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Conference Abstract

EPIC: Developing an experientially based website to support recovery following critical illness

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Abstract

Introduction: Each year, approximately 100,000 patients are admitted to an Intensive Care Unit (ICU) in the United Kingdom, approximately 75% of whom survive to hospital discharge. Survival is associated, however, with a significant burden of physical and psychosocial sequelae. Recovery can be protracted and incomplete, with important and sustained effects upon everyday life, social participation and return to work.

Recovery has been measured, almost exclusively, using standardised questionnaires and experiential knowledge is comparatively rare. We have developed a comprehensive understanding of the recovery process through an integrated programme of qualitative research comprising; a Doctoral thesis (Quality of life following prolonged critical illness: a mixed methods study), focus groups among patients and carers in a randomised controlled trial of enhanced acute hospital rehabilitation (the RECOVER study) and a longitudinal study of informal support and healthcare needs at up to one year following hospital discharge (the RELINQUISH study).

Key findings include: unmet informational needs in relation to the critical illness episode and common critical illness-related morbidity; shortfalls in acute hospital rehabilitation and discharge planning in relation to self-management and access to community resources respectively; a sense of isolation in relation to limited professional or peer community support, and the importance of family in negotiating recovery. In this project, we will work together with patients, families and clinicians to develop an experientially meaningful online resource that will support recovery by providing information (e.g. on common critical illness related sequelae) , advice (e.g. on managing recovery and accessing community resources), peer support and online access to relevant healthcare professionals.

Aim: We will work together with patients, families, and clinicians to develop and pilot a web-based resource that is sensitive and responsive to patients' experiences, needs and preferences.

Methods: We will hold a series of stakeholder meetings comprising former patients, family members and a range of relevant healthcare professionals. We will present our research findings and use a modified Delphi approach to elicit and rank (i) those aspects of experience which are of most importance to patients and family members at key stages and throughout recovery and (ii) potential informational and supportive strategies.

We will then develop web content for presentation at a series of focus groups with lay participants, wherein we will elicit perspectives on its coverage, acceptability and perceived utility. We will also elicit perspectives on: alternative formats (e.g. written word, webcasts, blogs and interactive media); whether and how participants wish to access relevant healthcare professionals for individualised online advice; whether and how participants wish to access other patients and family members for the purposes of peer support and the potential integration of other social media e.g. Twitter. We will use an iterative analytic process and member checking (wherein findings are fed back and validated by participants) to ensure that our resource is responsive to potential users' needs and preferences.

We will pilot our resource among a purposively sampled patient and family population and evaluate it using individual cognitive interviews to elicit “real time” perspectives and to ameliorate “developer effects” and bias.

Keywords:

intensive care, critical care, qualitative, recovery

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