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Development of resilience model in people with human immunodeficiency virus undergoing antiretroviral therapy

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ABSTRACT

Resilience that has not been formed and self-regulatory functions that are not optimal, play a role in low adherence to treatment for people living with HIV/AIDS (PLHIV). This study aimed to develop a resilience model of antiretroviral therapy (ARV) adherence and quality of life for PLHIV. This study used a cross-sectional approach to 185 PLHIV in Tulungagung, East Java, Indonesia who were selected using simple random sampling. Individual factors, disease representation, emotional response, social support, interpretation, coping, resilience, adherence, and quality of life were variables in this study that were measured using a questionnaire. The data were then analyzed descriptively and using structural equation model (SEM) based on partial least square (PLS). The results showed that individual factors (T=4.062), disease representation (T=3.755), emotional response (T=3.988), and social support (T=2.753) affected interpretation of disease. Interpretation of disease then influences coping (T=5.285). Coping affects resilience (T=4.045), resilience influences ARV adherence (T=2.846), and adherence affects quality of life (T=10.050). Other factors that directly influence ARV adherence are emotional response (T=3.120) and social support (T=3.255). This resilience model is relevantly able to improve adherence in PLHIV. Emotional response is a factor that has the strongest influence in shaping the resilience of PLHIV in the mechanism of adherence and quality of life.

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1. INTRODUCTION

Antiretroviral therapy (ARV) has been shown to reduce the amount of virus, improve health conditions and quality of life in people living with HIV/AIDS (PLHIV), and contribute directly to reducing the risk of transmission and death [1]. However, in practice, many people living with HIV/AIDS are disobedient in carrying out therapy and are often lost during a series of HIV care [2]. This is indicated by the lost follow-up (LFU) rate for ARV care and therapy which has increased to 26% [3]. Adherence with ARVs that is not optimal will have an impact on a progressive decrease in body immunity, worsening of disease, and will reduce the quality of life of PLHIV in physical, psychological, social, and environmental aspects [4], [5]. PLHIV often experience psychosocial problems such as depression, rejection, and anger because of their illness. Individual resilience needs to be formed and maintained to improve physical and mental health, which is related to a better quality of life and adaptation to disease [6]. The process of building resilience in PLHIV can experience obstacles due to the ability in coping and self-regulation that is still not optimal. Self-regulation influences self-control and improves the quality of life, which is the key to managing HIV/AIDS [7].

HIV/AIDS cases continue to experience increase every year both in the world and in Indonesia [8]. In 2021, 38.4 million people worldwide suffered from HIV, with 28.7 million of them undergoing ARV therapy [9]. Indonesia is one of the countries in Asia with a rapidly growing HIV infection rate [8]. East Java occupies the first position in Indonesia with the highest number of HIV cases in 2019, namely 8,935 cases [10]. Based on the 2021 report on HIV care and antiretroviral therapy from the Indonesian Ministry of Health, out of 269,289 PLHIV undergoing ARV therapy, 68,508 people (26%) experienced LFU [3], [11]. The LFU rate then influences the poor quality of life of PLHIV, including in the physical domain at 63.0%, the psychological domain at 58.0%, the social domain at 54.0%, and the environmental domain at 33.0% [12].

Factors that increase adherence to ARV therapy are the formation of resilience in individuals through adaptability as well as psychological and behavioral characteristics. PLHIV with greater resilience tends to be less affected by negative stressors that arise as a response to the conditions of difficulty experienced [6]. Higher resilience is significantly associated with a lower prevalence of depression in PLHIV [13]. Psychosocial factors such as interpretation of disease and emotional responses indirectly influence PLHIV adherence to treatment and then play a role in shaping adaptive coping and individual resilience in responding to experienced stressors. Adaptive coping mechanisms are characterized by the individual's ability to seek information and assistance in managing the disease. This will further improve the health behavior of PLHIV in treatment and produce the final result in the form of an increase in quality of life [14], [15].

Resilience is described as an individual's capacity to maintain, restore or improve mental health and be able to adapt to stressful life challenges and the individual's ability to make changes and transformations from difficult life pressures [16], [17]. The development of the resilience model in this study is integrated with self-regulation. The self-regulation process is closely related to the emotional regulation process. The process of emotional regulation broadly is the process of a person regulating all types of affective or emotional responses including attention, cognitive representations, and physical or behavioral responses [18]. Self-regulation can help a person to motivate and direct his actions in achieving a goal. Several aspects of self-regulation are metacognition, motivation, and behavior [19]. The two theories are considered suitable for integration because they have the same goal, namely to form adaptive coping in individuals in dealing with stressors or adversity, in this case, HIV disease. Previous research has only discussed the importance of building resilience in PLHIV to improve psychological conditions and achieve adaptive coping without paying attention to other factors such as emotional response and self-regulation [20]–[22]. Research related to the development of self-regulation-based resilience models on treatment adherence and quality of life for PLHIV is yet to be found. This study aimed to develop a resilience model of antiretroviral adherence and quality of life for PLHIV.

2. METHOD

This research was conducted at the Tulungagung Regency AIDS Commission (KPA; read: *Komisi Penanggulangan AIDS*), East Java in April 2023. The research design was explanatory research with a cross-sectional approach. The sample in this study was PLHIV registered at the KPA Tulungagung Regency, with inclusion criteria: PLHIV currently undergoing ARV treatment, able to communicate verbally and able to read written well, and at least 20 years old. While the exclusion criteria included: PLHIV accompanied by other diseases (comorbidities) and/or experiencing opportunistic infections that interfered with the research process, and PLHIV who were being hospitalized. The sample in this study was calculated based on the rule of the thumb sample size formula. The required sample size is calculated based on the maximum likelihood estimate, which is 5-10 times the number of parameters measured [23]. The development of this resilience model used 37 parameters, so the sample size used in this research is 5×37=185 respondents. The 185 of PLHIV were then selected randomly using a simple random sampling technique, via the Microsoft Excel application.

The variables analyzed in this study were individual factors, disease representation, emotional response, social support, interpretation, coping, resilience, antiretroviral adherence and quality of life of PLHIV. Individual factors were measured using a demographic data questionnaire, disease representation was measured using the brief illness perception questionnaire (B-IPQ) developed by Broadbent *et al.* [24] which consists of 9 question items. Emotional responses were measured using the depression anxiety stress scale (DASS-42) questionnaire developed by Nursalam [25] and consisted of 42 questions. The social support variable was measured through a modified psychological-social-spiritual response questionnaire [25]. Interpretation variables include perceived symptoms and social burden measured using the HIV disability questionnaire (HDQ) questionnaire developed by O'Brien *et al.* [26], and the stigma questionnaire developed by Fitryasari *et al.* [27]. Coping variables were measured using a coping questionnaire that was modified from the ways of coping questionnaire developed by Kolokotroni [28]. Measurement of resilience through the resilience scale for adults (RSA) questionnaire developed by Friborg *et al.* [29] and has been modified

according to the indicators developed, including personal competence, self-confidence, self-acceptance, self-control, and spiritual influences. The instrument for measuring adherence to ARV therapy used a modified patient medication adherence questionnaire (PMAQ) questionnaire by Duong *et al.* [30]. quality of life was measured using a questionnaire developed by The World Health organization quality of life (WHOQoL)-BREF adapted from WHO (2014) and developed by Nursalam [25]. The instruments used in the study were tested on 30 PLHIV, and met the requirements for validity (r=0.429–0.978) and reliability (Cronbach's alpha=0.706–0.964). The collected research data was then analyzed descriptively and inferentially using SEM-PLS test. It is confirmed that the research carried out has fulfilled several ethical principles and has received approval for ethical eligibility from the Health Research Ethics Commission Faculty of Nursing, Universitas Airlangga on April 3rd, 2023, with ethical certificate number 2813-KEPK.

3. RESULTS

3.1. PLHIV demographic characteristic

This study involved 185 PLHIV who were recorded at the KPA Tulungagung Regency in April 2023. The characteristics of the PLHIV who participated in this study are described in Table 1. Based on the results of the analysis in Table 1, it is known that the majority of PLHIV in Tulungagung Regency in April 2023 in this study are female (55.7%), and most of them were in the early adult age range (26-35 years). The majority of the respondents in this study had been diagnosed with HIV (35.7%) and had undergone treatment (36.8%) for more than 5-10 years. Knowledge of PLHIV related to HIV disease, treatment, and prevention of opportunistic infections is in a good category (78.9%).

Table 1. Demographic characteristic of PLHIV in Tulungagung Regency in April 2023 (n=185)

Characteristic	Indicators	Frequency	Percentage
Gender	Male	82	44.3
	Female	103	55.7
	Total	185	100.0
Age (year)	17-25	9	4.9
	26-35	63	34.1
	36-45	57	30.8
	46-55	56	30.3
	Total	185	100.0
Duration of illness	6 months–1 year	29	15.7
	>1–5 years	51	27.6
	>5–10 years	66	35.7
	>10 years	39	21.1
	Total	185	100.0
Duration of medication	6 months–1 year	29	15.7
	>1–5 years	51	27.6
	>5–10 years	68	36.8
	>10 years	37	20.0
	Total	185	100.0
HIV knowledge	Less	8	4.3
	Enough	31	16.8
	Good	146	78.9
	Total	185	100.0

3.2. Variable description

This study is composed of several construct variables that form the resilience model developed. In this section, the distribution of research variables will be shown in 185 PLHIV in Tulungagung Regency, East Java, Indonesia. Table 2 displays the results of the description of research variables.

Based on Table 2, variables that make up the model in this study are emotional response, social support, interpretation, coping, resilience, adherence, and quality of life. In this study, the average PLHIV had emotional responses in the form of stress (59.5%), anxiety (37.8%), and depression (24.9%) in the low category. The results showed that the majority of social support provided by families and health workers in terms of informational, emotional, and material support was of high value. Based on the results of the analysis in Table 3, it is also known that PLHIV has an interpretation of the disease in terms of perceived symptoms (73.5%), social burden (58.9%), and stigma (82.7%) with a low category. The majority of PLHIV in this study applied the principle of approach coping as much as 57.8% in solving problems. Resilience in PLHIV is measured in 5 sub-variables. The results of the analysis show that the majority of PLHIV have high resilience in all indicators, namely personal competence (49.2%), self-confidence (54.1%), self-acceptance (51.9%), self-control (53.5%) as well as spiritual influences (58.9%). Furthermore, the level of adherence of PLHIV in ARV treatment in this study was assessed from several sub-variables. Based on the research

results, it is known that almost all PLHIV have high medication adherence in terms of schedule adherence (93%), right amount (94.6%), right type (90.8%), management of side effects (92.4%) and motivation (81.1%). However, in receiving information, the majority were still in the moderate category (57.3%). The quality of life for PLHIV in this study was measured through 6 sub-variables. The analysis results show that most PLHIV have a high quality of life in physical (70.3%) and emotional (65.4%) aspects. However, PLHIV still has a low social welfare aspect of 29.7% with cognitive function (67%) and courage in disclosing status (53%) still of moderate value. In addition, it was found that more than half of PLHIV stated that they had a high level of depression in achieving quality of life (73.5%).

Table 2. Description of research variables

Indicators	Low	Moderate	High
Emotional responses			
Stress	144 (77.9)	34 (18.4)	7 (3.8)
Anxiety	151 (81.6)	27 (14.6)	7 (3.8)
Depression	146 (79)	16 (19.5)	3 (1.5)
Social support			
Family support	46 (24.9)	59 (31.9)	80 (43.2)
Health workers support	19 (10.3)	39 (21.1)	127 (68.6)
Interpretation			
Perceived symptoms	136 (73.5)	37 (20.0)	12 (6.5)
Social burden	109 (58.9)	63 (34.1)	13 (7.0)
Stigma	153 (82.7)	23 (12.4)	9 (4.9)
Coping			
Approach coping	11 (5.9)	67 (36.2)	107 (57.8)
Avoidance coping	55 (29.7)	109 (58.9)	21 (11.4)
Resilience			
Personal competence	7 (3.8)	87 (47.0)	91 (49.2)
Self-confidence	1 (0.5)	84 (45.4)	100 (54.1)
Self-acceptance	8 (4.3)	81 (43.8)	96 (51.9)
Self-control	1 (0.5)	85 (45.9)	99 (53.5)
Spiritual influences	0 (0.0)	76 (41.1)	109 (58.9)
ARV adherence			
On schedule	0 (0.0)	13 (7.0)	172 (93.0)
Right amount	4 (2.2)	6 (3.2)	175 (94.6)
Right type	0 (0.0)	17 (9.2)	168 (90.8)
Management of side effects	0 (0.0)	14 (7.6)	171 (92.4)
Receiving information	0 (0.0)	106 (57.3)	79 (42.7)
Motivation	10 (5.4)	25 (13.5)	150 (81.1)
Quality of life			
Physical	0 (0.0)	55 (29.7)	130 (70.3)
Emotional	15 (8.1)	49 (26.5)	121 (65.4)
Social welfare	55 (29.7)	116 (62.7)	14 (7.6)
Cognitive function	7 (3.8)	124 (67.0)	54 (29.2)
Depression level	11 (5.9)	38 (20.5)	136 (73.5)
HIV disclosure	20 (10.8)	98 (53.0)	67 (36.2)

The results of the analysis in Table 3 show that there are still PLHIV who are represented in terms of disease identity as a threat (43.8%), including indicators of causes (50.3%) and consequences of disease (42.2%) which are also perceived as a threat. The rest of PLHIV have good representation regarding HIV disease and do not consider their current disease to be a threat. The disease representation describes the individual's condition in developing and considering appropriate treatment strategies for the disease.

Table 3. Description of disease representation variables

Indicators	Threat	Not threat
Disease representation		
Disease identity	104 (56.2)	81 (43.8)
Cause	92 (49.7)	93 (50.3)
Consequences	107 (57.8)	78 (42.2)

3.3. Final model

The evaluation of the estimated significance aims to answer the hypotheses that have been formulated, and whether they can be accepted or rejected. Interpretation of the research hypothesis can be assessed from the t-statistic value >1.96 and the probability value (p-value) <0.05 or with an error rate of 5%. The results of hypothesis testing can be seen in the Table 4.

Table 4. The final model of research hypothesis testing results

Variable	Path coefficient	T statistics	p-value	Results
X1 Individual Factors → X5 Interpretation	-0.303	4.062	0.000	Significant
X2 Representation → X5 Interpretation	0.221	3.755	0.000	Significant
X3 Emotional Response → X5 Interpretation	0.363	3.988	0.000	Significant
X4 Social Support → X5 Interpretation	-0.189	2.753	0.007	Significant
X1 Individual Factors → Y1 Adherence	0.097	1.284	0.200	Not significant
X2 Representation → Y1 Adherence	-0.041	0.511	0.610	Not significant
X3 Emotional Response → Y1 Adherence	-0.245	3.120	0.008	Significant
X4 Social Support → Y1 Adherence	0.265	3.255	0.002	Significant
X5 Interpretation → X6 Coping	-0.395	5.285	0.000	Significant
X6 Coping → X7 Resilience	0.390	4.045	0.000	Significant
X7 Resilience → Y1 Adherence	0.244	2.846	0.009	Significant
Y1 Adherence → Y2 Quality of life	0.558	10.050	0.000	Significant

The results of the research analysis through SEM-PLS, obtained several influential factors in the formation of the model, namely individual factors (T=4.062), disease representation (T=3.755), emotional response (T=3.988), and social support (T=2.753) towards interpretation of disease. Interpretation of disease then influences coping (T=5.285). Coping affects resilience (T=4.045), resilience influences ARV adherence (T=2.846), and adherence affects quality of life (T=10.050). Other factors that directly influence ARV adherence are emotional response (T=3.120) and social support (T=3.255). The final model of the resilience model development study was obtained after reducing 2 (two) path coefficients that did not have a significant effect, namely individual factors (X1) on antiretroviral adherence (Y1) and disease representation (X2) on antiretroviral adherence (Y1). Based on the path coefficient value in the final model, it is known that the strongest factor constituting the model is emotional response with a path coefficient value of 0.363 which in turn influences interpretation. The image of the final (fit) model for the development of resilience model is shown in Figure 1.

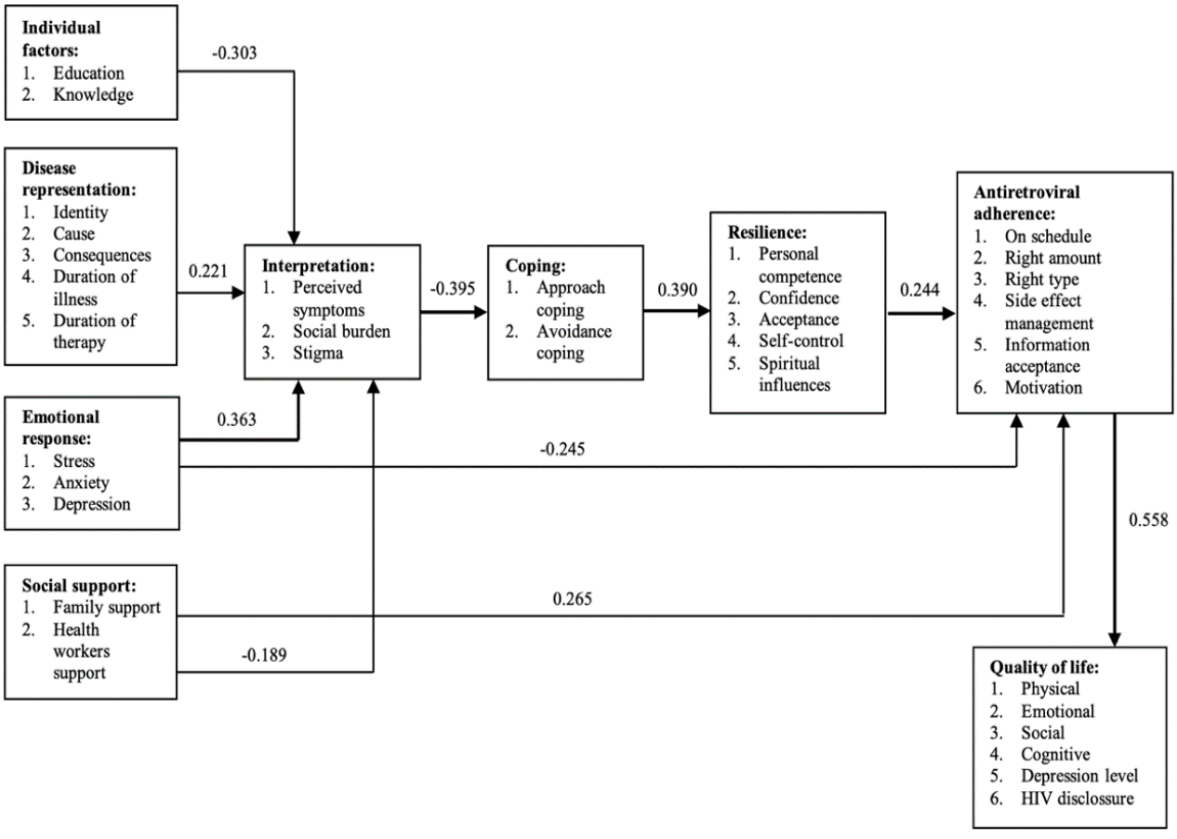

Figure 1. The final (fit) model for the development of resilience model

4. DISCUSSION

The resilience model in this study is significantly composed of individual factors, disease representations, emotional responses, and social support that shape disease interpretation. Disease interpretation then influences coping and forms the resilience of PLHIV, which in turn affects adherence to ARV treatment. People who are newly infected with HIV often have negative knowledge or images of HIV disease. Inappropriate knowledge and a strong belief that HIV infection is fatal and terminal can result in loss of life expectancy and meaning in life. The most important need at this stage is education and accurate information about HIV and available treatment to create positive interpretations related to disease and treatment [31]–[33]. In addition to forming positive interpretations through education and optimizing individual characteristics, social support also plays a role in forming positive judgments. Interpersonal relationships in question include interaction with family, friends, colleagues, and other relatives to provide psychological or physical assistance. Whether receiving or providing assistance, involvement in interpersonal relationships and activities serves as a psychological buffer against the stress, anxiety, or depression that commonly occurs in people with chronic illness. Interpersonal activities also help individuals cope with loss, maintain a sense of belonging, and strengthen self-esteem and self-efficacy [34].

In this study, the presentation of disease was composed of three indicators, namely perceived symptoms, social burden, and stigma. These three indicators will directly influence the coping mechanisms used by PLHIV. When confronted with an unpleasant situation, individuals differ in how they try to reduce feelings of stress through coping. Some forms of coping are adaptive and lead to resilience in dealing with stress while other forms of coping are maladaptive and can lead to anxiety disorders [35], [36]. The results of previous studies explain that there is a correlation between coping strategies and resilience. A high level of resilience is a characteristic of active coping strategies (active coping, planning, positive reframing) and acceptance. Low levels of resilience are associated with helplessness (substance use, behavioral release, self-blame, as well as avoidance or rejection) [37]. In addition to predicting positive trauma effects, the use of active coping mechanisms may be associated with lower cortisol levels, which in turn has a positive impact on the health status of HIV-infected persons. Positive coping strategies are correlated with better physical and mental health, better quality of life, psychological and spiritual growth, and lower levels of stress and psychiatric symptoms as a result of stress management. Meanwhile, negative coping strategies are associated with the occurrence of depression, lower perceived quality of life, and worse psychological and/or physical health, as well as higher levels of stress [38].

Resilience is a concept that is increasingly being applied by nurses and other health workers in the management of psychological distress [39], [40]. The recently developed resilience framework for nursing and health care also highlights the importance of resilience in reducing patient psychological distress [17]. Resilience has been considered as a key factor in a person's response to adverse situations [41]. Empirical studies have also shown that low levels of resilience can contribute to high levels of psychological distress in people with chronic diseases [42]. Resilient individuals also make intrapsychic efforts to motivate themselves to move forward. This effort is demonstrated by actively utilizing their mental strength. Resilience has been recognized as an important factor in the promotion and maintenance of mental health, well-being, and perceived quality of life (QoL) [43].

In the context of the health-illness process, resilience relates to the ability of people to cope with their illness, accept their limitations, adhere to treatment, adapt again, and live positively, and can be developed and expanded throughout life [44]. In the context of HIV/AIDS, resilience refers to the ability to accept one's condition, maintain a positive perception of the disease, prevent it is effects and restore the level of well-being and quality of life, and rebuild life even in a chronic condition [45], [46]. The research findings show that adherence to treatment for PLHIV is directly influenced by resilience, emotional response, and social support. Meanwhile, the resilience model is influenced by coping and interpretation. The formation of the interpretation or assessment of PLHIV is influenced by individual factors, disease representation, emotional response, and social support. The final result obtained is an increase in adherence to treatment, which in turn has an impact on improving the quality of life of PLHIV. Emotional response is a factor that has the greatest influence in developing resilience models by improving individual interpretation and coping. The emotional response in this study is composed of several indicators including stress, anxiety, and depression. These three indicators then influence the assessment of PLHIV regarding disease and treatment.

5. CONCLUSION

The conclusion of the study shows that the development of a resilience model is relevantly able to improve treatment adherence and quality of life in PLHIV. The developed resilience model is shaped by individual factors, disease representations, emotional responses, and social support that influence disease interpretation. An increase in the resilience aspect will improve adherence to PLHIV in treatment so that

optimal quality of life will be achieved. It is hoped that the results of this study can be used as a guide in providing care to PLHIV. In addition, it is hoped that PLHIV can openly seek help from health workers and the closest sources of support such as family when they encounter problems during treatment both from the physical, psychological, and social aspects.

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