



Intensified thinking: Implications for health related quality of life among people living with HIV/AIDS

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ABSTRACT

The scourge of HIV/AIDS is high in developing regions of the world especially Africa where many victims live daily with the distress and trauma associated with living with the disease. Health policies and research are increasingly interested in improving the living experience and quality of life of people living with HIV/AIDS (PLWHA). There is evidence that beyond physical ailments, thinking patterns could influence health outcomes. In this study we considered if intensively focusing/thinking on HIV/AIDS diagnosis will predict health related quality of life (HRQoL) Patients ($N = 201$) receiving anti-retroviral treatment from the University of Nigeria Teaching Hospital (UNTH) Ituku-Ozalla, Enugu completed measures of event centrality and HRQoL. We analysed for the associations with 4 different dimensions of HRQoL (physical, relationship, cognitive and treatment impact). We found that focusing thoughts on HIV/AIDS diagnosis was negatively associated with the cognitive aspects of HRQoL, as well as social relationships and treatment impact aspects of HRQoL. Furthermore, results showed that intensified thoughts regarding HIV/AIDS diagnosis negatively predicted relationship and cognitive dimensions of HRQoL. Hence this study provides evidence that intensified thinking about HIV/AIDS diagnosis is associated with poorer relationship and cognitive health outcomes.

Introduction

Assessment and maintenance of quality of life (QoL) of patients living with chronic illnesses, such as HIV/AIDS, is one of the priorities of health care practitioners for reasons which include allocation of resources and evaluation of impacts of programme (s) on the patients' concern. It is particularly used for monitoring the level of HIV/AIDS progression (Paschoal, 2000; Reis, Santos, & Gir, 2012). QoL in relation to health, also known as health-related quality of life (HRQoL), has become a concern for researchers, policy makers and health practitioners given its relevance in assessment of people with different health conditions towards understanding their health needs for improved health outcome planning (Osoba, 2011). Health-related quality of life is the functional effect of a medical condition and/or its consequent therapy upon a patient (Schipper, Clinch, & Olweny, 1996). It has to do with the effects of the disease and its treatment on the patient (Nilsson, 2012). Assessing HRQoL involves determining how health variables such as disease and its therapy are associated with certain dimensions of life that have been determined to be important to people in general (generic HRQoL) or to people who have a specific disease (condition-

specific HRQL) (American Thoracic Society, ATS, 2008). The dimensions of HRQoL include physical health, social relationships/roles, psychological/emotional, cognitive functioning, symptoms, health perceptions, and overall quality of life (ATS, 2008). Hays et al. (2000) observed that people living with HIV/AIDS (PLWHA) have poorer HRQoL than patients living with other chronic illnesses. Poor HRQoL among PLWHA may have resulted from traumatic experiences associated with the disease condition (American Psychological Association, APA, 2013).

Although the trauma of HIV/AIDS diagnosis may induce some level of growth or stress symptoms among patients, which may be a significant influencing factor in the patients' health outcome variables (Boarts, Buckley-Fischer, Armelie, Bogart, & Delahanty, 2009), patients' cognitive construal of his/her life story around the trauma may be a factor explaining variations in the HRQoL of the trauma victims. Some authors (e.g., Chukwuorji, Ifeagwazi, & Eze, 2017a, b; Haung, Lee, Katheswaran, Jones, Revicki, & Wu, 2017) have identified cognition

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as one of the outstanding areas of human differences that also influence behaviours and HRQoL. Traumatic experiences usually have significance in the victim's life story (Reiland & Clerk, 2017). The idea of traumatic event(s) dominating major facet of one's identity defines the concept of event (trauma) centrality (EC) (Berntsen & Rubin, 2007). Event/trauma centrality has to do with the extent victims of traumatic experience(s) think of themselves, either partly or exclusively, as ones who have had such experience(s) which forms the basis for making meaning towards other events (Groleau, Calhoun, Cann, & Tedeschi, 2013).

The theory of autobiographical memory identifies that the way we memorize the major events in our life is closely related to the way we understand ourselves, which, in turn, brings about negative health outcomes (Fitzgerald, 1988; Greening, Stoppelbein & Docter, 2002; Peterson & Seligman, 1984). Da Silva, Donat, Lorenzoni, de Souzer, Gauer, and Kristensen (2016) asserted that EC can be a potential facilitator of cognitive processes essential in negative health outcome among Brazilian sample. Park, Bharadwaj and Blank (2011) reported event centrality as a negative predictor of most measures of well-being in a sample of US cancer patients except physical dimension of HRQoL. Quinn and Chaudoir (2009) observed that centrality of one's identity around HIV status is one of the negative correlates of health and wellbeing among PLWHA in a US sample. Similarly, Brener, Callander, Slavin and Wit (2013) reported that HIV centrality was among the covariates of the worsening indices of negative health and well-being in an Australian sample. Boals and Schuettler (2011) identified EC as a predictor of both negative and positive health outcome among the US students' sample.

From the extant literature, none of the reviewed studies examined an African sample vis-a-vis event/trauma centrality and health-related quality of life among people living with HIV/AIDS. This study is therefore imperative given the central position currently being occupied by HIV/AIDS among trauma inducing illnesses (APA, 2007). Currently, Nigeria is the second country most hit by the scourge of HIV/AIDS epidemic globally (The Joint United nations Programme on HIV/AIDS, UNAIDS, 2016). We therefore set out to investigate, in the present study, if EC is implicated in the poor health-related quality of life of people living with HIV/AIDS in Nigeria. We hypothesized that:

1. Event centrality will significantly predict physical health symptoms dimension of health-related quality of life among people living with HIV/AIDS.
2. Event centrality will significantly predict cognitive symptoms dimension of health-related quality of life among people living with HIV/AIDS.
3. Event centrality will significantly predict relationship symptoms dimension of health-related quality of life among people living with HIV/AIDS.
4. Event centrality will significantly predict treatment impact symptoms dimension of health-related quality of life among people living with HIV/AIDS.

Method

Participants

Participants were 201 outpatients (male = 63, 31.3%, female = 138, 68.7%, mean age = 40.1, $SD = 10.5$) managed for HIV/AIDS in the University of Nigeria Teaching Hospital, Ituku, Ozalla, Enugu State, Nigeria. One hundred and sixty-two (80.6%) participants had minimum Senior School Certificate educational level while thirty-nine (19.4%) had minimum HND educational level. On ethnicity, majority of the respondents 194 (96.5%) were Igbo, 2 (1.0%) were of Yoruba ethnicity, while 5(2.5%) were of other ethnic minorities. Religious affiliations showed that 199 (99%) of the participants were Christians while only 2(.1%) were Muslims. Participants' marital statistics also showed that 44(21.9%) were single, 122 (60.7%) were married and still living with their spouse, 21(10.4%) were widows, 5(2.5%) widowers, while 9(4.5%) were divorced. On occupation, 70(34.8%) were traders, 46(22.9%) were civil servants, 41(20.4%) were employed in the private sectors, 15(7.5%) were farmers, 11(5.5%) were students, 11(5.5%) were retired, while 7(3.5) had no job. Also 177(88.1%) of the participants reported no other sicknesses other than HIV/AIDS, while 24(11.9%) reported other sicknesses such as diabetes, ulcer and cancer.

Instruments

Data was collected by means of a questionnaire comprising Centrality of Events Scale, Patients Reported Outcome Quality of Life-HIV (PROQOL-HIV), and a socio-demographic questionnaire.

Centrality of Events Scale

This is 7-item abridged version of the Centrality of Events Scale (CES; Berntsen & Rubin, 2006) developed to assess the extent to which an event is construed to be central to one's identity. Participants responded on a 5-point likert scale format ranging from 1 (totally disagree) to 5 (totally agree). Example of items include "This event has colored the way I think and feel about other experiences", and "I feel that this event has become central part of my life story." We changed the word "event" to "health condition" to suit the respondents' specific health challenge. Developers of the scale reported alpha reliability of .88 (Boals, Steward, & Schuettler, 2010) while the present researchers obtained .82 Cronbach's α reliability of internal consistency.

Patients Reported Outcome Quality of Life-HIV (PROQOL-HIV)

This is a 38-item-four factor questionnaire developed by Duracinsky et al. (2012) to measure health related quality of life specifically for PLWHA. The four domains include: physical symptoms (PHS, 11 items), relationship to others (intimate/social relationship) (10 items) cognitive symptoms (health concerns/mental distress) (10) and treatment impacts (TI, 10 items). Participants responded on a 5 – point likert scale format ranging from never = 0 to always = 4. Scores for each domain ranged between 0 (worst HIV HRQoL) to 100 (best HIV HRQoL). Reliability and validity analysis carried out showed that all measures have acceptable reliability and validity indices. Developers of PROQOL-HIV reported minimum alpha reliability of .77 across all domains. In the current sample, the reliability for the domains were .80, .80, .81 and .77 for the physical health symptoms, relationship to others, cognitive symptoms, and treatment impact domains, respectively.

Procedure

With the approval of the ethical research committee of the University of Nigeria Teaching Hospital to conduct the study (NHREC/05/01/2008B-FWA00002458-1RB00002323), researchers recruited and trained 3 research assistants who assisted in administration of the questionnaires in the hospital. The trained research assistants helped the researchers explain the nature of the study to the participants, what they were required to do and who was undertaking the research. Informed consent was obtained from each participant. Participants were assured of the confidentiality of their personal information. They were encouraged to honestly respond to the test items. After completion of

the questionnaire, which took about 12 minutes, researchers thanked the participants for participating in the study.

Design/Statistics

This is a survey research and cross-sectional design was adopted in the study. Pearson's correlation (r) analysis was conducted among the study's demographic variables, predictors and dependent variables while simple regression was applied for hypothesis testing. Statistical Package for the Social Sciences (SPSS version 22) was used in conducting the statistical analysis.

Results

Pearson's partial correlation in Table 1 indicated that, EC was negatively related to Cognitive symptoms domain of HRQoL. Those who reported centralizing HIV/AIDS around their life were likely to report negative experiences along cognitive health dimension of HRQoL. However, other demographic variables (gender, age, marital status, occupation, level of education and comorbidity of other sicknesses), were not significantly related to HRQoL. EC was negatively related to health concern/mental distress. Participants whose major facets of identity were dominated by the idea of having HIV/AIDS also reported more mental health distress. It was also found that EC was negatively related to intimate/social relationship). Hence the more a patient centralizes on HIV diagnosis, poorer relationship experiences with their intimate partners, family and social network of friends were reported. EC was also negatively related to treatment impact dimension of HRQoL. Participants whose major facets of identity were dominated by the idea of having HIV/AIDS also reported being burdened by their treatment processes. However, EC was not significantly associated with physical health symptoms dimension of HRQoL.

Regression results (Table 2) showed that EC predicted social relationship symptoms domain of HRQoL ($\beta = -.45$, 95% $CI [-.39, -.22]$, $t = -7.1$, $p < .001$), and cognitive symptoms domain of HRQoL ($\beta = -.38$, 95% $CI [-.51, -.21]$, $t = -5.7$, $p < .001$). However, EC did not significantly predict physical health symptom, and treatment impact symptoms dimensions of HRQoL. The results suggest that intensified focus on HIV/AIDS diagnosis was more associated with significant adverse outcomes on relationship with others as well as poorer mental health.

Table 1: Correlations between demographic variables, EC and HRQoL (physical health symptoms domain, health concerns and mental distress domain, intimate and social relationship domain and treatment impact dimensions)

Variables	1	2	3	4	5	6	7	8	9	10
1. Age		-.29**	.84	.19**	.32**	.04	-.09	-.01	-.05	.02
2. Gender			-.10	-.21**	-.10	-.15*	.04	-.04	-.06	.09
3. Education				-.08	.14*	.02	-.04	.06	-.01	.09
4. Occupation					.12	.01	.10	.01	.11	.08
5. Comorbidity						.03	.01	.07	.01	.09
6. Event Centrality							.05	-.45**	-.38*	-.13*
7. Physical Health								.13	-.12	.10
8. Relationship-Health									.07	.38*
9. Cognitive -Health										.10
10. Treatment Impact										.04

Note. * $p < .05$; ** $p < .01$; *** $p < .001$.

Table 2: Simple regression table demonstrating relationship between EC and Physical, relationship, cognitive and treatment impact symptoms domains of HRQoL

Variables	Physical symptoms			Relationship symptoms			Cognitive symptoms			Treatment impact		
	β	t	95%CI	B	t	95%CI	β	t	95%CI	β	t	95%CI
EC	.05	.63	-.53, 1.03	-.45	-7.1**	-.39, -.22	-.38	-5.7**	-.51, -.21	-.13	-1.8	-.98, .04

Note. EC = event/trauma centrality; Relationship symptoms = Intimate/social relationship; Cognitive symptoms = health concern/mental distress; * $p < .05$; ** $p < .01$; *** $p < .001$.

Discussion

The major goal of this study was to examine the predictive influence of EC on the dimensions of HRQoL in a sample of PLWHA in Nigeria. The relationship between EC and dimensions of HRQoL were also investigated. Consistent with previous research (e.g., Boals & Schuettler, 2011; Brener, Callander, Slavin, & Wit, 2013; Da Silva, Donat, Lorenzoni, de Souzer, Gauer, & Kristensen, 2016; Park, Bharadwaj, & Blank, 2011; Quinn & Chaudoir, 2009), it was found that EC significantly predicted domains of HRQoL. Specifically, we found in a Nigerian sample that intensified thoughts about being diagnosed and living with HIV/AIDS was related to experiencing more mental distress as well as poor intimate/social relationship. Thus, hypothesis 2 and 3 which stated that EC will negatively predict cognitive and relationship domains of HRQoL were supported.

Our findings concur with studies among patients with HIV/AIDS and other life-threatening illnesses. Quinn and Chaudoir (2009) reported that the more central HIV/AIDS is to the identity of PLWHA, the less their mental health adjustment. Bharadwaj and Blank (2011) reported that cancer identity centrality is negatively related to all domains except physical component of HRQoL. In the same vein, Helgeson (2011) who studied EC among cancer patients, and Helgeson and Novak (2007) who studied EC among diabetic patients found that intense focus on these illnesses were related to poor health adjustment outcomes. More precisely, we observed that EC was significantly

associated with cognitive and relationship domains of HRQoL among people living with HIV/AIDS. Our study specifically found that intense rumination and focus on illnesses as a core defining characteristic of a person, among PLWHA, was associated with exacerbated mental distress, and compromised relationship with significant others.

When a HIV/AIDS patient so much preoccupy his/her thoughts around the understanding that his/her identity and self is all about HIV/AIDS, such patient may experience associated maladaptive worries, thoughts, and feelings, and as well not get along very well with significant persons. One explanation to our current findings is within the stigmatization literature. People who suffer stigma due to their societal status, health conditions, or experiences are known to have varying beliefs regarding their identity which goes own to lead to psychological distress (Quinn et al., 2014). HIV/AIDS is a heavily stigmatized health condition especially in sub-Saharan Africa. Hence, the poor mental health and relationship outcomes identified in this study could as well arise from stigma experiences. Our study did not explore this (stigma-event centrality-psychological distress) pathway, but this will surely be a fertile position to explore in future research.

The consistency of findings regarding the association between EC and HRQoL outcomes across different ailments points to the importance of identity construction following diagnosis of every ailment. Clinicians who work with persons

with HIV/AIDS should pay attention to how patients construe themselves and how this personal construction of identity impacts the wellbeing of patients. Our study suggests that identity centrality on illness is associated with poorer mental health and unhealthy relationships. Clinicians should pay attention on HIV/AIDS patients as mental health deterioration could set in due to shifting identity construction. Rehabilitation programs for persons with HIV/AIDS should also extend to include modules on interpersonal relationships as well as mental health inoculation.

EC did not significantly predict physical health symptoms of HRQoL. This finding is in tandem with previous finding by Park, Bharadwaj, and Blank (2011), who found that EC was not significantly related to physical health symptom domain of HRQoL. Also, EC did not significantly predict treatment impact domains of HRQoL. It is difficult to explain why other domains (physical and treatment impact) were not statistically predicted by EC. Perhaps mental distress and relationship domains, like EC relates more to internal processes, bordering on issues of evaluation of self and others while the physical and treatment impact domains relate more to the physical manifestations of issues relating to HIV/AIDS.

Findings of this study have some limitations. The sample size (201 respondents) and the study setting (South East Nigeria) imply that the generalizability of our findings is limited to the region studied. The design of this study is cross-sectional and involves self-report measures, and causal inferences cannot be made from the findings from this study. Thus, interpretations and application of our findings should be made with caution. Nonetheless, the present study supports and extends the existing literature on the relationship between EC and HRQoL among PLWHA in Nigerian setting where the second largest global HIV/AIDS burden is recorded (UNAIDS, 2016).

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