Influence of the home environment on the prevention of mother to child transmission of human immunodeficiency virus/acquired immune-deficiency syndrome in South Africa

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\section*{Abstract}

The human immunodeficiency virus and acquired immune-deficiency syndrome (HIV/AIDS) is still a ‘family crises’ which marks the beginning of the deterioration of the family unit and the trauma in the emotional, psychological and material lives of both the mother and child. In South African context where the majority of HIV-positive mothers are young single women who live in extended families, disclosure to the sexual partner alone is not an adequate condition for the success of prevention of mother to child transmission (PMTCT). In South Africa, close to one in three women who attend antenatal clinics are HIV positive. KwaZulu-Natal is one of the worst affected provinces, where as many as 40–60% of pregnant women attending antenatal services are living with HIV infection. The study sought to investigate the link between the home environment and its contribution to the success of the programme on PMTCT of HIV/AIDS. A qualitative, explorative, descriptive and contextual study was used in this study to explore whether the home environment for the support system is available for the HIV-positive women on the PMTCT programme. The population of this study included all women who have undergone counselling and tested HIV positive and who have joined the programme on PMTCT of HIV/AIDS. Although 14 women agreed to participate in the study, only 10 women were interviewed as saturation was attained. Data were collected using semi-structured interview schedule. Interviews were audio-taped and field notes were taken. Content analysis was used and it was done manually. This study revealed that one of the major issues still surrounding HIV/AIDS and PMTCT is that of non-disclosure, selective disclosure and the stigma and discrimination that surrounds this disease.

\textbf{Keywords:} human immunodeficiency virus, acquired immune-deficiency syndrome, mother to child transmission of HIV, prevention of mother to child transmission, disclosure, support, success

\section*{Résumé}

Le virus immunodéficiant humain et le syndrome immunodéficiant acquis (VIH / SIDA) demeure une «crise familiale» qui marque le début de la détérioration de l’unité familiale et le traumatisme dans les vies émotionnelles, psychologiques et matérielles de la mère et de l’enfant. Dans le contexte de l’Afrique du Sud, où la majorité des mères séropositives sont des jeunes femmes célibataires qui vivent dans des familles élargies, la divulgation au partenaire sexuel seulement n’est pas une condition suffisante pour le succès de la prévention de la transmission mère-enfant (PTME). En Afrique du Sud près de 1 femme sur 3 qui fréquentent les consultations prénatales sont séropositives. KwaZulu-Natal (KZN) est l’une des provinces les plus touchées, avec 40 à 60% des femmes enceintes en consultations prénatales vivent avec l’infection à VIH. Cette étude visait à étudier la corrélation entre l’environnement familial et sa contribution au succès du programme de la prévention de la transmission du VIH/SIDA de la mère à l’enfant. Une étude qualitative, exploratoire, descriptive et contextuelle a été utilisée pour explorer le système de soutien disponible dans l’environnement familial pour les femmes séropositives par rapport au programme de PTME. La population de cette étude a consisté de toutes les femmes qui ont été conseillées et testées séropositives et qui avaient le programme de PTME. La saturation a été atteinte après avoir interrogé 10 femmes. Les données ont été recueillies à l’aide d’entretiens semi-structurés et l’enregistrement sur audiocassette. Une analyse thématique du contenu a été utilisée pour analyser les données recueillies. Cette étude a révélé que l’une des grandes questions entourant le VIH/SIDA et PTME est celle de non-divulgation, divulgation sélective et la stigmatisation et la discrimination liée à cette maladie.

\textbf{Concepts:} Virus Immunodéficitaire Human, Syndrome Immunodéficitaire Acquis, Transmission Mère à l’enfant du VIH, Prévention de Transmission de la mère à l’enfant, Divulgation, Soutien, Succès (French)
Introduction

According to the Joint United Nations Programme on human immunodeficiency virus/acquired immune-deficiency syndrome (HIV/AIDS) (UNAIDS Global Report 2013), there are 35.3 million people living with HIV globally. As a result of scaled-up HIV prevention services, the annual number of newly infected children in 2012 was 260,000 (230,000–320,000) in low- and middle-income countries, which was 35% lower than it was the case in 2009. From 2001 to 2012, there was a 52% decline in new HIV infections among children. Expanded access to services to prevent mother to child transmission (MTCT) prevented more than 670,000 children from acquiring HIV from 2009 to 2012. To reach the global target of reducing these new infections among children by at least 90% by 2015 (using a 2009 baseline), programme expansion will need to accelerate.

According to UNAIDS (2006), in South Africa (SA), close to one in three women who attend antenatal clinics are HIV positive. The number of pregnant women newly infected with HIV declined by 21% in SA, with over 80% coverage of anti-retroviral therapy (ART) (UNAIDS 2013). A decline in the transmission of mother-to-child infection rates at six weeks has been observed over the past few years, indicating that policy changes in conjunction with improved implementation of the prevention of mother to child transmission (PMTCT) programme have been effective. However, despite these gains, KwaZulu-Natal remains SA’s most affected province with an antenatal HIV prevalence of more than 40% in two of its districts and more than 1.6 million people living with HIV in 2011.

To reduce the rate of MTCT the involvement of the partner, family and community plays a vital role in providing the necessary physical, emotional, social and financial support needed by the HIV-positive women. Disclosure of HIV test results to a sexual partner is an important prevention goal for a number of reasons. This is supported by Kassaye, Lingerh and Dejene (2005), who believe the benefit of disclosure includes expanding and sharing the burden of helping people living with HIV/AIDS (PLWHA) beyond professional care providers, providing access for care and support of PLWHA and their partners. In relation to PMTCT, shared confidentiality is considered beneficial in order to prevent unwanted pregnancies and arrest the spread of HIV infection to uninfected partners. Another benefit is in assisting HIV infected women to plan for their future and their partners, to gain access and adhere to therapeutic regimens such as ART and replacement feeding for infants. This study aimed to establish the link that the home environment has in the contribution to the success of the PMTCT programme.

Aim of the study

The study aims to establish the link of the home environment and its contribution to the success of the programme on PMTCT of HIV/AIDS at a Provincial Hospital in KwaZulu-Natal Province.

Objectives of the study

- To identify and describe the factors that contributes to a home environment that can have a positive effect to a successful PMTCT programme.
- To explore and describe the challenges of the home environment faced by women on the PMTCT programme.
- To assess the influence and effect that support received within the home environment has for the pregnant women that is on the PMTCT programme.
- To make recommendations on the improvement of home environment for the successful PMTCT programme.

Significance of the study

The study will identify factors, within the home environment, that contributes positively to the success of the PMTCT programme, and the reasons for poor involvement of partners and significant others within the home environment. Lastly, recommendations can be made on how to improve the level of support received within the home environment. This study will also contribute to the existing body of knowledge regarding the psycho-social support needs within the home environment of the women on the PMTCT programme.

Research design and methodology

A qualitative, explorative, descriptive and contextual design was used. Qualitative research involves an emergent design that emerges in the field as the study unfolds. It is elastic and flexible. The goal of most qualitative studies is to develop a rich understanding of phenomena as it exists in the real world (Polit & Beck 2014:261). In this study, the researcher attempts to describe the influence of the home environment of the mothers in the PMTCT of HIV/AIDS at a Provincial Hospital in KwaZulu-Natal which is located in a peri/urban area.

Non-probability sampling approach was chosen for this study. This type of sampling is usually more convenient and economical and allows the study of populations when the researcher is unable to locate the entire population (Brink, van der Walt & van Rensburg 2012:139). The type of sampling method chosen for this study was purposive as it allowed the researcher to select the sample based on knowledge of the phenomena being studied. In this study all participants who were enrolled in the PMTCT programme and were able to understand English language were illegible to be sampled. Although 14 participants agreed to participate, only 10 participants were interviewed as data saturation occurred and no new data emerged.

Data collection

Data were collected during July and August 2012 using a semi-structured interview schedule with Section A for closed-ended short questions for demographic information and Section B with open-ended questions for the purpose of exploring phenomena related to the topic. The interviews were conducted in English by the researcher who is the educator and have knowledge of conducting interviews. Interviews were audio-taped and field notes were made. The central question that was asked was: ‘Describe
your experiences of your home environment and the support you receive from your family and friends?’ and this was explored further by using a prepared topic guide.

Data analysis
Interviews were transcribed verbatim. The researcher analysed the transcriptions by repeatedly reading the scripts to seek meaning in the data. Data were then grouped into themes and categories. According to Patton (2002), content analysis refers to the searching of text for recurring words or themes.

Trustworthiness
The aim of ensuring trustworthiness is to address ways to ward off researcher bias in the results of qualitative analysis. The four strategies proposed to ensure trustworthiness in this study were credibility, dependability, confirmability and transferability.

Credibility
This is concerned with the accuracy and truthfulness of scientific findings. Brink et al. (2012:172) asserted that the techniques used to achieve credibility included the following:

- Prolonged engagement – remaining in the field over a long period. The researcher continued with data collection until data saturation occurred.
- Triangulation – using a variety of sources in data gathering. The researcher made field notes as well as taped records of the interviews.

Transparency
This is described as a degree to which the results of a study can be generalized to other settings. Thick description is a term used by qualitative researchers which refers to a rich and thorough description of the research setting and of observed transactions and processes (Polit & Beck 2014). This was achieved by ensuring that the study participants and the research design were described in detail. The demographic details, as well as the details of the interview, and the details of the research design were described thoroughly.

Dependability
As cited by Brink et al. (2012:172), dependability is concerned with consistency, stability and repeatability of the informant’s accounts, as well as the researcher’s ability to collect and record information accurately. In this study, the researcher ensured that the data quality was checked for bias and that adequate participant checking was done periodically to ensure authenticity. This was done by ensuring that consistency was maintained when questioning and recording the information during the interview. An external independent person checked the tape-recording for reliability, and ensured that the information was transcribed correctly.

Confirmability
This means that the findings, conclusions and recommendations are supported by the data and that there is internal agreement between the investigators’ interpretation and the actual evidence (Brink et al. 2012:172). To ensure confirmability, the researcher ensured that the study data was retained and available for reanalysis by others. The tape recorder and notes were made available for audit by an outside person to confirm that the data were correct.

Ethical considerations
The data collection process commenced following an Ethical Clearance from UNISA Health Studies Higher Degrees Committee. Prior to commencing with data collection, permission was also obtained from the KwaZulu-Natal Department of Health Research Committee as well as from the relevant authorities of Ugu Health District Office and the District Hospital where the data were collected.

Participants that were eligible to participate in the study were first selected and the researcher then explained the details of the study.
and what was expected of them. Those participants who were willing to be part of the study were then taken to a private room where the consent form was read and explained and then signed. Each participant was told that participation was voluntary and that they could withdraw from the study at any time with no adverse outcomes. Confidentiality and anonymity was emphasized as each participant was recorded as a number and no names were used. Permission was also obtained to use a tape recorder during the interview.

Findings
Four themes which emerged from this study were: emotional and psychological trauma; barriers that prevented disclosure of status; financial challenges experienced by participants and perceptions of psycho-social support. Under the emotional and psychological trauma, three sub-themes were identified, namely shock and sadness; fear and stress; and disappointment and anger. Under barriers that prevented disclosure three sub-themes were identified, namely selective disclosure, stigma and discrimination emerged. Under financial challenges two sub-themes were identified: unemployment and low sources of income. Under perceptions of social support received two sub-themes which were identified, namely challenges experienced and benefits of social support (Table 1).

Emotional and psychological trauma experienced by the participants
The findings revealed that more than half of the respondents (57%) experienced various forms of emotional and psychological trauma that was expressed as shock, fear, disappointment and anger. These emotions were experienced either when they were first diagnosed as being HIV positive, on disclosure or the reason for non-disclosure, and or when they found out that their partner was already HIV positive and did not disclose his status. Many participants experienced disappointment and embarrassment because of getting a disease that is stigmatized and not readily accepted by society. Quotes that displayed emotions are:

I am too shocked still and cannot talk to anyone about it. I can’t believe it, hey! What will people say and how will I accept that he . . . gave this disease to me, really I can’t.

I felt very depressed and just cried and cried . . . it was very hard to accept my results, and now I worry about this baby. It is very difficult . . .

I know all about this disease as I had both my parents that had HIV and I know how sick they became . . . (sigh) and now for me to go through the same fears and trauma of having seen my parents suffer and die with no support. I am scared that the same (means the suffering) will happen to me.

This is corroborated by Van Dyk (2008:123) who revealed that varying emotional reactions follow individual’s diagnosis of HIV positive such as grief, shock, anger, guilt, sadness, embarrassment and fear.

Barriers that prevented disclosure of status
The second major theme related to the issues surrounding barriers to disclosure, which included selective disclosure, stigma and discrimination and social isolation. The impact of HIV diagnosis on the social lives and economic activities of the participants was the main reason for the refusal of most participants to fully disclose their HIV status. The barriers that were found in this study included stigma and discrimination and the fear of social isolation. Majority of the participants (64.3%) expressed selective disclosure to either only the boyfriend and or a friend or to a family member as well. The impact of being HIV positive and the effect it has on the social and economic lives of these participants was one of the contributory factors for either selective disclosure or non-disclosure. The findings revealed that those participants that did not disclose within their home environment (50%), was afraid to disappoint their family member or because either the parent was also sick with HIV (21.4%), the granny that they lived with was too old (14.3%) and they did not want to stress them. The remaining 14.3% lived with siblings and were too afraid of the negative reactions that may be received and the lack of financial support that on which they depended.

Stigma and discrimination was the major barrier experienced by (85.7%) participants. These participants revealed that there is still more stigma out in their communities and this was evident by only two (14.3%) participants that were open about their status at home and in the community. The majority feared being rejected, blamed and socially isolated within the communities. One participant that sold vegetables indicated to fear being rejected, blamed and socially isolated within the community. One participant that sold vegetables indicated that if anyone knew she was HIV positive, they would not buy from her. Women in this study were afraid of social isolation and limited support and this is confirmed by Olagbui, Ezeanochie, Agholor, Olagbui, Ande and Okonofua (2011) that women were fearful of disclosure because they felt that once their family learned about their HIV status, they will be rejected. According to Brickley, Le Dung Hanh and Nguyen (2008), societal stigmatizing attitudes penetrate family relationships resulting in discrimination within the family. Although pregnancy is one of the precious times for which a woman needs support from her partner, husband and family members today, there are infections like HIV that rob women of the necessary support. According to Mdlalose (2006), it was found that women disclosed their HIV status to trustworthy and supportive people who would empathize with them and provide them with advice on how to cope with the infection. However, they did not disclose to people with whom they did not have a good relationship as they feared that they would later discriminate and stigmatize them. Health Bridge (2007) analysed the challenges in the PMTCT of HIV in Africa and in its report documented some findings from Malawi. It showed that stigma and discrimination is still high in the community and many viewed HIV/AIDS positive individuals as having received a death sentence. Quotations displaying barriers of non-disclosure:

Too scared to tell ‘Gogo’, she will be disappointed. She helps to look after me and she is all I got.
Mom is also HIV positive and she is sick so I don’t want to stress her.

These findings revealed a strong negative association between disclosure of an HIV-positive status to the associated stigma and discrimination that results in the major barrier preventing full disclosure. This results in a poor support system in both the home and community for the women on the PMTCT programme. Participants who disclosed to their partners expected some benefit in the forms of social, emotional or financial support, but that was not the case in more than 14.3% of the respondents. These women expressed their experiences of rejection where the partners abandoned them, blamed them and physically or emotionally abused them. It was evident that disclosing to a friend was better received and the support received was beneficial or emotionally abused them. It was evident that disclosing respondents. These women expressed their experiences of rejection where the partners abandoned them, blamed them and physically or emotionally abused them. It was evident that disclosing to a friend was better received and the support received was beneficial to coping with the disease. One participant said:

I do home based care and work with people that also have HIV and I help them, but I won’t tell them because they won’t allow me in the house. They won’t want me to TOUCH them, because they will think I am going to make them sicker.

Poku, Linn, Fife, Azar and Kendrick (2005:345) confirmed with their study that the stigma affected self-worth, self-deprecation, body image and personal control. It was found that stigma diminished the social standing of the individuals; their identity was tarnished; and they felt inferior.

Limited financial support

Majority of the participants were experiencing financial problems as they were dependent on family members, partners or social grants as their only means of survival. Power relations in the family consistently give women (especially young women and girls) a low status. Bearing children may increase one’s status, but at the same time increase dependency on the extended family. These differences in power and independence inhibit women’s capacity to make their own decisions regarding PMTCT and other crucial issues.

The findings revealed that 64% of the 14 participants were unemployed and depended on a family member, a social grant or the partner for financial help. This financial dependence resulted in selective and non-disclosure of their status for fear of not receiving any financial help. There were 35.7% of participants that did not disclose their status to their partners because they needed their financial assistance to survive. This study also indicated that some women (21.4%) although knowing their status continued to have children as they received a social grant for each child, which helped them to support themselves and the family. It was evident that the low sources of income that these participants received had an impact on their quality of life and health. A few participants expressed their poverty, where sometimes they had no money to buy food and sometimes children had to only eat porridge for supper. Other problems experienced was that sometimes it was difficult to go to the clinic as there was no money or they had to work or sell her vegetables to get money to buy food. These factors indicate the stressful financial burdens these women faced, which directly impact on the health and underutilization of the PMTCT services. A women’s economic dependency on men, poverty, low decision-making powers in the family and community highly affects the utilization of PMTCT services. Also, women are overloaded with domestic work and other activities to generate income. As a result, they become busy and do not get enough time to attend to their health and to seek PMTCT services adequately. One participant said:

This man only buys drink and if I don’t give him the money then he fights. Sometimes there is nothing to eat … I have to give my children porridge in the night.

Another quote: I am not talking to him now and I won’t tell him, because I need him, because he helps me with money. I can’t lose him now because I can’t manage to have this baby if he don’t support and help me.

This is supported by Bond (2003) that poverty and stigma have a peculiar relationship: in the context of poverty, it is easy to ‘understand’ decisions that result in discriminatory actions. The intersections between poverty and stigma related to HIV and AIDS reinforce the fact that stigma cannot be isolated from other social processes and phenomena and that it must be understood in the context of other things happening.

Perceptions of psycho-social support

This study revealed two aspects to psycho-social support. On the one hand, findings indicated some of the challenges experienced by participants and the lack of support, and on the other hand two participants (14.3%) expressed the positive psycho-social benefits of full disclosure within the home and community. 85.7% of the participants expressed various forms of challenges that they experienced; ranging from total abandonment from their partners after disclosure, the fear of stigmatization due to the lack of community education and the fear of lack of psycho-social and financial support from family if they disclosed. Majority of the participants felt that people in the communities do not understand HIV and PMTCT and would stigmatize them if they disclosed.

One participant mentioned:

I need to keep calm, I don’t want to stress my baby. I will only tell them after. I don’t need to be stressed because I don’t know how they will react.

The study revealed the lack of community education and understanding of the PMTCT services. Some expressed that they attend clinic alone and they have to hide and take their treatment at home so that no one must know her status. It was evident with 14.3% of the participants who displayed inadequate knowledge regarding preventative and infant feeding strategies. Another challenge was that of choosing to breastfeed over bottle-feeding because of the negative perceptions of being seen as HIV positive that is associated with bottle-feeding.
The stigma associated with disclosure leads to negative changes in self-concept and emotional reactions towards those who invoke the stigma. HIV-positive individuals are likely to inform their significant others on condition that they perceive that the rewards of the disclosure outweigh the costs. The reasons for non-disclosure are justified by the disclosure's desire to reduce negative consequences.

The participants that indicated receiving some form of psycho-social support were those that disclosed their status. In addition, 28.6% of the participants expressed that the people to which they disclosed their HIV status helped to support them by encouraging them and this helps them to comply with their treatment modules. Two of these respondents (14.7%) were completely open about their status to family and the communities in which they lived. One participant indicated that the church that she attends was very supportive and encouraging. This indicates that sharing this burdensome disease with some significant person helps cope better with the stress. Another benefit that was evident was that 21.4% of the boyfriends that were also HIV positive and were on treatment helped to support each other, went to the clinic together and reminded each other to comply with their treatment.

These results indicate that to receive appropriate psycho-social support and compliance to the PMTCT preventative strategies, one needs to disclose their status. This helps a person to cope better and live a more positive lifestyle if they are motivated and encouraged to adhere to treatment. Serovich, Lim and Mason (2008) state:

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\text{that disclosing an HIV positive status can result in the gain of emotional, physical and social resources. The emotional benefits include social support, relief that comes from sharing a burdensome secret and the built-in reward of educating others about HIV.}
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Participants that did not disclose to anyone in the home environment felt that they were receiving adequate support within the institution either from the nursing staff or from the support groups that they joined. This contributes positively for women who are on the PMTCT programme as she is able to share her experiences and learn from others with similar problems. This support is limited within the institution only, and there is no continuity at home where the real challenges of adherence to treatment and other problems are experienced.

Conclusions

The findings of this study reveal that there is knowledge and awareness of the PMTCT programme that is being given to women at the antenatal clinics. However, the interpretation of this information is somewhat not too clear especially those with a low literacy level and possible communication barriers. The area where the study was conducted is a rural township and many of the participants (35.7%) had only been to a primary school which contributed to the poor education, unemployment and poverty factors. It was evident from a few of them that sometimes had no money for food or transport to get to the facility. Lower levels of education affect financial independence of the participants because even those that worked were earning very little to sustain themselves and their families. Some depended solely on a state grant for survival. These are contributory factors to underutilization of the comprehensive PMTCT services available, related to lack of understanding of key concepts to reducing MTCT of HIV/AIDS. This study also shows that socio-cultural factors within the home environment such as stigma and discrimination, gender inequalities, lack of support and abandonment and social isolation all played a major role in affecting the utilization of PMTCT services among pregnant women. Another major constraint was the poor acceptance of people living with HIV in the family as well as the community. This resulted in non-disclosure for fear of similar discriminations.

On a positive note, this study indicated that those women that disclosed their status to a partner or family member reaped positive rewards such as motivation, encouragement, accompaniment to the clinic, as well as someone to share their stressors with. As a result, all these forms of support contributed to compliance to treatment and effective utilization of the PMTCT services.

Limitations of the study

The findings of this study cannot be generalized to other areas, as it was limited to one Provincial Hospital in KwaZulu-Natal. Also, the participants in this study were from a rural background and thus cannot be generalized to an urban area.

Recommendations

Recommendations for strategies to improve the support systems of the home environment for women on the PMTCT of HIV/AIDS programme include the following:

- To increase the knowledge and awareness about the PMTCT programme and its preventative strategies to the communities at large, by using opportunities such as community gatherings, social events and religious functions to provide these awareness sessions and regular updates.
- Continuous health education and sensitization regarding HIV, MTCT, PMTCT and specific education on overcom- ing stigma and discrimination of PLWHA. The involve- ment of influential persons, religious leaders and teachers to disseminate this knowledge and updates on an ongoing basis would facilitate this.
- To encourage HIV-positive women to bring their male counterparts in during antenatal attendance so that coun- selling can be given to them as a couple. This would make the preventative strategies and compliance more readily accepted and supported. Support groups that consist of women that are on the PMTCT programme and living positively can be encouraged to take the support and edu- cation to the people out in the communities; this will have a positive effect if information comes from a person directly involved in this disease. Issues such as the benefits of psycho-social support within the home environment must be emphasized.

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