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Peyronie's disease - Beyond the bend

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Appendices

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Appendix A (translated from Dutch)

Questionnaire Peyronie's disease

Surname:
Initials:
Date of birth:



TO BE FILLED OUT BY THE PATIENT

This questionnaire considers sexual relationships and related language to be heterosexual. We do not mean to offend homosexual men. In case of homosexuality, please read anus or other substitute where vagina is mentioned.

What is the date today? - - 20..... (day-month-year)

In the passed you may or may not have undergone Peyronie's disease related surgery. If this is not the case, please proceed to question 11.

What was the date of surgery? - - (day-month-year)

1. Which procedure was performed? Please circle the correct procedure and if relevant the used grafting material. In case of multiple procedures please add the chronological order.
 - ☐ Surgery according to Nesbit with circumcision
 - ☐ Excision or incision and grafting (pericard/tachosil/gore-tex) with circumcision
 - ☐ Semirigid penile prosthesis
 - ☐ Inflatable penile prosthesis
2. Are you circumcized?
 - ☐ Yes, during the above mentioned procedure
 - ☐ Yes, previously
 - ☐ Yes, after the above mentioned procedure
 - ☐ No, because

3. You underwent surgery because of Peyronie's Disease. Would you be willing to undergo the same intervention with the knowledge of the end result?
☐ Yes ☐ No

4. If a friend of yours would be in your situation before surgery. Would you advise him to undergo the same intervention you underwent?
☐ Yes ☐ No ☐ I don't know

5. Can you mark the end result (0-10)?
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ No

6. Does there remain to be a curvature after surgery? Direction (multiple answers possible):
☐ Up ☐ Left ☐ No
☐ Down ☐ Right degrees

7. Has a new curvature developed since the intervention? Direction (multiple answers possible):
☐ Up ☐ Left ☐ No
☐ Down ☐ Right degrees

8. Did your penis shorten, because of surgery?
☐ Yes, ... cm ☐ No

9. For how long did you experience pain after surgery? (Please circle and indicate the appropriate time in days/weeks/months)

 None..... days/weeks/months

10. Did you develop any urinary tract symptoms since surgery and if so: which ones?
☐ No ☐ Yes

11. After being diagnosed with Peyronie's Disease, did you ever undergo psychological/psychiatric treatment?
☐ Yes, because of Peyronie's Disease ☐ No
☐ Yes, because of something else

12. How is your penile rigidity currently compared with before the disease (100%)? Please circle the right answer.

- ☐ 10% ☐ 20% ☐ 30% ☐ 40% ☐ 50%
☐ 60% ☐ 70% ☐ 80% ☐ 90% ☐ 100%

13. Do you experience premature softening/loss of tumescence?

- ☐ Always ☐ Often ☐ Sometimes
☐ Almost never ☐ Never

14. Do you experience loss of penile sensibility and if so: where?

- ☐ No ☐ Glans
☐ Other part,

15. What caused the penile sensibility loss?

- ☐ Surgery ☐ Peyronie's Disease
☐ Circumcision ☐ I don't know
☐ Something different,

16. Are you capable of having sexual intercourse?

- ☐ Yes ☐ No
☐ Yes, but I'm restricted by

17. During sexual intercourse, does the penis often fall out of the vagina?

- ☐ Yes ☐ Not applicable
☐ No

18. Can you reach an orgasm?

- ☐ Yes, easily ☐ No
☐ Yes, but it's not easy
☐ Yes, but it's very hard to do so

19. Was that easier before you suffered from Peyronie's Disease?

- ☐ Yes, it used to be easier
☐ No, it used to be the same
☐ No, it used to be harder

20. Do you have an exclusive (sexual) partner?

- ☐ Yes ☐ No

21. Does your partner experience pain during sexual intercourse, because of the shape of your penis?

☐ Yes ☐ No

22. Is your partner satisfied with your current sex life?

☐ Yes ☐ I don't know
☐ No ☐ Not applicable

23. Do you use erection stimulating drugs?

☐ Levitra (vardenafil) ☐ Cialis (tadalafil)
☐ Viagra (sildenafil) ☐ Other,
☐ Androskat injecties ☐ No

24. Do you experience any other Peyronie's Disease related problems?

☐ No ☐ Yes,

The International Index of Erectile Function

These questions ask about the effects that your erection problems have had on your sex life over the last four weeks. Please try to answer the questions as honestly and as clearly as you are able. Your answers will help your doctor to choose the most effective treatment suited to your condition. In answering the questions, the following definitions apply:

- **sexual activity** includes intercourse, caressing, foreplay & masturbation
- **sexual intercourse** is defined as sexual penetration of your partner
- **sexual stimulation** includes situation such as foreplay, erotic pictures etc.
- **ejaculation** is the ejection of semen from the penis (or the feeling of this)
- **orgasm** is the fulfilment or climax following sexual stimulation or intercourse

The first five questions refer to erectile function

Q1. Over the last month, how often were you able to get an erection during sexual activity?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

Q2. Over the last month, when you had erections with sexual stimulation, how often were your erections hard enough for penetration?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

Q3. Over the last month, when you attempted intercourse, how often were you able to penetrate your partner?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

Q4. Over the last month, during sexual intercourse, how often were you able to maintain your erection after you had penetrated your partner?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

Q5. Over the last month, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?

- | | | |
|------------------------|-------------------|-----------------------|
| 0. No sexual activity | 2. Very difficult | 4. Slightly difficult |
| 1. Extremely difficult | 3. Difficult | 5. Not difficult |

The next three questions refer to satisfaction with intercourse

Q6. Over the last month, how many times have you attempted sexual intercourse?

- | | | |
|----------------|--------------|----------------|
| 0. No attempts | 2. 3-4 times | 4. 7-10 times |
| 1. 1-2 times | 3. 5-6 times | 5. 11-20 times |

Q7. Over the last month, when you attempted sexual intercourse how often was it satisfactory for you?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

Q8. Over the last month, how much have you enjoyed sexual intercourse?

- | | |
|-----------------------|--------------------------|
| 0. No intercourse | 3. Fairly enjoyable |
| 1. No enjoyment | 4. Highly enjoyable |
| 2. Not very enjoyable | 5. Very highly enjoyable |

The next two questions refer to orgasmic function

Q9. Over the last month, when you had sexual stimulation or intercourse, how often did you ejaculate?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

Q10. Over the last month, when you had sexual stimulation or intercourse, how often did you have the feeling of orgasm (with or without ejaculation)?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

The next two questions ask about sexual desire. In this context, sexual desire is defined as a feeling that may include wanting to have a sexual experience (for example masturbation or sexual intercourse), thinking about having sex, or feeling frustrated due to lack of sex.

Q11. Over the last month, how often have you felt sexual desire?

- | | |
|---|------------------------------------|
| 0. No sexual activity | 3. Sometimes (about half the time) |
| 1. Almost never or never | 4. Much more than half the time |
| 2. A few times (much less than half the time) | 5. Almost always or always |

Q12. Over the last month, how would you rate your level of sexual desire?

- | | |
|---------------------------|--------------|
| 1. Very low or not at all | 4. High |
| 2. Low | 5. Very high |
| 3. Moderate | |

The next two questions refer to overall sexual satisfaction.

Q13. Over the last month, how satisfied have you been with your overall sex life?

- | | |
|---|-------------------------|
| 1. Very dissatisfied | 4. Moderately satisfied |
| 2. Moderately dissatisfied | 5. Very satisfied |
| 3. About equally satisfied and dissatisfied | |

Q14. Over the last month, how satisfied have you been with your sexual relationship with your partner?

- | | |
|---|-------------------------|
| 1. Very dissatisfied | 4. Moderately satisfied |
| 2. Moderately dissatisfied | 5. Very satisfied |
| 3. About equally satisfied and dissatisfied | |

The last question refers to erectile function

Q15. Over the last month, how do you rate your confidence that you can get and keep your erection?

- | | |
|---------------------------|--------------|
| 1. Very low or not at all | 4. High |
| 2. Low | 5. Very high |
| 3. Moderate | |

Appendix B (translated from dutch)

Doctor questionnaire

Dupuytren's disease

General

- What is today's date?
- Which hand(s) are affected by Dupuytren's disease?
- Left/right/recurrence yes/no

Extension deficit (in degrees)

- Extension deficit MCP of each ray of the left and right hand
- Extension deficit PIP of each ray of the left and right hand
- Extension deficit DIP of each ray of the left and right hand

Ectopic locations:

- Knuckle pads of each ray of the left and right hand
 - Yes/no
- Ledderhose's disease
 - Yes/no/beginning
- Peyronie's disease
 - Yes/no/not checked

Patient questionnaire

Dupuytren's disease

General

- What is today's date?
- What is your date of birth?
- What is your gender?
- What is your highest level of education?
- What is your ethnic background?
- What is your current occupational status?
- Have you performed physical labor involving your hands?

- How long have you been performing this physical labor?
- Do you have hobbies that involve manual labor? Dupuytren's disease
- Are you right-handed/left-handed/ambidextrous?
- Do you have a positive family history for Dupuytren's disease?
- Yes/no/I don't know
- For how long have you been experiencing symptoms of Dupuytren's disease?
 - 1 year/2 years/3 years/4 years/5 years/6 years/7 years/8 years/9 years/10-19 years/over 20 years/I don't know
- At what age did you first notice nodules or flexion of the fingers?
 - 0-9 years/10-19 years/20-29 years/30-39 years/40-49 years/50-59 years/60-69 years/70-79 years/ 80-89 years/over 90 years/I don't know

As you may know, Dupuytren's disease can also appear in different parts of the body: the fingers (knuckle pads), the soles of your feet (Ledderhose's disease) and the penis (Peyronie's disease).

- Knuckle pads are nodules on the joint between the first and second phalanges. Do you have knuckle pads?
- Yes/I think so/no/I don't know
- Do you also have hardening or nodules on the sole of your foot?
- Yes/I think so/no/I don't know

The next question only applies to men. In Peyronie's disease, hard plaques develop in the penis. These plaques can cause a curvature in erection.

- Do you have Peyronie's disease?
- Yes/I think so/no/ I don't know

Complaints and treatment of Dupuytren's disease

- Which complaints of Dupuytren's disease apply to you (multiple answers possible)?
- No complaints/difficulties pocketing hands/difficulties putting on gloves/difficulties with daily activities/difficulties shaking hands/problems with work/pain/difficulties with hobbies/other
- Why would you consider surgery (multiple answers possible)?
- Because it bothers me/because I'm afraid the disease will progress/on G.P.'s advice/plastic surgeon's advice/other
- Have you ever been operated on before because of Dupuytren's disease?

If so, when?

- No/left/right/both hands

- Has your hand ever been operated on for reasons besides Dupuytren's disease? If so, when?
 - No/left/right/both hands
- What do you think caused Dupuytren's disease in your case (multiple answers possible)?
 - No idea/manual labour/family history/hand injury/other
- Have you suffered from any of these diseases?
 - Epilepsy/diabetes mellitus/liver disease
- Do you use analgesics?
- Do you use anticoagulants?
- Do you use anti-diabetics?
- Do you use anti-epileptic drugs?
- Do you use any other drugs? Other questions
- How many alcoholic beverages do you consume per week?
 - None/1-2 per week/3-5 per week/6-10 per week/11-15 per week/16-20 per week/over 20 per week
- Do you smoke tobacco?
 - No/yes/not anymore since ...
- If you are currently a smoker: how many cigarettes do you smoke per day?
 - None/1-2 per day/3-5 per day/6-10 per day/11-15 per day/16-20 per day/over 20 per day
- Do you have any allergies?
 - Yes/no/I don't know

Peyronie's disease

General

- What is today's date?
- What is your date of birth?
- What is your highest level of education?
- What is your ethnic background?
- What is your current occupational status? Your complaints and treatment
- For how long have you been experiencing symptoms of Peyronie's disease?
 - 1 year/2 years/3 years/4 years/5 years/6 years/7 years/8 years/9 years/10-19 years/over 20 years/I don't know
- At what age did you first notice hard plaques in the penis and/or a curvature?
 - 0-9 years/10-19 years/20-29 years/30-39 years/40-49 years/50-59 years/60-69 years/70-79 years/ 80-89 years/over 90 years/I don't know
- Which complaints of Peyronie's disease apply to you (multiple answers possible)?

- No complaints/curvature of the penis during erection (upward/downward/to the left/to the right)/the penis does not become rigid enough/the penis becomes flaccid prematurely/entering the vagina with the penis is difficult/the penis is clearly shorter during erection/psychological burden/pain during erection/pain during intercourse/fear for cancer/not being able to aim well during urination/other
- Why would you consider surgery (multiple answers possible)?
 - Because it impedes me too much during intercourse/because it bothers my partner during intercourse/for cosmetic reasons/on G.P's advice/against G.P's advice/on urologist's advice/other
- Has your penis ever been operated on before? If so, when?
- What do you think caused Peyronie's disease in your case (multiple answers possible)?
 - No idea/trauma of the penis/family history/venereal disease/other
- Have you suffered from any of these diseases?
 - Epilepsy/diabetes mellitus/liver disease
- Do you use analgesics?
- Do you use anticoagulants?
- Do you use anti-diabetics?
- Do you use anti-epileptic drugs?
- Do you use any other drugs?
- Do you use drugs that stimulate the erection?
- Do you have a positive family history of Peyronie's disease?
 - Yes/no/I don't know
- Do you also have hardening or nodules in the palm of the hand or fingers (Dupuytren's disease)?
 - Yes/I think so/no/I don't know
- To your knowledge, does Dupuytren's disease occur in your family?
 - Yes/no/I don't know
- Knuckle pads are nodules on the joint between the first and second phalange. Do you have knuckle pads?
 - Yes/I think so/no/I don't know
- To your knowledge, do knuckle pads occur in your family?
 - Yes/I think so/no/I don't know
- Do you also have hardening or nodules on the sole of your foot (Ledderhose's disease)?
 - Yes/I think so/no/I don't know
- To your knowledge, does Ledderhose's disease occur in your family?
 - Yes/no/I don't know

Other questions

- How many alcoholic beverages do you consume per week?
 - None/1-2 per week/3-5 per week/6-10 per week/11-15 per week/16-20 per week/
over 20 per week
- Do you smoke tobacco?
 - No/yes/not anymore since ...
- If you are currently a smoker: how many cigarettes do you smoke per day?
 - None/1-2 per day/3-5 per day/6-10 per day/11-15 per day/16-20 per day/
over 20 per day
- Do you have any allergies?
 - Yes/no/I don't know

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Curriculum Vitae

Daan Carel John Mohede werd op 12 januari 1991 in Enschede geboren. Hij behaalde aldaar in 2009 aan het Bonhoeffer College het gymnasiumdiploma. Vervolgens ging hij Farmacie studeren aan de Rijksuniversiteit Groningen na uitgeloot te zijn voor Geneeskunde. De bachelor Farmacie succesvol afgerond hebbend, kreeg hij in 2013 via de Zij-instroom alsnog de kans Geneeskunde te studeren. Hij liep co-schappen in het Universitair Medisch Centrum Groningen (UMCG) en het Isala ziekenhuis in Zwolle. De interesse in de urologie en andrologie werd tijdens het eerste coschap gewekt en tijdens het keuzeco-schap in het UMCG verder ontwikkeld. In de wetenschapsstage werd onder supervisie van dr. M.F. van Driel en prof. dr. I.J. de Jong het startsein gegeven voor dit proefschrift door verschillende onderzoeken op te zetten. De verdiepingsstage volgde hij in het laboratorium van de Medische Biologie onder supervisie van prof. dr. R.A. Bank. In 2017 behaalde hij zijn bul. Na zijn afstuderen ging hij als arts-assistent en arts-onderzoeker urologie in het UMCG aan de slag. Zo kon hij onder supervisie van dr. A.M. Leliveld-Kors klinische ervaring in de urologie opdoen en verder werken aan zijn proefschrift. Hij presenteerde de voortgang van zijn onderzoeken tijdens vergaderingen van de Nederlandse Vereniging voor Urologie in 's Hertogenbosch en Nieuwegein en in 2018 op het jaarlijkse congres van de American Urological Association te San Francisco.

In 2018 werd hij aangenomen voor de opleiding Urologie in de regio Groningen (opleider dr. S. Roemeling). In 2019 begon hij de vooropleiding Algemene Heelkunde in het Dijklander Ziekenhuis te Hoorn (opleiders dr. E. Sonneveld en dr. J.W. de Waard). Gedurende de vooropleiding rondde hij dit proefschrift af. In het najaar van 2020 besloot hij de switch te maken naar de opleiding Heelkunde en werd hij aangenomen in de Opleidings- en Onderwijsregio Amsterdam.

Sinds 2014 is Safira Taylor zijn levensgezellin.

List of publications

This thesis

1. Peyronie's disease – current perspectives. Mohede DCJ, van Driel MF, de Jong IJ, Beck J. *Tijdschr Urol* 2018;8:112-120.
2. Medical treatments of Peyronie's disease: past, present, and future. Mohede DCJ, de Jong IJ, van Driel MF. *Urology* 2019;125:1-5.
3. Patient reported outcomes on sexual function after surgical treatment of Peyronies disease. Mohede DCJ, Weidenaar AC, van Driel MF, van de Wiel HBM, de Jong IJ. *J Urol* 2018;199:e911.
4. Homosexuality and Peyronie's disease. Mohede DCJ, van de Wiel HBM, Meijer B, de Jong IJ, van Driel MF. *Submitted*
5. Prevalence of Peyronie and Ledderhose diseases in a series of 730 patients with Dupuytren disease. Mohede DCJ, Riesmeijer S, de Jong IJ, Werker PMN, van Driel MF. *PRS* 2020;145:978-984.
6. A genome-wide association study for Peyronie's disease. Mohede DCJ, van Driel MF, Riesmeijer S, de Jong IJ, Werker PMN, Nolte IM. *Not for publication*
7. Verteporfin as a medical treatment in Peyronie's disease. Mohede DCJ, de Jong IJ, Bank RA, van Driel MF. *Sex Med* 2018;6:302-308.

Other publication

Unexpected metal in the pelvis. DCJ Mohede, NF Casteleijn, ECC Cauberg. *Nederlands Tijdschrift voor Geneeskunde*. 2017;161(0):D1699.