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Development of KET-U-T phenomenon to assess comprehensive care, support, and treatment in people living with HIV

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ABSTRACT

Background: Negative psychological responses related to HIV seropositivity status disclosure are prevalent and often remain unattended. We proposed a comprehensive care delivery method with biopsychosocial approach (comprehensive care, support, and treatment [C-CST]) along with an instrument (KET-U-T phenomenon) to assess its efficacy.

Methods: A total of 200 individuals HIV positive were consecutively enrolled in this study and equally distributed into pre- and post-C-CST groups. All participants were structurally interviewed to assess HIV-related information level, family support, and KET-U-T phenomenon (K=disappointment, E=emotion/anger, T=denial, U=effort, T=acceptance). Appropriate statistical analyses were done to determine the effect of C-CST on the KET-U-T phenomenon.

Results: Post test counselling for 100 individuals pre-C-CST, demonstrated HIV-related information level (68%) and family support (78%) inadequacy, with respective proportion of KET-U-T phenomenon components of; K: 43.0%, E: 12%, T: 30%, U: 100%, T: 15%. Significant improvement post C-CST observed in reduction of HIV-related information level (26%) and family support (38%) inadequacy, with respective proportion of KET-U-T phenomenon components of; K: 18%, E: 2%, T: 5%, U: 100%, T: 75% (p=0.000).

Conclusions: Comprehensive care, support, and treatment yielded significant improvement in negative psychological adaptation and seropositive status acceptance in PLWH as observed with the KET-U-T phenomenon.

Keywords: HIV seropositivity, comprehensive health care, psychological adaptation, KET-U-T phenomenon.

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INTRODUCTION

Disclosure of human immunodeficiency virus (HIV) positive status is almost always a life-changing experience with severe repercussions in terms of psychological responses it provoked. The development of these responses may vary in timing since the initial diagnosis and aggravate as the disease progresses.¹⁻⁴ Depression, decreased quality of life, and stigmatization are amongst the most substantial precursors.⁵⁻⁹ The requirement for lifelong treatment underlines the value of addressing psychological issues in people living with HIV (PLWH) on which efficacy is determined.¹⁰⁻¹⁴

Mounting evidence showed better outcomes from counseling, cognitive behavioral therapy, and mindfulness-based interventions in PLWH.¹⁵⁻¹⁸ However, a considerable gap remaining in screening and efficacious treatment urges the emergence of an integrated approach.¹⁹ Improvement in HIV-related knowledge and engagement of support groups, among others, were notable cornerstones of integral HIV management.^{20,21} Despite the subjective nature of acceptance of HIV status, its potential impact on long term treatment serves as a basis for its utility as a surrogate outcome for treatment efficacy.^{22,23}

Comprehensive care, support, and treatment

(C-CST) constituted of biopsychosocial approach with particular emphasis on recognizing and managing psychological in conjunction with biomedical problems. A constellation of negative adaptation in response to initial status disclosure (disappointment, emotion, and denial), therapeutic effort (C-CST), and the resulting acceptance of status is encapsulated in the KET-U-T phenomenon in which each letter stands for its respective Indonesian translation of the aforementioned components. The primary objective of this study is to assess the pattern of PLWH psychological responses by employing the KET-U-T phenomenon approach. The secondary objective involves investigating the relationship between C-CST intervention with patient information level, family support, and KET-U-T phenomenon improvement.

METHODS

A total of two hundred patients with confirmed HIV seropositivity status visiting Merpati Clinic in Wangaya Hospital, Denpasar, Bali, were recruited during the period of December 2014 to October 2018. Study participants were divided equally into two groups comprising of pre- and post-treatment with a year of C-CST intervention. The assessment

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instrument termed KET-U-T phenomenon consisted of initial negative psychological responses evoked by patients (*K=Kecewa* [disappointment], *E=Emosi* [emotion/anger], *T=Tolak* [denial]) and C-CST therapeutic efforts (*U=Upaya*) to assist in the development of patients' acceptance (*T=Terima*) of seropositivity status.

The definition of each subjective variable complying with Oxford Advanced Learner's Dictionary was implemented in this study and a mutual understanding of both research investigators and participants was reinforced.²⁴ Disappointment is defined as the feeling of being sad because something has not happened or been as good, successful, or as you expected or hoped. Emotion or anger is a strong feeling when something has happened that one thinks is terrible and unfair. Denial is a statement that something is not true or does not exist; the action of denying something. Effort is an attempt to do something, especially when it is difficult to do. Accept is to willingly take something that is offered; to say 'yes' to an offer, invitation, etc. Knowledge of HIV-related information level was verified by answering the following questions: "is HIV/AIDS a dangerous disease?", "is HIV/AIDS transmitted disease?", "are there HIV/AIDS drugs available?". Adequate information level requires at least two out of three questions answered correctly. Family support was grouped into always (anytime needed), sometimes (most of the time), and never to rare (excluded by family).

Statistical analysis was done using SPSS version 16 for windows to evaluate the effect of one year C-CST. The statistical analysis of the clients HIV/AIDS information level and family member's support using *Chi-square* (table 2x2), while *KET-U-T* Phenomenon using Kolmogrov-Smirnov nonparametric test with *p*-value <0.05.

RESULTS

Baseline characteristics of 200 participants assigned in pre- and post-C-CST groups were compared side-by-side in [Table 1](#). Both groups presented comparable sociodemographic characteristics. Most of the recruited patients were male in both groups with a considerable overlap of the mean age. While there were similar numbers of elementary and high school graduates of the pre-C-CST group, the number of high school graduates exceeded other levels of educational status in the post-C-CST group.

Considerable increment of HIV-related information adequacy and intensive family support was observed in the post-C-CST group ([Table 2](#)). Improvement in negative adaptation and seropositivity acceptance was also reflected in KET-

U-T phenomenon components, while the only constant variable being the C-CST delivery rate, which was designated by the "effort" component. The significant effect of C-CST intervention on HIV-related information and family support levels was congruent with improvement assessed with the KET-U-T phenomenon approach.

DISCUSSION

Psychological distress holds an essential role in the HIV care continuum as it determines vulnerability to infection acquisition and negative health outcome. It is noteworthy that the distress causes intersection of vulnerability which may lead to increased morbidity and mortality from the vicious cycle.¹⁹ Clinically significant distress impacted numerous lives regardless of gender, age, and status as key population.^{6,25-28} Mechanisms involved including premorbid distress which subsequently serves as a risk factor and continues to complicate along the disease course, or as a neuropathology complication associated with primary HIV infection.¹¹

Disappointment, anger, and denial were common recurring themes in studies covering the psychological aspect of HIV infection.²³ Disappointment was closely related to depression as it is perceived as life-ending and impending death.¹ Analysis using second-order factor model found an association between anger with avoidant coping represented by self-blame, denial, and behavioral disengagement. Furthermore, it was also indirectly related to HIV disease severity and strongly inversely associated with perceived social support.^{29,30} Vengeance was implicated as another pivotal consequence of anger leading to nondisclosure of HIV status.³¹ Denial may be considered the peak of negative adaptation as it occurred at the lowest extreme of the acceptance spectrum.³² This negative adaptation was interrelated with depressive symptoms and diagnostic and treatment hindrance.³³ Once PLWH could come to terms with the reality of the seropositivity, they moved toward acceptance and embraced the status as a part of their identity.³⁴

Diverse types of psychological interventions developed, namely cognitive-behavioral therapy, interpersonal therapy, group therapy, motivational interviewing, stress management, meditation, and family interventions.¹⁹ Nevertheless, delivering effective care in the settings of limited resources may be challenging, while improvement exerted in advanced care facilities may be less significant in a longer time frame.^{35,36} Therefore, the process of tailoring care strategy individualized to each facility setting should be prioritized.

Table 1. Baseline characteristics of study participants

Variables	Pre-C-CST	Post-C-CST
Sex, n (%)		
Male	66 (66.0%)	51 (51.0%)
Female	34 (34.0%)	49 (49.0%)
Age (Years), mean \pm SD	38.67 \pm 0.91	36.22 \pm 1.04
Educational status, n (%)		
Elementary school	39 (39.0%)	24 (24.0%)
Junior high school	17 (17.0%)	10 (10.0%)
High school	33 (33.0%)	53 (53.0%)
University	11 (11.0%)	13 (13.0%)

C-CST = comprehensive care, support, and treatment

Table 2. The effect of one-year C-CST implementation

Variables	Pre-C-CST N(%)	Post-C-CST N(%)	p-value
HIV-related information			p = 0.000*
Adequate	32 (32.0%)	74 (74.0%)	
Inadequate	68 (68.0%)	26 (26.0%)	
Family support			p = 0.000*
Always	22 (22.0%)	62 (62.0%)	
Sometimes	32 (32.0%)	26 (26.0%)	
Never	46 (46.0%)	12 (12.0%)	
KET-U-T phenomenon			p = 0.000*
K= <i>Kecewa</i> (disappointment)	43 (43.0%)	18 (18.0%)	
E= <i>Emosi</i> (emotion/anger)	12 (12.0%)	2 (2.0%)	
T= <i>Tolak</i> (denial)	30 (30.0%)	5 (5.0%)	
U= <i>Upaya</i> (effort)	100 (100.0%)	100 (100.0%)	
T= <i>Terima</i> (acceptance)	15 (15.0%)	75 (75.0%)	

C-CST = comprehensive care, support, and treatment, HIV = human immunodeficiency virus (HIV)

Similar assessments analyzing psychological adaptation were included in a quantitative systematic review by Evangeli et al.³⁷ Negative coping strategy represented by withdrawing, eating and drinking too much, taking it out on others, spending time alone, and sleeping was found to be a psychosocial predictor for HIV testing.³⁸ One component of the variable of interest, “take out on others”, was a particular match with the *Emosi* (emotion/anger) component of this study. The outcome reported was the actual testing procedure instead of, for instance, one more step forward which was the acceptance of the result thereof. No other studies included in the review was deemed adequate for comparison due to the vast array of psychological variables involved.

To the best of our knowledge, this is the first study addressing negative psychological adaptation, comprehensive treatment, and seropositivity acceptance in one integrated instrument. The

integration allowed researcher to compare targeted variable and outcome as a set at different points in the study timeframe. A significant increase in HIV knowledge and family support added robustness in the association found between comprehensive care, support, and treatment with KET-U-T phenomenon improvement.

Certain degree of limitation in this study may originate from the particularity of combining multiple variables into a single construct. The independent variables (i.e., negative adaptation) were subjective and thus mostly studied in qualitative studies. The dependent variable (i.e., acceptance of seropositivity) was rarely subjected to main variable of interest due to similar reason. Differences in measuring instrument, design, and outcome, in addition to the aforementioned reasons, led to a lack of study comparison. Research and treatment setting in the hospital clinic instead of community-based may also accounted for a smaller sample and therefore, the power of this study since patients visiting hospital represents the mere tip of an iceberg of the whole PLWH.

CONCLUSIONS

Comprehensive care, support, and treatment yielded a significant reduction of negative psychological adaptation and facilitated seropositive status acceptance in PLWH as observed with the KET-U-T phenomenon. Further study is needed to validate the novel comprehensive instrument to assess the psychological aspects of PLWH.

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CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

ETHICAL CONSIDERATIONS

The study procedure was approved by the Ethical Committee of Wangaya Hospital in Denpasar, Bali, Indonesia with register number: 07/RSUDW/Litbang/2014. The study was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants.

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AUTHORS CONTRIBUTION

KS designed the study, responsible for data acquisition, analyzing the data, writing and revising the final manuscript.

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