Chapter seven

Developing quality indicators for the care of HIV-1-infected pregnant women in a Dutch Caribbean setting

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Chapter 7

Abstract

Effective interventions to prevent mother-to-child HIV transmission (PMTCT) exist and, when properly applied reduce the risk of vertical HIV transmission. As part of optimizing PMTCT in the Dutch Caribbean we developed a set of valid, reliable and applicable indicators in order to assess the quality of prenatal and delivery care in HIV-infected (pregnant) women and their newborns. A multidisciplinary expert panel of 18 experts reviewed and prioritized recommendations extracted from locally used international PMTCT guidelines according a 3-step modified Delphi procedure. The content validity was assessed during 2 consecutive rounds with a panel meeting in-between. Subsequently, the feasibility, sample size, inter-observer reliability, sensitivity to change and case mixed stability of the potential indicators were tested for a data set of 153 HIV-infected women, 108 pregnancies of HIV-infected women and 79 newborns of HIV-infected women in outpatient and inpatient clinical setting of Aruba, Curaçao and St Maarten from 2000 to 2010. The panel selected and prioritized 13 potential indicators. Applicability could not be tested for 4 indicators regarding HIV-screening in pregnant women because of lack of data. Four indicators performed satisfactorily for Curaçao and 3 for St Maarten whilst none for Aruba. A systemic evidence- and consensus-based approach was used to develop quality indicators for PMTCT in 3 Dutch Caribbean settings. Applicability testing of quality indicators regarding PMTCT in different settings is essential before they are used in quality improvement approaches.
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Introduction

Acquired immunodeficiency syndrome (AIDS) is a leading cause of illness and death among women and children in countries with high rates of human immunodeficiency virus (HIV) infection. Mother-To-Child HIV Transmission (MTCT) is by far the most significant route of HIV-infection in children. Several interventions have proven to be effective to reduce MTCT, including elective caesarean delivery, substitution of breastfeeding and access to antiretroviral therapy during pregnancy, labour and post-partum. If properly applied, these interventions reduce the MTCT rates to 2%. For the Netherlands Antilles, 1812 HIV-1 cases have been reported in 2008, with 83 new cases in 2007. The Dutch Caribbean consists of Aruba and the Netherlands Antilles (Saba, St Eustatia, Bonaire, St Maarten and Curaçao) and has an estimated prevalence of HIV infection of 0.61%-1.05% in the adult population. Forty percent of the registered patients are female and there have been approximately 5 to 10 pregnancies annually in HIV-infected women. Since 1996 guidelines regarding the prevention of mother-to-child HIV transmission (PMTCT) have been implemented in regular health care systems in the Dutch Caribbean and the annual number of paediatric HIV cases has dropped dramatically since. However, new paediatric HIV cases have been reported in recent years. Limited data on the quality of care provided after implementation of the guidelines are available and the question rises whether opportunities for the prevention of HIV transmission were missed. Monitoring and evaluating the quality of care of HIV-infected women to achieve PMTCT is important for it can identify strategies to improve the quality of care provided and thereby lead to better outcome in the prevention of HIV transmission. As part of optimizing the quality of care of prenatal and delivery care in HIV-infected (pregnant) women in the Dutch Caribbean, this study has the aim to develop a validated and applicable set of quality indicators to measure the quality of care in HIV-infected (pregnant) women and their newborns in 3 Dutch Caribbean settings; Aruba, Curaçao and St Maarten.

Methods

Phase 1: Consensus procedure

Locally used PMTCT guidelines, including guidelines for care of HIV-infected pregnant women, were collected from which ninety-nine key recommendations were pre-selected by three independent researchers. Also, an extensive literature search was performed using PubMed to identify already existing quality of care indicators for the care of HIV-infected pregnant women. On the basis of the available literature, the level of evidence was graded for each recommendation to determine its scientific soundness or the likelihood that improvement of the quality indicator reflects improvements in quality of care. To assess the
validity of the preselected recommendations, the group judgment of experts was used with a 3-step modified Delphi approach. Therefore, a multidisciplinary assessment team was assembled with representatives of all involved medical areas, consisting of 19 experts: 3 paediatricians, 3 gynaecologists, 3 midwives, 2 general practitioners, 2 epidemiologists, 3 internal medicine specialists, 2 HIV/AIDS programme managers and 1 microbiologist. During 3 rating rounds the expert panel rated the preselected recommendations by judging their relevance in regard to effectiveness of PMTCT, the applicability of the recommendation for the current setting, and health care costs.

<table>
<thead>
<tr>
<th>Table 1: Level of supporting evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Level of supporting evidence</strong></td>
</tr>
<tr>
<td>A1</td>
</tr>
<tr>
<td>A2</td>
</tr>
<tr>
<td>B</td>
</tr>
<tr>
<td>C</td>
</tr>
<tr>
<td>D</td>
</tr>
</tbody>
</table>

Legend table 1: Data are from 1

During the first rating round the recommendations were formatted into a questionnaire and the experts were asked to rate the preselected recommendations using a 9-point Likert scale (with 1 defined as “hardly of any relevance/not suited as indicator” and 9 being defined as “very relevant/suited as indicator”). Also, panel members were asked to add additional recommendations for consideration or comments. Between the first and the second rating round, a panel meeting took place to evaluate and discuss recommendations for which no consensus was achieved. Recommendations with an overall median rating of 8 or 9, without disagreement, were considered to be face valid and reliable and were thus selected as potential indicators. Recommendations with an overall median of 1-3 and 4-6 were rated as invalid and questionable respectively, and were rejected. Disagreement was defined as ≥30% of scores in both the bottom (1-3) and the top (7-9) tertile. Recommendations with a median rating of 7 with agreement, and recommendations with an overall median rating
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of 8 or 9 with disagreement were discussed in the panel meeting and reformulated when necessary.

After the meeting, all of the discussed and reformulated recommendations (plus additional recommendations) were formatted in a second questionnaire and the panel members were asked to rate again. The final selection of recommendations was made by asking the panel members to prioritize the potential indicators by selecting the ‘top 5’ most important potential indicators. When 2 or more experts prioritized a recommendation in their top 5 the recommendations was selected as potential indicator and these were further developed by defining numerators and denominators.17

Phase 2: Applicability test of potential quality indicators

Before the indicator set is used in a specific setting, the applicability in the chosen practice setting has to be tested. So, the next step is to provide empirical evidence of the feasibility, sample size, reliability, sensitivity to change and case mix stability of each indicator (Figure 1). The applicability of the set of potential indicators was tested in the outpatient clinical setting of the HIV specialists and the clinical setting of the general hospitals in Aruba, Curaçao and St Maarten. Eligible patients included pregnant HIV-infected women, HIV-infected women of childbearing age and exposed children between January 2000 and January 2010. Data were selected by using clinical data systems of the general hospitals, the outpatient clinic of the gynaecologists, paediatricians, HIV specialists and national registries available at the Public Health Department of each island. In Curaçao, a national electronic registration system (Stichting HIV Monitoring, SHM)18 was consulted and in Aruba, the national registration database of the Services of Contagious Diseases, Public Health Department was used to select HIV-infected women of childbearing age. In St Maarten, no electronic database was available, so no patient selection could be made for indicators regarding HIV-infected women of childbearing age. Also, non-electronic registrations conducted by health care workers were consulted in the 3 settings. Excluded from analysis were pregnancies ending before the second trimester, pregnancies ended by abortion with unknown gestation duration, or deliveries abroad.

Feasibility of the indicator was defined as the availability of administrative data required to evaluate the indicator. An indicator was considered to be feasible if the data necessary to score the indicator could be abstracted from the available data for >70% of the cases.19

Sample size of the indicator was related to the number of patients to which the indicator could be applied. Considering the period and the estimated number of patients or events eligible for this study, the research team considered an indicator to be applicable if it could be applied to at least 15 patients or events.
Figure 1: Flow chart showing the development of quality indicators during the consensus procedure of phase 1 of the study and the applicability testing of phase 2 of the study.

**Phase 1**

- Questionnaire 1: N=99
  - Rejected: N=9
  - Accepted: N=57
  - No decision: N=33
  - New: N=2

  Panel meeting

**Phase 2**

- Questionnaire 2: N=35
  - Prioritization: N=85
    - Accepted: N=28
    - Rejected: N=7
  - Prioritized: N=13
    - Not measurable: N=4
    - Applicability testing in Curaçao, Aruba and St Maarten: N=9

**Curaçao**

- Not feasible: N=4
  (Indicator 5, 6, 12, 13)

- Not reliable: N=2
  (Indicator 9 and 12)

- Small Sample size: N=1
  (Indicator 6)

**Aruba**

- Not feasible: N=2
  (Indicator 5 and 6)

- Not reliable: N=3
  (Indicator 5, 12, 13)

- Small Sample size: N=9
  (Indicator 6 to 13)

**St Maarten**

- Not feasible: N=4
  (Indicator 5, 6, 12, 13)

- Not reliable: N=3
  (Indicator 5, 6, 12)

- Small Sample size: N=3
  (Indicator 5, 6, 11)

**Applicable set Curaçao**: N=4
(Indicator 7, 8, 10, 11)

**Applicable set Aruba**: N=0

**Applicable set St Maarten**: N=3
(Indicator 7, 8, 9)
Inter-rater reliability refers to the extent to which a measurement of an indicator is reproducible, between observers and between cases. A second investigator rated 10% of all the records in the 3 different medical centres to assess the inter-rater reliability. To assess the agreement between 2 investigators corrected for chance, a Cohen kappa coefficient was calculated. Indicators with a value of $\kappa < 0.60$ were considered unreliable.\textsuperscript{20}

Sensitivity to change was defined as the need to detect changes in quality of care in order to discriminate between and within subjects and show room for improvement of the care measured. Potential indicators with an overall performance score of $>85\%$ were defined as having little room for improvement and were not selected.

Case mix stability referred to the need to correct for certain patient characteristics. The relationship between patient parameters and the indicator result can identify whether there is need for correction for case mix. Indicators that are not case mix stable require comparable patient populations when comparing the quality of care. Patient characteristics possibly influencing the quality of care were defined as: type of health care insurance, age, non-indigenous status and number of previous deliveries. Outcome of the indicator was supposed to be influenced by the patient characteristic if the $p < 0.05$. Correction for these patient characteristics was performed and analysed if the characteristics were of influence to the outcome of the indicator.

Results

Phase 1: Consensus procedure

Of the in total 19 panel members, 15 panellists (79\%) completed the questionnaire in the first round, 15 panellists (79\%) completed the second round and 10 panellists (53\%) were present during the panel meeting. After the first rating round 57 recommendations were rated as potential indicators. (Figure 1) Nine recommendations were considered not-suitable as potential indicators. Thirty-three recommendations were discussed and reformulated during the panel meeting. Two recommendations were newly added. More than 200 comments were added, encoded and grouped by the research team for discussion during the panel meeting. After the second rating round 28 recommendations were selected as potential indicators and 7 recommendations were rejected. A final set of 13 recommendations was prioritized for which numerators and denominators were defined. (Table 2)
Table 2: Applicability of potential quality indicators of the prevention of mother-to-child HIV transmission in HIV-1-infected (pregnant) women and their newborns in Curaçao, Aruba and St Maarten.

<table>
<thead>
<tr>
<th>Indicator, setting</th>
<th>Sample Size, feasibility, % of available data, inter-rater reliability, κ, sensitivity to change, %, case-mix stable</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pregnant women</strong></td>
<td></td>
</tr>
<tr>
<td>1. HIV testing should be done in all pregnant women.</td>
<td>NA 0 NA NA NA</td>
</tr>
<tr>
<td>2. Pregnant women who decline HIV testing should be encouraged to be tested at subsequent visits.</td>
<td>NA 0 NA NA NA</td>
</tr>
<tr>
<td>3. Repeat HIV testing if risk factors are present during pregnancy.</td>
<td>NA 0 NA NA NA</td>
</tr>
<tr>
<td>4. Perform HIV rapid testing if HIV status is unknown at labour.</td>
<td>NA 0 NA NA NA</td>
</tr>
<tr>
<td><strong>HIV-infected women</strong></td>
<td></td>
</tr>
<tr>
<td>5. Offer preconception counselling and care to HIV-infected women of childbearing potential.</td>
<td>153 31 0.54 45 Yes</td>
</tr>
<tr>
<td>Total</td>
<td>Curaçao 136 18 0.60 35 Yes</td>
</tr>
<tr>
<td>Aruba</td>
<td>17 59 &lt; 0.0 83 Yes</td>
</tr>
<tr>
<td>St Maarten</td>
<td>NA 0 NA NA NA</td>
</tr>
<tr>
<td>6. Maximally suppress plasma HIV RNA levels prior to conception in HIV-infected women who wish to get pregnant.</td>
<td>14 18 0.82 50 Yes</td>
</tr>
<tr>
<td>Total</td>
<td>Curaçao 12 15 0.82 50 Yes</td>
</tr>
<tr>
<td>Aruba</td>
<td>2 18 1 50 NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td>NA 0 NA NA NA</td>
</tr>
<tr>
<td><strong>HIV-infected pregnant women</strong></td>
<td></td>
</tr>
<tr>
<td>7. Monitor CD4 cell count at the initial visit and at least every 3 months during pregnancy of HIV infected women.</td>
<td>91 97 0.92 16 No²</td>
</tr>
<tr>
<td>Total</td>
<td>Curaçao 54 94 1 18 Yes</td>
</tr>
<tr>
<td>Aruba</td>
<td>8 100 1 0 NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td>29 100 0.67 18 Yes</td>
</tr>
<tr>
<td>8. Monitor plasma HIV RNA levels at initial visit, 2 to 6 weeks after start antiretroviral therapy, monthly until undetectable, and then at least every 2 months during pregnancy.</td>
<td>91 81 0.92 0 NA</td>
</tr>
<tr>
<td>Total</td>
<td>Curaçao 54 80 0.86 0 NA</td>
</tr>
<tr>
<td>Aruba</td>
<td>8 100 1.0 0 NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td>29 80 0.67 0 NA</td>
</tr>
</tbody>
</table>
9. Discuss and provide combined antiretroviral prophylaxis to all HIV-infected pregnant women, regardless the HIV RNA level.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>91</th>
<th>92</th>
<th>0.57</th>
<th>74</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curaçao</td>
<td></td>
<td>54</td>
<td>91</td>
<td>0.52</td>
<td>77</td>
<td>Yes</td>
</tr>
<tr>
<td>Aruba</td>
<td></td>
<td>8</td>
<td>100</td>
<td>0.67</td>
<td>75</td>
<td>NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td></td>
<td>29</td>
<td>93</td>
<td>1</td>
<td>70</td>
<td>Yes</td>
</tr>
</tbody>
</table>

10. Give intrapartum and infant antiretroviral therapy prophylaxis to all HIV-infected pregnant women who do not receive antepartum antiretroviral therapy.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>24</th>
<th>92</th>
<th>0.76</th>
<th>0</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curaçao</td>
<td></td>
<td>16</td>
<td>91</td>
<td>0.72</td>
<td>0</td>
<td>NA</td>
</tr>
<tr>
<td>Aruba</td>
<td></td>
<td>2</td>
<td>100</td>
<td>0.67</td>
<td>0</td>
<td>NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td></td>
<td>6</td>
<td>93</td>
<td>1</td>
<td>0</td>
<td>NA</td>
</tr>
</tbody>
</table>

11. Perform a cesarean delivery at 38 weeks gestation if HIV RNA levels >400 copies/mL or unknown.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>53</th>
<th>92</th>
<th>0.74</th>
<th>49</th>
<th>No³</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curaçao</td>
<td></td>
<td>35</td>
<td>96</td>
<td>0.93</td>
<td>60</td>
<td>Yes</td>
</tr>
<tr>
<td>Aruba</td>
<td></td>
<td>7</td>
<td>100</td>
<td>0.60</td>
<td>29</td>
<td>NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td></td>
<td>11</td>
<td>83</td>
<td>0.35</td>
<td>27</td>
<td>Yes</td>
</tr>
</tbody>
</table>

12. Counsel HIV-infected pregnant women to avoid breastfeeding.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>91</th>
<th>65</th>
<th>0.06</th>
<th>81</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curaçao</td>
<td></td>
<td>54</td>
<td>67</td>
<td>&lt;0.0</td>
<td>50</td>
<td>Yes</td>
</tr>
<tr>
<td>Aruba</td>
<td></td>
<td>8</td>
<td>100</td>
<td>0</td>
<td>88</td>
<td>NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td></td>
<td>29</td>
<td>52</td>
<td>1</td>
<td>93</td>
<td>No¹</td>
</tr>
</tbody>
</table>

Newborn

13 Continue antiretroviral therapy prophylaxis in the newborn during 4 weeks post partum.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>79</th>
<th>24</th>
<th>0.77</th>
<th>79</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Curaçao</td>
<td></td>
<td>49</td>
<td>24</td>
<td>0.81</td>
<td>50</td>
<td>Yes</td>
</tr>
<tr>
<td>Aruba</td>
<td></td>
<td>8</td>
<td>75</td>
<td>0.11</td>
<td>33</td>
<td>NA</td>
</tr>
<tr>
<td>St Maarten</td>
<td></td>
<td>22</td>
<td>50</td>
<td>1</td>
<td>93</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Legend Table 2:** The indicators that were applicable in practice are shown in boldface font. NA, not applicable; ¹ Correction for multi-parity; ² Correction for non-indigenous, multi-parity and age; ³ Correction for insurance type.
Phase 2: Applicability test of potential quality indicators

The applicability test of the set of potential indicators took place in Curacao, St Maarten and Aruba from January 2010 till April 2010. Four potential indicators selected by the panellists focused primarily on HIV screening in pregnant women with unknown HIV status. However, since the chosen practice setting was limited to HIV-infected (pregnant) women and their newborns, applicability of the 4 ‘screening indicators’ could not be assessed. The other 9 potential indicators concerned HIV-infected (pregnant) women and their newborns. Inclusion of eligible patients led to a total number of 153 HIV-infected women of child bearing potential (136 in Curacao, 17 in Aruba, with no data availability for St Maarten), 108 pregnancies of HIV-infected women (54 in Curacao, 8 in Aruba and 29 in St Maarten) and 79 live born children of HIV-infected women (49 in Curacao, 8 in Aruba and 22 in St Maarten). Twelve pregnancies were excluded because they ended before the second trimester of gestation (10 in Curacao, 2 in St Maarten). Five pregnancies were excluded due to an abortion after unknown pregnancy duration (3 in Curacao, 2 in St Maarten).

Feasibility

Indicator 5 (‘preconception counselling for all HIV-infected women’) had a low feasibility for Curacao (18% of patients had available data) and moderate feasibility for Aruba (59%). Indicator 6 (‘maximally suppress viral load in HIV-infected women who wish to get pregnant’) scored low feasibility in Curacao and Aruba (15% and 17% respectively). In St Maarten feasibility for indicator 5 and indicator 6 could not be assessed, for there was no data set of HIV-infected women of childbearing potential.

Indicators 7 to 11 were feasible in all 3 settings, and indicator 12 and 13 were exclusively feasible in Aruba. (Table 2)

Sample size

In Curacao, indicator 6 (‘maximally suppress viral load in HIV-infected women who wish to get pregnant’) had a sample size of <15 patients and was therefore rejected. All other indicators had large enough sample sizes for Curacao. In Aruba only indicator 5 (‘preconception counselling for all HIV-infected women’) met the required sample size. In St Maarten, indicator 10 (‘HIV-infected pregnant women who do not receive antiretroviral therapy antepartum’) and indicator 11 concerning scheduled caesarean section could only be applied to 11 patients.

Inter-rater reliability

Indicator 12 (‘counselling breastfeeding’) scored a $\kappa<0.60$ in all 3 settings. Indicator 5 (‘pre-conception counselling’) scored a Cohen’s kappa coefficient $\kappa<0.60$ in Aruba. Also, indicator 13 (‘antiretroviral therapy in newborn’) scored low inter-rater reliability for Aruba ($\kappa=0.11$). Indicator 11 (‘scheduled caesarean section’) scored low inter-rater reliability for St Maarten.
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(κ = 0.35). Indicator 9 (‘discuss and provide antiretroviral therapy in all pregnant women’) scored moderate inter-rater reliability in Curaçao (κ = 0.52).

**Sensitivity to change**
None of the potential indicators showed an overall high performance score. The performance of indicator 12 and 13 scored above 85% in St Maarten and indicator 12 scored above 85% in Aruba. The range between the highest and the lowest score of each indicator between the different settings was high for the indicators 5, 11, 12, and 13 (48%, 33%, 43% and 60% respectively).

**Case mix stability**
In St Maarten correction for multiparous women was necessary for indicator 12 (‘counselling breastfeeding’). This indicator was more often measured in HIV-infected pregnant women with 2 or more pregnancies in the past than women with none or 1 pregnancy. No correction for non-indigenous status, type of health care insurance or age was necessary for any of the other potential indicators.

**Discussion**
This study shows the systematic development of quality indicators for HIV-infected (pregnant) women and their newborns in 3 different Dutch Caribbean settings; Curaçao, Aruba and St Maarten. Quality indicators are important as they provide insight in current care and they reveal areas that need further improvement of care. Thirteen indicators were selected and prioritized for the Dutch Caribbean: 4 concerning HIV screening in pregnant women, 2 concerning HIV-infected women, 6 concerning HIV-infected pregnant women and 1 concerning newborns of HIV-infected women. After testing the applicability of each potential indicator in practice only 4 indicators scored satisfactorily for Curaçao (monitoring CD4-cell count during pregnancy, monitoring HIV-RNA levels, intrapartum antiretroviral therapy and infant prophylaxis to all HIV-infected women who did not receive antepartum antiretroviral therapy, perform caesarean delivery at 38 weeks if HIV-RNA >400 copies/mL or unknown viral load) and 3 for St Maarten (monitoring CD4-cell count during pregnancy, monitoring HIV-RNA levels, discuss and provide combined antiretroviral therapy to all HIV-infected pregnant women), whilst none for Aruba.

No consensus exists on how to best monitor the quality of care in HIV-infected pregnant women.22 Most international studies report effectiveness of PMCT services in a country or region by outcome or coverage (indicating the percentage of children infected or the percentage of HIV-infected pregnant women accessing PMTCT services).11,22-27 However, in order to reach the global goal of eliminating MTCT, monitoring the quality of care seems as
equally important as ensuring access or coverage especially in countries or regions that have already achieved high access to PMTCT services due to integration of care.

Several organizations and study groups have developed indicators regarding care of HIV-infected pregnant women, mostly as part of a set of key indicators to measure the effectiveness of the implementation of a regional PMTCT program. \cite{28-35} Five of such indicators show similarity with the quality indicators in our study namely indicator 1 (‘HIV screening in all pregnant women’), indicator 5 (‘preconception counselling’), indicator 9 (‘antiretroviral therapy in all HIV-infected pregnant women’), indicator 12 (‘counseling breastfeeding’) and indicator 13 (‘antiretroviral therapy in newborn’). Remarkable however, most of these well-known and internationally used indicators are currently not applicable in a Dutch Caribbean setting because they currently show lack of feasibility, inter-rater reliability or have too small sample sizes.

This study shows the importance of testing potential indicators for their applicability which has also been reported by others.\cite{21} After assessing the applicability of each indicator in the 3 Dutch Caribbean settings, only 4 indicators could be satisfactorily tested in practice in Curaçao, 3 in St Maarten whilst none in Aruba. First, applicability can only be tested if data are available to give information about quality of care. In this study the indicators concerning HIV-infected women (indicator 5 and 6) and the indicator concerning newborns (indicator 13) showed low feasibility. For indicators with low feasibility it cannot be concluded that the limitation of data are due to improper data registration or incorrect implementation of the used guidelines. Therefore proper surveillance, tracking systems or registration tools for collecting the necessary data should be developed and be in place before these quality indicators can be applied in the Dutch Caribbean setting. Second, sizes of the samples on which the indicator can be applied have to be large enough. In small settings or in settings with low prevalence of HIV infection or with highly specific quality indicators accounting for only a specific proportion of the population, quality indicators cannot be used because of insufficient number of patients. This was shown in our study for the setting of Aruba in which only one indicator showed large enough sample size over a period of 10 years. Lengthening the time of the observation period in this case is not desirable since indicators should be dynamic and easily repeated. As the Caribbean region consists of multiple islands with relatively small populations like the Dutch Caribbean, the practical value of (specific) quality indicators has to be questioned and other methods of monitoring quality of care in such settings should be considered.

This study gives an overview of prenatal, delivery and child care in regard to PMTCT in 3 Dutch Caribbean islands. The study has led to identification of previously non-registered HIV-infected pregnancies and HIV-exposed children. Also, it created awareness of the quality of care regarding PMTCT and enhanced possibilities for further discussion among health care
professionals who are involved in planning and coordinating care. Although the applicability of some potential indicators was limited by overall small sample sizes and lack of feasibility it must be noticed that the set of potential indicators had an overall low performance score. Only 2 indicators scored above 85%. Future initiatives aimed at improving quality of care and eliminating vertical transmission of HIV-infection in Curaçao, Aruba and, St Maarten should therefore be based on these study results.

Since access to HIV treatment has increased world-wide, a trend towards reporting quality of HIV treatment should be encouraged. To our knowledge this is one of the first reports on quality of care of HIV treatment in the Caribbean.

A limitation of this study is the possible selection bias of the data that are selected during phase 2 of the study. In all 3 settings different clinical monitoring systems for HIV-infected patients were available, none of them aimed at collecting data regarding the quality of care of HIV-infected pregnant women. Although a unique Clinical Report Form for this study was developed, specific data could be missed because data was collected retrospectively. Also, it should be taken into account that there is no centralized registration of pregnant women available on each island with the result that implementation in practice of HIV screening in pregnant women cannot be checked (indicator 1 to 4) and cases (HIV-infected women and their newborns) might be missed. Also, no HIV rapid tests are available in the 3 settings which may lead to underreporting especially for those women of whom HIV sero-status is unknown during labour. This later may have influenced the applicability as well as the outcome of the quality of care provided, since reports show that patients who do not (timely) access proper care have worse outcomes.

Concluding, this is one of the first studies describing the systematic development of quality indicators for HIV-infected (pregnant) women. It shows the importance of applicability testing in different settings before implementing potential indicators into practice. Relatively small settings should consider other approaches to monitor quality of care. Further, this study identifies areas for improvement of data collection and registration as well as areas for improvement of quality of prenatal and delivery care in HIV-infected (pregnant) women and their newborns in the Dutch Caribbean.

Acknowledgments

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## References


