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Lessons from Designing for End-of-Life

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Abstract: The Delft Design for End-of-Life Lab aims to improve, through design, Quality of Death and Dying (QoDD), that is, the Quality of Life (QoL) in its final stage. In that context, quality of life is defined by the comfort experienced in the physical, social, psychological and existential domains, while taking into account what matters to people in the final stage of their life.

The different design research projects carried out in the End-of-Life Lab lead to insights in how to design for quality of life in its final stage. In return, these insights may be valuable starting points for reflections on designing for quality of life in general. These insights are related to designing as a process and to the related required sensitivities of designers. The key insights are: the need for a 'relation-centred' design approach, the need for time and patience, the need for room for uncertainties and the need for a care-ethics approach to moral dilemma's.

Keywords: End-of-Life, Quality-of-Life, Design Reflection, Design Sensitivity

1. Introduction

1.1 The promise of immortality?

Future perspectives on the role of technology in the development of humankind seem to take two opposing positions towards our mortality: defeating it or embracing it.

On the one hand, (medical) technology seeks to understand how to defeat death. First by understanding how to fix the problems that the aging body is facing, until these problems are solvable. Second by exploring how hybrid systems of human bodies merged with technology could significantly prolong our lives. And eventually by envisioning how technology could make our bodies obsolete all together, allowing us to live forever by 'downloading' ourselves into technological systems. However, although immortality at first glance seems an attractive future perspective to strive for, the benefits of true immortality are difficult to imagine: thorough reflections beyond the dream of just 'living a little longer' show the impossibility of giving meaning to an eternal life. Philosophers from different era's and backgrounds, such as Seneca, Montaigne and de Beauvoir argued that it is precisely *facing* our mortality that puts life into perspective and allows us to give meaning to it, to ask ourselves what really matters to us in life, and to act upon these values. On the

contrary, immortality will eventually take away our possibility to give meaning to our lives: there is no time frame and no ending to experience the urgency for reflection and for action.

The second position of (medical) technology would therefore not be to strive for immortality, but to embrace mortality as an essential and integrated aspect of life.

1.2 End-of-Life Care

End-of-life-care is about having the courage to face and embrace our mortality. When being confronted with an incurable, life threatening condition, End-of-Life care shifts from a curative approach to a comforting approach: the goal and focus of care shifts from adding days to one's life to adding life to one's days, or as Gawande (2014) phrases it, 'to allow people to live a life worth living until the end'. End-of-Life care focuses on providing comfort, while taking into account what matters to people in this final phase. Both comfort and meaning are not universally determined, but defined by the person facing his/her own death. Also, End-of-Life care questions *how* comfort and meaning are perceived in life's final stage.

1.3 The Delft Design for End-of-Life Lab

The Delft Design for End-of-Life Lab explores how design can contribute to the quality of dying, the quality of life in its final stage, by exploring how design can contribute to offering comfort in the physical, the social, the psychological and the existential aspects of life. In the lab, researchers and students, together with external organisations, explore the power of design for End-of-Life through design projects on different levels, for example as graduation projects, as part of design courses or as external funded research projects.

The insights presented in this paper are reflections on the activities carried out in the Delft Design for End of Life Lab, and based on lessons learned from End of Life care.

2. Insights from Designing for the End-of-Life

2.1 From "Human-centred" to "relation-centred" design

Designing often positions itself as "Human-centred": understanding people's needs, dreams and wishes and striving to meet these needs. Designing is thereby often focussed on individuals (alone or in groups) and about empowering them. From that perspective, individuality, autonomy and independency are values that matter to design for. In designing for the End-of-Life, these values are nuanced and put into a different, more *relational* perspective (Walter & Ross, 2014). As poetically phrased by John Donne: "No man is an island". No man lives or dies for himself alone. Dying transcends the individual, and addresses the relationships the individual has in his/her social surrounding, such as family, friends, formal and informal caregivers. The choices regarding death and dying are not made individually, but in relation to this social context. This relational autonomy, where not the individual, but the inter-dependent social relationships are essential, requires designing to shift from a "human-centred" to a "relation-centred" approach, and to focus not on individuals but on social interdependent systems.

2.2 From desired outcome to desired process

Designing may seem a straightforward process of formulating a desired new situation and finding the right means to achieve that envisioned improved future. End-of-life care, due to its multi-dimensional approach and to the nature of the processes it is facing, makes us aware of the

complexities and uncertainties care has to deal with once it is not about ‘fixing’ a medical problem, but about pursuing comfort and quality of life, where life is seen as the *process of living*. Life can thereby not be described as a desired ‘outcome’, or a desired ‘situation’. Likewise, designing for End-of-Life faces life as a *process* in all its complexities and uncertainties, thereby questioning how much designing is about being in control of the desired *outcomes*, or rather about creating desired *conditions for a desired process*. Designing for the end-of-life is thereby about the art of accepting complexity and uncertainty, and about shifting its focus from creating a desired outcome to creating desired conditions for quality of living.

2.3 Slowing down and allowing for inefficiency

Scholars researching the process of designing often aim at optimizing its creativity, efficiency and efficacy. Tools and methods developed to optimize designing follow that same trend. However, End-of-life care asks for slowing down, for patience, for asking the (existential) questions that do not have a clear answer and may well never have. Designing for End-of-Life requires these same dynamics of slowing down. It needs time to ask the difficult questions, time for reflection, time to be inefficient for the sake of having heard all involved multiple times, and patience to develop insights that are shared and accepted by all involved. This may lead to new tools and new methods that focus on the ‘slowness’ of existential questions raised in designing for the End-of-Life.

2.4 Care ethics: aligning diversity in moral values

End-of-life-care strives for quality of life until the end. However, a ‘good death’ is not a phenomenon that can be defined objectively. First, it is a personal experience: what seems desirable for one may seem a nightmare to another. Next, as stated in 2.1, life and death are not individual but relational processes, involving people with different perspectives: family, friends, caregivers, and ultimately society as a whole. In End-of-life-care these different perspectives, these differences on individual, cultural and societal level, touch upon our core values about life and death, and are thereby often difficult to bring in concordance with each other. Questions about euthanasia for example may lead to complex and heated discussions. Moreover, Designing for End-of-life adds the designer’s personal and cultural moral values to this complexity. The ethical dilemma’s involved in Designing for the End-of-Life however, are not to be debated in terms of who is right and who is wrong, neither in terms of who should win or loose. Dying in peace requires harmony and alignment of the different positions. A possible approach that respects all diversities involved is to find a common ground through dialogue; as is strived for in care ethics (Gilligan, 1993), where the focus of the dialogue is to create a new understanding out of conflicting perspectives.

2.5 To conclude: Courage and Sensitivity

The lessons learned from designing for the End-of-Life show that designers need to develop specific sensitivities to design for this domain. These sensitivities may be considered relevant for designers in general, when addressing meaning of life in their designs. For that cause, designers need to be sensitive for humans as *relational* beings rather than autonomous individuals: sensitive for the *time and patience* required to address existential questions rather than striving for efficiency in designing; sensitive for *creating desired conditions* rather than controlling outcomes, and sensitive for seeking the common grounds in moral dilemma’s, for seeking the dialogue needed to align diversity in moral values, rather than seeking the debate as to what is right and what is wrong.

It takes courage to face mortality in our life, and likewise designers will need to develop the courage to face mortality in designing and thereby facing the difficult questions about meaning of life and

living. This courage is supported by taking into account the personal values of the designer as one of the voices in the ethical dialogues that emerge from each project.

3. Reflections on the future of Design

This paper started with the position that striving for immortality will make us lose the ability to put life into perspective and to give meaning to it. It is precisely *embracing* our mortality that allows us to explore what is meaningful to us in our lives. More specifically, being in contact with the dying and listening to them, allows us to learn valuable lessons about life in general, as described by End-of-Life caregivers such as Steiner (2012).

Likewise, in Design, it might well be that without being aware of it we are embarked on a journey with a position implicitly reflecting the dream of immortality, of 'eternal growth', of eternal humankind. Also, in Design this implicit position towards the immortality of humankind may hamper our ability to give meaning to humanity and to act upon it. More on the short run we might fail to see where quality needs to prevail over quantity of life. In other words: quality of death and dying puts the meaning of life and living in perspective, likewise designing for quality of death and dying puts designing for meaning of life and living in perspective.

To conclude, to incorporate meaning in designing, Design needs to embrace the awareness of mortality, of human beings as well as of humankind, and incorporate the lessons learned in Designing for End-of-Life. They may well be valuable lessons for design in general, teaching us how to address quality of life and living. The themes to reflect on, which emerged from the current experiences within the Design for End of Life Lab, are by no means limited to the topics described in this paper. Future projects, encounters and dialogues will accentuate and enlarge the landscape of Design for End-of-Life, and thereby of Design.

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