Design Meets Death. A case of critical discourse and strategic contributions

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Abstract: End-of-life is a profound and inevitable part of life, and thus, human condition. It raises significant and critical questions around the meaning, purpose, fairness and quality of life, on multiple individual, inter-personal, and societal levels. Design for end-of-life is an emerging area, gaining visibility and interdisciplinary interest. Current contributions around design and end-of-life are however, limited and disjointed, lacking in critical knowledge base and strategic vision. While valuable, such rush into interventional, operational and incremental contributions, is archetypal of design's 'problem-solving' approach, and would risk obscuring the broader and potentially significant theoretical, methodological, and empirical contributions between design and end-of-life. This paper argues the case for adopting a 'problem framing', 'transdisciplinary', 'systemic' approach to this fascinating emerging field. By initiating, for the first time, a theoretically and empirically informed critical discourse between the two fields of design and end-of-life, critical questions, strategic opportunities, and significant contributions between the two fields could be identified and outlined.

Keywords: Design, Death, Dying, Palliative and End-of-life Care, Critical discourse

1. Addressing the Why - Design Meets Death

Death is a profound and inevitable part of life, and therefore, human condition. It raises significant and critical questions around the meaning, purpose, fairness, and quality vs. quantity of life - on multiple individual, inter-personal, and societal levels (Behrman and Field, 2003; Van der Geest et.al, 2014; Hexem et. al, 2011). Historically, as societies, we have tended to 'religionise' and 'medicalise' death, relying firstly on religion, and subsequently on medicine, to lead the way and act as the experts in holding our hand through end-of-life and dying experience. As we come to acknowledge the many facets of death and dying as a holistic, human centred concept, such 'singular expertise' is neither adequate, nor appropriate any more, no matter how effective in its own era.

Arguments around personalised medicine (Lloyd-Williams et.al, 2008), patient-centred care (Kane et. al, 2015), patient-reported outcomes (Aslakson RA, et. al, 2017), and human centred design (Giacomin, 2014), resonate strongly with wider calls to reclaim and reimagine end-of-life as a 'human', rather than a mere 'medical' domain (Davies, 2018). Hence, moving to 'humanise' death. Such approach however, needs a wider transdisciplinary discourse, outlook and collaboration.

While interdisciplinarity integrates knowledge and methods from different disciplines, transdisciplinarity aims to create a unity of intellectual frameworks beyond the disciplinary perspectives, embracing the complexity and diversity. Figure 1 positions transdisciplinarity across the disciplinary spectrum (Jensenius, 2012). Funtowicz and Ravetz (1993) argue 'when the very nature of a problem is not clear or under dispute, transdisciplinarity can help determine the most relevant problems and the key questions associated with them'. Death is perhaps, one of the few universal concepts that not only deserves, but also necessitates true transdisciplinarity, no matter how elusive the approach. This might help transform the end-of-life experience, and the role design can play in facilitating and advancing such transdisciplinary conversation and investigation, is potentially significant, and yet to be explored.
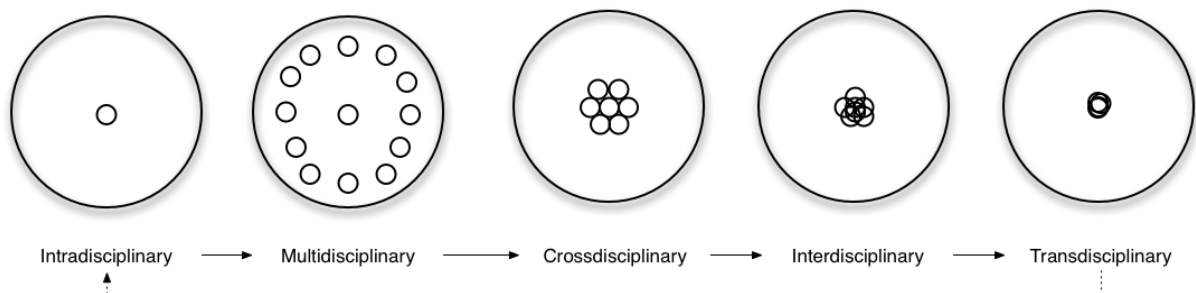

Figure 1. The disciplinary spectrum; intra, multi, cross, inter, trans (Jensenius, 2012)

Design-driven approaches such as Deign Thinking and Human Centred Design, are relatively well established within the wider healthcare innovation domain. Design[1] for end-of-life experience, however, is a new and emerging area, gaining visibility, momentum, and interest amongst palliative care specialists, designers, and the wider public (IDEO, 2016; End Well, 2017; HELIX, 2017; Reimagine, 2018). Such interest is inspired and closely aligned with the rapidly growing international evidence base on recognition of the individuals' right and desire to design their own end-of-life experience in ways that are meaningful, and truly reflect and celebrate them and their life (End Well, 2017).

So far however, design contributions in end-of-life are rather limited in scope and depth, disjointed, and mainly operational and incremental - in form of interventions and initiatives. It is argued, our current attempts in design for end-of-life - as a fascinating emerging topic - are lacking in three substantial elements:

1. Critical discourse and foundational research
2. Strategic vision and key opportunities
3. Radical innovation and significant contributions

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[1] In this paper, 'design' is referred to as an overarching discipline, spanning Product design, Service design, Digital design, Experience design, Graphic design, Strategic design, etc. in general, seen as a creative problem defining and solving process.

This is while there is a significant potential for design to use its empathic, futuristic and innovative power, to reimagine end-of-life. Still in its infancy, such opportunity is timely and unique to invest and build on the wider area of design for end-of-life. What is missing and critically needed, is a blueprint to establish, steer and facilitate a theoretically and empirically informed conversations and collaborations between the two fields of design and end-of-life.

As a result of this lack, there is, to date, no coherent framework for design and other disciplines in the biological, social and human sciences to work together to improve end-of-life care and experience. Foundational, critical, and exploratory approach to design and end-of-life; 1. Lays the foundation for addressing knowledge gaps, 2. Brings in key disciplines and voices 3. Offers a step-change in why, when and how individuals, healthcare system, and society as a whole, are introduced to and engage with death and end-of-life - potentially improving life trajectory and health outcomes.

2. Exploring the How - Design Meets Death

A quick overview of current design contributions to end-of-life, highlights architecture, interior design, and service improvements as the most common design fields. While valuable, such rush into interventional contributions, is archetypal of design's 'problem solving' approach and would risk obscuring the broader and potentially more significant theoretical, methodological, or empirical contributions. Volkart and Nessler (2017) identify two distinct sets of goal and outcome in their Revamped Double Diamond model. Meeting end-of-life, design needs to ensure the first and foremost goal i.e. 'doing the right things', in other words, 'problem framing' is achieved, before moving into the problem solving space (Figure 2).
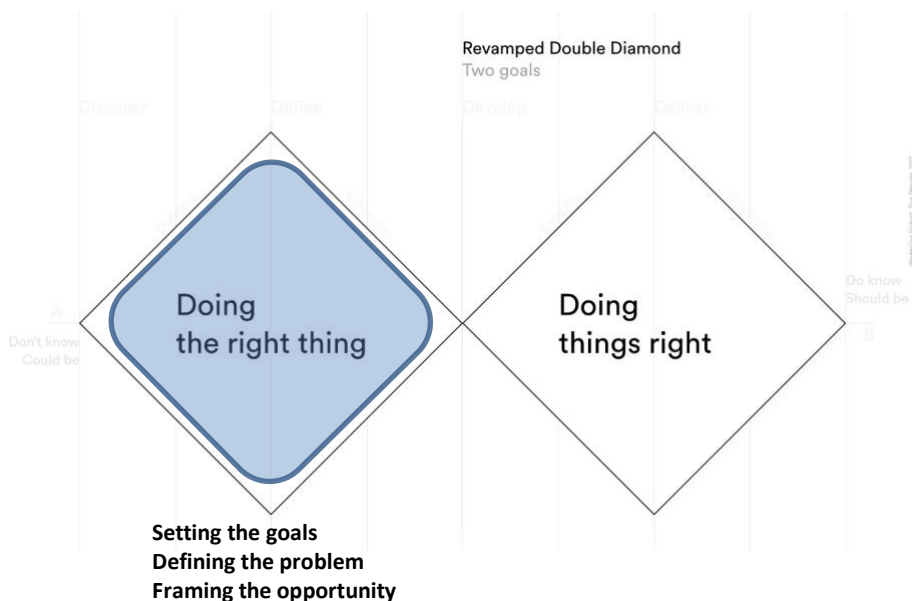

Figure 2. Design Meets Death - Emphasis on 'doing the right thing' first, through setting the goals, defining the problems, and framing the challenges (based on Volkart & Nessler, 2017)

Similarly, end-of-life 'experience strategy' needs to be well-established as the first and foremost outcome, before rushing into end-of-life 'experience design' as the typical expected outcome (Figure 3). Together, the diagrams highlight two key principles currently missing in most attempts around design for end-of-life experience.
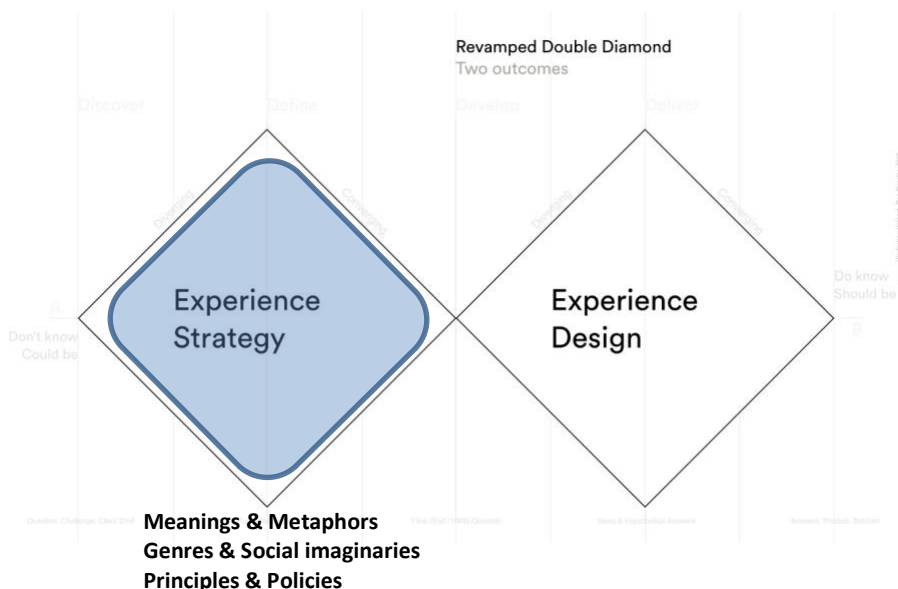

Figure 3. Design Meets Death - Emphasis on 'experience strategy' first, through identifying the meanings and metaphors, genres and social imaginaries, and principles and policies

Hence, the new approach should firstly identify the Why and the How, and then move into exploring the What of design and end-of-life collaboration. This needs to be achieved through a systemic approach, addressing two overarching theoretical and empirical questions:

> **Question 1**: What are the critical questions, strategic opportunities, and significant contributions around design and end-of-life?
>
> **Question 2**: Building on the above, how might design help reimagine and improve end-of-life experience?

It is argued that one current problem with approaches around design and end-of-life, is bypassing Question 1, immediately moving onto Question 2. This paper puts forward one potential approach to address these two fundamental questions:

2.1 Outlining a meta-map of end-of-life

A critical conceptual review of literature on death and end-of-life as a transdisciplinary human construct could be conducted:

- Analysis of meanings, metaphors, theories and models of death and end-of-life in health and life sciences; arts, humanities and social sciences; and physical sciences. Specific disciplinary investigations could cover: Palliative Care; Medicine; Health economics; Philosophy; Psychology; Sociology; Social gerontology; Neurology; Literature; Arts & culture; History; Religious studies; Metaphysics; and Spirituality;
- Synthesis of a transdisciplinary meta-map of end-of-life, unifying the knowledge on the topic while identifying critical convergences and divergences (mismatches, gaps, practicalities, complexities and wicked problems).

2.2 Creating and populating a conceptual framework of design and end-of-life

Mapping out the current and potential design and end-of-life discourses & contributions:

- Literature analysis and synthesis – using findings from meta-map of end-of-life, a framework could be outlined incorporating potential design contributions to end-of-life under 1.Theoretical 2. Empirical 3. Methodological and 4. Interventional (product; service; system; technique) levels;
- Literature analysis – populating the conceptual framework of design & end-of-Life with findings regarding existing contributions and identifying critical and strategic gaps and opportunities.

2.3 Mapping & co-defining end-of-life pathways and experiences within palliative care

Conducting research on system pathways, journeys and experiences within palliative care

- Qualitative and quantitative research to classify, map out, and highlight multiple existing and ideal pathways, systems and processes;
- Co-define design opportunities with multi-stakeholders using design and end-of-life framework to identify strategic and novel design opportunities.

Design and end-of-life have a lot to offer to and learn from one another, provided the foundations of the conversation is robust, wide and deep enough on the outset. If so, we could be embarking on a fascinating, novel and significant design chapter in twenty first century. The ecosystem is set by those who define the language, initiate, and continue the conversation.

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