Published in final edited form as:

J Assoc Nurses AIDS Care. 2012 July ; 23(4): 361–365. doi:10.1016/j.jana.2011.08.011.

Personal narratives, coping, and quality of life in persons living with HIV

Kathryn R. Macapagal, MEd [Ph.D. Candidate in Clinical Science],

Department of Psychological and Brain Sciences Indiana University Bloomington, Indiana, USA
Graduate Research Assistant The Kinsey Institute for Research in Sex, Gender, and
Reproduction Bloomington, Indiana, USA

Jamie M. Ringer, PsyD [Research Psychologist],

Roudebush VA Medical Center Indianapolis, Indiana, USA Assistant Research Scientist
Department of Clinical Psychiatry Indiana University School of Medicine Indianapolis, Indiana,
USA

Shannon E. Woller, PsyD [Clinical Psychologist], and

Roudebush VA Medical Center Indianapolis, Indiana, USA Assistant Professor of Clinical
Psychology Department of Clinical Psychiatry Indiana University School of Medicine Indianapolis,
Indiana, USA

Paul H. Lysaker, PhD [Clinical Psychologist]

Roudebush VA Medical Center Indianapolis, Indiana, USA Professor of Clinical Psychology
Department of Clinical Psychiatry Indiana University School of Medicine Indianapolis, Indiana,
USA

Keywords

coping; HIV; mental health; narratives; patient care; quality of life

Receiving a diagnosis of HIV can be a life-altering experience that results in significant psychosocial consequences, such as disruptions of one's life trajectory and goals, sense of self, relationships with others, and participation in social and occupational activities. For many, adapting to these changes can be extremely challenging, yet little is known about the processes that influence how well or poorly individuals are able to recapture the ability to function in these areas.

One factor that may influence psychological and social aspects of recovery from HIV is the personal narrative, or the way in which persons make storied sense of their conditions. Theoretically, a personal narrative should reflect an individual's unique way of making sense of his or her own life, including hopes, dreams, losses, and challenges. As suggested by Bruner (1992), it is through narratives that persons make meaning from life events, and subsequently the experiences of their lives move beyond simply being a collection of facts. Therefore, a personal narrative is a self-reflective act that should influence and be influenced by self-esteem, appraisals of opportunities, and the challenges posed by illness. As such, it

© 2011 Association of Nurses in AIDS Care. Published by Elsevier Inc. All rights reserved.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Disclosure: The authors do not report any financial interests or potential conflicts of interest.

can be hypothesized that personal narratives are uniquely related to patient wellbeing, or the extent to which persons flourish rather than languish in daily life.

In support of this possibility, qualitative studies have suggested the quality of HIV-infected patients' personal narratives is associated with how adaptively or maladaptively they manage their conditions and may predict how flexibly they are able to cope with HIV-related changes over time (Armendariz, Saunders, Poston, & Valente, 1997; Mohammadpour, Yekta, Nasrabadi, & Mohraz, 2009). Others have noted that narratives provide a medium through which HIV-infected persons can process and find meaning in stressful, traumatic life events, as well as come to terms with an identity as a person living with HIV (Plattner & Meiring, 2006; Schwartzberg, 1993). Finally, indirect support for the possibility that narratives play a role in wellness in HIV-infected individuals include studies of other chronic medical and psychiatric conditions (e.g., pain, psychosis) that have linked the coherence (i.e., quality and content) of personal narratives with patients' scores on self-report measures of coping and quality of life (Brown, Dick, & Berry, 2010; Lysaker, Clements, Hallberg, Knipschure, & Wright, 2002).

Thus, while there is reason to believe that the qualities of personal narrative may affect recovery from HIV, we are unaware of any quantitative studies to date that have addressed this question. Accordingly, in this study, we collected personal illness narratives from HIV-infected patients and rated the narratives' coherence and complexity using the Scale to Assess Narrative Development (STAND), a method originally developed for research on psychiatric patient populations (Lysaker et al., 2006). We then investigated associations between narrative coherence and observer-rated and self-report measures of coping and quality of life. Based on previous literature (Armendariz et al., 1997; Brown et al., 2010; Lysaker, Ringer, Maxwell, McGuire, & Lecomte, 2010; Mohammadpour et al., 2009), we predicted that HIV-infected persons with more coherent, detailed narratives would demonstrate significantly better outcomes on measures of quality of life and coping than would persons with less coherent narratives.

Method

Participants

Twenty-six HIV-infected men ages 28 to 69 (mean age = 52.1; $SD = 11.2$ years), 18 of whom had a chart diagnosis of AIDS at the time of the study, were recruited from the outpatient infectious disease clinic of a Midwestern Veterans Administration (VA) Medical Center. Participants (17 White, 9 Black) had an average of 13.8 years of education ($SD = 2.3$), had been living with HIV for at least 2 years, and were involved in a larger study of narratives in persons with severe mental and medical illnesses. Exclusion criteria included current diagnoses of severe mental illness, dementia, traumatic brain injury, substance dependence, or a psychiatric hospitalization within the previous 6 months. All study procedures were approved by the VA's institutional review board.

Measures

The *Indiana Medical Illness Interview* (IMII; Lysaker et al., 2002) is a semi-structured 30- to 60-minute interview developed to capture patients' illness narratives. This interview is divided into five sections that obtain patients' detailed life stories, understandings of their illness and how it has affected them, their sense of control over the illness, how the illness affects and is affected by others, and how they expect their futures will be different in terms of interpersonal and psychological function. In order to ensure that the narrative provided contains the patient's own conception of his or her illness, interviewers do not inquire about specific details or introduce new content.

The STAND (Lysaker et al., 2006) measures the degree to which a patient generates a coherent, meaningful narrative that demonstrates a sense of agency, social worth, and connectedness, and understands the degree to which illness impacts his or her life and the lives of others. The STAND is completed by trained raters and assesses four aspects of recovery in personal narratives: Illness Conception, Alienation, Agency, and Social Worth. These subscales assess individuals' understandings of their illnesses, the degree to which individuals maintain close relationships with others, the extent to which individuals believe they are able to affect events in their lives, and the degree to which individuals perceive themselves as valuable to others and society. Each subscale is rated on a 5-point Likert scale from 1-5, and subscales are summed to form a total score. Higher total scores on the STAND, which are indicative of more coherent, complex narrative content in these domains, have been associated with increased self-esteem, motivation for change, ability to cope, and quality of life in persons with psychosis (e.g., Lysaker et al., 2010; Lysaker et al., 2006). The STAND was adapted to rate illness narratives of medical patients for the purposes of this study. The average score on the STAND for this sample was 15.7 ($SD = 3.1$).

The *Quality of Life Scale* (QOLS; Heinrichs, Hanlon, & Carpenter, 1984) is a 21-item scale completed by trained raters following a semi-structured interview with a patient. The QOLS consists of four subscales: Interpersonal Relations, which measures frequency of social contact and quality of relationships with family, friends, and acquaintances; Instrumental Function, which measures vocational achievement and satisfaction with occupational functioning compared to pre-illness levels; Intrapsychic Foundations, which measures building blocks for successful functioning including personal interests, motivation, and sense of purpose; and Community Participation, which assesses degree of societal participation based on possession of personal effects and engagement in societal activities. Each item is scored on a 7-point Likert scale from 0-6, and items are summed to form subscale scores. Higher scores indicate better functioning in these domains. In this sample, the subscale means were 24.0 ($SD = 11.5$) for Interpersonal Relations, 10.7 ($SD = 9.7$) for Instrumental Function, 28.4 ($SD = 7.0$) for Intrapsychic Foundations, and 9.0 ($SD = 1.6$) for Community Participation.

The *Millon Behavioral Medicine Diagnostic* Coping Styles scale (MBMD; Millon, Antoni, Millon, Minor, & Grossman, 2006) is a self-report inventory designed to assess 11 coping styles characterized by adaptive and maladaptive cognitive, behavioral, and interpersonal strategies used to manage discomfort. To reduce the number of statistical comparisons during data analysis, the 11 coping styles were grouped into two larger scales. Scores on the Cooperative, Sociable, Confident, and Respectful coping styles subscales were summed to form an Adaptive Coping variable, on which high scores indicated behavioral or attitudinal assets. The Introversive, Inhibited, Dejected, Nonconforming, Forceful, Oppositional, and Denigrated coping styles subscales were summed to form a Maladaptive Coping variable, on which high scores indicated clinical liabilities. Means for this sample were 211.7 ($SD = 46.9$) for the Adaptive Coping and 391.8 ($SD = 110.8$) for Maladaptive Coping.

The *Hopkins Verbal Learning Test – Revised* (HVLTR; Brandt & Benedict, 2001) is a learning and memory task included to rule out the possibility that our findings were an artifact of cognitive factors. The HVLTR consists of three word lists read aloud to the respondent, who is asked to recall the words immediately and then after a delay. The age-adjusted t -scores for Total Recall ($M = 36.2$, $SD = 9.9$) and Delayed Recall ($M = 35.6$, $SD = 11.5$) were potential covariates for the analyses.

Procedure & Analysis

Upon arrival to the research unit of the hospital, participants gave written informed consent for the study. The IMII, QOLS, MBMD, and HVLTR were then administered and scored

by trained research technicians. The IMII was audiotaped and, following the test session, its contents were transcribed and de-identified. Two raters, who were blind to participant identity and test performance, scored the transcripts using the STAND. Raters were trained by the second author until they achieved reliability, and raters met regularly to discuss scores until consensus was achieved. Bivariate correlations explored associations between our variables of interest, and simple linear regressions were used to examine the degree to which STAND scores predicted outcomes on the coping and quality of life measures.

Results

Correlations between the measures of interest are found in Table 1. STAND scores were significantly positively correlated with Interpersonal Relationships and Adaptive Coping scores. STAND scores also were negatively associated with Maladaptive Coping and marginally correlated with Intrapsychic Foundations, but they were not significantly correlated with Instrumental Function or Community Participation. Age, years of education, HVLT-R scores, and whether or not a participant had a diagnosis of AIDS were not significantly associated with STAND scores; therefore, these variables were not entered as covariates into the regression analyses.

Linear regressions then examined the degree to which narrative coherence, as measured by the STAND, predicted coping and quality of life scores on the MBMD and QOLS. Higher STAND scores were associated with significantly lower Maladaptive Coping scores ($\beta = -.41$, $t(24) = -2.23$, $p < .05$) and higher Adaptive Coping scores ($\beta = .57$, $t(24) = 3.41$, $p < .01$). Regarding the QOLS, higher STAND scores predicted higher Interpersonal Relationships scores ($\beta = .71$, $t(24) = 4.97$, $p < .001$) and were a marginally significant predictor of Intrapsychic Foundations scores ($\beta = .37$, $t(24) = 1.95$, $p = .063$); however, the STAND did not significantly predict Instrumental Role or Community Participation scores.

Discussion

This study investigated the relationships between the complexity and coherence of the personal narratives and narrative content and quantitative measures of coping and quality of life in persons living with HIV. As predicted, greater narrative coherence was associated with having rater assessments of increased frequency of social contacts and capacity for forming lasting social bonds. Narrative coherence was also related to patients' self-reports of more adaptive, and less maladaptive, ways of coping with their medical conditions.

While the correlational nature of the study precludes drawing any causal conclusions, results do suggest some hypotheses for future research. For one, results are consistent with the possibility that the richer the narrative individuals with HIV can form of their lives, the more able they are to adjust to and cope with their conditions (e.g., sustain sufficient levels of motivation, manage difficult emotions, and remain engaged in one's surroundings). It may be that with a richer story of one's challenges and abilities, it becomes more and more possible for persons to better navigate the challenges posed by diseases such as HIV. More coherent stories of oneself as an agent facing these difficulties may allow for closer connection to others, allowing for others to empathize, which thus buffers against the loss of meaningful connections. Of note, these are at best speculations, and rival hypotheses cannot be ruled out, such as the possibility that enriched social connections also promote more coherent narratives.

Unexpectedly, narrative coherence was not significantly related to the community participation and vocational achievement aspects of the patients' quality of life, which suggests that adequate functioning in these domains may be independent of one's subjective

understanding of his or her illness. It is possible that narrative coherence is more related to social rather than instrumental elements of function. However, it is also possible that this study was not sufficiently powered to be able to detect these relationships.

With replication, these findings may have several clinical implications. For one, it may be that psychotherapeutic and supportive interventions that focus on developing and expanding the patient's personal narrative might assist individuals with HIV to develop more adaptive coping strategies and support or strengthen social connections. Interventions that broaden a patient's personalized account of challenges and larger life may serve as ways of assisting the patient to accept and master many of the devastating losses that come with HIV. Clinically speaking, employing narratives as a therapeutic tool seems like a promising means to help persons who are struggling psychologically with a new diagnosis of HIV to begin the processes of coping, recapturing identity, and making sense of life after diagnosis. Inquiring about patient illness narratives would allow health care providers to build rapport with the patient and obtain a clearer picture of the patient's unique experiences with illness. Additionally, obtaining patient narratives can ensure clinicians' considerations of the individual's preferences for treatment, needs, strengths, and cultural background, which could inform decision making about therapeutic and supportive aspects of patient care.

As most research conducted on HIV illness narratives has been primarily qualitative, this study is significant in that it is one of the first studies to show that more coherent, complex illness narratives of HIV-infected individuals are associated with higher scores on observer-rated and self-report indicators of psychological and social functioning. These findings suggest several avenues for research that may clarify causal processes underlying the development of illness narratives and psychological wellness. While generalizations that can be made from this study are limited by its unique patient population, with a larger sample of participants future studies could explore factors moderating relationships between narrative content and psychosocial wellbeing, such as symptoms of depression or anxiety. Alternatively, a longitudinal study could obtain narratives over a period of months or years following a diagnosis of HIV to examine changes in relationships between narrative content, coping, and quality of life over time.

Acknowledgments

Data collection was supported by the Veterans Administration Rehabilitation Research and Development Service. During manuscript preparation, the first author was supported by predoctoral training fellowships from the National Institutes of Health (TL1RR025759 to A. Shekhar) and the National Institute of Mental Health (F31 MH090895 to K.R. Macapagal).

References

- Armendariz A, Saunders JM, Poston SL, Valente SM. Exploring a life history of HIV disease and self-caring: Alfredo's story. *Journal of the Association of Nurses in AIDS Care*. 1997; 8:72–82. doi: 10.1016/S1055-3290(97)80020-9. [PubMed: 9152892]
- Brandt, J.; Benedict, RHB. *Hopkins Verbal Learning Test-Revised*. Psychological Assessment Resources; Lutz, FL: 2001.
- Brown CA, Dick BD, Berry R. How do you write pain? A preliminary study of narrative therapy for people with chronic pain. *Diversity in Health and Care*. 2010; 7:43–56.
- Bruner, J. *Acts of meaning: Four lectures on mind and culture*. Harvard University Press; Cambridge, MA: 1992.
- Heinrichs DW, Hanlon TE, Carpenter WT. The Quality of Life Scale: An instrument for assessing the schizophrenic deficit syndrome. *Schizophrenia Bulletin*. 1984; 32:464–473. doi:10.1093/schbul/10.3.388.

- Lysaker PH, Clements CA, Hallberg CP, Knipschure SJ, Wright DE. Insight and personal narratives of illness in schizophrenia. *Psychiatry*. 2002; 65:197–206. [PubMed: 12405078]
- Lysaker PH, Ringer J, Maxwell C, McGuire A, Lecomte T. Personal narratives and recovery from schizophrenia. *Schizophrenia Research*. 2010; 121:271–276. doi:10.1016/j.schres.2010.03.003. [PubMed: 20347269]
- Lysaker PH, Taylor A, Miller A, Beattie N, Strasburger A, Davis LW. The Scale to Assess Narrative Development: Associations with other measures of self and readiness for recovery in schizophrenia spectrum disorders. *Journal of Nervous and Mental Disease*. 2006; 194:223–225. doi: 10.1097/01.nmd.0000202512.54587.34. [PubMed: 16534441]
- Millon, T.; Antoni, M.; Millon, C.; Minor, S.; Grossman, S. *Millon Behavioral Medicine Diagnostic*. National Computer Systems; Minneapolis, MN: 2006.
- Mohammadpour A, Yekta ZP, Nasrabadi ARN, Mohraz M. Coming to terms with a diagnosis of HIV in Iran: A phenomenological study. *Journal of the Association of Nurses in AIDS Care*. 2009; 20:249–259. doi:10.1016/j.jana.2009.03.003. [PubMed: 19576542]
- Plattner IE, Meiring N. Living with HIV: The psychological relevance of meaning making. *AIDS Care*. 2006; 18:241–245. doi:10.1080/09540120500456227. [PubMed: 16546785]
- Schwartzberg SS. Struggling for meaning: How HIV-positive gay men make sense of AIDS. *Professional Psychology: Research and Practice*. 1993; 24:483–490. doi: 10.1037/0735-7028.24.4.483.

Table 1

Correlations between STAND, MBMD, and QOLS scores

	1	2	3	4	5	6
1 STAND Total	--	--	--	--	--	--
2 MBMD Adaptive Coping	.57 ^b	--	--	--	--	--
3 MBMD Maladaptive Coping	-.41 ^c	-.54 ^b	--	--	--	--
4 QOLS Interpersonal Relations	.71 ^a	.63 ^b	-.61 ^b	--	--	--
5 QOLS Community Participation	.16	.36	-.40 ^c	.50 ^b	--	--
6 QOLS Intrapsychic Foundations	.37 ^d	.51 ^b	-.32	.52 ^b	.69 ^a	--
7 QOLS Instrumental Function	.24	-.02	-.12	-.04	.03	.11

Note. STAND = Scale to Assess Narrative Development; MBMD = Millon Behavioral Medicine Diagnostic; QOLS = Quality of Life Scale

^a $p < .001$

^b $p < .01$

^c $p < .05$

^d $p < .06$.