

# Grief, empathy and compassionate care: an experience of a longitudinal clerkship

**Alice Leeming**

University College London (UCL), Medical School,  
Bloomsbury, London, UK

**Address for correspondence:**

Alice Leeming  
University College London (UCL),  
Medical School, Bloomsbury,  
London, UK  
E-mail: alice.leeming.14@ucl.ac.uk

A medical degree has traditionally been composed of two stages: a preliminary education in basic science followed by a series of clinical rotations. However, in recent years there has been increasing interest in complementary teaching methods, including longitudinal clerkships. These clerkships require students to spend an extended period of time accompanying one patient on their journey through various healthcare settings. The process aims to develop in students a better understanding of the social context of patients. It also provides a more comprehensive view of integrated clinical services and fosters a heightened sense of empathy for patients. This letter charts my experience following a cancer patient over a year. I explore how the nature of a longitudinal clerkship changed my ideas about responsibility and commitment. I examine the role of a clinician in alleviating the psychological suffering of their patients and how best they can provide that support. I will consider to what extent this experience will impact on my future clinical practice. I conclude by arguing that, in the case of this patient at least, the opportunity to keep coming back was highly important in terms of providing good and compassionate care. The scheme ensured a sense of constancy from which a truly meaningful student-patient relationship could emerge.

What can you do but laugh? This year I've had the privilege of getting to know M, a long-haired Rolling Stones fan in his sixties whose lung cancer is being battered into submission by immunotherapy. He was assigned to me by the medical school and I accompanied him to his appointments for a year as part of a

longitudinal clerkship (1). M is the sort of man who buys coffee in cafes for strangers who look like they are having a tough day and wears t-shirts proclaiming how grumpy he is even if every crease around his eyes says otherwise. He also very obviously adores his wife, P, whose own cancer has spread so far that the journey into hospital is too much. Before, she would start chatting to anyone in the waiting room and she was equally kind to this well-meaning but really quite useless medical student who has arrived in their lives at what feels like a most inopportune time. M and I have talked a little bit about how he's coping but whenever we step too close to the unimaginable horror and unjustness of it we stop, muted. After a brief (and seemingly never-ending) minute he always shakes himself and says something to the effect of "what can you do but laugh?" I never know how to respond. Sometimes he also says, "I can fall apart afterwards" and I don't know what to say to that either, apart from that's he's a brave and good man. This isn't the worst thing I could say, but it feels inadequate. It is difficult to ask important questions. Difficult for me, trying to turn suffering into knowledge, and difficult for the patient, trying to find a way through both. 'You have to laugh about it' says M "otherwise you'd...". The sentence always falls over before the great, hulking truth that sits so squarely in front of us. When the prospect of healing disappears then so too, in some sense, does the doctor. All your old tools – and all the old rules – have disappeared. There is just you and the patient, and the patient is looking at you. What are you doing here? You'd better think of something sharpish because time is running out. What can you do but laugh?

I wonder if I should ask whether he's afraid of death. Whether he thinks there is anything after. Whether he wants to go on after his wife. I wonder if it's best to say nothing. At the same time, whenever we sit there, peering into the abyss, I realise how afraid I am of these discussions and how easy it would be to get them wrong. I think about patients who have scared me before and I think about my grandmother, tentatively bringing up her own mortality at the dinner table and the speed at which we change the subject. I realise I'm not brave enough to have these conversations, so I sign up to go to a Death Café<sup>1</sup>.

<sup>1</sup> At these events attendees spend a couple of hours drinking coffee and talking about mortality.

The people I spoke to there had thought a lot about what it means to have a good death. There was a good deal of disagreement about where to die and with whom, and whether to take something to help and what to do with the body afterwards. Everybody agreed, however, that it is good to think about it in advance and that honesty – from relatives, doctors, yourself – is appreciated. Doctors who are able to have these conversations and sit for a moment with their patients in their suffering (which after all is what compassion means) are showing a kind of bravery. Everybody also agrees that this honesty is too seldom forthcoming.

It was all much messier than I had thought. When I had thought about putting your house in order I had pictured also a sort of tying-up of relationships. There would be last visits and long letters to and from the far-flung. Conversations with your loved ones about what life means and true words for friends so they know how important they have been. Perhaps I should have known that you'd be very lucky to die like that. Like with all forms of human intimacy, the multiplicity of actors makes it complicated and you might well end up with a son who refuses to talk about it, or a friend who disappears, or a sister who asks all the wrong questions.

When M died I didn't know what was best to do. In many ways, M and I were mates. We had shared music recommendations and jokes and hours in the waiting room. Was I a friend? A physician? An unwelcome hanger-on? The lines had blurred in my head – the "liminality" of a medical degree made suddenly stark (3) – and I found myself in a tripartite dilemma. I was uncertain about my relationship to M, as a medical student oscillating between the professional and the personal. I was unsure what this meant in terms the extent of my responsibility towards him, whilst feeling strongly that I had a duty to help. Perhaps most importantly I was completely clueless as to what form that help should take.

There is surprisingly little written about medicine in the context of grief (4)<sup>2</sup>. There is, of course, plenty written about both mortality and mourning in the anthropological, sociological and psychological literature but the implications for clinical practice concentrate much more on palliative care – perhaps reflecting the reduced role of physicians after a death. This disappearance of the doctors is in some ways to be expected given that their primary role as healers has come to an end. But even if it is expected patients may well feel somewhat abandoned when "all the doctors just suddenly go" (5).

There are, of course, practical and much-appreciated things a doctor can do before a death (6). The patient continues to need care, and medical help, to deal with nausea and constipation and fluid in the lungs. Afterwards doctors can provide reassurance

about "normal" mourning as well as keeping an eye out for more "complex" or "pathological" grief (4). Appropriate psychiatric interventions can be considered as well as facilitating access to local services of which the bereaved may be unaware (9). This still leaves space for the psychological support in coming to terms with a death (10) – but what does this space look like?

I wondered again how persistent I should be in my efforts to talk to M. It belatedly occurred to me that the people at the Death Café might be a slightly self-selecting group. M, at least outwardly, seemed to proceed with a quiet resilience and I quite understood if he, so obviously not prone to public emotion, did not wish to pour his heart out to me. After all, as Larkin puts it, "*Death is no different whined at than withstood*" (11). A doctor's role in the process of dying and its aftermath is different to that of a loved one and a balance must be found – and then lost, re-found, negotiated a hundred times. Although patients like M need thoughtful and committed doctors I shouldn't forget that most of the messiness of death is dealt with when the doctor is out of the room (6, 12). Patients might well not want to talk to this stranger with the leaflets and prescription sheets very much at all.

Over the next few weeks of clinic appointments and cups of coffee I also realised I had been wrong about the idea of sitting with someone in suffering. It's very easy (for me at least) to think that you can sit with someone in pain and because you care – because you really, honestly do care – they will feel better. It's not entirely untrue as a notion, but it's a romantic way of thinking about it and, as with most romantic notions, fails to give enough worth to the more mundane sides of compassion – duty and thoughtfulness and showing up when you say you will.

This is something I keep relearning – that there is more to love than feeling. When I was fifteen years old I was working at a summer camp. One night a seven-year-old boy made his way to the leaders' tent in tears; he missed his mum. I scooped him up with naive confidence and said, "don't worry – I'll be your mum tonight!" He looked at me with undisguised contempt. "You won't," he said. This boy knew what I didn't – that care is ideally not a one-off event. It is important to keep coming back. The patient preference for continuity of care is already established in almost all healthcare settings (13, 14) and here it is much the same, but with an added layer of commitment.

Perhaps it is presumptuous to say that these efforts at continuity have particular significance in societies (and medical cultures) which tend towards the reductionist. The extraordinary capability of biomedicine to see truth "in essences, not in relationships or in process" (15) has allowed it to become the most effective system of healing ever known, but maybe the concurrent fragmentation of our social structures (and disenchantment of our psyches) is the price we pay (16). At times of great tragedy here is an opportunity to make things a little less unbearably light.

I'm seeing M again next week. Not as part of our lon-

<sup>2</sup> Notwithstanding recent calls to action (7, 8).

gitudinal clerkship but to drink a pint with him as an uncomplicated friend. I don't think he's blown away by my cack-handed attempts at sympathy and clumsy jokes but if there is anything he appreciates I reckon it's that I'm still there. Even if we don't do very much but laugh.

## References

1. Ogur B, et al. The Harvard Medical School-Cambridge Integrated Clerkship: "An Innovative Model of Clinical Education". *Academic Medicine*. 2007;82(4):397-404.
2. Miles L, Miles C, Charles A. Death Cafe: What Is It and What We Can Learn From It. *OMEGA - Journal of Death and Dying*. 2017;151-165.
3. Gishen F, Zervos M. Between a doc and a hard case: a journey through liminality. *BMJ*. 2018.
4. Weber M, Weiher E, Smeding Ruthmarijke M. Arzt und Trauer. *Medizinische Klinik*. 2008;532-539.
5. Prigerson Holly G, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: "All the doctors just suddenly go". *JAMA*. 2001;1369-1376.
6. Aoun Samar M, et al. What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach. *Palliative Medicine*. 2018;1378-1388.
7. Stroebe M, et al. Grief is not a disease but bereavement merits medical awareness. *The Lancet*. 2017;347-349.
8. Logan EL, Thornton JA, Breen LJ. What determines supportive behaviors following bereavement? A systematic review and call to action. *Death Studies*. 2018;104-114.
9. Dyregrov A Dyregrov K. *Effective Grief and Bereavement Support: The Role of Family, Friends, Colleagues, Schools and Support Professionals*. s.l.: Jessica Kingsley Publishers. 2008.
10. Rabow MW, Hauser JM, Adams J. Supporting Family Caregivers at the End of Life: "They Don't Know What They Don't Know". *JAMA*. 2004;483-491.
11. Larkin, Philip. *Aubade. Collected Poems*. s.l.: Farrar Straus and Giroux. 2001.
12. Logan EL, et al. Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies*. 2018;471-482.
13. *Interpersonal Continuity of Care and Patient Satisfaction: A Critical Review*. Saultz, John W and Albedaiwi, Waleed. *Annals of Family Medicine*. 2004;445-451.
14. Haggerty JL, et al. Continuity of care: a multidisciplinary review. *BMJ*. 2003.
15. Gordon, Deborah. *Tenacious Assumptions in Western Medicine*. [ed.] Margaret Lock and Deborah Gordon. *Biomedicine Examined*. Dordrecht and London: Kluwer Academic Publishers. 1988;19-56.
16. Weber M. *The Sociology of Religion*. S.l.: Beacon Press. 1993 (originally published 1920).