

Menstruation after spinal cord injury and its effects on a woman's life from the perspective of an occupational therapist

Basic data



Name of research

Menstruation after spinal cord injury and its impact on a woman's life
from an
occupational
therapist's
perspective



Author



Language of the questionnaire

 Czech



Public address of the questionnaire

<https://www.surveio.com/survey/d/U8F1A5X2R7A9S4P3N>



First answer

31. 01. 2024

Last answer

10. 03. 2024



Duration

40 days

Statistics of respondents

56

Number of visits

34

Number of completed

0

Number of unfinished

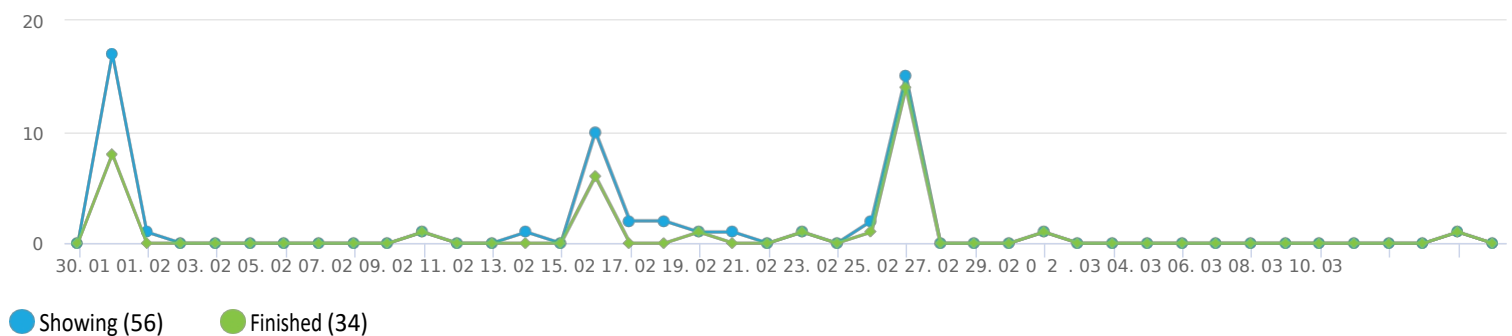
22

Display only

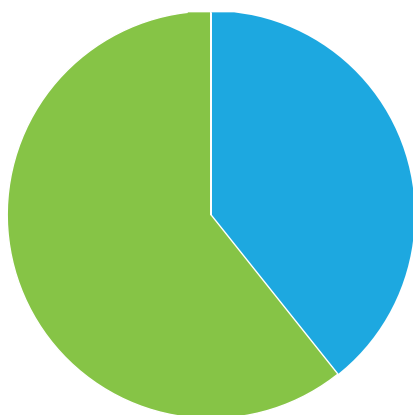
60,7%

Overall questionnaire completion rate

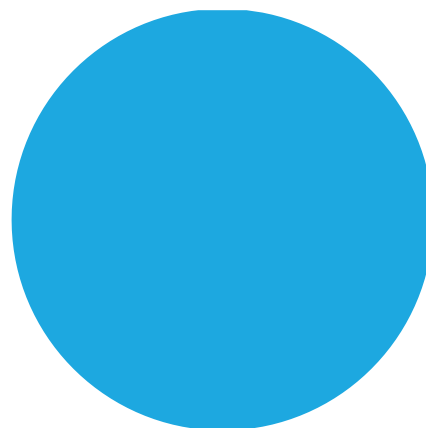
Visit history (31. 01. 2024 - 10. 03. 2024)



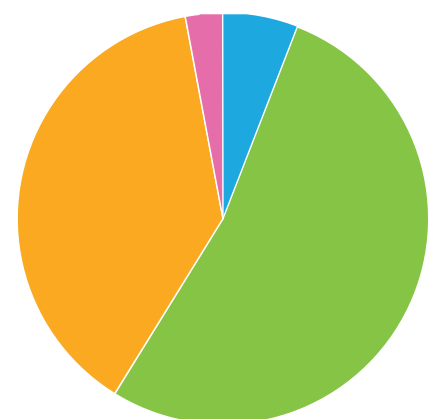
Total visits completion



Sources of visits



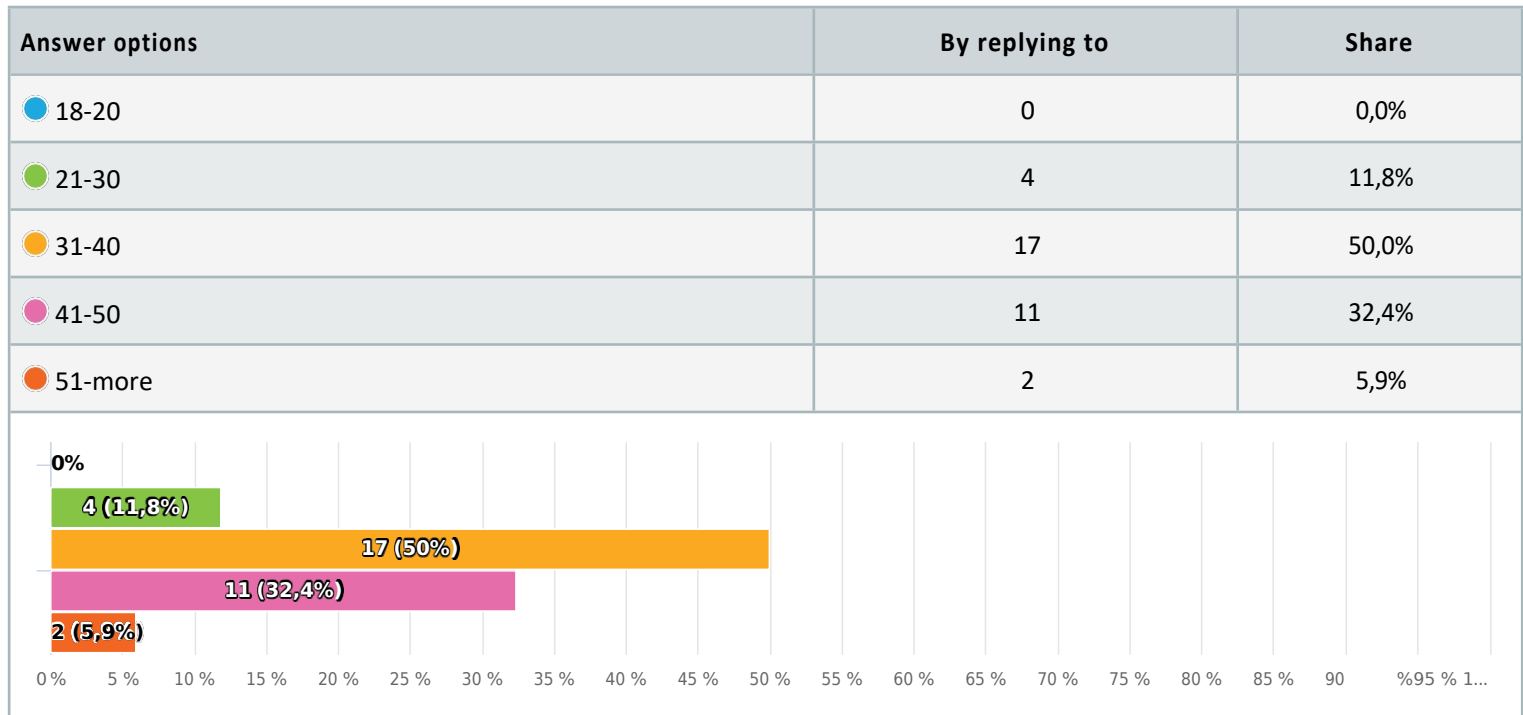
Time of questionnaire



Results

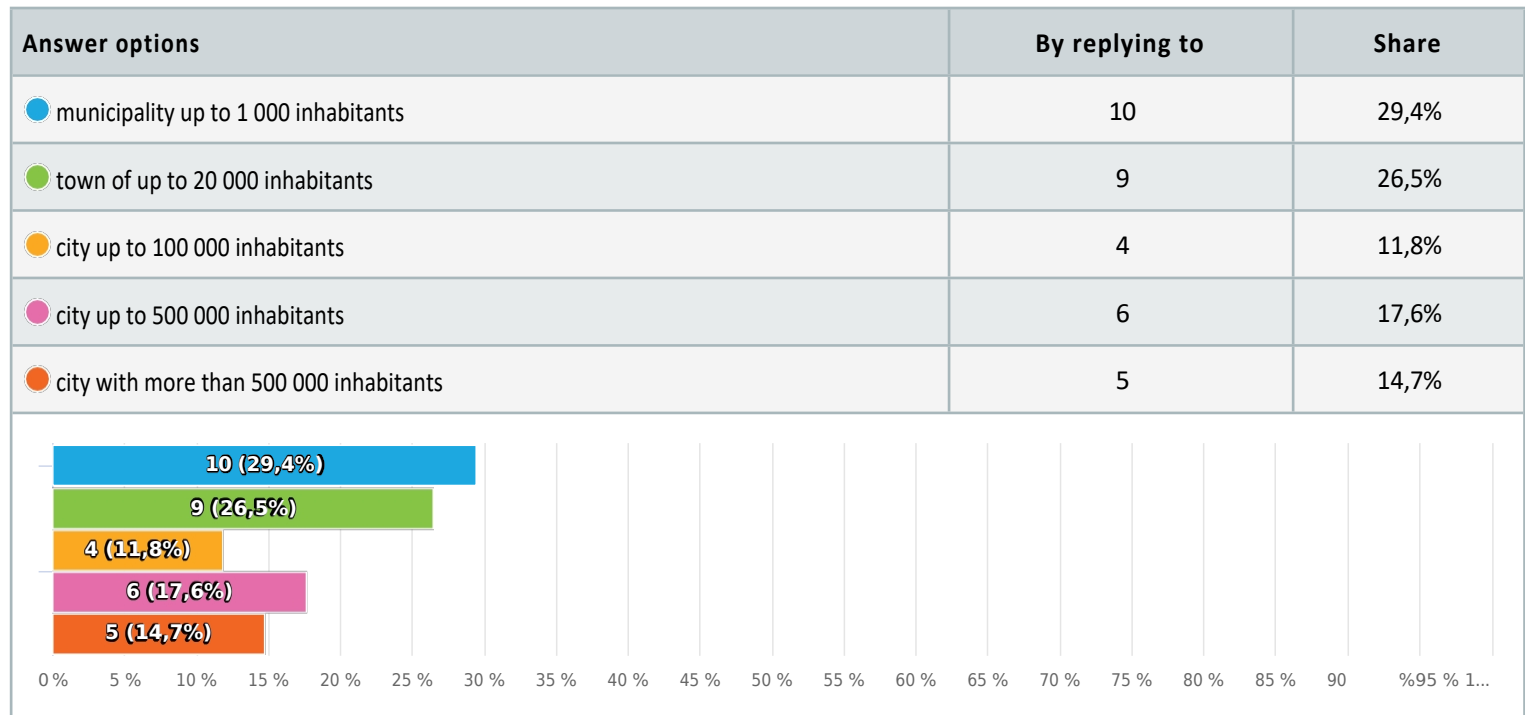
1 How old are you?

Choice of options , answered 34 x, not answered 0 x



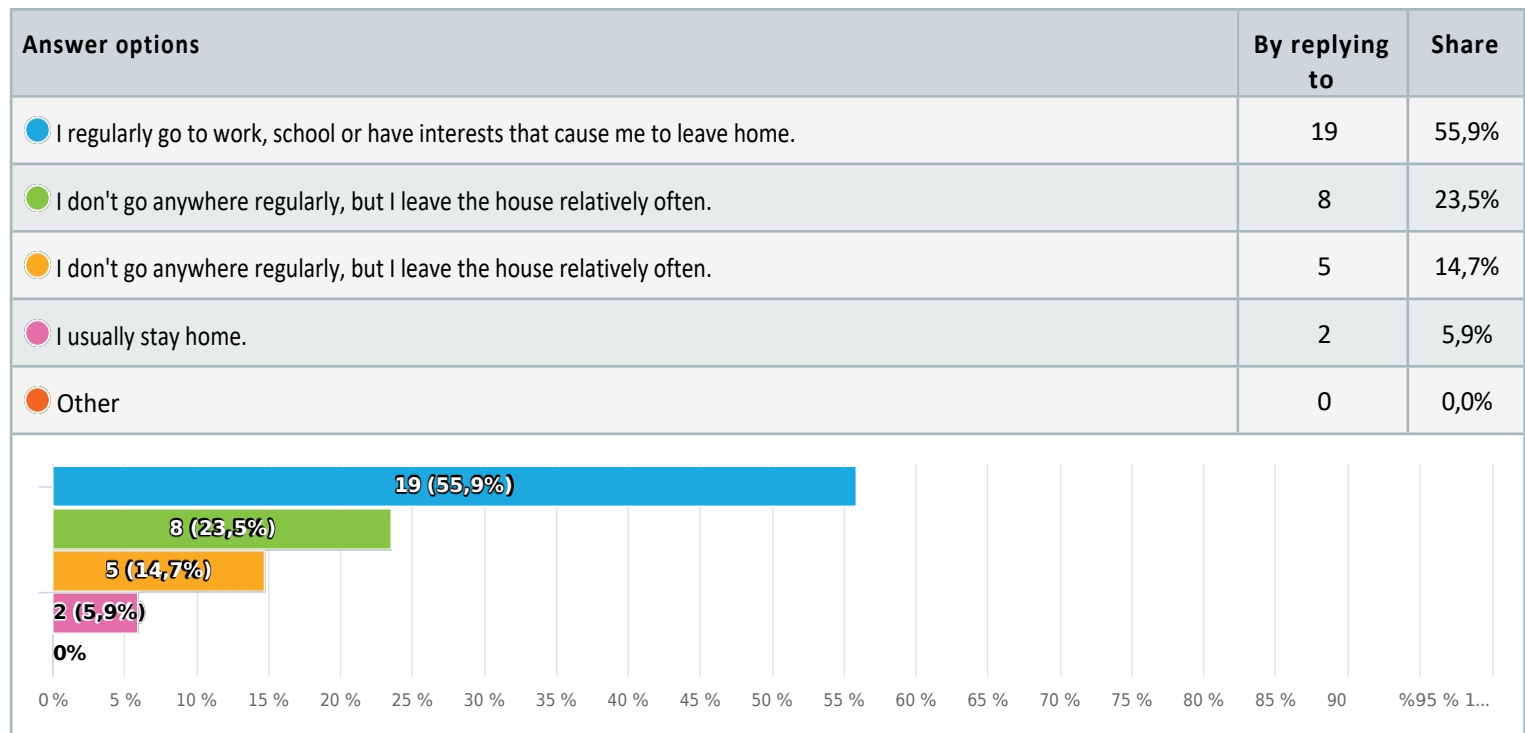
2 How big of a town/city do you live in?

Choice of options , answered 34 x, not answered 0 x



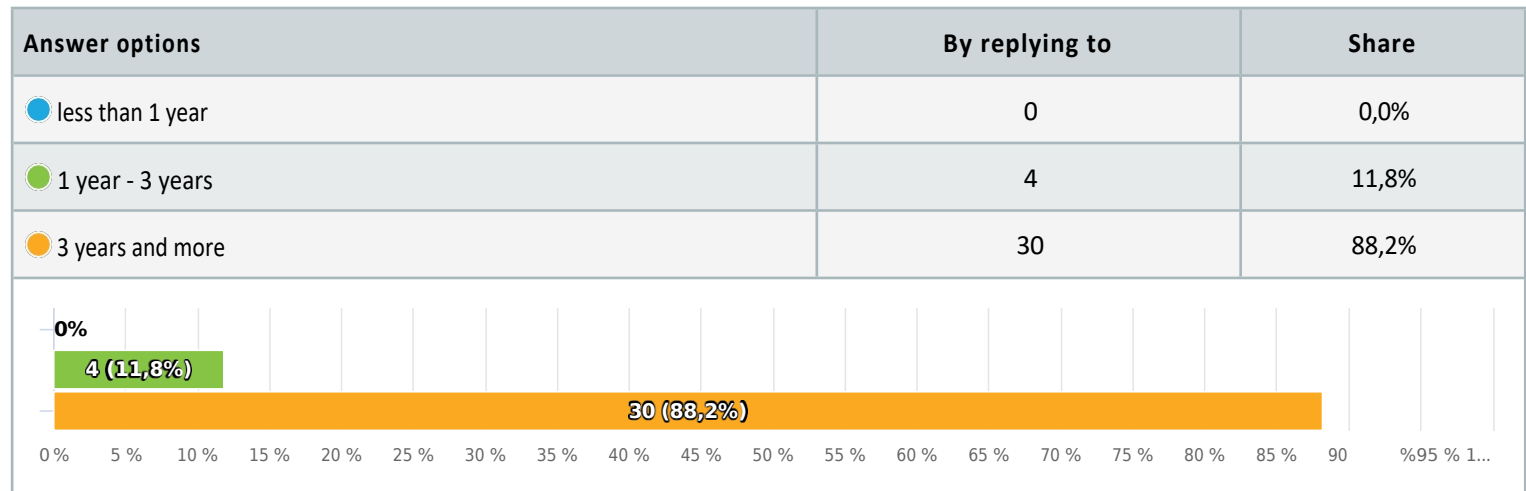
3 Do you go anywhere regularly?

Choice of options , answered 34 x, not answered 0 x



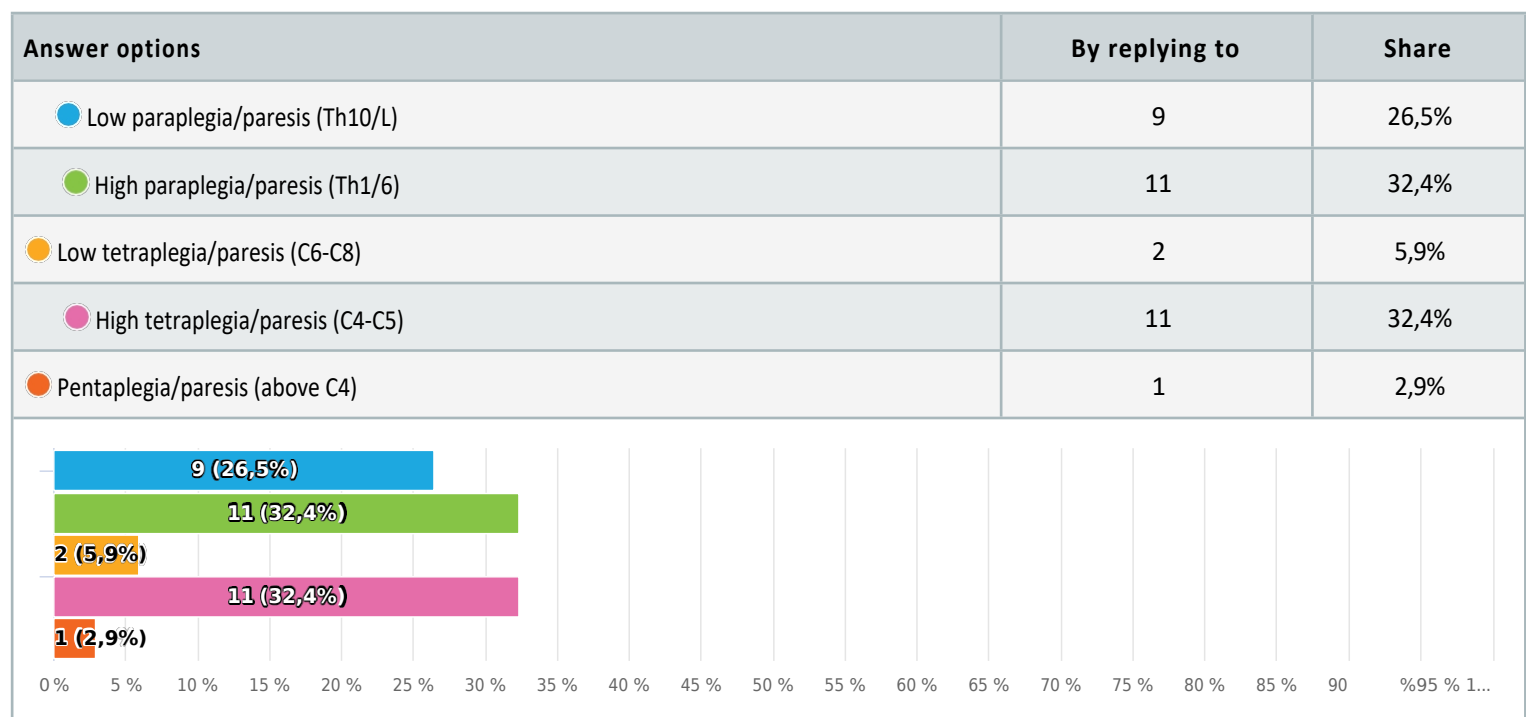
4 How long after the spinal cord injury?

Choice of options , answered 34 x, not answered 0 x



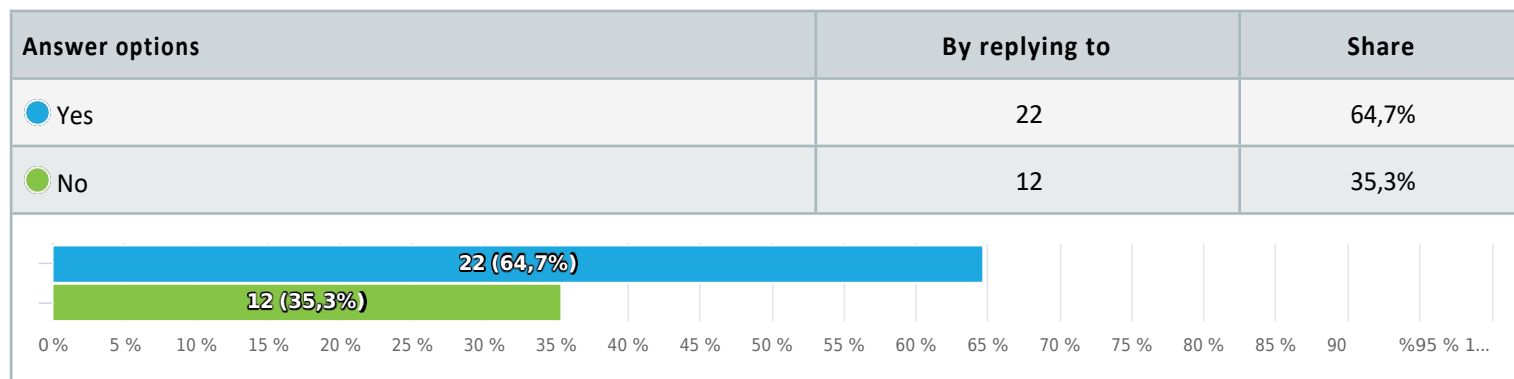
5 What is the height of the lesion/level of injury?

Choice of options , answered 34 x, not answered 0 x



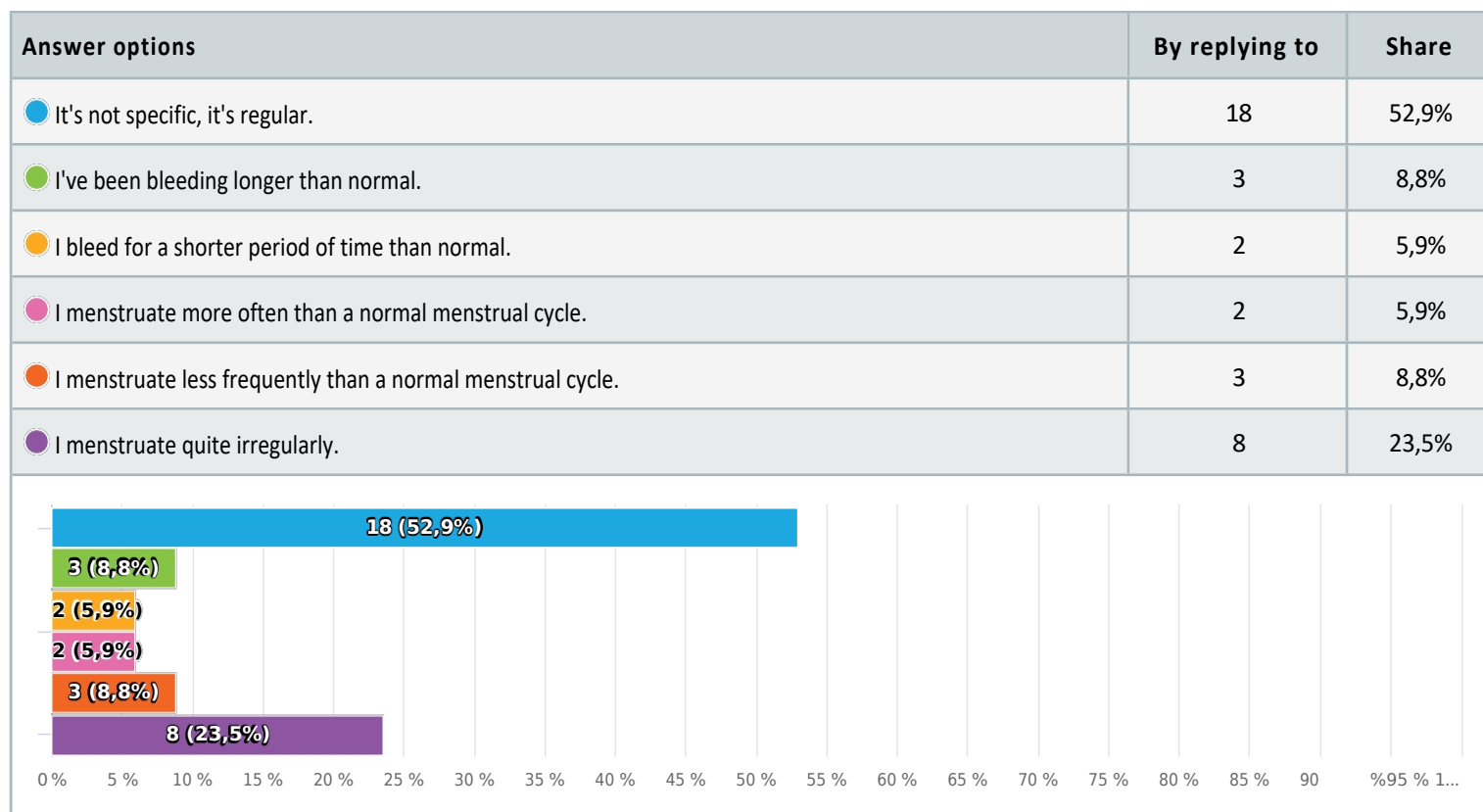
6 Is your menstrual cycle regular?

Choice of options , answered 34 x, not answered 0 x



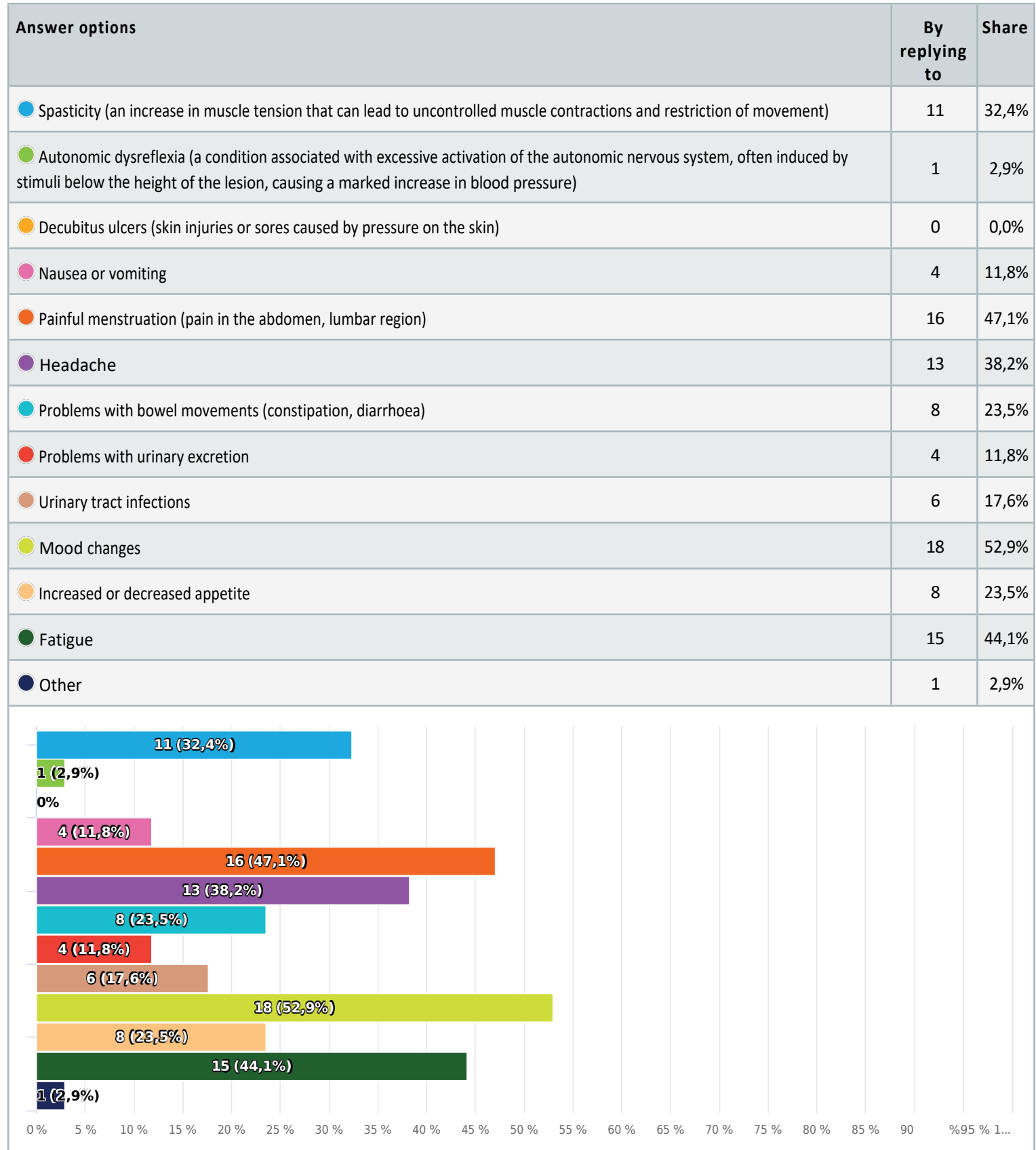
7 Is there anything specific about your menstrual cycle?

Multiple choice, multiple possible , answered 34 x, unanswered 0 x



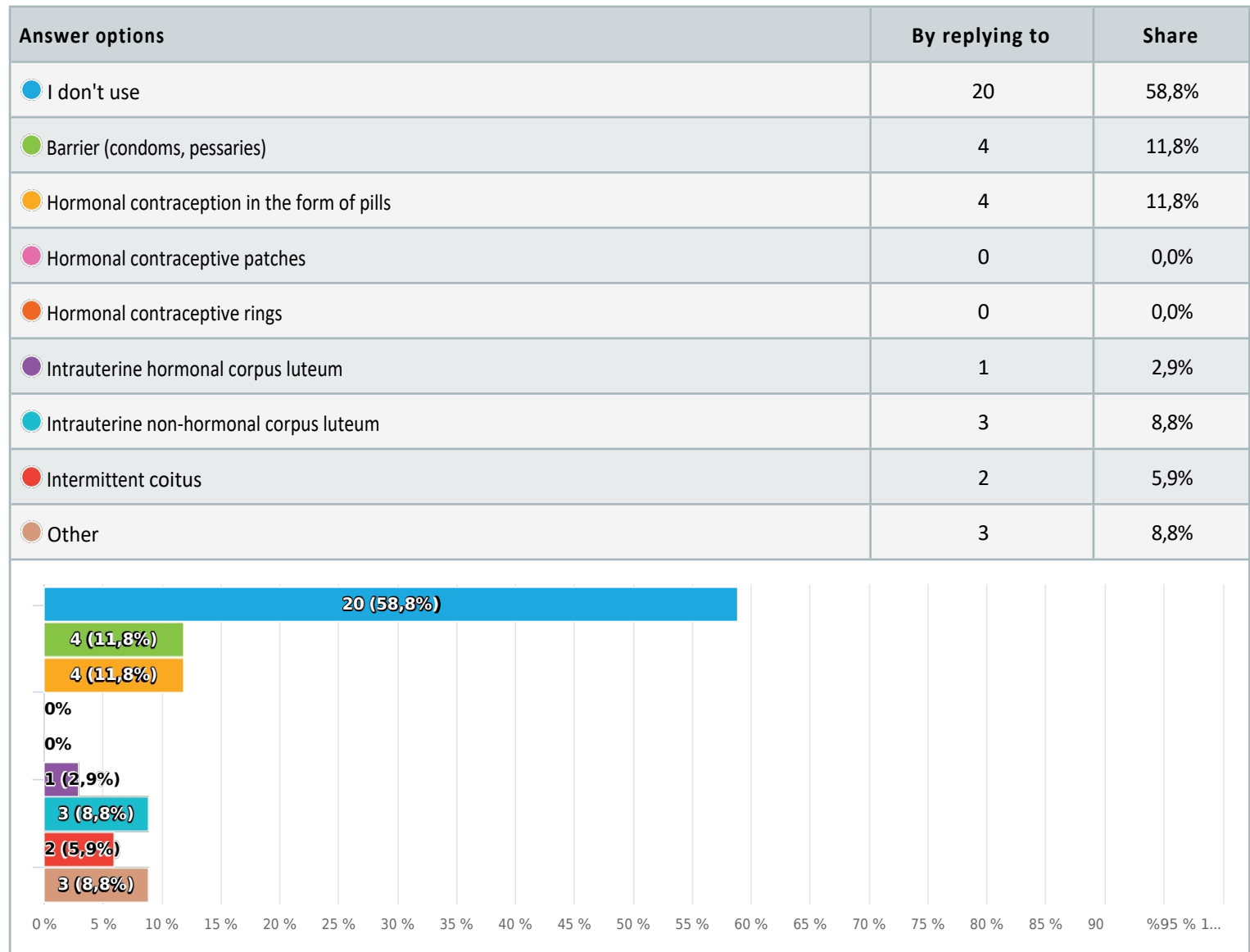
8 Please comment on what complications during menstruation do you perceive more than in the non-menstrual period?

Multiple choice, multiple possible, answered 34 x, unanswered 0 x



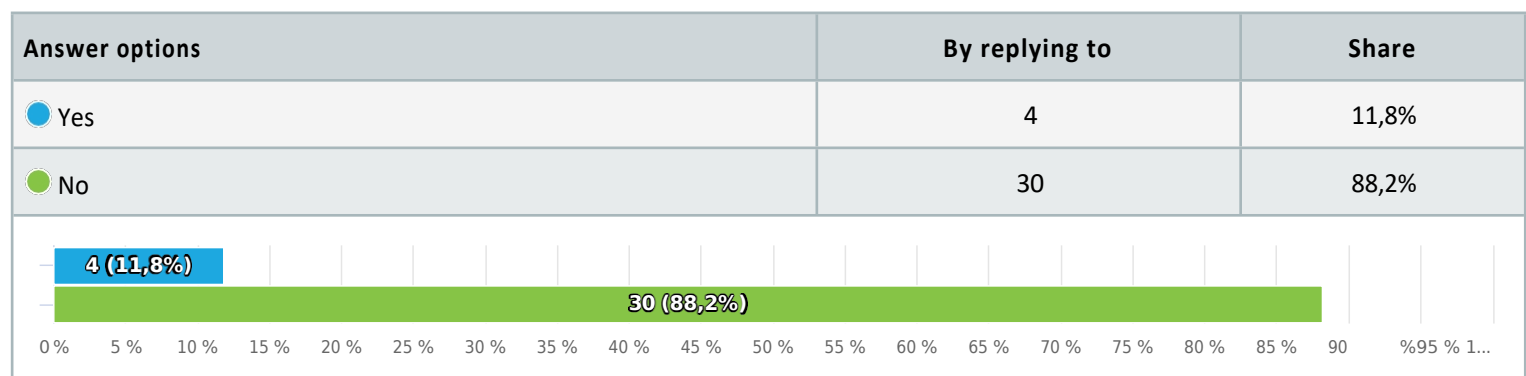
9 What kind of birth control do you take?

Multiple choice, multiple possible, answered 34 x, unanswered 0 x



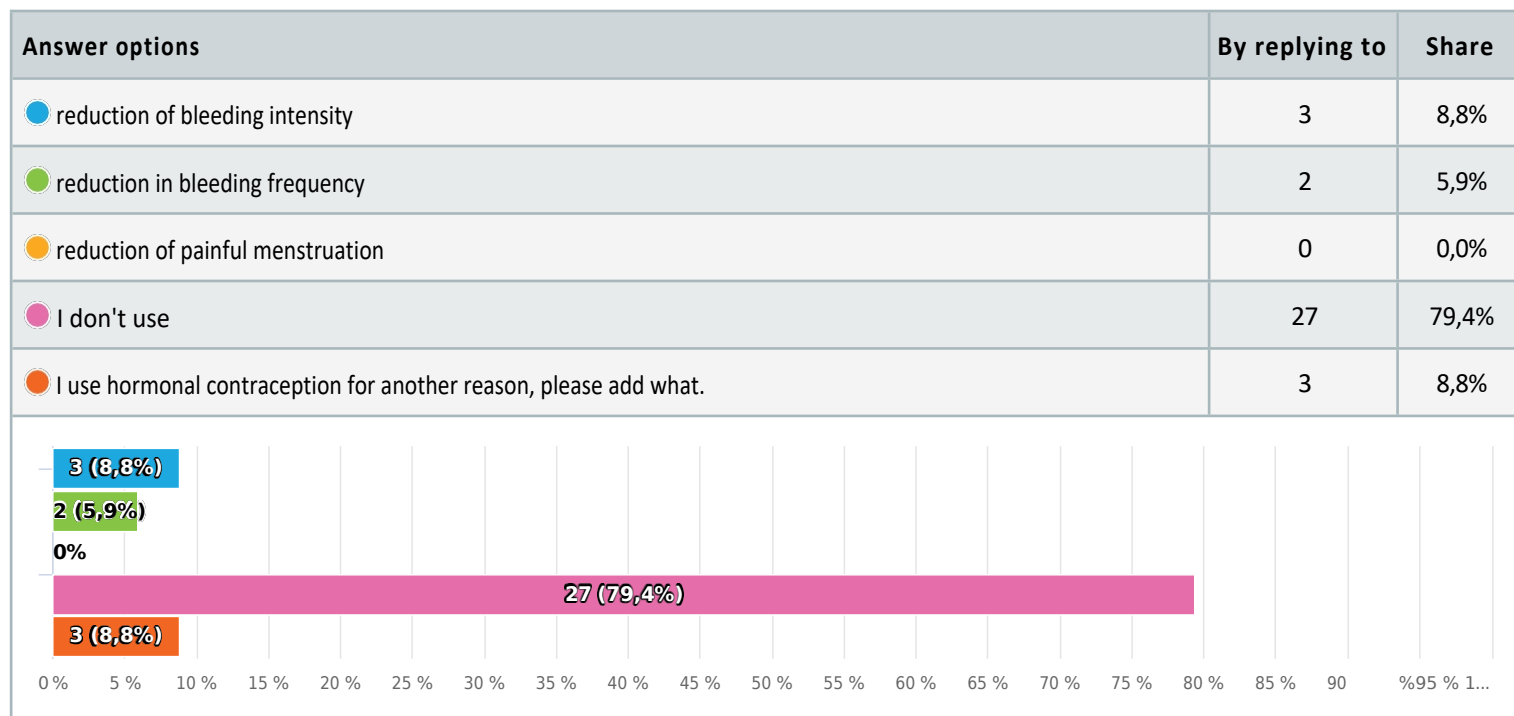
10 Are you taking birth control or other medications that affect your menstrual cycle?

Choice of options, answered 34 x, not answered 0 x



11 If you are taking hormonal contraceptives, for what reason?

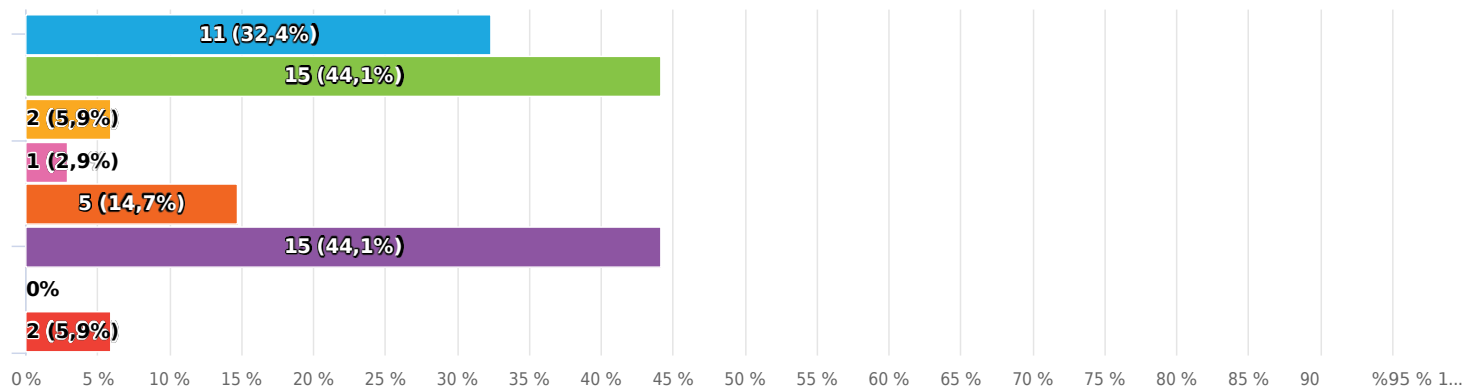
Multiple choice, multiple possible, answered 34 x, unanswered 0 x



12 What menstrual hygiene products do you use?

Multiple choice, multiple possible, answered 34 x, unanswered 0 x

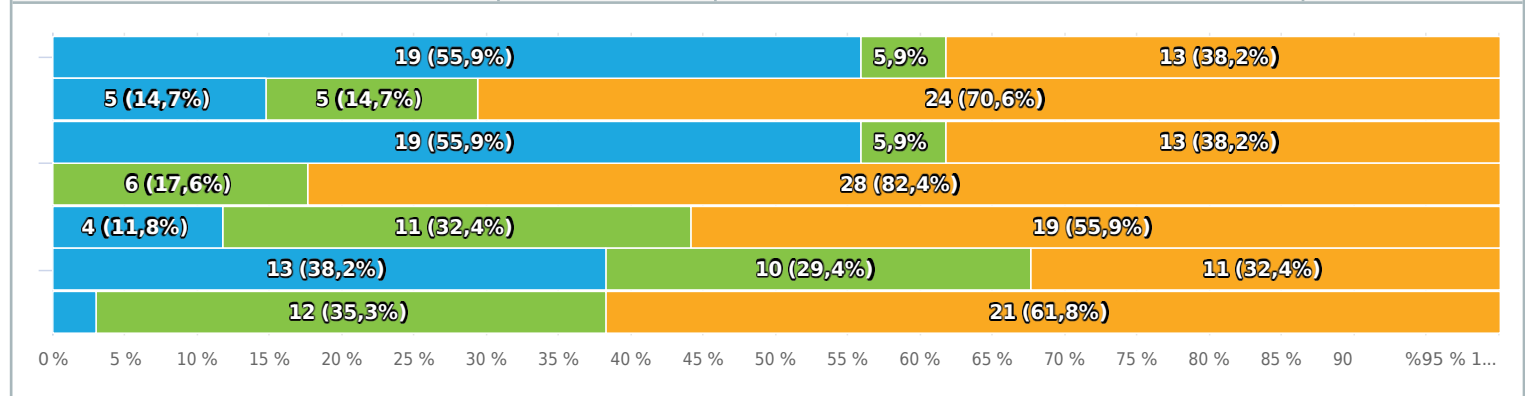
Answer options	By replying to	Share
☐ menstrual pads	11	32,4%
☐ menstrual tampons	15	44,1%
☐ menstrual cup	2	5,9%
☐ menstrual sponge	1	2,9%
☐ menstrual panties	5	14,7%
☐ diapers, diaper panties, insert diapers	15	44,1%
☐ tamponliner	0	0,0%
☐ something else	2	5,9%



13 Where do you exchange menstrual supplies?

Choice matrix, answered 34 x, unanswered 0 x

Answer	Commonly	In exceptional cases	At all
at home on the bed	19 (55,9%)	2 (5,9%)	13 (38,2%)
at home in a wheelchair	5 (14,7%)	5 (14,7%)	24 (70,6%)
at home on the toilet	19 (55,9%)	2 (5,9%)	13 (38,2%)
at home elsewhere	0	6 (17,6%)	28 (82,4%)
outside the home in a wheelchair	4 (11,8%)	11 (32,4%)	19 (55,9%)
outside the home on the toilet	13 (38,2%)	10 (29,4%)	11 (32,4%)
away from home elsewhere	1 (2,9%)	12 (35,3%)	21 (61,8%)



14 If you chose in the previous question that you routinely change your menstrual products "elsewhere at home" or "elsewhere away from home", please write where:

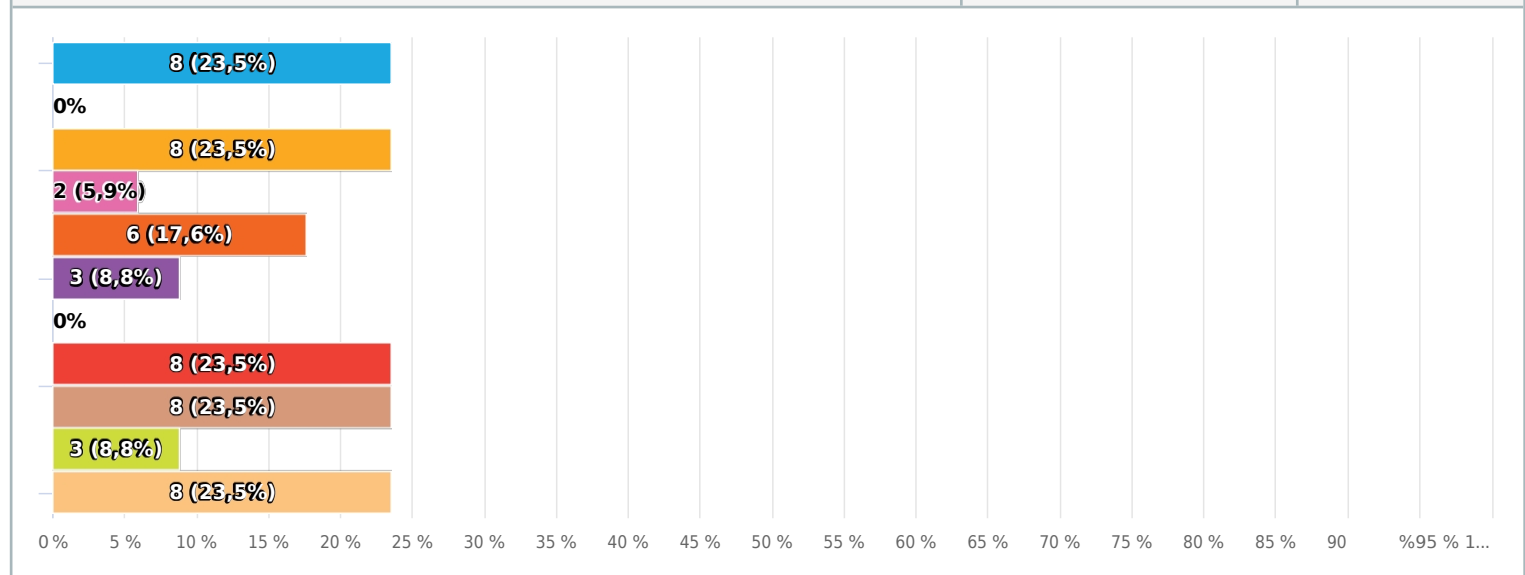
Text answer, answered 34 x, not answered 0 x

- (29x)
- car
- Outside the home only very rarely and only if I have the opportunity to lie down somewhere private e.g. when we are somewhere on a celebration with accommodation (so on a hotel)
- Sometimes in the car if necessary.
- When exchanging outside the home, bedside exchange is also necessary in these cases.

15 How were you introduced to the issue of menstruation after spinal cord injury?

Multiple choice, multiple possible, answered 34 x, unanswered 0 x

Answer options	By replying to	Share
Internet	8	23,5%
peer mentor	0	0,0%
women with spinal cord injury	8	23,5%
Occupational Therapists	2	5,9%
Doctors	6	17,6%
other medical staff	3	8,8%
Magazine	0	0,0%
gynaecologist	8	23,5%
spinal surgeons	8	23,5%
nurses	3	8,8%
Elsewhere	8	23,5%



16 What other information would you have liked to know before you encountered them in everyday life?

Text answer, answered 34 x, not answered 0 x

(20x)

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- What to do so that menstruation is not at all
- Information about the suitability and safety of using the cup
- hygiene during menstruation incontinent women
- self-care options and other women's experiences after spinal cord injury
- I don't think I need more information
- For example, you never know when menstruation will return, but before it does, the body often reacts inadequately and it takes a while to get used to the symptoms of the cycle... Headaches and spasticity often manifest themselves before menstruation and can make a person very uncomfortable
- I don't see a difference in menstruation before and after the injury. It's more the difficulty of changing sanitary products.
- I don't know
- I can't think of anything
- I can't think of anything
- Until 15 years ago, cycle information for women with spinal cord lesions was not freely available. I surfed the internet and searched in vain. After the injury, I became nervous when my menstrual cycle was absent for 8 months. Once it kicked in, it has been running regularly ever since I could adjust my watch accordingly. That actually surprised me too. What's different after the injury and very uncomfortable is the strength of the menstrual bleeding. I've been groping for a long time. Thank you to everyone who talks openly about menstruation, intimacy, sex, partnership, parenting.
- that after an injury it can take more than a year before the first menstrual period comes
- Greater incontinence during menstruation
- that menstruation is associated with greater spasticity

17 If your occupational therapist addressed any areas of menstruation with you, what were they?

Text answer , answered 34 x, not answered 0 x

- (21x)
- Unfortunately, the occupational therapist did not discuss menstruation, hygiene or the selection of appropriate menstrual aids with me. The only one who asked me about my cycle was my gynecologist.
- Communication, training
- self-reliance training and family training
- I am not aware of
- (2x) Not solved
- (2x) Not solved
- Didn't address it, there was no need
- Nothing was addressed
- I have not addressed this area with the occupational therapist.
- the file we practiced hand coordination (we managed to partially restore mobility - I have spastic quadriplegia with brown sequard syndrome with right-sided preleuviation - on the left we managed to restore mobility but there is no feeling, on the right it is almost to plegia, but the feeling is restored, the impairment is between C3 to C6)
- We haven't dealt with this at all

18 What other information would you like to receive?

Text answer , answered 34 x, not answered 0 x

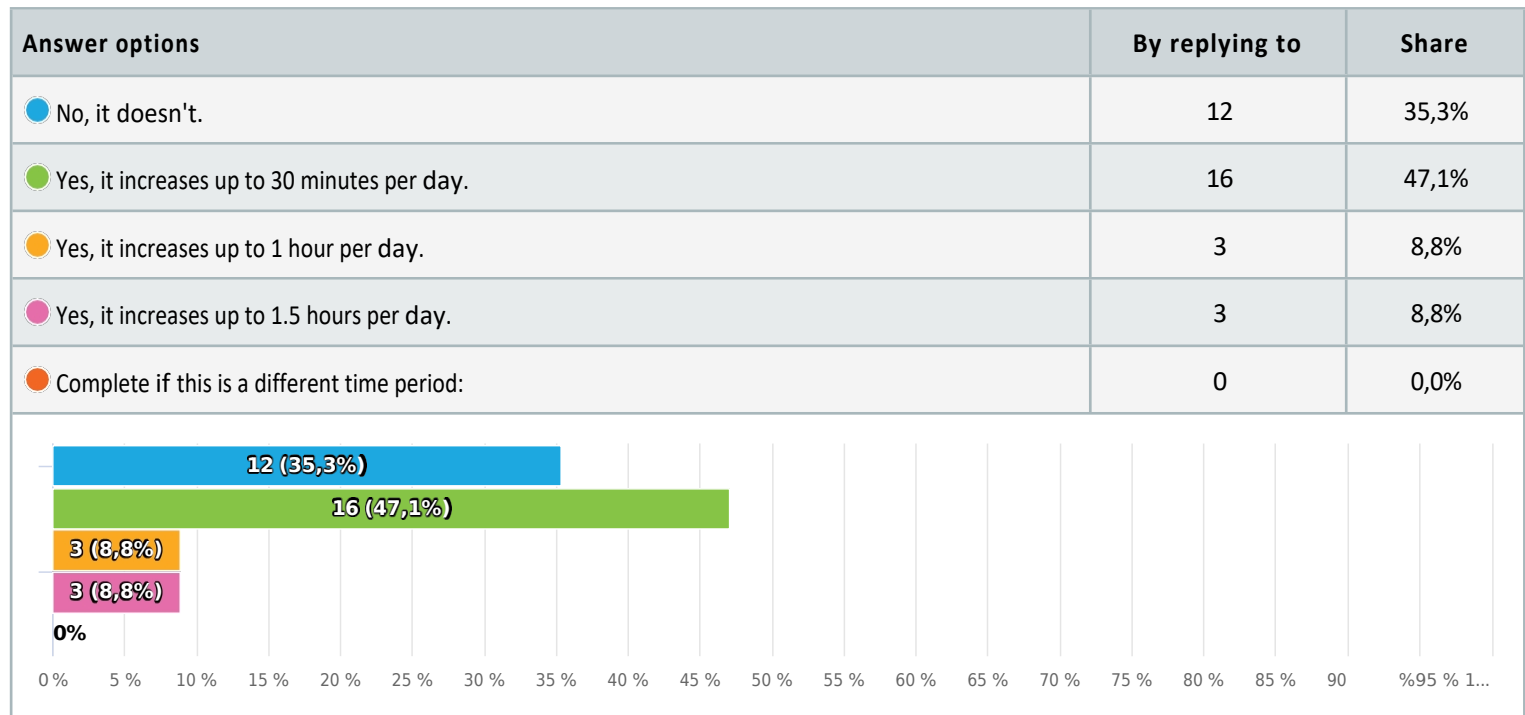
- (28x)
- I didn't even think to ask anything in this area
- (2x) I can't think of anything

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- I can't think of anything
- It's hard to judge, when I know everything after more than 20 years :(But certainly more interest in female reproductive organs, even today I still feel that more attention is paid to menses, just because they have these organs peeking out of their bodies and we don't... As far as sexuality is concerned.
- self-service gadgets

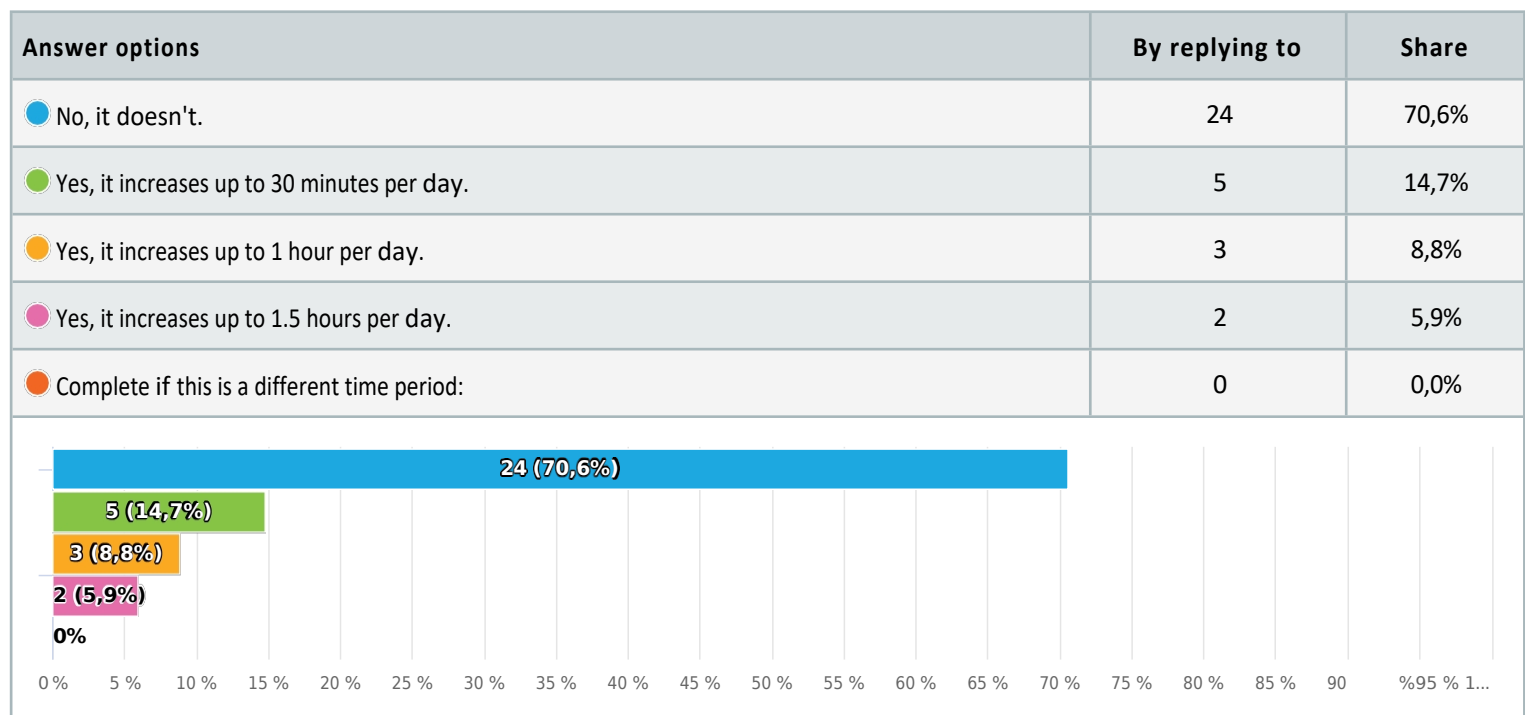
19 Does your need for time for personal hygiene during menstruation increase compared to the non-menstrual period?

Choice of options , answered 34 x, not answered 0 x



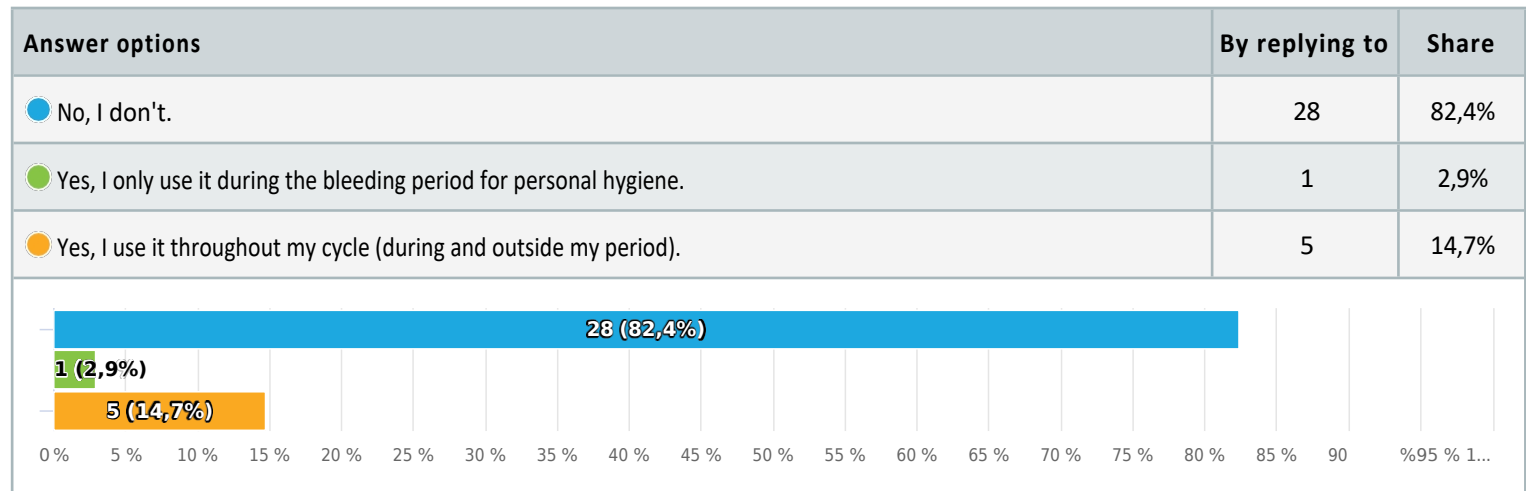
20 Does the time need for assistance from another person during menstruation increase?

Choice of options , answered 34 x, not answered 0 x



21 Do you use paid personal assistance services?

Choice of options , answered 34 x, not answered 0 x



22 If you use personal paid assistance, how much does one hour of this service cost you on average?

Text answer , answered 34 x, not answered 0 x

- ☒ (27x)
- ☐ 0
- ☐ 130
- ☐ 135
- ☐ 145
- ☐ (2x) 150
- ☐ 280

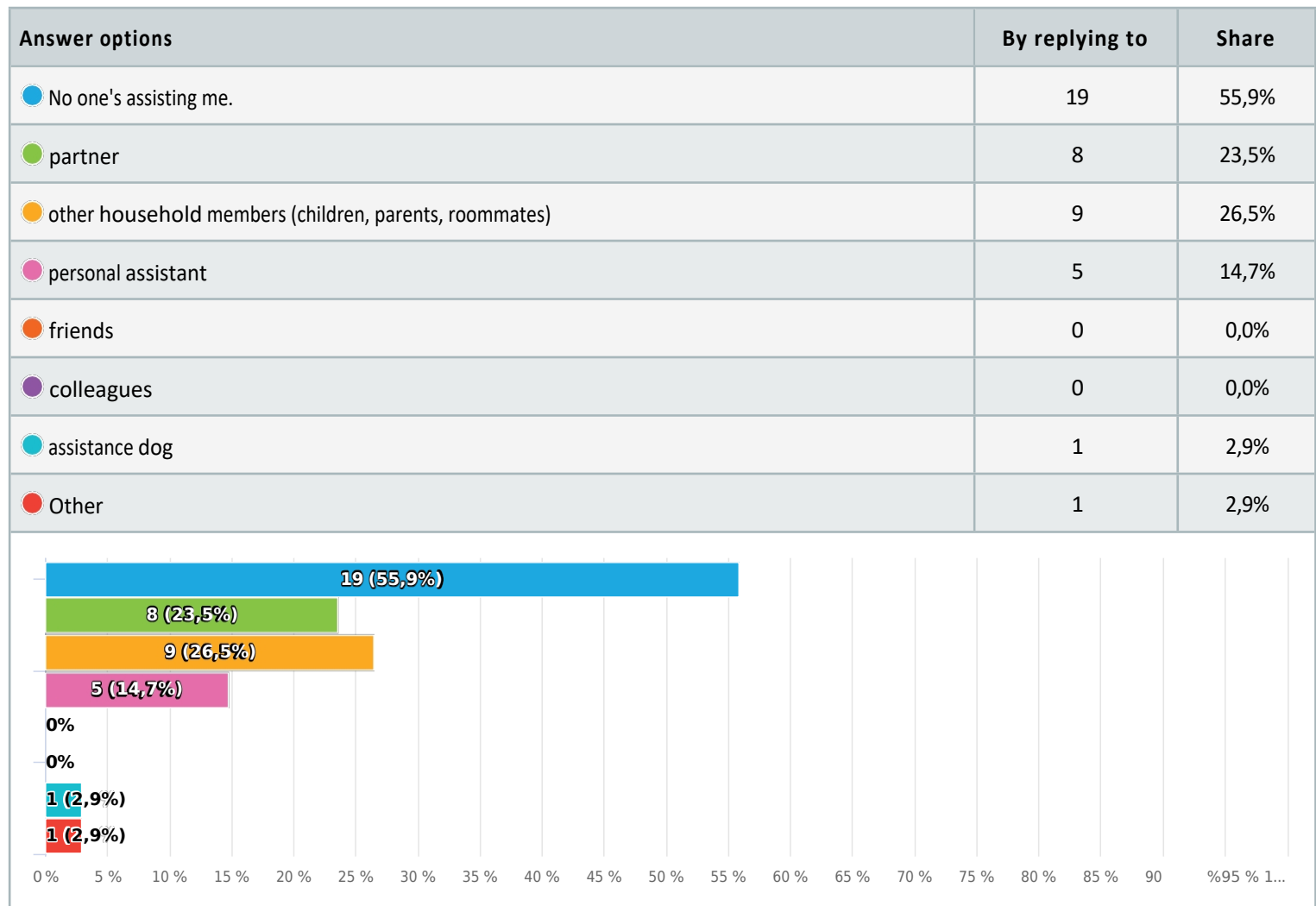
23 What is the potential increase in the price of personal assistance per day during menstruation compared to non-menstruation?

Text answer , answered 34 x, not answered 0 x

- ☒ (29x)
- ☐ (2x) 0
- ☐ (2x) 300
- ☐ 75

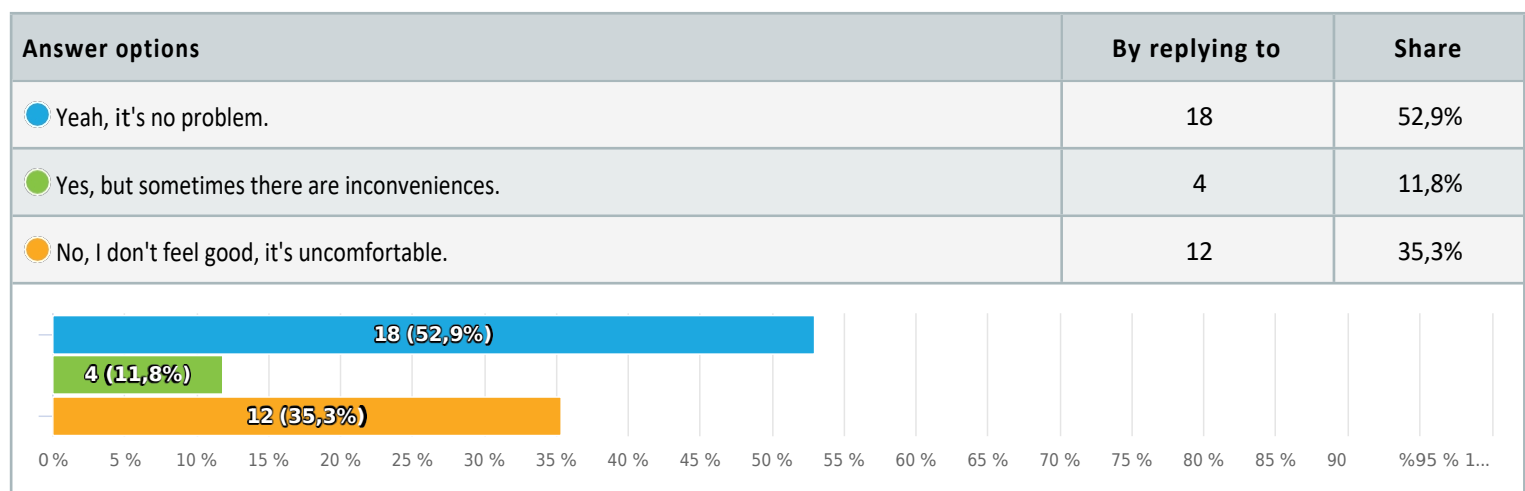
24 Who assists you with menstruation-related tasks?

Multiple choice, multiple possible, answered 34 x, unanswered 0 x



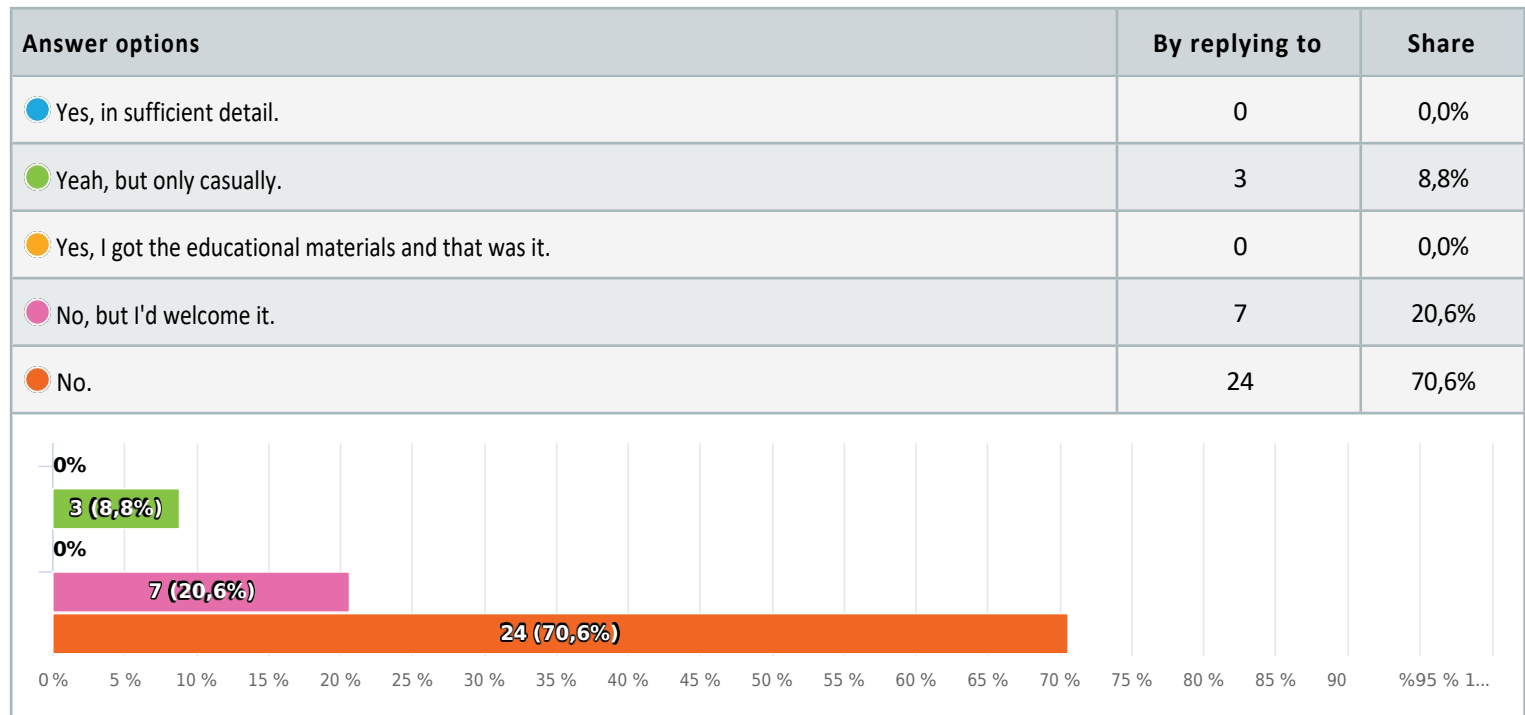
25 You can communicate intimate matters with an assistant.

Choice of options, answered 34 x, not answered 0 x



26 Has anyone ever addressed with you how to communicate with an assistant about intimate matters?

Choice of options , answered 34 x, not answered 0 x



27 Do you notice any other difference between assisting outside of menstruation and during menstruation?

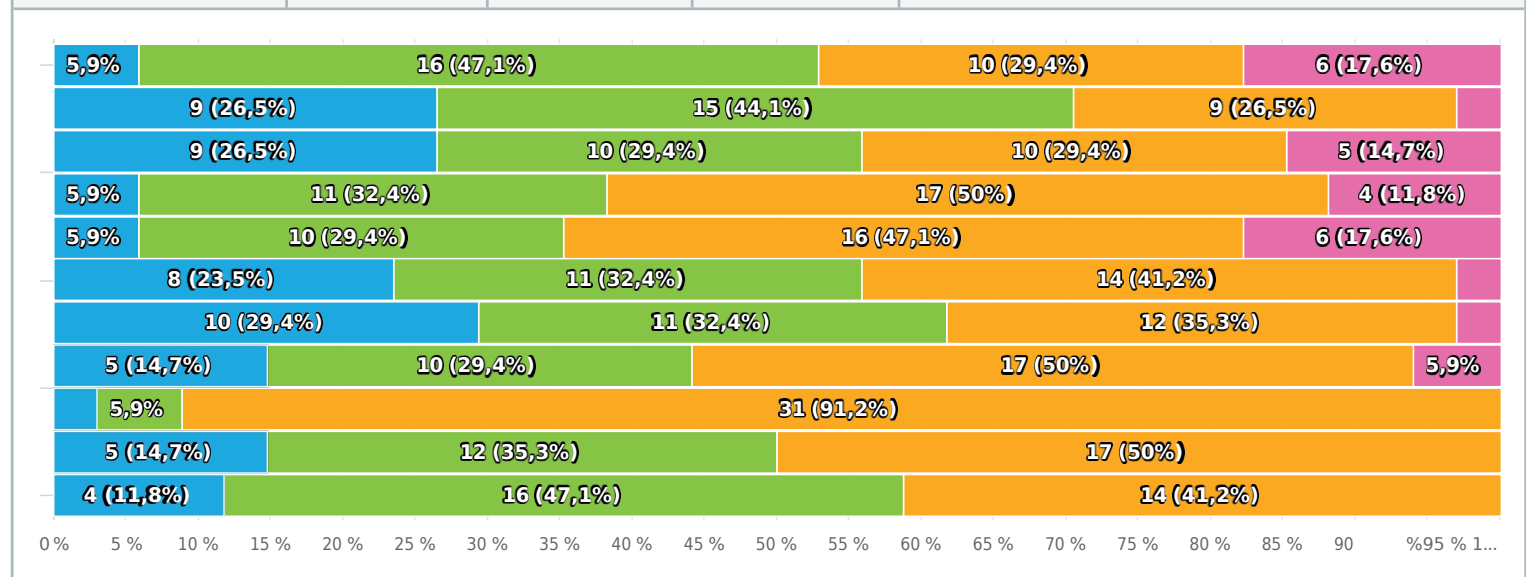
Text answer , answered 34 x, not answered 0 x

- ☐ (24x)
- ☐ I don't use assistance
- (2x) no
- ☐ No
- ☐ I don't perceive
- ☐ I don't use assistance in this regard
- ☐ I perceive myself that I keep more clean during my menstruation period, for example when I move from the shower to the trolley, from the toilet to the trolley.
- ☐ Shame, worse communication
- ☐ Definitely, I'm embarrassed during my period.
- ☐ During the mentoring period, I have to get help only from a personal assistant. I'd be embarrassed to deal with an assistant. And since I normally use an assistant. We always have to arrange to switch services so that the girls can assist on their periods.

28 How does menstruation limit you?

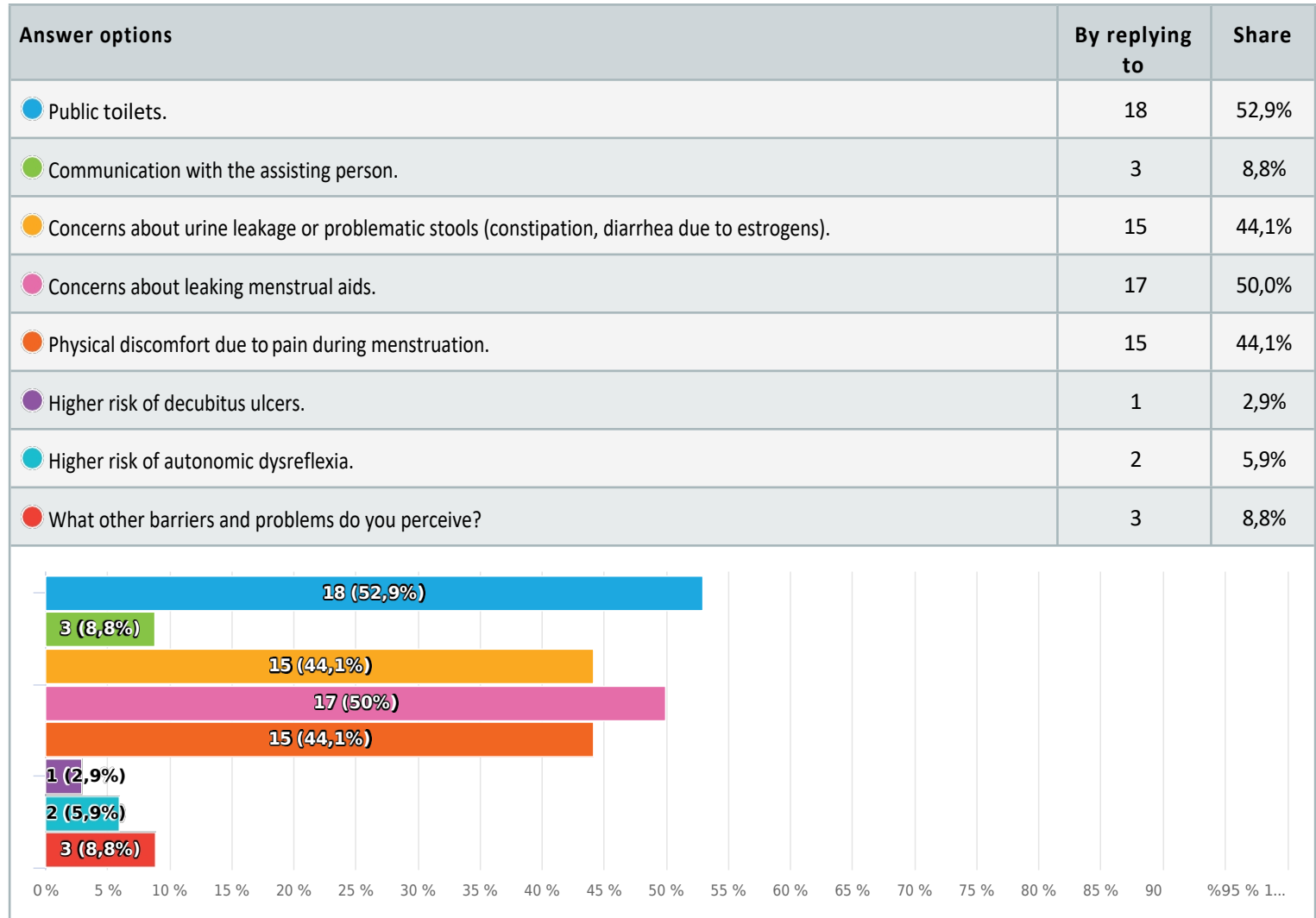
Choice matrix, answered 34 x, unanswered 0 x

Answer	Big limitation.	Slight limitation.	No restrictions.	I do not perform this item even in the off menstruation.
When studying or working.	2 (5,9%)	16 (47,1%)	10 (29,4%)	6 (17,6%)
In leisure activities.	9 (26,5%)	15 (44,1%)	9 (26,5%)	1 (2,9%)
In sports activities.	9 (26,5%)	10 (29,4%)	10 (29,4%)	5 (14,7%)
When taking care of the household.	2 (5,9%)	11 (32,4%)	17 (50,0%)	4 (11,8%)
In caring for others.	2 (5,9%)	10 (29,4%)	16 (47,1%)	6 (17,6%)
When dressing.	8 (23,5%)	11 (32,4%)	14 (41,2%)	1 (2,9%)
When performing personal hygiene.	10 (29,4%)	11 (32,4%)	12 (35,3%)	1 (2,9%)
When using the toilet.	5 (14,7%)	10 (29,4%)	17 (50,0%)	2 (5,9%)
When eating and drinking.	1 (2,9%)	2 (5,9%)	31 (91,2%)	0
When moving.	5 (14,7%)	12 (35,3%)	17 (50,0%)	0
When visiting doctors or offices.	4 (11,8%)	16 (47,1%)	14 (41,2%)	0



29 Select which barriers and problems you perceive as more significant during menstruation compared to the non-menstrual period.

Multiple choice, multiple possible, answered 34 x, unanswered 0 x



30 Can you think of anything else that menstruation limits you in? If so, please write what.

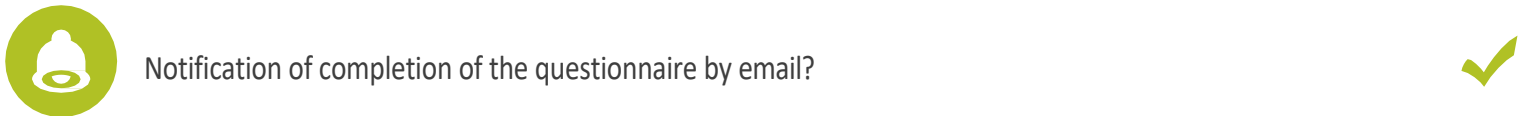
Text answer, answered 34 x, not answered 0 x

- ☐ .
- ☐ probably not
- ☐ More frequent visits to toilets, and this is always a problem outside the home
- ☐ When I don't sleep at home, I'm afraid of running at night.
- ☐ Menstruation does not restrict me in other areas
- ☐ no
- ☐ (8x) No
- ☐ Lack of accessible toilets in public places, during trips, etc., where it would be possible to change the menstrual device. The absence of a toilet shower, which I use at home.
- ☐ Don't come to mind

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- not applicable
- not applicable
- not applicable
- nothing
- Nothing
- I can't think of anything
- I can't think of anything :)
- it limits my sex life, when I have it, we both have the time and the mood, it's just that our periods don't favour us
- It limits everything
- PMS
- problematic catheterization at the time of MS
- Mainly changing menstrual supplies outside the home because I need to lie down. I therefore avoid staying away from home for long periods
- during clean intermittent catheterization.
- When sleeping - one suffers stronger spasticity and pain, it is harder to position oneself and fall asleep
- With tampons it is harder to insert the catheter
- a little in vacation and trip planning
- Great neuropathic pain
- Poor hygiene, I sit in a diaper all day. At night I sleep only on a mat, the whole menstrual period is complicated for a woman in a wheelchair.

Questionnaire settings



Annex: questionnaire

Menstruation after spinal cord injury and its impact on a woman's life from the perspective of an occupational therapist

Dear respondents,

With anticipation, I invite you to participate in an online survey that forms an integral part of my bachelor thesis. To complete the questionnaire, you must be **a woman over the age of eighteen with a spinal cord injury who is menstruating or has menstruated in the last three years if you have a spinal**

The topic of my research is "**Menstruation after spinal cord injury and its impact on a woman's life from the perspective of an occupational therapist**". I am a third year student in this field and would like to contribute to the understanding of the impact of menstruation on the daily life of a woman with spinal cord injury.

The aim of my thesis is to provide a detailed look at the differences between the period outside of menstruation and the period during menstrual bleeding in women with spinal cord injury, with an emphasis on identifying the areas that menstruation can affect. Your answers will help us better understand the barriers you face as a result of your disability and menstruation.

Your participation is very valuable and it will take you **approximately 15 minutes** to complete the questionnaire. Your answers will help to shift the therapeutic approach in this area and help to identify where work needs to be done in the rehabilitation of spinal cord injuries. Thank you for your willingness and support in this research initiative. Your responses will be included in the research and the questionnaire is completely anonymous.

Sincerely, Štěpánka Pilařová, student of occupational therapy, 3rd year

If you have any questions, please do not hesitate to contact me at my email: stepka.pilar@seznam.cz

1 How old are you?

Question Help: *select one answer*

☐ 18-20 ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ 51-more

2 How big of a town/city do you live in?

Question Help: *select one answer*

☐ municipality up to 1 000 inhabitants to 500 000 inhabitants ☐ town up to 20 000 inhabitants ☐ town up to 100 000 inhabitants ☐ city up to 500 000 inhabitants ☐ city with more than 500 000 inhabitants

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3 Do you go anywhere regularly?

Question Help: select one answer

- ☐ I regularly go to work, school or have interests that cause me to leave Home. ☐ I don't go anywhere regularly, but I leave the house relatively Often. ☐ I don't go anywhere regularly, but I leave the house relatively Often. ☐ Mostly I stay at home.
- ☐ Other

4 How long after the spinal cord injury?

Question Help: select one answer

- ☐ less than 1 year ☐ 1 year - 3 years ☐ 3 years and more

5 What is the height of the lesion/level of injury?

Question Hint: Paraplegia means a disability of the lower part of the body. Low paraplegia affects the limbs and trunk, but the upper body remains unaffected. High paraplegia affects the body at a higher level, including for example the chest and upper back. Tetraplegia, also known as quadriplegia, affects all four limbs. In low tetraplegia, some upper body functions may be preserved. High tetraplegia affects all four limbs and also the neck area, which can affect breathing. Pentaplegia refers to the involvement of all four limbs, the trunk and facial muscles.

- ☐ Low paraplegia/paresis (Th10/L) ☐ High paraplegia/paresis (Th1/6) ☐ Low tetraplegia/paresis (C6-C8) ☐ High tetraplegia/paresis (C4-C5)
- ☐ Pentaplegia/paresis (above C4)

6 Is your menstrual cycle regular?

Question Hint: (A regular menstrual cycle lasts 23-35 days and the bleeding itself lasts 3-7 days.) Choose one answer

- ☐ Yes ☐ No

7 Is there anything specific about your menstrual cycle?

Question Hint: (A regular menstrual cycle lasts 23-35 days and the bleeding itself lasts 3-7 days.) Select one or more answers

- ☐ It's not specific, it's regular. ☐ I've been bleeding for longer than normal. ☐ I bleed for a shorter period of time than normal. ☐ I menstruate more often than a normal menstrual cycle.
- ☐ I menstruate less frequently than a normal menstrual cycle. ☐ I menstruate quite irregularly.

8 Please comment on what complications during menstruation do you perceive more than in the non-menstrual period?

Question Help: select one or more answers

- | | | | |
|---|---|--|--|
| ☐ Spasticity (an increase in muscle tension that can lead to uncontrolled muscle contractions and restriction of movement) | ☐ Autonomic dysreflexia (a condition associated with excessive activation of the autonomic nervous system, often induced by stimuli below the height of the lesion, causing a marked increase in blood pressure) | ☐ Decubitus ulcers (skin injuries or ulcers caused by pressure on the skin) | ☐ Nausea or vomiting |
| ☐ Painful menstruation (pain in the abdomen, lumbar region) | ☐ Headache | ☐ Problems with bowel movements (constipation, diarrhea) | ☐ Problems with urinary excretion |
| ☐ Urinary tract infections | ☐ Mood changes | ☐ Increased or on the contrary, reduced appetite | ☐ Fatigue |
| ☐ Other <input type="text"/> | | | |

9 What kind of birth control do you take?

Question Help: select one or more answers

- | | | | |
|---|--|--|---|
| ☐ I don't use | ☐ Barrier (condoms, pessaries) | ☐ Hormonal contraception in the form of pills | ☐ Hormonal contraceptive patches |
| ☐ Hormonal contraceptive rings | ☐ Intrauterine hormonal corpus luteum | ☐ Intrauterine non-hormonal corpus luteum | ☐ Intermittent coitus |
| ☐ Other <input type="text"/> | | | |

10 Are you taking birth control or other medications that affect your menstrual cycle?

Question Help: Delay menstruation, reduce the intensity of bleeding... Select one answer

- ☐ Yes ☐ No

11 If you are taking hormonal contraception, for what reason?

Question Hint: Hormonal contraception can be in the form of pills, hormonal IUD, hormonal rings, patches... Select one or more answers

- | | | | |
|--|--|--|--------------------------------------|
| ☐ reduction of bleeding intensity | ☐ Reduction in bleeding | ☐ reduction of painful menstruation | ☐ I don't use |
| ☐ frequency I am using hormonal contraception for another reason, please add what it is. <input type="text"/> | | | |

12 What menstrual hygiene products do you use?

Question Help: select one or more answers

- ☐ menstrual pads
 ☐ menstrual tampons
 ☐ menstrual cup
 ☐ menstrual sponge
 ☐ menstrual panties
- ☐ diapers, diaper panties, insert diapers
 ☐ tamponliner
- ☐ something else

13 Where do you exchange menstrual supplies?

Question Hint: Choose one answer in each row

	Commonly	In exceptional cases	Not at all
at home on the bed	☐	☐	☐
at home in a wheelchair	☐	☐	☐
at home directly to the	☐	☐	☐
toilet at home	☐	☐	☐
elsewhere	☐	☐	☐
outside the home in a wheelchair	☐	☐	☐
away from home to directly to	☐	☐	☐
the toilet away from home			
elsewhere			

14 If you chose in the previous question that you routinely change your menstrual products "elsewhere at home" or "elsewhere away from home", please write where:

15 How were you introduced to the issue of menstruation after spinal cord injury?

Question Help: select one or more answers

- ☐ Internet ☐ peer mentor ☐ women with spinal cord injury ☒ Occupational Therapists ☐ doctors ☐ other medical Staff
- ☐ Magazine ☐ Gynaecologist ☐ spinal surgeons ☐ nurses
- ☐ Elsewhere

16 What other information would you have liked to know before you encountered them in everyday life?

17 If your occupational therapist addressed any areas of menstruation with you, what were they?

Help to the question: practicing self-sufficiency in hygiene, use or selection of menstrual aids, communication with an assistant,...

18 What other information would you like to receive?

19 Does your need for time for personal hygiene during menstruation increase compared to the non-menstrual period?

Question Help: select one answer

- ☐ No, it doesn't. ☐ Yes, it increases up to 30 minutes per day. ☐ Yes, increases up to 1 hour per day. ☐ Yes, it increases up to 1.5 hours per day.
- ☐ Complete if this is a different time period:

20 Does the time need for assistance from another person during menstruation increase?

Question Help: select one answer

- ☐ No, it doesn't. ☐ Yes, it increases up to 30 minutes per day. ☐ Yes, increases up to 1 hour per day. ☐ Yes, it increases up to 1.5 hours per day.
- ☐ Complete if this is a different time period:

21 Do you use paid personal assistance services?

Question Help: select one answer

- ☐ No, I don't. ☐ Yes, I only use it during the bleeding period for personal hygiene. ☐ Yes, I use it throughout my cycle (during and outside my period).

22 If you use personal paid assistance, how much does one hour of this service cost you on average?

Question Help: if you do not use paid personal assistance services, please do not fill in. Please do not use personal assistance. Please write only the number.

23 What is the potential increase in the price of personal assistance per day during menstruation compared to non-menstruation?

Question Help: if you do not use paid personal assistance services, please do not fill in. Please do not use personal assistance. Please write only the number.

24 Who assists you with menstruation-related tasks?

Question Help: select one or more answers

- ☐ Nobody's assisting me. ☐ partner ☐ other household members (children, parents, roommates) ☐ personal assistant ☐ friends
- ☐ colleagues ☐ Assist dog
- ☐ Other

25 You can communicate intimate matters with an assistant.

Question Help: select one answer

- ☐ Yeah, it's no problem. ☐ Yes, but sometimes there are inconveniences. ☐ No, it doesn't feel good, it makes me uncomfortable.

Menstruation after spinal cord injury and its impact on a woman's life from the perspective of an occupational therapist

26 Has anyone ever addressed with you how to communicate with an assistant about intimate matters?

Question Help: *select one answer*

- ☐ Yes, in sufficient detail. ☐ Yeah, but only casually. ☐ Yes, I got the educational materials and that was it. ☐ No, but I'd welcome it.
- ☐ No.

27 Do you notice any other difference between assisting outside of menstruation and during menstruation?

28 How does menstruation limit you?

Question Hint: *Choose one answer in each row*

	Big limitation.	Moderate restriction.	No restriction.	I don't do this item even in non-menstrual periods.
When studying or working.	☐	☐	☐	☐
In leisure activities. In sports	☐	☐	☐	☐
activities. Household care.	☐	☐	☐	☐
In caring for	☐	☐	☐	☐
others. When	☐	☐	☐	☐
dressing.				
When performing personal hygiene.	☐	☐	☐	☐
When using the toilet.	☐	☐	☐	☐
When eating and	☐	☐	☐	☐
drinking. When	☐	☐	☐	☐
moving.		☐	☐	☐
When visiting doctors or offices.	☐			

29 Select which barriers and problems you perceive as more significant during menstruation compared to the non-menstrual period.

Question Help: *select one or more answers*

- | | | | |
|---|---|--|---|
| ☐ Public toilets. | ☐ Communication with an assistant. | ☐ Concerns about urine leakage or problematic stools (constipation, diarrhea due to estrogens). | ☐ Concerns about leaking menstrual aids. |
| ☐ Physical discomfort due to pain during menstruation. | ☐ Higher risk of decubitus ulcers. | ☐ Higher risk of autonomic dysreflexia. | |
| ☐ What other barriers and problems do you perceive? | | | |

30 Can you think of anything else that menstruation limits you in? If so, please write what.