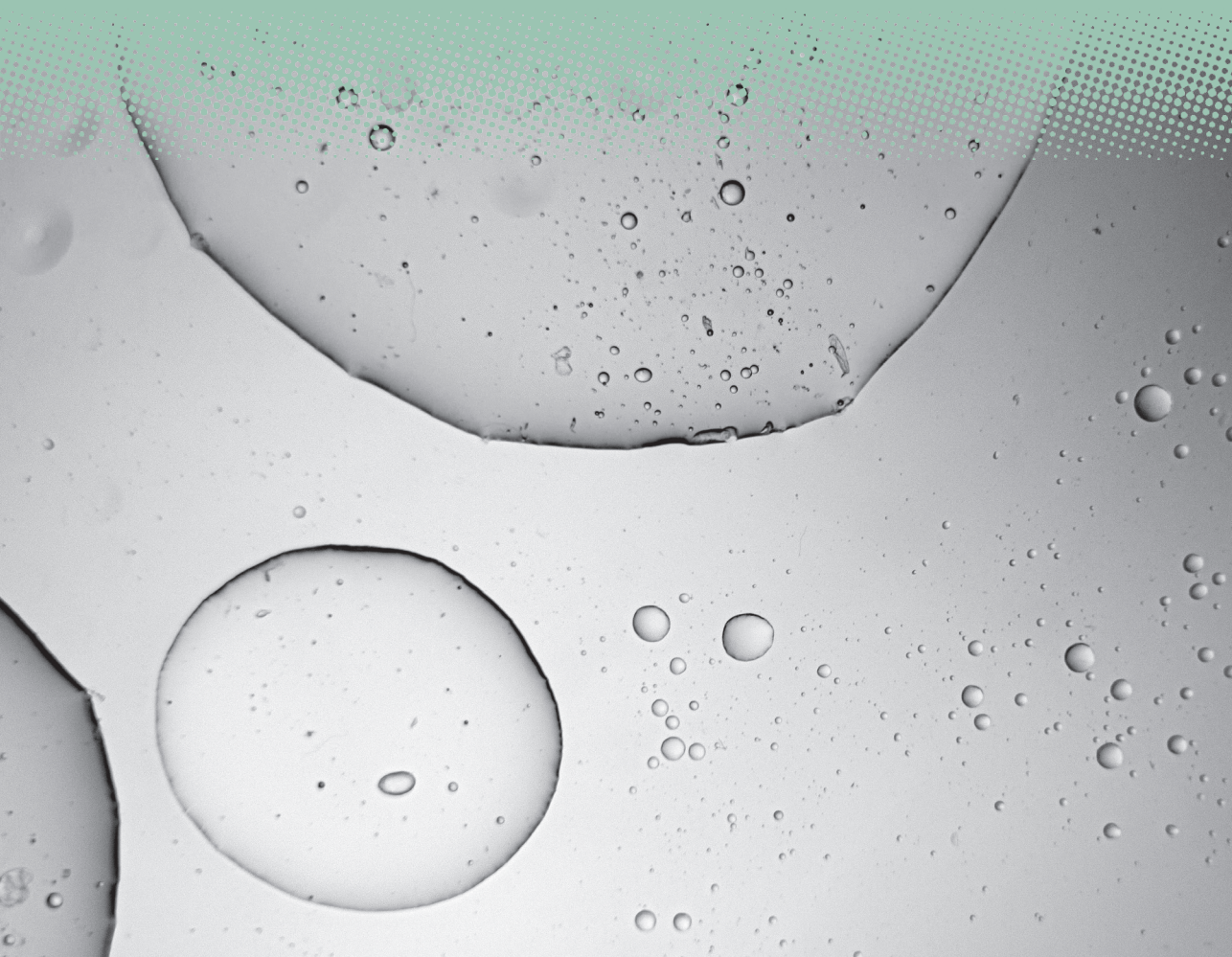


# Curare

Curare 45 (2022) 2

**Lebensanfänge und -enden.  
Ethnographische Erkundungen  
und methodologische Reflexionen**

**Beginnings and Ends of Life.  
Ethnographic Explorations  
and Methodological Reflections**



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# The Beginnings and Ends of Life as a Magnifying Glass for Ethnographic Research

Introduction to the Special Issue

JULIA REHSMANN & VERONIKA SIEGL

With bans on assisted suicide recently ended in several European states, such as Germany and Austria, and (quasi) bans on abortion recently reinstated in Poland and the United States but lifted in countries such as Ireland, Colombia and Argentina, public discourse around the boundaries of life and death, and whose right it is to decide for or against them, has become highly politicized. The recent political developments prove that it is no longer possible to take once-established rights and restrictions for granted. A critical engagement with the beginnings and ends of life is thus timely, for scholars and activists alike.

Being universal and fundamentally life-changing human experiences (WOJTKOWIAK & MATHIJSEN 2022), the beginnings and ends of life can serve as a productive prism through which to understand society and culture (AULINO 2019; DAVIS-FLOYD 2019; GARCIA 2016; GINSBURG & RAPP 1995; KAUFMAN 2015; LOCK 2002; VAN HOLLEN 2003). Taking this as a starting point, we argue that these experiences also serve as a magnifying glass for issues inherent in anthropological research and ethnographic fieldwork, while posing new questions relevant to an academic field that is called upon to remain self-critical and re-evaluate long-held traditions and taken-for-granted research practices, such as pseudonymization or conducting participant observation in sensitive contexts.

These questions are the focus of the present special issue, which brings together ethnographic research on the beginnings and ends of life, from MARCOS ANDRADE NEVES on transnational assisted suicide across Germany, the UK and Switzerland, to MIRA MENZFELD on dying in Germany and MOLLY FITZPATRICK on “natural birth” in Indonesia. This introduction will provide a conceptual and empirical framework for the three contributions. In the first part, we

briefly sketch how the beginnings and ends of life have been researched within anthropology, argue for the productivity of bringing these seemingly oppositional phenomena together and raise questions about the particularities of ethnographic research at the beginnings and ends of life. In the second part, we turn our attention to the politics of life and death. We show that, while the beginnings and ends of life are universal experiences, the way these play out in individual people’s lives is highly structured by intersecting inequalities. In the concluding section, we return to the methodological issues raised above and introduce the individual contributions in greater detail.

## Bringing the Beginnings and Ends of Life Together

Ethnographic engagements with the beginnings and ends of life have a long history within social anthropology. As SHARON KAUFMAN and LYNN MORGAN (2005) show in their elaborate review essay, this engagement has been subject to major transformations over time. While earlier studies scrutinized the beginnings and ends of life through the prism of structural-functionalism and in relation to religion, ritual, kinship and social cohesion, more recent studies have addressed these phenomena through the lenses of political economy, poststructuralism, globalization and postcolonialism (KAUFMAN & MORGAN 2005: 318f). They have shed light on local accommodations and adaptations of globally circulating bioscience, technologies, ethics and biopolitics, and expanded understandings of the affects, materialities and involvement of non-human actors at the beginnings and ends of life. Moreover, research in and beyond anthropology has pointed to the ambiguous boundaries between life and

death – revealing how these are shaped by cultural, political and scientific negotiations (BENKEL & MEITZLER 2021; DAS & HAN 2016; KAUFMAN & MORGAN 2005, NIEDER & SCHNEIDER 2007) and pointing to the many ways in which life and death, care and violence, illness and healing fold into each other. The beginnings and ends of life, thus, cover a multitude of very different biological processes, social events and subjective experiences, including various forms birth, assisted reproduction, embryonic stem cell research, abortion, pre- and perinatal death, organ transplants, palliative care, assisted suicide, euthanasia, cryonics or spiritual ideas around afterlife and reincarnation.

Reflecting on the connections between the beginnings and ends of life offers productive opportunities for anthropologists to unpack methodological concerns that become highlighted by the particularities of these existential, and liminal, phenomena – an issue that so far little has been written about. It was exactly this reflection that formed the starting point for the present special issue. Our own research on commercial surrogacy and selective abortion (SIEGL 2018a, 2018b, forthcoming 2023) as well as organ transplants and palliative care (REHSMANN 2018, 2021, 2022; SOOM AMMANN & REHSMANN 2022) had spurred countless conversations between us and made us realize that we were grappling with similar methodological puzzles in very different research settings. Both being interested in the role of affects and emotions in ethnographic fieldwork (REHSMANN 2019; SIEGL 2019), we wanted to investigate the obstacles and opportunities that ethnographic explorations in these existential settings present for us as researchers, and how they complicate long-held anthropological assumptions concerning participant observation, as well as notions like vulnerability, emotionality and intimacy. Our interest in these questions was also fuelled by the way friends, relatives or fellow researchers reacted to the topics of our research – often with awe, commenting on how they thought these topics must be “depressing” or somehow particularly “difficult” to work on. But why are these topics thought to be more challenging than others?

Discussing the end of life, MARIAN KRAWCZYK and NAOMI RICHARDS (2021: 409) criticize

assumptions that ethnographic research in this field poses more emotional challenges and requires more emotional intimacy than other fields of study. The authors argue against a romanticized view of ethnographic research on dying, that is, against an othering of this existential experience as inherently apart from other aspects of everyday life. While we fully support this argument, we contend that research on birthing and dying cannot be fully equated with other everyday experiences. Even following an integrative approach towards dying as part of life, questions to us as anthropologists nonetheless remain: What *are* the particularities of conducting research at the beginnings and ends of life? Are these settings somehow more intimate than others, do they require other modes of ‘being-with’, witnessing and participating? Are the research participants we encounter at the beginnings and ends of life somehow more vulnerable than others? How do we make sense of the existential gap between research participants and anthropologists conducting fieldwork on these matters? The “strength of the anthropological approach”, as SJAAK VAN DER GEEST (2007: 10) puts it, lies in its transparency regarding its limits in fully capturing experiences of “pain, illness and suffering”. If we accept the need for transparent humility, critical attentiveness and emotional reflexivity, ethnographic research on the beginnings and ends of life calls on us to look closely into the particularities of these settings, asking how they play out in anthropological research and what they tell us about the fields themselves.

### The Politics of Life and Death

The fact that all human beings are born and die is often used as a basis to argue that we are all equal in relation to these existential events. Likewise, early anthropological engagements with these topics were often merely descriptive and comparative, focusing on how the beginnings and ends of life were shaped in specific cultures (e. g. HERTZ 1960; JORDAN 1978). Regarding the beginnings of life, it was only with the influence of the feminist movements in the 1970s and 1980s that scholarly engagement gradually became more analytical and political, with classic works by, for example, FAYE D. GINSBURG and RAYNA RAPP

(1995) or ROBBIE DAVIS-FLOYD (1992). Such later engagements have shown that birth and death are not uniform processes but rather are determined by factors such as race, class, gender, disability, religion, nationality and others, as well as being entangled in local and global relations of power (DAS & HAN 2016; ENGELKE 2019; GINSBURG & RAPP 1995). Life and death, as these later works highlight, are inherently political.

The recently published report of the Lancet Commission on the Value of Death, for instance, refers to dying in the 21st century as a “story of paradox” (SALLNOW ET AL. 2022: 837) and stresses the global imbalance of some people being overtreated in hospitals, while most people worldwide remain un- or undertreated, lack sufficient access to healthcare or are even left to die. These unequal and deadly dynamics are captured by ACHILLE MBEMBE’s (2003) concept of “necropolitics” and are also analyzed ethnographically in the works of JOÃO BIEHL (2001) and NANCY SCHEPER-HUGHES (1993), both of whom tease out the connections between poverty, marginalization, neglect and death in Brazil. Linking the beginnings and ends of life, recent works have revealed the immense impact of race and racialization on pregnancy, labour and maternal death in the United States (DAVIS 2019; MULLINGS 2021) or the impact of a highly bureaucratic postcolonial health system on maternal death in rural Tanzania (STRONG 2020). Here, the concept of “stratified reproduction” (COLEN 1995; GINSBURG & RAPP 1995) has been productive in order to think through the ways in which the reproductive futures of some are encouraged, while those of others are inhibited – be it through high rates of maternal mortality, through forced or state-encouraged sterilization of peasant and working-class women (CHAPARRO-BUITRAGO 2022; RUDRAPPA 2012) or through the unequal distribution of and access to assisted and selective reproductive technologies (GAMMELTOFT & WAHLBERG 2014; INHORN 2021; NAHMAN 2016). Reproductive futures are also at stake in relation to the perceived safety of IVF treatments and the scientific and societal ignorance of the potentially harmful long-term effects of hormonal treatments, and the politico-economic dimensions that underlie these entanglements (JAIN 2013).

The development and spread of assisted reproductive technologies across the globe, particularly in high-income countries and among those with the means to afford them, are exemplary of the global rise of biomedicine. This rise has led to an increasing biomedicalization of birth and death with its focus on, among other things, epi/genetic risks, new diagnostic procedures and technoscientific innovations (CLARKE ET AL. 2003; CLARKE & SHIM 2011; DAVIS-FLOYD 1992; JORDAN 1993; KAUFMAN 2005, 2015; MARTIN 2001), with significant consequences for how birthing and dying are understood and practised. Under this “medical gaze” (FOUCAULT 2003), birthing and dying have moved from the home, family and community to clinical spaces – their “management”, thus, increasingly learned in institutions (Davenport 2000) and shut out of everyday life and familiar spaces (FRASER 1995; GOTTLIEB 1995; VAN HOLLEN 2003). This move came along with the devaluation of traditional knowledge and of the expertise of female-dominated fields like nursing and midwifery, being replaced by the authority of mostly *white*,<sup>1</sup> male biomedical knowledge. This knowledge constructed the reproductive and the dying body as risky and flawed, in need of intervention, management and correction (CHADWICK & FOSTER 2014; DAVIS-FLOYD 1994; KAUFMAN 2015; MARTIN 2001; ROSE 2007; SIEGL 2018a). Counterintuitively, the move to the clinic has also cast the beginnings and ends of life as moments of ultimate privacy and vulnerability – moments that, thus, need to remain hidden in patients’ rooms and well-guarded by clinical gatekeepers. This has had a fundamental impact on the im/possibilities of ethnographic research in such settings. While the introduction of ethics committees and informed consent procedures is, surely, to be welcomed in the context of clinic research, the streamlined approval forms, questionnaires and study protocols often fail to acknowledge the qualitative nature of anthropological research – with its explorative and relational approach, its focus on open and narrative interviews as well as its inherently situative ethics. Furthermore, questions of pseudonymization, anonymization, of un/naming research participants, organizations and institutions are very differently framed and negotiated from a clinical or an anthropo-

logical ethics perspective. The move to the clinic has, thus, rendered much ethnographic research on the beginnings and ends of life difficult and almost impossible to conduct. Our own experiences in this field suggest that talk about “privacy” and “vulnerability”, while primarily brought forward in the name of patients’ interests, also serves to ward off critical research altogether (SIEGL forthcoming 2023). As a consequence, many supposedly ethical questions are increasingly turned into political ones, determined by the interests of individual clinics with their entanglements with pharma and other industries.

The move to the clinic and, with it, the increasing biomedicalization (CLARKE ET AL. 2003) and technologization around reproduction and end-of-life care have allowed lives to be extended or ended, dying to be postponed or hastened, births to be scheduled, “anormal” pregnancies to be terminated, or reproduction to be outsourced or put on hold. These developments have significantly contributed to the re/making of life and death (ADRIAN 2020). As KAUFMAN and MORGAN point out, for those with access to the “new biomedical techniques, one’s corporal materiality no longer imposes strict limits on the body or self” (2005: 330). This renegotiation of what were previously considered the natural limits of human life is tightly linked to the notions of (individual) choice and self-responsibility (RAPP 1999; ROSE 2007). Choices are never neutral but carry a moral imperative; it is the “right” or “appropriate” choice one must make, carrying with it the ever-dooming risk of choosing “wrongly”. Recent ethnographies have shown the many ways in which people’s dying and end-of-life are “choreographed” (STONINGTON 2020) and “scripted” (BUCHBINDER 2021), and how end-of-life decision-making is tied up with cultural complexities that question Western understandings of the individual and their rational decision-making (STAVRIANAKIS 2019; ZIVKOVIC 2021). Choices in the context of the beginnings and ends of life are saturated with ideas of potential and risks, of what these could be, of that which might happen. Choices around prenatal tests, choices about implantation, choices for or against life-prolonging treatments, choosing to end a life – one’s own or that of another. Weighing risks, uncertainties and the *potential* consequences of one’s choices. While

the contributions in this special issue focus on research outside the classical clinical institutions, they all relate to them, and partly come into being by people’s choices to look for an alternative to biomedical approaches and clinical settings, from the choice to have a ‘natural birth’ in midwifery clinics (FITZPATRICK 2022), to deciding to end one’s life in the flat of an assisted suicide organization (ANDRADE NEVES 2022), to the choices of terminally ill people in private homes and hospices (MENZFELD 2022). And yet: for most of the world’s population, choices remain limited by unequal access to healthcare and it is those with more resources who are given the option to choose – be it the choice between clinics, for or against clinics, or for more or less medical intervention or care.

### Methodological Reflections on Studying the Beginnings and Ends of Life

Reflections on the unequal dimensions of life and death are relevant not just in relation to the research topic per se but also in relation to methodological questions – including our positionality as anthropologists, own involvement in the fields we study and the entanglements between our private and professional lives.

Many scholars have detailed how ethnographic knowledge informs their personal encounters with the beginnings and ends of life, and vice versa – whether in the context of birth (GOTTLIEB 1995), assisted reproduction (JAIN 2013), pre- and perinatal loss (ADRIAN 2020; LAYNE 2003), the loss of friends and relatives (BEHAR 1996; REHSMANN 2019; ROSALDO 1993; WACKERS 2016) as well as own experiences with life-threatening diagnoses (JAIN 2013; MARKS 2012). These accounts show how personal encounters can offer a “cognitive opening” (DAS 2020: 316) to understanding such existential experiences. Of these personal accounts, RUTH BEHAR’s book *The Vulnerable Observer* (1996) is probably one of the most cherished ones, arguing that we should not try to separate the person from the anthropologist, but we need to make visible and work with our own histories, experiences and emotions. With this argument, BEHAR echoes other feminist calls for acknowledging the positionality, intersectionality and shifting power relations in fieldwork settings

(ABU-LUGHOD 1990; BEHAR & GORDON 1995; DAVIS & CRAVEN 2016; HARAWAY 1988; HARDING 2004; OAKLEY 1981; STACEY 1988).

What heightens the importance of reflecting on these issues in fieldwork settings at the beginnings and ends of life is the fact that both research participants and researcher often enter these settings without knowing beforehand how to negotiate them. Giving birth, at least for the first time, is not an “ordinary” experience in a person’s life, as is dying. With little or no experience to draw upon, these encounters involve a lot of uncertainty. This aspect is taken up by MIRA MENZFELD’S contribution to this special issue. Drawing on Turner’s thoughts on threshold and transition dynamics, MENZFELD argues that her ethnographic fieldwork with dying people in Germany was often marked by what she calls “liminal asymmetries” – since she herself was neither confronted with a lethal diagnosis nor in the process of dying herself. “Liminal asymmetries” refers to the fact that the dying find themselves in a betwixt-and-between state, from which they wish for a kind of liminal guidance and companionship that the researcher herself cannot offer; as well as the fact that there are crucial experience hierarchies in these research relationships, since the dying inhabit a very different mode of being and regard themselves as less privileged and agentic than the researcher. MENZFELD argues that being aware of and accepting these “liminal asymmetries” as well as explicitly naming them can help alleviate frustration and helplessness for both researchers and research participants.

Experiencing birth and death are also not ordinary experiences for most researchers. The lack of options to ‘sufficiently’ prepare for witnessing the death or birth of other people might be an explanation why some anthropologists identify a necessity or demand for some sort of “training” in preparation for fieldwork in such existential settings: For instance, ADRIENNE E. STRONG (2020) and MOLLY FITZPATRICK (2022) underwent training as doulas, i. e. a non-medical birth support person, before starting fieldwork on birthing and midwifery practices, and SCOTT STONINGTON (2020) and MENZFELD (2022) underwent training as an end-of-life doula and a voluntary terminal carer respectively prior to

their ethnographic research on dying and end-of-life care. Training can help develop the right kind of sensitivity and self-confidence for encountering the beginnings and ends of life. Moreover, it can prepare us for fieldwork situations that might demand that we step out of the corner, out of the position of the observer. Becoming involved in settings of life and death – to assist, support, lend a hand and intervene – can be an inherently ethical demand in such settings, as it carries a different weight than involvements in less immediate life and death matters. The potential consequences of our actions, or inactions, tend to be significantly more pressing and irrevocable when it involves birth or death. Sometimes we act more than anticipated, which might cause us discomfort regarding our self-conception as anthropologists.

The demand to get involved in clinical and care work, to participate in daily tasks without having “proper” professional training, can not only be explained by the existential demands of giving birth or dying, but also emphasizes the fact that medical institutions, care homes, midwifery clinics, birthing centres and hospices are chronically understaffed and underresourced. In the contexts we discuss here, the lack of trained staff might quickly turn into a matter of immediate life and death – unlike in other contexts, in which the harmful effects of the privatization and underfunding of healthcare and the broader care sector materialize more slowly. STRONG, for example, refers to her motivation to train as a doula prior to fieldwork as “in the hopes of being useful” (2020: 18) in the Tanzanian clinic where she planned to conduct fieldwork. Besides concerns regarding sufficient personnel, her hope to be of use in the respective clinic hints at the sometimes-awkward position observing, waiting, chatting, scribbling ethnographers occupy in the diverging temporalities of medical settings amidst the rushing and waiting of nurses and doctors, patients and relatives. There is no easy role for anthropologists, who do not fit into the three common roles of the patient, the medical worker and the relative or visitor, and they may therefore appear as inappropriately occupying space and time (WIND 2008: 82f). The assumed need to be trained as a doula or terminal carer before fieldwork also points to implicit and explicit norms in

these medical settings, which centre around expertise and formal knowledge. These are relevant not only regarding the question of *how* to intervene but also *whether* to intervene or not. While these questions depend to some degree also on whether one is allowed or feels able to intervene, to *not* intervene can also be a sign of expertise. Often the result of careful, expertise-driven and experience-based considerations, decisions to refrain from an intervention require a deep understanding of the matter at hand. This is as crucial for anthropologists as fieldworkers, as it is for midwives or doulas during birth (FITZPATRICK 2022; SKEIDE 2018) and terminal carers or palliative care professionals during people's dying (ANDRADE NEVES 2022; BORGSTROM, COHN & DRIESSEN 2020; MENZFELD 2022).

The contributions in this special issue pick up on recent discussions in anthropology which emphasize different approaches to "participation" that encounters at the beginnings and ends of life demand. Similar to ANNEKATRIN SKEIDE (2018), who reflects on the proximity of the roles of midwives/doulas and ethnographers as witnesses, MOLLY FITZPATRICK (2022) argues that being a "doula-ethnographer" while doing fieldwork on natural birth in Bali meant combining the very similar characteristics of both fields, such as empathy, understanding, listening or stepping back with one's own assumptions and assessments in order to foreground the birthing woman. At the same time, being able to assist legitimized FITZPATRICK'S presence in these settings and provided her with an affective understanding of what giving birth meant to the women she accompanied in Bali. More so, she argues that the existential, intimate and emotional nature of such experiences creates the need for ethnographers to go beyond mere presence and engage in an affective and embodied way. But FITZPATRICK also cautions that providing care as an anthropologist does not dissolve the discomfort one might feel as "witness" to such experiences – rather, ethical questions regarding our presence and our role need to be negotiated again and again, from moment to moment. In sum, she makes a strong plea for moving from a mode of "being-there" to a mode of "being-with" when doing research on birth. In the context of palliative care and dying, "being-with" has also been conceptualized as a

form of participatory presence, an active passiveness or entering a situation without an agenda. ANNELIEKE DRIESSEN, ERICA BORGSTROM and SIMON COHN (2021), for instance, discuss the importance and qualities of "being-with" when caring for people at their end of life – an important feature of palliative care that became disrupted and often impossible to maintain during COVID-19 lockdown measures.

Thinking of the onto-hierarchical differences between researchers and research participants at the end of life (MENZFELD 2022), MARCOS ANDRADE NEVES (2022) asks whether ethical preferences can outlive the people who make them. His article centres on the dilemma between acknowledging the importance of naming practices within political struggles for the right to assisted suicide and the anthropologist's responsibility in protecting research participants who – due to their death – will never have the opportunity to know how their stories will be told by the anthropologist. Based on his fieldwork on assisted suicide in the UK, Germany and Switzerland, ANDRADE NEVES argues that we need to consider the "afterlife reverberations" of our research – "the affects and expectations that ripple in the aftermath of a research participant's death from their research choices made in life" (2022: 18). Considering these, ANDRADE NEVES contends that it might be the anthropologist's responsibility to re-evaluate research participants' choices and opt for un-naming rather than naming practices. In his contribution, what is 'ethical' becomes hard to grasp and contested. The article sheds light on the situational and temporal aspects of research ethics, which – as we have argued above – make it difficult to attend to ethical questions in a standardized way, as often proclaimed in clinical settings.

### Concluding remarks

Taken together, the contributions to this special issue illustrate that ethnographic explorations at the beginnings and ends of life raise crucial questions for anthropology's methodological "tool-kit" of pseudonymization, participant observation, self-reflexivity and positionality. They also highlight how ethics in anthropological research is always situative and negotiated,

and, thus, transgresses clearly defined and neatly drawn definitions of most ethical boards and biomedical ethicists. In the existential moments of giving birth or dying, the presence of an ethnographer risks being perceived as awkward, inappropriate or unwelcomed – particularly in clinical settings, where anthropologists need to negotiate their roles and responsibilities not only with those birthing and dying, but also with clinical staff and within clinical routines, timelines and temporalities. These negotiations are evident also in settings that constitute alternative or complementary institutions to the clinic, such as the midwife-led birth clinic in Bali, the homes and hospices in Germany, or the semi-private spaces that facilitate assisted suicide in Switzerland.

As this special issue aims to maintain, the beginnings and ends of life serve as a magnifying glass – for ethnographic research and anthropological concepts, for questions concerning what ‘ethical’ means in these contexts, as well as for the political dimensions that run through these existential experiences. Access to maternal healthcare, as well as to alternatives to clinical care like midwife-led birthing centres, is as unequally distributed as access to competent palliative care at the end of life or the legal option and medical expertise for assisted dying. Giving birth and dying, as existential and universal as these experiences are, have, thus, inherent political dimensions. It is these which require us as anthropologists to remain critical and reflective of our doings, of the topics we choose to explore, the people we include in our research and our writing – keeping in mind how our doings potentially reverberate. The following contributions discuss these methodological and ethical issues and offer concepts that can be productively adapted to other research contexts. We hope that this special issue, although firmly grounded in the study of the beginnings and ends of life, will be an inspiration for researchers beyond this specific focus.

## Notes

1 We use the term “white” in italics to point to the constructed nature of skin colour as a marker for differentiation and hierarchization (NDUKA-AGWU & HORNSCHEIDT 2010: 32f).

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**Lebensanfänge und -enden. Ethnographische Erkundungen  
und methodologische Reflexionen**

**Beginnings and Ends of Life. Ethnographic Explorations  
and Methodological Reflections**

Herausgegeben von

edited by JULIA REHSMANN & VERONIKA SIEGL

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