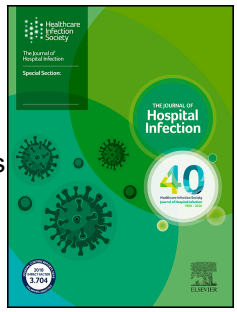
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Patient perspectives of healthcare associated infection: "You don't know what impacts it will have on your life".

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Title: Patient perspectives of healthcare associated infection: "You don't know what impacts it will have on your life".

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Abstract

Background: Healthcare associated infections (HAIs) are not present on admission but contracted while a patient is undergoing hospital treatment. While the prevalence of HAIs, their causes and treatments have been researched in varied contexts to date, the patients' perspectives of contracting and living with the consequences of HAI remains under-researched.

Objective: To explore the patients' experience of having an HAI.

Methods: We conducted a qualitative phenomenological study which drew on data from semi-structured interviews to explore the lived experiences of patients who had recently contracted an HAI while in hospital. Participants were recruited from two Australian hospitals during 2019 and 2021. Telephone interviews were conducted with ten participants by two research team members and transcripts from these interviews were qualitatively analysed using a thematic coding process to identify the patients' perspectives of contracting an HAI.

Results: The participants had a range of different HAIs. The participants described how the experience of having an HAI can be very isolating and distressing from the patient perspective, with life-long implications. This contributes to our understanding of the way in which patients are impacted emotionally and mentally as a result of contracting an HAI.

Conclusion: There is a need for improved, person-centred communication about the source, treatment, and prognosis of HAIs. The findings from our study indicate the importance of considering patients' voices in their own health care.

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Patient perspectives of healthcare associated infection: "You don't know what impacts it will have on your life"

Introduction

As many as one in ten patients will contract a healthcare associated infection (HAI),[1] yet little is known about the impact of HAIs from the patients' perspective. Improving a holistic understanding and knowledge about patient perspectives of HAI, including impacts on their physical, mental and emotional health, is essential for informing patient-centred healthcare and evidence-based practice.[2]

Research conducted over the past decade indicates that a patient's understanding of and involvement in the care, surveillance, and prevention of HAIs in general is one which should be increased.[4-6] A systematic review conducted by Currie and colleagues synthesised data from 17 studies, spanning five countries and found that "all forms of HAI led to adverse consequences on patients' social lives and relationships" but their work did not extend knowledge of patient perspectives of contracting an HAI.[3] By engaging patients more fully in their own care, this approach may increase their understanding, impacting their confidence in their health-care professional.[7-9]

Our study aims to help address calls from previous researchers to improve the care of patients with HAIs by attending to their sociocultural contexts in conjunction with their clinical treatment. The research explores the experience of patients with different HAIs in hospitals from outside Europe and the US.

Methods

Design

This qualitative phenomenological study draws on data from semi-structured interviews to explore the lived experiences of patients who had recently contracted an HAI while in hospital.[10] In situations where little is currently known about participants' perspectives, qualitative research methodologies can provide an emic (insider's)

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understanding of complex social phenomena.[11] This qualitative approach focuses on the patients' lived experiences of developing and living with HAIs and provides insight into the way patients respond to and make decisions about their own healthcare, and how they relate to healthcare professionals, family members and wider social networks. Additional information regarding the design and methodological approach is provided in the supplementary material.

Research aim and questions

By consulting a number of patients who had recently contracted an HAI, this study aimed to identify key themes of the patient HAI experience, and gain insights from them into how management of HAIs might be improved. The following research questions sought to address the aim of the study:

1. What were the experiences of patients recently affected by HAI?
2. What effect has the HAI had on patients' health and their daily lives, since discharge from hospital?
3. How well did patients feel they coped with having an HAI, and what could have helped improve coping responses?
4. What, if anything, could improve the care provided to patients experiencing an HAI?

Setting and participants

Participants were drawn from two hospitals, one from New South Wales and one from Tasmania, Australia. These two publicly-funded hospitals have approximately 400 overnight beds each, provide elective and emergency treatment and have an intensive care unit. Participants who recently contracted an HAI from one of these hospitals were eligible to participate. Those with cognitive impairment and/or who were under 18 years of age were excluded from the study. A non-probability sampling method was used to invite participants to contribute to this study. An infection control professional (Registered Nurse) in the participating hospitals identified potential patient participants and independently confirmed that each participant had an HAI. National and internationally recognised criteria for defining an HAI were used.[12,13]

The recruitment process involved each infection control professional at each site, identifying patients who acquired a HAI. The identification of patients with a HAI was undertaken using their existing continuous surveillance processes. When a patient with a HAI was identified, the infection control professional provided the potential patient participants with: 1) information about the research project; 2) an invitation to participate in the study; and 3) a consent form to indicate the patient's willingness to participate in the study. If a patient agreed to provide an interview, their contact details were forwarded to the research team.

Participants were interviewed within three months of hospital discharge (i.e., post-discharge) at a time convenient to them. A maximum timeframe of 12 months since acquiring the HAI applied to reduce the risk of recall bias and to increase the researchers' ability to confirm the patient had an HAI diagnosis. Recruitment of participants occurred between January 2019 and June 2021. The timeframe for recruitment was impacted and interrupted by the COVID-19 pandemic. During 2020, research at hospitals was suspended in addition to the research team having other competing COVID-19 priorities and commitments.

Data collection process and instrument

Telephone interviews (n =10) were conducted by two team members who were experienced interviewers and experienced in qualitative research. Interviews occurred between October 2019 and July 2021 and each interview ranged from 13 to 57 minutes in duration (total 297 minutes; average 30 minutes per interview). A further two patients gave consent to participate in an interview, but subsequently withdrew from the study due to health issues.

A semi-structured interview guide was used to ensure consistency between interviewers. The interview guide also provided interviewers with prompts and suggestions for how to promote interviewee responsiveness (see supplementary material). Interviews were audio recorded and transcribed verbatim. All patients were assigned a randomly chosen pseudonym to protect patient confidentiality. The interview transcripts were read for accuracy and de-identified; and individual responses to each research question was

collated, before being imported into qualitative data analysis software (NVivo, QSR V.12 Plus) for data management, coding and analysis.

Data analysis

All interview data were initially organised under four key topics which reflected the focus of each research question. Within each of the topic-focused data pools, the data were thematically coded using a thematic analysis approach,[14,15] to identify the patients' perspectives about the topics encompassed in this study's purview; that is, patients' experiences of contracting an HAI, perceived effects of HAIs on patients' health and daily lives, patients' views about coping with having an HAI and patients' ideas about how their care could have been improved. As such, four thematic analyses were conducted to identify themes present in each pool of data that was categorised by topics in each of the research questions. To ensure the participants' intentions in their original comments were retained, *in vivo* codes (reflecting the spoken words of the participants) were attached to selected subthemes within the data.[16] Data saturation was deemed to have been achieved when no new themes or nodes were identified under each of the major themes (informed by the topics of the research questions), and the research questions were satisfactorily answered. The use of qualitative data analysis software (NVivo©) provided an accessible audit trail of coding decisions for peer review and discussion within the research team, thus enhancing rigour of the research process. Additional information regarding data analysis is provided in the supplementary material.

Participants

The ten participants in this study (6 males; 4 females) were all aged 18 years and over; mostly married (n=6), retired (n=5), self-employed (n=2), or not currently working (n=3). All participants in the study were recently discharged from hospital. All had been

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diagnosed with an HAI. The primary HAIs contracted by the participants were bacteraemia (n=4), urinary tract infection (n=2), surgical site infection (n=2) and soft tissue infection (n=2). One participant acquired pneumonia in addition to a surgical site infection.

Ethics approval

Ethics approval was granted by the Avondale University's Human Research Ethics Committee on 21 February 2019 [Ref. no. ETH.2019.002], the Tasmanian Health and Medical Research Ethics Committee on 9 May 2019 [Ref. no.: HOO18020] and the Northern Sydney Local Health District [Ref. no: 2019/ETH13984].

Results

The results of this study provide insight into the patients' lived experiences of having, responding to and being impacted by an HAI. By thematically coding their responses a deeper understanding was gained of the patients' experiences of contracting HAIs across a wider range of contexts than has been reported to date. The results below are presented, firstly, within a structure according to each of the topics represented by the study's four research questions and, secondly, to reflect the themes identified in the participants' interview comments about their HAI experiences. To ensure the participants' voices are authentically reported, a number of direct quotes from the raw data are included to further illustrate the themes evident in the interview data. Details on the participants gender is provided in supplementary material.

Key topics and emerging themes

Four key themes were identified from the data analysed (see Table 1 and supplementary material), including: 1) contracting a HAI; 2) impact of contracting a HAI; 3) coping with an HAI; 4) suggestions for improving the management of patients who contract HAIs. These themes were interrelated, for example, the patients' perspectives about their experience of having an HAI (subthemes: communication; centrality of care) influenced the way in which they felt they coped with having an HAI (subthemes:

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belief, trust and being accountable; lost in the system) and patient perceptions about how best to improve management of HAI (subtheme: communication breakdown). In many cases, patients described their physical health in conjunction with commentary about their feelings, suggesting holistic self-reported observations about their own health.

Topic 1: Contracting an HAI

When participants were asked about their experience of recently contracting an HAI, their comments reflected three key themes:

1. the *processes* associated with contracting the HAI and being treated for the HAI;
2. how they were *cared for* – physically and emotionally; and
3. *communication* by those around them, especially in relation to receiving information about their illness/es.

Patients perceived the experience of contracting an HAI as a process, beginning with the initial infection, followed by rapid declines in physical and psychological health. Despite contracting an HAI, Participant 1 and Participant 2 were not particularly negative about their experience. While acknowledging the disadvantages of contracting an HAI, not all participants were accusatory about the cause of their HAI. For example, Participant 2 endured two separate hospitalisations for his HAI, 5-6 months apart, which he described as "bad luck … they try very hard to keep infections away" (Participant 2).

Central to the patient's HAI experience was whether they felt cared for, listened to and believed when voicing their concerns. They felt their medical and personal treatment was important, thus highlighting the value they placed on their physical *and* emotional wellbeing. They commented on receiving adequate pain relief, receiving support for dealing with the effects of HAI-related incontinence, and the availability or lack of availability of nursing staff and how this impacted on the patients themselves (i.e., patients not "left alone"). Patients observed that nurses were understaffed and too busy to provide care, or that patients were rushed through the system, despite needing further

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treatment. For example, Participant 3 believed he was sent home prematurely and, according to his parents, was clearly "not right".

The participants in this study reported that communication of relevant information was fundamental to how they made sense of their HAI experience. Placed in an induced coma, it was only during his post-recovery stage that Participant 4 was "pasting things together". Participant 5 and Participant 3 felt they were well informed; but other patients (Participant 8, Participant 7, and Participant 6) received limited information about their HAI which caused concern, distress and, in one case, regret. Participant 6's HAI proved difficult to treat, despite implant replacement surgery. Had Participant 6 been told metal implants posed risks of bacterial adhesion, he reported that he may have decided against having the implant.

Topic 2: Impact of having an HAI

Participants reported wide-ranging impacts on their health and daily lives, as a result of contracting an HAI. Their comments were categorised into three themes. Varied impacts were described as:

1. physical, psychological and emotional impacts;
2. temporary and ongoing impacts; and
3. social and financial impacts.

The impacts of having an HAI, as described by patients, ranged across varied aspects of their lives – social, emotional, financial, family-related, psychological and physical. Temporary patient impacts associated with contracting an HAI were diverse, including: extreme and debilitating pain, disorientation, psychological and emotional distress, loneliness and uncertainty, uncontrollable diarrhoea, nausea, unplanned surgical procedures, and disruptions to family schedules. Other effects were more ongoing, and in some cases still unresolved, several months later. For example, Participant 6, Participant 2, Participant 4, and Participant 7 all reported disrupted routines due to insomnia, tiredness, and lack of strength. Participant 7 was "very weepy", still reeling from the impact of the HAI on her health and household finances. Participant 2, who

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was self-employed and unable to work due to his illness, described having "moments of despair", but refused to dwell on these.

Both Participant 10 (awaiting organ transplant) and Participant 8 were now fearful about the possibility of future HAI acquisition; and Participant 8, Participant 7, and Participant 6 all reported ongoing urinary incontinence and diarrhoea. For Participant 6, this meant being careful not to "go too far for too long" (Participant 6). Participant 6's daily activities remained severely hampered as a result, even down to the loss of important social and household roles. Participant 3 and Participant 2 had likewise reported feeling they had lost their independence, including their driving ability, due to the HAI.

Many of the impacts described by the participants were multiple and related. For example, a physical consequence of having an HAI (e.g., incontinence) could impact on a person's social life if they chose not to engage in social events because they felt trepidation about being too far away from a bathroom. Thus, while the patients' reported separate and distinct effects of contracting an HAI, they also offered commentary about the interplay of these effects and lamented how the result of these multiple effects impacted negatively upon their daily routines and activities.

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Topic 3: Coping with an HAI

Participants provided diverse comments about how they coped or did not cope with having an HAI. They viewed themselves as a patient in the hospital system and a recovering patient at home after being discharged. Their comments were interspersed with thoughts on their medical condition as well as the social interactions with those around them. As in the themes identified in relation to other topics discussed during the interviews, a strong link was evident in the way in which the participants' viewed their physical health and other aspects of their health, especially their emotional condition. Their comments about coping with an HAI were categorised into several themes (Figure 1).

Patients reported adopting various coping experiences (ranging from coping poorly to coping well). Participant 7 had "not really" coped with her HAI due to poor communication and negative comments from another patient sharing her ward. Participant 6 struggled emotionally. Participant 1 was apprehensive about his long-term prognosis, given his heart attack and subsequent HAI: "I don't think my heart was given the chance. If I had any one criticism, my heart lost out on four weeks" (Participant 1). In contrast, Participant 2, Participant 5, and Participant 4 coped well, although Participant 4 was still unclear about why his HAI occurred, thus highlighting a perceived lack of information about his condition (mentioned earlier). Participant 8 believed that the nurses had attributed Participant 8's HAI to her compromised immune system, rather than the visibly soiled toilet that Participant 8 reported as having been forced to share with other patients. Participant 6 perceived that he was not told anything about his medical condition, and subsequently experienced deep depression: "Psychologically, it's been a real battle". For some patients and their families, the experience of contracting an HAI brought an increased awareness about their own vulnerability: "[you] realise that you're not bullet proof" (Participant 9).

While rationalisation and comparing oneself to others helped some patients cope with their situation, patients also commented on the nurse-patient relationship as being closely related to their recovery. Conversely other patients reported feeling disparaged or "lost in the system" (Participant 1). When patients reported feeling neglected, such experiences were typically related to timeliness of care. The participants' comments about their physical health were rarely expressed without some reference to other aspects of their wellbeing (emotional, social and psychological) and the impact this care, or lack of care, had on varied aspects of their life and their view of themselves. In extreme cases, the need to cope with having an HAI even affected their identity with one participant describing how the experience of contracting an HAI, and the subsequent treatment of the HAI, resulted in her realisation that the experience had "launched me into old age" (Participant 9).

Several patients became interested in and proactive about their health and care, thus promoting coping through an improved sense of control. Following months in hospital and rehabilitation, Participant 5 was looking forward to a new leg prostheses and

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putting the HAI behind him: “it was treated, and that was that” (Participant 5). Participant 9 was likewise hopeful but had remaining doubts about her HAI: “a bit of an unknown and you wonder” (Participant 9).

Topic 4: Improving the management of patients contracting an HAI.

Participants made suggestions about how their management, as a patient who had contracted an HAI, could have been improved. Their comments were categorised into four themes which reflected their observations about:

1. their expectations, as patients, of how they should be treated;
2. communication breakdowns between the patient and their health carers;
3. how the hospital environment impacted on their care; and
4. satisfaction with the way they were cared for.

Participant 5, Participant 3, Participant 9, Participant 2, and Participant 4 were generally satisfied with their care and felt that management of their HAI could not be improved. Despite having had a traumatic time in hospital, Participant 6 likewise, had no suggestions for improvement. He did, however, question why he was kept in a four-bed ward with other patients while experiencing diarrhoea: “Privacy … All you’ve got is a curtain, and you’ve got to call for a pan. They don’t get there in time because there’s a ward full of patients” (Participant 6).

Communication inconsistency between patients and health carers was commonly highlighted. For example, Participant 1 reported that he was only informed of the results of his CAT scan when he pressed for them, three days after the scan was conducted. Patients noticed issues associated with communication to and from patients to medical staff. For example, patients such as Participant 2, Participant 6, and Participant 10 complained that the nursing and medical staff refused to listen to or act on patients’ concerns; thus, they felt this allowed infections to fester and spread. There was an expectation by the patients that healthcare staff were adequately trained and would provide quality care: “That’s what you’re a nurse for … it’s important to do your job”

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(Participant 10); in multiple instances, patients commented that the care provided was inadequate.

Discussion

This study, this first of its kind conducted outside of Europe and the US, highlights the distressing and debilitating effects that can be incurred by patients contracting and being treated for an HAI. Although some patients appeared to cope remarkably well with the experience compared to others, all patients experienced significant pain, ill-health, and disruption to their daily lives. These negative effects were often described in relation to the patients' internal thoughts and reflections. The financial impacts of patients having an HAI appeared limited (possibly due to patients being retired); and most healthcare costs were covered by private health insurance or Medicare (Australia's healthcare system). This is similar to a study conducted by Mo and colleagues,[6] and may be a reflection of the healthcare system in Australia.

Despite person-centred care being a foundational principle in Australian healthcare systems, it appears that the patients in this study who contracted an HAI felt that person-centred care was lacking in multiple cases. On the whole, patients did not feel their pain and distress was taken seriously. Currie et al., reported similar findings (subtheme: 'I know versus they say').[3]

The experience of having an HAI is embedded within social-cultural contexts, including time and place.[3] This shapes patients' perceptions about the HAI and themselves, and their perceptions of responses of healthcare staff.[17-19] Timeliness and flexibility of care that attends to the needs and values of patients is important for achieving person-centred care but depends on the quality of the healthcare worker-patient relationship.[2,20] Having adequate infection control training and an understanding of HAIs is also crucial for healthcare professionals to enable them to reassure and advise patients, assess and correctly manage infection risks, and be confident of their own safety.[17,21,22]

This study found that communication failed in many cases to take account of each individual patient's needs and level of understanding; hence, most patients in this study were still unsure of their actual HAI diagnosis or what it meant in terms of their long-

term health or infection risk. Diagnostic and prognostic uncertainty had implications for how patients made sense of their HAI experience. This finding concurs with other studies, including Barratt et al.,[17], Eli et al., [23], and Garner and Cook [18]. Wiklund et al.,[21] who found that patients often resorted to searching the internet for information about their antibiotic-resistant infection; the information gained then helped patients develop strategies for managing ongoing health risks.[21] Patients need to be given an accurate diagnosis to prevent patients accessing wrong or misleading information, which could heighten existing anxieties or trauma.

The way in which patients reported their experiences of contracting an HAI frequently involved descriptions of aspects of their physical health alongside aspects of their mental, emotional and/or psychological health. Their reflections tended to include multi-dimensional comments about how the HAI impacted their lives, especially their mental, emotional and/or psychological health. Whereas Currie and colleagues reported impacts of HAIs on patients' social lives and relationships,[3] the results of this study indicate that the impacts of HAIs may have wider influences on a patient's wellbeing, also incorporating aspects of their mental, emotional and psychological health.

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Limitations

Data collection was limited to two Australian hospitals and most patients were drawn from a similar age group (predominantly retired), hence some of the effects of contacting an HAI (for example, work capacity) may be downplayed. Because patient recruitment and data collection were also hampered by COVID-19 restrictions, interviews were conducted over a two-year period. The study was conducted with the primary purpose of investigating the patients' perspective of contracting an HAI, so further studies may incorporate correlation between patients' reported perceptions with actual events and medical practices.

Conclusion

Recommendations for policy and practice that flow from the findings of our study

include the need for improved, person-centred communication about the source, treatment, and prognosis of HAI.[18,25] Knowledge and training about HAIs will be critical for clinicians to feel confident in providing care to patients with a diagnosed or suspected HAI. The experience of contracting an HAI can be isolating and distressing from the patient perspective, with perceived long-term implications. Future research could explore the feasibility of patient HAI peer-support networks, which may be delivered online.

Our findings indicate the importance of including patients' voices to improve their health care. Some key central concepts emerged from this study, namely, that patients in this study wanted to be informed about and engaged in their own medical treatment. Furthermore, the patient experience was described in multi-dimensional ways, not in segmented observations. By investigating patients' perspectives, these results contribute to a research-informed approach to person-centred care that supplement the evidence-based clinical practices used to prevent and treat HAIs.

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Declarations of interest

The authors have no conflicts to declare.

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Authorship statement

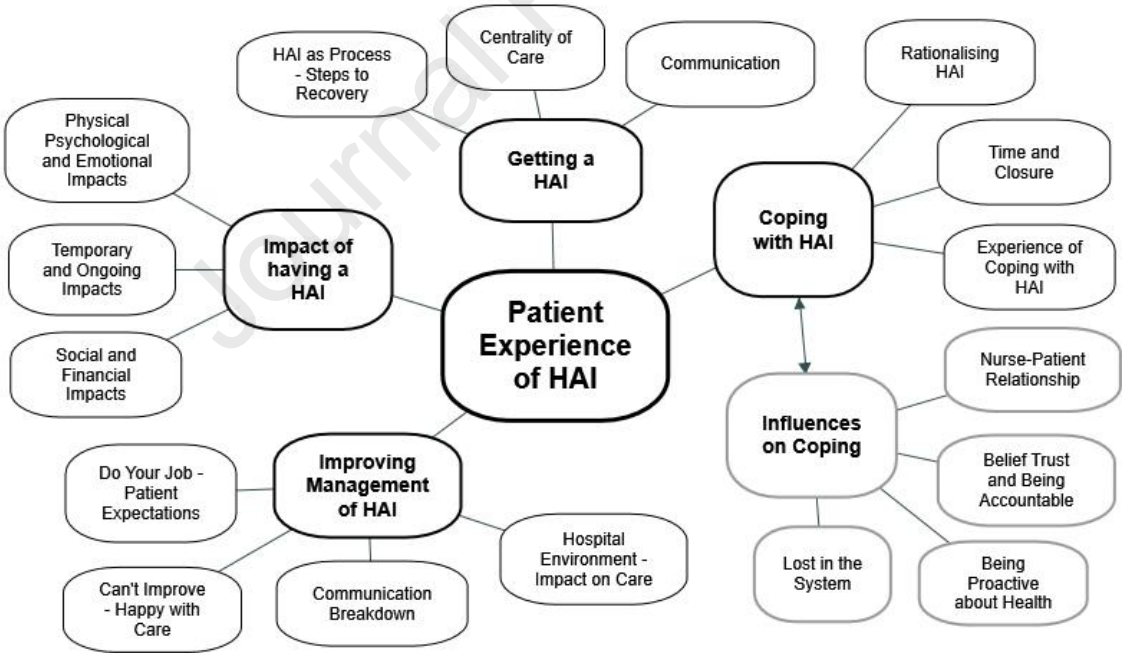
BM, PLR, MN and CR designed the study, based on work undertaken by KC. MA and FD were primarily responsible for recruitment and determination of a HAI. CR and MN undertook interviews. CC and MN were primarily responsible for data analysis. BM, KP and CC drafted the manuscript. All authors provided critical input into the paper, revision and approved the final version.

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Figure 1: Themes from analysis



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Table 1. Illustrative quotes for research questions and subthemes

Question/ Theme	**Subtheme**	**Illustrative Quote ^**
Experience of getting a HAI in hospital	*Centrality of care*	"Any medically-minded surgical person should have picked up that you don't have a burning pain deep behind a wound without there being something wrong. But they've refused to believe me" (Participant 6). "I thought I was just going in for an iron infusion. And the site in which they did the iron infusion, I got a staph infection in ... that really annoyed me ... I was in for two weeks not two days" (Participant 10).
	Communication	"They [nurses] didn't tell me. They were just talking among themselves. And .. I have to ask the nurse, and the nurse said, 'I'm going to get the doctor to explain it to you'" (Participant 8). "They said, "You've got an infection, you've got an infection," but they never said what it was" (Participant 7).
	HAI as process – steps to recovery	"I guess I am a person who takes one step at a time. So I wasn't particularly anxious, I just thought well, go through the process, get into hospital, and they would start dealing with it. So emotionally, or psychologically, I think I'm fairly well rounded, in a way. But I wasn't panicking at all" (Participant 9). "I'm still on flucloxacillin and will be for the rest of my life" (Participant 6).
Impact of HAI	*Temporary and ongoing impacts*	"I still feel, I don't understand the [HAI] and then when I went into the hospital here the other week … there was a gentleman in another booth, and I could hear him talking … he got a staph infection, and he now had a knee one and he's got one again. So I need to get my knee done and I just don't trust to go and get it done" (Participant 7). "Well, I'm pretty scared actually to go – I'm actually due for a lung transplant. But … I'm really worried. Does this [HAI] happen to all patients … how many patients go through it?" (Participant 10).
	Mind and body (physical, psychological and emotional) impacts	"Well, it's not so much affected my health. It's affected my mobility because … in a wheelchair, transferring from walkers to wheelchair and things like that… it's just bit awkward to get around" (Participant 5). "I can't go anywhere without [wife] of course, she has to drive for six weeks … can't do anything" (Participant 2).
	Social and financial impacts	"My husband's, he's been doing all the cooking and a lot of the housework and all that sort of thing … very supportive, and now I don't even know where to go in the kitchen, I don't know where he puts things" (Participant 9)

		"It's all the things we did together. 13 weeks, we were apart. Now you're imagine … in the house by herself. I'm in hospital, when I should have only been a week, it was developed for three months. It became a bit tense the first couple of times because she said "now this is what we're doing now" … I felt pushed out" (Participant 6).
	Stigma – feeling horrible	Participant 7: "the next thing I can hear is, "How dare you put me in a ward with this women with an infection"
Patient coping with HAI	*Coping experience*	"It's a lonely road when the lights go out in the hospital. And it's a time to reflect. And it's a time where you shed a tear or two" (Participant 6). "Oh well it's just one of these things I suppose" (Participant 3).
	Rationalising HAI	"I don't think you can ever really prepare for something like this. It comes as a bit of 'Why me' situation. I don't know what the percentages are, and let's say it's 1 in a 100 … I thought, gee, I've only had a heart attack and they've taken a little cannula, it would appear in my left arm was the introduction of the staph and … well, what are the chances" (Participant 1). "It's alright for three other people, I should say. The ward I was in, they all ended up asleep all day. And I'd sit there, and you sit and think, mainly, it's the nights. For me anyway, I'd reminisce and wonder, why am I stuck? Or why was it me that this happened to, why did it happen in the first place" (Participant 6).
	Time and Closure	"I think the time span is a bit of a killer … Yeah, like you can't do a lot in hospital when you've got a bug like this" (Participant 1). "Since then, we've got – they're making new legs and all that. So hopefully it'll be a lot better when it's finished" (Participant 5).
What could have helped cope better with HAI	*Nurse-Patient Relationship*	"I had a nurse come in every day. And those nurses were lovely. I was wondering why I couldn't have them in hospital. They were great … they cheered me up emotionally so much" (Participant 10). "Some of the younger nurses took time out with every other patient everyone to have a check. The older one's like my wife's age, were experienced and gave you the feeling that they knew exactly what you were doing. And they'd say, oh, we've had patients that have had infections before, and you felt that you had the confidence" (Participant 6).
	Lost in the System	"If someone had told me what it was, not just I've got an infection. They should have sat down and explained it to me. I don't know why, why me? And the only answer I got for that was that it lives on your skin. It's very common evidently" (Participant 7). "They shouldn't have left [IV] in there. Had they have checked the site they would have noticed that it was red and it was infected. Because [my specialist] had a look at it and he just – he went right off. He just said, get that out and get it out now" (Participant 10).
	Being Proactive about Health	"[The] nurses encouraged me to take an interest in what they were doing … it stood me in good stead, because on one particular night, one of my infusions disappeared a lot quicker than what it should, and I was able to raise the question to someone, "Oh look it's been taking

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		three hours, this only took an hour and a half, has something changed or whatever," and it turns out that in fact, someone had been trained or shown the wrong way and I had, in fact, the infusion too quickly… [after that] I kept an eye on everything they did" (Participant 1).
	Belief, Trust and being Accountable	"The Panadol swap was not the right thing to do. They think I'm a fool … Even when [in delirium] I thought the North Koreans were abducting me, the nurses just stood and laughed about it the next day, they all had a joke and said, well, you know, everything's safe look, you are in hospital, and whatever" (Participant 6). "The nursing staff could have been a bit nicer. Apologising. An apology would have been nice. I didn't get an apology. [Dr] my specialist, couldn't apologise anymore than – it wasn't his fault. But the nurses that did it, they should have apologised as far as I was concerned. And the head nurse seemed to be very – she was quite nasty. Like I didn't deliberately get a staph infection. It wasn't my fault" (Participant 10).
Suggestions for how hospitals/ staff can improve management of HAI	*Can't improve – happy with care*	"I don't think you can. They were religious in changing the dressings. Vascular surgeons cleaned it all out. And, at one stage, it looked like the size of a pea" (Participant 5). "No, I thought the people in ICU were terrific. It was amazing. It just blows me away, the skills that people have in there, and people were really patient and that. Because, when I was in hospital… I had a lot of diarrhoea, and it would just happen, I'd have no indication it was going to happen, it would just go. And they had a lot of cleaning up to do, it was just awful, I felt so sorry for them. But they didn't complain, they said, "That's what we're here for." I thought 99% of them were fantastic" (Participant 9).
	Communication breakdown	"Maybe a little bit more information, like talking to you and explaining why this happened, and how we're going to fix it, and why we're expecting this – like I understand a little medical terms and all that. I would like more information. Explain to the patient not to the nurses … If the patient doesn't understand, they can clarify what that means" (Participant 8). "For them to tell you what's wrong, sit down and explain. Not thinking someone else has told you. Make sure you tell them" (Participant 7).
	Do your job – patient expectations	"In the wards, … I felt they were a bit too busy, and you're left to your own devices … weren't attended to as much as you were in ICU, but then I guess that's the way it is, you can't expect them – they're just so busy and underpaid and overworked" (Participant 9). "When they were doing invasive stuff, like working and changing the dressing on the PICC line, for example, at every time then I did notice people were very, very thorough with their own hygiene and own personal protection, but some of the other times, I felt there was no consistency … I'm not sure about the level of risk that I presented. I know that I was in a single room … on one or two occasions, I noticed that the kitchen staff came in with no gown, no gloves" (Participant 1).
	Hospital environment –	"The privacy of it. Because there was a ward for four people. All you've got is a curtain, and you've got to call for a pan. They don't get there quite in time because there's a ward full of patients. So, I'm on the board, yes I've called, no it's too late. You've got three other

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	issues impacting care	people probably going oh, my God. So, there is probably a need to put incontinent people … with a bit more segregation. Now I know that it's probably impossible. That's how I see it" (Participant 6). "I could have possibly been more vocal myself, but … these people are sometimes run off their feet, they're understaffed and things like that and you sort of think … there's a person down the road just lost a leg or you know, and here am I, got all my legs and arms and my mind's working okay, sometimes. Should I really be worrying them?" (Participant 1).

Note: ^ Additional quotes to support each question and subtheme are provided in supplementary material. Quotes in this table have been limited)

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