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## **HIV-related stigma and health-related quality of life among children living with HIV in Sweden**

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## Abstract

The relationship between HIV-related stigma and health-related quality of life among children living with an HIV infection is unknown, although studies among adults with HIV infection suggest a negative relationship. The objectives of this study were to describe HIV-related stigma and health-related quality of life among children with perinatal HIV living in Sweden, and to investigate the relationship between these two factors in the same group. In a cross-sectional nationwide survey, HIV-related stigma was measured with the 8-item HIV Stigma Scale for Children forming three subscales and one general scale; higher scores indicate greater stigma. Health-related quality of life was measured with the 37-item DISABKIDS Chronic Generic Module, forming six subscales and a general scale; higher scores indicate better quality of life. Structural equation modeling was used to explore the relationship between HIV-related stigma and health-related quality of life. Fifty-eight children participated, age 9-18 years (mean 13.9); 94 % had non-European origin. The HIV stigma general scale showed a mean score of 17.6 (SD 5.0; possible range 8-32), with the highest mean subscale score for *disclosure concerns*. DISABKIDS Chronic Generic Module general scale showed a mean score of 80.7 (SD 14.1; possible range 0-100). HIV-related stigma was negatively associated with health-related quality of life (standardized  $\beta$  -0.790,  $p=0.017$ ). To conclude, children living with HIV in Sweden appear to rate their health-related quality of life similar to or better than those with other chronic conditions. However, the results also highlight that concerns related to disclosure of their HIV infection seem to be common which, together with the strong negative association shown between ratings of HIV-related stigma and HRQoL, indicate that disclosure concerns would be a relevant target for interventions to decrease HIV-related stigma and increase HRQoL in children living with HIV.

## Introduction

Approximately 3.3 million children are currently living with HIV around the world and the number is rising thanks to more effective and increasingly available combination antiretroviral therapy (cART) (WHO., 2013; Hogg et al., 2010). This situation poses new challenges, including issues related to growing up and becoming an adult living with HIV (Hazra., 2010), and may influence children's health related quality of life (HRQoL).

HIV is associated with stigmatization and discrimination among adults with HIV, which has been shown to have an impact on their HRQoL (Sayles., 2007; Vanable et al., 2006; Clark et al., 2003). Stigma related to HIV may delay help-seeking for health problems and lead to low treatment adherence (Weiss et al., 2006; Rao et al., 2012). HIV stigma can be expressed as *enacted*, *anticipated* and *internalized*. *Enacted* stigma refers to the experience of having been subjected to prejudice and discrimination from others, *anticipated* stigma to expectations of receiving such treatment from others, and *internalized* stigma as an internalization of negative beliefs towards individuals with HIV including oneself (Earnshaw & Chaudoir., 2009). There is limited research on the consequences and experiences of HIV-related stigma among children (Bhana., 2008).

HRQoL can be seen as a combination of well-being and good health (Helseth & Misvaer, 2010; WHO, 1948). Age and sex are factors that may influence HRQoL in children (Michel et al., 2009). It is known that children living with chronic conditions can have difficulties regarding physical activities, mental health and social relationships (Epstein et al., 2005; Bystrom et al., 2012; Hanberger et al., 2009; Ylimainen et al., 2010). Further, factors that influence children's HRQoL seem to be similar in different cultural contexts (Wee et al., 2006).

It is essential to understand how HIV-related stigma affects children living with HIV and their HRQoL in order to promote wellbeing, reduce the HIV-related stigma and improve their HRQoL (Deacon et al., 2005). Thus, the aims of this study were to describe the experience of HIV-related stigma and HRQoL among children with perinatal HIV infection living in Sweden, and to investigate the relationship between the two factors in the same group.

## Materials and Methods

### Study design

This is a cross-sectional nationwide study of children living with perinatal HIV infection in Sweden. Participants were recruited from all clinics (n=18) treating children with HIV in Sweden with the inclusion criteria: (1) having perinatal HIV; (2) having received care for HIV in Sweden for more than five years; (3) being 8-18 years old at the time of invitation to participate; (4) being informed about having HIV; (5) understanding and speaking Swedish. All HIV-infected children aged 8-18 years (n=107) who matched the inclusion criteria (n=82) were invited to participate and of these 71 % (n=58; 27 girls and 31 boys aged 9-18, mean 13.9, SD 2.5) agreed. The non-participants comprised 13 girls and 11 boys aged 8-18 years (mean 14.7, SD 3.5). The participants did not differ from non-participants with regard to age ( $t [80] 1.67, p 0.10$ ) or sex ( $\chi^2 [1, n=82] 0.39, p 0.53$ ).

### Data collection

Data collection was performed between October 2011 and November 2012. Prospective participants were informed about the study by a registered nurse or physician during a regular appointment at the clinic. Children who consented were asked to complete the study questionnaire at the clinic or take the questionnaire home and return it by mail. If the questionnaire was not returned within three weeks, the nurse reminded the participant twice.

### Measures

The 8-item HIV Stigma Scale for Children (HSSC-8) (Wiklander et al., 2013) was chosen to measure HIV-related stigma. The HSSC-8 is a sum scale and consists of eight statements forming one general HIV-related stigma scale and three dimension scales:

- 1) *disclosure concerns* (anticipated stigma), 2 items
- 2) *negative self-image* (internalized stigma), 3 items
- 3) *concerns with public attitudes* (anticipated stigma), 3 items.

Responses to each of the eight statements are rated on a 4-point Likert-type scale from “strongly disagree” (1) to “strongly agree” (4), with a possible range on the general scale between 8 and 32, where a higher score represents greater stigma. The responses to the items in each dimension are summed to give dimension scores; the possible range is 3-12 on the 3-item dimensions (*negative self-image* and *concerns with public attitudes*) and 2-8 on the 2-

item dimension (*disclosure concerns*). Non-responses to an item on the HSSC-8 were replaced by the median value of the responses of all participants to the items in the same dimension. We have previously shown that the HSSC-8 is internally consistent with an overall Cronbach's  $\alpha$  of 0.80 in the total scale,  $\alpha$  0.78 in the dimension of *negative self-image* and  $\alpha$  0.80 in the dimension of *concerns with public attitudes* (Wiklander et al., 2013). In the dimension of *disclosure concerns*, however, Cronbach's  $\alpha$  was 0.55, which is less than the generally accepted standard of 0.70 (Machin et al., 2007).

To measure HRQoL, the 37-item DISABKIDS Chronic Generic Module (DCGM-37) was used. The DCGM-37, was developed as part of the European DISABKIDS project (Bullinger et al., 2002). The DCGM-37 consists of 37 items assigned to six dimensions that report HRQoL characteristics related to chronic conditions in general. The dimensions in the DCGM-37 are: 1) *independence* (autonomy and living without impairments); 2) *physical limitations* (functional limitations, perceived health); 3) *emotions* (emotional worries and concerns); 4) *social exclusion* (feeling left out); 5) *social inclusion* (acceptance of others, positive relationships); 6) *treatment* (perceived emotional impact of treatment). The dimensions are hypothesized to measure mental, social, and physical domains of HRQoL and can also be combined to a general score. Each item is rated on a 5-point Likert-type scale ranging from 1 (never) to 5 (very often). For each dimension, scores are calculated and transferred to a scale from 0 (worst possible HRQoL) to 100 (best possible HRQoL) (Schmidt et al., 2006). Non-responses in a DCGM-37 dimension were replaced with the median value of the responses of the participant to the other items in the same dimension. In the current study, the Cronbach's  $\alpha$  coefficient was 0.92 for the total DCGM-37 scale. For the DCGM-37 dimension scales,  $\alpha$  was 0.83 for *independence*, 0.70 for *social exclusion*, 0.87 for *social inclusion* and 0.87 for *treatment*. Two of the dimensions – *emotions* ( $\alpha$  0.63) and *physical limitations* ( $\alpha$  0.68) – showed a lower Cronbach's  $\alpha$  than the original scale (Schmidt et al., 2006). The DCGM-37, containing background questions concerning age and sex, has been used in children with various conditions, both internationally and in Sweden (e.g. Schmidt et al., 2006; Af Sandeberg et al., 2008). To the best of our knowledge, this is the first time it has been used in children with HIV.

Three study-specific questions concerning disclosure about having HIV were developed. The questions covered whether the respondents had told anyone about having HIV and, if so, who. The phrasing of these questions was guided by the clinical experience of pediatricians and

pediatric nurses. Clinical characteristics and information about native country were obtained from the medical records of the participants.

## Data analyses

Statistical analyses were conducted with IBM SPSS and AMOS, version 22 (IBM Corp., Armonk, N.Y.). Descriptive analyses included calculation of means and standard deviations. Comparisons between participants and non-participants were calculated with the independent samples t-test for age and the  $\chi^2$ -test for sex. When analysing the material, we used structural equation modelling (SEM), an inclusive statistical approach for testing hypotheses about relationships among measured and latent variables (Blunch., 2013) to explore relationships between HIV-related stigma and HRQoL.

The latent variables used for the SEM were HRQoL as measured by dimensions in the DCGM-37 and HIV stigma as measured by dimensions in the HSSC-8. Measurement models representing relationships between stigma and HRQoL were estimated. In the SEM analysis, only five of the six DCGM-37 dimensions were used as manifest variables; the dimension *treatment* was not used because some participants were not receiving treatment. Treatment was instead used as an exogenous observed dichotomous variable (“medication”; treatment vs. no treatment). Age and sex were also represented as exogenous variables. The latent variable L1 in the model represents all omitted causes and any random or measurement error.

The fit of the model was evaluated by examining various statistics.  $\chi^2$  statistics were used to assess the magnitude of the discrepancy between the sample and fitted covariance matrices. A significant test indicates a poor fit (Blunch., 2013). The following goodness of fit indices were used to assess the model fit:

- Comparative fit index (CFI) – range from 0 (indicating poor fit) to 1 (indicating perfect fit); a value >0.90 indicates acceptable fit to the data (Blunch., 2013).
- Root mean square error of approximation (RMSEA) – range from 0 to 1; values in the range of 0.00 to 0.05 indicate close fit, those between 0.05 and 0.08 indicate fair fit, and those between 0.08 and 0.10 indicate mediocre fit. RMSEA values >0.10 indicate unacceptable fit (Blunch., 2013).
- The Tucker-Lewis index (TLI) – range from 0 to 1; values near 1 indicate a good fit (Blunch., 2013).

## Ethical considerations

The study was approved by the Regional Ethical Review Board of Stockholm, (2007/1530-31 and 2011/1120-32). Participants were provided with full details regarding the aims of the study and the procedure. All participants received written and oral information regarding confidentiality and the voluntariness of participation before signing informed consent. For children younger than 15 years, consent was also obtained from one of their legal guardians.

## Results

### Sample characteristics

The questionnaire was completed by 58 of 82 eligible children aged 9-18 years, of whom 50 were currently on cART. Of the 58 participating children, 34 had told someone about their HIV, 21 had not told anyone and three did not respond to the question. The participants were of non-European origin (n=45) and European origin (n=9) whilst four were of unknown origin.

### HIV-related stigma

HIV stigma as measured by the HSSC-8 generated a mean score of 17.6 (SD 5.0; possible range of 8-32) for the total scale. Of the three measured HIV-related stigma dimensions, *disclosure concerns* (2 items) represented the dimension with the highest mean (6.7, SD 1.5; possible range of 2.0-8.0) followed by *concerns with public attitudes* (3 items), mean 6.6 (SD 2.8; possible range of 3.0-12.0) and *negative self-image* (3 items), mean 4.3 (SD 2.1; possible range of 3.0-12.0).

A total of 46 of the respondents had mean scale scores on the upper half of the *disclosure concerns* subscale (means above 5 on a scale of 2-8), reflecting agreement or strong agreement on the *disclosure concerns* variables. In contrast, a majority had mean scale scores on the lower half of the scale (equal or below 7 on a scale with a range of 3-12) on the *concerns with public attitudes* (n=38) and *negative self-image* subscales (n=51), reflecting disagreement or strong disagreement (Figure 1).

Figure 1

## Health-related quality of life

HRQoL as measured by the DCGM-37 showed a mean score of 80.7 (SD 14.1) of a possible maximum of 100 for the total scale. Results of the subscales are presented in Table 1 with the highest mean found in the dimension *social exclusion* (89.5, SD 13.5) and the lowest mean in the dimension *social inclusion* (71.0, SD 18.1).

Table 1

## Relationships between HIV-related stigma and health-related quality of life

Figure 2 shows the relationships between HIV-related stigma and HRQoL. The hypothesized data fit measurement model correlating HRQoL and HIV-related stigma fits the data adequately, ( $\chi^2$  43.638, p 0.210; CFI 0.966; TLI 0.949; RMSEA 0.056). See Table 2 for the estimates of the model. The association between HIV-related stigma and HRQoL was strongly negative (standardized  $\beta$  -0.790; p 0.017); higher stigma was associated with poorer HRQoL. The interpretation of this standardized coefficient is that if HIV stigma increases by one SD, HRQoL will decrease by 0.79 SD. Age, sex or treatment did not show any statistically significant contribution to the model.

Table 2

Figure 2

## Discussion

In the present study, the ratings indicate that the respondents experienced low HIV stigma related to *negative self-image* and *concerns with public attitudes*, and more profound HIV stigma related to the dimension *disclosure concerns*. Furthermore, the study revealed a negative relationship between HIV-related stigma and HRQoL.

Children may have difficulty recognizing anticipated stigma, e.g. *concerns with public attitudes*, based on naivety as this form of stigma is associated with life experiences, perceptions and past experience of stigma (Earnshaw & Chaudoir, 2009). Clinical experience indicates that children can be made aware of anticipated stigma in the form of *disclosure*

*concerns* through their parents, who often teach them not to reveal to others that they are living with HIV infection as a way of protecting the child from stigma.

Notwithstanding, more than half of the respondents had told someone outside the family or healthcare system about having HIV. Furthermore, the results of this study indicate that children living with HIV infection do not experience high levels of internalized stigma as measured in the *negative self-image* dimension. A child's ability to experience internalized stigma may be dependent on the child's age and cognitive development (Rogoff., 1990), but also society, context and culture may influence how stigma manifests and is perceived (Parker & Aggleton, 2003). HIV prevalence among children in our research context is low, approximately 140 children and adolescents aged 0-18 years (Inficare HIV L. Navér personal contact 3 December 2014; prevalence 0.006 %) of a total population of about 2.2 million children in Sweden. Therefore, it might be that expectations among the general public that a child could be HIV-infected are rare which, in turn, may decrease the risk of children living with HIV being subjected to stereotyping as a result of people categorizing others. Also, when a person has a congenital disease or defect, it becomes part of the self (Goffman, 1963), which may decrease the susceptibility to stigmatizing mechanisms. Moreover, children living with perinatal HIV might not experience more pronounced levels of the HIV stigma dimensions *negative self-image* and *concerns with public attitudes* since children are more likely to normalize situations appearing in daily life (e.g. bullying) even if the situation would have been perceived as stigmatizing by adults (Deacon et al., 2005).

Knowledge concerning how children with perinatal acquired HIV experience their HRQoL of life is scarce. When comparing ratings of the participants in this study with norm data from the DISABKIDS European field study (n=1152) (Simeoni et al., 2007) children living with perinatal HIV seemed to rate higher or similarly in mental health domains and slightly lower in the social and physical health domains. Further, it seemed that the participants rated their HRQoL similarly or higher than children with other chronic conditions (e.g. Bystrom et al., 2012; Hanberger et al., 2009; Ylimainen et al., 2010).

Our study indicates that there is a negative relationship between HIV-related stigma and HRQoL. This is consistent with studies conducted among adults living with HIV (Sayles et al., 2007). Furthermore, it has been found that perceived HIV stigma has a significantly negative impact on HRQoL for adults living with HIV (Holzemer et al., 2009). It is possible

that children with HIV are at risk of developing similar difficulties to adults owing to HIV-related stigma. Thus, it is essential to obtain a deeper understanding of how stigma affects children living with HIV to be able to provide preventative support along the way to becoming an adult living with HIV. Additional research is also needed to further understand the relationship between HIV-related stigma and HRQoL in children living with HIV, and how it affects them in their daily lives.

There are some limitations to the study that should be noted. First, the HRQoL instrument is a generic measure that is broad in scope; thus, it may be unable to detect factors with weak but important relations to health, e.g. age and sex, within this specific population (Bryant & Fernande, 2011). However, the DCGM-37 is commonly used and has been psychometrically evaluated and found to be reliable and valid in a Swedish context (Af Sandeberg et al., 2008). Second, although we have previously evaluated the HSSC-8 for its psychometric properties (Wiklander et al., 2013), more studies are needed to establish clinically meaningful cutoff points. Third, this study has no matched comparison group of children, so there is a risk of misinterpreting results as related to HIV even though they may have other underlying causes. Fourth, the HSSC-8 dimension *disclosure concerns* did not reach the standards for good reliability. Finally, the original HIV Stigma Scale contained four dimensions of stigma (Berger et al., 2001), but, as constructed, the fourth dimension *personalized stigma* (corresponding to the enacted stigma mechanism (Earnshaw & Chaudoir, 2009)) was found not possible to use in the target group since children had difficulties understanding how to handle items regarding situations they had not experienced (Wiklander et al., 2013).

An advantage of this study is that the sample was recruited from virtually all available known cases of children living with HIV in Sweden. Further, the participating children did not differ from the non-participants in age or sex distribution indicating that the sample is representative and therefore should reflect the experiences of HIV-related stigma and HRQoL of children living with HIV in Sweden reasonably well. However, since we do not know the reasons for non-participation, there is a risk of selection bias on other grounds and, together with the fact that some children from the target population were not approached because of not fulfilling all inclusion criteria, generalizations from the study should be made with care.

## **Conclusion**

We found that children living with perinatal HIV in Sweden, apart from having concerns related to disclosure of their HIV infection, appear to have relatively little experience of internalized and anticipated HIV stigma. Furthermore, these children appear to have similar or better HRQoL in comparison to European norm data. Since there was a negative relationship between HIV-related stigma and HRQoL, we suggest that health professionals dealing with this group of patients should pay attention to and support matters related to HIV stigma, especially concerns regarding disclosure of their HIV infection, as a way to potentially improve the child's HRQoL.

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