**The Adolescent HIV Disclosure Cognition and Affect Scale: preliminary reliability and validity**

**Michael Evangeli MA, MSc, ClinPsyD1**

1 Department of Psychology, Royal Holloway University of London, TW20 0EX, UK. Tel: 00441784443851. Email: [michael.evangeli@rhul.ac.uk](mailto:michael.evangeli@rhul.ac.uk)

Correspondence to: Dr Michael Evangeli. Department of Psychology, Royal Holloway University of London, TW20 0EX, UK. Email: [michael.evangeli@rhul.ac.uk](mailto:michael.evangeli@rhul.ac.uk)

**Acknowledgements**

This work was supported by ViiV Healthcare UK (UK/HIV/0102/14s). The Author would like to thank the UK Children’s HIV Association (CHIVA), particularly Amanda Ely, and Irina Lut for help with this project. The author would also like to acknowledge the assistance of the Collaborative HIV Paediatric Study (CHIPS) Steering Committee for enabling access to data and to Lindsay Thompson for CHIPS data linkage and the provision of summary data.

**Abstract**

***Objectives:*** Globally, there are 2 million HIV positive 10 to 19 year-olds**.** One challenge for this population is sharing their HIV status with others (onward HIV disclosure). There are no multi-item, multi-dimensional scales of HIV disclosure cognitions and affect for young people living with HIV.

***Methods:*** An18-item measure of HIV disclosure cognition and affect was developed, administered to 65 adolescents living with HIV (aged 12 to 16 years). Data was explored using principal component analysis and preliminary construct and criterion validity assessed.

***Results:*** Three factors were revealed: negative disclosure attitudes and feelings, self-efficacy, and positive disclosure attitudes and feelings. The full scale and its subscales were internally consistent. The total score showed statistically significant positive relationships with HIV disclosure in the last six months, HIV disclosure intention and self-perception.

***Conclusions:*** Preliminary evidence of the measure’s good psychometric properties suggests it may be helpful in future clinical and research work.

**Key words: HIV/AIDS; adolescents; coping; adjustment.Introduction**

Globally, there are 2 million HIV positive 10 to 19 year-olds ([WHO, 2014](#_ENREF_46)). This population comprises both young people with perinatally acquired HIV (PAH) and behaviourally acquired HIV (BAH), and face many challenges including adhering to complex medication regimes, managing HIV stigma, and developing intimate relationships whilst minimising onward HIV transmission risk. One particular challenge is sharing one’s HIV status with others (onward HIV disclosure).

Onward HIV disclosure across HIV-positive populations has a number of potentially positive consequences. HIV partner disclosure can reduce unprotected sexual activity, partly through greater condom negotiation and use ([Hightow-Weidman et al., 2013](#_ENREF_19); [King et al., 2008](#_ENREF_25); [Pinkerton & Galletly, 2007](#_ENREF_34)), and can facilitate partner HIV testing ([King et al., 2008](#_ENREF_25)). Sharing one’s status can improve engagement in care ([King et al., 2008](#_ENREF_25); [Spangler, Onono, Bukusi, Cohen, & Turan, 2014](#_ENREF_41)), and help in initiating and adhering to antiretroviral (ART) treatment ([Ekama et al., 2012](#_ENREF_11)), through the availability of disclosure-specific support or reduced hiding of medication from others ([Calabrese et al., 2012](#_ENREF_8)). There may also be psychological benefits to HIV status sharing. Well-being may be enhanced (although evidence is equivocal ([Kittner et al., 2014](#_ENREF_26))), through increased social support ([Smith, Rossetto, & Peterson, 2008](#_ENREF_40)), the development of more helpful cognitive appraisal of HIV-related stressors and enhanced self-esteem ([Quinn & Chaudoir, 2009](#_ENREF_36); [Vyavaharkar et al., 2011](#_ENREF_43)). HIV disclosure may reduce general anxiety levels, although again, evidence is equivocal ([King et al., 2008](#_ENREF_25); [Kittner et al., 2014](#_ENREF_26)). Finally, thoughts about sharing one’s status may be associated with considerable anxiety that could impact on social and psychological functioning ([Evangeli & Wroe, 2016](#_ENREF_14)).

Studies have reported low rates of onward HIV disclosure to any recipient in young people with PAH ([Lee & Oberdorfer, 2009](#_ENREF_27)), and low rates of onward disclosure to partners ([Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009](#_ENREF_5); [Mbalinda, Kiwanuka, Eriksson, Wanyenze, & Kaye, 2015](#_ENREF_31); [Tassiopoulos et al., 2013](#_ENREF_42); [Weintraub et al., 2016](#_ENREF_44)), and peers ([Nostlinger, Bakeera-Kitaka, Buyze, Loos, & Buve, 2015](#_ENREF_33)) in this population. In addition, lower rates of onward disclosure have been reported in young people with PAH compared with behaviourally infected young people ([Abramowitz et al., 2009](#_ENREF_2)).

Qualitative studies have revealed the subjective difficulty of disclosing one’s HIV-positive status to others, particularly to partners. Themes from in-depth interviews from young people with PAH include a fear of negative responses from others, a lack of disclosure self-efficacy, a fear that the disclosure recipient will tell others and the importance of parental attitudes towards onward disclosure ([Hogwood, Campbell, & Butler, 2013](#_ENREF_20); [Marhefka et al., 2011](#_ENREF_30)).

The qualitative literature on onward HIV disclosure in adolescents and young adults living with HIV is only complimented by a small quantitative literature on potential determinants of onward HIV disclosure ([Weintraub et al., 2016](#_ENREF_44)). This may be partly due to the absence of reliable and valid multi-item, multi-dimensional scales of HIV disclosure cognitions and affect in HIV-positive populations more generally. Ideally such a scale would contain items that covered constructs contained in theories that have been applied to HIV disclosure. For example, the Theory of Planned Behavior ([Ajzen, 2011](#_ENREF_3)), recently used in a study of paediatric HIV disclosure ([Jemmott et al., 2014](#_ENREF_23)), emphasises the importance of HIV disclosure attitudes (evaluation of the expected outcome of disclosure), subjective norms (perceived social pressure to disclose), and perceived behavioural control (subjective sense of control over disclosure, closely related to the concept of self-efficacy). The tendency in the literature has been to use single item or very short scales (≤ 5 items) to measure each construct separately ([Abler et al., 2015](#_ENREF_1); [Greene, Carpenter, Catona, & Magsamen-Conrad, 2013](#_ENREF_17); [Holmes & Shea, 1997](#_ENREF_21); [Nostlinger et al., 2015](#_ENREF_33); [Semple, Patterson, Shaw, Pedlow, & Grant, 1999](#_ENREF_39)). Shorter scales are likely to be less reliable and valid than longer scales (which are better able to capture the complexity of psychological constructs). The use of multidimensional scales of the psychological determinants of HIV disclosure is consistent with theoretical models suggesting distinct but related components to HIV disclosure decision-making ([Evangeli & Kagee, 2016](#_ENREF_13)).

One study reports the development of two longer scales (47 items in total) to examine reasons for past disclosure and non-disclosure ([Derlega, Winstead, Greene, Serovich, & Elwood, 2002](#_ENREF_10)) in adults living with HIV. These scales, however, neither assessed current cognitions and affect, nor measured normative beliefs or disclosure self-efficacy. Two recent studies assessed attitudes (14 items), self-efficacy (3 items) and intention towards disclosure to sexual partners (14 items) in HIV-positive men who have sex with men (MSM: mean age 42 years) ([M. J. Brown, Serovich, Kimberly, & Umasabor-Bubu, 2015](#_ENREF_7); [Hu, Serovich, Chen, Brown, & Kimberly, 2016](#_ENREF_22)). The authors used multi-item scales, which showed good psychometric properties. A single multi-dimensional scale was not developed, however, and neither HIV disclosure outcome expectancies nor HIV disclosure affect were assessed.

In sum, there have been few attempts to construct multi item scales of HIV disclosure determinants, with the most comprehensive efforts taking place in adult MSM populations. There have been no attempts to construct *multidimensional* scales of HIV disclosure and there are no existing measures specifically designed for adolescents living with HIV (many of whom will be living with PAH). There may be a number of additional HIV disclosure issues that affect adolescents with PAH compared with their behaviourally infected counterparts. These include: having to consider HIV partner disclosure from the onset of sexual relationships, concerns about revealing their mother’s HIV positive status, and the effect of negative parental attitudes towards disclosure ([Evangeli & Foster, 2014](#_ENREF_12)).

The development of a brief, reliable and valid multi-item, multi-dimensional measure of HIV disclosure cognition and affect for adolescents living with HIV may help in the development or assessment of interventions that aim to reduce HIV disclosure anxiety ([Evangeli & Wroe, 2016](#_ENREF_14)) or enhance HIV disclosure decision-making and HIV disclosure rates in this population (by focussing on factors such as HIV disclosure self-efficacy). A measure with good psychometric properties could also help in future observational studies that aim to characterise HIV disclosure determinants and their relation to HIV disclosure behaviour.

This study aimed to develop a brief, multi-dimensional measure of HIV disclosure cognition and affect specifically for adolescents with PAH, aged 12 to 16 years of age. This age range characterises a period where those living with PAH will be likely to know they have been diagnosed with HIV([WHO, 2011](#_ENREF_45)) but may not have shared their status with others. As this developmental stage is one where sexual onset may not have occurred for some, we sought to construct a measure that assessed HIV disclosure thoughts and feelings to *any* other person (rather than just to partners, for example). We based on our measure on the Theory of Planned Behavior ([Ajzen, 2011](#_ENREF_3)) as this is one of the few theories applied to HIV disclosure that has emphasised the importance of self-efficacy ([Evangeli & Kagee, 2016](#_ENREF_13)). Self-efficacy has been frequently highlighted as a key determinant of successful action across behavioural domains ([Bandura, 1986](#_ENREF_4)). We hypothesised that higher scores on a reliable measure of HIV disclosure affect and cognition (e.g., more positive HIV disclosure attitudes) would be related to higher rates of HIV disclosure intention and HIV disclosure behaviour.

**Methods**

**Participants**

The potentially eligible sample were 77 adolescents (aged 12 to 16 years) living with HIV attending a UK residential intervention for children living with HIV. The intervention was a week-long intensive peer engagement support camp with individual emotional support provided by professional staff; participatory HIV knowledge and understanding workshops; and creative and performing arts workshops encouraging expression of experiences of growing up with HIV. Peer support was provided by older peers with HIV. The intervention was offered all 12-16 year olds living with HIV in the UK and all of the young people who wished to attend were offered a place.

Sixty five young people consented to take part in the study (84% response rate). Demographic and clinical characteristics, obtained directly from participants and from the Collaborative HIV Paediatric Study (CHIPS) database ([Judd et al., 2007](#_ENREF_24)), are presented in Table 1.

**Table 1 here**

**Ethics**

Ethical approval was obtained through the Royal Holloway University of London Psychology Department Ethics Committee (2015/052). Approval to use data from the CHIPS database was obtained from the CHIPS Steering Committee, with participant identifiers allowing anonymous linkage of data for each individual.

**Procedure**

The *item generation phase* involved reviewing measures used in studies assessing HIV disclosure in HIV-positive populations. In addition, the author (a clinical psychologist with extensive clinical and research experience focussing on HIV disclosure issues) and a senior member of the UK Children’s HIV Association’s (CHIVA) staff (with extensive experience as a social worker and provider of services to young people living with HIV) generated questions using the Theory of Planned Behavior ([Ajzen, 2011](#_ENREF_3)) as a guide. In addition, members of the CHIVA Youth Committee (young people living with HIV) were asked to suggest items and areas for questions to be developed. A list of potential items was developed and feedback from members of the CHIVA Youth Committee was sought during the *piloting phase*. Piloting involved asking whether questions were clear, understandable, and relevant. The list of items was redrafted based on this feedback, in addition to considering whether any items were redundant. The *administration phase* took place at the start of the intervention, in August 2015, before any intervention activities had taken place. Parental consent was obtained prior to written informed consent/assent from the young people. The draft measure (and additional measures) was administered in paper and pencil form, face to face. Information was collected directly with participants on date of birth, gender and country of birth. Participants were not financially compensated for completing the measures. The *reliability phase* involved the use of Principal Components Analysis and examination of internal consistency of the measure and its subscales.

The *validation phase* involved exploring the relationship between the measure and variables expected to be related to HIV disclosure cognitions and affect (all asked at the same time as the draft measure was administered, except for HIV disclosure occurrence at 6 month follow-up in February 2016). These were:

1. HIV disclosure occurrence at baseline and six month follow-up, “*Have you told any people that you are HIV positive in the last 6 months who didn’t know beforehand?”* It was anticipated that pro-disclosure cognitions and affect would be related to HIV disclosure occurrence at baseline and six month follow-up (versus non-occurrence).
2. HIV disclosure intention, “*How much do you agree with the following statement about telling people who do not know your status that you are HIV positive: “I intend to tell someone new about my HIV status in the next 6 months.”* Responses were on a 5 point likert scale*: strongly disagree* to *strongly agree.* It was anticipated that pro-disclosure cognitions and affect would be related to higher levels of HIV disclosure intention.
3. HIV stigma ([Wiklander et al., 2013](#_ENREF_47)). Seven items from the preliminary version of the *HIV stigma scale for children (HSSC-12)* ([Wiklander et al., 2013](#_ENREF_47))were used. The questions assessed HIV disclosure concerns, concerns with public attitudes about HIV and personalized stigma. An example item was, “*I have lost friends by telling them I have HIV*”. The minimum score was 7 with a maximum score of 28 (α=0.71). Response options were on a 4-point likert scale from “*strongly disagree*” to “*strongly agree*”. It was anticipated that pro-disclosure cognitions and affect would be related to lower levels of HIV stigma.
4. Quality of Life. The *KIDSCREEN-10* index *(*[Ravens-Sieberer et al., 2007](#_ENREF_37))was used. This measure assesses physical and psychological well-being, autonomy and parent relation, social support and school environment within the last week (minimum score 10, maximum score 50). An example item *was, “Thinking about the last week…Have you felt sad?”* Response options were on a 5-point likert scale from “*never*” to “*always*” (α=0.82). It was anticipated that pro-disclosure cognitions and affect would be related to higher levels of quality of life.
5. General health. A single question from the *KIDSCREEN-10* index *(*[Ravens-Sieberer et al., 2007](#_ENREF_37))was used: “*In general how would you say your health is?”* The response option was on a 5-point likert scale from “*excellent*” to “*poor*”. It was anticipated that pro-disclosure cognitions and affect would be related to better general health.
6. Self-perception. The 5 item self-perception subscale from KIDSCREEN – 52 (minimum score 5, maximum score 25) was administered ([Ravens-Sieberer et al., 2005](#_ENREF_38)). An example item was, “*Have you been happy with the way you are?*” Response options were on a 5-point likert scale from “*never*” to “*always*” (α=0.76). It was anticipated that pro-disclosure cognitions and affect would be related to higher levels of self-perception.

**Analysis**

Analysis used SPSS 21. The distribution of missing data was assessed with Little’s Missing Completely at Random Test ([Little, 1988](#_ENREF_28)) before using Expectation Maximisation to impute missing data. Principal Components Analysis (PCA) was then carried out using both orthogonal (varimax) and oblique (oblimin) rotations. Scree plots were examined to determine the number of factors to extract and analyses were re-run specifying the number of factors. Items were dropped from the scale if their factor loading was low or if they loaded on more than one factor. If any items were dropped, PCA was re-run. Cronbach’s alpha was calculated for the final total scale and its subscales and item-total correlations were examined. The relationship between the final measure and subscale total scores and other variables was assessed using independent t tests (for HIV disclosure occurrence in the 6 months prior to baseline), with bootstrapped confidence intervals (for HIV disclosure occurrence at 6 month follow-up, given the reduced sample size at this data point), and Pearson’s correlations (for HIV disclosure intention, HIV stigma, general health, self-perception and Quality of life) with bootstrapped confidence intervals where parametric assumptions were not met. Two tailed tests were used.

**Results**

**Item generation, piloting and administration**

The item generation phase produced 28 items (12 disclosure attitudes, 11 disclosure self-efficacy, three normative belief and two affect). These were derived and adapted from a number of published sources ([Derlega et al., 2002](#_ENREF_10); [Holmes & Shea, 1997](#_ENREF_21); [Murphy, Armistead, Marelich, Payne, & Herbeck, 2011](#_ENREF_32); [Semple et al., 1999](#_ENREF_39); [Wiklander et al., 2013](#_ENREF_47)) as well as generated by the author and research team, and the CHIVA YC. Feedback during the piloting phase resulted in seven items being dropped (four self-efficacy, two attitude, one normative belief), most commonly due to the *perceived* similarity of meanings between items (e.g., predicting feeling *better* and *less anxious* was reduced to a single item, “*I will feel better”).* For each item on the resulting 21 item measure, participants were asked. “*How much do you agree with the following statement about telling people who do not know your status that you are HIV-positive*?” Responses were on a five-point likert scalefrom *strongly disagree* to *strongly agree* to allow for a range of responses.The measure consisted of: ten attitude items (six negatively phrased and reverse scored, to minimise the possibility of response sets), for example, *“People will support me”;* two normative belief items, for example, “*Most people in my situation would not tell other people that they’re HIV positive”*; two affect items, for example, *“I am afraid to tell others that I’m HIV positive”*; and seven self-efficacy items, for example, *“I am confident that I can find the right words to say if I share my HIV status with others”* Questions were written in either the present or future tense. Scores on each item were added to produce a total score. Higher total scores indicated more pro-disclosure cognitions and affect.

**Principal Component Analysis and reliability**

There was minimal missing data (1.1%), which was missing at random. Thus Elaboration Maximisation was appropriate to use. Once this data had been imputed, PCA was carried out. PCA was used instead of Factor Analysis as this is more appropriate for a novel measure with no existing empirical theory about the structure of relationships between items ([J. D. Brown, 1999](#_ENREF_6)).

Extraction based on the point of inflexion in the scree plot suggested either a three or factor solution (see Figure 1 for final scree plot).

**Figure 1 here**

A four factor solution was attempted, despite the relatively small size of the fourth factor (eigenvalue on the original 21 item scale, 1.31; 6.21% variance explained). The majority of items on the fourth factor, however, were also loaded on other factors. PCA was, therefore, re-run specifying the extraction of three factors. This process led to three items being dropped from the measure, two due to low factor loadings, and one due to loading on more than one factor. The final 18-item measure (minimum score 18, maximum score 90) consisted of eight items loading on the first factor, six items loading on the second factor and four items loading on the third factor. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (0.693) and Barlett’s Test of Sphericity (p<0.001) were both acceptable ([Field, 2013](#_ENREF_15)). Both orthogonal (varimax) and oblique (oblimin) produced the same factor solution. The measure had a Flesch-Kincaid reading ease score of 90.5 (easily understood by an average 11 year-old student). Table 2 shows the factor loadings for all items (those >0.4 displayed).

**Table 2 here**

Cronbach’s alpha for the overall measure was very good (α=0.79), with subscale alphas all very good or excellent (factor 1, α=0.88; factor 2, α=0.89; factor 3, α=0.78).

**Factor interpretation**

Factor 1 was labelled *negative disclosure attitudes and feelings.* Example items included, “*People will reject or judge me”*. Factor 2 was labelled *self-efficacy.* Example items included, *“I am confident that I can get support from others if I tell them about my HIV status”.*  Factor 3 was labelled *positive disclosure attitudes and feelings.* Example items included, *“I will feel better.”*

**Validity**

Regarding criterion-related validity, those young people who had disclosed their HIV status to anyone in the previous six months at baseline had a higher total score (mean 61.40, sd 9.63) than those who had not disclosed their status (mean 55.66, sd 9.75) (t(63)=2.05, p=0.05, d=0.59, 95% CI 0.01 -1.16) reflecting a medium sized effect. There were no statistically significant differences between those participants who had previously disclosed their HIV status and subscale total scores.

Forty seven of the original sample of 65 (72%) completed a six month follow-up assessment of HIV disclosure behaviour in the previous six months. Those young people who had disclosed their HIV status to anyone in the previous six months at follow-up had a higher total score on the measure at baseline (mean 61.66, sd 7.94) than those who had not disclosed their status at follow-up (mean 55.76, sd 9.39). This difference, 5.90, BCa 95% CI (-1.10 – 11.87), was not significant, (t(45)=1.46, p=0.15, d=0.64, 95% CI -0.23 - 1.50), but represented a medium sized effect. There were no statistically significant differences between HIV disclosure in the previous six months at follow-up and subscale total scores.

There was a positive statistically significant relationship between the total score and HIV disclosure intention (r (63) = 0.28, 95% CI 0.04-0.49, p=0.02) with a medium effect size. There was also a positive statistically significant relationship between scores on subscale three (higher levels of positive disclosure attitudes and feelings) and HIV disclosure intention (r(63) =0.31, 95%BCa CI 0.05-0.56, p=0.01) reflecting a medium sized effect. There were no statistically significant relationships between subscales one and two and HIV disclosure intention.

Regarding construct validity, the relationship between total score and HIV stigma was not statistically significant (r (59) =-0.17, 95% CI -0.4-0.09, p=0.20) representing a small to medium effect. There was a statistically significant relationship between lower scores on subscale one (more negative disclosure attitudes and feelings) and higher levels of HIV stigma (r (59) = -0.32, 95% CI -0.53 - -0.08, p=0.01) representing a medium sized effect. There was a statistically significant relationship between higher scores on subscale three (more positive disclosure attitudes and feelings) and higher levels of HIV stigma (r (59) = 0.35, 95 BCa CI 0.08 – 0.57, p=0.01) representing a medium effect size. There was no relationship between subscale two and HIV stigma.

The relationship between the total score and quality of life was not statistically significant (r (57) = 0.18, 95% CI -0.08 – 0.42, p=0.18) with a small to medium effect, and there were no significant relationships between any of the subscales and quality of life. There was, however, a statistically significant relationship between total score and self-perception (r (56) = 0.36, 95% CI 0.11 – 0.57, p=0.01) with a medium effect size. The only significant relationship between any of the subscales and self-perception involved subscale one. Lower levels of negative disclosure attitudes and feelings was associated with higher level of self-perception (r (56) = 0.37, 95% CI 0.12-0.57, p<0.01), a medium sized effect. The relationship between the total score and general health was not statistically significant (r (43) =0.11, 95% CI -0.19 – 0.39, p=0.48) representing a small effect. There were no significant relationships between any of the subscales and general health.

**Discussion**

This study developed a measure of HIV disclosure cognitions and affect for adolescents living with PAH that shows promising evidence of reliability. Three factors were extracted representing negative disclosure attitudes and feelings, disclosure self-efficacy, and positive disclosure attitudes and feelings. The separation of attitudes and self-efficacy (closely related to the constructs of perceived behavioural control or behavioural skills) was broadly consistent with health behaviour models that have been applied to HIV-related behaviours ([Ajzen, 2011](#_ENREF_3); [Fisher, Fisher, Amico, & Harman, 2006](#_ENREF_16)). The separation of negative and positive disclosure cognitions and affect, however, does not support existing models. In addition, the inclusion of normative and affect items within the negative attitudes and feelings factor suggests that a clear separation between attitudes, normative beliefs and affect may not be present in this population.

Some promising *preliminary* evidence of the construct and criterion-related validity of the scale was found. As expected, pro-disclosure cognitions and affect were related to both past disclosure (suggesting that these experiences may have been positive) and disclosure intention. The latter is important as it suggests a causal chain between disclosure cognition and affect, disclosure intention and actual disclosure. The relationship between the scale and HIV disclosure in the following six months did not reach statistical significance, although this may have been due to the small sample size as there was a medium effect size for this relationship.

A positive relationship was also found between the measure and more positive self-perception. The subscale correlational analysis suggests that those young people who felt better about themselves held more positive attitudes and experienced more positive feelings about HIV disclosure. The relationship between the overall measure and HIV stigma was weak. There were, however, interesting statistically significant relationships between individual subscales and HIV stigma, with differing directions of associations with positive and negative disclosure attitudes and feelings. The relationship between higher levels of HIV stigma and more positive disclosure attitudes and feelings was unexpected. This may reflect participants’ ambivalence about sharing their status, with beliefs about positive responses to disclosure from some recipients co-existing with beliefs about stigmatizing response from others. There may have been some measurement error, though, associated with the use of the HIV stigma scale that was adapted for the current study and failed to measure all components of HIV stigma (particularly internalised stigma).

The relationships between both general health and a short measure of quality of life, and the measure, were weak. It may that the other variables assessed (disclosure occurrence, disclosure intention and self-perception) are more likely to be causally related to HIV disclosure cognitions and affect than broader constructs such as quality of life and general health.

Given the absence of a multi-item, multi-dimensional scale (in any HIV-positive population), the measure is an important addition to the literature. The measure is comprehensive (covering both cognition and affect), brief (18 items), at an appropriate level of complexity for the target population, and potentially adaptable to other HIV-positive populations. In addition, the measure shows preliminary evidence of good psychometric properties, despite the relatively small sample size, which may have limited statistical power. In relation to the sample size it has been shown that if a factor has four or more loadings greater than 0.6, it is reliable regardless of sample size ([Guadagnoli & Velicer, 1988](#_ENREF_18)). The current scale met this criterion. In addition, the fact that the mean communalities were above 0.6 in this study may justify a sample size of less than 100 ([MacCallum, Widaman, Zhang, & Hong, 1999](#_ENREF_29)). Finally, the fact that both the Kaiser-Mayer-Olkin measure of sampling adequacy was well within the acceptable range ([Field, 2013](#_ENREF_15)), and the presence of statistically significant relationships between the overall measure and disclosure behaviour, disclosure intention, and self-perception, suggests that the sample size was satisfactory for the majority of aims of this study.

In relation to limitations, it is not possible to determine whether disclosure affect and cognitions for young people living with PAH attending this residential intervention differ from the broader population from which they were drawn. Demographic and clinical characteristics were, however, consistent with national data ([CHIPS, 2015](#_ENREF_9)). The measure only focused on direct disclosure (the person living with HIV sharing their status with others) rather than cognitions and affect relating to indirect disclosure (somebody else revealing the HIV-positive person’s status to others), or guessed disclosure (others concluding that the person living with HIV is HIV-positive) ([Preau et al., 2015](#_ENREF_35)). In an attempt to maintain brevity and to comprehensively assess central constructs such as HIV disclosure attitudes and self-efficacy, some aspects were not assessed (e.g., preparedness to disclose and satisfaction with current level of disclosure). Finally, the measure assessed disclosure thoughts and feelings to *any* recipient rather than to partners, friends or family. This produced a more generally applicable scale that can be administered to adolescents living with HIV regardless of their relationship status. Young people living with HIV may, however, hold different beliefs and have different feelings relating to disclosure dependent on the recipient. This possibility could be tested by adapting the wording of the measure for specific recipients, although it will be important to assess the reliability and validity of the scale under these altered conditions. In addition, further work in developing the measure could involve a cognitive interviewing stage where participants are asked which recipient they have in mind when responding to the items. Future studies should assess the psychometric properties of the scale on larger samples of young people with perinatally acquired HIV. The measure may need to be adapted to be suitable for use with related populations (e.g., behaviourally infected young people) and both translated and adapted for use in in resource limited countries with a greater prevalence of young people living with PAH. Validity could be established more comprehensively for the measure as a whole and its subscales. For example, the ability of scores on the scale to predict future HIV disclosure could be assessed with a larger sample.

**Implications for Paediatric Psychology Research and Practice**

The existence of an HIV disclosure cognitions and affect scale may allow for theoretical models of HIV disclosure to be tested and refined. It may also be clinically useful when an in-depth assessment of HIV disclosure determinants is required as part of therapeutic work with young people living with HIV, for example, when there is considerable anxiety about sharing one’s status that is impacting on functioning ([Evangeli & Wroe, 2016](#_ENREF_14)). The measure may also help in the development of testing of future interventions to enhance HIV disclosure in young people living with HIV ([Evangeli & Foster, 2014](#_ENREF_12)). For example, the close relationship between the measure and disclosure occurrence, disclosure intention and self-perception, suggests that positive and negative disclosure attitudes and feelings, and disclosure self-efficacy, could all be part of an intervention to enhance HIV disclosure rates or to increase the preparedness to disclose.**References**

Abler, L., Sikkema, K. J., Watt, M. H., Hansen, N. B., Wilson, P. A., & Kochman, A. (2015). Depression and HIV Serostatus Disclosure to Sexual Partners Among Newly HIV-Diagnosed Men Who Have Sex with Men. *AIDS Patient Care STDS, 29*(10), 550-558. doi: 10.1089/apc.2015.0122

Abramowitz, S., Koenig, L. J., Chandwani, S., Orban, L., Stein, R., Lagrange, R., & Barnes, W. (2009). Characterizing social support: global and specific social support experiences of HIV-infected youth. *AIDS Patient Care STDS, 23*(5), 323-330. doi: 10.1089/apc.2008.0194

Ajzen, I. (2011). The theory of planned behaviour: reactions and reflections. *Psychol Health, 26*(9), 1113-1127. doi: 10.1080/08870446.2011.613995

Bandura, A. . (1986). *Social foundations of thought and action: A social cognitive theory*. London: Engelwood Cliffs.

Birungi, H., Obare, F., Mugisha, J. F., Evelia, H., & Nyombi, J. (2009). Preventive service needs of young people perinatally infected with HIV in Uganda. *AIDS Care, 21*(6), 725-731. doi: 10.1080/09540120802511901

Brown, J. D. (1999). Principal components analysis and exploratory factor analysis: definitions, differences, and choices. *JALT Test Eval SIG Newsl, 13*, 26-30.

Brown, M. J., Serovich, J. M., Kimberly, J. A., & Umasabor-Bubu, O. (2015). Disclosure and Self-Efficacy Among HIV-Positive Men Who Have Sex with Men: A Comparison Between Older and Younger Adults. *AIDS Patient Care STDS, 29*(11), 625-633. doi: 10.1089/apc.2015.0133

Calabrese, S. K., Martin, S., Wolters, P. L., Toledo-Tamula, M. A., Brennan, T. L., & Wood, L. V. (2012). Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. *AIDS Care, 24*(9), 1092-1096. doi: 10.1080/09540121.2012.699670

CHIPS. (2015). Collaborative HIV Paediatric Study (CHIPS) Annual Report 2014-15. London.

Derlega, V. J., Winstead, B. A., Greene, K., Serovich, J., & Elwood, W. N. (2002). Perceived HIV-related Stigma and HIV Disclosure to Relationship Partners after Finding Out about the Seropositive Diagnosis. *J Health Psychol, 7*(4), 415-432. doi: 10.1177/1359105302007004330

Ekama, S. O., Herbertson, E. C., Addeh, E. J., Gab-Okafor, C. V., Onwujekwe, D. I., Tayo, F., & Ezechi, O. C. (2012). Pattern and determinants of antiretroviral drug adherence among Nigerian pregnant women. *J Pregnancy, 2012*, 851810. doi: 10.1155/2012/851810

Evangeli, M., & Foster, C. (2014). Who, then what? The need for interventions to help young people with perinatally acquired HIV disclose their HIV status to others. *Aids, 28*, S343-S346. doi: Doi 10.1097/Qad.0000000000000334

Evangeli, M., & Kagee, A. (2016). A model of caregiver paediatric HIV disclosure decision-making. *Psychol Health Med, 21*(3), 338-353. doi: 10.1080/13548506.2015.1058959

Evangeli, M., & Wroe, A. L. (2016). HIV Disclosure Anxiety: A Systematic Review and Theoretical Synthesis. *AIDS Behav*. doi: 10.1007/s10461-016-1453-3

Field, A. . (2013). *Discovering Statistics using IBM SPSS Statistics: 4th Edition*. London: Sage.

Fisher, J. D., Fisher, W. A., Amico, K. R., & Harman, J. J. (2006). An information-motivation-behavioral skills model of adherence to antiretroviral therapy. *Health Psychol, 25*(4), 462-473. doi: 10.1037/0278-6133.25.4.462

Greene, K., Carpenter, A., Catona, D., & Magsamen-Conrad, K. (2013). The Brief Disclosure Intervention (BDI): Facilitating African Americans' Disclosure of HIV. *Journal of Communication, 63*(1), 138-158.

Guadagnoli, E., & Velicer, W. F. (1988). Relation of sample size to the stability of component patterns. *Psychol Bull, 103*(2), 265-275.

Hightow-Weidman, L. B., Phillips, G., 2nd, Outlaw, A. Y., Wohl, A. R., Fields, S., Hildalgo, J., & LeGrand, S. (2013). Patterns of HIV disclosure and condom use among HIV-infected young racial/ethnic minority men who have sex with men. *AIDS Behav, 17*(1), 360-368. doi: 10.1007/s10461-012-0331-x

Hogwood, J., Campbell, T., & Butler, S. (2013). I wish I could tell you but I can't: adolescents with perinatally acquired HIV and their dilemmas around self-disclosure. *Clin Child Psychol Psychiatry, 18*(1), 44-60. doi: 10.1177/1359104511433195

Holmes, W. C., & Shea, J. A. (1997). Performance of a new, HIV/AIDS-targeted quality of life (HAT-QoL) instrument in asymptomatic seropositive individuals. *Qual Life Res, 6*(6), 561-571.

Hu, J., Serovich, J. M., Chen, Y. H., Brown, M. J., & Kimberly, J. A. (2016). Psychometric Evaluation of the HIV Disclosure Belief Scale: A Rasch Model Approach. *AIDS Behav*. doi: 10.1007/s10461-016-1478-7

Jemmott, J. B., 3rd, Heeren, G. A., Sidloyi, L., Marange, C. S., Tyler, J. C., & Ngwane, Z. (2014). Caregivers' intentions to disclose HIV diagnosis to children living with HIV in South Africa: a theory-based approach. *AIDS Behav, 18*(6), 1027-1036. doi: 10.1007/s10461-013-0672-0

Judd, A., Doerholt, K., Tookey, P. A., Sharland, M., Riordan, A., Menson, E., . . . Childhood. (2007). Morbidity, mortality, and response to treatment by children in the United Kingdom and Ireland with perinatally acquired HIV infection during 1996-2006: planning for teenage and adult care. *Clin Infect Dis, 45*(7), 918-924. doi: 10.1086/521167

King, R., Katuntu, D., Lifshay, J., Packel, L., Batamwita, R., Nakayiwa, S., . . . Bunnell, R. (2008). Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS Behav, 12*(2), 232-243. doi: 10.1007/s10461-007-9307-7

Kittner, J. M., Brokamp, F., Thomaidis, T., Schmidt, R. E., Wiltink, J., Galle, P. R., & Jager, B. (2014). Disclosure and Experienced Social Support are not Related to Anxiety or Depression in a German HIV Patient Cohort. *Infect Chemother, 46*(2), 77-83. doi: 10.3947/ic.2014.46.2.77

Lee, B., & Oberdorfer, P. (2009). Risk-taking behaviors among vertically HIV-infected adolescents in northern Thailand. *J Int Assoc Physicians AIDS Care (Chic), 8*(4), 221-228. doi: 10.1177/1545109709341082

Little, R. (1988). A Test of Missing Completely at Random for Multivariate Data with Missing Values. *Journal of the American Statistical Association, 83*(404), 1198-1202.

MacCallum, R. C., Widaman, K. F., Zhang, S. B., & Hong, S. H. (1999). Sample size in factor analysis. *Psychological Methods, 4*(1), 84-99. doi: Doi 10.1037/1082-989x.4.1.84

Marhefka, S. L., Valentin, C. R., Pinto, R. M., Demetriou, N., Wiznia, A., & Mellins, C. A. (2011). "I feel like I'm carrying a weapon." Information and motivations related to sexual risk among girls with perinatally acquired HIV. *AIDS Care, 23*(10), 1321-1328. doi: 10.1080/09540121.2010.532536

Mbalinda, S. N., Kiwanuka, N., Eriksson, L. E., Wanyenze, R. K., & Kaye, D. K. (2015). Correlates of ever had sex among perinatally HIV-infected adolescents in Uganda. *Reprod Health, 12*, 96. doi: 10.1186/s12978-015-0082-z

Murphy, D. A., Armistead, L., Marelich, W. D., Payne, D. L., & Herbeck, D. M. (2011). Pilot trial of a disclosure intervention for HIV+ mothers: the TRACK program. *J Consult Clin Psychol, 79*(2), 203-214. doi: 10.1037/a0022896

Nostlinger, C., Bakeera-Kitaka, S., Buyze, J., Loos, J., & Buve, A. (2015). Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. *AIDS Care, 27 Suppl 1*, 36-46. doi: 10.1080/09540121.2015.1051501

Pinkerton, S. D., & Galletly, C. L. (2007). Reducing HIV transmission risk by increasing serostatus disclosure: a mathematical modeling analysis. *AIDS Behav, 11*(5), 698-705. doi: 10.1007/s10461-006-9187-2

Preau, M., Beaulieu-Prevost, D., Henry, E., Bernier, A., Veillette-Bourbeau, L., & Otis, J. (2015). HIV serostatus disclosure: development and validation of indicators considering target and modality. Results from a community-based research in 5 countries. *Soc Sci Med, 146*, 137-146. doi: 10.1016/j.socscimed.2015.10.034

Quinn, D. M., & Chaudoir, S. R. (2009). Living With a Concealable Stigmatized Identity: The Impact of Anticipated Stigma, Centrality, Salience, and Cultural Stigma on Psychological Distress and Health. *Journal of Personality and Social Psychology, 97*(4), 634-651. doi: 10.1037/a0015815

Ravens-Sieberer, U., Auquier, P., Erhart, M., Gosch, A., Rajmil, L., Bruil, J., . . . European, Kidscreen Group. (2007). The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Qual Life Res, 16*(8), 1347-1356. doi: 10.1007/s11136-007-9240-2

Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Duer, W., . . . Kidscreen Group, E. (2005). KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert Rev Pharmacoecon Outcomes Res, 5*(3), 353-364. doi: 10.1586/14737167.5.3.353

Semple, S. J., Patterson, T. L., Shaw, W. S., Pedlow, C. T., & Grant, I. (1999). Disclosure of HIV seropositivity to sexual partners: An application of social cognitive theory. *Behavior Therapy, 30*(2), 223-237. doi: Doi 10.1016/S0005-7894(99)80005-7

Smith, R., Rossetto, K., & Peterson, B. L. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care, 20*(10), 1266-1275. doi: 10.1080/09540120801926977

Spangler, S. A., Onono, M., Bukusi, E. A., Cohen, C. R., & Turan, J. M. (2014). HIV-positive status disclosure and use of essential PMTCT and maternal health services in rural Kenya. *J Acquir Immune Defic Syndr, 67 Suppl 4*, S235-242. doi: 10.1097/QAI.0000000000000376

Tassiopoulos, K., Moscicki, A. B., Mellins, C., Kacanek, D., Malee, K., Allison, S., . . . Pediatric, H. I. V. Aids Cohort Study. (2013). Sexual risk behavior among youth with perinatal HIV infection in the United States: predictors and implications for intervention development. *Clin Infect Dis, 56*(2), 283-290. doi: 10.1093/cid/cis816

Vyavaharkar, M., Moneyham, L., Corwin, S., Tavakoli, A., Saunders, R., & Annang, L. (2011). HIV-disclosure, social support, and depression among HIV-infected African American women living in the rural southeastern United States. *AIDS Educ Prev, 23*(1), 78-90. doi: 10.1521/aeap.2011.23.1.78

Weintraub, A., Mellins, C. A., Warne, P., Dolezal, C., Elkington, K., Bucek, A., . . . Abrams, E. J. (2016). Patterns and Correlates of Serostatus Disclosure to Sexual Partners by Perinatally-Infected Adolescents and Young Adults. *AIDS Behav*. doi: 10.1007/s10461-016-1337-6

WHO. (2011). Guidelines on HIV disclosure counselling for children up to 12 years of age. Geneva: World Health Organisation.

WHO. (2014). Global update on the health sector response to HIV. Geneva: World Health Organisation.

Wiklander, M., Rydstrom, L. L., Ygge, B. M., Naver, L., Wettergren, L., & Eriksson, L. E. (2013). Psychometric properties of a short version of the HIV stigma scale, adapted for children with HIV infection. *Health and Quality of Life Outcomes, 11*. doi: Artn 195

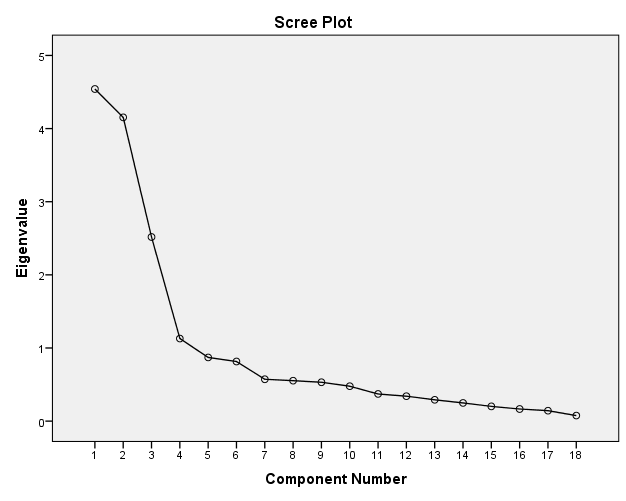
Doi 10.1186/1477-7525-11-195

|  |  |  |
| --- | --- | --- |
|  |  | Frequency (%) |
| Gender | Female  Male | 37 (57)  28 (43) |
|  |  |  |
| Age (in years) | 12  13  14  15  16 | 13 (20)  7 (11)  13 (20)  18 (28)  14 (22) |
|  |  |  |
| Region of birth | Africa  UK  Other Europe  Asia  Not specified | 34 (52)  26 (40)  2 (3)  2 (3)  1 (2) |
|  |  |  |
| Age at Naming/  Paediatric Disclosure  (in years) | <10  10-12  >12  Not specified | 17 (26)  37 (57)  8 (12)  3 (5) |
| Ethnicity | Black African/Black Caribbean  White/Mixed/Other  Missing | 46 (71)  14 (22)  5 (8) |
| CD4 count (mm3, n=58) | Median  IQR | 689  513-942 |
| Viral Load (copies/mL, n=52) | <50  >50 | 43  9 |
| Antiretroviral regimen (n=54) | **Nucleoside Reverse Transcriptase Inhibitors (**NRTIs) + Protease Inhibitor  2NRTI + Nevirapine  2NRTIs + Efavirenz  Other | 22 (41)  16 (30)  14 (26)  2 (4) |

**Table 1: Sample demographic and clinical characteristics (n=65)**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Factor | Item | Mean (SD) | Factor loading | | Eigenvalue | | | Variance % |
| 1 | I’m worried they will tell others. | 2.30 (1.28) | | 0.81 | | 4.54 | 25.22 | |
|  | People will reject me or judge me. | 2.88 (1.35) | | 0.78 | |  |  | |
|  | People will think negatively about my family. | 2.46(1.21) | | 0.78 | |  |  | |
|  | It will affect my relationship with them. | 2.44 (1.24) | | 0.76 | |  |  | |
|  | I am afraid to tell other people that I have HIV. | 2.42 (1.20) | | 0.75 | |  |  | |
|  | People will worry about me. | 2.57 (1.21) | | 0.70 | |  |  | |
|  | Most people in my situation would not tell other people that they’re HIV positive. | 2.46 (1.15) | | 0.68 | |  |  | |
|  | People will harm me. | 3.78 (1.05) | | 0.59 | |  |  | |
| 2 | I am confident that I can find the right words to say if I share my HIV status with others. | 3.45 (1.24) | | 0.89 | | 4.15 | 23.07 | |
|  | I am confident that I can tell the other person what I feel and what I need if I tell them I am HIV positive. | 3.52 (1.12) | | 0.88 | |  |  | |
|  | I am confident that I can choose the right time and place to share my HIV status with others. | 3.66 (1.20) | | 0.81 | |  |  | |
|  | I am confident that I can deal with how others respond if I share my HIV status with them. | 3.32 (1.23) | | 0.80 | |  |  | |
|  | I am confident that I can make the right choices about whom to share my HIV status. | 3.83 (1.10) | | 0.80 | |  |  | |
|  | I am confident that I can get support from others if I tell them about my HIV status. | 3.43 (1.09) | | 0.62 | |  |  | |
| 3 | I will feel better. | 3.69 (1.14) | | 0.82 | | 2.52 | 13.99 | |
|  | People will support me. | 3.81 (0.93) | | 0.81 | |  |  | |
|  | It is the right thing to do. | 3.24 (1.24) | | 0.78 | |  |  | |
|  | It will be easier to take my medication and look after my health. | 3.81 (1.16) | | 0.69 | |  |  | |

**Table 2: Summary of Principal Components Analysis for The Adolescent HIV Disclosure Cognition and Affect Scale**



**Figure 1: Scree plot for The Adolescent HIV Disclosure Cognition and Affect Scale**