

SISTER: STILLERFAHRUNGEN HIV-POSITIVER FRAUEN (breastfeeding experiences of women living with HIV)

Questionnaire **SISTER (STILLERFAHRUNGEN HIV-POSITIVER FRAUEN)**

ENGLISH

The following questions are always related to the pregnancy and breastfeeding period you already knew about your positive HIV-status. If you breastfed more than once since your HIV-diagnosis, please refer to your youngest child.

Please give the first three digits of your postal code for a rough classification of the place of your residence:

1. How old are you today?

___ ___ years

2. How old have you been when you became pregnant?

___ ___ years

3. What is your country of birth?

4. If you are not born in Germany: How long have you been living in Germany to date?

- < 1 year
- 1-5 years
- 6-10 years
- > 10 years

5. Did you graduate from school?

- No
- Yes _____ (please state your highest degree)

6. Did you learn a profession?

- No
- Yes _____ (please specify what kind of profession)

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7. Have you been working when you became pregnant?

- No
- Yes

8. Have you been working during pregnancy?

- No
- Yes, until the ____ ____ week of pregnancy

9. Have you been/are you working while you have been/are breastfeeding?

- No
- No, I am still in maternity protection („Mutterschutz“)
- Yes, I started working again ____ ____ months after giving birth

10. How many times have you been pregnant excluding this pregnancy?

____ ____ (please state the number)

11. How many times did you give birth excluding this pregnancy?

____ ____ (please state the number)

12. Did you get tested for HIV during your last pregnancy?

- No, because I had already been diagnosed HIV-positive before
- Yes, during the first trimester (1.-12. week)
- Yes, during the second trimester (13.-27. week)
- Yes, during the last trimester (later than pregnancy week 28)

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13. If HIV had been diagnosed before your last pregnancy: How long did you know about your positive status?

- < 1 year
- 1-5 years
- 6-10 years
- > 10 years

14. How openly do you live with your HIV-diagnosis?

- Nobody knows about it
- Only a few people (1-5 people), who I care about, know about it
- Some people (5-10 people), who I care about, know about it
- A lot of people (more than 10 people), who I care about, know about it

15. If you have been in a relationship during this pregnancy: Did your partner know about your HIV-diagnosis?

- No
- Yes

16. What HIV-drugs did you take when you got pregnant?

- none
- _____ (please list your medication)

17. What HIV-drugs did you take during this pregnancy?

- none
- _____ (please list your medication)
- _____ (please list your medication)
- _____ (please list your medication)

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18. What was/is your HIV-therapy during the breastfeeding period?

- none
- _____ (please list your medication)

19. Do you have other chronic diseases additionally to HIV? (E.g. high blood pressure, diabetes, hepatitis, etc.)

- No
- Yes, _____
(please specify your comorbidity)

20. Have you been supported by a midwife when you were pregnant?

- No
- Yes

21. Have you been/are you supported by a midwife during the breastfeeding period?

- No
- Yes

22. Did you get a professional lactation consultation?

(Multiple answers possible)

- No
- Yes, from a midwife
- Yes, from a lactation consultant
- Yes, from a gynecologist
- Yes, from: _____

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23. If you got a lactation consultation: Where did you get it?

(Multiple answers possible)

- In hospital
- In the birthing center (Geburtshaus)
- At home
- Other place: _____ (please specify)

24. When did you make up your final decision to breastfeed your child?

- Before pregnancy
- During pregnancy
- After delivery

25. Who supported you to make your decision about breastfeeding?

(Multiple answers possible)

- nobody
- my partner
- my family
- my HIV-consultant
- my gynecologist
- my family doctor
- other mothers living with HIV
- local support groups (Selbsthilfegruppen)
- others: _____

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26. Why did you decide to breastfeed your child?

(Multiple answers possible)

- breastfeeding promotes a faster restitution of the womb after giving birth
- breastfeeding promotes a faster weight-loss for mothers after giving birth
- breastfeeding is lowering the risk of breast cancer for the mother
- I feel breastfeeding is part of a normal life with HIV
- breastmilk is cheaper than formular milk
- breastfeeding is lowering the risk for allergies for the newborns
- breastmilk promotes the development of the newborn's immune system
- breastmilk is always available
- the composition of ingredients in my breastmilk is perfect for my child
- breastfeeding promotes a close bond between mother and child
- other reasons:

(please tell us your personal view on breastfeeding)

27. If you disclosed your HIV-status to medical staff: How was the feedback on your decision to breastfeed?

(Please make only one cross in every category 1= negative until 5=positive)

- | | | |
|----------------------|--|---|
| HIV-consultant | 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> | (I did not tell them : <input type="checkbox"/>) |
| Gynecologist | 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> | (I did not tell them: <input type="checkbox"/>) |
| Midwife | 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> | (I did not tell them: <input type="checkbox"/>) |
| Nurses | 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> | (I did not tell them: <input type="checkbox"/>) |
| Pediatrician | 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> | (I did not tell them: <input type="checkbox"/>) |
| Lactation consultant | 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> | (I did not tell them: <input type="checkbox"/>) |
| Other medical staff | 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> | _____ |

(please specify what medical staff)

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28. Did you breastfeed a child before your positive HIV-diagnosis?

- No
- Yes

If yes: Did you live in Germany or in another country then?

- In Germany
- In a different country: _____ (please specify the country)

29. Did you breastfeed a child after your HIV-diagnosis but before this pregnancy?

- No
- Yes

If yes: Did you live in Germany or in another country then?

- In Germany
- In a different country: _____ (please specify the country)

30. Where did you get information about breastfeeding in general?

(Multiple answers possible)

- Friends
- Family
- HIV-consultant
- Gynecologist
- Lactation consultant
- Midwife
- Family doctor
- Information center (e.g. pro familia)
- Other mothers with HIV
- Internet
- Other resources: _____

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31. Where did you get information about breastfeeding with HIV?

(Multiple answers possible)

- Friends
- Family
- HIV-consultant
- Gynecologist
- Lactation consultant
- Midwife
- Family doctor
- Information center (e.g. pro familia)
- Other mothers with HIV
- Internet
- Other resources: _____

32. If you already stopped breastfeeding: How long did you breastfeed your child?

___ ___ weeks or ___ ___ months respectively

33. How long did you breastfeed exclusively (without feeding any other food)

___ ___ weeks or ___ ___ months respectively

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34. Why did you stop to breastfeed?

(Multiple answers possible)

- the time of breastfeeding was sufficient for me
- drinking weakness of the child
- pain while breastfeeding
- milk engorgement
- mastitis (inflammation of the breast)
- breaking trough of the child's teeth
- I started to go back to work again
- no acceptance of my partner
- insufficient milk production
- I needed to take a medication which contradicted to breastfeeding
- child refused the breast
- elevation of HIV viral load
- switch of HIV-drugs
- other concomitant disease
- worry of mother-to-child HIV-transmission
- other reasons: _____ (please specify)

35. If you are still breastfeeding: How long have you already been breastfeeding?

___ ___ weeks or ___ ___ months

36. If you are still breastfeeding: How long do you plan to breastfeed in total?

___ ___ weeks or ___ ___ months

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37. Did you have any problems with breastfeeding? (e.g. infection of the breast, milk engorgement, sore nipples)?

No

Yes:

(please specify)

38. If there were any problems: Who did you contact for support?

(Multiple answers possible)

gynecologist

midwife

lactation consultant

family doctor

other: _____ (please specify)

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39. Would you choose to breastfeed again if you had another child?

- Yes
- No
- I do not know

40. Would you recommend breastfeeding to other HIV-positive women?

- Yes
- No
- I do not know

41. How did you deliver your child?

- Vaginal delivery
- C-section

42. In what country did you deliver your child?

_____ (please name the country)

43. Where did you deliver?

- University clinic
- general hospital
- birthing center
- home birth
- other place: _____ (please specify)

44. In which pregnancy week did you deliver?

_____ + _____ (please state the week plus the day if possible. E.g.: 40+3; you can find the information in your Mutterpass)

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45. If you already knew about your HIV-infection before this pregnancy: How was your HIV viral load when you got pregnant?

- below the limit of detection (<50 copies/mL)
- >50 copies/mL

46. How was your viral load during pregnancy?

- below the limit of detection (<50 copies/mL)
- >50 copies/mL

47. How was/ how is your viral load during the time of breastfeeding?

- always below the limit of detection (<50 copies/mL)
- at least one time >50 copies/mL

48. If you already knew about your HIV-infection before this pregnancy: How was your CD4 cell count when you got pregnant?

- <350 / μ L
- >350 / μ L

49. How was your CD4 cell count during pregnancy?

- <350 / μ L
- >350 / μ L

50. How was/how is your CD4 cell count during the time of breastfeeding?

- at least one time <350 / μ L
- always >350 / μ L

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51. Was your breastmilk analysed during the breastfeeding period?

(Multiple answers possible)

- No
- Yes, the HIV viral load was tested at least once
- Yes, the level of HIV drugs was measured at least once
- Yes, other tests: _____ (please specify test)

52. If your breastmilk was analysed: Do you know the results?

- No
- Yes,

(please state the results if possible)

53. Do you want to tell us something else about your personal breastfeeding experience?

Thank you so much for your support! The results of this study will be published as soon as possible.

Please send the questionnaire anonymously back (without sender's address) to the study center:

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