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Full Length Research Paper

An exploration of the home environment for the support system available for the HIV positive women on the PMTCT program: A qualitative study

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In Kwa-Zulu Natal (KZN), one of the worst affected provinces as many as 40 to 60 % of pregnant women attending antenatal services is living with HIV infection. A qualitative, study was used in this study to explore the home environment for the support system available for the HIV positive women on the PMTCT program. The population of this study included all women who have been counselled and tested HIV positive and who have joined on Prevention of mother to child transmission of HIV/AIDS. A total of ten women were interviewed as saturation was attained. Data were collected using semi-structured interviews and tape recording used and interviews were transcribed verbatim. Data analysis: Content analysis was used and it was done manually. Four themes emerged from this study were: emotional and psychological trauma; barriers that prevented disclosure of status; financial challenges experienced by the participants and perceptions of social support received. This study revealed that non disclosure, selective disclosure stigma and discrimination surround this disease.

Keywords: Human Immunodeficiency Virus, Acquired Immune-Deficiency Syndrome, Mother to Child Transmission of HIV, Prevention of Mother to Child Transmission, Family, Support.

INTRODUCTION

According to the latest data from the Joint United Nations Program on Human Immuno Virus/Human Immunodeficiency Virus (HIV/AIDS, 2006), almost 60 million people have been infected with HIV/AIDS worldwide. In 2008 an estimated 2.7 million new infections globally have been reported with around 430 000 children being born with HIV infection mainly related to mother to child transmission. Sub Saharan Africa remains most affected by HIV infection with over 67% of all people living with HIV infection worldwide and approximately 91% of all new infections are among children.

According to UNAIDS,2006, in South Africa close to 1 in 3 women who attend antenatal clinics are HIV positive. In Kwa-Zulu-Natal (KZN) one of the worst affected provinces as many as 40 to 60 % of pregnant women attending antenatal services are living with HIV infection. To reduce the rate of Mother to child transmission (MTCT) the involvement of the partner, family and community play 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, et al. (2005), that the benefit includes expanding and sharing the burden of helping People Living with HIV/AIDS (PLWHA) beyond professional care providers, providing access for care and support programmes, planning for future care, and enhancing the quality of life of PLWHAs 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 anti retroviral therapy (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.

Statement of the Research Problem

During contact and discussions with women on the

PMTCT programme the researcher found that many women chose not to disclose their HIV status to their family due to fear of stigma and rejection; hence most women joined a support group within the institution.

Aim of the study

The study aim is to establish the link of the home environment and its contribution to the success of the programme on prevention of mother to child transmission of HIV/AIDS at a Provincial Hospital in Kwa-Zulu Natal Province.

Research Purpose

The purpose of this study was to explore and describe the link between home environment and its contribution to the success of the PMTCT programme of HIV/AIDS at a Provincial Hospital in KZN 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 HIV infection rate amongst infants and children continue to increase in KZN.The identified and described factors will assist pregnant women who are in the PMTCT programme on how to deal with the challenges they are faced with. Recommendations will 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 psychosocial support needs within the home environment of the women on the PMTCT programme.

Research design and methodology

A qualitative, design was used in this study to explore and describe the home environment for the support system available for the HIV positive women on the PMTCT programme and the influence this has on her compliance to treatment. The context of this study was a Provincial Hospital in Kwa-Zulu Natal province.
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 (Patton: 2002)˙ 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. Sampling was done until data saturation occurred and no new data emerged.

Data Collection

Data were collected 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. 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 analyzed the transcriptions by reading the scripts over and over 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- This was achieved by researcher reflecting and summarizing the information at the end of the interviews to confirm that the information was interpreted correctly.
- Dependability- This was achieved by ensuring that the study participants and the research design were described in detail.
- Conformability- In this study the researcher ensured that the data quality was checked for bias by recording and checking that the tape by an outside independent person for reliability, and that the information was correctly transcribed.
- Transferability- To ensure conformability the researcher ensured that the study data were retained and available for reanalysis by others. The tape recorder and notes were available to audit by an outside person to confirm the data was correct.

Ethical considerations

The data collection process commenced following an Ethical Clearance from UNISA Health Studies Departmental Higher

Degrees Committee. Prior to commencing with data collection, permission was also obtained from the Kwa-Zulu 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 that 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 were 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.

RESULTS

Data Themes and Categories

Four themes that emerged from this study were: emotional and psychological trauma; barriers that prevented disclosure of status; financial challenges experienced by the participants and perceptions of social support received. Under the emotional and psychological trauma, three subthemes were identified: shock and sadness; fear and stress and disappointment and anger. Under barriers that prevented disclosure three subthemes were identified: selective disclosure; stigma and discrimination and: social isolation related to non disclosure. Under financial challenges two subthemes were identified: unemployment and low sources of income. Under perceptions of social support received two subthemes were identified: Challenges experienced and benefits of social support.

Emotional and Psychological trauma experienced by the participants

The findings revealed that six respondents 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 expressed disappointment and embarrassment because of getting a disease that is stigmatized and not readily accepted by society. One participant said “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”.

These findings revealed a strong association between being diagnosed as HIV positive and the psychological impact this has on the women, as well as the stress it causes on the current pregnancy. The worries and stress stemmed from always thinking about the effect of the disease on their health and the shattered future plans and hopes for their children. It is also evident that there is a need to be able to disclose to significant others in order to receive the necessary support that is critical to proper utilization of all the benefits of the PMTCT services. In a study conducted in Addis Ababa – Ethiopia revealed that knowledge of PMTCT services is high, but having knowledge about PMTCT does not necessarily guarantee attitudinal change to subsequent use of PMTCT services. Adequate knowledge on how to prevent MTCT of HIV to pregnant women and their families as well as the necessary support will increase the uptake of PMTCT services Skinner, Mfecane, et al. (2005).

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 her HIV status. The barriers that were found in this study included stigma and discrimination and the fear of social isolation. Six participants 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 were five as they were afraid to disappoint their family member or because either the parent was also sick with HIV, One participant lived with the granny who was too old and they did not want to stress them. The remaining participant lived with siblings and was too afraid of the negative reactions that may be received and the lack of financial support that they depended on.

Stigma and discrimination was the major barrier experienced by eight participants. These participants revealed that there is still a lot of stigma out in their communities and this was evident by only two 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 that if anyone knew she was HIV positive they would not buy from her. According to a study by Mdlalose (2006) it was found that women disclosed to trustworthy and supportive people who would empathize with them and provide them with advice on how to cope with their HIV status. 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.

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 that disclosed to their partners expected some benefit in the forms of social, emotional or financial support, but were not the case in more than one of the participants. 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 expressed how her friend motivated her to take her treatment and always reinforced positive living and protection of her baby from HIV.

Limited financial support

Majority of the participants were experiencing financial problems as they were dependant 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 (Mekkonnen, 2009).

The findings revealed that six of the ten 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 four of the 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 two participants 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 that poverty, where sometimes they had no money to buy food and sometimes children had to 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 impacts 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 (Skinner, Mfecane et al.2005).

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 expressed the positive psycho-social benefits of full disclosure within the home and community. .Nine 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 don't 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 one of the participants that displayed a lack of knowledge with regards to the ARV treatment that they were already on. Only two had an idea about their CD^4 cell counts, but displayed inadequate knowledge regarding preventative and infant feeding strategies. Another challenge was that of choosing to breastfeed over bottle feeds because of the 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 (Drieskell, Solomon et al.2008).

The participants that indicated receiving some form of psycho-social support were those that disclosed their status. Three of the participants expressed that the people that they told helped to support them by encouraging them and this helps them to comply with their treatment modules. Two of these respondents were completely open about their status to family and the communities that they lived in. 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 two participants of the boyfriends that were also HIV positive and were on treatment helped to support each other, go to clinic together and remind each other to comply to 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) states: “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”.

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 that are on the PMTCT programme as she is able to share her experiences and learn from others with similar problems. This support is limited to 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 revealed that there is knowledge and awareness of the PMTCT programme that is being given to women at this particular antenatal clinic but the interpretation of this information is somewhat not too clear especially those with a low literacy level and possible communication barriers. Lower levels of education affects financial independency of the participants because even those that worked were earning very little to sustain themselves and the families. Some depended solely on a state grant for survival. These are contributory factors to under utilization of the comprehensive PMTCT services available, related to lack of understanding of key concepts to reducing mother to child transmission of HIV/AIDS.

This study also showed 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, which together all contributed to compliance to treatment and effective utilization of the PMTCT services.

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:

- Continuous health education and sensitization on HIV, MTCT, PMTCT and specific education on overcoming stigma and discrimination of PLWHA. Involve influential persons, religious leaders and teachers to disseminate this knowledge and updates on an ongoing basis.
- All staff working closely with mother and child or teenagers should receive training in HIV/PMTCT and regular refresher courses on counselling so that there are no missed opportunities to disseminate this information.
- Support groups that consist of women that are on the PMTCT programme and living positively can be encouraged to take the support and education to the people out in the communities; this will have a positive effect if information comes directly from a person directly involved in this disease. Issues such as the benefits of psycho-social support within the home environment must be emphasized.
- The study was contextual, therefore, other studies can be conducted in other hospitals and provinces to compare their findings so that the results can be generalised.

Limitations of the study

The findings of this study cannot be generalized to other areas especially other provinces, as it was limited to one Province in a public service hospital. Also the participants in this study were from a rural background and thus cannot be generalized to an urban area background.

REFERENCES

UNAIDS (2006). Report on the Global AIDS Epidemic, Joint United Nations Program on HIV and AIDS, Geneva.

Brink H(2008). Fundamentals of Research Methodology for health care professionals. 2nd ed. Cape Town: Juta.

UNAIDS (2008). Joint United Nations Programme on HIV/AIDS. Report on global Aids epidemic. 2008. Geneva.

Patton MQ(2002). Qualitative Research and Evaluation Methods. 3 rd ed. Thousand Oaks: Sage.

Kassaya KD, Lingerh W, Dejene Y(2005). Determinants and outcomes of disclosing HIV-sero positive status to sexual partners among women in Mettu and Gore towns, Illubabor Zone southwest Ethiopia. Ethiop.J Health Dev. 19(2): 126-132.

Skinner D, Mfecane S, Gumede T, Davids A(2005). Barriers to accessing PMTCT services in a rural area of South Africa. African J. AIDS Res. (2): 115-123.

Mdlalose BNN(2006). Women's experiences of being HIV positive. The stigma related to HIV and disclosure. PhD thesis.

Mekonnen GM(2009). Factors influencing utilization of PMTCT service in Addis Ababa-Ethiopia. PhD thesis.

Driskell JD, Soloman E, Mayer K, Capistrant B, Safren S(2008) Barriers and facilitators of HIV disclosure among sexually risky HIV infected men. J. HIV/AIDs Social Services. (7): 135-156.

Serovich LM, Lim JY, Mason TL(2008). A retest of two HIV disclosure theories: the woman story. Health Social work. 33(1): 22-31.