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Krishnaswamy, Priyanka H.; Middleton, Eilidh; Hagen, Suzanne; Guerrero, Karen Lesley ;
Booth, Jo

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1 **Women's Experiences of Urinary Infections and Impact on Life: Explorative**

2 **Qualitative Study**

3 Dr Priyanka H Krishnaswamy^{1*}, MRCOG, Eilidh Middleton², BSc, Professor Suzanne
4 Hagen³, PhD, CStat, Dr Karen Lesley Guerrero⁴, FRCOG, Professor Jo Booth³ PhD, RN

5
6 ¹ Subspecialty Registrar in Urogynaecology, Queen Elizabeth University Hospital, Glasgow,
7 G51 4TF, United Kingdom

8 ² Medical Student, University of Glasgow, Glasgow, G12 8QQ, United Kingdom

9 ³ Professor, Glasgow Caledonian University, Glasgow, G4 0BA, United Kingdom

10 ⁴ Consultant Urogynaecologist, Queen Elizabeth University Hospital, Glasgow, G51 4TF,
11 United Kingdom

12
13 *** To whom correspondence should be addressed:** Priyanka H Krishnaswamy, Phone
14 number +44 (0)7442066328. Email: priyanextdoor@yahoo.com

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18

19

20 **Abstract**

21 **Importance**

22 Despite high incidences of urinary tract infections (UTIs), little is known about how
23 bothersome symptoms are, effects on women's life and sexual activity, leaving a gap in our
24 understanding of the physical and emotional effects of UTI on women.

25 **Objectives**

26 The aim of this study was to explore women's experiences of UTI and the perceived impact
27 on their quality of life.

28 **Study Design**

29 Qualitative interviews were undertaken with twenty-three women who had experienced at
30 least one UTI, recruited from different settings- primary care, general gynaecology clinics,
31 urogynaecology clinics and online via social media. Data were analysed thematically.

32 **Results**

33 Three themes described women's experiences of UTI: Women in all groups reported a wide
34 range of physical symptoms and described financial and psychological impact of UTIs. This
35 impact seemed worse in women recruited via social media who also reported experiencing
36 strong emotions and worries about close family members. UTI support groups were
37 considered useful, with women being grateful for consultations with alternative health
38 practitioners and presuming safety of natural products.

39 **Conclusions**

40 Having a UTI appeared to affect women in a variety of ways. These ranged from having
41 different physical symptoms, being psychologically afflicted by these symptoms and this
42 affecting their quality of life in different ways. While this research adds to the growing
43 evidence that UTIs affect women in these aspects, it also adds to the existence literature by
44 further expanding on this in women in a range of settings – in the community and in different
45 health care settings.

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61 ***"Simply Stated":***

62 **Objective**

63
64 Even though many women suffer from infections affecting their urinary system, we have
65 little understanding of how difficult women find the associated symptoms, their daily
66 routines, mental health and sexual activity.

67

68 **Description**

69 Women from four different settings were invited to participate in this study. This was in
70 primary care, Gynaecology clinics, Urogynaecology clinics and online via social media
71 (SM). This exploratory study described women's feelings about having urinary infections.

72

73 **Findings**

74 Every woman reported at least one UTI with women from the SM category having
75 suffered from frequent and lengthy episodes of UTIs, being on preventative
76 medicines and were using medical terminologies to describe their
77 symptoms. Women in all groups reported a wide range of physical signs of UTIs, impact of
78 UTIs on their lives and having experienced emotional and financial impacts with this. This
79 effect seemed worse in women in the SM category who also reported being
80 worried about close family members. While this research adds to the growing evidence that
81 UTIs affect women in these aspects, it also expands on this to women in the community as
82 well as in different health care settings.

83

84

85 ***"Why This Matters?":***

86 Urinary tract infections (UTI) are more common in women across all age groups compared
87 with men and have been associated with significant short-term morbidity worsening quality
88 of life. Despite the high incidence of UTIs, there is little known about how bothersome
89 symptoms are, the effects on patients' quality of life, daily routine or sexual activity in
90 women attending to see health care practitioners for different reasons. There is, therefore, a
91 gap in the understanding of the physical, emotional and other impacts that UTIs have on
92 women's lives.

93

94 While there have been other papers looking at and demonstrating the impact of UTIs, this
95 has been in specific subgroups of women- with cystitis, recurrent UTIs in older women, with
96 spinal cord injury (SCI), with uncomplicated UTIs or in online groups alone. The aim of this
97 study, however, was to explore women's experiences of urinary infection and the perceived
98 impact on quality of life in a cross-section of women in different settings, from those who
99 had only ever experienced a single uncomplicated UTI in the past to women with chronic,
100 recurrent UTIs.

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105

106 **Introduction**

107 There are high incidences of urinary tract infections (UTIs)¹ in women across all ages², and
108 are associated with significant short-term morbidity, strongly influencing quality of life^{3,4} and
109 restricting daily activities^{5,6}. Despite this, there is little known about how bothersome UTI
110 symptoms are, their effects on sexual activity⁷ and mental health. Potentially important
111 epidemiological information pertaining to the disease is not captured since reporting by
112 physicians is not required⁶ leaving a knowledge gap in the understanding of the effects on
113 women's lives. 85% of women's self-diagnosis of UTIs has been demonstrated to be correct
114 not needing microbiologically confirmation⁸.

115 The aim of this study was to explore women's real-world experiences of urinary infection
116 and the perceived impact on quality of life in a cross-section of women in four different
117 groups.

118

119 **Material and Methods**

120 This exploratory qualitative investigation formed the qualitative arm of a larger cross-
121 sectional questionnaire-based study which looked at experiences of women with UTIs and
122 the use of Complementary and Alternative Medications (CAMs) to prevent and treat them.
123 Non-pregnant women aged over 18 years with a history of having experienced at least one
124 episode of perceived UTI, were invited to participate between July - December 2020
125 [approved by the Ethics Committee (Integrated Research Application System ID 283407)]
126 from four settings:

- 127 i) Attending their General Practice (GP) for any reason
- 128 ii) Seeking secondary care in general gynaecology (GG) out-patient clinics
- 129 iii) Seeking tertiary care in Urogynaecology (UG) out-patient clinics
- 130 iv) Online via social media (SM) posts and UTI support groups on Facebook

131 After informed consent, they chose to be interviewed either in person, via telephone or video,
132 conducted by a single interviewer (PK) during the COVID pandemic. Interviews were semi-
133 structured ensuring relevant topics were discussed yet allowing in-depth exploration of
134 participant's views and experiences with field notes made during the interview. There were
135 no re-interviews with no further contact with participants.

136 **Analytical approach**

137 Each interview was recorded, anonymised, transcribed verbatim and imported to NVivo
138 12.5.0⁹ for thematic analysis using Braun and Clarke's five stage approach¹⁰ with a
139 systematic approach and an audit trail. Data familiarisation, creation of initial reflexive
140 thoughts and codes generated with further refinement, collapse into larger categories, pattern
141 identification, capture of emergent themes and comparison across answers refining the
142 ongoing analytic and reflexive processes. Each transcript was reviewed and coded by
143 principal researcher and two team members and reviewed further ensuring that codes and
144 themes were correctly and consistently applied. Results were compared across groups and
145 post coding meetings conducted so that a team approach towards analytical triangulation and
146 interpretation of results was taken with description of major and minor themes. A
147 phenomenological approach within an Interpretivist paradigm utilised and was reported
148 according to Standards for Reporting Qualitative Research (SRQR) guidelines¹¹

149 Reporting on reflexivity to enhance transparency and overall rigour, subjectivity of the
150 researchers is acknowledged, the principal investigator being a female registrar in
151 Urogynaecology and the second, a female medical student with no prior relationship to
152 participants prior to study commencement, vastly different perspectives and experiences in
153 this subject with both having research interests in the topic.

154

155 **Results**

156 While most participants recruited were from Scotland, two women in SM were in England
157 and one, the United States.

158

159 Figure 1 demonstrates recruitment: 23 participants were interviewed with women's
160 experiences being quoted as group (GP, GG, UG and SM) and participant number to
161 maintain anonymity and ease reader interpretation. There were no dropouts after accepting to
162 participate in the study as a convenient time and date were agreed at the time of recruitment.

163

164 All participants opted for telephone interviews from the convenience of their home with the
165 researcher in her office, no non-participants were present and lasted between 3 and 46
166 minutes (mean: 15 minutes). The themes developed are detailed in Table 1 with quotes from
167 participants illustrating each theme elaborated in Supplemental Tables 1-3.

168

169 **1. Physical Experience of UTIs**

170 a. Frequency

171 Every woman in the study reported having experienced at least one UTI, some in all groups
172 reporting recurrence and all in SM being on long-term preventative medications, prescribed
173 by Health Care Practitioners (HCPs) and/or self- managed, with frequent, recurrent and
174 prolonged episodes of perceived UTIs.

175

176 In SM, more women used recognised medical definitions when compared to the others, for
177 instance, in terms of frequency of UTIs experienced, possibly because they were more literate
178 about this due to the long-term nature of this, as well as seeking help from HCPs.

179

180 b. Symptoms of UTIs

181 Women across all groups experienced a wide range of UTI symptoms (Table 2). This was
182 described in isolation as well as in association with other medical conditions with women
183 reporting a deterioration in general health, with routine activities and concomitant mobility
184 being negatively affected.

185

186 Multimorbidity was described by more women in GG and UG, with UTIs being reported with
187 co-existent urinary incontinence symptoms, lichen sclerosis and fibromyalgia. Worsening
188 symptoms of either UTIs or co-existent conditions was described, with struggles to

189 differentiate between these symptoms and necessitating treatment for both conditions or
190 being treated for the “wrong” condition. Women who underwent intravesical Botulinum A
191 Toxin therapy for Overactive Bladder symptoms stated identifying a UTI based on strong
192 odour and colour of urine rather than typical symptoms described by others, possibly
193 explained by reduced bladder sensation following this.

194

195 c. UTI Triggers

196 A variety of triggers for a UTI were reported with sexual intercourse being most often
197 mentioned along with dehydration and physical stressors on the body such as getting wet,
198 sitting in the cold, being stressed and undergoing different treatments for cervical cancer.

199

200 2. **Impact of UTIs on everyday living**

201 While women across all groups reported this, women in SM were more emphatic about this.

202 Most women in the first three groups and all in SM stated that UTIs negatively impacted their
203 daily life, affected numerous dimensions like sleep, appetite, ability to move, function and
204 their energy levels. Some women, however, stated barely noticing an impact and “just getting
205 on with it” or taking antibiotics.

206 a. Health

207 Women across all groups spoke about their health being affected with most stating that a UTI
208 added to their other health conditions, worsening the impact on health overall, with some
209 mentioning being unwell, needing hospitalisation and intravenous antibiotics.

210 Some women in the first three groups reported their health being unaffected by UTIs, and a
211 “high pain threshold” being a reason to continue routine activities even if unwell with a
212 presumed UTI.

213 b. Social

214 Most women across all groups, mentioned an impact on social activities. All women in SM
215 described inability to participate in social activities: being unable to travel, practical issues
216 with needing the toilet and avoiding activities involving alcohol intake due to dehydration-
217 related risk of developing UTIs. Women stated watching the type of fluids they drank and
218 what they ate - cutting out fizzy drinks and alcohol with an impact on clothing choice,
219 ensuring they had spare clothing, dark clothing and stating that they needed to frequently
220 change underwear in attempts to avoid UTIs.

221 c. Financial

222 All women in SM reported a huge financial impact: paying for treatments obtained from
223 different sources including overseas, private health care practitioners, travel to Accident &
224 Emergency departments, importing Phage Therapy and travel abroad for treatment of
225 suspected embedded UTIs.

226 A few women in the other groups mentioned the expensive nature of protection used with
227 UTI-related incontinence and medications bought over the counter. However, the income of
228 some was not impacted by this with this being accepted as a part of life.

229 d. Work

230 Women in SM reported work being greatly affected by UTIs, difficulty in focussing at work,
231 working freelance, need to stop working and being on disability benefits.

232 In UG, all women seemed to carry on working even when they had UTIs and were
233 symptomatic. There were conflicting opinions in GP and GG, ranging from work being a
234 struggle, needing time off, reducing, quitting or retiring because of symptoms of UTIs in
235 combination with other health issues while some continued to work, despite discomfort or
236 fatigue.

237 e. Close Relationships, Sexual Activity and Hormonal Medications

238 In the first three groups, some stated being unable to maintain close relationships, while
239 others had no issues with this. Women in SM stated inability to do so because of constantly
240 researching ways to prevent or treat UTIs, perceived lack of empathy and difficulties with
241 treating UTIs.

242 In the first three groups, most felt that having a UTI affected sexual intimacy because of
243 perceived inability due to symptoms. In SM, women attributed recurrent UTIs to sexual
244 activity, stating fear of developing a UTI, planning medications and taking measures to avoid
245 UTIs - voiding and washing after sex, taking medications around sex and worrying about

246 potential symptoms despite this. Some reported a clear halt to being sexually intimate, stating
247 a split from their partners due to this.

248 Avoiding a UTI seemed to also affect some women's choices of contraception with fears
249 about condoms causing or worsening symptoms in all groups. Women expressed worries
250 about taking hormonal medication- for contraception or as Hormone Replace Therapy (HRT)
251 as well as worrying about family members using these. They also worried about
252 exacerbating perceived occurrences of UTIs with the use of hormonal medication.

253

254 3. **Psychological Impact of UTIs** (450 words)

255 Many women across the first three groups and all in SM mentioned psychological impacts of
256 a UTI.

257 a) Anxiety, Stress and Low Mood:

258 Anxiety was a recurrent theme mentioned in all groups and expressed emphatically by
259 women in SM. Anxiety about symptom severity, impact on life, what their symptoms meant,
260 if they had a UTI, would develop one or get unwell with it and having notable accidents at
261 work.

262 Only women in SM described being stressed about which bacteria was causing their UTIs,
263 nature of fluid and food intake and this influencing bacteria in their bladder, lack of reliable
264 testing for UTIs, undergoing special diagnostic tests in the UK and abroad, excessive use of
265 antibiotics, lack of good quality research on CAMs, perceived lack of effective treatment for
266 recurrent UTIs within the UK, needing to travel abroad and being unable to do in the

267 pandemic. They expressed worries about vaccinations against UTIs and how this worked,
268 stress about going on holiday – sanitation abroad, symptoms and management with UTIs,
269 potential consequences, making prolonged plans and carrying enough medications in case of
270 being unable to access appropriate healthcare.

271

272 Women across all groups mentioned feeling low, mental health worsening with a “huge”
273 (SM:4) impact with a UTI.

274 b) Anger

275 All in SM expressed anger for different reasons- at themselves for not seeking timely
276 treatment and blaming this for developing a presumed embedded UTI; with HCPs- GPs for
277 lack of referrals to specialists, specialists for conflicting or inadequate advice, the necessity to
278 be stubborn to find a solution and perceived inadequate counselling before surgical removal
279 of ovaries and the role that vaginal atrophy played with UTI occurrence. They also reported
280 anger at perceived lack of appropriate testing when symptomatic with a negative urine test,
281 being told that they have a mental health problem, being expected to accept being in pain and
282 research in this subject being inadequate due to gender bias.

283

284 c) Fear

285 Women in all groups expressed fear about several possibilities- perceived inability to
286 recognise signs of, prevent and treat UTIs, access services in a timely manner leaving them
287 unwell or their kidneys affected.

288

289 Some women across all groups and all in UG and SM groups mentioned close family
290 members experiencing UTIs, worries over their health, potential hereditary nature and
291 associations with a vaginal delivery or aging. The taboo nature of discussing UTIs within the
292 family was also mentioned.

293 d) Sources for Reassurance

294 All women in SM and some in other groups mentioned finding information on UTI support
295 groups a great source of support because they could freely obtain, share and compare
296 information about preventing and treating UTIs.

297

298 **Discussion** (557 words)

299 This study provides a rare insight into women's perspectives of experiencing UTIs across
300 different settings, having experienced perceived UTIs. It engaged with participants ranging
301 from those who were not bothered by UTIs (some in GP) to women from SM who felt that
302 their life revolved around this.

303 Women in SM reported suffering from frequent and prolonged episodes of UTIs, possibly
304 sought information online or were more severely impacted than women in the other groups,
305 seeming to have extensive knowledge about symptom management, impact on their lives,
306 risk factors, ongoing research and future developments. It also appears that UTI support
307 groups online were a valuable resource although it is impossible to predict information

308 accuracy information and potential biases. It is perhaps necessary, therefore, to explore
309 further the need for ongoing support not available from formal medical services in this group.

310

311 Results from this paper concur with previous literature, although those were in specific
312 subgroups of women making them less generalisable. Diverse symptom descriptions were
313 typical for women with cystitis¹² with recurrent UTIs in older women affecting physical and
314 psychological health, restricting daily life, increasing dependence on access to relief and
315 receiving inadequate care¹³. Women identified UTIs with the word ‘bother’¹⁴ with a Twitter-
316 disseminated survey describing a drastic impact on physical and mental health leading to
317 severe limitations in life activities¹⁵. Recurrent UTIs in people with spinal cord injuries
318 demonstrated distress from perceptions of it as stigmatizing with fear of antibiotic reliance,
319 seeking alternative prevention and management strategies and causing barriers to social
320 participation with adverse effects on quality of life¹⁶. Additionally, women with at least one
321 uncomplicated UTI (uUTI) expressed negative emotions with activities of daily life,
322 relationships, treatment and management approaches, treatment failure and recurrent
323 uUTIs¹⁷. Our study adds to this by including women who had experienced UTIs in the past
324 but were not always seeking treatment for it and provides us with the views of women in
325 different circumstances. The similarity of results despite differences in sample populations
326 and methods of analysis makes this study credible and confirms previous literature in this
327 topic.

328

329 With a study of this nature, transparency with methods and results ensures reliability, validity
330 and authenticity with transferable results. There were limitations with the study, however. As
331 an initial exploratory and descriptive study, this was not designed to be explanatory or
332 completely interpretive given the size and type of methods used. Transcripts were not
333 returned to participants for comments and no feedback was obtained on the findings. While
334 generalisable, it is still not completely representative of women's experiences with UTIs,
335 with unknown clinical histories and natural biases in reporting based on groups recruited
336 from and prior experiences. As women in SM were active online, they might have more
337 access to information when compared to others. Additionally, while there are no prescription
338 charges in Scotland where most participants were based, financial impacts are postulated to
339 be worse in England where these are applicable and possibly being worse still for women in
340 the US with limited access to public health funds.

341 Having a UTI appeared to affect women in a variety of ways, ranging from different physical
342 symptoms, being psychologically affected and this impacting their quality of life. While this
343 research concurs with available literature about this impact, it also adds to it by further
344 expanding on this in women in a range of settings.

345

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394 Abbreviations:

395 GP: General Practice Group

396 GG: General Gynaecology Group

397 UG: Urogynaecology Group

398 SM: Social Media Group

399 Figure Legends:

400 Figure 1: Participants recruitment to study

401