

Understanding the patient experience of health-care associated infection: a qualitative systematic review

Currie, Kay; Melone, Lynn; Stewart, Sally; King, Caroline; Holopainen, Arja; Clark, Alex M.; Reilly, Jacqui

Published in:
American Journal of Infection Control

DOI:
[10.1016/j.ajic.2017.11.023](https://doi.org/10.1016/j.ajic.2017.11.023)

Publication date:
2018

Document Version
Author accepted manuscript

[Link to publication in ResearchOnline](#)

Citation for published version (Harvard):
Currie, K, Melone, L, Stewart, S, King, C, Holopainen, A, Clark, AM & Reilly, J 2018, 'Understanding the patient experience of health-care associated infection: a qualitative systematic review', *American Journal of Infection Control*, vol. 46, no. 8, pp. 936-942. <https://doi.org/10.1016/j.ajic.2017.11.023>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please view our takedown policy at <https://edshare.gcu.ac.uk/id/eprint/5179> for details of how to contact us.

Title: Understanding the patient experience of healthcare associated infection: A qualitative systematic review

Authors:

Kay Currie^a PhD^{*}, Lynn Melone^a BSc (Hons), Sally Stewart^a MSc, Caroline King^a PhD, Arja Holopainen^b PhD, Alex M. Clark^c PhD, Jacqui Reilly^a PhD

^a Department of Nursing and Community Health, School of Health and Life Sciences, Glasgow Caledonian University, Glasgow, Scotland, UK

^b Nursing Research Foundation/ The Finnish Centre for Evidence-Based Health Care, Finland

^c Faculty of Nursing, University of Alberta, Canada

* Address correspondence to Professor Kay Currie, Department of Nursing and Community Health, School of Health and Life Sciences, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA, Scotland, UK

Telephone number: +44 1413313472

Email address: K.Currie@gcu.ac.uk

Conflicts of interest: None to report

Understanding the patient experience of healthcare associated infection: A qualitative systematic review

ABSTRACT:

Background: The global burden of healthcare associated infection (HAI) is well-recognised; what is less well known is the impact HAI has on patients. In order to develop acceptable, effective interventions, greater understanding of patients' experience of HAI is needed.

Objectives: This qualitative systematic review sought to explore adult patients' experiences of common healthcare associated infections.

Methods: Five databases were searched. Search terms were combined for qualitative research, HAI terms and patient experience. Study selection was conducted by two researchers using pre-specified criteria. CASP quality appraisal tools were used. Internationally recognised PRISMA guidelines were applied. Noblit & Hare's (1988) approach to meta-synthesis was adopted.

Results: Seventeen studies (2001-17) from five countries addressing five common types of HAI met the inclusion criteria. Four inter-related themes emerged: 'the continuum of physical and emotional responses'; 'experiencing the response of healthcare professionals'; 'adapting to life with an HAI'; and 'the complex cultural context of HAI'.

Conclusions: The impact of different HAIs may vary; however, there are many similarities in the experience recounted by patients. The bio-socio-cultural context of 'contagion' was graphically expressed, with potential impact on social relationships and professional interactions highlighted. Further research to investigate contemporary patient experience in an era of antimicrobial-resistance is warranted.

Keywords: healthcare associated infection, patient's experience, systematic review, meta-synthesis

Disclosure statement: No conflicts of interest

HIGHLIGHTS

- Qualitative research synthesis of patients' experiences across different HAIs
- Continuum to enhance understanding of physical and emotional responses across HAIs
- Importance of practitioner-patient communication to minimise distress
- New perspectives on how contemporary understandings of 'contagion' produces stigma
- Analysis of patients' HAI experiences to inform care quality improvement

BACKGROUND

Infection or colonisation of patients with a healthcare associated organism causes preventable adverse clinical outcomes, additional healthcare costs, and personal costs to patients. In Europe, Healthcare Associated Infection (HAI) prevalence was reported at 6% for 2011/12, which approximates to 4,100,000 patients with HAI each year.(1)(2) In the United States in 2011, HAI prevalence was estimated at 4%, or 1 person in every 25 acute care patients on any given day having at least one HAI.(3) International data shows that HAIs are the most frequently occurring adverse event worldwide, with reports from high income countries indicating a combined prevalence of 7.6%.(4)(5) The challenges posed by HAI are particularly pressing in an era of increasing antimicrobial resistance, where identification and management of infected or colonised patients is problematic and reducing transmission of organisms between patients becomes the critical element of infection prevention and control (IPC).(6) For the purposes of this article, both infection and colonisation with healthcare associated organisms will be referred to as 'healthcare associated infection' (HAI).

Despite the damaging effects and costs of HAIs, crucially, there is little knowledge of how patients and their families are affected in the immediate and longer term. Two systematic reviews related to patient experience of HAI could be located; the first(7) is limited to two studies on the patient experience of Meticillin resistant *staph.aureus* (MRSA), the other(8) included patients with multi-drug-resistant infections but focused particularly on the patients' experience of isolation. This evidence gap is important because the World Health Organisation(9) and many national Government organisations responsible for healthcare delivery have stated that patient centred, safe, effective care is a global health priority(10) To develop acceptable, effective interventions and treatments for HAI, greater understanding of patients' experience of HAI and the impact it has on their recovery is needed. Consequently, this qualitative systematic review focuses on patient experiences of both colonisation and infection from bacteria that commonly cause healthcare associated infection.

REVIEW QUESTIONS

1. *What is the adult patients' experience of healthcare associated infection or colonisation during and/or following hospital admission?*
2. *What is the perceived impact of infection or colonisation on adult patients' daily living; family relationships; finances; work?*
3. *How does type of infection or colonisation influence adult patient experiences?*

METHODS

A protocol was developed for the review.(11) Internationally recognised quality standards - the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' (PRISMA) - were used to design and conduct this systematic review.(12)

Inclusion criteria

The PICoS framework(13) was used to develop eligibility criteria (Table 1).

Population / Participants	Adult patients (aged over 18) who had experienced an HAI during a hospital admission.
Indicators / phenomenon of Interest	Patients' experiences of colonisation and/or infection of HAI, particularly concerning patients' daily living, family relationships, finance and work situations during admission and/or post-discharge.
Context	Any country and in any hospital, community, or patient's home setting
Study design	qualitative research designs including (but not limited to) thematic analysis, grounded theory, phenomenological analysis and mixed method studies with qualitative components
Exclusion criteria	Studies which focused on specific aspects of care associated with HAI, for example experience of contact isolation only or psychological impact of isolation only, were excluded.

Search strategy and study selection

A systematic search was performed using MEDLINE, CINAHL (Cumulative Index to Nursing and Allied Health Literature), PsychINFO, Web of Science, and EMBASE databases, combining general and specific HAI terms with patient experience terms (search strategy available from authors). Cochrane, Database of Abstracts of Reviews of Effects (DARE), Joanna Briggs Institute (JBI) and PROSPERO databases were searched for existing systematic reviews on the patient experience of HAI. The search was limited to studies published in English, between January 2000 and May 2017. Search results were initially screened by two researchers for relevancy by article title and abstract, then full-text screened against the eligibility criteria. The date of the last search was 22nd May 2017.

Quality assessment

The quality of all included studies was assessed using criteria from the Critical Appraisal Skills Programme (CASP)(14) Qualitative Appraisal Tool. CASP does not specifically recommend any scoring or grading system; however, we adopted a scoring system developed by Chatfield *et al.*(15) to generate a score of 1-20, assessed against the 10 CASP quality criteria. Where the authors did not meet the CASP criterion, a score of 0 was allocated; partial compliance scored 1; full compliance scored 2. On this basis, and whilst acknowledging the subjective element of quality appraisal, studies scoring 10 or below were ranked as lower quality (L), those scoring 11-15 were ranked as moderate (M), and those scoring 16-20 higher (H) quality, but none were excluded on the basis of lower quality. No CASP criterion was weighted as more important than another in terms of quality indicator. Quality appraisal involved assessment and agreement by two independent reviewers.

Data extraction

A standardised template was used to record information regarding study characteristics and summarised findings (appendix 1). Original qualitative data, including participant quotes and author interpretations, was extracted separately for each included study and entered onto Nvivo[®] software to enable meta-synthesis. Data was extracted by one reviewer and the content independently validated by a second reviewer.

Data synthesis

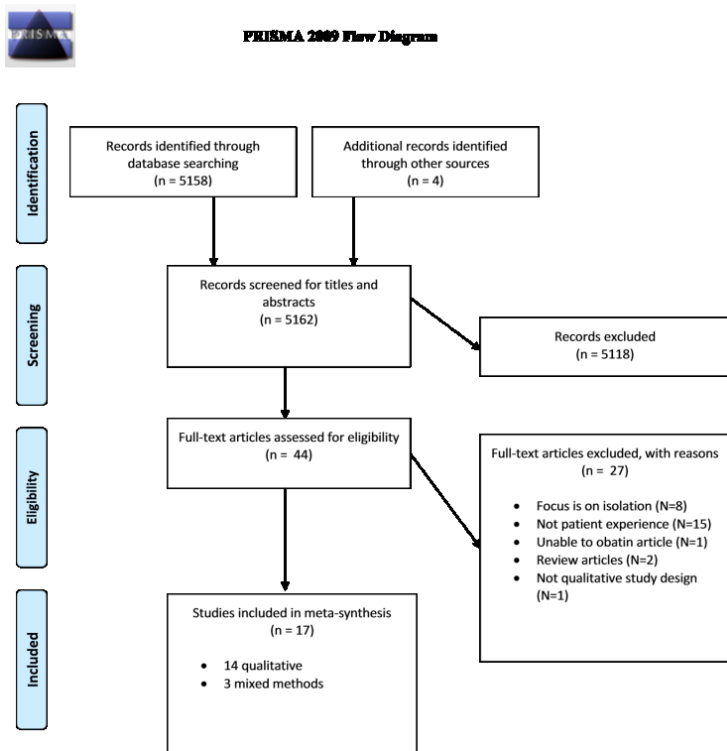
A recognized approach was used to synthesize the findings from the individual qualitative studies.(16) Based on an initial reading of all the findings, a preliminary set of abstracted themes was developed. These lower-order themes were then re-analysed taking account of the whole dataset and were translated into the final, higher-order, themes focused on patients' experiences in relation to the research questions and different types of infection / colonisation (see Table 2 below). Rigor in was maintained by peer review of thematic analysis and team discussion of final interpretations.

RESULTS

Included studies

A PRISMA diagram(17) of the search and study selection is presented in Figure 1.

Fig 1. PRISMA Flow Diagram of studies of results of search strategy



Appendix 1 (available from authors) presents study characteristics and summarised findings for each included study, as well as the category of quality appraisal.

Studies reported data gathered in 5 countries from 2001-2017 (7 in Sweden; 6 in UK; 3 in USA; 1 compared USA and France). Both qualitative studies (n=14) and mixed method studies (n=3) with qualitative data were included. Participant numbers ranged from 6 to 24 participants per study (total of 240 participants in review). Four studies reported patient in-hospital experience only; 4 reported post-discharge experience only; 9 reported both in-hospital and post discharge experience. Studies addressed either healthcare associated infection *or* colonisation with a HAI /drug resistant organism (where this differentiation was provided by the author) and causative organism where known. This incorporated studies of Meticillin resistant *Staphylococcus aureus* [MRSA] (7 studies) (18)(19)(20)(21)(22)(23)(24); surgical site infection [SSI] (4 studies)(25)(26)(27)(28); *Clostridium difficile* infection [CDI] (4 studies)(29)(30)(31)(32); *Staphylococcus aureus* blood stream infection [BSI] (1 study)(33); and extended spectrum β -lactamase [ESBL] producing bacteria (1 study)(34). No studies reporting patient experience of Carbapenemase Producing Enterobacteriaceae (CPE), an HAI of increasing global concern, were located.

The methodological quality of included studies varied. Common weaknesses included lack of a theoretical framework; limited methodological positioning (i.e. descriptive thematic analysis rather than conceptual interpretation of data); no mention of ethical approval; limited discussion of researcher positionality or reflexivity; limited detail on data analysis; no mention of data saturation; limited discussion of strengths and limitations or recommendations for future research or practice.

Results of meta-synthesis

The first review question ‘*What is the adult patients’ experience of healthcare associated infection or colonisation during and/or following hospital admission?*’ is addressed by two key themes; first, the ‘*continuum of emotional and physical responses to HAI*’; second ‘*experiencing the response of healthcare professionals to HAI*’. The impact on patients’ daily lives, family, relationships, finances, and work (review question 2), are described within the third theme ‘*adapting to life with an HAI*’. All of the aforementioned themes were shaped by a fourth theme; ‘*the complex cultural context of HAI*’. We have integrated findings which highlight similarities and differences in experiences (review question 3) throughout each of the four main themes. Table 2 indicates the main themes and associated sub-themes. Original data extracts illustrating synthesised findings for each type of HAI are provided in appendix 2 (available from author).

Table 2: Main themes and associated sub-themes

Theme	Associated sub-theme
Theme 1: <i>Continuum of physical and emotional responses</i>	<ul style="list-style-type: none"> • “I know” Vs “They say” • Experience of physical symptoms • Experience of emotional responses
Theme 2: <i>Experiencing the response of healthcare professionals to HCAI</i>	<ul style="list-style-type: none"> • Frustration of trying to obtain information from HCPs • Inconsistent use of protective measures by HCPs • Stigmatising interactions • Impact on subsequent healthcare • Value of interactions with infection specialists
Theme 3: <i>Adapting to life with an HAI</i>	<ul style="list-style-type: none"> • Fear of transmission of infection • Impact on social relationships • Impact on daily activities • Impact on employment or financial concerns
Theme 4: <i>The complex cultural context of HAI</i>	<ul style="list-style-type: none"> • The social stigma of ‘contagion’ • The uncontrolled body

Theme 1: Continuum of emotional and physical responses to HAI

The emotional and physical responses of patients experiencing an HAI can be conceptualised as existing at varying points on a continuum from minimal to extreme distress. Some patients experienced significant physical symptoms and others less so; some patients demonstrated significant emotional distress due to their situation (whether or not physical symptoms were present), others less so. This is not to suggest that emotional and physical responses occurred in isolation, as the inter-connectedness of mind and body is acknowledged. However, positioning along this continuum was influenced by the type of HAI experienced.

A key distinction between the infection versus colonisation experience of patients can be described as the difference between “I know” (characteristic of patients with SSI and ESBL infections who know there is something very wrong but initially lack a medical diagnosis)(25)(27)(34) versus “They say” (typifying the experience of the patients colonised with MRSA, who lack symptoms but are given a diagnostic label by the medical professions).(18)(19)(20)(22)(23) Emotional responses were also influenced by the socio-cultural context of infection (theme 4) and shaped by interactions with Health Care Professionals (HCPs) (theme 2). This continuum of emotional and physical responses is illustrated below by describing the typical experience of patients with different HAIs.

At the lower end of the physical response continuum, the experience of physical symptoms was frequently absent for patients colonised with MRSA. This made it difficult for some patients to accept there was anything ‘wrong’ or to understand the need for measures to manage MRSA colonisation, particularly after discharge from hospital.(19)(20)(22)(23)

Conversely, patients with SSI experienced an unfolding situation, often initiated by extreme and sudden pain as well as profuse wound leakage, where they had to deal with significant physical and emotional distress while seeking an explanation of their symptoms. This was characterised in the literature as ‘suffering, not being taken seriously’; ‘waiting in discomfort’; ‘searching for answers’. (25)(27) A similar picture was described in the one study of patients infected with ESBL producing bacteria, some of whom were experiencing recurrent urinary tract infections, where the theme ‘Worrying about something being wrong without knowing what’(34) resonated with the experiences described in several of the SSI studies.

Whilst MRSA colonised patients generally lacked physical manifestations of the condition, for them the emotional response to the diagnosis and management of being colonised dominated. Here, the socio-cultural influences on perceptions of infection were most intense, where patients in all seven studies described ‘feeling dirty’; ‘having the plague’; ‘like a modern day HIV’; ‘feeling like a

leper'.(18)(19)(20)(21)(22)(23)(24) The way MRSA patients were told about their colonisation also influenced subsequent responses, either generating significant emotional upset or a more relaxed attitude where little was perceived as problematic,(18) particularly when information was provided by an infection specialist.(24)

This type of emotional response was not characteristic of the patient with SSI, whose concern centred on finding the cause of the symptoms(25) and dealing with despair(27) rather than feeling socially isolated due to a diagnostic label. It did however feature in the study of patients with ESBL, with women expressing greater guilt, anxiety, and fear over possible transmission, whereas men tended to express greater anger and irritation over lack of information regarding their situation.(34)

Patients with CDI seemed to experience a combination of extreme physical symptoms, accompanied by embarrassment, anxiety and depression. Uncontrollable diarrhoea, anorexia, and extreme fatigue produced significant physical distress(29)(30)(31)(32) described in one study as 'the worst thing ever'.(29) Patients' reported bowel disorders as being particularly challenging and loss of bowel control, the need for rapid access to toilets, and unpleasant odours provoked feelings of embarrassment for patients in both hospital and family settings.(29)(30) Whilst patients with CDI reported hospital staff being understanding and sympathetic to their plight,(30) embarrassment, guilt and the uncertainty about how long physically draining symptoms would last were reported to lead to feelings of depression.(29)(31)(32)

Theme 2: Experiencing the response of healthcare professionals to HAI

A recurring theme through all included studies, irrespective of infection or colonisation type, was patient concern regarding the quality of interactions with HCPs. Not being taken seriously was highlighted by some patients with SSI, who knew there was something wrong but felt staff were dismissive of their symptoms.(25)(26) Many patients had limited understanding of their illness or management and experienced frustration when trying to obtain information from HCPs. (19)(23)(24)(25)(31)(33)(34) Some studies reported patients felt information from staff was generally adequate, although they also sought additional information themselves, e.g. via the internet. (19)(20)(30)

Patients perceived that clinical staff's lack of knowledge of specific HAIs was manifested by staff anxiety and uncertainty in how to deal with the patient and inconsistent and sometimes excessive use of protective measures, particularly for colonised patients.(19)(20)(21)(23)(24)(34) This was exacerbated in Sweden by the use of the 'MRSA card',(18)(21) which patients had to present at each healthcare encounter, often leading to concern in HCPs who were uncertain how to react. Colonised

patients also reported that some staff were disrespectful in their interactions, which the patients with MRSA and ESBL perceived as being stigmatising.(21)(23)(34)

Some studies mentioned the adverse impact that MRSA or ESBL had on subsequent restrictions to normal access to healthcare, with patients being excluded from rehabilitation classes,(23) having to wait until the end of clinic appointments to be seen,(24)(34) or not being able to attend clinics at all with staff coming to their home in protective clothing instead.(20)

Conversely, patients who were able to speak to infection specialists reported being given constructive information and being reassured about their condition.(19)(21)(24)(30)

Theme 3: Adapting to life with an HAI

Some patients reported that being colonised or infected with an HAI had little impact on their daily lives.(20)(22)(34) However, a common theme related to post-discharge experience of all colonisation or infection types except SSI, was the fear of transmission of infection and therefore feeling the need to protect others.(18)(19)(20)(21)(23)(24)(29)(31)(32)(34) In many cases, this fear had significant impact on the patient's daily lives, their relationships with family, and implications for their future work and finances.

Concern of possible transmission to family members, particularly grandchildren, was highlighted by many patients with MRSA, CDI and ESBL, with the result that some restricted their contact with family or friends. (18)(19)(20)(23)(24)(29)(31)(32)(34) Patients were unsure whether or not to disclose their MRSA status to others, for fear of being rejected, either within their family or at work.(18)(20) Some patients, primarily those colonised with MRSA, reported being excluded or distanced by family members.(19)(23) Patients with CDI often self-excluded from social events and family contact, not only because of fear of transmission but also due to the unpleasant symptoms which they perceived as socially undesirable.(29)(31)(32) Similarly, patients with SSI and leaking wounds highlighted the impact that 'seeing the wounds' had on close family relationships and the impact that necessary wound care had on both themselves and family carers.(26)(27) Negative impact on sexual relationships was also mentioned, particularly in relation to CDI.(29)(32) Thus all forms of HAI led to adverse consequences on patients' social lives and relationships.

Many patients reported changes they made to taking hygiene precautions. There was evidence from one study that the impact of ESBL infection may have gendered components(34) that is, women were more proactive than men in taking precautions to prevent possible transmission, for example, extensive cleaning at home using alcohol or chlorine, separate toilets, advising family members on

hygiene measures; however, other studies highlighted extensive hygiene precautions being taken with no mention of gendered influences.(18)(20) Other changes to daily living were mentioned by patients with MRSA, often with a significant degree of uncertainty about what was acceptable risk or excessive precaution, for example, cleaning the home,(18)(20) washing hands,(24) avoiding traveling on public transport, playing sports, visiting friends, going to the hairdresser,(23) going to the gym(20) or swimming.(18)

Possible impact on employment or financial concerns was mentioned in a few studies although limited data was provided. For patients with MRSA the primary concern related to whether or not they would be able to work in certain occupations, such as health or child care, and whether or not to disclose their condition to employers or workmates for fear of being rejected.(18)(20) For those with CDI, their concerns related more to their physical capacity to return to work.(29)(31)(32) Again, some but limited mention was made of the financial costs for patients with CDI and SSI who had to hire additional help to assist them with either daily care or household tasks,(29) or whose spouses had to take time off work to provide support.(28) Accounts from patients with SSI suggest that the economic costs for them of adaptations required to their lives post-discharge from hospital could be substantial and often underestimated.(25)(27)(28)

Theme 4: The complex cultural context of HAI

Further conceptualisation of data reported in the previous themes consistently pointed to the influence of the complex cultural context in which infection or colonisation occurs. In comparison to many other medical conditions, 'having an infection' provoked responses in the patient, their family, and clinical staff that were shaped by social norms and expectations of the person 'being clean' versus 'feeling dirty'.(18)(19)(20)(21)(22)(23)(24) These socio-cultural norms were influenced by concerns of 'being contagious' and a risk to others(18)(19)(20)(21)(23)(24)(29)(31)(32)(34) and potentially driven by media stories which may exaggerate the danger of 'super-bugs'.(19)(33) Interestingly, patients with SSI reported a distinction between their infection and MRSA, expressing relief that they didn't have MRSA which they associated with 'dirty' hospitals.(27)(28)

Socio-culturally, competent adulthood is understood through self-control of our bodies and bodily functions; hence experiencing uncontrollable diarrhoea, as in CDI,(29)(30)(31)(32) or seeping, purulent wounds, as in SSI,(25)(27) contradicts the social norm of being in control of body function.

As a consequence of this cultural context for 'infection', patients then faced many challenges in interacting with others, including healthcare professionals, their family, workmates and wider society, around concerns regarding the transmission of infection perceived by both patient and

'others'. These interactions between patient-and-others usually took place in a climate characterised by induced fear and uncertainty, where limited understanding of risk and appropriate risk reducing behaviour was constrained by lack of information and knowledge. This was most striking where front-line healthcare professionals [HCPs] lacked knowledge of the causes and consequences of HAI; could not provide the patient with adequate information,(19)(23)(24)(25)(31)(33)(34); adopted inconsistent infection precautions,(19)(20)(21)(23)(24)(34); and may respond in ways which heighten the patient's feeling of being stigmatised, or 'like a leper'.(20)(21)(23)(34)

The importance of cultural context, place, and time also emerged as influential. This is particularly noticeable in relation to several studies conducted in Sweden during the mid-2000's, when MRSA was relatively rare.(18)(20)(21)(23)(24) Swedish clinical staff at the time seemed highly concerned but perhaps poorly informed about MRSA infection, and colonised patients were given a 'MRSA identification card', which they had to produce at each healthcare encounter; this combination of contextual factors was reported to be perceived as highly stigmatising.

DISCUSSION

To the authors knowledge this is the first qualitative systematic review which comprehensively synthesises evidence of the patient experience of different categories of healthcare associated acquisition of an infection or colonisation. The emerging themes are strongly inter-connected and should be understood as a whole rather than as disconnected components.

In summary: patients' experience of HAI could be expressed as a continuum of physical and emotional responses that were strongly influenced by the varying nature of different forms of HAI. Irrespective of the type of HAI, daily living was often significantly affected; for many patients with MRSA or ESBL, excessively and unnecessarily so, for patients with CDI and SSI unexpectedly and alarmingly so.

For all HAI except SSI, the influence of sociocultural context of HAI was particularly prominent: being seen as 'dirty' and shameful, coloured patient experience, resulting in stigmatization and fear of contamination. In turn, this socio-cultural context also then influenced relationships, resulting in a distancing from family, friends and work, with many patients afraid to disclose their diagnosis for fear of rejection. In particular, patients colonised with MRSA or ESBL noted strong and frequently negative responses from HCPs. Unlike most other medical conditions for which HCPs responses towards patients tend to be supportive, reactions towards and interactions patients with HAIs are particularly informed by socio-cultural discourse. As with members of the wider society, HCPs may be concerned to distance or protect themselves from 'contagious' patients.

The nature of 'contagion', which heavily influenced patients' experiences, needs to be considered within social and temporal contexts which shape how infection and its impact on people is understood at any given point in history.(35)(36) MRSA, in particular, has a 'moral career' in the media associated with attribution of blame around poor hygiene practices of nurses, doctors and hospitals.(37) Thus, broader narratives and media discourse around blame for different types of HAI could, in part, inform patients' understandings of what they were experiencing and others reactions to this.

Symbolic interactionist theory explains that humans create understanding of their 'self' and their situation based on their interpretation of their interactions with others in a specific context.(38): "'selves' experience, suffer, create meaning, and they act".(39)(p.14) Indeed, interpretation of the place of the 'self and others' in the context of HAI strongly shaped patient responses to their experience. Consequently, HAI should be seen as a medical condition to be treated but also as a socially constructed reality that shapes patient experiences and responses of patients, HCPs and family members. Recognizing and understanding this socio-cultural context is essential to being able to provide care that meets patients' needs and concerns.

Interpretation of this qualitative synthesis should also take account of the times and locations of the individual studies. Not all authors provided data collection dates, however where reported, many of the findings related to patient experiences up to the mid-2000's. This temporal aspects of context is relevant particularly in relation to MRSA, as the ability to manage patients effectively may be influenced by HCPs past exposure to patients with MRSA infection. Low prevalence in some countries may contribute to lower staff confidence in dealing with MRSA colonised patients. For instance, in Sweden the incidence of MRSA in all *S.aureus* isolates is relatively low (ranging from 0.54% in 2000 to 1.01% in 2005) in comparison to the UK (43.6%), Greece (42.1%) and Romania (59.8%) in 2005(40) Despite these international variations in prevalence, our review included several Swedish studies of patient experience but no studies from countries with very high (>50%) proportion of MRSA isolates. Increased exposure to HAI cases may reasonably be expected to improve clinical staffs' knowledge and change behaviours over time. Thus previous findings may not necessarily be reflective of contemporary HCP practice.

Biology is important also to recognize. When considering the impact of HAI on daily living, once again similarities and differences, based on the type of HAI, emerge. Patients with MRSA found it particularly difficult to make sense of their experience of colonisation due to being un-symptomatic. Despite this symptom ambiguity, the impact of MRSA on daily life was significant for many patients. The risk literature would suggest that what can be concern or risk in one context is not necessarily so

in another.(41) For patients who are carriers of MRSA it is the hospital context within which they are screened where the carriage of MRSA has the greatest implications for themselves and for other patients who are unwell and vulnerable to infection. The studies synthesised suggest, however, that for HCPs and patients with MRSA, the nature of this risk for everyday lives outside of hospital requires further examination and more proportionate advice should be offered.

Conversely, the physical impact of SSI and CDI symptoms on daily activities was significant. The “horror stories”(27) described in relation to patients’ experiences of SSI were concerning. Such stories are a device used by patients to draw attention to their situation, when not being taken seriously seems beyond belief as their experience of their symptoms is so extreme. The framing of these stories by patients suggests a mismatch between patient experience of SSI and HCPs perceptions of the extreme depth of the emotional and physical impact on patients. Similarly, for patients with CDI, accounts of the emotional and physical effects of profuse, ‘smelly’ diarrhoea heighten awareness of patient’s own distress at their plight. To enable HCPs to provide the necessary information and support for patients, the use of patient stories as a developmental tool for professional learning has grown in recent years.(42)(43)(44)(45) Thus, patient stories of their experiences of HAI could usefully inform HCP education programmes.

The conclusions from this review are limited by the moderate quality and scope of the included studies. In terms of study quality, the appraisal scoring system used(15) is novel and the application of a numerical score to appraise qualitative research may be contentious. However, the robust peer review of analysis and synthesis of the included studies adds rigour to the metasynthesis. These factors should be taken into account in relation to the above discussion.

RECOMMENDATIONS

Future research needs to further explore the complexities of the relationships between biological, social and contextual aspects of HAI and their associated care. In particular, there is a need for greater understanding of the socio-cultural and socioeconomic components of the patient experience of a range of HAI. This work should inform recommendations for how contemporary HCPs can best respond to these socio-cultural influences.

Furthermore, HCPs responses to patients with different types of HAIs require further exploration. Gaps in knowledge or training, particularly in the light of new and emerging antimicrobial resistant organisms should be addressed. Consideration should be given to how HCPs attitudes and behaviours can be shaped, for example, by the use of patient stories or similar educational or behaviour change techniques.

Further research on the impact of HAI on daily activities should inform the development and testing of a patient information approach which deals with immediate concerns and transition to home from hospital, with specific information for different organisms and in relation to infection and colonisation.

CONCLUSIONS

This qualitative systematic review brings together, for the first time, studies into patient experiences of different types of HAIs. Whilst the type of HAI was influential in some respects, the four themes described in this synthesis illuminate the commonalities, as well as distinctions in the patient experience of HAI.

HAI is a significant event in the patient's care journey and subsequent life that is influenced by biological, social and contextual dimensions. Avoiding this unintended consequence is paramount; however, where it occurs, understanding and taking account of the patient experience can help HCPs to interact and respond in a constructive way, providing more effective support at this challenging time.

REFERENCES

- (1) European Centre for Disease Prevention and Control. Point prevalence survey of healthcare-associated infections and antimicrobial use in European acute care hospitals 2011-2012. 2013
- (2) European Centre for Disease Prevention and Control. Annual epidemiological report 2014: Antimicrobial resistance and healthcare-associated infections. 2015.
- (3) Magill SS, Edwards JR, Bamberg W, Beldavs ZG, Dumyati G, Kainer MA, et al. Multistate point-prevalence survey of health care-associated infections. *N Engl J Med* 2014 Mar 27;370(13):1198-1208.
- (4) Allegranzi B, Bagheri Nejad S, Combescure C, Graafmans W, Attar H, Donaldson L. Report on the Burden of Endemic Health Care-Associated Infection Worldwide A systematic review of the literature. 2011. World Health Organisation.
- (5) Allegranzi B, Bagheri Nejad S, Combescure C, Graafmans W, Attar H, Donaldson L, et al. Burden of endemic health-care-associated infection in developing countries: systematic review and meta-analysis. *Lancet* 2011;377(9761):228-241.
- (6) World Health Organization. WHO Global Strategy for Containment of Antimicrobial Resistance. 2001;WHO/CDS/CSR/DRS/2001.2.
- (7) MacDonald P. Exploring patients' experiences of MRSA to help reduce HCAs. *Nurs Times* 2008 03/04;104(9):32-33.

- (8) Mutsonziwa GA, Green J. Colonised and isolated: a qualitative metasynthesis of patients' experiences of being infected with multiple drug resistant organisms and subsequent isolation. *Healthc Infect* 2011;16(4):147-155.
- (9) World Health Organization. WHO Patient Safety: Making health care safer. 2017; WHO/HIS/SDS/2017.11.
- (10) Scottish Government. A Route Map to the 2020 Vision for Health and Social Care. 2013, available from <http://www.gov.scot/Resource/0042/00423188.pdf> (accessed 20.10.17)
- (11) Currie K, Melone L, Reilly J, Stewart SA. The patient experience of healthcare associated infections (HCAI) during admission and post discharge: a systematic review and narrative synthesis – protocol. Available at: http://researchonline.gcu.ac.uk/portal/files/25209339/Currie_ECONI_patient_experience_systematic_review_protocol.pdf (accessed 19.10.17)
- (12) Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ* 2009 Jul 21;339:b2535.
- (13) The Joanna Briggs Institute. Joanna Briggs Institute Reviewers' Manual: 2014 edition 2014.
- (14) CASP. Critical Appraisal Skills programme- CASP (Qualitative Research) Checklist. 2017; Available at: <http://www.casp-uk.net/casp-tools-checklists>, (accessed 19.10.17)
- (15) Chatfield SL, DeBois K, Nolan R, Crawford H, Hallam JS. Hand hygiene among healthcare workers: A qualitative meta summary using the GRADE-CERQual process. *J Infect Prev* 2017;18(3):104-120.
- (16) Noblit G, Hare R. *Meta-ethnography: Synthesizing Qualitative Data*. London: Sage; 1988.
- (17) Liberati, A., et al., 2009. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *BMJ* 339:b2700 available at: doi: <https://doi.org/10.1136/bmj.b2700>
- (18) Andersson H, Lindholm C, Fossum B. MRSA-global threat and personal disaster: patients' experiences. *Int Nurs Rev* 2011 03;58(1):47-53.
- (19) Criddle, P. and Potter, J. Exploring patients' views on colonisation with meticillin-resistant *Staphylococcus aureus*. *B J Infect Cont* 2006;7(2):24-28.
- (20) Lindberg M, Carlsson M, Högman M, Skytt B. Suffering from meticillin-resistant *Staphylococcus aureus*: experiences and understandings of colonisation. *J Hosp Infect* 2009 11;73(3):271-277.
- (21) Skyman E, Bergbom I, Lindahl B, Larsson L, Lindqvist A, Thunberg Sjöström H, et al. Notification card to alert for methicillin-resistant *Staphylococcus aureus* is stigmatizing from the patient's point of view. *Scand J Infect Dis* 2014 06;46(6):440-446.
- (22) 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 08;48(4):275-280.

- (23) Skyman E, Sjöström HT, Hellström L. Patients' experiences of being infected with MRSA at a hospital and subsequently source isolated. *Scand J Caring Sci* 2010 03;24(1):101-107.
- (24) Skyman E, Lindahl B, Bergbom I, Sjöström HT, Åhrén C. Being Met as marked - patients' experiences of being infected with community-acquired methicillin-resistant (MRSA). *Scand J Caring Sci* 2016;30(4):813-820.
- (25) Andersson AE, Bergh I, Karlsson J, Nilsson K. Patients' experiences of acquiring a deep surgical site infection: An interview study. *Am J Infect Control* 2010 11;38(9):711-717.
- (26) Sanger PC, Hartzler A, Han SM, Armstrong CAL, Stewart MR, Lordon RJ, et al. Patient perspectives on post-discharge surgical site infections: towards a patient-centered mobile health solution. *PLoS One* 2014 12/01;9(12):e114016-e114016.
- (27) Tanner J, Padley W, Davey S, Murphy K, Brown B. Patients' experiences of surgical site infection. *J Infect Prev* 2012 09;13(5):164-168.
- (28) Tanner J, Padley W, Davey S, Murphy K, Brown B. Patient narratives of surgical site infection: implications for practice. *J Hosp Infect* 2013 01;83(1):41-45.
- (29) Guillemin I, Marrel A, Lambert J, Beriot-Mathiot A, Doucet C, Kazoglou O, et al. Patients' experience and perception of hospital-treated *Clostridium difficile* infections: a qualitative study. *Patient* 2014;7(1):97-105.
- (30) Madeo, M and Boyack, M. Using the lived experiences of patients with *Clostridium difficile* infection to improve care. *Nursing Times* 2010;106(36).
- (31) Pakyz AL, Moczygemba LR, VanderWielen LM, Edmond MB. Fecal microbiota transplantation for recurrent *Clostridium difficile* infection: The patient experience. *Am J Infect Control* 2016 05;44(5):554-559.
- (32) Zellmer C, De Wolfe T, Van Hoof S, Blakney R, Safdar N. Patient perspectives on fecal microbiota transplantation for *Clostridium Difficile* infection. *Infectious Diseases and Therapy* 2016;5:155-164.
- (33) Burnett E, Lee K, Rushmer R, Ellis M, Noble M, Davey P. Healthcare-associated infection and the patient experience: a qualitative study using patient interviews. *J Hosp Infect* 2010 01;74(1):42-47.
- (34) Wiklund S, Hallberg U, Kahlmeter G, Tammelin A. Living with extended-spectrum β -lactamase: A qualitative study of patient experiences. *Am J Infect Control* 2013 08;41(8):723-727.
- (35) Brachman PS. Infectious diseases - past, present, and future. *Int J Epidemiol* 2003;32(5):684-686.
- (36) Curtis VA. Dirt, disgust and disease: a natural history of hygiene. *J Epidemiol Community Health* 2007 Aug;61(8):660-664.
- (37) Crawford P, Brown B, Nerlich B, Koteyko N. The 'moral careers' of microbes and the rise of the matrons: An analysis of UK national press coverage of methicillin-resistant *Staphylococcus aureus* (MRSA) 1995–2006. *Health, Risk and Society* 2008;10(4):331.

- (38) Blumer H. Symbolic Interactionism [1969]. *Contemporary Sociological Theory* 2012:62.
- (39) Charmaz K, Belgrave LL. Modern Symbolic Interaction Theory and Health. In: Cockerham WC, editor. *Medical Sociology on the Move: New Directions in Theory* Dordrecht: Springer Netherlands; 2013. p. 11-39.
- (40) European Centre for Disease Prevention and Control. Data from the ECDC Surveillance Atlas - Antimicrobial resistance. 2017; Available at: <https://ecdc.europa.eu/en/antimicrobial-resistance/surveillance-and-disease-data/data-ecdc>. (accessed 19.10.17).
- (41) Lupton D. *Risk*. Cambridge: Cambridge University Press; 1999.
- (42) Buckley A, Corless L, Mee S. Using patient stories to reflect on care. *Nurs Times* 2016 03/09;112(10):22-25.
- (43) Callanan C. Recording patient stories as an aid to training and service improvement. *Nurs Manage (Lond)* 2012 12;19(8):20-22.
- (44) Evans G. Patient stories: MRSA is gut-wrenchingly humanized, and lawmakers are listening. *Hosp Infect Control Prev* 2011 07/02:7-9.
- (45) Godfrey K. Time to unleash the potential of patient stories. *Nurs Times* 2015 02/04;111(6):11-11.