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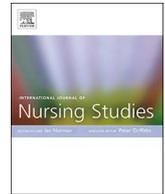
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Participant experiences of clean intermittent self-catheterisation, urinary tract infections and antibiotic use on the ANTIC trial – A qualitative study

Doreen McClurg^{a,b,*}, Kerry Walker^{a,b}, Rob Pickard^c, Paul Hilton^c, Holly Ainsworth^c, Kelly Leonard^d, Sheeba Suresh^e, Annette Nilsson^f, Nicola Gillespie^b

^a Nursing, Midwifery and Allied Health Professions, Research Unit, United Kingdom

^b Glasgow Caledonian University, Room A603 Govan Mbeki Building, Glasgow, G4 0BA, United Kingdom

^c Newcastle University, The Medical School, Newcastle upon Tyne, NE2 4HH, United Kingdom

^d Urology Research Nurse, Addenbrooke's Hospital, Cambridge, United Kingdom

^e Ipswich Hospital NHS Trust, Ipswich, Suffolk, United Kingdom

^f Research & Development, University Hospitals Birmingham NHS Foundation Trust, United Kingdom

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ABSTRACT

Background: Recurrent urinary tract infections are a commonly reported problem in people who use clean intermittent self-catheterisation. Yet there is a lack of knowledge regarding both the impact on people's lives, the use of prophylactic anti-biotics and perceptions of patients on their use.

Aims: To explore the views and experiences of adults who use clean intermittent self-catheterisation for long-term bladder conditions, with a focus on urinary tract infection experience and prophylactic antibiotic use.

Design: A qualitative descriptive study.

Methods: Twenty-six semi-structured qualitative interviews were conducted with individuals recruited from the ANTIC Trial (Antibiotic treatment for intermittent bladder catheterisation: A randomised controlled trial of once daily prophylaxis). Participants were intermittent self-catheter users aged 18 years or older. Interviews took place between August 2015 and January 2016. Transcript data were analysed thematically.

Findings: Three overarching topics were revealed with corresponding themes: the experiences of intermittent self-catheterisation and urinary tract infections (normalisation, perceived burden); attitudes towards antibiotics for urinary tract infection treatment (nonchalant attitudes, ambivalence towards antibiotic resistance); and experiences of low-dose prophylaxis antibiotics (habitual behaviour and supportive accountability).

Conclusion: The emotional and practical burden of catheter use and urinary tract infection was considerable. Beliefs pertaining to antibiotic use were based on utility, gravity of need and perceived efficacy. These opinions were often influenced by clinician recommendations.

What is already known about the topic?

- Patients who use intermittent self-catheterisation are susceptible to urinary tract infections.
- Although sometimes prescribed it is unknown if prophylactic antibiotics would decrease the number of infections that patients experience.

What this paper adds

- Urinary tract infections can add significant health burden to the

patients who undertake intermittent self-catheterisation.

- Although there was some awareness of antibiotic resistance there was varying understanding of their effectiveness and an ambivalent attitude to the use of low-dose prophylactic antibiotics.
- Should efficacy be proven patients would be willing to take prophylactic antibiotics.

1. Introduction

Recurrent urinary tract infections in clean intermittent self-catheterisation users have been reported to affect between 12% and 88% of

* Corresponding author at: Glasgow Caledonian University, Room A603 Govan Mbeki Building, Glasgow, G4 0BA, United Kingdom.

E-mail addresses: Doreen.mcclurg@gcu.ac.uk (D. McClurg), kerrywalker@btinternet.com (K. Walker), robert.pickard@Newcastle.ac.uk (R. Pickard), Paul.Hilton@newcastle.ac.uk (P. Hilton), Holly.ainsworth@newcastle.ac.uk (H. Ainsworth), kelly.leonard@addenbrookes.nhs.uk (K. Leonard), sheeba.suresh@ipswichhospital.nhs.uk (S. Suresh), Annette.Nilsson@uhb.nhs.uk (A. Nilsson), Nicola.Gillespie@gcu.ac.uk (N. Gillespie).

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cohorts and does not seem to be related to frequency of use, type of catheter or use of meatal wipes (Di Benedetto, 2011; Bolinger and Barriers, 2013; Wilde et al., 2018). In clinical practice, symptomatic and/or microbiology proven urinary tract infection are typically treated with an antimicrobial regimen to treat the bacteriuria (Bolinger and Barriers, 2013). Research has identified once daily low dose antibiotic prophylaxis as an effective preventative strategy for people who suffer from recurrent urinary tract infection without retention (NICE, 2003; Morton et al., 2002; Albert et al., 2004). Yet there is currently lack of unequivocal evidence for effectiveness in clean intermittent self-catheterisation users who suffer recurrent urinary tract infection (Niel-Weise and van den Broek, 2005; Wyndaele et al., 2012) and although there are studies that have examined patient experiences' of clean intermittent self-catheterisation (Bolinger and Barriers, 2013; Wilde et al., 2018; Cobussen-Boekhorst et al., 2016) there are no qualitative studies specifically focussing on the effect urinary tract infection have on such patients or on their perceptions of antibiotic treatment. Such an investigation would help understand patient self-care for urinary tract infection and adherence to clinical antibiotic recommendations.

1.1. Aims

This paper sits within a larger body of research, which aims to establish whether low-dose antibiotic prophylaxis lead to improved patient outcomes in adult clean intermittent self-catheterisation users in a routine care setting (Niel-Weise and van den Broek, 2005). Here we report on the qualitative sub-study of the randomised controlled clinical trial. The aims were as follows.

1. To add to the current literature that describes patient experiences of both clean intermittent self-catheterisation and urinary tract infection
2. To explore participant's perceptions of and attitudes towards antibiotic regimens for urinary tract infection treatment
3. To describe the perceived effectiveness of low-dose prophylactic antibiotics for urinary tract infection treatment.

2. Methods

2.1. Design

A qualitative descriptive approach was adopted, using in-depth tape-recorded interviews over the telephone. Semi-structured interviews were used to allow for flexible data collection and to capture variation in responses and interpretations of the research topic. This aligned with the aims of the study, which were to qualitatively explore the nuances of human experience.

2.2. Setting

Participants were recruited from the ANTIC trial (Brennand et al., 2016) in the period of August 2015 to January 2016. This included primary and secondary care settings across seven locations in the United Kingdom.

2.3. Participants

Convenient sampling was used to recruit participants from both the prophylaxis and non-prophylaxis arms of the larger ANTIC randomised controlled clinical trial. Twenty-six individuals were interviewed, 15 females and 11 males, with median age of 56.5 (range 25–81) years (see Table 1). Reasons for using clean intermittent self-catheterisation included neurological bladder, prolapsed intervertebral disc, and urinary retention. Time using clean intermittent self-catheterisation ranged from 2.5 years to 26 years (median: 8.5 years).

Table 1
Descriptive characteristics of study participants.

Participant	Sex	Age (years)	How long using CISC (years)	Reason use CISC	Study arm
1	M	54	5	Spinal injury	P
2	M	54	2	MS & spinal injury	NP
3	F	50	7	MS	P
4	F	59	4.5	Urinary retention & ulcerated colitis	NP
5	F	54	15	MS	NP
6	F	72	3	Urinary retention	P
7	M	68	2.5	Urinary retention	NP
8	F	46	10	MS	NP
9	F	29	26	Spina Bifida	P
10	M	57	3.5	MS	P
11	F	53	5.5	MS	P
12	F	64	7	Urinary retention/ stress incontinence	NP
13	F	48	2.5	Urinary retention	P
14	M	67	2.5	Urinary retention	P
15	M	62	5	Urinary retention	P
16	F	51	3	Prolapsed intervertebral disc	P
17	M	63	14	Nerve damage from spinal column	NP
18	F	81	3	Urinary retention	NP
19	M	51	3	Transverse Myelitis – paralysed from C6 down	P
20	M	53	26	Spina Bifida	P
21	M	71	2	MS	NP
22	F	69	4	MS	NP
23	F	63	10	Urinary retention post hysterectomy	P
24	F	35	26	Spina Bifida (Mitrofanoff)	P
25	M	71	9	Prolapsed intervertebral disc	P
26	F	25	20	Mitrofanoff	NP
Average	F: 15 M:11	56.5	8.5		P: 15 NP: 11

Notes P denotes prophylaxis, NP denotes no prophylaxis.

2.4. Data collection

Interviews were semi-structured in nature, informed by a topic guide used to prompt responses pertinent to the research aims (Appendix A, Supplementary material). This included the experience of using clean intermittent self-catheterisation, the impact of urinary tract infection, health beliefs concerning antibiotics, and the experience of taking part in the ANTIC Trial (see Appendix B, Supplementary material). KW conducted all interviews via private telephone at a time that was convenient to the participant. Interviews were audio-recorded and fully transcribed, with an average duration of 35 (17–59) min. All transcripts were checked for accuracy by KW and any identifiable information was removed prior to analysis.

2.5. Data analysis

Data were managed used NVivo v.10 software (QSR International Pty., Ltd., 2012) and analysed thematically following the six phases outlined by Braun and Clarke (Braun and Clarke, 2006). This included familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun and Clarke, 2006). Team meetings (KW, JC and DM) were held regularly to discuss the analytical process and refine key themes until consensus was reached. No participants were involved in the analysis process.

2.6. Ethical considerations

This study was approved by the North East Tyne and Wear South NHS Research Ethics Committee (Ref: 13/NE/0196). Participants consented to the qualitative sub-study at the same time as consenting to the main randomised controlled clinical trial, both verbally and in writing. Consent was reconfirmed verbally when the qualitative researcher (KW) made first contact. Participants were assured that their personal information and interview responses would remain confidential and anonymised. It was made clear that they could withdraw from the qualitative study at any time and this would not affect their clinical care or involvement in the main randomised controlled clinical trial.

2.7. Findings

Within the text participants are represented by their interview number, gender and study arm respectively. **P** indicates that the participant was in the intervention arm of ANTIC trial (receiving low-dose prophylaxis antibiotics), and **NP** denotes the control group, or non-prophylaxis arm.

The emotional and practical burden of clean intermittent self-catheterisation and Urinary tract infection was variable yet significant in participants' lives and influenced their perception antibiotic use. The findings will be presented within three broad categories; experiences of clean intermittent self-catheterisation and urinary tract infection; attitudes towards antibiotics for treatment; and experiences of low-dose prophylaxis antibiotics.

2.8. Experiences of clean intermittent self-catheterisation and urinary tract infection

2.8.1. Normalisation

A key contributor to the theme of normalisation was the length of time taken to psychologically adapt to using clean intermittent self-catheterisation daily. In general, participants acknowledged a change in perspective towards clean intermittent self-catheterisation from initial use to how they felt following a period of time (and/or at time of interview). This prolonged period of adaptation was often preceded by initial psychological resistance.

“At first, I didn't like them. It took me a wee while to get used to what you're actually doing. I would say it can take as much as a year before you're comfortable – it takes a while to find your niche I think. Now, they're just an absolute life-saver, its wonderful!”

Participant 3, Female, P.

A number of participants attributed their immediate aversion to clean intermittent self-catheterisation to lack of knowledge about their bodies and the clean intermittent self-catheterisation process.

“I wasn't [okay with intermittent self-catheterisation] because I had no idea what was involved. But now I'm much more comfortable with it, I'm very patient with the process... I'm never silly about it and it's a question of just relaxing you know, and not worrying about it.”

Participant 7, Male, NP.

Alongside the interaction of co-morbidities and aversion to clean intermittent self-catheterisation in general, Participant 16 also expressed the impact of using clean intermittent self-catheterisation on her intimate relationships. She described threats to her self-esteem as a direct consequence of using clean intermittent self-catheterisation; factors that proved challenging to overcome.

“I think the biggest issue that both of us have, is that we had a really good sex life before and that has been affected massively because obviously hygiene is paramount and if my back's not good and with catheterising, oh it's just awful really. They [catheters] irritate my

skin so I get sore skin as well. So if you're having intercourse and your skin's broken you've got all that worry as well as all that pain, so that's difficult. It's just like not one little thing, it's a few things together”

Participant 16, Female, P.

Participants detailed a range of experiences in relation to the gravity of impact of using clean intermittent self-catheterisation in their daily lives. There was a strong sense of considering the process of clean intermittent self-catheterisation as 'normal' which led to perceived acceptance of clean intermittent self-catheterisation as a bladder management tool. Many participants believed it to be no greater burden than the way other people who do not use clean intermittent self-catheterisation pass urine and felt that using clean intermittent self-catheterisation had not changed their self-image. Clean intermittent self-catheterisation was labelled as 'just one of those things.'

“You just get on with it. To me, it's just the same as going to the toilet. I don't think about it really.”

Participant 13, Female, P.

Positive appraisal of clean intermittent self-catheterisation intensified the perception of normalisation and eased both the physical and psychological burden of urinary problems. A number of individuals noted that introducing clean intermittent self-catheterisation had led to increased independence and personal autonomy over their long-term bladder condition. Two males were able to return to employment following clean intermittent self-catheterisation initiation and cited benefits such as increased financial security and increased self-esteem.

“[clean intermittent self-catheterisation] has changed me altogether; it changed my life. In the first week I says 'this is brilliant, best thing since coloured tellies came out, this is great, I can do what I want to do'. I don't have a problem with it.”

Participant 2, Male NP

The concept of normalisation was also closely linked to participants developing confidence and establishing routines with clean intermittent self-catheterisation. Incorporating the practicalities of clean intermittent self-catheterisation within their lifestyle enhanced psychological adjustment and often encouraged a favourable attitude towards the process. For many, this was characterised by a pragmatic and organised approach to daily living, to help protect against potential inconveniences whilst being mindful of their own abilities.

“I just take some [catheters] with me; it [clean intermittent self-catheterisation] doesn't prevent me from getting out and about.”

Participant 19, Male, P.

Although participants generally displayed psychological adjustment to clean intermittent self-catheterisation, there were also some that perceived it to pose a negative impact on their lives. Examples included impeding their ability to enjoy social activities and relax with friends, and avoiding going abroad. One participant expressed his concerns at staying away from home due to the potential embarrassment at disclosing clean intermittent self-catheterisation use and associated pragmatism.

“The biggest thing is, it's [clean intermittent self-catheterisation] fine at home, it's just a real pain when you're not at home. I loath to have to stay overnight cause it's more of a hassle both for you... you don't want to talk to your hosts about it, but you need reasonably unencumbered access to a bathroom for yourself.”

Participant 15, Male, P.

2.8.2. Perceived burden of urinary tract infection

Experiencing urinary tract infection was reported as intrinsic to living with bladder problems and using clean intermittent self-catheterisation. Symptoms were perceived on a spectrum of severity

depending on the individual, the frequency of Urinary tract infection and perceived disruption in everyday life. One participant described the personal burden of having a urinary tract infection and the challenges to treatment provision.

“... well firstly it’s [experiencing a urinary tract infection] a bit debilitating, and secondly it’s a bit depressing, you know, psychologically it’s not good for you. It’s also just a hindrance trying to get a doctor’s appointment, it’s quite a hassle, you can’t guarantee you’re going to get it that quickly and then you’ve got to wait to get the antibiotics, so yeah it’s just a hassle.”

Participant 15, Male, P.

A number of participants implied that because urinary tract infections were so prevalent in their lives, they were highly attuned to the preliminary stages and symptoms of urinary tract infection. For some, this included normalising the feeling and experience of urinary tract infection such that they did not perceive them to impact their lives to a great extent; “a bit uncomfortable, but not debilitating” (Participant 14, Male, P). For these individuals, the experience of urinary tract infection had been internalised as ‘normal’ and a likely consequence of their bladder problems and/or co-morbidities. Having a urinary tract infection, or indeed, the potential of having a urinary tract infection, did not seem to impede upon being social, going on holiday or other parts of their lifestyle.

For others, having a urinary tract infection was perceived to have an adverse and restrictive impact on their lives. One participant explained that having a urinary tract infection can trigger a relapse of his MS, whilst others commented on the inconvenience of public toilet availability. One male and one female voiced the impact of urinary tract infection on their relationships, which included the challenges to intimacy and expression of sexuality.

“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.”

Participant 20, Male, P.

2.9. Attitudes towards antibiotics for urinary tract infection treatment

2.9.1. Nonchalant attitude

Participants described a range of attitudes towards antibiotics and taking antibiotics. However, many reported feeling ‘fine’ about taking them with an overarching nonchalant (i.e. unworried) perspective. Antibiotics were perceived as favourable in certain circumstances, particularly if they achieved the desired results or they were deemed necessary by medical professionals.

“You just do it [take antibiotics]. If the results achieve what you want it to then you’ll do it.”

Participant 3, Female, P.

“The more infections I was having the more inclined I would be to do it...” (15MP)

Participant 15, Male, P

and

“like a lot of people yes you’re thinking of the longer term but at the same time you want the now to be the best you can... never know what’s around the corner.”

Participant 14 Male,

Though a relaxed attitude towards taking antibiotics was common, many participants professed that they did not wish to take antibiotics unnecessarily. Instead, they preferred to trust medical opinion and rely on health care professionals to assess the gravity of need for antibiotic

treatment. Alternative self-management strategies for Urinary tract infection were drinking more water, cranberry juice, or waiting to see if symptoms worsened.

2.9.2. Ambivalence towards antibiotic resistance

“I’m not one of those people that worries about taking too many tablets. If it works, I’ll take them.”

Participant 13 Female, P

Participants conveyed mixed awareness and understanding of the concept of antibiotic resistance. A number of participants thought that ‘over-using’ antibiotics was unwise as it could reduce their future effectiveness. The possibility of the body becoming immune or resistant to antibiotics deterred some participants from taking antibiotics, though a minority did express strong concerns specific to the hypothetical development of bodily resistance.

“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.”

Participant 7, Male, NP.

Participant 14 elaborated by saying that he would rather take low dose prophylactic antibiotics than a high-dose course as he prefers the thought of preventing infections as opposed to treating them. A number of individuals reiterated this notion of ‘little but often’ and disclosed a positive perception of prophylaxis.

2.10. Experience of low-dose prophylaxis antibiotics

2.10.1. Habitual behaviour

For those taking prophylaxis antibiotics, there was a general sense that this behaviour had become automatic and part of an established routine. Many participants were already taking medications for co-morbidities and so taking another tablet became an adjunct behaviour. ‘Adding on’ another tablet was perceived as trivial and relatively straightforward and there was a general sense that participants did not perceive this to be a challenge or pose any difficulties.

“I just took it in the morning before I went to work; it was only one a day.”

Participant 13, Female, P.

Another mechanism for incorporating prophylaxis consumption into daily life was by exploiting already habitual behaviour. Examples include taking at breakfast time or before going to sleep at night. Some participants relied on partners to ensure that the prophylaxis was taken each day.

“I’ve got 18 tablets a day so she’s [wife] got them all morning, afternoon, evening, tea time. And she moans if I miss them.”

Participant 2, Male, P.

A minority of individuals confessed to occasionally forgetting to take the prophylaxis. These lapses were often attributed to mitigating circumstances such as fluctuating work patterns and lifestyle choices, alongside sheer forgetfulness. Not remembering to take the prophylaxis did not seem to cause concern or endure over time, but instead was assumed as a natural event of a year-long commitment such as the ANTIC trial.

2.10.2. Supportive accountability

Adhering to the prophylactic antibiotics in ANTIC was aided by the perception of supportive accountability. Participants enjoyed having the support of ANTIC researchers and research nurses at their disposal, and often cited them as helpful, informative and friendly.

“I was on it [ANTIC trial] a year and it was as if someone was listening to me. And it was nice that they kept a check on me every

three months.”

Participant 21, Male, NP.

Participants also cited curiosity and personal altruism for continuing with the ANTIC trial, such that adhering to the protocol was perceived as “giving something back” and “helping others” that may be in a similar situation. A minority also professed that they were eager to see if prophylaxis antibiotics helped them personally by means of reducing urinary tract infection incidence.

3. Discussion

The findings demonstrate the variation of physical and psychological impact perceived amongst clean intermittent self-catheterisation users and support previous literature that has shown clean intermittent self-catheterisation to contribute to a positive perception of quality of life and enhanced self-dignity and self-esteem (Shaw and Logan, 2013; Shaw et al., 2007). The dynamics of how participants both perceived clean intermittent self-catheterisation and psychologically adapted to this form of bladder management, was linked to a variety of factors such as reasons for clean intermittent self-catheterisation, frequency of clean intermittent self-catheterisation, lifestyle, age and gender. This often had a direct impact on their perception of quality of life, either restoring, maintaining or damaging. These findings draw parallels to previous research that proposed two subcategories of positive and negative impacts on quality of life of using clean intermittent self-catheterisation (Edokpolo et al., 2012). In the present study, all aspects of quality of life that were discussed (whether favourable, neutral or negative), contributed to a general sense of normalisation of clean intermittent self-catheterisation and the process of acceptance, adaptation or maladaptation to the intricacies of using clean intermittent self-catheterisation.

However, there were some individuals for whom this psychological distress persisted over time, or at least to the time of interview. Despite accruing 4–15 years of experience with clean intermittent self-catheterisation, these individuals perceived clean intermittent self-catheterisation as a heavy burden (both practically and psychologically), and engaged in avoidance strategies such as decreasing water intake.

Though rates may vary depending on individual circumstances, previous research has demonstrated that incidence and experiences of urinary tract infection symptomatic episodes to be common in those who use clean intermittent self-catheterisation (Bolinger and Barriers, 2013; Wilde et al., 2018; Albert et al., 2004). Our findings validate the variety and magnitude of urinary tract infection symptoms, alongside the recorded incidence of urinary tract infection, can present a challenge to many individuals who use clean intermittent self-catheterisation and experience recurrent urinary tract infection. The experience of urinary tract infection was often perceived as a burden to lifestyle, working life and social life, particularly within those who experienced more than one per month. Yet, psychological distress from recurrent urinary tract infection remained individualised, with a spectrum of connotations from ‘an inconvenience’ through to ‘untenable’ and ‘depressing.’ Availability of medical assistance and appropriate antibiotics complicated short-term psychological distress until symptoms were eased.

Another aspect that was important to this specific population concerned the interaction of urinary tract infection incidence and exacerbation of co-morbidities. Though some participants described the positive impact that clean intermittent self-catheterisation had on their lives, others discussed the negative aspects, particularly when considering the urinary tract infection incidence and exacerbating co-morbidities.

Urinary tract infection relapses made clean intermittent self-catheterisation more of a challenge and were particularly pronounced in the early stages of developing a urinary tract infection. This may have implications for HCPs who wish to provide patient-centred care and

support those with neurological diseases and bladder problems, as though clean intermittent self-catheterisation can positively transform some lives, those with comorbidities may experience additional and unforeseen difficulties.

This study enhances understanding of views on, and attitudes towards, the use of antibiotics specific to urinary tract infection treatment and prevention in those who use clean intermittent self-catheterisation and suffer recurrent Urinary tract infection. Participants seemed unconcerned at the concept of taking antibiotics for urinary tract infection treatment when considering ‘on an as needed basis’. Discrepancies lay in the circumstances in which this was appropriate and whether high dose versus low dose were ‘more beneficial’. For those in the prophylaxis arm of the main randomised controlled clinical trial experiencing a reduction in urinary tract infection incidence and symptom severity altered their perspective on low-dose antibiotics such that there was a positive trend towards agreeing with using prophylaxis long-term to prevent future urinary tract infection episodes. These findings highlight that positive perception of low-dose antibiotics may be related to positive health experience i.e. reduction in urinary tract infection incidence and urinary tract infection symptom severity. This study is the first to consider public opinions on, and experiences with, low-dose prophylactic antibiotics. However, the attitudes and perspectives of antibiotics presented here are specific to a population that may have normalised perceptions of antibiotic use, due to the high incidence of recurrent urinary tract infection and thus gravity of antibiotic need.

Despite fears concerning bodily resistance in regards to repetitive antibiotic use, our participants conveyed ambivalence or mixed feelings when discussing antibiotic resistance in that anti-biotics had to be used when there was a urinary tract infection present. This aligns with previous research which has shown a sample of the general public to have concerns about the adverse effects of taking antibiotics (Norris et al., 2013; Brooks et al., 2008) with some demonstrating aversion to taking them but when necessary took them with resignation rather than enthusiasm. The present study highlights that those who use clean intermittent self-catheterisation and experience recurrent urinary tract infection deem low dose prophylactic antibiotics as acceptable, and may even prefer this option to taking high dose antibiotics when an infection occurs.

Fears concerning resistance complicated whether individuals were happy to take antibiotics longer term, however differences in advice given by different clinicians obscured these perceptions further. This draws parallels with previous research that demonstrated uncertainty in primary care patients specific to the nature, cause and implications of antibiotic resistance (Gardner, 2015). Moreover, participants in the present study did not regard the potential risks of antibiotic use to influence their present behaviour in terms of using antibiotics prophylactically, implying a psychological distance from the problem. This has important implications for prescribing practice such that health care providers have a duty to individualise care and support those who may prefer to take low-dose antibiotics.

Adhering to once-a-day low-dose antibiotics exploited mechanisms of habit formation in this population. Habits are learned dispositions to past behaviour and are triggered automatically by environmental cues (Gardner, 2015). We found participants in the present study to link in with pre-existing behaviours (e.g. having breakfast or getting ready for bed), to trigger taking their once daily prophylaxis consumption. Lally et al. (2011) have also demonstrated existing routines to be particularly conducive to embedding new behaviours due to the predictability and stability of these patterns and also reducing the cognitive effort required to perform. By exploiting the automaticity of an already ingrained behavioural pattern, participants in the present study successfully extended their existing habits with the adjunct behaviour of taking an antibiotic.

Despite the variation in, impact of, and gaining access to low-dose antibiotics, participants felt generally positive about their experience on the ANTIC trial. Research has shown that when individuals gain

personal evidence of medication effects, they are more likely to view it as favourable (Brown and Bussell, 2011). This in turn encourages their motivation to continue with this treatment (Michalak et al., 2004). Support provided by clinicians or coaches via telephone and internet platforms have also been shown to enhance adherence (Christensen et al., 2009; Mohr et al., 2011). The assumption is that though high levels of intrinsic motivation encourages adherence to treatment, extrinsic ‘help’ is also often required (Tate, 2006). In the present study, the three monthly appointments were often perceived as beneficial and may have fostered internal motivation to adhere to treatment; both in respect to once daily prophylaxis and also the general protocol for non-prophylaxis patients. Human support in studies has been shown elsewhere to enhance adherence more so than automated systems (Fry and Neff, 2009).

3.1. Limitations

Interviewing participants in a trial of antibiotic use may have meant we interviewed a select group of participants who held particularly positive or negative views about the use of prophylactic antibiotics. In addition, although the participants in this study included a range of socio-economic positions and ages, it cannot be assumed these experiences and opinions to be universal across all individuals who use clean intermittent self-catheterisation and experience recurrent Urinary tract infection. Furthermore, it should be noted that the study only included clean intermittent self-catheterisation users who suffer from repeated Urinary tract infection and thus their opinion of benefit from clean intermittent self-catheterisation use may not be the same as those who do not suffer repeated Urinary tract infection. It is also possible that only those who perceived a positive experience on the AnTIC trial were motivated to participate in the interviews. Relying on retrospective recall for descriptions of clean intermittent self-catheterisation experiences, urinary tract infection events and antibiotic usage may not provide a true representation of real time perceptions. The qualitative interviews were undertaken in the first 7 sites to have participants completing their follow-up assessments and who had agreed to be interviewed and were selected on gender, age and group allocation. A final limitation could be the narrow sampling framework for the participants, as they were not sampled according to site, adherence, non-adherence, or length of clean intermittent self-catheterisation use. However, taking the main trial demographics into consideration, we believe that the qualitative sub-study did interview a good variation of participants.

4. Conclusion

The emotional and practical burden of clean intermittent self-catheterisation and urinary tract infection was considerable in participants’ lives. The process of psychological adjustment to clean intermittent self-catheterisation and urinary tract infection was complex, characterised by cognitive, attitudinal and situational factors. Participant accounts detailed acceptance around taking and using antibiotics for recurrent urinary tract infection. A minority of individuals felt concerned at using antibiotics prophylactically, particularly in relation to negatively impacting potential future effectiveness, however most were willing to use prophylactic antibiotics if it reduced the number of urinary tract infections and said they felt that living well today was important. These attitudes impacted their behaviour towards taking antibiotics, either prophylactically or not, and were also influenced by HCP recommendations. The findings of this qualitative study should be interpreted alongside the results of the main ANTIC Clinical Trial (Brennand et al., 2016).

Conflict of interest

None of the authors have conflicting interests to declare.

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Ethical approval

North East Tyne and Wear South NHS Research Ethics Committee (Ref: 13/NE/0196).

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.ijnurstu.2018.01.012>.

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