

## USERS EXPERIENCES OF KETAMINE BLADDER SYNDROME (KBS)

### Hypothesis / aims of study

Ketamine is a dissociative drug used in anaesthesia, palliative pain care and veterinary medicine. It is also used recreationally as a 'club drug'. While the precise aetiology is unclear, when used regularly and in increasingly higher doses, ketamine can cause considerable and potentially irreversible damage to the bladder and urinary tract, resulting in ulceration, fibrosis, bleeding, pain, urgency, frequency and incontinence. The prevalence of KBS is unclear but believed to be increasing. Little is yet known about how patients are affected by KBS, their understanding of the condition, their rationale for seeking medical help or their experiences of healthcare services. This study aimed to explore ketamine users' experiences of KBS, along with associated healthcare provision issues.

### Study design, materials and methods

The research was undertaken using a qualitative approach, informed by Grounded Theory methodology. 12 participants (7 men, 5 women; mean age 26 years, range 20-43 years) were purposively recruited into the study through Continence services and, a local voluntary drug aid agency. Data were collected through semi-structured interviews. Demographic and KBS symptom questionnaires were also completed. Interviews were digitally recorded, transcribed verbatim and analysed thematically using Nvivo 10. Data analysis was validated using a process of inter-rater reliability. Consistent with the methodology, data collection and analysis occurred simultaneously. Survey data were analysed descriptively and facilitated detailed analysis of qualitative data.

### Results

All participants were poly-drug users and most had been using ketamine since their teens. Ketamine was snorted in powder form and consumed socially with other users. KBS symptoms typically developed shortly after participants started using ketamine more frequently and in larger quantities. Common lower urinary tract (LUTs) symptoms included frequency, urgency, hesitancy, difficulty voiding, urge incontinence and, subsequently, significant haematuria and abdominal pain, which caused considerable anxiety and concern. Conventional pain management was inadequate and self-medication with ketamine was therefore common, even though it further exacerbated KBS symptoms. Fear and embarrassment adversely affected medical help seeking. Limited primary care assessments, repeated incorrect diagnoses, inappropriate treatments and inadequate advice and support were common. Participants also felt that they were judged, ignored and treated with contempt by most health professionals.

### Interpretation of results

This problem was usually left undiagnosed or misdiagnosed, commonly treated with antibiotics as a urinary tract infection; this approach did not relieve symptoms. Pain control was not well managed resulting in self medication; a vicious cycle of more ketamine, risking further damage to the urinary tract. KBS poses a growing public health problem, however knowledge of the condition was poorly understood by health professionals. Consequently, this limited the nature and extent of information, advice and support offered to those with KBS. Raising awareness amongst the relevant health professionals is required, particularly in relation to assessment, management and effective pain relief. Early diagnosis and timely intervention are also essential. Helping users to moderate or to stop taking is complex and patients with KBS should be referred to drug agencies, for specific drug-related cessation support. The results demonstrate a need for a more compassionate and preventative approach to addressing the issues faced by these vulnerable young people. This information will become increasingly important as experimental/recreational drug usage becomes more common place within teenage and young people's culture.

### Concluding message

The study highlights the need for a more integrated, multi-agency approach, which incorporates an appropriate primary care assessment, timely diagnoses and referral to specialist urological, pain management and substance misuse teams.

### Disclosures

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