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## Title page

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Participants' experiences of ketamine bladder syndrome (KBS): a qualitative study

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**Author details:**

Paul GILL RN, PhD  
Senior Lecturer (Adult Nursing)  
School of Healthcare Sciences  
Cardiff University  
35-43 Newport Road  
Cardiff  
CF24 0AB

Karen LOGAN OBE, MSc, RGN  
Consultant Nurse  
Continence Service,  
Aneurin Bevan University Health Board  
Llanfrechfa Grange Hospital  
Cwmbran  
Gwent  
NP44 8YN

Bev JOHN BA, PhD  
Reader, Psychology  
Faculty of Life Sciences and Education,  
University of South Wales  
Pontypridd, UK  
CF37 1DL

Fallon REYNOLDS  
Drink Wise Age Well Prevention Team Leader  
35 Taff Street,  
Pontypridd  
CF37 4TR

Chris SHAW RN, RM, PhD  
Reader (retired)  
Faculty of Life Sciences and Education  
University of South Wales  
Pontypridd, UK  
CF37 1DL

Kim MADDEN PhD  
Trial Manager  
Centre for Trials Research, Cardiff University  
Heath Park, Cardiff  
CF14 4XN

**Corresponding author:**

Dr Paul Gill  
School of Healthcare Sciences  
Cardiff University  
35-43 Newport Road  
Cardiff  
CF24 0AB  
Tel: 00 44 (29) 20688605  
Email: [GillP3@cardiff.ac.uk](mailto:GillP3@cardiff.ac.uk)

## **Participants' experiences of ketamine bladder syndrome (KBS): a qualitative study**

### **Abstract:**

**Aim:** To explore recreational ketamine users' experiences of ketamine bladder syndrome (KBS) and related healthcare provision issues.

**Research problem/Literature Review:** KBS is an emerging condition caused by chronic, recreational ketamine use, which can result in extensive, irreparable damage to the bladder and urinary tract. However, little is yet known about how patients are personally affected by the condition, their help seeking behaviour or experiences of related healthcare services.

**Methodology:** A qualitative study, informed by Heideggerian hermeneutics was undertaken. Twelve participants affected by KBS were purposively recruited into the study from an NHS continence service and a drug support agency in South Wales, UK. Data were collected through recorded, semi-structured interviews and analysed using a three-step approach.

**Results:** Participants were predominantly younger, poly-drug users and typically developed KBS following prolonged, habitual ketamine use. The effects of KBS were considerable and included incontinence, haematuria, profound abdominal pain and embarrassment and were exacerbated by delays in help seeking, disjointed medical care and on-going ketamine use, which was integral to the self-management of KBS pain.

**Conclusions:** KBS has significant impact on those affected and can result in extensive, irreversible damage to the bladder and urinary tract. The condition, and its management, is further compounded by chronic poly-drug use, chaotic lifestyles and a range of complex, related co-morbidities, which require a collaborative, multi-disciplinary approach. Anderson's behavioral model of health services use provides an appropriate framework for better understanding help seeking/avoidance behaviour in this cohort, which can help inform clinical practice.

### **Funding / competing interests:**

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### **BACKGROUND**

Ketamine is a dissociative drug used in anaesthesia, palliative pain care and veterinary medicine (Morgan and Curran, 2011). It is also used recreationally as a 'club drug', particularly among younger drug users and is now one of the most popular drugs among UK clubbers (Morgan and Curran, 2011). It is mainly snorted in powder form, generally consumed socially with other users and can cause hallucinations, out of body experiences and intense detachment from reality (referred to as 'the k-hole') (Muetzelfeldt *et al.*, 2008). It is not thought to be addictive, but tolerance and dependence can develop over time.

The aetiology is unclear, but 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 and incontinence (Mason *et al.*, 2010). The condition is commonly known as ketamine bladder syndrome (KBS). The prevalence of KBS in the UK is unknown but, consistent with escalating ketamine use, is believed to be increasing. Survey data suggest that only around 10% of symptomatic recreational ketamine users actually seek medical help (Winstock *et al.*, 2012) although it is unclear why. There is no curative treatment, although abstinence from ketamine may help reduce irritation and inflammation in some patients (Logan, 2011).

To inform this study, a comprehensive literature review was undertaken using CINAHL, MEDLINE and PsychINFO databases. The following search terms were used, in various combinations: ketamine, bladder, syndrome, KBS, urinary, ulcerative and cystitis. Papers published in English were sought, no date restrictions were applied. From around 2007 onwards, there is an emerging programme of research in this area, although most relevant literature is in the form of medical case studies, reviews and discussion papers, which primarily highlight symptom effects and treatment challenges. No studies were found that specifically explored the personal experiences of those affected by KBS.

Consequently, little is yet known about how patients are affected by KBS, their understanding of the condition, motivations for seeking help or their experiences of related healthcare services. An in-depth understanding of these complex issues could therefore help to inform related clinical practice. This study was subsequently undertaken to explore these multifaceted issues.

## **METHODOLOGY**

### **Aim:**

To explore recreational ketamine users' experiences of KBS and related healthcare provision issues.

### **Methodology:**

To better understand participants' experiences, a qualitative approach, informed by Heideggerian hermeneutics, was used. The methodology is interpretative and is therefore appropriate in helping to uncover common meanings in narratives and to comprehend situational contexts (Majdalani *et al.*, 2014). The methodology allows participants to reflect on and describe their experiences and social practices, in depth, through 'naturalistic conversations', which help to reflect their lived experiences (Omeri and Atkins, 2002; Clayton *et al.*, 2014).

### **Sample and recruitment**

Participants were purposively recruited into the study in Spring-Autumn 2013 from a regional NHS continence service and a community based drug support agency in South Wales, UK. Participants were identified, approached and recruited into the study by gatekeepers in each organisation, using an agreed inclusion/exclusion criteria, which were developed in consultation with both centres. Respondents were invited to participate if they were adults, ketamine users, experiencing KBS and able to provide informed consent. Respondents were not invited to participate if they were legal minors, unable to provide informed consent, diagnosed with other bladder problems (e.g. pre-existing bladder problems and/or other urological conditions, not related to ketamine use) or unaware of their condition.

Suitable participants were provided with a participant information pack, which included a covering letter, participant information leaflet, expression of interest form (EOI) and freepost envelope. Those interested in the study completed an EOI form and returned it to the research team. The project research assistant (RA), who was not involved in their treatment or care, then contacted prospective participants to discuss the study in more detail, answer any questions and, if appropriate, arranged to meet. On meeting, the RA ensured they met the inclusion criteria and, if they were happy to participate, written consent was obtained prior to data collection.

Twelve participants (7 men, 5 women) were recruited into the study. Participants' mean age was 26 years (age range 20-43 years). At the time of recruitment, all were poly-drug users, most were unemployed, one was in part-time training, one was self-employed and two were employed part-time. Further participant demographics are presented in **table 1**:

**Table 1. Participant demographics**

<b>ID code</b>	<b>Gender</b>	<b>Estimated number of years using ketamine</b>	<b>Estimated daily dose (grams) at peak usage</b>
F101	Female	6	Not specified
M102	Male	7	2–8g
F103	Female	11	1g
M104	Male	10	Not specified
F105	Female	11	8–10g
M106	Male	8	50g (timeframe not specified)
M107	Male	12	10-15g
F108	Female	6	9g
F109	Female	<1	1g
M110	Male	13	5g
M111	Male	3	2g
M112	Male	8	20g

### **Data collection**

Data were collected through semi-structured interviews, which were conducted in private by the RA, at the drug support agency premises. Interviews lasted 30-60 minutes. The interview schedule was devised following a review of the literature and in discussion with gatekeepers at both recruiting organisations.

Consistent with the espoused methodology, interview questions were open and provided a framework for discussion, while allowing participants to talk freely about their experiences of ketamine use, KBS and associated healthcare provision issues. To obtain an in-depth understanding of participants' experiences, several techniques were used during the interview, as and where appropriate, including probing, clarifying, restating and summarising (Gill and Lowes, 2014).

To establish appropriateness, the interview schedule was piloted on the first three participants recruited. The schedule was found to be appropriate and not amended. All pilot data were therefore incorporated into the main study findings.

### **Data analysis**

Interviews were digitally recorded, transcribed verbatim and analysed using Linsdeth and Norberg (2004) three-step approach, which involves naive reading, structural analysis and comprehensive understanding. In the first step (naive reading), interviews were listened to and interview transcripts were read and re-read with an 'open mind' to establish a sense of the collective data and to inform the next analysis stage. In the structural analysis phase, initial sub-themes and, subsequently, themes were identified and formulated that conveyed a sense of participants' experience (Gill and Lowes, 2014). The final phase (comprehensive understanding) involved an in-depth interpretation of the data and reflection, revision and reconsideration of the themes identified during the analytical process (Gill and Lowes, 2014).

Data analysis was led by two researchers (CS and PG) but all phases were discussed critically within the research team, to further facilitate interpretation of the data. Data analysis was managed using Nvivo10.

### **Ethics**

University and NHS Research Ethics Committee (REC) and R&D approvals were granted in Winter 2012/13. Written informed consent was obtained from all participants prior to interview. Participants were assured of anonymity and confidentiality and advised that they could pause or stop the interview and/or withdraw from the study at any time, without prejudice. To ensure anonymity and confidentiality, names have been replaced by a unique identification code, which indicates gender (M or F) and chronological order of recruitment (e.g. F101, M102).

### **FINDINGS**

Four key themes were identified from analysis of the data:

- Ketamine use and associated bladder symptoms
- Pain experience and pain management
- The psychosocial impact of KBS
- Healthcare service experiences

#### **Ketamine use and associated bladder symptoms**

Most participants were introduced to ketamine in their teens by an older relative (e.g. brother) or friend and, at the time of initiation, were already poly-drug users. Ketamine was primarily snorted as a powder and generally consumed socially with friends. All maintained that they were initially unaware of the potentially adverse effects of ketamine on the bladder. However, as tolerance and dependence gradually increased, ketamine was used more frequently (often daily) and in increasingly higher doses, to gain the desired dissociative effect. Consequently, most participants developed noticeable KBS symptoms within around 6-24 months of this change in use.

Common KBS symptoms included bladder storage or voiding problems, frequency, nocturia, urgency, hesitancy, urinating with interrupted flow, leakage, voiding small volumes of urine

and, in many, urge incontinence often occurred if they could not reach a toilet in time. Most symptoms were unpredictable, interchangeable, embarrassing and distressing. However, as they were insidious and common amongst other users, they became 'an acceptable norm'. Nonetheless, some symptoms were more serious and of far greater concern. For example, urinary retention, requiring catheterisation and, eventually, intermittent self-catheterisation:

*I was going a lot more, but when I was going, I wasn't passing much and really bad burning and blood in my urine. Then just before my 18<sup>th</sup> birthday I was admitted because I couldn't go to the toilet anymore. F108*

One of the latter KBS symptoms was haematuria, which was initially infrequent and relatively minor but gradually increased significantly, causing considerable concern:

*When I first noticed, I didn't think nothing of it because it wasn't hurting. It was just little strings of blood and then it was like just blood, there weren't no urine in it.... It would be like clots, like pure blood... Within about six months, it was like nothing you've ever seen.... Every time I was weeing, it looked like a murder scene in my toilet. M106*

### **Pain experience and pain management**

One of the most progressive, profound KBS symptoms was pain, which was exacerbated by regular ketamine use. Pain was commonly experienced in the abdomen, supra-pubic, lower back and/or genital regions and was particularly severe when needing to urinate and/or when urinating. While the nature and intensity often varied, KBS pain was described as intense, cramping and was often unbearable:

*It felt like my vagina was on fire... like I was being torn apart. It got that excruciating my mum took me to hospital. I was in that much pain I was screaming... tell them to get some pain relief. They were trying to ask me questions and I couldn't answer because I was in absolute agony, it was worse than childbirth... it felt like somebody was slicing me open. F105*

Most participants lived with severe, chronic, debilitating pain, which was extremely difficult to manage, as most prescribed analgesia, including Tramadol, provided inadequate pain relief:

*There's not much you can do about it, painkillers wouldn't work, nothing would work, because the pain was like I've never experienced. M112*

Participants felt that most health professionals did not fully appreciate the severity of their pain, although they acknowledged that their chronic substance misuse probably affected General Practitioners (GP's) analgesic prescribing practices. Consequently, self-medication was common:

*These last few days I've been taking stupid drugs that I've been buying off people, like prescribed medication they're on, because nothing's happening. I even bought a bottle of Oramorph off someone the other week. M104*



Ketamine appeared to be the only drug that provided effective, short-term pain relief and it was therefore consumed regularly to manage pain. However, participants were aware that this further exacerbated their KBS. Many therefore felt hopelessly trapped in a perpetual destructive cycle of use, abuse and ongoing harm:

*I'm in pain constantly, I've been on/off Tramadol 2 years and it's not working. I've been off ketamine for 7 months but Friday I went back to it because it's the only thing that's getting rid of the pain. The pain's got to the stage where I can't bear it, hence why I've started taking ketamine again and I didn't think I ever would. I take it and then I'm in agony when it wears off. I don't want to get back on that cycle, but it's the only option I've got. No one seems to be listening and there's nothing I can do for the pain. **F108***

### **The psychosocial impact of KBS**

KBS had a considerable psychosocial impact on participants. As symptoms worsened, most were reluctant to venture too far from the toilet, as they often needed to urinate urgently and frequently, which adversely affected their ability to leave the house, socialise and even work:

*I lost my job because I had to keep going to the toilet. I thought I can turn my life around because I've got a job. But where I kept going to the toilet every half hour, they let me go.... I still can't use public transport because.... I have to get off after a five minute journey. **M104***

Given the age of most participants, symptoms such as incontinence and haematuria, also caused considerable embarrassment and anxiety regarding their future health. Problems were further compounded by poly-drug dependency, which commonly resulted in disorganised lifestyles, insomnia, lethargy and depression. Furthermore, participants acknowledged the detrimental impact their problems had on loved ones and their ability to have meaningful relationships, as sexual intercourse was often too painful.

### **Healthcare service experiences**

Participants were initially reluctant to seek medical help, as preliminary KBS symptoms were 'normalised'. Feelings of embarrassment and self-loathing were common and compounded by the fear of being stigmatised. The social nature of ketamine use also commonly resulted in 'friend of a friend stories' about painful, embarrassing medical procedures, which were off-putting. Some participants were also concerned that worsening symptoms were indicative of terminal illness:

*I was scared, I thought I was dying. I thought I was peeing out organs. I was too afraid to go to the Doctors in case he was going to tell me I had cancer, you're dying. I didn't want to know that, I'd rather not know and not have those worries. **M106***

The eventual triggers for seeking help were worsening symptoms (particularly incontinence, severe pain and haematuria) and pressure from family and friends. GP's were generally the first point of contact, although subsequent A&E visits, following episodes of severe pain and/or heavy bleeding were common. However, during these initial consultations, not only were they not asked about ketamine use, despite presenting symptoms, but they also did not routinely volunteer such information, because they were too embarrassed to do so.

Even when they eventually did disclose ketamine use to their GP, the significance of such information was apparently not acknowledged.

Misdiagnosis (e.g. urinary tract infections; UTIs) and repeated, unnecessary courses of antibiotics were therefore common and compounded the belief that GPs had a very limited understanding of KBS. It was only when symptoms did not resolve that participants were eventually referred to a urologist and subsequently diagnosed with KBS. Participants were commonly advised that, while no curative treatment was available, symptoms would probably eventually resolve if they stopped using ketamine. While this advice was considered appropriate, in and of itself, it was considered unhelpful, as participants required further dedicated help and support to quit:

*There needs to be specialist knowledge about drug misuse and you should be signposted straight away. The question should be asked of any person with bladder problems, have you ever used Ketamine? If they say yes, they should get referred to a drug service that's got knowledge about it. [They say you have to stop it] but it's like telling a kid to stop eating sweets. [It's mentally addictive] and it helps with the pain too. M110*

Experiences of healthcare services varied. While some healthcare encounters were regarded as positive (e.g. where there was a good relationship with health professionals), most participants felt that they had largely been judged, blamed, ignored and treated with contempt by many health professionals. The provision of information and support about chronic ketamine use and KBS was also found to be limited. Furthermore, due to 'chaotic lifestyles', engagement with health professionals was problematic and clinic non-attendance was therefore common.

## **DISCUSSION**

### **The impact of KBS**

KBS has a considerable impact on those affected. Frequency, nocturia, urge incontinence, incontinence, haematuria (Chu *et al.*, 2007; Middela and Pearce, 2011; Wood *et al.*, 2011) and debilitating pain are common. Analogous with the psychosocial effects of urinary incontinence (Shaw *et al.*, 2008) and substance misuse (Macleod *et al.*, 2004; Dutra *et al.*, 2008) more generally, this study demonstrates that feelings such as embarrassment, uncertainty, anxiety, guilt, self-loathing and depression are common and pervasive. The emotional impact is perhaps further compounded by participants' relatively young age and the perceived self-inflicted nature of their condition. Advanced symptoms appear to result in behaviour modification, such as staying close to a toilet, which can subsequently contribute to social isolation.

The long term consequences of KBS are unclear (Colebunders and Van Erps, 2008; Oxley *et al.*, 2009; Mason *et al.*, 2010) but are probably related to condition severity and duration of habitual ketamine use, especially if on-going. However, in advanced stages, damage to the bladder and urinary tract are likely to be extensive, intractable and potentially irreversible. Such patients, most of whom are relatively young, may therefore require several invasive procedures and treatments for symptomatic relief, and in severe cases, bladder reconstruction or cystectomy, which will usually require costly, lifetime follow-up (Cottrell and Gillatt, 2008; Raison *et al.*, 2015). Other long-term effects of chronic ketamine use are

also poorly understood but can include lethargy, insomnia, impaired cognition, paranoia and psychosis (Morgan *et al.*, 2004; Muetzelfeldt *et al.*, 2008; Tackett-Gibson, 2008). These problems, particularly when combined with poly-drug use (which further obfuscates the disease process), are likely to contribute to the development of chaotic lifestyles and complex co-morbidities, which adversely affect quality of life and further complicate patient management.

### **Complexity of KBS and chronic substance misuse**

Several factors related to chronic substance misuse compound the complexity of KBS and its management. Most chronic ketamine users are young poly-drug users (Muetzelfeldt *et al.*, 2008; Cheung *et al.*, 2011; Winstock *et al.*, 2012). While existing research indicates that habitual ketamine use causes KBS (Wood *et al.*, 2011), it is possible that the condition and/or many of the associated problems are related to, or exacerbated by, poly-drug use.

KBS pain is severe and very difficult to manage. However, because of chronic substance misuse problems, anecdotal evidence suggests that GP's are reluctant to prescribe opiates. Self medication is therefore common, which is associated with significant risks, such as adverse side-effects and over-dosage. Ketamine is also instrumental in pain self-management because of its short-term effectiveness. However, this practice not only causes further, potentially irreversible damage to the bladder and urinary tract but it also makes ketamine cessation extremely difficult. Furthermore, because of its dissociative effects, users commonly limit the potential for harm by consuming ketamine with other users, which results in the development of close drug-related friendships (Joe-Laidler and Hunt, 2008; Riley *et al.*, 2008). Consequently, these social networks further complicate ketamine cessation and probably compound feelings of hopelessness.

### **Assessment and management of patients with KBS**

It is estimated that around 20-30% of chronic ketamine users will experience lower urinary tract symptoms (LUTS) (Shahani *et al.*, 2007; Bhattacharya, 2011; Wood *et al.*, 2011; Winstock *et al.*, 2012), typically within 3-24 months of habitual ketamine use (Tsai *et al.*, 2009; Srirangam and Mercer, 2012; Jalil and Gupta, 2012). However, it is unclear what specifically triggers the condition (e.g. toxic thresholds) and/or whether it is exacerbated by other factors (e.g. gender and poly-drug use).

Case study evidence indicates that symptoms, especially if mild to moderate, are potentially reversible following ketamine cessation (Cottrell and Gillatt, 2008; Cottrell *et al.*, 2008; Ma, 2008; Tsai *et al.*, 2010; Cheung *et al.*, 2011). Management is therefore dependent on timely diagnoses, specialist referral and ketamine cessation. However, appropriate management, particularly within primary care, appears to be problematic, as many GPs have a poor understanding of KBS and symptoms typically resemble UTIs and other LUTS (Logan, 2011; Srirangam and Mercer, 2012). Diagnosis is further complicated, due to the lack of appropriate questioning, and/or voluntary disclosure, regarding chronic ketamine use in presenting patients. Consequently, misdiagnosis, recurrent inappropriate treatments and significant delays in specialist referrals, of 12-18 months or more, are common, by which time many patients are likely to have advanced KBS and a range of other health-related problems that may require multi-agency input.

## **Help seeking and avoidance**

Delays in seeking medical attention can adversely affect disease progression and the development of more complex co-morbidities, which are usually more difficult and costly to treat. Identifying factors that affect help seeking behaviour can therefore help to inform the development of appropriate interventions that may promote expeditious access to relevant healthcare services. However, while help avoidance is common in KBS, particularly in the early stages, when the condition is potentially reversible, a meaningful rationale for this behaviour has not yet been adequately explicated.

This study indicates that several factors inform help seeking/avoidance behaviour. The wider, related urinary incontinence and substance misuse literature, also respectively offer additional, constructive insights into these complex issues. Furthermore, Andersen's behavioral model of health services use (Andersen 1995) provides an expedient framework for better understanding the fundamental components that commonly inform help avoidance/seeking in healthcare. The model was originally developed in 1968 (and has since undergone several iterations) to facilitate understanding of how relevant healthcare services are accessed and/or used (Babitsch et al., 2012). It has subsequently been applied in extensively many healthcare studies, including related substance misuse (Rapp et al., 2006) and urological research and was therefore considered appropriate for this patient population. Andersen (1995) proposes that several key variables, notably, predisposing characteristics (e.g. demographics, social networks, and health beliefs), enabling/inhibiting factors (e.g. psychosocial issues and social support) and situational need (e.g. condition impact and problem recognition), interact to facilitate and/or impede healthcare use.

Several predisposing characteristics appear to confound help seeking behaviour in this study. Analogous with the related urinary incontinence literature (Shaw et al., 2008, Wang et al., 2015), the relative young age of most participants and the general association of troublesome urinary symptoms, such as incontinence, with aging, are likely to be significant barriers to help seeking. Social networks are also problematic, as they largely consist of other chronic ketamine users, many of whom, as Chu et al (2008) postulate, may also be symptomatic but not receiving treatment. Failing to see drug related problems as sufficient concerns are common amongst many habitual drug users and their social group (Rapp et al., 2006). 'Friend of a friend' stories about embarrassing, painful urological procedures are also ubiquitous within these social networks and extremely off-putting. Furthermore, many chronic ketamine users remain somewhat ambivalent about the cause of and risks associated with KBS, which probably further compounds help avoidance.

Numerous enabling/inhibiting factors also inform this process. The emotional impact of KBS is considerable. Consequently, as demonstrated within the wider, related literature, feelings such as embarrassment, self-loathing and fear of being stigmatised are known to be significant barriers to help seeking (Cunningham et al., 1993; Shaw et al., 2008, Cheung et al., 2011; Wang et al., 2015). The perception that ketamine is a 'horse tranquiliser' (Moore and Measham, 2008) may further exacerbate help avoidance because of concerns about particularly 'deviant behaviour'. Synonymous with the wider substance misuse literature, unemployment and disorganised lifestyles are common and known to adversely affect help seeking and healthcare engagement (Friedmann et al., 2000, Rapp et al., 2006). However, the multifaceted nature of KBS, related to the inextricable amalgamation of ketamine/poly-drug dependence and chronic bladder symptoms, probably further compound this problem. Furthermore, given the prevalence of additional, related co-morbidities in poly-drug users,

including potential mental health problems, help seeking is likely to be further complicated in this cohort. Finally, due to chaotic lifestyles and apparent social isolation, access to meaningful social support, which is integral to help seeking, is limited. However, subsequent pressure from family and friends, as a result of ongoing, worsening symptoms, appears to be a key help seeking facilitator.

Establishing treatment necessity generally involves appraisal of several issues, such as symptom severity, perceived health risk, treatment effectiveness beliefs and readiness for treatment (Cunningham et al., 1994; Shaw et al., 2008). However, mild KBS symptoms are normalised and tolerated, probably because of their insidious nature and commonality amongst fellow ketamine users. Help avoidance is therefore common, when symptoms are regarded as inconsequential (Cunningham et al., 1993, Shaw et al., 2008, Cheung et al., 2011). It is also likely that help seeking appraisal entails several considerations; notably, KBS symptoms, other complex co-morbidities and long-term substance misuse problems, which many may not yet be willing or able to meaningfully address. It is therefore unclear what the precise priorities are for help seeking in KBS, although the 'tipping points' appear to be prolonged, worsening symptoms, particularly pain, incontinence and haematuria, which adversely affect quality of life and are perceived as significant health threats. However, this typically occurs later in the condition, when damage to the bladder and urinary tract may be irreversible. These multifarious issues not only therefore highlight the complexity of help seeking in KBS but also the subsequent challenges faced by health professionals in developing suitable initiatives to help facilitate timely access to appropriate support services.

### **IMPLICATIONS FOR PRACTICE AND RELATED RESEARCH**

Findings from this study indicate that Anderson's behavioral model of health services use (Andersen, 1995) provides an appropriate theoretical framework for understanding the key facilitators and barriers to help seeking in KBS. However, as Andersen (1995) acknowledges, little is yet known about the primacy of individual determinants or the interactive effects of key variables (Rapp et al., 2006), although, given the nature of this qualitative study, these issues are beyond the scope of this research. The application of Andersen's model is therefore not intended to provide a definitive exposition of these complex issues, but rather, it merely offers health professionals a useful framework for comprehending the complexities associated with help seeking, avoidance and engagement, which can subsequently help to inform clinical practice. In particular, it can help to facilitate the development of appropriate strategies to reduce and/or prevent harm, moderate help seeking obstacles and promote expedient approaches to patient management.

Given the limited understanding of KBS amongst many health professionals, especially GPs, there is a need to raise awareness of the condition and approaches to management, through dissemination and training, so that clinicians are better able to treat and support patients. Effective harm prevention/reduction strategies are also required to better inform existing (and prospective) users about the harmful effects of chronic ketamine use. Information provision should emphasise the particularly undesirable effects of KBS, such as incontinence, haematuria and pain, which users are likely to find disconcerting. To help promote timely engagement with healthcare services, drug support agencies in particular, need to highlight the potential reversibility of symptoms when identified early.

Management of KBS should largely focus on minimising bladder damage through appropriate assessment, timely referral and abstinence from ketamine use. Health professionals should therefore ask patients presenting with severe, persistent and unresponsive LUTS about ketamine use (Cottrell and Gillatt, 2008; Mason et al., 2010; Jenyon and Sole, 2013; Srirangam and Mercer, 2012) in an appropriate, sensitive manner. This routine practice may also help to reduce embarrassment or stigma associated with ketamine use.

As KBS is inexorably associated with poly-drug dependence, chronic bladder problems and a range of multifaceted, related co-morbidities, the condition should be considered as part of a more complex whole, the management of which is beyond any one professional group. Instead, a collaborative, multi-disciplinary approach is required, which involves nurses, GPs, urologists, pain and drug support teams. There is also a need for greater liaison between health and social care services (Winstock et al., 2012) to ensure a more integrated approach to the management of those with such complex needs. Clearly, the most important aspect of KBS management is early ketamine cessation and this must therefore be the key message that health professionals convey to patients (Logan, 2011; Morgan and Curran, 2011). However, because of its social nature, analgesic function and dependency issues, health professionals should acknowledge that KBS patients will require further specialist help and support to facilitate ketamine abstinence, as they are unlikely to achieve this by their own volition.

Drug support agencies are best placed to advise in the management of drug dependency. However, findings suggest that substance misuse regimens are likely to be complex and costly, due to tolerance, dependence and ongoing poly-drug use and, therefore, to be effective, may even require removing the user from their current social network. An effective approach to pain management is also essential to help minimise the likelihood of continued ketamine use (and/or other drugs) for pain self-management. There is therefore a need for pain teams to advise nurses, GPs and urologists about appropriate pain management. Engaging poly-drug users in healthcare services is, however, an ongoing, obstinate problem and devising meaningful strategies to promote engagement remains a significant challenge that requires further work.

This study has also highlighted several areas in need of further research that could further help inform practice and policy. These include the need for:

- Accurate epidemiological data to establish the nature and extent of chronic ketamine use and KBS.
- Research that better informs understanding of KBS aetiology and/or factors that may exacerbate disease progression.
- Research that explores the perspectives of health professionals involved in treating this patient group, to better understand the challenges associated with KBS management.

### **Study limitations**

While this study provides a novel, in-depth insight into participants' experiences of KBS, there are several limitations associated with this research. Due to the size and nature of the sample, findings may not be representative of the wider KBS, or chronic ketamine user, population. During data collection, it was also apparent that some participants struggled

with particular recall issues, such as ketamine dose/frequency specificity. Consequently, the veracity of aspects of some accounts is perhaps questionable. It is also important to recognise that all participants were poly-drug users. Many of the issues raised, may not therefore be due to ketamine alone, but are perhaps instead related to the effects of chronic poly-substance misuse and/or other underlying co-morbidities.

## **CONCLUSION**

This study demonstrates that KBS has a profound impact on those affected, commonly resulting in significant and potentially irreversible damage to the bladder and urinary tract. The condition is further compounded by ketamine and poly-drug dependence, related co-morbidities and delays in help seeking, which further complicate patient management. Findings from this study also suggest that Anderson's behavioral model of health services use (Andersen, 1995) provides a relevant framework for understanding help seeking/avoidance behaviour in this patient population, which can help inform clinical practice and related research.

However, in the absence of a curative treatment, management of KBS, requires a multi-disciplinary approach, which focuses on promoting timely healthcare access, specialist referral and providing appropriate assistance to facilitate ketamine abstinence.

### **What is known about this topic**

- Habitual, recreational ketamine use can result in significant, irreversible damage to the bladder and urinary tract, causing a range of obstinate problems, including urinary incontinence and pain. Ketamine cessation may help to reduce bladder damage and reverse symptoms in some patients.

### **What this paper adds**

- Initial KBS symptoms are normalised due to their progressive nature and commonality amongst other ketamine users, which results in delayed help seeking, exacerbates disease progression and further complicates patient management.
- While ketamine cessation is essential, due to tolerance, dependence and pain management issues, users are unlikely to achieve this alone and will therefore require further specialist support to abstain.
- Given the association with poly-drug dependence, chronic bladder problems and other related co-morbidities, KBS should be regarded as a core component of a more complex whole, the management of which requires an integrated, multi-disciplinary approach.

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