Development of a spiritual-based palliative care model for the quality of life of people with HIV/AIDS

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Abstract

People living with HIV (PLHIV) require a focus on their quality of life to prevent deterioration. This study aims to establish a spiritual-based palliative nursing model to enhance the quality of life for PLHIV. A cross-sectional study of 225 PLHIV receiving treatment at Said Sukanto Hospital, Jakarta. Data, including demographic, disease, psychological, spiritual, support, services, spiritual-based palliative care, spiritual meaning in illness experience, and quality of life variables, were collected using a researcher-modified questionnaire. Data were analyzed using descriptive and structural analysis through Partial Least Square Equation Modeling (SEM-PLS). The outer model demonstrated construct validity ($\lambda > 0.5$) and high reliability (composite reliability > 0.7). The inner model exhibited moderate power ($R2 > 0.33$) and predictive relevance (1.009). Goodness-of-fit indicators (RMS Theta = 0.072, NFI = 0.971, SRMR = 0.098) confirmed the model's suitability. Hypothesis testing indicated the significance of all variables ($p<0.05$). The findings support the application of a spiritual-based palliative nursing model to enhance the quality of life for PLHIV. This model offers a holistic approach encompassing physical, psychological, social, and spiritual well-being, providing a comprehensive framework for healthcare providers and policymakers to improve care for PLHIV.

Introduction

HIV remains a significant global public health problem and has claimed 40.1 million lives. By 2021, 650,000 people will die of HIV-related causes, and 1.5 million people will acquire HIV.[1] Scientists continue to fight against it. The discovery of anti-retroviral therapy (ART), while not a cure for HIV, has been able to prevent new viruses from being produced in newly infected cells.[2] Moreover, with increasing access to effective HIV prevention, diagnosis, treatment, and care, including for opportunistic infections, HIV infection has become a chronic health condition that can be managed. This shift has enabled people living with HIV (PLHIV) to lead long and healthy lives, focusing on the quality of life.[3,4]

The facts show that most HIV patients (63.7%) have a poor quality of life.[5] Research results in Iran concluded that most PLHIV have low quality of life scores.[6,7] In Nigeria, the average score for the quality of life for PLHIV is low in the domain of social and environmental relations, and in China, other studies have shown a decrease in the quality of life for PLHIV in the physical health domain.[8] The low quality of life underlines the policy formulation by the Ministry of Health of the Republic of Indonesia regarding Palliative Care. This policy is based on the

consideration that cases of incurable diseases are increasing and aims to improve health services for clients with such diseases, including palliative care.[9]

Palliative care aims to enhance the quality of life of patients and their families, encompassing physical, psychosocial, and spiritual aspects.[10] However, in practice, palliative care for PLHIV has predominantly focused on managing physical and psychological symptoms like pain, shortness of breath, anorexia, constipation, nausea, fatigue, delirium, anxiety, and depression.[11] It identifies the current shortcoming, emphasizing that palliative care for PLHIV tends to treat physical symptoms but hasn't paid sufficient attention to spiritual aspects.

A spiritual-based palliative care approach can help individuals remain calm when facing problems and endure suffering,[12] serving as a key to overcoming difficulties,[13] and increasing resilience when experiencing sadness. It allows individuals to be more accepting,[14] serving as a resource in dealing with life events that cause stress and helping them accept reality more realistically. This research aimed to develop a spiritual-based palliative care model to improve the quality of life for PLHIV.

Materials and Methods

Research design

The research employed an explanatory research design. This approach aimed to analyze the factors that influenced the quality of life of PLHIV using a cross-sectional method. It delved into how demographic, disease, psychological, spiritual, support, and service system factors impacted the ability to find spiritual meaning in the experience of illness and the overall quality of life for PLHIV. The research was conducted at Said Sukanto Hospital, Jakarta, which was chosen due to its specialization in treating PLHIV patients.

Study participants

Sample size determination followed the rule of thumb, which suggested a sample size of 5 to 10 times the number of indicators (observed variables). As there were 27 indicators in this study, the minimum sample size was 5 x 27, which equaled 135 samples. Therefore, the researchers included 225 respondents, all of whom were HIV patients. The sampling technique used nonprobability sampling with a purposive sampling method. The criteria for selecting participants were PLHIV patients undergoing hospitalization, aged 21 years or older, possessing a competent level of consciousness, being able to read and write, having good hearing and vision, and not being in critical condition or suffering from many opportunistic infections.

Variable, instrument and data collection

Independent variables encompassed demographic factors (age, gender, education, occupation, religion, economic status, and marital status), which were measured using a patient demographic data questionnaire containing personal information. Disease factors (early diagnosis, opportunistic infections, and ARV adherence) were assessed using the WHOQOL-HIV BREF questionnaire and the Morisky Medication Adherence Scale/MMAS. Psychological factors (anxiety and depression) were gauged with the Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI-II), respectively. Spiritual factors (personal beliefs, religious practices, and spiritual satisfaction) were assessed using the PLHIV-focused Spiritual Questionnaire developed by Nursalam.[15] Support system factors (family support, caregivers, peer groups, and religious communities) employed a questionnaire modified by the researcher. Service factors (nursing services, service availability, access to services, and the health team) were also measured using a questionnaire modified by the researcher. The spiritual-based palliative care variable was evaluated with a questionnaire designed by the researcher, which incorporated elements of spiritual well-being to enhance patient outcomes during treatment and in life. The dependent variable, consisting of spiritual meaning in the experience of illness (symptoms of pain and loss), was assessed with a researcher-modified questionnaire. The quality of life for PLHIV (covering physical aspects, psychological aspects, level of independence, social relations, environmental health, and spirituality) was measured using the WHOQOL-HIV BREF. The research instruments were previously validated for their reliability and validity, using a 4-point Likert scale: strongly agree = 4, agree = 3, disagree = 2, and strongly disagree = 1. All instruments were tested for validity and reliability on 40 PLHIV, obtaining a calculated r value of 0.270 – 0.991 (r table 0.257) and reliability with Cronbach's Alpha 0.714 – 0.974 (Cronbach's Alpha > 0.6), confirming their validity and reliability.

Data analysis

The analysis used the PLS (Partial Least Square) approach. PLS allowed for structural equation modeling with relatively small sample sizes and did not require multivariate normal assumptions. The PLS model specification in path analysis encompassed three types of relationships: the inner model, outer model, and weight relation.

Results

As per the data presented in Table 1, it is evident that the observed demographic factors showed the following results: 37.3% of the respondents were in the age range of 26-35 years, 74.2% were male, 51.1% had completed high school, and 64.9% worked as private employees. The majority of the respondents practiced the Muslim faith (92.4%), were married (43.6%), and had an income status of 54.2% below the regional minimum wage.

Based on the results of the outer loading values, it is evident that the outer loading values for all latent variables exhibit a result of $\lambda \geq 0.5$ and a statistical T value ≥ 1.96. Variables with valid measurements include demographic factors, disease factors, psychological factors, spiritual factors, support system factors, health service factors, spiritual meaning in the experience of illness, and quality of life for PLHIV (Figure 1).

Based on the data processing results presented in Table 2, an evaluation of the structural model (inner model) was conducted to assess its validity. The test results indicate that when the T-statistics value is ≥ T-table (1.96) or the p-value is < the significant alpha level of 5% or 0.05, it is considered to have a significant influence of the independent variables on the dependent variable.

The research findings reveal that several variables, including X1 (demographic factors), X2 (disease factors), X3 (psychological factors), X4 (spiritual factors), and spiritually based palliative care (Y1), along with the spiritual meaning of the illness experience (Y2), play a significant role. Notably, X4, representing spiritual factors, serves as one of the latent variables in this research, signifying the level of spirituality among PLHIV, which is manifested through their attitudes and behaviors. This includes components related to personal beliefs, religious practices, and spiritual satis-

faction. It is evident that spiritual factors have a noteworthy impact on enhancing the quality of life for PLHIV, as indicated by the T-statistics value of 5.054 (less than 1.96) and a p-value of 0.040 (greater than 0.05).

The research model's path analysis identifies the most influential path as originating from X7 (spiritual-based palliative care), which subsequently impacts both Y1 (spiritual meaning of illness experience) and Y2 (quality of life of PLHIV). The path analysis reveals an original sample value of 0.791 with a p-value of 0.000.

According to the model fit image provided above, the RMS Theta value is 0.072, which is less than 0.102, and the NFI value is 0.971, exceeding the threshold of 0.9. Therefore, based on these two model assessments, the model meets the criteria for model fit. Similarly, the SRMR (Standardized Root Mean Square) value is 0.098, slightly below 0.10. Consequently, the model is deemed to be a good fit for the research data (Table 3).

Discussion

The research results demonstrate that all hypotheses significantly influence the independent and dependent variables. Spiritual-based palliative care is a developmental model studied to enhance the quality of life in PLHIV. The palliative approach was initially aimed at improving the quality of life for clients and families facing life-threatening illnesses through the prevention, assessment, and treatment of pain, as well as other physical and psychosocial issues.[7,16,17] In this study, palliative care was combined with spirituality as an active and positive process involving the search for activities that restore a person's sense of coherence, internal wholeness, and inner peace. Therefore, a palliative model combined with spirituality can enhance the quality of life in PLHIV patients.

Based on the overall results of the study, it can be observed that in the development of a spiritual-based palliative care model for quality of life in PLHIV, the best path is from service factors to spiritual-based palliative care, ultimately leading to the path of the ability to find the spiritual meaning in the experience of illness, which affects the quality of life in PLHIV patients. This indicates that the quality of spiritual-based palliative care and services is the most dominant factor contributing to the improvement of the quality of life for PLHIV. Therefore, in its development, it should be studied how to enhance both of these factors.[18,19]

Spiritual-based palliative care is the most significant factor in improving the quality of life of PLHIV patients, which includes indicators of symptom management, spiritual support, and end-of-life care.[20] This spiritual-based palliative care can help individuals remain calm when facing problems and endure suffering due to their illness.[21] Psychologically, PLHIV often experiences low self-confidence, prolonged stress, anxiety, and depression, and spiritually, they may undergo a crisis of faith due to feelings of guilt and sin, as well as a sense of approaching death.[14]

The quality of life for PLHIV is greatly influenced by spirituality, as it serves as an essential contributor to well-being in improving their quality of life. Spirituality acts as a bridge between decisions and meaningfulness in life.[22] According to Bornet *et al.* (2017),[23] treatment is based on spiritual abilities, including the ability to determine the meaning of life and engage in worship according to one's religious beliefs. PLHIV often recognize their illness as a test from God to assess their faith, leading them to strengthen their beliefs, which ultimately impacts their quality of life. When illness strikes, a person's spiritual health can aid in

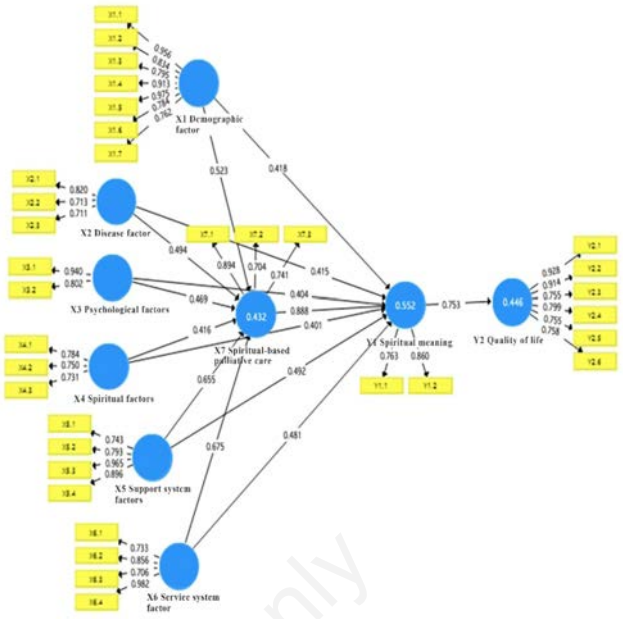

Figure 1. Research outer loading value.

Table 1. Characteristics of research respondents (n=225).

Indicator	F	%
Age		
17-25 Years	16	7.2
26-35 Years	84	37.3
36-45 Years	73	32.4
46-55 Years	52	23.1
Gender		
Man	167	74.2
Woman	58	25.8
Education		
No school	4	1.8
Elementary school	33	14.7
Junior high school	52	23.1
Senior high school	115	51.1
University	21	9.3
Work		
Doesn't work	56	24.9
Private employees	146	64.9
Businessman	23	10.2
Religion		
Islam	208	92.4
Protestant	14	6.2
Catholic	2	0.9
Buddha	1	0.5
Economic Status		
< Regional minimum wage	122	54.2
≥ Regional minimum wage	103	45.8
Marital status		
Not married yet	71	31.5
Marry	98	43.6
Divorced	48	21.3
Death divorce	8	3.6

recovery because they believe their efforts will be successful.[23] This helps PLHIV endure difficult times and not give up on their illness. Quality of life is associated with spirituality, which involves drawing closer to God by adapting one's lifestyle according to God's commands, establishing a spiritual and social network, and maintaining an optimistic spirit. Combining palliative care with spirituality can motivate individuals to gain religious and spiritual experiences, achieve physical health, and alleviate self-anxiety, ultimately leading to a higher quality of life.[24,25]

Recommendations for improving the quality of life of PLHIV in developing a spiritual-based palliative care model have theoretical and practical implications. The spiritual-based palliative care model contributes to strengthening and developing existing theories, such as the theory of palliative care and spiritual well-being. It shows that demographic factors, disease factors, psychological factors, spiritual factors, support system factors, spiritual-based palliative care, and service system factors directly influence the ability to find spiritual meaning in the experience of illness, thus improving the quality of life for PLHIV.[26] The application of a spiritual-based palliative care model in improving the quality of life for PLHIV will provide nurses with guidance on the need for spiritual studies to determine interventions that fulfill spiritual support in collaboration with religious volunteers. The model can also be used to enhance the health status, motivation, enthusiasm, and belief of PLHIV in their recovery by emphasizing spiritual meaning.

Conclusions

The development of a spiritual-based palliative care model has been demonstrated to significantly influence the spiritual meaning of the experience of illness and the quality of life among PLHIV. This model encompasses various factors, including demographic factors (age, gender, education, occupation, religion, economic status, and marital status), disease factors (early diagnosis, opportunistic infections, and ARV adherence), psychological factors (anxiety and depression), spiritual factors (personal beliefs, religious practices, and spiritual satisfaction), support system factors (family support, caregivers, peer groups, and religious communities), and service factors (nursing care, service availability, access to services, and healthcare teams). These factors serve as mediating elements in the development of this model. The study's results indicate that the future benefits of this model include making significant contributions to improving the quality of life for PLHIV through spiritually-based palliative care. Nurses and other healthcare professionals can apply interventions to provide care for PLHIV.

Table 2. Research hypothesis testing results.

Hypothesis	Original sample (O)	T Statistics (|O/STDEV|)	P	Significance
X1 Demographic factor -> X7 Spiritual based palliative care	0.523	10.859	0.004	Significant
X1 Demographic factor -> Y1 Spiritual meaning in the experience of illness	0.418	7.623	0.045	Significant
X2 Disease Factor -> X7 Spiritual-based palliative care	0.494	9.825	0.041	Significant
X2 Disease Factor -> Y1 Spiritual meaning in the experience of illness	0.415	6.873	0.038	Significant
X3 Psychological Factors -> X7 Spiritual-based palliative care	0.469	8.496	0.014	Significant
X3 Psychological Factors -> Y1 Spiritual meaning in the experience of illness	0.404	5.243	0.048	Significant
X4 Spiritual Factor -> X7 Spiritual based palliative care	0.416	7.313	0.048	Significant
X4 Spiritual Factor -> Y1 Spiritual meaning in the experience of illness	0.401	5.054	0.040	Significant
X5 Support System Factor -> X7 Spiritual-based palliative care	0.655	14.176	0.000	Significant
X5 Support System Factor -> Y1 Spiritual meaning in the experience of illness	0.492	9.341	0.001	Significant
X6 Service system factor -> X7 Spiritual-based palliative care	0.675	16.705	0.000	Significant
X6 Service system factor -> Y1 Spiritual meaning in the experience of illness	0.481	9.160	0.000	Significant
X7 Spiritual-based palliative care -> Y1 Spiritual meaning in the experience of illness	0.888	26.397	0.000	Significant
Y1 Spiritual meaning in the experience of illness -> Y2 Quality of Life	0.753	16.647	0.000	Significant

Table 3. Results of model fit testing research.

	Saturated model	Estimated model
SRMR	0.101	0.098
d_ULS	8.313	8.313
d_G	4.903	4.903
Chi-Square	2215.232	2215.232
NFI	0.971	0.971
rms Theta	0.072	

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