## Guideline for the management of terminal haemorrhage in palliative care patients with advanced cancer discharged home for end-of-life care

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## ABSTRACT

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Received 22 March 2012 Accepted 17 July 2012 Published Online First 4 September 2012 **Objective** Terminal haemorrhage is a rare and distressing emergency in palliative oncology. We present an algorithm for the management of terminal haemorrhage in patients likely to receive end-of-life care at home, based on a literature review of the management of terminal haemorrhage for patients with advanced cancer, where a DNAR (do not attempt resuscitation) order is in place and the patient wishes to die at home.

**Method** A literature review was conducted to identify literature on the management of terminal haemorrhage in patients with advanced cancer who are no longer amenable to active interventional/invasive procedures. Electronic databases, the grey literature, local guidelines from hospitals and hospices, and online web portals were all searched systematically. The literature review was used to formulate a management algorithm.

**Results** The evidence base is very limited. A threestep practical algorithm is suggested: preparing for the event, managing the event ('ABC') and 'aftercare'. Step 1 involves the identification and optimisation of risk factors. Step 2 (the event) consists of A (assure and re-assure the patient), B (be there – above all stay with the patient) and C (comfort, calm, consider dark towels and anxiolytics if possible). Step 3 (the aftercare) involves the provision of practical and psychological support to those involved including relatives and professionals.

**Conclusion** Terminal haemorrhage is a rare yet highly feared complication of advanced cancer, for which there is a limited evidence base to guide management. The suggested three-step approach to managing this situation gives professionals a logical framework within which to work.

#### **INTRODUCTION**

Terminal, catastrophic or life threatening bleeding is an uncommon palliative care emergency.<sup>1</sup> It is a feared and dreaded complication of advanced cancers, most notably, but not exclusively, of the head and neck.<sup>2</sup> The distress associated with terminal haemorrhage is multi-factorial, with the sight of blood a notable cause of trauma to those witnessing this event, including relatives and caregivers.

With the growing demand from patients to be discharged home for terminal care, the potential for terminal haemorrhage to occur in the home setting is likely to rise, thus increasing the current dilemma for patients, relatives, caregivers and healthcare professionals, who will be faced with the prospect of managing a terminal haemorrhage in the patient's home. When the home has been identified as the preferred place of care and/or death, it is important to assess the feasibility of home management in the event of terminal haemorrhage. However, alerting the patient and family to the possibility of a terminal haemorrhage is complex: the patient and family must be prepared for this possibility but creating and escalating fear of an event which may never happen must be minimised.

In an inpatient setting, the event will probably be managed by healthcare professionals, but in the community setting it is likely to be the family and caregiver who largely manage the event because of the rapidity of onset and likelihood that a healthcare professional may not be present. By definition, a terminal haemorrhage may result in death in minutes.<sup>1</sup> It is important to assess the patient and family's understanding of the condition and prognosis, along with their coping strategies, before mentioning the risk of major haemorrhage.

Management of terminal haemorrhage in the home setting therefore warrants specific considerations, particularly where the preferred place of care and/or death is the home and in order to facilitate an alternative to admission to a hospice or hospital.

## **METHODS**

Electronic databases were searched using MetaLib which searches the following: EMBASE (1980-2011), Ovid MEDLINE (1980-2011), Pubmed (1980-2011), the Cochrane Library (2011) and the grey literature of guidelines for the management of terminal haemorrhage. Local guidelines from hospitals and hospices in the UK were also reviewed via an online web portal (palliativecareguidelines. scot.nhs.uk) and the Google Scholar search engine. The search strategy employed the following keywords: 'terminal haemorrhage', 'terminal bleeding', 'catastrophic bleeding', 'carotid artery rupture', 'advanced cancer', 'haemorrhage and terminal care', 'palliative care emergencies', 'palliative' and 'home care'. Searches were limited to articles in English relating to human adults up until October 2011. Exclusion criteria were children, surgical, invasive, radiotherapy or stenting management.

The above search did not yield any guideline specifically aimed at the management of terminal haemorrhage in patients discharged home to die. However, 40 potentially relevant articles were retrieved and reviewed. Ten articles were chosen as being relevant (table 1). Two further articles were used to source information on the background, investigations and general management of terminal haemorrhage in the palliative care setting.<sup>12</sup> Pertinent evidence was graded using the criteria developed for creating clinical guidelines (figures 1 & 2).<sup>3</sup>

#### RESULTS

Articles retrieved using the above searches were used to obtain an overview of current evidence and published expert opinion of 'best practice' in order to develop an algorithm for the management of terminal haemorrhage in patients with advanced cancer within the specialist palliative care setting, where a DNAR (do not attempt resuscitation) order is in place and the patient's wish is to die at home.

This algorithm is relevant to oncology, specialist palliative care, general practice and primary care, and haematology.

The key studies informing the development of this guideline are listed in table 1. These reports concentrate solely on the management of patients with advance cancer in a palliative care setting who have exhausted feasible surgical, radiotherapeutic, endovascular, stenting and other invasive options.

The currently available evidence is classed as grade 3 and 4 (non-analytical studies, expert/consensus opinion) and was used to inform the development of the algorithm. The current version of the algorithm was not developed in a formal consensus process (ie, with expert opinions supported by a scientific organisation), but simply reflects the authors' opinions based upon review of the current literature. Thus the recommendations resulting from this limited evidence base are class D (figure 2). Wider comment and contributions are invited.

## **Definition and incidence**

The current published literature suggests that haemorrhage or bleeding is likely to occur in 6-10% of patients with advanced cancer.<sup>4</sup> In contrast, terminal haemorrhage – bleeding which is considered to be "major, from an artery, which is likely to result in death within a period of time that may be as short as minutes" – has a reported incidence of 3-12%.<sup>1</sup> These figures are likely to be an over-estimate of the true incidence of terminal haemorrhage due to the nature of the data on which they are based, which have been evaluated elsewhere.<sup>1</sup>

The incidence of terminal haemorrhage in different cancer types varies, being highest in head and neck cancers (with a reported incidence of carotid artery rupture of 3-4% in this patient group).<sup>1</sup> However, in a recent study of patients with advanced haematological malignancies in a palliative homecare programme, 123 out of 469 patients (26%) developed significant episodes of bleeding with two being the median number of haemorrhages per patient.<sup>5</sup>

The variability in reported incidences is due to many factors with potential contributors including the varied aetiological and patho-physiological processes culminating in a terminal haemorrhage.<sup>6</sup> Furthermore, there is no agreed definition and terms such as 'terminal haemorrhage', 'catastrophic bleed', 'major bleed' and 'haemorrhagic complications in patients with advanced cancer' are used inter-changeably in the published literature.

| 1++ | High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias  |
|-----|---|
| 1+  | Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias   |
| 1-  | Meta-analyses, systematic reviews, or RCTs with a high risk of bias   |
| 2++ | High quality systematic reviews of case control or cohort or studies<br>High quality case control or cohort studies with a very low risk of confounding or bias and<br>a high probability that the relationship is causal |
| 2+  | Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal   |
| 2-  | Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal   |
| 3   | Non-analytic studies, e.g. case reports, case series  |
| 4   | Expert opinion  |

Figure 1 Grading of published studies.

A: based on ≥ one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; <u>or</u> based on evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results
B: based on evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; <u>or</u> extrapolated evidence from studies rated as 1++ or 1+
C: based on evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; <u>or</u> extrapolated evidence from studies rated as 2++.
D: Based on evidence level 3 or 4; <u>or</u> extrapolated evidence from studies rated as 2+

Figure 2 Grading of recommendations.

## **Feature**

## Patho-physiology and causes of terminal haemorrhage

Terminal haemorrhage results in a rapid reduction in the circulating blood volume and can be due to internal (ie, erosion of thoracic or abdominal vessels resulting in haemoptysis and haematemesis, respectively) and external factors (ie, rupture of the carotid or femoral artery).<sup>6</sup> Bleeding may occur following local insult to the vessel as a result of cancer, surgery, radiotherapy or tumour invasion, or a systemic process such as coagulopathy, thrombocytopenia or disseminated intravascular coagulation.<sup>4</sup>

Causes of terminal or catastrophic bleeding can be categorised into three classes: (i) the tumour itself; (ii) treatment related factors; and (iii) systemic or other factors (figure 3).

Tumour-related factors associated with an increased risk of bleeding include fungating and haematological malignancies, the location and size of the tumour (ie, large head and neck carcinomas abutting the vascular bundle in the neck)<sup>7–9</sup> as well as coagulopathy secondary to liver metastases or bone marrow involvement.

Treatment-related factors predisposing to an increase risk of bleeding include surgical procedures (eg, radical neck dissection) and radiotherapy, which remains the most commonly implicated risk factor for bleeding in head and neck tumours, as well as poor or complicated wound healing.<sup>2</sup>

Systemic factors associated with an increase bleeding risk include thrombocytopenia, disseminated intravascular coagulation (DIC), coagulopathy, age >50 years, 10–15% loss of body weight and common co-morbidities such as diabetes mellitus.<sup>2</sup>

# Signs and symptoms that may be suggestive of impending terminal haemorrhage

A 'sentinel', 'herald' or warning bleed is any bleeding that may precede a life threatening haemorrhage.<sup>1</sup> In practice, this definition denotes any bleed, regardless of how trivial or small, and should raise the alarm for risk factor identification and modification (figures 3 and 4). Impending bleeds in head and neck cancers may present as ballooning or visible pulsatile arterial vasculature.<sup>10</sup> Minor bleeds should be investigated when appropriate for evidence of underlying vascular damage which may predispose to a catastrophic bleed.<sup>11</sup> Equally, direct observation of a fragile artery during previous surgical intervention may help identify patients at risk. Imaging (CT, MRI, US Doppler or PET scans) may also reveal arteries or vessels susceptible to bleeding.

Of particular importance, as some patients may have no predisposing signs or symptoms before a terminal haemorrhage, healthcare professionals should be alert to this possibility in all patients with risk factors prior to discharge home for terminal care.

#### Management of terminal haemorrhage

Management of terminal haemorrhage in patients with advanced cancer follows a dual model of care with the emphasis on supportive care alongside symptom control with pharmacotherapy. The current consensus and models of care for the management of terminal haemorrhage in the palliative care setting are founded on a limited body of evidence. The limitations arise from the absence of grade 1 and 2 evidence,

| Tumour-related factors  | Treatment-related factors:   | Systemic ('Other') factors:   |
|---|--|---|
| <ul> <li>Tumour type – head and neck<br/>tumour, haematological malignancies,<br/>fungating tumours, Gastrointestinal<br/>tumours with previous bleeding</li> <li>Tumour size</li> <li>Tumour site – close to major vessels<br/>(review anatomy and imaging)</li> <li>Metastasis/secondary tumours i.e.<br/>liver metastasis</li> </ul> | <ul> <li>Surgical interventions i.e. radical neck dissection, post-operative haematoma</li> <li>Radiotherapy</li> <li>Wound-healing complications i.e. poor wound healing, infections</li> <li>Fistula i.e. Pharyngocutaneous</li> <li>Fungating tumour with artery invasion.</li> </ul> | <ul> <li>Haematological complications:<br/>thrombocytopenia, Bone-marrow<br/>failure, DIC- disseminated<br/>intravascular coagulation,<br/>coagulopathy</li> <li>*Co-morbidities: diabetes<br/>mellitus, age &gt; 50, 10-50% loss<br/>of body weight</li> <li>*Drugs – anti-coagulants,<br/>warfarin, low-molecular weight<br/>heparins.</li> </ul> |

Figure 3 Risk factors for terminal haemorrhage.

#### Modify modifiable factors to reduce the risk of bleeding:

- Rationalisation of anti-coagulants, weighing the risk of bleeding against the risk of thrombotic complications for patients on drugs such as warfarin, heparin, nonsteroidal anti-inflammatory drugs (NSAIDs). These drugs may potentiate the risk of bleeding.
- Review drugs that may interfere with the coagulation pathway and or potential platelet dysfunction i.e. Aspirin, SSRI, Sodium valproate

Figure 4 Modifiable factors to reduce the risk of bleeding

and thus the recommendations arising from grade 3 and 4 evidence have recommendation levels C and D. Much of the current published literature is therefore based on consensus and 'expert' opinion, with the empirical data limited to one case report, one case series and one retrospective qualitative study of healthcare professionals' experiences.<sup>2 11</sup> <sup>12</sup>

The aim of management is (i) to initiate supportive measures and (ii) to administer crisis medications.

#### Supportive measures

The presumed fatality associated with a severe life threatening haemorrhage, the limited time available for active management and the shock of the event itself along with the setting (hospital, hospice or home) are all factors that work synergistically to increase the stress and challenge of managing a terminal haemorrhage.

## Speak reassuringly to patient

Defusing the anxiety associated with this stressful situation is important for the effective management of terminal haemorrhage in a hospital/hospice setting as well as in the patient's home where access to medical facilities and other healthcare professionals is limited. Consequently, accepting the limits of the situation is a key goal in enabling delivery of reassurance and support to the patient with catastrophic bleeding.<sup>13</sup>

## Dark towels to reduce the distress of the visibility of the bleed

The distress associated with terminal haemorrhage is multifactorial. However, the sight of blood is a notable cause of trauma to those witnessing this event as well as to the patient themself.<sup>4</sup> The use of dark towels disguises large volumes of blood and decreases the associated distress. This has long been a recommendation and more recent research has confirmed the perceived benefit of this practice.<sup>2</sup> This should be relayed to relatives or carers in the home setting to ensure that dark towels are immediately available in the home.

## The use of crisis medications in the event of terminal haemorrhage

To date, most published guidance and indeed current practice advocates the use of sedatives or anxiolytic (crisis) medications as the mainstay of the management of terminal haemorrhage.<sup>12</sup>

#### Use of sedatives

The current practice of using sedatives or anxiolytics – most commonly midazolam administered by any feasible route

– aims to reduce the distress of the patient.<sup>4</sup> An initial dose of midazolam of 10 mg (intravenously/subcutaneously/intramuscularly or via the buccal route) is commonly recommended with the aim of inducing rapid sedation in case the patient recovers and remembers the event. Importantly, the use of crisis medications is not aimed at hastening death but at reducing awareness (and therefore distress) until the inevitable outcome of death has occurred.<sup>6</sup>

## Opioids

While opioids are suggested in some guidelines, several concerns with this practice are reported in the literature.<sup>1</sup> For example, the administration of large doses of opioids to patients without pain raises ethical dilemmas and the connotation of 'back door euthanasia'.<sup>114</sup> Consequently, opioids are only recommended where the patient is clearly not about to die and is complaining of pain and/or breathlessness.<sup>2</sup>

The focus on the administration of these medications in a distressing, challenging and stressful environment may leave individuals caring for the patient feeling demoralised and incompetent.<sup>2</sup> The qualitative study by Harris *et al*<sup>27</sup> on the use of crisis medication in the management of terminal haemorrhage due to incurable cancer, provides evidence to support the potentially detrimental effect that the administration of crisis medication has on the caregiver or healthcare professional managing the event. These studies revealed a strong consensus among nurses who have actively managed terminal haemorrhages that the use of crisis medication is unnecessary, and limited observed benefits to support the administration of sedatives/anxiolytics in the management of terminal haemorrhage. The report also highlighted the practical limitations and challenges presented by the focus on the administration of medications, not least the efficacy of any drug, by whatever dose or route, in patients who are undergoing a major bleeding episode capable of depleting the circulating blood volume with such rapidity that death can occur within in a few minutes.<sup>15</sup>

Current guidelines vary as regards the suggested dose, choice of drug and route of administration in this scenario and a UK-wide survey found a similar variation in prescribing practice for 'crisis medication', with intramuscular midazolam 10 mg most commonly employed.<sup>16</sup> Correctly, some authors have raised multiple concerns about the likely efficacy of such doses in patients already on higher doses of benzodiazepines or with

| A -assurance (and re-<br>assurance)                        |   |  |
|--|---|--|
| event had been anticipated - Reassure the patient that you | <b>B</b> -be there!<br>Above all stay with the patient.   |  |
| are here with them and will remain with them               | When and where possible offer<br>to hold the patient's hand and<br>speak reassuringly to maintain<br>a controlled-atmosphere of<br>support. | <b>C</b> - comfort and calm<br>Comfort measures to optimise<br>dying with dignity should be<br>employed such as use of dark<br>towels, and, if feasible<br>administration of anxioytic<br>medications. |

a history of substance misuse and in patients with rapid loss of circulating blood volume impairing absorption, distribution and therefore the efficacy of the drug.<sup>1</sup>

As a result, the emerging recommendation for the management of terminal haemorrhages is for healthcare professionals and/or relatives to remain with the patient, providing comfort and support in the little time available.<sup>2</sup> When possible, crisis medications should be considered, and given when practical (figure 5). However, the mainstay of management in the event of major haemorrhage is to remain with the patient and provide verbal support, using dark towels to disguise the sight of blood.<sup>2</sup>

## ALGORITHM FOR THE MANAGEMENT OF TERMINAL HAEMORRHAGE IN PALLIATIVE CARE PATIENTS WITH ADVANCED CANCER DISCHARGED HOME FOR END-OF-LIFE CARE

Managing terminal haemorrhage in a healthcare institution is challenging. However, in the patient's home, where access to medical facilities and other healthcare professionals is limited, this event may generate a distressing, challenging and stressful environment for those caring for the patient. Consequently, based on existing evidence, the guideline and management algorithm below have been created to facilitate preparation for a terminal haemorrhage, management of the event and postevent care for all involved in the home setting (figure 6).

## Step 1: Preparing for the event

#### Identify patients at risk of bleeding (risk factors for bleeding)

Consider the potential and risk of bleeding in patients with certain tumour, treatment or systemic-related factors (figure 3). Further evaluate the risks with reference to the anatomical location, size and site of the tumour and any recent radiological imaging to confirm tumour proximity to the local vasculature.

## Modify risk factors when and where appropriate

Modifiable risk factors should be identified and when and where possible addressed to reduce the risk of bleeding (figure 4).

#### The role of the multidisciplinary team

At the multi-disciplinary team (MDT) meeting, a decision should be made about discussing the possibility of a terminal haemorrhage with the patient and their family. Whether or not to alert the patient and their family to the possibility of a terminal haemorrhage is a difficult decision as they should be prepared but this may introduce fear of an event which might never happen. In an inpatient setting the decision may be to not tell the patient and their family, but in the community setting the family and caregiver are likely to primarily manage the event because of the rapidity of onset and likelihood that a healthcare professional will not be able to get to the home in time.

It is useful if discussions about how a terminal haemorrhage should be managed at home involve a number of professionals, including a palliative care consultant/specialist nurse, the general practitioner (GP), district nurses, hospice-based community palliative care teams, and the patient and their family. The results of such discussions should be shared with the out-of-hours team, hospice team, community palliative care nurses, district nurses and local ambulance team. A record of the discussion may also be kept with the community DNAR order to enable easy access in the event of the emergency. The MDT should explore the role of a '999' call in this situation, particularly if the local ambulance service are able to place an 'alert' on such calls from the patient's address. The role of the ambulance (or paramedic car/motorbike) would be to provide acute support during the immediate distress of the event, as they are likely to be the first healthcare professionals capable of reaching the home quickly. The role of the ambulance crew is not to resuscitate the patient or provide admission to

#### PREPARATION FOR THE EVENT 1) Identify patients at risk i.e. those with:

- Head and neck cancers
- Haematological cancers
- Tumours invading or at close proximity to major vessels

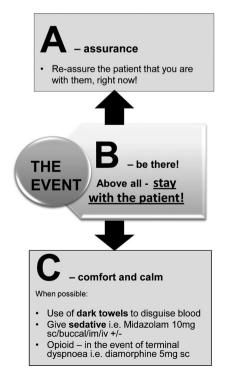
#### 2) Modify risk factors:

 Identify modifiable factors and implement measures to REDUCE risk i.e. stopping anticoagulant drugs.

## 3) Engage in sensitive discussions.

When appropriate with:

- Patients and relatives
   Other professionals i.e. palliative care team, GP, district nurses, out-of-hours team, and local ambulance team.
- Consider discharge with anxiolytics, opioid, community orders against resuscitation.



# Supportive measures: Provide immediate support and reassurance to family, caregivers, and staff present. Disposal of waste: Dispose of clinical waste as appropriate – i.e. using yellow bags provided to patient on discharge. Psychological support: Offer on-going psychological support, bereavement

AFTER THE EVENT

support, bereavement counselling +/- debrief session for all involved including family, care-givers and staff.

Figure 6 Algorithm for the management of terminal haemorrhage in the community.

|  | Table 1 | mary of key studies in the literature review |
|--|---------|--|
|--|---------|--|

| Author  | Title  | Database                          | Grading of<br>evidence | Grade of<br>recommendation |
|---|--|-----------------------------------|------------------------|----------------------------|
| Harris and Noble <sup>1</sup>                     | Management of terminal hemorrhage in patients with<br>advanced cancer: a systematic literature review  | 2010 EMBASE (Ovid)                | Grade 4                | D                          |
| Harris <i>et al</i> ²                             | The use of crisis medication in the management<br>of terminalhaemorrhage due to incurable cancer:<br>a qualitative study*  | 2011 EMBASE (Ovid)                | Grade 4                | D                          |
| Cartoni <i>et al</i> <sup>5</sup>                 | Hemorrhagic complications in patients with advanced<br>hematological malignancies followed at home: an<br>Italian experience                                       | 2009 MEDLINE<br>(Ovid),<br>PubMed | Grade 4                | D                          |
| Harris <i>et al<sup>7</sup></i>                   | Nurses' views of the coping and support mechanisms<br>experienced in managing terminal haemorrhage*  | 2011 Ovid                         | Grade 4                | D                          |
| Rimmer <i>et al</i> <sup>10</sup>                 | Management of vascular complications of head and<br>neck cancer  | 2011 Pubmed                       | Grade 4                | D                          |
| McGrath and Leahy <sup>13</sup>                   | Catastrophic bleeds during end-of-life care in<br>haematology:controversies from Australian research*  | 2009 PubMed                       | Grade 4                | D                          |
| Pereira and Phan <sup>4</sup>                     | Management of bleeding in patients with advanced<br>cancer*  | 2004 Pubmed                       | Grade 4                | D                          |
| García-Egido and<br>Payares-Herrera <sup>18</sup> | Managing hemorrhages in patients with head and<br>neck carcinomas: a descriptive study of six years of<br>admissions to an internal medicine/palliative care unit* | 2011<br>MEDLINE (Ovid),<br>PubMed | Grade 3                | D                          |
| Richards <sup>8</sup>                             | Guidelines for the management of airway bleeding and carotid artery rupture, September 2007*   | September 2007                    | Grade 4                | D                          |
| Hume and Wilcox <sup>9</sup>                      | Guidelines on the management of bleeding for palliative<br>care patients with cancer, November 2008*   | November 2008                     | Grade 4                | D                          |
| MacKay and Cook <sup>19</sup>                     | Policy, procedure & guideline for the management of carotid artery rupture related to the terminal care of the head & neck cancer patient*                         | January 2011                      | Grade 4                | D                          |
| Johnson <i>et al</i> <sup>20</sup>                | Management of a Catastrophic Terminal Event.<br>July 2008 3 counties cancer network  | July 2008                         | Grade 4                | D                          |

a healthcare institution. This should be clearly discussed and recorded with the ambulance service.

If being discharged home from a hospital/hospice, the patient should be supplied with a 'crisis pack' – a container for the storage of crisis medications (ie, anxiolytics). Crisis packs may have a limited role in a rapid terminal haemorrhage but may be used to contain other useful items such as dark towels and yellow disposal bags for blood stained items. While in many cases the crisis pack will not be used (due to a variety of issues identified by Harris *et al*<sup>2</sup>), it is still worthwhile ensuring that such packs are present in the home, particularly if the bleeding event is not a true terminal event but a major bleed which continues for some time before resulting in death and during which there would be a much clearer role for anxiolytic medication.

Some patients may express a preference to be admitted to a hospice or hospital should bleeding start and this should be respected. However, in a true terminal haemorrhage there is a high likelihood of death before reaching the destination or even before the ambulance arrives. Professionals may review more closely the presence of risk factors and communicate a 'best judgement' of high or low risk to the patient in sensitive discussions (eg, a patient with a head and neck tumour encroaching on the carotid artery who has experienced 'herald' bleeding is at high risk, as opposed to a patient with a tumour in the vicinity of the carotid artery but with no other risk factors who is at lower risk) and allow the patient to consider options of place of care. Most patients perceived to be at risk of terminal haemorrhage will never actually experience the event, which is the underlying challenge in communicating risk to the patient.<sup>1</sup> Nevertheless, and particularly for patients at home, this risk should be broadly raised. The degree to which the professional can explore the detail of the potential scenario with the patient will be highly dependent on the knowledge, understanding, insight, acceptance and coping strategies of the patient and their family. These are challenging conversations to facilitate and may be best undertaken by a more senior or experienced member of the team of professionals looking after the patient.

#### Step 2: Managing the event

The most important aspect of management in the event of a terminal haemorrhage in the home setting is to remain with the patient – "above all stay with the patient".<sup>17</sup> The patient and their relatives should be reminded and re-assured of this during these discussions. The crisis pack should be accessed when practicable, however as death may occur within minutes, the relative should aim to stay with the patient, providing verbal support and disguising the sight of blood with dark towels until such time as he/she is able to access further assistance.<sup>2616</sup>

The general objective for the management of terminal haemorrhage in patients with advanced cancer, where a DNAR order is in place and the patient has been discharged home for end-of-life care, is to follow the 'ABC' (figure 6): Assure, Be there, and Comfort and calm. In the stressful and anxious environment created by the sight of blood and distress of the event, it can be challenging to recall algorithms and goals of management. Consequently, the ABC aide memoire aims to simplify the processes involved and defuse some of the anxiety associated with the situation, while providing support for all individuals present at the event. Although this guideline is aimed primarily at healthcare professionals, in reality healthcare professionals may not be at the patient's home at the time of the event. Furthermore, as death may occur within minutes (as is expected in a terminal haemorrhage), the event may be over before the arrival of a district nurse, palliative care nurse or any other healthcare professional from the community setting. Consequently, the relative may find it helpful to dial '999' in order to obtain acute support during the immediate distress of the event. The role of the ambulance crew is not to resuscitate the patient or (necessarily) provide admission to a healthcare institution but to support the patient and their family in managing the patient at home. Thus, the ABC aide memoire provides an overarching management principle to be adapted and used in conjunction with and in support of caregivers.

## Step 3: After the event

## Supportive measures

Following the event, all individuals (relatives and healthcare professionals alike) involved in the management of a terminal haemorrhage should be offered support to facilitate postevent adjustment. This is particularly important for families as feelings of bereavement following such a traumatic death are likely to be distressing and may require extended delivery of aftercare such as postevent debriefing and counselling.<sup>13</sup>

#### **Disposal of waste**

The aftermath of a terminal haemorrhage can be upsetting and may involve blood staining of items such as clothes, furniture and carpets. Consequently, support is required by the family to facilitate cleaning, clearing and disposing of waste items. Thus it may be appropriate to provide families with yellow bags when patients are discharged home from hospital for use in the disposal of waste following the terminal haemorrhage. This may be part of the crisis pack along with dark towels and anxiolytics.

The body of the deceased patient will need to be collected, cleaned and prepared for burial or cremation in keeping with the wishes of the patient and their family.

**Contributors** EU formulated the idea, algorithm and aide memoire, compiled the guidelines and wrote the drafts. DGH edited the drafts.

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#### REFERENCES

- Harris DG, Noble SI. Management of terminal hemorrhage in patients with advanced cancer: a systematic literature review. *J Pain Symptom Manage* 2009;38:913–927.
- Harris DG, Finlay IG, Flowers S, et al. The use of crisis medication in the management of terminal haemorrhage due to incurable cancer: a qualitative study. Palliat Med 2011;25:691–700.
- Scottish Intercollegiate Guidelines Network (2002), SIGN 50. A guidelines developer's handbook. Edinburgh. Scottish Intercollegiate Guidelines Network.
- Pereira J, Phan T. Management of bleeding in patients with advanced cancer. Oncologist 2004;9:561–570.
- Cartoni C, Niscola P, Breccia M, et al. Hemorrhagic complications in patients with advanced hematological malignancies followed at home: an Italian experience. *Leuk Lymphoma* 2009;50:387–391.
- Hanks G, Cherny NI, Christakis NA, et al. Oxford Textbook of Palliative Medicine. Fourth Edition. Oxford, UK: Oxford University Press 2010.
- Harris DG, Flowers S, Noble SI. Nurses' views of the coping and support mechanisms experienced in managing terminal haemorrhage. Int J Palliat Nurs 2011;17:7–13.
- Richards B. Guidelines for the management of airway bleeding and carotid artery rupture. 2007. Available from: http://www.royalfree.nhs.uk (accessed 10 December 10 2011).
- Hume B, Wilcox S. Guidelines on the management of bleeding for palliative care patients with cancer. *Yorkshire Palliative Medicine Clinical Guidelines Group*. 2008. Available from: http://www.ycn.nhs.uk (accessed 10 December 2011).
- Rimmer J, Giddings CE, Vaz F, et al. Management of vascular complications of head and neck cancer. J Laryngol Otol 2012;126:111–115.
- Oneschuk D. Subcutaneous midazolam for acute hemorrhage in patients with advanced cancer. Can Fam Physician 1998;44:1461–1462.
- 12. Forbes K. Palliative care in patients with cancer of the head and neck. *Clin Otolaryngol Allied Sci* 1997;22:117–122.
- McGrath P, Leahy M. Catastrophic bleeds during end-of-life care in haematology: controversies from Australian research. Support Care Cancer 2009;17:527–537.
- 14. **Finlay I**. 'Assisted suicide': is this what we really want? *Br J Gen Pract* 2005;**55**:720–721.
- 15. Back I. Palliative medicine handbook. Third Edition. Cardiff, UK: BPM Books 2001.
- Harris D, Noble SI. Current practice in the management of terminal haemorrhage by palliative care teams in the U.K. *Palliat Med* 2010;24:S232.
- Kane KK. Carotid artery rupture in advanced head and neck cancer patients. Oncol Nurs Forum 1983;10:14–18.
- García-Egido AA, Payares-Herrera MC. Managing hemorrhages in patients with head and neck carcinomas: a descriptive study of six years of admissions to an internal medicine/palliative care unit. J Palliat Med 2011;14:124–125.
- MacKay F, Cook C. Policy, procedure & guideline for the management of carotid artery rupture related to the terminal care of the head & neck cancer patient. Available from: http://www.ruh.nhs.uk (accessed 10 December 2011).
- Johnson S, Wilderspin N, Reid C et al. Management of a Catastrophic Terminal Event. 3 Counties Cancer Network. July 2008. Available from: http://www. the3ccancernet.org.uk (accessed 10 December 2011).



## Guideline for the management of terminal haemorrhage in palliative care patients with advanced cancer discharged home for end-of-life care

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