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Children's HIV Status and the Acceptance Stage of Grief amongst HIV-Positive Women

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Abstract

Background: Women living with HIV (WLWH) commonly grieve but may pass through the grieving process until reaching the acceptance stage. We try to identify the relationship between children's HIV status and the acceptance stage of grief amongst WLWH. **Method:** This cross-sectional study utilised consecutive sampling of 235 HIV-positive women in Jakarta, Indonesia. The women were assessed with the Acceptance of Disease and Impairments Questionnaire (ADIQ). **Results:** Most of the respondents were housewives (65.5%), had been diagnosed over one year previously (74.5%), had an HIV-positive spouse (60.4%), had more than one child (51.5%) but none who were infected (73.6%) and assumed that their HIV status was caused by their spouse (50.2%). The respondents' median score of acceptance of their HIV status was relatively high (3 on a 1-4 scale). This showed a significant negative correlation between children's HIV status and the acceptance stage amongst HIV-positive women ($p = 0.01$). **Conclusion:** Mother-to-child HIV transmission may disrupt the mother's acceptance stage because of feelings of guilt and difficulty disclosing their status. Because the children's HIV status was correlated with the mother's acceptance stage, WLWH must comply with the Preventing Mother-to-Child Transmission of HIV (PMTCT) program during the perinatal period.

Keywords: children, HIV, grief, women.

Introduction

Women are commonly at a higher risk of contracting HIV to heterosexual intercourse than other transmissions. In addition, women can be infected with HIV through blood transfusion and injection drug use; however, the percentage of women infected by these methods is generally low (15.2% and 0.6%, respectively) compared to heterosexual transmission (61.5%).¹ Furthermore, the proportion of HIV-positive women is higher amongst married women with an HIV-infected sexual partner (59.7%) compared to unmarried women (11.6%) or widows (28.7%).² Another study in Jakarta discovered that most HIV-positive women were housewives (60%).³ Accordingly, women are more vulnerable to contracting HIV from an HIV-infected spouse.

Furthermore, women are at risk of transmitting HIV to their children, known as vertical transmission. A previous study has stated that 31.7% of 281 infants aged 15 months were diagnosed as HIV positive after screening; vaginal infection and pus output on the mother's breast were predictors of mother-to-child transmission.⁴ This vertical transmission can disrupt the psychological condition of the mothers because they feel guilty about transmitting HIV to their children.^{5,6}

Several previous studies have addressed the grieving process of HIV-AIDS patients in general⁷; however, there are still limitations regarding the description of the acceptance stage of grief in women living with HIV (WLWH) and factors related to it. Therefore, the purpose of this study was to identify the relationship between children's HIV status and the acceptance stage of grief amongst HIV-positive women.

Methods

This study used a cross-sectional design. This study involved 235 HIV-positive women outpatients at several of public health centres in five districts of DKI Jakarta Province, Indonesia, during June 2016. Sample size was calculated based on 5% margin of error, 95% confidence level and 10% absolute precision. Since prevalence of acceptance stage of grief was unknown, a prevalence rate was set 50% to increase the power. The minimum sample size was 106 HIV-positive women, considering 10% compensation for possible respondent drop out. Respondents were selected using the consecutive sampling method using the following inclusion criteria: HIV-positive women, with or without a spouse, receiving antiretroviral treatment and volunteer to become a respondent.

Normally distributed variables are presented as mean and standard deviation. Non-normally distributed variables after data transformation are presented as median and minimum–maximum score using univariate analysis. Spearman test was used to assess correlation between numerical data and ordinals. Results with $p < 0.05$ were considered statistically significant. The Acceptance of Disease and Impairments Questionnaire (ADIQ) was used to collect the data.⁸ The Ethical Committee of the Faculty of Nursing, Universitas Indonesia approved this study (No. 0393/UN2.F12.D/HKP.02.04/2016).

Results

The median acceptance score of the respondents were 3 (2.88 ± 0.72). This score is relatively high (on 1 to 4 scale), indicating that the respondents were well-accepting of their HIV status.

On average, the respondents were 31.85 years old ($SD = 5.41$ years). Over half of the respondents were housewives (65.5%) who had known their HIV status for more than one year (74.5%) and who had an HIV-positive spouse (60.4%). Most of the respondents had more than one child (51.5%) but no children who were HIV positive (73.6%). Most of the respondents assumed

Table 1. Respondents' Age, Occupation, Duration of Diagnosed HIV Status, Spouse's HIV Status, Number of Children, Children's HIV Status and Assumption of Transmission in HIV-Positive Women in DKI Jakarta Province, June 2016 (n = 235)

Variable	Mean	SD	n (%)
Age	31.85	5.41	
Occupation			
Housewife			154 (65.5)
Other			81 (34.5)
Duration of diagnosed HIV status			
Less than one year			60 (25.5)
More than one year			175 (74.5)
Spouse's HIV status			
Positive			142 (60.4)
Negative			27 (11.5)
Unknown			66 (28.1)
Number of children			
0			35 (14.9)
One child			79 (33.6)
More than one child			121 (51.5)
Children's HIV status			
No kids are positive			173 (73.6)
≤25% of my kids are positive			11 (4.7)
≤50% of my kids are positive			19 (8.1)
≤75% of my kids are positive			7 (3)
>75% of my kids are positive			25 (10.6)
Assumption of transmission			
Infected spouse			118 (50.2)
Injection drug use (IDU)			49 (20.9)
Sexual intercourse with more than one partner			26 (11.1)
Blood transfusion			4 (1.7)
Unknown			38 (16.2)

Table 2. Relationship between Respondent's Characteristics with Acceptance Stage in HIV-Positive Women in DKI Jakarta Province, June 2016 (n = 235)

Independent variable	Acceptance	
	r	p
Age	-0.02	0.79
Occupation	0.07	0.27
Duration of diagnosed HIV status	0.06	0.33
Spouse's HIV status	0.02	0.73
Number of children	0.02	0.81
Children's HIV status	-0.15	0.01*
Assumption of transmission	-0.05	0.44

* $p < 0.05$

that their HIV-positive status was caused by their spouse (50.2%) (Table 1).

There was a weak, negative correlation between the children's HIV status and the acceptance stage of grief amongst the HIV-positive women. Therefore, the respondents displayed greater acceptance when they had fewer HIV-positive children. The analysis showed that this correlation was significant ($p = 0.01$) (Table 2).

Discussion

Kubler-Ross has stated that grief has five stages: denial, anger, bargaining, depression and acceptance.⁹ Grief is a fluid and dynamic process that will naturally resolve itself for most people.¹⁰ Acceptance—as the last stage of grief—occurs when individuals are able to live at peace with their loss.⁹

Grief is common amongst HIV-positive individuals. A previous study has shown that patients experienced stress and grief when they were first diagnosed with HIV/AIDS.¹¹ Grief in HIV-positive women is even more intense because of HIV-related stigma and gender discrimination.^{6,12} Another study has demonstrated that HIV-positive women had a unique acceptance stage of grief because they assume double roles: as a woman and/or mother. They also have capacities for childbearing and breastfeeding.¹³ The nature of women is unique but may put them at risk for vertical HIV transmission from mother to child.

Reproductive-aged mothers have a risk of transmitting HIV to their children. A study has shown that most HIV-positive women were of an average age of 32 years, indicating that they were of reproductive age and were capable of childbearing. This result was in line with another study showing that most HIV-positive women were of reproductive age, had children and did not use birth control.¹⁴ HIV transmission was more prevalent amongst younger women than amongst older women because young women are more likely to engage in unsafe sexual intercourse, which is one of the risk factors for HIV infection.¹⁵ HIV transmission from

mother to child may cause the anxiety in mothers.¹⁶ Nevertheless, it can be prevented by adhering to the Preventing Mother-to-Child Transmission of HIV (PMTCT) program.^{17,18} Patients who routinely access public health centres and frequently receive health care and counselling gain positive outcomes and, therefore, are more likely to have a higher commitment and adherence to the PMTCT.^{13,19}

A previous study has shown that 62.9% of HIV-infected women in South Ethiopia were fully aware that they may transmit HIV to their children; however, only 11.5% had sufficient knowledge regarding the period of transmission.²⁰ Furthermore, this study revealed that the level of knowledge was associated with education, occupation and information received from antenatal care and communication with their partner regarding antenatal care and HIV/AIDS. In addition to the knowledge level, HIV transmission can be influenced by the awareness level of women. Previous studies have found that most HIV-infected mothers were unaware of their HIV status and were late to undergo the necessary laboratory tests to examine their HIV status in health care facilities.^{21,22} Delayed HIV screening may lead to HIV transmission from the mother to child before the mothers are able to exercise preventive measures and treatment.²³ These reports support the results of current study, which demonstrated that a quarter of respondents had HIV-positive children who were infected during pregnancy, birth, or puerperium.

The comprehensive PMTCT program may effectively prevent mother-to-child HIV transmission. The greatest attention toward HIV transmission should be given during the perinatal period (pregnancy, birth and breastfeeding). Non-adherence to the PMTCT program may collectively increase the risk of HIV transmission from mother to child. The optimal implementation of the PMTCT program aims to achieve zero HIV transmission from mother to child.²³ In addition, this program may reduce psychological effects of HIV amongst the mothers. Previous studies have found that mothers were highly concerned about the safety of their foetuses and the risk of HIV transmission to their children and, consequently, experienced grief.^{6,16}

Moreover, recent studies have demonstrated that HIV-positive women could complete the acceptance stage of their grief. Moreover, a low acceptance level of grief was linked with self-blaming amongst HIV-positive women.²⁴ By contrast, a high acceptance level was associated with spiritual coping.²⁵ Another study has revealed that HIV status disclosure influenced acceptance.³ WLWH are more likely to disclose their status to health care providers so that they can receive health care and prevent HIV transmission to their children. Conversely, they may also keep their HIV status secret to protect their children from HIV-related stigma.³

Recent studies shown has that the acceptance of HIV-positive status was related to the women's values of their fate and their concern about the future of their children. The basic nature of women causes them to be more concerned about who will assume the responsibilities to nurture their children after they pass.^{6,26} Thus, HIV-positive women tend to be more motivated to stay alive for themselves and for the rest of their surviving children.²⁷ A study in South Africa has revealed that HIV-positive women were struggling to feed their children and to protect them from HIV-related stigma.⁶ HIV-positive women positively accept their status because they consider themselves healthy and are able to perform routine activities of daily living.^{28,29} This self-view may help WLWH accept their HIV status and may contribute to improving their immunity and quality of life.³⁰ All the respondents who visited public health centres and received health care and peer support in our study had a good general appearance.

Our study found that children's HIV status was significantly correlated with the acceptance stage of grief amongst HIV-positive women. This may be caused by the women's views regarding their children's health. Mothers will be less anxious when they knew that their children are HIV-negative. This finding was in line with a previous study that revealed the stress and anxiety level of pregnant women diagnosed with HIV.¹⁶ Women are more likely to reach the acceptance stage of grief when their children's HIV status is negative. In addition to anxiety, feelings of guilt can make women feel terribly sad. However, the mother's guilt may be reduced if the children are not infected by HIV from their mother.³¹ Children's HIV-negative status can decrease anxiety and feelings of guilt of the mother. Consequently, the mother can move to the acceptance stage. We found a correlation between the child's HIV status and the acceptance stage of HIV-positive women.

These results are in line with previous studies suggesting that feelings of guilt in people with HIV/AIDS can lead to a poor living condition.³² If they do not resolved this feeling of guilt, it is difficult for them to move on to the acceptance stage of both status and treatment, which in turn results in a poor quality of life. We found that 70% of respondents had children who were all HIV-negative, which was correlated with the acceptance stage. Thus, in general, their living condition was also relatively good.

Most of the respondents in this study were patients who had been diagnosed as HIV-positive for a long time and had received counselling in primary care facilities. Therefore, the respondents were dominated by mothers who had accepted their status and continued living their life and raising their children. The respondents believed that if HIV-positive patients adhere well to the treatment guidelines and cope well with the stress, they have a greater chance of having an HIV-negative child. This

result is supported by previous research that the number of children and their status is related to the mental well-being of the quality of life amongst HIV patients.³³

In addition to feeling guilty, sad and anxious regarding their children's health, it is difficult for mothers to disclose the child's status, particularly if her child is also HIV positive. The decision of parents to disclose their HIV status to their children is more complex compared to other family members.³⁴ A previous study found that parents expressed uneasiness to start a conversation because they are afraid of stigma, which can interfere their children's psychology.³⁵ Some studies reported that although children were HIV-negative, they might still be stressed out by their mother's HIV-related stigma.³⁶ Therefore, when the child is determined to be HIV-negative, it can indirectly affect the psychology of a mother so that she will easily accept her HIV-positive status and continue to live her life optimistically.

Conclusions

This study found that the acceptance stage of grief in HIV-positive women was completely achieved and was associated with a negative HIV status in children. Since the HIV status of children is correlated with the acceptance stage of HIV women, mother-to-child HIV transmission must be prevented. The PMTCT program has been initiated by the government. This program should be properly performed during pregnancy, childbirth and the breastfeeding period. Healthcare providers should ensure that women with HIV are obedient to treatment and follow all the components of the PMTCT program.

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Conflict of Interest Statement

None declared.

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