



Carbapenemase-producing Enterobacteriaceae screening: Focused patient insights

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ABSTRACT

Background: Anti-microbial resistance (AMR) is predicted to cause 10 million deaths annually by 2050. This prediction has shaped local policies, with a focus on antimicrobial stewardship and source isolation. However, the impact of these interventions on the individual patient is often overlooked, and the patient perspective is infrequently included in AMR strategies.

Aim(s)/Objective(s): Our objective was to explore the lived patient experience through a Carbapenemase Producing Enterobacterales (CPE) Outbreak. Specifically, we aimed to understand the patient's knowledge of CPE, risks associated with AMR and their experience with rectal screening and source isolation.

Method(s): Using a PPIE (public and patient involvement and engagement) framework, during a CPE outbreak, we engaged in one to one conversations with adult inpatients who had capacity, discussing the effects of AMR exposure. CPE-positive (n = 8) and CPE-negative (n = 2) participants were included. The latter had undergone > 3 CPE screens, were high-risk of AMR acquisition and in source isolation.

Results: Our one-on-one conversations revealed poor levels of patient knowledge about CPE and AMR risk, with many participants expressing concerns about the limited or lack of information provided by healthcare providers. Experiences with rectal screening was generally reported as uncomfortable, with passive acceptance for it. Opinions on source isolation were mixed, with feelings of being bored or lonely emerging as a common sentiment.

Discussion and/or Conclusion(s): These discussions underscore the necessity for improved patient education and communication surrounding CPE and antibiotic resistance, specifically tailored to meet the needs of frailer populations. This study also highlights the critical role of healthcare staff in consistently providing clear information to patients. It is vital patient empowerment is encouraged, and focused efforts made to close this knowledge gap and enhance the patient experience.

Introduction

The increasing prevalence of Carbapenemase-producing Enterobacterales (CPE) exemplifies the growing problem of antimicrobial resistance (AMR) (Sader et al., (2019–2021)). It is predicted by 2050 AMR will account for 10 million deaths annually (O'Neill, 2016). This startling figure has prompted the development of global and local policy, aimed at reducing and containing the spread of AMR pathogens. Among those at an increased risk for CPE infections are the frailer elderly population, owing to multiple comorbidities, exposure to various antibiotic courses, and transitions of care from acute-care hospitals to

community settings (Tinelli et al., 2022). AMR policies often focus on antimicrobial stewardship and source isolation, with little consideration on the impact of these practices on the individual patient (Ukhsa. Framework of actions to contain carbapenemase-producing Enterobacterales., 2022). Despite the value of patient and public involvement and engagement (PPIE) in AMR research, its inclusion in AMR strategy remains inconsistent (Barello and Acampora, 2023).

Given CPE transmissibility, effective containment necessitates screening and isolation protocols. We engaged in PPIE work involving conversations with both CPE-positive and CPE-negative participants to gain insights into their lived experience of CPE screening, isolation, and

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education, as perceived by patients during a CPE outbreak setting.

Methods

This work was undertaken as part of patient and public involvement and engagement (PPIE) activities at a large NHS teaching hospital in the north of England, during a period of increased CPE screening. The patient participants were approached based on recent experience of CPE screening and source isolation. All had capacity to participate and were willing to share their views. Participants ($n = 10$) included both individuals who had screened positive ($n = 8$) and negative ($n = 2$) for CPE.

The conversations were informal and conversational in style, guided by a loose framework developed by the microbiology clinical team in collaboration with IPC. The intention was not to conduct formal interviews but to better understand patients' experiences and perceptions, to inform future service improvement.

Insights were collated contemporaneously through field notes. These were reviewed and grouped inductively by the clinical author in discussion with the wider team, to identify common threads. As this was PPIE rather than research, no formal thematic analysis or coding framework was applied.

This qualitative evaluation was conducted in a large NHS teaching hospital in the north of England during a period of heightened CPE surveillance. Eligible participants were identified by the clinical microbiology team based on recent CPE screening and source isolation. Inclusion criteria included the ability to provide informed consent, recent experience of CPE screening, and capacity to reflect on their experiences.

Results

Limited Understanding of CPE risk

While some patients understood AMR as being related to the overuse of antibiotics, majority of patients either lacked prior knowledge of AMR or held misconceptions about its meaning. A minority of patients associated the term "antimicrobial resistance" with their personal experiences, such as prolonged hospital admissions and antibiotic use.

One participant stated, when asked if they thought AMR was a problem:

"Nothing, because the antibiotics I've been given have reduced the infection markers for me."

Additionally, 3 individuals reported they were told not to worry about antibiotic resistance by medical staff. Most participants did not know why they were moved into source isolation.

Inadequate communication

Nine out of ten patients reported that they had not been properly consulted or informed about CPE by a doctor since their admission and were vaguely informed by other healthcare staff about the need for isolation.

Out of 10 patients, only 3 received the hospital CPE information pamphlet. In addition, one was given a CD player with a video guide. Among these, one patient with upper limb paraplegia was unable to pick up the leaflet, while another struggled to read it due to a lack of reading glasses.

Passive acceptance

There was a general acceptance of rectal swabs for CPE screening as a part of routine hospital care, as exemplified by one participant's opinion:

"I often think that there must be a reason for it, so they wouldn't do it unnecessarily, would they?"

There was a lack of awareness that CPE rectal screening is voluntary, and they could decline the test if they so wished.

Regarding capacity and screening, 7 out of 10 participants believed that in patients who lacked capacity to consent to a CPE rectal swab, a rectal screening swab should still be taken if it can help identify CPE.

Feeling secluded

Opinions on isolation were mixed; some patients appreciated the quiet, while others desired more engagement. All patients, however, reported feeling isolated and bored, their responses revealed masked emotions. One patient said the following:

"...it wouldn't hurt to talk and say, hello, you all right? Do you need anything?"

Discussion

These conversations underscore the need to improve patient education and communication around both CPE and antimicrobial resistance. The current approach, often reliant on passive information delivery, fails to account for the specific vulnerabilities of a frailer inpatient population. Communication must be adapted to accommodate sensory, cognitive, and emotional limitations common in this group.

From this work, and in recognition of the complexities surrounding consent for CPE rectal screening, a submission was made to the hospital's local ethics committee. While the committee acknowledged the broader public health benefit of screening; particularly its role in preventing nosocomial transmission, the direct benefit to the individual patient was considered less compelling. In particular, for patients lacking capacity, the justification for proceeding with CPE screening based on implied consent was felt to be ethically insufficient.

The committee advised that, where capacity is present, formal consent should be explicitly sought. In situations where capacity is lacking, discussion with next of kin or legal proxies is required, alongside consideration of less invasive sampling strategies such as stool collection. This shift reflects a broader move towards balancing population-level infection control measures with the principles of individual autonomy and dignity.

This work also highlights the critical role of frontline staff in maintaining and conveying consistent messaging. Without this, patients remain uncertain about the purpose of isolation and the implications of screening. Bridging this gap will require not only clearer educational materials but also a culture of proactive explanation. Engaging patients meaningfully in their care has the potential to enhance trust, adherence, and ultimately the success of infection control interventions.

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