

Rydström, L.-L., Wiklander, M., Ygge, B.-M., Navér, L. & Eriksson, L. E. (2015). Legal guardians understand how children with the human immunodeficiency virus perceive quality of life and stigma. *Acta Paediatrica*, 104(9), pp. 940-947. doi: 10.1111/apa.13062



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Original citation: Rydström, L.-L., Wiklander, M., Ygge, B.-M., Navér, L. & Eriksson, L. E. (2015). Legal guardians understand how children with the human immunodeficiency virus perceive quality of life and stigma. *Acta Paediatrica*, 104(9), pp. 940-947. doi: 10.1111/apa.13062

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REGULAR ARTICLE

Legal guardians understand how children with the human immunodeficiency virus perceive quality of life and stigma

Lise-Lott Rydström (lise-lott.rydstrom@ki.se)^{1,2}, Maria Wiklander^{1,3}, Britt-Marie Ygge^{2,4}, Lars Navér^{2,5}, Lars E. Eriksson^{1,6,7,8}

1.Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden

2.Astrid Lindgren Children's Hospital, Karolinska University Hospital, Stockholm, Sweden

3.Department of Clinical Sciences Danderyd Hospital, Karolinska Institutet, Stockholm, Sweden

4.Department of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden

5.Department of Clinical Science, Intervention and Technology, Karolinska Institutet, Stockholm, Sweden

6.Department Learning, Informatics, Management and Ethics, Karolinska Institutet, Solna, Sweden

7.Department of Infectious Diseases, Karolinska University Hospital, Huddinge, Sweden

8.School of Health Sciences, City University London, London, UK

Keywords

Health-related quality of life, HIV-related stigma, Human immunodeficiency virus, Legal guardians, Proxy

Correspondence

L-L Rydström, Registered Nurse, MSc, PhD student, Division of Nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, SE-141 83 Huddinge, Sweden.
Tel: +46851770425 |
Fax: +468311101 |
Email: lise-lott.rydstrom@ki.se

Received

24 February 2015; revised 24 April 2015; accepted 28 May 2015.

DOI:10.1111/apa.13062

BACKGROUND

Thanks to improved antiretroviral treatment, children infected with the human immunodeficiency virus (HIV) can now expect to reach adulthood (1) and this has led to new challenges for their families and for the care of these children. Legal guardians need to understand their child's perceptions of life in areas such as health-related quality of life (HRQoL) and HIV-related stigma, so that they can give the child the best support they can as they make the transition to an adult living with an HIV infection (2).

Proxy measures are often used to assess patient reported outcomes in children, such as HRQoL, when the children are unable to speak for themselves due to, for example, the stage of their cognitive development or illness (3). Proxy measures can also be used together with the children's own measures to compare concordance in the ratings of legal guardians and their children (2,3). Knowledge about the concordance between legal guardians' and children's ratings of HRQoL could enable healthcare providers to provide individualised support and information to children

and their legal guardians, which might help to solve or prevent problems that occur during the child's upbringing (4). Although there are several studies comparing HRQoL proxy reports and self-reports among children with other chronic diseases (5,6), there are, to our knowledge, no published studies comparing HRQoL ratings between legal

ABSTRACT

Aim: This aim of this study was to describe how legal guardians assessed health-related quality of life and HIV-related stigma in children with the human immunodeficiency virus (HIV) compared to the children's own ratings.

Methods: A cross-sectional nationwide study was performed to compare how 37 children aged from eight to 16 years of age with perinatal HIV, and their legal guardians, assessed the children's health-related quality of life and HIV-related stigma. Data were collected using the 37-item DISABKIDS Chronic Generic Module and a short eight-item version of the HIV stigma scale.

Results: Intraclass correlations indicated concordance between the legal guardians' ratings and the children's own ratings of the child's health-related quality of life and HIV-related stigma. There were no statistically significant differences between the ratings of the two groups and gender did not have any impact on the results. Both groups indicated that the children had concerns about being open about their HIV status.

Conclusion: The results of this study indicated that legal guardians understood how their children perceived their health-related quality of life and HIV-related stigma. The results also indicated the need for interventions to support both the children and legal guardians when it came to disclosing the child's HIV status.

Key notes

- This study compared how children living with early-acquired human immunodeficiency virus (HIV) and their legal guardians rated the children's health-related quality of life and HIV-related stigma.
- There were no statistically significant differences between the two groups, and gender did not have any impact on the ratings.
- The results indicated the need to support both the children and the legal guardians when it came to disclosing the child's HIV status.

guardians' proxy ratings and the self-ratings of children living with an HIV infection. In the studies of proxy reports and self-reports among children with other chronic diseases, the results diverge depending on the child's disease or the context where the study was performed (5,6).

Proxy measures of disease-related stigma are unusual, but have been used in relation to people living with dementia and schizophrenia (7,8). As far as we are aware, there are no earlier studies concerning proxy ratings of HIV-related stigma. In general, there is little knowledge regarding HIV-infected children and their families and how HIV-related stigma influences their lives. Most studies are performed on children with unknown HIV status living in families where at least one of the members has an HIV infection. These children are known as children affected by HIV (9). However, in a previous qualitative study we found that HIV-related stigma was a factor that influenced the lives of children with HIV and their families. We also found that it was common for children to be told by their legal guardians and health professionals to keep their HIV status secret, both within and outside the family, in order to avoid stigma (10). HIV-related stigma is known to be multifaceted. The personal and contextual views of legal guardians, resulting from their own experiences of being exposed to HIV-related stigma, might influence the legal guardians' advice to the child about how to avoid disclosure and how to handle living with HIV (11).

It has been argued that legal guardians' perceptions of their child's HRQoL can significantly influence their use of health care (12). It is therefore essential to understand legal guardians' perspectives of their children's health in relation to the children's own experiences when developing interventions that provide support and assistance for families with children living with HIV. The aim of this study was to describe how legal guardians assessed the children's experience of health-related quality of life and HIV-related stigma in comparison with the children's own ratings.

METHODS

In this study, the term legal guardians refer to all those individuals who took part in the study who had a legal responsibility for the child. It includes biological parents, foster parents, adoptive parents and other forms of legal guardians.

Study design and data collection

This study was a nationwide cross-sectional study with self-administered questionnaires.

Data were collected between October 2011 and November 2012. The inclusion criteria were that the child and legal guardian were able to understand and speak Swedish, that the child had an early or perinatally acquired HIV infection, had attended HIV care in Sweden for more than five years, was eight to 16 years old when they were invited to join the study and were aware of their HIV infection. Participants were recruited from all Swedish adult and paediatric clinics that treated children with HIV. The intention was that all

children living with HIV in Sweden and their legal guardians matching the inclusion criteria should be invited to participate.

Prospective participants were informed about the study by their registered nurse during a regular appointment at their clinic. If they consented, the child and one legal guardian attending the hospital appointment were asked to complete the study questionnaires at the clinic. The legal guardian and child answered the questionnaires separately, but at the same time and with a nurse in the room. In a few cases, the participants preferred to answer the questionnaires in their homes and mail them to the research group. If the questionnaire was not returned within three weeks, the nurse reminded the participants up to two times.

The children and their legal guardians answered separate sets of questions about HRQoL and HIV-related stigma. The children's ratings of their own HRQoL were assessed using the 37-item DISABKIDS Chronic Generic Module for children, henceforth referred to as the HRQoL scale. Legal guardians' ratings of their children's HRQoL were assessed using the 37-item proxy DISABKIDS Chronic Generic Module items, referred to as the proxy HRQoL scale. The HRQoL scale and proxy HRQoL scale consist of one total scale and six subscales that measure mental, social and physical domains of HRQoL. Each item is rated on a five-point Likert-type scale ranging from one (never) to five (very often). For each question, raw scores were coded, summed and transformed into a scale from zero (worst possible) to 100 (best possible) following the standard scoring of the instrument (13). If there were nonresponses to an item in a dimension of the HRQoL scale or proxy HRQoL scale, the item response was replaced with the median value from the participant's answers to the other items in the same dimension. This is, to our knowledge, the first time this instrument has been used among legal guardians of children with HIV infection. Both the HRQoL scale and proxy HRQoL scale showed proof of internal consistency in this study. Cronbach's α values for the dimensions on both the child and proxy versions were 0.83 and 0.83 for *independency*, 0.73 and 0.68 for *physical limitation*, 0.65 and 0.73 for *emotions*, 0.64 and 0.59 for *social exclusion*, 0.88 and 0.83 for *social inclusion*, 0.86 and 0.78 for *medication* and 0.93 and 0.91 for the *total scale*.

The eight-item HIV stigma scale for children, henceforth referred to as the stigma scale (14), and the proxy version of the eight-item HIV stigma scale for children, the proxy stigma scale, were used to assess the children's HIV-related stigma. These two scales were developed and adapted from a Swedish version of the widely used HIV stigma scale (15), which is described below. Both are sum scales and consist of eight statements divided into three dimensions: *disclosure concerns* (two items), *negative self-image* (three items) and *concerns with public attitudes* (three items), as shown in Table 1. Responses to the eight statements are rated on a four-point Likert-type scale from 'strongly disagree' to 'strongly agree', with a possible range between two and eight (two items) or three and 12 (three items) for the

Table 1 Presentation of all items from the HSSC-8 child and proxy version

| Item child version | Item proxy version | Dimension |
|--|--|--------------------------------|
| 1. I work hard to keep my HIV a secret | My child works hard to keep his/her HIV a secret | Disclosure concerns |
| 2. Most people believe a person who has HIV is dirty | My child believes that most people believe a person who has HIV is dirty | Concerns with public attitudes |
| 3. Having HIV makes me feel unclean | Having HIV makes my child feel unclean | Negative self-image |
| 4. Most people think a person with HIV is disgusting | My child believes that most people think a person with HIV is disgusting | Concerns with public attitudes |
| 5. Having HIV makes me feel I'm a bad person | Having HIV makes my child feel he/she is a bad person | Negative self-image |
| 6. Most people with HIV are rejected when others learn | My child believes that most people with HIV are rejected when others learn | Concerns with public attitudes |
| 7. I am very careful whom I tell that I have HIV | My child is very careful whom he/she tells that he/she has HIV | Disclosure concerns |
| 8. Having HIV in my body feels disgusting | My child believes that having HIV in his/her body feels disgusting | Negative self-image |

HSSC-8 = HIV stigma scale for children 8 items; PSSC-8 = proxy version of the HIV stigma scale for children 8 items.

dimension scales. Higher scores represent greater stigma. In contrast to the original HIV stigma scale, these two scales do not include measurements of personalised stigma as we found in an earlier study that this was not applicable to measure this type of stigma in children (14).

The process of developing and adapting the stigma scale for use with children has been described elsewhere (14). Internal consistency for the stigma scale in this study was shown by Cronbach's α 0.81 for the *concerns with public attitudes* dimension, 0.75 for the *negative self-image* dimension and 0.55 for the *disclosure concerns* dimension. The scale was further adapted for use as a proxy version by adjusting the items for children to proxy statements. In the proxy version, the items are phrased as statements regarding their child's experiences of HIV stigma, for example 'My child works hard to keep his/her HIV a secret' (Table 1). Interviews (16) with five legal guardians were used in the adaptation process to evaluate the understanding and interpretation of the items and whether it was possible to use the same items in the proxy version as in the child version of the scale (unpublished work). The think-aloud interviews indicated that it was possible to use the corresponding items from the child version rephrased in the proxy version. The proxy stigma scale has not been previously evaluated and two of three dimensions were shown to be internally valid. Internal consistency for the proxy stigma scale in this study was shown by Cronbach's α 0.81 for the *concerns with public attitudes* dimension and 0.73 for the *negative self-image* dimension. The third dimension, *disclosure concerns* (two item scale), showed a low internal consistency (Cronbach's α 0.22), so it was decided to treat the two items belonging to this scale as separate items instead of combining them to a scale. Nonresponses to any item in the stigma scale or proxy stigma scale were replaced with a median value of all other participants' answers, children or legal guardians, respectively, for that particular item.

In addition to the HRQoL and HIV stigma instruments, some study specific questions were used in separate versions for children and legal guardians. The questions regarded background information and information about disclosure of the child's HIV status to people in his or her social environment. The latter was considered a significant factor in relation to the stigma dimension *disclosure concerns*.

Data analyses

All statistical analyses were conducted with IBM SPSS 22 (IBM Corp, Armonk, NY, USA). An independent *t*-test was used to test for differences in age and a chi-square test to test for gender difference between participants and non-participants. The intraclass correlation coefficient (ICC) was used to measure the strength of agreement between the children's and corresponding legal guardian's measurements of the children's HRQoL and HIV-related stigma. The ICC should be as close as possible to one to show agreement, where 0.5 is acceptable, 0.7 is good, 0.8 is optimal and 0.9 is excellent agreement between measurements (17). Paired sample *t*-tests were used to test whether there were differences in how children and legal guardians rated the child's HRQoL and HIV-related stigma. Wilcoxon signed-ranks tests were used to measure whether there were differences in how children and legal guardians rated the child's experiences regarding the two separate items belonging to the HIV-related stigma measure, *disclosure concerns*. A chi-square test was used to analyse potential differences between children and legal guardians regarding frequency of reported disclosure of the child's HIV status to people in his or her social environment. To measure if there was any relationship between the child's gender and the concordance between child and legal guardian ratings, *t*-tests for independent samples were used to compare the delta scores, that is the legal guardian scores minus child scores, for pairs with male versus female children.

Ethics statement

The study was approved by the Regional Ethical Review Board of Stockholm, Sweden (2007/1530-31 with amendments 2011/1120-32 and 2012/6-32). Participating children and legal guardians were provided with full details regarding the aims of the study and the procedure. All participants, legal guardians and children, received both written and verbal information regarding confidentiality and voluntary participation before they separately signed a consent form. For children younger than 15 years of age, a legal guardian filed an additional consent form agreeing to the child's participation.

RESULTS

Sample characteristics

Of the 62 eligible legal guardian–child pairs, 37 pairs participated (Fig. 1). The participating pairs were 18 girls and 19 boys and their corresponding legal guardians, comprising 25 mothers or stepmothers, 10 fathers or stepfathers and two with an unknown relationship to the child. The children were aged 8–16 years and the mean age was 13.1, with a standard deviation (SD) of 2.2 years. Of the participating children, 31 were of non-European origin and five were of European origin. The origin of one child was not available. Five of the 37 children were born in Sweden. Data about the legal guardians' origin, social background or HIV status were not collected.

Attrition

There was no statistically significant difference in gender or age between the children of nonparticipating children–legal guardian pairs (14 girls and 11 boys with a mean age of 12.8 years, SD 2.7) and the children of participating children–legal guardian pairs ($p = 0.570$ and $p = 0.624$, respectively).

Health-related quality of life

The analysis showed acceptable to excellent concordance between the HRQoL scale ratings of the legal guardians and those of their children. All the ICCs were statistically

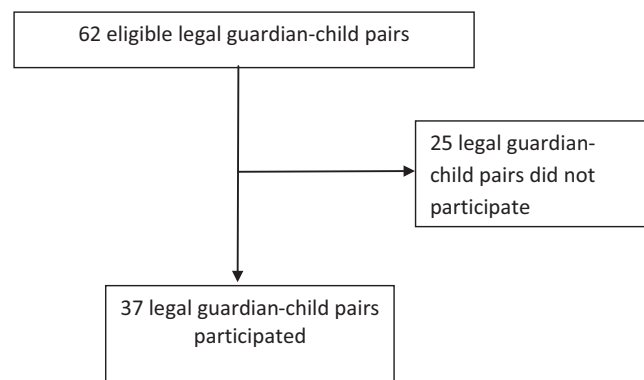


Figure 1 Illustrating participants and nonparticipants of legal guardians and children (8–16 years).

significant and varied between 0.522 for *social inclusion* and 0.821 for *emotions* (Table 2). There were no statistically significant differences between how legal guardians and children rated the child's HRQoL in either the general scale or any of the six dimensions of the HRQoL scale (Table 2).

HIV-related stigma

The analysis of the HIV stigma ratings showed good to optimal concordance between the stigma scale ratings of the legal guardians and those of their children. All the ICCs were statistically significant, varying between 0.639 for the *disclosure concern* item, *child careful about telling about their HIV* and 0.750 for the *negative self-image* dimension (Table 3). There were no statistically significant differences between how legal guardians and children rated HIV-related stigma (Table 3).

In the questions about disclosure of HIV status to people in their social environment, 46% ($n = 17$) of the participating children reported that they had disclosed their HIV infection to people outside the family. However, only 25% ($n = 9$) of the corresponding legal guardians stated that they thought their children had disclosed their status to others ($\chi^2 [1, n = 30] = 5.12, p = 0.024$) (Table 4).

Comparisons regarding gender

The child's gender was not found to influence the concordance between child and legal guardian ratings for either the HRQoL scale measures (Table 5) or the stigma scale measures (Table 6).

DISCUSSION

This is, as far as we know, the first study comparing the ratings of legal guardians and their children for HRQoL and for HIV-related stigma among children with early-acquired HIV infection. The results showed acceptable to excellent agreement as analysed by ICC. No differences were found regarding how legal guardians rated their children's HRQoL and HIV-related stigma compared with their children's own ratings as analysed by paired samples *t*-tests and Wilcoxon signed-ranks tests. We interpreted these results as a good indication that the legal guardians, in the investigated context, understood how their children perceived their HRQoL and HIV-related stigma.

In this study, the results from the HRQoL ratings showed that the agreement between the ratings of legal guardians and their children was optimal to excellent for the general and dimension scales. Interestingly, it was in the dimension *emotions* that the highest agreement was found. This is in contrast to many studies investigating HRQoL of children with other chronic conditions, where better agreements have been seen in children's observable behaviour in contrast to children's internal states or feelings (2,3). The high agreement in the *emotions* dimension of the present study might be related to the fact that the majority of legal guardians who answered the questionnaire were mothers and it is likely that many of them were themselves infected with HIV. If legal

Table 2 DCGM-37 and PDCGM-37, descriptive statistics and comparisons between children's and legal guardians' (proxy) ratings of children's HRQoL (n = 37 children and 37 legal guardians)

| DCGM-37 and PDCGM-37 | Child Mean (SD) | Proxy Mean (SD) | t/p* | ICC/p† |
|----------------------|-----------------|-----------------|--------------|-------------|
| Independency | 82.32 (17.08) | 80.52 (17.87) | -0.672/0.506 | 0.726/0.001 |
| Physical limitation | 80.74 (16.12) | 77.02 (16.94) | 1.401/0.170 | 0.682/0.001 |
| Emotions | 76.44 (22.86) | 72.49 (21.54) | 1404/0.169 | 0.821/0.001 |
| Social exclusion | 88.51 (12.74) | 88.40 (12.77) | 0.056/0.956 | 0.709/0.001 |
| Social inclusion | 70.04 (19.34) | 66.10 (18.48) | 1.115/0.272 | 0.522/0.014 |
| Medication‡ | 72.53 (23.49) | 73.31 (21.22) | -0.206/0.838 | 0.707/0.001 |
| Total scale | 79.51 (16.66) | 76.76 (14.42) | 1.493/0.144 | 0.850/0.001 |

DCGM-37 = DISABKID Chronic Generic Module for children 37 items; PDCGM-37 = proxy.

DISABKID Chronic Generic Module 37 items; HRQoL = health-related quality of life.

*paired sample t-test between the children's and legal guardians' (proxy) ratings.

†ICC = intraclass correlation of the children's and legal guardians' (proxy) ratings.

‡n = 34.

Table 3 Descriptive statistics for HSSC-8 and PHSSC-8 (n = 37 children and 37 legal guardians)

| | Child Mean (SD) | Proxy Mean (SD) | Test statistic (p) | ICC* (p) |
|--|-----------------|-----------------|--------------------|----------------|
| Negative self-image† | 4.59 (2.46) | 4.43 (2.28) | 0.261‡ (0.796) | 0.750 (0.001) |
| Concerns with public attitudes† | 6.11 (2.96) | 5.27 (2.43) | 1.893‡ (0.066) | 0.657 (0.001) |
| Disclosure concern item: Careful about whom to tell about their HIV§ | 2.95 (1.13) | 3.14 (1.06) | -0.911¶ (0.362) | 0.639 (0.001) |
| Disclosure concern item: Works hard to keep HIV a secret§ | 2.65 (0.79) | 3.73 (0.61) | -0.577¶ (0.564) | 0.696 (<0.001) |

HSSC-8 = HIV stigma scale for children 8 items; PHSSC-8 = proxy version of the HIV stigma scale for children 8 items.

*ICC, intraclass correlation of the children's and legal guardians' (proxy) ratings.

†Three item scale with a possible range of 3–12.

‡t, paired sample t-test between the children's and legal guardians' (proxy) ratings.

§Items one and seven from the HSSC-8 with a possible range of 1–4.

¶Z, Wilcoxon signed-ranks test between the children's and legal guardians' (proxy) ratings.

Table 4 Children's answers to questions about whether and to whom they had disclosed their HIV status and legal guardians' answers to questions about whether and to whom they believe their child had disclosed her or his HIV infection

| | Children (n = 21) | Legal guardians (n = 22) |
|----------------------------------|-------------------|--------------------------|
| Disclosed the HIV infection (n)* | 17 | 9† |
| Told friend, boy/girlfriend | 6 | 0 |
| Told adult relative | 1 | 1 |
| Told other person | 1 | 0 |
| Told the school nurse | 6 | 7 |
| Told the teacher | 1 | 0 |
| Told unspecified‡ | 2 | 1 |

*Refers to persons outside the family and healthcare team.

†Children vs legal guardians, X² (1, N = 30) = 5.12, p = 0.024.

‡Some participants had just answered yes or no without specifying to whom they had disclosed.

Table 5 Analysis of the relation between the child's gender and the concordance between child-legal guardian ratings of the children's health-related quality of life as measured by DCGM-37 (n = 37)

| DCGM-37 dimension | Girl Mean (SD)* | Boy Mean (SD)* | t/p† |
|---------------------|-----------------|----------------|-------------|
| Independency | -0.46 (13.24) | -3.07 (19.03) | 0.48/0.634 |
| Physical limitation | -3.94 (17.93) | -3.51 (14.72) | -0.08/0.937 |
| Emotions | -6.55 (18.87) | -1.50 (15.44) | -0.89/0.379 |
| Social exclusion | -3.24 (10.94) | 2.85 (12.88) | -1.55/0.131 |
| Social inclusion | -6.25 (19.76) | -1.75 (23.34) | -0.63/0.532 |
| Medication‡ | 1.96 (18.81) | -0.56 (24.79) | 0.33/0.747 |
| Total scale | -3.17 (10.94) | -0.94 (10.71) | -0.62/0.537 |

DCGM-37 = DISABKID Chronic Generic Module for children 37 items.

*Delta scores (legal guardian subtracted by child scores).

†t-test for independent samples.

‡n = 34.

guardians were infected with HIV, they might have had a greater understanding of the emotional impact of living with the HIV infection, which in turn might lead to a greater understanding of the child's situation. This greater understanding might lead to decreased differences in ratings

between children and their legal guardians (18). Furthermore, in concordance with other studies reporting agreement between children and legal guardians, the weakest agreement was in the dimension *social inclusion*, which describes the perception of positive feedback from friends and family (3,13).

Table 6 Analysis of the relations between the child's gender and the concordance between child-legal guardian ratings of the children's experience of HIV-related stigma as measured by HSSC-8

| | Girl Mean (SD)* | Boy Mean (SD)* | t/p† |
|---|-----------------|----------------|-------------|
| Negative self-image | -0.06 (1.86) | -0.11 (1.97) | 0.08/0.938 |
| Public attitude | -0.61 (2.43) | -1.05 (2.97) | 0.49/0.625 |
| Disclosure concern item: Careful about whom to tell about their HIV | 0.22 (1.31) | 0.16 (0.96) | 0.17/0.856 |
| Disclosure concern item: Works hard to keep HIV a secret | -0.06 (0.24) | 0.21 (0.96) | -1.22/0.241 |

HSSC-8 = HIV stigma scale for children 8 items.

*delta scores (legal guardian subtracted by child scores).

†t-test for independent samples.

In general, little is known about how children living with HIV experience HIV-related stigma and how legal guardians think their children experience HIV-related stigma. It is likely that the coherence between the ratings of legal guardians and those of their children is based on the same factors as for HRQoL (3,19). The high level of agreement in our study indicates that legal guardians have good knowledge of how their children experience HIV-related stigma regarding all the aspects investigated: *concerns with public attitudes, negative self-image* and *disclosure concerns*. The consistency in the ratings also reveals potential situations that may pose difficulties for both children and legal guardians. The mean values in both groups were on the upper end of the scale for the two *disclosure concerns* items focusing on being open and daring to talk about HIV. This, together with the fact that the participating children's responses indicated that they had been more open to friends and others than their legal guardians believed, points towards a need for interventions to support both children and legal guardians in dealing with matters related to disclosure of the child's HIV status. In addition, being able to be open and talk about one's life situation (3) has been found to be an essential factor in achieving good treatment effects and increased quality of life (3). This further underscores the significance of developing interventions to support families with children living with HIV regarding issues of disclosure.

Another finding of this study was that the child's gender did not influence the agreement in legal guardian-child

ratings. Previous studies concerning the agreement of parent-child ratings of the HRQoL of children with other chronic conditions have shown that gender can be a factor (19–21). For example, a study of children living with asthma found that the agreement was better between girls and their legal guardians. This was interpreted as being due to socially constructed gender differences and the fact that sons and daughters differ in their relationships and closeness to their legal guardians (20). The absence of gender differences in the present study might be because the majority of the participating legal guardians were mothers, who might have had their own experience of living with an HIV infection. This common experience between child and mother might increase the understanding between the mother and child regardless of the child's gender (22).

Certain limitations of the current study should be taken into account. The HIV stigma proxy measure we used had not been previously psychometrically tested. The internal consistency analysis of the third dimension *disclosure concerns* in the proxy version revealed a low Cronbach's α indicating that the two statements measured different aspects of concerns related to disclosure of the child's HIV status. We understand the first item in this scale, '*My child works hard to keep his/her HIV a secret*', to be about fears and the second item, '*My child is very careful whom he/she tells that he/she has HIV*', to be about keeping things to themselves and choosing if and when to tell others about their HIV infection. Most of the participating children were not European, indicating that the majority of their legal guardians also had a non-European background and therefore might have had difficulties understanding the statements in the scale due to language difficulties or cultural contexts (22). This is judged to have been a potential problem in the few cases where the questionnaires were filled out at the participant's home and the responsible nurse was not present to clarify any questions. On the other hand, the participants were provided with contact information for the study team and encouraged to contact them or their clinic if they had any concerns.

As participants were recruited through their registered nurse, there is a risk that potential participants were not asked due to staff forgetting or just wanting to protect the families against stressors (personal communication). In addition, when they were asked to participate by health-care staff, some people may have felt obliged to participate because they felt that they would not be well thought of or receive inferior care if they did not take part. The risk of the latter ought to be minimised by the fact that the researchers were external and not engaged in the participants' health care and by the participants' healthcare providers not having access to the participants' responses, which were returned in sealed envelopes directly to the researchers. The response rate for the study was 60%, which is generally considered to be good (23,24). However, a nonresponse rate of 40% in an already small sample might be a problem, especially as the largest

number of nonresponses –15 of the 25 nonparticipants – was from legal guardians of older children aged 14–16 years. Nonresponses might have been higher among legal guardians of older children because these children commonly attend clinic visits without their legal guardians, while younger children almost always attend with an adult, usually a legal guardian or an older sibling. Furthermore, as the majority of participating children were not of European origin, the often high levels of stigma associated with HIV in immigrant communities might have led to the legal guardians choosing not to participate, because they were worried that their families' HIV status would be revealed and they could face exclusion from their own ethnic group (25). Also, even if further details regarding socio-economic background were not collected from the participants of the present study, it is known that the majority of children living with HIV in Sweden live in socio-economically weak areas (details received from InfCare 2015, www.infcare.se). The nonparticipants might be those with more negative life experiences and therefore, as two-fifths of the possible participants declined to participate, caution should be taken before drawing generalised conclusions from the results of this study. However, the results are thought to indicate how children in this particular age range with HIV and their families perceive children's experiences of life, although more studies are needed to be able to make stronger generalisations.

The strengths of the study are that it was a nationwide study and all adult and paediatric clinics treating HIV-infected children were invited to participate. The goal was to invite all children with early-acquired HIV treated at each clinic and their legal guardians to participate.

CONCLUSION

The result of this study contribute to the limited literature regarding legal guardians' awareness of how HRQoL and HIV-related stigma is experienced by children with early-acquired HIV infection. We found that legal guardians and children in the present sample rated the children's HRQoL and HIV-related stigma similarly, indicating that the legal guardians had a good understanding of how their children perceived their HRQoL and HIV stigma. However, the results also indicated that the children were more open about their HIV infection than their legal guardians thought. Both legal guardians and children had concerns related to the child's disclosure of his or her HIV, which suggests a need for interventions to support both children and legal guardians in matters related to disclosure of the child's HIV status. Furthermore, data on the level of children's disclosure of their HIV infection differed from that of the legal guardians and individual HRQoL and HIV-related stigma ratings spanned a wide range. This suggests that HRQoL and HIV-related stigma ratings may be of significance when designing individualised interventions for children living with HIV infection.

ACKNOWLEDGEMENTS

The authors would like to thank all participants and healthcare professionals who made this study possible.

FUNDING STATEMENTS

The study was partly funded by the Doctoral School in Health Care Sciences and the Strategic Research Program in Care Sciences, Karolinska Institutet and the Kempe-Carlgrenska Foundation.

CONFLICT OF INTERESTS

The authors have no conflict of interests to declare.

References

1. Palmisano L, Vella S. A brief history of antiretroviral therapy of HIV infection: success and challenges. *Ann Ist Super Sanita* 2011; 47: 44–8.
2. Eiser C, Varni J. Health-related quality of life and symptom reporting: similarities and differences between children and their parents. *Eur J Pediatr* 2013; 172: 1299–304.
3. Eiser C, Morse R. Can parents rate their child's health-related quality of life? Results of a systematic review. *Qual Life Res* 2001; 10: 347–57.
4. De Los Reyes A. Introduction to the Special Section: More than measurement error: Discovering meaning behind informant discrepancies in clinical assessments of children and adolescents. *J Clin Child Adolesc Psychol* 2011; 40: 1–9.
5. Marques JC, Oliviera JA, Goulardins JB, Nascimento RO, Lima AM, Casella EB. Comparison of child self-reports and parent proxy-reports on quality of life of children with attention deficit hyperactivity disorder. *Health Qual Life Outcomes* 2013; 11: 186.
6. Su CT, Wang J-D, Lin C-Y. Child-rated versus parent-rated quality of life of community-based obese children across gender and grade. *Health Qual Life Outcomes* 2013; 11: 206.
7. Penn DL, Kohlmaier JR, Corrigan PW. Interpersonal factors contributing to the stigma of schizophrenia: social skills, perceived attractiveness, and symptoms. *Schizophr Res* 2000; 45: 37–45.
8. Katsuno T. Dementia from the inside: how people with early-stage dementia evaluate their quality of life. *Age Soc* 2005; 25: 197–214.
9. Deacon H, Stephney I. *Understanding HIV/AIDS stigma: a theoretical and methodological analysis*. Cape Town, South Africa: HSRC Press, 2007: 8.
10. Rydstrom L-L, Ygge B-M, Tingberg B, Naver L, Eriksson LE. Experiences of young adults growing up with innate or early acquired HIV infection - a qualitative study. *J Adv Nurs* 2013; 69: 1357–65.
11. Klitzman R, Marhefka C, Mellins C, Wiener L. Ethical issues concerning disclosures of HIV diagnoses to perinatally infected children and adolescents. *J Clin Ethics* 2008; 19: 31–42.
12. Varni J, Setoguchi Y. Screening for behavioral and emotional problems in children and adolescents with congenital or acquired limb deficiencies. *Am J Dis Child* 1992; 146: 103–7.
13. Schmidt S, Petersen C, Mühlhan H, Simeoni MC, Debensason D, Tgyen U, et al. *The DISABKIDS questionnaires: quality of life questionnaires for children with chronic conditions*. Lengerich, Germany: Pabst Science Publishers, 2006: 75.
14. Wiklander M, Rydström L-L, Ygge B-M, Naver L, Wettergren L, Eriksson LE. Psychometric properties of a

- short-version of the HIV stigma scale, adapted for HIV-infected children and adolescents. *Health Qual Life Outcomes* 2013; 11: 195.
15. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Res Nurs Health* 2001; 24: 518–29.
 16. Göransson KE, Ehnfors M, Fonteyn ME, Ehrenberg A. Thinking strategies used by Registered Nurses during emergency department triage. *J Adv Nurs* 2008; 61: 163–72.
 17. Fayers PM, Machin D. *Quality of life: the assessment, analysis and interpretation of patient-reported outcomes*, 2nd edn. West Sussex, England: John Wiley & Sons Ltd, 2007: 97.
 18. Snow AL, Cook KF, Lin P, Morgan RO. Proxies and other external raters: Methodological considerations. *Health Serv Res* 2005; 40: 1676–93.
 19. Upton P, Lawford J, Eiser C. Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Qual Life Res* 2008; 17: 895–913.
 20. Petsios K, Priftis KN, Tsoumakas C, Hatziaiorou E, Tsanakas JN, Galanis P, et al. Level of parent-asthmatic child agreement on health-related quality of life. *J Asthma* 2011; 48: 286–97.
 21. Lundberg V, Lind V, Eriksson C, Petersen S, Eurenus E. Health-related quality of life in girls and boys with juvenile idiopathic arthritis: self- and parental reports in a cross-sectional study. *Pediatr Rheumatol Online J* 2012; 10: 33.
 22. Åsander A-S, Rubensson B, Munobwa J, Faxelid E. 'We have taken care of our children according to an African-Swedish method': HIV-infected Ugandan parents in Sweden. *J Ethn Migr* 2013; 39: 791–808.
 23. Groves RM. Nonresponse rates and nonresponse bias in household surveys. *Public Opin Quart* 2006; 70: 646–75.
 24. Babbie E. *The practice of social research*, 11th edn. Belmont, CA: Wadsworth, 2007: 262.
 25. McMahon T, Ward PR. HIV among immigrants living in high-income countries: a realist review of evidence to guide targeted approaches to behavioural HIV prevention. *Syst Rev* 2012; 1: 56.