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State of the Science Review

Understanding the patient experience of health care–associated infection: A qualitative systematic review

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Background: The global burden of health care–associated infection (HAI) is well recognized; what is less well known is the impact HAI has on patients. To develop acceptable, effective interventions, greater understanding of patients' experience of HAI is needed. This qualitative systematic review sought to explore adult patients' experiences of common HAIs.

Methods: Five databases were searched. Search terms were combined for qualitative research, HAI terms, and patient experience. Study selection was conducted by 2 researchers using prespecified criteria. Critical Appraisal Skills Programme quality appraisal tools were used. Internationally recognized Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were applied. The Noblit and Hare (1988) approach to meta-synthesis was adopted.

Results: Seventeen studies (2001-2017) from 5 countries addressing 5 common types of HAI met the inclusion criteria. Four interrelated themes emerged: the continuum of physical and emotional responses, experiencing the response of health care 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 biosociocultural 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.

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BACKGROUND

Infection or colonization of patients with a health care–associated organism causes preventable adverse clinical outcomes, additional health care costs, and personal costs to patients. In Europe, health care–associated infection (HAI) prevalence was reported at 6% for 2011-2012, 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 1 HAI.[3] International data show 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 colonized patients is problematic and reducing transmission of organisms between patients becomes the critical element of infection prevention and control.[6] For the purposes of this article, both infection and colonization with health care–associated organisms will be referred to as an 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 2 studies on the patient experience of methicillin-resistant *Staphylococcus aureus* (MRSA), and the other[8] included patients with multidrug-resistant infections but focused particularly on the patients' experience of isolation. This evidence gap is important because the World Health Organization[9] and many national government organizations responsible for health care delivery have stated that

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patient-centered, 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 colonization and infection from bacteria that commonly cause HAI.

The review questions for this article are as follows: (1) What is the adult patients' experience of HAI or colonization during or after hospital admission?; (2) What is the perceived impact of infection or colonization on adult patients' daily living, family relationships, finances, and work?; and (3) How does type of infection or colonization influence adult patient experiences?

METHODS

A protocol was developed for the review.[11] Internationally recognized quality standards—the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—were used to design and conduct this systematic review.[12]

Inclusion criteria

The PICoS as noted in Table 1 framework[13] was used to develop eligibility criteria (Table 1).

Search strategy and study selection

A systematic search was performed using MEDLINE, CINAHL, PsycINFO, 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, Joanna Briggs Institute, 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 2 researchers for relevancy by article title and abstract, and then full-text screened against the eligibility criteria. The date of the last search was May 22, 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; and full compliance scored 2. On this basis, and acknowledging the subjective element of quality appraisal, studies scoring ≤10 were ranked as lower quality, those scoring 11-15 were ranked as moderate quality, and those scoring 16-20 were ranked as higher 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 2 independent reviewers.

Table 1

PICoS indicator	Eligibility criteria
Population / Participants	Adult patients (aged over 18) who had experienced an HAI during a hospital admission.
Indicators / phenomenon of Interest	Patients' experiences of colonization 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.

HAI, health care–associated infection.

Table 2
Main themes and associated subthemes

Theme	Associated subtheme
Theme 1: Continuum of physical and emotional responses	• I know vs they say • Experience of physical symptoms • Experience of emotional responses
Theme 2: Experiencing the response of HCPs to HAI	• Frustration of trying to obtain information from HCPs • Inconsistent use of protective measures by HCPs • Stigmatizing interactions • Impact on subsequent health care • Value of interactions with infection specialists
Theme 3: Adapting to life with an HAI	• Fear of transmission of infection • Impact on social relationships • Impact on daily activities • Impact on employment or financial concerns
Theme 4: Complex cultural context of HAI	• Social stigma of contagion • Uncontrolled body

HAI, health care–associated infection; *HCP*, health care professional.

Data extraction

A standardized template was used to record information regarding study characteristics and summarized findings (Supplementary Appendix S1). Original qualitative data, including participant quotes and author interpretations, were extracted separately for each included study and entered onto NVivo software (QRS International, Warrington, UK) to enable meta-synthesis. Data were 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 reanalyzed, 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 or colonization (Table 2). Rigor was maintained by peer review of thematic analysis and team discussion of final interpretations.

RESULTS

Included studies

A Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram[17] of the search and study selection is presented in Figure 1.

Supplementary Appendix S1 presents study characteristics and summarized findings for each included study and the category of quality appraisal.

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