

Adjustment as process and outcome: Measuring adjustment to HIV in Uganda

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ABSTRACT

“Adjustment” in health refers to both processes and outcomes. Its measurement and conceptualisation in African cultures is limited. 263 people living with HIV and receiving antiretroviral therapy in clinics in Uganda completed a translated Mental Adjustment to HIV (MAHIV) scale, depression items from the Hopkins checklist and demographic questions. Factor analysis revealed four MAHIV factors of active coping, cognitive-social adjustment, hopelessness and denial/avoidance. Correlations with depression supported the MAHIV’s validity and the importance of active coping, whilst the role of cognitive adjustment was unclear. Factors were process or outcome focused, suggesting a need for theory based measures in general.

KEYWORDS

HIV; adjustment; cross-cultural; psychometrics; measure

INTRODUCTION

Much is written about adjustment to long-term health conditions, including HIV, and interventions to improve adjustment have been developed. This is despite difficulties in defining what is meant by adjustment (Brennan, 2001). "Adjustment" is often used interchangeably with "coping" and sometimes with "adaptation". It has been defined as the "presence or absence of diagnosed psychological disorder, psychological symptoms or negative mood" (Stanton et al., 2007: 568) and includes the cognitive and behavioural responses to a diagnosis (Watson et al., 1988). However this highlights the difficulty that whilst adjustment is a process, it is often defined in terms of its outcomes (Brennan, 2001).

Models of adjustment include elements from several theories. Coping theories (Lazarus and Folkman, 1984) highlight the importance of active, problem focused coping and the damaging impact of avoidance coping (de Ridder et al., 2008). Various cognitive appraisal processes including cognitive adaptation theory (Taylor, 1983) conceptualise adjustment as including shifts in focus and standards that enhance self-esteem, meaning and mastery. Social comparison theory addresses the processes of judging one's experience in relation to the perceived experiences of others, often achieving self-enhancement. Comparing oneself to those worse off appears to be an adjustment process linked to better psychological outcomes, whilst comparing oneself to those doing well can be associated with inspiration, facilitating adjustment through motivation (Wood and VanderZee, 1997). The social-cognitive transition model of adjustment (Brennan, 2001) highlights the role of expectations based on previous life experience, which may be updated due to illness experience and this process may involve stress and denial.

The role of culture, race and ethnicity in these complex processes of adjustment is unclear (Stanton et al., 2007). Adjustment occurs within a person's socio-cultural context. Different adjustment processes may be more or less socially acceptable, relevant or effective in these different contexts. The majority of studies around "adjustment to chronic illness have been done in white, middle-class populations and in specific chronic diseases, thus limiting the generalisation of findings to ethnic groups, patients with low socioeconomic status and other chronic conditions" (de Ridder et al., 2008: 252). Investigating adjustment to a condition like HIV in a low-middle income country such as Uganda contributes to the literature by exploring the construct in a different socio-cultural setting.

Adjustment to HIV has been studied typically in USA, Europe and Australia. Meta-analysis revealed that cognitive reappraisal was consistently related to better psychological outcomes, whilst avoidance based coping (or a failure to adjust) had an inconsistent relationship with outcomes (Moskowitz et al., 2009). Stress and coping theory has been found to explain adjustment to HIV well, for example problem-focused coping strategies rather than avoidant strategies also predict good adjustment (Pakenham and Rinaldis, 2001). Positive appraisal of HIV associates to better psychological outcome (Bova, 2001). Denial coping is linked to higher depression (Carrico et al., 2006). Social comparison theory is also relevant, with upward comparisons beneficial to psychological outcome (Derlega et al., 2008).

The measurement of adjustment needs to cover both positive and negative elements of adjustment, for example both avoidant processes and active adjustment (Stanton and Revenson, 2011). Measures do not necessarily relate to theory, despite a need for research based on sound methods relating to theory (Stanton and Revenson, 2011). Some measures focus primarily on the outcome of adjustment such as the "Psychosocial Adjustment to Illness Scale" (Derogatis, 1986) and its self-report versions, which

covers vocational environment, sexual relationships, social environment, psychological distress, relationship with parent and family and health care orientation, asking about function, behaviour and affective outcome (Rodrigue et al., 2000). Other measures are more focussed on the process of adjustment, such as the "Mental Adjustment to Cancer" (MAC) scale (Watson et al., 1988) and the "Mental adjustment to HIV" (MAHIV) measure (Ross et al., 1994). The measures have been found to have variable structure and require relating back to theory.

The "Mental adjustment to HIV" (MAHIV) was developed from the "mental adjustment to cancer" (MAC) scale (Watson et al., 1988). The measure contains a mix of items covering processes such as "I carry on with my life as previously" and outcomes "I suffer great anxiety". The original MAC scale had five factors of fighting spirit, anxious preoccupation, helplessness/hopelessness, fatalism and avoidance. Further research found an alternative factor structure of the MAC, comprising hopelessness, vigilant participation, positive attitude and positive reappraisal (Schwartz et al., 1992). This difference was seen as partly due to cultural differences between American and British participants.

When first adapted from the MAC, the MAHIV contained 40 items, covering five factors of helplessness-hopelessness, fighting spirit, denial-avoidance, fatalism and beliefs in influencing the course of HIV (Ross et al., 1994). This differed from the MAC scale, with greater emphasis on personal influence of the course of illness seen in HIV. In subsequent research a four factor solution was found with hopelessness and fighting spirit as in the original, however the other factors were personal control and minimisation (Kelly et al., 2000). Use of the measure with an Australian sample of people living with HIV poor internal consistency (alpha less than 0.5) on two of the five factors, namely fatalism and beliefs in influencing the course of HIV (Begley et al., 2008). These observations of poor fit of the original MAHIV scale may reflect

changes in HIV care, including the more widespread availability of effective anti-retroviral therapy (ART) that has fewer side effects and can prolong life-expectancy. It is important to note however that the MAHIV displays evidence of construct validity. MAHIV scores can distinguish between those with symptoms of psychological distress and those who do not have this (Grassi et al., 1998). The Luganda version of the measure for use in areas of Uganda has been used and shows an increased risk for suicidality (aOR 2.54, 95% CI 0.93-6.93) amongst those with a negative coping style (Kinyanda et al., 2012). This study however did not explore the factor structure of the measure.

The MAC and MAHIV were developed with little reference to theories of coping or adjustment, indeed, the MAHIV development paper contains no reference to theory, although it specifies its focus as mental attitudes and psychological responses (Ross et al., 1994). Watson et al (1988) did report theoretically supported associations between coping types and outcomes using the MAC, specifically that fatalism was linked to distress and fighting spirit was associated with better outcomes. The association of denial to outcome was unclear. MAHIV research revealed active coping as linked to both better and worse psychological outcomes and denial, avoidant or detachment from affect has been linked to depression (Kelly et al., 2000). The mixed association of active coping to psychological outcomes conflicts with theoretically predicted relationships (Grassi et al., 1998).

Research into processes of adjustment to HIV in low-middle income countries and in African nations is limited. This is despite the higher global burden of HIV in the region. Measures to investigate adjustment have not been developed for use in this setting. MAHIV factor analysis research has been limited to samples of asymptomatic homosexual men in American or Australia samples (Ross et al., 1994; Kelly et al., 2000). The MAHIV scale has been previously translated into Luganda and used in research (Kinyanda

et al., 2011), however factor analysis and psychometric properties were not fully reported. Factor analysis can contribute to theory by exploring the structure of items, providing coherent domains that may reveal an underlying structure that reflects theoretical construct and can support, develop or challenge any existing theory (Floyd and Widaman, 1995). This is particularly relevant as the structure of the MAHIV is unstable and factors include items that reflect both process e.g. “I have plans for the future” and potentially reflecting outcome e.g. “I suffer a great deal of anxiety” (Kelly et al., 2000). This study aimed to 1) use factor analysis to explore the structure of the MAHIV in a low-middle income country to investigate how the structure relates to adjustment theory and 2) explore the reliability and validity of the Luganda version of the measure.

METHODS

Participants

263 participants with HIV and on ART were recruited from ART delivery sites (government hospital Entebbe, three government health centres around Entebbe and a branch of the non-governmental “The AIDS support Organisation”) in Wakiso District, central Uganda. Participants must have been on ART for more than one year to be eligible. A list of eligible patients was compiled for each facility, which was then stratified by age and gender. Participants were selected randomly from the lists.

Measures

The items for this measure had previously been translated and used by Kinyanda et al (2011), however their study did not focus on exploring the measurement properties. Items were translated from the original English, into Luganda and then back-translated to ensure accuracy and similarity of meaning.

From the original MAHIV scale, item 24 “At the moment I take one day at a time”, 26 “I try to keep a sense of humour” and 40 “I try to fight the illness” did not translate in a meaningful way and were therefore excluded from the item pool. The remaining 37 items were translated and used.

The fifteen item depression section of the Hopkins Symptom Check List (DHSC) (Derogatis et al., 1974) was used. Scores range from 15 to 60, with higher scores indicating more symptoms of depression. This measure is commonly used as a screening tool for depression and is validated for use in Uganda in the Luganda language and has good predictive validity to detect depression and good internal consistency (Bolton et al., 2004).

Age and gender were collected. Participants also completed items forming a socio-economic status (SES) score. SES scores were created from variables such as having electricity, having piped water, having a house with a good roof (iron/tile) and having a paid job. The SES scores were created through inverse frequency weighting, where rarest items are given greater weighting in the score (weights for each variable are derived by dividing total sample size by number of participants who have the item, these are then summed to create the overall score). Higher scores indicate greater assets and socio-economic status.

Procedure

These data were collected as part of a larger study exploring aspects of life on ART. Ethical approval for the study was obtained from the Uganda Virus Research Institute and the University of East Anglia, UK. Overall approval was granted by the Uganda National Council for Science and Technology. Informed consent was gained from participants in written format, or witnessed oral consent was used, endorsed

by thumb print. Participants completed the translated MAHIV, the DHSCL and details of their demographics and socio-economic status.

Analysis

Exploratory factor analysis (EFA) was used, as the factor structure of the measure has been found to be variable. The sample size is adequate for EFA, being greater than the recommendations of 150-200 participants (Floyd and Widaman, 1995). Principal components analysis was conducted using IBM SPSS version 20.0. Prior to analysis the data were assessed and defined as suitable for EFA as Bartlett's test of Sphericity was statistically significant ($p < 0.001$) and the Kaiser–Meyer–Olkin (KMO) test was 0.842, greater than the required 0.5 (Ferguson & Cox, 1993).

The number of factors extracted was based on the data and was defined as the number of factors with eigenvalues > 1 . (Ferguson and Cox, 1993). The scree plot was also examined to guide the number of factors included (Cattell, 1966). Subsequent iterations of factor analysis constrained the number of factors to explore a range of solutions. Varimax rotation was applied. Items that had no clear primary loading or had large cross-loading were removed during the process. Items were considered to load on a factor if the absolute value of the factor loading was greater than 0.4 with minimal cross-loading (minimal cross-loading where magnitude of primary loading minus magnitude of secondary loading is greater than 0.2) on another factor (Ferguson & Cox, 1993).

Measurement reliability (internal consistency) was calculated using Cronbach's alpha. In addition, construct validity was assessed in relation to hypotheses derived from the research literature, using correlations and t-tests. Adjustment to HIV should relate to scores of low mood (Kinyanda et al., 2011;

Kinyanda et al., 2012). Moderate correlation is expected with better adjustment associated with lower depression. Active coping methods should have a small negative correlation with denial/avoidance type coping (Hansen et al., 2013). Owing to a conceptual overlap between hopelessness and depression, any factor relating to hopelessness should correlate most strongly with the depression scores. Women are hypothesised to use more active coping than men (Moskowitz et al., 2009) and less denial. Denial/avoidance type coping is proposed to correlate with socio-economic status, with higher levels amongst those with lower status (Catz et al., 2002). From research in adjustment to cancer, fatalistic type factor should correlate with age, with greater fatalism at older age (Grassi et al., 2005).

RESULTS

Sample characteristics

The 263 participants had a mean age of 39.8 years (s.d. 9.76). 67.3% of the sample were female. SES scores range from 0 to 18.08 with a mean of 6.4 (s.d. 4.32). Mean scores for the DHSCS was 22.0 (s.d. 5.50).

Factor analysis

The PCA for eigenvalues < 1 produced a 9 factor solution, however factors 4, 6 and 9 had no items loading principally (all items shared loading on more than one factor, with difference between loadings less than 0.20) and factors 5 and 8 had only one item with a primary loading (loading more than 0.40). In addition, factors 5 to 9 each contributed less than an additional 5% of variance to be explained. The scree plot showed a levelling off of the amount of variance explained by further factors at around five factors. A constrained five factor solution was then sought, which revealed that one of the factors had

just one item, presenting an unsuitable solution. As such, a four factor solution was sought, with varimax rotation applied to facilitate interpretation.

In the four factor solution, nine items had either no primary loading (greatest loading less than 0.4) or had large cross-loadings. These items were removed from the scale and are listed in Table 1.

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The factor analysis was repeated with the remaining 28 items. The resulting 4 factor solution is shown in Table 2. Loadings of variables on factors and percents of variance accounted for are shown, together with Cronbach's alpha's to show internal consistency. Variables are ordered and grouped by size of loading and loadings under 0.30 are not shown, to facilitate interpretation. Some items were reversed scored so that for all factors a higher score links to proposed "better" adjustment.

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Overall, the four factor solution accounted for 46.1% of the variance. The scale is constructed such that a higher score indicates greater adjustment.

Correlations between the factors are shown in Table 3. This shows medium correlations between factors 1, 3 and 4. Factor 2 did not correlate with factor 3 and showed only a small correlation with factor 4.

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In sum, the four factors for the MAHIV were active coping, cognitive-social adjustment, hopelessness and denial/avoidance. The factors have alpha's above 0.7, indicating acceptable internal consistency (Cronbach, 1951).

Construct validity

The factors were correlated with depression scores, to assess construct validity. Factor 1 correlated at $r=-0.132$ ($p=0.036$), factor 2 correlated at 0.137 ($p=0.031$), factor 3 correlated at -0.481 ($p<0.001$) and factor 4 correlated at -0.362 ($p<0.001$). The overall scale correlated at -0.309 ($p<0.001$). These correlations are in the expected direction (negative correlation as better adjustment associated with lower depression scores), except for factor 2. Factor 2, unlike the other factors, showed a small correlation with depression indicating that higher scores on this factor were associated to higher depression scores. This is despite the fact that all significant correlations between the factors are positive. This factor then has an unexpected relationship with the depression scores.

Analysis revealed significant differences in adjustment levels between men and women (one-tailed hypothesis) for active coping ($t(261)=3.450$, $p=0.0005$, 95% CI mean difference 0.565 to 2.073, lower in

women). SES did not correlate significantly with any of the MAHIV factors ($r=0.078$, $p=0.206$; $r=-0.021$, $p=0.738$; $r=0.015$, $p=0.803$; and $r=0.003$, $p=0.958$ respectively). Age also shown no significant correlation with any MAHIV factors ($r=0.065$, $p=0.295$; $r=0.093$, $p=0.133$; $r=0.054$, $p=0.379$; and $r=0.051$, $p=0.412$ respectively).

DISCUSSION

Factor analysis revealed a four factor solution, using only 28 items. The factors cover 1) active coping, 2) cognitive-social adjustment, 3) hopelessness and 4) denial or avoidance. Analysis showed adequate internal consistency and small to medium correlations between factors. Relationship with depression scores and demographic variables were inconsistent. This is the first study to explore the structure of adjustment measurement for people living with HIV in Uganda.

The active coping factor comprised of both cognitive and behavioural elements of adjustment. The cognitive-social adjustment factor primarily included comparison and judgement processes. The hopelessness factor reflects emotional outcomes. Denial or avoidance related largely to the absence of adjustment process, where processes could not be engaged in. Active coping has been well-established to be associated to better outcomes, whilst hopeless and denial/avoidance relate to poorer adjustment (Moss-Morris, 2013). Both are part of stress and coping theory (Lazarus and Folkman, 1984).

Comparisons to others and one's own past show the relevance of social comparison theory and cognitive appraisal processes. The measure's structure then covers both successful and unsuccessful adjustment, a feature important to complete measurement of the construct (Stanton and Revenson, 2011).

Factors 1, 2 and 4 relate to processes of adjustment. Factor 3, hopelessness, includes only items that relate to the emotional outcomes of adjustment. Several authors have expressed a need in adjustment research to separate process from outcome (for example Brennan, 2001) and results here provide statistical support for that separation. If we are to accurately measure adjustment, we must ensure we are measuring the process as distinct from the outcomes, as this is vital for analysis that elucidates how adjustment is achieved. Other measures of adjustment should be developed to make a similar distinction.

The four factor solution here contrasts markedly to the original five factor structure (Ross et al., 1994). Items from the original "Belief in influencing course of disease" items are included in our factors 1, 2 and 3. Most similar to the original MAHIV factors was the hopelessness factor. Five of the six items in our hopelessness factor were also part of that original MAHIV factor. Fatalism was not seen as a separate factor here, rather four of the six items originally in this factor were in our "active coping". Active coping also had items from the original "fighting spirit" and "belief in influencing the course of the disease" factors respectively in the original measure. The distinction of these subsets of active coping was not supported herein.

Our different factor structure suggests that adjustment to HIV in our sample has different important elements, which may relate to both cultural differences and the change in HIV prognosis. Fatalism may be less evident as participants were all on life saving medication. Positive appraisal and positive outlook items were part of the active coping factor, however other elements of cognitive adjustment were together with socially related elements. This cognitive-social adjustment factor, despite good internal

consistency, is conceptually challenging to define. This may reflect the less individualistic nature of Uganda society (Åsander et al., 2013). Using the doctor, god and comparisons with others then may be less conceptually separated to using comparisons with one's own past in such a society. Items relating to comparisons to past-self or others are grouped together. This is different to previous versions of the measure. Social comparison theory is relevant to adjustment (Wood and VanderZee, 1997; Derlega et al., 2008) and it may reflect an underlying theoretical structure that these items fall together here with other judgement related variables.

Active coping, hopelessness and denial/avoidance correlated negatively with depression scores, as expected. The largest correlation was between hopelessness and depression (at $r=-0.481$), as they both reflect emotional outcome. Greater cognitive-social adjustment is related to higher depression. Items framing HIV as down to the doctors, in God's hands and focusing on blessing may reflect a degree of low self-efficacy or perceived control. Somewhat oddly, the cognitive-social adjustment factor has a positive correlation with active coping, which in turn has a negative correlation with depression. The larger correlation with active coping than with depression suggests these cognitive-social adjustment elements may be linked to behaviours and a positive attitude. Factors were largely independent, as inter-correlations were not large. Research with larger sample sizes could explore any mediation or moderation between these variable to provide more detail in the way in which adjustment processes inter-relate.

Construct validity hypotheses were not all upheld. Relationship to depression scores were largely as predicted. Active coping was lower in women, contrary to the hypothesis. This difference was small and replication is required with detailed analysis of the role of other potentially confounding factors such as

education and religion. Neither age nor SES were related to coping. This may reflect differences in adjustment in relation to the social-cultural situation, with lower SES overall than perhaps included in other, Western based studies and the potential effect of time since diagnosis complicating the relationship between age and adjustment.

This study has several limitations. Adjustment may be different in nature to people who are not on ART. No measure of time since diagnosis was included. Further research should explore these issues. The MAHIV items were derived from research with Western samples. It may be that there are local understandings of adjustment and relevant factors that were not included. Qualitative research may provide candidate items to create a specific, locally focused measure of HIV adjustment. Nonetheless, the use of generic items facilitates comparisons of adjustment cross-culturally. The MAHIV items do not include areas that may be theoretically relevant to adjustment. The MAHIV includes no clear items accessing perceived meaning in illness or process relating to social and occupational adjustment. Finding meaning, gaining control and restoring self-esteem are core elements of cognitive adjustment (Taylor, 1983), which are not clearly addressed by these items.

In conclusion, analysis revealed four factors, reflecting three adjustment processes and one outcome factor. MAHIV usefully separates process from outcome. This version of the scale has good internal consistency and some evidence of reliability. Further research should continue to address the need to separate process of adjustment from outcomes of adjustment through the development of measures that are theoretically grounded.

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Table 1 Items excluded from analysis

Item number	Item	Factor for MAHIV Ross et al (Ross et al., 1994) version
3	I feel that problems with my health prevent me from planning ahead	Denial-avoidance
10	I have been doing things that I believe will improve my health - exercise	Belief in influencing course of disease
20	I am determined to put it all behind me	Fighting spirit
23	I am not very hopeful about the future	Helplessness-hopelessness
27	Other people worry about me more than I do	Helplessness-hopelessness
33	I avoid finding out more about HIV	Denial-avoidance
35	I feel fatalistic about my illness	Helplessness-hopelessness
36	I feel completely at a loss about what to do	Helplessness-hopelessness

Table 2 Factor structure of Luganda MAHIV

Ross factor	Item number	Item	1	2	3	4	Factor
Belief	1	I have been doing things that I believe will improve my health – diet	.484				1 = Active coping % Variance 12.4 Alpha 0.775
Belief	4	I believe that my positive attitude benefit my health	.559			-.348	
Belief	6	I firmly believe that I will get better	.515				
Fight	13	I have plans for the future	.544				
Belief	16	I think my state of mind can make a lot of difference to my health	.635				
Fight	18	I try to carry on life as I've always done	.551				
Fatalism	29	I am trying to get as much information as I can about HIV	.682				
Fight	31	I try to have a very positive attitude	.594				
Fight	32	I keep busy so I don't think about it	.500				
Fatalism	8	I've left it all to my doctors		.589			2 = Cognitive-social adjustment % Variance 11.8
Belief	11	Since my diagnosis I now realise how precious life is and I'm making the most of it	.341	.608			
Belief	12	I've put myself in the hands of God		.815			
Fatalism	15	I've had a good life, what I have now is a blessing	.300	.688			

Fatalism	19	I would like to make contact with others in a similar situation		.682			Alpha 0.776
Fatalism	28	I think of other people who are worse off		.563			
Fight	39	I try to count my blessings		.609			
Helpless	9	I feel that life is hopeless *			.486		3 = Hopelessness
Helpless	14	I worry about HIV getting worse*			.649		
Helpless	22	I suffer great anxiety*			.783		
Helpless	25	I feel like giving up*			.575		% Variance
Fight	34	I see my illness is as a challenge*			.631		11.4
Helpless	37	I feel angry about what has happened to me*			.728		Alpha = 0.763
Denial	2	I feel that I can't do anything to cheer myself up*				.720	4 = Denial / avoidance
Belief	5	I don't dwell on my illness				.440	
Fatalism	7	I feel that nothing I do will make a difference*				.790	
Helpless	17	I feel that there is nothing I can do to help myself*			.322	.658	10.5
Helpless	30	I feel that I can't control what is happening*			.369	.579	Alpha = 0.739
Denial	38	I really don't believe my HIV test result*				.481	

* These items are all reversed scored.

Table 3 Correlations between MAHIV factors

Factor	1	2	3	4
1	-	0.303**	0.310**	0.400**
2		-	0.006, p=0.924, n.s.	0.160*, p=0.009
3			-	0.464**
4				-

* p<0.01, **p<0.001