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

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. 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 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.

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.
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 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. 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 (FJ Miller 2015, TED talks, https://www.youtube.com/watch?v=apbSsILLLh28).

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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.
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? 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,
*Un TIMELY 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?

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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. 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 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?
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. 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

(c) cultivate hope, not for the future but the present.
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.
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.
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!

References:

General Medical Council (2010): Treatment and care towards the end of life: good practice in decision making. Glossary of terms, Manchester.