

ARTIKKELI



Designing Terminal Encounters with Erikson and Kübler-Ross for Life Before Death

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Abstract

Designing digital interaction for people facing the end-of-life at an early or middle adult life is a challenging task. The user, who may be a person of similar age, culture and social status as the designers, is nevertheless living in a reality nothing short of alien to them. For the designer, approaching the users and considering their circumstances – their reality is extremely stressful.

A theoretical framework is built to help the designers. Two psychological theories that address the end-of-life have been fused together through the Grounded Theory paradigm. The first theory is the Erikson’s Stages of Psychosocial Development, focusing primarily on the ninth stage. The second theory is the Kübler-Ross’s Five Stages of Grief, taken in her original, non-sequential manner describing a person’s grief over their own demise (preparatory grief) rather than more general grief.

Co-Design, Agile and Design Science Research are brought together with this theoretical framework to assist the user to face their own death and to realistically appreciate that reality, which gives the designers solid ground on which to stand, when facing this ultimate application area.

The outcome is a framework of 13 categories of human desires at end-of-life, accompanied with conceptual ideas of how to meet these desires with digital solutions.

Introduction

This paper proposes an initial version of a unified cognitive psychological theory for adult human mindset at the end-of-life. First, we introduce our motivations and background in this section. Next, we describe our research design in conceiving this new theory. Third, we present our grounding material in the two psychological theories by Erik and Joan Erikson and Elisabeth Kübler-Ross by analysing their content to prepare to fuse them together. The outcome is then presented in its own section

Synthesis. Finally, we offer our conclusions, initiate discussion, and give consideration for our future interests related to this work.

Life Before Death

Life Before Death (LBD) is a cross-disciplinary research initiative whose goal is “to design a digital artefact for adult people in a terminal stage of illness or injury to help them make the best possible out of the remaining life they still have.” Thus, LBD is an item of thanatechnology – technology that guides us

on issues of mortality (Sofka 1997). Furthermore, it is a Reality Guide (Mäntylä et. al. 2014; Suovuo et. al. 2016) to help people understand their remarkably changed reality as they are facing death.

The LBD initiative will observe the perceived desires of a person at end-of-life from three directions: First, in this study, we derive a theoretical framework from two existing psychological theories that cover this area, approaching from the understanding of the human psyche and condition. Second, in a following study, we will investigate the experiences of practitioners of palliative care and other people with expertise and practice in the area, drawing upon what these people have actually observed in practice. These two results will be combined. Third, as we begin the co-design process, we will involve the primary source, the people at end-of-life themselves.

“Adult” in the goal definition refers to people of approximately 20 to 60 years of age, which is compatible with the range of Erikson’s theory’s life stages 6 (young adulthood) and 7 (adulthood) (Cesario et al 2010; Darling-Fisher and Leidy 1988). This range has been chosen as the initial target of the LBD initiative, because they are of age to make their own decisions, and still generally too young to have typically started considering their own mortality. The primary goal of the LBD initiative is a public digital service that improves mental health and quality of life, in particular at end-of-life.

Because the majority of the authors have a Nordic background, it is natural for us to see the Nordic-born co-design as the methodology for designing and constructing LBD. Our more exact methodology of co-design is as described by Sanders and Stappers (2008). Co-design is useful when the outcome should be as close to the eventual user’s reality as possible. We combine Co-Design with design science research (DSR) (Hevner and Chatterjee 2010), and agile methodologies (Beck

and Andres 2004; Sutherland and Schwaber 2013). Both co-design and DSR state background theories as a vital element. Also, the agile methodologies lean towards knowing and following the best practices. This is our motivation for coming up a single unified psychological framework for the purpose of the LBD initiative.

Review on the literature on the end-of-life psychology

Our research focus has been in the area of palliative care. Palliative care precedes hospice care, but the length of hospice care is typically so short that lengthier processing of psychological crisis is not essential there, rather than facing more acute circumstances. Hence, we conducted a rudimentary literature review on Web of Science Core Collection¹, using the search terms “palliative” and “psychology” to be found in the abstract.

To gain some understanding on the most current topics in end-of-life psychology and grief, we took 30 most “relevant” articles, as estimated by the database, and searched them for citations relating to psychology and grief. Citations referring to each paper’s authors own earlier work were excluded as this would have made these author’s citation count excessive. This search came up with references to both of our theoretical sources, Erikson once, and Kübler-Ross twice, which confirms that these are still relevant sources. It was also not surprising to find Maslow’s Theory of Human Motivation be cited in two papers. Overall, the resulted in 108 references with 273 authors. I. J. Higginson was cited in 3 publications, J. Addington-Hall, N. I. Cherny, D. Clark, R. L. Fainsinger, P. K. and J. Huggard, A. H. Maslow, G. Rodin, C. Seale, D. Spiegel, M. L. S. Vachon and C. Zimmermann in 2 each.

Higginson et al. (2007) investigated the needs of the patients in palliative care and discovered the

¹ The search was conducted with the editions: Science Citation Index Expanded (SCI-EXPANDED)--1900-present, Social Sciences Citation Index (SSCI)--1900-present, Arts & Humanities Citation Index (AHCI)--1975-present, Conference Proceedings Citation Index – Science (CPCI-S)--1990-present, Conference Proceedings Citation Index – Social Science & Humanities (CPCI-SSH)--1990-present, Book Citation Index – Science (BKCI-S)--2009-present, Book Citation Index – Social Sciences & Humanities (BKCI-SSH)--2009-present, Emerging Sources Citation Index (ESCI)--2015-present, Current Chemical Reactions (CCR-EXPANDED)--1985-present, Index Chemicus (IC)--1993-present, As accessible by the University of Turku.

need theories of Maslow and Bradshaw as proper explanations for the findings. Khan, Gomes and Higginson (2014) continued this empirical study of the patients' needs, gathering data and creating a new theory rather than leaning on existing big theories. With Sarmiento et al. (2017), Higginson focused on studying palliative care at home, discovering such arrangement fulfilling a widely expressed need by the patients.

When surveying the close acquaintances of people who had died in 1990, Seale, Addington-Hall and McCarthy (1997) applied the typology of awareness contexts by Glaser and Strauss, relating it to Kübler-Ross. Like Higginson, Addington-Hall studied, with Hotopf et al. (2002) and Lan Ly et al. (2002), the causes of depression in end-of-life circumstances of advanced disease. The finding of the study was that research needs to be done. Addington-Hall also does not refer to any grounding theory.

Clark (1999) shortly discussed Kübler-Ross's theory, while focusing on expanding palliative care's approach of pain more towards "total pain", including "physical, social, emotional and spiritual elements." Fairsinger with Thompson et. al. (2009) interviewed patients of palliative care to analyse their level of acceptance of their prognosed demise and compare it with their reported symptoms. As with Addington-Hall, Fairsinger also cites Glaser and Strauss's *Awareness of Dying*, and Kübler-Ross's *On Death and Dying*.

Instead of depression and pain, Rodin and Zimmermann investigated death-related anxiety with Vehling et al. (2017). They also referred to their earlier paper (Rodin and Zimmermann, 2008), where they analysed psychoanalytical theories, including Erikson and Kübler-Ross. Ten years later, they continued their work with An et al. (2018), still referring to Kübler-Ross's theory. During this work they have come up with their own CALM-method for helping with the anxiety (Nissim et al. 2011).

Spiegel et al. (2007) combined psychology to the palliative care of patients with terminal breast cancer. Their approach is developed in their Supportive-Expressive Group Therapy, where they studied the therapy's effect on prolonging the life-expectancy of the patients.

Research Design

The question that leads medical doctors, particularly in the palliative field, is: "Will this treatment improve the patient's quality of life?" This is a question to which an engineer can relate. Yet, how does one measure in LBD what is improvement and what is not? A solid set of indicators are necessary, so our research question must be:

RQ: What is the taxonomy of desires of a person during life before death?

Figure 1 depicts a diagram of three classes of desires within the space of all possible desires. RQ searches qualitatively the area of the desires of a person during life before death. This provides for a means of quantitatively measuring the cumulative sum of the mismatch vectors between that space and the space of desires provided for by the LBD service.

The space of all possible desires

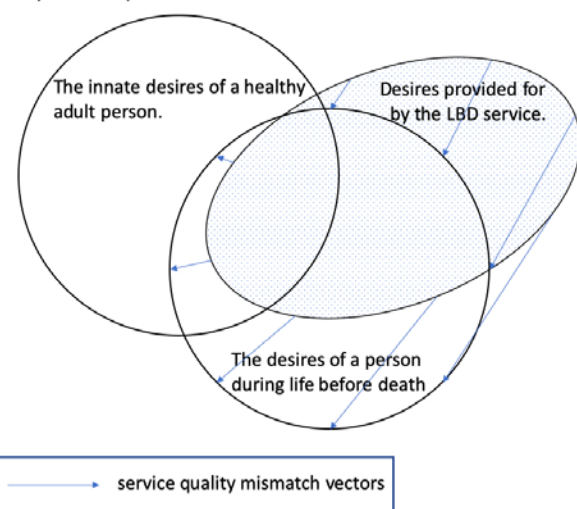


Figure 1. The offset of the taxonomy of desires of a person during life before death and the taxonomy of desires provided by an instance of the digital LBD service.

We followed the principles of Straussian Grounded Theory (GT) (Bryant and Charmaz 2007; Virnes 2014), taking our source material from two established theories – their defined categories, explanations and examples. Erikson's theory considers a person's psychological growth from birth to death (Erikson and Erikson 1998). Kübler-Ross's theory

considers how a person faces the crisis of death (Kübler-Ross and Kessler 2005). While aware of the critique further discussed in the next section, we find these two rooted in empirical clinical study, conducted by far more qualified people than we as computer scientists would be.

We first analysed the theories to construct with sets of thematic categories for both, relating to the research question. This analysis formalized the theories into “checklists”, where each item should be identifiable as a phenomenon that could be checked, when observed in user behaviour. The checklist for Erikson’s theory consists of the attainable strengths and the conflicts and ritualisms involved at each stage. The checklist for Kübler-Ross’s theory consists of the five stages and certain detailed features of these stages. This analysis process is described in more detail in the next section separately for both theories.

The constructed categories were then compared together and aligned, so that any equivalent categories could be merged together. Initially, two of the authors studied the checklists and came up with their proposals for alignment. They then met, compared the proposals and came up with a single initial fusion. During the following three months, in-between other work, the authors studied the connections with the theories to propose adjustments. The proposals were discussed and executed.

Eventually, we found good matches between Erikson’s strengths and Kübler-Ross’s stages, as well as between Erikson’s conflicts and the detailed features of Kübler-Ross. Erikson’s ritualisms did not seem to align well with anything on Kübler-Ross’s theory, so they were omitted from the fusion.

The two background theories and their critique

Our chosen theories were Erikson’s stages of psychosocial development (Erikson and Erikson 1998), and Kübler-Ross’s five stages of grief (Kübler-Ross 1997), which both are still widely referred in the scientific literature. Furthermore, they are the ones with which the authors of this paper are best familiar, and consider as the most thoroughly focusing works concerning approaching death.

The theories face a lot of criticism in general (Miller 1989), particularly for being related to, or a direct part of, psychoanalysis, which remarkably fell out of popularity from the way of behaviorism in 1913 (Watson 1913). While these critiques are valid, most can be ignored, as the focus of this study is on categorizing of different types of typical desires rather than trying to explain their root causes. The aim is also not to generate a psychiatric treatment for people, but rather build features that resonate with their reality.

One criticism towards psychoanalytical theories is that they “shift the goal posts” when trying to be approached and questioned. They do not make strong predictions that could be clearly falsifiable (Grünbaum 1977). Thereby, the theories are often not considered as strong psychological theories to explain the development and behaviour of a person. Yet, support from among the psychologists, such as Miller (1989), promote the application of theories from psychoanalytical, behavioural, as well as neuro-cognitive era, jointly as well as separately, as they each provide some clarity of vision upon issues that have not been adequately addressed. Thus, we find as an important part of this work is to boldly establish “goal posts” – the indicators, to provide tools for quantitative examination of accomplishments.

Another criticism towards these theories is if they can be generalized outside the cultural contexts from which they were derived. For LBD, this is not a problem either, as the target area of the initiative is at least initially confined into the same general culture, where these three theories have been built.

Erikson’s stages of personal development

Erik and Joan Erikson created a theory of stages of psychosocial development (Erikson and Erikson 1998). This theory is still seen valid and applied in studies involving crisis and even death (Cesario et al 2010). The theory, particularly as extended by Joan in 1998, considers the life of a person from birth to death as a series of stages, where each stage is a period of growth accompanied by a conflict to resolve. In a study on women with ovarian cancer, Cesario et al. (2010) observed how the worries of the patients tend to align with the stages of Erikson’s theory, where

each patient should be in their given age.

Most studies involving the ninth stage of Erikson’s theory seem to consider the life of elderly people, nearing the age of their statistical life expectancy. For our purpose, studies such as Cesario et al. (2010) are inconveniently rare. Rather than the typical study that observes how to identify and resolve the conflicts in the eighth and ninth stages, our question is what happens when death is approaching during the sixth or the seventh stage. Does such situation cause the “ninth stage” to begin immediately, skipping over the remaining in-between stages; or does it call for hurry to resolve the remaining conflicts, so that the ninth stage can be begun; or does it make it impossible for a person to complete the ninth stage that should help them approach their death? If the ninth stage begins immediately, will the person tackle the ninth stage versions of conflicts, or will these remain excluded too from the ninth stage?

Where Freud, according to Erikson, considered all parts of the person’s mind being complete upon birth and only growing, Erikson based their theory on the embryological fundament of “epigenesis”. In epigenesis, everything is built on their origins in the seed, not initially being formed to serve their eventual purpose (Erikson and Erikson 1998, 27).

Erikson mentions “gerotranscendence” as the final developmental advancement in the ninth and last stage. This advancement differs from the earlier eight stages, as in the ninth stage the challenge

involves all the eight earlier challenges, except that what earlier was considered as the initial assumption (the syntonic quotient) and what was considered as the challenger (the dystonic element) appears now as the opposite. For the first developmental stage, where assumed trust was threatened by mistrust, now a person has found themselves in mistrust and will have to perceive what can still be trusted – what hope there prevails. Whether a person being pushed from a stage earlier than eight to stage nine will first face these challenges from syntonic quotient to dystonic or not, the challenges still would appear to be the same (Erikson and Erikson 1998, 107).

The significant features of different stages are repeated in Erikson and Erikson (1998) in three occasions. They are convened in a chart (Erikson and Erikson 1998, 38), discussed throughout the text, and again reiterated in the section concerning the ninth stage. One of them is the two sides of the psychological crisis/conflict. Second one is the attained basic strength. The third one is the ritualism involved in the stage. For each stage, these three features were chosen for the Erikson’s checklist of relevant issues of a (dying) person, as shown on Table 1. These were each accompanied with “a goal post” description of how the feature would possibly present itself on a person.

Table 1. The Checklist for Erikson

	Virtue/Strength	Conflict	Ritualism
1	Hope	Trust vs. Mistrust	Idolism
	<i>Mentioning of possibilities of the future</i>	<i>Mentioning of things that one can trust. Aversely, mentioning of fears.</i>	
2	Will	Autonomy vs. Shame/Doubt	Legalism
	<i>Expressing one’s own opinion on thing, particularly related to one’s medical treatments</i>	<i>Confidence on issues, particularly on one’s medical treatment. Doubt, puzzlement or even shame, particularly related to one’s own medical treatment.</i>	<i>Holding unyieldingly onto rules and details</i>

3	Purpose	Initiative vs. Guilt	Moralism
	<i>Considering one's effect on other people's life</i>	<i>Asking questions and taking other initiative and generally being proactive, particularly in one's medical treatment. Apologizing for one's own condition.</i>	
4	Competence	Industry vs. Inferiority	Formalism
	<i>Recognizing one's own capabilities, particularly in taking care of one's medical treatment.</i>	<i>Properly conducted tracking of one's condition. Frustration of not accepting/understanding the prescriptions of caretakers. Feeling like being treated and handled rather than involved.</i>	
5	Fidelity	Identity vs. Identity confusion	Totalism
	<i>Considering one's responsibilities towards one's family and career.</i>	<i>Considering one's role within family and society.</i>	<i>Totalization of the world image.</i>
6	Love	Intimacy vs. Isolation	Elitism
	<i>Judging things by one's own taste and preference.</i>	<i>Confiding things to people within intimacy. Confiding things to one's own self alone in isolation. Fear of abandonment.</i>	<i>Marked more by snobbery than by a living style.</i>
7	Care	Generativity vs. Stagnation	Authoritism
	<i>Expressing concern over other people's wellbeing</i>	<i>Generatively providing care and answers to others. Stagnatively providing judgement over other people's activities.</i>	<i>Ungenerous and ungenerative use of sheer power for the regimentation of economic and familial life.</i>
8	Wisdom	Integrity vs. Despair	Dogmatism
	<i>Studying and expressing understanding of particularly one's own treatment and circumstances. Observing the circumstances (of others) at the moment and after one's death.</i>	<i>Recognizing integrity in one's own life and its consequences, or despair in dissatisfaction over one's life and its consequences.</i>	

Kübler-Ross's Stages of Grief

In 1969 psychiatrist Elizabeth Kübler-Ross released her ground-breaking book *On Death and Dying*, detailing her observations of and work with terminally-ill patients as they deal with the end-of-life (Kübler-Ross 1997). Literature on grief labels this type as preparatory, which describes grief from the perspective of the one who is dying. This contrasts with acute grief, which is experienced by survivors after someone has died. Anticipatory grief can be

experienced by both the dying and survivors as they prepare for an impending loss. From the outset Kübler-Ross's observations were grounded by both pastoral and medical concerns, as her framework developed in an interdisciplinary seminar that included both theological and medical students. Through her observation of over 200 patients at various stages in terminal illness (pre-diagnosis until hours of life left), she developed her five stages of grief.²

These stages of grief assume that the patient has

2 Kübler-Ross was not the first to develop these five stages of grief, but she became the most well-known. See the critiques in Parkes (2013) and Bregman (1989).

a fear of death, and that modern approaches to death aim to extend life, no matter what the outcome of that life may be. Modern medicine and technology have attempted to mitigate the grief, shame, guilt, anger and rage that naturally constitute the grieving process. Those grieving impending death are seen on the outside because of the double-taboo: the first being over displaying these emotions in a semi-public space, and the second is in dealing with death itself (the quintessential taboo of modern Western culture).

Kübler-Ross notes attempts at fleeing from or denying death is compounded by death's increasing "gruesome" nature, caused by it being "more lonely, mechanical, and dehumanized" (Kübler-Ross 1997, 8). The compartmentalization and professionalization of medicine has deteriorated the relationship between the patient and the doctor, where the former is treated more as a thing rather than a person, where cries for "rest, peace, and dignity" are met with more tests and medications. Kübler-Ross's paradigm for grief is an attempt to counter this trend and attend to the emotional needs of the dying.³

One issue that must be acknowledged with Kübler-Ross's paradigm is that it has been interpreted as both descriptive and prescriptive, almost to the point of limiting other possible stages or phases leading to death (Bregman 1989; Corr 2015). It is important to note that in her original paradigm, the stages of grief are only descriptive; some of her later followers attempt to prescribe the stages, in a linear manner, to all who are grieving. Such an approach is counter to Kübler-Ross's original thought and has had disastrous results with the grieving being implanted with guilt for not completing the stages exactly. She also argues that the stages can be cyclical, overlapping or happen in a different order.

Kübler-Ross's paradigm is also not absolute, meaning that grief does not necessarily follow as she described.⁴ For the purposes of the study, her

paradigm provides language that concretizes the experience of grief, putting words to thoughts and feelings that may seem indescribable by one who is actively dying.

For many the first reaction to news of a terminal illness is denial, which is the first stage in Kübler-Ross's theory. She notes that this reaction is "a healthy way of dealing with the uncomfortable and painful situation with which some of these patients have to live for a long time" (Kübler-Ross 1997, 39). This denial originates from the unconscious mind believing that all are immortal and thus incapable of dying. In her observations of patients, this stage is often temporary as a defence mechanism that is eventually replaced by partial acceptance. This denial is usually accompanied by isolation. Such isolation can be caused for two reasons. First, the dying person can avoid others in order to reinforce denial, as external people could "break" the fantasy that the dying person has established. Second, others may avoid the dying person out of frustration or a misplaced sense of helping the dying person cope with grief.

Kübler-Ross identifies the second stage as anger, but it could also take on the characteristics of "rage, envy, and resentment" (Kübler-Ross 1997, 50). The individual who encounters these emotions tend to direct them externally to family, friends and medical professionals, such that all the people connected with the dying person cannot do anything correctly. For this reason, this stage of grief is one of the most understood. As she notes, "maybe we too would be angry if all our life activities were interrupted so prematurely; if all the buildings we started were to go unfinished, to be completed by someone else ... what else would we do with our anger, but let it out on the people who are most likely to enjoy all these things?" (Kübler-Ross 1997, 51).

The crucial form of interaction at this stage is respect and understanding, listening to the concerns of

³ It is important to note that emotions differ based on culture and context and thus require a caregiver to go deeper than the one-word emotional label of each stage. See Bregman (1989).

⁴ Kübler-Ross's use of the word "stage" has made most readers think sequentially. Her colleague Carl Nighswonger (1972) described the process of grief as a "walk" through several dramas. A decade later, William Worden (1983) reframed the grief process as a series of four "tasks" that could be embraced or rejected.

the dying patient that underlie the angry emotions. The goal of this interaction is to affirm that the dying patient is still a human being, valuable and worthy of being cared for, and allowed to function.

Anger can also originate from losing control of one's life decisions, especially for individuals who are accustomed to having control over other aspects of life. Dying often means giving up such control, either because of physical limitations or because family takes away such control in self-governance.

Kübler-Ross defines the third, lesser-known stage "bargaining" by stating that "if we have been unable to face the sad facts in the first period and have been angry at people and God in the second phase, maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable from happening" (Kübler-Ross 1997, 82). She sees this move from anger to bargain as a parallel from childhood development, when a child asks for a favour after expressing anger does not get the desired result. Experience has taught the dying person that good behaviours of some sort can be rewarded, even if it is to temporarily postpone pain, the loss of ability, or even death.

In the fourth stage, the loss of control and function is coupled with the anger potentially caused by distanced family and friends caused in the second stage, which leads the dying person into a state of depression. Kübler-Ross identifies two types of depression that occurs at this stage. The first is caused by past loss, which can include financial or employment loss caused by the illness, change in family roles because of decreased ability, or a combination of the two. This type of depression is often accompanied by guilt or shame.

The second is caused by impending/future loss. "When the depression is a tool to prepare for the impending loss of all the love objects, in order to facilitate the state of acceptance, then encouragements and reassurances are not as meaningful" (Kübler-Ross 1997, 87). Kübler-Ross notes that this type is usually silent, which requires caregivers to provide verbal cues to assist the dying person to emotionally

prepare for what is ahead.

Hopelessness is an emotion that is often central during this stage of grief. Caregivers want to resolve this problem by giving hope, even to the extent of false hope. Such false hope will make things worse since it prevents the dying person from progressing to the final stage of acceptance. The key is to provide authentic hope while being truthful about what is to come. False hope may bring the dying person back to the second stage of anger.

Kübler-Ross notes that a dying person who has had enough time and support to go through the previous stages of grief should be able to arrive at a place of acceptance.⁵ She emphasizes that this stage is not equivalent to being happy or as everything has come to conclusion; rather, it is a time that is "almost void of feelings" (Kübler-Ross 1997, 113). For this reason, this stage is often characterized by more nonverbal communication instead of verbal communication. Kübler-Ross's observations note that many patients at this stage stay in silence and are appreciative of quiet encounters.

Some patients will attempt to fight until the very end, which family and friends may seem as a laudable, but it actually makes it more difficult for patients to reach acceptance, which hinders dying with peace and dignity. Kübler-Ross states that "those patients do best who have been encouraged to express their rage, to cry in preparatory grief, and to express their fears and fantasies to someone who can quietly sit and listen" (Kübler-Ross 1997, 119).

Patients who are terminally ill at a younger age (and thus have not gone through Erikson's stages of the life-cycle) will need more assistance going through the stages of grief. Kübler-Ross observes that those who have died at the stage of acceptance (and thus without fear and despair) take on a quality of early infancy, a phase of passivity in which nothing is asked of them.

These concepts are convened in Table 2.

⁵ Here, it is important to remember that the stages are descriptive, and Kübler-Ross's language here has led some to read them as prescriptive. More helpful for this study is that she emphasizes the need for time before being able to come to acceptance.

Table 2. The Checklist for Kübler-Ross

Stage	Feature	Indicator
1. Denial and Isolation	Temporary disconnection from reality	Expressing doubt over whether the current situation is real or not.
	Belief that self is immortal and incapable of dying	Expressing lack of responsibility over risks in one's actions.
	Avoidance of others to reinforce denial.	Avoiding contact with other people, such as caretakers and relatives, who would cause one to admit the current situation.
	Caregivers isolate dying because of frustration or discomfort	Being avoided by others due to them having experience or just fear of one persisting on denying one's own circumstances.
2. Anger	Dying person feels that life has been interrupted/disrupted prematurely	Expressing dissatisfaction over one's life being cut short.
	Outward directed (delivering emotions towards others without receiving any feedback)	Expressing negative attitudes towards others, not thinking of one's own self.
	Loss of control	Expressing sensations of not having control of one's own life and circumstances.
3. Bargaining	Attempt to postpone the inevitable	Taking any and all means to prolong circumstances.
	Depending on "good behaviour" to be rewarded by extended life	Attempting to improve one's ways of life, in effort to help the circumstances.
	Asking favours from the universe	Prayers. Donations to medical research.
4. Depression	Looking to the past i) Financial loss ii) Employment loss iii) Change in family roles iv) Characterized by guilt or shame	Concentrating on loss of wealth and career positions. Finding changes in one's role in the family. Expressing guilt or shame in these losses.
	Looking to the future i) Impending losses ii) Tends to be silent	Contemplating future hardships. Remaining passive and silent when discussing the future.
	Hopelessness i) Caregivers attempt to give hope, even false hope	Expressing lack of hope for anything worth looking forward to in the future. Being patronised by the caregivers with vain or false promises of the future.
5. Acceptance	Requires time and support	Expressed thoughts naturally not focusing on one's imminent demise alone. Smiles and other gestures expressing one's thoughts not being focused on one's imminent demise alone.
	Not "happy", but void of feelings	
	Primarily nonverbal	

Synthesis

Within this section we abbreviate Erikson as E and Kübler-Ross as KR. The two tables (1 showing E and 2 showing KR) are compared to each other to form the new framework.

Figure 2 shows the conclusion of how we identified connections between the lists. The connections between the main categories are marked with thicker lines, and the connections between smaller details with thinner. Colour coding has been used to mark the KR's categories to which the lines connect and dotting to help distinguish thinner lines of the same

colour. The ritualisms from the checklist for E are not included in the picture, as their lack of correspondence to the checklist for KR became apparent during the connection work, and hence they were dropped out from the final model at this point. For clarity, the sub-features within KR's categories in this figure are not in the same order as in the checklist (and were originally on the whiteboard). They are reordered to minimize the overlapping of connecting lines.

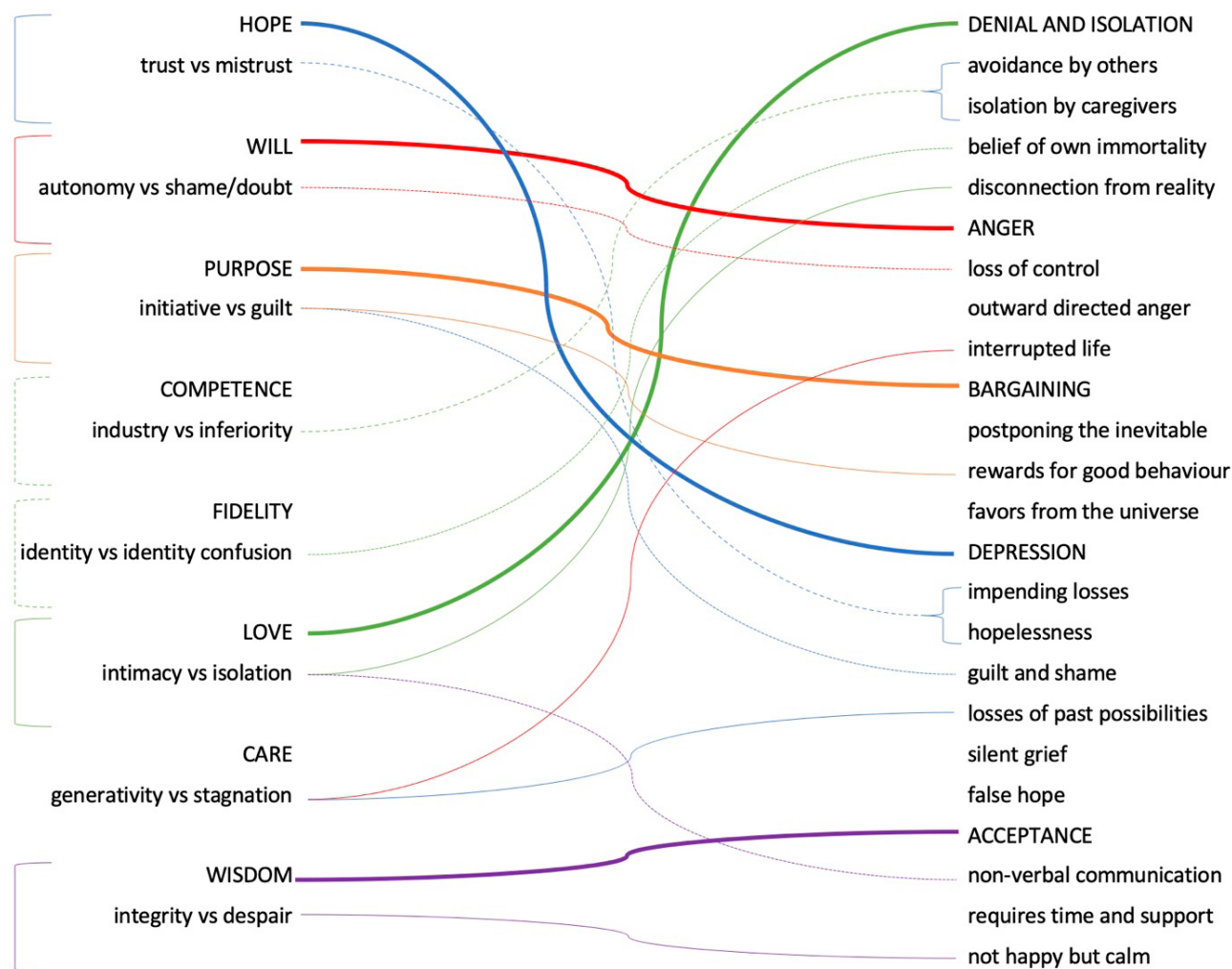


Figure 2. Connections identified between the two checklists.

The outcome of this work is 13 categories of adult human desires and behaviour relating to when approaching death, as shown in Table 3. The first five categories correspond with the five stages of KR as such (albeit in a different order), as well as the E's

strengths that a person can be expected to gain during their stages 1–3, 6 and 8. Figure 3 demonstrates this structure.

Table 3. Categories formed by fusing together Erikson’s and Kübler-Ross’s theories.

Category	Erikson	Kübler-Ross
1 Expectations	1.a Hope (1st stage strength)	4 Depression, 4th stage
2 Power	2.a Will (2nd stage strength)	2 Anger, 2nd stage 2.b Outward directed (anger)
3 Worth	3.a Purpose (3rd stage strength)	3 Bargaining, 3rd stage
4 Interruption	6.a Love (6th stage strength)	1 Denial, 1st stage
5 Reasonability	8.a Wisdom (8th stage strength)	5 Acceptance, 5th stage
6 Trust	1.b Trust vs. Mistrust (1st stage conflict)	4.b, 4.c Impending losses and false hope (Depression)
7 Control	2.b Autonomy vs. Doubt (2nd stage conflict)	2.c Loss of control (Anger)
8 Guilt	3.b Initiative vs. Guilt (3rd stage conflict)	3.b, 4.a.iv “If only’s” (Bargaining, Depression)
9 Involvement	4.b Industry vs. Inferiority (4th stage conflict)	1.c Avoiding others 1.d Being excluded (Denial)
10 Disbelief	5.b Identity vs. Confusion (5th stage conflict)	1.b Disbelief (Denial)
11 Presence	6.b Intimacy vs. Isolation (6th stage conflict)	1.a Disconnection with reality 1.c Avoiding others (Denial) 5.c Non-verbal communication (Acceptance)
12 Heritage	7.b Generativity vs. Stagnation (7th stage conflict)	2.a Interrupted life (Anger) 4.a Losing what one had (Depression)
13 Serenity	8.b Integrity vs. Despair (8th stage conflict)	5.b The calm acceptance (Acceptance)

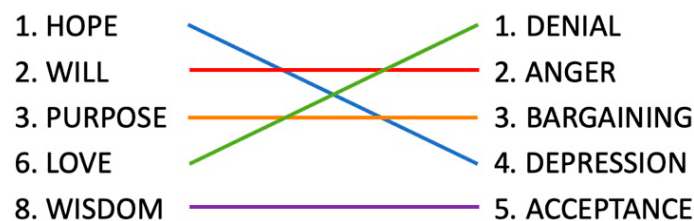


Figure 3. How the five categories of Kübler-Ross connect with five stages of Erikson.

Erikson's strengths in stages 4 (Competence), 5 (Fidelity), and 7 (Care) find no pair in KR's model, and are thereby excluded from the fusion. Competence could be perceived in the fusion category 9 (Involvement), but without a suitable equivalent stage in KR's theory, we perceive it more proper to take the conflict of this stage from E's theory. Fidelity appears difficult to see as a distinct from Will, Purpose, Competence, Care and Love, especially when trying to reflect it against KR's theory. Like competence, as there is not proper pairing for it in KR's stages, it was excluded from the fusion. Also Care fails to pair, and yet, we can find a match of the conflict related to each of these three excluded stages in KR's theory for the fused framework.

Interestingly, these excluded strengths all are social ones, unlike for example Hope (1.a) and Purpose (3.a), which can be experienced in solitary. Even Love (6.a) as Erikson describes its meaning in their theory, is considered primarily narcissistic. By consequence, we notice that Kübler-Ross focuses on more personal experience than shared experience. Even, when social interaction with other is mentioned, it tends to be from a negative perspective, such as false hope given by others, avoidance of others, and expressing anger towards others.

The categories 6–13 correspond with E's conflicts at each stage 1–8, as well as with the more detailed phenomena within KR's 5 stages. As both categories 1–5 and 6–13 are ordered according to E's corresponding stages, it is easy to note that 1–5 are similar to 6–8, 11 and 13. E's 1 stage connects to KR's 4, 2 to 2, 3 to 3, 6 mainly to 1, and E's final stage 8 to KR's final stage 5. E's strengths of stages 4 and 5 did not find a match in KR's stages, but their conflicts can be connected to KR's denial similarly as E's strength and conflict of stage 6, which could be interesting for any future analysis of E's theory.

The 13 categories of the fusion framework are as follows: expectations, power, worth, interruption, reasonability, trust, control, guilt, involvement, disbelief, presence, heritage, and serenity.

Expectations

KR's Depression unintuitively connects with E's Hope. We call this category *expectations*. Erikson de-

scribes Hope as "pure future" and "expectant desire". It is based on either trust or mistrust of what is to come. Kübler-Ross's Depression comes after a person first denies the grief, then exhorts anger towards the grief, and then has attempted to bargain with the grief. At this point, struggling ends and expectation begins (Kübler-Ross and Kessler 2005).

Indicators for processing issues of the *expectations* category involve questions of what a person can yet expect from the future. From a bleak and depressed perspective, all is over and nothing else remains but death. On the opposite end, a person may shield themselves from their reality and make unrealistic plans. Making plans for the future are a significant part of this category, both in acceptance and denial of the real circumstances.

Power

KR's Anger is primal power that is directed outwards without listening. This resonates with E's strength of Will, where expectant hope has made way to the personal will that is threatened by shame and doubt. The risk of facing shame and doubt easily inhibits the person from listening. KR's Anger could be said to be childish in E's perspective, as it connects to the infantile, second development stage. This *power* is active. It can be directed at oneself, but more importantly, it is seeking for contact with others.

The *power* category is indicated by the person expressing themselves without much control, or capability of receiving feedback.

Worth

In E's theory, the stage for the development of Will is followed by the stage for the development of Purpose, and in KR's theory, the stage of Anger is followed by the stage of Bargaining. In our fusion, we match these two elements in the category called *worth*. A person is searching for their worth as they try to bargain for extra time, trying to understand the purpose of their existence, now that they are facing the inevitable end of it.

Unlike *expectation*, which is considering what will happen in the future, *worth* considers how much influence the person has on the future. A person should feel that they are needed rather than

useless. Also, unlike uncritical extortion of *power*, the person is trying to determine how the world responds to them. Indicators involve analysing what the person is still able to affect the world.

For a designer of digital interaction, the *worth* category relates to the concept of agency. (Murray 2012)

Interruption

KR's stage of Denial resonates strongly with E's stage of Love, where a person is focused in their work more than caring for others – the care for others over narcissism is only at the latter two stages. This would appear visible in the conflict of this stage, where intimacy is placed against isolation. In KR's Denial, a person becomes isolated by their own actions and the reactions of people around them. These both match with the illusion of immortality – the analogy of life being an endless highway. *Interruption* is the initial form of discovering mortality at adult age.

Interruption is indicated by observations of observing things that have so far been a regular part of life, but now must be abstained, cancelled, or altered.

Interruption involves the change in *expectations*. *Interruption* may also lead to activities involved with *worth*, as the person notices what they are no longer capable of, or how their influence on the world has changed.

Reasonability

E's eighth stage is about self-reflection and understanding that life begins to be over. KR's fifth stage is the Acceptance of the reality – not the kind of acceptance that the situation is good, but the kind that the person is not denying the reality. This fuses into the category we call *reasonability*.

Reasonability rationalizes expectation into a realistic balance, away from irrational extremes of nothing or everything being possible. It also reins *power* and submits it into starting to listen too.

Trust

E's conflict between trust and mistrust aligns with the fears of impending losses in KR's Depression. We found *trust* as a suitable name for this category, as both sides of E's conflict of the first developmental

stage are basically about trust – one directly, and the other as its opposite. Also, KR's described fear of impending losses can be rephrased as a question of being able to trust the future. This fear is further increased with the risk of caretakers providing false hope.

Indications of the *trust* category involve questions of believing in the expectations: confidence instead of doubt. Lack of *trust* may lead into worst cases of uncritical wielding of *power* or depressive lack of *expectations*. *Interruption* events may strain *trust* and lead into processing of *trust* issues.

Control

E's second stage conflict questions the person's autonomic exhortations of will with possible shame and doubt of the consequences. This resonates with KR's description, that in the Anger stage a person exhorts their will against the reality of the situation and everything around it, leading typically not to a hoped outcome. The category composed of this connection is named *control*.

Control is indicated by the person making plans of action and successfully following them through. *Reasonability* and viable *expectations* are a prerequisite of *control*. The person must have *trust* in their *worth* and through them, exhort their *power* in a controlled, responsive manner.

Guilt

As KR states, the person may have many “if only I”-thoughts of their past choices. This relates to E's Guilt as an opposing force to initiative. That again is also convenient for these “if only”-questions described as a part of KR's stage of Depression, where initiative is strongly suffocated (Kübler-Ross and Kessler 2005).

Indicators of *guilt* are reminiscing the past and contemplating one's past activities. *Guilt* is, in a sense, the opposite of *expectations*. The person may base their expectations partially on motivations of guilt, trying to fix things broken in the past, or at least make amends. *Guilt* may affect one's *worth*, for example through *interruption* of a past status.

Involvement

Distinct from *power* and *presence*, we find *involve-*

ment relating to the conflict of industry and inferiority in E's theory. KR does not make such distinction inside the Denial stage. This is the person's will and possibility to be an active part of their medical treatment and a maker of their own life choices, rather than being just an object of others. It should be present as in the Anger stage, possibly intense during the Bargaining stage, less visible during the Depression stage, and stabilized at the Acceptance stage.

Involvement is indicated by functional interaction between the person and their caretakers. *Power*, *worth*, *reasonability* and *trust* need to be in balance for *involvement* to be possible. The person needs to have a proper sense of control, where they still are capable of listening and trusting the caretakers, and their own worth sufficiently. *Involvement* may be shattered with issues of *interruption*.

Disbelief

In the Denial stage, KR describes in detail *disbelief*, which can be matched with E's fifth stage conflict between identity and identity confusion. The obtained roles are no longer functional in the new circumstances, which may lead the person to be troubled with wondering how to be, or just choose to ignore the change of circumstances altogether.

Indicators of *disbelief* are trying to find proper course of actions and behaviour to a situation that is new and where the person does not have a ready set yet. The person may be aware of their *worth* in the situation, even if they are in disbelief of how they should exhort this *worth*.

Presence

Erikson's conflict between intimacy and isolation is connected to the isolation of KR's Denial, as well as E's eight stage conflict, but also to KR's Depression and Acceptance. As E describes, intimacy is contrasted with isolation when growing up because a person arrives with aims of intimacy that is threatened by isolation. When approaching death, in E's ninth stage, a person tends to arrive with isolation because friends and others having died and the person having retired from the daily work; or in KR's model, being abandoned and isolated in the stage of Denial, but the following stages eventually bring intimacy

back to the person's life, as conflicts are successfully resolved. We name this category *Presence*.

Presence is indicated by a person considering the current circumstance. Pondering about how they are experiencing it. Also, the presence of others is an important part of this category. When uncritically exhorting *power*, a person is not fully experiencing the presence of anything else than their own self. *Involvement* may take place through *reasonability*, even if a person is not really sensing themselves present in the situation, especially if *disbelief* is elevated.

Heritage

Heritage is a category where a person, according to E's theory, is concerned about their life's achievements, such as children, work and all they have built, which connects with KR's described feelings of interrupted life at the Anger stage and fear of losses at the Depression stage. What will happen to the person's life's work?

Indicators of *heritage* include the will for autobiographical work, as well as considering the issues of one's testament and final will.

Serenity

Serenity is a state present in both theories as a final harmony and understanding of the situation. In E's theory, it is the person's sensed integrity over disgust, for the life they have lived. In KR's theory, the stage of acceptance is the calm, serene acceptance of reality and the ability to continue one's life forwards. Both theories conclude the development of events to this state, which sounds interestingly like "happily ever after" of fairytales. Yet, E states that person either becomes serene or desperate based on this conflict, and KR sees this state as something to achieve, rather than something to be granted.

Serenity is indicated by lack of open issues and lack of questions and troubled feelings. Kübler-Ross describes this as being almost void of feelings.

Conclusion

In this paper, we answer the RQ with a taxonomy of 13 categories. This taxonomy categorizes the desires relevant at end-of-life stage, particularly when this stage occurs in the western culture, prematurely at

adult age. The taxonomy is a fusion of Erikson's and Kübler-Ross's psychoanalytic theories, with sample indicators that help identify to which desire any idea or question refers.

Essentially, the framework is expected to help the researchers in the design process to: 1) accumulate data showing how well the theoretical expectations match the reality, and if the theory itself should be corrected, 2) identify when the users and engineers have a potentially distorted idea of any given phenomenon, and 3) identify own researcher bias.

Looking at the first four rows on Figure 3, it is interesting to see how the two theories align symmetrically. The final stage in both cases is essentially the resolution of a situation. If one would consider *anger* and *bargaining* (also, *will* and *purpose*) sufficiently similar in order to be considered as a single item, then it could be seen like the process of going through grief along the path described by KR would be progressing deeper and deeper back to our most early developed characteristics of our personality as discovered by E. In other words, a person first faces the crisis with their most sophisticated personality through denial, but the magnitude of the issue penetrates through the layers, until the person faces *depression* with primal, infantile mechanism of pure *hope*, before *acceptance* and *wisdom* can be attained.

Future Work

The earlier research on the psychology of the end-of-life period still relies on the big old theories from Freud, Erikson, Kübler-Ross and Maslow, although there is a lot of contemporary empiric research being done to form new theories. On our behalf, we have come up with a fusion of Erikson's and Kübler-Ross's theories from the perspective of end-of-life and in-vite dialogue.

With this initial theoretical framework now created in the rigor cycle of DSR, we are ready to proceed to the evaluation cycle with it, to confirm our findings empirically. However, we need to stop on our way there at the design cycle, where we apply the framework to come up with a design prototype for evaluation.

We also have another path to follow, as we intend to include Heidegger's philosophy more integrally

into our framework. As notable in the reviewed existing literature, the denial building anxiety and depression are a central phenomenon in life before death. Heidegger (1927, §51–53) noted death is an event that we all must face that we should not fade away from our minds. If people want to make the best out of their remaining life, it is important not to deny death. Instead, people can take it as something imperturbable and anxious which offers a possibility for self-investigation that people tend to deny in their lives. This kind of being-towards-death (see more Heidegger 1927) can help people to understand one's prevailing life, likewise limitations and possibilities in one's remaining life. However, this kind of attitude is no easy task and may need the support that LDB is aiming to offer. We have planned this addition of a third theory for attempting to saturate our top-down GT work.

The LBD initiative may provide a possibility to evaluate the ninth stage of Erikson's theory, particularly in relation to people who would by their normal development be expected to be entering the eighth stage, or even earlier, rather than now finding themselves approaching the end-of-life due to their circumstances.

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