

Dying and death reimagined

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Abstract: This article presents an interview with lead authors Dr Libby Sallnow and Dr Richard Smith of the 'Report of the Lancet Commission on the Value of death: bring death back to life' published in January 2022. The authors are interviewed by Julian Abel, Director of 'Compassionate Communities UK', and Allan Kellehear the Co-Editor-in-Chief of 'Palliative Care & Social Practice'. The interview covers the reasons why the authors believe it is now time to review our major ways of providing care at the end of life including the current efforts in palliative care. The interview also underlines the important points made in the Report, provides reflections on some of its limitations, and suggests the role readers may play in contributing to the Report's recommendations and challenges.

Keywords: dying, end-of-life care, medicine, modernity, professionalization

We begin our interview with Libby Sallnow and Richard Smith, Lead authors of the Report of the Lancet Commission on the Value of Death.¹

JA: *The Lancet Commission Report on The Value of Death characterizes dying in the 21st century as a paradox – could you explain what you were referring to by that description?*

LS (Libby: Sallnow) When we began to look at this thorny and challenging issue of what death means in the 21st century, we started with the premise that death was over-medicalized – that was the impetus to think about what's wrong with our experience of death and how could we change it. But when you begin exploring this in any detail, as we did as commissioners, we realized that that's not the whole story for everyone. In fact, there's not just one story of how people are experiencing dying or how people are caring for their dying around the world. So, when we began to look upstream, we found that actually there are paradoxical experiences. Some people are over-treated at the end-of-life with treatments that they either wouldn't wish for and that are prolonging dying or

actually increasing suffering but at the same time, in other places, people are under-treated, not able to access pain relief at the end of life for their symptoms. Many people are also unable to access preventative treatments that would stop them dying 'avoidable deaths' or to access screening programs that could prevent them dying deaths that are premature. So, we began to have this idea that people are simultaneously overtreated and under-treated. We see this, if you look internationally, between countries, but you can also see this within the same city or the same neighbourhood in a single country. It was this inequity, this deep inequity, about how people are dying that appears to not have one core cause. Actually, it has multiple different strands, so that, we came up with this idea of death and dying of dying today as being an example of a paradox, whereby people were reaching death through very different routes.

RS (Richard Smith) I mean to put it in very stark terms, our commission followed on from the Lancet Commission on Palliative Care and Access to Pain Relief which made clear that about 80% of people in the world die without any access to basic palliative and even to morphine. So, that's happening on one side, and then on the other side, we've got this excessive treatment that has become very common in high income countries. We think probably increasing suffering rather than reducing it, and consuming an enormous number of resources that could be much better spent elsewhere. We started with the idea that this excess was a problem in high income countries, which is certainly true, but the amount of this style of care that is being exported to low- and middle-income countries is terrifying.

If you look at India, it has some of the worst aspects of this paradox. Medicine in India is like an extreme version of the United States. You've got dozens and dozens of specialists, and many people in India worry about being overtreated, and yet at the same time, many people are dying without any access to basic care and morphine. The Lancet Commission on Palliative Care argued that the divide between overtreatment at the end of life for some and under-treatment or no treatment for many is perhaps the most extreme divides in global health today.

JA: *So, when you say that people suffer unnecessarily because of overtreatment would you like elaborate on that and tell us a bit more about what you mean?*

RS: I think the word suffering is almost embarrassing to doctors. Doctors think they are here to treat disease, sort and fix things, cure people, or make diagnoses. Suffering is not really what we're about.

I've just read *Walk with the Weary*, the autobiography of M R Rajagopal, a member of the commission, an Indian

Palliative Care physician, the founder of much of what's happened with the innovative palliative care scheme in Kerala. He makes the point very forcefully looking back on his years in palliative care that doctors are not so interested in suffering. They're a bit embarrassed by suffering – and I think suffering is not just about pain.

There was a very influential article in the New England Journal of Medicine arguing some years ago that we didn't think enough about suffering and what suffering is. One of the ways to think about suffering is that you become very disconnected from the person that you are, that you become almost an object within a collection of organs. I think that's what happens a lot at the end of life. People are suffering in a way that is awful. They may be having their disease treated. They may even be having their pain treated, but their suffering is not being responded to.

JA: *Is it worth adding into that because you mentioned it in the commission about the Ubuntu philosophy of: 'I am because you are', that we are embedded in relationships and that a core part of our suffering is a lack of acknowledgement and support of those relationships?*

LS: Absolutely. That's why we made clear in our recommendations that social relationships must be understood, nurtured, created, and supported, because these are fundamental to our health. We see large numbers of studies coming out, getting at different angles of what it is that relationships do for us in health terms, particularly concerning networks or connections or around social capital. However, we conceptualized it as they influence all aspects of our wellbeing, ourselves, and in our sense of self. They affect connection, meaning and purpose, and also hard endpoints like survival. So, we wanted to bring that front and centre of the Report. As we said earlier, we began by looking at over-medicalization and under-treatment, but actually, as you step back, these

networks of connections are not being understood very well or prioritized within our formal healthcare services. Professional/patient relationships are much more transactional. You have a blood pressure tablet. You have opioids for pain. We don't understand the role that relationships between healthcare providers and patients. But then as people in communities we often don't understand or prioritize relationships. I mean they need to be prioritized throughout the whole life course, but at the end of life in caring, dying, and grieving, they really should be front and centre. They're really not and that is the challenge sitting before us.

AK (Allan: Kellehear) *You put that very eloquently. But one of the interesting things that rears its head to me in this context is the negative role of the Covid pandemic. One of the things that occurs to me about Covid is that we seem to have gone backwards on those very principles – the primacy of relationships in health and wellbeing in life and death.*

LS: Absolutely and an example of that ultimate medicalized death is people dying in intensive care. It is a dramatic illustration. I was a doctor working both in people's homes and in intensive care during the pandemic, so that, I had an inside view of both worlds. I saw these really polarizing extremes during the pandemic where you had people at home dying with healthcare professionals zooming in giving advice over the phone, face-timing, and so on, but really having very little hands-on care, whereas in the hospital you had families zooming in but no hands-on connection. No hands-on relationships, just those professional relationships. However, you also had other differences so in the community, for example, people couldn't get any medication for breathlessness or pain and people were dying often with really difficult symptoms.

In the hospital, they were all being managed but in that setting they had

no real social connection, little meaning, and no sense of themselves and those issues around suffering that Richard was describing. Whereas in their homes, they were fully connected but quite frightened, often because families didn't know how to manage. COVID-19 shone a light into, and then highlighted, the polarizing experiences that are happening every day, and it also gave us a kind of a hyper-real example of dying with no one you know around you, in isolation from your family.

AK: *I think to me it also shows a lack of how far we still need to go to get cooperation between acute care medicine and colleagues from the palliative and bereavement sectors. Clearly our Covid strategies weren't designed in an inclusive way with those colleagues, or they wouldn't have done these things in the first place. So, we've got a long way to go on this still. The obsession with medical rescue was highlighted by the pandemic and it marginalized our colleagues in palliative and bereavement care in particular, not that we need more evidence of the marginalization of these end-of-life specialisms. It really indicates in some sense that we started to go back to the 1950s way of responding to death and dying. You know, 'Death as The Great Evil that needs defeating by Medicine' – an enemy that we should combat at all costs. Our understandings of suffering, to return to Richard's reference again, are unbalanced and highly focussed on embodiment rather than the relationships that depersonalize and do equal damage to the human spirit. When you become just a body, something merely to be worked on, and Covid has really highlighted this type of emphasis, how little progress we appear to have made on being able to push back on those solely materialist understandings about suffering at the end of life.*

RS: One of the things I wonder about is whether the little progress you speak of, Allan, is the result of creating a specialty called palliative care. Death and dying has ceased to be the

everyday business of every health professional as it would have been in the past. When you talk about the growing gap between palliative care and acute medicine is that because palliative care became a specialty?

All this takes me back to the time when I was a medical student in Edinburgh in the 1970s and Cicely Saunders came to talk at the college of physicians in Edinburgh. There was a big audience, and the way I heard her talk was: 'I've had an extraordinary idea that instead of ignoring the dying and shoving them off into a corner somewhere and hoping they get on with it as quickly as possible, may be, we should pay attention to them!' We should think not only about their pain, but about their other symptoms, and about them as human beings – this is how we should help them. Let's help them live their life as fully as possible to the last moment. 'And the audience responded "Wow". There was a tremendous round of applause, but I sat there thinking, "well how did we ever get to a position that we didn't do that anyway?" Surely, that's what any human being would do. You wouldn't shove the dying off in a corner'.

I worry that by creating palliative care as a separate specialty we have allowed care of the dying to become the province of one specialist group rather than all health professionals. One of the things we would like to see because of our commission is that being able to care for people at the end of life becomes fundamental to every health professional who's going to encounter people who are dying. It would become a generic competency rather than one that belongs to a specialist group. I think that is the vision that Cicely Saunders had originally, but once you create a new specialty and new empire it takes on its own momentum.

AK: *Yes, I'm sure it's a multifaceted problem because it's a multifaceted system issue. But to be fair, the main reason there IS*

a specialism like Palliative Medicine is because curative-oriented medical specialists of every stripe did actually fight the dying process and ignore the dying experience. The 'naturalness of dying', if I might put it that way, was gradually marginalized or eclipsed by a 20th century death-denying arrogance that prioritized medical rescue at all costs.

That style of medical practice was consistently observed to fail the dying person right through the 1940s through to the 1960s and that is a matter of public record. There's been endless number of social science studies documenting this and more than a few medical studies as well. It's the consistent embarrassment of dying as medical failure which seemed to be a social theme in care during that period. The isolation of the dying person has been documented again and again in medical editorials and in sociological studies of the care homes and in hospitals of the era, the sequestering, if you like, of death and dying in healthcare facilities is so well documented Is there little wonder that medicine developed a breakaway group to lead that change in our response to death.

RS: I'm interested in what you said about 'the naturalness of dying'. We draw attention in our report to how dramatically death has changed since the 40s. Death was familiar until then and often rapid from infection or trauma with limited interventions. Now, death is unfamiliar to many, happens slowly, and doctors have many ways to intervene, leading to overtreatment.

One of the main conclusions of our report is that simply blaming doctors for overtreatment will not lead to improvement. This is a systems problem where there are many, many different actors at work. So, I'm not blaming palliative care, but I don't think that developing a specialty was the optimum response. Indeed, here we are more than 50 years after the development of palliative care, and the problem of overtreatment and poor

care at the end of life is getting worse not better. Developing a separate specialty doesn't seem to have been the right way to go.

AK: Well, you know what they say about progress – it's 1 step forward 2 steps back!

JA: A historical perspective is that the formation of palliative medicine as a specialty and palliative care in general was a reaction to the isolation of death. Yet the technological development and culture of modern medicine has influenced the practice of palliative care, to be more symptom and needs based. We hope we are finding our way back to see palliative care is socially based with medical components, which is the practice of public health palliative care. You use the term a realistic utopia which seems to have a striking resemblance to public health palliative care, or health promoting palliative care. But this phrase does not appear in your key messages. Are your principles indeed public health ones? And if they are, why did you not use that phrase if they're not public health ideas? How would you better characterize them, Libby?

LS: Well, I'm really happy to discuss this. So, to any reader who is familiar with the principles of New Public Health and the participatory approaches in palliative care and end-of-life care (I use those terms separately and distinctly), they will recognize the themes of public health run implicitly through this entire document. We showcase the Kerala model, which is well known as one of the most systematic examples of a public health approach to palliative care in the world. And, all the way through we pick up on all the different aspects of social justice, relationships in compassionate communities, compassionate cities, and the multiple perspectives that are needed at times of death, dying, care and loss in addition to the professional ones.

So, it is founded on a lot of those principles and we discuss these in detail using examples of compassionate communities, death doulas, compassionate cities, death awareness movements, and so on. But, we also wanted to have a broader perspective beyond this, because we wanted to look at some of the traditional models of public health which sit within a public health approach – ones around opioid availability, lack of access to basic universal health coverage, those kind of health systems aspects that are essential, and of course, the training of healthcare professionals. We wanted to develop the thinking that has been pioneered over the past 20 years in public health palliative care thinking, but the term public health can be restrictive in some ways. The readers of the journal and those listening to the podcast will be aware of what a public health approach to end-of-life care is but the understanding of this can be quite limited across a broader readership. We thought about who would be reading this and we wanted to speak to those beyond who were already united under this vision. There is also question of whose responsibility is this, if it is a broader public health challenge, beyond palliative and end-of-life care then we need to speak to those audiences.

There are also challenges of the colonial perspective of much traditional public health. Does it respond to diverse needs, does it speak to marginalized people? Is it empowering or disempowering? One of the last changes we made to the report before publication was to change death, dying, loss, and care being a public health challenges to being a public health challenges. We wanted to situate this in the broadest frame possible, including but beyond public health. This was where the systems approach came in.

RS: So, having been critical of palliative care, let me now be critical of public

health. Both Libby and I have been very influenced by a friend of ours, Pritt Tamber, whom I've known for a very long time. He was a doctor who came to work at the BMJ, and he's devoted his professional life to studying communities and how there can be great improvements in health and when communities become 'empowered', for want of a better word, and develop agency. One of the criticisms he has made is that, although public health people talk about the importance of community development, they often disempower communities. The public health people arrive and say, 'You know you seem to have a lot of diabetes here, or you're obese, or you smoke too much and what are we going to do about that?' They start with the wrong kind of lens rather than asking 'What are the issues that matter the most to you?'

But more troubling is that Pritt has seen many examples of communities that begin to move forward and then the public health people move in with their journals, their academic methods, their measuring, and their big salaries, and kill the whole thing dead. Public health has the same problem as palliative care. They become a community with their journals and ways of thinking and they get in the way of broader social movements.

As Libby is emphasizing, the Commission is not just about public health and palliative care. When we put together the members of the commission, we were keen not to have too many palliative care people. We thought we needed to paint the issue on a much broader canvas, and that's what we've tried to do. Readers can decide whether we've succeeded.

JA: Allan, do you want to say something about the difference between the epidemiological aspects of Public Health and the New Public Health?

AK: Yes, I can do that, but Richard and Libby are both aware of these kinds of

distinctions. I mean I think you know for listeners and readers I think there's a general understanding that public health palliative care is health promoting palliative care, so health promotion traditions are the emphases. And we understand that universities, and particularly university researchers, are steeped in the surveillance traditions so their ranks are characterized by epidemiologists, health service researchers, the bench scientists and so on – and these are not the major players in the health promotion approach to palliative care. This, to be fair, is an internal debate within public health and in palliative care circles. We constantly debate this in palliative care. David Clark is a very good example of somebody who has said, well there are many different types of public health, and which public health are you? So, it's actually quite a broad church this field of public health. So the short answer is we're everything in it. But in palliative care when we talk about the practice we're really talking about health promotion, that said, I accept Richard's and Libby's observation that this commission report is for a much wider audience. Not just those of us in palliative care, and for many people in palliative care, for those outside the Public Health Palliative Care Mafia, so to speak. The Commission Report is about public health with a capital P and H and I can understand them trying to navigate away from specific traditions with public health to open up a broader social and political vision for a better healthcare future for death, dying, and its care. So, I get that, and I accept the answer notwithstanding the internal debates.

JA: *The report argues that any meaningful change will depend on system changes to our death systems. Could you tell us a bit more about what you mean here?*

LS: This really evolved during the four years that we were thinking, crafting, writing and reviewing the commission report. And we had the idea of systems and of how they influence everything in our lives – you know

education systems, financial systems, families, and community assistance, and it fitted with this upstream idea which is again a very new public health idea of looking at the broader contributions beyond merely who's around at the moment of death. We wanted to go upstream and have this much broader idea, and so that, systems were always a part of our report but as we began to really craft the report, as a kind of document nearer to submission, we realized that actually systems' thinking was a thread right through the entire report.

We began to build on this thread running through and you'll see in the report all the different headings reflect a systems perspective. We looked at power and inequality through a systems lens, or how we would understand care at the end of life through a systems lens. It really became a fundamental part of the report. One of the challenges with historical efforts to shift how people live, die, and grieve and the experiences around that, is that responses have been too reductionistic and too linear. It's really satisfying to think if we increase opioid availability then people will have better deaths. Or if we increase service availability of certain services, people will have better deaths. You want to try to get rid of the confounding factors but we challenge that wholeheartedly. We need to accept and understand these confounding factors, they are a part of reality. We need to look at, not only the components, but the multiple relationships that exist within systems. They're constantly changing. They're not necessarily benign. They can reinforce power and patterns of disadvantage so we wanted to bring this lens, which in some areas, people are already working very comfortably with in other areas. This is new and so we wanted to emphasize that for any meaningful change across death and dying systems, people would need to understand the multitude of players

involved. You have to have palliative care, you have to have health care, but you have to look beyond that too: To the police, to coroners, to religious organizations, to policies, to the media, or to television. All have a different role. Without understanding the intersection between these different roles, we're not going to have any meaningful change.

RS:

I would add that we increasingly we recognize that lots of the world's major problems are systems problems and if we don't think about them in that way, we're never going to make progress. Margaret Chan, the previous director-general of WHO, talked about 'whole of government and whole of society problems and responses'. When we think about climate change, poverty, or antimicrobial resistance, we get the idea, but I don't think that we've recognized until now that it's also true of death and dying. When we started the Commission, I thought we definitely had a problem of over-medicalization and that the way to address that was through working with hospitals, doctors, and other health professionals. But I was wrong. We need to recognize the importance of the whole system.

I was strongly influenced by a previous Lancet commission on obesity, where the authors had spent years working on randomized trials of a range of interventions aimed mostly at individuals and families. They made very little progress and came to recognize that obesity is a systems problem. What's difficult, I think, is that it's quite easy to think of linear reductionist interventions but trying to change systems is much more difficult and complicated.

LS:

That kind of simplicity can be beguiling because you want to have an answer A equals B, but the fundamental thing for me, in terms of what I learned, the more we read about systems and thinking is that it comes

back to relationships. It's not only the number or the type of people, organizations, or institutions that exist within a death system, but also it's the relationships that exist between the components and the processes that influence outcomes. That really resonates with my experience of caring for people at home. It's not only the people who are in the networks, but also it's the relationships that exist between them. It's the relationships, or the lack of relationships, that often determines the final outcomes.

JA: *Just to clarify, the relationships between different components of the system need to be a cohesive interaction between health and social care, and communities inside a civic participation approach.*

As we all know from working in these environments, these individual components often don't communicate well with each other. For instance, health and social care largely ignore community. And

'community' is worth defining as not merely as our local neighbourhood but also our places of worship, workplaces, our educational institutions, and so on. Are you are saying let's put all of these things together, creating unified action across all of these different sectors?

LS: Absolutely, and an intervention in one place will have a potentially unanticipated effect impact on another part of the system. So, the idea that we'll improve death and dying by doing one small intervention here or there, is preposterous. We really need to understand how each influence impacts on the rest of the system.

RS: Yeah, and I think it's very important to recognize the system is not just institutions. It's also how we think about death. What are the perceptions about death? What is the history that got us to this point? We can probably make a bigger difference by

changing how people think about death than by changing care systems. That's why, as suggested by Richard Horton, our commission was called the Lancet Commission on the Value of Death. It's an odd title and makes people think. Many people start from the idea that death has no value and is a big negative.

AK: *One of the interesting things listening to the three of you, as a sociologist, is how sociological you guys seem to have become! And the traps for young players here, I can tell you from looking at the last fifty years of sociological debate between the sociology discipline and the professions, is how disempowering structural analysis can be if you talk simply about systems and how they work with each other. You could just imagine that in the 1970s when sociologists talked about that, talked about the 'welfare system', or talked about 'medicine as an institution of social control'. In response to that, doctors used to say, well okay, after they managed to extricate themselves from being intellectually and emotionally paralyzed by that observation. They would just simply ask: What are we supposed to do about that? There's no good saying you know society is to blame – tell us what we can practically do about this.*

I mean it was common for some sociology colleagues to suggest (less politely) that social workers were the running dogs of the capitalist elite. So that when workers fell out of the workforce such as when they got sick or where they got unemployed, the social workers were meant to polish them up and put them back. So social workers were really 'cooling out the mark' (was the phrase of the day) but social workers were dismayed at this idea and criticism. Under this type of analysis, the choices seemed to be either quit social work, or quit the profession of medicine, or start a political revolution! One of the interesting things about this conversation, and to some extent the commission report is, yes there is that is a political analysis here which is sound. However, the inter-linking

death systems emphases – whether it’s the environment, the death industry, the funeral industry, the cremation industry or whether it’s palliative care/hospice systems or hospitals – yes, it’s all linked. And yes, it’s all about power and inequality, but what is anybody (your readers) supposed to do about that exactly?

RS: I got into worrying about how we relate to death when I heard Ivan Illich speak in 1974. I was a student in Edinburgh. It was just the most galvanizing experience of my life and I’ve never really recovered from it. A man of great charisma he spoke at Edinburgh University, surrounded by ghastly old academic fossils. He spoke in a very powerful and beautiful way and said the major threat to health in the world today is modern medicine. He utterly convinced me because a lot of the experiences I’d had up until that time. I dropped out of medical school. This was on a Friday, and I spent the whole weekend roaming Edinburgh completely distraught and kept out of medical school on Monday. But by Tuesday I thought ‘Well, what am I going to do with myself?’ I’d done the hippy trail to India the previous summer, and I thought that I didn’t want to just sit on a beach in Goa and be stoned all the time. I wanted to be engaged in birth, life, health, and death, but in a broad away. I thought that I could never become a consultant physician or whatever, and I’d have to do something different. That’s how I ended up as editor of the BMJ, where I could exercise my dubious interests.

JA: *I think as well you know, like three of us on here, that that as physicians that your life is based on action. It’s based on doing things, hopefully a helpful way. The practice methods of New Public Health are what you do about it. It’s how you engage. I worry about definitions because definitions somehow constrict things. But there’s a place for action and a place where things can happen where you can effect changes*

and the big difference is if you’re working as a clinician, you’re confined to very small interactions with the people that you’re working with. When thinking about things more broadly in the way that you outline in the Lancet Commission on the Value of Death you’re thinking about whole populations. You’re thinking about action everywhere because we’re all in this together.

LS: Can I say one more thing on that? I want to just draw a comparison between the four of us here, because I think we’ve dealt with the challenge that Allan laid down just then in very different ways. Allan was also a medical student and dropped out for a range of different reasons. But Richard speaks of a kind of an epiphany, a paradigm shift. Allan also had a different inspiration, and saw that medicine was not going to be his way to tackle the complex issues. I had that paradigm shift when I went out to Kerala and saw the model of palliative care the community had developed. I’ve always had a strong belief in the social determining more than the medical, in terms of our outcomes in life. I come back to the challenge that Allan laid down, ‘are we to just bemoan the structural challenges within which we exist?’ But what happened for me when I went to see what was happening in Kerala was that it was a very clear, tangible example of when you start small, you began shifting the mindset and the paradigm about what it means to die well. You start to ask, ‘who has responsibility for this?’ And you begin asking those provocative questions, even at the beginning. That for me led me to a different route in to tackling these challenges, along different routes that you have both taken. The same with Julian, both of us went on to participate within the system. My effort has always been to have in and one foot outside of the formal palliative care system, or of the biomedical health-care system and to challenge it from within. It’s interesting that the four of

us signed up to medical school and have all become disillusioned at some point but have dealt with that in different ways.

JA: *I think it's a great point. You know, I left medicine at one point because I was so disillusioned with it, and likewise nearly ditched medical school altogether as well. Actually, it was more interesting at that moment to fix my car than it was to go back to medical school. But I fixed it successfully enough to go back and carry on anyway. I'm going to move on to the next question which is: you showcase a major non- cross-cultural theory, such as 'terror management theory', but give no space to its critics from the social sciences, from sociologists Walter or Kellehear, or even the evolutionary psychology community. What was your attraction to this psychoanalytic theory in an otherwise empirical and social approach to the topic?*

RS: Well, I'd better fess up on that one. I started this commission, and I began to put together people, and thank goodness, I found Libby very quickly, otherwise goodness knows where we would've ended up. I'd read Ernest Becker's book 'The Denial of Death, and I found it very powerful. But I also recognized that the book came from a psychoanalytic background, and I wondered what sort of evidence there was to support what he said. Then I'd heard Sheldon Solomon speak at a conference, and I was very taken with his empirical work. He speaks powerfully and is a great proponent of terror management. The way he described his work was that he was seeing if he could produce any empirical evidence for Becker's theories, and it seemed to me they did. So, I was keen to include Sheldon in the commission.

We realized, however, that somehow that the work didn't fit neatly with the way we were putting the commission together. Terror management ended up sort of as a side-line. It wasn't central to the report, but

Sheldon was always very supportive, very helpful, and it seemed a shame to abandon the work altogether. It's a fair criticism that we didn't explore everything as deeply as we might have done, and we could have conducted a more critical analysis of terror management theory. It would be interesting to explore it more later.

AK: *I have to say again, looking at it with a social science eye, I was rather surprised to see that there. The interesting thing about Solomon and a whole bunch of his colleagues producing the so-called 'evidence' is that he keeps reproducing the evidence from the same kinds of societies. If you look at the hunter-gatherer societies, for example, they stand in stark contrast to basically everything Ernest Becker has said and even Becker himself says yes, there's a lot of evidence against this kind of thing, but we're just kind of going to park that to one side in this book because I want to argue a different point of view and he's very polite about it. But no one ever mentions this bracketing out approach in his academic argument.*

Academically, we all know the debates over the proportional influences of environment versus endowment and the psychoanalytic people are notoriously determinist about their views of the structure of the psyche. One of the interesting things about the Freudians is that when they get old, they like to become sociologists, but they have the indelible birthmark of psychology. That kind of psychological epistemology runs through Becker and his acolytes. Unfortunately for them, there is a copious amount of literature challenging their views, including what they view as 'evidence'. But I thought it was very interesting not so much that you mentioned it, but that it was mentioned without that kind of critical context.

RS: Yes, that's a failure. But I've gone the opposite way with psychoanalysis. I was brought up thinking it was junk science and that it would be a big challenge for 21st century historians

to explain the obsession with psychoanalysis. But as I read more and more books by psychoanalysts, I have found a lot of interesting ideas. Maybe it's better to think of it not as a scientific tradition but as a literary tradition.

JA: *I wonder whether in the use of use of Terror Management Theory, you're highlighting essentially an element of the problem that's happened with the dying experience and medicine. And that it's a very individual individualistic approach which is all about our survival, rather than thinking that dying is actually about us together, about communities, and taking that community-based approach in which it's not just the individual life alone.*

It's great that Allan mentioned hunter-gatherers and indigenous communities because this very approach is embedded into their whole culture and somehow, we need to find our way back to that. I think much of our discussions are about finding our way back away from this individualistic perspective. And you know Compassionate Communities UK has a podcast called 'survival of the kindest' and it's called 'survival of the kindest' specifically for that reason, that actually the idea of the individual winner takes all/survival of the fittest theory of evolution is as weak as terror management theory because and we can take the evolutionary imperative of social connection as the defining characteristic of human beings and not some misguided idea of individual survivorship. Somehow, we've lost that broader social message or lesson in human intellectual history.

RS: Yes, and medicine has lost it badly. Medicine has become such an individualistic enterprise. This commission has taught me about the importance of thinking more about relationships.

I'm 70, and you think I might have come earlier to the recognition of the fundamental importance of relationships. Suddenly, I find that everything I read talks about the

importance of relationships. I've just read a biography of Edmund Burke, and he was very, very strong on it back in the 18th century. John Donne was also familiar with this insight: we all know the phrase 'no man is an island'. The commission has also taught me that climate change, the pandemic, and the denial of death all come from the delusion that we are masters of nature rather than very much part of nature.

JA: *I really like the connectedness of the United Nations 17 sustainable development goals because when you take these community-based interventions, the impacts spill out in so many different directions in the way that Libby has mentioned and includes things like climate change, inequity, poverty, and health*

AK: *So, I just want to say I think that the strength of the report – and there are many strengths of the report – but one of the most abiding strengths of the report is its public intellectualism. It provides a great analysis that is an accessible analysis, a very public analysis very different from a lot of academic work. It showcases some of the important shiny bits of the best insights we have around death and dying from the clinical world and from the social science and humanities world in the last fifty years. So, it's a very successful piece of science communication from that point of view – compelling and evocative but critical at the same time. And yes, it fails around some of the edges but inevitably anything that ambitious will creak here and there, but I think overall it's been a fantastic and ambitious piece and it must be said during this interview that you're both to be congratulated on moving this massive amount of material around in a very digestible way so that we can all feed from it accessibly. I mean you've saved many of us a lot of reading by condensing all of this stuff and processing it on our behalf and we and individual critics can say, you know you missed this, and you missed that, and I can have a nibble at you for terror management and*

somebody else can have a nibble on something else. But I think you know the final question that we must come to in this discussion must be that when the final analysis is all said and done, when the dust has settled, what are our readers to do with all this? How can they become part of this? How can they become part of the changes you recommend? In the context of those recommendations that you make, what should they do differently. What would you say to our colleagues out there who accept the broad outline of the analysis, are sympathetic to the recommendations, and now want to be part of that change?

LS: You're absolutely right Allan, and this is just meant to be the beginning of sustained change. This is not meant to be kind of an encyclopaedic kind of tome on all aspects of death. It was meant to galvanize positive action. To bring together a lot of the key thinking and the challenges, and also to be hopeful. That's where we got the idea of the realistic utopia – a kind of high-level vision of how future death, dying, and caring could be, and of our collective responsibility in that context. The whole kind of premise of the report is for action, and we're building a program of work to support it because the publication was always just one step in a program, a whole program of change. We want people to think personally what can they do after reading it. Many of the recommendations apply to us as people and so making change on your road in your community, within your family, starting conversations, beginning to look at the role we all play in normalizing death and dying. And then there's part that people can play in whatever other roles they may occupy. This is about how we can begin to shift narratives and challenges within professional disciplines or other roles within communities. We want to build a collective – a group of people who are doing this because and we know that some of what we recommended is happening already. There are

examples of the realistic utopia all over the world. We didn't want to suggest that we need to all start from scratch.

So, the challenge is how to spread these examples, how to understand them, and to ensure that they are available not just to certain groups around the world but everyone. We have a website now that contains a link where you can sign up to be part of this action (<https://commissiononthevalue-ofdeath.wordpress.com/>). We want to hear from people who are already doing some practice, who've got examples to share. We want to understand across the world where systems approaches exist, crucially from beyond palliative care, or from beyond health care in the matter of death, dying, grief, and caring. We want to understand where different examples might challenge and improve on how people are dying or grieving, and how we can begin to share these experiences with others. We're building a program of action. We want people to take part and we want people to get in contact.

RS: Yes, I would emphasize that although writing the report took us 5 years, making change happen that's hard, very hard. But the one thing I would ask people to do is actually to read the full report. You speak about it kindly, Allan, but I suspect that most people will read only the executive summary. They might look at the recommendations and the realistic utopia, they often won't read the whole thing; but I think you really need to read the whole thing to understand what we are saying. I was very involved in writing the executive summary, and you miss a lot if you just read it. I urge people to take the time to read the whole thing and think about it.

Libby and I are kind of debating different ways of trying to make change happen, and we are clear that if we don't move beyond palliative care

then we will fail. We need to have conversations with people from every part of death systems, including oncologists and intensive care professionals.

Our report was published in the *Lancet* because a lot of us are doctors, and it's with doctors that we have the most credibility. It's also where a lot of the power is and where a lot of the resources are. So, we want to work with doctors and other health professionals, but we also want to work beyond healthcare, beyond medicine, and public health.

One of the things I think about – and it's very relevant to this particular discussion—is how much we simply work with what's already there. I don't think we should go and do completely our own thing, not that we've got the resources to do so. Most of our work after the publication of our report must be in partnership, working with others and thinking hard.

JA: The civic component of lives that we all lead, our cultures and within our societies, needs to be integrated with professional services.

LS: And I would agree having worked in this area and thought a lot about it. For decades now, how we link compassionate communities to oncologists or intensivists is a challenge. There's no conversation really, no connection. Getting oncologists to learn about end-of-life care discussions is hugely important, but that's seen as totally separate to helping create compassionate communities' initiatives. But for me, working across different areas of what we understand as a system, I see massive separation and silos. Actions for me as a palliative care doctor are seen as separate to me as a person living, in a community. Someone who's part of health care systems must begin making links. I was teaching some students on a Masters course about public health approaches and I set them

the challenge to map their own death systems as a healthcare professional AND as a patient. Often in these systems it is the relationships that are lacking. People talk about integration a great deal. Often people don't quite know what that means, but to me it means it means having a conversation. One of the biggest challenges if we are to shift how people experience death dying and loss is to make those connections, have those conversations across siloes. That sits with all of us to pick up the phone, have a zoom call, even write a letter, but to have those conversations where we can say 'how could we change this together?' because at the moment we're working in silos and that's why we're not achieving significant change.

JA: *It's worth bringing into this, that when we're having a conversation, we're not having a professional conversation necessarily, but we're having a conversation about what matters most to people. And again, that's not just the person who's dying but anyone involved with the experiences of death, dying, loss, and caregiving. Of course, that's all of us, multiple times in our life. What we're trying to get at is to say look, there is a professional component but it's an integration into a cultural context for everyone that makes the biggest difference.*

Allan is absolutely right to mention the triumph of what you've managed to do and that you've taken this very broad view and said to people change – don't carry on doing what you've always done. It's a marvellous piece of work and fantastic that it's out there. So, congratulations to you all and everyone who contributed. Are there things that either of you want to say before we wrap up.

RS: A lot of our work relates to where is healthcare and medicine going generally. Just before the pandemic, I met someone who was beginning to specialize in palliative hepatology, and I thought are we going to go on like this? One of medicine's problems is its never-ending split into new and

ever more specialist areas. While we're trying to deal with whole people, we're getting into ever smaller components. Medicine – not just in relation to death and dying – has a problem of fragmenting human experience. Increasingly people have no single but multiple problems and end up seeing 15 different doctors all of whom tell the person different things.

This report is a lot about asking where medicine is going, where is health care going, because it's not sustainable in the form it is now, which is widely accepted. A lot of what we need to do to address end of life care mirrors some of these dilemmas in medicine and healthcare more widely.

JA: Exactly. May be Libby, you'd like to wrap up with a final comment.

LS: Yes, What I was left feeling after writing the report, apart from quite a profound sense of exhaustion (!), was that we came together as a group of professionals with many different experiences and though we all are people, this is still quite a professional, professionally led report. We didn't capture the experience of people living with dying, caring, or grieving now. We all do bring these experiences of loss, care, and of death with us as people, but we didn't explicitly go out to capture that. One of the key actions that we're focussing on, is to engage much more publicly with this. There are many ways that we may look at doing that, but I think

that was something we recognize was overlooked but is definitely a priority going forward. This can't be solely professions led. We need to work through partnerships with all people who are experiencing these challenges today.

Interviewee consent

Libby Sallnow and Richard Smith provided informed consent to be interviewed and for the interview to be published in *Palliative Care & Social Practice*.

Disclaimer

The opinions expressed in this interview are those of the interviewees and interviewers and do not necessarily reflect the views of SAGE Publishing.

Reference

- 1 Sallnow L, Smith R, Ahmedzai SH, *et al.* Report of the Lancet Commission on the Value of Death: bringing death back into life. *Lancet* 2022; 399(10327): 837–884.

Interviewee bios

Dr Libby Sallnow is a community palliative care doctor working in London and an academic researching public health and social approaches to death, dying, and loss. She explores these issues through her roles at St Christopher's Hospice and University College London in the UK, Vrije Universiteit Brussel, Belgium, and the WHO Collaborating Centre for Community Participation in Palliative and Long-Term Care, India.

Dr Richard Smith trained as a doctor in Edinburgh and was former editor of the British Medical Journal and the Chief Executive of the BMJ Publishing Group until 2004. He is current chair of the UK Health Alliance on Climate Change as well as chair of the Point of Care Foundation – an organization devoted to humanizing health care.