EXPERIENCES OF PMTCT SERVICES BY HIV+ MOTHERS IN THE EASTERN CAPE OF SOUTH AFRICA

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Abstract

A performance assessment aimed at getting information on operational quality of PMTCT services among health facilities in a resource-poor municipality of the Eastern Cape was conducted in 2004. This paper reports findings of a sub-section of the performance assessment, i.e. experiences of the PMTCT programme by HIV+ mothers. A focus group study was carried out among a convenient sample of 109 HIV+ mothers who were on the PMTCT programme in four health facilities offering the programme. Ten focus group interviews were conducted with these women by trained moderators.

Generally, participants had a good basic knowledge of HIV/AIDS during pregnancy and a good understanding of the PMTCT programme, how it works, why it is necessary and its different components. While participants acknowledged that they received ANC, delivery, PNC and infant care services as well as quality information on the PMTCT programme, they felt that the quality of the programme and ability to comply with required feeding practices were compromised by various factors. These factors included improper conduct of some nurses, technical care sometimes not given (e.g. not examined), inadequate supplies (NVP/formula not available), poor health care organization, and inaccessible health care facilities with limited space as well as too long waiting time. Participants also indicated that they experienced lack of emotional and financial support, stigma and discrimination from their spouses, families and communities. In terms of support groups for PLWHA, participants indicated that support groups were beneficial to them spiritually, socially, emotionally and psychologically. The information emanating from this study should be considered when identifying best practices for expanding and providing PMTCT services.

Key words: PMTCT, Eastern Cape, HIV/AIDS, South Africa

Introduction

Mother-to-child transmission (MTCT) is by far the largest source of HIV infection in children below the age of 15 years (Peltzer, Skinner, Mfecane, Shisana, Nqeketo & Mosala, 2005: 27). An estimated 200 million women around the world become pregnant each year, of which 2.5 million are HIV-positive (UNAIDS, 2002:5F). At least half a million infants and children have already died from AIDS, undermining child survival gains made in earlier years through comprehensive child health programmes (UNICEF, 2003: 8). HIV/AIDS accounts for 7.7% of deaths of children under five years of age in Sub-Saharan Africa and in certain countries accounts for more than 40% of deaths (Walker, Schwartlander & Bryce, 2002: 284). Based on annual antenatal surveillance, approximately 34.5% of pregnant women between 25 and 29 years were HIV+, and about 29.5% of pregnant women aged 30 to 34 were living with the virus in South Africa in 2001. In 2004, an estimated 37 000 children in South Africa acquired HIV from their mothers around the time of birth and an additional 26 000 children were infected with HIV through breastfeeding (Medical Research Council, 2004: 15). MTCT is an overwhelming source of HIV infection in young children (De Cock, Fowler, Mercier, de Vincenzi, Saba & Hoff et.al., 2000: 1175). Prevention of mother-to-child transmission (PMTCT) programmes have now been introduced in most countries affected by the epidemic with programmes moving from pilot projects to national programmes in Kenya, Malawi, Uganda, Botswana and South Africa (Chopra, Doherty, Jackson & Ashworth, 2005: 350).

The overall prevalence among antenatal care attendees for the Eastern Cape Province of South Africa has risen to 27.1% in 2003 (Department of Health, 2003: 10). It is also estimated that, in the Eastern Cape Province, there are 50,000 HIV positive children who acquired their infection from their mothers (Department of Health, 2005: 5).

The South African PMTCT programme which began in July 2001 targeted all 9 provinces for PMTCT interventions. At that time, it was determined that the PMTCT program would start on a small scale with two pilot sites in each province to look at the operational issues inherent with the introduction of PMTCT services and to ensure that

the lessons learned from the pilot sites would inform broader implementation of PMTCT services. In the Eastern Cape, the two pilot sites where Cecilia Makiwane Hospital with its feeder clinics and Rietvlei Hospital.

In July 2002, the constitutional court issued a court order ordering the South African government to make PMTCT services available to all pregnant women using public health facilities. The PMTCT programme has since then expanded in compliance with the court order. The basic minimum package of PMTCT services in line with WHO guidelines (WHO, 2001: 2) includes: VCT; provision of Nevirapine (NVP) for the mother and the infant, infant feeding counseling, replacement feeding for women who have made an informed decision to use replacement feeds, follow-up testing of the infant at 12 months. The national program has expanded rapidly during the last 12 months. As of July 2004 the national coverage of PMTCT services was 45%, with at least KwaZulu Natal, Gauteng, and the Western Cape Province achieving almost universal coverage of PMTCT services. Expansion in the other provinces has varied. Recent provincial reports indicate that there are approximately 2064 PMTCT sites around the country. On the basis of VCT uptake and sero-positivity rates, it is estimated that 6,343 HIV+ pregnant women have been identified in the national PMTCT sites (McCoy, Besser, Visser & Doherty, 2002: ii). However, the recorded number of HIV+ women who have delivered with the administration of NVP to both mother and baby is 1,932. Some of the reasons for this large difference in numbers are: HIV testing usually occurs several months before delivery; women accessing the PMTCT service antenatally may deliver elsewhere and an under-recording of statistics in the labour wards. The experience with implementation of PMTCT services has varied considerably, with some provinces and sites doing well, whilst others have struggled (McCoy et.al., 2002: ii). Many of the difficulties and constraints to full and effective implementation were identified as being systemic in nature (as opposed to the functioning of the PMTCT programme specifically). Expansion of services in the Eastern Cape has been extremely challenging due to the vastness of the province and limited resources. This province is economically disadvantaged, with relatively inadequate access to services compared to the other eight provinces. In 1996, 68.3% of households in this province had insufficient electricity supply; 46.5% did not have access to basic water supply, and 35.8% did not have access to basic sanitation

(RSA National Treasury, 2001:7). The province has the highest unemployment rate in the country (48.5%), with a per capita disposable annual income of R7800 ($918) (Mahlalela, Rohde, Meidany, Hutchison & Bennett, 2001: 3). The poverty rate (percentage of population in poverty) was estimated at 63.3% (Mahlalela et.al. 2001: 4), the second highest in the country. However, despite these obstacles, there are approximately 302 facilities offering PMTCT services (37.6% coverage). In addition, the province boasts 15 "master" trainers and 64 trainers for PMTCT. These numbers mean that each Local Service Area has sufficient numbers of trainers to cascade the PMTCT and Infant Feeding Training Course throughout the province.

The WHO guidelines require that a health care facility be fully equipped if it is to effectively provide PMTCT services. However, in South Africa, the majority of health care facilities do not meet this standard. Problems like staff shortage, poor delivery of medication, lack of proper consultation and counseling rooms, are experienced in several health institutions throughout the country. A 2002 evaluation of 18 PMTCT pilot sites (Doherty, Besser, Donohue et.al., 2003: 15 and Doherty, McCoy & Donohue, 2005: 213) in all provinces found an HIV prevalence of 30% among women tested and 85% of tested women received their results, only 55% of HIV+ women attending the pilot facilities received nevirapine prophylaxis. By December 2005, the South African government PMTCT programme had been implemented in 77% of public health facilities but a large portion of pregnant women still do not receive HIV test during pregnancy and less than 50% of pregnant women known to be HIV+ receive NVP at the time of delivery. Implementation of the PMTCT programme remains a challenge, especially in poor rural areas. HIV/AIDS usually raise difficult and personal issues such as health, relationships, financial security, death or emotional feelings about sexuality. Other people's prejudices, discrimination and wider social and economic issues also cause many problems for the people living with or affected by HIV.

There is a growing consensus among those involved in implementation of PMTCT interventions that questions remain concerning factors influencing the potential success of such efforts. In the light of the above-mentioned, a performance assessment of all key health facilities providing PMTCT services in a resource-poor municipality of the Eastern Cape was conducted in 2004 in order to get information on operational quality at the

level of service provision as well as assess knowledge and perception of quality of services with the overall goal of identifying best practices for expanding and providing PMTCT services. This paper reports findings of a sub-section of the performance assessment, i.e. experiences of the PMTCT programme by HIV+. The rationale for the study was to come up with best practice guidelines for PMTCT so as to help improve the effectiveness and efficiency of PMTCT services and inform any planned expansion of the programme.

Methods

Design and setting

A qualitative focus group study was carried out among HIV+ mothers who were on the PMTCT programme in the four health facilities offering the PMTCT programmes in a rural district of the Eastern Cape (EC) Province. The EC Province is situated along the south-east coast of South Africa and covers an area of 170 000 km^2, representing about 14% of the country's landmass. It has a population size of approximately seven million, representing 16% (third largest) of the South African population (RSA National Treasury, 2001: 3. The non-urban population amounts to nearly 4 100 000, and dense concentrations of rural and peri-urban settlements occur in other districts and areas. The EC is beset with huge backlogs in infrastructure and problems related to poverty and underdevelopment, inherited from the apartheid era. The population of the district in which the study was undertaken is 1.8 million people, with an average population density of 114 people per square km. Some 65% of the people are unemployed, 49% do not have access to sanitation and 77% do not have a safe water source. The majority of health care facilities in this district have no water or electricity. Shortage of doctors is a major problem affecting the quality of care in the district hospitals. The main health problems in the district are TB, HIV/ AIDS, STIs and poor maternal and child health (which includes malnutrition) (Stats SA, 2005: 14).

Sample and procedure

A convenient sample of HIV+ women who were members of the PMTCT programme participated in the study during the month of July 2004. These women were approached by the PMTCT programme co-ordinator to join the focus group discussion on the day they visited the clinic for attendance of their PMTCT meetings. Ten focus group interviews were conducted with these women in four health facilities (1 hospital, 2 clinics and 1 Community Health Centre). There were six participants who refused to participate. A final sample of 109 PMTCT mothers (all Xhosa by ethnicity) was drawn from the four health facilities. The mean age of the participants was 24.5 ranging from 14 to 45. They generally had a low level of education and low socioeconomic status and were generally unemployed. About 50% of them were married.

Focus group guiding questions

The following eight questions were used to explore participants' experiences of the PMTCT programme:

- *What is your understanding of HIV/AIDS during pregnancy?*
- *Can someone explain the PMTCT programme? (How it works, why we need it, what are the different components of it)*
- *Why it is important to promote the PMTCT programme?*
- *Recall about the type of PMTCT services offered including ANC, delivery, PNC and infant care.*
- *Recall about the quality of PMTCT and related services received including treatment of infant.*
- *What is your ability of the mother to comply with appropriate infant feeding practices?*
- *What is the role of the support group in your life?*
- *What are the actual and or perceived challenges in the provision of PMTCT*

Conducting Focus Group Interviews

Moderator selection and preparation: 2 moderators were selected (1 peer facilitator and 1 researcher) as facilitators or moderators of focus group discussions. These moderators were chosen because they assessed, among others, communication skills such as listening, probing, reflecting, paraphrasing, attending, observing and responding which researchers maintain that they are necessary when conducting focus group interviews (Clark, Riley, Wilkie & Wood, 1998:137-138; De Vos & Fouché, 1998:90; Feldman, 1995:31; Lindlof, 1995:33 and Schurink *et al.* 1998:319). However, further training was provided to the moderators to ensure that they were well prepared to deal with anticipated problems such as the disruptive behaviour of an emergent leader among participants and also to help them to: develop a genuine interest in hearing other people's thoughts and feelings, become spontaneous, have a sense of humour, become empathic, be able to admit own biases, express thoughts clearly and be flexible.

Size of focus groups: The average number of participants in each group was 10. The group size was small enough for all the participants to have the opportunity to share insights, to identify themselves as members, to engage in face-to-face interaction and to exchange thoughts and feelings among themselves. It was also large enough to provide diversity of perceptions as recommended in literature (Schurink *et al.* 1998:317; Feldman, 1995:39 & Smit, 1995:26; Leggett, 1997: 14 & Folch-Lyon et al, 1981: 443).

Procedure: The procedures followed for the focus group interviews were derived from Krueger (1994: 113). The field work team was warmly welcomed. The team members introduced themselves. Accordingly, the moderators welcomed the participants, thanked them for taking time to meet with them and put them at ease. They made them feel relaxed in order to develop trust amongst themselves. The first question was posed and this served as an "ice-breaker" to create a comfortable environment in which participants felt free to share their opinions. The purpose of the focus group discussion was explained to the participants prior to the beginning of the discussion. The team indicated that they were there to explore their experiences of PMTCT services. They indicated that the information gathered would help the district municipality to fine-tune and improve its *ongoing* PMTCT efforts. The moderators reassured participants that all views were

acceptable; they were free to argue, disagree, question and discuss issues with others in the room. Participants were also requested to enlist their names on the attendance register. The moderators then moved on to the subsequent questions, ensuring that opinions were elicited from all the participants, while encouraging and maintaining a lively and relevant discussion. It was necessary, from time to time, to "probe", in order to elicit additional information or clarification. Moderators took notes using notepads and recorded the focus group discussions on audio-tapes. The discussion of focus group interviews was recorded accurately without neither changing the words nor leaving out material. The moderators observed and recorded non-verbal cues in each group, e.g. the emotional tone of the discussion, important hand gestures and unusual behaviour. All fieldwork team members took notes in order to ensure that all information was captured. The discussion facilitator also wrote key points on the flip chart. The researcher combined her notes, the notes transcribed from the tape, the notes compiled by field work team members and the key points highlighted on the flip chart in compiling each focus group discussion report. The focus group discussions were conducted in Xhosa. Each focus group discussion lasted for about two and half hours. Issues of confidentiality were discussed. Every participant, the moderators and the researcher was assured of confidentiality.

Data analysis

After fieldwork, qualitative data analysis was conducted. The researcher and moderators observed the guidelines for analyzing qualitative data as outlined by various researchers using a phenomenological approach (Poggenpoel, 1998: 334-337 in De Vos; Miles & Huberman, 1994: 10 and Clark *et al.*, 1998: 113). They:

- Paid attention to words and phrases in participants' own vocabularies that capture the meaning of what they do or say;
- Identified different themes and looked for underlying similarities between them;
- Named and categorised themes (open coding); and
- Made connections between a category and its subcategories (axial coding)

The researcher did open coding, i.e. identifying, naming, categorizing and describing phenomena. Essentially each line, sentence, paragraph was read in search of the answers

to the questions which had been asked. Axial coding was done, i.e. relating categories in focus group interviews' data. Subsequently, thematic content analysis was done, i.e. categories were generated using techniques such as checking for word repetitions, key words in context, cutting and sorting.

Trustworthiness

Qualitative data analysis requires clear, explicit reporting of data so that the reader will be confident of, and can verify, reported conclusions. It requires keeping analytic strategies, coherent, manageable and repeatable as the study proceeds (Miles and Huberman, (1994:439). The researcher adopted various strategies to ensure trustworthiness of the interpretation of the data espoused by Miles and Huberman (1994: 262-277). These included:

- *Participant checking:* Periodic feedback sessions were held to present the results of the data collection to the participants to test whether they agree with them.
- *Data cross-checking:* this activity involved the researcher stepping back to consider what the analyzed data mean and to assess their implications for the questions at hand. This helped the researcher to ensure that the data are credible, defensible, warranted, and able to withstand alternative explanations.
- *Moderator reviews:* the focus group moderators had regular meetings to cross-check the quality of each other's data sets.
- *Ongoing reflection on data:* the researcher began the analysis almost in tandem with data collection. This helped the researcher to identify tentative interpretations or emerging hypotheses during the fieldwork process. While some of the hypotheses were refined or overturned or rejected at the end of the study, they provided an important account of the unfolding analysis and the internal dialogue that accompanied the process.
- *Peer reviews:* the researcher brought two peers who were knowledgeable on qualitative analysis as well as the substantive issues involved in the study, into the analytic process. Approximately 20% of the data were given to these peers to rate the initial codings. These peers served as a cross-check, sounding board, and source of new ideas and cross-fertilization. A 96% agreement rating was achieved.

Ethical Considerations

Ethical approval for the study was secured at the Walter Sisulu University Ethics and Bio-safety committee. Participants were advised on: (a) their status as volunteers, (b) their right to refuse to answer any question, (c) the legal liabilities of their participation, (d) confidentiality, and (e) limitations of anonymity due to the nature of the study. All participants in the study were provided with informed consent information sheets, which stated clearly the purpose of the research. These documents were read out to participants in Xhosa. Respondents were given an opportunity to decline participating before or at any point in the study. The research team answered all participant questions.

Study Limitations

The selection of research sites was not randomly done. The researchers' dependence on the local health authorities in selecting facilities might have affected the nature of the sample, as well as opened up the possibility of selection bias. The researcher also relied on an unpredictable sample size, which depended on the numbers of PMTCT clients visiting the sites during the duration of the study. Participants who were too sick on the day of the focus group were excluded from the sample.

Results

The understanding of HIV/AIDS during pregnancy

Generally, HIV+ mothers had a good basic knowledge of HIV/AIDS during pregnancy. They knew how HIV could be prevented from infecting the unborn baby by indicating that an HIV+ pregnant woman must take NVP tablet to prevent HIV transmission to the baby. They knew and emphasized the importance of getting of VCT when pregnant to determine one's status so as to know whether to breastfeed or formula feed when the baby is born and to take precautionary measures. They knew that condoms are effective in preventing HIV, unwanted pregnancy and Sexually Transmitted Diseases. They also had knowledge on the behaviour to be practiced by HIV+ mothers, i.e. family planning, visiting the hospital regularly, eating healthily, practicing safe sex-condomise, avoiding stress, total sexual abstinence if possible and having only one partner. They indicated that

they learned more about HIV/AIDS during their ANC visits to their respective clinics. Their knowledge became evident in the following expressions:

"When one is pregnant and positive, it does not automatically mean that the child will die. The child dies if one did not know they are HIV+. So it is important to visit the clinic/ doctor at early period of pregnancy (1st month)"
"It is possible for the baby to be born HIV- provided the mother takes NVP"
"It is important for a pregnant woman to go for an HIV test as soon as possible so that she can get NVP in order to prevent HIV transmission to the unborn baby".
"It is important to use condoms during pregnancy to prevent STIs in order to have a healthy baby"

Understanding of the PMTCT programme

Focus group participants were asked about their understanding of the PMTCT programme, how it works, why it is necessary and its different components. Generally participants knew about PMTCT. They had knowledge regarding breastfeeding for HIV+ mothers, i.e. exclusive breastfeeding for 3/12 (no water, no solids, no bottle for 3 months), importance of breastfeeding in creating strong bond between mother and baby and its nutritious value as well as the importance of making sure that the nipples of an HIV+ mother who is breastfeeding do not have sores and the child does not have mouth sores to prevent HIV transmission. They had knowledge regarding formula feeding for HIV+ mothers, i.e. exclusive formula feeding for 3/12, no breastfeeding, and no solids. Further, they had knowledge regarding nutrition, i.e. eating healthy food, avoiding stress and getting family support. They also had knowledge regarding administration of NVP, i.e. giving NVP drops to the new born baby within 72 within hours, getting NVP 8hrs before delivery and that the baby has a chance of living HIV negatively through the intervention of NVP. Participants indicated that women should avoid giving birth at home to avoid infecting the new born baby as they need to get NVP when in labour and the new born baby needs to get syrup within 72 hours after birth. They also knew the importance of disclosing one's status to next of kin especially spouse and VCT.

"I heard about PMTCT here at the clinic. It has to do with knowing how to look after the child especially when one is HIV+; women who refuse to get tested may die or may lose their children"

"PMTCT means you must breast feed for 3 months and not mix with other things"

"It is educational for HIV prevention purposes, it involves family planning, it has to do with practicing safe sex, and also giving NVP drops to the new born baby within 72 hours.

."It teaches how to protect the child from being infected with HIV, One need to get NVP at least 8hrs before delivery"

"Don't use bottle when positive, Breastfeed for 3 months, after 3 months you give the child formula"

"It involves exclusive breast feeding for 3/12 or exclusive formula feeding for 3/12. If the mother wants to breastfeed she may, but only for 3 months. She should not mix feed but should breastfeed only. After 3 months the mother can formula feed".

Importance of promoting the PMTCT programme

Participants indicated that the PMTCT programme should be promoted because it helps one to get professional advice, to make a decision on whether one wants to have a child or not being HIV+, to have the courage to undergo an HIV test, to know one's own status in order to conduct oneself responsibly and to protect the child from being infected. The program should be promoted to prevent stigma, in order for people to use prevention measures, to encourage disclosure, to promote acceptance, to prevent pregnancy, to educate the community because they ask questions when one does not breastfeed, to promote safer sex, have early diagnosis and to equip parents with knowledge because they deny HIV/AIDS and to change risk behavior. Participants further indicated that the PMTCT programme should be promoted because it saves lives; it brings hope to the hopeless. The following expressions were uttered in support of the above-mentioned:

"Some women when they are diagnosed HIV+ they lose hope thinking that their life has ended. The PMTCT program brings back the hope of having a healthy child in spite of the HIV+ positive status"

"It is through being in a PMTCT program that the mother gets formula and NVP syrup and tablet"

"I think it should be the thought of knowing that the child is not born to die. She has a chance of living through the intervention of NVP. It also gives health to mothers /parents who are moneyless for upbringing of their children nutrition wise"

"This program is important because young people are dying. By being involved in this program, the future generation is preserved".

"The PMTCT programme makes me feel that I am not all alone, it provides me with emotional support which I cannot find anywhere"

"The programme must be known to all people through pamphlets, radio, etc. I do not want to imagine how an HIV+ who is not in this programme is dealing with this"

"People will sleep around not using the condom because they don't understand the implications. So this programme is important for youth"

"PMTCT children are to be raised differently unlike other children. They are supposed to be looked after in a different way"

"I had a child in 2000 and she died. After the death of my child I took a test and found that I was HIV positive. I then joined the program and now I have the second child and she is safe now"

"If you don't know your status, you stay in the dark and do the wrong things which will harm your baby"

"My sister was diagnosed positive after a long period of her refusing to test. When she went to the doctor she was already too weak. Her child and herself could not survive. The doctor told her that if she had come earlier she would have been helped; as I am speaking she is dead"

"My child died because I didn't know about this programme then"

Types of PMTCT services received

Participants indicated that they received the following services during ANC: counseling, VCT, general health assessment, immunisations, taught about nutrition, safe sex, and were given condoms, get NVP at 28/52 of pregnancy, education about HIV/AIDS, choice about feeding options, bloods, blood pressure and sugar levels, education about physical exercise and about the effects of traditional medicines. During delivery participants indicated that they received the following services: injection to keep the uterus contracted, general health examination, asked whether they have taken NVP on admission, asked whether they got NVP before giving birth/administered NVP on myself, asked whether it was their first time giving birth and how did they give birth previously, told not to push so that the baby does not get infected, put on drip if the blood pressure has gone high and vaginal examination. During postnatal care (PNC), participants indicated that they received the following services: baby given NVP syrup, given a date to see the doctor again, got injection to prevent excessive bleeding, counseled on how to conduct oneself sexually and how to look after the baby. In terms of infant care, participants indicated that their children had been given BSG, Polio immunisation and multivitamins. They were also taught about feeding practices such as how to use mug to feed the baby and the measurements thereof; how to keep the child's eating utensils clean i.e. putting the child's eating utensils in boiling water; what to feed the child with after 3 months, e.g. giving the child fresh fruits rather than preserved fruits because they are less nutritious. They were told to follow immunizations according to schedule. The infants were given bacterium syrup, bottle of cotromoxazole and supplements. Mothers were given more education on hygiene, weight and growth monitoring, formula supply (at least 8 tins per month). They were also told to collect 8 tins of formula monthly, to visit the Doctor monthly for general physical examination. This phrase captures PMTCT services received:

"I came for a test at 6 months. At 7 months I was given NVP and when I was in labour at home, I took NVP, my baby is now HIV-".

Quality of PMTCT services received

Quality of PMTCT services was assessed within seven categories, namely: programme information received, conduct of staff. technical care, supplies, health care facility, and health care organization and waiting time.

PMTCT Programme information received: Participants felt that the quality of the PMTCT programme in terms of offering information was good. They felt that the information received was detailed and clear. They knew what PMTCT is all about, how the programme works, why it is important and its different components.

The PMTCT programme quality is good. The programme educates us, empowers us, helps us to accept our status and saves our children"

Conduct of staff: While some participants indicated that the quality of the programme was good because nurses were supportive as they showed care and compassion and respected their privacy; other participants indicated that the quality of the programme was compromised by those nurses who showed discriminative attitudes.

"Some of the nurses used to shout at us saying we are too many and that they even regret why they tested us".
"When we get to the clinic some of the nurses label us saying "Abantu baka Lulu (meaning Lulu's (a nurse) people) or abantu baka Nomsa (meaning Nomsa's (a nurse) people)", Nomsa and Lulu are not here today".
"I was tested and came for results. I was ill-treated and not given the results for my status. As I was leaving, the water broke and immediately I gave birth to the child. I didn't get NVP though the baby got the syrup".

Technical care: participants indicated that they generally received quality care during ANC, delivery, PNC and infant care. The only factor which they felt compromised the quality of care was the nurses' requirement of morning urine before examination without which they do not provide PMTCT services.

"If you don't have urine you won't be examined because they need morning urine".

"Sometimes you fall ill during the day having not kept the morning urine; you are forced to stay at home because the nurses will not attend to you"

"Sometimes one forgets to keep the first morning urine. One ends up cheating and just keeping urine collected during the day so that the nurses can attend to her"

"I find it rude not to be examined because of not bringing urine with, what if I woke up not knowing that I'll feel sick that day? Obviously I would not have kept the morning urine".

Supplies: participants felt that the quality was not good since facilities provided inadequate formula for mothers, sometimes there was shortage of formula supply at the clinic and some facilities did not have Rapid HIV Testing resulting in not knowing one's status immediately.

"The formula supplied by the clinic is not enough to last for a month".

"Sometimes when we go to the clinics to fetch formula on a scheduled date we are told that the formula is finished and when the formula comes, we are not given the formula in retrospect. If it was out of stock that month you forfeit it"

"The facility is using laser, which means clients have to come back some other time for the results. Sometimes clients deliver before getting the results, which then means the client had not enrolled onto the program and therefore did not receive the NVP tablet. In these cases only the baby receives the NVP syrup; sometimes people never come back to check the test results".

"I went for ANC and got tested but never knew my results. I only discovered that I was positive when I was given NVP during labour and when I saw my baby being given NVP syrup after birth"

Health care organization: Some of the participants said the PMTCT program was of good standard because it made them feel accepted and cared for, support groups were helpful, because they were able to disclose their status to their next of kin. However,

others felt that the health care organization was not good enough since they are sometimes returned home without receiving services because the nurse who is supposed to be helping them is not present at work that day.

"We get treatment, formula, you feel you are being looked after, the support group is powerful, etc"

"Some nurses would just say come tomorrow, nurse so and so is not in today. You end up not coming because you do not have travel money to go to the clinic again".

Health care facility: participants indicated that there were no resting places in the health care facilities. People have to sit under tree shadows. The small space was regarded as reducing proper reception of people who are ill. Water was reported to be available and toilets were reported not to be very clean. Sometimes, privacy and confidentiality were compromised due to lack of space. They further indicated physical accessibility of the health care facilities was sometimes a problem because they are far and because of the expenses involved.

"Our clinics are very small to accommodate all patients"

"Requesting all pregnant women to go to the district hospital outpatient ward for the first and second antenatal visit can increase the difficulty of seeking care, as the amount of travel time and transportation costs increase. The costs of traveling should not be an obstacle for women to access the intervention".

"Continuity of care and adherence is one, if not the most important, issue the system must address successfully. First, women need to return to obtain the results of their HIV test. Then they need to go back for each of the important subsequent steps. Finally, they need to comply with their treatment".

Waiting time: participants indicated that there was insensitivity towards patients who needed urgent attention as well as general laxity in dealing with patients in very long queues.

"We sometimes spend the whole day in queue and nurses don't bother"

"Nurses take their time during lunch and tea breaks and when it is time to knock off, they stop working irrespective of whether or not there are still patients on the queue"

Ability of the mother to comply with feeding practices

Participants indicated that there were challenges in complying with feeding practices. The challenges ranged from family pressure, limited access to clinics, shortage of formula in clinics, shortage of formula in nearby shops and financial difficulties. While they knew safe feeding practices, they experienced pressure from their next of kin to breastfeed because of lack of understanding. Some parents thought mothers deliberately did not want to breastfeed because they wanted boyfriends or they wanted to sleep around. Participants further indicated that sometimes parents want to give their babies traditional medicines, which is not allowed. Family members also persuaded mothers to feed children with other foods such as "Nestum". Participants also indicated that they sometimes found it difficult to comply with proper feeding practices because their nearest clinic has run out of formula or they have transport problems to get to the clinic to collect formula or do not have money to buy formula in the nearest shop or they have money to buy formula in the nearest shop but it is out of stock or it is never sold in the nearest clinic.

"Other women choose to breastfeed only because the costs of infant formula feeding are high"

"Family members insist that the baby should be given solids within the first three months so that s/he grow quickly and be strong"
"Some family members say: what type of a baby is this that does not breastfeed?"

Experience of support groups in HIV+ mothers

Participants indicated that support groups provided a sense of belonging, an environment to openly express and share own feelings, relieve stress, provided emotional and mutual support. They indicated that support groups provided insight on HIV/AIDS and related issues, prepared them for becoming comfortable with disclosure of their HIV status, educated them about their human and legal rights and promoted positive living with HIV.

Participants indicated that support groups relieve them emotionally because they are stigmatised in their communities. The general feeling about HIV/AIDS in the community is negative; HIV/AIDS is a taboo subject. Participants indicated that they sometimes are ill-treated by some community members. Support groups help them to cope with above challenges because they share them.

"I agree with the saying that a problem shared is half-solved. The beginning of the solution to the problem is to share it".
"A child, who does not cry, dies unnoticed".
"We support one another and lead exemplary life to show people that HIV/AIDS is not the end of life".
"Support groups help us to learn, grow, support each other and share burdens"
"I always feel comforted after attending the support group because I feel loved and cared for"
"The PMTCT programme makes me feel that I am not all alone, it provides me with emotional support which I cannot find anywhere"

Challenges experienced by mothers in the PMTCT programme

Participants identified challenges which they experienced about being in the PMTCT programme. These challenges are family, finance and community related.

Family related challenges included lack of support and cooperation from spouses and in-laws.

"Our husbands don't want to use condoms- they say "Inkomo zethu azina kuphumela iplastic", literal translation: "their cows could not be given to the wife's family for using a plastic", meaning that they defy using condoms saying it is their right to sleep with their wives without a condom because they have paid lobola for them.
"Sometimes our husbands accuse us for being lose and for having brought the virus saying "ngobubufebe bakho" meaning "it is because of your mischief and sexual promiscuity that I contracted HIV".
"Sometimes when telling our husbands that there is a disease called HIV/AIDS and that they are suffering from the disease and asking them to go for an HIV test, they refuse saying: "suka, ayikho lonto, meaning shut up, there is nothing like that".
"Once the in-laws know that their "Makoti" meaning "Bride" is HIV+ they don't give any support. They start accusing you that you have brought AIDS to their son.
"We are sometimes accused by our in-laws that we do not want to breastfeed because we do not want to smell milk so that we can attract other men"
"Sometimes our in-laws refuse us to go to the clinic for our meetings. When you go to the clinic they say Uya emadoden, meaning she is going to her men".

Financial challenges. Participants indicated that some of them stay far from clinics; they do not have money to go to the clinic as often as required. They wished to be given financial support to attend clinic visits.

"Most of us are unemployed. Whenever we ask for transport money to go to the clinic, we are sometimes not given"
If formula gets finished before the clinic's stipulated period, we have to buy formula from the supermarket. If we do not have money, we are left with no option but to mix feed".

Community related challenges

Some of the participants indicated that they were afraid to disclose their HIV status because once people in their communities know; they are stigmatized and discriminated against. They felt that awareness rising in communities is critical.

"People out there do not accept us, they think we were being promiscuous; they distance themselves and laugh saying she has a disease with "Amagama amathathu" meaning a disease with three words".

"People whisper saying: "Don't touch that one, she has a disease with three names; once people know that you are HIV+, you become a laughing stalk"

"People continue to make fun of us"; husbands and boyfriends ask sometimes why is it that mothers are not breastfeeding, and go on to say "if you are HIV positive I will kill you".

"Some family members discriminate against us saying: You do not deserve anything because you are going to die",

Discussion

Understanding of HIV/AIDS during pregnancy

In the current study, women had a good knowledge of HIV/AIDS during pregnancy. This is not surprising given that previous studies have shown that females have more knowledge on HIV/AIDS than their male counterparts. For instance, Phaswana-Mafuya and Peltzer (2005: 139) in a study involving staff members at institutions of higher learning in the Eastern Cape, found that female participants (M=5.9, SD=1.2) had significantly more HIV knowledge than male participants (M=5.4, SD=1.6) (t=-4.41, p<. 001). Similarly, in an adult survey conducted by Peltzer (2003: 15) in a rural community

of Phalaborwa, women had more HIV/AIDS knowledge than men. Abdool-Karim *et al.* (1991: 340) also found among urban black mothers in Durban, and Abdool-Karim (2001: 193) found among women aged 14 to 44 years in a peri-urban and a rural community in KwaZulu Natal that the levels of their AIDS knowledge were high. Important to note is the fact that HIV infection has increased among women globally and nationally. The figures are alarming: 19.2 million of the 38.6 million adults (aged 15-49) living with HIV/AIDS are women (UNAIDS, 2006: 2). In Sub-Saharan Africa, 58% of the HIV positive adults are women. Globally, the incidence of HIV/AIDS among women has risen at a shocking rate. In 1997, 41% of HIV infected adults were women and this figure rose to 50% at the end of 2002. In 2002, the prevalence of HIV infection among South African women attending antenatal clinics was 26.5% (South Africa, 2003: 33). Among all 15- to 24-year-olds, 12% of women were infected, compared with 6% of men (Shisana & Simbayi, 2002: 44). While women's greater biological susceptibility to HIV helps explain this difference, a host of sociocultural and economic factors rooted in gender power inequities exacerbate women's vulnerability to infection. Therefore, knowledge alone is not a sufficient condition for behaviour change and positive attitudes, but it at least a step in the right direction.

Understanding of the PMTCT programme and the importance of promoting it

Participants had a good understanding of the PMTCT programme, how it works, why it is necessary and its different components. They had knowledge regarding required breastfeeding practices for HIV+ mothers, formula feeding for HIV+ mothers, nutrition, administration of NVP, VCT and disclosure of one's status. Similarly, Peltzer et.al. (2005) found that 90% of the pregnant women surveyed in four districts offering PMTCT in Eastern Cape Province, had received adequate information on most of the PMTCT components such as HIV testing, counseling, confidentiality, NVP dosage, feeding options and disclosure of HIV status to spouse. In the same vein, Jackson et.al (1997: no page number) also found, in their structured observations of consultations and exit interviews with women in 3 different PMTCT pilot sites in South Africa, that women were well-informed about the PMTCT programme, i.e. 73% of HIV- women were

informed of the advantages of exclusive breastfeeding (EBF); most women were told what the nevirapine was for and when and how to take it. Further, Creek, Ntumy, Mazhani, Moore, Smith , Shaffer, Kilmarx (2004: no page number), in a study of midwives and counselors based in public healthcare facilities in Francistown (Botswana) found that knowledge of PMTCT drug and infant feeding protocols was high. Contrary to the current study's findings, with regard to women's knowledge, Jackson et.al (1997: no page number) found that there was substantial confusion regarding the risks of breast-feeding and formula feeding, however a majority understood mixed feeding to be a risk for both HIV transmission and other infections. It could then be concluded that the PMTCT programme rendered to women in the current study complied with the national protocol which states that the PMTCT programme should cover health education on ARV treatment and feeding options for pregnant women, VCT, supply of NVP pack, free formula provision and PMTCT integrated to ANC (Peltzer et.al., 2003:2).

Types of PMTCT services received and perceptions of their quality

While participants acknowledged that they received ANC, delivery, PNC and infant care services as well as quality information on the PMTCT programme, they felt that the quality of the programme was compromised by various factors. These factors included improper conduct of some nurses, technical care not given sometimes (i.e. if one does not have morning urine), inadequate supplies (i.e. irregular supply of formula and NVP), poor health care organization, inaccessible health care facilities with limited space as well as too long waiting time. These factors also affected the ability of mothers to comply with required feeding practices. Mashego and Peltzer (2005: 19) in a study of community perception of quality of primary health care services in a rural area of Limpopo Province, South Africa, also found that participants were negative on items related to health personnel conduct (poor reception, poor communication, discrimination, lack of care and compassion and lack of respect for privacy); technical care (lack of examination, lack of explanation of treatment, poor responsiveness and poor treatment outcomes); drugs (lack of availability, lack of explanation and effectiveness of drugs). Data from the 2003 primary health care facilities survey for the Limpopo Province (Health Systems Trust,

2004:9f) also found lack of equipment, poor and lack of infrastructure and lack of drugs, to compromise the quality of care. Mavundla (1998: 28), also found among rural patients in the Eastern Cape of South Africa that the majority (75.5%) commented about medicines which were usually out of stock in the clinics. In a study by Gilson, Alilio and Heggenhougen (1994: 772) on community satisfaction with health services in Tanzania, lack of drugs was expressed as a problem by some respondents. The findings in this regard are very important because views of patients are attracting more and more importance (Donabedian, 1980:4ff; WHO, 1990:15ff). Patients' perception of quality of care is critical to understanding the relationship between quality of care and utilization of health services (Baltussen et.al., 2002: 42; Reerink & Sauerborn, 1996: 131).

Experience with support groups

In the current study it was found that support groups were viewed as beneficial to PMTCT mothers spiritually, socially, emotionally and psychologically. This experience with the definition of a support group as a structure or meeting wherein people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning, such as emotional, spiritual, physical and psychological needs (Department of Health, 2003: 12). Philips (1998: 24) states that support groups provide a listening ear, acceptance and reassurance, which are therapeutic to an individual. Similarly, other studies have shown that support groups provide an environment where people who share similar life stressors or affliction can share information, knowledge, ideas and experiences (Summers, Robinson, Zisook, Atkinson, McCutchan, Deutsch et al, 2000: 262). Support groups are ideal for dealing with the effects of stigma, isolation, loneliness and other consequences of being HIV positive (DoH, 2003). Miller and Cole (1998: 49), Moskowitz (2003: 620), and Summers et al in Visser et al (2005:333) note that social support groups or social networks have been shown to prolong the lives of those involved as compared to counterparts not involved in such networks. Cohen, Gottlieb, & Underwood (2000: 4) maintain that psychosocial support, through support group activity, promote health and well being.

Challenges experienced by HIV+ mothers

Participants indicated that they experienced lack of emotional and financial support, stigma and discrimination from their spouses, families and communities. The results in this regard are not surprising given the fact that researchers point out that at the time when those infected with HIV really need social support the most, PLWHA who reveal their status are often subjugated to victimisation and discrimination and this has even, at times, resulted in death of PLWHA (Ramlagan, Petros, Simbayi, Arihihenbuwa, & Brown, 2006: no page number). This happens everywhere starting from their own homes, within the communities they live in, as well as at work. In a similar study of pregnant women within the PMTCT programme in Gauteng, South Africa, Dorkenoo, Gumede, Maluleke and Shaikh (2003:20f) also found that stigma persists at the family and community level. Peltzer, et.al. (2005: 38) in their study of factors influencing the utilization of PMTCT services by pregnant women in the Eastern Cape, South Africa, also found that women were isolated, insulted, excluded from family and community events because of their HIV status. It could be reiterated as in Peltzer et.al's study (2005: 38), that community education and awareness campaigns on PMTCT are essential components for the success of the programme. Such education should reinforce male involvement and other family members, particularly mothers-in-law, who have influence over the options open to women who are HIV+. Bassett (2002: 347) argues that men need to hear advocacy messages concerning their responsibility for caring for their families, and therefore to support their partners getting comprehensive pregnancy care, including PMTCT. South Africa, which is believed to have the second largest number of people living with HIV/AIDS (PLWHA) in the world after India (UNAIDS, 2006: 22), has an estimated HIV prevalence rate of 10.8% among all people aged 2 years and older (Shisana, Rehle, Simbayi, Parker, Bhana, Zuma et al, 2005: 15). Visser, Mundell, Villiers, Sikkema and Jeffery (2005: 333) argue that PLWHA suffer in silence that can contribute to the development of depression and hopelessness. As such, the health and well being of PLWHA is seriously compromised. In order to improve the quality and sustainability of PMTCT services, and to ensure a smooth and effective expansion of the programme, the challenges highlighted above must be addressed concurrently.

Conclusion

In this qualitative study with HIV+ mothers about their perception of PMTCT services, a number of positive aspects of PMTCT service deliver were acknowledged such as the provision of adequate information on HIV/AIDS during pregnancy, the importance of PMTCT and the provision of PMTCT services in various stages from ANC, delivery, PNC and infant care. However, some challenges were highlighted regarding conduct of staff, technical care, health care facility, health care organization, and shortage of supplies, long waiting period, stigma and discrimination. These factors not only compromise the ability of mothers to adhere to required feeding practices but compromise the overall quality of PMTCT services. The findings suggest the need to look closely into improved availability of supplies, i.e. an uninterrupted supply of NVP, rapid HIV tests and related laboratory supplies. There is a need for government to give support to clinics to provide adequate services. Further, the results suggest the need: for improved attitude of service providers towards patients – an attitude which communicates empathy and compassion. Improving staff attitudes at the same time developing their knowledge and skills are important elements of the success of the PMTCT programme. The findings highlight the need for improved physical accessibility. Inadequate physical space and privacy has hampered the ability to provide adequate counseling and HIV testing services. Plans to upgrade the physical infrastructure of PHC facilities across the Eastern Cape Province and other South African provinces need to be expedited. The study further suggests the need: for massive community education, social mobilisation and awareness to alleviate community stigma, family pressure, spousal abuse and improve disclosure of HIV status by HIV+ mothers; for programs that make HIV positive women financially independent; and to strengthen support groups of PLWHA as they provide opportunities for information/experience sharing as well as strength psychological well being of infected and affected persons. Community stigma and stigma in health care settings should be recognized and addressed by PMTCT managers, e.g. fostering couple and community discussion on HIV and by normalizing HIV counseling, testing and care. Meeting basic needs of PMTCT mothers is a key priority. Policy makers

should respect these patient preferences to deliver effective improvement of the quality of care of PMTCT services as a potential means to increase utilization of health care.
This study shows great need for more work in the PMTCT area in order to put into place systems that can address the gaps in order to bring some improvement in health care delivery. Future research can engage the concerns raised by these mothers in the present exploratory study in a broader survey using more quantitative data for further information towards intervention that encompasses the most important component of quality assurance, viz. user satisfaction that is based on the experiences of the consumers themselves. This study has highlighted important issues to be considered in improving the effectiveness and efficiency of PMTCT services and to inform any planned expansion of the programme. It is important to mention that some of the above-mentioned recommendations have been incorporated in a procedures manual which has been developed and is currently being disseminated throughout the Eastern Cape Province as a PMTCT mentoring tool.

Acknowledgements

Regional Training Center of Walter Sisulu University for making resources available to conduct the study
Eastern Cape Department of Health for providing permission and support
HIV+ mothers who consented to participate in the study
Authorities in the health facilities where the study was conducted for giving permission to conduct the study

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