

DESIGNING MEANING IN END-OF-LIFE CARE

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Introduction

This symposium's objective is to discuss how design and technology can **improve quality of life** for people with palliative care needs. But what exactly does "quality of life" mean in this context?

Clearly, quality of life is more than just physical comfort and painlessness, because life, and the good life in particular, is for most of us not just a state of the body, but also a state of the mind, or rather a state of the human being as a whole, which includes the network of relationships with other people and both animate and inanimate things, which over time and at any given moment form and transform the experience of our self and the world. Pain or suffering, then, may not necessarily be the problem, and if it is not the problem, or at any rate not the *main* problem, then painlessness or comfort may not be the solution to improving quality of life. But what else can there be?

1. SUFFERING AND DEATH: MEANINGFUL OR MEANINGLESS?

Man, the bravest animal and most prone to suffer, does not deny suffering as such: he wills it, he even seeks it out, provided he is shown a meaning for it, a purpose of suffering. The meaninglessness of suffering, not the suffering, was the curse that has so far blanketed mankind, – and the ascetic ideal offered man a meaning!

Friedrich Nietzsche, *Genealogy of Morals*, III.28

What makes a life bad is not suffering, but is *meaningless* suffering.

Perhaps the suffering that is associated with death and death itself may not always be bad either. Perhaps they, too, are bad only if they are *meaningless*.

1. Suffering and Death: Meaningful or Meaningless?

Nietzsche, for example, suggests that what makes a life bad is not suffering as such. What brings us down, what we cannot bear, is *meaningless* suffering.

Could something similar hold for the suffering that is associated with death, and indeed for death itself? Perhaps the pain that one experiences as one is dying and the pain (emotional or psychological) that is caused in the prospect of one's own imminent death, is only bad to the extent that it is meaningless. Death itself may not always be bad either. Perhaps it, too, is bad only if it is *meaningless*.

2. MEANING AS PURPOSE

What is meaningful suffering? What is a meaningful death?



meaning as *purpose*

- Both suffering and death are meaningful if they are good for something that is (considered to be) good.

Can it also be meaningful in other ways, even if it does not serve any good purpose?

2. Meaning as Purpose

So what is meaningful suffering? And what constitutes a meaningful death? One possible (common) understanding of meaning is in terms of *purpose*.

* Suffering is meaningful if it is good for something. My death, too, is meaningful if it is good for something. ((This is why people are often willing to bear considerable suffering and even death if they think it helps advance a good cause, for example to suffer or die in defence of their country, their faith, or in order to save the life of someone else.))

* Suffering and (my) death are good for something which is itself good, or at any rate something that I, the one who suffers, the one who is dying, considers good.

But even if we accept that a death, my death, serves no good purpose and is therefore, in that sense, not meaningful, can it still be meaningful in other ways?

3(1). MEANING AS CONNECTION

Only our *prospective* death can be meaningful or meaningless for us.

Thus, the meaninglessness of death is always the meaninglessness of the process of dying. Accordingly, a meaningful death is a meaningful process of dying, which is a part of life.

A meaningful death is a meaningful life towards the end of that life.

3. Meaning as Connection

Obviously we can only perceive our death as meaningless or meaningful while we are still alive. So it is only ever our *prospective* death that can be meaningless for us.

This means that the perceived meaninglessness of our own death is always the perceived meaninglessness of the process that leads to death, the process of dying. The meaninglessness of death is the meaninglessness of the process of dying. Accordingly, a meaningful death is a meaningful process of dying. And since the process of dying is always a process of life, or a lived process, a meaningful death is ultimately a meaningful life, and a meaningless death is a meaningless life.

In a way we are of course *always* in this process, always heading towards death since the moment our life began. However, following the definition used by the General Medical Council (2010), we approach the end of life, i.e. death, when we are “likely to die within the next 12 months”. It is this period in our life, when we know or feel that death is not far, the life that precedes death, the end of life phase, which can easily be perceived as meaningless.

3(2). MEANING AS CONNECTION

What it [a life-limiting illness] does is take your future away, and by taking your future away it makes very difficult to live the present, because our present is a negotiation of our present toward the future”

Gillian Howie (2016),

“How to Think about Death: Living with Dying” in: *On the Feminist Philosophy of Gillian Howie. Materialism and Mortality*, eds. Victoria Browne and Daniel Whistler, p.139

The process of dying is essentially a process of increasing disconnection

Time

The disconnection of our present from the future is a disconnection of us from the present, experienced as an “evacuation of meaning” (Howie 2016, 132).

Community

The disconnection from others, those who will still be alive when we die.

Death is often seen as the end of *everything*. And if death is the end of everything, then the process of dying is essentially a process of increasing disconnection.

Time

The disconnection of our present from the future is a disconnection of us from the present, experienced as an “evacuation of meaning” (Howie 2016, 132).

Death renders *meaningless* what is happening in the hours, weeks, months before it. A time spent in waiting is meaningless time: it makes the past irrelevant and the present purely transitional, worsened in this case by the fact that there is not even *a* future, any future, at the end of the waiting period.

Community

The disconnection from others, those who in the prospect of our imminent death stand in opposition to us: they will still be alive when we die.

A rift opens between the one who is dying and those who are not, and this rift gets even deeper if the process of dying and end-of-life care is left to the ‘experts’ and the dying is something that happens away from life, away from home, our communities, our families, our things: we feel even more alienated from everything than we already

4(1). RESTORING MEANING: CONNECTIVITY

Death is part of life. To treat it as alien to it increases the disconnection, which makes life and death meaningless because it separates from the living context in which all meaning arises.

Thus, in order to safeguard the meaningfulness of our life even when it approaches the end, we need to find ways to preserve or re-establish our *connection* to the world.

4. Restoring Meaning: Connectivity

Ultimately, if we treat death as alien to life, as outside of life, then our death will always be disconnected from our life, which indeed would make meaningless both our death and our life in the prospect of death. This increasing disconnection is in itself a source of suffering or loss of meaning, because, whatever is isolated, detached from everything else, loses the context in which it may be meaningful.

If this is correct, then, in order to safeguard the meaningfulness of our life even when it approaches the end, we need to find ways to preserve or re-establish our *connection* to the world.

4(2). RESTORING MEANING: CONNECTIVITY

(1) Recovering the Present

- Acknowledge the importance of immediate sensory gratification by providing access to things that please our senses, which provide comfort, reinstall a sense of wonderment, and help us recover the present.
- Open spaces for encounters with the unexpected, by breaking the existing patterns, by restoring possibilities for newness.
- Generally aim higher than just at making life, including the end of life and the process of dying, less horrible. We should try to make it more wonderful instead (PJ Miller 2015, TED talks, <https://www.youtube.com/watch?v=apbSsILLh28>).

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4(3) RESTORING MEANING: CONNECTIVITY

Those things which seem to take meaning away from human life include not only suffering but dying as well. I never tire of saying that the only really transitory aspects of life are the potentialities; but as soon as they are actualized, they are rendered realities at that very moment; they are saved and delivered into the past, wherein they are rescued and preserved from transitoriness. For, in the past, nothing is irretrievably lost but everything irrevocably stored

Viktor Frankl (2004),
Man's Search for Meaning p. 123-4.

Victor Frankl:

Being past is not being “irretrievably lost”, but “irrevocably stored”.

(2) Re-evaluating the past

- Death cannot take away what has already happened, it cannot make what was done undone.
- *Death is not the ultimate annihilator.* It can take away neither the ugliness nor the beauty of what has been done.

Our usual inclination is to say that becoming past is disappearance and hence loss. What is past is no longer, almost as if it had never been. What is real is the present, which of course turns into past almost immediately. Victor Frankl's perspective seems to be the exact opposite, which is rather refreshing: “in the past, nothing is irretrievably lost but everything irrevocably stored”.

(2) Re-evaluating the past

When one is dying one may feel that one's life wasn't worth much, that one hasn't achieved much and that whatever one did and had in the past is now precisely that, namely past: gone, no longer relevant, meaningless. But death cannot take away what has already happened, it cannot make what was done undone. So one can rejoice in the past.

However, recalling the past can also be source of considerable sorrow and thus suffering. It may lead to regrets and guilt in recognition of all the shortfalls, of all the potentialities that weren't realised.

But since one cannot undo what one has done, *death is not the ultimate annihilator.* It can take away neither the ugliness nor the beauty of what has been done.

4(4). RESTORING MEANING: CONNECTIVITY

Let the youthful soul look back on life with the question: what have you truly loved up to now, what has elevated your soul, what has mastered it and at the same time delighted it? Place these venerated objects before you in a row, and perhaps they will yield for you, through their nature and their sequence, a law, the fundamental law of your true self. Compare these objects, see how one complements, expands, surpasses, transfigures another, how they form a stepladder upon which you have climbed up to yourself as you are now...

Friedrich Nietzsche,
Untimely Meditations, III.1, p.129

Adopting the perspective of the
'youthful soul':

Focus on beauty, on recovering and
increasing beauty, not merely
minimising ugliness.

*But what beauty can there be in the
present, a present that unlike a
healthy youth's has very limited, if
any, future to hope for?*

In a sense, paradoxical as it may be, when reaching the end of life one should do what Nietzsche prescribed for the 'youthful soul': "Let the youthful soul look back on life with the question: what have you truly loved up to now, what has elevated your soul, what has mastered it and at the same time delighted it?"

Our focus then, should be on beauty, on increasing beauty, not merely minimising ugliness, because beauty is just as real.

But what beauty can there be in the present, a present that unlike a healthy youth's has very limited, if any, future to hope for?

5(I). RESTORING MEANING: HOPE

There is no meaningful human life without hope.

Hope can be:

- goal-directed hope, the kind we are most familiar with
- open-ended hope, which is “characterized by an openness of spirit with respect to the future” and which “casts a positive glow on life” (Webb 2007, “Modes of Hoping”, *History of the Human Sciences* 20/3. p. 68)

A patient suffering from a life-limiting illness may be sustained by the hope for a cure, a hope for a miracle. But then again, isn't life, the life I've already had, the life I am having now, itself nothing short of a miracle?

5. Restoring Meaning: Hope

A meaningful human life without hope is difficult to imagine. Darren Webb distinguishes two overarching meta-modes of hoping:

- * goal-directed hope, the kind we are most familiar with
- * open-ended hope, “characterized by an openness of spirit with respect to the future and casts a positive glow on life” (Webb 2007, 68).

A patient suffering from a life-limiting illness may be sustained by the hope for a cure, a hope for a miracle. But then again, isn't life, the life I've already had, the life I am having now, itself nothing short of a miracle?

5(2). RESTORING MEANING: HOPE

Just like in a beautiful piece of music where there is a sense of hope. And it's not clear whether it is the oboe that conveys that, or it is a little rustling of bells, or it is that very subtle or sudden introduction of a bit of guitar that came and went, or may be even that tambourine that came for one second. So hope is like music because its quality is not really confined to one particular thing. It is the combination of elements that gives it its alluring quality.

Papastergiadis interviewed
by Zournazi (2002), *Hope. New Philosophies for Change* p. 81-82

Hope is an embodied affect; that is, hope is the feeling that inclines toward the beautiful and that provides a sense of being alive.

Coleman and Moreno Figuera (2010),
"Past and Future Perfect? Beauty, Affect and Hope",
Journal for Cultural Research 14/4, p. 361

Howie: open-ended hope as a 'habit' that may help us live well up to death.

'I hope you are finding this conversation interesting.'

'I hope you really mean what you say.'

Instead of hoping that everything will turn out well, we hope and trust that everything *is* well already.

This sense of hope is "just like in a beautiful piece of music", "a feeling that ... provides a sense of being alive"

Howie spoke of open-ended hope as a 'habit' that may help us live well up to death; but if there can be open-ended hope that makes no claim on the future, then this habit consists in hoping for the present.

Examples in everyday language where we use hope in this way: 'I hope you are finding this conversation interesting', or 'I hope you really mean what you say'.

We are not hoping that everything will turn out well but we are hoping and trusting that everything (or at least everything that truly matters) *is* well already. This sense of hope is "just like in a beautiful piece of music", "a feeling that ... provides a sense of being alive"

In other words, I hope that things that are happening now, things that it is really hard, nay impossible, to actually know, are the way that they appear to me in the best possible light.

6(1). DESIGNING MEANING

The process of dying can be experienced as meaningful not only if it serves a purpose, but also if it provides us with opportunities to:

- (a) discover what *connects* us to the world (primarily through the senses)
- (b) re-evaluate the past as not lost but present
- (c) cultivate *hope*, not for the future but the present.

6. Designing Meaning

To summarize, the process of dying can be experienced as meaningful not only if it serves a purpose, but also if it provides us with opportunities to (a) discover what *connects* us to the world (primarily through the senses), (b) re-evaluate the past as not lost but present, and (c) cultivate *hope*, not for the future but the present.

6(2). DESIGNING MEANING

Place *meaning* at the centre of the end-of-life care design.

Possible objective: provide opportunities to rediscover connections, re-evaluate the past, and cultivate hope.

But also: encourage and facilitate the re-thinking, re-evaluating and, more importantly, talking about death and the experience of the process of dying.

So, what is our proposal for designing meaning? Essentially, it is a proposal to place meaning at the centre of the end-of-life care design. From that point of view, the three opportunities identified above could very well form the objectives of such design. At a most fundamental level however, such attempt involves re-thinking, re-evaluating and, more importantly, talking about death and the experience of the process of dying.

6(3). DESIGNING MEANING

We all need to be equipped to offer patients honest conversations about what they can expect in the future, to give them choices and control over the remainder of their lives. This is not just about high-quality palliative care in the last weeks or days, but about holding conversations much earlier after diagnosis of a progressive or terminal condition, including frailty.

Talking about Dying: How to begin honest Conversations about what lies ahead, RCP, October 2018.

Death as a failure, not to be acknowledged or talked about. Report insists that this needs to change.

Missing from report: a *positive* conception of what living well when one is in the last phase of one's life might mean, and what it would require beyond some bare minimum of choice and control.

Recognizing the tangible absence of, and urgent need for, substantial and meaningful discussion of living with dying, a report just published by the Royal College of Physicians urges:

We all need to be equipped to offer patients honest conversations about what they can expect in the future, to give them choices and control over the remainder of their lives. This is not just about high-quality palliative care in the last weeks or days, but about holding conversations much earlier after diagnosis of a progressive or terminal condition, including frailty.

The report confirms that healthcare professionals have the tendency to over treat patients and still see death as a failure, a taboo, which they feel ill-prepared and uncomfortable to discuss with patients. Even if healthcare staff would be inclined to start conversations about the end-of-life early enough this “*doesn't seem to be valued by management*”, and hence when such conversations do actually take place, it is at times of crisis, when they can no longer be avoided. What is missing from this report and perhaps from our contemporary society more generally, is an indication of a *positive* conception of what living well when one is in the last phase of their life might mean, and what it would require beyond some bare minimum of choice and control.

ACADEMIC RESIDENCY

Philosophy Department, University of Liverpool
NHS Research and Development
North West

Professor Dame Janet Beer, Vice Chancellor of University of Liverpool, said “Every one of us has a stake in these issues and we hope through this project to help to prepare the NHS for the future.”

Professor Stuart Eglin, CEO of NHS R&D NW, said: “I am delighted to host this residency with my team and hope that this is the beginning of a new way of thinking about the future of health and care research.”

THINKING MATTERS

Join us at the launch event:

Thursday 29 November 2018,
17:00-19:00
Bluecoat Arts Centre, Liverpool

Book your free ticket:

[http://www.thebluecoat.org.uk/
events/show/events](http://www.thebluecoat.org.uk/events/show/events)

So, this talk today, forms for us the first step in the process of developing the design of a model of situated cross-institutional collaboration, the Academic-in-Residence model, which the Philosophy Department University of Liverpool introduced in 2013 in partnership with the Bluecoat Arts centre, and which we hope that some of you here will also consider developing in new directions. The Academic-in-Residence model has since been adopted by other colleagues and adjusted to best fit the strengths and needs of the academics and partners involved.

We (Panayiota Vassilopoulou and Michael Hauskeller), together with our colleague Dr Rachael Wiseman, are about to launch a new Residency with the NHS R&D North West, which we have been co-designing for the last six months.

Unlike other forms of collaboration, Residencies afford the opportunity to inhabit a space or institution, co-explore priorities and activities, and co-develop research and training agendas.

While residencies in healthcare environments are not entirely new, they tend to focus on the patients, which understandably are and should be at the core of any attempt to improve quality of life. However, we want to complement these efforts with an attempt to focus on the directors, managers, decision makers, and trainers, who, like all of us of course, are also themselves current or future patients, family or friends to

Thank you!

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