





## REVIEW

# Experiences of urinary tract infection: A systematic review and meta-ethnography

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## Abstract

**Aim:** To understand the experience of urinary tract infection (UTI) by synthesizing primary qualitative research findings and developing a conceptual model that illustrates this experience.

**Method:** A systematic search of Medline, PsychInfo, Embase, and CINAHL from inception to August 2020 to find qualitative research exploring the experience of UTI. Qualitative evidence synthesis in the form of meta-ethnography was undertaken. Findings are reported in keeping with eMERGe guidance.

**Results:** We included 16 qualitative studies in the synthesis of evidence, providing data from over 1038 participants aged 13–97 years. We developed nine themes: the impact of UTI on my whole body; impact on quality of life, activities, and the associated psychological toll; I know my body and my experience has taught me when I need to seek care; worry and the transition to medicalization; antibiotics are a valuable treatment approach; antibiotics are a last resort; being heard, seen, and cared for with dignity; self-judgment; and the end of the road, a need for information and cure. These themes supported a conceptual model to illustrate the patient experience of UTI.

**Conclusions:** The conceptual model communicates the wide and varied symptoms of patients' UTI experiences and how they process this and make care decision based on past health experiences. For some, there appears to be a sense of hopelessness and frustration. This model may be used to highlight the need for improvements in diagnostic and treatment pathways. Future research to further understand the nuances of acute, recurrent, and persistent UTI is needed.

## KEYWORDS

meta-ethnography, patient experience, qualitative evidence synthesis, qualitative research, urinary tract infection, urogynaecology

## 1 | INTRODUCTION

Urinary tract infection (UTI) is one of the most common bacterial infections encountered in healthcare.<sup>1</sup> It is known to be associated with a range of symptoms, typically urinary frequency and urgency, although symptoms can vary and not all people with these symptoms have a UTI.<sup>2</sup> It is particularly common in women, and the lifetime risk may be as high as 50%.<sup>3</sup> For those who do get a UTI, there is a high risk of recurrent episodes.<sup>4</sup> Given the frequency with which it can occur and the impact of related symptoms, it is unsurprising that the healthcare costs associated with UTI are significant, running into the billions of dollars in the United States.<sup>5</sup>

As with many medical conditions, much of the published research looking at UTI is quantitative in nature. Studies have focussed on diagnostics and therapeutics, potentially limiting our understanding of the patient perspective.<sup>6,7</sup> Undertaking health research with a patient-centered approach to understand the perspective of those living with particular health conditions is advocated by multiple organizations, including the World Health Organisation (WHO).<sup>8,9</sup> Central to increasing this understanding is the use of qualitative research that can explore in depth concepts that cannot be addressed by quantitative methods.

The collation of qualitative research findings to make them accessible to the public and policy makers, and for clinical practice and education, is a process known as qualitative evidence synthesis (QES). The Cochrane Qualitative Research Methods Group has acknowledged the importance of including such qualitative findings within evidence-based healthcare.<sup>10</sup> To date, no such QES has been undertaken of qualitative studies that explore UTI, a condition with great diagnostic and therapeutic uncertainties. In this study, we utilize meta-ethnography, a form of QES, to provide insight into patient experiences so as to inform researchers and clinicians as they try to address these uncertainties and improve care.<sup>11–14</sup>

The aim of this study was to undertake a systematic literature search to identify and synthesize qualitative research that has explored the experience of living with UTI, to better understand this health experience and improve knowledge transfer for the purpose of healthcare improvement.

## 2 | MATERIALS AND METHODS

We have used the eMERGe guidelines to report our synthesis and findings, which have been developed specifically for studies utilizing meta-ethnography for QES.<sup>15</sup> We did not need to seek ethical approval because this

study synthesized evidence from previously published primary research studies.

### 2.1 | Selecting meta-ethnography

The rationale and aim of this study was to understand the experience of UTI as a precursor to the PURSUE study (People with URogynaecological conditionS: Understanding Experiences), a National Institute for Health Research (NIHR) funded study of people's experiences of urogynaecological conditions and services.<sup>16</sup> Using search terms previously developed to identify QES, we did not identify any pre-existing QES looking at experiences of UTI.<sup>17</sup> To understand experiences and develop a conceptual model that explained what it was like to have a UTI, we chose meta-ethnography, first described by Noblit and Hare in 1988.<sup>18</sup> Rather than simply describing the findings of previous studies, meta-ethnography encourages a conceptual approach to develop an understanding of experience by synthesizing primary research finding to “make a whole of something more than parts alone imply.”<sup>18</sup> This has been used to better understand experiences of living with urinary incontinence and pelvic organ prolapse.<sup>14,19</sup> A systematic review was undertaken of the Medline, PsychInfo, Cinahl, and Embase databases using the search terms outlined in Table 1.

### 2.2 | Deciding what is relevant

We included qualitative studies that explored the experience of UTI. We used thesaurus and free text terms for qualitative research, combined with condition-specific thesaurus and free text terms. Table 1 reports the elements of STARLITE (Sampling strategy, Type of study, Approaches, Range of years, Limits, Inclusion and exclusions, Terms used, and Electronic sources) as recommended for qualitative research.<sup>20</sup> A single reviewer screened titles and abstracts for relevance.<sup>18</sup> The threshold for inclusion following screening was low and any uncertainty about inclusion was resolved with a second reviewer. Two reviewers appraised all relevant studies using the Critical Appraisal Skills Program (CASP) checklist and included all studies that were felt to be “satisfactory.”<sup>18,21</sup>

### 2.3 | Reading studies and understanding inter-related concepts

We uploaded each included manuscript onto NVivo 11 software. This software allows reviewers to keep

TABLE 1 STARLITE report

STARLITE category	Description
Sampling strategy	Comprehensive
Type of studies	Qualitative research, fully reported
Approaches	Electronic databases
Range of years	To April 2020
Limits	Languages: English
Inclusion and exclusions	N/A
Qualitative Methods - Thesaurus Term	MEDLINE: exp "FOCUS GROUPS"/OR exp "ANTHROPOLOGY, CULTURAL"/OR exp "QUALITATIVE RESEARCH"/OR exp "NURSING METHODOLOGY RESEARCH"/OR exp "INTERVIEWS AS TOPIC"/PSYCHINFO: exp "THEMATIC ANALYSIS"/OR exp "SEMI-STRUCTURED INTERVIEW"/OR exp "NARRATIVE ANALYSIS"/OR exp "INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS"/OR exp "GROUNDED THEORY"/OR exp "FOCUS GROUP"/OR exp "QUALITATIVE METHODS"/OR exp PHENOMENOLOGY/OR exp ETHNOGRAPHY/OR exp "GROUP DISCUSSION"/CINAHL: exp "PHENOMENOLOGICAL RESEARCH"/OR exp "GROUNDED THEORY"/OR exp "ETHNONURSING RESEARCH"/OR exp "ETHNOLOGICAL RESEARCH"/OR exp "ETHNOGRAPHIC RESEARCH"/OR exp "ACTION RESEARCH"/OR exp "NATURALISTIC INQUIRY"/OR exp "QUALITATIVE STUDIES"/OR exp "ANTHROPOLOGY, CULTURAL"/OR exp "FOCUS GROUPS"/OR exp "DISCOURSE ANALYSIS"/OR exp "CONSTANT COMPARATIVE METHOD"/OR exp "PURPOSIVE SAMPLE"/EMBASE: exp HERMENEUTICS/OR exp "QUALITATIVE RESEARCH"/OR exp PHENOMENOLOGY/OR exp "PERSONAL EXPERIENCE"/
Qualitative methods – free text	qualitative ADJ5 (theor* OR study OR studies OR research OR analys*).ti,ab OR (ethnog*).ti,ab OR (phenomenolog*).ti,ab OR (hermeneutic* OR heidegger* OR husserl* OR colaizzi* OR giorgi* OR glaser OR strauss OR (van AND kaam*) OR (van AND manen) OR ricoeur OR spiegelberg* OR merleau).ti,ab OR (constant ADJ3 compar*).ti,ab OR (grounded ADJ3 (theor* OR study OR studies OR research OR analys*).ti,ab OR (narrative ADJ3 analys*).ti,ab OR (discourse ADJ3 analys*).ti,ab OR (conversation ADJ3 analys*).ti,ab OR ((lived OR life) ADJ3 experience*).ti,ab OR ((theoretical OR purposive) ADJ3 sampl*).ti,ab OR ((field ADJ note*) OR (field ADJ record*) OR fieldnote*).ti,ab OR (participant* ADJ3 observ*).ti,ab OR (action ADJ research).ti,ab OR ((digital ADJ record) OR audiorecord*).ti,ab OR (((co AND operative) AND inquir*) OR co-operative) AND inquir*).ti,ab OR ((semi-structured OR semistructured OR unstructured OR structured) ADJ3 interview*).ti,ab OR (feminis*).ti,ab OR (humanistic OR existential OR experiential).ti,ab OR (social AND construct*).ti,ab OR (poststructural* OR post structural* OR post-structural*).ti,ab OR (postmodern* OR post modern* OR post-modern*).ti,ab OR ('appreciative inquiry').ti,ab OR ('interpretative phenomenological analysis').ti,ab OR (face ADJ3 interview*).ti,ab OR ((depth OR in-depth) ADJ3 interview*).ti,ab OR (abductive ADJ analys*).ti,ab)
Condition Terms	Urinary tract infection, cystitis, pyelonephritis, and pyuria
Electronic sources	Medline, PsychInfo, Cinahl, Embase

track of data without the need for a data extraction sheet and link it to developing ideas. We extracted contextual information to allow us to determine how studies were related to each other. One reviewer read all studies in alphabetical order by author to identify ideas. Similarly, a second reviewer read the papers to identify, compare and discuss any differences. The aim of this was to develop ideas, rather than reach consensus.

## 2.4 | Translating studies

Two reviewers “translated” the ideas between studies: this process of translation involves comparing ideas from different studies and sorting them into categories with a shared essence. Two reviewers worked together to write each category in accessible first-person language to further refine its meaning. Once we had a list of categories, the same process of constant comparison

and abstraction between categories allowed us to develop final themes.

We used the four domains of the GRADE-CERQual framework<sup>22</sup> to reflect on our confidence in these final themes. This framework promotes the following stages of reflection: (1) what were the studies “methodological limitations”; (2) were the studies “relevant”; (3) was the data supporting each theme “adequate” (the “degree of richness and quantity of data”); (4) was there theme “coherence” (consistency across studies)?

## 2.5 | Evidence synthesis

The final stage of meta-ethnography is to organize the themes into a conceptual model through a process of comparison, thinking, and discussion; multiple draft versions of a model were made before reaching a final agreement on a model that synthesizes ideas into a line of argument. We used Google Jamboard as an interactive white board to work with each other during social distancing due to the COVID-19 pandemic (Tables 2 and 3).

## 3 | RESULTS

### 3.1 | Literature search

The systematic literature search yielded 328 titles which were screened, leaving us with 52 abstracts. Twenty-four abstracts were excluded (Figure 1) because they did not include data that were patient-based narrative ( $n = 12$ ), or they were not about UTI ( $n = 12$ ). Full text screening and quality appraisal were undertaken of the remaining 28 manuscripts using the CASP checklist critical appraisal.<sup>21</sup> At this point, a further 12 manuscripts were excluded because they were not about experiences of UTI ( $n = 6$ ), they failed to meet quality standards ( $n = 4$ ), they did not contain data that were patient-based narrative ( $n = 1$ ), or they did not utilize qualitative methodology ( $n = 1$ ). The remaining 16 manuscripts were published between 1999 and 2020. They were undertaken in the United Kingdom (nine manuscripts),<sup>23–31</sup> multiple countries/international (two manuscripts),<sup>32,33</sup> Ireland (two manuscripts),<sup>34,35</sup> Norway (one manuscript),<sup>36</sup> Sweden (one manuscript),<sup>37</sup> and Brazil (one manuscript),<sup>38</sup> in a combination of primary and secondary care environments as well as being part of clinical research studies. Participant numbers ranged from 6 to 94, and one study used online comments obtained data from 675 online forum users, giving at least 1038 participants across the 16 studies.<sup>32</sup> Participant ages ranged from 13

to 97 years, with adolescents contributing to posts analyzed by a study looking at an online forum for women with cystitis.<sup>33</sup> Only two studies included men; one had 11 men out of 26 participants,<sup>25</sup> and another 19 men out of 30 participants.<sup>26</sup> A further two studies did not specify participant gender.<sup>27,35</sup> Four studies specifically looked at the management of UTI.<sup>23,24,30,34</sup> Two studies looked at those who used clean intermittent self-catheterization (CISC).<sup>25,26</sup> Other specific participant groups included pregnant women,<sup>31,32,38</sup> the older population,<sup>27,37</sup> and those with spinal cord injury.<sup>28</sup>

We extracted 88 concepts from the primary studies and organized these into 34 conceptual categories, further refined into nine themes (Table 4): (1) the impact of UTI on my whole body; (2) impact on quality of life, activities, and the associated psychological toll; (3) I know my body and my experience has taught me when I need to seek care; (4) worry and the transition to medicalization; (5) antibiotics are a last resort; (6) Antibiotics are a valuable treatment approach; (7) being heard, seen, and cared for with dignity; (8) self-judgment; and (9) the end of the road, a need for information and cure. The themes, illustrated by the conceptual categories and exemplary data from the primary qualitative study, are outlined below.

### 3.2 | The impact of UTI on my whole body

This theme incorporates patient's experience of the symptoms associated with a UTI and the associated discomfort, both locally to the urinary tract as well as more widespread systemic manifestations. Those episodes that were more severe, as well as repeated UTIs, took both a physical and mental toll.

“At the end of peeing I feel a terrible pain in my lower belly which spreads upwards in the body towards my head.”

Malterud et al. 1999<sup>36</sup>

“I recently had a severe UTI. It was the first time I've had it where I actually had a really painful abdominal cramp that went with it, almost felt like my bladder was being torn outside my body. A really horrible tearing sensation, and I actually went to A&E ... that was probably the worst sensation I've ever had.”

Hearn et al. 2018<sup>28</sup>

TABLE 2 Study characteristics

Ref.	Participants	Age	Gender	Country	Condition, context	Data collection	Analysis
Duane et al. <sup>35</sup>	42	18–70	NK	Ireland	UTI, primary care	Focus groups	Thematic analysis
Eriksson et al. <sup>37</sup>	20	79	F	Sweden	Recurrent UTI, older population	Semi-structured interview	Content analysis
Flower et al. <sup>33</sup>	N/A	13–65	F	Multiple/International	Cystitis and OAB, online forum	Internet forum	Qualitative description
Ghouri et al. <sup>32</sup>	675	N/A	NK	Multiple/International	Pregnancy and UTI, internet forum	Data from internet forum	Thematic analysis
Leydon et al. <sup>23</sup>	20	21–64	F	UK	UTI, RCT participants	Semi-structured interview	Thematic analysis
Leydon et al. <sup>24</sup>	20	21–64	F	UK	UTI, RCT participants	Semi-structured interview	Thematic analysis
Baerheim et al. <sup>36</sup>	94	19–97	F	Norway	UTI, primary care	Free text questionnaire	Giorgi's Phenomenological approach
McClurg et al. <sup>25</sup>	26	25–81	F + M	UK	CISC users with UTI,	Semi-structured interview	Thematic analysis
Okamoto et al. <sup>26</sup>	30	23–86	F + M	UK	CISC users with UTI,	Semi-structured interview	Thematic analysis
Saukko et al. <sup>27</sup>	14	71–89	NK	UK	UTI, older population, hospital	Purposeful sampling interviews	Not specified
Hearn et al. <sup>28</sup>	12	28–68	F + M	UK	Spinal cord injury & UTI	Open question interview	Interpretative phenomenological analysis
Lecky et al. <sup>29</sup>	29	20–65	F	UK	UTI, primary care	Focus groups	Theoretical domains framework
Little et al. <sup>30</sup>	21	N/A	F	UK	UTI, RCT participants	Semi-structured interviews	Thematic analysis
Alves et al. <sup>38</sup>	6	>18	F	Brazil	Pregnancy and UTI	Semi-structured interviews	Analysis of technical content
Duane et al. <sup>34</sup>	14	N/A	F	Ireland	UTI, primary care	Semi-structured interviews	Framework analysis
Ghouri et al. <sup>31</sup>	13	18–43	F	UK	Pregnancy and UTI	Semi-structured interviews	Thematic analysis

Abbreviations: F, female; NA, not applicable; M, male, NK, not known.

TABLE 3 Study aims

Ref.	Aim
Duane et al. <sup>35</sup>	To explore GP and patient attitudes and experiences regarding the use of delayed antibiotic and symptomatic treatment for UTI in ambulatory care.
Eriksson et al. <sup>37</sup>	To describe and explore older women's experiences with repeated UTIs.
Flower et al. <sup>33</sup>	To undertake a qualitative study to analyze naturalistic data available from an Internet forum dedicated to supporting women with cystitis.
Ghouri et al. <sup>32</sup>	To explore women's experiences of UTIs in pregnancy to develop an understanding of their concerns and to optimize and encourage behaviors that facilitate appropriate use of antibiotics.
Leydon et al. <sup>23</sup>	To explore interviewees' attitudes towards antibiotics, their experience of a delayed antibiotic prescription, and their views on the cause of urinary tract infection.
Leydon et al. <sup>24</sup>	To explore women's experiences of self-care and their journey to GP care, when faced with symptoms of a UTI
Baerheim et al. <sup>36</sup>	To explore the contents and presentation of symptoms experienced by female patients with lower urinary tract infections.
McClurg et al. <sup>25</sup>	To explore the views and experiences of adults who use clean intermittent self-catheterization for long-term bladder conditions, with a focus on urinary tract infection experience and prophylactic antibiotic use.
Okamoto et al. <sup>26</sup>	To elucidate the views of intermittent catheter (IC) users regarding urinary tract infection (UTI) symptom presentation, terminology for describing signs and symptoms, the cause of UTI, and management strategies.
Saukko et al. <sup>27</sup>	Not stated in manuscript. Inferred aim—to explore the communication of UTI between patients and health professionals.
Hearn et al. <sup>28</sup>	To establish the impact of chronic, recurrent UTIs on people with spinal cord injury (SCI).
Lecky et al. <sup>29</sup>	To develop an evidence-based, shared decision-making intervention leaflet to optimize management of uncomplicated UTI for women aged.
Little et al. <sup>30</sup>	To explore patient experiences of UTI, beliefs regarding treatment and views about the management strategy of “backup” or delayed antibiotic prescribing.
Alves et al. <sup>38</sup>	To identify the perception of pregnant women with recurrent urinary tract infection (RUTI) on the disease and hospitalization.
Duane et al. <sup>34</sup>	To explore GP and patient attitudes and experiences regarding the use of delayed antibiotic and symptomatic treatment for UTI in ambulatory care.
Ghouri et al. <sup>31</sup>	To explore views about antimicrobial resistance (AMR) in women who experienced UTIs in pregnancy.

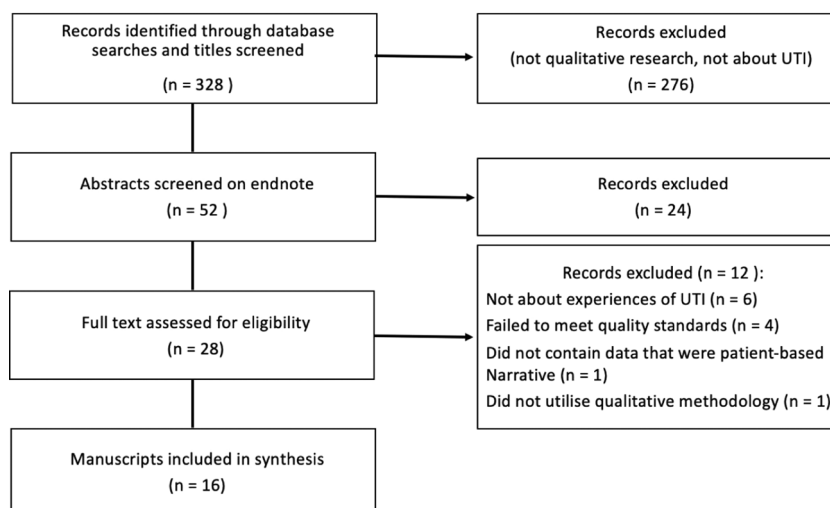


FIGURE 1 Search results

TABLE 4 Conceptual categories supporting final themes

Conceptual categories	Theme
<ul style="list-style-type: none"> <li>– I am in agony</li> <li>– I have blood in my urine</li> <li>– This is taking its toll on my entire body</li> <li>– This affects different parts of my body</li> <li>– This just adds insult to injury</li> </ul>	The impact of UTI on my whole body
<ul style="list-style-type: none"> <li>– I will only go do the doctor if it bad enough</li> <li>– I will wait and see and bide my time</li> <li>– I know from experience what to look out for</li> <li>– I felt empowered having the choice of when to take antibiotics</li> </ul>	I know my body and my experience has taught me when I need to seek care
<ul style="list-style-type: none"> <li>– I am missing out on the normal things in life</li> <li>– This is so emotional for me</li> <li>– I am driven by worry and fear and have lost my spontaneity</li> <li>– I have to closely manage every part of my life</li> <li>– Learning to cope</li> </ul>	Impact on quality of life, activities, and the associated psychological toll
<ul style="list-style-type: none"> <li>– This time it just doesn't seem right to me</li> <li>– I have reached the point that I need to seek help</li> <li>– This might become something worse if I don't get treated</li> <li>– This might be something serious</li> <li>– I need to have the urine dip test</li> </ul>	Worry and the transition to medicalization
<ul style="list-style-type: none"> <li>– Antibiotic would be the last resort for me</li> <li>– I am always on the lookout for alternatives</li> <li>– Antibiotics have side effects</li> <li>– You can become resistant to antibiotics</li> </ul>	Antibiotics are a last resort
<ul style="list-style-type: none"> <li>– There is no substitute for antibiotics for infection</li> <li>– It must be much safer to take antibiotics than to have an infection</li> <li>– I take antibiotics to prevent infection</li> </ul>	Antibiotics are a valuable treatment approach
<ul style="list-style-type: none"> <li>– I am not being listened to or taken seriously</li> <li>– It is important to have faith in your own doctor</li> <li>– I trust my doctor and will follow their recommendations</li> </ul>	Being heard, seen, and cared for with dignity
<ul style="list-style-type: none"> <li>– It must be something that I have done</li> <li>– I am worried that others will judge me</li> </ul>	Self-judgment
<ul style="list-style-type: none"> <li>– I want to sort this out once and for all</li> <li>– I have tried everything and nothing has helped</li> <li>– want more knowledge about why I have this and what I can do to avoid or treat it</li> </ul>	The end of the road, a need for information and cure

Participants described the affect UTI had on their whole body, in anatomical locations away from just their bladder and urethra.

“Within 24 h I will change quite considerably, I become ill quickly. For me, that means feeling dizzy, feeling sick, having really acute back pain, having frequency, the urethra burns, and it's very painful, and then the urine starts getting really thick and really smelly.”

Hearn et al. 2018<sup>28</sup>

“It's so depressing - I don't get 'simply cystitis- that infection (sic) that seems to only live on in text books!' - I get vile infections that are really hard to shift. I get shaking and shivering, terrible diarrhoea, waves of nausea and generally end up losing about half a stone when I get an attack.”

Flower et al. 2014<sup>33</sup>

The experience often exacerbated other health conditions and UTI contributed to a 'toll' on their body and health.

“Generally miserable in all of my body. I feel completely out of order.”

Malterud et al. 1999<sup>36</sup>

### 3.3 | Impact on quality of life and the associated psychological toll

Having a UTI has wider implications than just physical symptoms and this theme describes the experience of missing out on the normal things in life and an inability to fulfill social roles.

“I was in pain quite a lot and I couldn't just get on with my normal day-to-day things... I went to work but it was very difficult. So I went to the doctor's.”

Leydon et al. 2009<sup>24</sup>

“It obviously makes you feel bad about yourself and it makes you feel like you want to keep away from people, go to bed a bit early. It impacts your relationship with your wife, personally, sexually, because you don't feel good about yourself, you've got an infection and it's not particularly pleasant.”

McClurg et al. 2018<sup>25</sup>

Some recognized that this impact on life came with an emotional toll and that it could affect their psychological outlook.

“I am completely influenced and I feel unhygienic and that I smell bad, and yes, of course it affects me psychologically.”

Eriksson et al. 2014<sup>37</sup>

Both impact on quality of life and the psychological toll created fear and worry, and symptoms prevented spontaneity.

“It's something that is out of my control, and when something is out of your control, it can make you feel really quite low, because you can't self-help. You start to feel helpless.”

Hearn et al. 2018<sup>28</sup>

This theme highlighted a need for constant vigilance, and the burden of having to plan and manage various facets of life.

“My UTIs control my life, my bladder controls my life. Every time I go out of the house my bag has to be packed with all the pads, the catheters, everything.”

Hearn et al. 2018<sup>28</sup>

### 3.4 | I know my body and my experience has taught me when I need to seek care

This theme describes having knowledge of one's own body, based on their previous health experiences and how this knowledge shapes their individual approach to UTI and health decisions. This knowledge could empower an individual to wait and bide their time or conversely to seek medical treatment.

“I'm quite willing to listen, but I know my own body.”

Leydon et al. 2010<sup>23</sup>

“Normally if it's going to shift, it'll shift quite quickly, you know, you get some sort of feeling that it's going to be moving on and you're going to be OK. But this time I didn't so I thought, you know, I'm going to the doctor.”

Little et al. 2009<sup>30</sup>

“Before [the GP visit] I had taken, done the usual thing, drink plenty of fluid, that didn't work, so I'd been into the chemist and bought one of the over the counter remedies. That didn't work, so that's when I went to the doctor in the end.”

Leydon et al. 2009<sup>23,24</sup>

However, the choice of waiting or seeking care, even with experience, could be complex and create a dilemma.

“Well, I sort of sat there and went, oh, not three more days, but then when I thought about the side effects, it was like, well... do I really want the side effect [of thrush]... then that's going to be another three, four days... of more pain in the same area and I just thought, well... you've had it for seven days and if you wait another three it will hopefully have gone anyway.”

Leydon et al. 2010<sup>23</sup>



For those given “self-start antibiotics,” whereby they could commence antibiotics on the basis of their symptoms, this choice about treatment appeared to give a feeling of empowerment and a sense of security.

“I guess in the back of my mind there was a slight reassurance that if all else fails I’ve got it [the prescription].”

Leydon et al. 2010<sup>23</sup>

### 3.5 | Worry and the transition to medicalization

The experience of UTI raised the dilemma of whether to seek medical attention and this theme describes the worry that there was something more threatening about their symptoms that did not match their previous experiences, which warranted medical attention.

“I think I said to the doctor at the time y’know it wasn’t horrendous it was just niggling and I just knew it wasn’t right’ ‘This time was different.’ ‘I woke up with really bad stabbing pains in my back, um, and it just felt different... so I went to the doctor. It didn’t feel the same...”

Leydon et al. 2009<sup>24</sup>

For some, it was simply that they had reached a threshold where they felt they needed to seek care for their symptoms.

“Start by trying to deal with it on your own and then if it really doesn’t go away, go to the doctor.”

Duane et al. 2016<sup>34</sup>

The desire to seek a diagnosis and/or treatment was driven by a fear of progression and worsening of symptoms, or that there may be a more sinister underlying cause of their symptoms.

“I just got concerned that there may be something fundamentally wrong with my system that needed to be looked at and he just told me there wasn’t really anything I need to worry about.”

Little et al. 2009<sup>30</sup>

“[I] was spiking a very high temperature and feeling like I had the flu, I would go to the GP and I would want antibiotics, to be honest with you, because if it gets to that stage it can go to your kidneys and that’s dangerous.”

Lecky et al. 2020<sup>29</sup>

### 3.6 | Antibiotics are a valuable treatment approach

This theme describes the value placed on antibiotics for those that felt that there was no substitute. Antibiotics appeared to provide a quick, effective, safe treatment, and strategies implemented to avoid or delay their use was unfavorably viewed.

“I think one is influenced by one’s job. If I have to go to a meeting in [place name] I’ll go to the doctor and get antibiotics and take them straight away because I’ve got to be fit.”

Little et al. 2009<sup>30</sup>

Some felt that antibiotics had a valuable role in preventing the development of UTI through their use as prophylaxis, although some recognized this as having potential negative implications.

“long term antibiotics have allowed me to get my life back on track.”

“I also worry that I will become resistant to this too and then I will be left without an antibiotic which works for me.”

Flower et al. 2014<sup>33</sup>

### 3.7 | Antibiotics are a last resort

This theme of “antibiotics are a last resort” described the thoughts and experiences of those that seek nonantibiotic treatment. It describes a desire to avoid taking prescribed medication, with antibiotics being used only when other treatments failed. Some described themselves as not “someone who takes antibiotics.”

“I don’t really like taking antibiotics unless I’m, you know, unless I think I’m dying

[laughter]... I wouldn't take antibiotics for [UTI] unless it was really, really, really, really bad."

Lecky et al. 2020<sup>29</sup>

"I don't like taking antibiotics anyway, I don't – I'm not someone who takes antibiotics."

Ghourri et al. 2019<sup>32</sup>

Some preferred alternative and natural remedies; experiences of these remedies and their efficacy were raised and discussed. Participants described concerns about antibiotic side effects and antimicrobial resistance.

"I had taken, done the usual thing, drink plenty of fluid, that didn't work, so I'd been into the chemist and bought one of the over-the-counter remedies. That didn't work, so that's when I went to the doctor in the end."

Little et al. 2009<sup>30</sup>

"They always try and give me antibiotics first. I'm like 'no, no, no' ... I think they kill you as much as they cure you. Often, they make me feel worse before I feel better. If I can fight a UTI naturally, I will try ... they make me feel quite vulnerable ... I'd like a magic pill, that's going to stop them from happening. Unlikely, [but] I'd like the fear of resistance to antibiotics not to be there."

Hearn et al. 2018<sup>28</sup>

Those who recognized that antibiotics were effective simultaneously had fears that they could be overused.

"If you're on antibiotics regularly the bacteria just form resistance. I would only take them if I felt it was absolutely necessary – I think it might be counter-productive. I'm very wary about taking them, I think it's a big, big worry at the minute."

McClurg et al. 2018<sup>25</sup>

### 3.8 | Being heard, seen, and cared for with dignity

This theme describes the desire to have a voice, to be engaged with and cared about by individual

practitioners as well as the wider healthcare system. Some felt that they were not being listened to or taken seriously, that their clinician did not really care, or that the medical system was not good enough for those with UTI.

"I had had a bad experience in the past of a GP who refused to prescribe me anything until he (of course it was a man!) had sent off a urine test. This would've meant waiting days for the results and I was in agony."

Flower et al. 2014<sup>33</sup>

Some felt that their own knowledge and experience was not always recognized by their clinicians.

"I'm quite willing to listen, but I know my own body."

Leydon et al. 2010<sup>23</sup>

"the fact that he was asking [slight laughter] me to delay even longer was, oh, I don't want to do this but I think I did and then I think it got to the stage where I just thought no."

Little et al. 2009<sup>30</sup>

The importance of the relationship between clinician and patient was clear, and others described positive experiences of being understood, taken seriously, and continuity of care.

"He listens to you. Some doctors don't listen to you. They just brush you by. He listens to you and takes you seriously and do something about it."

Duane et al. 2016<sup>34</sup>

### 3.9 | Self-judgment

There were several concepts that contributed to a theme of self-responsibility and that the presence or emergence of a UTI was in some way the responsibility of the individual having been at fault or having made a mistake.

"I don't know why but it makes me feel like such a failure each time the results come back with an infection still present. I get angry with myself that I can't get my body to do its job to fight it and I'm putting my

[unborn] baby at risk. Stupid I know but I can't help."

Ghouri et al. 2019<sup>32</sup>

Tied into this was the concept that avoiding UTI was down to an individual's responsibility to maintain lifestyle measures to keep the UTI at bay.

"To try and prevent infection, I don't drink alcohol. Not for 3 years. I don't have caffeine. I was concerned that I was taking chocolate as an energy boost but I am really limiting anything with it; I don't have sugar in anything, I've not had sugar in anything for about 35 years."

Okamoto et al. 2017<sup>26</sup>

"The key is to get the body to heal properly, that takes a lot of time and a lot of focus. It is layers of healing - so sorting out IBS [Irritable Bowel Syndrome], the bladder, the gut, it all takes a long time to re-balance. Using alternative therapies mean that you feel more confident when twinges come on and you feel more in control, as you know you can treat them herbally and you don't have to take antibiotics."

Flower et al. 2014<sup>33</sup>

For some participants, the presence of a UTI led to some sense of judgment, either internalized or fear of judgment from others.

"I don't want to be that wee-smelling cripple in the chair, don't want to be that person. You know, that perception of being dishevelled and dirty and smelly and not very pleasant. Nobody wants to have a smelly person in their surroundings."

Hearn et al. 2018<sup>28</sup>

### 3.10 | The end of the road, a need for information and cure

Within this final theme were a number of concepts that collectively illustrated a feeling of having exhausted all therapeutic options and yet there still existed an ongoing need for information and treatment. There was a need for a definitive long-term solution despite the complexities

this presented. This created many uncertainties within the UTI suffering population.

"Over the years I have used many different antibiotics, sometimes to clear infections and for a period of about 6 years I took them when we had sex as a preventative. However, I am now resistant to many of these drugs."

"I am 43 yrs old and have been experiencing cystitis type problems for 25 yrs."

Flower et al. 2014<sup>33</sup>

"My problems were never investigated and I think that is quite bad because I have had these infections for so many years."

Eriksson et al. 2014<sup>37</sup>

Within this theme, there was sometimes a sense of hopelessness and desperation which could be mitigated by contact with other people suffering with UTI.

"The big thing for me is the anxiety over the resistance getting worse. Then I feel 'is this it? Am I going to go this week?' ... it makes me confront my mortality a lot."

Hearn et al. 2018<sup>28</sup>

"It's such a lonely illness try [to] get some company or people to talk [to] on the phone/text or Mumsnet of course."

Ghouri et al. 2019<sup>32</sup>

### 3.11 | Developing a conceptual model

Finally, we developed a conceptual model that facilitates the understanding of the patient perspective of UTI as shown in Figure 2. The "experiencing UTI" phase was the collection of, and movement between, three themes of "the impact of UTI on my whole body," "impact on quality of life, activities, and the associated psychological toll," and "I know my body and experiences have taught me when I need to seek care." Moving on from this phase was "control of my body and my health," including the themes of "worry and the transition to medicalization," "antibiotics are a valuable treatment approach," "antibiotics are a last resort," "being heard, seen, and cared for with dignity," and "self-judgment." Finally, there was a sense of being "failed by the system, the end of the road"

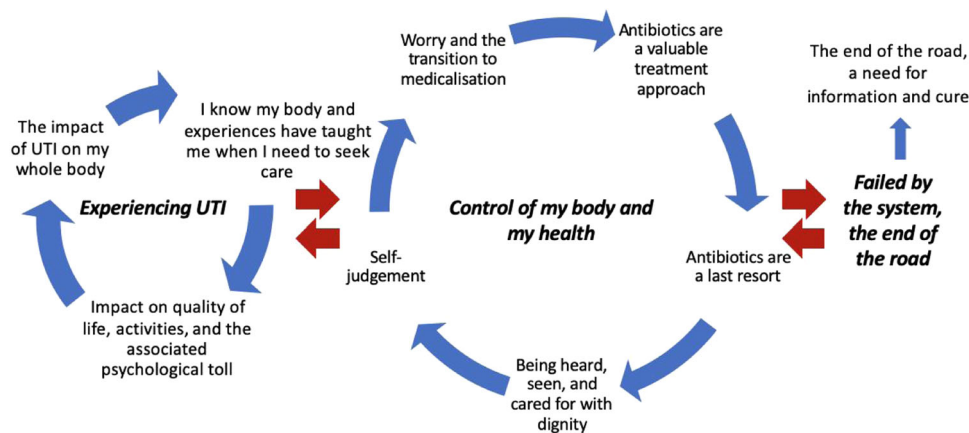


FIGURE 2 Conceptual model

manifested by the theme “the end of the road, a need for information and cure.”

## 4 | DISCUSSION

This meta-ethnography of findings from 16 primary qualitative studies draws on 1038 patient’s experiences of UTI. The nine themes identified were developed into a conceptual model with three phases. First, that of “experiencing UTI” leading to physical and psychological manifestations of the condition that have an impact on daily life. This is moderated by self-knowledge and individual’s previous experiences, which feeds into a second phase of “control over one’s body and health.” This involves a complex interplay between that individual’s perceived role in preventing or developing a UTI, their decision to seek medical care, and how that experience of medical care feels as well as their views on the role of conservative, complementary, and medical therapies, particularly with reference to antibiotics. For some, these two evolving as well as relapsing and remitting phases that interface with each other can lead to a third and final phase of being “failed by the system, the end of the road” whereby desperation and frustration leads to a need for more information and a cure. These three phases are not distinct and it is likely, but not necessary, that people transition between them. This conceptual model gives an insight into the potential complexity of diagnosis, treatment, and long-term management of the condition of UTI. These complexities, such as patient experiences due to the delayed or failed diagnosis of UTI, is also recognized within quantitative research into the condition whereby limitations in the clinical diagnosis of UTI is well documented.<sup>39</sup>

The nine themes provide a focus for those wishing to better understand the patient experience of UTI and how

these inter-relate through the conceptual model. It is clear that symptoms are wide and varied, and that manifestations of UTI affect the physical body not just in terms of the lower urinary tract but also having systemic sequelae. This corroborates and further expands on the findings from large observational studies.<sup>40</sup> These symptoms affect psychological and functional components of health, with an overall impact on quality of life, and qualitative studies of other pelvic floor disorders such as prolapse report similar findings.<sup>41,42</sup> People use their experience of previous UTIs, as well health and illness more broadly, to interpret their symptoms and their impact. Crucially and central to this is the decision making around whether or not to seek medical care versus watching and waiting. This mirrors primary qualitative studies that have explored women’s decisions about engagement with care for conditions such as prolapse.<sup>43</sup>

The concept of control over body and health highlights an element of worry or concern about more severe forms of UTI or more sinister pathology that drive the decision to access healthcare. For others, it ties into their knowledge of their own body and decisions as to when medical intervention is needed. We did not find the taboo and silence that might lead to a failure to seek medical care, in contrast to similar studies of other pelvic floor disorders such as urinary incontinence and prolapse.<sup>14,19</sup> However, data suggest a possible feeling of shame and self-judgment that could potentially act as a barrier to appropriate care: there was a sense that the patient had the responsibility to avoid a UTI in the first place and an element of self-judgment at having done something to precipitate the episode. This resonates with feelings of shame reported in women with vaginal prolapse.<sup>44</sup>

The findings suggest that the role of antibiotics from a patient perspective appears to fall into two approaches. In some cases, antibiotics provide the cornerstone of

treatment. This may be because people have unsuccessfully tried natural remedies or watchful waiting before seeking care, or it may be because they seek a definitive and fast resolution to their symptoms. In other cases, the desire to avoid antibiotics may be because people wish to seek more natural remedies or expectant management, or it may be related to concerns about harm and adverse events or antimicrobial resistance. This dichotomy reflects the wider discussion in the literature about patient expectation with respect to antibiotic use, particularly in the context of increasing antimicrobial resistance.<sup>45</sup>

The final theme highlights the need for information, access to care, treatments and research, and innovation in to the treatment of UTI. The findings suggest that people living with UTI can feel they have reached the end of the road. They feel a need for further information, better access to care, and that they have exhausted all treatment options leading to a sense of desperation about their clinical picture and a need for a permanent solution or cure. Frustration, a need to seek help, and a sense of hopelessness are well-recognized concepts within other studies of women with pelvic floor disorders and raise questions about the available diagnostic and therapeutic options for women with UTI.<sup>41,43,44</sup>

#### 4.1 | Strengths and weaknesses

The innovation of this study is that it is the first QES of studies looking at with the experience of UTI, providing unique insights into a common condition. Findings from qualitative research are an interpretation of data and therefore inevitably influenced by the context and experiences of reviewers. This is recognized as a strength of an interpretive paradigm that aims to develop useful ideas. A systematic search strategy with robust quality appraisal of primary research provided an evidence-based strategy upon which to undertake our analysis. The use of meta-ethnography is well established and we have previously appraised its utility as well as challenges in examining and analyzing data in this way.<sup>46</sup> The study incorporates over 1038 patients across a wide range of ages, utilizing a number of qualitative methodologies, and undertaken in a number of countries, which adds to the transferability of our evidence synthesis. Further construction of a conceptual theory to summarize our findings improves accessibility of our findings for patients, policy makers, clinicians, and researchers.

This study only included those manuscripts published in English and were predominantly undertaken in Northern European countries, challenging the transferability to non-English speaking populations beyond this geographical area. It is likely that there are gendered

differences in the experiences of UTI that we have not explored; only a very limited numbers of men participated in the primary studies and we were therefore unable to decipher any gendered differences. Further research to explore the complex gendered experience of UTI would be useful. There was no distinction in this analysis between data from those with a single episode of UTI versus relapsing or recurrent UTI, likewise for those with an active UTI at the time of participation versus those recalling experiences, and it is likely that experiences would vary between these types of patients and episodes. There are also challenges around different patient groups, recognizing that participants may have been pregnant, utilized catheters, or had other health conditions that were related to UTI. Further research to explore these differences would be useful. Meta-ethnography is a third-order construct, meaning an interpretation of interpretations; while the full critique of this methodology is beyond the remit of this paper, we recognize that the nuances and findings of primary studies, and certainly the original intended meaning from patients, maybe lost in this approach.<sup>47</sup> It may also be the case that the meaning and themes from primary studies are contextual to a specific care environment or social environment rather than specifically to UTI; no medical condition exists in a silo, and therefore some themes born out from this analysis may reflect experiences that were not directly a result of UTI. Finally, as a pre-cursor study to a fully funded project, the conceptual model development was limited to the four authors and therefore may not be as encompassing as those produced within the context of larger groups.

#### 4.2 | Clinical and research implications

It is clear that symptoms of UTI are wide and varied both in their physical manifestations, for example lower urinary tract versus systemic, but also their psychological and functional components; this highlights a need for patient, clinician, and researcher education to facilitate recognition beyond the classic clinical features of UTI described within medical literature.<sup>2</sup> Development or core outcome sets for UTI may therefore be indicated, in keeping with those that have been developed for other pelvic floor disorders as part of CHORUS, an International Collaboration for Harmonizing Outcomes in Research, and Standards in Urogynaecology and Women's Health (<https://i-chorus.org>). Such heterogeneity in presentation reinforces the calls for better diagnostic modalities so that those with UTI do not have delays in treatments due to failures in diagnosis.<sup>39</sup> It also highlights the importance of the "patient voice" and a need

for clinicians to recognize patients' understanding of their individual health experiences in shaping assessment and treatment, including the point at which medical help is sought.

Areas for potential future research highlighted from this study include further qualitative work to better develop understanding of the impact of UTI on patients to facilitate medical and social support mechanisms and therefore improve health-related quality of life. There appears to be heterogeneity with respect to when to seek medical care and the role of natural and medical therapies; understanding patient drivers of these and cross-referencing this with quantitative studies of effective treatments and care pathways could help streamline healthcare system approaches to care for the patient group. Indeed, the findings suggest that some patients may feel uncertain and under-served by the current status of diagnosing and managing UTI and this would justify further work in this regard. We identified limited research on UTI affecting specific patient groups, such as pregnant women, and further exploration would highlight whether their needs are met by current systems or whether group-specific care pathways are needed. There was limited data on men in the primary studies and exploring gender or sex differences for people with UTI would be a further area of interest.

## 5 | CONCLUSION

Nine themes were developed from twelve qualitative studies that have been integrated into a conceptual model to explain patient's experiences of UTI. Manifestations of UTI are wide and varied, and patients process these based on previous health and UTI experiences. These feed into the patient's decision making about seeking medical care and choosing natural versus medical therapies. Current diagnostics and therapeutics for UTI appear inadequate for some patients, leading to a sense of hopelessness and frustration. These findings, in combination with further qualitative research looking at the areas highlighted, may provide useful findings for policy makers and clinicians to improve patient outcomes by enhancing patient centred care with awareness of the patient perspectives of this common condition.

## CONFLICT OF INTERESTS

The authors declare no conflict of interest.


## ETHICS STATEMENT

This was a review and synthesis of publicly available data and therefore no ethical approval was required.

## DATA AVAILABILITY STATEMENT

Data are available on request from the authors. The data that support the findings of this study are available from the corresponding author upon reasonable request.

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