

# Grit in the waterworks

– patient experiences of living with stones in the upper urinary tract

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## Introduction and Objective

It is known that course of disease with stones in the upper part of the urinary tract (SUPUT) is prolonged and inefficient due to the need for more interventions, relapse, comorbidity and a lack of patient compliance resulting in several meetings with health professionals. Patients suffer from physical and psychological issues, which can be chronic, disabling and impact quality of life. A recent review shows that patient experiences have mainly been studied using the SF36 survey and authors encourage new studies working with patient experiences related specifically to patients with SUPUT.

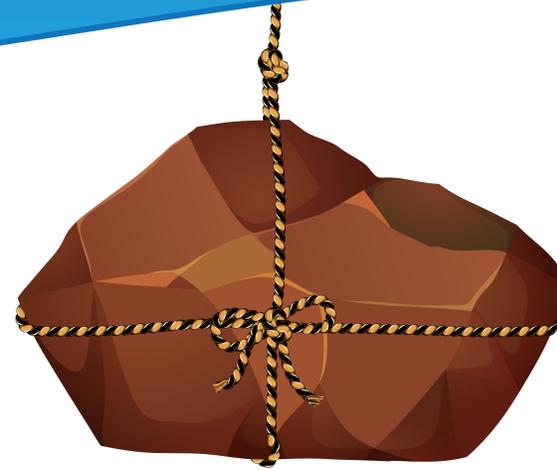
The purpose of this study was to investigate patient experiences of living with SUPUT for minimum two years, focusing at the impact on everyday life, quality of life and contacts with health professionals.

## Materials and methods

A two phased qualitative studydesign with individual- and focusgroupinterviews was chosen where first phase qualified the second with sharpened thematic focus. Inclusion criteria were patients with minimum two years course of SUPUT. Recruitment was strategic aiming at maximal variation in gender and age. All interviews were recorded and transcribed Thematic analysis was conducted inspired by Braun and Clarke.

First studyphase consisted of six individual semi-structured interviews conducted in October 2015 at the hospital or in their home according to informants choice. The informants were 3 men and 3 women aged 25 - 64 years..

In the second phase patient experiences were further investigated through two focus group interviews with 9 women and 9 men aged 25 – 68 years, because the dialogue between peers might bring new perspectives. The focus group interviews took place at the hospital in March 2017.



## Results

A life characterized by unpredictability and uncertainty were the main findings. Patients reported that living with stonedisease is “a ticking bomb” and a chronic disease. Multiple strategies were employed to manage everyday life in order to establish some degree of predictability and control. The fear of new painful attacks followed by massive fatigue was always present and guided decisions regarding work and social life in periods with and without actual stones.

Unpredictability and uncertainty also characterized the patient experiences with health professionals with limited access to expert knowledge and treatment combined with unclear treatment-courses

## Conclusion

SUPUT was experienced as a chronic disease due to unpredictability and uncertainty causing patients to structure everyday life according to the disease. SUPUT thus had a significant negative influence on patients life in periods with and without actual stones. Unclear and prolonged treatmentcourses contributed to the experience of unpredictability and uncertainty. Clinical practice should consider organizing treatmentcourses for SUPUT patients aiming at clear and quick access to experts and treatment.

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