Recurrent cystitis: patients’ needs, expectations and contribution to developing an information leaflet – a qualitative study

Louisa Bey, Pia Touboul, Véronique Mondain

ABSTRACT

Objectives Recurring cystitis (RC) is a common complaint among women. It has a significant impact on patients’ quality of life. The physical discomfort and psychological distress related to RC are rarely addressed and women’s needs in terms of information and advice have not been sufficiently explored, particularly in France in spite of their frequent episodes of RC. This study aimed to assess women’s needs and expectations in view of developing a patient information leaflet to help them understand and better cope with their condition, thus offering them more autonomy and empowering them to self-manage whenever possible.

Method Qualitative study using recorded semi-structured interviews with patients suffering from RC.

Setting Interviews conducted with women suffering from RC in Corsica, France.

Participants 26 patients interviewed between January 2018 and April 2018.

Results Knowledge of the condition was heterogeneous, but most women reported a major impact on daily life, a high level of anxiety, various management strategies and wished to avoid taking antibiotics, preferring alternative approaches. Patients reported a lack of understanding and sympathy on the part of physicians and society and wished for more autonomy with delayed/back-up prescriptions, a multidisciplinary follow-up and, most of all, appropriate information.

Conclusion The information leaflet should improve patients’ knowledge and capacity for self-care, contribute to standardise practice and limit inappropriate antibiotic use.

INTRODUCTION

Cystitis is an extremely frequent complaint, one out of two women developing an episode over her lifetime. It is a benign condition generally treated with antibiotics prescribed by the primary care physician.

Recurring cystitis (RC) is defined as the occurrence of at least four episodes of cystitis over a 12-month period, according to the French Language Society for Infectious Diseases (SPILF). Although the prevalence rate of RC among the female population is not known, some studies on small cohorts of patients suggest it may be quite high. Many women report the major impact of the condition on their daily life, as pain and urinary frequency can be invalidating, as well as on their sexual activity. The significant psychological consequences, which are dominated by anxiety, have rarely been explored.

According to the French National Agency for Medicines and Health Products Safety, urinary tract infections (UTI) currently rank third among ambulatory antibiotic prescriptions in France. Choice of antimicrobial agents and duration of treatment both appear inappropriate: fluoroquinolone and third generation cephalosporin prescriptions and treatment duration are excessive and do not take either the epidemiology of antimicrobial-resistant bacteria nor the impact on the gut microbiota into account, and thus do not comply with recommendations. In some countries, treatment is discussed with patients and alternatives to antimicrobial treatment
are offered, which have not shown an increased rate of complications or recurrence compared with patients treated with antibiotics.\textsuperscript{11-13} Such an approach should be made more broadly available to women with RC and with no risk of complications. The UK National Action Plan aims to prevent the need for antimicrobials and improve the publics’ infection prevention behaviours. Indeed, the primary objective of a recent qualitative study conducted in the UK was to explore patients’ needs on provision of self-care, which could reduce consultations and unnecessary antibiotic use. An information leaflet was developed to this end.\textsuperscript{14} In France, the needs and expectations of patients suffering from RC have not been evaluated.

The ReSO-InfectiO PACA EST includes a group of healthcare institutions, laboratories and health authorities in the Provence Alpes Côte d’Azur (PACA) region in South-Eastern France and aims to conduct research and harmonise the management of infectious diseases across the area. Infectious diseases physicians of the ReSO InfectiO PACA EST, coordinated by infectious diseases specialists at Nice University Hospital, consulting women referred for RC, conducted a survey of trigger factors, care pathways and management.\textsuperscript{15} This showed that women wished for more autonomy and treatment options. To this end, a qualitative survey was conducted among women with RC to inform the contents of an information leaflet intended to improve patients’ knowledge and to help them manage their condition.

**METHODS**

Qualitative semistructured interviews were undertaken by a single researcher trained in qualitative research methods, with a purposive sample of female patients with a definite diagnosis of RC, that is, at least three episodes of cystitis over 12 consecutive months, over 18 years of age, with no cognitive impairment.\textsuperscript{16}

**Geographic study setting**

The Ajaccio area conurbation in Corsica

Patients were recruited via their community-based general practitioner (GP), gynaecologist or urologist as well as via hospital-based physicians. Recruitment was subsequently extended to include patients attending medical laboratories (where information describing the study was delivered through leaflets posted in waiting rooms), pharmacists and via social networks. A snowball effect was produced as recruited patients had contacts with women with similar complaints. Recruitment continued until content saturation was achieved, as observed through immediate debriefing and ongoing data analysis.\textsuperscript{17-19} Indeed, data saturation is considered to be reached when there is enough information to replicate the study, when the ability to obtain additional new information has been attained and when further coding is no longer feasible.\textsuperscript{20}

**Interview**

The interview guide (online supplemental appendix 1) included a brief introduction, a qualitative section with seven neutral, open-ended questions that followed a guiding thread with the possibility of using topical probes if necessary, and a quantitative section with sociodemographic (age, educational level, socioprofessional category, area of residence) and medical details related to RC (attending physician, age at start of RC, main past or current medical conditions). The interview guide was initially tested on two patients and proved satisfactory. No further alteration was required.

**Data collection**

Recorded interviews were conducted and recorded according to patients’ availability and in any quiet location they chose by a single trained researcher (LB). The aims of the study and the interviewing procedure were explained, and patients provided written informed consent to participate.

**Data analysis**

Each recorded interview was transcribed verbatim by a single trained secretary, with as many details as possible, both verbal and non-verbal. A debriefing procedure by the researcher (LB) took place immediately following each interview to record the overall impression and identify the main ideas put forward by the patients and was shared with coauthors (PT, VM). This allowed to identify the point when theoretical data saturation was reached after discussion and agreement from all researchers, that is, no new ideas arose, and discontinue recruitment.\textsuperscript{18,19} Inductive thematic analysis\textsuperscript{18} was performed using NVivo software. This included six stages: getting acquainted with the content of the interview (familiarisation), followed by initial coding where codes were approved by all researchers after discussion, identification of overarching themes, grouping of themes or categories of ideas, exploration of links and interaction between themes, description and supporting quotations, according to an iterative procedure.\textsuperscript{18,20} On an ongoing basis, this data analysis procedure was discussed among all the coauthors at all the different stages to reach agreement and conducted in accordance with their comments. Each category was summarised in the results section and illustrated with relevant quotes (online supplemental appendix 2). At the end of the results section, the implications derived from these results were illustrated in a...
table intended to be used as a basis for developing the information leaflet (online supplemental appendix 3).

**Patient and public involvement statement**

Patients or members of the public were not directly involved in the design and planning of this study.

**RESULTS**

**Quantitative results**

Participants

A breakdown of patient inclusion is illustrated in the flowchart shown in figure 1.

Patient characteristics are shown in table 1.

Among the stated risk factors, many women mentioned insufficient hydration, sexual intercourse, pregnancy and parturition, withheld micturition, constipation, and stress.

Physicians

Among the 53 physicians contacted, 50 agreed to participate in recruiting patients (33 community-based practitioners: 31 GPs, 2 gynaecologists and 17 hospital-based practitioners: 9 accident and emergency physicians, 4 gynaecologists, 2 urologists and 2 infectious disease specialists).

Interviews

The interviews were conducted between 30 January 2018 and 3 April 2018. Their mean duration was 22 min (range 9–39 min). Sixteen interviews took place in a medical setting, six in patients’ home, three in patients’ workplace and one in a coffee shop.

Recruitment

Among the 26 patients interviewed, 8 had been recruited via their physician (mainly GPs), 5 via leaflets, 7 via Facebook and 6 through snowball sampling.

**Qualitative results**

Results of patient interviews are detailed in table 2.

**DISCUSSION**

This qualitative survey of women’s needs and expectations regarding recurring RC has revealed their need to understand and self-manage their condition. Such patient empowerment is indeed increasingly favoured insofar as women are aware of those situations, which might require a physician’s intervention. Avoiding unnecessary consultations and antibiotic prescriptions thanks to an information leaflet specifying both prevention and management is a major objective which has been advocated namely through a National Action Plan in the UK to ‘raise public awareness to encourage self-care and reduce expectations of antibiotics’. Unlike the present study, the qualitative study conducted in England involved both patients and healthcare providers and was based on focus groups, rather than face-to-face interviews, with a comparable number of patients and a similar approach in seeking patients’ opinion on informing a leaflet.

**Strengths and limitations**

**Strengths**

This qualitative study in the form of individual interviews revealed the expectations and needs of patients suffering from RC, as well as their opinions and attitudes. The method provided the opportunity for an in-depth approach of the subject, thanks to the conversational character of the interviews, which were able to overcome any embarrassment these might have caused. The semi-structured interview guide contained open questions that allowed to adjust the interview as it progressed. It was tested and found suitable after two pilot interviews.

The various recruitment approaches resulted in a diverse and complementary theoretical sample, with a substantial number of respondents with varied characteristics, regarding age, number of years with the condition, age when it began, educational level.

To reduce loss of information to a minimum, each interview was followed by immediate debriefing. Thematic analysis was optimal thanks to the use of N-Vivo software.

**Limitations**

Participants’ response was subject to their level of comprehension and motivation and the time they could allow for the interview. As in all qualitative face-to-face surveys, adjusting to the patient introduces an inevitable bias linked to the interaction between patient and interviewer.

Physicians’ involvement was lower than expected as only 5 of all 31 contacted GPs recruited patients. This may be because physicians omitted or forgot to inform patients, or patients refused to participate.

Several patients’ profession was related to healthcare, as information on the study and contact details were provided in healthcare facilities, and also due to snowball sampling. This may have translated into heightened health-related awareness of their condition, and thus stronger support for the proposed intervention.

Lastly, qualitative thematic analysis and interpretation of results necessarily imply a degree of subjectivity on the
part of the researcher. Coauthors were involved in every step of the analysis.

**Interpretation of findings in the light of published research**

**Patients’ knowledge of the condition, its causes and risk factors**

Confusion regarding the difference between cystitis and urinary infection could explain patients’ inadequate strategies, such as resorting to antibiotics because of smelly urine. Few patients had any idea of the origin of their condition. Indeed, the physiopathology of recurrent cystitis remains obscure and multifactorial. In the case of relapsing RC, the possible presence of intracellular uropathogenic *Escherichia coli* within the bladder epithelium could interfere with an effective immune response and give rise to re-emergence of infection from this reservoir, which may require reconsidering treatment approaches.

Several patients mentioned hormonal causes. Oestrogen insufficiency has been described as a causative factor. The SPILF suggests local oestrogen therapy after menopause if approved by the gynaecologist. Oestrogen insufficiency results in decreased Lactobacillus vaginal colonisation and *E. coli* proliferation, and a study of local prophylactic treatment with probiotics shows encouraging results. In the present study, none of the patients took topical oestrogens and only one took probiotics.

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Table 2. Summary of results and implications (patient quotes are listed in online supplemental appendix 2)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Key findings</th>
<th>Quotes</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of the condition, its causes and risk factors</td>
<td>Patients were confused regarding the difference between cystitis and urinary colonisation: they had queries regarding the link between smelly urine and infection, requesting a definition of cystitis, an explanation of the causes and risk factors. Several patients mentioned hormonal causes—pregnancy, menopause, endometriosis and oral contraception—as risk factors. Many patients associated cystitis with sexual intercourse. Hereditary factors were also mentioned. Patients also identified stress and fatigue, postvoiding residual urine, insufficient hydration. They wished for written explanations.</td>
<td>1Q01, 1Q02, 4Q01, 4Q03, 16Q01, 26Q01, 20Q01, 1Q04, 28Q01, 1Q01, 1Q02, 28Q03, 6Q01</td>
<td>Patients need a clear definition and understanding of RC, urinary tract infection and colonisation, and causes thereof, with clear, written, illustrated information.</td>
</tr>
<tr>
<td>Impact on daily life</td>
<td>Patients described intense pain and anxiety interfering with their social, professional, family and sexual life. A burning sensation on voiding and urinary frequency were particularly invalidating and resulted in social isolation: home confinement, interference with work or having to take sick leave. Patients also reported a major impact on their sexual activity, leading to abstinence during episodes, but also to reduced sexual activity at other times.</td>
<td>10Q01, 1Q02, 27Q02, 19Q01, 1Q01, 1Q02, 1Q02</td>
<td>The link with hygiene, diet, hormonal status (vaginal dryness) should be explained and accompanied with a diagram illustrating anatomical details.</td>
</tr>
<tr>
<td>Coping strategies</td>
<td>Few patients resorted to analgesics. Preventative measures regarding hygiene and diet, particularly increased fluid intake, were usually known but unevenly implemented, though some wished for more information on the subject. Many patients resorted to various forms of cranberry preparations. Half of them had a back-up prescription for antibiotics provided by their physician.</td>
<td>28Q03, 23Q04, 24Q1, 6Q02</td>
<td>Patients should be encouraged to increase their fluid intake and resort to analgesics, and should be provided with a back-up prescription of antibiotics in anticipation of future episodes.</td>
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<tr>
<td>Investigations</td>
<td>Several patients had undergone various investigations (ultrasound examination, urinary tract scan, cystoscopy…), others wished for further testing or specialist advice. One patient confused urine test and cervical swab.</td>
<td>19Q03, 2Q04, 2Q01</td>
<td>Patients need a definition of urine microscopy and culture. The relevance of urine dipstick test and urine culture for the management strategy of RC should be explained.</td>
</tr>
<tr>
<td>Antimicrobial therapy and possible alternatives</td>
<td>Various antibiotic treatment strategies were used: fluoroquinolones, fosfomycin-trometamol, cotrimoxazole, nitrofurantoine, amoxicillin, with frequent self-medication, mainly with FT but also nitrofurantoin or cotrimoxazole leftovers from a previous infection. Patients considered there should be alternatives to antibiotics. They were concerned that antibiotics would harm their health, result in adverse events, and lead to emergence of bacterial resistance.</td>
<td>1Q7Q, 1Q46</td>
<td>Patients need to be reminded of indications for antibiotic therapy and preferential compounds according to type of RC. A short explanation on bacterial resistance should be given, as well as advice on non-antibiotic strategies.</td>
</tr>
<tr>
<td>Views on physicians’ approach</td>
<td>Patients resented the constraint of repeated visits to the general practitioner, who was often difficult to reach immediately. Several wished to self-manage their infection and requested back-up prescriptions for urine culture and single dose FT treatment. Lack of anticipation on the part of physicians led to patients performing a urine culture without a prescription (so were not reimbursed) and to self-medication. Patients reported lack of information, empathy and support, investigations and follow-up. Some were fatalistic, accepting their condition as inevitable (referring to female family members and friends with the same problems). Antibiotics were considered overprescribed and banal, and conducive to neglecting investigations into causes and risk factors. Women wished for information regarding diet and hygiene measures. They also wished for alternatives. Some tried ‘natural’ approaches, that is, phytotherapy or aromatherapy, despite their cost.</td>
<td>1Q04, 2Q05, 2K01, 1Q02, 1Q01, 20Q01, 1Q02, 11Q02</td>
<td>Patients require clear, written management advice, and should be informed on how and when to self-treat and be provided with back-up prescriptions accordingly. The relevance and timeliness of investigations should be explained, and guidelines for an investigation strategy for simple cystitis and for cystitis at risk for complications. A multidisciplinary approach and a yearly dedicated medical consultation should be made available.</td>
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Some patients mentioned hereditary factors, and a history of UTI in mothers has been noted by infectious disease specialists, suggesting possible genetic susceptibility to infection, although this may also be related to behavioural factors within families. The high frequency of RC on initiation of sexual activity is described in the literature. However, stress, fatigue and apprehension of further episodes were also identified as risk factors, as well as bowel dysfunction, as identified in an ongoing prospective study conducted in our area.

Impact on daily life
Social isolation, sexual abstinence during episodes, but also reduced sexual activity at other times were mentioned and have also been described in an Italian study. The major psychological impact, namely anxiety, resulting both from the RC episodes themselves (but which could also be a possible cause) and from the lack of adequate management, emphasises the need for a multidisciplinary approach, taking the stress factor into.

Patients’ coping strategies
The variety of strategies to cope with RC point to a wish by many patients to avoid antibiotics and to self-manage their condition: herbal medicine, aromatherapy. The importance of increasing fluid intake was widely known, if not sufficiently applied. Although many patients resorted to various forms of cranberry preparations, these have not been evaluated in terms of effectiveness, while French recommendations advise a minimum daily dose of 36 mg proanthocyanidin. Back-up antibiotic prescriptions, often mentioned in this survey, have been advocated, along with guidance as to their appropriate use.

Investigations
While urine culture was performed too often for simple RC, dipstick tests were infrequent despite recommendations by the SPILF. However, the cost of dipstick tests is not endorsed by the national health insurance, which limits their use. Another inappropriate approach was to treat urinary colonisation revealed by an unnecessary follow-up urine microbiology and culture after a clinically effective antibiotic course, which should not lead to further antimicrobial prescription.

Antimicrobial therapy and possible alternatives
Although a wish to avoid antibiotics was expressed, these were used by many patients, especially Fosfomycin -trometamol (FT) due to the convenience of a single dose, but also inappropriate use of other compounds, whether self-administered or inadequately prescribed by a physician. Such variable coping measures when confronting initial signs of cystitis highlight the need for standardised approaches since the stated treatment strategies did not conform with recommendations: self-medication with fluoroquinolones, systematic urine culture, secondary adaptation of antibiotic treatment to susceptibility test results for uncomplicated RC; regular empirical antibiotic treatment for potentially complicated RC, with a single, thus suboptimal, FT dose; nitrofurantoin as antibiotic prophylaxis, which is strictly contra-indicated according to French guidelines. Many non-antibiotic options for RC have been explored. Treatment strategies have been evolving in Scandinavian countries and in Germany, where painkillers/non-steroid anti-inflammatory drugs can be offered for treating cystitis with mild/moderate symptoms in a watch and wait approach although their efficacy remains controversial. Immunotherapy using a vaccine based on a bacterial extract is currently being tested. Lastly, among the various approaches aiming to alleviate pain and stress, hypnosis could prove useful: it has been shown to alleviate symptoms in irritable bowel syndrome and to reduce the need for analgesics during surgical procedures. Preliminary results of its use in RC are promising (ongoing hypnocyst protocol by the same author, unpublished data).

Patients’ views on physicians’ approach
The discrepancy between symptom intensity and the reputedly benign character of RC stands out as a frustrating situation whereby the condition is not seriously considered, although patients’ distress has recently been acknowledged.

The lack of physicians’ and society’s understanding regarding RC contrasts with the major impact of the condition on patients’ activities, perception and degree of anxiety. Ignorance of the cause of RC, cost of antibiotic alternatives, lack of investigation or of conclusive results thereof led patients to adopt a fatalistic attitude. This was noted by Italian authors who concluded to the ‘cost of resignation’ related to physicians’ lack of involvement. Certain patients even expressed surprise at being questioned regarding their opinions on their management of RC.

Patients’ request for more autonomy has been addressed in France with a strategy put forward in 2014, targeting selected, educated women with no risk factor, subject to two times yearly reassessment: this consists in self-treatment thanks to a delayed prescription, following a (non-reimbursed) dipstick test to confirm cystitis. A recent qualitative survey conducted in the UK pointed to the need for addressing physicians’ knowledge and skill gaps on UTI in women under the age of 65 years, including non-pharmaceutical recommendations for self-care.

Lastly, the request for more thorough, multidisciplinary management relying on various strategies is not in line with recommendations put forward by the SPILF for uncomplicated RC in 2014: in non-menopausal women with a normal pelvic and urethral clinical examination, no further investigation is systematically required. In other situations, for women at risk for complications,
management should be decided by a multidisciplinary team. Few women (25%) had consulted a urologist or a gynaecologist, while infectious disease specialist advice was very rarely sought.

Clarification of this trajectory should result in more standardised approaches and reduce patients’ anxiety.

**Implications**

**Information leaflet**

Based on the requests put forward by the interviewees, an information leaflet should be made available and include the following items to meet the needs and expectations of patients with RC:

- A reminder of the definitions.
- Description of the known causes and risk factors of RC supported by a diagram and information on the usefulness and timeliness of urinalysis, dipstick test and urine microscopy and culture.
- Procedure to be followed when first signs of cystitis appear.
- Role of antimicrobial treatment and preferred compounds.
- Summary of possible non-antibiotic treatments.
- Clear suggested strategy for initial investigations/ specialist referral.

Such an information leaflet can be considered as a means of patient empowerment, as recommended by the SPILF in 2014 and which has still not been put into practice. It can contribute to patient education, aiming to involve patients in their healthcare and quality of life, while reducing inappropriate antibiotic use.

The effectiveness of information leaflets has been demonstrated in various contexts, namely regarding paediatric antibiotic prescriptions when coupled with GP online training. A patient–clinician shared decision-making leaflet was developed in the UK that addressed the consultation barriers and promoted patient empowerment, with both leaflet and corresponding explanations delivered by the physician.

Although the use of such a leaflet will depend on the physician’s wish to grant patients more autonomy and on the time available for dialogue, this may prove beneficial for both in the long run. Patients would have a clear, handy and relevant resource, which would contribute to reduce their anxiety by addressing several of their queries and describe the procedure to follow in case of cystitis. For previously selected and educated patients provided with back-up of urine microbiology and culture and/or antibiotics, the leaflet would increase autonomy. A printed resource facilitates memorisation and assimilation. Clear and explicit definitions can eliminate any confusion and thus prevent inadequate treatment. A diagram can help understand the links between risk factors and hygiene and dietary measures to adopt. Improved understanding should lead to better adherence to the suggested management strategy. A summary of various non-antibiotic treatments, whether validated or not, can meet patients’ request, describe how each should be administered and allow patients to test their respective effectiveness. Lastly, its use would contribute to improve to harmonise the currently highly disparate management approaches reported by patients.

Such an approach reflects most patients’ demands. The leaflet (online supplemental appendix 3) could thus contribute to train physicians from various specialties in good clinical practice. This could even be complemented with a specific resource for physicians.

Assessment of this resource on a wider scale is now necessary, by distributing it to the Réso GPs and their patients, to confirm its relevance and consequently offer it to all women suffering from RC.

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**Contributors**

VM and PT were responsible for the study design. LB conducted the interviews. LB and PT analysed the results. PT drafted the manuscript. VM is acting as guarantor.

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**Competing interests**

None declared.

**Patient and public involvement**

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication**

Consent obtained directly from patient(s).

**Ethics approval**

This study involves human participants. Ethical approval was not required as, according to French law and the Ethics Committee, the present study is not considered as research on human subjects but as a satisfaction survey. In France, ethical approval is not required according to Article R1121-1-1 of the French Public Health Code. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review**

Not commissioned; externally peer reviewed.

**Data availability statement**

No data are available.

**Supplemental material**

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**REFERENCES**


