Supporting patients with uncertain recovery: the use of the AMBER care bundle in an acute hospital

Simon Noah Etkind, Jennifer Karno, Polly M Edmonds, Irene Carey, Fliss E M Murtagh

ABSTRACT

Objectives Patients who are deteriorating, with uncertain recovery and with a short prognosis often have complex needs. The AMBER care bundle systematically manages these patients by promoting consistent communication and care planning. To describe how the AMBER bundle is applied in a UK hospital. To identify factors affecting the use of the AMBER bundle in patients who subsequently died. To gain preliminary data with regard to potential markers of deterioration in groups less frequently supported by AMBER

Methods Retrospective review of electronic case notes for all deaths over 11 months on five inpatient wards where AMBER was implemented.

Results N=149. Median age 80, IQR 72–87. Admission diagnoses: cancer (25%), non-cancer (31%), multimorbidity (44%). 38% were supported by AMBER. Patients with cancer were more frequently supported by AMBER (62% vs 30% p<0.001). Illness trajectory was defined a priori as ‘predictable gradual’ (40%), ‘predictable rapid’ (22%), ‘unpredictable’ (21%) or ‘sudden death’ (17%). ‘Predictable gradual’ deterioration resulted in more frequent support by AMBER (62% vs 21%, p<0.001). Patients were supported by AMBER after median 10 days of admission (IQR 5–17 days), and died median 9 days later (IQR 3–15 days). Patients with multimorbidity or unpredictable deterioration were less frequently supported by AMBER. Potential markers of deterioration were acute kidney injury, delirium, falls and comorbidity.

Conclusions The use of the AMBER care bundle is affected by illness trajectory and diagnosis. Future work should clarify predictors of deterioration in patients with an unpredictable course.

BACKGROUND

Health needs are often highly complex in advanced illness. Identifying patients who are deteriorating with uncertain recovery allows us to support complex needs with tools such as the AMBER care bundle. The AMBER care bundle is used in hospital inpatients who have been identified as facing uncertain recovery and are at risk of dying in the next 1–2 months. The tool requires nursing and medical staff to develop a clear plan for the patient’s further care, including a decision on escalation of care, and to include the patient and family in care planning. The patient’s status is reassessed daily, and communication with the patient and family is prioritised. The AMBER care bundle therefore provides a systematic approach to managing complex needs and uncertain recovery, and allows patients and medical teams to be clearer about the aims of treatment, without limiting its scope.

The AMBER care bundle is a relatively new intervention and requires evaluation. As part of this evaluation we should describe how it is used, and identify whether patients who could benefit from it are identified. Here, we describe how the AMBER care bundle is used in patients who subsequently die in hospital. Many patients supported by AMBER survive to hospital discharge, and we are therefore describing only one aspect of this tool.

Initially, we observed which patients were supported by the AMBER bundle, and factors affecting this. One such factor is trajectory of illness, a concept which has been investigated, but is less well understood in final hospital admission. Then we looked for patients who were not as frequently supported by this tool to see if there is potential to identify these patients better. Evaluation of these aspects of the AMBER care bundle’s use will help to change practice and improve care.
AIM
To describe factors affecting the use of the AMBER care bundle in patients who die in hospital, particularly the effect of illness trajectory; and to gain preliminary data with regard to patients who deteriorate unpredictably.

METHODS
Case-note review: We undertook, in a single teaching hospital, a retrospective case-note review of all patients who died over an 11 month period in five medical wards where the AMBER care bundle was implemented. Two reviewers shared data collection from electronic case notes, accessed from a National Health Service (NHS) computer. The reviewers cross-checked their work to ensure consistency. One reviewer collected further information from the fully computerised medical records, using an agreed proforma.

Disease categories: Patients were allocated disease categories based on their main reason for admission. This was either ‘cancer’, ‘non-cancer’ or ‘multi-morbidity’ (defined as ≥two major comorbidities).

Illness trajectories: Based on initial data we defined trajectories of final illness among patients who died. These were defined a priori as ‘predictable-gradual’, ‘predictable-rapid’, ‘unpredictable’ and ‘sudden death’ (see figure 1). Categorisation was by two reviewers based on medical records and disagreements were resolved by discussion—this method has previously resulted in good agreement when assessing suitability for AMBER care bundle at case-note review. We also recorded the length of terminal phase—defined clinically as the point from which patients consistently deteriorated to death.

Specific groups: Some patients had an unpredictable trajectory with poorly recognised deterioration (group C, figure 1). We identified potential markers of deterioration in this group. We collected data on variables that might inform prognosis.

Analysis: Data were collated in a spreadsheet and analysed in SPSS V19 using descriptive statistics. The relationships between trajectory of illness, disease category, use of the AMBER bundle and length of admission were investigated using $\chi^2$ testing for categorical data, and Kruskal-Wallis and Mann-Whitney U testing for continuous data.

Ethics: This project was approved by the authorised signatory for service evaluation studies at the NHS Trust concerned.

RESULTS
Our sample of 149 had a median age of 80, IQR 72–87. Length of stay was median 15 days (IQR 8–25 days, maximum 278 days), and length of terminal phase was 10 days (IQR 5–17 days, maximum 83 days).

AMBER care bundle: 56/149 (38%) of our sample were supported by the AMBER care bundle. Median time in hospital prior to its start was 10 days (IQR 5–17 days) and patients died a median of 9 days (IQR 3–15 days) later; 23/37 (62%) patients with cancer were supported by the care bundle, which was significantly more than the 33/112 (30%) of patients recorded the length of terminal phase—defined clinically as the point from which patients consistently deteriorated to death.

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A. Predictable- gradual deterioration during admission
- Patient has life limiting diagnosis
- Poor prognosis recognised
- Deterioration over > 7 days to several weeks with time for discussion of prognosis and end of life care preferences

B. Predictable- rapid deterioration during admission
- Admitted with very poor prognosis
- Deterioration recognised, but little time for advance care planning
- Deterioration over 24h -7 days until death

C. Unpredictable course during hospital admission
- Not expected to die during hospital admission but potential risk of deterioration
- Change in clinical course over 24h – 7 days with either a new diagnosis or an unexpected progression of a known illness.

D. Sudden death
- Either death within hours of admission or,
- Unexpected event leading to death over minutes to hours during admission
- No scope for planning. Recognition difficult

Figure 1 Illness trajectory definitions.
without cancer ($\chi^2=13.055, p<0.001$). Patients supported by the care bundle had a longer admission ($U=3581.5, p<0.001$) and longer terminal phase ($U=2545.5, p=0.001$).

Trajectory of illness: 60/149 (40%) of patients had predictable-gradual deterioration. Thirty-seven (62%) of these patients were supported by the AMBER care bundle. This was more than other trajectories ($\chi^2=26.346, p<0.001$). Predictable-gradual illness trajectory also resulted in longer admission ($H=48.395, p<0.001$) and longer terminal phase ($H=68.941, p<0.001$). (See table 1).

Thirty-one patients deteriorated unpredictably. These patients were less frequently supported by the AMBER care bundle, and a higher proportion (19, 61%) had multimorbidity. These patients had a median length of stay of 12 days (IQR 5–34) before the terminal phase. Terminal phase lasted median 5 days. We found high admission rates of acute kidney injury (AKI), delirium and falls in this population (See table 2).

**DISCUSSION**

**Use of the AMBER care bundle**

For the first time we have described how the AMBER care bundle is used across patient groups in patients who subsequently die in hospital. We have identified patient groups which were less frequently supported. This is important because it increases our understanding of which patients are reliably identified as deteriorating.

Patients whose deterioration is better understood are more likely to be supported by the AMBER care bundle, and two factors affect the understanding of deterioration. First, recognition of deterioration takes time; we found that patients who were supported by the AMBER care bundle were admitted to wards which used the care bundle for several days before they were supported by it. The rapidly deteriorating group of patients may therefore have deteriorated too quickly to be identified as suitable for AMBER.

Second, the illness trajectory of some conditions, such as cancer, is better understood than others, and these patients were more frequently supported by the care bundle. Patients with multimorbidity were less frequently cared for by the AMBER care bundle, which could indicate that they are less easy to identify. This is important because in an ageing population, the prevalence of multimorbidity will increase. We need to be able to identify and support these patients effectively.

**Importance of predictability**

It is important to know that some patients deteriorate unpredictably since this is the first step in identifying

**Table 2 Prevalence of possible predictors of deterioration in the unpredictable group**

<table>
<thead>
<tr>
<th>Potential markers of deterioration on admission</th>
<th>Unpredictable group (from case-note review)</th>
<th>Hospital population (from discharge data)</th>
<th>Wider population (From literature)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls/collapse</td>
<td>39%</td>
<td>1.9%</td>
<td>3%</td>
</tr>
<tr>
<td>Delirium</td>
<td>35%</td>
<td>2.4%</td>
<td>20.7%</td>
</tr>
<tr>
<td>Acute kidney injury</td>
<td>29%</td>
<td>7.7%</td>
<td>7.2%</td>
</tr>
<tr>
<td>Admissions in last year mean, median</td>
<td>1.16, 1</td>
<td>–</td>
<td>3.5</td>
</tr>
<tr>
<td>Karnofsky performance status mean, median</td>
<td>39, 40</td>
<td>–</td>
<td>5.3, 10</td>
</tr>
<tr>
<td>Abnormal physiology*</td>
<td>29%</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Length of stay (days) Mean, median</td>
<td>34, 17</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Charlson comorbidity index</td>
<td>2.9, 3†</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

*Defined as local early warning score >2.
†A Charlson score of 3 equates to 19.27% 1-year mortality.
Short report

and supporting them prospectively. In our unpredictable group, patients were in hospital for several days before they deteriorated, and subsequently deteriorated rapidly. These patients were supported less frequently by the AMBER care bundle and could have been better supported had they been identified, and the care bundle used earlier in the phase where prognosis was uncertain.

There was high prevalence of AKI, delirium and falls on admission in the unpredictable group. These were much higher than comparator data sources. These should be investigated as possible predictors of deterioration.

Limitations

The AMBER care bundle is a complex intervention and we present evidence on only one component of this since we focused only on patients who died. Since we used mortality data, we cannot comment on the 58% of patients supported by the care bundle who survived to hospital discharge in this time period. This was a single site design, and there is evidence that the AMBER care bundle is used differently in different hospitals. To fully evaluate AMBER, a multisite design is needed, and this is in development.

The retrospective nature of case-note reviews intrinsically limits the relevance of illness trajectory to clinical practice. Further work is needed to assess the usefulness of allocating illness trajectory prospectively.

Analysis of the unpredictable group was limited by small subgroup size. Furthermore our case-note review method is likely to have different sensitivity to the methods used to estimate prevalence of AKI, delirium and falls in discharge data and the literature. This difference in data collection methods limits the comparison between these sources.

CONCLUSION

We have described the use of the AMBER care bundle in a hospital population. In those who died, the AMBER care bundle was more frequently used where there was more certainty regarding deterioration to death, compared with those where there was greater uncertainty. Some groups of patients whom the AMBER bundle was designed to support (ie, those with multimorbidity and an unpredictable illness trajectory) were less frequently supported, suggesting that in this hospital the care bundle is not yet being used as effectively as hoped. We have suggested markers which might identify patients who deteriorate unpredictably, and further investigation of these is warranted. These findings will be useful to further development the AMBER care bundle and other tools for the care of patients with uncertain recovery.

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Contributors

SNE was involved in project design, data analysis and drafting and revision of the article. SNE is the guarantor. JK was involved in data collection, analysis and reviewed drafts and approved the final paper. PME was involved in project design, reviewing and approval of the paper. IC was involved in conceptualising and review of the project and final approval of the paper. FEMM was involved in project design, drafting and reviewing of the paper and final approval. FEMM is the guarantor. The palliative care team at King’s College Hospital were involved in data collection.

Competing interests

None.

Ethics approval

This project was approved by the authorised signatory for service evaluation studies at the NHS Trust concerned.

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