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# Accounting to the end of life. Scarcity, performance and death

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## Abstract

This paper follows accounting to the end of life. We question how accounting can influence the way life ends to understand the conceptions of life, health and normality that inform accounting valuations of life itself. Specifically, we conducted an ethnographic study of a hospital's geriatrics and palliative care unit to analyse how accounting influences, and is informed by, conceptions of what makes a life worth living. The end of life problematises accounting and makes visible assumptions on what constitutes a good life. We draw on Agamben and Canguilhem to show that accounting builds on, and reproduces, several discursive positions – scarcity and the need for efficient resource allocation; separability and the possibility to isolate segments; commensuration and the possibility to relate each situation to standardised categories; valuation and the reduction of life to exchange values; normativity and the definition of normality through statistical regularities. We then discuss the kind of life that is included in accounting valuations of life itself and the dehumanising consequences accounting practices can have on the end of life. We conclude with opening questions on how to imagine forms of accounting that would acknowledge our vulnerability and allow for an art of living while dying.

## Introduction

What makes the value of life? What makes a life worth living?

The prolongation of life, the idea that life could be extended beyond its 'natural' boundaries, is probably the greatest 'miracle' achieved by modern medicine (Hughes, 1956; Geer et al., 1961). Technological advances create such unprecedented possibilities that the question emerges of what should constitute acceptable boundaries to the prolongation of life. Should caregivers attempt anything to maintain life or can it result in a 'bad life', a life 'not worth living'? And, if not all lives can be considered good lives, how can one assess the value of life?

Such questions raise ethical, sociological, and political issues. In an increasing number of settings, accounting matters as well. Important medical improvements and economic growth could have secured universal access to healthcare. Instead, various discourses have used

accounting to portray healthcare as increasingly unaffordable and justify policies of rationing and cost ‘containment’ (Preston, 1992; Arnold et al., 1994; Lawrence et al., 1997; Samuel et al., 2005). Such discourse of scarcity in turn promoted a more systematic use of accounting in healthcare management (Covaleski et al., 1993). Such rationing practices constitute and naturalize ‘the care for life’ as a scarce resource to allocate efficiently.

Against a view of healthcare as a fundamental human right (Arnold et al., 1994; Lawrence et al., 1997), accounting has been used to construct healthcare as a commodity (Samuel et al., 2005). Some patients or pathologies become more profitable than others, creating hierarchies of patients’ ‘worth’. In other words, accounting puts ‘a price on life’ (Samuel et al., 2005) and reduces healthcare to its exchange value. A proliferation of performance measures and calculative practices produce evaluations and attributions of value to life itself. They influence which lives should be given priority and which are portrayed as less worthy of medical resources and activities, of the time and space required to treat, cure and save lives.

The end of life problematises these calculative practices and makes visible assumptions on what makes a life worth living. This paper thus follows accounting to the end of life to understand how accounting influences the way life ends and the conceptions of life, health, and normality that inform accounting valuations of life itself. Organisations that are dedicated to life, but regularly confronted with death, develop a regime of death, that is a set of mechanisms, practices, technologies to ‘organise death’ despite its inherently disruptive nature (Le Theule et al., 2020). In a context of scarcity and rationing, such ‘thanatopolitics’ (Agamben, 1998) influence and are influenced by accounting. Turning issues associated with the end of life into questions of resource allocation is denying the political and sociological dimensions of life. Such a conception of life reduces it to what Agamben (1998) calls ‘bare life’.

To understand how accounting is influenced by, and influences, conceptions of what gives a life value, this paper studies the intersection between accounting and the end of life. Precisely, it draws on a two-year long ethnographic study of a hospital’s geriatrics and palliative care unit. In geriatrics and palliative care units, dying patients stand alongside others expected to leave the unit ‘cured’. Geriatrics patients suffer from a general deterioration of their overall condition, which makes the possibility of dying an option. There is no consensus on how to treat and care for patients in such a condition. Most patients require ‘health-restoring treatments’, but some are so close to death that ‘dying has become inevitable’ (Iedema et al., 2005, p.852). Then they receive palliative care that ‘vacillates between life-sustaining clinical intervention and modes of care that privilege comfort and support’ (ibid., p.846). In such a setting, caregivers have to decide on who should live and who can be allowed to die (Glaser & Strauss, 1965; 1968; Sudnow, 1967; Seymour, 2000; Iedema et al., 2005; Le Theule et al., 2020).

The end of life creates specific challenges to accounting. Healthcare accounting produces categorizations of pathologies (Coombs, 1987; Preston, 1992), statistical classifications of patients (Covaleski et al., 1993), and a standardization of medical practices (Llewellyn & Northcott, 2005; Samuel et al., 2005; Kurunmäki & Miller, 2008; Llewellyn et al., in press). It builds on assumptions – such as the idea that one should leave a hospital ‘cured’ – that the end of life problematises. Studying the intersection between accounting and dying helps understand, and question, such assumptions on the separability of medical activities, the definition of normality through quantitative statistics, and the segmentation of the body as a sum of organs. These questions have also been debated within medicine itself, especially after the influential theorization by Canguilhem (1966; 1991) of the difference between the normal and the

pathological as a question of general condition of the body as a whole. A general deterioration of someone's overall condition unsettles traditional conceptions of what constitutes a 'normal' life. Conflicts emerge between alternative conceptions of health and normality.

We thus draw on Agamben (1998) and Canguilhem (1966; 1991) to show that accounting builds on, and reproduces, several discursive positions – scarcity and the need for efficient resource allocation; separability and the possibility to isolate segments (e.g., portraying practices as a set of clearly separable activities, or a body as a sum of organs); commensuration and the possibility to relate each situation to standardised categories; valuation and the reduction of life to exchange values; normativity and the definition of normality through statistical regularities. These positions can be debated in any setting, but they become particularly questionable when applied rigidly to the moment of our greatest vulnerability while our increasing fragility forces us to face our deepest anxiety – the feeling of our finitude. With Canguilhem (1966), we argue that the inherently political dimension of the end of life calls for a 'holistic' view, one that values the patient as a person and recognizes the person as embedded in a social milieu. This means to treat questions of health, and questions of life itself, as incommensurable. More generally, this paper analyses the intersection between accounting and the end of life to understand how accounting influences the 'art of living' but also to question and problematise the current situation and reaffirm the value of life while dying and encourage to think new arts of living while dying.

The remainder of this article is structured as follows. In the first section, we introduce literature on accounting and healthcare, before drawing on the works by Canguilhem and Agamben to explore the notion of normality and its relationship to life itself. We then present the research methods used in this article, and discuss the specific challenges of fieldwork in such a sensitive setting. The results are presented in three sections; the first questions the conceptions of life, health and normality that inform accounting; the second focuses on situations when the question emerges of which life is worth saving; the third examines palliative care and the exception of the dying subject. We then discuss the kind of life that is included in accounting valuations of life itself and the dehumanising consequences accounting practices can have on the end of life. We conclude with opening questions on how to imagine forms of accounting that would acknowledge our vulnerability and allow for an art of living while dying.

## Scarcity, health, and the value of life

This article studies end of life situations to understand how accounting influences, and is informed by, specific notions on what gives a life value. Next, we present the literature on healthcare and accounting to examine how care has been constituted as a scarce resource to allocate efficiently. We then introduce works by Canguilhem and Agamben to explore further the notion of normality and its relationship to life itself.

### *The constitution of care as a scarce resource*

How healthcare should be organised, regulated, practiced or valued is neither consensual nor stable over time but underwent important historical changes and remains a contested issue. The various fields of knowledge, material spaces, financial regulations, institutional arrangement and governmentalities of healthcare changed dramatically over the last century (Preston, 1992). Several waves of healthcare reforms have been justified by, and introduced, a form of 'mistrust' (Marcon & Panozzo, 1998) and criticism (Kurunmäki & Miller, 2008) of 'professional judgment' and 'clinical freedom', that is the idea that clinicians only can make

decisions impacting the welfare of patients (Preston, 1992; Bishop & Boden, 2008; Kurunmäki & Miller, 2008), a position portrayed as excessive power and professional protectionism. Instead, as Kurunmäki and Miller (2008) put it, ‘regulating or governing by accounting numbers was to become the dominant credo and the norm to be aspired to’. Previous literature identified three main discontinuities concerning the introduction of an economic rationality, the reduction to exchange values and the naturalisation of scarcity.

The first discontinuity concerns the introduction of an economic rationality. Treating healthcare as a fundamental human right (Lawrence et al., 1997, p.675) is to view health as ‘incommensurable’ and beyond economic rationality. If healthcare costs have been increasing this is justified by the important achievements and high prestige of medicine (Preston, 1992). It would be wrong, then, to ‘put a price’ on health and suffering (Samuel et al., 2005). In other words, the value of health is too great to be measured. Various waves of accounting reforms and changing calculative infrastructures have challenged such a view and introduced explicit, standardised, quantified measurements that allow a comparison and monetarisation of medical activities (Preston, 1992; Covalleski et al., 1993; Broadbent & Laughlin, 1998, Llewellyn et al., in press). These reforms have contributed to constituting healthcare as a service and health as a commodity (Arnold & Oakes, 1995; Samuel et al., 2005). The use of accounting has become a way not only to improve cost-consciousness, efficiency, value for money and resource allocation but also to increase transparency, accountability and even the quality of ‘services’ provided (Preston, 1992; Marcon & Panozzo, 1998; Gebreiter & Ferry, 2016). In the process, the ‘care for life’ has been constituted as a resource to allocate efficiently.

The second discontinuity concerns the valuation of healthcare. A crucial inflexion came from the introduction of practices referred to as ‘prospective payment’ in countries such as the US (Preston, 1992; Covalleski et al., 1993; Preston et al., 1997; Samuel et al., 2005), ‘payment by results’ in the UK (Llewellyn & Northcott, 2005; Kurunmäki & Miller, 2008; Llewellyn et al., in press) and ‘Tarification à l’activité (T2A)’ in France (Belorgey, 2010; Juven, 2013). Based on the assumption of a stable relationship between diagnoses, activities and costs, these systems produce a ‘variabilisation’ of healthcare funding depending on volume, type and mix of activities. They create incentives for medical practitioners to improve funding through increased efficiency but also to alter diagnosing and treatment patterns (Preston, 1992) and to focus on the ‘profitability’ of individual treatments (Kurunmäki & Miller, 2008). They offer measures for the value of treatments, the value of patients, the value of a life. Beyond the risk of encouraging deviant practices and the questions of professional ethics, these dispositifs illustrate how healthcare has been reduced to its exchange value.

The third discontinuity concerns the naturalisation of scarcity. During the second half of the 20<sup>th</sup> century, several countries developed healthcare systems leaning towards a conception of healthcare as a right. The great achievements of the medical field of knowledge was guaranteeing its autonomy. Various waves of reform, however, challenged this situation. Even if some argued that we have entered a world of post-scarcity (Bookchin, 2004), literature related the preoccupation with cost-efficiency to the emergence of a discourse of scarcity and rationing, that is a discourse portraying healthcare as confronted to limited resources and hence in need of more efficient resource allocation (Preston, 1992; Arnold et al., 1994; Lawrence et al., 1997; Kurunmäki & Miller, 2008). Many reformers claimed, or assumed, that healthcare had become ‘unaffordable’ and presented a more systematic use of accounting (and related refinement of cost accounting systems) as necessary to assess efficiency, monitor costs and guarantee financial robustness. Under a situation of scarcity, the discourse goes, accounting systems

should allow the calculation of the costs of individual patient treatments to permit resource allocation and avoid that some patients receive ‘excessively’ expensive treatments ‘at the expense of others, possibly not admitted to hospitals because of scarcity of resources’ (Lawrence et al., 1997, p.672). The discourse of scarcity thus constitutes the allocation of resources as the core valued activity. The aim is no longer to find the resources necessary to fund the expansion of a right to health but to ‘contain’ or reduce funding and find ways to allocate such scarcity.

Previous literature studied the emergence of an economic rationality and related commodification of healthcare, its reduction to exchange values and the naturalisation of scarcity. These discontinuities did not emerge spontaneously from market forces but were constituted through accounting dispositifs and calculative practices introduced by governments and regulatory bodies. This paper contributes to this stream of research by questioning the conceptions of health, life, and normality that inform such dispositifs and how they influence the end of life. To resituate accounting in debates on what gives life value, the next section presents considerations on life and normality.

### *Normality, pathology and the end of life*

To problematise the conceptions of life, health and normality that inform accounting practices, we explore works by Canguilhem and Agamben on the notion of normality and its relationship to life itself.

Canguilhem (1966; 1991) studied various theorisations of medicine to question their conception of normality. In the 19<sup>th</sup> century, several authors developed a ‘quantitative’ model of health. Their main assumption is that “pathological phenomena are identical to corresponding normal phenomena save for quantitative variations” (Canguilhem, 1991, p.35). To authors such as Broussais or Comte, sickness is merely a change in intensity in the action of stimulants which are already operating in a state of health. There is a reduction of a quality (sickness) to a quantity, a threshold, a measurement. On this assumption they build an ‘additive theory’ according to which a pathology comes from the addition or subtraction of something to the state of health. This suggests “a theory of the relations between the normal and the pathological, according to which the pathological phenomena found in living organisms are nothing more than quantitative variations, greater or lesser according to corresponding physiological phenomena” (ibid., p.42).

Against the quantitative model, Canguilhem conceives of health as a general state in unstable equilibrium and disease as a disturbance of such equilibrium. This rejects the additive theory but also the idea of ‘localization’, according to which one can identify a specific site for each pathology – an organ, a tissue, a cell. According to Canguilhem, the alteration of a normal state can only be understood holistically and the distinction between the normal and the pathological separates general aspects of ‘whole functional totalities’. Quantitative variations are mere symptoms and the goal of medicine no longer consists in localizing quantitative thresholds but in assessing abnormal behaviors.

Canguilhem argues that the quantitative model ‘artificially’ separates the diseased from their environment (their ‘*milieu*’), losing both the subjective dimension of the disease (which Canguilhem, 1991, p.198, conceives as an experience, ‘a test in the affective sense of the word’) and the indivisible totality of individual behavior. Medicine goes beyond mere anatomy and physiology by putting ‘the physician in contact with complete and concrete individuals and not with organs and their functions’ (p.88). It apprehends a ‘conscious individual totality’ and

grasps the ‘experience men [sic] have in their relations with the whole of their environment’ (ibid., p.88). Medicine becomes an art of living: “An art of living – as medicine is in the full sense of the word – implies a science of life” (ibid., p.87).

The great originality of this thesis is that it contradicts prior attempts to ‘dehumanise’ illness. Indeed, classic authors tried to identify ways to understand diseases independently from the conscious experience of the diseased persons. To that effect, they defined illness by its effects:

“Now with at least one of these effects, pain, we unequivocally leave the plane of abstract science for the sphere of concrete awareness. This time we obtain the total coincidence of disease and the diseased person, for pain-disease, to speak as Leriche does, is a fact of the level of the entire conscious individual, it is a fact which Leriche’s fine analyses, relating the participation and collaboration of the whole individual to his pain, allow us to call “behavior.” (ibid., pp.98-99)

Pain cannot be apprehended independently from the conscious, holistic experience of the person, which nuances any effort to identify localized, dehumanised, purely physiological pathologies. Disease emerges not only from physiological variations but also from social alterations. Any definition of health relies on a conception of normality or, better, from an awareness of the normal. Canguilhem (1966, p.67) speaks of a ‘lived notion of the normal’, an expression unfortunately lost in translation.

However, Canguilhem rejects the idea of a simple opposition between normality and pathology. In a quantitative and localized model, regularities are observed that become external ideals, values allowing the evaluation of the normality of a state of health. Any deviation is considered abnormal and for that reason devalued. By contrast, Canguilhem rejects the mere possibility to distinguish in any absolute way the normal from the pathological. First, he notes that the normal is not amenable to objective measurement. Then, “there is no fact which is normal or pathological in itself” (Canguilhem, 1991, p.144) as “the abnormal can be evaluated only in terms of a relationship” (ibid., p.188). Second, he shows that the disease institutes its own norm: “the pathological must be understood as one type of normal, as the abnormal is not what is not normal, but what constitutes another normal” (ibid., p.203). “The pathological is one kind of normal” (p.196).

Instead of seeking the truth of the normal, Canguilhem suggest to study forms of normativity, that is capacities to institute new norms:

“Being healthy means being not only normal in a given situation but also normative in this and other eventual situations. What characterizes health is the possibility of transcending the norm, which defines the momentary normal, the possibility of tolerating infractions of the habitual norm and instituting new norms in new situations. (...) Health is a margin of tolerance for the inconstancies of the environment [milieu].” (196-197)

To Canguilhem, then, what matters is not normality, nor the ability to respond to given values, but the capacity to create new norms – what he calls being ‘normative’. Health is being able to create new, flexible, adjustable norms – to institute new values. Health becomes a ‘vital momentum’ and disease a reduction of the capacity to institute new norms for one-self. According to this conception, the diseased person reaches a normality but fails to remain ‘normative’. Recovery is not the reinstatement of a previous state but the stabilization of a general condition (possibly different from what it was before). The new norms are not necessarily equivalent to the ones observed before the disease but the aim remains to reach new

norms. Health and disease are forms of relation to the world grasped in a manner both relative and holistic, through a consciousness and a certain art of living.

This conception of normality and pathology exerted a considerable influence on French philosophers of the second half of the 20<sup>th</sup> century, as well as on an important proportion of medical practitioners. When revisiting his own work 20 years later, however, Canguilhem remarked that his theses apply particularly well to ‘young’ persons. In old age the notion of normality takes a different meaning. As Pickard (2009) shows, historically, geriatricians justified the very existence of their specialist area by differentiating between “normal” and “pathological” aging, and the idea that the latter needs special care and experts able to tell the difference. Pickard (2009, p.75) suggests that this ‘enabled a distinction to be made between a “normal abnormal” (the steady state for an older person judged to be “at risk”) and an “abnormal abnormal”, which then required an intervention.’ The discursive constructions of normality and abnormality become valuations of life itself, relating to differentiated valuations of the life of the patients being treated.

To refine further our apprehension of the notion of ‘life itself’, and question the kind of life that is included in conflicting valuations of life itself, we draw on Agamben’s work on ‘bare life’. Agamben (1998) looks at the thinking behind the definition of the value (or lack of value) of life itself. This leads him to ask the question of what makes a life ‘not worth living’. Conceived as biological minimum (Butler, 2004) or a merely bodily existence (Marti & Fernandez, 2013), a bare life is one that is denied any political relevance. The end of life disrupts biopolitics and creates a state of indeterminacy and undecidability where the norm, the normative, and life itself enter a state of exception.

Agamben (1998; 2005) does not attempt at defining normality through a study of pathology but through a study of ‘the exception’, defined not as any abolition of the norm but as a suspension of the norm. Primarily interested in forms of government, Agamben (2005) defines the exception as a suspension of a juridical order, a suspension of the law itself. However, he also mentions situations when the exception refers to and encompasses life and remarks that, then, the exception becomes a ‘relation that binds and, at the same time, abandons the living being to law’ (Agamben, 2005, p.1). The state of exception is a biopolitical structure ‘in which law encompasses living beings by means of its own suspension’ (ibid., p.3). The exception destabilises the normal by creating a ‘threshold of indeterminacy’, a ‘zone of indifference where inside and outside do not exclude each other but rather blur with each other’ (Agamben, 2005, p.23; see also Agamben, 1998, pp.26-32).

Interestingly, Agamben seems to follow Canguilhem’s distinction of normality and normativity by arguing that the state of exception, if it does not comply with previous norms, in fact creates its own norms – ‘if it has no law, it makes law’. Agamben (2005) defines the ‘normative’ as a realisation of existing norms and thus contrasts it with the exception where the old norms are suspended. Yet his definition of a constitutive law is consistent with Canguilhem’s definition of the normative as a production of new norms. The state of exception does not follow the juridical order (the law as defined by legislation) but creates its own law. Agamben argues that the exception is illegal yet ‘juridical and constitutional’, where Canguilhem would argue that it is abnormal yet normative. The exception ‘is realized in the production of new norms’ (Agamben, 2005, p.28).

In both cases the suspension of the norm relates to life itself. For Canguilhem the failure of previous norms leads to increased normativity from life itself. For Agamben, the state of exception is one where power targets ‘bare life’ (Agamben, 1998). However, this does not mean



that a 'state of nature' would replace the previous human and social norms. Only human norms can create the absence of a norm; a normative void is inherently political (Agamben, 1998; 2005). The state of exception is one that institutes 'a threshold of undecidability between anomie and *nomos*, between life and law' (Agamben, 2005, p.86).

To follow accounting to the end of life, then, is to see emerge the complexities of normativity and how they influence, and may be influenced by, accounting. What conceptions of health, life, and normality inform accounting valuations of life itself? What is this life that is included in accountings for the end of life? And, in turn, how does accounting influence (the value of) life and the end of life? To address these questions, we draw on an ethnography of an acute-care geriatrics unit. Next we present the research methods and the ethical, philosophical and sociological challenges of studying such a sensitive field.

## An ethnography of an acute-care geriatrics unit

### *The study design*

To study accounting for the end of life, this paper draws on an empirical research conducted in an acute-care geriatric unit of a Parisian suburbs hospital. The unit covers two floors with 22 beds on each floor. Each room contains two beds, except in palliative care which uses single rooms (a bed can be added for a family member). Each doctor, assisted by a junior doctor (who spends six months in the unit), is in charge of eleven beds, three of which are for palliative care patients. There are 33 nurses and nursing auxiliaries, supervised by a nursing manager, for the two floors. The unit also includes non-medical staff, plus a dietician, a social worker, a psychologist, and two medical secretaries.

This study relies on an ethnographic study which spread over two years, at the frequency of two days per week on site. It was mainly held on the second floor of the site through shadowing over two doctors and two junior doctors. This was complemented by a video-ethnography lasting for two weeks in the unit, day and night. A variety of situations were observed, including emergency situations and more 'mundane' situations where nothing appeared to be happening. Morning meetings, handovers, discussions with families, conversations in the hospital rooms with patients, doctors and junior doctors, meetings with the social worker, and the doctors' routine work were also witnessed. Observations were completed by formal and informal interviews with doctors and nurses. The influence of accounting emerged through observations of medical activities but, besides the ethnographic material, we examined documents about the latest waves of healthcare reforms as well as documents on the accounting dispositifs, about their roles, uses and limitations, both nationally and in the specific hospital studied.

### *Shadowing geriatricians*

The research project started with the idea to explore the effects of the succession of public hospital reforms in France. The first author (together with Carine, a documentary maker) contacted managers of a middle-sized hospital of the Parisian suburbs who accepted to discuss the project. They emphasized the importance of the patient-doctor relationship and assessed whether we would be able to work together. This sensitive field thus required considerable commitment: a prolonged and regular presence seemed necessary to gain acceptance from the medical staff and patients.

During the first meeting, the medical staff asked us "to see things through their eyes" and "to discover the invisibilities" of their work. It appeared as a rather enigmatic invitation. Our

answer was methodological. We decided to follow the medical staff, doctors and junior doctors, ‘forming one body’ with them – and our almost literal shadowing fulfilled this purpose (Czarniawska, 2007). Our attire and behavior helped us to ‘blend in’ – even though we always introduced ourselves as management researchers. We would follow the same rituals as the doctors. Everybody (doctors and nurses) around the table was taking notes, so were we. Then we would begin the patients’ visits, following the same doctor during a week. As her, we held our notebooks in one pocket of our white coat and coloured pens in the other pocket. As her, we would never take notes in front of the patient, always waiting to get out of the room, in the corridor, to do it. These notes sessions are opportunities for discussions about the patient. We would ask some technical questions of clarification, to follow the reflections, diagnosis and decisions. But, surprisingly, the doctors would also ask us some questions about the patient, quite similarly as they would do with junior doctors. We realized that the corridor constitutes a central place for the negotiation and resolution of an array of complexities inherent in how multi-disciplinary care intersects with the uncertain trajectories of disease (Long et al. 2007; Iedema et al., 2006).

The sensitiveness of the subject means that our own cultural being cannot be overlooked. With this in mind, we followed the symbolic interactionists (Geer et al., 1961; Glaser & Strauss, 1965; 1968; Strauss & Glaser, 1970; Hughes, 1971; Becker, 1998) who insist on the researcher constantly asking herself “How come...?” (Becker, 1998), to exercise empathy, to be willing to be disturbed or unsettled. We tried to be attentive and receptive to what seemed meaningful for the person under observation, and resist temptation to impose our own relevance criteria (Hughes, 1971). It also meant exploring why what we imagine to be striking observations seemed to be ignored by the doctors under observation.

### *Gaining trust*

Observation in such a delicate setting, not only requires getting “physically melted” in the environment, but also requires understanding and following the ground rules of behaviour in the service. This field taught us that being fully present was an intense, emotionally and physically demanding exercise. Some caregivers helped us along the way, accepting to be moved and vulnerable themselves even after many years in the department. The doctors regularly talked about the questions they ask themselves, their doubts, sources of happiness and pains. They would sometimes cry. They accepted these emotions and behaviours, which were not taboo, and regularly shared them with colleagues and with us. End-of-life decisions are not purely technical but involve important debates, hesitations and complexity and ad-hoc behaviours. We witnessed sessions when doctors explained to newcomers how they should behave, insisting on the concepts of collegiality and vulnerability. We also observed practices, how caregivers work together, in a collegial spirit, to navigate between the fragile separation between “therapeutic obstinacy” and legitimate life-prolonging measures.

The medical staff and patients became used to our presence. After a few weeks, we had the feeling that the unit staff formed a single team, and we were part of that team. Little by little, our relations with the doctors and junior doctors developed into friendships. This closeness raised the issue of our posture as researchers. It was important for us to make sure we would not betray the trust of the people who provided us with information.

### *Intimacy, suffering, death*

Death and suffering were very present in the unit. Attending the dying and the elderly implies a very impaired self-control, specific attitude, and particular mind-set. It requires

slowing down the pace from our usual life, and becoming empathetic and vulnerable (Carroll, 2007). It also requires to share intimate discussions, including about death. In an emotionally charged terrain, emotional engagement, far from undermining or devaluing research practice, may authenticate it in ways similar to the positive effects of emotion work in some aspects of palliative care nursing practice (Watts, 2008; Li and Arber, 2006, Ingebretsen and Sagbakken, 2016). Within highly sensitive research of this kind, without a shared emotional space that offers the possibility of trust, a shared narrative space may be difficult to establish (Watts, 2008).

In this case, the fact that the first author was chronically ill and faced some intense suffering crises during the field study participated in this shared emotional space. She could feel that the patients were actually noticing her physical weakness, even if they would not ask questions. Both the researcher and the patients shared a sense of vulnerability and frailty associated with an impaired body experiencing intense suffering. When Carine and the first author encountered or visited patients without doctors being present (for instance if the doctors were attending training sessions or were off duty), discussing on a one-to-one basis (or standing by a speechless patient), they would physically touch the patients, softly holding their hands while talking to them, as the doctors from this unit would themselves do. The power of touch to ease emotional distress is a technique to settle participants in their story telling, which they often find stressful and painful (Watts, 2008).

### *Data collection and data interpretation*

The analysis of the data was performed through three major steps. First, Carine and the first author would compare and confront their feelings and findings on a weekly basis. They would very often focus on different dimensions of the situations they observed.

A second phase of the analysis was performed around the filming. Carine and the first author produced more than 30 hours of unedited film. Filming was not improvised and followed intense preparation. Carine is a professional documentarist and the first author followed technical training. Together they discussed technical constraints beforehand. For instance, they considered various filming angles and what to film (should they focus on patients? Should the film them at all? Should they remain outside patients' room yet include them in the frame?) but also the possible positioning of the camera to capture a scene and the position of the boom operator (to capture sound without too much interference in a noisy and busy environment; but also how to avoid the boom going into the frame or how the operator needs to follow the lead of the camera who acts as main orchestrator). Some environments and situations were deemed impossible to capture adequately. Another difficulty came from the duration of the camera batteries. At that time, the selected model of camera was running on 40-minute batteries. This may seem anecdotal, but had profound impact on the filming work.

Choices were also made regarding the 'directing threads'. While observing and shadowing doctors for months, Carine and the first author considered that organising their tacit scripts around the doctors would make the story more difficult to follow for the spectator. Instead, they chose to focus on a selection of patients' stories. However, in documentaries as in ethnography, the unpredictability of the situations, the sequence of events or the actions and reactions of participants, is the rule. The video-ethnographer must be ready to welcome the unexpected, by preparing herself technically, but also by anticipating the directing threads. But nobody holds the script.

Carine and the first author began to sift through many weeks later. Once again, they did this work separately, and then confronted their feelings about what mattered, what was occurring and how they could give sense to these observations. This work led them to put together a preliminary edit of four film clips. As the first author says, editing is an interpretation of reality. Objectivity is neither claimed nor desired. However, as the first author says, it is a truth. It is a way of connecting the spectator with an interpretation of reality co-constructed by the director and the editor.

The third phase began when two additional researchers, co-authors of this paper, joined the team. In a way, any co-author, not having physically and sensitively experienced the field, always has a partial and mediated access to it. The narrative drawn from the field diary or a video is fragmented and sensitive. The ethnographer records her memories, what she is trying to keep alive. The roles were then tacitly distributed among the ethnographer and the rest of the team. The ethnographer entrusted the co-authors with a personal selection of the data that has touched her. Since they did not participate in the data collection, the film considerably facilitated their engagement with the field. The film clips provided a feeling of depth and direct exposition, leading us to seek out additional details and explanations, and fostering collective reflexivity.

We engaged into a dialogue to establish common understandings through discussions of the film. We discussed for instance the off-screen that the ethnographer would see, and that the others could not see. And what was pointing at some (Barthes, 1980) and which had not touched others. Building a shared and coherent storyline, as for film editing, implied extensive discussions about what we could see on the images, what was missing, what was hidden and needed to be enlightened. The discussions extended to impressions, feelings and meanings. Sometimes, the first author provided additional material (interviews, journal excerpts) that could further substantiate, or contradict, initial interpretations. Then, again, different interpretations and understandings emerged and were discussed. Meanings were progressively co-constructed and partially stabilised. Once an agreement had been reached about the key aspects of the scenes filmed, we produced long descriptions of the scenes that most clearly brought out the main issues.

### *Patient consent and ethical issues*

One important aspect of this research was to obtain consent also from the patient, the patient's family. The acceptance of our presence by the participants was far from taken for granted. Each step of this acceptance, from the hospital management to the patients' relatives, was perceived as a gift. Written consent was given by all the people filmed or interviewed.

We took time to explain what we wanted to do, our initial project to observe the impact of accounting and management reforms on the doctors' practices. "Reciprocity of disclosure" contributed to the depth and quality of the data collected (Sword, 1999). We also listened carefully to the suggestions and remarks of the patients. They shared the concern that life in hospitals tend to be misunderstood by people who do not experience it. And they also shared the concern that it was crucial that young doctors should be further trained to experience empathy and loyalty towards their patients.

These exchanges participated in the crafting of a common angle, a direction. The use of deep listening and empathy helped build trust in a "shared narrative space" (Watts, 2008). The field study constituted a certainly chaotic path which was largely shaped by this collective project we shared by the medical staff, the families, the patients and ourselves. Studying work

is not just looking *at* workers; it is looking *with* them; and trying to capture at how they look at things.

In our discussions within the team of researchers, we remarked that caregivers seemed affected by some dying people more than others. The first author told the others that ‘not all deaths are equally important’, a reflexion that resonates with Butler’s (2009) notion of a differential distribution of grievability. We also considered including the issue of abuse and mistreatments by some caregivers. However, we felt that they would necessarily obscure much of the rest of the message we wanted to convey. Indeed, it seemed to us that the reflex of intellectual sequestration of our feeling of finitude, as readers, would very easily seize the opportunity of the sensationalism of abuse – which is already widely documented – to escape introspection into our own anxieties.

This article focuses on extracts of the ethnographic journal during which issues around ‘what makes the value of life’ were suddenly raised. We selected moments that seemed particularly sensitive, of question of life and death, and that illustrated debates around the value of life itself.

## Empirical findings

This section presents the findings of the ethnographic study. The French public healthcare sector has undergone major transformations since the 1990s (Belorgey, 2010; Juven, 2017). The most significant reform, introduced by law of 18 December 2003, is a prospective funding system known as ‘*tarification à l’activité*’ or T2A. In addition to this funding reform the internal organisation of hospitals was also changed. The law of 2 May 2005 introduced the concept of ‘new governance’, creating clinical divisions deemed accountable for their economic performance. Admitting a patient to the geriatrics and palliative care unit – or indeed any hospital unit – has thus become a decision about allocating scarce resources (time, beds, budgets). Below we analyse the conceptions of life, health and normality that inform accounting, decisions on which life is worth saving, and the exception of the dying subject to understand what is this life that is valued through accounting.

### **Working at the acute-care geriatrics and palliative unit at Suburbs<sup>1</sup> hospital**

Geriatrics has been officially recognized as a medical specialty in France in 2004. It aims to provide to patients aged 75 and over a response adapted to poly-pathology (see below) and to ensure continuity of care with a view to reintegration of patients into their previous environment. Its fields of application include risk assessment and prevention, the control and monitoring of chronic conditions whose prevalence increases with age, medical and social emergencies, the different dimensions of care and end-of-life care. The latter is important because, at least in France, the end of life increasingly happens in hospitals.

At Suburbs, the ‘unit manager’ of the geriatrics service is a doctor. He has a vision – to develop a service appropriate to the specificities of poly-pathological patients, and train the team in palliative care (these notions are detailed below). All the nurses in the unit are young (under 30), except for the night nurses (who are over 40). The nurses and nursing auxiliaries work in three shifts (6am-2pm, 2-9pm, and 9pm-6am). The night shift is covered by one nurse and two nursing auxiliaries for all 44 beds. The work in these units is considered challenging

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<sup>1</sup> The name has been changed to preserve anonymity

and nurses rarely stay for long despite a bonus paid to newly-qualified nurses joining a geriatrics unit.

Each day begins with a handover meeting involving two nurses and two doctors. The nurses inform the doctors of how the night went, the latter adding notes to their paper files before giving new instructions to the nurses. Next, the doctors begin their rounds to see all the patients, pushing two very large trolleys, one for the computer and the other holding the patient files. The nursing auxiliaries change the beds and wash the patients. The nurses are in charge of giving out the medication. At lunchtime, if any patients are being discharged, the doctors must dictate the discharge letters to the medical secretaries. During the afternoon, the doctors fill in the patient discharge and admission files. They then see the new incoming patients and meet their families. At the end of the day, the doctor assesses the cost of the discharged patient by entering data into management databases.

### *Accounting and the disruption of age*

#### **Resource optimization, commensuration and the ‘normal’ patient**

Demand for geriatrics care, especially in hospitals, is rising with the generally aging population. Yet, strict control of healthcare expenditure creates the need for accounting measures to monitor costs, allocate scarce resources, and improve efficiency. Hospital units (including geriatrics) are subjected to a variety of metrics. The hospital management dedicates an important part of time and resources to provide metrics to the various units, in order to assess and compare their performance within the hospital and at a national level.

A unit’s performance is mainly assessed through two indicators, the “rate of bed occupancy” and the “weighted index of mean stay length”. Such accounting valuations define a unit’s performance by its ability to ‘rotate the beds’. Traditionally, medical practitioners have seen empty beds as a form of preparedness necessary to face unforeseen emergencies. Through accounting valuations beds not ‘occupied’ by a patient are constituted as a sort of ‘idle capacity’ (as would hotel beds, for instance). The implicit goal becomes to optimize the utilization of assets. The consequence of a focus on occupancy rates is to encourage hospitals to reduce their capacity, and hence their flexibility and ability to react to crises. It is also probably easier to make decisions about ‘beds’ than to keep in mind the persons working around those beds when trying to ration and ‘contain’ costs. The most visible effect, however, is the amount of time and attention caregivers – including doctors – need to spend on an administrative task – finding beds for their patients. Doctors and nurses-in-chief spend hours every day on the telephone orchestrating the rotation of patients in a saturated health system, trying to find a bed for new patients in the ward, and finding an appropriate place for discharged patients, since their condition may have changed over their hospital stay.

The rotation of beds also means to monitor the duration of ‘stays’ and avoid patients staying longer than ‘necessary’. Such measurement can be seen as both a measure of productivity and of the rotation of assets. At Suburbs, however, the hospital’s management draws on these measurements to influence patients flow:

*Laurent: We were gutted yesterday after the division budget meeting because we realized that it’s the financial logic that’s taking precedence. Tools such as the PMSI<sup>2</sup>, which is a pricing tool, are being hijacked, diverted by*

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<sup>2</sup> PMSI: Programme de médicalisation des systèmes d’information, refers to the system used to follow the medical activity of healthcare institutions. It records ‘normalised medico-

*management for epidemiological purposes. [...] A patient admitted to cardiology has a standard bed occupancy of 4 days. For the same heart condition, in geriatrics, the patient stays 15 days. So the management believes that cardio is more profitable and that it's therefore necessary to send more patients to cardiology and not put heart conditions in geriatrics. But the heart attack patients that get admitted to geriatrics aren't ordinary cardio patients, they're the oldest patients and/or the poor and destitute...<sup>3</sup>*

This extract illustrates what can happen when pathologies are isolated from the general condition of patients. Noting that, for a given pathology, geriatrics patients tend to stay longer than other patients, some would discourage admissions to geriatrics units. Here accounting measures are used, not to allocate funds, but to influence patients flows and increase revenue. This is why Laurent, a doctor at Suburbs hospital, considers that the 'financial logic', i.e. the codification tools, are being used by the hospital management to promote a new valuation system intended to guide patient assessment and categorization. Average lengths of stays are used to calculate and compare cost efficiency ratios. The same diagnosis (here a heart condition) can be used for different types of patients but the management considers them comparable and produces 'average costs' and revenues. The decision to prioritise stays in cardiology rather than in geriatrics does not mean that the life of geriatrics patients is devalued but that its 'cost' is considered higher and the 'performance' of the ward (its ability to discharge patients rapidly) lower. In the process, the general condition of the patient is made invisible.

What these examples show is that the end of life is entangled in a complex of dispositifs including accounting metrics and categories. These explicit, standardised, quantified measurements allow a comparison and monetarisation of medical activities by drawing on standardized definitions of pathologies and diagnoses and national statistics to produce commensuration. They reframe all patients as commensurable, that is as following the same form of abnormality. Geriatric patients hence become comparable to any patient through their diagnosis and length of stay. There is no room left for any 'normal abnormality', any unstable balance of abnormalities defining the general condition of a person.

Such commensuration then allows the financial valuation of the hospital as a whole, through a 'tarification à l'activité' (literally, activity-based tariff). In a way not dissimilar to payment-by-results and prospective payment systems, it values medical activity through a number of combined pathologies, on which the hospital will receive government funds. Hospital accounting thus works through a categorization of patients by their 'pathology' and a list of activities (and related standard cost) necessary to treat a given pathology (Juven, 2013). The main assumption of such accounting system is that one patient is given a single diagnosis followed by a homogeneous set of treatments, triggering homogeneous medical costs. Patients with several, related pathologies create opportunities for optimization:

Izabel thinks about what to put as the main diagnosis within the coding system. She would always check which ordering between pathologies pays the most. For example: a patient has fallen and has a fracture. But she discovered that he has fallen because he has a heart pathology. The heart problem brings in extra revenue so, Izabel chooses the heart problem

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administrative data' inspired by the US Diagnostic Related Groups coding system. It is used to feed national statistics which feed the 'T2A' (prospective payment).

<sup>3</sup> This is an extract from an interview. The reminding extracts all come from fieldnotes.

as a first diagnosis. She knows that it is more profitable to order the various diagnoses this way.

The French system allows several diagnosis codes to be entered but requires the doctors to identify one ‘principal’ diagnosis, relegating the others to the status of ‘associated’ diagnoses. In most hospitals, doctors are offered trainings on how to appropriately code, which usually turn into exchanging tricks to optimise the coding of their patients’ cases. Choosing which pathology is encoded as primary can have substantial effects, significantly modifying the tariff of the hospital stay. The regulator tries to reduce ‘gaming’ by regularly modifying tariffs, without realising that the system itself is what fosters it. If this coding activity is variously valued by medical practitioners, most of them consider that playing the game is crucial to ‘defend’ the resources (in particular the number of nurses) allocated to their unit and to the hospital.

The calculative infrastructure we studied thus redefines resource allocations through measures of ‘activities’, diagnosis and the rotation of beds. Various performance indicators produce categorisations, standardisations and commensurations of pathologies and of patients. Older patients are systematically devalued by these chains of calculation. Such value, however, builds on assumptions about the separability of activities and mutually exclusive categories of care and on the assumption of a stable relationship between diagnoses, activities and costs. The notion of poly-pathology, discussed in the next section, questions these assumptions.

### **Poly-pathology: A holistic view to value the normal abnormal**

Prospective payment systems assume a commensurability of patients, a standardisation of abnormalities, and a separability of activities. In this, they do not entirely differ from most medical conceptions that tend to assume a unique cause of the pathology (one illness or trauma), a single target (one organ), and a clearly defined passage from one state to another (from a pathological, abnormal state to a cured, normal state). Geriatrics patients differ dramatically from these models as they suffer from poly-pathologies. This not only means that they suffer from several abnormalities in the same time but also that their multiple pathologies interact with one another:

Ms L., 76, has an acute form of Alzheimer yet remains ‘spruce’. She comes from the emergency room after a stroke. There is a risk of relapse, and the stroke can have worsened the Alzheimer. To avoid the risk of relapse, some treatments for the Alzheimer have to be suspended.

This patient suffers from several pathologies with incompatible treatments. The geriatricians then need to assess priorities and compatibilities; here one of the pathologies is life-threatening and hence has priority even if it risks creating a general deterioration of the overall condition of the patient. This illustrates the importance to have a holistic view of diagnosis to understand the interaction of pathologies. Also, the sets of diagnoses evolve during the stay as geriatrics patients are typically unstable ones. This eludes attempts at identifying stable, ‘homogeneous’ groups of diagnoses, treatments, activities, or costs:

Mr. A., 76, suffers from urinary infection. He is malnourished and suffers from acute scoliosis. Izabel (geriatrician doctor) wonders why he is that malnourished and has such anaemia. He does not eat, or very little. She asks a series of questions to his wife and to his daughter, who seem to live the discussion as an interrogation. Defensive, they end up explaining that they are trying to help him eat but that he has not an easy character. The family doctor ordered food supplements. Izabel suspects cancer to be the real cause.



This extract illustrates the complexity specific to a geriatric's diagnosis. Any medical diagnosis is complex but geriatrics patients have a plurality of pathologies in interaction. In the above example, a patient is admitted for a urinary infection but the doctor is 'interpellated' by something entirely different – undernourishment. This had been seen by a family doctor who had prescribed food supplements but the geriatrician considers the possibility of other causes – a cancer could have caused the other pathologies, now viewed as mere symptoms of another disease. Geriatricians have to consider the patients as whole persons, not sums of organs, to reach a diagnosis. The role of relatives is particularly important when patients are unable to express themselves. But, in any case, life itself becomes part of the diagnosis.

A holistic view including life itself in the definition of a patient contradicts accounting's attempts to separate and standardize. The commensuration principle is lost and patients appear as living persons. Such holistic view also challenges the medical model that Canguilhem criticized and that still informs most hospital practices – a model based on three main key representations: a segmentation of the body as a sum of organs, an identification of a pathology explaining the physiological abnormalities and a treatment aiming at bringing the patient back to health. Instead, the systemic dimension of geriatric patients' multiple and entangled pathologies means that geriatricians need to identify and stabilize the co-evolution of various abnormalities. Principles of causality, stability and homogeneity are lost. For geriatrics patients, the objective is not necessarily to come back to 'health' (to a normality defined as identical to a previous state) but to reach a general, although fragile, balance of abnormalities.

In other words, the 'drivers' of activity are multiple, holistic (they interact with each other) and unstable, which defies attempts at standardization, commensuration and homogenisation. Understanding the entanglement of pathologies and stabilizing abnormalities in interaction are time-consuming activities, and do not necessarily generate medical 'acts' that can be billed under the T2A system. Geriatrics units, treating and caring for patients suffering from poly-pathologies, thus create specific categorization and valuation difficulties.

### *Contested valuation of life itself: What makes a life worth living?*

The calculative infrastructure we studied does not exclude life entirely. However, 'performance measurements' including notions of life and death work against geriatrics patients. For instance, hospitals monitor survival rates for risky operations, and geriatric patients are among the highest-risk patients in terms of mortality. They also have relatively lower post-operation life expectancy and quality of life than other patients, and those are two key considerations when assessing who is 'worth' an operation, in particular in a context of scarcity. Such measurements thus tend to discount the value of the life of older patients.

This is also the case for some doctors to whom any patient admitted to the acute-care geriatrics unit is already in such a poor general state of health that the question arises of how much treatment should be given. In a situation of scarcity, caregivers would rather devote their time and efforts to patients for whom they have hopes of making a difference, but there is no consensus on what it means to undertake a meaningful, valuable intervention. The value of life is never as visible as when doctors have to decide whether a life is still worth living. The contested valuations triggered by such a decision are visible in the following extract:

We enter a double room with the junior doctor (Marine, geriatrician). One patient seems young (no more than 70) and looks well, sitting alert and joking. She is clearly enjoying her black pudding and mashed potato. The

only problem appears to be that her drip is coming out and another vein will have to be found, or else she will have to take her medication orally.

When we leave the room, Marine explains that in fact this patient has cancer in one kidney and the other kidney has stopped working. She will die in around three weeks. There is the possibility of an operation that could give her an additional two or three weeks, but the urologists are refusing to perform this operation on a patient who is going to die afterwards anyway. Marine still appears fairly disturbed by this medical decision. In early January, the patient is due to become a great-grandmother and she desperately wants to see her descendant, which in Marine's opinion is a good reason for operating. But the urologists are too busy and have emergency cases which they consider more important, concerning patients with a longer life expectancy.

This scene brings out the fundamental question of who should be saved, even for a short period of time, and who should be allowed to die. In geriatrics, there is one death each week on average, and geriatricians have had to learn to let them go. Yet, they sometimes believe they can, and should, save someone. The criteria that can justify operating, or not operating, are not merely physiological. This patient 'looks well' and is 'enjoying' her food, criteria that are often used to assess 'vital energy' and 'intellectual faculties'. Yet an operation that would prolong her life will not be performed by the urologists, because she is 'going to die afterwards anyway'. Here, an inverted conception of age, as time left to live, is used to assess whether a patient should have an operation or be left to die. The geriatrician, in contrast, brings in non-medical information: 'the patient is due to become a great-grandmother and she desperately wants to see her descendant'. This last wish of a dying person, the desire to see that life will continue after her death, is being refused, and this 'disturbs' the geriatrician. A dying person with strong vital energy and a wish to see the birth of a great-grand daughter – for Marine, the geriatrician, the patient still has a political life. But the decision is not hers to make. She is confronted with doctors – here a urologist – who 'are too busy and have emergency cases which they consider more important, concerning patients with a longer life expectancy'. These doctors reduce the patient to a person almost already dead, whose life can be 'let to die'. Implicitly, to them, the value of her life is close to nil.

In a general context of scarcity, the geriatricians' work involves constant negotiation to have their patients recognized as worth treating. Whether their objective is about finding a patient a place in intensive care, obtaining services from a member of the mobile emergency team, or getting help from a fellow doctor, they always have to 'prepare their case' and prove their patient is worth the treatment:

Christian has to go to the cardiology unit to ask for an opinion about a patient who seems to be recovering well but has complicated heart problems. He wants a second opinion to adapt the medication. Christian tells us that cardiologists' opinions are hard to get, they tend to take the geriatricians for timewasters and think they're 'bothering them for nothing'. So the geriatricians must prepare their case well [if they are] to avoid making [another] wasted trip to the cardiology unit. *Christian: 'In fact, the cardios just think, "well, with very old patients, it isn't worth operating"'*.

This situation is highly illustrative, as the patient concerned actually died before Christian returned. It is understandable that doctors are reluctant to take action that could be totally futile.

The geriatricians must therefore convince their fellow doctors of the value of the elderly patient, and show that they are not ‘bothering them for nothing’. Geriatricians need to prove that their patients’ lives are still worth living.

Such consultations are made more difficult by the geriatrics unit’s location, which is 15-20 minutes’ walk away from the hospital’s main building. Going there requires strong motivation in winter and on rainy days; at any time of year, this distance both increases the time spent by doctors to visit geriatric patients and for geriatricians to go and obtain advice for their patients, and symbolically signals their lower status. Yet they need to meet face to face because the information necessary to assess the worthiness of an intervention goes beyond that conveyed through the medical record.

Metrics, material spaces, risk assessments and prestige differentials all converge to devalue geriatrics patients. Geriatricians have to navigate within these material constraints and negotiate with other units. The time geriatricians devote to ‘defending a case’ is invisible in the accounts, and reduces their efficiency, but reflects the value they see in a patient’s life. Not everyone assigns great value to patients whose life expectancy is considered short. Age is often perceived as a chronological decline, a depreciation of the value of a life. Yet this notion of a chronological, bio-essentialised definition of age does not remain uncontested. Some geriatricians offer an alternative understanding of the value of time left to live. The shorter that time, the greater its worth and hence the intensity with which it should be lived. Under this stance brevity does not make time ‘non-valuable’, but invaluable.

Overall, the negotiation to determine whether a patient’s life is worth saving involves a mix of heterogeneous criteria. Physiological and medical arguments intermingle with sociological information. The emergence of a shared view is far from spontaneous. Some caregivers refuse to act, tacitly attributing a nil value to the geriatric patient. They consider the patient too close to death for any intervention to be considered relevant, and the patient can thus be allowed to die. Other caregivers are willing to listen to the geriatrician’s arguments but are not fully convinced, as if the ‘default’ value of any geriatric patient is nil. The assessment of the value of a life is thus embedded in several fields of normativity – physiological life versus political life; chronological age (in the inverted conception) versus vital momentum; non-valuable time versus invaluable time – that together shape a discursive struggle in which the decision to keep someone alive is neither easy nor instantaneous but negotiated, contested and debated. A life is attributed value, considered worth living and meaningful, if it can still be recognised as a political life.

### *Palliative care and the exception of the dying subject*

In the accounting system, there is no code for ‘death’, although death does imply a set of specific tasks to be performed. Proximity to death creates a state of exception. The accounting system recognises this by offering a specific code that refers neither to a diagnosis, nor to an act, but to a type of care – palliative care. Palliative care means that the aim is not to restore health anymore but to accompany (notably through pain management) the end of life. In palliative care units, the medical staff expect death to come for a regular number of patients, and specific protocols and routines are set up accordingly, creating a state of exception.

### **To be or not to be Z515**

Coding a patient as a palliative care patient means that the ‘activity’ will be recorded (and funded) based on a number of days, instead of the number of medical acts. Additionally, in

terms of funding, there are three different rates for palliative care depending on the location of the stay: either in a palliative care unit (PCU), in a recognized bed of palliative care in another unit (IB), or in an unspecified bed (meaning that the patient is neither in PCU nor in IB).

Coding a stay as Z515 (“palliative care”)<sup>4</sup> requires specific filing of administrative forms following strict procedures, which creates additional paperwork for the doctors and requires input from colleagues in different units in a context of scarce resources. To be accounted for as a palliative patient one needs to 1) have a serious and incurable disease, 2) which will be granted multi-professional care, 3) receive at least three specific treatments (to be checked in a list describing the usual care – nursing care, pain management, treatment of symptoms) and 4) be subject to a diagnosis identifying the main reason of entry into the service as being the implementation of palliative care. The most problematic criterion relates to the multi-professional care. Consultation meetings must take place in which at least three different professions should intervene, and a detailed account must be indicated in the administrative file of the patient. These professions are detailed in a closed list – psychologist, physiotherapist, social worker, speech therapist, etc. If the four criteria are not met, the case should not be coded Z515 as a primary diagnosis. It is then possible to code palliative care in significant associated diagnosis (SAR), if the first three criteria are met (the exception has not been met and palliative care becomes a secondary diagnosis, not a general state).

The rationing of the hospital’s resources makes the last criterion difficult to meet. Additionally, the time laps of the dying process is uncertain, and death sometimes arrives before the criteria have been met, which means the patient cannot be classified as Z515. This renders the task of coordinating these professional interventions even more difficult and potentially useless. The bureaucratic burden of this coordination task, including the filing of the administrative forms following strict procedures, is also perceived as highly time-consuming for geriatricians, who are pressured to improve their time efficiency. Geriatricians can consider some patients as requiring palliative care (according to a combination of criteria which include physiological, mental and social dimensions) yet prove unable to meet the accounting criteria, which means that the patients are denied the palliative status and its related funding. Interestingly, these conflicting categorisations do not relate to competing professional criteria that would lead to different diagnoses, but rather to the type of care and administrative work that has been devoted to the patient.

For each stay coded Z515, a unit receives around €1,500 per day, up to a maximum of €6,000 per patient. There is a special rate for stays under 24h, at around €600. From a strictly accounting perspective, a palliative care unit would thus achieve its best revenue levels with patients who stay just one to four days. The accounting system thus suggests an optimal timeframe for dying.

Recently, the Cour des Comptes (the French National Court of Auditors) reported that some hospitals were optimizing their performance by playing the system: they were ‘rotating’ their palliative care patients. It was observed that some hospitals would discreetly send patients back home or make arrangements with another hospital for further care. This rotation, or nomadism, is a response to the ‘bed blocker’ issue (patients considered to ‘extend’ their stay beyond what has been calculated as a normal length of stay are said to ‘block’ the rotation of

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<sup>4</sup> According to the French National Centre for Palliative Care and End-of-Life, Z515 is the only code for palliative care – as defined by the World Health Organization’s International Classification of Diseases. It corresponds to a serious, advanced, life-threatening pathology. (<http://www.soin-palliatif.org/actualites/mieux-comprendre-t2a-et-son-application>)

beds). Some patients are ‘declassified’ as palliative care patients in order to meet accounting performance criteria. The regulator has tried, unsuccessfully, to reduce the risk of such practices by changing the tariffs. However, it is important to note that not all geriatricians are willing to play the system this way. Most refuse patient nomadism and reject the idea of an optimal timeframe or controlled time of death.

The Z515 illustrates how death disrupts accounting. And yet, various metrics and dispositifs still encourage caregivers to engage in performance management of the dying, or maybe rather in a theatrical performance of optimal allocations of resources. The consequences of such performance largely depend on what caregivers do with the measures they receive, but they can have disastrous effects for the patients and their families, as most macabrely revealed by the euphemism of patient nomadism. Numerous dying patients also fail to be accounted as palliative patients i.e. meeting the Z515 criteria. Beyond questions of classification, these “treated-as-palliative” patients do not appear as palliative care patients in the hospital’s accounting system, which feeds into national statistics, and therefore affects resource allocation (including human and financial resources). In a vicious circle, the invisibilisation of dying subjects reinforces the underfunding of palliative care patients. The accounting system is making part of the palliative care population invisible.

### **A state of exception**

In the hospital studied, the geriatrics department includes a palliative care unit. The medical team simultaneously works with ‘dying’ and ‘non-dying’ patients, and some patients pass from one status to the other during their stay. At Suburbs, there are only three beds in the palliative care unit, which are used most of the time. If there are no left beds in the palliative care unit, palliative patients might get access to ‘palliative’ beds in the geriatrics unit. This means that some patients are treated for palliative care while remaining hospitalised in a regular acute geriatrics double room, and only get access to a part of the ‘care package’, mostly the pain management and nursing care. The categorisation as ‘palliative’ has important practical and material implications:

We follow Izabel, a doctor, as she checks on new admissions to the geriatrics unit. The latest patient is an 80-year-old woman who suffers from Alzheimer’s disease and is also bedridden. She has a lung infection, and is extremely thin and shrivelled, with pressure sores. Izabel removes most antibiotics from her prescription, but adds one antibiotic to manage the infection. The patient lives with her sister, who is also bedridden and has psychiatric problems. Izabel decides to move her to palliative care, prescribing painkillers and morphine. She is waiting to see the family if there is any, to talk with them.

This case illustrates the various criteria used to move a patient from ‘medical treatment’ to ‘palliative care’. The geriatric patient becomes a dying patient as a result of an analysis combining the physiological data relating to the physical condition (‘bedridden, pulmonary infection, very very lean, pressure sores’), indications of the level of suffering (‘shrivelled up’), and includes elements of the mental health (‘Alzheimer’) as well as an evaluation of autonomy, social life and vital momentum (‘lives with her sister who is also bedridden and has psychiatric problems’). The patient is judged to be in such poor condition – physiologically, mentally but also socially – that the medical care given (essentially pain management) no longer aims at

restoring her health but at keeping her comfortable. The doctor keeps some antibiotics, not to ‘treat’ or ‘cure’, but to avoid discomfort. The patient has become a dying person.

The nearing of death creates a state of exception. In a dying patient’s room, the usual operating rules of the hospital organisation are suspended: visiting time restrictions are relaxed, a visitor can stay overnight in the patient’s room (which is usually forbidden), caregivers take more time to talk with the family. Another manifestation of this exception is spatial, in a fashion not dissimilar to what Foucault (1967) called a ‘heterotopy’. The patient is moved to a single room. This has several objectives and meanings, but clearly signals to other health practitioners (and often, indirectly, to the family) that the end is approaching. It also keeps death out of sight of other patients. The exception also concerns the apprehension of time, or what we could call a heterochrony. With dying patients, some doctors and nurses engage in activities that go well beyond traditional ‘care’. A few telling examples were recorded in the fieldnotes:

Palliative patient X is depressed. Doctor A went to play Scrabble with her.

(...)

Patient Y is at the palliative care stage and refuses to eat. Christian, a doctor, skips his own lunch break to feed her.

Caring for dying patients includes activities that are time-consuming and not ‘relevant’ in a traditional medical sense. Yet some geriatricians see them as valuable enough to give up their own time to provide patients with special attention. The time left to live is shrinking, which gives it more value. They value the ‘invisibilities’ of their work. They will take time (not with all patients and not all the time, but more often than most doctors) to perform certain tasks that are becoming invisible because they have been left out of the system’s definition of medical activity.

## Discussion

We started this paper with fundamental questions about the value of life. We suggested to address them by following life in its final ramification – the end of life. Philosophers, historians and sociologists have typically addressed this question by focusing on ‘what comes next’, i.e. death, and its impact on what comes before – our feeling of finitude and death anxieties. They have overlooked an important moment in between – the moment of dying. The practices that emerge during the moment of dying depend on representations and rituals that are historically situated and socially constructed (Ariès, 1975; Elias, 1985). They also shape, and are shaped by, a set of dispositifs, technologies, discourses and power relations (Agamben, 1998; Le Theule et al., 2020). In a world where modern medicine has improved greatly the ability to treat, cure and save lives, the question of how to define acceptable boundaries to the prolongation of life remains open. Questions over who can decide not to prolong a life and based on which criteria reveal the entanglement of conflicting ideals and discourses on what gives a life value but also of technologies and practices that together constitute a regime of valuation of ‘life itself’. This paper furthers these conceptions of ‘thanatopolitics’ (Agamben, 1998) by studying how they influence, and are shaped by, accounting itself.

Mediating between philosophical, ethical, sociological, professional and economical rationalities, calculative practices constitute the dying subject in a specific way, making life itself calculable, visible and amenable to intervention. Death itself may be the great liberator, but, while dying, we remain subject to accounting.

Accounting, as is most visible in hospitals and healthcare systems (Preston, 1992; Samuel et al., 2005), is built on several assumptions about life itself. Healthcare accounting produces a

set of categories of care, pathologies and patients. To achieve commensuration, it builds on assumptions of separability (of medical activities and specialties but also of ‘organs’ and pathologies) and standardisation (the possibility to relate each situation to standardised categories). Accounting produces what Wällstedt (2020) calls, after Deleuze, a ‘dividualisation’ of the person, the division of individuals into standardised categories to make them calculable and amenable to intervention. But what is this life that can be included in such commensuration? What remains when life is reduced to what can be compared and standardised among all lives? Agamben (1998) answers with the concept of ‘bare life’ or ‘naked life’, life reduced to a biological minimum or, rather, a physiological minimum. Dispositifs that work to make life commensurable first need to strip it of anything that would make it incommensurable, which constitutes what Agamben calls ‘political life’.

We are not arguing that accounting is not political or does not have political effects. Quite the opposite. By obfuscating the political life of dying patients, the calculative practices we studied have strong political effects. Accounting metrics produce commensuration and decontextualisation that can result in decisions that deny political life. Agamben does not provide any explicit definition of what ‘political life’ is, perhaps because the definition itself of what should count as political life can only emerge through politics and political life itself. Instead, Agamben (1998) studies what happens when it disappears. Specifically, he insists on what makes a person *homo sacer*, that is a person who can be killed without the killing counting as homicide. Our own empirical study shows what this can mean in a specific context where some lives are no longer considered worth saving. It also illustrates the efforts of some to reassert, protect and follow to the end the political life of the dying. And it shows how this encounter between various conceptions of what makes a life worth living is mediated by a complex of technologies, practices and instruments, including an accounting dispositif.

Of course, ‘decision-makers’ are often aware of the contexts in which numbers are produced and can reintroduce such context when making decisions. But in themselves, the numbers do not convey such context and decision makers can draw dehumanising conclusions based on decontextualised metrics. Chwastiak (2001), for instance, argued that, by reducing political processes to their economic implications, accounting can convert the ‘unthinkable’ – in her case, nuclear war – into a technical and mundane resource allocation problem. However, hospitals are not part of what Mbembe (2003) calls necropolitics, or the subjugation of life to the power of death. Hospitals are institutions dedicated to life and biopolitics, and caregivers largely work to include and respect political life in their practice (Le Theule et al., 2020). Yet specific calculative practices have been introduced that deny such political life to the dying.

To problematise the decontextualisation, or even dehumanisation potential of accounting numbers, it can be useful to introduce Canguilhem’s (1966) theorisation of the normal and the pathological. In particular, Canguilhem (1966) questioned the reduction of normality to a set of quantitative regularities and averages. Instead, he offered the notion of a ‘holistic’ view of a patient as a person embedded in a social milieu. A holistic view of life means to understand health not as the absence of diseases themselves conceived as discrete pathologies but as a general condition. Care, then, should acknowledge not only the indivisible wholeness of the person (Wällstedt, 2020) but also our embeddedness in a social milieu and political life. The accounting system we studied builds on standardized definitions of pathologies and diagnoses (Preston, 1992; Covaleski et al., 1993; Llewellyn & Northcott, 2005). But a given pathology does not always require the same care, as the newly popularised notion of ‘underlying conditions’ made visible during the Covid-19 crisis. Reframing all patients as commensurable

misrecognises persons' general conditions that are too idiosyncratic for standardized definitions of diagnosis and treatment to remain relevant. A holistic view implies to abandon the notion of commensurable pathologies. This means to treat questions of health, and questions of life itself, as incommensurable.

The calculative practices we studied made life itself calculable and visible in specific ways. Payment by results (or 'prospective payment'), in particular, creates a hierarchy of pathologies, disciplines and patients. Such infrastructure reduces healthcare to a commodity to be priced at its exchange value (Samuel et al., 2005). Some patients or pathologies become more 'profitable' than others. Reducing the implicit value of geriatric patients is to reduce the 'profitability' of their care. A regime of worth emerges through proliferating indicators and chains of calculation that influence which lives should be given priority and which are portrayed as less worthy of medical resources and activities, of the time and space required to treat, cure and save lives.

In the process, this accounting regime naturalises the notion of scarcity and with it the necessity of triage. But who can decide that you should be 'triaged out', or that your life has no value anymore and is no longer worth living? How can accounting influence such a decision?

The notion that healthcare resources are necessarily limited and that scarce resources need to be allocated efficiently has become so obvious that willing to question it may seem provocative. Scarcity has been presented as morally positive both by tenants of a 'morality in markets' through the notion that morality converges with financial interests to 'economise near the end of life' (Livne, 2014) and by supporters of a welfare state through the notion that the allocation of scarcity should guarantee 'equal opportunities' (Wällstedt, 2020). And yet, in 'post-scarcity' societies, this idea is not natural but emerged through discursive struggles. By contrast, seeing healthcare as a right, like education or security for instance, conceives it in terms of universal access. Then, the question is not about how to allocate scarce resources but about finding the means to fund a specific capacity. Instead, healthcare has been portrayed as 'excessively expensive' and in need of rationalisation. A complex of accounting practices has naturalised the need of rationing. Through indicators and performance measures, a calculative infrastructure reinserts into daily medical practices a sense of scarcity and the obviousness of the need to allocate healthcare 'efficiently'.

Medical practices themselves can produce a specific kind of scarcity. For instance, traditional conceptions of what makes the value of medicine see care as a way to 'restore health' defined as the reinstatement of a previous state of health. Instead, geriatrics care sees normality as the possibility to produce new norms, not the return to anterior norms. It follows a non-dehumanised vision of illness aiming at providing care for the 'lived notion of the normal' (Canguilhem, 1966). Unable to meet the main criteria typically used to define the value of medicine, drawing on a different understanding of normality, geriatrics care – and palliative care even more so, even though it does produce a miracle, that of allowing death without suffering – appears as less 'valuable'. The normal abnormal cannot be 'treated' and is therefore not perceived as worthy of the caregivers' time when it could be used to treat other patients. The normal abnormal is perceived as less 'valuable' and made 'unaffordable'. Beyond the discontinuities introduced by healthcare reforms, various calculative practices, drawing on a traditional understanding of medicine as much as on accounting measures, thus converge to discount the value of the end of life.

Death, however, disrupts such an accounting regime. The end of life creates a state of exception that problematises accounting itself. In the case we studied, palliative care is no



longer funded based on a number of ‘acts’ but on a number of days. The main logic of the calculative infrastructure of ‘*tarification à l’activité*’ no longer holds when the end is near. Yet a new tariffication emerges that suggests that there should be an optimal number of days to give someone palliative care. A new tempo is introduced. Any ‘bed rotation’ in such a situation is only a macabre euphemism for ‘letting someone to die’. In fact, some hospitals have been accused to do so by engaging in ‘patient nomadism’, a form of ‘gaming’ on life and death. We have not observed any such behaviour in our own fieldwork and it has been strongly condemned. These optimising practices are considered outrageously violent and indecent. ‘Speeding up’ the end of palliative care denies any form of political life of the dying patient, and almost certainly implies a bad death (Le Theule et al., 2020). In other words, the moment of dying exposes the most questionable assumptions of the accounting infrastructure we studied. Any drive for performance and efficiency would seem grotesque in front of dying patients.

Caregivers then have to follow an alternative conception of time, space and even of the aim of their action – no longer to restore health but to accompany through the end of life and perform a ‘good death’ (Le Theule et al., 2020). This, however, means that caregivers’ work becomes invisible and escapes accounting records. Wällstedt (2020), studying care homes, sees a possibility of freedom in such a separation, arguing that workers can sequester accounting spaces from care spaces where they still see individuals as ‘whole persons’. Our findings show that keeping ‘rival programmes’ ‘spatially apart’ can become difficult when proliferating indicators connect accounting to daily, ‘local’ activities and a holistic view runs the risk of reduced funding and increased invisibility. This nuances the view that ‘spaces of dissension’, liminalities emerging from ‘the heterogeneity of discourse’ and the incompleteness of instruments of calculation, necessarily create spaces of freedom where power relations can be altered and ‘problems’ turned into ‘possibilities’ (Wällstedt, 2020). Spaces of dissension are not enough; what is needed is the courage of the exception. By that, we neither mean to encourage the arbitrariness of power nor the return to the autonomy of the expert. What is needed is a conceptualisation of how spaces of dissension can bring about the exception as a suspension of dehumanising technologies.

If a holistic view includes the social context and hence accounting itself, the exception becomes a choice of which aspects of the normal can, or should, be suspended. The persons we followed choose to suspend standard rules, time, and space of the organisation. The life of dying patients is incommensurable and the care for the end of life becomes an exception, that is both a heterochrony and a heterotopy – an alternative valuation of time and space, which becomes invaluable and protected from standard norms. Agamben (2005) defines the exception as a suspension of a juridical order, a suspension of the law itself. But beyond the juridical order, the exception can also be seen in a suspension of a neoliberal economic order that creates a permanent state of scarcity, reduces care to its exchange value, and problematizes healthcare as a scarce resource to allocate optimally. When accounting numbers become the norm, constitute the normal, and redefine valuation regimes, then the exception does not disrupt the law but suspends processes of commensuration, quantification and monetarization.

## Conclusion

The end of life is a life to be lived. We need an art of living while dying; we need an art of dying. The end of life questions the art of living in its final ramification. Distant from death, willing to ‘sequester’ our death anxieties, we tend to see it as an end, an instantaneous passage

between life and death. We lose sight of the process of dying, and hence of the life that still lives while dying, as if it had already ceased to be politically, ethically and sociologically relevant. It becomes uncomfortable to acknowledge, and hence maintain and foster, the presence of a political life until the end. In dying itself, the value of life remains contested.

Organisation scholars argued that alienation and oppression can be related to our death anxieties and fantasies of immortality (Sievers, 1990; 1993) and that an ability to ‘face up to death’ (Reedy & Learmonth, 2011) could expose the vanity and futility of the constant striving for organisational position and status. The ‘Covid-19 crisis’ (Yu, 2020; Huber et al., in press) arguably disrupted the ‘sequestration of death’ (Giddens, 1991) and forced us all to think about our finitude, the vulnerability of others, how we can become a danger to others and about our own vulnerability. However, even though the Covid-19 crisis gave such questions public visibility and encouraged us to collectively ‘face up to death’, the very notion of a crisis portrayed the situation as an exception. Instead, our ethnographic work – started years before the pandemic – showed that scarcity, triage and the reduction of life to its exchange value already existed and were not caused by a crisis but by specific public policies and related calculative practices.

The ‘great lockdown’ that followed the Covid-19 crisis also showed how quickly we chose to isolate ourselves from our political life. Commentators and researchers articulated a variety of measurements of life and death, risks and ‘cure’, almost all focused on bare life – as were the solutions offered. To protect our biological life, we sequestered our political life, giving yet another meaning to the ‘loneliness of the dying’ and the ‘social repression’ of death (Elias, 1985).

Scarcity and the need for efficient resource allocation and valuation practices that reduce life to exchange values, which inform the accounting system we analysed, did not help responses to the crisis. The Covid-19 crisis rendered visible, but also opened a debate about, triage. Various commentators and political actors seemed shocked at the idea of triage. Yet triage is a necessary consequence of rationing and cost containment. Rationing policies have long targeted ‘empty beds’ as idle capacity, until it became a central indicator to adapt infrastructure to the pandemic (Huber et al., in press). Empty beds no longer signalled waste but measured the capacity of the whole care system to survive – only empty beds could ‘save the healthcare system’. This measure soon emerged as partial and questionable, however, as ‘available beds were practically useless without readily available trained personnel’ (ibid., p.7). More broadly, the measurement itself obscures fundamental debates on the value of life and the naturalness of scarcity, as well as normative assumptions on what makes a life worth living and the commensurability of the dying. Instead, considering health as a human right leads to consider unoccupied beds and available trained staff not as waste but as crucial requirements to secure a universal access to care.

Scarcity sometimes resulted in patients sent to distant hospitals (in a new form of ‘patient nomadism’ or ‘relocation’) or served to justify the erection of boundaries and exclusion (some countries, for instance, refused to have care home patients sent to hospitals). These choices illustrate the limits to commensuration, a standardisation of pathologies reducing patients to bare lives. The limits to segmentation and separability also appeared when trying to isolate care ‘units’, denying important interactions in and between such ‘units’. Finding ‘resources’ for ‘Covid units’ meant to ‘poach’ staff from other units. Staff shortages increased pressure on understaffed units, with consequences for the care given. Overworked units had less time to dedicate to inter-professional cooperation, with direct effects on patients and relatives.

Cascading effects of local imbalances illustrated the embeddedness of care and multiple interactions necessary to reach a general, although fragile, balance of the system of care. As in Canguilhem's (1966) description of normality as a general condition of the body as a whole, the functioning of health care systems can be destabilised by local perturbations. The crisis exposed the limits to scarcity, separability, commensuration, valuation and normativity.

Confronted to calculative practices that deny the political life of the dying, the persons we followed had the 'courage of the exception', meaning that they sometimes had to suspend what they perceived as dehumanising technologies to reaffirm the value of the life of the dying. The 'courage' of the exception is not meant to portray caregivers as heroes, although this paper was submitted at a time when people throughout Europe spontaneously decided to 'clap for carers' and when caregivers themselves noted that they would rather see more funds allocated to healthcare systems. Yet there is a form of heroism when someone has to suspend their engagement with an accounting system that influences so strongly funding mechanisms in order to reassert that the end of life is, or should be, a life worth living.

However, the courage of the exception should not be seen as a call for the arbitrariness of power. The end of life is too important to remain in the hands of potential heroes, only able to decide when to suspend dehumanising norms or to define some norms as dehumanising. The exception did not come without suffering either, and many caregivers we met have since resigned, feeling that it had become an untenable job. Instead, we need a form of accounting that would recognise the political life of the dying. This raises the issue of how to imagine accounting dispositifs that would not reduce the end of life to a dehumanised, dispossessed, isolated life but maintain, even foster, political life to the end. The question is not so much about how we can measure the value of life but how we can define non-dehumanising calculative practices. What would be modes of calculation, calculative practices that would not be dehumanising? How can accounting include and respect political life and the art of living, even while dying? But how can we imagine accountings that would not produce dehumanising forms of commensuration? Is accounting necessarily a process of commensuration and decontextualisation, or can it offer a holistic view of life?

Butler (2004) argued that death confronts us with our vulnerability, and hence other people's vulnerability, shaping the ties we have to others. The question becomes, then, to imagine forms of accounting that allow for an acknowledgment of our vulnerability.

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