facts, MTCT, PMTCT and ART Information.
2. Disclosure
3. Positive Living for Mothers/Partners and Babies
4. Safe Motherhood, Birth Planning, Labour/Delivery and Post Natal Car.
5. Infant Feeding.
6. Family Planning

A typical day in a Family Support Group

- Begin with a prayer
- Introductions
- Review of objectives of the group and their expectations
- Discuss the importance of confidentiality in the group and the importance of not sharing with others outside the group
- Educational Talk – Speaker is to conduct an interactive learning session in group discussion NOT lecture.
- Refreshments determined by the group, budget and preference
- Testimonies of members
- Any other activities e.g. MDD, games etc
- Feed back from the group
- End with a prayer.

b) Teaching Methodology for PSS Groups

All sessions to be interactive through sharing experiences, discussion, brainstorming demonstration and role play.

c) Selection of Speakers

The focal person is responsible for selecting speakers who should be knowledgeable on the topics and be able to conduct an interactive talk with the group. If possible, speakers should be part of the service provision at the facility unless otherwise it necessitates

inviting somebody from outside.

d) Monitoring and Evaluation

Forms to be designed for registration, monitoring and evaluation. This enables members to review effectiveness and efficiency of group processes, and to learn from their experiences.

Program Coverage

The FSG intervention, as afore mentioned, has been implemented in 8 districts of the country. These include, Kyenjojo, Bundibugyo, Bugiri, Nakapiripirit, Wakiso, Nakaseke, Kamuli and Kaliro districts. The total number of FSGs in the 8 districts is 26, as shown in the table below.

Table 1: Number of FSGs Supported through Local Governments

District	Number of FSGs
Kyenjojo	4
Bundibugyo	4
Bugiri	6
Nakapiripirit	4
Wakiso	3
Nakaseke	2
Kamuli	2
kaliro	1
Total	26

Results of the intervention

Sources of Information

To obtain information on the success of the FSG interventions and its effect on male involvement in PMTCT programs, UPHOLD program reports were analyzed. In addition, 18 Focus Group Discussions were held with clients enrolled with FSGs to explore members' knowledge and spouses' attitudes. This was the major source of data for this paper.

The effect of FSGs on Male involvement in PMTCT programs

Qualitative reports on program implementation indicate that Peer Family Support Groups (FSG) are having a positive and symbiotic effect on male involvement in PMTCT services.

FSGs provide a way to assist women or couples to accept their diagnosis, decrease depression, reduce stigma and discrimination and increase disclosure. The groups provide fora for discussing family planning and an easy way for health providers to follow up women and or couples and seem to be cost effective because it only uses minimum resources to access a large population of HIV positive women and or couples.

Through FSGs, Counselors have often encouraged the women to ask their husbands to accompany them to the care centers, listen and be part of the care dialogue so as to be able to provide the necessary help. This attempt is beginning to yield results and gradually men are beginning to realize the importance of their support.

Sometimes counselors are requested by the women to visit their homes and convince their husbands to come and take a test which is partly accepted and partly not most probably because of the stigma that still prevail in the communities or simply fear of “if I test positive; what next”?

Some men have been invited by the health workers to come and discuss matters that concern their families and some have come and after counseling, they accept to test and joined the Family Support Groups.

However in some cases, in the long run men who have slowly begun to fall sick on and off, just voluntarily come and seek help much after their wives have been actively involved in the FSGs. In all these, disclosure has been the most difficult issue to tackle especially when women come to test first and test HIV positive. The fear surrounding disclosure is gender based violence, family break up because men tend to believe that

when a woman goes to test, she is suspicious about the infection and so could have been the ones who could have “brought in the virus”. However, when disclosure is well-done, it catalyses male involvement and once disclosure is done more tests are done in the same household

It has been observed that couples who are benefiting from the PMTCT service together seem happier in their relationship and have a more positive attitude towards their status even if both may have tested positive. In most cases men are the sole bearers of household requirement like money, decision making, sexuality and reproduction, so when they are involved, amicable discussions are held around sharing resources and couple dialogue which promote happy and positive living which essentially prolongs life for those who are infected, making way for the coming baby to enter a happy home.

Where both couples are involved, taking of Niverapine and eventually ARV becomes easy in that the couple reminds one another, and once in the group, it becomes like a larger part of the family where home visits to those who may be too ill to participate in meetings are carried out to find out reasons for abstention. HIV tests also act as point of entry for other tests like STI, TB and Malaria since the latter carry almost no stigma around them.

A success story of disclosure and Male involvement in a Family Support Group

Ms Rehema Namuwaya is a 22 year old mother of three; Sharif Katege aged 6 years, Shafik Wegulo aged 3½ years and Aisha Naigembe who is 8 months. She is a housewife married to Mr. Dan Kigenyi aged 26. Dan has another child called Dennis Isabirye aged 9 years who lives with his mother in a nearby village.

The family of five lives in Kigandalo village, Kigandalo parish of Kigandalo Sub County about 150metres away from Kigandalo health centre IV in Mayuge district, Uganda East Africa.

Dan is a seasonal businessman who is currently not at work because of lack of money. He hopes that when he gets some money he will go back to do some business in Iganga

town. He deals in sale of shoes and clothes he buys from Kampala and sells them in Iganga town.

Dan and Rehema are members of “*Tweyambe*” Family Support Group (FSG) at Kigandalo Health Centre IV which meets once every fortnight on Wednesday.

This is Rehema’s story before and Dan joined “*Tweyambe*” FSG.

Rehema went to the Health Center for Ante Natal Care in June 2005 when she was pregnant for this last child. The Mid-wives told Rehema about the availability of counseling and testing services at the center and the benefit of counseling and testing. When she opted in, she was counseled and tested. The test result revealed that she was HIV positive. She was also told about the Family Support Group (FSG), the function and the benefit of being a member. She decided to join and began attending the group’s meetings which happens once in two weeks on a Wednesday.

”The day I received my result, that same night after our supper I called out to my husband and disclosed to him my HIV status”. During Post Test Counseling, it was suggested to Rehema that it would be good if the husband could be counseled and tested so that both of them could know their status as entry point to care that may be relevant to them. He resisted saying he can not ‘go there to start worrying’; machines too can lie’; adding ‘If you want, (telling Rehema), you go for the tests since you are the one with little life’.

Dan, Rehema’s husband left her for another woman in Iganga saying he did not have HIV/AIDS.

After a long time of counseling by the health workers, Rehema’s husband accepted to be counseled and tested probably also from the suspicion and pain he had from the boil which was at the back of his neck. He also accepted to join the Family Support Group (FSG).

“I was told by my wife, Dan says about the FSG, after she had gone for Ante Natal Care, she told me that the health worker said she needs my support in order give birth with

contentment that her husband cares. I refused at first because, *Abantu bakulingiriza!*’ literally meaning, ‘People stare at you! People look at you!’”

When I got the boil I was compelled to go because I was suspicious and afraid about the painful boil I had at the back of my neck. ‘Nowadays I go for the meetings and find them useful because of the information and discussions we have although sometimes I miss some of them because of some work I might be doing in the trading centre here.

Dan also said, ‘*ebiyabakazi nabileka kubanga tebinghasa*’ meaning ‘I have left things to do with women because they don not benefit me’”.

When asked how “*Tweyambe*” (the name of their FSG) helped them, Rehema said before she joined she used to have fevers and colds but ever since she joined and has been using Septrin she was much better. Dan said that he used to suffer from malaria quite often, however, after joining the FSG and obtaining Septrin and ITN, the last time he had malaria was in June 2006”.

They also reported receiving counseling for the health workers and fellow group members which has strengthened them. Rehema added, “last week on the 18th October 2006, the health workers took our blood and explained to us that it was to be taken for examination to find out whether we are due to taking drugs for HIV/AIDS patients” meaning ARVs. “We are also told the importance of feeding the children on breast milk only for 6 months after which we start them on other feeds” Rehema said

Finally when asked what they wanted to accomplish with the rest their lives, with a stammer and in a small voice Rehema said “to die when my children have grown up from this stage and having planned something for them”. Dan said “to last longer to work for my children and I have stopped having more children. I want to build for them”.

This is one couple among many couples who can testify about the usefulness of PMTCT and all related care in the minimum package of PMTCT.

In Rakai, a woman who had delivered at home brought back her baby after 6 days for Niverapine syrup; a sign that she received quality counseling. She also revealed that she took Niverapine tablet as the midwife had told her

Recommendation and conclusion

Every district to develop an infrastructure that would allow the health facilities providing PMTCT services to create and facilitate FSGs and to allocate the necessary resource to enable the scaling up of these groups in MOH PMTCT sites.

It is also a recommendation from the MOH to stakeholders that FSGs are established throughout the country and a network of FSG for HIV positive pregnant women/ mothers and their partners are created. National guidelines to be developed for the establishment of FSG and to include a FSG support component to the counsellor training. Preliminary results of study done by AIC and EGPAF in October 2004 are showing that FSG should be an essential component of the PMTCT Program.

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