

SAPC hot topic: bringing death back to life – a dangerous idea?

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The 2012 Society of Academic Primary Care Conference held in Glasgow in October heard seven 'dangerous ideas' in a soapbox session, designed to be deliberately provocative. Each of the speakers was allowed one slide and three minutes to state their case, followed by seven minutes of lively discussion. The one proviso was that speakers had to somehow justify their ideas while the audience critically questioned and commented. The rather subversive suggestions included:

- *GPs should give up first contact care to non-medical practitioners* – proposed by Professor Tony Kendrick, Dean of Hull York Medical School
- *Stopping smoking can seriously damage your health* – Dr Deborah Lycett, University of Birmingham
- *Resilience: a new metric for primary care* – Dr Trevor Thomas, University of Bristol
- *University linked localities instead of academic general practices* – Dr Paul Thomas, NHS Ealing
- *Computers says no* – 'you reap what you sow' *an argument for more flexible training* – Dr Cathy Reagan
- *An international course on family medicine in Palestine* – Professor Paul Wallace, University College London

At the end, a vote was taken and the dangerous idea thought most worthy for consideration in 2012 was *Bringing death back to life* by Professor Scott A. Murray, University of Edinburgh. Here he and a colleague detail why this dangerous idea

might be tremendously beneficial for patients and doctors alike.

Bringing death back to life

Dying is a universal human activity, and it shows no sign of abating. Everyone born will live and then die, the death rate holding stable at 100% as illustrated in the figure. Despite the impact of non-smoking campaigns and the value of various screening and early diagnosis initiatives, death will still be 100% fatal. It is without doubt a condition for which a cure remains beyond our grasp.

So death is a fact of life: let us face it

Thus, noting that death is a fact of life, and cannot be prevented forever, we should face up to it and give timely opportunities to our patients to raise the subject if they wish. The idea might sound dangerous to GPs who strive at all costs to maintain a good relationship with their patients. We might be afraid that talking about dying might upset our patients, causing some to lose hope and become demoralised. We might be afraid that it might lead to really dangerously long consultations. However, research reveals that most patients with life-threatening illnesses would greatly value the opportunity to talk about what the future might hold for them with someone they know and can trust (Murray *et al.*, 2006). In fact, we can confidently state that bringing death back to life would be good in five distinct ways: for patients, for their relatives, for doctors, for the National Health Service (NHS) and for society in general.

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Potential beneficiaries of bringing death back to life

Our patients

First, most patients who are approaching the end are looking for an opportunity to talk about what the future might hold for them. Our in-depth qualitative research has shown that nearly everyone with a life-threatening progressive illness has two narratives competing in their mind: the public restitution narrative of 'I am just fine', and the more private realistic narrative that they will die one day (Murray *et al.*, 2002). Most people know they will die, and would like a chance to talk with someone they can trust, someone who has walked with death before. Therefore, if patients say they are 'just fine', and you feel that they are at risk of dying in the near future, why not gently ask them: 'But are there ever days when you do not feel so fine?', and wait and listen.

Moreover, we have found out in the United Kingdom that, where planning for the future has been raised by GPs and the patient is placed on the practice supportive and palliative care register, most of this group dies at home. Whereas those not on the register more frequently have unplanned deaths in hospital (Harrison *et al.*, 2012). As it is recognised that most people would actually prefer to die at home, helping them discuss their own immortality might allow them greater choice in not only where they died but also in other aspects. Patients are often waiting for the doctor to raise the issue of dying, but like an elephant in the room, it is raised neither by the GP nor the patient nor the family carer, and thus we must take time to actively listen (Boyd *et al.*, 2010).

Family carers

Second, talking with relatives and informal carers of patients about the future is greatly appreciated by them. Such people are rarely acknowledged as providing as much practical care as they do, and are the main coordinators of care for our most ill patients, where they are available. Even when a patient is admitted to a care home, relatives greatly appreciate being involved in planning for their stay in the home, their Resuscitation Status should they collapse and their death in due course. Indeed, advance care planning routinely done on admission to a care home,

together with the relative, can be really effective in improving care and carer satisfaction (Watson *et al.*, 2006).

Doctors and nurses

Third, talking more openly about death as a clinician allows a deeper relationship with patients. An open awareness about what might happen tends to create a more comfortable and easier platform to help people. If a diagnosis that someone may well die is made, the patient and doctor then can together face up to that and optimise the patients' health so that they can live as well as possible and then die well. 'Health promoting palliative care' is a new concept that calls for 'Living to the full and then dying well'. It can be very satisfying for the clinician to be able to focus positively on helping the patient optimise their quality of life before the best death possible for them. We cannot prevent dying but we can face up to it and prevent needless distress and minimise suffering (Kellehear, 1999).

The NHS

Fourth, talking about dying can also save the NHS many millions of pounds worth of futile treatment, and prevent numerous complaints and iatrogenic risks. Overzealous treatment frequently occurs in each of the three trajectories of physical decline (Murray *et al.*, 2010). In cancer care, palliative chemotherapy is still common in the last week of life, and response rates for many conditions remain borderline. Similarly, in the organ failure trajectory, patients with heart failure and chronic obstructive pulmonary disease are frequently admitted out of hours, as they are anxious about their breathlessness, when a reassuring visit by a clinician they know and trust might obviate the need for admission. For those dwindling at the end of life in the frailty trajectory or with dementia, advance care planning can decrease admissions from care homes by up to 50%, and avoid many inappropriate hospital admissions (Hockley *et al.*, 2010). We need to eliminate the iatrogenic needless suffering fuelled by our denial of death (Enkin *et al.*, 2011).

Society in general

Finally, if there were more discussions about death and dying in the community generally, in

our clubs, pubs and even schools, patients and doctors would find it easier to raise it in consultations. We as doctors can help promote a public discourse about death and dying by supporting campaign groups such as ‘Good Life, Good Death, Good Grief’ (<http://www.goodlife-deathgrief.org.uk/>) in Scotland and ‘Dying matters’ (<http://www.dyingmatters.org/>) in England. These coalitions produce helpful resources to provoke public discussions, and to bring death back as a character that is sometimes introduced, when appropriate, in conversation. If people talk more about death and dying before they are ill, they will find it easier to raise their mortality later. Moreover, as Iona Heath has written, ‘if we avert our eyes from death we also erode the delight of living, the less we sense death the less we live’ (Heath, 2008).

Conclusion

We have absolutely no doubt that bringing ‘death back to life’ would be good for our patients, for their families, for us as clinicians seeking to help our patients live well to the day they die, and then die well, for the NHS, which stands to avoid much futile treatment and complaints from unexpectedly bereaved relatives and for society, in general, so that we can all live life to the full.

It may sound dangerous to consider our patients’ and with it, of course, our own mortality. But let us give patients the opportunity to talk about what the future holds for them, and start mapping it out in partnership, which can be so empowering for them and us. Let us not be fearful of the smell of death and be willing to talk more freely about death and dying. Much more often than not this promotes real hope in patients, not a futile hope that they will not die, but a hope that they will be able to cope well with and hence somehow overcome it. Our patients have everything to gain, and it is the last great opportunity

and privilege to really care for them to and at the very end.

*Under the wide and starry sky,
Dig the grave and let me die.
Glad did I live and gladly die*

*(lines inscribed on Robert Louis Stevenson’s
tomb in Samoa)*

References

- Boyd, K., Mason, B., Kendall, M., Barclay, S., Chinn, D., Thomas, K., Sheikh, A. and Murray, S.A.** 2010: Advance care planning for cancer patients in primary care: a feasibility study. *British Journal of General Practice* 60, e449–58.
- Enkin, M., Jadad, A.T. and Smith, R.** 2011: Death can be our friend. *British Medical Journal* 343, d8008.
- Harrison, N., Cavers, D., Campbell, C. and Murray, S.A.** 2012: Are UK primary care teams formally identifying patients for palliative care before they die? *British Journal of General Practice* 62, e344–52.
- Heath, I.** 2008: *Matters of life and death: key writings*. London: Radcliffe Publishing.
- Hockley, J., Watson, J., Oxenham, D. and Murray, S.A.** 2010: The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliative Medicine* 24, 828–38.
- Kellehear, A.** 1999: Health-promoting palliative care: developing a social model for practice. *Mortality* 4, 75–82.
- Murray, S.A., Boyd, K., Kendall, M., Worth, A., Benton, T.F. and Clausen, H.** 2002: Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *British Medical Journal* 325, 929.
- Murray, S.A., Sheikh, A. and Thomas, K.** 2006: Advance care planning in primary care. *British Medical Journal* 333, 868–69.
- Murray, S.A., Kendall, M., Boyd, K., Hight, G. and Sheikh, A.** 2010: Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: secondary analysis of serial qualitative interviews. *British Medical Journal* 340.
- Watson, J., Hockley, J. and Dewar, B.** 2006: Barriers to implementing an integrated care pathway for the last days of life in nursing homes. *International Journal of Palliative Nursing* 12, 234–40.