The management of patients with clinically uncertain recovery: the ImproveCare feasibility cluster RCT of the AMBER care bundle

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Why was research needed?

This study was led by Dr Jonathan Koffman, from King's College London, in collaboration with University of Hull, and University of Cambridge, supported by South London Collaborations for Leadership in Applied Health Research and Care (CLAHRC) and Clinical Research Network. The study was funded by the National Institute for Health Research (NIHR)*.

Care of unwell hospital patients whose situations are clinically uncertain and at risk of dying is a growing concern.

To improve their care, the AMBER Care Bundle was developed. The AMBER care bundle aims to better identify patients in this group, train healthcare professionals to better communicate their concerns patients and their families, and with them develop what is important to realise their preferences for place of care, and death if relevant. Patients’ status and their wishes are then revisited.

Before hospitals use the AMBER care bundle, we need to know if it is safe and improves care. We therefore investigated where the AMBER care bundle requires improvement and how to conduct a larger study evaluating it compared with usual care. We collected information from patients, their families, and healthcare professionals at different time points. We also examined patients’ clinical notes.

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What did we do?

We worked with 4 district general hospitals across the country, 2 hospital wards supported patients and families with the AMBER care bundle, and 2 carried on supporting their patients and families in their usual way.

We collected information from patients, relatives and healthcare professionals about the study design, the AMBER care bundle, care and treatments at different time points to improve care.

What did we find?

Our findings show the AMBER care bundle was largely acceptable to patients, relatives, and healthcare professionals, and that it was generally supported patients as intended. We successfully recruited and collected information from from 65 very unwell patients at the beginning of the study, and at two further time points (3-5 and 10-15 days). However, very limited data were collected at the final time point due to over a third of all patients (37%) participants being discharged from hospital.

The focus groups with healthcare professionals, and interviews with patients and relatives identified important changes required to improve the way in which the AMBER care bundle operates and supports patients and their relatives, and the way the study was conducted.

For the AMBER care bundle, changes include simplifying the type of patients considered to be appropriate to benefit from its support, and improving the communication training healthcare professionals receive so they can better talk and listen to patients’ and families’ concerns.

The recommendations to improve the study include reconsidering how to recruit potential patient participants in the control arm of the study. The present system involved many hundreds of patients being screened to identify a considerably smaller number. Moreover, some healthcare professionals, especially in the comparison arm found it hard to discuss the nature of the study and clinical uncertainty with patients and families, which hindered recruitment. We also recommend extending the time for recruitment, and simplifying the consent processes to involve more patients. Last, how much data required from patients must be reconsidered to reduce the burden placed on them, many of whom were very frail and unwell. If these changes were made a future trial of the AMBER care bundle may be possible.

What is next?

- We will be making some suggestions about how the AMBER care bundle can be refined.
- Our findings will be published in academic, open-access journals.
- We will disseminate our findings to academic and clinical audiences at international conferences (e.g. 16th World Congress of the European Association for Palliative Care - May 2019)

THANK YOU!
We are very grateful to all patients, families, healthcare professionals, public patient representatives and research staff who made contributions to our study.

*Cicely Saunders International
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