HIV prevention in South Africa:

Prevention of Mother to Child Transmission

Target Audience Formative Research

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BACKGROUND

South Africa has a high HIV/AIDS prevalence with an estimated 5.2 million people living with HIV. Despite positive gains (South Africa's epidemic seems to be leveling off) prevalence is still at 10.9%.[1] Declines in HIV rates among 14–24 year olds over the past 5 years are not reflected among older age groups, and the current level of HIV infection continues to overwhelm the health system.

Key prevention strategies must be evidence-based and should employ a combination of structural, behavioural and bio-medical interventions[2]. In southern Africa behaviour change imperatives mostly relate to safer sex including: decreasing multiple concurrent sexual partners (MCP), decreasing intergenerational sex, increasing the age of sexual debut, and increasing the consistent and correct use of condoms. Although condom use has increased substantially over the past 5 years from 57–87% and 8–40% among 15–24 and 50+ year old men, respectively, these gains are insufficient to stop the spread of HIV on their own.

Two bio-medical interventions – male circumcision (MC) and PMTCT have been identified by the South African National AIDS Council (SANAC) as key prevention priorities. Both require intensive communication strategies to ensure success.

PMTCT not only prevents HIV in children but also creates an opportunity to engage men and women at health services in further prevention and access to health care. All sexually active people need to be informed about PMTCT.[3]

INTRODUCTION

The Soul City Institute of Health and Development Communication (SC IHDC) is a social change project which aims to impact on society at the individual, community and socio-political levels. Soul City is a nongovernmental organization; it was established in 1992.

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[1] People 2 yrs and older. Shisana O, Rehle T, Simbayi LC, Zuma K, Jooste S, Pillay-van-Wyk V, Mbelle N, Van Zyl J, Parker W, Zungu NP, Pezi S & the SABSSM III Implementation Team (2009) *South African national HIV prevalence, incidence, behaviour and communication survey 2008:A turning tide among teenagers?* Cape Town: HSRC Press.

[2] Combination HIV Prevention Programs: Engaging Stakeholders to Tailor and Combine Behavioural, Structural and Biomedical Strategies to Reduce HIV Transmission. UNAIDS 2010.

[3] Second National HIV& AIDS Communication Survey. Road show presentation 2010.

The Soul City strategy is to use mass media (including television drama, radio drama and print booklets in multiple languages) combined with community education and social mobilisation to create a positive environment for social change.

METHODOLOGY

This was a qualitative national cross sectional study with adults (over 16 years). Couples and health service providers were interviewed individually. The interviews followed a pre- tested discussion guide. However the interviewing was free attitude allowing new information to emerge. The information was recorded and transcribed verbatim. It was then translated into English and analysed thematically, using rapid analysis method. 18 focus group discussions and 4 In-depth interviews were conducted in 9 provinces nationally. The research participants were from a mix of urban, rural, informal settlement and rural-informal/peri-urban residential areas. Their ages ranged from 16- 45 years old.

The groups were separated into three categories namely, special groups (women, men and couples who were in the PMTCT programme); general public men (not asked about their HIV status); and general public women (not asked about their HIV status). In addition, three interviews with the health workers and one with a young mother of a toddler were conducted.

OBJECTIVES

The research aimed:

To gain insight into target audiences' understanding, attitudes and practices relating to the PMTCT programme in South Africa

To understand the acceptability of the PMTCT interventions.

To understand challenges faced by people living with HIV around having children.

To understand any myths or misinformation about PMTCT.

To uncover barriers to accessing these prevention services.

To examine the best way to communicate these issues to both male and female audiences.

FINDINGS

The report focuses mainly on the findings from the special groups and from the health workers interviews. The general public had heard about the programme but did not have much insight into how it works and very little input came out of those groups other than their attitudes about pregnancy in the times of HIV.

PREGNANCY DURING THE TIMES OF HIV AND AIDS

WHAT IF I AM POSITIVE?

People, in general, whether they know their HIV status or not, are always keeping in mind when they find themselves pregnant that the baby might get infected. For those who don't know their status, the first thought that comes to mind is what if they have HIV –how will they make sure the baby is safe? Even those who know their status and have planned to have a healthy baby worry because they keep seeing other people losing their pregnancies through miscarriages and some having babies that are infected. Their concern is that thegeneral public is ignorant about the ways of saving unborn babies from contracting HIV and when they know that someone is positive, they expect them not have children. The study reveals that for many people pregnancy is a time of stress and regrets, especially for those who don't know their HIV status.

Some people, however, know that it is possible now to have an HIV free baby if you do test on time and follow the Prevention of Mother to Child Transmission programme (PMTCT).

> *F: I think about how you don't know your own status and you've fallen pregnant. For many of us the thoughts come to you, even if you have not tested: what if I'm HIV positive? What will my baby be like? And even when you are on the PMTCT programme, it does come to you to ask, will my baby really be safe or after I have this baby, what will my health be like? Will I survive long enough to take care of this baby? What will I do? (F 25-35; MP urban)*
>
> *You sometimes get stressed thinking what if your child gets infected? And in my case I was scared of infecting my husband with HIV but all that did not happen; everything went well. (F 25-25; WC urban)*
>
> *M: And sometimes you see many people who are HIV positive getting miscarriages. You don't stop asking yourself what will happen to your girlfriend if she falls pregnant. Those things are scary because the reality is that many people who get miscarriage are HIV positive. (Couple 34-36; NW rural)*
>
> *F: I think it is a big risk to be pregnant especially now because we have HIV and AIDS unless if you trust your partner I think is important for all people to test, even if you do not want to have a baby. It is important to know your status, to know where you stand. (Teenage mother- MP urban)*
>
> *My views are people now can fall pregnant while they are HIV positive and give birth to HIV negative babies and that is only if you got tested for HIV in time and received treatment to prevent your baby from being infected. (F 25-35; WC urban)*

CHILDREN ARE IMPORTANT IN LIFE

Many participants in all the group discussions felts that having a child is an important need felt by every adult so, although people are aware of the challenges HIV brings into their lives they will not stop trying just because they know that they have HIV. They said that now that it is possible for people to live with HIV for a long time because of treatment, it would not make any sense and it would be unfair to expect those living with HIV to write off thoughts of having children of their own. Some married couples are encouraged by their parents to at least have two children when they find out that they have HIV. They said that they welcome the programme that would help people living with HIV to have healthy children.

> *M: We both decided with the influence of our mother to have at least two babies while we are still healthy....-F: In Swati culture children are very important to have in a marriage. its dangerous to have only one child because if something happens to him/her or he/she dies you will be left with nothing so if you have two or more its good... (Couple 30-32; MP urban)*

> *M: People don't understand; you see, having HIV does not mean that you are going to die. So I thought that what if I don't die and live until I am old? Am I going to die without having a child? I decided that I wanted to have a child and I will do anything to make sure that my child is healthy and does not get HIV. (Couple 34-36; NW rural)*

> *W: When I discovered that I was like this (HIV positive), I decided that I don't want to have children anymore. You see the good thing is that I already had two children when I discovered. So can you imagine someone who does not have children at all? They want to have children and it will be unfair if we say because they are HIV positive they shouldn't have children. (F 20-30 NW rural)*

THERE IS A PILL THAT BRINGS HOPE

In all the groups the participants said they know of or that they have heard about the pill that can help women who are pregnant and have HIV to deliver babies without HIV and some were aware that there are ways of making sure that the baby does not get infected after it is born. Some of the participants told of their success stories or of other people's stories that managed to go through the PMTCT programme and had HIV negative babies. They said there was no cause to worry anymore, as long as people follow the guidelines of how to plan for pregnancy and live a healthy lifestyle. Some of the women had been through the experience of transmitting HIV to their babies because in the past there was nothing they could do. They said when they found out that they were pregnant again they wanted to make sure that this time round, their babies would be fine.

W: Unlike in the past there is hope now. I mean there is the pill, nevirapine for all women who are positive and are pregnant. That pill is important because it protects children from getting the virus. (F 20-30 NW rural)

What encouraged me to go for PMTCT was my past experience with my first child, I didn't want to go through what I did the second time around; I told myself I will make sure my second child won't get infected and I was told of the PMTCT programme so I attended the programs and now I have a HIV negative child…my first child is also well; healthy and doing fine. (F 25-35; WC urban)

F: I think it's right because these days you can protect the baby from HIV…-by going to the clinic, where they will check HIV and give you pills that will protect the baby. By the time you give birth, you can give birth to a child who has no HIV. (F 20-30; GP urban)

F: When a woman is pregnant she should undergo HIV testing. A woman should test so that she protects her child from being infected with HIV/AIDS....-F: If you are positive they give you a pill to take home with and when you on labour you take this pill to protect the child. (F 20-30; KZN rural)

F: I saw a woman who said that she got it in 1998 and she has a third child and she says all the children are fine. You can conceive another baby, when you are pregnant you can go to the clinic they will give you pills to protect the child. (F 25-35; MP urban)

Yes that is correct, take me for example, I am HIV positive, my husband is HIV negative and we have a HIV negative baby because we followed the PMTCT programme. (F 25-35; WC urban)

The Health workers said the programme starts with counselling and health education for women at ante-natal clinics and it is intensified for those women who are HIV positive and their partners. People are taught about how to have healthy babies even when one if HIV positive, which includes using condoms to prevent infecting the unborn baby and to make sure that the mother does not get infected during pregnancy. The women are told to involve their partners from the beginning and though some of the women fail to do this, those who manage receive support from the partners. The women are encouraged to know their status and their CD4 count because it helps to have a higher CD4 count before a woman falls pregnant.

Yes personally I would say it is better for them not to fall pregnant however if they want to have children and see it as a dire need, at least they must wait, maybe the CD4 count is low, let them wait to boost the CD4 count, at least about 400 and above, they can try when they are physically boosted and fit it is then that they can try. (HW; GP urban)

They must make sure that they attend the health care facility as early as possible and they must know their status in terms of the CD4 Count where do the stand so that the treatment can

be based on their level, the stage of HIV & AIDS, and also they must adhere to the treatment that they are given, you know, as in the times that they should take the treatment, the diet, things that they must avoid you know like multiple partners. (HW; GP urban)

THE PMTCT PROGRAMME

The special groups of people who were in the programmes in deferent parts of the country gave deeper insight into how the programme works. The participants spoke openly and pointed out some of the mistakes that people make, based on their own their experiences. Some said they did not know about the programme until they came to the clinic for ante-natal care. Some of the people learned about the programme after being tested positive for HIV and when they had a wish to have a child they were guided through the programme to plan for pregnancy. They said that many people who don't know their status and who are not pregnant would not know about the PMTCT programme because it is for pregnant and HIV positive women and couples.

They explained that the programme is about following guidelines on making sure that a baby is not infected while the mother is pregnant and after birth. It was said that when a woman is pregnant she should test for HIV early so that she could get onto the programme on time to try and save her unborn child. The other thing all the groups pointed out is that people should always use condoms during the pregnancy to avoid infecting the baby in the womb.

The participants were knowledgeable about how the programme works.

My understanding of PMTCT would be that every person who is HIV and pregnant or already has a baby is following health precautions on making sure that her child is not infected, for instance in our PMTCT group we were taught how to sterilize baby bottles, washing hands before preparing baby's food, wiping you nipples before breastfeeding and all other things; and while you are pregnant you always use a condom, eat health food, drink lots of water, exercise and don't allow any stress disturb you. (F 25-35; WC urban)

It involves a lot of counselling; infant feeding counselling, adherence to treatment and partnership counselling. We start the counselling from the first time we find that the woman is positive, making sure she understands the implications and encourage her to disclose to the partner or anyone in the family. (Senior HW; MP urban)

F: The programme is working fine, I have two healthy children that are HIV Negative and healthy. Two months after falling pregnant my CD4 count dropped and I started using the treatment, and then my viral load went back to normal, undetectable. If only women could start the programme early, everything would go well...-M: I would like to see women starting on the programme just immediately after conceiving, it helps. (Couple 30-32; MP urban)

F: now it's 14 weeks. You can start later but it's best to start early. You have to start taking the treatment by 14 weeks ideally. (F 25-35; MP urban)

F: personally, I was not yet on treatment, they said I will be given a pill to start on. The name of that pill is stavudine and given at 7months. They said I should take the pill when I have seen some signs of labour, izikhundla (drop of blood). The baby was also given drops to take for 28 days. I'm still continuing with stavudine daily. (F 20-30; KZN rural)

F: When you are in labour you have to take the nevaropine and the AZT every three hours. And then when your baby is born, it depends on the weight of the baby. At a certain weight you are given a certain dose of nevaropine to give the baby through a syringe squirt into the mouth once a day. And it has to be at the same time, everyday. (F 25-35; MP urban)

W: the other thing that was good was that they give you the pill to take home and you can only take it when you feel the labour pains. So there can never be a mistake there. It is good that they give you before time so there is no chance of going to labour having not taken the pill. (Couple 34-36; NW rural)

The health workers spoke of dual therapy that that is given to a pregnant woman with a CD4 count above 350 and the triple therapy given if the CD4 count is below 350. Both these involve taking 300mgAZT twice daily till delivery and then single dose of 600mgAZT at the start of labour plus a single dose of 200mgnevirapine followed by 300mgAZT three hourly till she delivers. After delivery the AZT is stopped and the woman's CD4 count is done again at post natal check-up; if it's lower than 200, the woman is referred to the ARV clinic. A PCR test is done on the baby after six weeks of birth and if the results show that the baby is HIV positive, it is referred to the ARV clinic to go onto treatment.

They mentioned that ideally, the treatment should start at 14 weeks but it can be started even hours before she delivers if a woman presents late to the health facility and is already in labour:

So you start afresh; you counsel the person get the consent, you test the person so that you can start the treatment as fast as you can. If the person is in labour you can start with the stat doses and continue and try as much as possible to make sure that the child can be saved. (HW; GP urban)

The programme used to start at 28 weeks and now the guide says 14 weeks but it depends on when the woman comes; we do start it even when they come at 32 week. I think when it says 14 weeks, it means to say the treatment should not start before but it can start anytime before delivery. Some even come at 30, 34 weeks but it is said that there are higher chances for those babies whose mothers start at 14 weeks to be (HIV) negative than for those whose mothers start at 38 weeks. (Senior HW; MP urban)

Infant feeding options on the programme

The participants said that all mothers and couples are given a right to choose how they would feed their babies such that they save them from being infected after birth. In all the groups, it came out that many people choose formula to feed their babies, mainly because the milk is given for free at government health facilities and that there is no chance of infecting the baby. They said breastfeeding poses many challenges for women living with HIV and AIDS because one is always having the fear that the babies might get infected before they wean them off the breast. The main concern being that the mother is not always around the baby and if it happens that she leaves her baby with other people, they will give the baby other food, thus putting the baby at higher risk of being infected.

Some of the mothers and other family members do not believe that breast milk alone would be enough for the baby and exclusive breastfeeding was said to be difficult because it means that the baby should not even get water or any medicines that families believe are necessary when the baby is growing.

> *In hospital, you are told to breastfeed till 6months not more than that, and don't mix any feeding. If you are going to give a bottle, it should be the bottle feeding only (F 20-30; KZN rural)*
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> *F: At the clinic they said whether you are HIV+ or negative you will breast feed the baby and not give anything like porridge, so there is nobody who can ask you why you are not breast feeding because everybody will be breast feeding. So this is an advantage for everybody, HIV+ or negative -you see, that is the advantage. (F 20-30; GP urban)*
>
> *W: They said if I breast feed I should do it for 6 months and I should not give the child any other food during that time including medicine. I thought that was going to be difficult. How can a child live without medicine? So I thought I rather give my child formula. Even now she is still taking formula. The good thing is that this milk (formula) is free. (Couple; NW rural)*
>
> *F: I mean if you have to breast feed the baby you are not sure whether it will be sick or not, so I think (tinned) milk is better… (F 20-30; GP urban)*
>
> *F: I have decided to give the baby milk because I will not stand the breast feeding, it means the baby must only have the breast what size will I be -When will you reach six months? I think the bottle is better; today's babies eat a lot. (F 20-30; GP urban)*
>
> *Same like me I was asked what I wanted to use, breastfeeding or bottle-feeding then I chose bottle feeding because the government gives Nan powered milk for free. (F 20-30; KZN rural)*
>
> *F: Most mothers choose formula feeding. Exclusive breastfeeding is hard because you are not at home all the time. And then the child gets fed porridge by other people. (F 25-35; MP rural)*
>
> *F: Also once the baby is born if you decide to breastfeed then you breastfeed only, you do not feed the baby anything besides breastfeeding because if you do the child might be infected…- Yes that is true because when I had my second baby I wanted to breastfeed but thought what would happen if I leave my baby with a friend and then she feeds her something then that would put my child at risk of being infected so I ended up not breastfeeding. (F 25-35; WC informal)*

F: You can choose the breast if you know that the child will always be on your side. So there are some people who are able to guarantee that. But it is more difficult. And there is also the risk that you don't wean your child at 6 months so you continue to breast feed plus adding other foods. (F 25-35; MP rural)

M: You never know when you are risking. So we decided that we do not want to risk; we thought what if she gets HIV from breast milk? We did not want to risk…-And after 3 months we started giving her other food like baby food… yes we give her food like purity but when we don't have it, her mother cooks her soft porridge (Couple; NW rural)

M: Feeding was a challenge we needed to sit down at look at everything -which form of feeding was going to suitable for us, the challenge with breastfeeding was after three months she had to go back to work so we opted for formula milk. (M 30-45; MP urban)

For some people breastfeeding was seen as something that would help them save money so that they can buy other needs for the baby. It came out that the free milk from the hospital is not always available so, they choose breastfeeding because they would not have any money to buy the milk.

M: I was lucky because she was breastfeeding the child so it was not a problem at the early age and I started saving for pampers since they are expensive. (M 25-27; MP urban)

Stigma around bottle feeding

The study reveals that some of the mothers feel the stigma associated with the free milk that they receive at the hospitals and clinics. The participants spoke of having to make sure that they hide the tins when they come from the clinic and they said it is difficult because these tins are bright in colour and many people already know that they are given to babies whose mothers are HIV positive.

W: Just like when you give your child a bottle and not breast milk. People start to think that 'this one is positive' because you are giving your child bottle milk not breast. (F 20-30; NW rural)

F: As along as you give your baby pelagon they know that you are from the clinic, they see these big tins, and they will say you got them from the clinic…-F: Even if you are not sick when you buy it they make their conclusion, you are even afraid to buy it because people will tell you that you are positive (HIV+). (F 20-30; GP urban)

F: Nan and pelagon are different even in colour, the containers are orange, it is known because at the clinic they give it free. I can say in those days it was rare but during this time of HIV it is where it has become popular. (F 20-30; GP urban)

I fed my child bottle milk only. It was good because I got the milk for free at the hospital. The problem with the milk that they offer at the hospital is that everyone can see that it is the milk from the hospital. It is Nan, and Pelagon and it looks sour when it is in the bottle. So people talk and they know that kind of milk is for children whose mothers are HIV positive. (F 20-30; NW rural)

Mixed Feeding

Although many people know that they should avoid mixed feeding, some people do give other food to their babies. Some of the young mothers are forced by their families who believe that when the baby cries it is because it is hungry and that milk alone would not be enough. With some it happens because after choosing breastfeeding, they are unable to explain to other family members why they don't give other foods because they are not able to disclose.

> *F: I will breast feed and at the same time give formula milk. (HIV+) (F 20-30; GP urban)*
>
> *Her grandmother said that she was always hungry and we must buy her nestum and feed her. Then we got her nestum and fed her, and she ate it and also had the milk. The nurses told me I must not continue feeding her nestum. So I stopped and only gave her bottle milk. I guess there were challenges because I was used to her feeding on one "skotela" (container) of S 26 milk for a month. After going to the clinic and I had to stop feeding her food, I had to buy two containers of S26 because she was to only feed on that. She had both of them in one month! (Teenage mother; MP urban)*
>
> *You can have a problem because if they don't know, you won't' get any support even with the treatment you are taking. They can feed the child things that he is not supposed to eat and he can be infected. I had problems with my first child. I was not properly trained and I fed my child "incumbe "(**groud mealies, soaked and cooked like soft porridge but it's very thick**) and she got infected. (F 20-30; KZN rural)*

PEOPLE NEED TO KNOW ABOUT THE PROGRAMME

Many people who were on the programme expressed some concern that not many people in the general public know about the PMTCT programme. They said there was a need to run communication programmes for the people to learn about the PMTCT programme. Some suggested that all pregnant women, not only those who are HIV positive should attend the programme because of the teachings and the information they receive.

> *F: I knew about PMTCT after finding out that I'm HIV Positive and I wanted to know how I can safely have a healthy baby that is HIV Negative at the clinic. That's when I knew about it...-M: I knew about it through my wife and our doctor. (Couple 30-32; MP urban)*
>
> *F: It would be wise to talk to people in the community. Why? So that they know that there is a programme like this **before** they fall pregnant. So that when we do fall pregnant we can come into it. F; health workers have to have time to talk to new mothers. (F 25-35; MP urban)*
>
> *Another thing that should encourage women to go to PMTCT is the teachings that one receives there, you are taught a lot of things and I feel all women not only ones living with HIV but all pregnant women should attend the PMTCT programme. (F 25-35; WC urban)*

WOMEN COME LATE TO THE PROGRAMME

The discussions show that some of the women who become pregnant without planning end up presenting late for ante-natal care and the PMTCT programme. In all the groups, the participants spoke about it as a problem that leads to babies getting infected when they could have been saved if the mothers went to the clinic early.

> *F: I got pregnant and I saw that there were some changes but I would have my periods at their time. I saw that I was gaining weight; I was eating a lot, and would have morning sicknesses; I didn't tell myself that I was pregnant. It was at seven months that I realised that my belly was becoming hard and growing. I decided to come to the clinic..- So most of the time I blame myself, especially when she gets sick, and think had I acted early - when I suspected that I might be pregnant my baby would be fine and not positive. (Teenage mother- MP urban)*

> *F: So I found out when I fell pregnant that I am HIV positive. So that's when I found out about the PMCTC and it was the older programme that you could join when you were 7 months pregnant. (F 25-35; MP urban)*

NGOS AND SUPPORT GROUPS PLAYING A PIVOTAL ROLE IN THE PMTCT

The participants said that most of the information and the support were provided by NGOs that are linked to the health centres. They said that the NGOs show better understanding of the programme than the health workers. People in all the groups praised the support provided by the support groups under the PMTCT programme. They said that without the support groups, people living with HIV would be lost because the health workers are too busy; they don't have time to explain and give adequate information to people.

> *W: I also feel that the support group has helped me a lot. The nurses at the clinic and at the hospital don't have time to talk to patients. Even those counsellors they have their own people. They don't care about the many people that they see there. At least with the support group you can get a lot of information about many things including grants. (F 20-30 NW rural)*

> *F: You get support here. At home I am always alone this where I get support and a chance to share with other women and when I get my pills I'm able to find my facilitator and just sit and talk to her. (F 25-35; MP urban)*

> *W: and at the PMTCT programme we treat each other as family, we help and support each other and that is the kind of relationship we have. I remember there was this lady that was really battling with taking care of her child; she didn't have money for clothes, bar soaps and nappies so we went to see where she stayed and the conditions that she was living in were not good for a person who is HIV positive and with a baby. We then decided to donate some clothes for her and*

the baby helped her get the government grant and we sometimes went to her place to help her with her laundry and some stuff. (F 25-35; WC urban)

M: Support group has helped me a lot to overcome problems. During support group we sit down as men and talk; everyone will voice out his problem and that's where you get to hear that people have problems have more than you do. When you hear other people stories you will cry but after that you will feel better and you will find a way to tackle your problem. (M 30-45; MP urban)

F: I would like to edge people to join the support groups because talking about it will make it easy for you and you will get more information. There more you don't talk about it it's when you get sicker because you are suppressing everything inside. (Couple 30-32; MP urban)

PLANNING FOR PREGNANCY

The study shows that many people don't plan their pregnancies and they don't try to find out about their HIV status before falling pregnant. In the special groups, many women and couples put a lot of emphasis on the need for people to plan and to know their HIV status before falling pregnant. They said it is important for women who are positive to know their CD4 count and to prepare themselves, physically and emotionally for pregnancy. Some of the discordant couples related their stories about how they needed to be careful to make sure that the negative partner would not get infected during trying to conceive and after conception. They spoke of constantly checking their CD4 count and the viral load and being guided by the doctor on when they can stop using condoms, pointing out that it is vital do go back to using condoms as soon as they conceive to avoid infecting each other and the unborn baby.

F: If your CD4 count is fine and your viral load is undetectable and the doctor is saying physically you are fit to get pregnant, then you are fit to get pregnant. I think that's important. We have to encourage women to ask at the clinic – is it the right time for me to fall pregnant…? (F 25-35; MP urban)

F: My husband married me knowing that I am HIV positive and you know that when you get married you have to fall pregnant or have a son that will take over the name. I informed the doctor that I am HIV positive and my husband is HIV negative and that we want a child. The doctor ask me about the treatment I was currently taking then and after I was told that I would have to change it for my CD4 count to be on the right level for me and my husband to conceive without infecting my husband. (F 25-35; WC urban)

M: It was not a mistake. We knew that we wanted to have a baby. Also I felt that we are both fine now and we are not sick. So I thought if we can just try and if she falls pregnant, we will go back to using condoms.. (Couple 34-36; NW rural)

M: We spoke as a couple and then went to the doctor to consult; we checked the viral load if it can be controlled through CD4 count. They monitored my woman if she will be able go through the 9 months period of pregnancy. The doctor would put her on medication and she had to follow that medication as per the doctor's instructions. (M 30-45; MP urban)

M: We went to the doctor first and told him our intention that we want to have a baby; he told us if my wife wants to conceive we have to count the days after her menstrual cycle is completed...- F: The doctor gave us thirteen days after my menstruation, the fourteen day we can start trying then we back to the doctor after five days of trying he said we must try again the following month; I discovered I was pregnant. (Couple 30-32; MP urban)

The health workers said the programme has many benefits if it is followed well; it helps couples living with HIV to fulfil their dreams of becoming parents but they warned people not to think that now they can have as many children as they please. They said that the programme calls for proper planning, making sure that the couple will have enough support.

They should have a CD4 count of about 350 but to be sure of a healthy pregnancy it should be 500 and above. They should use condoms even all the time and only when they are ready for the pregnancy they would stop it but should go back to it during the pregnancy... ***-Why?*** *- because during pregnancy there are a lot of infections that can come in and they go straight to the baby. (Senior HW; MP urban)*

When they come to the clinic already pregnant we teach them about using condoms to prevent re-infection and the transmission of HIV. Some people get pregnant while they are HIV negative but because they lack knowledge, they end up being HIV positive during their pregnancy. So we educate them about all this. (HW; MP urban)

MANY DO NOT PLAN

Many women who were part of the PMTCT programme said their pregnancy was not planned, "it just happened". Some women said their partners did not want to use protection and that even if they use condoms all the time; the women thought the men pierced the condom. Some of the women said they knew their status when they found themselves pregnant without planning and with some, it was not the first time that they had unplanned pregnancy. For many of them, this caused them a lot of anguish, leading to them trying ways of aborting the pregnancy. For those who learned about their HIV status when they were pregnant, they related stories about how difficult it was to deal with the shock of finding out that they have HIV and to deal with unplanned pregnancy at the same time.

F: I saw him put the condom on, so how it is that I fall pregnant, I don't know, he wouldn't explain to me. When I found out I felt suicidal; I am very depressed, especially since yesterday...-Today I am supposed to fetch my medication (F 25-35; MP urban)

F: I did not plan, as we were having sex the baby was conceived; it was unplanned but I already knew my status because I had been coming for check up, and blood test and the baby came. I was on contraceptives, I then became lazy (F 20-30; GP urban)

F: he had made it clear to me that he doesn't want any children because of personal reasons so when I had found that I was pregnant there only thing I was thinking was to terminate the pregnancy. (F 25-35; WC urban)

W: The only problem is that I was feeling bad that the nurses at the clinic were going to say to me I am useless because I had another baby while I knew my status....-Yes, all went well. I gave birth naturally with both my babies. I did not have any complications and I received nevarapine for both of them. (F 20-30 NW rural)

Personally, I had no straight boyfriend, the father of my first child left me. Now the fear was what my father going to say, my mother was going to ask me who is the father of my child and already the guy had left me the day he heard that I was pregnant. So I was going to get the child, I'm positive and his father was not known. So the decision I took was to abort this child. (F 20-30; KZN rural)

F: With me, the biggest challenge was that I am a married woman, but I got the child outside, it was just a shame because my real husband who infected me had died. He left me with the disease and l was left with the children. My decision was to abort the child...-F: I don't' want to lie, we all tried to abort. (F 20-30; KZN rural)

PARTNER INVOLVEMENT

The participants, especially those who were in the programme spoke at length about the need to involve men in PMTCT. Some of the women related how their partners were supporting them during the pregnancy and after the baby was born. Mostly, the support the women were expecting was for the man to be there; to help with house chores, help with caring for the baby and show her more love. Some men and women said sometimes when the man is unemployed he felt challenged but some had come to terms with it and were happy to support in other ways than only financially. Some of the men said because they did not know much about pregnancy, they always panicked if their partner seemed in pain or showing signs of discomfort but they relied on the information they received from support groups and the doctors.

I also think men should be involved in PMTCT programs also because some mothers live with their partners and sometimes leave the child with the father so they also should receive PMTCT sessions and also for supporting their partners (F 25-35; WC urban)

M: Sometimes lack of information of not knowing what to do when she is pain I would panic maybe the child is playing inside the womb or turning she would start screaming any you start panicking. (M 30-45; MP urban)

F: Mine was willing to help me unfortunately he had no other means, he was not working and he was already sick. So he could not help me even to go the clinic I went alone...- F: My partner was also happy that I was pregnant but had no money to support the pregnancy. (F 20-30; KZN rural)

M: It was tough for me I didn't have a job at that time but she had a job. Financially I was not supporting her but emotionally I was there all the time when she needed me. She will ask me to take the child to the doctor but I will feel bad because I didn't have any money to support my child when I spoke to my good friends I related my story to them and my mother they told me its not only about money you can still give emotional support to your girlfriend and the child its not only about money. My presence was more important. (M 25-27; MP urban)

F; Yes…-those massages and some of the things that he does you see, like some of the chores he will tell me not to do…-By helping with household chores, cooking and washing, ironing and cooking. (F 20-30; GP urban)

M: From my side it was to stick to the doctors schedule make sure we follow all the dates according to the doctor's orders and remind her and make sure she takes her medication all the time. The medication does not taste so good so I had to encourage her to stick to the stipulated times of the medication. (Couple –MP urban)

My husband was so supportive when I was pregnant because he wanted a child more than I did; he came with me to the PMTCT programs and even reminded me for taking my treatment. Pregnant women living with HIV should get all the support they need from their partners if not so then from any family member. (F 25-35; WC urban)

W: Well, I was lucky enough because my man was there and when I told him that I was HIV positive, he said to me we should not be in rush to tell other people. We kept our status between ourselves and focussed on our child. The other thing is that we received counselling. So it was only us and the clinic who knew about our status. We only told our families later. When he died, we had already told the family that we are positive. (F 20-30 NW rural)

M: I had to support her because like I told you, she was sick sometime before falling pregnant. So even though I didn't tell her, I was a little bit worried about what might happen. So I gave her all the support because this is my baby too. You know, when I was not going to work, we went to the clinic together...-W: yes we went together. Even the nurses know us. (Couple 34-36; NW rural)

The health workers emphasized the need for men to be involved on the programme and said the problem is that some women fail to disclose their HIV status to their partners. They said that if the man gets involved there is a better chance for the woman to receive support and that she can get cooperation from the man to make sure that they use condoms during the pregnancy. In Mpumalanga the programme has a support system called "patient advocates" for couples and the health workers said this encourages partner involvement but it is difficult for those that do not disclose to their partners.

> *I think when the mother comes you know during the ante-natal clinic, for the bookings I think it is better to be accompanied by their partners, because if they both test and they know their status it is better because they will use condom and they will continue using the condom to prevent further transmission of the virus. And also support the mothers and remind them of taking their treatment in due time. (HW; GP urban)*

> *Others are afraid to disclose when they get home; they try other ways like telling him that at the clinic they told her to bring her partner so that they can be tested. When she comes with him we both pretend as if it is for the first time that she is tested for HIV and when they test positive together the man becomes supportive and agree to go through counselling with her. (Senior HW; MP urban)*

> *If the partner tests and he is also positive we allocate them the patient advocate...-the patient advocates are the follow up support system…- I think they are encouraged by the support the couples receive from the patient advocates as well as the support they get when they come to the clinic because in this programme they have a relationship with a health worker; they don't come in and talk to different people all the time, they know where to go and who to ask for when they need help. But there are some women who find it very difficult to tell the men; they just tell them the tablets are for helping the baby grow well. (Senior HW; MP urban)*

MANY MEN DON'T GET INVOLVED

Unfortunately, many women don't get any support from their partners during the time of pregnancy; some are on the PMTCT programme alone, without their partners' knowledge. Some of the women spoke of ways to keep their status and their involvement in the programme a secret mainly because of the fear of losing the relationship; they said that men run away because they are afraid of HIV and that men are still in denial about the existence of HIV. Men are afraid to even know their own status and always wait for the woman to test and then they make conclusions that if she is positive it means he too is positive. It was said that some of the men keep quiet about their own status till such time that the woman discloses to him and that some men refuse to use condoms

even when the women have told them that they have tested positive for HIV. In one of the men groups it was mentioned that, in particular men who have been circumcised don't want to use condoms; they believe that they are less at risk when it comes to HIV infection.

W: the problem is that when it comes to HIV, you only see women. Most men don't care. You are lucky if you are a woman and your man supports you. As we talk right now, many men are at taverns drinking and acting like they are not positive. They are not there with their partners. (F 20-30 NW rural)

F: Many men usually don't support women in any way during pregnancy – they treat it as your problem alone- that it's your burden alone. And even when the baby is born, it is your burden alone to carry. The man may be at home but you still have to be in charge of taking care of the baby. Men don't take that initiative...- F: they don't get involved. (F 25-35; MP urban)

No he did not. It's very hard going through pregnancy alone and even worse when you are HIV positive and needing support from your loved ones. I do hear from other people that he wants to return and offer his support and reclaim his position as a partner because some people tell him that what he is doing is wrong and that he has to make things right. (F 25-35; WC urban)

W: At first he could not believe that I was positive and he started accusing me that I am seeing my ex boyfriend. I decided to leave him them because I had a lot of stress. The only thing that he does is to buy the child some clothes whenever he can. Since then I have decided that I am going to take care of myself and leave him alone. (F 20-30 NW rural)

F: Mine does not, if I have a baby that's it; he only knows that I have a baby he has no role to play except to buy the babies clothes. He has never accompanied me to the clinic. Men are not the same. (F 20-30; GP urban)

First of all it's not easy telling your partner that you have been diagnosed with HIV because you first have to deal with the shock of hearing the news; and then there is the family and your partner, so some women tend to keep it to themselves and then you will hear the partner asking why is the baby not breastfed, why is that and so on. There is that fear of losing your partner because men think it's usually women that pass HIV. (F 25-35; WC urban)

W: Men, they run away when you tell them about HIV...-W: I think the reason why men are not supportive is because they are afraid. Whenever you talk about HIV, they think death. (F 20-30 NW rural)

F: And they test through their partners – so if she's negative, that means I'm negative and if she's positive, then I am too. (F 25-35; MP urban)

THEY REFUSE CONDOMS

F: My boyfriend was so difficult, even though he knew that we were positive he would not want us to use condoms. I was always scared that if I don't separate with him, I will die. I took the decision to leave him since he would not use condoms; I left mine because I was scared of dying. (F 20-30; KZN rural)

M: Another thing to mention that's a big problem here in our place is men who are circumcised don't want to use condoms. Wife wants to use condoms at home but he will refused "how I can use condoms when I have circumcised and if you have circumcised you are 60% safe". The woman is HIV Positive the man does not want to come forward and test and still he does not want to use condoms (M 30-45; MP urban)

F: women are dependent on men – they will say, I refuse to use a condom in my own house with my own wife. So that is why even women who know their status end up pregnant – she is forced by the situation to sleep with the man. And sometimes he will force you and when you are married, you can still get raped – but you have fear about reporting him because how will your children live after if he gets taken away? So we women are very vulnerable. (F 25-35; MP urban)

F: Today's boys don't want condoms they say condoms are out of fashion. They want it the way they know it. Condom! It is no longer wanted by the boys. (F 20-30; GP urban)

M: One other problem is that when a women is pregnant they couple say they must give the baby strength (go tiisa phuana) without using protection and that way they get more infected by AIDS so they are killing the baby. (M 25-35; NW informal)

My man also refused to use a condom; when I informed him that I was pregnant, he said, "how if I tell you that I'm also on treatment". I was shocked, because we never discussed about our HIV status before. Now the issue was the pregnancy, I asked him to use the condom now that I was pregnant; he said I should not bother myself there is treatment these days. I felt at ease because my CD4 was also high. (F 20-30; KZN rural)

WAYS OF DEALING WITH DIFFICULT PARTNERS

Some women have found ways of dealing with the difficult partners; they just hide everything from their partners and tell them false information. Other women just tell the men the truth and leave it up to them to act on the information in their own time.

F: Maybe he does not even know his status and yet you know your status. If you tell them your status they normally run away…-He runs away, so it is up to you not to tell him, just give any lame excuse. You simply tell him that at the clinic they said we must use the condom to protect

the baby and not you, he will stop; there is no way he can refuse to protect the baby. (F 20-30; GP urban)

F: During pregnancy you know your own status but you don't know his, and he also does not know your status, that is where the problem is because you will even be afraid to tell him and even to take your pills because he will ask you what are those for? You are now forced to hide them. You guard any chance you get, like late when he is still at work, things like that. You can even pretend that you are suffering from a headache because you know it is time for you to take your pills. (F 25-35; MP urban)

F: Well I just had to tell him because he is the father of the baby, the decision I took is that I am pregnant and this is the situation, whether he leaves me or not it is up to him. The decision I had to make was to simply tell him that things are like this, I just told him. He then denied and said there is no such. I then went for another test coming back I told him that it still says the same thing and you also have to go and test. Coming back from the clinic I had condoms and told him the nurse said we should use condoms. He asked why? I said the nurse said we should use condoms, nothing will come right: our main concern is to protect the baby. He then agreed. I told him one day you will get a chance. Today I went with him to the clinic to check, and found out it was like that, shame he had to accept that there is no other way. (F 20-30; GP urban)

CHALLENGES FOR POSITIVE MOTHERS

F: Another challenge is feeding; people will always question "why you are not breastfeeding your child"? Be it friends and some family members as well, that's the problem that I have right now...-I ask them why they are asking me such questions or on the day that I'm feeling fine I will explain to them why I'm not breastfeeding; sometimes I just lose it completely and tell them where to get off and I fail to explain why. (Couple –MP urban)

My problem was how I was going to explain why my child was not eating food after 3 months…-So I had to make a means to stand for what I thought was good for me and the baby. Another thing is that it becomes very difficult to say no to your mother because she knows and she raised you. And even though she did not agree with me, I ended up feeding my child the bottle. (F 20-30 NW rural)

W: I think the biggest challenge was the illness. You never know when you will get sick. So if you get sick during your pregnancy, everything can go wrong. You have to be extra careful…- I was also afraid that I would be sick. Especially when you are pregnant, you get many symptoms, sometimes you feel dizzy and you begin to think that maybe you are sick because you are HIV positive. You forget that some things like getting dizzy or vomiting happens to every pregnant woman. Not only to positive women. (F 20-30 NW rural)

W: the other decision was to decide when I was going to tell my family about my status; that is a very tough decision because they have to know. It was tough because as an HIV positive

person I don't raise my child like any normal child; I cannot just take recommendations from people. So I had to be careful. That is why I had to tell my family so that they can get used to the way me and my child live. (F 20-30 NW rural)

W: yes, but with that one I decided to have my baby naturally because it is good to have a baby the normal way. You see for someone like me, it was going to be complicated because what if I get sick afterwards. Another thing is operations are painful especially during winter. People who have had an operation suffer a lot. (Couple 34-36; NW rural)

ADVICE FOR PEOPLE WHO WANT TO HAVE HEALTHY BABIES

IT IS IMPORTANT TO KNOW YOUR STATUS

When I fell pregnant with my first child I never got tested for HIV, so after the birth of my baby the doctors discovered that the baby was not well. It was decided that she should be tested for HIV and I asked that I test too. The results came positive and it was too late for my child because I was never tested early and got the right treatment to prevent her from being infected. That is why I say it is best that you get tested immediately after receiving news that you are expecting a child because if I had done so maybe my child would have been negative now. (F 25-35; WC urban)

F: You have to encourage women to know their status; no matter if you are still planning your pregnancy or you are pregnant already...-So that you can get into the programme quickly. (F 25-35; MP urban)

F: I would advise them to test and to always know their status. I only knew my status when I was pregnant. It was very frustrating because I did not know what to do with the baby and I did not have enough information about pregnancy and HIV. I didn't know anything. It would have been better if I knew my status before. (F 20-30 NW rural)

F: Also they (Other women) should know their status so that if they are positive, they should decide whether they want to have children or not and be ready to do the right things. (F 20-30 NW rural)

F: Everyone has a fear of finding out they are HIV positive but things now are easy than before because there are organisations that support people living with HIV, more people now are aware of HIV and you can live longer if you change your lifestyle. Look at us; some of us have decades living with HIV but we are still here health and moving on. Being diagnosed HIV doesn't mean you are to die tomorrow; the world does not end there. Do not kill yourself before the virus does; I told myself that I will never let HIV kill me, I am yet to live and watch my children grow. (F 25-35; WC urban)

DISCLOSURE IS IMPORTANT

F: The other thing I see is that it is important to tell the people around you about your situation. That will help you so that when you are taking treatment you don't feel fear. Because the PMTC treatment has its routine so if you don't tell the people you live with in the house, you might find it difficult to take your pills if you've hidden them and maybe the family is sitting right where you've hidden them. So you can't take them. So it's important to talk about your condition, so that you can get support from those you live with. (F 25-35; MP urban)

F: In case there is something wrong with the baby and you have a visitor at home, it is going to be very difficult because you cannot even give the baby panado as they have said that you don't give anything except the breast. Now your visitor will want to know what is wrong. That is the difficulty you have after giving birth. (HIV+) (F 20-30; GP urban)

W: You know when talk about baby feeding, I remember when my baby was still feeding on breast milk only, there were these children next door who liked my child a lot and they would come and ask to play with the child. I would always be cautious because these children liked giving her things to eat. So I would make sure that I watch them all the time. Another thing is that it is difficult to watch a child all the time because it is not part of our culture to deny people your child. So people will think there is something wrong with you when you do that. (F 20-30; NW rural)

W: With me I didn't tell my family anything. On the day when they came to fetch at the clinic, I had already told the nurses that I was going to bottle feed. When my mother came to fetch me, I told her that the doctor said I should not breast feed because I have hepatitis and if I breast feed my child was going to have jaundice. My mother then accepted. (F 20-30; NW rural)

USE CONDOMS

F: The other thing is that you have to use a condom while you are still nursing – until your baby is weaned. Because men are not always faithful and he insist that he will not use a condom in his house. As we know, many women are abused in their households. So we have to teach women to have courage to stand up against this for the sake of her baby's protection. And if you can see that this man will be a problem, you should leave. (F 25-35; MP urban)

M: What I can say is people must always use protection when they have sex and secondly plan for your pregnancy don't just things for the sake of doing things. Test for HIV now and then and stay faithful to your partner if you not in committed relationship use protection all the time. (M 30-45; MP urban)

M: Use condoms; if she is pregnant use condoms all the time no matter if you are both Negative for the duration of the pregnancy to prevent a child from being infected. (M 30-45; MP urban)

M: When they discover that the woman is pregnant, they stop using condoms. I mean this thing of re-infection is serious and many people don't know. When we discovered that she was pregnant, this nurse at the clinic told us that we must continue to use condoms because we will re- infect ourselves. I also thought that I may infect the baby if I don't use condoms. (Couple 34-36; NW rural)

F: If you bring up using a condom with them its like you are insulting them. It's a subject you can't bring up. Saying, use this...-he might take it but do things on it like cutting it open… and so when you find yourself pregnant by accident, you feel very afraid. (F 25-35; MP urban)

F: We need to condomise. It cannot be the man's choice that he will not use a condom, and then you are left with the consequences. If he says he will not use it and you are care about your life and the life of your baby, you should rather abstain then. (F 25-35; MP urban)

W: and also they should involve their families because if you keep you status a secret, your family would want to raise your child like a normal child. Like when it comes to feeding, they would want to give your child anything and that will harm the child especially if you have been told to do exclusive feeding like giving breast milk only or giving formula only. (F 20-30 NW rural)

CHALLENGES FOR THE PROGRAMME

LACK OF DISCLOSURE

The health workers cited the lack of disclosure as the major challenge of the programme, saying it leads to many other problems with adherence. They mentioned stigma as the root cause for this problem; mothers are afraid to tell families and partners, fearing to lose their relationships and trying hard for other people not to know about their status. They said sometimes this leads to the mothers coming to deliver but forgetting their pill they need to take when labour starts at home, making it difficult for the nurses because they now have to ask someone at home to bring the treatment. The mothers fail to even adhere to their choice of infant feeding because when they get back home they are not able to justify their reasons not to breastfeed their babies.

The health facilities have come up with measures to help decrease the stigma by making sure that during consultation all the pregnant women are attended in one area, without any differentiation.

You find that this woman chooses the bottle (formula milk) to feed her baby and when she gets home she is told "babies of this family are supposed to get the breast milk for two years; if your baby cannot be breastfed, it means he/she is not of this family". So because she has not disclosed it will be hard to give reasons why she is not breastfeeding and she will end up stopping the bottle and giving her baby the breast. (Senior HW; MP urban)

Other patients do not tell their families that they have been diagnosed HIV positive, when they are in labour only to find that they left the pills at home. It becomes a problem when their families have to bring the treatment. These mothers will tell you No! I don't want them to see the treatment because I did not disclose their status. (HW; GP urban)

Hence I am saying it is still having a stigma, maybe it is the way that it is transmitted .You know? They haven't accepted it. You find that the pregnant woman is HIV+ she will ask you not to tell the husband that she has been diagnosed HIV+ because the partner will leave her. (HW; GP urban)

They use the same facility however if a pregnant woman is attended this is done in a private room alone to avoid the stigma. If those who are HIV+ are going on one side and those who are HIV- on the other side, obviously they would know that those ones are HIV+ and we who go that side are HIV- that is another stigma. It is better to mix them and when they go to the consulting room they go in privately. What ever is being done in that room is between her and the nurse; nobody will know whether she is HIV+ or HIV- (HW; GP urban)

LACK OF ADHERENCE TO FEEDING OPTIONS

The health workers said that they are aware that the mothers have challenges around infant feeding options, especially when they have to choose formula feeding while they are unemployed. They said the milk the women receive at the clinics is not always enough as the baby grows and sometime it is not available and the women have to find ways of supplementing and if they have no money to buy, they give the baby other foods.

These mothers do mix and they will tell you that the baby does not get enough, and this milk is a six week supply with 6 tins, as the child gains weight she will need more milk, meaning the mother must go buy the supplement until the date set to collect more milk. The mother then decides that she will mix with other food and all those things. The Government is aware of this challenge that the milk gets finished; as the child is growing she put more weight and 50mls is not going to be enough, maybe at one time it will take the whole 150mls a bottle or 200mls. The Government must supplement; give the mothers more milk. (HW; GP urban)

Sometimes it does happen that the hospital runs short of the supply but the women are told during the counselling sessions that they should keep money aside and be ready to buy the formula if we run out of it. We encourage them to register for the child grant so that they can be able to buy the milk for themselves. (Senior HW; MP urban)

The other thing you give these mothers milk when they go home they share it with others and some even sell it to get money for bread. They are always poor they are not working; these are the challenges that we address everyday and the Government is aware. (HW; GP urban)

WOMEN COME LATE AND THEY DEFAULT

Though the health workers said they start the treatment at any stage after 14 weeks of pregnancy, sometimes the women come too late for the health facility to save the unborn baby from getting infected. In Gauteng the nurse said all this is because of the language barrier; people come to Gauteng from different parts of the country and even from other countries and find it difficult to communicate and understand what they are taught at the clinic. This s aggravated by literacy levels of the clients and traditional beliefs which lead to mixing ARVs with traditional medicine.

The health workers said it is difficult to trace the defaulters because women give wrong information and avoid attending clinics near where they live. In Gauteng this was said to be a major problem because people don't stay in one place for long

> *Those who are pregnant for the first time come very early, around 12 weeks but the women*
>
> *who are having third, fourth pregnancy they come in late, just to get the delivery card so that when it is time they can go to the maternity clinic and show that they have been to the ante-natal clinic. That is one of the challenges for the programme; women delay to come to the clinic. (Senior HW; MP urban)*
>
> *On the side of the patient it is the language barrier you know, like I am Zulu speaking, people are coming as far as the North they speak Sepedi, Seshangane, they come as far as Malalwi, Zimbabwe, at least those who are speaking Ndebele is similar to Zulu, others are speaking Shona. During the education and the explanation, something is missing there. (HW; GP urban)*
>
> *We are having a high defaulter rate. After sometime long after the treatment is finished, they will tell you I did not have money, today they stay here tomorrow they stay there, they will tell you I was still trying to get money to go to the clinic. You know. That is another problem that we have. (HW; GP urban)*
>
> *you will tell the patient that if you come to the clinic you must always carry your tablets and your card with you because it is having everything about you so that wherever you go they can see how far the other nurse has gone, they don't do those things…-they will tell you I am visiting here I am actually from Heidleburg and going back tomorrow and I don't have my card, I was suppose to go to the clinic next week Wednesday and I thought I will be in Heidelburg. (HW; GP urban)*

STAFF SHORTAGES

The participants acknowledged that the health facilities are understaffed, which makes it difficult for the health workers to have enough time with every patient. They feel that people miss out on proper information about their condition and this may lead them not to adhere to the programme.

> *So now if one is a nurse and they are teaching at the same time. They will end up not doing some of the things the right. So, there has to be enough staff so that there can be people teaching and others doing other things. When there is shortage of staff you end up not telling people everything, you just say here is your treatment; come back on such and such a date, and they think, I have my baby why should I come back to the clinic. (HW; MP urban)*

> *Now they end up not coming because you didn't educate them well. The more I educate them well, the more they will come to the clinic for their appointments. In everything we do, teaching is number one. The person has to understand their situation, their sickness if they are sick, and how it goes (what happens). This is the teaching that is important, treatment will come after. (HW; MP urban)*

IDEAS TO IMPROVE THE PROGRAMME

> *F: The thing is that it does happen sometimes that here is no formula milk available. Sometimes for a year. So we are asking that there always be enough formula milk available. So that even the person who cannot afford it can still choose to use formula feeding. This is what places some babies at risk. So we need for there to be enough formula. (F 25-35; MP urban)*

> *I would like for the folders to be changed, everyone knows that when you are carrying a pink folder you are going to the PMCTC ward and you are HIV positive so I feel all the folders should look the same because some people are still getting used to the fact that they are HIV positive so it's not easy passing through all those people knowing that they are talking behind your back and some staring at you. (F 25-35; WC urban)*

> *F: I think it would be good for Soul City to put it on TV so that more people can know about PMTCT… -F: And emphasise that more men need to use condoms. They must have love for their women; they need to support them. (F 25-35; MP urban)*

> *F: I think TV is the best way to pass information – more people watch TV than read and listen to the radio. But books – the saying goes if you want to hide something from black person*

write it down. So it will be good for people to know that to test they should do 1, 2 and 3. So Soul City does help a lot. (F 25-35; MP urban)

W: What I want to say is that women's bodies are different. That pill is good for some women and not good for others. I remember when I was in labour with my second child, I was given that pill and I vomited. I just couldn't take it. Then I went to the hospital; I went there very early so they checked me again and they gave me another pill. At least with that one I did not vomit...-W: Yes, it can be a problem because if you vomit what will happen; by the time you arrive at the hospital it will be too late. The baby will be coming and you won't have another chance to get that pill. (F 20-30 NW rural)

F: if you could use your voice to push govt to teach people – we have learned everything we know from NGOs. When we test we find the NGOs here. Even the nurses at the clinics leave on Friday and come back on Monday. It means on the weekend there is no one to help us people with HIV. So without the NGOs we wouldn't survive. We don't have allowance and access to nurses at the clinic. They tell you, everyone will be back on Monday. (F 25-35; MP urban)

Discussion

Many people know or have heard about the PMTCT programme. In the general public group discussions, the participants said they have heard about the pill that helps prevent babies from getting HIV from their mothers and some had seen people they know having gone through the programme successfully. The study shows that people who are in programme were satisfied with the process and were hoping that more people could learn about the PMTCT programme so that many children could be saved from HIV.

The role of NGOs and support groups was highlighted as an important part of the programme and the participants recommended that more NGOs be involved because they felt that this would be the only way for the larger public to be informed about the benefits of the programme. NGOs play a major role in providing support and information to people in the programme and this seems to help the health professionals to focus on the clinical side of the programme.

The findings show that the use of condoms among married couples and people living together is still very lax, even among those who already know their HIV status. This leads to many unplanned pregnancies and it could pose a challenge to the PMTCT programme. There is a need to strive towards getting men involved in planning for pregnancy and following all the guidelines towards saving their unborn babies, including the use of condoms after conception.

The communication strategy needs to highlight that for the success of the programme and for the nation to benefit from it, people should be prepared to understand and follow the guidelines of the whole programme and not rely on taking the pill in isolation, hoping that it will do all the work.

There are other requirements, as mentioned by the participants that need to be observed for couples to successfully get the desired results; to have children that are born free of HIV. The emphasis would include the use of protection and the follow up on infant feeding; all these call for proper planning and attending the pre-natal clinic early in the pregnancy.

Conclusion

The study shows that the PMTCT programme is up and running in the country and its guidelines are well understood by both the health workers and people who have been involved in it. The research also confirms the importance of communication around PMTCT for the benefit of the general public.