Nonsurgical treatment of chronic idiopathic urinary retention: A scoping survey of physiotherapists' perspectives.

Abstract

Background: Treatment for chronic idiopathic urinary retention often involves invasive or surgical inventions. Physiotherapy may have a range of non-invasive treatments to offer, but this is under studied.

Purpose: To survey healthcare professionals exploring their experience and understanding of nonsurgical treatments for chronic idiopathic urinary retention

Materials and methods: An online survey was conducted using purposive sampling to include healthcare professionals who see patients with chronic idiopathic urinary retention.

Results: There were 100 responses with 20/100 (20%) answering the optional "specialist" questions. Ninety percent perceived that chronic idiopathic urinary retention occurred with other conditions. Perception of recovery was poor. Only 3/30 (15%) perceived that more than half of patients improve. Nonsurgical interventions included: education, pelvic floor physiotherapy, biofeedback, and tibial nerve stimulation. There were moderate to high levels of interest in treating this condition but low levels of confidence in ability. Seventy percent (70/100) perceived a lack of support from referrers and multidisciplinary colleagues.

Conclusions: Health professionals were interested in treating chronic idiopathic urinary retention and perceived that physiotherapy had something to offer this patient group. The low reported levels of confidence in ability reflects the lack of supporting literature.

Keywords: Chronic idiopathic urinary retention, Fowlers syndrome pelvic physiotherapy, nonsurgical treatment, biofeedback, education, tibial nerve stimulation,

Contribution of paper:

- Physiotherapists are likely to see chronic idiopathic urinary retention alongside other conditions, such as persistent pain conditions and functional neurological disorder. It is therefore useful to know that core physiotherapy skills which can be utilised by non-specialist clinicians may benefit people with this problem.
- These core skills include education, movement retraining and breathing exercises. These could form a useful adjunct to more specialised pelvic health physiotherapy, by forming the first step on a stepped approach to care.

Introduction:

Chronic idiopathic urinary retention describes a complete or almost complete inability to void urine in the absence of a surgical or medical cause and usually affects women. The mechanism of chronic idiopathic urinary retention is unknown but is hypothesised to be due to brain bladder axis dysfunction with inhibitory peripheral and central mechanisms (Kavia et al., 2010) (1). Peripherally there can be idiopathic dysfunction of the external sphincter, known as Fowlers Syndrome, pelvic floor dysfunction and/or detrusor underactivity (Osman NI, 2014) (2). One study found that chronic idiopathic urinary retention often coexists with pain disorders and Functional Neurological Disorder (Hoeritzauer et al., 2016) (3) There are few treatment options and long-term outcome is often poor (Osman NI, 2014) (2). The main treatments are invasive procedures including; sacral neuromodulation (De Ridder et al., 2007) (4) or

botulinum toxin injections into the bladder sphincter muscle (Panicker, 2018) (5). These procedures have significant complication rates, including up to half of patients needing a surgical revision due to an impacted stimulator and a third of patients reporting high levels of pain at the stimulator box site or in their lower limbs. (De Ridder et al., 2007) (4). Intermittent or indwelling urethral or suprapubic catheters are routinely used but can be associated with pain and infection. Some patients have urinary diversion procedures undertaken, with stoma formation (Osman NI, 2014) (2).

Non-surgical interventions, often delivered by physiotherapists, are described for conditions similar to chronic idiopathic urinary retention. For example, pelvic health physiotherapy is considered part of the routine management for dysfunctional voiding (Tarcan et al., 2019) (6) and chronic pelvic pain (Bittelbrunn et al., 2022) (7); tibial nerve stimulation has shown promising results in non-obstructive urinary retention (Gaziev et al., 2013) (8); biofeedback may be helpful for dysfunctional voiding (Krzemińska et al., 2012) (9) (Minardi et al., 2010) (10); and it has been reported that idiopathic retention may respond to psychotherapy (Bilanakis, 2006) (11).

Our experience as Neurologists, Psychiatrists, pelvic health physiotherapist and neuro physiotherapists with an interest in Functional Neurological Disorder, has found that when pelvic pain management improves, dysfunctional voiding can also improve, and that chronic idiopathic urinary retention in the presence of functional neurological disorder sometimes improves during rehabilitation in small numbers of patients. This observed improvement in symptoms, spurred the authors on to investigate non-surgical treatments further, but this remains a largely hypothesis driven approach.

Aims

Our aim was threefold:

1. To use a scoping survey to explore the UK experience and understanding of nonsurgical treatments for chronic idiopathic urinary retention
2. To gather evidence which might inform clinical practice and future research in this under-studied area
3. To identify a group of interested professionals to create pilot consensus recommendations

Materials and methods:

An online survey was designed and delivered using Qualtrics ZM platform. The survey was open for 8 weeks from 30 November 2022 with the aim of sampling 100 clinicians.

A purposive sampling technique was used where we identified clinicians in the UK, who regularly come across patients with and/or have an interest in treating chronic idiopathic urinary retention. No sample size calculation was undertaken because the treatment is usually surgical so there are only a small number of specialists who are treating these patients non-surgically. After keeping the survey open for eight weeks and sending two reminders to the Pelvic Obstetric and gynaecological physiotherapy Chartered Society of Physiotherapy group, and hosting a lecture for the Functional Neurological Disorder physiotherapists, we had a sample size of 100 which seemed reasonable for a scoping survey of this uncommon condition.

The survey was designed to derive information from clinicians who were both experienced and interested and only those with experience in treating CIUR were asked to complete the detailed questions about

prognosis and treatment. This included two broad groups: Pelvic Health physiotherapists, and Neuro-physiotherapists with an interest in Functional Neurological Disorder. The survey was shared on two platforms, Pelvic Health Physiotherapy closed Facebook group and the Pelvic, Obstetric and Gynaecologist Physiotherapy special interest group within the Chartered Society of Physiotherapy, where initial contact with potential respondent was made by email. The survey was also advertised during a free webinar on chronic idiopathic urinary retention delivered by one of the authors (IH) and participants were encouraged to share the invitation with colleagues.

The survey was developed by an expert panel that included Neurologists (IH, JS), Physiotherapists (GN, SM) and a Psychiatrist (CM). The usability and technical functionality were tested, and it was piloted to ensure clarity of questions.

The survey included a mixture of 23 multiple choice questions and open-ended questions, and on piloting took less than 15 minutes to complete. Respondents with limited chronic idiopathic urinary retention treatment experience could skip questions 8 to 19. The survey explored the participants' clinical experience of chronic idiopathic urinary retention, treatment strategies used, perceptions about the usefulness of therapy and perceived prognosis (Appendix 1).

Simple descriptive analysis of multiple-choice responses was performed. Themes were drawn from free text responses. Ethics approval was obtained through Edinburgh Medical School Research Ethics Committee (22-EMREC-039).

Results

We received complete responses from 100 clinicians, 99 were physiotherapists and one was an Occupational Therapist.

Demographics, clinical experience, and training

Most respondents were female (87%) with just under half having additional post graduate qualifications: Post graduate diploma (14%), Master's degree (28%), Doctoral (7%). Eighty-six percent had five or more years' experience and 46% had at least 20 years' experience. Almost half (41%) had experience in pelvic health physiotherapy.

Clinical Exposure and Presentations of chronic idiopathic urinary retention

50/100 respondents (50%) saw patients with a diagnosis of chronic idiopathic urinary retention as part of their clinical practice.

20/100 (20%) went on to answer the optional questions (questions 8-19) as they felt sufficiently experienced to answer detailed questions. Of this group 95% were female, 80% had more than 5 years' experience and 50% had more than 20 years' experience. Sixty percent had post graduate qualifications: Post graduate diploma (15%), Master's degree (40%), Doctoral (5%).

Amongst this subgroup of 20, 4 (20%) rarely saw patients with chronic idiopathic urinary retention; 11/20 (55%) reported chronic idiopathic urinary retention represented one quarter or less of their caseload; 3/20 (15%) reported patients with chronic idiopathic urinary retention represented between 25-50% of their caseload; and 2/20 (10%) reported patients with chronic idiopathic urinary retention represented over 75% of their caseload.

Of these 20 clinicians, 90% of respondents considered chronic idiopathic urinary retention to exist with other conditions and symptoms, including functional neurological disorder, other neurological diseases, fibromyalgia, pelvic pain, and bowel dysfunction.

Nonsurgical treatment strategies

The nonsurgical interventions used for chronic idiopathic urinary retention were described by the 20 respondents who answered the optional questions. These answers were grouped into categories according to the level of experience and/or training required for implementation by a physiotherapist. The first category included standard techniques deemed to be common to all physiotherapists and indeed other healthcare professionals. Subsequent categories included more specialised interventions. Treatment strategies are summarised in Table 1.

Perception of prognosis

In optional questions exploring perception of the prognosis of chronic idiopathic urinary retention, we asked respondents to estimate the percentage of patients that: (a) make a complete recovery; (b) make a partial recovery; (c) report improved quality of life following treatment despite ongoing symptoms; and (d) receive no benefit from physiotherapy. The results are displayed in Table 2.

General perception of improvement in symptoms of chronic idiopathic urinary retention following physiotherapy was poor. Nineteen/twenty (95%) of respondents perceived that less than half of patients treated with physiotherapy would have complete recovery of symptoms, but most felt that the majority of patients make some recovery with physiotherapy.

Perceived indicators of Prognosis

We explored perceived indicators of prognosis by asking respondents to list facilitators and barriers to symptom improvement. The responses were themed into factors related to the therapist, patient, and healthcare system and social factors, and are shown in Table 3.

Multidisciplinary Involvement, onward referral, patient resources

Seventy percent (70/100) of respondents reported not having sufficient support from referrers and multidisciplinary colleagues. Most (58%, 58/100) refer patients to psychology/psychiatry services frequently but commonly encountered difficulties accessing these services. Multidisciplinary treatment involving psychology and occupational therapy was considered important for treatment success by some respondents across a range of questions. Only two respondents were aware of online patient resources for chronic idiopathic urinary retention. These were Neurosymptoms.org and UK Bladder and Bowel Foundation.

Attitudes and Interests

Of the complete study population (n=100), 52% had moderate and 27% high levels of interest in treating patients with chronic idiopathic urinary retention. Most (92%) were confident that patients with chronic idiopathic urinary retention could improve with nonsurgical interventions.

Discussion:

This was a cross sectional online survey which captured the experience of 100 clinicians with an interest in chronic idiopathic urinary retention in the UK. Only 20 respondents had sufficient experience in treating this condition to answer all the questions. Our survey identified a range of different treatment approaches (Table 1) that were used for people with chronic idiopathic urinary retention. The interventions ranged from simple strategies that could be employed by non-specialists, to more specialist interventions that require specific training and experience. Education was seen as a core part of treatment, which coincided with a common perception that lack of understanding (from patients and clinicians) was a major barrier to symptom improvement.

More specialist techniques are utilised by pelvic health physiotherapists and include active physiotherapy like pelvic floor training, and techniques such as pelvic floor manual therapy, as well as biofeedback, and tibial nerve stimulation. These are more widely studied in conditions such as spinal cord injury and multiple sclerosis (Al Danden, 2020) (12). It is possible that the cumulative effect of various treatments might be useful or that there might not be one quick fix, but rather several things might improve symptoms and quality of life. Self-management and individualised tailored is care likely to be important.

Multidisciplinary treatment or physiotherapy embedded within a multidisciplinary team was perceived as being important, in particular with access to psychology and specialist nurses. This aligns with other similar conditions (Rixon, 2023) (13). It was perceived as often difficult for therapists to access other specialists/disciplines. Developing clear pathways for accessing multidisciplinary care, including mental health support and specialist nursing is likely to help this patient group.

Chronic idiopathic urinary retention was perceived by (90% of respondents) as coexisting with other conditions including pelvic pain, neurological conditions (including functional neurological disorder) and fibromyalgia. Better treatments for these coexisting problems may have a positive impact on bladder function. For example, improving motor symptoms and mobility may help access to using a toilet, as well as improving symptoms of constipation. Greater mobility may also mean more 'connection' with the lower half of the body, including the bladder in some patients. Optimising pain management and reducing pain medications could also be helpful, especially given that both opioids and gabapentinoids are known to promote urinary retention (Panicker et al, 2018) (5).

Due to the high prevalence of coexisting conditions seen alongside chronic idiopathic urinary retention patients may be treated in subspecialties, like pain medicine or neurology, that assume that chronic idiopathic urinary retention is an urological issue unrelated to their other conditions or the medications they may be receiving for these conditions.

A striking finding was the perception of poor prognosis. Of the 20 respondents with the most experience, 95% perceived that less than half of patients make a complete recovery from symptoms following physiotherapy. However, of the whole population 79% (n=79) had high to moderate levels of interest in treating this condition and 92% (n=92) felt that there would be some improvement with physiotherapy. This suggests an interest, engagement and hope for nonsurgical treatment and improved quality of life in patients with chronic idiopathic urinary retention. It is interesting that quality of life was perceived as more likely to improve following physiotherapy than the symptoms, suggesting that physiotherapy may improve quality of life despite ongoing symptoms. This is no different to other chronic conditions where the focus of care is to optimise self-management and quality of life.

We recognise several important limitations to this work, especially the small sample size, the self-selected sample and the design of the survey which reduced the sample to 20. The number of pelvic health physiotherapists who responded was low and <5% (41/1400) of the overall Pelvic Obstetric and gynaecological physiotherapy Chartered Society of Physiotherapy membership. This may be due to the standard treatment of chronic idiopathic urinary being surgical management and may reflect lack of pelvic health physiotherapists being involved in these patient's care. It may also be due to questionnaire fatigue of this specialist physiotherapy group or may be due to lack of awareness of the survey, resulting in a small sample and missing important experience from pelvic health physiotherapists. Only those with experience in treating chronic idiopathic urinary retention were asked to complete the detailed questions about treatment (questions 8 to 19 and our sample was self-selecting and there is no knowledge about non-responders, therefore the representativeness of the information cannot be estimated. Therefore, this should be seen as a scoping survey only. This was a small sample but enabled collection of experience and the creation of a small group of interested clinicians to undertake further research.

Conclusion:

This survey of healthcare professionals found that as a group, the respondents were interested in helping people with chronic idiopathic urinary retention. The perception was that resolution of symptoms with nonsurgical interventions was poor, but that physiotherapy may offer promising techniques for improving quality of life. Treatments for this population were categorised with stepped complexity, which included standard physiotherapy techniques to more specialised interventions provided only within pelvic health physiotherapy.

We have highlighted key areas of important future research and perceived barriers to improvement including a lack of evidence for treatment, lack of multidisciplinary support and insufficient access to specialist services. This small scoping exercise suggests that further work is merited to explore in more detail non-surgical treatments for chronic idiopathic urinary retention and their outcomes in prospective cohorts and to develop consensus recommendations for nonsurgical treatments of chronic idiopathic urinary retention.

Ethics approval was obtained through Edinburgh Medical School Research Ethics Committee (22-EMREC-039).

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Appendix

Appendix 1: Physiotherapy chronic idiopathic urinary retention/Fowlers syndrome survey questions

1. What is your gender? *Male, Female, Non binary/prefer not to say*
2. How many years of experience in Physiotherapy do you have? *0-1, 2-5, 5-10, 11-20, 20+*
3. How many years of experience in pelvic or women's health physiotherapy do you have? *None, 0-1, 2-5, 5-10, 10+*
4. What training have you undertaken? (Please tick all relevant) *Undergraduate degree, additional diploma, Masters, MD, PhD*
5. Have you undertaken additional training in women's health physiotherapy? *Yes, no*
6. Where do you work? (Tick all that apply) *Acute inpatient setting, Rehab/outpatient/community, private hospital, private practice, NHS*
7. In your clinical practice, do you see women with a diagnosis of Fowler's syndrome or Chronic Idiopathic Urinary Retention (> 3 months) or intermittent complete urinary retention i.e. cannot void at all, (totally relying on catheterisation or ISC), that does not have a structural, neurological, gynaecological or other explanation? *Yes, no*
   If yes, please indicate which of the following presentations of Fowler's syndrome or Chronic Idiopathic Urinary Retention causing persistent or intermittent complete urinary retention that you see in your practice (tick all that apply):*Isolated urinary retention, Idiopathic urinary retention, part of pelvic pain, part of Fibromyalgia, part of Functional Neurological Disorder, part of neurological disease, part of bowel dysfunction*
8. How often do you see patients with Fowler's syndrome or Chronic Idiopathic Urinary Retention causing persistent or intermittent complete urinary retention?
   Please select one of the boxes below. *Never or very rarely, <25%, <50%, <75%, 100% of the cases that I see*
9. If you see patients with Fowlers syndrome or Chronic Idiopathic Urinary Retention, causing persistent or intermittent complete urinary retention, what treatment or strategies do you use with this group? Please list all treatment approaches in the box below. (For example: pelvic physiotherapy, tibial nerve stimulation, psychotherapy, biofeedback). They don't have to be physiotherapy ones.
10. What proportion of patients would you estimate to make at least partial recovery (e.g. between 50-100% improvement) following physiotherapy for Fowler's syndrome and Chronic Idiopathic Urinary Retention causing persistent or intermittent complete urinary retention? *0-5%, 5-10%, 10-25%, 25-50%, 50-75%, 100%*
11. What proportion of patients would you estimate to make a complete recovery following physiotherapy for Fowler's syndrome and Chronic Idiopathic Urinary Retention causing persistent or intermittent complete urinary retention? *0-5%, 5-10%, 10-25%, 25-50%, 50-75%, 100%*

12. What proportion of patients would you estimate to have an improved quality of life despite ongoing symptoms and are discharged from physiotherapy because of improvements in symptoms? *0-5%, 5-10%, 10-25%, 25-50%, 50-75%, 100%*
13. What proportion of patients would you estimate receive no benefit from physiotherapy treatment for Fowler's syndrome and Chronic Idiopathic Urinary Retention causing persistent or intermittent complete urinary retention? *0-5%, 5-10%, 10-25%, 25-50%, 50-75%, 100%*
14. For patients who make a partial recovery or gain only some benefit from physiotherapy for Fowler's syndrome and Chronic Idiopathic Urinary Retention causing chronic or intermittent complete urinary retention, please use the box below to describe how patients typically benefit.

15. What factors might indicate a positive prognosis? Please comment.
16. What do you see as common barriers to improvement in medically unexplained chronic (>3 months) or intermittent complete urinary retention? Please comment.
17. Do you receive sufficient information and support from referrers and/or multidisciplinary colleagues when treating urinary retention? *Yes, No*
18. Are you able to access psychological therapy or Psychiatry support for your patients with urinary retention? Please comment.
19. How interested are you in seeing patients with Fowler's syndrome and Chronic Idiopathic Urinary Retention causing persistent or intermittent complete urinary retention? Please select one box. *High levels of interest, moderate levels of interest, low levels of interest*
20. Do you think patients with Fowler's syndrome and Chronic Idiopathic Urinary Retention causing persistent or intermittent complete urinary retention could have improvement of symptoms with Physiotherapy? *Yes, no*
21. Are there any resources for treating patients with Fowler's syndrome or Chronic Idiopathic Urinary retention causing persistent or intermittent complete urinary retention that you are aware of? Please describe. If online, please link the resource here.
22. Are you interested in participating in a project aimed at developing MDT treatment and assessment and treatment recommendations and patient education for people with Fowler's syndrome and Chronic Idiopathic Urinary Retention causing persistent or intermittent urinary retention?

Tables

Table 1. Nonsurgical treatments strategies of chronic idiopathic urinary retention as described by clinicians.

Type of treatment	Examples of possible strategies
Standard Physiotherapy	• Movement retraining (e.g. optimising sit to stand, transfers, walking • Education
Specialist Physiotherapy	• Psychologically informed physiotherapy • Biofeedback • Mindfulness • Education about FND/Psychoeducation • Pain management
Specialist Physiotherapy in Pelvic Health	• Pelvic floor physiotherapy • Bowel and bladder training • Trans Tibial Nerve Stimulator (TTNS) • Queen Square bladder stimulator (handheld vibrating device used to initiate urination) • Manual therapy to pelvic floor
Refer to other specialties	• Urology and gastroenterology • Specialist nurses with an interest in chronic idiopathic urinary retention • Psychology, specialist nurses (but perceived as difficult to access onward referrals)
Occupational Therapy	• Access to toilet and mobility • Creating toilet routine • Providing appropriate equipment to improve toilet access and toileting posture. • Pain management • Incontinence management

Table 2. Predicted impact of nonsurgical interventions of chronic idiopathic urinary retention on symptoms (n=20)

Proportion of patients expected to be impacted	Clinicians expected partial improvement of symptoms	Clinicians expected complete improvement of symptoms	Clinicians expected no recovery of symptoms	Clinicians expected improvement in quality of life
In less than 50% of patients	17 (85%)	19 (95%)	19 (95%)	14(70%)
In more than 50% of patients	3 (15%)	1 (5%)	1 (5%)	6 (30%)

Table 3. Physiotherapists' perception of barriers and facilitators to recovery in patients receiving physiotherapy for chronic idiopathic urinary retention

Perceived prognostic Factors	Positive perceived prognostic factors	Perceived Barriers to improvement
Relating to the therapist	• Incorporating education about chronic idiopathic urinary retention as part of treatment plan.	• Lack of knowledge, training, and experience of clinician • Urinary retention is not the focus of treatment (i.e., they only receive treatment for a co-existing problem). • Clinical assessments can be considered invasive
Relating to the patient	• Receptive to education about chronic idiopathic urinary retention and gaining understanding of the condition • Mastery of strategies to manage symptoms • Improved mood • Agreement or confidence that the diagnosis is correct • Improvement in coexisting symptoms, such as pain or functional weakness • Improved quality of life with treatment • Motivation to change (e.g., a goal to stop catheterisation) • Engagement in treatment	• Poor understanding of the condition • Continue to seek an alternative diagnosis • Lower health literacy • A history of pelvic trauma • Coexisting mental health problems (significant anxiety, unresolved trauma) • Coexisting pain and fatigue • Somatosensory disturbance in the saddle area • Prolonged use of analgesia
Relating to the health care system/society	• Early diagnosis and access to treatment • Access to multidisciplinary treatment • Reduced hospital admissions	• Limited access to specialist services • Negative experiences with health professionals • Social stigma of incontinence • Lack of training & knowledge amongst health professionals

Figures - none

Data availability statement: The anonymised survey data can be made available on request to the corresponding author.