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(Re)defining nurse and patient roles in routine postoperative neurosurgical care: empowering autonomy and strengthening collaborative roles

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Chapter 3
Patient perspectives on indwelling urinary catheters and fluid balances after trans-sphenoidal pituitary surgery: a qualitative study

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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 11 patients were interviewed on the neurosurgery ward.

Results
Five major themes emerged: (1) conflicting information and preoperative 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.

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. While 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 13 patients, 12 of which agreed to participate and 1 declined due to personal reasons. One patient was interviewed in the endocrinology outpatient clinic and 11 patients were interviewed on the neurosurgery ward. Data saturation was reached after 12 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 behaviours and accompanying motives (21). Interviews were performed in Dutch.

Table 1: interview topics

1. How did patients experience the postoperative care on the neurosurgical ward?
– 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
– Postoperative 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

Legend: IDUC = indwelling urinary catheters

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 3-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 analysed 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.

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

	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)

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'.*

Theme 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 post-operative 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 programme.

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.

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