



# 5 years after introduction of a transition protocol: An evaluation of transition care for patients with chronic bladder conditions

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## Summary

### Introduction

In recent years, more attention has been given to the transition of adolescents in urological care. In 2010, the current team investigated the needs of children with chronic bladder conditions, in preparation for transfer to adult care. A transition protocol was developed and implemented. The current study evaluated current transition care, in order to further improve the transition process.

### Objective

To give insight into the current transition care of adolescents with chronic bladder conditions since the introduction of a transition protocol in 2011.

### Study design

A total of 124 patients with chronic bladder conditions, born 1980–2003, received a questionnaire. The study population was divided in a pre-transfer ( $n = 97$ ) and post-transfer group ( $n = 27$ ). The questionnaire was based on that used for a national study and was supplemented with specific urological questions. The questions for the pre-transfer patients investigated their level of independence, what subjects were discussed with the healthcare professionals, and their expectations and wishes regarding transfer to adult urology care. The post-transfer group was asked for their opinions about their transfer process.

### Results

A total of 61% ( $n = 76/124$ ) responded (pre-transfer 61/97 patients and post-transfer 15/27 patients).

Their knowledge about their condition and related issues was generally good. The subjects 'future', 'relationships', 'sexuality' and 'fertility' were discussed more with the nurse practitioner than with the pediatric urologist in comparison with 2010. The last three subjects were only discussed with one third of the adolescents (Summary table). The bond with the pediatric urologist was the most common reason to continue care at the Pediatric Urology department. Adolescents aged >18 years were better prepared for transfer to adult urology than in 2010. The majority of the post-transfer patients were transferred because of being aged >17 years. Most patients in the post-transfer group were pleased with the current transition process.

### Discussion

The results showed that changes occurred after implementation of the personal patient transition protocol. The mean age of the pre-transfer group was younger compared to 2010; this influenced some of the results. Therefore, they were divided into two age groups, for more reliable outcomes. More attention to subjects like relationships and sexuality could further improve the satisfaction of adolescents in transition.

### Conclusion

The older adolescents seemed better prepared for their transfer from pediatric to adult urology than in 2010. The majority was satisfied with the current transition protocol. Tailor-made transition care seemed to be the best option.

**Summary table** Subjects discussed during consultation in 2015.

Pre-transfer group	Future	Relationships	Sexuality	Fertility
The subject is being discussed	64%	34%	28%	24%
The pediatric urologist (alone) discusses the subject	51%	58%	38%	50%
The nurse practitioner (alone) discusses the subject	16%	32%	31%	29%
Both discuss the subject	32%	11%	25%	14%

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## Introduction

Many conditions in pediatric urology are chronic, and require lifelong urological care to preserve renal function, promote continence, and monitor sexual or reproductive health [1]. Advances in neonatal care and prevention of end-stage renal failure have increased long-term survival of patients with congenital urological diseases, including spina bifida and bladder exstrophy [2]. As a result of this development, more and more adolescents make their transfer from pediatric to adolescent and adult care, defined as transition [3,4]. In recent years, there has been more attention on this transition process within urological care. Literature shows that transition still needs to be improved, and transition often takes place well into adulthood [1,2]. Binks et al. identified many barriers concerning transition for patients with spina bifida; they suggested a key element for transition programs: the timing of the transfer should be established in consultation with the pediatric provider and family. Before leaving child-centered care there should be a long preparation period, and patients should be able to take care of themselves independently. Implementation of a transition clinic and an up-to-date medical summary from the child-centered team are key elements for a successful transition [5].

In 2010, the current Pediatric Urology department participated in the nationwide quality improvement program 'On Your Own Feet Ahead'. The aim of the program was to improve the transition from pediatric to adult care, and improve self-management of adolescents with chronic conditions. In 2010, van der Toorn et al. [6] investigated the needs of adolescents with chronic bladder conditions, in the preparation for transfer from pediatric to adult urological care. After this study, the current Urology department implemented a brochure about personal transition care, an Individual Transition Plan (ITP), a transition coordinator, and a transition clinic. From the age of 12 years, patients receive a questionnaire asking about their knowledge about their condition and their wishes about which subjects they would like to discuss during the consultation, and the timing of transfer to adult care. The current clinic does not have a strict age for the actual transfer; timing of transfer to adult care is decided in consultation with the patient and can take place from the age of 16 up to about 25 years.

The current study aimed at giving insight into transition care, in order to further improve the transition process. It investigated whether knowledge about their condition, independence, and the satisfaction of the patients with the transition process improved since the introduction of the transition protocol 5 years ago.

## Material and methods

In the current survey study, all patients diagnosed with neuropathic bladder due to spina bifida, bladder exstrophy or other rare congenital or acquired chronic bladder disorders were included, like caudal regression syndrome, anorectal malformation, and severe PUV. All patients visited the Pediatric Urology department and were born 1980–2003. The population was divided into two groups: a

pre-transfer and post-transfer group. The pre-transfer group (still receiving care from a child-centered urological team) was formed by patients who will make the transfer to adult care in the future. These patients contacted the pediatric urologist between 2011 and 2015. Patients in the post-transfer group had already been transferred from pediatric to adult care at the current department or elsewhere. For the transfer a combined consultation with the nurse practitioner and pediatric and adult urologist at the transition clinic was offered. There was no correction for intellectual level between patients.

Data were collected through written questionnaires. Patients who did not respond within 2 weeks received a telephone call to remind them and to ask the reason for not responding (yet). Patients had to state whether they received help filling out the questionnaire. The questionnaires were based on validated questionnaires from the 'On Your Own Feet Ahead' program, supplemented with specific urological questions that were not validated. Questions for the patients in the pre-transfer group concerned knowledge of the urological disorder and related issues. Patients were asked if they talked about the future, relationships, sexuality and fertility with the pediatric urologist or the nurse practitioner. Also questions about degree of independence, the role of parents during consultations, and expectations and preferences regarding transition were discussed. The adolescents aged >18 years who still received care from the pediatric urologist were asked an additional question: the reason for pediatric care, and whether and when the adolescent would like to make the transfer to adult care. In the questionnaire, a four-point Likert scale was used for questions about knowledge of disease and a five-point Likert scale was used for statements that could be agreed or disagreed on. Questions in the post-transfer group examined the reasons for transfer and, if so, by whom they had been prepared by. Furthermore, some questions were similar to those in the pre-transfer group. The opinion and satisfaction about the transition was asked. By completing and returning the questionnaire, participants gave their informed consent.

Statistical Package for the Social Sciences (SPSS) version 20.0.01 was used for analyzing the quantitative results. Cronbach's alpha was calculated when questions were clustered to determine the homogeneity of the questions. Chi-squared tests were performed to compare ordinal variables between the two measurement dates (2010 vs. 2015). *P*-values <0.05 were considered statistically significant.

## Results

### Patient characteristics

A total of 76/124 (61%) patients completed the questionnaire: 61/97 (63%) in the pre-transfer group and 15/27 (56%) in the post-transfer group. About half (53%) of the respondents were male in the pre-transfer group, 85% (*n* = 23) were female in the post-transfer group. The mean age of the responding pre-transfer group was 18.2 ± 4.5 years (range 12–31) and 24.1 ± 3.6 years (range 20–31) in the responding post-transfer group. Age was unknown in

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