EPIC: A patient and family focused website to support recovery following critical illness

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What’s New in ICU? 26th of June 2013
Funders

- Edinburgh and Lothian Health Foundation
- Scottish Intensive Care Society
- Edinburgh Critical Care Research Group
- Health Services Research Unit
Collaborators

- Prof Tim Walsh (intensivist/researcher)
- Dr Janice Rattray (nurse researcher)
- Prof Pam Smith (nurse researcher)
- Dr Susanne Kean (nurse researcher)
- Dr Tara Quasim (intensivist/researcher)
- Shaun Maher (charge nurse, ICU)
- Mr Bob Glen (former ICU patient)
- Mr Neil Francis (web developer)
Overview

• Background
• A qualitative meta-synthesis
  • Doctoral thesis (QoL following prolonged critical illness)
  • RCT of enhanced rehabilitation (RECOVER study)
  • Longitudinal qualitative study (RELINQUISH study)
• The website so far...
Background

- ~100,000 admissions annually to ICUs in the UK
- ~330,000 ICU bed days (~£500million)
- High in-hospital mortality (~33%)

N.b. Demographic trends
- Absence of central Scottish funding for follow up
- Policy emphasis on primary healthcare
Physical morbidity

- Muscle wasting
- Profound weakness
- Fatigue
- Joint stiffness
- Peripheral neuropathy
- Severe weight loss
- Voice changes
- Hair loss

Adapted from Griffiths et al (1999) BMJ; 319: 427-429
Psychosocial morbidity

**Psychological**
- Anxiety (12-43%)
- Depression (10-30%)
- Post traumatic stress disorder (10-39%)
- Post traumatic stress symptoms (9-51%)

**Cognitive**
- Impaired short term memory
- Impaired executive function (decision making)
A qualitative meta-synthesis*

Interview based research as part of:

- **PhD**: Quality of life following *prolonged* critical illness (2005)

- **The RECOVER study**: Trial of enhanced in-hospital rehabilitation (2010)

- **The RELINQUISH study**: Longitudinal qualitative study of healthcare and support needs at up to 1 year after hospital discharge (2010)

*Over 100 in depth interviews with patients (and some family members) at <1 year after hospital discharge*
PhD: key findings

**ICU experience**
- Amnesia*
- Delirium*
- Hallucinations*

Limited understanding of the critical illness event and morbidity

(*linked to psychosocial morbidity)

**Ward care**
- Amnesia & delirium
- Debilitation
- Dependence
- Specialty specific care
- Staff attitudes

Desperation for hospital discharge
PhD: key findings

Ward rehab
- Importance
- Limitations
- Discharge criteria

Getting home
- Abandonment
- Family
- Self management

Debilitation at hospital discharge

Protracted, incomplete recovery
RECOVER: RCT of enhanced hospital rehabilitation (n=240)

Key elements

• **Case management** (dedicated rehab. assistant)
  • Physiotherapy
  • Dietetic
  • Occupational Therapy
  • Speech & Language Therapy
  • Follow up phone call

• **Information**
  • Common morbidity
  • Consultant visit
  • Lay summary
  • Visit to ICU
  • Intensive Care Recovery Manual (Jones et al)
RECOVER focus groups (n=4)

With patients and families (at >3 months after hospital discharge)

- Importance of information and involvement in care
- Desire for ongoing rehabilitation
- Desire for psychological support
- Importance of family involvement
RELINQUISH: healthcare and support needs

**Aim:** to identify common issues at key stages in the recovery process

Interviews with patients (n=24)
- Prior to hospital discharge
- 4-6 weeks
- 6 months
- 12 months after hospital discharge
RELINQUISH: key findings

- Poor communication between hospital and community (eg home aids and adaptations)
- Ongoing physical and psychological issues
- Limited understanding among GPs
- Financial issues
- Impact on/of family on recovery
Key findings: summary

Improved understanding of the experiences, needs and preferences of patients in terms of addressing the physical, psychological, emotional, economic and social issues they face in their everyday lives.
Website aims

To provide:

- **Information** (e.g. on common problems)
- **Advice** (e.g. on self-management, accessing benefits)
- **Support** (from other patients, healthcare staff)
- **Access to healthcare professionals** (online and real time, face to face)
Development: patient involvement

- Evidence base!
- Study design (co-applicant)
- Concept
- Content (utility, breadth, sensitivity)
- Media
- Personalisation features
- Ease of use
- Online evaluation

focus group methodology
## Schedule of meetings

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<td>FG2 Your time in ICU</td>
<td>FG3 Your time on the wards</td>
<td>FG4 Getting back to normal</td>
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<td>Knowledge Exchange Event</td>
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Expert advisory group

Representation from:
• Intensivists
• ICU nurses
• ICU Follow Up and Outreach services
• Physiotherapy (ICU and ward)
• Dietetics (ICU and ward)
• Occupational Therapy
• Speech and Language Therapy
• Pharmacy
• Chaplaincy
• *Social Work (TBA)
• *Community-based clinicians (TBA)
Expert Advisory Group: purpose

Expert content on:

- Professional role/activities
- Commonly reported issues
- New/bespoke issues raised by patients and families (via contact facility)
- Webcasts
- Consultation? (online or face to face)
The website so far.....
Feedback (focus group work)

“It’s great to hear about other people’s experiences. You do tend to have a sense of isolation...like you’re the only one..”

“I wish there’d been something like that when I came out of hospital. It might’ve saved me a couple of pointless trips to the GP”

“I really like the families' page. You often feel like you’re on the outside of everything....until they come home”
Future work
References


QUESTIONS?

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