



Short report

The socio-economic impact of multidrug-resistant nosocomial infections: a qualitative study

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SUMMARY

The burden of healthcare-associated infections (HCAIs) has traditionally been measured using clinical and economic outcomes. We conducted semi-structured interviews with 18 patients or their caregivers affected by HCAI caused by multidrug-resistant organisms to better understand the human impact of HCAI. Most patients had misconceptions about HCAI and antimicrobial resistance, leading to strong negative feelings towards HCAIs despite positive views of their healthcare providers. Communication issues across power imbalances need to be addressed to help deal with trauma of HCAIs. A holistic approach to HCAIs incorporating patient perspectives will likely help guide policymakers developing solutions to improve patient outcomes.

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Introduction

Public engagement in patient safety and infection prevention is widely recognized [1]. However, an in-depth understanding of the patients' and their caregivers' perspectives on healthcare-associated infections (HCAIs) has not been well explored. Only one of 14 qualitative studies on patients' experiences with HCAIs included in-depth interviews with

patients with HCAIs [2]. Most studies document provider perspectives on improving quality or communication.

Mandatory public reporting of hospital-level HCAI data has been somewhat controversial and is often difficult to interpret and thus limited as a public engagement modality [3]. By contrast, in this study we aimed to examine patients' and caregivers' unique experiences of multidrug-resistant (MDR) HCAIs to give a broader picture of their impact.

Methods

We recruited 18 adult participants from the National University Hospital, a major tertiary institution with more than

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Box 1

Questions used during interviews

1. Basic information

- Where are you working and how many years have you been working there?
- What do you do as your job? What did you do before?
- Which was the most recent school or highest qualification you received? Did you specialize in any particular subject?
- Who do you live with?

2. Knowledge about infection

- Why did you come in to hospital? What is your diagnosis? When were you sick?
- How did you get your infection? How do you think the infection came about?
- Which symptoms you experienced can be attributed to the infection?
- Do you think this bacterium can be passed on to other people? How so?
- What treatment were you given? What do you think about the treatment you have received? What happened as a result of the treatment?
- Did you develop any complications? What are the consequences of the infection?
- Do you know what are hospital-acquired infections?
- What do you understand to be the main causes of nosocomial infections? Do you think you have a role to play in acquiring the infection?
- What can be done to prevent nosocomial infections?
- Who gave you this information? How did you find this information?

3. Feelings about infection

- How do you feel about the infection? Why do you feel this way?
- Do you think the infection is serious? How has this infection affected your health?
- What do you feel about the treatment?
- Did the experience affect your outlook on your health and life?

4. Feelings about quality of care

- How was your stay in hospital?
- What do you think about the care provided for you by the hospital?
- How did you feel about the communication and information provided to you? What do you think about the communications between staff?
- How did you feel about the information you received? Do you think enough information is provided to you? Or would you like to know more/less?
- What are some of the good and bad practices you observed?
- How much control did you feel that you had over your health whilst in the hospital? Would you like to participate more in the care of your health?
- If you would like that to happen, how do you think you can change that?
- Does acquiring a nosocomial infection affect your confidence in the healthcare system?
- Did finding out more make you worry more about your health? Did finding out more help you to understand what is happening?
- Will you bring up your concerns to your doctors or nurses? How did you bring up these concerns to your healthcare providers?

5. Impacts of the infection on social dynamics in the family, work and society

- Who were the ones helping you while you were sick?
- How has acquiring the infection affected your family life, relationships with your friends and colleagues? Are these changes likely to be permanent?
- Have you tried to overcome these difficulties?
- Do you feel left out or isolated?

6. Financial impact

- Has this affected your work? Are you able to do what you usually do at work now?
- What are the long-term/short-term financial costs to you?
- Are there any missed opportunities because of the infection?
- How did you cope with these changes?

1000 beds in Singapore. Two potential participants declined to be interviewed due to scheduling conflicts. All patients contracted MDR infections after 48 h of inpatient stay and were randomly chosen from the infectious disease inpatient and referral services. Five participants were non-communicative and were represented by their main caregivers.

Qualitative semi-structured interviews lasting 40–90 min were conducted with the participants during continuing therapy for their acute HCAI (Box 1). Interviews were recorded and transcribed. An independent translator was engaged as needed. The study team analysed the transcripts individually and summarized findings into themes. We stopped recruitment

when our data analysis showed repetitive findings and reached thematic saturation.

Ethics approval was obtained from the National Health Group Domain Specific Review Board (Reference number 2010/00309). Written informed consent was obtained from all the participants prior to each interview.

Results and discussion

The participants were 11 men and seven women, ranging from 28 to 80 years of age (Box 1). The majority (11; 61.1%) had at least secondary school level education (equivalent to 10 years of formal schooling). The sites of HCAIs were surgical site infections of the soft tissue (7; 55.5%), surgical implant infections (7; 55.5%), complicated urinary tract infections (3; 16.7%), and central-line associated bloodstream infections (1; 5.6%). The most frequent MDR organisms (MDROs) were methicillin-resistant *Staphylococcus aureus* (MRSA), extended-spectrum β -lactamase (ESBL)-producing Enterobacteriaceae, and MDR *Pseudomonas* spp. and *Acinetobacter baumannii* (see Table I).

Knowledge about HCAIs

Most participants had poor knowledge of HCAIs and antimicrobial resistance, specifically in clinical features, epidemiology, and prevention. The composite mean and median knowledge scores were 2.9 out of 9, and 2 out of 9, respectively, regardless of education level or economic status (Supplementary Table I).

Five participants cited the Internet as their main source of information (Supplementary Table II). However, they recognized its limitations and would have preferred to hear more from their healthcare providers.

Yes. We definitely need more information. I am not from a medical background, so going through Google is very difficult. (Participant 8)

There were also several misconceptions. For instance, many thought that contracting infections was an expected unavoidable consequence of hospitalization or surgery. Some suggested that HCAIs were air-borne, water-borne or a 'rejection reaction' of the body to surgical implants.

Some people can adapt to metal plates, some cannot and develop rejection like in my case. (Participant 2)

Infections are from the bad air in the hospitals. (Participant 4)

MRSA was the only MDRO well known to the participants, possibly because the hospital has a well-publicized MRSA bundled programme including active surveillance with public and patient education materials [4]. However, all had difficulty distinguishing MRSA colonization versus infection. One caregiver was more concerned about the patient's MRSA colonization than about the MDR Gram-negative bacteria causing the patient's chronic osteomyelitis.

Four patients felt responsible for their state of health, often resulting in guilt, isolation, and shame.

I shouldn't have been distracted at work. I don't blame anyone else ... Losing my leg is losing my life. I will not be able to support my family. I came to Singapore for a better life, but now I not only didn't make any money, I ended up losing a leg. (Participant 2)

There are significant hurdles in empowering patients to deal with HCAIs. First, HCAI and antimicrobial resistance are not well understood [5]. The paternalistic belief among healthcare workers that education may produce undue stress on the patients, and the fear of endangering patient–healthcare worker rapport, are also problems [6]. However, we found that both misconceptions and lack of knowledge aggravated patients' negative feelings about HCAIs. Patients who exhibited an internal locus of control were also more likely to express feelings of powerlessness, hopelessness, and guilt. Thus, we propose empowering and educating patients to promote safety, which may improve their relationships with healthcare workers.

Feelings and perceptions about the infection

Fourteen patients or their caregivers expressed strong feelings about having acquired an HCAI, independent of their demographic characteristics, knowledge, and financial impact. The most frequent descriptive words included 'sad', 'frustrated' 'fearful', 'worried', 'anxious', 'powerless', and 'traumatized'. Contracting HCAIs after a period of recovery following the initial hospitalization resulted in disappointment and feelings of hopelessness. This prominent finding is underexplored in previous studies, which focused on patients' experience of the quality of care that they received rather than their perceptions of the HCAIs [2].

... all the nightmares ... Every time I go to sleep, I get headaches. Life has become scary. I have had heart palpitations and flashbacks. (Participant 2)

I don't know where I am going in the future [with my hand having extensive myositis and osteomyelitis from an IV plug insertion]. I can't even pray [with my hands like this] ... (Participant 15)

One patient was diagnosed with major depression requiring anti-depressive treatment after the HCAI episode. Ten participants felt physical discomfort from the infection or hospital stay, citing antibiotic complications and loss of function or in-dependence in general.

The antibiotics part was the worst experience. Polymyxin B is very strong. My face, my tongue started getting much darker. My whole face was very numb. Because the numbness never went away, it affected my eating, drinking, and even the way I talk, because I couldn't move my tongue properly. And then a few days later, they told me my kidney got affected because of the antibiotics. I lost about 12 kg over this period. (Participant 7)

A minority of the participants felt less strongly about HCAIs. They also tended to be more fatalistic (i.e. exhibiting an external locus of control), perceiving their underlying medical condition such as cancer to be more severe than the HCAI.

This infection is part of my illness [leukaemia]. What will come will come. Why get upset? (Participant 6)

Feelings about the quality of care given

Four patients expressed anger and disappointment as they felt that their infections were a result of the inadequate care but were hesitant to speak out, as they did not think that they had the authority to do so and were fearful of affecting the relationship with their healthcare providers. This power

Table 1
Basic demographics of participants

No.	Age (years)	Gender	Ethnic group	Language used during interview	Marital status	HCAI	MDRO	Antibiotics received	No. of surgeries or procedures ^a	Occupation	Education level	Mode of healthcare financing ^b
1	40	Female	Malay	English	Married	CAUTI	ESBL-P <i>Escherichia coli</i>	Ertapenem	1	Nurse	Junior college/polytechnic	Self-funded, Medisave
2	40	Male	Chinese	Chinese	Married	SII	MRSA	Vancomycin	>5	Construction worker	Undisclosed	Private insurance, employer
3	28	Male	Chinese	English	Married	SII	MRSA	Vancomycin	2	Airport manager	University graduate	Self-funded, private insurance, Medisave
4	51	Male	Indian	English	Married	SSI	MRSA, ESBL-P <i>E. coli</i>	Carbapenem, vancomycin	>5	Unemployed	Secondary school/vocational institute	Self-funded, Medisave
5	23	Female	Malay	English	Single	SSI	MDR <i>Acinetobacter baumannii</i> , MDR pseudomonas	Polymyxin B, carbapenem	4	Shopping mall customer service	Secondary school/vocational institute	Self-funded, Medisave
6	55	Female	Chinese	English	Married	CLABSI	MRSA	Vancomycin	1	Tuition centre owner	Junior college/polytechnic	Self-funded, private insurance, Medisave
7	26	Male	Indian	English	Single	SSI	MDR <i>A. baumannii</i> , MDR pseudomonas, ESBL-P enterobacter, MRSA, ESBL-P <i>E. coli</i>	Polymyxin B, carbapenem, vancomycin	>5	Start-up company founder	University graduate	Self-funded, private insurance
8 ^c	80	Female	Chinese	English	Widowed	SII	MRSA	Rifampicin, piperacillin–tazobactam, vancomycin	1	Retiree	Undisclosed	Self-funded
9	46	Male	Chinese	Chinese	Married	Complicated UTI	ESBL-P <i>E. coli</i> and klebsiella, MDR <i>A. baumannii</i>	Doripenem, meropenem	0	Hawker	Primary school and below	Self-funded, Medisave
10	38	Male	Caucasian	English	Married	SSI	MRSA, <i>Mycobacterium abscessus</i>	Amikacin, imipenem, ceftazidime, clofazimine	>5	Chemist	Postgraduate	Self-funded
11 ^c	56	Male	Chinese	English	Single	SSI	ESBL-P enterobacter, MRSA	Piperacillin–tazobactam, vancomycin, vlineamycin	0	Unemployed	Secondary school/vocational institute	Self-funded, insurance, Medisave
12 ^c	56	Female	Chinese	English	Married	SII	MRSA	Vancomycin, sulfamethoxazole–trimethoprim	0	Unemployed	Primary school and below	Financial assistance from social circle

(continued on next page)

Table 1 (continued)

No.	Age (years)	Gender	Ethnic group	Language used during interview	Marital status	HCAI	MDRO	Antibiotics received	No. of surgeries or procedures ^a	Occupation	Education level	Mode of healthcare financing ^b
13	24	Male	Chinese	English	Single	SII	MRSA	Vancomycin, minocycline	1	Tuition teacher	Junior college/ polytechnic	Self-funded, Medisave, government subsidies
14	58	Male	Chinese	Chinese	Married	SII	ESBL-P <i>E. coli</i>	Meropenem	5	Sales person	Primary school and below	Self-funded, Medisave, government subsidies
15	51	Female	Indian	English	Married	SSI	MDR pseudomonas, stenotrophomonas	Piperacillin–tazobactam, levofloxacin	3	Administrative assistant	Secondary school/ vocational institute	Self-funded, government subsidies
16	63	Female	Chinese	English	Married	Complicated UTI	ESBL-P <i>E. coli</i>	Meropenem, ertapenem	2	Administrative executive	Secondary school/ vocational institute	Employer
17 ^c	65	Male	Chinese	Chinese	Married	SSI	CRE	Polymyxin B, meropenem, tigecycline, ertapenem	2	Unemployed	Undisclosed	Self-funded, private insurance
18 ^c	64	Male	Chinese	English	Single	SII	MRSA, ESBL-P <i>E. coli</i>	Vancomycin, cefepime, bactrim, ceftazidime	>5	Unemployed	Undisclosed	Government subsidies

HCAI, healthcare-associated infection; MDRO, multidrug-resistant organism; CAUTI, catheter-associated urinary tract infection; SII, surgical implant infection; SSI, surgical site infection; CLABSI, central line-associated bloodstream infection; UTI, urinary tract infection; ESBL-P, extended-spectrum β -lactamase-producing; MRSA, methicillin-resistant *Staphylococcus aureus*; CRE, carbapenem-resistant Enterobacteriaceae.

^a Surgeries and procedures directly related to the HCAI.

^b A mandatory social security savings scheme managed by the central provident fund and funded by contributions from employers and employees while the patients are gainfully employed.

^c Patient's representative attended the interview on behalf of the patient.

imbalance could potentially undermine the patients' trust in the healthcare workers.

I think I got the infection from the operation theatre. I blame them. I lost confidence in the hospital after this (infection). (Participant 1)

The majority, however, continued to attribute positive qualities to the healthcare workers (e.g. 'kind', 'committed', 'responsible'). They felt that healthcare workers were not to blame for the HCAIs.

The infection is everywhere. It is not the doctors' or the nurses' fault. It is known that hospitals are full of bugs. They are already doing their best to prevent this. (Participant 3)

Patients and their caregivers were however, often confused by the information provided and expressed the need to be more involved in their own care.

Doctors said that [the patient] has a kind of bacteria that antibiotics cannot kill. They then isolated him to prevent transmission to other patients. We don't know what this is about. (Participant 11)

For two patients, the poor communication compounded their anxiety and led to suboptimal treatment.

I think he [the doctor] freaked me out [telling me about possible amputation with the infection] so I avoided going to the hospital as much as I could. So when my infection got worse ... (Participant 13)

Financial impact

Eight participants were not personally affected by the high costs of HCAIs due to either the government subsidies or their own private insurance plans. Hospital bills in Singapore are usually co-paid by a mandatory medical savings account (for residents) or by various private insurance schemes, thus significantly affecting those without insurance and non-citizens. Those with lower education levels and underlying chronic conditions such as end-stage renal failure and malignancies tended to have limited remaining savings and thus suffered heavier financial burdens from co-payments despite government subsidies. The patients were more likely to feel angry, hopeless, and regretful.

My savings are finished. My wife takes care of me and has no time to work. Her savings are gone. [My wife] needs to buy food for me, visit me, and spend on transport to come here. (Participant 14)

Six patients also felt that there were substantial opportunity costs from the extended absence and the loss of productivity.

I was hoping for a promotion a few months ago. Now I think my boss has a bad impression of me. (Participant 1)

The financial loss, however, was often secondary to the emotional trauma.

[The HCAI] is more than the hospital bill. My loss, my time, the pain, the agony, cannot be calculated. I have to let go of everything to take care of my mother. (Participant 8)

Impact on social and family dynamics

Fourteen patients felt that they remained close to their friends and family who supported them, with seven highlighting that their familial bonds improved through adversity.

My daughter came to visit me often and has become closer to me. (Participant 14)

However, four said that their family relationships were stressed because of the MDR HCAIs.

Once, my son, who is paying the medical bills, came to visit me and we had a quarrel. It happened out of the blue, and he walked out of hospital and didn't talk to me for the next three days. (Participant 15)

In contrast to previous findings from North America and Europe, only five patients experienced social isolation and stigmatization despite having MDR HCAIs although there were a few complaints about feeling bored with no one to talk to [7]. This could be related to the low level of awareness of MDROs among the public and the lack of strict isolation boundaries imposed on these patients outside of the acute hospital inpatient setting.

All of us (family members) come to visit him. My son and daughter-in-law come every day. [The carbapenem-resistant Enterobacteriaceae] is just inside his body and does not transmit. (Participant 17)

To our knowledge, this study is the most extensive qualitative study of the impact of HCAI to date in terms of interview hours, range and number of participants. We acknowledge that there are limitations. The sample size is small compared to quantitative studies, although we were able to capture a full range of emerging themes until thematic saturation. The advantage of a small cohort is that it allows the in-depth exploration of complex socio-economic and psychological effects of HCAI [8]. We also did not include a control group of patients who were treated for non-hospital-acquired infections or non-MDRO infections, as this was not the focus of the study.

Our findings highlight the need for a holistic and individualized approach in caring for patients with HCAI. Well-designed education materials on antimicrobial resistance and HCAI for patient and public engagement, targeted to different patient needs, are important.

A risk-based assessment can also be performed to identify patients with HCAI and their families who may benefit from psychological, emotional, or financial support. A multidisciplinary approach including social workers and psychologists dealing with HCAIs as a form of post-traumatic stress disorder may be needed to help patients overcome emotions and complete their recovery. Patient empowerment may potentially reduce the power imbalance in healthcare and promote constructive feedback to improve outcomes for all patients and especially those with MDRO HCAIs.

Conflict of interest statement

None declared.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jhin.2018.08.013>.

References

- [1] World Health Organization. Technical series on safer primary care. Geneva: WHO; 2016. Available at: <http://www.wipo.int/amc/en/mediation/> [last accessed March 2018].

- [2] Burnett E, Lee K, Rushmer R, Ellis M, Noble M, Davey P. Health-care-associated infection and the patient experience: a qualitative study using patient interviews. *J Hosp Infect* 2010;74:42–7.
- [3] Linkin DR, Fishman NO, Shea JA, Yang W, Cary MS, Lautenbach E. Public reporting of hospital-acquired infections is not associated with improved processes or outcomes. *Infect Control Hosp Epidemiol* 2013;34:844–6.
- [4] Tambyah PA, Kumarasinghe G. Methicillin-resistant *Staphylococcus aureus* control at the National University Hospital, Singapore: a historical perspective. *Ann Acad Med Singapore* 2008;37(10): 855–60.
- [5] World Health Organization. Antibiotic resistance: multi-country public awareness survey. Geneva: WHO; 2016. Available at: <http://www.who.int/drugresistance/documents/baselinesurveynov2015/en/> [last accessed March 2018].
- [6] Masnick M, Morgan DJ, Sorkin JD, Kim E, Brown JP, Rheingans P, et al. Lack of patient understanding of hospital-acquired infection data published on the Centers for Medicare and Medicaid Services Hospital Compare Website. *Infect Control Hosp Epidemiol* 2016;37:182–7.
- [7] Newton JT, Constable D, Senior V. Patients' perceptions of methicillin-resistant *Staphylococcus aureus* and source isolation: a qualitative analysis of source-isolated patients. *J Hosp Infect* 2001;48:275–80.
- [8] Green J, Britten N. Qualitative research and evidence based medicine. *BMJ* 1998;316:1230–2.