

## BEGINNINGS

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# The limits of the world

This is not the book I wanted to write—indeed, perhaps no book whose main subject matter concerns death and disease can be described as a book that someone *wants* to write—but the circumstances of the world sometimes dictate otherwise, and over time stories about the lived experiences and imaginative lifeworlds of persons living under the shadow of death began to fill the blank pages. As such, *The art of life and death* attempts to understand how the world appears to persons who are close to death and who are confronting their own mortality and nonexistence after being diagnosed with a terminal illness—namely, those diagnosed with HIV/AIDS in New York City. *The art of life and death* also pertains to persons living with other illnesses or under conditions of uncertainty and disruption. When living under such circumstances, the contingencies of life and death are made explicit on a frequent, often daily, basis. Many taken-for-granted beliefs and practices are called into question or undergo reevaluation and adaptation as people learn to understand themselves and the workings of their bodies in new, sometimes radically different ways. A typical day may include complex cycles of emotion, hope, doubt, uncertainty, joy, and reflection, together with periods of mundane activity, as people adjust to their new circumstances. Often, the world is seen with a renewed and different intensity, as the influential playwright Dennis Potter described when interviewed on live television while he was dying from cancer: “Things are both more trivial

than they ever were, and more important than they ever were, and the difference between the trivial and the important doesn't seem to matter" (Potter 1994).

In presenting an experience-near ethnography of life and death, the following chapters attempt to bring to life the ongoing and often unseen transformations in knowledge and understanding that occur when living with existential uncertainty: transformations in self identity and body image; transformations in long-standing religious and moral commitments; transformations in everyday social roles and relations; transformations in the perception of time, existence, and nature; and last but not least, transformations in the type of imaginative and emotional lifeworlds people inhabit when confronting death or attempting to negotiate a new life.

"Before there was wonder at the miracle of life," Hans Jonas (2001: 8) wrote, "there was wonder about death and what it might mean." For while it is obvious that life cannot exist without death and vice versa, the question of how life and death are so thoroughly conjoined and yet differentiated is still to be answered. Moreover, from the very first panvitalistic impulses, where everything in the world was understood to be animated and alive, to broader existential questions about the meaning and purpose of life, it is more often death rather than life that in the first instance calls for an explanation. For Jonas, "the *problem* of death is probably the first to deserve this name in the history of thought. Its emergence as an express problem signifies the awakening of the questioning mind long before a conceptual level of theory is attained" (2001: 8). It is a problem that has remained active throughout history and continues to test the combined knowledge of science, religion, and culture, generating multiple (often conflicting) reasons concerning the purpose of death and how it has become incorporated into life. Meanwhile, from the perspective of individual persons confronting their own mortality who have become acutely aware of their temporality and contingency, there exists the daily challenge of how life and death are negotiated in specific moments as a particular kind of social, familial, religious, or moral being.

There are commonalities and discrepancies found within most life events and experiences, which tend to become intensified and exacerbated in relation to the processes of death and dying. These pertain both to the species and what Gregory Bateson ([1936] 1958) termed the *ethos* and *eidos* of the social group, that is to say, the shared emotional, moral, and cognitive norms that bind persons together or differentiate between them. For Bateson, these are not immutable, are subject to moral variation over a person's lifetime, and possess

substantial latitude within and between societies. Nevertheless, these provide a collective mechanism through which persons come to reflect on and understand themselves not only as humans or as social and cultural beings but also as a particular individual with a particular life biography; that is to say, as a finite, mortal human being who is situated in society and history but who can also live, act, and imagine the world in a different way.

This involves the person in an ongoing process of interpretation and understanding through which the constitution and contingency of life is frequently made explicit and persons contemplate their past, present, and future in relation to the many other possible lives they might have ended up living. The actual and alternative life courses someone imagines provide an emotional and moral framework of interpretation and understanding. As such, a person's thoughts, dreams, and imaginaries of a life lived otherwise are not immaterial fantasies or abstractions but are constitutive of embodied being and understanding. The events that comprise our lives are continually being relived, reimagined, and re-told so as to interpret and reshape experience or inform future action. This is the idea of life as an unfinished, ontogenetic process grounded in the contingency of being and world: a being who is born onto a particular soil with a particular social, economic, and gendered status—and whose life course is subject to random events, luck, and happenstance—which are all negotiated and understood in the context of ongoing social and moral relations, practical activity, and the wider forces of the global political economy (Irving 2017). Often, it is in those moments of realization wherein the contingencies of life and death are most intensely experienced, spoken about, and reflected on, that we can also trace a history of philosophical, religious, and anthropological inquiry itself.

For William Barratt ([1958] 2011), the modalities of subjectivity and personal inquiry that emerge in the face of contingency mark a decisive transformation in existential understanding that is reflected at the level of the history of thought. Whereas many disciplinary approaches and schools of thought have asked the question, *what is a human being?*, it requires a further existential shift to ask, *who am I?* For Barratt, the first question presupposes “a world of objects, a fixed natural and zoological order, in which man was included; and when man's precise place in that order had been found, the specifically differentiating characteristic of reason was added” (2011: 95). By contrast, the questions *who am I?* or as pertinently *why me?*, *what will become of me?*, and *who am I among?* have their origins in a more vital, if obscure, realm of uncertainty and inquiry located within the lives of the questioners themselves, which for Barratt often

betrays a personal sense of dereliction and loss that goes beyond the impulse to define human beings and social groups or categorize them within a broader scientific, biological, or anthropological order.

Moments of subjective transformation and personal questioning might be generated, for example, in times of affliction, liminality, schism, and communitas (Turner 1969, 1982), a falling out of the world or ongoing experiences of existential disorientation (G. Becker 1997; Al-Mohammad 2016), changes in perception generated by movement and shifts in identity and belonging (Kondo 1990; Jackson 2013) or incongruities and contingencies that “cannot simply be ‘writ away’ through contextualization” (Crapanzano 2015: 160; see also Crapanzano and Jackson 2014). Such moments of personal and critical reflection regarding life and death can be strategically cultivated—for example, through religious practice and contemplation, ritual events, or therapy, self-analysis, and introspection—or else might emerge unbidden and spontaneously within the flow of people’s mundane everyday experience and interactions. Whether embedded squarely within quotidian life or seen from the margins, it involves a smaller or larger scale movement in which a person comes to reevaluate their habitual orientation and understanding of themselves, others, nature, the universe, and the gods, thereby turning the question of *who am I?* into an ethnographic question about life and its relationship to death.

Death poses an intractable problem not just for individual persons but also for families, societies, and cultures, often locating them near the limits of knowledge, emotion, and understanding. Attempts to come to terms with death, including comprehending the boundaries between the living and the dead or imagining what happens to the person afterward, stretch back to the origins of humanity, as evidenced by a wide range of funeral and death-related practices. There is also clear evidence that burial and death rituals were not only central to early human societies but also to Neanderthals (Mithen 2006), who demonstrated a similar awareness of mortality beyond the more straightforward realms of reflex, instinct, and self-preservation.

Nietzsche already alerted us to how humanity, although part of the animal world, can no longer understand itself as just another species within nature due to our efforts to know and understand ourselves ([1882] 1974). As a consequence, human beings have loosened the bonds of nature, challenged the gods, and created the conditions for our own peculiar anxieties about death and dying. Charles Taylor summarized the problematical nature of the species: “Man as a living being is not radically different from other animals, but at the same time

he is not just an animal plus reason, he is a quite new totality; and that means that he has to be understood on quite different principles" (Taylor 1979: 19).

In becoming such, human beings have not only questioned the meaning and purpose of existence but have been confronted by the problem of how to reclaim life in the knowledge of death and nonbeing. Stories of death and dying have been told through culture and history and have provided an essential means for passing on as well as challenging personal, moral, and religious understandings. With the advent of art and writing it became possible to signify and share thoughts and feelings about death in new and more durable ways. To date, a vast body of work has accrued on a subject that has troubled and inspired generations of poets, writers, and artists, alongside prophets, philosophers, and scientists. In this, it is possible to discern the stirrings of a different kind of self (Taylor 1992) and the generation and transmission of new forms of knowledge and moral practice whose realization takes the form of persons aware of their own individuality and agency but also their shared fate and status as finite, mortal beings.

## DEATHLY ENCOUNTERS

From medical and legal perspectives, there are a number of different ways of defining death—from the cessation of breathing and the heartbeat to notions of brain death, where the brain stem is no longer functioning but the majority of the organism remains alive (Lock 2004; Kastenbaum 2011). Strictly speaking, the human body is not even a singular entity—or for that matter entirely human—but an amalgamation of many different organisms. Consequently, although death may mark the cessation of consciousness, life continues at the level of cellular activity and metabolic processes (Mims 1999). As the twenty-first century progresses, the borders between life and death are becoming increasingly complicated, not just through the copresence of different, often contested, social, religious, and biomedical understandings but also through technological advancements, organ transplants, the use of genetic material, and new developments in brain and computer science that are trying to establish direct communication between our brains and computers, and exploring how consciousness might be downloaded, stored, and distributed.

Death presents an equally thorny problem to the humanities and social sciences, and at times there is little consensus between different disciplines. While

philosophy, psychology, and psychoanalysis gravitate toward universal themes and explanations, anthropologists focus on the diverse social, cultural, and religious practices that mediate death and maintain the continuity of the social group. As such, anthropological approaches try to understand the many and varied beliefs and practices that shape people's perceptions and do not focus solely on the destiny of the individual or the shared phylogeny of the species but on the common and discrepant ways human beings understand life and respond to death. Although individual people die, society, culture, and humanity endure through the handing down of language, knowledge, and moral perspectives between generations, necessitating a comparative ethnographic understanding of how death is negotiated through different social institutions, cultural traditions, and religious practices.

When approached ethnographically, it soon becomes apparent that there are as many ways of dying as there are of living, in which case emotions such as fear, dread, and anxiety—which are often seen as elemental or universal in medicine, psychology, and psychoanalysis—may have more to do with specific cultural epistemologies and ways of being than the human condition *per se*. However, the variety of responses and attitudes toward death both *within* and *between* societies shows how death can neither be reduced to a specific social, religious, or moral perspective nor to a timeless and universal truth. Albert Camus alerted us to the error of mistaking the intensity of one's feelings and emotions for a shared social characteristic, or by extension, one of humankind. No matter how strongly someone may feel about death or how committed an individual or social or religious group is to a particular perspective or worldview, it does not mean it is shared by others or possesses universal validity.

There is as much variation within a person's life as there is between persons. "Anyone who turns his prime attention to himself," wrote Michel de Montaigne in *Of the inconstancy of our actions*, "will hardly ever find himself in the same state twice" (2003: 377). "We are entirely made up of bits and pieces, woven together so diversely and shapelessly that each one of them pulls its own way at every moment. And there is as much difference between us and ourselves as there is between us and other people. '*Magnam rem puta unam hominem agere*' [Let me convince you that it is a hard task to always be the same man]" (Montaigne 2003: 380). This does not make a person's ideas, emotions, and presuppositions about death *wrong* but it does make them personal, situational, and socio-historical, highlighting how death is a complex, polythetic phenomenon that encompasses multiple modes of experience and understanding. As such, death can no more

be defined by a particular sociological, anthropological, or medical model than the death-related practices of a given person, social group, or historical period define it in perpetuity for all humankind.

Death lies at the very foundations of society insofar as many important social and cultural phenomena—from language, religion, and education to art, medicine, and science—have their origins in the attempt to transcend individual finitude and ensure life and knowledge are transmitted between generations (Bloch and Parry 1982). Indeed, “without mortality, no history, no culture—no humanity” (Bauman 1992: 7), reinforcing how death is not simply a destructive presence but also a creative life-force that also gives rise to social, cultural, and religious forms that provide meaning and purpose in the face of the body’s eventual demise (Robben 2004; Kaufman and Morgan 2005; Hallam and Hockey 2006). The knowledge of our eventual death—alongside the capacity to imagine a range of possible outcomes, including reincarnation, an eternal afterlife, the disintegration of self and consciousness, or one’s constitutive atoms and molecules being dispersed across the universe—sets humans apart from other species. As the anthropologist Ernest Becker wrote shortly before his own death from cancer:

The essence of man is really his *paradoxical* nature, the fact that he’s half animal and half symbolic. We might call this existential paradox the condition of *individuality within finitude*. Man has a symbolic identity that brings him sharply out of nature. He is a symbolic self, a creature with a name, a life history. He is a creator with a mind that soars out to speculate about atoms and infinity, who can place himself imaginatively at a point in space and contemplate bemusedly his own planet. This immense expansion, this dexterity, this ethereality, this self-consciousness gives to man literally the status of a small God in nature, as the Renaissance thinkers knew. Yet, at the same time, as the Eastern sages knew, man is a worm and food for worms. This is the paradox: he is out of nature and hopelessly in it; he’s dual, up in the stars and yet housed in a heart-pumping, breath-gasping body that once belonged to a fish and still carries the gill marks to prove it. His body is a material fleshy casing that is alien to him in many ways—the strangest and most repugnant way being that it aches and bleeds and will decay and die. Man is literally split in two: he has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order blindly and dumbly to rot and disappear forever. It is a terrifying dilemma to be in and to have to live with. (E. Becker 1997: 26)

Illness, misfortune, and uncertainty frequently reveal gaps in knowledge and generate questions that distance persons from their familiar understandings of themselves or the world (Reynolds-Whyte 1997). As such, the encounter with illness and mortality is not just a medical, religious, or ethical problem but a profoundly ethnographic one insofar as persons from all social and cultural backgrounds can be found reflecting on the reasons for their illness, searching for meaning, or interrogating the moral purpose of their life. When a question first comes to mind, it rarely stands alone but is distilled from and embedded within an entangled mass of related questions and uncertainties (Collingwood [1940] 2002). People's expressions of uncertainty and contingency—as embodied in questions such as *why me?*, *what should I do?*, *what is happening to me?*, *what's going on?*, or simply *why?*—are all common questions forged out of simple words but often exist beyond the realm of medical science and religious explanation. People ask questions in many different ways—rational, rhetorical, angry, pleading, speculative, in dreams, in prayer, and in dialogue with others—which are not always an ultimate quest for truth but an attempt to get through the night and make the world livable again. Consequently, although questions are often a means for seeking answers they are also a pragmatic strategy for opening up a dialogue, seeking solace, or creating stability in a context of misfortune and uncertainty.

Questions are not disembodied but are located “within our life, within our history: they are born there, they die there, if they have found a response, more often than not they are transformed there” (Merleau-Ponty 1968: 104). As such, a question is located at the boundary of the known and unknown world and needs to be understood as a particular kind of embodied inquiry grounded in the questioner's practical concerns and life circumstances. People's questions disclose a specific bodily experience and moral understanding of the world and might be asked during times of uncertainty, hope, suffering, pragmatic need, or the realization of life's transience. They are typically formulated and expressed in language to a range of human and nonhuman agents—including oneself and others, medics, and religious representatives, as well as wider society, God, and the universe—for particular reasons, such as to seek knowledge, create obligations, express anger, to find meaning and cathartic relief, justify a way of being, or simply to obtain a response and acknowledgement.

The act of questioning encompasses social, cultural, and moral presuppositions that are embedded within a specific form of life (Wittgenstein [1953] 2009) and articulated in particular contexts: for example, a home, hospital, a



bar, or church. This brings a range of other persons into the realm of someone's personal and emotional experience, including friends, family, and medical professionals, illustrating how illness creates a shared social, cosmological, and medical context of knowing and understanding that is rarely confined to the individual but constituted between persons in places. Although the questions people ask emerge from a shared set of social concerns and presuppositions, they can also reveal significant personal and moral differences that individuate and distinguish people's experiences and understandings of illness, including how persons negotiate disruption, pain, and uncertainty.

The act of questioning is predicated on preexisting knowledge and understandings of the world insofar as "every inquiry is a seeking. Every seeking gets guided beforehand by what is sought" (Heidegger 1962: 24). For example, asking God for help presupposes a particular understanding and interpretation of God's character and discloses a specific social, moral, and existential worldview. When seen in the field, the questions people ask during times of crisis and distress invariably confirm, modify, or challenge established understandings of the world. However, there are also many occasions when questions remain unanswered or unanswerable. To repeatedly put one's faith in medical science and remain sick or ask God, "*why me?*" and receive no answer, exposes an emotional and existential dislocation between person and world. As such, the questions people ask often articulate a moment in which the limits of existing knowledge and understanding are made public and are not only directed toward particular agents or discursive forms—for example, religion or science—but toward the fact of being alive in *this* body, in *this* time, and in *this* place.

## TIME, FINITUDE, AND PHENOMENOLOGY

The original intention behind *The art of life and death* was not to investigate illness or death but to explore the perception of time in response to a problem Maurice Merleau-Ponty identified toward the end of *The phenomenology of perception*: "The problem is how to make time explicit as it comes into being and makes itself evident, time at all times underlying the notion of time, not as an object of our knowledge, but as a dimension of our being" (Merleau-Ponty 1992: 415).

This places Merleau-Ponty in a long line of thinkers, including Edmund Husserl, William James, Henri Bergson, and Martin Heidegger, who have

attempted to understand time not as an abstract philosophical concept but as part of embodied life and experience: a problem that becomes even more challenging when considering the diverse character of people's lives in different societies and across historical periods. Although time is a precondition for life, experience, and action, it is notoriously elusive and frequently recedes from conscious awareness when immersed in everyday concerns and activities. At the very point one attempts to understand or direct attention toward time, its character is transformed and thus perceived differently. As Augustine of Hippo (354–430) famously lamented, the more we try to comprehend what time is, the more distorted and mysterious it becomes:

For what is time? Who can easily and briefly explain it? Who even in thought can comprehend it, even to the pronouncing of a word concerning it? But what in speaking do we refer to more familiarly and knowingly than time? And certainly we understand when we speak of it; we understand also when we hear it spoken of by another. What, then, is time? If no one asks of me, I know; if I wish to explain to him who asks, I know not (Book Eleven: XIV).

Without time there would be no sentience, no life, no death, and no social existence insofar as human beings are formed as persons, think, act, and inhabit the world in time; carry out their domestic and working lives in time; and experience moods, feelings, and emotions in time. Although time is invested in all the senses of sight, sound, taste, touch, and smell—and is the medium through which perception, knowledge, and understanding emerge—it cannot be perceived in itself and is instead discerned in things such as rhythm, movement, the passing of the seasons, and bodies that grow, age, and die. In the ancient Greek tradition, before the concept or word for time even existed, the primary focus was on the phenomena of *change* (Lloyd 1976). Why did crops ripen and people get old and die? Why did flowers wither and animal flesh rot while rocks endured? That is to say, what was the animating force that lay behind the visible and sensory properties of change and transformation?

Such concerns were already present before the dawn of Socratic philosophy and can be found in the myths and legends of the ancient Mediterranean where the titan Chronos lived on the horizon at the furthest edge of the world (Turetsky 1998). Chronos fathered a number of sons and daughters and in some accounts ended up eating his own children, thus furnishing a graphic example of the past devouring the future. The implication here seems clear: time is simultaneously a

creative and destructive phenomenon that is necessary for birth and life but exists beyond the sphere of human influence and understanding. The world and its contents are brought into existence by time—including life, consciousness, and the body, which cannot exist in stasis—but ultimately all things that are born into the world end up being devoured by the very same phenomenon that enabled them.

Time always needs an *other*. That is to say, time can only be conceptualized in terms of difference and understood in comparative terms. Thus, human time is contrasted with the time of trees, rocks, the planet, Gods, eternity, and the universe. Or as Johannes Fabian (1983) argued, the time of one “culture” is defined in relation to other cultures, so that different ways of being—for example, hunter gatherers—are erroneously described as belonging to the past while other societies are seen as modern. However, perhaps the most persistent and significant of others has been the phenomenon of death insofar as experiences and understandings of time stand against the human organism’s fundamental mortality and finitude. Consequently, a number of influential philosophers—including Heidegger, Emmanuel Levinas, and Jacques Derrida—have ventured that death presents the ultimate otherness, which for Heidegger is intrinsically “nonrelational” (1962: 303) and for Levinas diminishes us to a state of sobbing and infancy (1996).

Such conceptualizations reveal an overly static phenomenology of death, typically couched in Western notions of fear, dread, and anxiety. Importantly, they do not accurately reflect the experiences and understandings of the men and women I worked with, whose orientations toward death would change within and between situations: during times of illness, when drunk, when playing music, when walking, when looking at the ocean, or when laughing. People’s moral actions and concerns about death are as much concerns about life (Parry 1994) and the dominant sense that emerged from my fieldwork was that in many ways death is quite straightforward and instead it is *life* that is extraordinary in its otherness: life in its infinite variety and multiplicity, life in relation to illness, time, and the body, life in contrast to what is imagined to exist beyond death. For a life with HIV/AIDS is a life continually *made strange* and retains the capacity to enchant or surprise. Or shock.

Many social-scientific and philosophical theories about time have focused on the idea of time as a linguistic or cultural construct, while other approaches, including some that draw on physics, argue it is an illusion or deny it exists at all (see Turetsky 1998; Birth 2012). Regardless of its ontological status, time as a collective social phenomenon is measured by a wide range of quotidian, ritual, and mechanical means that provide frameworks for structuring society

and coordinating action, ranging from the daily organization of work and leisure to shared social events and ritual occasions that mark the passage of time, such as birthdays, anniversaries, and commemorations. Such modes of social organization provide the primary materials for the anthropology of time, and there is a substantial literature concerning the different ways of structuring time across the world's cultures (Gell 1996; James and Mills 2005).

Far less common are anthropological studies "with the people in," which bring a sustained ethnographic and phenomenological focus to people's lived experiences of time. An ethnographic, fieldwork-based approach to time does not hinge on whether time is real or illusory but on how temporality is disclosed in people's lives, thoughts, practical activities, and concerns. Consequently, a key aim when beginning this book was to turn Merleau-Ponty's phenomenological problem of temporality into an ethnographic question by placing it directly into the field and working alongside persons for whom the passage of time was made explicit, often on a daily basis. For the persons I worked with, life was encountered as overtly temporal following the diagnosis with HIV/AIDS; they thereafter not only found themselves face to face with death but also the subject of a burgeoning social, national, and political crisis. Consequently, by paying close attention to people's situated perceptions and embodied understandings, a key aim of this book has been to identify people's lived experience of time, as framed by an ongoing condition of mortality and finitude, in an era of rapid social, moral, and political change.

From a phenomenological perspective, time begins and ends with the lived body, which provides the foundational conditions for thought, experience, and action and is the medium through which knowledge of time emerges for us as individuals and as a species. As we cannot step outside our bodies—outside the flow of life and action—people's perceptions of time are continually recast from the standpoint of finite bodies embedded from moment to moment in a world of memory, action, and the future. And while the body-in-action is not the only means for establishing the grounds of understanding, it offers the best starting point for exploring how perceptions and experiences of time and space are generated during periods of health and illness.

Approached ethnographically, it is possible to identify the common and idiosyncratic ways persons engage with time and mortality, not as a representative member of a particular society, social category, or humanity as a whole but as an individual person living under specific conditions of illness and uncertainty, who is subject to different moods and emotions, and who lives with incomplete

knowledge about themselves and the world. As such, my intention is less to explain experiences of time in terms of shared social structures or overarching cultural models but to try to catch those moments when an explicit temporal awareness emerges within a person's situated actions and expressions of being a body continually engaged in the world.

## BODIES IN ACTION: THE CONTINGENCIES OF LIVING AND DYING

The human body is a site of considerable commonality and difference. Whereas running a mile for some people is an enjoyable, life-affirming experience, for other people it is a painful, interminable ordeal that leaves them struggling to breathe or conceive of anything outside the moment. Each day presents numerous ways of coordinating nerves, lungs, muscles, and metabolism with specific emotions, moods, and trajectories of thought and memory, all of which have the potential to generate different experiences of being a body-in-the-world, reinforcing how perception is not determined by phylogeny, action, or social context alone and that people do not engage with the world through identical bodies or shared states of being and belief.

In fact, "normal" bodies do not exist in any tangible or empirical sense—instead they are produced by statistics, averaging out differences and dividing bodies into classifications of normal and abnormal—to produce normative bodies that act as the mark against which other bodies differ or fall short of (Hacking 1990; Butler 1999). For Georges Canguilhem ([1943] 1991), bodily life is grounded in action and movement (without which the organism would cease to exist) and occurs in environments that are diverse and in a process of change. Normality, when understood as a mode of life, as opposed to an outcome of normative forms of classification, encompasses the entire range of the organism's many and varied adaptations to changes in their own body and the surrounding environment, with the consequence that definitions and experiences of health and sickness are neither completely predetermined nor reducible to normative measures and statistical averages. "Especially in humans, health is precisely a certain latitude, a certain play in the norms of life and behaviour. What characterizes health is a capacity to tolerate variations in norms on which only the stability of situations and milieus—seemingly guaranteed yet in fact always necessarily precarious" Canguilhem 2008: 132). Or in Paul Rabinow's

summation of Canguilhem's work: "Life is not stasis, a fixed set of natural laws, set in advance and the same for all, to which one must adhere in order to survive. Rather, life is action, mobility and pathos, the constant but only partially successful effort to resist death" (Rabinow 1994: 17).

From Canguilhem's perspective, it is no more normal to be healthy than it is abnormal to be sick: both are constitutive of people's embodied experience and ongoing negotiation of life. It is a perspective that is developed anthropologically in Veena Das and Clara Han's (2016) consideration of how life and death are interwoven into the fabric of experience—for example, in the way that certain Buddhist practices see life and death as working together within each moment. "What if we took such ways of conceptualizing the relation between life and death as present not only in exotic practices," they ask, "but also in concepts generated from the experiences of everyday life and its perils" (Das and Han 2016: 1)? Human beings only exist on this earth in a perceiving, sensing, and embodied form before death transforms us into a lifeless corpse (Fink 2016). An embodied awareness of what it means to be alive in the moment and in the world, and the different possible forms this might take, is not just linked to instantiations of anomaly, disruption, or illness but might also be heightened, for example, when listening to music, in love, or walking in the street.

The world that the living body inhabits and acts in is not pre-given (Al-Mohammad 2016; Pina-Cabral 2017) but is constituted and disclosed from moment to moment through the different senses. The body's sense organs produce and reveal contrasting properties: whereas the eye sees a world dominated by stable entities and emplaces objects in space, sound is more amorphous and unfolds over time, while touch is localized and highly sensitive to movement. Combinations of smells, sights, sounds, tastes, and textures continuously impress themselves onto the nervous system, but at the very same time a person transforms and modifies the environment through their thoughts, movements, and actions. As such, both the perceiving organism and inhabited environment are in a process of constant change and adaptation through which life and personhood is individuated and expressed.

In his works, *Life, death, and the body in the theory of being* (1965) and *The phenomenon of life: Toward a philosophical biology* (2001), Hans Jonas, who along with fellow Jewish students Emmanuel Levinas, Hannah Arendt, and Henri Marcuse studied under Heidegger, considered how life continually adapts and attunes to new or changing environmental conditions—for example, in the way that trees and plants are capable of sensing sources of light and water or

responding to temperature and soil conditions—which for Jonas, provides an empirical starting point from which to build a phenomenological account of organic life and serves as the basis of two related projects. The first, following Heidegger’s ambiguous relationship with Nazism, concerned an investigation of how Being or *Dasein* in its broadest sense, relates to ethics, and the second attempted to formulate a schema for the analysis of biological life forms that was consistent with modern scientific understanding. In tracing the flow of life from unicellular organisms through plants and flora to animals and human beings, Jonas notes how plants and trees are driven by metabolic needs, accompanied by diurnal and seasonal rhythms and environmental responsiveness. In animals, these metabolic needs are combined with motility, perceptual and sensory awareness, and emotion, and in the case of human beings, encompasses self-reflexive capacities including thinking, imagining, reasoning, and moral and ethical understanding.

As such, for Jonas, life is precarious and contingent because of its dependence on metabolic processes and exchanges with a mutable environment. Simply to be in the world is to exist in a conditional state that necessitates different kinds of action. For humans, action incorporates within it an ethics—for example, through the choices we make, the ways we move, how we express ourselves and speak to other people, or relate to plants, animals, material things, and the planet. This is not to conflate action with ethics or an attempt to ascribe a value judgment on the particular ethics that are lived and performed as good or bad. Instead, it is to assert that ethics has as its starting point our animal condition (MacIntyre 1999) and to recognize the complex intertwining of ethics, contingency, and action that shapes a person’s past, present, and future relations and existence in the world. No account of ethical and moral life is possible independent of biology or that does not consider the forms of life available to us as animals with specific metabolic needs and the cognitive capacity to remember our infancy, contemplate the future, and conceptualize different ways of being and acting in world (MacIntyre 1999).

“In a word, ethics concerns existence” (Lambek 2015: 18). Consequently, in asking, “where is the ethical located?” Lambek argues it is most clearly found and manifested in our everyday actions, social relations, and linguistic practices rather than in a separate realm of philosophical and religious discourse. “The task is to recognize the ethical dimension of human life—of the human condition—without objectifying ethics as a natural organ of society, universal category of human thought, or distinct kind of human practice” (Lambek 2010: 10).

As an intrinsic component of human activity, the ethical is always situated in relation to alternative, sometimes conflicting, possibilities and life choices that shape our continued being-in-the-world (Lambek 2015), which for Immanuel Kant ([1800] 1963), coalesces into the pragmatic query, *what should I do?*

The existential question of how to live amid the exigencies and ethics of action is often characterized in terms of a conflict between divergent forces, for example, good and bad, faith and reason, individual and society, life and death, and often takes cross-cultural form in the relation between *fate* and *free will* (Malik 2015). The sources of fate might be variously understood in terms of smaller or more powerful gods; biology, phylogeny, and genetics; social structures, class, and habitus, et cetera, while free will might take the guise of creativity, inspiration, and agency; resistance and opposition; independence and individuality. More straightforwardly, those areas of action in which the person has no choice or control do not relate to ethics, unlike those areas where the person has some movement and latitude. A further implication is that our being-in-the-world is contingent and incorporates numerous possible presents and futures whose character remains open and undetermined, and that there is always some form of practical and contiguous connection (as opposed to merely conjectured or abstract association) between life and death.

A striking example of the critical role of contingency in establishing the contours of life and death can be found in William Barratt's account of the French scientist and mathematician Blaise Pascal. Born into a wealthy family, Pascal struggled with illness throughout much of his childhood and adult life. By his twenties, he had introduced important new ideas in mathematics, geometry, and physics that laid the foundations for much modern theory. Pascal had already been working on gambling, chance, and concepts of probability when his father broke his hip in a serious accident on the ice. Pascal witnessed what he regarded as his father's miraculous recovery from a condition that could otherwise be fatal. Then, on November 23, 1654, Pascal experienced an ecstatic vision and intense religious awakening that by many accounts followed a profound brush with chance a few weeks earlier. Pascal was out driving his six-horse carriage across a bridge over the Seine when his carriage lurched, the door was thrown open, and Pascal was almost flung to his death. So powerful were these events that he wrote a document about his experience and sewed it into his coat, secretly transferring it and re-sewing it whenever he changed coats, so as to keep it as close to him as possible at all times. The document served as a perpetual reminder of the proximity of life to death, not just in terms of how



life is perpetually shaped by chance, contingency, and random events but also in terms of how nonbeing and uncertainty are imminent within the structure of all human existence. Thereafter, Pascal dedicated much of his thinking to understanding the role of contingency, arbitrariness, and oblivion in shaping existence and long before Heidegger and Sartre introduced their ideas concerning human contingency and nothingness.

The arbitrariness and suddenness of this near accident became for him another lightning flash of revelation. Thereafter he saw Nothingness as a possibility that lurked, so to speak, beneath our feet, a gulf and an abyss into which we might tumble at any moment. No other writer has expressed more powerfully than Pascal the radical contingency that lies at the heart of human existence—a contingency that may at any moment hurl us all unsuspecting into non-being. Death does not arrive punctually by appointment. (Barratt [1958] 2011: 117)

The contingencies of life and death are shaped by structural, political, and ecological factors, and incorporate within them a range of associated and ancillary understandings whose meaning varies across linguistic communities in relation to concepts such as freedom, empowerment, causation, destiny, providence, natural and divine justice, the necessity of nature, and various other forces associated with luck, chance, and providence (Crapanzano 2015). As *subjects of luck* constituted between personal and impersonal aspects of fortune and fate—and as realized through different social and culturally grounded modes of interpretation and imagination—people’s recurrent interactions and engagements with the contingencies of life can be seen as events, much like a roll of a dice, whereby “the cosmos is engaged and challenged to reveal itself” (da Col and Humphrey 2012: 15). Partly anticipatory and partly remedial, it is a process of engagement where the conjoined forces of contingency and necessity do not exist as absolutes beyond the sphere of agency but are personalized and reshaped through action wherein humans can exert some influence over these forces up to and including luck, nature, the gods, and the universe (da Col and Humphrey 2012).

Here an affinity can be found between philosophical, theological, and ethnographic approaches in which there is no radical separation of person and world, ethics and action, contingency and necessity, illness and health, or even living and dying: they are all necessary conditions of life. Echoing Paul Stoller’s work among the Songhay (2005), Das and Han (2016) consider how life involves responding to an ever-changing world that requires negotiating and anticipating

different possible presents and futures. For the Songhay, the paths of life are perilous and phenomena such as sickness, death, and bad luck are unavoidable. However, the forces of fate are not all encompassing and as such invocations and divination enable anticipatory or remedial actions that allow persons to adjust their life course to make it more livable. Following Canguilhem and Wittgenstein, Das and Han similarly draw attention to life as an ongoing process of adaptation and transformation, including those moments when anomaly shifts to disease in which a person's embodied responses to life events cannot always be specified beforehand in the way "that the scale of the human body or the range of the human voice cannot be determined in advance but must be found in each case" (see Das and Han 2016: 17).

This shifts the anthropological focus away from the more stable or enduring patterns of sociality, relationality, and moral action, toward the precarities of life and death as generated by fluctuating global markets, unexpected and revolutionary events, biopolitical developments, and advances in biology, technology, and medicine. A key implication, beyond the established idea that politics, economics, and ethics are inseparable from the sphere of life, is the more radical assertion that the social is not foundational and does not form the ground of all being. Instead, the social is itself seen as a provisional and precarious activity that is not necessarily pregiven and needs to be worked at rather than assumed.

This reminds us that all academic theory is founded on a series of epistemological and "absolute presuppositions [that] do not need justification" (Collingwood [1940] 2002: 44), which for anthropology encompasses concepts such as society, relationality, and context, which need to be recognized as modes of disciplinary analysis rather than determinants of people's lives. As such, "if we take the problem of individuality—or variation—instead as a starting point for the mutual inflection of biological and social norms, 'context' begins to appear in a different light" (Das and Han 2016: 16). For disciplines founded on the primacy of the social, this presents a key challenge but also opens up a number of different anthropological starting points for exploring people's lives by beginning instead, for example, with the personal or a feeling of bodily unease (Al-Mohammad 2016); the idiosyncratic and eccentric (Rapport 2008); a sense of weightlessness or vertigo (Irving 2013); or finding oneself at the boundary of life and death (Jackson 2016), so as to refocus the epistemological presuppositions of anthropology on the particularity of the living and moving body in a world of action and change.

An ethnography of particular bodies in action—rather than presupposing normative capacities and abstract potentialities—focuses on the body as it makes its way in the world and draws attention to how bodily potentials are constituted within moments of health, well-being, disruption, decline, and inability. Too often, the literature on bodies, embodiment, and the environment is located at rarefied levels of theoretical abstraction or solipsism that has little relevance to the diversity of bodies on the ground where obstacles such as stairs, hills, stamina, coordination, and the differentiation of actual bodies in health and sickness are overlooked. Fortunately, queer theory, gender studies, and disability studies continue to destabilize the statistically normalized and socialized human body. Here, Eli Clare writes from a queer and disabled perspective:

I want to write about the body, not as a metaphor, symbol or representation, but simply as the body. To write about my body, our bodies, in all their messy complicated realities. I want words shaped by my slurring tongue, shaky hands, almost steady breath; words shaped by the fact that I am a walkie—someone for whom a flight of stairs without an accompanying elevator poses no problem—and by the reality that many of the people I encounter in my daily life assume I am “mentally retarded.” Words shaped by how my body—and I certainly mean to include the mind as part of the body—moves through the world. (Clare 2001: 359)

In these words a sense of impatience can be discerned about the way writings about the body often gloss over corporeal differences to reinscribe social norms and values to produce sterile theories about messy bodies. In talking about bodies in their specific, complicated, and untidy realities rather than through assumptions of habitual unity or presupposing every body can enact universal phylogenetic abilities, Clare avoids reifying and generalizing his own bodily experience or simply reversing the gaze by privileging the experience of one particular body over others. The fact that “no one is ever more than temporarily able-bodied” (Breckenridge and Vogler 2001: 349) cautions us against setting up “the abled-body” as the norm and thereby mistaking social and linguistic labels of difference for empirical or ontological differences, as highlighted by Clare’s observation that “words” are more often shaped by his body as it extends out into the world rather than the other way around. By paying closer ethnographic attention to the variability of the body—including moments of bodily instability and the effect this has on personhood, gender roles, sexuality, identity, and status—it is possible to provide a better understanding of how the body

creates the conditions for multiple modes of experience and expression. Indeed a more empirical, in-depth analysis “of bodily difference might open up new avenues of exploration, or stretch existing ones” (Staples 2003: 295), and allow us to understand how different bodily experiences facilitate different modes of being-in-the-world (Rapport 2000).

Significant levels of variation are found not just between persons but also within the individual, whose body changes over the life course, including during periods of health and sickness. There is as much diversity within an individual’s bodily history as between different individuals, given that people grow and age and do not go through life with an invariable body, making it difficult to ascribe any single social or universal characteristic to the body. Or as Canguilhem states, it is not possible to “determine the normal by simple reference to a statistical mean but only comparing the individual to itself, either in identical successive situations or in varied situations” (2008: 113).

During periods of illness, many simple tasks and modes of embodied knowledge become compromised by an inability to carry them out to the same level, revealing facets previously naturalized through practice but now tarnished and degraded, as described by anthropologist Robert Murphy, whose ethnography of his descent into quadriplegia includes the following account of trying to brush his teeth:

I brush my own teeth, using a toothbrush with a special thick handle, but Yolanda [Murphy’s partner] first must squeeze the toothpaste tube—my grip is no longer strong enough. Since I cannot lean forward over the sink on my own, she has to push my head over it so that I can rinse my mouth afterwards. (Murphy 2001: 197)

[Inability and impairment] is a precondition of my plans and projects, first premise of all my thoughts. Just as my former sense of embodiment remained taken-for-granted, positive and unconscious, my sense of disembodiment is problematic, negative and conscious. My identity has lost its stable moorings and has become contingent on physical flaw. (Murphy 2001: 105)

The mind and body of someone diagnosed with a life-threatening illness constitutes an entire anthropological field in itself, and Murphy brilliantly combines anthropological theory and personal reflection on learning to live with existential uncertainty, sickness, disruption, and a changing body, all of which

form part of the apprenticeship to illness and a new social identity. Stoller similarly combines personal experience and anthropological theory to describe the state of “betweenness” that is common to both anthropology and illness (2005, 2009). Stoller draws upon anthropology’s extensive use of spatial metaphors in its theoretical descriptions of social life to suggest an anthropologist’s fate often involves being located between different social, cultural, and moral understandings of the world. Living between things, Stoller asserts, has several existential repercussions in that a person gets pulled in different directions at the same time and often experiences a sense of indeterminacy.

The figure of *the between* offered Stoller a more explicitly personal perspective following his diagnosis with cancer. By using anthropology to understand his illness journey and confrontation with death, Stoller developed an approach to living with cancer by resorting to the incantations and practices he learned while training as an apprentice sorcerer among the Songhay. For the Songhay, it is not possible to avoid illness, as it is constitutive of life and therefore a person must be willing to face it. At the same time, divination, spirit possession, and other mediating actions can help restore balance, which for Stoller encompassed a personal and professional quest for meaning and an affirmation of sorcery and storytelling.

Murphy’s and Stoller’s books stand alongside a number of other excellent first-person accounts by persons diagnosed with serious or long-term illnesses that provide intimate empirical insights into people’s lifeworlds during illness or when engaging with mortality (e.g., Hull 1992; Toombs 1992; Stacey 1997; Bauby 2008; Marks 2016). Especially relevant to this book are first-person accounts of HIV/AIDS by persons all now departed (Collard 1993; Guibert 1995, 2015; Brodkey 1996; Moore 1996; Monette 1997; Conigrave 2010) that attempted to document and describe life with the disease, including the streams of inner thought and expression that are not necessarily externalized or made apparent to the wider world. The thoughts and ideas these writers left behind informed the writing of this book and its attempt to understand how lived experiences of illness are shaped by trajectories of inner expression, imagination, and reverie that exist beneath the surface of people’s public interactions.

## OUTLINE OF A SYNDROME

Drawing on over twenty years of research carried out among persons with HIV/AIDS in New York City, *The art of life and death* is based on a long-term

ethnographic collaboration with persons who consented to share their lives as they experienced illness, approached death, and eventually reclaimed life. By offering an ethnographic account of how the world appears to people close to death, it attempts to understand the diverse ways people engage with mortality and reestablish social existence amid conditions of liminality, betweenness, and uncertainty. Life with many illnesses, including HIV/AIDS, is not one of stasis or steady decline but consists of undulating cycles of illness and recovery that can persist for days, months, or even years. These cycles are closely linked to experiences of hope, elation, expectation, and self-reflection as well as sorrow, doubt, and despair, illustrating how illness is accompanied by ongoing shifts in perception, emotion, and understanding that are never fixed but emerge momentarily in relation to changing circumstances and existential concerns.

Today, over forty million people (forty million different minds, forty million different bodies) are living with HIV/AIDS. For every person living with the disease there are tens or even hundreds of others who are affected: friends, partners, parents, children, neighbors, relatives, work colleagues, medical staff, volunteers, counselors, et cetera. In many ways, these persons can also be said to be “living with HIV/AIDS” insofar as their lives and practices are deeply affected by this most complex and unpredictable of diseases. Thus, it is not just forty million infected persons whose lives have been touched by HIV/AIDS, but a substantial proportion of the entire human race.

HIV/AIDS is a relatively new disease. Over a few short decades, it has formed a diverse, global population of infected *and* affected persons that crosses oceans, continents, sexualities, and genders, and continues to cast an enormous shadow over the world as one of the leading causes of death. That HIV/AIDS has become a disease of global proportions in so short a period of time emphasizes how interconnected the world has become through cultural flow, mass-transportation, political and economic migration, wars, and tourism. In just a few decades HIV/AIDS has fundamentally transformed the minutiae of daily life and practice of millions of persons around the world from the workplace to the bedroom. But, as ever, these transformations are not equally distributed. Poverty, sexuality, gender, and ethnicity are some of the many factors that increase the likelihood of contracting HIV/AIDS and influence how people live and cope with the disease.

Living with HIV/AIDS is something that is experienced among others and is caught and passed on by others through a vast interconnected chain of body and being that stretches across time, history, and continents. At the global level,

it is possible for people to identify certain commonalities in thinking and being that are potentially shared by millions of HIV+ people in which thoughts, dilemmas, and emotional responses cut across social categories and cultural boundaries to form a kind of global *communitas*. Meanwhile, at the local level, people's lives are grounded in specific social, political, and economic circumstances, and incorporate different religious and moral worldviews, meaning that even if certain experiences of AIDS are shared, they are not the same.

Importantly, HIV/AIDS is an *immune deficiency syndrome*; that is to say, a collection of different illnesses and symptoms brought together under a single umbrella category. The difference therefore concerns the ontology of the disease itself because people do not die from AIDS but from the different opportunistic illnesses and infections that remain unchecked by a compromised immune system. As common ailments and illnesses vary between locations, HIV/AIDS is a different disease in different parts of the world. Each region has its own prevalent infections and people live with different illnesses. For example, tuberculosis is the leading cause of AIDS-related death throughout Africa, whereas in the United States it is pneumonia. Each involves a distinctive illness trajectory and is characterized by a range of different symptoms. However, even common AIDS-related conditions, such as diarrhea, are likely to be experienced differently because of access to health care. A person might die from HIV-related diarrhea in parts of Africa but a person in New York will survive and in turn be exposed to further opportunistic infections and illnesses over the course of a longer illness journey. Consequently, it is not just life but also the potential roads to death that are different in different locations.

Even untreated, HIV/AIDS can have quite a long gestation period and people often live with the disease for several years before noticing any adverse physical effects. In many cases it is *the world* that seems to change before the person notices or experiences their illness (see Good 1994). Hidden behind these transformations lies the virus, busily implementing changes in body and consciousness that might remain unknown to the person themselves but have already become apparent to other people: changes that are betrayed by the way someone walks and holds their body or in the themes and concerns their conversations return to. After the onset of the first few episodes of sickness, HIV/AIDS becomes more recognizable and its effects can be slow and gradual, liberating and cathartic, or sudden and earthshaking.

When AIDS becomes part of one's social network, it becomes ingrained into mind, memory, and the senses in ways that are hard to forget. All the men

and women in this book possess a tangible understanding of what the end of life looks like—of dementia, forgetfulness, and diminished linguistic capacity—of what can happen to people’s cognitive abilities and their bodies during illness. Most have been in close proximity to others who have died from AIDS and have witnessed their own body as it declines and loses control of basic functions. Historically, the burden of caring falls on women and knowledge of illness is largely gendered (Obbo 1998). However, HIV/AIDS has formed an intimacy with disease and decline among a generation of gay men that many other men do not possess. The experience of caring for and nursing someone dying from AIDS exists in all the senses. Heart-wrenching scenes of pain and suffering—alongside sounds and smells—become impressed into memory and body, including unforgettable images from the final weeks of care and witnessing someone deteriorate, often eliciting thoughts, emotions, and images in which people are confronted by a sense of their own future, as expressed in the words *am I to become that?* For, as Euripides wrote so long ago, “the plain sight of our destiny is the cruelest thing of all.”

Persons living with HIV/AIDS do not just look toward other people’s bodies but also to their own to obtain a sense of their well-being and assess how active the virus is inside them: changes in skin complexion, deterioration in muscle strength or lung capacity, common colds, weight loss, infections, and new body shapes are all scrutinized through the frame of illness. This is not so much a self-directed glance as an extended practice of becoming attuned to and learning about one’s body through the modalities of seeing, listening, feeling, smelling, and tasting. It is an ongoing interrogation and questioning of the body that is partly phenomenological, partly imagined, partly mediated by technology, and is interpreted through specific epistemological and discursive frameworks.

In *Teratologies* (1997), Jackie Stacey writes about her diagnosis with cancer at a young age and how she imagined and experienced her body in terms of the often unavoidable images and cultural representations of disease that circulate in popular discourse and media, including images of horror, abnormality, betrayal, vulnerability, and a body in disharmony or at war with itself. These sit alongside dominant moral and gendered expectations of meeting certain social responsibilities, aesthetic standards, and modes of suffering. Such images do not solely exist “out there” in culture but are incorporated within mind, body, and being itself. Stacey describes how she came to embody a series of cultural expectations in which she was required to act and understand herself through



specific narrative tropes, including the feminized victim who is subjected to outside forces and the masculine hero who transcends them and conquers disease. She recounts how words, actions, and silences, alongside bodily symptoms and surfaces, are read and decoded as part of a broader semiotic system of images and representations that often become internalized by the patient as something shameful, monstrous, or unspeakable and that underpins language itself:

**teras** (med.), *n.* a monstrosity:

**teratogeny**, *n.* the production of monsters:

**teratology**, *n.* the study of malformations or abnormal growths, animal or vegetable: a tale of marvels:

**teratoma**, a tumour containing tissue from all three germ layers:

[Gr. *teras*, *-atos*, a monster.]

(*Chambers dictionary*, 1973; in Stacey 1997: 61)

The interior bodies of people living with HIV are dependent upon technology to render the virus and its effects visible. Scientific instruments allow the human eye to observe infected or damaged cells that exist beyond the threshold of human vision (Haraway 1991; Sturken 1997). Originally confined to medical practitioners, the general public now sees images of organs, cells, and viruses on television, in magazines, and on the internet wherein images of HIV, infected blood, and skin cells are blown up and reproduced in high definition and vivid colors. The images themselves are often ambiguous and are rarely looked at without also imagining some intent or agency: a surplus of meaning and emotion animates the abstract shapes and representations of the virus, placing the imagination at the center of people's understanding of interior body space.

The virus is imagined through prevailing social-political frames: the virus invading, the virus attacking, the virus eating away the immune system, an unwelcome alien whose origins lie elsewhere and the body as temple infected by something impure (Haraway 1992). People experience their bodies as an intimate and familiar source of understanding that they have known all their lives but in listening, attending to, and reimagining the body with a new purpose it also becomes unknown, other, and strange. It is simultaneously a realm of felt, subjective experience and an object of ongoing attention that is part of the external world. The body thus becomes a medium of individuation through which persons each learn to see and understand themselves as a particular kind of social, moral, and phenomenological being or self.

## THE ART OF LIFE AND DEATH

*The art of life and death: Radical aesthetics and ethnographic practice* is the second book in HAU's Malinowski Monograph Series. Alongside its precursor, João de Pina-Cabral's *World: An anthropological examination* (2017), the book is committed to an open-ended, moral, and political exploration of human experience through ethnography. A central question for Pina-Cabral is how ethnography, as a radical intellectual endeavor, can shed light on what it is to be human by considering the mutual constitution of personhood and world. What do we actually mean when we refer to a world, in all its material, animal, and personal dimensions, and how is it shaped by perception, sensation, thought, and action? This poses difficult, occasionally intractable, epistemological and practical problems for anthropologists and their attempts to understand the many different ways of being human.

A principal aim for both books, and the series in general, is to build new ethnographic approaches to understanding social and cultural life. A further objective for the book at hand is to engage with recent debates in visual, sensory, and medical anthropology concerning phenomenological experiences and ways of knowing not just through theory—whose relationship to ethnography exists in a productive and unsettled alliance—but as signified by the book's title, through the development of new ethnographic practices that aim to open up areas of research concerning the radical shifts in inner expression and aesthetic perception that have hitherto been overlooked in anthropology.

In its narrow etymology, ethnography means the act of *writing about people* but can be more broadly understood as the many and varied modes of working with people in the field that generate knowledge about social life and activity *and* the theorization, analysis, and documentation of this knowledge through writing, alongside alternative, artistic, and nontextual forms of representation (Cox, Irving, and Wright 2016). Not all would agree with this description, given that ethnography is a changing and diverse field within and beyond anthropology. It is therefore instructive that ethnography has recently been the subject of extensive debate and critical discussion that has disclosed many different approaches and understandings (see da Col and Graeber 2011; Astuti 2017; da Col 2017; Ingold 2014, 2017; Miller 2017).

I find it reassuring that no overarching definition has yet emerged from these debates. This leaves room for experimentation and reinforces how ethnography, whether understood as a fieldwork practice, mode of inquiry, or means of

representation, is a creative and often-disruptive process of knowledge-making that resists orderly definition. Indeed, whenever a term's inherent polysemy and mutability becomes too restricted or stabilized it is necessary to look at the powers at work and their reasons for attempting to narrow and systematize a particular meaning, be that social, political, or academic (see Volosinov 1973). "I mistrust all systematisers and I avoid them," declared Nietzsche, "The will to system is a lack of integrity" ([1888] 2003: 35), underlining how ethnography's lack of systematic definition, which some find troubling, can equally be read as an index of vitality and a consequence of the new and unanticipated forms of anthropological knowledge that arise out of face-to-face fieldwork encounters and various other forms of research, including working with archives, artifacts, and media, which in my case also involved performance, diaries, notebooks, artworks, and first-person accounts of terminal illness. Whether fieldwork and complementary forms of research are framed as ethnographic or not is of far less interest, importance, and relevance than the shared insights and new theoretical possibilities that emerge concerning the human condition.

Beyond questions of polysemy and power, *The art of life and death* seeks to extend the kind of practical understanding of humanity that Kant described as a "knowledge of the world" (*Weltkenntnis*) that develops through active participation (*mitgespielt*) as opposed to scholastic or speculative knowledge, which Kant regarded as mere intellectual posturing unless grounded in practical action and experience. This not only highlights the partial and provisional grounds of knowledge but also how the comparative and generalizing claims of anthropology are constructed out of particular ethnographic encounters and interactions. The ways in which the resulting materials are assembled into broader theoretical concepts and understandings of the world is written into the anthropological project itself: reinforcing the inseparability of ethnography from theory (da Col 2017) and Bronisław Malinowski's point that "theory without material is sterile and material without theory is not illuminating" (quoted in da Col 2017: 1).

Although Malinowski was referring to language and magic, ethnography also encompasses the embodied, inchoate, and tacit dimensions of perception that are the subject of this book. The assembled chapters attempt to develop an exploratory ethnographic approach to understanding the emergent and ever-changing realms of inner expression and imagery that comprise lived experience. Given there is no objective access to the minds, bodies, and experiences of other people—not to mention the inherent problem of comprehending and rendering intelligible our own mind, motivations, and actions—this presents a

substantial challenge to the social sciences, sciences, and humanities. For anthropology, as I argue in the following pages, understanding people's emergent and situated modes of thinking and being is first and foremost a practical and methodological problem to be worked on in the field rather than a conceptual one to be written about from afar. I also argue, and then seek to address, how existing social scientific methods and measures are often too static to research and represent the complex assemblages of internally represented speech, perception, and imagery that are expressed in consciousness. Although these are central to social life and the human condition, they are rarely, if ever, the ethnographic focus of journal articles and monographs, and as I argue in later chapters, this means anthropology is currently only telling half the story of human life.

Formulating a better and more complete understanding of human beings requires engaging with the entirety of subjectivity and activity. A key contribution of the book therefore concerns how theoretical, philosophical, and ethnographic approaches might be combined to reconceptualize a fuller, more realistic, and empirically viable understanding of the human subject. In doing so, *The art of life and death* develops and advocates for new, ethnographically grounded ways of researching how lived experience is constituted by complex trajectories of inner dialogue and ongoing shifts in perception, and then seeks to understand how these relate to extrinsic audible and observable action. The intention is not to claim privileged access to human consciousness nor to reinvent the wheel (see da Col and Graeber 2011) but to offer an empirical and experimental contribution and counterpoint to recent theories of embodied cognition and experience in visual, sensory, and medical anthropology by making links across the arts and sciences, including the performing arts and neurology.

The relationship between life and death is rarely predictable or straightforward. When I started my research on HIV/AIDS in London in the early 1990s, AIDS was seen as a death sentence. The later development of effective antiretroviral medications (ARVs) in 1996–97 radically transformed HIV/AIDS from an acute to chronic illness across many parts of the world. Hundreds of thousands of people, who without medication would have died, found themselves alive. A collective reorientation commonly known as the Lazarus Effect moved people away from death and back toward life and the future. Nevertheless, there still remains an uncertainty as to where HIV/AIDS may take humanity. Huge numbers of people across Africa and Asia continue to die, infection rates are rising once more in many Western countries, while those who resist infection or remain healthy without medical intervention are in a position to pass on

their genes, immunity, or longevity to following generations. Science and human adaptation might not be able to outstrip the evolutionary potential of the HIV virus, and mutant strains have become immune to certain combinations of antiretroviral medication. However, at the time of writing, recent breakthroughs in cell biology promise new ways of tackling both HIV/AIDS and cancer.

Between 2010 and 2014, I received two research grants from the Wenner Gren Foundation in New York and the Economic and Social Research Council (UK) to try to reestablish contact with persons living with HIV/AIDS who I worked with during the 1990s. Many of the people I worked with were learning the art of how to “live again,” having experienced intense, life-threatening episodes of illness, negotiated the likelihood of death, and having often made irreversible life decisions. Unsurprisingly, many found it impossible to return to previous ways of thinking and being, and have made substantial lifestyle changes and career choices that affect how they live today.

By working collaboratively with persons from different stages of my research, *The art of life and death* attempts to understand how people have learned to live a meaningful existence in the pre- and post-antiretroviral eras while negotiating a terminal illness. Collaborative approaches with persons have the capacity to displace the historical power relationship between researchers and researched by allowing persons to be the subjects of their own existential inquiry rather than objects of study. Recognizing the capacity for people to be their own theorists, while taking seriously their role in shaping anthropological theory and debate, has the potential to open up new fields of interest and new directions for anthropology to follow. This not only allows for ethical, evidence-based understandings of the day-to-day experience of living with illness and uncertainty in all its complexity and diversity but also helps identify mutually shared areas of interest and concern between anthropologist and informant. This provides a means of ensuring that the debate is not conducted at levels of theoretical abstraction remote from people’s lives and concerns and generates relevant empirical and analytical data about the lifeworlds of illness.

On these grounds, it makes no sense to categorize or reduce life with HIV/AIDS to one of sorrow and suffering. Emotions are mutable and overlapping in that happiness can be ambivalent and touched with sadness, while suffering can be welcome and virtuous, meaning that what can be distinguished analytically cannot necessarily be separated at the level of experience (Throop 2015). As importantly, although sorrow and suffering can be found in almost all human biographies and are certainly present in this book, the individuals I worked with

rarely describe and understand themselves or their experiences in these terms. Indeed, it is often a source of considerable concern and frustration to persons with HIV/AIDS that their lives are so routinely and casually theorized in terms of suffering and other associated tropes within academic and public discourses that fail to represent the complexity, diversity, and mutability of people's lived experience. Persons are frequently placed in a sick role, reduced to instantiations of suffering or else denied the opportunity to be full persons based on common misunderstandings of the disease. Persons living with HIV/AIDS around all parts of the world are living healthy productive lives and experience extended periods of well-being—especially since effective antiretroviral medications were made more globally available following concerted political action in Brazil, South Africa, and India—but still often encounter discrimination—for example, when seeking work, in their parental role, and so forth—while being perfectly capable to perform their various responsibilities. Consequently, a shared aim of the research is to challenge one-dimensional connotations of suffering, inability, and distress by humanizing people's lives and experiences.

As such, the book's most important guiding principle is that the individuals being represented must be able to recognize themselves, their lived experience, and moral worldview within its pages. This necessitated forming socially inclusive dialogues with interested persons and according them an active role in shaping the book's subject matter, not just in relation to human finitude and existential uncertainty but also the properties of everyday life such as laughter, shopping, silence, lying in bed, or listening to music. Being open to the opportunities ethnography affords involves taking ideas, whether they are found in academic discourse, personal conversations and diaries, modernist literature, or pop songs, and then placing them directly into the field so as to explore the continuities and discontinuities "between who we are and what we might become" (Jackson 2011: ix). Each of the chapters presents a shared journey of knowledge and involves various changes in perception related to the city and its environs. Each then goes in different directions, to consider the historical, the material, the political, the confessional, the phenomenological, the aesthetic, and the ironic as experienced through people's changing circumstances of being. The reader may or may not agree with my theoretical approach and analysis, but I hope to have provided sufficient ethnographic depth to people's life experiences and stories, corroborated by those I worked with, to open up different theoretical paths and allow for alternative explanations and modes of analysis that I encourage and welcome.

I reestablished contact with around fifteen people, and many of their life journeys can be found in this book. Among these, seven underwent major career changes, five developed but survived HIV-related cancers, one attempted suicide, two returned to college, one person became a mother, one became an ordained minister, and one was incarcerated in prison: virtually all would be dead if not for antiretroviral medication. As such, they are currently living in a future and forging a life in a world they never thought they would be alive to see. This recalls how “the art of living” (Nehamas 1998) is a creative act of *poesis*, that is, an ongoing set of activities through which life is shaped, made, and enacted and entails manifold ways of living a life rather than just one. However, the art of living takes on a second meaning in many of the pages of this book, given the close attention to the processes of artistic expression and the inclusion of artworks made by people while experiencing bodily instability and confronting existential uncertainty.

Many of the people I worked with found themselves asking similar questions about life and death—and were subject to the same limitations in understanding and responding to those questions as we all are—about how to carry on living in circumstances that were not of their choosing. Or put another way, what choices and actions do people make in order to have a good life? (Robbins 2013); to enable a good or bad death? (Desjarlais 2016); or when preparing for the personal, familial, and economic consequences of loss? (Irving 2017; Al-Mohammad forthcoming). Last but not least, although *The art of life and death* is about living with the uncertainty of illness, the intention is to offer a broader, collaborative exploration of existentiality and the human condition, including how human beings engage with questions of time and finitude, the phenomenology of the body, and what it means to be a mortal being in a world of perpetual change.

As such, *The art of life and death* is their story but also our own, for on some levels it is the story of all human beings