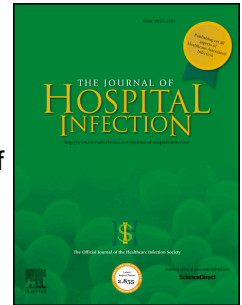


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Becoming patient-centred: sobering insight into CPE-positive patients' experiences of clinical care

B.L. Slevin, N.H. O'Connell, P. Treacy, C.P. Dunne, I. Oliver



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Letter to the Editor

Becoming patient-centred: sobering insight into CPE-positive patients' experiences of clinical care

Sir,

As recently reviewed in this journal by French et al,¹ there is expanding literature regarding carbapenemase-producing Enterobacteriaceae (CPE) outbreaks, control measures and their effectiveness. These papers report the number of cases (CPE infection or colonization) involved in outbreaks, multi-component infection control measures including patient screening; contact precautions (e.g. gowns, gloves); cohorting of patients; and patient isolation. However, there is scant mention of how a CPE diagnosis and subsequent treatment can impact patients' lives.

University Hospital Limerick (UHL) was, in 2011, the site of the first Irish CPE outbreak;² since then, we have reported both outbreaks and their management, with emphasis placed on clinical parameters.³⁻⁵ However, in the context of quality improvement (QI) we recognised that there was a gap in our knowledge relating, specifically, to the experience of those patients central to our CPE incidences.⁶

Concurrent with members of our infection control team participating in a Royal College of Physicians of Ireland (RCPI)-delivered QI Diploma, UHL experienced an increase in newly-identified CPE-positive patients between June and August 2015. This increase provided subject matter for an opportunistic project based on the premise that the social aspects of isolation have been determined in previous research papers,⁷⁻⁹ but that the perspectives of CPE-positive Irish patients had not been captured previously. Cognisant that even a cursory internet search can readily identify multiple alarmist stories of "superbugs", ineffective drugs of last resort and associated deaths leading, in the event of a CPE diagnosis, to increased distress and anxiety for both patients and their families, we sensitively surveyed such patients using a series of open ended questions.

The outcomes were sobering. While patients expressed a high level of satisfaction with the physical design of our newly-established Infection Control Cohort Ward, they were confused by communication to them of their CPE and the explanatory leaflets provided to them. Further, they used emotive terms such as "Leper", "Pariah" and "Plague" to describe their treatment by staff, demonstrating clearly the need for consistent, effective education of healthcare professionals regarding multidrug-resistant organisms and holistic needs of affected patients.

We as healthcare professionals often do not look beyond specimens and infection control aspects of managing patients with CPE. However, the impact of a CPE diagnosis on patients and their families should not be underestimated as it influences both their subsequent quality

of life and future aspirations and, in many cases, involves ongoing engagement with medical treatment and hospitalisations. Listening to the voices of those receiving our care is just the beginning. The challenge is to use these narratives to improve practice and the patient experience.

Conflict of interest statement

None declared.

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B. L. Slevin ^{a,*}

N. H. O'Connell ^{a,b}

P Treacy ^a

C.P. Dunne ^b