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Planning the Passage: How Living Wills Could Help Breaking the Death Taboo and Give Cultural Change a Nudge

> *Death is when other people's body clocks*
> *strike the hour every minute*
> (Heathcote Williams, 1973)[1]

The lines mentioned above are taken from Heathcote Williams' poem *Death is taboo but there's no taboo against dying* in which the author tries to catch multiple occurrences of death and obviously wants to break the taboo. The English writer pursues his goal not only with poetry, but also visually, when he begins 37 lines one below the other with the word »Death«, which looks pretty impressive in print. The elected quote may evoke different images among readers, but the common ground should be that dying and death are omnipresent in human life although both might be out of sight. Especially in Western societies like Germany most people die in the secluded space of institutions nowadays, primarily in hospitals and senior homes. The medical supply in German hospitals is highly advanced. Like in many other wealthy countries institutional medical care is characterized by huge technical progress. In intensive care units patients can be kept alive by machines that manage many existential body functions like breathing and nutrition supply. As a consequence, death can be artificially avoided—theoretically (and if affordable)—for an undetermined period. In addition, studies circulate that predict an increasing number of patients who will receive intensive care in future especially at the end of life.[2] Facing growing opportunities for life-prolonging measures people are requested to describe their wishes for medical treatment

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[1] Williams, Heathcote: Death is Taboo but there's no Taboo against Dying, in: The Transatlantic Review (1973), No. 48, p. 31.

[2] E.g. Carolin Fleischmann-Struzek et al. evaluated retrospectively the case-based hospital statistics in Germany from 2007 to 2015 and come to the conclusion, that among hospital deaths, the proportion of patients receiving intensive care increased by 2.8% annually from 20.6% (2007) to 25.6% (2015). In the 65+ age group, the number of people who died in hospital and received intensive care rose three times as fast as the number of hospital deaths. Fleischmann-Struzek, Carolin et al.: Hospitalisierung und Intensivtherapie am Lebensende. Eine nationale Analyse der DRG-Statistik zwischen 2007 und 2015, in: Deutsches Ärzteblatt 116 (2019), No. 39, pp. 653–660. – Direct and indirect quotes from

in a living will in case they are not able to consent or deny certain treatments. Citizens are asked to figure out their personal conditions under which they finally want to die.

The aim of this chapter is to provide a cultural studies perspective on the living will in recent German society. As the anthropologists Billy Ehn, Ovar Löfgren, and Richard Wilk put it, cultural studies »explore the mysteries of everyday life, all those seemingly trivial tasks and routines that shape people's lives, often in unconscious ways« and which »play a powerful role, especially in the reproduction of society.«[3] Although the history of living wills in Germany began back in 1978, when a German-language version of a patient letter was published by Wilhelm Uhlenbrock for the first time,[4] they have only gained wider attention over the last 20 years.[5] The legal regulation of living wills and their incorporation into the German Civil Code in 2009 to safeguard patients' rights can be seen as an important marker for the relatively young broader relevance of the topic in the everyday lives of ordinary people.

I will show a) how the preparation of a living will challenges the authors when they are asked to define their personal boundaries within the passage from life to death, and b) how a taboo around death and dying inflicts the whole endeavor, and finally c) point out the transformative power of liminality and taboos. Above all, the chapter strives to emphasize the potential of living wills to overcome the unconscious social reproduction of a death taboo that still remains in certain contexts.

In this light it might become clearer why I have chosen Williams' quote at the beginning. It was not just because it looked appealing with »Death« and »taboo« in the title—I chose it, moreover, because of the artist himself and Williams' general attitude towards taboos. The artist, who died in 2017, is known for being a »fire-eater« with »anarchist ener-

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literature and sources in German language were translated by the author. Bibliographical references are given in accordance with the German-language originals.

[3] Ehn, Billy/Löfgren, Ovar/Wilk, Richard: Exploring Everyday Life. Strategies for Ethnography and Cultural Analysis, Lanham et al. 2016, p. 1.

[4] Uhlenbruck, Wilhelm: Der Patientenbrief. Die privatautonome Gestaltung des Rechts auf einen menschenwürdigen Tod, in: NJW (1978), No. 12, p. 566–570.

[5] Florian Greiner provides a detailed historic overview in his recently published postdoctoral thesis, in which he analyses the change in ideas about ›good‹ and self-determined dying in the second half of the twentieth century in West- and East-Germany. Greiner, Florian: Die Entdeckung des Sterbens. Das menschliche Lebensende in beiden deutschen Staaten nach 1945, Berlin 2023.

gy«[6] and was one of the founders of *Suck*, an underground porn-magazine in the UK that contributed to a liberal sex life including queerness in the 1970s.[7] So, one can say, Heathcote Williams had a taste for taboos and pushing the limit. I find this quite inspiring here. But how can I get on board like this? Are dying and death still taboos in recent Western societies? Different voices give different answers. I turn to that question first.

Taboo or not Taboo?[8]

Looking backwards it can be said very briefly that from the middle of the twentieth century—when Geoffrey Gorer noted in his *Pornography of Death*[9] in 1955 that death had replaced sex as a taboo—until the early twenty-first century the dominant idea in the humanities was that death had vanished as a social experience as it was more and more institutionalized, mainly in hospitals. During this period several prominent academics felt an urge to raise awareness on the significant absence of death in everyday life and testified that we lived in a »death-denying culture.«[10] In the late 1960s Walter Benjamin stated that »in the course of modern times dying has been pushed further and further out of the perceptual world of the living.«[11] French sociologist Philippe Ariès described the *mort inter-*

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[6] Gowrie, Grey: Heathcote Williams. A Tribute, in: London Magazine (2017), Aug/Sep, pp. 10–13.

[7] Coveneye, Michael: Heathcote Williams Obituary, in: The Guardian 02.07.2017, www.theguardian.com/culture/2017/jul/02/heathcote-williams-obituary (23.01.2024).

[8] For the genealogy and scientific history of ›taboo‹, starting with captain James Cook's explorations and focussing on Sigmund Freud's implementation in psychology, see: Gutjahr, Ortrud: Tabus als Grundbedingungen von Kultur. Sigmund Freuds Totem und Tabu und die Wende in der Tabuforschung, in: Benthien, Claudia/Gutjahr, Ortrud (eds.): Tabu. Interkulturalität und Gender, München 2008, pp. 19–50.

[9] Gorer, Geoffrey: The Pornography of Death, in: Encounter 5 (1955), No. 4, pp. 49–52. I like to add private economical resources as another crucial taboo in Germany.

[10] E.g.: Kellehear, Allan: Are we a ›Death-denying‹ Society? A Sociological Review, in: Social Science and Medicine 18 (1984), No. 9, pp. 713–721; Blum, Mechthild/Nesseler, Thomas (eds.): Tabu Tod, Freiburg im Breisgau 1997; Callahan, Daniel: Death and the Research Imperative, in: New England Journal of Medicine 342 (2000), No. 9, pp. 654–656; Feldmann, Klaus: Tod und Gesellschaft. Sozialwissenschaftliche Thanatologie im Überblick, Wiesbaden 2010, p. 77; Jüchen, Aurel von: Das Tabu des Todes und der Sinn des Sterbens, Stuttgart 1984.

[11] Benjamin, Walter: Illuminations, New York 1969, p. 93f.

dite, the forbidden death, in his *Western Attitudes toward Death*[12] in 1974 and some years later the *invisible death*[13] in Western societies. German sociologist Norbert Elias published his observations on *The Loneliness of the Dying*[14] in 1985, and in the early 1990s Polish sociologist Zygmunt Baumann reminded us that the awareness and knowledge of human mortality provides the way to the »major source of life's meaning.«[15] At the beginning of the twenty-first century Hubert Knoblauch and Arnold Zingerle again stressed the displacement of death from social frames into institutional contexts.[16] But at the same time different evaluations came up as well leading to the assumption that the death taboo had become less relevant or even had been overcome.[17]

Gerd Göckenjan, a specialist for German health politics, clearly doubts that death still is repressed and tabooed completely in recent German society. He explicitly states that it would be wrong to say that dying and death are not communicated about. In his view rather a division of the topic can be observed: There would be actually little to say about death in our society, death would be the incomprehensible non-existence, essentially left to its own devices—on the other hand, a great deal would be said about dying, dying would be a widely discussed, public topic.[18] Göckenjan also notes that the public discussion of death started in the

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[12] Ariès, Philippe: Western Attitudes toward Death. From the Middle Ages to the Present, London 1974.

[13] Id.: Invisible Death, in: The Wilson Quarterly 5 (1981), No. 1, pp. 105–115.

[14] Elias, Norbert: The Loneliness of the Dying, New York/London 2001 [1985].

[15] Baumann, Zygmunt: Mortality, Immortality and other Life Strategies, Cambridge 1992, p. 9.

[16] Knoblauch, Hubert/Zingerle, Arnold: Thanatosoziologie. Tod, Hospiz und die Institutionalisierung des Sterbens, in: Knoblauch, Hubert/Zingerle, Arnold (eds.): Thanatosoziologie, Berlin 2005, pp. 11–27.

[17] E.g.: Lee, Raymond L. M.: Modernity, Mortality and Re-Enchantment. The Death Taboo revisited, in: Sociology 42 (2008), No. 4, pp. 745–759; Scharf, Susan: Ein Tabu bricht auf. Vom sich wandelnden Umgang mit Sterben, Tod und Trauer, Hamburg 1999; Staudt, Christina: From Concealment to Recognition. The Discourse on Death, Dying, and Grief, in: Bartalos, Michael K. (ed.): Speaking of Death. America's new Sense of Mortality, Westport, CT/London 2009, pp. 3–41; Walter, Tony: Modern Death. Taboo or not Taboo?, in: Sociology 25 (1991), No. 2, pp. 293–310; Wong, Paul T. P.: Meaning Making and the Positive Psychology of Death Acceptance, in: International Journal of Existential Psychology & Psychotherapy 3 (2010), No. 2, pp. 73–82; Zimmermann, Camilla/Rodin, Gary: The Denial of Death Thesis. Sociological Critique and Implications for Palliative Care, in: Palliative Medicine 18 (2004), No. 2, pp. 121–128.

[18] Göckenjan, Gerd: Sterben in unserer Gesellschaft – Ideale und Wirklichkeiten, in: Aus Politik und Zeitgeschichte (APuZ) 4 (2008), pp. 7–14.

1970s and is closely connected to the ideas of the hospice movement until today.

Göckenjan makes a good point with his reference to the hospice movement that started in the UK and quickly spread upon Western countries during the 1960s and which has to be recognized as a big influence for a growing public discourse of death and dying throughout the last decades. But can dying and death be separated so strictly as topics? I guess at least when it comes down to conversations in everyday life you cannot be so decisive. Besides that, not everybody necessarily shares the very secular opinion that death is an »incomprehensible non-existence«. Imaginations of an after-life can be very diverse in Western societies nowadays because of their pluralism and a growing attraction of alternative spiritual concepts. I find it more fruitful to take a closer look at the explicit spheres where death and dying are matters of communication and to focus on differences in quantity and quality of dying- and death-related communication in various contexts.

Philipp A. Mellor observed already in the early 1990s an »explosion of academic and popular interest in the subject of death« and saw a growth in the »sociology of death« in contrast to a lack of considerations of death in social life. As a logical consequence he states the »presence and absence of death« at the same time.[19] According to Mellor's observation, many recent authors notice a large increase in death topics in the media sphere, in public broadcasting, movies, and computer games.[20] And they are very right! The television program offers more than enough crime scenes, portrays of serial killers and takes viewers into the pathology department. The news report about disaster deaths and war victims, documentaries describe the conditions in hospices or palliative care units, and on the radio, on the internet, and in magazines professional advice is given regularly on what to do in the event of the death of a relative—or why and how one should draw up a living will.

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[19] Mellor, Philip A.: Death in High Modernity. The Contemporary Presence and Absence of Death, in: Clark, David (ed.): The Sociology of Death. Theory, Culture, Practice, Oxford/Cambridge 1993, pp. 11–30, here p. 11.

[20] See e.g.: Douglas, Davies: Essay. Death, the Great Taboo, in: New Scientist 196 (2007), No. 2625, pp. 48–49; Mohr, Ernst: Tod und Tabu in der Pandemie. Kulturökonomische Lehren aus der Covid-19-Politik, Bielefeld 2023, here p. 32; Walter, Tony/Littlewood, Jane/Pickering, Michael: Death in the News. The Public Invigilation of Private Emotion, in: Sociology 29 (1995), No. 4, pp. 579–596.

Hence, the following findings are at first surprising: according to the latest representative study from 2022 by the German Hospice and Palliative Association (DHPV), in which over 1000 adults were surveyed, 60% were convinced that the German population does not pay enough attention to dying and death.[21] People in Germany obviously feel that something is missing in the communication about death and dying, even though a superfluous amount of material is offered non-stop. Dying and death seem to be very present somehow, somewhere—but at the same time very absent elsewhere. What exactly is missing and where? As so often when dealing with cultural phenomena, and especially under the guiding topic of liminality, it is fruitful to look at the ambiguities and the *in-betweens*. In the following I will show what I think is missing and where, by diving deeper into my own empirical data and analytical findings.

Presence and Absence of Death in the Context of Living Wills

Ernst Mohr, a professor of cultural economics, analyzed the dynamics of political decision-making during the Covid-19 pandemic in Germany. Although I do not share Mohr's rigorous point of view that the *mort interdite* as a taboo generator was the biggest driver of governmental pandemic decision-making in Germany,[22] he catches a good notion when he asks: »what exactly is taboo?«[23] Mohr says that death and dying are not taboos in general anymore—they are always, similar to Mellor, present and absent at the same time. Therefore he places his comment under the leading concept of a ›differentiated taboo‹.[24]

I follow Mellor and Mohr and frame a living will as a representation within that ›differentiated taboo‹. Starting from there I will show how a qualitative investigation of living wills on the micro-level of everyday

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[21] DHPV: Sterben in Deutschland – Wissen und Einstellungen zum Sterben. Repräsentative Umfrage der Forschungsgruppe Wahlen Telefonfeld GmbH im Auftrag des Deutschen Hospiz- und PalliativVerbands e.V., 2024. URL: www.dhpv.de/presseinformation/wie-deutsche-ueber-das-sterben-denken.html (25.01.2024).

[22] There is more to say but for instance Mohr neglects the possibility that the governmental protection of intensive care units during the Covid-19 pandemic served the goal to prevent individuals from an agonising death by asphyxiation at home.

[23] Mohr: Tod und Tabu in der Pandemie, p. 54.

[24] ibid. See also: Feldmann: Tod und Gesellschaft. Feldmann provides a differentiated overview on sociological discourse on death.

life in combination with the theoretical concepts of liminality and taboo can help to reveal concrete social and cultural structures of the so far somewhat wobbly term. But beforehand I provide some more central features of living wills, especially concerning Germany.

Living Wills in Germany

In a living will, German adults can declare their wishes for medical treatment in the case of emergency when they can no longer approve or reject measures, for example after a serious accident, a stroke, or in an advanced stage of dementia. The document belongs to the group of advanced directives, which are set up for a situation in future when the author is not able to give instructions anymore. The best-known example of an advanced directive is the last will, in which a testator specifies how his estate is to be distributed in the event of his/her death. The living will does not deal with material possessions but with one's own body and being and is a result of the patients' rights movement. Its function and effectiveness are anchored by law since 2009 and it must be obeyed by caregivers, yet there is no official obligation to have one. A living will is a voluntarily matter as well as to register it officially in a particular data base, which is the *Central register of precautionary measures of the Federal Chamber of Notaries*. Thus, living wills can be done and stored in a very private way. Consequently, there are no exact figures on living wills in Germany[25] but different organizations regularly try to collect data on the topic. According to the German Institute for Public Opinion Research 28 % of German adults possessed a living will in 2014.[26] Looking at the German Elderly People Survey (DEAS), a regular German representative study among people aged 40+, it can be estimated very carefully that about half of Germans aged 50+ have a living will today.[27] So overall, there has been an upward trend over the last past years. The trend is supported by institutions providing medical services as

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[25] Cf. Deutscher Bundestag (German Parliament): Zahl der Patientenverfügungen. Kurzmeldungen, 2020. URL: www.bundestag.de/webarchiv/presse/hib/2020_07/707306-707306 (Jan 26 2024).

[26] IfD Allensbach (Institute of Demoscopy Allensbach): Deutlicher Anstieg bei Patientenverfügungen, 2014. URL: www.ifd-allensbach.deuploads/tx_reportsndocs/PD_2014_20.pdf (Feb 03 2024).

[27] Wurm, Susanne et al.: Verbreitung von Patientenverfügungen bei älteren Erwachsenen in Deutschland, in: Journal of Health Monitoring 8 (2023), No. 3, pp. 59–65.

they have a serious interest in the availability of a living wills as it gives medical professionals guidance and security in critical situations. Thus, living wills undoubtedly can be seen as a widespread phenomenon in German everyday life.

The following findings and thoughts are based on a qualitative ethnographic study I conducted in 2018.[28] I wanted to investigate the development processes of living wills of common people in Germany. Participatory observation at a patient rights organization and fourteen semi-structured interviews were implemented. The latter included owners of living wills as well as advisors who provide information.[29] The core results revealed how patients' autonomy is limited as the composition of a living will is embedded in an interactive ›assemblage‹[30] that is highly influenced by juridical and medical expert knowledge and contingent assumptions of a ›preventive self‹[31] that becomes active in medical future planning and ›risk management‹.[32]

Although this is not a representative study, the first significant finding is that all owners have drawn up a ›lethal‹ living will, which means that the purpose of the directive is to avoid an artificial prolongation of life

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[28] Dornhöfer, Julia: Sterben? Mit Sicherheit! Die Patientenverfügung und die Konstituierung eines Präventiven Selbst, Freiburger Studien zur Kulturanthropologie, Special Issue, No. 3, Bielefeld 2019.

[29] The sample included owners of living wills aged from 40 to 85 years. All owners were of good health at the time they composed their living wills. Empirical data was collected and analysed by following the standards of Grounded Theory including the identification of central categories. Further information on methods and methodology: Bernard, H. Russell: Research Methods in Anthropology. Qualitative and Quantitative Approaches, 5th ed., Lanham et al. 2011; Glaser, Barney G./Strauss, Anselm L.: The Discovery of Grounded Theory. Strategies for Qualitative Research, New Brunswick et al. 2009.

[30] The concept of ›assemblage‹ was originally developed by Gilles Deleuze and Félix Guattari. For Michi Knecht the concept supports heuristic orientation in the empirical analysis of heterogeneous, social-technical or bio-cultural imaginations and interactions. See: Knecht, Michi: Nach Writing Culture, mit Actor-Network. Ethnografie/Praxeografie in der Wissenschafts-, Medizin- und Technikforschung, in: Hess, Sabine/Moser, Johannes/Schwertl, Maria (eds.): Europäisch-ethnologisch Forschen. Neue Methoden und Konzepte, Berlin 2013, pp. 79–106. For more information see also: DeLanda, Manuel: Assemblage Theory, Edinburgh 2016.

[31] Lengwiler, Martin/Madarász, Jeannette: Präventionsgeschichte als Kulturgeschichte der Gesundheitspolitik, in: Lengwiler, Martin/Madarász, Jeannette (eds.): Das Präventive Selbst. Eine Kulturgeschichte moderner Gesundheitspolitik, Bielefeld 2010, pp. 11–28. See also: Bröckling, Ulrich: Vorbeugen ist besser… Zur Soziologie der Prävention, in: Behemoth. A Journal on Civilisation 1 (2008), No. 1, pp. 38–48.

[32] Beck, Ulrich: Risk Society. Towards a New Modernity, London 1992.

in certain circumstances. Theoretically, it is also possible that the directive specifies that everything possible should be done to keep the patient alive. But in the case of a lethal living will the owners themselves must reflect and define when they want to pass away, although they, maybe, could be kept alive. The question they have to answer is no less than: under what specific conditions do I *not* want to live anymore? What are my personal criteria under which I prefer to die?

Countless websites provide answers to this question, which can be accessed very quickly. Many organizations offer templates for costless download, even the German Federal Ministry of Justice (*BMJ*) presents modules for an individual living will online without charge.[33] At the same time a veritable market for advice on living wills has evolved. For example, the *German Society For Humane Dying* (DGHS) or *DIPAT*, which is a commercial enterprise for living wills and medical emergency data, charge regular annual contributions. The clear majority of my sample wanted professional assistance, because as non-experts they are aware that they do not feel capable to evaluate the offered examples. They feel insecure and look for help. The authors of a living will want to talk to experts who illustrate diverse health scenarios and explain the consequences of different choices. Since a change in the law on living wills in 2016, professional advice is highly recommended. This is because living wills are now only binding if the treatment situations and wishes are described as detailed and specific as possible.[34] But although living wills primarily deal with medical content, people very often seek help from lawyers and notaries as the costly service benefits another common motivation: the authors want to stress the official character of the document and its importance. It makes them feel safer about the validity of their wills although they know that a juridical form is not mandatory. The mentioned observations led to my interpretation that common people tend to feel overwhelmed by setting up a living will on their own as the requirements concerning the content seem to be too demanding.

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[33] BMJ (German Federal Ministry of Justice): Patientenverfügung. Wie sichere ich meine Selbstbestimmung in gesundheitlichen Angelegenheiten? URL: www.bmj.de/SharedDocs/Publikationen/DE/Broschueren/Patientenverfuegung.html (05.02.2024).

[34] BGH (Federal Court of Justice): Anforderungen an Vorsorgevollmacht und Patientenverfügung im Zusammenhang mit dem Abbruch lebenserhaltender Maßnahmen. URL: juris.bundesgerichtshof.de/cgi-bin/rechtsprechung/document.py?Gericht=bgh&Art=pm&pm_nummer=0136/16. (08.02.2024).

Many researchers have already shown a multitude of limitations of advanced health directives like the contingency of future health planning,[35] the situational and influential context of personal decision making,[36] and the danger of a normative perception of a well-organized ›successful dying‹ in contrast to ›bad dying‹ without any forward planning.[37] In my view another major challenge lies in the task of figuring out personal boundaries for a *new liminal condition*, namely the very emergency for which living wills are made.

The Emergency Case as a Liminal Period

Through my research I met the couple Carol and Tom.[38] By the time I interviewed them they were in their late forties and it was about one year ago when they saw their personal notary to get their living wills fixed. The trigger for this was that Tom's younger cousin had suffered a dramatic accident with serious brain damage and with expected severe impairment for the future. After a shocking visit to the hospital, Carol and Tom decided that they themselves did not want life-sustaining measures in this case and should take precautions. Furthermore, Carol was involved in conversations with a friend about this topic around that time.

A central question in all interviews was about people's personal ideas when they think life prolonging treatments should be stopped—the main purpose of their living wills so to say.

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[35] Cf. Fagerlin, Angela/Schneider, Carl E.: Enough. The Failure of the Living Will, in: Hastings Center Report 34 (2004), No. 2, pp. 30–42.

[36] Cf. Drought, Theresa/König, Barbara A.: »Choice« in the End-of-Life Decision Making: Researching Fact or Fiction?, in: The Gerontologist 42 (2002), No. 3, pp. 114–128. Also: Knecht, Michi: Jenseits von Kultur. Sozialanthropologische Beiträge zum Verständnis von Diversität, Handlungsfähigkeit und Ethik im Umgang mit Patientenverfügungen, in: Ethik in der Medizin 20 (2008), pp. 1–12.

[37] Cf. Schneider, Werner: Der ›gesicherte‹ Tod. Zur diskursiven Ordnung des Lebensendes, in: Knoblauch, Hubert/Zingerle, Arnold (eds.): Thanatosoziologie. Tod, Hospiz und Institutionalisierung des Sterbens, Berlin 2005, pp. 55–79.

[38] The author uses anonymisation to protect the privacy of the participants. The interviews were originally conducted in German, quotations were translated into English by the author.

I: Could you describe your ideas on when, under what circumstances, you would not want life-sustaining measures?

Caro: Perhaps I can start, I have a concrete example: a friend of mine, her mother had a stroke. Machines could stabilize her but she was not able to communicate with anybody in any form, neither by eye blink, nor by facial expressions or handgrip, absolutely nothing. She lived for another eight years in a body that was like a prison so to say […] So, perhaps, if it turns out that you are extremely depending, that you are not yourself anymore and just alive by machines, medication, with an extremely low quality of life or nearly no quality of life at all, that would not be desirable for me.

Tom: Yes, well, if conscious living is no longer possible, if you are totally controlled by doctors, nurses, a law, whatever, if you are deprived of all personal freedom, then I would have the idea that I no longer want to be there just to maintain my life.

Carol stresses in her description the ability to interact socially. She would not like to live forth in a state of isolation from the surrounding world, in her »own prison«. Tom's ideas are a bit more about his conscious function and his ability of self-determination. Particularly remarkable is that all narrators imagine themselves as patients who are no longer alive, but not yet dead. They are neither one nor the other, but an exact term for that seems to be missing.

Diane, 41 years old, is another person I interviewed. She and her husband had drafted their living wills ten years ago and also consulted a notary for help. This was because Diane's husband got scared when his father was reanimated in hospital, even though he had terminal cancer and unbearable pain. Diane's idea about her end of life is very similar to Carol's. She says:

Diane: […] so when life is only possible by artificial respiration and the person, one's self, is absolutely gone, for me personally that would no longer be a life. The imagination of being imprisoned in my body scares me terribly.

Maybe Carol and Diane got the »prison picture« from their notaries. To be honest, I did not ask about the origin of the image. Nevertheless, it is striking that both use the prison metaphor to describe their personal boundary between life and death which is associated with ideas of apathy, the incapability of interaction, exclusion, and isolation. Even Tom's »loss of freedom« matches with this. Their words could be interpreted to mean that the narrators use the prison metaphor as they cannot classify the boundary any better than by »when you are locked up in yourself, this is no longer life«. The expression »dying« does not seem to fit here, because dying is generally perceived as a process, sometimes a very slow process, but nevertheless as a continuous movement towards death whereas the described situations are static. Processuality is absent in these end-of-life descriptions, it is banned by machines and medication. From the perspectives of the agents the linearity of their being is frozen, but classifying the state with an exact term seems to be problematic as they use personal normative metaphoric descriptions of »a life worth living or not«.

In her work *Purity and Danger* Mary Douglas identifies classifications as the foundation for social order.[39] In a later article she writes: »Anyone who is prepared to support the social system finds himself impelled to uphold the classification system which gets meaning from it.«[40] By analyzing social images of purity and pollution Douglas concludes that any social structure is based on applying distinctive classifications that are interwoven and mutually dependent like ›alive/dead‹, because »classification involves definition; definition involves reducing ambiguity.«[41]

In his highly acclaimed contribution on liminality *The Forest of Symbols* Victor Turner directly refers to Douglas' work: »Dr. Mary Douglas, of University College, London, has recently advanced […] the very interesting and illuminating view that the concept of pollution ›is a reaction to protect cherished principles and categories from contradiction‹.«[42] The inspiration Turner received from Douglas' work cannot be emphasized enough. At least it was Douglas' discovery on the functional task of classifications that led Turner to his characterization of liminal beings:

> From this standpoint, one would expect to find that transitional beings are particularly polluting, since they are neither one thing nor another; or may be both; or neither here nor there; or may even be nowhere (in terms of any recognized topography), and are at the very least ›betwixt and between‹ all the recognized fixed points in spacetime of structural classification.[43]

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[39] Douglas, Mary: Purity and Danger. An Analysis of Concept of Pollution and Taboo, London/New York 2002 [1966].

[40] id.: Taboo, in: Cavendish, Richard (ed.): Man, Myth, and Magic, Vol. 21, London 1979, pp. 2767–2771, here 2770.

[41] ibid.

[42] Turner, Victor: The Forest of Symbols. Aspects of the Ndembu Ritual, Ithaca/London 1967, p. 97.

[43] ibid.

Besides as »betwixt and between« Turner specifies liminal beings as »twofold« and as characters who »are at once no longer classified and not yet classified.«[44] Turner's description of liminal beings corresponds to the narrations of Carol, Tom, and Diane when they anticipate criteria for when their lives should end in an emergency case. Therefore, I argue, that the emergency case as one of the biggest drivers of living wills can be conceptualized as a liminal state. This conclusion becomes even more comprehensible by the words of the anthropologist Bjørn Thomassen who notes that »liminality refers to something very simple and universal: the experience of finding oneself at a boundary or in an in-between position, either spatially or temporally.«[45] In the context of living wills the liminal emergency case occurs spatially located not only in hospitals, but within one's own body, and has a—at least theoretically anticipated—determined ending.

Several researchers have already applied the concept of liminality to patients in vegetative state.[46] But obviously one can disagree to conceptualize the emergency case as a liminal period because something crucial is missing here about liminality, which is namely a ritual or at least some kind of symbolic ritual. Douglas' and Turner's contributions are located in the field of ritual theory. Turner himself developed the concept of liminality by analyzing an initiation ritual among the Ndembu in Africa that marks the transition from ›boy‹ to ›man‹ as a ›rite of passage‹. As a ritual the transition is conducted in a very specific choreography that resembles a certain series of ritualistic performances and in which ›masters‹ guide ›neophytes‹ through the liminal period as instructors who themselves have passed that passage before and inherit first-hand knowledge of the transition.[47] Hence, concerning the context of living wills, besides a ritualistic choreography also guiding masters are absent in the scenario of a medical emergency case. Patients in an emergency case can be interpreted as neo-

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[44] ibid., p. 96.

[45] Thomassen, Bjørn: Thinking with Liminality. To the Boundaries of an Anthropological Concept, in: Horvath, Agnes/Thomassen, Bjørn/Wydra, Harald (eds.): Breaking Boundaries. Varities of Liminality, New York/Oxford 2015, pp. 39–58, here p. 40.

[46] Cf. Kuehlmeyer, Katja/Borasio, Gian Domenico/Jox, Ralf J.: How Family Caregivers' Medical and Moral Assumptions influence Decision Making for Patients in the Vegetative State. A Qualitative Interview Study, in: Journal of Medical Ethics 38 (2012), No. 6, pp. 332–337; Zulato, Edoardo/Montali, Lorenzo/Castro, Paula: Regulating Liminality. Making Sense of the Vegetative State and Defining the Limits of End-of-Life Action, in: British Journal of Social Psychology 51 (2023), No. 6, pp. 1733–1752.

[47] Turner: The Forest of Symbols, pp. 93–111.

phytes in transition, but neither lawyers nor doctors can guide through the passage by first-hand knowledge as it is impossible that they have ever crossed the passage to death themselves before. But as Thomassen writes: »liminal experiences are not always safely embedded within a ritual structure—liminality, applied to a broader social science and historical perspective, can also refer to events that simply happen, and happen *to* us.«[48] Thomassen cites revolutions or the collapse of a society caused by catastrophe as examples. By doing so, he clearly distinguishes between liminality in ritual passages and forms of liminality without rituals and masters. When we have to deal with the second type, Thomassen states, the central question should be: »what happens in liminal situations that unfold outside the spatial and temporal boundaries of expert-led ritual passages?«[49]

My own research concentrated on narratives about individual configurations of prospective medical treatments in emergency cases and in my opinion individual imaginations of the future patients have a lot in common with neophytes. To answer Thomassen's question, more research is required with a special focus on liminality in situations when living wills become effective in people's lives. Nevertheless, framing the emergency case as a liminal state helps to understand central difficulties authors of living wills have to face as the challenges are medical ones, but also cultural ones evolving from dichotomic categories. Furthermore, dealing with the *in-between* inherits the possibility of rearranging existing power relations and the alternative distribution of self-empowerment and agency because, according to Turner, liminality can be »partly described as a stage of reflection.«[50] Liminal occasions are »privileged spaces where people are allowed to think about how they think, about the terms in which they conduct their thinking, or to feel about how they feel in daily life«.[51] Understanding the living will as a guideline for a liminal state could help actors to engage more self-aware and perhaps more suitable because actors who are »thinking with liminality«[52] can explore ways of change and improvement. But that involves the task of overcoming a fundamental taboo on dying and death which still exists as I will now show.

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[48] Thomassen: Thinking with Liminality, p. 41.

[49] ibid.

[50] Turner: The Forest of Symbols, p. 105.

[51] Ibid., p. 102.

[52] Thomassen: Thinking with Liminality, p. 41.

Missed out Conversations about the End of Life

As already mentioned, the majority seek professional help for drawing a living will and it is actually surprising how broad the circle of providers is that disseminate information on dying and death. But when the situational context changes and family members are engaged, it suddenly gets very quiet. This becomes clear when you take a closer look at the role of the representative who is responsible for enforcing a living will in the end.

It is common standard that consultants recommend to name a legal surrogate in a living will, often with the advice that the person should be a bit younger than the author, and a second surrogate, in case the first one is not able to do the job. A frequently used example of this is when both spouses who have appointed each other as representatives are in a coma after a car accident. If there is no surrogate named in the document at all the Guardianship Court appoints a person. This might be a relative, yet can also be a complete stranger, depending on the patient's social network and the court's assessment. The legal procedure in Germany is such that the surrogate is involved in the medical decision-making process and speaks on behalf of the patient. In my sample most people chose a person as surrogate they feel very close to. Middle-aged people in committed relationships choose mainly the partner as first surrogate and younger relatives as substitutes, older single people prefer their daughter or son if they have children.

Similar to Carol and Tom, Diane chose her partner as first surrogate and, in case he might not be able to fulfil the job, her younger sister. I asked Diane to describe how she involved her sister in the process.

> Diane: I was told to ask her [by the notary] and I asked and she needed time to think it over. She was very shocked at first, yes, totally shocked at first, she didn't know if she could do it, so, well, she needed time to think it over and then I simply wanted a clear yes or no. I could have accepted a no, as it is a difficult burden, but then she came around for a cup of coffee, read through it and then there was just: okay, I'm in.

Diane and her sister did not share any more words on the content and this is quite typical. People frequently told me that their surrogates were simply informed about being named, but did not even get a copy of the living will. Some advisors told me that they keep hearing that people make a living will, but the document disappears in a drawer without a single word being said about it. In practice, this is risky. Because if the drafters do not have the confidence to draw up the directive with the specific medical descriptions of situations and treatment wishes required by the court, it can be assumed that their representatives, as medical non-experts, will find it difficult to interpret the living will in an emergency. The recommended standard turns the living will into a highly formalized and hypothetical medical document. Its content challenges interpretation skills and does not always fit with the real situation. Is a particular treatment necessary for pain relief or is it life-prolonging? Does the treatment support a feasible recovery? What indeed is actual life-prolonging? Often it is very difficult to tell one from the other. Furthermore, as Carol, Tom, and Diane have described, authors themselves are much more concerned about their social death as a reason for withdrawing life-support measures than about specific medical issues. When I asked people why they had not spoken to their surrogates and explained their wishes in their own words, the most common answer was: »he/she knows me well«. But this is simply a convenient assumption, at best a wish, but not necessarily the truth. How much do we really know about what our parents and siblings want in an emergency, what ideas and wishes they have about their death? There may be exceptions, however, but in my study topics like these were avoided in communication among close family members like the ›elephant in the room‹.

In a podcast titled »Are we not talking about death enough?« the philosopher and cultural scientist Thomas Macho says, that death would be always present in our everyday lives, that it is shown in countless pictures, but as soon as death affects us or a close relative, we would still find it difficult to talk about it. Death would be, so to speak, a ›second-order taboo‹.[53] Janina Wildfeuer, Martin W. Schnell and Christian Schulz share the opinion that talking about dying and death involving relatives is mostly limited to »a particular environment, namely, with patients and their relatives undergoing palliative care, thus in a clearly medicalised situation.«[54] So there is actually a lot of talk about death, but not in the family circle. Dying and death are still taboo there. It is therefore not

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[53] Podcast (in German language) available under: www.detektor.fm/gesellschaft/zurueck-zum-thema-tabuthema-tod (10.06.2024).

[54] Wildfeuer, Janina/Schnell, Martin W./Schulz, Christian: Talking about Dying and Death. On New Discursive Constructions of a Formerly Postulated Taboo, in: Discourse & Society 26 (2015), No. 3, pp. 366–390, here p. 367.

surprising that numerous studies have shown that choosing a relative as surrogate is not a guarantee that one's wishes will be fulfilled on the deathbed.[55]

Norbert Elias observed that people in modern Western societies feel insecure how to behave the right way especially when close ones are dying. They »find it difficult to press dying people's hands or to caress them, to give them a feeling of undiminished protection and belonging. Civilization's overgrown taboo on the expression of strong, spontaneous feelings ties their tongues and hands.«[56] Following Elias the source of that insecurity is in an existing taboo on showing strong emotions in connection with a rising »threshold of repugnance.«[57] Elias explains the existence of taboos as consequences of a Western civilization process very convincing, but Mary Douglas offers a general theory on taboos for cultural analysis. Douglas shows how dichotomic classifications form cultural patterns, shape the language of thoughts and thus the way members of a community interpret the world around them. And according to Douglas, these patterns are never perfect. They have weaknesses as the world is not organized in the fixed categories that human societies apply to it: »human classifications are always too crude for reality« and taboos would work like blinds that cover up the weaknesses of a classification system.[58] Ortrud Gutjahr sharpens the character of taboos further. According to her, there is a consensus in recent scientific research that taboos would be understood as rules of avoidance that regulate human behavior in social communities beyond explicit prohibitions and laws.[59]

Although it is not officially forbidden, Diane and her sister avoid a deeper conversation about the content of Diane's living will, about her personal wishes and ideas—because a taboo is at work and influences the sisters' behavior in this situation. The power of taboos and their huge

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[55] E.g.: Kuehlmeyer, Katja/Borasio, Gian Domenico/Jox, Ralf J.: How Family Caregivers' Medical and Moral Assumptions influence Decision Making for Patients in the Vegetative State. A Qualitative Interview Study, in: Journal of Medical Ethics 38 (2012), No. 6, pp. 332–337; Wijdicks, Eelco F. M./Rabinstein, Alejandro A.: The Family Conference. End-of-Life Guidelines at Work for Comatose Patients, in: Neurology 68 (2007), No. 14, pp. 1092–1094; Vig, Elizabeth K. et al.: Beyond Substituted Judgment. How Surrogates Navigate End-of-Life Decision-Making, in: Journal of the American Geriatrics Society 54 (2006), No. 11, pp. 1688–1693.

[56] Elias: The Loneliness of the Dying, p. 28.

[57] ibid., p. 30.

[58] Douglas: Taboo, p. 2770.

[59] Gutjahr: Tabus als Grundbedingungen von Kultur, p. 19f.

impact on human actions are clearly evident here. Following Gutjahr, taboos should be understood as silent agreements that reach from speaking habits over lifestyles up to feelings, wants and wishes deep into the interpretations of the world and the self of everybody. Taboos would be passed on to the next generation in the socialization process and guide actors, very often unconsciously.[60]

With this knowledge about taboos, it might look like there would be no way out of the dilemma and that society is stuck in a dead-end-street. But this is not the case at all. Scientific discourse including Gutjahr regularly stresses that taboos are not static. Mary Douglas herself emphasizes that we need to »correct our tendency to think of taboo as a rigidly fixed system« as »the classifying process is always active and changing. New classifications are being pushed by some and rejected by others.«[61] Consequently, taboos which are interwoven and dependent on classifications must have a dynamic character, too. In addition, existing taboos can be intentionally broken by community members. Hence, for Gutjahr the transformation of a taboo or even its final abolition can be seen as a significant indicator of cultural and social change.[62] The current reorganization of sexual categories enhanced by the queer movement is a good example. To break a taboo is a critical act as the taboo breaker risks social exclusion—but it is not impossible.

Michael Hebb from the University of Washington saw a need to break the death taboo by intention when he realized that individuals »haven't talked to their families about their preferences, and no one had asked.«[63] Hebb initiated *Death over Dinner*[64] to get the missing conversation started, »the most important and costly conversation America isn't having.«[65] In 2013 a website was launched as a helping tool to create an occasion and a space for exchange with family members and friends about the end of life. Users can book a virtual *Death over Dinner* but are mostly encouraged to take the offer as an inspiration for a real dinner at home with a good meal in a cozy atmosphere. Campaigns like *Death over Dinner* are needed in Germany, too. Creative and easy-to-implement ideas on how to talk

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[60] ibid., p. 47.

[61] Douglas: Taboo, p. 2769.

[62] Gutjahr: Tabus als Grundbedingungen von Kultur, p. 20.

[63] Hebb, Michael: Let's Talk about Death (over Dinner), Cambridge 2018, p. 7.

[64] https://deathoverdinner.org

[65] ibid.

about death in the family are extremely rare. Such ideas would not only help to support representatives in an emergency case, they would also help the authors to reflect, find out and express their personal wishes.[66] As Lambert South and Elton state: »talking about death may help people work through their fears and better understand what they want during the end of life and also makes one's care preferences known to others.«[67] This insight is reminiscent of Elisabeth Kübler-Ross, who encouraged people to speak more openly and less fearfully about death back in the 1960s. Taboos have endurance.

Conclusion: Think Liminal and Break the Death Taboo!

Authors of living wills are challenged by many difficulties and scientific research does its best to improve the tool by identifying pitfalls and generating solutions for improvement. Especially medical orientated disciplines create a considerable and helpful output on the topic of living wills. Yet, underlying cultural influences are easily overseen and living wills are rarely perceived in regard to liminality although exactly that perspective can offer precious insights.

As I have shown, the medical emergency case in which a living will comes to its practical terms can be seen as a liminal state. Authors of living wills therefore have to deal with a matter that is not only medically and legally demanding, but also beyond common categories of life and death. Advances in medical technology have created an »anomalous event«[68] with the possibilities of prolonging life that does not fit into the existing cultural classification system. Mary Douglas distinguishes five ways how societies react to anomalous events: 1. reduction of ambiguity and imposed classification, 2. elimination, 3. ignorance, 4. stigmatization, and 5. incorporation.[69] Contemporary living wills represent the first strategy as authors more or less have to reduce the ambiguity of the anticipated liminal by mainly biological criteria in order to impose the

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[66] Cf. McCormick, Sheila: Conversations on Death and Dying. Exploring Performance as a Prompt, in: Palliative Care & Social Practice 17 (2023), pp. 1–10.

[67] Lambert South, Andrea/Elton, Jessica: Contradictions and Promise for End-of-Life Communication among Family and Friends. Death over Dinner Conversations, in: Behavioral Science 24 (2017), No. 7(2), pp. 1–12, here p. 1f.

[68] Douglas, Mary: Purity and Danger, pp. 48.

[69] ibid., pp. 48–50.

labels ›alive‹ or ›dead‹ on the state. The task becomes even more difficult as there are no ›masters‹[70] with reliable first-hand knowledge. Furthermore, the effectiveness of living wills is limited by an existing taboo on dying and death within family bonds. Although many authors of living wills choose close relatives as their representatives, probably many children, sisters, and brothers are left behind with not much more than assumptions about the true wishes of close family members at the end of their lives. Combining research on living wills with liminality and taboos not only reveals the limitations and hurdles of the everyday search for meaning in relation to decisions and actions at the end of life. This very approach also offers starting points for improvement as liminality and taboos themselves inherit the potential of change and transition. Taboos have socially inclusive and protective functions and at the same time limit sociality when blind spots of a classification system occur like the emergency case in end-of-life treatment. In the context of living wills the blind spot is exactly the matter of fact that has to be thought through. Promoting a way of ›thinking with liminality‹ toward end-of-life decisions more resolute could encourage people to enter a deeper stage of reflection on the existential issue and to develop their own expressions and selection of categories—to create and share their *personal end-of-life narratives*. The hospice movement and the patient rights movement have successfully shown that it is possible to break the death taboo in the public sphere. But at the level of common everyday life, there is still more initiative required. Counselling institutions and interest groups that deal with the topic of living wills should always be aware of this fact and continue to take it into account. Adoptable role models are still needed.

Taboos are powerful, persistent but not sacrosanct. To those who doubt this, I heartily recommend the reception of Heathcote Williams' work as an empowering introduction.

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[70] Turner: The Forest of Symbols, see above.

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