

Stroke Care - More Than Just Saving Brain

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“My grandfather died of a stroke 14 years ago. The one thing that troubles my mother to this day is whether it was the right thing not to hydrate him as he was dying.”¹

Most physicians who treat patients who suffer from a stroke are aware that the burden of suffering can be immense and not limited to the victim of the stroke. There has been very little research, however, that explores the means available to help individuals and families cope with this suffering. Patients, their families and health care providers frequently struggle with issues such as the role of artificial nutrition and hydration in the context of a rapidly deteriorating condition. Blacquiere et al, in this edition of CJNS², found evidence of conflict, in their study of the palliative care provided to patients and their families after severe strokes. Interactions between health care staff and patient’s families around hydration and feeding contained conflict in 45.7%. This retrospective study is important because it adds data to this under-researched area.³

Importantly, they also demonstrate how a palliative approach can be provided by non-palliative care specialists, aided by a simple order set. There is increasing evidence that order sets (such as the Liverpool care pathway⁴ and Palliative care for advanced disease⁵) can enhance the care provided to patients with life-limiting illness. Specialist palliative care providers will find gaps in the actual order set (e.g. where is the referral to spiritual care?, where is the use of haloperidol for management of agitated delirium?) and may question the “knee-jerk” use of certain medications (e.g. scheduled morphine without a pain assessment in opioid naïve patients, or scopolamine which will add to dry mouth but whose efficacy in reducing “death rattle” is in doubt⁶). However the right intent is there and that deserves praise. A palliative approach - attending to the physical, social, psychological and spiritual needs of patients and their families⁷ living with critical illness- can prevent and relieve suffering. Such an approach can enhance the quality of life of people regardless of the length of prognosis and has an emphasis on living well and not only dying well. When palliative medicine was recognized as a medical specialty in the United Kingdom in 1987, it was defined as “...the study and management of patients with active, progressive, far-advanced disease, for whom the prognosis is limited and the focus of care is the quality of life”⁸ and palliative medical care was primarily directed at individuals living with advanced cancer. Many experts in palliative medicine would now agree that palliative medical care is not disease-specific, and should not be limited to end-of-life care.

Language is very important when discussing palliative interventions. The authors point out how families express the “recurring idea that “palliative care” meant “no care””, and yet the article itself refers to treatment as “active” or “palliative”. It may be better to speak in terms of goals of care as “comfort

orientated” or “comfort and life prolonging” in intent. Note that attention to comfort is present in both goals and is not the exclusive preserve of patients who are dying. Interventions and support intended to maximize quality of living should be provided concurrently with interventions intended to control disease, where appropriate, or they can be the entire focus of care when no disease-modifying interventions are available⁹.

Frequent, recurrent, compassionate communication with patient and their families after a sudden, devastating stroke is a necessity. This needs to be a core part of any guideline or care pathway in palliative care. By understanding and appreciating the beliefs and values of our patients and their families, it is usually possible to find the consensus between their goals of care and what it is medically appropriate to provide. The knowledge, skills and attitudes required in order to provide comfort, manage symptoms and support individuals and families are not necessarily intuitive and are very frequently not well taught in medical schools^{10,11}. Opportunities exist to improve collaboration between neurologists, the inter-professional team and specialist palliative care providers to address gaps in the provision of palliative care for stroke.

This work from Halifax helps those of us who practice stroke medicine remember that our role is not just to provide disability preventing treatments such as thrombolysis, but also to treat people who are at the end of their life after a stroke, with the goal of maintaining dignity and comfort.

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REFERENCES

1. Author’s quote – Simon J.
2. Blacquiere DPV, Gubitz GJ, Dupere D, McLeod D, Phillips S. Evaluating an organized palliative care approach in patients with severe stroke. *Can J Neurol Sci.* 2009;36:731-4.
3. Stevens T, Payne SA, Burton C, Addington-Hall J, Jones A. Palliative care in stroke: a critical review of the literature. *Palliat Med.* 2007;21(4):323-31.
4. Veerbeek L, van Zuylen L, Swart SJ, van der Maas PJ, de Vogel-Voogt E, van der Rijt CC, et al. The effect of the Liverpool Care Pathway for the dying: a multi-centre study. *Palliat Med.* 2008; 22(2):145-51.
5. Luhrs CA, Penrod JD. End-of-life care pathways. *Curr Opin Support Palliat Care.* 2007;1(3):198-201.
6. Wee B, Hillier R. Interventions for noisy breathing in patients near to death. *Cochrane Database Syst Rev.* 2008 23;(1):CD005177.

7. World Health Organization. Geneva. WHO definition of palliative care. [updated 2009; cited 2009 Sept 4]. Available from <http://www.who.int/cancer/palliative/en/>.
8. Doyle B, Hanks G, Cherny N, Calman K. Section 1: introduction. In: Doyle B, Hanks G, Cherny N, Calman K, editors. Oxford textbook of palliative medicine. Oxford: Oxford University Press; 2005. p. 1.
9. Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, et al. A model to guide hospice palliative care: based on national principles and norms of practice. 2005 August [cited 2009 Sept 4]. Available from http://www.chpca.net/resource_doc_library/model_to_guide_hpc/A+Model+to+Guide+Hospice+Palliative+Care+2002-URLUpdate-August2005.pdf.
10. Ostgathe C, Voltz R, Nauck F, Klaschik E. Undergraduate training in palliative medicine in Germany: what effect does a curriculum without compulsory palliative care have on medical students' knowledge, skills and attitudes? *Palliat Med.* 2007;21(2):155-6.
11. Pereira J, Pautex S, Cantin B, Gudat H, Zaugg K, Eychmuller S, et al. Palliative care education in Swiss undergraduate medical curricula: a case of too little, too early. *Palliat Med.* 2008;22(6):730-5.