ORIGINAL PAPER

Individual beliefs and family resilience among people living with HIV

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Abstract

Introduction: Human immunodeficiency virus (HIV) has become a manageable chronic disease with the help of antiretroviral therapy (ART). Positive individual beliefs of people living with HIV (PLWH) is increasing, shaping a great resilience. Resilience occur not only in PLWH, but also in their families. Family resilience affect PLWH confidence to manage their health. This study aimed to analyze the relationship between individual beliefs and family resilience among PLWH.

Material and methods: Cross-sectional survey among 100 PLWH using purposive sampling was used in the present study. Instrument was adopted from family empowerment scale (FES) questionnaire. Depression management, adherence to treatment, managing symptoms, communication with healthcare providers, social support, and fatigue were assessed to examine the relationship with family resilience. Spearman's rho test was applied for data analysis.

Results: Most of the respondents were males (51%) and between 30-49 years old (72%). Communication with healthcare providers ($p = 0.01$, $r = 0.271$), social support ($p = 0.00$, $r = 0.375$), adherence to treatment ($p = 0.04$, $r = 0.283$), and family resilience had a moderate relationship, while depression management ($p = 0.06$, $r = 0.271$), symptoms management ($p = 0.10$, $r = 0.256$), and fatigue management ($p = 0.16$, $r = 0.108$) did not correlate.

Conclusions: Consistent medical care treatment is the key to viral suppression; therefore, interventions are needed to simultaneously address key factors at different levels. Furthermore, poor adherence results in negative outcomes, including morbidity and mortality as well as an increased likelihood of transmitting HIV to sexual or drug-using partners.

HIV AIDS Rev 2025; 24, 2: 142-147
DOI: https://doi.org/10.5114/hivar/156093

Key words: AIDS, family resilience, HIV, individual beliefs, PLWH.

Introduction

In order to improve health and reduce human immunodeficiency virus (HIV) transmission, the World Health Organization (WHO) encourage people living with HIV (PLWH) to start antiretroviral therapy (ART) right after its diagnosis. HIV medical treatment care includes diagnosis, linkage to care, being retained in care, adhering to treatment, and viral suppression commonly referred to as the HIV care continuum. With the expansion of access to ART, HIV has evolved from a fatal disease to a manageable chronic condition [1, 2]. Medical Monitoring Project (MMP) data were

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Article history:
Received: 28.08.2022
Revised: 10.10.2022
Accepted: 26.10.2022
Available online: 05.05.2025

collected between 2015 and 2019 to examine a three-item ART adherence and reasons for missing ART, with forgetting as the most common reason for missing ART dose (77.3%). Younger age, poverty, recent drug use, depression, and unmet needs for ancillary services were the predictors for lower ART adherence. To overcome these problems, family is considered to play an important role in supporting PLWH and each other [3, 4].

Individual beliefs of PLWH about ART have become more positive over time. These positive beliefs, considered in the context of PLWH plans and hopes for the future, shape a great resilience. Individual beliefs in HIV medical treatment care are an important quality of adherence [2]. Delayed engagement in HIV care threatens the success of HIV treatment program, and may be influenced by depression [5]. Individual belief systems are powerful forces in resilience, coping with crisis and prolonged adversity by making meaning in their experience, linking it to the social world as well as cultural and spiritual beliefs [6].

HIV medical treatment care increases survival rates among HIV-positive adults. However, PLWH continues to face numerous difficulties at individual, inter-personal, and neighborhood level, leading to worse health behaviors. In individual belief, most frequently reported barriers in linkage into HIV care include fear of stigma, lack of disclosure, being asymptomatic at the time of diagnosis, and denial. Sanga *et al.* [7] reported that belief in witchcraft and spiritual healing were hindering factors in linkage into HIV care. In other study, individual belief become modifiable attitude to improve HIV testing uptake [8]. Resilience resources may facilitate good health behaviors, and help PLWH overcoming negative effects of adversities. Resilience was defined as the individual dynamic characteristic that moderates negative effects of stress, promotes the positive adaptation, and effective coping strategies [9]. Along with PLWHA, families are often judged and stigmatized, given their association with a family member who is HIV-positive [10, 11].

Family highly contribute to the quality of life (QoL) of PLWH. Those who take care of PLWH often feel burdened and tired, they have to spend time in hospitals and provide support to their family members living with HIV. Family burden in taking care of PLWH causes psychological stress. Some of the families may feel burnout and abandon hope, but some of the families become resilient, and empower PLWH to build their confidence and support each other [12].

Family resilience is defined as the ability of family, as a functional system, to withstand and re-bound from adversity. The way a family confronts and manages disruptive life challenges, buffers stress, effectively re-organizes, and moves forward with life, influence immediate and long-term adaptation for every family member and viability of family unit. The concept of resilience is used to describe how people can "bounce back", even after experiencing crises, trauma, or stressors [2, 13]. Therefore, this study analyzed the relationship between individual beliefs and family resilience among PLWH.

Material and methods

This quantitative study focused on the relationship between individual beliefs and family resilience among PLWH using a cross-sectional study approach. Inclusion criteria were as follows: HIV/AIDS diagnosis for at least 6 months, aged 20 years and above, no psychiatric disorders, and literacy. Exclusion criteria were hospitalized and severely ill patients. Based on the above, study sample included 100 respondents, with purposive sampling selection used at Dr. Soetomo Hospital.

Data were collected with an instrument adopted from family empowerment scale (FES) on QoL and psychological fulfilment that was tested for validity. The questionnaire contained six indicators on Likert's scale, and interpretation was done using SPSS. Descriptive statistics were employed to depict demographic characteristics of respondents. Spearman's rho test was used to assess the relationships between individual beliefs (depression management, adherence to treatment, managing symptoms, communication with healthcare providers, social support, and fatigue management) and family resilience.

Ethical clearance

This research has received ethical approval from the Research Ethics Committee at the Faculty of Nursing, Universitas Airlangga, Surabaya, with certificate number, 2038-KEPK in 2020. The researchers respected the respondent's code of ethics by always maintaining honesty, confidentiality, and preventing adverse events to occur.

Results

Demographic characteristics of the respondents

The results in Table 1 show the demographic distribution of the respondents. The predominant age of the participants was 30-39 years and 40-49 years, and majority were Muslims in terms of religion. More than half (51%) of the respondents were males and married (39%), while those that were single, divorced, and widowed constituted 19%, 9%, and 33% of the study population, respectively. One-third of the subjects' latest education level was elementary school (33.0%), with more than one-half working as employees (53%), followed by entrepreneur (10%) and unemployed (37%). The major income was under regional minimum wage (UMR).

Individual beliefs variables

Depression management and family resilience

The results on depression management among the respondents revealed that the highest depression management levels were good (73%), with cumulative scores for

Table 1. Characteristics of the respondents

Factor	*n* (%)
Age	
20-29 years	6 (6.0)
30-39 years	36 (36.0)
40-49 years	36 (36.0)
50-59 years	21 (21.0)
> 55 years	1 (1.0)
Sex	
Male	51 (51.0)
Female	49 (49.0)
Education	
Elementary school	33 (33.0)
Junior high school	16 (16.0)
Senior high school	28 (28.0)
Bachelor's degree	23 (23.0)
Marital status	
Single	19 (19.0)
Married	39 (39.0)
Widowed	33 (33.0)
Divorced	9 (9.0)
Occupation	
Civil servant	0 (0.0)
Employee	53 (53.0)
Entrepreneur	10 (10.0)
Unemployed	37 (37.0)
Income	
< UMR	71 (71.0)
> UMR	29 (29.0)
Religion	
Islam	80 (80.0)
Christianity	20 (20.0)

poor, fair, and good family resilience levels as 9, 51, and 13, respectively. Followed by poor depression management (14%), the cumulative scores for poor, fair, and good family resilience were 1, 9, and 4, respectively, while fair depression management (13%) had the cumulative scores of poor, fair, and good family resilience as 2, 9, and 2, respectively. The results of statistical test analysis using Spearman's rho test revealed a *p*-value of 0.06 and r of 0.271, showing that depression management and family resilience were not relatable (Table 2).

Adherence to treatment and family resilience

The results on adherence to treatment among the respondents demonstrated that the highest adherence levels were good (73%), with cumulative scores for poor, fair, and good family resilience as 7, 48, and 18, respectively. Followed by poor adherence (14%), the cumulative scores for poor, fair, and good family resilience were 0, 12, and 2, respectively, while fair adherence (13%) with cumulative scores for poor, fair, and good family resilience was 3, 7, and 3, respectively. The results of statistical test analysis using Spearman's rho test obtained $p = 0.04$ and $r = 0.283$, showing that there was a moderate positive correlation between adherence to treatment and family resilience (Table 2).

Symptoms management and family resilience

The results on symptoms management among the respondents revealed that the highest symptom management levels were good (73%), with cumulative scores for poor, fair, and good family resilience as 5, 59, and 9, respectively. Followed by poor symptoms management (14%), the cumulative scores for poor, fair, and good family resilience were 1, 11, and 2, respectively, whereas fair symptoms management (13%) with cumulative scores for poor, fair, and good family resilience was 1, 10, and 2, respectively. The results of statistical test analysis using Spearman's rho test showed a p-value of 0.10 and r of 0.256, which means that symptoms and family resilience was not relatable (Table 2).

Communication with healthcare providers and family resilience

The results on communication with healthcare providers among the participants showed that the highest communication levels were good (73%), with cumulative scores for poor, fair, and good family resilience as 7, 49, and 17, respectively. Followed by poor communication (14%), the cumulative scores for poor, fair, and good family resilience were 2, 8, and 4, respectively, while fair communication (13%) with cumulative scores for poor, fair, and good family resilience showed 1, 9, and 3, respectively. The results of statistical test analysis using Spearman's rho test revealed $p = 0.01$ and $r = 0.247$, which means that there was a moderate positive relationship between communication with healthcare providers and family resilience (Table 2).

Social support and family resilience

The results on social support among the respondents demonstrated that the highest social support levels were good (73%), with cumulative scores for poor, fair, and good family resilience as 6, 54, and 13, respectively. Followed by poor social support (14%), the cumulative scores for poor, fair, and good family resilience were 4, 10, and 0, respectively, whereas fair social support (13%) with cumulative scores for poor, fair, and good family resilience was 1, 11, and 1, respectively. The results of statistical test analysis using Spearman's rho test achieved $p = 0.000$ and $r = 0.375$, which means that there was a moderate positive relationship between social support and family resilience (Table 2).

Table 2. Analysis of the relationship of individual beliefs with family resilience in PLWH

Variables	Family resilience						Statistic tests: Spearman's rho
	Poor		Fair		Good		
	n	%	*n*	%	*n*	%	
Depression management							
Poor	1	7.1	9	64.3	4	28.6	p = 0.06 r = 0.271
Fair	2	15.4	9	69.2	2	15.4	
Good	9	12.3	51	69.9	13	17.8	
Adherence to treatment							
Poor	0	0.0	12	85.7	2	14.3	p = 0.04 r = 0.283
Fair	3	23.1	7	53.8	3	23.1	
Good	7	9.6	48	65.8	18	24.7	
Symptoms management							
Poor	1	7.1	11	78.6	2	14.3	p = 0.10 r = 0.256
Fair	1	7.7	10	76.9	2	15.4	
Good	5	6.8	59	80.8	9	12.3	
Communication with healthcare providers							
Poor	2	14.3	8	57.1	4	28.6	p = 0.013 r = 0.247
Fair	1	7.7	9	69.2	3	23.1	
Good	7	9.6	49	67.1	17	23.3	
Social support							
Poor	4	28.6	10	71.4	0	0.0	p = 0.00 r = 0.375
Fair	1	7.7	11	84.6	1	7.7	
Good	6	8.2	54	74.0	13	17.8	
Fatigue management							
Poor	1	7.1	10	71.4	3	21.4	p = 0.161 r = 0.108
Fair	1	7.7	10	76.9	2	15.4	
Good	9	12.3	50	68.5	14	19.2	

Fatigue management and family resilience

The results on fatigue management among the participants showed that the highest fatigue management levels were good (73%), with cumulative scores for poor, fair, and good family resilience as 9, 50, and 14, respectively. Followed by poor fatigue management (14%), the cumulative scores for poor, fair, and good family resilience were 1, 10, and 3, respectively, while fair fatigue management (13%) with cumulative scores for poor, fair, and good family resilience showed 1, 10, and 2, respectively. The results of statistical test analysis using Spearman's rho test had p = 0.161 and r = 0.108, which means that there was no correlation between fatigue management and family resilience (Table 2).

Discussion

HIV-related adverse experiences, such as depression, life-time victimization, discrimination, and disproportionate psycho-social (e.g., substance abuse) are related to resilience, mastery, and health outcomes. They also influence QoL of PLWH and family resilience [14-16]. Individual belief has significant correlation with resilience, as this is a belief in capacity to make a difference. Individual greater beliefs have a correlation with chronic pain that impact PLWH depressive symptoms, and that treatment would eliminate AIDS. This implies that PLWH resilience has a number of ways, including level of knowledge of their illness, self-responsibility, persistence, increased QoL, low level of psychological distress, positive beliefs, and ability to relinquish control over uncertainty of life with HIV infection [17-19]. Individual belief has become care-centered, where the belief about HIV is positive and easier to follow HIV care or program. This individual belief is also supported by family, which is the most supportive factor among PLWH.

Historically, the family has always been perceived as the social institution to provide love, security, and protection. Family empowerment is important for PLWH [12, 16].

Interventions in family provide an opportunity to approach structural barriers, such as poverty, healthcare access, and mental healthcare policies. In a previous study, the important role of family functioning was shown to predict depression [20, 21]. Our findings demonstrated that communication with healthcare providers, social support, adherence to treatment, and family resilience have a moderate relationship, while depression management, symptoms management, and fatigue management do not correlate. This is in line with a previous study, showing that receiving social support improves QoL of PLWH by increasing their beliefs and impacting their economic status [22]. Healthcare providers can assist PLWH in exerting control over their challenges through patients' advocacy, and by empowering them to engage in the interactive process of commitment, belief, and positive outlook [23]. Improving PLWH QoL related to resilience, mastery, and health outcomes among PLWH includes adherence to treatment with ART [14, 15, 24]. Moreover, empowerment of family can be used to increase the independence of families and patients in the treatment of PLWH [25].

Family resilience allows PLWH to develop their ability and not limit their actions. Furthermore, social support builds their confidence and support for each other. There was a positive relationship shown between social support with ART adherence [11, 12]. Religion/spirituality, family resilience, and social support promoted adherence to care. It strengthens their individual beliefs to cope with their diagnoses [24]. Another study showed that the lack of social support and poor communication with healthcare providers affect the behaviors and attitudes of PLWH in a healthcare setting. For example, clinic visit adherence and trust in a medical provider are some factors associated with healthcare behaviors [26].

Overall, the current findings showed that most of the respondents have good individual beliefs and fair family resilience. The way families view their problems and their preferences, can make a difference between coping and mastery, or dysfunction and despair. Each family's shared beliefs are anchored in cultural values, and influenced by family's position and experiences in the social world over time [13]. From a cultural perspective, the family is a healthcare unit with its own views on health and illness, attitudes, and forms of care, such as support for ART adherence [4, 27]. Consistent medical care treatment is the key to viral suppression, so interventions are needed to simultaneously address key factors at different levels [14]. Furthermore, poor adherence results in negative outcomes, including morbidity and mortality as well as an increased likelihood of transmitting HIV to sexual or drug-using partners [2]. Therefore, there is an urgent need for developing efficient intervention programs, which can lead to maximize family support, involving PLWH families, with a particular attention to family dynamics in daily interactions [28].

Study limitations

The current study has two limitations, which need to be acknowledged. Firstly, this research provides results, which are representative of the Indonesian population. The results were validated using several samples and internationally recognized measurement tools. However, cross-sectional studies have a number of limitations, including the inability to estimate incidence and draw conclusions about causes. The second limitation is the study's small sample size.

Conclusions

Family resilience plays an important role in individual beliefs. It has an impact on the QoL of PLWH. Moreover, family resilience helps PLWH face barriers in accessing and adhering to treatment that enables long and healthy life. Individual beliefs and family resilience reduce the effect of numerous adversities in PLWH, potentially enabling PLWH to overcome the negative effects of difficulties (e.g., stigma and discrimination).

Disclosures

1. Institutional review board statement: This study was approved by the the Research Ethics Committee at the Faculty of Nursing, Universitas Airlangga, Surabaya (approval number: 2038-KEPK).
2. Assistance with the article: The authors would like to express their gratitude to the respondents and those who helped in the implementation of this study.
3. Financial support and sponsorship: None.
4. Conflicts of interest: None.

References

1. Gottert A, Friedland B, Geibel S, Nyblade L, Baral SD, Kentutsi S, et al. The people living with HIV (PLHIV) resilience scale: development and validation in three countries in the context of the PLHIV Stigma Index. AIDS Behav 2019; 23 (Suppl 2): 172-182.
2. Jaiswal J, Singer SN, Lekas HM. Resilience and beliefs in the effectiveness of current antiretroviral therapies among recently disengaged low-income people of color living with HIV. Behav Med 2020; 46: 75-85.
3. Crim SM, Tie Y, Beer L, Weiser J, Dasgupta S. Barriers to antiretroviral therapy adherence among hiv-positive Hispanic and Latino men who have sex with men – United States, 2015-2019. MMWR Morb Mortal Wkly Rep 2020; 69: 1437-1442.
4. Campbell L, Masquillier C, Thunnissen E, Ariyo E, Tabana H, Sematlane N, et al. Social and structural determinants of household support for ART adherence in low- and middle-income countries: a systematic review. Int J Environ Res Public Health 2020; 17: 3808. DOI: 10.3390/ijerph17113808.
5. Cholera R, Pence BW, Gaynes BN, Bassett J, Qangule N, Pettifor A, et al. Depression and engagement in care among newly diagnosed HIV-infected adults in Johannesburg, South Africa. AIDS Behav 2017; 21: 1632-1640.
6. Myers-Walls JA. Strengthening Family Resilience (3rd ed.). J Fam Theory Rev 2017; 9.
7. Sanga ES, Mukumbang FC, Mushi AK, Lerebo W, Zarowsky C. Understanding factors influencing linkage to HIV care in a rural setting, Mbeya, Tanzania: qualitative findings of a mixed methods study. BMC Public Health 2019; 19: 383. DOI: 10.1186/s12889-019-6691-7.
8. Ryan S, Hahn E, Rao A, Mwinnyaa G, Black J, Maharaj R, et al. The impact of HIV knowledge and attitudes on HIV testing accep-

tance among patients in an emergency department in the Eastern Cape, South Africa. BMC Public Health 2020; 20: 1066. DOI: 10.1186/s12889-020-09170-x.
9. Focà E, Fornari C, Arsuffi S, Vetrano MC, Calza S, Renzetti S, et al. Psychological and emotional impact of COVID-19 pandemic on people living with chronic disease: HIV and cancer. AIDS Behav 2022; 26: 2920-2930.
10. Chaudhary S, Kakchapati S. Social stigma, discrimination, and their determinants among people living with HIV and AIDS in Sudurpashchim Province, Nepal. HIV AIDS Rev 2022; 21: 230-238.
11. Dulin AJ, Dale SK, Earnshaw VA, Fava JL, Mugavero MJ, Napravnik S, et al. Resilience and HIV: a review of the definition and study of resilience. AIDS Care 2019; 30: 6-17.
12. Nursalam N, Efendi F, Tristiana D, Misutarno M, Priyantini D. Family empowerment model based on belief and health related quality of life among housewives with HIV/AIDS. Syst Rev Pharm 2020; 11: 246-251.
13. Walsh F. Strengthening family resilience. Guilford; 2015.
14. Gottert A, McClair TL, Pulerwitz J, Friedland BA. What shapes resilience among people living with HIV? A multi-country analysis of data from the PLHIV Stigma Index 2.0. AIDS 2020; 34 (September): S19-S31.
15. Emlet CA, Shiu C, Kim HJ, Fredriksen-Goldsen K. Bouncing Back: Resilience and mastery among hivpositive older gay and bisexual men. Gerontologist 2017; 57: S40-S49.
16. Raniga T, Mthembu M. Family resilience in low income communities: a case study of an informal settlement in KwaZulu-Natal, South Africa. Int J Soc Welf 2017; 26: 276-284.
17. Kartono R. The role of peer support group to restore the ability of resilience of people with HIV/AIDS (PLWHA). J Unmuh Jember 2019; 119-136. Prosiding ICOGISS 2019: International Confrence On Governance Innovation And Social Sciences.
18. Penn TM, Trost Z, Parker R, Wagner WP, Owens MA, Gonzalez CE, et al. Social support buffers the negative influence of perceived injustice on pain interference in people living with HIV and chronic pain. Pain Rep 2019; 4: e710. DOI: 10.1097/PR9.0000000000000710.
19. Halkitis PN, Jaiswal J, Griffin-Tomas M, Krause KD, D'Avanzo P, Kapadia F. Beliefs about the end of AIDS, concerns about PrEP functionality, and perceptions of HIV risk as drivers of PrEP use in urban sexual minority men: the P18 Cohort Study. AIDS Behav 2018; 22: 3705-3717.
20. Sikkema KJ, Dennis AC, Watt MH, Choi KW, Yemeke TT, Joska JA. Improving mental health among people living with HIV: a review of intervention trials in low- and middle-income countries. Glob Ment Health (Camb) 2015; 2: e19. DOI: 10.1017/gmh.2015.17.
21. Wouters E, Masquillier C, le Roux Booysen F. The importance of the family: a longitudinal study of the predictors of depression in HIV patients in South Africa. AIDS Behav 2016; 20: 1591-1602.
22. Erwansyah RA, Rumambo Pandin MG. PLWHA's perspective on community stigma for getting social support and improving life quality in the digital era. medRxiv [Internet] 2022; 2022.01.17.22269334. Available from: http://medrxiv.org/content/early/2022/01/19/2022.01.17.22269334.abstract.
23. Popoola T, Rajeswaran L. Making the case for hardiness among people living with HIV in Nigeria. J Nurs Dr Students Scholarsh 2016; 4: 38-45.
24. Duthely LM, Sanchez-Covarrubias AP, Brown MR, Thomas TE, Montgomerie EK, Dale S, et al. Pills, PrEP, and pals: adherence, stigma, resilience, faith and the need to connect among minority women with HIV/AIDS in a US HIV epicenter. Front Public Health 2021; 9: 667331. DOI: 10.3389/fpubh.2021.667331.
25. Nursalam N, Yusuf A, Widyawati IY, Asmoro CP. Development model of family empowerment and peer group support in independence of caring on Indonesian's migrant worker (TKI) infected by HIV. J Ners 2016; 10. DOI: https://doi.org/10.20473/jn.v10i2.1347.
26. Turan B, Budhwani H, Fazeli PL, Browning WR, Raper JL, Mugavero MJ, et al. How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. AIDS Behav 2017; 21: 283-291.
27. Farias DHR, Almeida MFF, Gomes GC, Lunardi VL, Queiroz MVO, Nörnberg PKO, Lourenção LG. Beliefs, values and practices of families in the care of hospitalized children: subsidies for nursing. Rev Bras Enferm 2020; 73 (Suppl 4): e20190553. DOI: 10.1590/0034-7167-2019-0553.
28. Yu YJ, Li X, Qiao S, Zhou Y. Family relations in the context of HIV/AIDS in Southwest China. AIDS Care 2016; 28: 1261-1268.