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# Patient perspectives on indwelling urinary catheters and fluid balances after transsphenoidal pituitary surgery: a qualitative study

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# Patient perspectives on indwelling urinary catheters and fluid balances after transsphenoidal pituitary surgery: a qualitative study

Jeanne-Marie Nollen, RN, MSc[1], Anja H. Brunsveld-Reinders, RN, PhD[2] , Wilco C. Peul, MD, PhD, MPH, MBa[3], Wouter R. van Furth, MD, PhD[3]

[1]Department of neurosurgery, Leiden University Medical Center, the Netherlands, [2] Department of quality and patient safety, Leiden University Medical Center, the Netherlands

*Email addresses:*

J.M.Nollen@lumc.nl

A.H.Brunsveld-Reinders@lumc.nl

W.C.Peul@lumc.nl

W.R.van_Furth@lumc.nl

*Corresponding author:*

Jeanne-Marie Nollen

Albinusdreef 2, 2300 RC, Leiden

The Netherlands

Postbox 9600

J.M.nollen@lumc.nl

0618174099

## Abstract

### Objectives

To explore the perceptions and experiences from patients who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery regarding IDUCS (indwelling urinary catheters) and the post-operative fluid balance.

### Design

Qualitative study using semi-structured interviews.

### Participants

Twelve patients who underwent transsphenoidal pituitary gland tumor surgery and received an IDUC during or after surgery.

### Setting

One patient was interviewed in the endocrinology outpatient clinic and eleven patients were interviewed on the neurosurgery ward.

### Results

Five major themes emerged. Theme 1 describes how patients struggled with conflicting information and the effects of pre-operative expectations during hospital admission. Theme 2 highlights challenges associated with bedrest, particularly for women. Theme 3 describes the patients' role in decision making in different settings in relation to information provided by healthcare professionals. Theme 4 illustrates the battle with reduced mobility, being dependent on others, emotional consequences and the fear of permanent reduction in physical ability. Theme 5 describes the lack of control over the fluid balance and the consequences after discharge.

Incomplete and conflicting information was given to patients both pre- and postoperatively regarding IDUC placement and fluid balance management, which led to confusion and uncertainty. If bedrest was mandatory, IDUCS were preferred particularly by women. Reduced need to mobilize, shame, fear of judgement and dependence on nurses were listed as consequences of IDUC use.

**Conclusions**

This study provides insight into the challenges patients experience in relation to the IDUC and fluid balance. Perceptions on the necessity of an IDUC varied among patients and were influenced by both physical and emotional impediments. A clear, frequent and daily communication between healthcare professionals and patients to evaluate IDUC and fluid balance use is necessary to increase patient satisfaction.

**Keywords:** urinary catheterization, pituitary gland, nurse-patient relationships, interviews

**Strengths and limitations**

- To our knowledge, this article is the first to explore patient perspectives regarding IDUCS and monitoring the fluid balance after (para)sellar tumor surgery.
- This qualitative study provides a broader understanding of challenges related to IDUCS and fluid balance in relation to bed rest and diabetes insipidus.
- Two researchers listened to the interviews and individually coded the papers, before discussing the results.
- This study sample consisted of more females than men.

## Introduction

During the last decades, a global shift has occurred in multiple care settings from care being task-focused to patient-centered (1). To evaluate hospital care and the corresponding processes, patients' perspectives play a crucial role as they offer information that goes beyond the scope of regular hospital staff evaluations (2). Especially qualitative patient feedback could improve healthcare professionals' awareness and adds to a greater understanding of patients' experiences (3).

Two frequently studied topics to gain insight in hospital care during the postoperative phase are indwelling urinary catheters (IDUCS) and fluid balances. While studies investigating fluid balances have primarily focused on accuracy and diagnostic value in critical care settings rather than focus on patient' perspectives, patient' experiences with- and perceptions of IDUCS in the postoperative phase have been widely researched (4-6). Patients have connected IDUCS with both infectious-, including urinary tract infections (UTIS), and non-infectious problems, such as pain and discomfort (7). These studies focused on general surgical populations despite literature indicating that patients' perspectives could be influenced by their specific illness and operation and that research should therefore keep the patients' true needs and specific situations in mind (8).

One group of patients who are thought to provide additional information on IDUC and fluid balance experiences are patients who underwent transsphenoidal pituitary gland and (para) sellar tumor surgery. In the University Hospital, IDUCS are not routinely placed during this surgery due to the relatively short operation time of 2-3 hours (9). Despite this policy, IDUCS are frequently inserted postoperatively at the neurosurgical ward. Two potential postoperative complications influence IDUC placement and the necessity of monitoring the fluid balance in this specific population.

First, pituitary patients are at risk of developing the electrolyte disorder Diabetes Insipidus (DI) which can be detected by monitoring a fluid balance every 3-6 hours (10). On the ward, nurses measure the urine volume in an urinal and a personal fluid balance chart, including images of different sized cups with the accompanying content in milliliters (ml), is used by patients to register the fluid intake. As DI can occur in the 10 days following surgery, the fluid balance needs to be monitored after discharge (11). IDUCS can contribute to a reliable fluid balance and are convenient for nurses when monitoring the urinary output (12, 13).

Second, to prevent post-transsphenoidal cerebrospinal fluid leakage, bed rest, with elevation of the head of bed at 30° for 24-hours, is a frequently occurring postoperative instruction which could influence the patient's ability to urinate. (14, 15). Bed rest is identified as a risk factor for a retention bladder, which is defined as the inability to urinate despite a full bladder and can lead to complications including UTIS and stretched bladder muscles (16, 17). If a patient develops a retention bladder, IDUCS are the primary intervention (18).

Previous studies have explored pre- and post-surgery symptom burden and established the need for support before, during and after hospital admission (19, 20). However, to the best of our knowledge, patient perspectives regarding IDUCS and monitoring the fluid balance have not been studied in this specific patient population and setting despite having a major impact during the acute postoperative phase. Consequently, this study aims to explore the perspectives and experiences from patients who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery regarding IDUCS and fluid balances on a neurosurgical ward.

## Methods

### Study design

A qualitative study design was adopted which involved semi-structured interviews with patients who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery to explore their perceptions and experiences regarding IDUCS and the post-operative fluid balance.

### Setting and participants

The study was conducted in a 16-bed department of neurosurgery at a University Hospital in the Netherlands. Participants who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery, received an IDUC in the peri- or postoperative period, and aged >18 were approached face-to-face if they were admitted on the neurosurgical ward or by phone if they were discharged and had a check-up at the endocrinology outpatient clinic in the first six weeks after surgery. One test-interview was conducted to clarify the topic list. Convenience sampling was used to approach thirteen patients, twelve of which agreed to participate and one declined due to personal reasons. One patient was interviewed in the endocrinology outpatient clinic and eleven patients were interviewed on the neurosurgery ward. Data saturation was reached after twelve interviews which means that it is likely that no new information will arise during additional interviews (21).

### Data collection

A semi-structured interview guides was developed with the aid of the Attitudes, Social influence and Self-efficacy model (ASE-model) and expert knowledge (table 1). This model was deliberately chosen as it helps to elaborate on demonstrated health behaviors and accompanying motives (22). Interviews were performed in Dutch.

| Interview topics |
|---|
| 1. How did patients experience the postoperative care on the neurosurgical ward?<br>• Nursing care |

- Communication
- Complications
- Pre-operative consultation in outpatient clinic
- Experience with IDUC
- Experience with fluid balance

2. How and to what extent was the patient involved in the decision to insert and remove the urinary catheter?
    - Pre-operative information
    - Shared decision making
    - Role nurse/physician
    - Influence bedrest
    - Post-operative complications
3. How did patients experience the moment of IDUC insertion and removal?
    - Comfort
    - Physical situation
    - Time of day
    - Shared decision making
    - Nurse's role
    - Complications after removal
    - Fluid balance before and after removal
4. What was the patient's role in monitoring the fluid balance?
    - Bedpan/urinal
    - IDUC
    - Fluid balance chart
    - Patient participation
    - Collaboration with nurses
5. How did the IDUC affect mobilization and interaction with caregivers/family members?
    - Stigma and feelings
    - Barriers

Table 1: interview topics

Two pilot interviews were conducted. The topic list was adjusted twice based on the feedback of the test-participant and two participants who experienced difficulties explaining their role regarding IDUC removal. The audio-recorded interviews were held in a three month period, from mid-September until mid-November 2019, in a place and time that suited the participant. The interviews were set out to take approximately 30 – 45 minutes. An oral summary was presented to each participant at the end of the interview to verify their story. Interviews were conducted by an experienced neurosurgical nurse who was not involved in the care of the participating patients.

**Data analysis**

The interviews were transcribed verbatim and analyzed through thematic analysis (23). Two researched independently conducted the coding process and discussed the findings with one another. Transcripts were read and reread to become familiar with the data. During the first phase of coding, the data was segmented in meaningful parts. These parts were provided with summarizing labels (codes). Subsequently, the codes were compared within and between transcripts by two researchers resulting in categories of codes on a more conceptual level. Finally, the created categories were described into themes. An iterative approach was adopted to enable continuous evaluation of the data (24). The software program Atlas.ti 8.4.15 was used to provide structure to the process of data analysis (25). Analysis was performed in Dutch and quotations were translated to English by a native speaker.

**Ethical considerations**

All study procedures were in accordance with the declaration of Helsinki and the medical ethics committee of Academic Hospital approved the study protocol (N19.015) (26). Participants received an information sheet and an informed consent form prior to the interviews. All participants provided written informed consent. Furthermore, participants were asked for their permission to record the interview with a voice recorder.

**Patient and public involvement**

The research question is developed by the researchers through their experience with the care for pituitary patients. Patients were not involved in the design and conduct of the study, the choice of outcome measures and recruitment tot the study. Patients agreed with plans for dissemination of the results through scientific publication and education for nurses on the University hospital ward.

## Results

### Patient characteristics

The sample included 12 patients (table 2) of which 83 percent (n = 10) were female. The mean age of the participants was 55 years (range: 39 – 73 years). Four patients had an IDUC inserted during the operation. Eight patients had an IDUC inserted postoperatively on the ward as they developed a retention bladder. A retention bladder is defined as the inability to urinate in combination with the bladder ultrasound indicating a large volume (>500cc). One patient who received an IDUC during the operation developed a retention bladder after IDUC removal which required re-catheterization. The interviews had a duration of 23 – 58 minutes.

| | n (%) |
|---|---|
| Gender | |
| Male | 2 (17) |
| Female | 10 (83) |
| IDUC inserted during surgery | 4 (33) |
| IDUC inserted on ward | 9 (75) |
| Retention bladder | 9 (75) |
| Bedrest | 7 (58) |
| Diabetes Insipidus | 5 (42) |
| Cerebrospinal fluid leakage | 1 (8) |
| | |
| | Mean (min – max) |
| Age | 55 (39 – 73) |
| Length of hospital stay | 4 (3 – 8) |
| Days IDUC inserted | 2 ( 1 – 7) |

Table 2. Characteristics of study population (n = 12)

Legend: IDUC = indwelling urinary catheters

### Themes

Four major themes emerged: 1. conflicting information and pre-operative expectations, 2. IDUCs perceived as patient-friendly during bedrest, particularly for women, 3. little room for patients' opinions, 4. physical and emotional limitations and 5. fluid balance causes confusion. Quotations are included to illustrate the text.

### Theme 1: Conflicting information and pre-operative expectations

Patients received contradicting information during their pre-operative consult at the outpatients clinic, which resulted in confusion regarding receiving an IDUC during the operation. During this pre-operative consult, several patients were informed by the nurse that they would not receive an IDUC during the operation, whereas the information booklet stated the opposite, which was experienced as confusing. Some patients declared that they did not discussed the IDUC during the consult and did not read the booklet prior to surgery, so therefore they were unaware of the possibility of having an IDUC.

All participants received information during the pre-operative consult on how to monitor the fluid balance after discharge, however, information on how to monitor the fluid balance during the hospital admission was provided to only to some of the participants. Postoperatively, patients reported a large variation between nurses and their willingness to explain the fluid balance and having the patient monitor the input.

Two participants had undergone the same operation in the past and were expecting to receive an IDUC based on their previous experiences. One participant was not content when she found out after her operation that she did not have an IDUC: “I missed my IDUC. Because I had no discomfort from the IDUC the first time but I found it so dehumanizing to urinate on the bedpan, especially because I was unable to empty my bladder and needed an IDUC because of that. In the end, there were four towels under me and I was completely covered in urine”.

The participants’ pre-operative attitudes toward an IDUC leaned towards the negative and were predominantly influenced by stories told by their friends and families who had experiences with IDUCS. One participant illustrated: “I was so scared of receiving and IDUC because I heard experiences from friends who had it (an IDUC) before and they said it hurts so bad to insert and remove it. So, after I heard all their terrible stories I thought no way I want an IDUC”.

Additionally, the interviews revealed multiple stigmas surrounding IDUCS: “It is what we were thought by our parents in the old days. People were very dramatic about IDUCS, for me it is still a very sensitive subject. I was shocked when I found out I probably was getting one but there are more people in the hospital with one, I know that. But I have this image in my head of an elderly person in a wheelchair and then carrying around that bag… it makes you look so ill”. A few participants expressed feeling indifferent towards receiving an IDUC as they trusted the medical staff to make the appropriate decision.

### Theme 2: IDUCs perceived as patient-friendly during bedrest, particularly for women

Female participants described their positive experiences with the IDUC in combination with postoperative bedrest. The general opinion was that providing a patient with an IDUC is more patient-friendly compared to having to use the bedpan. The majority of the participants felt that once the postoperative restriction mobility has ended, the IDUC had lost its added value.

Several complications regarding the bedpan were described. First, patients experienced a lack of privacy: “In my room, one other patients was waiting for his operation, another person was waiting for his wife to come back from surgery. I’m sorry but I cannot urinate comfortably with others in the room. I couldn’t urinate on the bedpan and I couldn’t sit straight up in bed because I had bedrest. The placement of the IDUC was an issue because they needed around six or seven attempts. It took almost 40 minutes before the IDUC was placed. Very painful and embarrassing for me. But when the IDUC was finally placed it was such a relief”.

Second, using the bedpan was perceived as unsanitary: “I had to urinate after the surgery but it was very difficult on the bedpan. I was so afraid that the urine would touch me or that I would wet my bed. It was so stressful and disgusting”. Third, participants felt dependent on nurses’ schedules resulting in patients developing a retention bladder or having to try to control their bladder. Finally, bedpans were associated with physical discomfort.

Participants explained that the IDUC was generally promptly removed by a nurse once the mobility restriction had ended, which was usually around noon. Postponed removal, commonly until 06:00 AM the next morning, was caused by nurses being too busy or the nurse's wish that the physiotherapist mobilized the patient beforehand. The 06:00 AM removal made a strong impression on the patients: "I was sleeping and it was very early in the morning and then she (the nurse) came in with great fanfare, all lights on, she pulled the IDUC out and that was it. While I was barely awake so I found that very uncomfortable".

### 3. Little room for patients' opinions

Patients had different perspectives on how they viewed their role in the decision to insert or remove the IDUC. If the IDUC was inserted per-operative, patients were generally of the opinion that they were informed sufficiently during the outpatient clinic consult prior to the operation. If an IDUC was required post-operatively, in a more acute situation due to a retention bladder, patients felt that nurses did not inform them adequately about their options and did not take their opinion into consideration. Most patients wished they were involved more in the shared decision making process.

The participants who did not receive an IDUC during the operation felt pressured by nurses to urinate promptly after their return to the ward, which generated extra stress and anxiety: "I just woke up after the surgery and then they [nurses] checked how much fluid there was in my bladder and they said that it was too much. I had 1.2 liters of urine in my bladder and then I had 5 minutes to urinate, but I was still groggy from the surgery. After the time was up they inserted an IDUC. It all went so fast. I just wished they had inserted the IDUC during the surgery" (P13).

If insertion was necessary due to a retention bladder, the information provided by the nurses was not always deemed sufficient “I didn’t really have an idea of what it would be like to have an IDUC. I never had one before and then all of a sudden they inserted one but they [nurses] didn’t explain how they were going to do that, so that was very shocking to me. When I asked what was going to happen they explained a little bit but only after I asked for it. I just wish they told me earlier” (P3). Two participants expressed the wish to remove the IDUC but did not feel that their opinion was valued or taken seriously as the IDUC was not removed for another day.

**Theme 4: physical and emotional limitations**

Despite the majority of the patients declaring that they experienced the IDUC as positive, multiple complications related to the IDUC emerged during the interviews. The majority of the participants felt that an IDUC reduces the need to mobilize since it makes mobilizing to the bathroom mostly redundant. Practical limitations, including difficulties with walking and showering due to the IDUC, added to reduced mobilization. One patient explained: “All the hassle walking with the IDUC bag, I mean where do you put that thing. It limits my mobility so much. It really bothers me”. The increased strain on the tube when walking or turning over in bed led to discomfort and caused some patients to be scared that the IDUC might be disconnected and leak urine.

Reduced mobility was not experienced as bothersome by all participants: “You feel it (the IDUC) pull and they you are afraid that it breaks so you have to be a bit careful, you cannot toss and turn in the bed. But lying still was no problem for me, I liked it”. A few participants felt uninformed by nurses and were left questioning about the postoperative mobilization policy. One participant illustrated: “I was happy lying in the bed but if no one says that you can walk you will stay in bed just because you don’t know if you are even allowed to walk with an IDUC”.

Being dependent on nurses was also mentioned as a barrier to mobilize: “I barely left my bed because then the nurse needs to help me and attach it to something. I didn’t want to bother them [nurses] too much because they were so busy all the time”.

Shame and fear of being judged for having an IDUC by nurses, other patients and visitors resulted in most participants with an IDUC to refrain from mobilizing to areas outside their room and by trying to cover the IDUC: “I think it is embarrassing to walk around with an IDUC. That’s why I tried to camouflage the bag with a cardigan or large trousers. I know I should not worry about that but I found the IDUC so distasteful to see”.

Since an IDUC is a foreign material, most patients who received an IDUC post-operatively experienced pain and discomfort when the IDUC was inserted. Patients complained of having bladder spasms, urine leaking next to the tube, and feeling the need to urinate after the IDUC was inserted: “I woke up during the night and then I had a feeling of I need to urinate but that was impossible because I had an IDUC. I found that very annoying”. After IDUC removal, several patients experienced a burning sensation when they urinated which sometimes lasted for a couple of days.

Aside physical discomfort, the interviews disclosed emotional strain caused by IDUCS. Several patients were afraid to develop a UTI as a result of the IDUC and these fears were confirmed by nurses. These patients wanted their IDUC removed sooner than those who did not experience these fears. Before and shortly after the IDUC was removed, a few patients were uncertain if their bladder could instantly regain its function and were worried that they could become incontinent. One participant explained: “Just after the removal I was scared about what was going to happen. Did I have to run to the toilet every minute? At a certain point the IDUC gave me a feeling of peace because I didn’t have to think about urinating. I was afraid that I needed to go to the bathroom 6 times each night and that I might be incontinent”.

### Theme 5: fluid balance causes confusion

During the hospital admission, despite being instructed pre-operatively to monitor their fluid balance, only some participants monitored their fluid intake. The personal fluid balance chart was used simultaneously by the patient, nurses and hospital food service workers which led to confusion and deviating charts. One participant illustrated: “I lost complete control of my input because some nurses wrote it down but other nurses didn’t so it was very confusing to me. I didn’t know if I was supposed to monitor my intake or not”. Participants also experienced difficulties with the fluid balance chart: “I am always guessing how much ml is in one cup because the chart is difficult to understand. The nurses don’t know either, they tell me different amounts per cup”.

Several participants voiced concerns regarding monitoring the fluid balance at home: “the nurse monitored what was going in and out so of course I am starting to worry now that I am going home and have to do it myself. The nurses already worry if there is half a liter difference in the fluid balance and I really don’t understand what all the fuss is about”. Most participants would prefer more education on how to monitor the fluid balance as well as having the ability of guided practice.

Participants did not monitor the urinary output as they were not offered this option. Most participants were willing to monitor their output during the days after the surgery since it contributes to a sense of control and adds meaning and purpose to their recovery: “I would like to monitor the output just so I know what is going on with my body. But I think it would be difficult to measure it the day of the surgery since you are feeling not too good then.. but from day two on it would be no problem for me”. Only one participant explicitly stated that she would find it disgusting to monitor the output during the hospital stay. Support and advice was often sought from the patients’ support system when monitoring the fluid balance at home.

## Discussion

The aim of this study was to explore patient perspectives regarding IDUCS and monitoring the fluid balance after transsphenoidal pituitary and (para)sellar surgery. The findings highlights both positive and negative aspects of having an IDUC. Despite patients describing a broad range of physical and emotional limitations related to IDUCS, they were preferred under the condition of bedrest, especially by females. Our findings suggests that patients' experiences are largely influenced by the information they receive from healthcare professionals both before and during their hospital admission. Additionally, our study shows that despite patients being instructed to monitor the fluid intake, nurses take responsibility of this task leaving the patient unprepared to monitor the fluid balance after discharge.

Most female participants were in favor of IDUC use during the period of mandatory bedrest due to negative experiences with the bedpan. Loss of privacy, dependency on nurses, embarrassment, psychical discomfort and hygiene aspects, all described in previous research, contributed to patients preferring IDUCS instead of bedpans (27).

In this study, the importance of managing patients' expectations and the consequences of patients receiving insufficient information, as described in previous research, were confirmed (28). The experienced quality of patient information is an important factor related to patient-centered care as it contributes to increased patient participation (29, 30). Patients experienced negative effects including stress and confusion by receiving conflicting and too little information regarding IDUC placement and removal. Although it was not mentioned in this study by any of the participants, literature additionally reported that patients may question the competence of the health care professionals due to contradictory and incomplete information (31).

Patient participation levels in relation to shared decision making as well as involvement in clinical care were discussed. Shared decision making was experienced as more present pre-operatively during scheduled consultations in contrast to acute situations, e.g. a retention bladder, postoperatively on the ward. Patients were feeling pressured and overlooked by nurses. Literature acknowledges this phenomenon and states that shared decision making is influenced by the physical setting and variability of the illness and that therefore acute situations may lead to a healthcare provider-led approach (32). This passive role assigned to patients postoperatively could be converted to an equal distribution of power between both parties through educational programs for nurses and strategies (e.g. decision flowcharts) that focus on increasing patients' decision-making capacity (33).

This study highlights the need for patient involvement in clinical care during the hospital admission to ensure a safe transition from the hospital to the home setting, since patients need to monitor the fluid balance post-discharge without the presence of nurses. The lack of training and guidance during the postoperative period could be explained by nurses feeling hesitant to relinquish responsibility to patients as patient safety could be jeopardized (34). Additionally, a lack of time and the absence of a standardized educational protocol for nurses to train and educate patients could be of influence (35). A practice environment where patients and their relatives are trained to monitor both the fluid intake as well as the output to enable a gradual shift in responsibility, whilst still practicing in a safe and controlled setting, could strengthen patients' confidence (32, 36). To the best of our knowledge, no study has been conducted on such a specific educational program.

Mobility challenges related to the IDUC, including prolonged time to ambulation (walking without the support of a nurse), immobility and discomfort, overlap with previous findings (37). In this study, patients reported feeling dependent on nurses' directives which could have delayed the moment of mobilization and thereby have a negative influence on the discharge date (38, 39).

Prior to the surgery, some patients developed an aversion toward IDUCS due to social influences. Postoperatively, patients felt embarrassment about the IDUC and feared judgement from others. Although extensively described in long-term IDUC use, the influence of social stigmas (e.g. embarrassment) has been little reported in IDUC related studies in a hospital setting (40, 41).

The incidence of urinary retention in this study was 75% (9 out of 12), which does not fall in the reported incidence range of 5 – 70, and is significantly higher than the reported 5% in general surgical populations (16, 42). This high incidence could partly be explained by postoperative bedrest, however, additional influencing factors including perioperative fluids, concurrent diseases, duration of the surgery and perioperative medications were not reported since this was not the aim of the study (43). The results from this study could be different if the incidence of urinary retention, and subsequent catheterization rate, were lower.

A major strength of this study is that a combination of patients who received an IDUC during the operation and postoperatively and may or may not have developed a retention bladder were interviewed. Due to this approach, a broad range of experiences and perspectives was gathered. In addition, by applying a code-recode procedure during the data analysis, the creditability of the study increased.

A limitation of the study was the relatively small and specific patient population, in addition to this study being conducted in a single ward in a university hospital. Therefore, the results may not be immediately generalizable to other patient populations and hospitals. The results, however, provide information that could be used by others to get insight in the patient perspective and complicated dilemma's patients face during hospital admission. Second, interviews were conducted both on the ward as in the outpatient clinic. It could be possible that perspectives from the patient who was interviewed several days after discharge from the hospital changed their opinion due to having time to reflect on their hospital admission and to discuss their experiences with others. Patients who were interviewed during their hospital admission might have more vivid memories of their experiences due to the short time after surgery.

Further research is necessary to access the possibilities of patient involvement in monitoring the fluid balance during the hospital admission. Furthermore, a nurse-led training program should be developed and implemented on the ward to increase patient participation and build patients' confidence.

## Conclusion

IDUC placement and fluid balance measurements are important aspects of peri-operative patient care after transsphenoidal pituitary gland and (para)sellar tumor surgery and has a major impact on the patient's overall evaluation. Patients who receive an IDUC during or after transsphenoidal pituitary gland and (para)sellar tumor surgery experience a broad range of complications and are faced with a multitude of challenges related to communication and participation in care. In addition, insufficient information, predominantly provided by nurses, has a large impact on patient experiences and comprehension of the provided care. Patient involvement in both clinical care (e.g. monitoring the fluid balance) as well as shared decision making could be improved. Implementing an inpatient training program to increase patient participation in clinical care is likely to be beneficial for the transition from the hospital to the home setting.

### Author's contributions/contributorship statement

Jeanne-Marie Nollen: Conceptualization, Methodology, Formal Analysis, Investigation, Writing- Original Draft.

Anja Brunsveld-Reinders: Conceptualization, Methodology, Formal Analysis, Writing: Review & Editing, Supervision.

Wilco Peul: Conceptualization, Writing: Review & Editing, Supervision.

Wouter van Furth: Conceptualization, Writing: Review & Editing, Supervision.

### Competing interest

The authors have no conflicts of interest to report.

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### Data sharing agreement

Data is available upon request.

### Ethics approval

This study involves human participants and was approved by the Medisch-Ethische Toetsingscommissie Leiden - Den Haag – Delft in the Netherlands (N19.015).

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## Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

**Page/line no(s).**

### Title and abstract

| | |
|---|---|
| Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | 1 |
| Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 1-2 |

### Introduction

| | |
|---|---|
| **Problem formulation** - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | 4-5 |
| **Purpose or research question** - Purpose of the study and specific objectives or questions | 5/24-26 |

### Methods

| | |
|---|---|
| **Qualitative approach and research paradigm** - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale** | 6/2-5 |
| **Researcher characteristics and reflexivity** - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | 7/38-39 |
| **Context** - Setting/site and salient contextual factors; rationale** | 6/7-13 |
| **Sampling strategy** - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale** | 6/13-17 |
| **Ethical issues pertaining to human subjects** - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 8/12-17 |
| **Data collection methods** - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of | 6/20-23, 8/7-8 |

| | |
|---|---|
| sources/methods, and modification of procedures in response to evolving study findings; rationale** | |
| **Data collection instruments and technologies** - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 6/25-27, 7/1-38 |
| **Units of study** - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 6/13-14 |
| **Data processing** - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts | 8/1-3, 8-10 |
| **Data analysis** - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale** | 8/4-8 |
| **Techniques to enhance trustworthiness** - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale** | 8/2-3, 9-10 |

## Results/findings

| | |
|---|---|
| **Synthesis and interpretation** - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 9-15 |
| **Links to empirical data** - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 10-15 |

## Discussion

| | |
|---|---|
| **Integration with prior work, implications, transferability, and contribution(s) to the field -** Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 16-19/1-12 |
| **Limitations** - Trustworthiness and limitations of findings | 18/24-26, 19/1-7 |

## Other

| | |
|---|---|
| **Conflicts of interest** - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 3/10-12 |
| **Funding** - Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 3/13-14 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

BMJ Open

# Patient perspectives on indwelling urinary catheters and fluid balances after transsphenoidal pituitary surgery: a qualitative study

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# Patient perspectives on indwelling urinary catheters and fluid balances after transsphenoidal pituitary surgery: a qualitative study

Jeanne-Marie Nollen, RN, MSc[1], Anja H. Brunsveld-Reinders, RN, PhD[2] , Wilco C. Peul, MD, PhD, MPH, MBa[3], Wouter R. van Furth, MD, PhD[3]

[1]Department of neurosurgery, Leiden University Medical Center, the Netherlands, [2] Department of quality and patient safety, Leiden University Medical Center, the Netherlands

*Email addresses:*

J.M.Nollen@lumc.nl

A.H.Brunsveld-Reinders@lumc.nl

W.C.Peul@lumc.nl

W.R.van_Furth@lumc.nl

*Corresponding author:*

Jeanne-Marie Nollen

Albinusdreef 2, 2300 RC, Leiden

The Netherlands

Postbox 9600

J.M.nollen@lumc.nl

0618174099

## Abstract

### Objectives

To explore the perceptions and experiences of patients who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery regarding IDUCS (indwelling urinary catheters) and the postoperative fluid balance.

### Design

Qualitative study using semi-structured interviews based on the Attitudes, Social influence and Self-efficacy model and expert knowledge.

### Participants

Twelve patients who underwent transsphenoidal pituitary gland tumor surgery and received an IDUC during or after surgery.

### Setting

One patient was interviewed in the endocrinology outpatient clinic and eleven patients were interviewed on the neurosurgery ward.

### Results

Five major themes emerged: 1. conflicting information and pre-operative expectations, 2. IDUCs perceived as patient-friendly during bedrest, particularly for women, 3. little room for patients' opinions, 4. physical and emotional limitations and 5. fluid balance causes confusion. Information regarding IDUC placement and fluid balance given to patients both pre- and postoperatively did not meet their expectations, which led to confusion and uncertainty. The IDUC was perceived as preferable if bedrest was mandatory, preferred particularly by women. Patient could not mobilize freely due to the IDUC and felt ashamed, judged by others and dependent on nurses.

### Conclusions

This study provides insight into the challenges patients experience in relation to the IDUC and fluid balance. Perceptions on the necessity of an IDUC varied among patients and were influenced by both physical and emotional impediments. A clear, frequent and daily communication between healthcare professionals and patients to evaluate IDUC and fluid balance use is necessary to increase patient satisfaction.

**Keywords:** urinary catheterization, pituitary gland, nurse-patient relationships, interviews

**Strengths and limitations**

- This qualitative study provides a broader understanding of challenges related to IDUCS and fluid balance in relation to bed rest and diabetes insipidus.
- Semi-structured interviews were used to systematically explore set topics whilst allowing flexibility to explore participants' thoughts, feelings and beliefs.
- Two researchers listened to the interviews and individually coded the papers, before discussing the results.
- This study sample consisted of more females than male participants.

## Introduction

To evaluate hospital care and the corresponding processes, patients perspectives play a crucial role as they offer information that goes beyond the scope of regular hospital staff evaluations (1).

Two frequently studied topics to gain insight in hospital care during the postoperative phase are indwelling urinary catheters (IDUCS) and fluid balances. Whilst studies investigating fluid balances have focused primarily on accuracy and diagnostic value in critical care settings rather than focus on patient perspectives, patient experiences with and perceptions of IDUCS in the postoperative phase have been widely researched  (2-4). Patients have connected IDUCS with both infectious-, including urinary tract infections (UTIS), and non-infectious problems, such as pain and discomfort (5). These studies focused on general surgical populations despite literature indicating that patients perspectives could be influenced by their specific illness and operation and that research should therefore keep the individual needs and specific situations in mind (6).

One group of patients who are a useful source of information about IDUC and fluid balance experiences are patients who underwent transsphenoidal pituitary gland and (para) sellar tumor surgery. In the university hospital, IDUCS are not routinely placed during this surgery due to the relatively short operation time of 2-3 hours (7). Despite this policy, IDUCS are frequently inserted postoperatively at the neurosurgical ward.

Two potential postoperative complications influence IDUC placement and the necessity of monitoring the fluid balance in this specific population. First, pituitary patients are at risk of developing the electrolyte disorder Diabetes Insipidus (DI) (8). Accurate monitoring of the fluid balance, every 3-6 hours postoperatively, is essential for the early detection of DI as well as the consideration of desmopressin therapy, which is the primary pharmacological treatment (9). On the ward, nurses measure the urine volume in a urinal and patients use a personal fluid balance chart to register the fluid intake. As DI can occur in the 10 days following surgery, the fluid balance needs to be monitored after discharge (10). IDUCS can contribute to a reliable fluid balance and are convenient for nurses when monitoring the urinary output (11, 12).

Second, to prevent post-transsphenoidal cerebrospinal fluid leakage, bed rest, with elevation of the head of bed at 30° for 24-hours, is a frequently occurring postoperative instruction which could influence the patient's ability to urinate. (13, 14). Bed rest is identified as a risk factor for a retention bladder, which is defined as the inability to urinate despite a full bladder (>500 ml) and can lead to complications including UTIS and stretched bladder muscles (15, 16). If a patient develops a retention bladder, IDUCS are the primary intervention (17).

Previous studies have explored pre- and post-surgery symptom burden of DI and established the need for support before, during and after hospital admission (18, 19). However, to the best of our knowledge, patient perspectives regarding IDUCS and monitoring the fluid balance have not been studied in this specific patient population and setting despite having a major impact during the acute postoperative phase. Consequently, this study aims to explore the perspectives and experiences of patients who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery regarding IDUCS and fluid balances on a neurosurgical ward.

## Methods

### Study design

A qualitative study design was adopted which involved semi-structured interviews with patients who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery to explore their perceptions and experiences regarding IDUCS and the postoperative fluid balance.

### Setting and participants

The study was conducted in a 16-bed department of neurosurgery at a University Hospital in the Netherlands. Participants who underwent transsphenoidal pituitary gland and (para)sellar tumor surgery, received an IDUC in the peri- or postoperative period, and were aged >18 were approached face-to-face if they were admitted to the neurosurgical ward or by phone if they were discharged. Convenience sampling was used to approach thirteen patients, twelve of which agreed to participate and one declined due to personal reasons. One patient was interviewed in the endocrinology outpatient clinic and eleven patients were interviewed on the neurosurgery ward. Data saturation was reached after twelve interviews which means that it is likely that no new information will arise during additional interviews (20).

### Data collection

A semi-structured interview guide was developed based on the Attitudes, Social influence and Self-efficacy model (ASE-model) and expert knowledge (Table 1). This model was deliberately chosen as it helps to elaborate on demonstrated health behaviors and accompanying motives (21). Interviews were performed in Dutch.

| Interview topics |
|---|
| 1. How did patients experience the postoperative care on the neurosurgical ward?<br>• Nursing care<br>• Communication<br>• Complications |

| |
|---|
| • Pre-operative consultation in outpatient clinic<br>• Experience with IDUC<br>• Experience with fluid balance |
| 2. How and to what extent was the patient involved in the decision to insert and remove the urinary catheter?<br>• Pre-operative information<br>• Shared decision making<br>• Role nurse/physician<br>• Influence bedrest<br>• Postoperative complications |
| 3. How did patients experience the moment of IDUC insertion and removal?<br>• Comfort<br>• Physical situation<br>• Time of day<br>• Shared decision making<br>• Nurse's role<br>• Complications after removal<br>• Fluid balance before and after removal |
| 4. What was the patient's role in monitoring the fluid balance?<br>• Bedpan/urinal<br>• IDUC<br>• Fluid balance chart<br>• Patient participation<br>• Collaboration with nurses |
| 5. How did the IDUC affect mobilization and interaction with caregivers/family members?<br>• Stigma and feelings<br>• Barriers |

Table 1: interview topics

Two pilot interviews were conducted. The topic list was adjusted twice based on the feedback of one test-participant and two participants who experienced difficulties explaining their role regarding IDUC removal. The audio-recorded interviews were held in a three month period, from mid-September until mid-November 2019, in a place and time that suited the participant. An oral summary was presented to each participant at the end of the interview to verify their story. Interviews were conducted by an experienced neurosurgical nurse who was not involved in the care of the participating patients.

**Data analysis**

The interviews were transcribed verbatim and analyzed through thematic analysis (22). Two researchers independently conducted the coding process and discussed the findings with one another. Transcripts were read and reread to become familiar with the data. During the first phase of coding, the data was segmented into meaningful parts. These parts were provided with summarizing labels (codes). Subsequently, the codes were compared within and between transcripts by two researchers resulting in categories of codes on a more conceptual level. Finally, the created categories were described into themes. An iterative approach was adopted to enable continuous evaluation of the data (23). The software program Atlas.ti 8.4.15 was used to structure the process of data analysis (24). Analysis was performed in Dutch and quotations were translated into English by a native speaker.

**Ethical considerations**

All study procedures were in accordance with the declaration of Helsinki and the medical ethics committee of Academic Hospital approved the study protocol (N19.015) (25). Participants received an information sheet and an informed consent form prior to the interviews. All participants provided written informed consent. Furthermore, participants were asked for their permission to record the interview with a voice recorder.

**Patient and public involvement**

The research question was developed by the researchers through their experience with the care for pituitary patients. Patients were not involved in the design and conduct of the study, the choice of outcome measures and recruitment for the study. Patients agreed with plans for dissemination of the results through scientific publication and education for nurses on the University hospital ward.

## Results

### Patient characteristics

The sample included 12 patients (Table 2) of which 83 percent (n = 10) were female. The mean age of the participants was 55 years (range: 39 – 73 years). Four patients had an IDUC inserted during the operation. Eight patients had an IDUC inserted postoperatively on the ward as they developed a retention bladder. One patient who received an IDUC during the operation developed a retention bladder after IDUC removal which required re-catheterization. The interviews had a duration of 23 – 58 minutes.

| | n (%) |
|---|---|
| Gender | |
| Male | 2 (17) |
| Female | 10 (83) |
| IDUC inserted during surgery | 4 (33) |
| IDUC inserted on ward | 9 (75) |
| Retention bladder | 9 (75) |
| Bedrest | 7 (58) |
| Diabetes Insipidus | 5 (42) |
| Cerebrospinal fluid leakage | 1 (8) |
| | |
| | Mean (min – max) |
| Age | 55 (39 – 73) |
| Length of hospital stay | 4 (3 – 8) |
| Days IDUC inserted | 2 ( 1 – 7) |

Table 2. Characteristics of study population (n = 12)

Legend: IDUC = indwelling urinary catheters

### Themes

Five major themes emerged: 1. conflicting information and pre-operative expectations, 2. IDUCs perceived as patient-friendly during bedrest, particularly for women, 3. little room for patients' opinions, 4. physical and emotional limitations and 5. fluid balance causes confusion. Quotations are included to illustrate the text.

### Theme 1: Conflicting information and pre-operative expectations

During the pre-operative consult, five patients were informed that they would not receive an IDUC during the operation, whereas the information booklet stated the opposite. Three patients stated that they did not discuss the IDUC during the consult and did not read the booklet prior to surgery, so therefore they were unaware of the possibility of an IDUC. Three participants expressed feeling indifferent towards receiving an IDUC as they trusted the medical staff to make the appropriate decision.

All participants received information during the pre-operative consult on how to monitor the fluid balance after discharge; however, information on how to monitor the fluid balance during the hospital admission was provided to only four participants. Postoperatively, patients reported a large variation between nurses and their willingness to explain the fluid balance and having the patient monitor their input.

Two participants had undergone pituitary surgery in the past and were expecting to receive an IDUC based on their previous experiences. One participant was not content when she found out after her operation that she did not have an IDUC: “I missed my IDUC. Because I had no discomfort from the IDUC the first time but I found it so dehumanizing to urinate on the bedpan, especially because I was unable to empty my bladder and needed an IDUC because of that. In the end, there were four towels under me and I was completely covered in urine”.

The participants’ pre-operative attitudes toward IDUCs leaned towards the negative and were predominantly influenced by stigmas and stories told by their friends and families. One participant explained: “I was so scared of receiving and IDUC because I heard experiences from friends who had it (an IDUC) before and they said it hurts so badly to insert and remove it. So, after I heard all their terrible stories I thought no way I want an IDUC”. Another patient added: “It is what we were taught by our parents in the old days. People were very dramatic about IDUCs; for me it is still a very sensitive subject. I was shocked when I found out I probably was getting one but there are more people in the hospital with one, I know that. But I have this image in my head of an elderly person in a wheelchair and then carrying around that bag… it makes you look so ill."

**Theme 2: IDUCs perceived as patient-friendly during bedrest, particularly for women**

Eight female participants described their positive experiences with the IDUC in combination with postoperative bedrest. The general opinion was that providing a patient with an IDUC is more patient-friendly compared to having to use the bedpan. Ten out of the twelve participants felt that once the postoperative restriction mobility had ended, the IDUC had lost its added value.

Several complications associated with the bedpan were described. First, patients experienced a lack of privacy: "In my room, one other patient was waiting for his operation, another person was waiting for his wife to come back from surgery. I'm sorry but I cannot urinate comfortably with others in the room. I couldn't urinate on the bedpan and I couldn't sit up straight in bed because I was on bedrest. The placement of the IDUC was an issue because they needed around six or seven attempts. It took almost 40 minutes before the IDUC was placed. Very painful and embarrassing for me. But when the IDUC was finally placed it was such a relief". Second, using the bedpan was perceived as unsanitary: "I had to urinate after the surgery but it was very difficult on the bedpan. I was so afraid that the urine would touch me or that I would wet my bed. It was so stressful and disgusting". Third, participants felt dependent on nurses' schedules resulting in patients developing a retention bladder or having to try to control their bladder. Finally, bedpans were associated with physical discomfort.

Participants explained that the IDUC was generally promptly removed by a nurse once the mobility restriction had ended, which was usually around noon. Postponed removal was caused by nurses being too busy or the nurse's wish that the physiotherapist mobilized the patient beforehand. Postponed removal, at 06:00 AM, made a strong impression on the patients: "I was sleeping and it was very early in the morning and then she (the nurse) made a lot of noise, put all the lights on, pulled the IDUC out and that was it. While I was barely awake so I found that very uncomfortable".

### 3. Little room for patients' opinions

Patients had different perspectives on their role in the decision to insert or remove the IDUC. The four patients that had an IDUC inserted during surgery felt that they were adequately informed sufficiently during the outpatient clinic consult. If an IDUC was required postoperatively, patients felt that nurses did not inform them adequately about their options and did not take their opinion into consideration.

The eight patients who did not receive an IDUC during the operation felt pressured by nurses to urinate promptly after their return to the ward, which generated stress and anxiety: "I just woke up after the surgery and then they [nurses] checked how much fluid there was in my bladder and they said that it was too much. I had 1.2 liters of urine in my bladder and then I had 5 minutes to urinate, but I was still groggy from the surgery. After time was up they inserted an IDUC. It all went so fast. I just wished they had inserted the IDUC during the surgery" and "I didn't really have an idea of what it would be like to have an IDUC. I never had one before and then all of a sudden they inserted one but they [nurses] didn't explain how they were going to do that, so that was very shocking to me. When I asked what was going to happen they explained a little bit but only after I asked for it. I just wish they told me earlier". These eight patients wished they were involved more in the shared decision making process.

### Theme 4: physical and emotional limitations

The majority of the participants felt that an IDUC hinders mobilization and reduces the need to be active since it makes mobilization, especially to the bathroom, mostly redundant. One patient explained: "All the hassle walking with the IDUC bag, I mean where do you put that thing. It limits my mobility so much. It really bothers me". The increased strain on the tube when walking or turning over in bed led to discomfort and caused two patients to be scared that the IDUC might be disconnected and leak urine. Being dependent on nurses was also mentioned as a barrier to mobilize: “I barely left my bed because then the nurse needed to help me and attach the IDUC to something. I didn’t want to bother them [nurses] too much because they were so busy all the time”.

Reduced mobility was not experienced as bothersome by all participants: “You feel it (the IDUC) pull and then you are afraid that it breaks so you have to be a bit careful, you cannot toss and turn in the bed. But lying still was no problem for me, I liked it”. A few participants felt uninformed by nurses and were left with questions about the postoperative mobilization policy. One participant illustrated: “I was happy lying in the bed but if no one says that you can walk you will stay in bed just because you don’t know if you are even allowed to walk with an IDUC”.

Shame and fear of being judged for having an IDUC by nurses, other patients and visitors resulted in six participants to refrain from mobilizing to areas outside their room and by trying to cover the IDUC: “I think it is embarrassing to walk around with an IDUC. That’s why I tried to cover up the bag with a cardigan or large trousers. I know I should not worry about that but I found the IDUC so distasteful to see”.

Since an IDUC is a foreign material, six patients who received an IDUC postoperatively experienced pain and discomfort when the IDUC was inserted. Patients complained of having bladder spasms, urine leaking next to the tube, and feeling the need to urinate after the IDUC was inserted: “I woke up during the night and I had a feeling of urinating but that was impossible because I had an IDUC. I found that very annoying”. After IDUC removal, three patients experienced a burning sensation when urinating which sometimes lasted for a couple of days.

Aside from physical discomfort, the interviews disclosed emotional strain caused by IDUCS. Four patients were afraid to develop a UTI as a result of the IDUC and these fears were confirmed by nurses. Before and shortly after the IDUC was removed, two patients were uncertain if their bladder could instantly regain its function and were worried that they could become incontinent. One participant explained: “Just after the removal I was scared about what was going to happen. Did I have to run to the toilet every minute? At a certain point the IDUC gave me a feeling of peace because I didn’t have to think about urinating. I was afraid that I needed to go to the bathroom 6 times each night and that I might be incontinent”.

**Theme 5: fluid balance causes confusion**

During hospital admission, only two participants monitored their fluid intake. The personal fluid balance chart was used simultaneously by the patient, nurses and hospital food service workers which led to confusion and deviating charts. One participant illustrated: “I lost complete control of my input because some nurses wrote it down but other nurses didn’t so it was very confusing to me. I didn’t know if I was supposed to monitor my intake or not”. Participants also experienced difficulties with the fluid balance chart: “I am always guessing how much ml is in one cup because the chart is difficult to understand. The nurses don’t know either, they tell me different amounts per cup”.

Four participants voiced concerns regarding monitoring the fluid balance at home: “the nurse monitored what was going in and out so of course I am starting to worry now that I am going home and have to do it myself. The nurses already worry if there is half a liter difference in the fluid balance and I really don’t understand what all the fuss is about”. Ten patients would prefer more education on how to monitor the fluid balance as well as having the ability of guided practice.

Participants did not monitor the urinary output as they were not offered this option. Nine participants were willing to monitor their output during the hospital admission: “I would like to monitor the output just so I know what is going on with my body. But I think it would be difficult to measure it on the day of the surgery since you are not feeling well then.. but from day two on it would have been no problem for me”. Only one participant explicitly stated that she would find it disgusting to monitor the output during the hospital stay.

## Discussion

The aim of this study was to explore patient perspectives regarding IDUCS and monitoring the fluid balance after transsphenoidal pituitary and (para)sellar surgery. Despite patients describing a broad range of physical and emotional limitations related to IDUCS, they were preferred under the condition of bedrest, especially by females. Our findings suggest that patients' experiences are largely influenced by the information they receive from healthcare professionals both before and during their hospital admission. Additionally, our study shows that despite patients being instructed to monitor the fluid intake, nurses take on responsibility for this task leaving the patient unprepared to monitor the fluid balance after discharge.

Most female participants were in favor of IDUC use during the period of mandatory bedrest due to negative experiences with the bedpan. Loss of privacy, dependency on nurses, embarrassment, physical discomfort and hygiene aspects, all described in previous research, contributed to patients preferring IDUCS instead of bedpans (26).

This study confirms the importance of managing patients expectations and the consequences of patients receiving insufficient information (27). The quality of patient information is an important factor related to patient-centered care as it contributes to increased patient participation (28, 29). Patients experienced negative effects including stress and confusion by receiving conflicting and too little information. Although it was not mentioned in this study by any of the participants, literature additionally reported that patients may question the competence of the health care professionals due to contradictory and incomplete information (30).

Shared decision making was experienced as more present pre-operatively during scheduled consultations in contrast to acute situations, e.g. a retention bladder, postoperatively on the ward. Patients felt pressured and overlooked by nurses. Literature acknowledges this phenomenon and states that shared decision making is influenced by the physical setting and variability of the illness and that therefore acute situations may lead to a healthcare provider-led approach (31). This passive role assigned to patients postoperatively could be converted to an equal distribution of power between both parties through educational programs for nurses and strategies (e.g. decision flowcharts) that focus on increasing patients' decision-making capacity (32).

This study highlights the need for patient involvement in clinical care during the hospital admission to ensure a safe transition from the hospital to the home setting. The lack of training and guidance during the postoperative period could be explained by nurses feeling hesitant to relinquish responsibility to patients as patient safety could be jeopardized (33). Additionally, time constraints and the absence of a standardized educational protocol for nurses to train and educate patients could be of influence (34). A practice environment where patients and their relatives are trained to monitor both the fluid intake as well as the output to enable a gradual shift in responsibility, whilst still practicing in a safe and controlled setting, could strengthen patients' confidence (31, 35). To the best of our knowledge, no study has been conducted on such a specific educational program.

Mobility challenges related to the IDUC, including prolonged time to ambulation (walking without the support of a nurse), immobility and discomfort, overlap with previous findings (36). In this study, patients reported feeling dependent on nurses' directives which could have delayed the moment of mobilization and thereby have a negative influence on the discharge date (37, 38).

We found that social influences, and stigmas could lead to embarrassment and fear of judgement from others. Although extensively described in long-term IDUC use, limited research has been conducted on the influence of social stigmas (e.g. embarrassment) in hospital settings (39, 40).

The incidence of urinary retention in this study was 75% (9 out of 12), which does not fall in the reported incidence range of 5 – 70, and is significantly higher than the reported 5% in general surgical populations (15, 41). This high incidence could partly be explained by postoperative bedrest; however, additional influencing factors including perioperative fluids, concurrent diseases, duration of the surgery and perioperative medications were not reported since they were outside the scope of this study (42). The results from this study could be different if the incidence of urinary retention, and subsequent catheterization rate, were lower.

A major strength of this study is that a combination of patients who received an IDUC during and after the operation were interviewed. Due to this approach, a broad range of experiences and perspectives was gathered. In addition, by applying a code-recode procedure during the data analysis, the validity of the study increased.

A limitation of the study was the relatively small and specific patient population, in addition to this study being conducted in a single ward in a University hospital. However, we do feel that the results can be used for different patient groups who also require fluid balances. Additionally, the results provide information that could be used by others to obtain insight into the patient perspective and complicated dilemmas patients face during hospital admission. Second, interviews were conducted both on the ward and in the outpatient clinic. It could be possible that perspectives from the patient who was interviewed several days after discharge changed due to having time to reflect on their hospital admission.

Further research is necessary to assess the possibilities of patient involvement in monitoring the fluid balance during hospital admission. Furthermore, a nurse-led training program should be developed and implemented on the ward to increase patient participation and build patients' confidence.

## Conclusion

IDUC placement and fluid balance measurements are important aspects of peri-operative patient care after transsphenoidal pituitary gland and (para)sellar tumor surgery and have a major impact on the patient’s overall evaluation. Patients who receive an IDUC during or after pituitary surgery experience a broad range of complications and are faced with a multitude of challenges related to communication and participation in care. In addition, insufficient information, predominantly provided by nurses, has a large impact on patient experiences and comprehension of the provided care. Patient involvement in both clinical care as well as shared decision making could be improved. Implementing an inpatient training program to increase patient participation in clinical care is likely to be beneficial for the transition from the hospital to the home setting.

### Author’s contributions/contributorship statement

Jeanne-Marie Nollen: Conceptualization, Methodology, Formal Analysis, Investigation, Writing-Original Draft.

Anja H. Brunsveld-Reinders: Conceptualization, Methodology, Formal Analysis, Writing: Review & Editing, Supervision.

Wilco Peul: Conceptualization, Writing: Review & Editing, Supervision.

Wouter van Furth: Conceptualization, Writing: Review & Editing, Supervision.

### Competing interest

The authors have no conflicts of interest to report.

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### Data sharing agreement

Data is available upon request.

### Ethics approval

This study involves human participants and was approved by the Medisch-Ethische Toetsingscommissie Leiden - Den Haag – Delft in the Netherlands (N19.015).

### Word count

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**Standards for Reporting Qualitative Research (SRQR)***

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**Page/line no(s).**

**Title and abstract**

| | |
|---|---|
| Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | 1 |
| Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 1-2 |

**Introduction**

| | |
|---|---|
| **Problem formulation** - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | 4-5 |
| **Purpose or research question** - Purpose of the study and specific objectives or questions | 5/24-26 |

**Methods**

| | |
|---|---|
| **Qualitative approach and research paradigm** - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale** | 6/2-5 |
| **Researcher characteristics and reflexivity** - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | 7/38-39 |
| **Context** - Setting/site and salient contextual factors; rationale** | 6/7-13 |
| **Sampling strategy** - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale** | 6/13-17 |
| **Ethical issues pertaining to human subjects** - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 8/12-17 |
| **Data collection methods** - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of | 6/20-23, 8/7-8 |

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| sources/methods, and modification of procedures in response to evolving study findings; rationale** | |
| **Data collection instruments and technologies** - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 6/25-27, 7/1-38 |
| **Units of study** - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 6/13-14 |
| **Data processing** - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts | 8/1-3, 8-10 |
| **Data analysis** - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale** | 8/4-8 |
| **Techniques to enhance trustworthiness** - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale** | 8/2-3, 9-10 |

**Results/findings**

| | |
|---|---|
| **Synthesis and interpretation** - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 9-15 |
| **Links to empirical data** - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 10-15 |

**Discussion**

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|---|---|
| **Integration with prior work, implications, transferability, and contribution(s) to the field -** Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 16-19/1-12 |
| **Limitations** - Trustworthiness and limitations of findings | 18/24-26, 19/1-7 |

**Other**

| | |
|---|---|
| **Conflicts of interest** - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 3/10-12 |
| **Funding** - Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 3/13-14 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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