

QUALITATIVE STUDY ON HIV & WOMEN IN SARAWAK: HIV & WOMEN

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Being diagnosed with Human Immuno Deficiency Virus (HIV) is a stressful event to almost all who are infected. Often, the situation is even worse if it happens to women with children. Positive treatment given by the society is often the biggest encouragement for them to live on. Therefore, it is important that the unfortunate ones are tactfully and empathetically treated by the health care providers and the society.

Since 1992, I have been involved in counselling people living with HIV/AIDS. Much has been said by HIV/AIDS activists; tears have been shed and much thought have—come through my mind. Even though the support given by the Malaysian Government in the regime of treatment has improved tremendously, there has not been much change in the society's perception on people living with HIV. This is a heart breaking journey for our nation.

Literature reviews on HIV cases are generally informative but prior to this, there had not been a literature which specially addressed the coping and experience of HIV infected women with children.

The sharing of these actual transcripts is aimed to change the perception of people towards women being diagnosed with HIV and to stimulate the loving nature of everyone, particularly the nurses.

The phenomenological method of inquiry developed by Colaizzi was selected as the frame work for data

collection, analysis and interpretation because it is thought to be the most compatible with the aims of the study.

The phenomenological method is an inductive, descriptive research method. According to Omery, the task of the method is to investigate and describe human experience. This exploration was neither attempting to validate or develop a theoretical frame work, nor to predict or control events or people. Rather, the aim was to capture, describe and understand experience as they are lived narratives.

To understand the experience of another person we must attend to the meaning of that experience to that person. To people who face a similar situation, some experience may be uniquely individual while many are common to people of similar cultures, beliefs and up-bringing environment. The phenomenological method endeavours to record not only into the personal issues, but also the shared meanings associated with a phenomenon.

The participants

For the purpose of this journal publication, only two transcripts are to be shared. The study used convenience samples, as the phenomenological method is not generally concerned with statistical demand; convenience sampling was an acceptable approach to the participants' recruitment. Moreover, it is rather emotional and heart breaking while having them to share their feeling and experience. There were six women

who participated in the study and they were from the HIV Clinic of Kuching Hospital. The project was approved by the Hospital Ethical Committee, and all participants signed the consent form after being told about the purpose and nature of study. They had all been

assured on the confidentiality of their identities in the journal publication.

The participants were of ages between 26 to 38 year-old and they had three to six children. The data were collected on their second visit after being diagnosed with HIV. The in depth interview focussed on the women's coping strategies and feeling of being informed on the diagnosis of HIV. The interviews were taped and transcribed word by word by two independent lecturers.

Coping strategy – “the only woman with children”

Open ended question –

Interviewer “I understand that you have just lost your husband. Would you like to share with us on your plan on coping with the days to come so we could see how we could help you”.

Madam K said “When i was diagnosed with HIV I felt like I was the only woman with HIV in Sarawak, who is there to support us and moreover, my husband has just passed away. In reality, I dare not tell anybody.”

“I have six children; the eldest daughter is only 10 year-old and the youngest son is only seven months old. We are currently staying at the labourers' squatters near the construction site (Bangsan).” Madam K said “I never keep money, in the past my husband used to buy food for my family and now he had gone. What I have only RM 500.00 that was given by the contractor after my husband funeral. I have a motor bike at the (Bangsan) but I do not know how to use it, and my

children have not been going to school since their father was unwell.” Even though I consider this woman to be a strong lady for being willing to participate in the interview, she broke down in tears.

The women cried for half an hour and we served her a drink and comforted her by holding her. The children were running around and seemed ignorant except for the 10 year-old daughter remained very silent while the woman was holding on to her youngest boy tightly. The boy was staring at her mum.

Then Madam K looked at her baby and said “Baby, your dad left us. Am i being punished? If Mum died, who else will look after you all (my children).” She broke down in tears.

After half hour of crying, Madam K finally managed to express “Thank you and I am feeling a little better and relieved. Luckily, you allowed me to cry and stay here for a long time”.

Madam K later left the room with her children. Just before they left the room, the researcher asked her if she was confident to go home and gave her some token RM150.00. She smiled and left the room.

Findings and intervention

Madam K was experiencing a new meaning of life and fear of suffering, as she has children to responsible after being diagnosed of having infected with HIV. Many people did not realize about actually how and what is life until a new encounter. At this crucial moment, PLWHIV/AIDS needs comfort and care. Nurses are often the first person that encountered with them. In accordance with Benner and Wrubel “it was the nurses' connection and concern for patients' situation” that enable PLWHIV to live on with quality of life.

Helpful intervention is touch and allows the times for patients to express their feeling. The therapeutic approach is clearly expressed by Madam K. Therefore, nurses must have this quality characteristic in encountering with PLWHIV/AIDS.

Madam W was the second woman who entered the interviewed who was referred by the primarily care team in participating the study - "Woman of non stop" Interviewer; "Good morning Madam W, I understand you are

Madam W said: "It is so unfortunate for me have gotten HIV. It is horrible to have such a disease. Why and how did my husband get it? How could I have allowed myself to get this disease? It is a shame and a worry, now what am I going to do? One of these days, I would just kill myself. Now I can see what is really important and what is not. I never realized I was this strong and I appreciate everything from that day onward. E...m.. What is life! What is life?"

Madam W continuously said "What about my husband? Was he aware of having transmitted the virus to me?" Was the person who gives the infection to him aware of this HIV infection?" "Could I have been cheated by my husband?" Hai Ya! Horrible! Horrible! Why did this happen to me and I have four children now, if it is only myself and with no others to border, it will make my life simpler. Hai Yai! So unfortunate! so unfortunate!"

Madam W had been with us for the last two hours and I intended to request for her consent to participate in this study. But before we started to explain on the purpose of the study, she requested and asked: "Anything you need me to sign and I know what is HIV/AIDS is and there is no cure".

I explained to her the purpose of the study and was aiming to reach a helping situation but she just could not stay any longer. She signed the consent and off she went.

It was a challenge for us to have a client like her; I just could not hold her back.

Finally, we decided to call her on her cell phone, but we could only reach the voice mail.

At 6.30pm on the same day, I managed to trace her at one of her siblings' house. I told the family member that I am her good friend wanted to meet her. Bear in mind of keeping the client's confidentiality on the disease. It was a great challenge to ensure the safety of a patient. Fortunately, she was willing to meet me.

The findings and intervention

Madam W was a referred case from Primarily Care team; she had been informed on the wholesome of HIV/AIDS prior entering to be the study subject.

During the first few days or few weeks of being diagnosed HIV, the level of anxiety presented or even resulted in emotional crisis can be ascertained. Loss of adequate coping mechanism and the signs and symptoms of denial and bargaining with terms are the common phenomenal in most of newly diagnosed with life threatening illness. The nursing intervention includes listening and discussing with patients their fears, rationally highlighting their identifiable strengths to cope with the newly encountered situation is crucial. Nursing intervention on taking the initiative and dispensing information which support hopefulness, discretion and judgment needs to be used before

providing people newly diagnosed with HIV. Provision of detailed information about the disease, when the patient has not requested it may seriously threaten a newly diagnosed patient with HIV.

Robert recommended to start the conversation as "if there's anything

you don't understand, or anything more you would like to know about the illness I am happy to answer your questions" would be appropriate. Some patients may want to know about and understand only certain aspects of the disease. Thus, it is essential that nurses listen carefully to what patients have to say so that relevant information can be provided.

Confidentiality

Definitely, many people newly diagnosed with HIV need to be assured uphold on their diagnosis. All health care providers are to be educated on this ethic.

Recommendations

A useful way to help patients deal with the various psychological anxieties which occurs to most people being newly diagnosed HIV is to form support groups. This group are best lead by the Clinical psychologist. However, the nurses or health care providers that are trained to handle these newly diagnosed PLWHIV plays a critically role.

In summary, being diagnosed with HIV meant different things to different people. Most participants were fearful after being diagnosed with HIV and wanted people to support their children.

This finding shows one of the biggest differences for women with HIV compared to all others. By nature, women generally have strong mind even though they are more emotionally expressive, and their sense of responsibility towards their children is beyond words. It was evident that participants had a change of focus in life and were seeking a new understanding of life. Participants also expressed losing their direction of life and feeling ashamed. Majority of them perceived HIV as a dead end.

References

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