

Development of guidelines for the assessment of abuse in women living with HIV/AIDS in Malawi

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Abstract

The aim of the study was to develop guidelines for the assessment of abuse in women living with HIV/AIDS in Malawi. In phase one of the research, the experiences of these women were explored through a descriptive phenomenological study that involved 12 women living with HIV/AIDS who had encountered abuse. In phase 2, guidelines for the assessment of abuse were developed. Information from the interviews and a review of the literature was used to compile the draft guidelines. The guidelines were refined through a Delphi study carried out by nurses in the field of HIV/AIDS and gender-based violence. The guidelines could assist nurses to identify and address the abuse of women living with HIV/AIDS in a timely manner. Since the guidelines are inclusive of the actions nurses should take to encourage women to talk about their experiences, it is foreseen that their implementation could improve the quality of care rendered to the women.

Keywords: Abuse, assessment, guidelines, HIV/AIDS, women.

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Introduction

The abuse of women and the prevalence of HIV/AIDS are considered to be overlapping epidemics where one impacts on the other (World Health Organization (WHO), 2006). Women who are in violent relationships are at greater risk of having HIV/AIDS while women who have HIV/AIDS are more likely to experience abuse from their family and friends (van Rensburg, 2007; Ramachandran, Yonas, Silvestre & Burke, 2010).

Living with HIV/AIDS can impact negatively on the general well-being of people (Abel, Hopson & Delville, 2006). When women who live with HIV/AIDS also experience abuse their well being is compromised further. Abuse may interfere with their independence in accessing health services and their ability to adhere to anti-retroviral treatment (ART). Abused women tend to endure their suffering in silence (Ellsberg & Heise, 2005) and nurses and other health professionals who care for women living with HIV/AIDS may not be aware of the abuse.

Thirty-four-million people globally were living with HIV/AIDS, by the end of 2010, of whom 50% of the infected adult population were women (WHO, UNAIDS & United Nations Children's Fund (UNICEF), 2011). The worst affected region is sub-Saharan Africa, with 68% of all people living with HIV/AIDS residing in this part of Africa. By the end of 2010 the number of adults and children living with HIV/AIDS in sub-Saharan Africa was estimated at 23.5 million (WHO, UNAIDS & UNICEF, 2011). In Malawi the adult prevalence rate of HIV was estimated to be 10.6% in 2011 (National Statistics Office, 2011).

Malawi is a country situated within the sub-Saharan region with a population of about 13 million people of whom 51% are women (National Statistics Office, 2011). It is a low-income country characterised by a heavy burden of communicable and parasitic diseases with high levels of child- and adult mortality (Zere et al., 2007). Women in Malawi bear the burden of HIV/AIDS more than their male counterparts. The reasons for this largely remain the gender inequalities between men and women (Ministry of Women and Child Development, 2005). Women in Malawi have little access to resources such as an own income and other assets. They have also received an education that hinders their decision-making ability regarding engagement in sexual risk behaviour (Kathewera-Banda et al., 2005). Women are financially dependent on their husbands/partners and they can therefore not negotiate the use of condoms. For this reason, for women, inequality in income is a major driver of the HIV infection (Feldacker, Ennet & Speizer, 2011).

In Malawi, like in most sub-Saharan African countries, nurses form the core of the health care services. Women who are living with HIV/AIDS and are on ART visit the clinic monthly for an assessment by a nurse and for their ART medication. Nurses are, therefore, responsible for identifying all their health needs, which include the occurrence of abuse. As women tend to hide the occurrence of abuse the first author of this article identified a need for assessment guidelines that could help nurses to identify incidents of abuse early in order to manage them properly. Therefore, the aim of this study was to develop guidelines for the assessment of abuse of women living with HIV/AIDS in Malawi. Guidelines for clinical practice could assist health professionals to make informed decisions in specific circumstances in health care settings (WHO, 2003). Such guidelines could be used to assess the occurrence of abuse of women living with HIV/AIDS.

Phase 1 of the research

In this phase of the research, a descriptive phenomenological approach was used and in-depth interviews were carried out with 12 women who received their ART from two clinics in the Lilongwe District Health Office in Malawi. They were purposively selected, as they were living with HIV/AIDS and experienced

abuse from their husbands/partners, family and friends. These 12 women were invited to discuss with the first author the abuse that they suffered. The interviews were transcribed and analysed through the processes described by Collaizi (cited in Streubert & Carpenter, 2007) and Dahlberg, Dahlberg and Nyström (2008). Through eidetic reduction the natural dimensions of the experiences of the participants were transformed into the phenomenological dimension of the experiences (Finlay, 2002). The concrete example of the phenomenon (abuse of women living with HIV/AIDS) was varied in every possible way to identify the features that were vital (Wertz, 2005) to describing the essence of the phenomenon. The essence referred to the 'violating experiences' of the participants. They had to endure abuse from their husbands/partners, family and friends. The constituents that substantiated the essence of their experience referred to: harm, blame, humiliation, abandonment and hopelessness (Chilemba, Van Wyk & Leech, 2014).

Harm

The harm that the participants experienced manifested in a variety of ways. The husbands/partners of the participants were not supportive of the idea that condoms should be used at all times, which resulted in disagreements that forced the participants to take part in unprotected sex. Such forced sex exposed the participants to being re-infected with the virus: *"When I take condoms he uses them for three days; then says 'no condoms'."* All the participants experienced repeated incidents of physical assault: *"Then he started beating me without real issues."* When the participants consulted healthcare facilities repeatedly for the same vague physical symptoms they realised that it could be related to the ongoing harm that they experienced: *"I think this (abuse) affects my health. When I got there (at the hospital) they found that I had stomach ulcers so they told me that ulcers start when you think a lot."* The physical secondary harm that they had to live with was aggravated by the emotional pain that they felt as a result of the poor treatment that they had to endure from their husbands/partners, family and friends: *"It pains me a lot.... nobody goes to the market to choose the type of virus....anyone can be infected."* The participants were convinced that the maltreatment was undeserved and that the people close to them should have supported them. Instead, they even had to hide their medication from their loved ones: *"When I come from the hospital with the medication, when I reach my home, I have to hide the bottles; otherwise he [the husband] would break them."*

Blame

The participants were forced by their circumstances to blame themselves for having HIV/AIDS and for the harm that they experienced. They internalised the blame from others: *"I might be found to be in the wrong..."* Their husbands/partners were the persons who blamed them most for having HIV/AIDS and for being rejected by their loved ones: *"Maybe you got the virus*

from somewhere else, this [you and your health] should not concern me.” The participants were accused of being unfaithful to their husbands/partners and that they got HIV/AIDS because of their infidelity: *“He said that I brought it [the virus] home.”*

Humiliation

The husbands/partners of the participants were at the forefront, leading other people to humiliate their wives: *“When chatting with his friends he takes my medication and shows it.”* Such incidents were the source of humiliation by friends and family members through gossip: *“At times you can go to the water point.. .they make comments”*. Once the family members became aware that a member of the family was infected with HIV they refused to exchange clothes with them, which was often done before the diagnosis: *“We can’t exchange clothes; they refuse.....they say you will give us AIDS.”* Many of the incidents were related to ignorance but, nonetheless, it caused severe hurt and made them think that no one cared for them.

Abandonment

Some husbands/partners left the participants to fend for themselves as soon as they were diagnosed with HIV/AIDS: *“The marriage was over,”* while others chased the participants away: *“Just pack your things and go.”* A general reaction of the husbands/partners was that the participants’ HIV/AIDS did not concern them: *“It does not concern me.”* The participants were left alone to cope with the disease and the negative reactions from their husband/partner and even family: *“My parents abandoned me”*.

Hopelessness

The participants felt a deep sense of despair (*“I gave up and got used to a difficult life”*) as they often had to beg others to help them: *“I would go round begging”*. Their husbands/partners no longer supported them: *“He does not leave any money for me to buy food”* and they often had to go without food: *“He leaves us hungry”*. The life circumstances of these women were desperate and they felt they had no escape from such a life – *“It [life] is very difficult”* and *“I have nowhere to go.”* Such thoughts were compounded by the thought of being abused continually – *“When he comes back, he beats me”* – prompted suicidal ideation. *“It can make me to be tempted [to commit suicide]”* were the words of one participant.

A discussion of the literature on the essence and constituents of the phenomenon is not provided in this article as the focus is on the development of the guidelines to assess experiences of abuse.

Phase 2 of the research

The phase focused on the development of guidelines for the assessment of abuse of women living with HIV/AIDS. The authors translated the constituents harm, blame, humiliation, abandonment and hopelessness into statements for the assessment of abuse of women living with HIV/AIDS in Malawi:

Nurses are to explore the occurrence of humiliation as a form of abuse of women living with HIV/AIDS.

- Nurses are to identify feelings of hopelessness as a manifestation of abuse of women living with HIV/AIDS.
- Nurses are to assess blame as a form of abuse of women living with HIV/AIDS.
- Nurses are to focus on the occurrence of harm when assessing women living with HIV/AIDS.
- Nurses are to assess the occurrence of abandonment as a manifestation of abuse of women living with HIV/AIDS.

A comprehensive literature review was carried out to explore the body of evidence relating to the activities for the assessment of humiliation, hopelessness, blame, harm and abandonment. The activities for each statement were formulated on the basis of the evidence from the literature. The statements and the related activities formed the guidelines for the assessment of women living with HIV/AIDS in Malawi. For the refinement of the draft guidelines the authors obtained the input of experts in HIV/AIDS and gender-based violence through a Delphi study.

Sample for the Delphi study

Ten nurses working at clinical, research and academic institutions and who have had experience in taking care of women with HIV/AIDS and with women who have experienced gender-based violence were selected through purposive sampling to participate in the refinement of the draft guidelines. Six nurses were from South Africa, three nurses were from Malawi and one nurse was from Botswana (Table 1).

Delphi round one

The participants were invited to take part in the refinement of the guidelines through email and provided with a leaflet on what was expected from them to make an informed decision about participation. Their anonymity as members of the participant group was ensured. Once they had confirmed their involvement, the draft guidelines were emailed to them with instructions on how to refine it

through reformulation if necessary. They could also indicate that an activity be added or removed. Each statement and related activities had to be individually evaluated for applicability to the assessment of abuse of women living with HIV/AIDS in a southern African country such as Malawi.

Table 1: Descriptive information of the Delphi study participants

Positions of participants	Qualifications of participants	Relevant experiences of participants
Senior lecturer	RN, PhD	Involved in home based care programming with postgraduate students and interacts with women living with HIV/AIDS. Lectures in community health nursing.
Senior lecturer	RN, DCur	Lectures in midwifery.
Youth and prevention specialist	RN, MCur, PhD scholar	Works with an international organization dealing with gender-based violence partners. Expert in gender activities. Participated in gender-based violence internet assessment.
Primary health care nurse	RN, MCur, PhD scholar	Experience in primary health care nursing. Manages a centre for women and child health.
Senior lecturer	RN, DCur	Experience in trauma counselling and psychotherapy. Lectures in mental health and psychiatric nursing.
Deputy director and HIV/AIDS/STI & TB programme manager	RN, PhD scholar	Has worked in the HIV/AIDS services since 1992 on both regional and national level.
Public health specialist	RN, MPH	Works in programmes for gender equity and gender-based violence. Has worked in HIV/AIDS national programmes.
Lecturer and dean of nursing science	RN, PhD	Trainer of trainers (programme for professional groups that include nurses) in gender health. Lectures in home-based care, HIV/AIDS and community health nursing.
Lecturer	RN, MPH	Trainer in youth behaviour change. Activist on women's sexual and reproductive health Lectures in community health nursing.
Head of post-basic nursing programme	RN, PhD	Involved in HIV and gender programmes since 1989. Founded and managed 2 HIV/AIDS centres. Member of women organizations.

They were also provided with a short summary of phase one of the research so that they could understand how the statements were developed. Upon receipt of the first round of responses, similarities and differences in the participants' responses to the draft guidelines were identified. The most frequent comments were that activities lacked clarity or were repetitive. The guidelines were

accordingly revised and emailed to the participants for a second round of refinement.

Delphi round two

The participants were asked to evaluate the revised guidelines in the same manner they had done in round one. The responses that were received from the second round of evaluation were analysed and their recommendations for change considered. Only a few changes were recommended and were subsequently implemented. As no response contradicted any other, the authors decided that consensus of opinion had been reached.

Ethical considerations

The Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria and the Research and Ethics Committee of the University of Malawi approved the study protocol (documents 199/2010 and P.01/11/1028). Written permission from the applicable officer to conduct the research in clinics of the Lilongwe District Health Office was obtained and all the participants of phase one and two of the research gave informed consent to take part in the research.

Trustworthiness of findings

The guidelines were based on the experiences of the participants of phase one and a comprehensive literature review. The use of two rounds of refinement of the guidelines and the consensus of opinion on the content of the guidelines contributed to the trustworthiness of the findings (Hasson, Keeney & McKenna, 2000).

A final set of guidelines as findings of the research

The statements and related activities are presented below as making up the results of the research. A preamble is provided (below) to provide nurses who intend to use the guidelines with background information.

Title: Guidelines for the assessment of abuse of women living with HIV/AIDS in Malawi

Preamble: Women living with HIV/AIDS encounter abuse from their partners, family and friends. Many of the women endure the abuse in silence. They do not report their experiences of abuse to nurses for the necessary intervention to be done. Applicable guidelines can assist nurses to identify and address the abuse of women living with HIV/AIDS in a timely manner. The guidelines provide information on the manifestations of abuse on the basis of the experiences of

women living with HIV/AIDS and evidence from literature. The guidelines were further developed on the basis of consensus of a Delphi study carried out among nurses in the field of HIV/AIDS and gender-based violence.

Women living with HIV/AIDS narrated their experiences to the researchers through in-depth interviews. Experiences of abuse among women living with HIV/AIDS were explored and described using a phenomenological study. The abovementioned step was followed up by an extensive review of literature that was conducted for the purpose of developing a more comprehensive understanding of the abuse that women who live with HIV/AIDS experience. Finally, the draft guidelines were formulated on the basis of the findings and the extensive review of the literature.

Five guidelines were developed, each having a rationale and activities that could be used by the nurse during the assessment of women living with HIV/AIDS. The questions raised in the guidelines do not necessarily have to be asked in any specific order. Nurses could keep the guidelines at hand and use them as a reference to focus on the areas that have to be addressed when they are dealing with women living with HIV/AIDS and who experience abuse. Such women should be encouraged talk about their experiences. The guidelines could lead to an improvement of the quality of care rendered to the women, which would promote their health and well being. The guidelines are set out as follows:

Guideline 1: Nurses are to explore the occurrence of humiliation as a form of abuse of women living with HIV/AIDS.

In the identification of humiliation in women living with HIV/AIDS nurses should:

- Encourage the women to express any feelings of being unfairly treated in any way as a repercussion of having HIV/AIDS.
- Explore any feelings expressed by the women of being disrespected, ridiculed or insulted by the actions of their significant others.
- Determine whether the women have been made to feel unrecognised by the actions of others in relation to their HIV/AIDS.
- Ascertain whether the women feel they have been gossiped about or they have been ridiculed in their homes, communities or at work.
- Identify whether the women feel their honour and dignity have been adversely affected or jeopardised in any way by the actions of others, on account of their HIV/AIDS.
- Establish whether the women feel ashamed in response to the actions of others in relation to their HIV/AIDS.
- Determine if the women feel excluded or rejected in their interaction with others within their social network.

- Explore any feelings that the women might have of being betrayed in their relationships with others, which feelings have caused them to become distrustful.
- Explore any inhumane treatment the women might have encountered and their feelings about it.

Guideline 2: Nurses are to identify feelings of hopelessness as a manifestation of abuse of women living with HIV/AIDS.

In the identification of hopelessness in women living with HIV/AIDS nurses should:

- Determine if the women feel that their lives have no sense or meaning.
- Determine the women's feelings of powerlessness in improving their situation for the better.
- Explore whether the women feel that their situation is impossible to overcome.
- Establish whether the women feel like giving up on life.
- Determine whether they feel that the changed relationships with significant others leave them without family and other social support.
- Explore if the women feel a diminished sense of self-esteem as a result of the actions of others.
- Identify any loss of motivation in the women to deal with their situation.
- Assess any decrease in affective emotions towards themselves and other people.

Guideline 3: Nurses are to assess blame as a form of abuse of women of living with HIV/AIDS.

In the assessment of feelings of blame in women living with HIV/AIDS nurses should:

- Explore whether the women have been called names or shamed in public for having HIV/AIDS.
- Determine whether the women have been referred to as being worthless by others because of their having HIV/AIDS.
- Ascertain if the women feel that others have considered them to be a burden for possibly having had to rely on their assistance earlier or needing to rely on them in the future.
- Establish if the women have been referred to as being the sources of infection after disclosure of their HIV/AIDS.
- Explore whether the women feel they deserve blame and have to take responsibility for being victimized.

- Examine whether the women are being treated as if they no longer are similar to their relatives and friends.

Guideline 4: Nurses are to focus on occurrence of harm when assessing women living with HIV/AIDS.

In the assessment of factors that may contribute to harm in women living with HIV/AIDS nurses should:

- Explore circumstances under which the women are forced to engage in unprotected sex (predisposing them to re-infection with HIV).
- Establish whether the women worry about the potential transmission of HIV to an unborn child, neonate or partner.
- Assess whether the women have suffered any injury or emotional pain as a direct or indirect consequence of having HIV/AIDS.
- Identify any losses that have been suffered, which losses might include status, income, good health and spirituality, resulting in perceived poorer quality of life.
- Ascertain if feelings of being stressed by the actions of other people are experienced.
- Determine if there is an inability to take ART medication as a result of the lack of support from family or friends.
- Assess whether the women's basic needs of love, security and belonging are not being met.

Guideline 5: Nurses are to assess the occurrence of abandonment as a manifestation of abuse of women living with HIV/AIDS.

In the assessment of women living with HIV/AIDS nurses should:

- Explore any feelings the women might have of being rejected by members of their social network.
- Identify the existence of negative feelings about self and diminished self-esteem because of the actions of others.
- Establish the level of deterioration in social support (so that the women have to fend for themselves) compared to previous circumstances.
- Assess if the women have suffered a loss of identity and status, such as that of being a wife, partner or a part of a stable social group.
- Explore if any relationships in the women's lives have deteriorated and potential feelings of betrayal and pain with regard to this.
- Ascertain whether the women feel that others have avoided physical or social contact with them.
- Explore any issues of lacking access to necessary care that the women might experience.

- Determine the extent of limitations in relation to resources as a consequence of abandonment.

Implications for nursing

The findings of the study revealed that women living with HIV/AIDS experienced abuse from their husbands/partners, families and friends. Owing to the stigma attached to gender-based violence women try to hide it from other people (Ellsberg & Heise, 2005) and nurses tend to focus more on physical abuse. Episodes of abuse, for this reason, are not identified and are therefore not managed. Abuse manifests in different ways and is not limited to being cursed at, humiliated or ignored or beaten (Kathewera-Banda et al., 2005). It can make it difficult and oftentimes impossible for the women living with HIV/AIDS to adhere to the prescribed treatment regimens.

This study highlighted the need for nurses to address the abuse of women living with HIV/AIDS. The situation on the ground, however, indicates that women are not able to disclose their experiences of abuse to the nurses. This inability to disclose such experiences is the result of high patient loads and staff shortages, which reduce the likelihood of the women receiving appropriate care and support. If nurses made a deliberate effort to find out from the women whether they experience abuse and to what extent it happens will encourage them to confront such experiences. At this point, together with the nurses, the women could explore avenues to mitigate the impact of such abuse through available channels and referrals. The proposed guidelines for the assessment of abuse of women living with HIV/AIDS could help nurses to identify a range of abuses that women in Malawi might experience. The process of guideline development is never complete. Follow-up research should be conducted to evaluate the use of the guidelines in practice.

Conclusion

It is crucial for nurses to explore with the women encounters of abuse because living as an HIV/AIDS-positive woman is very difficult. The guidelines developed in this study provide information on the manifestations of abuse. It was based on the experiences of women living with HIV/AIDS and evidence from the literature and developed with consensual input from nurses in the field of HIV/AIDS and gender-based violence. Applicable guidelines could assist nurses to identify and address the abuse of women living with HIV/AIDS in a timely manner. Since the guidelines are inclusive of the actions nurses should take to encourage women to talk about their experiences, it is foreseen that their (the guidelines) implementation could improve the quality of care rendered to the women.

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