

Enquiry into Practice: Management of Terminal Catastrophic Intracranial Haemorrhage in Palliative Care.

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Abstract

The management of terminal catastrophic haemorrhage is a rare clinical palliative emergency for which the management is based largely on anecdotal and experiential guidelines, with no high grade evidence but rather robust contention and controversy. Whilst often rapid and deadly, inevitably dramatic and devastating for the treating health professionals and family, the key management areas include risk identification, supportive practices, the use of sedative medication and the ethical issues faced in the management of terminal haemorrhage.

Keywords: *Terminal catastrophic bleed, fatal intracranial haemorrhage, palliative care emergency, crisis medications, supportive measures.*

Introduction

Terminal catastrophic haemorrhage, including intracranial haemorrhages, in the palliative care setting is a rare clinical reality that has profound effects encompassing imminent and rapid death of the patient and distressing and dramatic implications for the health care staff and the patient's family. The management of this clinical palliative emergency is based largely on anecdotal and experiential guidelines, with no high-grade evidence, rather robust contention and controversy.

By definition, a terminal catastrophic haemorrhage is a major arterial bleed whereby death is rapid due to the significant internal or external loss of blood volume (Harris & Noble 2009). The clinical context for the purpose of this enquiry into practice is in the advanced cancer demographic in "whom invasive or interventional procedures and cardiopulmonary resuscitative measures are no longer appropriate" (Harris & Noble 2009, p 914). The goals of care are for supportive palliative care and comfort (Pereira & Phan, 2004).

With respect to the assessment task it is evident that there is a paucity of literature directly related to terminal catastrophic cerebral or intracranial bleeds. In much of the literature, it is often referenced in relation to tumours of

the head and neck within the haematological cancer literature and management guidelines identified under various generic terminologies including palliative emergencies, bleeding, acute or sudden severe haemorrhage.

Patients with large intracranial haemorrhages may be identifiable as presenting with a rapid onset of neurological symptoms, decreased consciousness related to increased intracranial pressure and a low Glasgow Coma Scale (GCS) rating (Quinones Hinojosa, Gulati, Singh & Lawton, 2003). Koji, Manabu, Osamu, Takahiro, Toshikazu, Junya & Naoyuki (2014) also identify the rare but evident cases of radiation induced intracranial aneurysms in the head and neck tumour patient population. As these aneurysms originate from arterial walls they can rupture, dissect the artery and produce catastrophic extravasation of arterial blood leading to subsequent hypovolaemia and possibly death (Koji et al., 2014). Definitive diagnosis requires radiological imaging, however in end-stage palliative management this would be unnecessary.

Harris & Noble (2009) submit that most of the figures quoted in the literature related to patients with head and neck cancers but there was no definitive data available for death by haemorrhage or type of cancer. More acutely Chen, Tai, Tsay, Chen, & Tien (2009) identified intracranial haemorrhage as the second leading cause of death in the acute myeloid leukaemia patient population and 14% of patients died of fatal haemorrhage in the in-

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duction phase of treatment. Quinones-Hinojosa et al (2003) identified acute leukaemia with thrombocytopaenia and the haemophilia patient population at risk of death caused by massive intracranial haemorrhage - fatal in 50% of cases. From the literature and available guidelines it seems that irrespective of the location of the fatal haemorrhage, the planning, care, support and management appears to be largely the same.

Palliative care is the primary specialty at this Victorian small sub-acute facility comprising of an inpatient ward and community nursing service. Surprisingly, there are no written policies, procedures, clinical pathways or hospital guidelines available for the management of catastrophic haemorrhage. In separate discussions with the manager of the Community Palliative Care Service, the Nurse Unit Manager of the in-patient ward and the Clinical Director of Palliative Care, the key areas that management identified were: risk identification, supportive practices such as having dark towels to camouflage blood loss, the importance of staying with the patient, anticipatory medication orders for midazolam and morphine either intramuscularly or intravenously, staff support and advanced care planning. However, all these practices and knowledge were experientially based and historically rooted in current practice.

This did however, support much of the literature on the palliative management of terminal haemorrhage and the level of evidence available to guide practice. Harris & Noble (2009) highlight in their systematic literature review that none of the literature on the palliative management of terminal haemorrhage was above a Level 5 on the Oxford Centre for Evidence Based Medicine Level of Evidence (2009). Level 5 evidence is rated as "based on expert opinion without explicit critical appraisal or based on physiology, bench research or first principles" (Harris & Noble 2009, p 915). This similarly reflects the level of evidence rated as Level 5 in the more recent Joanna Briggs Institute (JBI) Best Practice Recommendations with particular reference to using crisis medications in the palliative care terminal haemorrhage scenarios for both inpatient and community care scenarios (JBI, 2014). McGrath & Leahy (2009) also submit that there is scant research on the topic of catastrophic bleeds during end of life care, identifying personal preference and anecdotal reports guide health professionals. Whilst the focus of their research and guidelines is end of life haematology, the broader

care and supportive management overlap in both identified practices as well as the controversies.

The incidence of catastrophic bleeding is rare in the advanced cancer population and is cited by Harris & Noble (2009) to be between 3-12 % or 6-10% (McGrath & Leahy, 2009). Whilst rare, catastrophic bleeds are a significant palliative care emergency associated with certain, often imminent death. Within the literature there are 3 - 4 key areas, including identifying at risk patients, employing key supportive measures, the use of sedative medication and ethical issues faced in the management of terminal haemorrhage (Harris & Noble, 2009).

Chen et al. (2009) identify in their retrospective study prolonged prothrombin time, prior brainstem haemorrhage, subarachnoid haemorrhage and epidural haemorrhage as prognostic factors in intracranial haemorrhage in acute myeloid leukaemia patients, particularly the acute promyelocytic leukaemia sub group of patients. Quinones Hinojosa et al., (2003) cite Graus, Rogers & Posner's (1985) work that identifies the acute promyelocytic leukaemia patient population as high risk, given more than 60% die of intracranial haemorrhage. Whilst early detection of coagulopathy and swift correction can reduce haemorrhagic complications (Chen et al., 2009), Pereira & Phan (2004) suggest the benefit versus burden of anticoagulant therapy and monitoring must be considered, particularly in advanced disease.

In the head and neck cancer population the main risk factors are surgery, radiotherapy, postoperative healing issues, visible arterial pulsation, the presence of a pharyngocutaneous fistula, fungating tumours with artery invasion and other generalised factors such as being over the age of 50years, 10-15% body weight loss, malnourishment, diabetes, immunodeficiency, generalised atherosclerosis, a smaller precursor bleed and direct radiological observation of a tumour infiltrating an arterial wall (Harris & Noble, 2009). McGrath & Leahy (2009) report the possibility of identifying patients at risk of a catastrophic bleed as controversial but more relevant to the haematology patient group, identifying acute leukaemia, lymphoma and myeloma patients citing thrombocytopenia and disseminated intravascular coagulation as high risk symptoms.

Paradoxically, the distinct unpredictability of terminal haemorrhage is a clinical reality de-

scribed in the Harris, Finlay, Flowers, & Noble (2011) study when unexpected patients haemorrhaged. Therefore, awareness by all nursing staff of the potential and a clinical care pathway seems crucial to streamline care and management, particularly in relation to supportive measures and to support and educate new, less experienced staff or students within the organisation.

Much of the emphasis is placed on planning and implementation of supportive practice should terminal haemorrhage occur. Again the literature is limited to Level 5 evidence, based on a few case reports and expert opinion (Harris & Noble, 2009; Joanna Briggs Institute, 2014). In the literature review by Harris & Noble (2009) and subsequently Harris et al. (2011) qualitative research, merit was identified in the timely implementation of supportive measures. They implore the importance of staying with the patient, providing psychological support to patients and their family, applying pressure if bleeding is external, using dark coloured or green towels to camouflage blood, positioning patients in a lateral position, applying oxygen and importantly debriefing and peer support for staff. Harris et al., (2011) identify through staff interviews that staying with the patient overrode the importance of getting crisis medication. They also identified that this is not what the guidelines have previously focused on as priority.

These measures are reflected in the Therapeutic Guidelines in Palliative Care (Palliative Care Expert Group, 2010) and are further supported by the Yorkshire Palliative Guidelines (Yorkshire Palliative Medicine Clinical Guidelines Group, 2008) and the Scottish Palliative Care Guidelines on bleeding (NHS Scotland, 2014), which propose the assurance that someone is with the patient at all times and suggest that patient support and non-drug management might be more important than any crisis medication. The Care Management Guidelines for Emergencies in Palliative Care Tasmania denote in bold, the imperative of not leaving a patient alone if they are having a severe acute haemorrhage (Department of Health & Human Services, 2009). Nauck & Alt - Epping (2008) identify that one of the most important obligations in palliative care is being with the patient at this time.

After such an event, it is widely acknowledged that supportive debriefing and counseling of staff and family is valid. Yet Harris & Noble (2009) identify that the management of children who witness such an event is poorly rec-

ognised. The Yorkshire Palliative Medical Clinical Guidelines Group (2008) and Scottish Palliative Care Guidelines (2014) support whole team debriefing and ongoing bereavement support to families and staff members as a necessary component of care.

Whilst high profile in the literature and theoretically sound, medication administration at this time is also based on limited evidence and has never been formally assessed (Harris et al., 2011). There is no clinical evidence available to inform best route of sedative agent in the management of terminal haemorrhage (Harris & Noble, 2009). While the aim in medication administration during a terminal catastrophic haemorrhage is generic in assuaging distress and providing comfort, much contention arises across the literature in relation to the type of medication to use - benzodiazepine versus opioids or both, the route - subcutaneous (S/C), intramuscular (IM), intravenous (IV) or rectal (PR), the dosage or indeed whether to use any medication at this time.

Harris et al., (2011) conclude in their qualitative study that the use of crisis medication in the management of terminal haemorrhage due to incurable cancer rarely benefits the patient and can detract from the supportive nursing care. In fact there was "complete concordance" (Harris et al. 2011, p693) between medical and nursing staff on this point. This practice is supported by the JBI Best Practice recommendations for the use of crisis medications with palliative care patients experiencing terminal haemorrhage in both the hospital and community setting and states "providing support to the patient is the priority" (JBI 2014, p2), and unless prefilled syringes are instantly available little benefit in their use is suggested in the community setting. The JBI (2014) encourages the administration of crisis medications IV if access is available in the inpatient setting.

Although the notion of prefilled syringes is discussed variably in the literature, it is a questionable practice forbidden in some organisations for sound ethical and legal reasons. Whilst supportive measures are front-line, medication administration is thought to benefit if the dying process is not as rapid as anticipated. In the absence of PICC/IV lines, IM administration of midazolam 10mg is preferred and repeated at 10 minutely intervals if indicated.

The Yorkshire Palliative Care Guidelines (2008) for the management of bleeding for

palliative care patients with cancer, do inform and advise that if it is felt to be appropriate to have medication ordered, it should be rapid and readily available for IM or IV administration, as the S/C route is likely to be ineffectual due to peripheral shutdown and its' unpredictable absorption and metabolism. Consideration of whether the patient is opiate-naïve or not, should be raised. Comprehensively, the guidelines do suggest other options such as diazepam PR, midazolam buccally and lorazepam sublingually if nursing staff were not present - such as at home.

The Tasmanian Care Management Guidelines in Emergencies in Palliative Care advocate as wise, the practice of having a crisis order where the identified risk of severe bleeding and death is "inevitable", purporting the merit of rapid sedation to avoid the anxiety and distress the symptoms of shock produce (Department of Health & Human Services, 2009). These guidelines are more focused around the intervention of medication administration at the time of haemorrhage and promote having the medications drawn up ready for use as well as some expectation that the family may need to administer them. Nowhere in these guidelines are debriefing or bereavement support outlined, rather the focus is on the merit of explanation to the family of the use of medications.

McGrath & Leahy (2009) nominate agreement by the health professionals on the issue of administering sedation and pain relief to patients having a catastrophic bleed as an important supportive strategy. Pereira & Phan (2008) cite other less recent publications in support of having rapid sedative medications available and families instructed on S/C administration. Whilst the Therapeutic Guidelines: Palliative Care (Palliative Care Expert Group, 2010), support that the unlikely effect of medications being administered in time to relieve any distress and emphasise the practice of staying with the patient, they do however propose that medications being in the home with instructions on how to administer may relieve anxiety. The local Community Palliative Care Service does not allow pre-filled syringes. However there may be anticipatory medications and orders in the home of patients identified at risk.

Pereira & Phan (2004) and the JBI (2014) advocate for family members and health care providers to be sensitively informed of the risk and management plan of the potential for a terminal haemorrhage, as these events are

always distressing. Individual consideration, respecting the different capacities of individuals and families is felt to be the better premise and the consensus identified by McGrath & Leahy (2009). The Yorkshire Guidelines on the management of bleeding for palliative care patients with cancer (Yorkshire Palliative Medicine Clinical Guidelines Group 2008), support that the assessment of each particular individual and family must be weighted, citing good practice offers the opportunity for patients and families to raise concerns related to management or mode of death and especially the consideration of the presence of children in the home. Nauck & Alt-Epping (2008) propose that to a greater extent in relation to impending haemorrhage than any other palliative care emergencies, good communication, explanations and the establishment of a rapport in advance with the patient and family is warranted.

McGrath & Leahy (2009) identify the importance of advanced care directives or a statement of choices, so that the appropriate course of management is adhered to should a catastrophic bleed occur, as well as preparation of the carers in the home situation. The Yorkshire Palliative Medicine Guidelines (Yorkshire Palliative Medicine Clinical Guidelines Group, 2008) advocate that discussions and decisions regarding bleeding management should be made early, documented and shared with all service providers including out of hours services. They advocate that advanced care directives for those identified as high risk for major bleeding must be individualised, reviewed and clearly documented.

The Therapeutic Guidelines in Palliative Care (Palliative Care Expert Group, 2010) emphasise that if a haemorrhage is anticipated, then planning must include preparation of the carers of the potential and how to provide comfort, which is felt to be paramount. The Tasmanian Care Management Guidelines (Department of Health & Human Services, 2009) identify the importance of planning, anticipating and having a strategy that is communicated early with balancing information to the patient and carer in a way so as not to provoke anxiety waiting for the inevitable which may never eventuate. This reflects some ethical issues raised in the literature related to informing the patient of the risk of terminal haemorrhage, timing and method of discussing patient preferences versus their right to know, the merit of outlining an event that may never occur, but potentially increasing anxiety at a time of heightened angst

(Harris & Noble, 2009; McGrath & Leahy, 2009).

With increased clinical awareness and management of this phenomenon, as well as the identified lack of policies or procedures related to the management of catastrophic bleeds, it is believed that the development of a clinical pathway and supporting hospital policy is warranted. Whilst the local practice is sound within the current national and international guidelines, formal documentation rather than the reliance on historical practice regimes would be a positive educational tool for new staff and students.

Conclusion

There is clearly a scarcity in the literature regarding the management of catastrophic hemorrhages in the palliative care population. Several international guidelines exist to help guide practice. However there is no consensus regarding the pharmacological interventions and management strategies for these events. As this event is an inevitably dramatic and devastating for the patient, their family and the health professionals involved, potentially triggering psychological trauma for those witnessing it, further research and evidence is required to guide practice and develop clear procedures to optimise management and attain positive end-of-life outcomes.

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