Micturition Problems After Bladder Distension During Hospitalization in Sweden

"I'm Not Ill, Just Damaged for the Rest of My Life"

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Background: Urinary retention is a common complication following hospital care, which can result in overdistension of the bladder and, at worst, chronic bladder damage and persistent micturition difficulties.

Objectives: The purpose of this study was to explore patients' experiences of micturition problems after bladder distension and their effects on the patients' everyday lives.

Methods: The Swedish Patient Insurance LÖF was used to identify patients from January 2007 to June 2010 who have reported micturition problems after hospital care and have had their injuries classified as avoidable bladder damage due to overdistension. Narrative interviews were conducted with 20 volunteers and analyzed by qualitative content analysis.

Results: The micturition problems affected everyday life through constraints (dependence on disposables and access to toilets, clothing restrictions, limitations on social life and career), suffering (pain, infections, impaired sex life, leakage), and concerns for the future (fear of worsening symptoms and fear of losing control with age). Aspects related to having been harmed by the healthcare system were the harm could have been avoided (lack of knowledge, insufficient routines, mistrust), obstacles to overcome when reporting an injury (difficulties in obtaining knowledge about the possibility of reporting an injury, ambivalence toward reporting their healthcare providers), and a wish to improve care (raise awareness, prevent harm to others).

Discussion: Bladder distension is a healthcare-related injury that can cause suffering and practical, emotional, and psychosocial problems with a great impact on the life of the person affected and anxiety for the future. The healthcare system must, therefore, raise awareness and improve preventive routines.

Key Words: bladder distension • complications of hospitalization • lower urinary tract symptoms • patient safety • qualitative research

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Urinary retention (inability to void) is a common complication associated with hospital care. Factors that may inhibit voiding in the awake patient include supine position, lack of privacy, anxiety, and stress. Anesthesia, intravenous fluids, opiates, and pain are other common risk factors that can cause urinary retention (Ringdal, Borg, & Hellström, 2003; Tammela, 1995). Surgical, orthopedic, and obstetrical patients are exposed to many of these factors and are at particularly high risk of urinary retention. Estimated incidence of postoperative urinary retention varies, and rates as high as 70% have been reported (Lamonerie et al., 2004).

Urinary retention can lead to large bladder volumes. When bladder volume exceeds 500 ml, there is clear risk of overdistension of the muscle fibers in the bladder wall that can result in postvoid residual volumes, urinary tract infections, and an inability to void (Baldini, Bagry, Aprikian, & Carli, 2009). For most patients, this will lead to transient urinary retention requiring one or a few intermittent catheterization before the bladder regains functional capacity, but damage to the detrusor muscle can be permanent if duration of distension is prolonged or the bladder volume is large (Tammela, 1995). Risk for bladder damage increases if the overfilled bladder is not treated within 1–2 hours (Pavlin, Pavlin, Gunn, Taraday, & Koerschgen, 1999), and long-term bladder dysfunction can occur if the period of overdistension exceeds 4 hours (Choi & Awad, 2013).

Patients with permanent bladder damage might need to perform life-long self-catheterization. This can affect the patient's life in various ways, including both practical difficulties and psychological and cultural factors associated with worry and stigma (Shaw, Logan, Webber, Broome, & Samuel, 2008). A great number of patients undergo hospital care and surgery

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everyday and are, therefore, at risk of urinary retention and bladder distension. Patients in hospitals often have an altered sense of the urge to void and difficulty recognizing high bladder volumes (Madersbacher et al., 2012). Healthcare staff must support patients by monitoring their bladder volumes and taking preventive measures—including intermittent catheterization when indicated—to avoid overdistension (Choi & Awad, 2013; Steggall, Treacy, & Jones, 2013). Hospital routines to prevent bladder distension have been insufficient, and this has led to the risk of patients suffering from persistent micturition difficulties (Joelsson-Alm, Nyman, Lindholm, Ulfvarson, & Svensén, 2009).

Bladder damage due to overdistension can be classified as a patient injury, which is defined as "harm caused to a patient as a result of their health care, and which could have been avoided" (Øvretveit, 2009, p. 12). If a patient in Sweden suffers an injury while in the healthcare system, the patient may, in some cases, be entitled to financial compensation under the Patient Injury Act, which is administrated by the Patient Insurance LÖF. The Swedish healthcare system is mainly tax-financed and decentralized; county councils and municipalities serve as the main providers of both hospital care and primary care. All Swedish county councils and regions have taken out patient insurance with the Patient Insurance LÖF. To receive compensation, the patient must report the injury within 3 years of the incident, and compensation is awarded only for avoidable injuries. Each case is evaluated by experienced specialists at the Patient Insurance LÖF (Hellbacher, Espersson, & Johansson, 2007; LÖF, 2011).

Little is known about short-term and long-term urinary tract problems caused by bladder distension and the impact that these problems have on self-perceived quality of life. The main purpose of the current study was to explore patient experiences of micturition problems after bladder distension and the effects of these problems on their everyday life. The study also aimed to explore patient experiences of having been exposed to a healthcare-related injury.

METHODS

Design

A qualitative descriptive design was chosen as the phenomenon of interest—bladder distension—was poorly understood and described in the literature. Two research questions were formulated: "How would persons who had experienced bladder distension describe their micturition problems and their effects on everyday life?" and "How would persons with bladder distension describe their experiences of being exposed to healthcare-related injuries?"

Selection of Participants

The Swedish Patient Insurance LÖF registry was used to identify patients from January 2007 to June 2010 who reported micturition problems after hospital care and who subsequently had their injuries classified as avoidable bladder damage due to overdistension. Thirty-two cases were found. Of these, three patients had died and one was seriously ill. The remaining 28 patients were informed about the study by mail and were asked if they were willing to participate in an interview. Patients were assured confidentiality and the possibility of withdrawing from the study at any time without this having any influence on their future care. A reply form and a prepaid return envelope were provided together with the information letter. Participants were not entitled to financial remuneration or other benefits.

Data Collection

Interviews took place at a location that was decided in consultation between the researcher and the respondent. Most interviews took place in the respondent's home. To encourage the respondent to speak freely, the form of the interview was narrative. There were two open-ended questions: "Can you describe your bladder problems and how these have affected your everyday life?" and "Can you tell me about your experiences of being exposed to a healthcare-related injury?" A digital voice recorder was used during the entire interview, and the same researcher conducted all interviews during the period October to December 2010.

Ethical Considerations

The study was approved by the institutional review board at the Karolinska Institutet (No. 2010/1095-31), and written informed consent was obtained from all participants before the interviews took place.

Data Analysis

Data were analyzed using inductive qualitative content analysis. This method is preferable when existing knowledge of the phenomena to be studied is limited (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). The units of analysis were the individual transcripts of the interviews. The content was analyzed using the method of Elo and Kyngas (2008).

The researcher who conducted the interviews (EJA) became completely familiar with the texts by reading them thoroughly several times. The content of the transcribed interviews were sorted into two domains corresponding to the two research questions, and each domain was analyzed separately. The text was condensed to meaning units—which were labeled by codes. Coding is a crucial step in the process of analyzing data from texts, and thus, the codes were discussed with two other researchers (JU and CN) before going further into the analysis by creating categories and subcategories within the two domains (Creswell, 2009; Graneheim & Lundman, 2004). To ensure rigor and consistency of interpretation, the analysis was discussed by the researchers, and agreement was reached at every step to ensure that all analyses were supported by the data and reflected in the transcripts. According to Elo and Kyngas

(2008), content validation requires the use of a panel of experts to support concept production or coding issues as each researcher interprets the data depending on their subjective perspective. The final model was further validated by an independent, external researcher with expertise in qualitative descriptive methods.

The whole content analysis procedure was performed in the source language (Swedish), and when preparing the manuscript, an external, bilingual, accredited translator was used to translate the codes, categories, and quotations to English. To ensure the adequacy of the translation, the researchers reviewed and discussed the translation until agreement on meaning was reached. The original quotations in Swedish are shown alongside the English translation (see Table, Supplemental Digital Content 1, http://links.lww.com/NRES/A126).

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RESULTS

Participants

Twenty-one patients volunteered and were planned to be interviewed, but one patient cancelled the interview due to sudden illness. A total of 20 interviews were performed (Figure 1). Participants were between 28 and 78 years of age at the time of injury and had a wide variety of reasons for hospitalization. Table 1 presents the main characteristics of the informants.

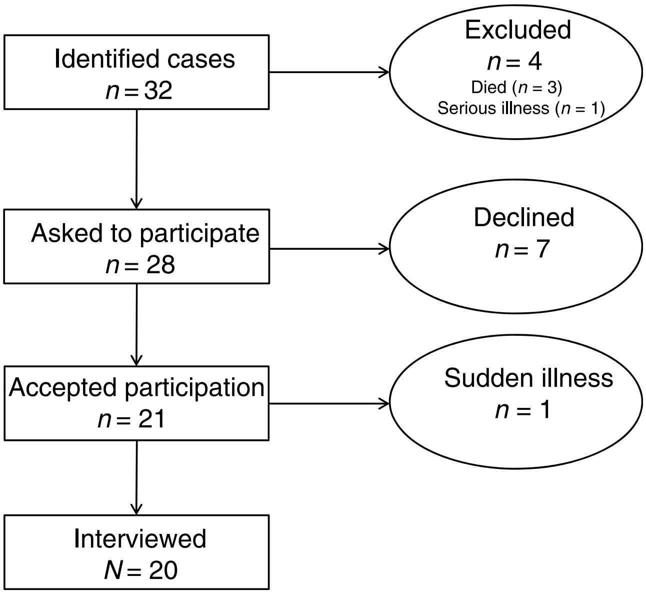

FIGURE 1. Participant enrollment flow diagram.

TABLE 1. Participant Characteristics

Characteristic	*n*	%
Gender		
Female	13	65
Male	7	35
Age at injury (years)		
<50	7	35
50–70	9	45
>70	4	20
Diagnosis at injury		
Orthopedic surgery	7	35
Gynecologic surgery	4	20
General surgery	3	15
Pregnancy/childbirth	4	20
Infection	1	5
Adverse drug reaction	1	5
Micturition status at interview		
Daily clean intermittent catheterization	11	55
Indwelling Foley catheter	1	5
Other micturition problems	7	35
No problems	1	5

Note. N = 20.

The time between the injury and the interview ranged between 1 and 10 years—with a median of 4 years. Twelve people had a permanent inability to empty the bladder and were compelled either to perform daily self-catheterization or to have an indwelling Foley catheter. Seven people had regained some of the bladder function and were able to void, but experienced other persisting micturition problems, such as recurrent urinary tract infections, a reduced ability to feel the urge to void, and the need to use alternative voiding techniques (credé maneuver, tapping, double-voiding, etc.). For one of the participants, the micturition problems had disappeared completely. The interviews lasted between 14 and 90 minutes (*Mdn* = 49 minutes) and were transcribed verbatim by the interviewer.

Overview of Findings

The results are presented as categories and subcategories in the two domains: "The impact of micturition problems on everyday life" and "Aspects of having been harmed by the healthcare system." Each category is supported by quotations from the participants. Figure 2 shows an overview of domains, categories, and subcategories.

Micturition Problems and Everyday Life

Constraints. All participants described restrictions on everyday life, regardless of the severity of their symptoms. *To be dependent on access to toilets* was perceived as a major constraint. The participants described a need to always know the locations of toilets and always to be able to gain rapid access when necessary. This was especially prominent in connection with travel

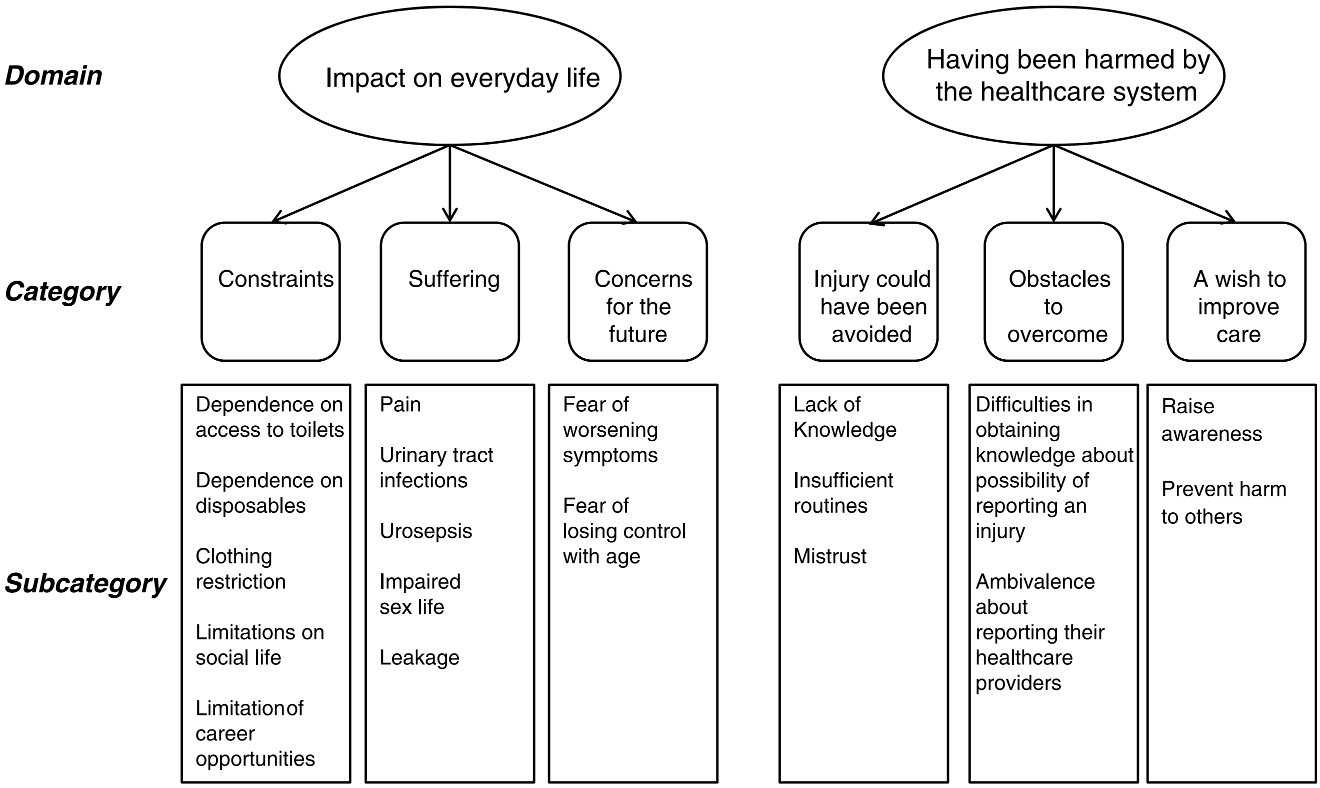

FIGURE 2. Overview of domains, categories, and subcategories.

and has led to the respondents taking fewer trips, taking shorter trips, or choosing a mode of transport with better access to toilets. Visits to the toilet could be very time-consuming and stressful—both for those who performed self-catheterization and for those with alternative voiding techniques. Some of the participants described how this led to a mania that dominated their minds and—especially during the first months after the injury—made it difficult to concentrate on anything else.

> That summer we couldn't travel anywhere. I had to stick to the toilet: it was the only thing that existed in my life. The entire day was organized around where the toilets were.

That summer we couldn't travel anywhere. I had to stick to the toilet.

Leisure activities, such as going to the cinema, theater, or concerts, could be limited by the availability of toilets—as could many outdoor activities—especially during the winter (such as skiing, ice fishing, and snowmobiling).

The size and hygiene standard of the toilet were also important: too small a toilet made it hard to perform self-catheterization, whereas dirty toilet rings and sinks were seen as sources of infection. Several participants expressed a very uncomfortable feeling of being dependent on public toilets no matter what their standard was, and not being able to postpone voiding until a cleaner, more suitable toilet was found.

For those who needed to perform self-catheterization, *the dependence on having the necessary disposables* (catheters, cleaning equipment, alcohol-based hand rub) available at all times was a constraint with great practical implications. The participants described the need for careful planning of the day to ensure the ability to perform catheterization, always carrying bags large enough to hold the disposables, and the need to equip the most commonly used toilets at home and at work.

> And then to always, always, always bring catheters. There are bags with pins, catheters, and mirrors everywhere. Now I don't even dare to try to catheterize without a mirror.

Another problem mentioned by the participants was *clothing restrictions.* One of the female participants found it very hard to wear skirts or dresses, as the need to hold the skirt up made catheterization more difficult. Tightly fitting jeans or trousers could worsen genital irritation and were avoided by some people. Some respondents avoided wearing light-colored trousers because of the risk of getting stains if leakage occurred.

Limitations on social life arose not only from the practical difficulties with toilets and disposables but also from feelings of embarrassment and fatigue. Some participants described how they avoided meeting people and would rather be alone with their problems. Older participants, in particular, found it difficult to talk about their problems with other people—except the immediate family. Younger participants, in contrast, were very keen on not hiding their problems and not letting their injuries limit their lives. Three participants were injured because of postpartum bladder distension, and they all described feelings of guilt because they had felt unable to care for their newborn children properly.

Younger participants were very keen on not hiding their problems and not letting their injuries limit their lives.

> I could not focus on the child at all; the only thing that occupied my mind was the micturition problems. . .//. . .I felt like a bad mother, I was angry and irritable all the time. And he (the baby) lay screaming at the changing table. Oh, it was terrible! I was soaked with sweat and needed to pee but couldn't do it.

Micturition problems had led to *limitation of career opportunities* for three participants. Being unable to perform tasks outside the office without access to toilets was one restriction that had had an impact on careers. One person was unable to work at all because of recurrent urinary tract infections and a related deterioration of arthritis.

Suffering. Various aspects of suffering were a recurrent theme in the interviews. The participants used emotive and strong words to describe their symptoms and feelings.

> It was the beginning of a hellish trip.

Pain was a common problem: several participants had experienced pain when inserting catheters, and others described a vague, constant pain in the stomach or a feeling of soreness in the genital area. Most patients had lost the sense of urge, and many of them instead recognized the need to void from increasing pain in the bladder region. Some of the patients had had a suprapubic catheter for a few months after the injury while waiting to see if the bladder would recover, and both the insertion and the regular changes of the suprapubic catheter were experienced as extremely painful and unpleasant.

Urinary tract infections had affected 18 of the 20 participants, and nine of them had recurrent infections every year. Several participants experienced the infections and the fear of future infections as the most stressful part of their micturition problems. The infections led to increased pain (especially when catheterizing/voiding), more frequent visits to the toilet, disturbed sleep, and negative side effects of antibiotics. For people with chronic diseases such as rheumatism, the infections could result in a worsening of disease symptoms and the need for changes in medication (such as an increase in the dose of cortisone).

> These micturition problems are actually a bigger problem than the rheumatism, although I've had surgery in almost every joint. . .//. . .The urinary tract infections, I have no control over them. That is the most stressful part.

For four participants, the urinary tract infection had led to *urosepsis.* The participants experienced this life-threatening condition as fearful and anxiety provoking. One participant who had recently received hospital care for her second episode of urosepsis in the same year stated:

> I was about to give up. I told my daughter before going to the hospital: "No, I can't stand this anymore, what's the point of living when it's like this?". . .//. . .I am terrified of getting it [urosepsis] again.

Impaired sex life was described by both male and female participants. Chronic soreness in the genital area because of self-catheterizing, fear of leakage, or infection could lead to reduced desire, erection difficulties, and an effect on the relationship with the partner. The presence of an indwelling catheter had a devastating effect on sex life.

> The injury affected our sex life and togetherness for the whole of that summer [with indwelling catheter] and for several months after. Moreover, I'm much older than my husband and it complicates the case further. . .// . . .sex is still quite important.

Leakage and the related embarrassment of odor affected many participants—both those who performed self-catheterization and those with alternative voiding techniques. If urination was delayed (due to, e.g., no toilets being available or forgetting to set the alarm clock), even persons without voiding ability could leak some urine if the bladder was too full.

Concerns for the future. *A fear of worsening symptoms* (pain, infections, leakage, difficulties in catheterizing) was described in most of the interviews. The participants were aware that their injuries were chronic and that they had little chance of improvement.

> Actually, it feels terrible to know that I will have to keep doing this [self-catheterizing] the rest of my life.

Several respondents felt that they currently managed their micturition/self-catheterization in a satisfactory manner, but they were worried about *losing control with age* and being unable to take care of themselves.

> What about when I get old. . .I'm 50 years old today, imagine when I'm 78? Today I'm the only one who knows how to take care of my micturition problems. What if I become senile, how will they be able to handle this? I think it's awful, I see myself with big giant nappies. . ..

The participants found it difficult to talk about these concerns, as they were linked to strong feelings of anxiety. Several became tearful and distressed when talking about their concerns for the future.

Aspects of Having Been Harmed by the Healthcare System

The injury could have been avoided. A theme that arose often when respondents narrated how the injuries had arisen was that the staff had not understood the seriousness of the situation and had not been aware of the possible consequences for the patient. The participants were surprised over the *lack of knowledge* among the staff about urinary retention and bladder distension and *insufficient routines* to prevent large bladder volumes at the care unit. The respondents had not themselves been aware of the risk of bladder damage due to large volumes, as there is no widespread knowledge of the problem among the public, but they expected health professionals to be experts in complications associated with hospitalization. Several respondents described how they felt that the staff had *mistrusted* them, and many of the participants had had to insist on having their bladder volumes checked. They felt that the staff did not take their complaints seriously. An inability to void was not considered to be an important problem by the staff. "If only they had listened to me" was a common remark, indicating also deficiencies in communication.

> Not being believed—that was terrible, they did not believe that my problems were important. I almost felt violated. . .//. . .The nurses made a mistake when the bladder ultrasound showed that there was more than 1000 ml in the bladder and they didn't catheterize me at once. In this situation, not taking the problem seriously, failing to take the correct action. . .I see it as a huge problem for the health care system. I think that such incidents are not uncommon.

The participants were well aware that their injuries could have been avoided if the staff had monitored their bladder volumes and taken the correct actions when bladder volumes were high. It was important for them to emphasize that they had been actually damaged by the healthcare.

> I'm not ill, just damaged. That's how it feels: I'm damaged for the rest of my life.

Obstacles to overcome when reporting an injury. A major obstacle was *difficulties in obtaining knowledge about the possibility of reporting an injury* and applying for financial compensation. Respondents had, in many cases, come across this information more or less by chance. Only one respondent had been informed by the responsible caregiver, and it was instead friends, relatives, and other healthcare personnel who had informed and encouraged them to report their injuries. Two participants previously had other healthcare-related injuries and had an earlier experience of reporting such injuries.

Some of the participants expressed *ambivalence toward filing a report about their healthcare provider.* One reason for this was a reluctance to report, for example, a surgeon who had otherwise done a good job, or the sympathetic nurses on the ward. Another reason was fear of reprisal; respondents felt unsafe in reporting personnel on whom they would depend for future care. Some participants described incidents in which they had met the person responsible and had met both anger and neglect.

> I was afraid of a negative reaction from my physician: He was supposed to also do the surgery on my other foot. You belong to a very vulnerable group as a patient, and you don't dare to say everything you want to say because next time, you might depend on their service.

A wish to improve care. A common motive for agreeing to participate in the study was that it gave the respondents a chance to highlight the problem and *raise awareness.* Several of the participants expressed a strong desire that the experience with micturition problems that they had been through should not happen to other people and a wish to *prevent harm to others.*

> Hopefully we will make a difference, so that there will be a change in health care, and those who come after us will get better treatment. . .//. . .I also hope that both students and staff become aware of the problem; this is something that may occur; this can actually happen.

DISCUSSION

This study shows that micturition problems after bladder distension have a large negative impact on the affected person's life. This is not surprising, as lower urinary tract symptoms (LUTS) play an important role in how people perceive their quality of life. Coyne et al. (2009) studied 30,000 men and women aged over 40 in the United States, the United Kingdom, and Sweden in a population-representative survey. The authors concluded that a negative effect of LUTS is apparent across several domains of health-related quality of life and that LUTS are associated with high levels of anxiety and depression. The respondents in the study described here also reported anxiety and depression, and they reported that these effects may persist after the first traumatic period immediately following the injury. Persistent micturition problems and deep concern for the future, such as a fear of pain, fear of infection, and a fear of losing control, were common sources of anxiety.

Negative experiences of suprapubic catheters—in particular during the insertion—were evident. This may be due to insufficient preparation and information from the staff, as other studies (Robinson, 2008; Sweeney, Harrington, & Button, 2007) have found, but the intensity of the traumatic and painful experiences of insertion that the respondents described was surprising. This area needs to be studied further.

The micturition problems among the participants at the time of the interview differed—depending on the severity of the bladder damage they had undergone—but they had many experiences in common. Problems related to access to clean toilets were brought up prominently in all interviews. This has previously been described in studies of intermittent self-catheterization (Shaw et al., 2008; Wilde, Brasch, & Zhang, 2011), but this study shows that the problem also affects people with other micturition problems and alternative voiding techniques. Infections, leakage, and limitations to social life are other persisting problems regardless of micturition status.

I'm not ill, just damaged. That's how it feels: I'm damaged for the rest of my life.

Analysis of the aspect of having been harmed by the healthcare system revealed that the participants had experienced that healthcare workers displayed significant gaps in knowledge about bladder distension and that preventive routines were insufficient. One possible explanation for the low awareness of bladder distension is that the phenomenon is poorly described in both medical and nursing textbooks. There is also a lack of clinical guidelines; Johansson et al. (2013) were the first to publish evidence-based guidelines for preventing urinary retention and bladder damage during hospital care.

Mistrust and poor communication led to a failure to notice and remedy the participant's symptoms in time. This was crucial, as the risk for permanent bladder damage increases if the overfilled bladder is not treated within 1–2 hours (Pavlin et al., 1999). It is well known that poor communication contributes to medical errors, but the focus in most studies has been on poor communication between staff (Neale, Woloshynowych, & Vincent, 2001; Sutcliffe, Lewton, & Rosenthal, 2004; Tanaka et al., 2012), not the communication with the patient. Several participants in the study reported here felt that the failure by staff to listen to them was the main cause of their injuries.

The obstacles that must be overcome when reporting an injury need to be discussed. It was remarkable that only one participant had been informed by the responsible healthcare provider about the possibility of filing a report and obtaining financial compensation. An ambivalence toward reporting a healthcare provider may be explained by the fact that patients are in a vulnerable position; they have been harmed by the people in whom they placed trust and on whom they depend for future care (Vincent & Coulter, 2002). The healthcare system must address these issues in order to decrease the huge number of unreported cases—most medical injuries never trigger a complaint (Bismark, Brennan, Paterson, Davis, & Studdert, 2006; Christiaans-Dingelhoff et al., 2011). An aggravating factor is the low rate at which people with micturition problems seek medical advice (Lai, Wun, Luo, & Pang, 2011; Nørby, Nordling, & Mortensen, 2005; Wennberg et al., 2009). Patient reporting is reliable (King et al., 2010) and has a high validity (Pukk-Härenstam et al., 2009), and it must be encouraged.

Many studies have shown that patients with healthcare-related injuries wish that the healthcare system would highlight the problem and take measures to prevent the same harm from happening to other patients. This was obvious in this study, too, and it implies a major responsibility for healthcare management to raise awareness and improve routines for the prevention of bladder damage due to overdistension.

Limitations

The data obtained from the interviews were very rich and extensive, and publication limitations meant that the authors had to choose what to present. Other researchers may have made other choices and focused on other parts of the data.

The participants had all managed to overcome the obstacles to reporting their injuries and had received medical care for their micturition problems. This is not very common among patients who have suffered bladder damage after hospital care. It would have been interesting to interview patients who had not reported their injuries, although finding such patients would present great difficulties.

Conclusion

Bladder distension is a healthcare-related injury that can cause suffering and practical, emotional, and psychosocial problems with a great impact on the life of the person affected and anxiety for the future. The healthcare system must raise awareness, improve preventive routines, and reduce communication barriers with patients.

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