

Neurogenic bladder and bowel dysfunction - incontinence and life situation in adolescents and adults with spina bifida

AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet, kommer att offentlig försvaras i Academicum, hörsal Arvid Carlsson, Medicinaregatan 3, torsdagen den 4 februari 2021 klockan 9.00.

av Magdalena Vu Minh Arnell

Fakultetsopponent: Professor Einar Arnbjörnsson, Lunds Universitet

Avhandlingen baseras på följande delarbeten:

- I. Vu Minh Arnell M, Seljee Svedberg K, Lindehall B, Jodal U, Abrahamsson K. Adults with myelomeningocele: An interview study about life situation and bladder and bowel management. *J Pediatr Urol.* 2013 Jun;9(3):267-71.
- II. Vu Minh Arnell M, Seljee Svedberg K, Lindehall B, Möller A, Abrahamsson K. Health-related quality of life compared to life situation and incontinence in adults with myelomeningocele: Is SF-36 a reliable tool? *J Pediatr Urol.* 2013 Oct;9(5): 559–66.
- III. Vu Minh Arnell M, Abrahamsson K. Urinary continence appears to enhance social participation and intimate relations in adolescents with myelomeningocele. *J Pediatr Urol.* 2019 Feb;15(1):33. e1-33. e6.
- IV. Vu Minh Arnell M, Korsgaard R, Abrahamsson K. The voice of adults with myelomeningocele - experience of urinary incontinence and how it affects life. In manuscript.

Handledare: Professor Kate Abrahamsson

Biträdande handledare: Professor Anders Möller

**SAHLGRENKA AKADEMIN
INSTITUTIONEN FÖR KLINISKA VETENSKAPER**



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Neurogenic bladder and bowel dysfunction - incontinence and life situation in adolescents and adults with spina bifida

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ABSTRACT

BACKGROUND: In individuals with myelomeningocele, (MMC), survival rate has significantly increased over the past 40-50 years due to medical innovations. In the coming years, many adolescents will be transferred to adult care.

AIMS: To investigate life situation, quality of life, follow-up in adult care and the incidence and experience of incontinence in adults with MMC. To compare the incidence of incontinence with a youth group and investigate whether continence is one of the prerequisites for an active life and close intimate relationships.

METHODS AND RESULTS: Study I Sixty-nine adults (27–50 years) with MMC participated in a structured telephone interview. Pads for urinary and fecal incontinence were used by 87% and 14% had contact with a urotherapist. About 60% were single, 90% had attended high school and 67% had a job. Study II The validated HRQoL instrument SF-36 was answered by 61 of 69 individuals. There were significantly lower scores for the overall physical quality of life while scores for the overall mental quality of life were higher than for the reference group. Neither physical nor mental quality of life was affected by whether the individual had fecal incontinence, lived with a partner or had children. Study IV In a descriptive qualitative semi-structured interview, 9 adults described their personal experience of living with incontinence. Study III All 16-18-year old's with MMC (25) from western Sweden were included in a prospective cross-sectional study regarding urinary and fecal incontinence. All were followed according to the national care programs and 68% (17/25) were urinary continent. Of these, 12 had an active social life and eight had experience of having a partner. Of the 8 with incontinence, none had an active social life or a close physical intimate relationship.

CONCLUSION: Incontinence is common in adults with MMC and few have urotherapy support. Life situation and incontinence are not reflected in the generic HRQoL instrument SF-36. The adults' experience of how incontinence affects life is consistent with reports from individuals with acquired incontinence. In the adolescent study, the results indicate the importance of follow-up and active treatment strategies to achieve urinary continence. Continence seems to be a success factor for an active social life and close intimate relationships.

KEYWORDS: spina bifida, myelomeningocele, adults, life situation, follow-up, HRQoL adolescents, continence, incontinence

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