

Pregnancy-related urinary incontinence, does it bother?

Citation for published version (APA):

Moosdorff - Steinhauser, H. (2021). *Pregnancy-related urinary incontinence, does it bother?* [Doctoral Thesis, Maastricht University]. Ridderprint. <https://doi.org/10.26481/dis.20211105hm>

Document status and date:

Published: 01/01/2021

DOI:

[10.26481/dis.20211105hm](https://doi.org/10.26481/dis.20211105hm)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

CHAPTER 10

SCIENTIFIC AND SOCIETAL IMPACT

Pregnancy and delivery are the most prominent risk factors for the development of urinary incontinence (UI) in women. The results of this thesis will shed light on various aspects regarding pregnancy-related UI like prevalence, experienced bother, anticipated course, therapeutic effect of physical therapy, and help-seeking behavior as well as the experiences of peri-partum UI of women and health care professionals (HCP). The findings presented in this thesis will add to the body of knowledge of HCPs and researchers as well as policy makers. It can help researchers in for instance research planning, HCPs in their UI management and communication with peri-partum women, and provide policy makers with more details on the prevalence and incidence of peri-partum UI and their experienced bother. This chapter will highlight how the results have been and will be further disseminated, and elaborate on what the findings mean for a broad audience.

DISSEMINATION OF RESULTS DURING PHD TRAJECTORY AND PLANS FOR THE FUTURE

During the PhD trajectory the results of our studies were firstly shared in peer-reviewed scientific journals as described at the beginning of each chapter. Secondly, results were shared at multiple international conferences of the International Continence Society (ICS). The ICS members attending the meetings consist of urologists, urogynecologists, physical therapists (PT), nurses and researchers with a focus on continence and pelvic floor disorders. At ICS 2019 and 2020 the results of chapter 2 and 7 were presented. In The Netherlands the results of chapter 2 were presented at the 2019 conference of the Royal Dutch Society for Physical Therapy (KNGF).

At ICS 2021, the results of this dissertation in general, the problems we encountered with the inclusion of participants in the randomized controlled trials (RCT), and the actions taken to improve this, will be presented. In addition, I will also write a blog post and make a YouTube video on this dissertation for my social media channels. They will be posted on <https://www.pelvicnewschannel.com> and on YouTube (<https://www.youtube.com/channel/UCZIOBILVAuESzlu0OdXjJlw>). The blog will also be translated into Spanish, Portuguese and Japanese. The objective of the blog and YouTube channel is to share scientific research with colleagues with an interest in the pelvic region, especially pelvic physical therapists. By providing easily accessible short versions of studies with the implications for clinical practice

in multiple languages, colleagues who otherwise might not be aware of these studies or for whom the English language is a barrier, also have access.

SCIENTIFIC AND SOCIETAL IMPACT OF THE GENERATED KNOWLEDGE

The initial primary aim of this dissertation was to study the long-term (cost-) effect of pelvic floor muscle group therapy (PFMGT) compared to care as usual (CAU) during pregnancy and post-partum in two RCTs. However, the inclusion rate in both studies was very low, even after several facilitating changes were made to the inclusion process. The low inclusion rate in comparison to the high prevalence of UI was thoroughly discussed by all who (the research team and the HCPs) were involved in the studies. The fact that not only the presence of UI, but especially the experienced bother in relation to UI, could be responsible for explaining the tendency to participate, seemed very relevant to us and worthwhile to investigate. Therefore, the main focus of the thesis changed from the (cost-) effect of PFMGT, to learning more about other aspects of UI in pregnancy and post-partum, such as UI prevalence, experienced bother and help-seeking behavior in relation to UI. Sharing our inclusion strategies and encountered problems and subsequent actions taken with researchers will help planning future research in this field.

Prevalence and bother

As reported prevalence numbers of pregnancy related UI vary greatly between studies, one of our aims was to provide more accurate prevalence numbers. The International Consultation on Incontinence (ICI) recommends reporting prevalence numbers of UI with the experienced bother.¹ Therefore we also studied the experienced bother of UI. This is important information for research planning and policy makers because women with a higher level of experienced bother of UI seek more help.²⁻⁴ Our systematic reviews on the prevalence, incidence and experienced bother of UI during pregnancy and between 6 weeks and 1 year post-partum are to our knowledge the first ones in this field. No such study exists regarding pregnant women and for post-partum women it can only be compared with the study of Thom *et al.*⁵ However, Thom *et al.* only reports for women up to 3 months post-partum and does not report incidence and bother.

We showed that although the overall prevalence of UI during pregnancy and post-partum is high, 41% and 31% respectively, the experienced bother is low to moderate. It was also obvious that it is not common practice yet to report bother in prevalence studies and that bother is heterogeneously assessed (chapter 2 and 3).

Our results showed that the numeric rating scale (NRS, 0= no bother-10= extreme bother) might be an appropriate measurement instrument to quantify experienced bother of UI. The NRS is a valid and reliable, unidimensional, measurement instrument, widely used in pain research. However, to our knowledge the NRS for bother of UI has not been studied with regard to validity, reliability and responsiveness in women. A cut-off point for clinically relevant bother of UI also needs to be established. The NRS is quick to administer, easy to interpret, and very well suited to add to an electronic patient file. Therefore, the NRS has the potential to help HCPs in communicating with patients and in clinical decision making.

We observed a great variety of words used to describe 'bother' of UI in our studies (chapter 2 and 3). A more clearly defined concept of bother could help in the assessment, standardisation of communication and reporting of study results. The International Continence Society (ICS) has multi-disciplinary working groups developing standardisation of terminology.⁶ We advise to include the concept of bother for further clarification. When we asked Dutch women with pregnancy-related UI what word they would use for their experience of UI, several words were suggested and none of them was the word the research team thought beforehand was the most appropriate. This shows the importance of studying the 'best' word to discuss bother, country-specific because of differences in language and culture. Knowing the word that resonates the best with women regarding bother of UI can help HCPs in their communication with patients and with other HCPs (multidisciplinary). In addition, it can facilitate the interpretability and comparison of research results. Moreover, it is useful when information is developed regarding UI in women

Help-seeking behavior

Women in our studies indicated that they would seek help if there was an increase in the amount and frequency of urine loss, occurrence at unexpected moments or an increase in negative feelings regarding their UI (chapter 6 and 7). Only a small number of peri-partum women actually sought help for their UI. Reasons for not

seeking help were often based on the belief that UI would resolve by itself and that it is a normal consequence of pregnancy and delivery. This misconception is important knowledge for HCPs, as they can provide peri-partum women with trustworthy information. Information on causes, solutions and where they can get help when they need it. To further optimize information provision regarding UI, a deeper understanding of the wishes and needs of peri-partum women is necessary. Therefore, we need to acquire more knowledge about 1) what information peri-partum women need at 2) which peri-partum period and 3) the best strategy to provide this.

Good information sites are available. Examples are 'the pelvic floor' by HCPs of the University of Antwerp, Belgium at <https://www.thepelvicfloor.be/> (in Dutch), and 'pelvic floor first' from the Continence Foundation of Australia at (<http://www.pelvicfloorfirst.org.au/> (English).

Pelvic floor muscle therapy

Based on the promising effects of pelvic floor muscle therapy (PFMT), described in the first version of the Cochrane systematic review on 'pelvic floor muscle training for prevention and treatment of UI and fecal incontinence in antenatal and postnatal women', we planned our two RCTs.⁷ They were designed following the recommendations of the CONSORT statement to ensure high quality. The latest update of this Cochrane review reports that there is still uncertainty regarding the treatment effect of PFMT provided in the pre- or post-partum period.⁸ However, we have to keep in mind that these results are based on a small number of studies of (very) low quality. Current peri-partum multi-disciplinary guidelines recommend PFMT for post-partum UI.⁹⁻¹¹

Unfortunately, our studies on the long-term effect of PFMT compared to care-as-usual were underpowered and results therefore need to be interpreted with caution. Our study showed a positive effect of PFMT started post-partum (chapter 5). However, this effect seems to diminish longer term. There is still uncertainty as to why PFMT during pregnancy or post-partum does not show the positive effect as in the general female population. The question remains if PFMT would be effective for a specific group of women with UI during pregnancy, for example, primigravid women with no UI prior to pregnancy. Starting PFMT between 6 weeks and 3 months post-partum might be too early in effectiveness studies. Based on

the current evidence we recommend offering women with UI after delivery PFMT as a treatment option. Therefore, we suggest changes in the current peri-partum care as will be discussed next.

Peri-partum care

Dutch guidelines regarding pre-partum care incorporate no discussion of or recommendations for pelvic floor dysfunctions like UI and for the post-partum period recommendations vary.^{10,12} There may be a difference between the need of peri-partum women and the HCP regarding this topic. Therefore, more attention and uniformity regarding this topic in peri-partum guidelines is warranted.

We suggest it is time for a change in post-partum care. Currently, women get their final obstetric check at 6 weeks post-partum. But at that time, women have not yet (fully) started with sports and/or their job and as a consequence the symptom threshold, for pelvic floor dysfunctions like UI, might not have been reached yet. A check at 6 months after delivery for women at risk for pelvic floor dysfunctions might be more appropriate. A specialized (pelvic) PT would be very well suited for this task as this is an expert in pelvic health and exercise.¹³ They have the knowledge to empower women in self-management by providing information, instruct a proper pelvic floor muscle contraction with a vaginal assessment and give a pelvic floor muscle training program. In The Netherlands, the Dutch Society for Pelvic Physical therapy has developed and pilot tested a concept called the 'post-partum consultation'. Based on the pilot study the concept needs further refinement and needs to be studied with appropriate numbers of participants conjoint with a cost-analysis. A post-partum consultation has the potential to be a valuable extension of current peri-partum care, for women with or at risk of UI, and empower women to seek help and become 'motherfit'.

Education

The pelvic floor muscles and pelvic floor dysfunctions are hardly discussed in the curricula of physical therapists in The Netherlands, although pelvic floor dysfunctions are very prevalent. Basic knowledge of the pelvic floor, dysfunctions and the relation with the moving body should therefore be part of the curriculum. This also raises interest and awareness for the specialization of pelvic physical

therapist. In the curricula for HCPs involved in peri-partum care like the gynecologist, midwife or specialized pelvic physical therapist it is important to emphasize the importance of asking a woman specifically about UI together with the experienced bother. In addition, HCPs should learn how to assess experienced bother and know where women can find trustworthy information and get good quality care to remain or become 'motherfit'.

HCPs in training can contribute to the body of knowledge regarding research questions on peri-partum UI. If existing research questions are specifically adapted for students, taking into account the amount of time students have for a (graduation) project (sub-questions), this could be a win-win situation on all accounts. For this purpose, good contacts between (or within departments of) research institutions, educational institutions, HCP courses, but also with professional associations is a prerequisite. At the moment, contacts exist between various stakeholders with regard to research questions for specialized pelvic physical therapy in training, though informally. Collaboration could be more effective if this would be formalized.

CONCLUSION

The initial primary aim of this dissertation to study the long-term (cost-) effect of pelvic floor muscle group therapy (PFMGT) compared to care as usual (CAU) during pregnancy and post-partum did not succeed due to very low inclusion rates. However by sharing our inclusion strategies and encountered problems and subsequent actions taken with researchers will help planning future research in this field. To reveal possible reasons of the disappointing inclusion numbers other aspects of UI in pregnancy and post-partum such as UI prevalence, experienced bother and help-seeking behavior in relation to UI were studied. We showed that although the overall prevalence of UI during pregnancy and post-partum is high, the experienced bother is low to moderate and few women seek help. It was also evident that prevalence studies do not report the accompanying bother standardly and that bother is heterogeneously assessed. UI is not a standard question for the majority of HCPs in peri-partum care. More attention and uniformity regarding UI in peri-partum guidelines is warranted.

As a consequence of the hurdles we had to take, the key factors in medical decision

making for patients with UI had to be reviewed. That lead to profound insight in the most important variables that are almost unnoticedly weighed by those offered care or execute RCTs. From our experiences and observations we learned that we should better understand and systematically weigh what factors women drive to decide on starting therapy. We hypothesized on five issues that might contribute to deciding to seek help: 1) the impact of the symptom indicating the underlying problem is considered life-threatening or not, 2) the consequence of expectant management as compared to active treatment, 3) experienced bother, 4) knowledge regarding PFM(G)T, and 5) the costs in time, effort and finance for accepting and undergoing treatment. Holding a clear view on all these factors might be incredibly helpful on designing future studies and care trajectories and weighing the necessity to implement them upfront.

The results have been and will be shared in various ways to reach as many researchers, HCPs and the general public. Our results can help researchers with research planning, HCPs regarding communication with patients, and policy makers can use our results in calculating future health care cost.

REFERENCES

1. Abrams P, Cardozo L, Wein A, eds. *Incontinence 6th Edition*. ICI-ICS. International Continence Society, Bristol, UK; 2017.
2. Mason L, Glenn S, Walton I, Hughes C. Women's reluctance to seek help for stress incontinence during pregnancy and following childbirth. *Midwifery*. 2001;17(3):212-221.
3. Kinchen KS, Burgio K, Diokno AC, Fultz NH, Bump R, Obenchain R. Factors associated with women's decisions to seek treatment for urinary incontinence. *J Womens Health (2002)*. 2003;12(7):687-698.
4. Schreiber Pedersen L, Lose G, Høybye MT, Elsner S, Waldmann A, Rudnicki M. Prevalence of urinary incontinence among women and analysis of potential risk factors in Germany and Denmark. *Acta Obstet Gynecol Scand*. 2017;96(8):939-948.
5. Thom DH, Rortveit G. Prevalence of Postpartum Urinary Incontinence: A Systematic Review. *J Wound Ostomy Continence Nurs*. 2011;38:525-26.
6. (ICS) ICS. *ICS Glossary of Terminology*
https://www.ics.org/glossary?gclid=Cj0KCQiA-aGCBhCwARIsAHD15x_Mp81EyuUcYQ4Ter8ZweGevTXZHwgiS_91k7WYbAbvCfhcxYUSIMaAo7cEALw_wcB#S. Accessed 10 March, 2021.
7. Hay-Smith J, Mørkved S, Fairbrother KA, Herbison GP. Pelvic floor muscle training for prevention and treatment of urinary and faecal incontinence in antenatal and postnatal women. *Cochrane Database Syst Rev*. 2008(4):Cd007471.
8. Woodley SJ, Lawrenson P, Boyle R, et al. Pelvic floor muscle training for preventing and treating urinary and faecal incontinence in antenatal and postnatal women. *Cochrane Database Syst Rev*. 2020;5(5):Cd007471.
9. Nederlands Huisartsen Genootschap (NHG). Standaard Zwangerschap en kraamperiode (M78) (tweede herziening). . https://www.knov.nl/uploads/knov.nl/knov_downloads/150/file/Zwangerschap%20en%20kraambed.pdf. Accessed 8 February, 2021.
10. Koninklijke Nederlandse Organisatie van Verloskundigen (KNOV). Multidisciplinaire richtlijn postnatale zorg 2018; https://www.knov.nl/serve/file/knov.nl/knov_downloads/2882/file/Postnatale_zorg_opgemaakte_versie_door_IB_md_10_aug_2018.pdf. Accessed 8 February 2021.
11. National Institute for Health and Care Excellence (NICE). Postnatal care up to 8 weeks after birth (CG 37). 2006; <https://www.nice.org.uk/guidance/cg37/resources/postnatal-care-up-to-8-weeks-after-birth-pdf-975391596997>. Accessed 2 March, 2021.
12. (CPZ). CPZ. Zorgstandaard integrale geboortezorg. 2020; 1.2:<https://www.kennissetgeboortezorg.nl/wp-content/uploads/2020/11/zorgstandaard-integrale-geboortezorg-1.2.pdf>. Accessed 2 March, 2021.
13. Westerik-Verschuuren L, Moosdorff-Steinhauser HFA. Beroepsprofiel Bekkenfysiotherapeut. 2014; <https://nvfb.kngf2.nl/Vakgebied/kwaliteit/beroepsprofiel.html>. Accessed 14 March, 2021.