

Human and Person When Life Is Fragile: New Relationships and Inherent Ambivalences in the Care of Dying Patients

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Abstract

In this paper, we focus on how medical staff care for people who are dying and on the increasing use of diverse technologies to ease the experience of dying. Because it is accepted patients cannot recover, the primary value to preserve life underpinning much of biomedical practice is contrasted by a commitment to make people's last period of life as fulfilling and meaningful as possible. Drawing on illustrative cases from an ethnography of palliative care in central London, we discuss how these different priorities construct the patient in different ways. We present two different repertoires of

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practice, the first of which cares for human life, while the second adopts an idea of personhood to support and maintain patients' social ties with the wider world. The two concepts inscribe different boundaries of the patient and can help guide what might be the best thing for staff, patients, and others to do. Our examples show that while these two repertoires can emerge in tension in end-of-life care, they are never fully opposites. We argue for a reaffirmation of the concept of the person to accompany contemporary posthuman and more-than-human debates in order to think about "more-than" beyond a focus on the material.

Keywords

human, personhood, death and dying, end-of-life care, more-than-human, United Kingdom

In the autumn of 2018, Irene's¹ situation was frequently raised during the weekly specialist palliative care team meetings. She had lung cancer and was dying. After one of her lungs collapsed, a nurse specialized in respiratory issues who supported her alongside the palliative care team arranged for the provision of oxygen to ease the breathlessness and make her last weeks of life more bearable. The gas was stored in large cylinders in her home, next to a green leather sofa, and took up significant space in the small living room. The tubes curling away from the tank across the carpet allowed Irene to reach every part in the small apartment.

Irene's situation was described by her palliative care team as "complex," largely because she continued to be a smoker. Specialist nurse Mark told his colleagues how Irene, despite several warnings not to smoke while wearing the oxygen mask, had accidentally "set her face on fire." After that incident, she smoked outside on the balcony of her flat, away from the oxygen supply. But as her lung capacity continued to deteriorate, Mark knew that being on the balcony without the support of the equipment would become increasingly difficult: he suspected she would soon revert to smoking inside, if she had not done so already. From Mark's perspective, the problem stemmed from what two competing dependencies she had in her life: on the oxygen and on the smoking. In combination, these put Irene at risk, and potentially also those living around her. So when her respiratory nurse finally decided she had no choice but to withdraw the equipment on grounds of general safety, Irene refused, and was rude and aggressive before slamming her door. As concern grew among health-care workers involved in

Irene's case, Mark suggested that it should be brought before the hospital's ethics board. Unfortunately, he could not be present during the meeting, which was attended by his team leader, a palliative care consultant.

In Mark's absence, after discussing Irene's circumstances, the board members swiftly framed the case in terms of official responsibility and liability, proposing to develop a protocol for future instances of this kind as quickly as possible. They unanimously concluded that Irene should not have been given the oxygen in the first place because she was a smoker. But none of this helped clarify how to care for Irene in the meantime. Mark and the rest of the palliative care team were unsettled by the fact that institutional values and obligations were apparently being prioritized over a focus on her personal well-being and were deeply troubled by being uncertain about their duties and professional boundaries. They discussed where, in all these entanglements of bodies, machines, and institutional liabilities, lay the team's commitment to care for Irene, as a person? And even if they did not get involved in institutional policy-making, should their professional concerns focus solely on Irene's clinical needs, or should they also support her fierce independence—especially because she would probably not live for much longer?

This case points to how contrasting conceptualizations of patienthood often arise from shifting relationships between people, things, and phenomena. At the end of life, when preserving life is no longer a possibility, questions about which values should guide care can be particularly vexing. In this paper, we attend to the variations of being a patient as they emerge from situations like Irene's. Such variants arise from differing aims foregrounded by clinical staff, the range of medical equipment or medication that may or may not be used, and contrasting values that steer staff and others when they are aware recovery is not possible and that they are caring for someone who will die. We focus on what we identify as two repertoires of patienthood which serve as implicit frameworks to guide the practice of health-care professionals: that of the patient as human and that of the patient as person. Although conceptualizations of human and person may often overlap, they can emerge as differing when the medical imperative is not straightforward and there are diverging understandings of what kind of patient is being cared for. Conceptualizing a patient in end-of-life care as human gives precedence to biological function to ensure the best chances at survival, whereas regarding them as a person broadens the scope to wider processes that may make living as meaningful and significant as possible. Importantly, we as researchers are not imposing the human/person distinction onto our observations; as we show, it often emerges subtly in health-

care contexts where there are potential shifts of emphasis, and frequently happens for patients who are in the last stages of their life. However, rather than claim they are oppositional and mutually exclusive, or even that they exhaust the ways in which patienthood can be enacted, our ethnographic study of end-of-life care reveals a much more subtle and nuanced process of continual negotiation and navigation between the two, which we explore further in this paper.

Importantly, our accounts also resonate with recent debates about post-human and more-than-human perspectives. Although this literature is very diverse, it consistently highlights the entanglements humans have, and need to have, with other organisms and inanimate objects. Many of the cases we present echo this line of argument, because people who are dying frequently rely more explicitly on things intrinsic to their very ability to remain alive. But while these arguments are compelling, they can fail to convey human subjectivity and the experience of knowing that death is imminent. Older discussions about personhood are potentially more pertinent here, since they tried to capture how people, as inherently subjective and social actors, are continually made by the social relationships they have with others. By examining when and how ideas of being a person emerge in contrast to being a human for palliative care staff, it is possible to attend to some of the qualities and experiences that accounts of being human, and indeed more-than-human, fail to fully take into account. In the empirical examples that follow, we highlight that this is not merely a theoretical concern, but a central aspect of the practice of end-of-life care.

Persons, Humans, and More-than Accounts

Although there is a vast literature on the concept of personhood, from debates in philosophy through to neuroscience, in this paper, we draw primarily from discussions in social anthropology to provide a theoretical starting point. In a seminal publication first published in 1938, Marcel Mauss (1985) presented a historical overview of the Western notion of personhood. He argued that over the last two millennia, the notion of “person” has progressively come to be defined by essentialist internal characteristics that serve to differentiate humans from other organisms, and which are increasingly independent from everyday social interactions. Mauss contrasted this with accounts from other cultures where being a person arises from specific roles and relationships an individual has over the course of their life, and which together confer an individual with a particular place and standing in their community. In this alternative

portrayal, it could be said that personhood is a shared acknowledgment between how someone views themselves and how others view them (Mead 1982). This general assertion inspired subsequent anthropologists, who were attracted by its relativist stance and implicit critique of Western individualism (Dumont 1986). Many ethnographies described the specific significance of kinship systems, religious positions, political standing, or jural roles in the construction of personhood over the life course (see, e.g., Fortes 1987; Richards 2013; Rosaldo 1980).

Emphasis placed on the cultural specificity of the category inspired important debates about the social construction of childhood (Lancy 2014), gender (Moore 1994), and older people (Corwin 2020); as well as discussion about when a person's life begins and when it ends (Franklin and Lock 2003). Perhaps unsurprisingly, in most cases, women could never achieve the same formulation of personhood as men because they were excluded from many if not all public roles which afforded official status and power. Although we would not want to endorse this, what remains compelling in these early ethnographic accounts is the potential for the concept of personhood to be both a moral and social category that is dynamic and contingent. Rather than an abstract notion based on fixed universal capacities and qualities, a person is fashioned by the ongoing activities and interactions they have with others (Carrithers, Collins, and Lukes 1985; Shweder and Bourne 1982). This means that personhood can and does change over time, depending on the lives led, the contexts they are in, and the relationships that shape them.

Recent academic enquiry in the social sciences has largely shifted away from discussing personhood in favor of debates about what it is to be a human. Clearly, while there is overlap between the two terms, here we do not wish to suggest the solution is simply to establish a rigid distinction. Instead, we seek to highlight the different interests explored in this literature compared with earlier work. Whereas earlier debates about personhood tended to resonate with research into social identity, cultural belonging, and the stable functioning of a social group, recent work concerning what it is to be human tends to show a more materialist orientation. Initial literature exploring such things as the human body and the sensorial, embodied experience of the world (Classen 1993; Csordas and Harwood 1994) soon expanded after scholars listed the multitude of relationships and biological dependencies humans have with other organisms, objects, and technologies. When taken together, developments in science and medicine, as well as their indirect influence on disciplines in the social sciences, have helped foster a growing resistance to the idea of the human as integral,

enduring, and discrete. Sometimes, accounts challenge the boundary between what is human and what is not by demonstrating how being human is extended and distributed beyond the skin (e.g., Fox and Alldred 2020; Svendsen 2021). In other instances, the focus is internal, describing the extent to which nonhuman elements residing within and attached to the body are not inherently alien, but fundamental to human health and living (Lorimer 2016). By describing the ways in which humans are intimately connected and entangled with nonhuman entities, whether they are other organisms or inanimate objects, the notion of what is “essentially human” is forever disrupted (Svendsen 2021). Such posthuman and more-than-human approaches argue for creative and innovative ways to understand the relationships between people and other things, and the social and moral ambiguities that arise from their entanglements. And further, that there is ethical and political potential in decentering traditional ideas of the human (Badmington 2000; Wolfe 2010). These approaches offer radical ways to think about how we might reflect on what “us” really means, and how we might better live and relate in the world (Braidotti 2016).

Nevertheless, in many instances, this turn to more-than-human accounts foregrounds material, physical interconnections at the cost of eclipsing the more social, symbolic dimensions discussed in earlier literature on personhood. Given the realities of people as reflexive and aware organisms that are always a combination of the material and the semiotic (Haraway 1991), there can be substantial value in drawing judiciously from both approaches. At a theoretical level, then, we are interested in resisting any partition between material accounts of the body and being more-than-human, from the dynamic interactions that construct us as social persons—because this risks reproducing the assumption that the social is not material, and that what presents itself as material is not also symbolic. What is more pertinent is to ask how and why the divide between the material and the social gets made in specific contexts (Ingold 2010), and what values and knowledge are drawn on in the process. In this paper, we specifically explore how these contrasting ideas condense into different constructions of patienthood toward the end of life: one is an iteration of the patient as a discrete human, with a focus not only on the physical body but also the body as the site of clinical intervention. By contrast, in the other, the patient is recognized as an interacting person struggling to maintain continuity and meaning in their social world. The distinction often becomes apparent in end-of-life care because shifting values underlying biomedical support sometimes generate quite distinct approaches to what comprises appropriate care, and indeed what constitutes the patient. We take these shifts between repertoires, that is

“modes of ordering” (Law 1994) that bring together values, actions and knowledge (Pols 2006), as our starting point to explore how the care given not only can reflect different sets of values, but that different forms of care enact different kinds of patients.

Person-centered Care at the End of Life

Dying brings questions of living to the fore. When life is fragile and the possibility of death is palpable, establishing what it is to be human and what it is to be a person are not abstract concerns: they are ever-present for practitioners, patients, and family members alike. As someone approaches the end of their life, their status increasingly runs counter to the widespread biomedical assumption that care can be equated to treatment and, ideally, cure. Knowing that a patient will die in the next few weeks or months compels health-care workers to reevaluate their role and purpose: what might comprise appropriate treatment, what is the ultimate purpose of intervening, and how to shape the limited “time left” (Kaufman 2005). In this process, the dying person emerges as a social subject (Farman 2017). Drawing on research conducted in the United Kingdom, we describe how the very practice of medicine, including the use of technological innovations, can foreground wider cultural concerns. Central to this is the notion of “person-centered care,” which has increasingly become influential in diverse areas of biomedicine in response to critiques of medicalization, the asymmetrical power relationship between paternalistic professionals and patients, and a more general demand to consider the patient’s point of view (Balint 1986; Kitson 1999; Rogers [1961] 1995; Steinhäuser et al. 2000). To counter the claim that a great deal of clinical practice and the technologies, it employs are too reductive, a person-centered approach is said to promote a reorientation of the clinical gaze to foreground the patient’s own perspective, experiences, and values, which in the past have tended to be secondary considerations. The new expectation is that medical professionals take into account a patient’s individual circumstances, the ideas they hold, and the context they live in to identify common ground for clinical support, decisions, and appropriate intervention.

Informed by the idea that a biopsychosocial approach should be adopted to treating illness (Engel 1977), person-centered care emphasizes that biological, psychological, and social factors are all relevant and goes some way in acknowledging they interact with each other. Invariably, however, the plethora of descriptions of the interdisciplinary model, now widely adopted in clinical training programs, as well as visual representations, tend to place

the biological as central, with concentric rings or hierarchical arcs that signal individual, social, and cultural spheres of influence. In other words, “the patient” remains anchored to a biological, clinical foundation, determining what is made visible and what is not. Thus, the notion of the whole person is established through an additive logic, incorporating more and more elements into an existing clinical understanding of the patient. As a result of this additive logic, more multidisciplinary ways of working have emerged, which solicit and integrate different health and social care specialties and perspectives (Thomas et al. 2018), rather than a radical rethinking of how medicine is done.

However, critics argue that using the concept of the person in medicine is unhelpful because the term will always be vague; there can never be a single, authoritative definition of what a person is, and therefore it is unlikely to genuinely improve the position of those being cared for. Instead, care should focus on people’s existing capabilities and on mitigating their incapacities (Higgs and Gilliard 2016; Slater 2006). Yet, accepting that what it is to be a person is undoubtedly ambiguous and indeed will always be historically and culturally relative, we wish to elaborate on the role of this ambiguity in medical care, and explore its potential to contrast with solely biological, clinical ideas of the patient. As we go on to describe, the move to care for the so-called whole person shifts the traditional patient as an object of clinical practice and intervention into new territories, where different kinds of knowledge and values emerge and sometimes conflict.

Certainly, these issues have particular salience for patients who are approaching the end of their life, where the limits of medical treatment are all too apparent, and cure is no longer the guiding principle for decisions regarding care and treatment (Chapman 2008; Kaufman 2005). Given that physical decline is inevitable, end-of-life care staff shift their efforts to make the last period of life as full and comfortable as possible, encompassing many more activities beyond disease and symptom control (Driessen, Borgstrom, and Cohn 2021; Lawton 1998). In the United Kingdom, specialist end-of-life care is provided by palliative care teams. Members of these multidisciplinary teams not only have been trained in the specific and often complex clinical issues that can arise but have a wider remit to provide more general care and support for patients with progressive, advanced disease and for their families. They strive to ensure patients with a terminal diagnosis are as physically comfortable and pain-free as possible and, through a multidisciplinary approach, provide emotional, social, psychological, and spiritual support for the patient, their family, close friends, and other professionals involved (Association for Palliative Medicine of

Great Britain and Ireland 2019; Borgstrom et al. 2021). As a result, the team's activities encompass prescribing medication and other clinical interventions, securing social services, and assisting with many of the more practical aspects that can arise in the last few weeks of someone's life.²

The specialist palliative care staff are determined to resist the assumption that dying is a medical failure per se, and instead work hard to frame a patient's final stage as an integral part of life, and one that is potentially rich and rewarding. However, it is not always easy to include these broader, person-centered dimensions of somebody's life within everyday biomedical practice. During fieldwork, it became clear to us that when life is fragile, ideas of person and human can become disentangled to such an extent that they can sometimes appear divergent, and sometimes in tension with one another. Crucially, as the clinical gaze expands from preserving life according to physiological criteria to trying to ensure someone's life is as rich and meaningful as possible, what care is and what it seeks to do often need to adjust (Driessen, Borgstrom, and Cohn 2021; Pasveer 2020). The shift not only alters the focus of biomedical efforts, but the very idea of the life they are caring for, and the nature of death within it. This raises questions about definitions of death and also about the very ideas of what being a human is and how the value of life is determined, made, and unmade (Kaufman and Morgan 2005).

Our fieldwork was conducted in London between 2018 and 2020 with a palliative care team working in hospital and another in the adjacent community (Borgstrom, Driessen, and Cohn 2020). We followed various staff members over an extended period, during which we observed staff-patient encounters as well as staff interactions with other specialties. We also attended training about end-of-life care for nonspecialists; observed over seventy weekly multidisciplinary team meetings (MDT meetings) in hospital and the local community; accompanied individual health-care workers on other engagements, such as meetings with the hospital intensive care team, in primary care practices and at multidisciplinary "frailty hub" discussions; and lastly, we conducted ethnographic interviews with staff and patients, informed by observations, to gain a deeper understanding of broader considerations and connections. Ethical clearance was obtained from our university's ethics committee alongside the standard ethics process for the National Health Service (NHS), plus an additional review required because we might potentially have direct access to confidential clinical information. We provided study information and answered queries prior to obtaining formal written consent from everyone directly participating in the study: health-care professionals, patients, and relatives. All those

who we came into contact with, but would only be part of the wider contextual observations, were nevertheless informed about the study and given the opportunity to request us being present.

From initially suspecting potential ambiguities between a focus on being a person compared to a human in everyday medical activities, we traced enactments of both repertoires through our ethnographic material. From this, we present here a selection of cases that illustrate how the two repertoires emerge as distinct during end-of-life care, highlighting what happens when more-than-human can mean less-than-person—at a time when personhood directly competes with clinical priorities, and when boundaries overlap. In closing, we reflect on what our analysis offers to the study of end-of-life care specifically, and to conceptualizations of life more broadly, while drawing out the implications for science and technology studies.

When More-than-human Can Mean Less-than-person

After surgical implantation of a titanium plate in Amanda's head, an abscess formed underneath, which developed into septic encephalopathy. She was rapidly admitted into the intensive care unit (ICU), where both staff and various technologies in use are orientated toward supporting specific organ systems of the body such as breathing or kidney function. Those who require intensive support of more than one of these life-support systems are identified as complex cases, not only because they require input from different clinical specialists but also because staff must constantly be vigilant to ways system-specific technologies and medications might interact.

Amanda received high doses of antibiotics and was intubated to enable mechanical ventilation. The process entailed inserting a tube down her windpipe that was connected to a computerized machine that continuously pumped air in and out of her lungs. The equipment monitors oxygen levels, pressure, temperature, and duration of a single inhalation to mimic unaided breathing. But because it is such an uncomfortable arrangement the body's reflexes continually battle with the artificial support, so patients need to be fully sedated in all cases. Despite every effort, Amanda's health deteriorated; being connected to the ventilator maintained her breathing, but it was not sufficient to keep her physiological condition stable. Over time, staff came to feel that the machine was actually being obstructive. As such, they felt that care needed to shift from the imperative to keep her alive, to ensuring she was as comfortable as possible now that she was understood to be dying.

There has been much discussion about the issue that a definitive, bioscientific definition of death not only has altered over time but can differ from one country to another; death is multiple, in that there are different criteria and parameters that may be drawn on to define it (Pernick 1999; Schofield et al. 2015). Identifying whether and when someone is dying can be just as ambiguous—even within biomedicine (Schulz et al. 2015). Although the term “diagnosed” is loosely used in medical evaluations to describe whether someone may be in their last months or weeks of living, the process does not follow a typical diagnostic procedure. A range of physiological signs and measurements are drawn on, but many wider functional and social criteria are also taken into account in a flexible way to determine whether the label is appropriate. Describing a patient as being at the end of life is an intervention in itself, which should typically initiate a shift to palliative care or coordination with the (specialist) palliative care team. But in addition, the agreed diagnosis triggers a reevaluation of what the role of health care in this period can and should be.

This was the case for Amanda. Specialist palliative care consultant Christoph became involved, initiating conversations with the family to “support them to let go.” He drew on his position as an outsider to provide a different perspective and open up a conversation about shifting the focus of care. A meeting between the lead neurological consultant, Amanda’s family and Christoph was arranged, during which the possibility of removing the breathing tube to allow her to decline naturally was very carefully raised. Initially the family were adamant that their duty to Amanda was to fight to keep her on life-support. But over the course of a few days, the difficult discussion initiated an important change of viewpoint. For the family, seeing Amanda so utterly reliant on medical equipment while unconscious and unaware of her situation began to feel that she—as a person—was already not fully present. Whereas previously it had been the attachment to the equipment that had sustained Amanda and the possibility of her survival, a new shared understanding was established in which, paradoxically, it was precisely the impetus to protect Amanda as a person that made it acceptable to allow the tubes to be disconnected and let her die. Another way of understanding this change was that the divide between the material and the social was renegotiated when the priority of maintaining Amanda’s vital functions was replaced by foregrounding Amanda as someone the family wished could be a social person, who should be able to interact with and relate to the world. “Letting go” became a means to “hold on” to Amanda.

Amanda's case exemplifies how, although life can be extended using a greater and greater array of medical technologies to support and redistribute body processes in more-than-human configurations, this is often accompanied by the sense that, through this very process, the person can increasingly be disregarded. Foregrounding the patient as a human or as a person emerges as distinct repertoires, bringing together actions, values, and knowledge that order the world in particular ways (see Pols 2006, 79-80). As such, this is a symbolic or semiotic process as much as a physical one. In other words, it is important not only to highlight the role of practical, technical aspects of care but also pay attention to the extent to which acknowledging relationships (or lack thereof) shapes how patients may relate to themselves and, equally, how others may relate to them.

We frequently observed how the highly specialized orientation of ICU provision led to its staff not feeling fully equipped to deal with the increasing ambivalence between championing interventions to support the physically deteriorating and vulnerable body, and the different kind of care that foregrounds the patient as a person. Calling on the palliative care team helped them not have to face this as an overt conflict. The more general point, then, is that contemporary biomedicine and its complex forms of technology can unravel differing values and ways of regarding the patient at end of life that can sometimes feel oppositional. Crucially, this is not only something that clinical professionals have to deal with but also relatives and others who all want what's best for a dying patient but struggle to ascertain what that should be.

When Personhood Directly Competes with Clinical Priorities

Other instances reveal that the concept of intensive care not only encompasses concentrated input from staff, technology, and drugs but rests on the idea such efforts should be time-limited. Patients are expected to be moved out onto more regular hospital wards as soon as their physiological systems can function without support. Before the COVID-19 pandemic, which altered practices quite dramatically, we observed that if someone had been in an ICU ward for more than two weeks, staff regularly found themselves questioning the value and impact of their intensivist commitment.³ The very success of coordinated efforts by staff and nonhuman actors in keeping someone alive precipitates discussion about whether the patient's body has become entirely dependent on external support, and if it can ever successfully be "weaned" off the machines. The issue is not that these technologies

have been problematically designed, but that they are designed according to one specific remit—to maintain the physical body for as long as possible.

By contrast, seeking advice from the palliative care team indicates a recognition that the life a patient has left needs to be cared for in a different way; recognizing that the patient needs support for the everyday activities and interactions that make life meaningful foregrounds a different, more expansive version of the patient. The imperative to preserve the body as much as possible is replaced by the acknowledgment that to maintain a sense of personhood at such a vulnerable time, a patient needs assistance to remain active and extended into the world. There is often an apparent paradox when someone approaches the end of their life and their health is said to be deteriorating; dependencies on others can become more evident, not less, while new relationships with other people and things become more critical. The vulnerability of a failing body not only requires greater support, but as more and more things (such as a ventilator or oxygen tanks) become overtly integral to the processes of living, any sense of the body being bounded is destabilized.

One such example concerned Martin, a patient who had been on ICU for more than 50 days with no sign of him improving. He had been either asleep or semi-conscious throughout this time. His family—wife, children, and parents—were slowly coming to terms with this. When his case was raised at an ICU MDT, the palliative care consultant Dorothy widened the scope of discussion by mentioning that the family wanted to find a way to mark Martin's imminent birthday. So Dorothy and clinical colleagues in ICU spent an extraordinary amount of time and effort—in itself evidence of the value and significance placed on such moments—to find a way for him, on his hospital bed and still connected to an array of life-sustaining machines, to be wheeled along the hospital corridors, down a service lift, and out into the small concrete forecourt at the base of the hospital building. It was an act that acknowledged how, by seeing the sky, the single tree planted in the paving, and surrounded by his loved ones, he could engage with the outside world, and in turn be shaped by it. Not only did this enable Martin to maintain some continuity and meaning in his social world but was also hugely important for those close to him, because they would later be able to recall him interacting with them outdoors, rather than just remembering the intrusive physical tangle of wires and pipes in an enclosed space that maintained his bodily functions.

Caring for patients near to end of life often entails relying on many other people and technological interventions, yet the concern for specialist staff participating in this study was that focusing solely on perpetuating a body to

internally function can increasingly curtail the ability to interact with the world in a way that is meaningful to patients, staff, and family members. That such extraordinary efforts were invested to make this moment happen for Martin attests to how little emphasis is placed on such connections in a system focused on the survival of the human body.

A problem routinely faced by staff is that living and interacting socially can mean a patient is made more physically vulnerable and is at risk of dying sooner. Abdul, a man in his eighties who lived alone, was in just such a situation. He suffered from a high number of conditions: asthma, dementia, depression, sleep apnea, and heart arrhythmia. Additionally, his heart, kidneys, and liver were deteriorating. As his palliative care nurse Johannes put it, “basically, all his organs are ill.” Abdul lived in a one-room ground floor flat in central London, where he spent all his time apart from a weekly afternoon shopping trip arranged by a local support service. His home was a small rectangular space of about twenty square meters, with only two skylights for windows, a tiny kitchen area, and a very old hospital bed in the corner. In many ways, his apartment looked like a storage room—the walls were lined with rudimentary shelves constructed from large wooden planks on metal hooks, piled up with medicines, cardboard boxes, and medical equipment, some left unused since his mobility decreased. Underneath, a big, broken flat screen TV stood on the floor next to more boxes. The place was not disorderly *per se*, but everything was functional: a microwave, a kettle, and the packets of medication—there were no signs of any personal items.

Abdul worried about living alone. Although he had the support of his son and grandson, and even a long-standing invitation to stay in their house outside the city, he felt compelled to remain in his flat so that he could keep his various health-care appointments. Johannes, a member of the palliative team, worried the different specialists who focused on Abdul’s various conditions never looked at the overall situation. So Johannes initiated a conversation with Abdul’s respiratory nurse and GP to streamline the various appointments and reduce the effects of compartmentalization. The specialist palliative team member was worried Abdul had too readily embraced what he termed a “patient identity” at the expense of focusing on his family ties. Although Abdul repeatedly said he did really want to move in with his son eventually, Johannes felt he had become stuck, literally; the sense of vulnerability and fear forcing him to live in a small, dark space with virtually no social interaction beyond the appointments with his care team.

The cases illustrate how palliative care staff frequently sit on the fault line between caring for a patient's medical condition and trying to ensure that while patients are still alive they can experience, and be part of, the world they inhabit. It is not simply that, in an abstract way, these two different repertoires of care and the patient compete—and potentially even contradict—each other. Rather, the very practices adopted by staff foreground the different aspects of the patient as human and the patient as a person. Focusing on shielding a patient from all the possible hazards associated with dying can eclipse the idea that they should and interact in the world as much as possible. But if dying is part of living, as the specialist palliative team espouse, then those risks themselves need to be embraced as part of life—with very different possibilities of living and dying as a result.

When Boundaries Overlap

A further case presents a similar tension for the care team—between their commitment to support and encourage relationships that engender the continued sense of being a person, and the reality that a patient's decline can lead to a growing dependence on clinical support and a focus on life that is only defined in physiological terms. Twan was a man in his sixties with an advanced brain tumor. He had started to deteriorate rapidly but wanted to spend his last weeks in a caravan in the fairly remote grounds of a Buddhist retreat in Wales surrounded by friends. But it was unclear to what extent end-of-life services would be available there, so his care team in London was hesitant. The fact he considered traveling hundreds of kilometers to affirm his religious beliefs and being part of a community demonstrated precisely the values of living and being that the palliative staff hoped to foster. But at the same time, they were compelled to protect the patient from the clinical consequences of traveling to the remote retreat. The team found it impossible to reconcile the two. Twan was initially adamant that he wanted to live his last period in a supportive social environment, even if this meant he might have no—or at best very little—medical support. But the team were not convinced that he was aware the next two weeks would likely be his last or what these final days might actually be like. Explaining everything to him in some detail, Twan slowly changed his mind and agreed to stay in his home in London. The decision did not fully resolve the tension, but his growing practical and clinical needs meant the focus of care for Twan gravitated toward supporting him where he was: stationary and more secure, and known to and supported by the palliative care team who could offer appropriate support to the dying body in its changing states.

Continually shifting repertoires between supporting his desire to maintain a sense of personhood, and providing care directed at his clinical needs, helped staff temporarily deal with things, but other difficulties soon emerged. A week after discussing his situation at an MDT meeting, his palliative nurse learned that Twan could only tolerate his pain if he lay motionless on the cold tiles of his bathroom. Because Buddhism teaches that death is the final stage of growth, Twan insisted that he did not want any pain relief drugs, fearing they might cloud his thoughts. Although the team was aware of this belief, hearing it like this shocked them, because one of their unambiguous roles is to ensure patients are pain-free in their last days. So they shifted repertoires anew: after initially considering moving Twan to a local hospice, they decided he would not want to be effectively rendered passive and arranged for him to have a floor mat and a less potent painkiller instead. They also offered his family and friends some prebereavement counseling, so they could continue to support him as his needs increased over his last few days.

Stonington has described very similar cases of clashes between Buddhist values about life and ancestry beliefs in Northern Thailand, with the increasing influence of biomedical end-of-life practice and the ethical framework that underlines it (2020). But rather than interpreting Twan's case in terms of bioethical ambiguity that can arise when negotiating different cultural worldviews, we want to emphasize the productive nature of that ambiguity for the delivery of health-care services. On the one hand, palliative staff think about the care they provide as practices directed to the interior—to the illness, the symptoms, the suffering of pain—yet on the other, they are dedicated to thinking about the kind of life a patient can lead when they are dying. The clash between human and person, then, does not necessarily just arise between two different cultural perspectives but is an embedded feature of the contemporary palliative care provision we observed. Each emerges from privileging different priorities, and hence sometimes making divergent decisions about what is best. Foregrounding care in terms of protection and safeguarding versus helping someone experience and engage in the world as much as possible often means that the very boundaries of the patient are where these differences become manifest.

Take Michelle, who was in her nineties, spent most of her time asleep. She lived with her family after they moved her out of the nursing home. Regrettably, she developed gangrene in a toe which rapidly spread to her entire foot. The family happened to be proponents of nontraditional medicine, which mostly involved herbal treatments. They treated Michelle's foot by applying raw garlic and onions, which initially seemed to bring about an improvement.

Gangrene and other forms of necrosis are clinically very worrisome because they indicate the presence of dead or dying tissue and are often a symptom of an underlying infection. Staff were worried that if nothing more substantial was done, it would probably lead to complications. The daughter told a member of the team that she planned to order maggots via the Internet to treat her mother's wounds. The nurse discouraged this, explaining there are different kinds of maggots and administering them requires specialist knowledge. But countering their wishes more forcefully did not seem appropriate to the nurse. Later, when the wider team discussed the case, they remained worried and the possibility the family might apply maggots to open wounds without specialist knowledge was deemed highly risky, while not doing anything about the gangrene risked sepsis.

Maggots have been used to treat wounds for centuries, recently becoming an accepted technique used by tissue viability specialists within biomedicine. In biosurgery, the fly larvae can effectively "clean up" a wound by feeding on the dead tissue, helping to demarcate healthy from necrotic tissue, and hence the living body from dead material. Viability, then, implies the body's ability not merely to remain as it is but to have the potential to repair itself. Leaving healthy next to necrotic tissue often prevents wound healing and increases infection risk. So, one of the key dilemmas in Michelle's case lay at the surface of her skin, and what should be the palliative team's priority. Should it have been the clinical concern about the risk of using maggots outside the care team's control, which might introduce or spread infection in the body? Or should it be to support and encourage her family, who, by continually seeking ways to do their very best for Michelle, were determined to care for her as an involved member of the family and a person being loved. To simply obstruct the actions of the patient's family was regarded by the staff as insensitive and too authoritarian. After all, if maggots were used, they could then be regarded as part of the network that not only sustained Michelle's body but also her active role as a person, through the relationships with her family that they helped facilitate. In other words, thinking about what was ultimately in Michelle's best interests was not clear, because the boundary of her as a delimited patient and the boundary of her as a person embedded in a social world no longer aligned neatly.

Concluding Thoughts: Generative Ambiguities

We have illustrated how, through health professionals' everyday practice of looking after people at the end of life, ideas of the patient as a biological entity or as a person constituted by relationships they have with others can

emerge as distinct and sometimes competing objects of care. Once someone's death arises as an explicit consideration in the present, as opposed to a vague sense that it is inevitable at some stage in the future, "person" and "human" present themselves as different, and sometimes contrasting, enactments of the patient.

At one level, we have argued that the increasing evocation of person-centered care in many areas of medicine, especially in end-of-life care, needs to be addressed more critically, particularly because it may appear as unquestionably desirable. But we have also shown that, in practice, caring to support a patient's relationships so their life can remain as meaningful as possible also relies on a clinically oriented, instrumental form of care derived from different values and practical choices. In other words, that an unresolvable tension is often inevitable. Our cases illustrate how this tension emerges for care professionals as they oscillate between two repertoires of patienthood, the human and the person. The first revolves around maintaining function and reducing deterioration of the internal body, while the second entails concern for how a patient might maintain relationships with other people, particular places, or inanimate things that have meaning to retain a sense of who they are in the present, as well as for those who will remember them after their death. However, our point has been that while the two repertoires emerge from different values that underlie the care provided, they rarely if ever substitute each other completely. So although these two repertoires may suggest stark opposites, and hence contradictory forms of medical care, our observations reveal a much more subtle and nuanced process of continual negotiation between notions of what is a person and what is human. As a result, we have tried not to suggest the simple replacement of a reductive, technical approach for a broader multidisciplinary person-centered one but rather convey how staff often find themselves having to jostle between making clinical decisions based on established biomedical knowledge and technical possibilities and supporting patients in a broader, much more improvised way so that their last period of life is as meaningful as possible. The work of trying to do both, and finding ways to deal with the ambiguity, is a key facet of palliative and end-of-life care.

A further line of argument we have alluded to concerns "more-than" accounts, which are now a mainstay in science and technology studies. As some connections in the world increase and others recede, the boundaries of the patient alter, determining what kind of actions might be taken by staff, patients, and others. For example, looking after a widening assemblage might include regularly checking that a machine is working correctly, or

devising means to ensure all the wires and trolleys and body remain securely connected together as they are wheeled along a hospital corridor. Certainly, attending to these increasing physical ties and dependencies with objects such as tubes, wires, and even maggots blurs where the boundary of the patient actually ends. But beyond describing how the patient becomes more distributed, our cases suggest that the overt nature of such entanglements can raise questions about how the patient might continue to be seen as a person and maintain the kind of interactions with others that constitute such a status. In other words, although a patient who is physically dependent on a distributed assembly of medical technologies may well be represented as more-than-human, this may well reciprocally threaten the cultural values underlying ideas of personhood. In many other situations, this discord is likely to be transitory and tolerated, but end-of-life contexts often catalyze a great deal of rapid work to find ways to counter this potential loss of personhood. It can lead to new directions of care, which can downplay those ties seen to disrupt or obstruct personhood, while promoting others that foster some sense that the person is still present and able to interact with other people and things in the world they are still actively part of.

Our examples consequently illustrate how the two different repertoires adopted in the context of end-of-life care include material elements and social relationships, as well as particular actions that enact cultural values about what it means to be a human or a person. Often, the very boundaries of the patient emerge as a key site where these different enactments diverge. From concern over the viability of gangrenous tissue, to the risks of providing oxygen for someone who is breathless, the cases presented in this paper do not portray boundaries as a categorical distinction between two opposing forms of patienthood. Instead, our illustrations point to boundaries as the place where the two repertoires emerge and operate in tandem, generating friction and deliberation about what might be the best form of care to offer. Focusing on these details differentiates our argument from existing literature that describes how dying people may experience a social death—a state in which somebody is treated by others as if they were already dead (Borgstrom 2017; Lawton 2000; Sudnow 1967). Based on our ethnographic study of two specialist palliative care teams in London, we suggest that the social death framing does not reflect the complexity health-care professionals face, as by definition it ignores the inevitable entanglement of the semiotic and the material. To reiterate the point: the common distinction between a social and a biological death effectively perpetuates a divide between the social and the material that our descriptions purposefully avoid.

A further extension of our argument is that there may be two different notions of life at work here. While the life of a patient as a bounded human refers to the healthy functioning of the body and maintenance of core capacities and characteristics, the life of a patient as a person refers to the individual living their life in the world. Ultimately, then, this article problematizes the notion of end-of-life in medicine not, as others have, in terms of uncertainty about defining an absolute end point (Kellehear 2008; Lock 2001) but in terms of what kind of life is understood to be ending. Anthropological discussions have long noted how the category of person regularly serves as a micro social entity (Strathern 2018). Along these lines, questions concerning the nature of the patient as a human or as a person that emerge from the practices of a particular medical specialty might actually be indicative of a much wider cultural ambivalence: in times of existential uncertainty, contrasting values associated with the objective and material, and those associated with the social and subjective, can emerge as distinct and discordant. By attending to conceptualizations of personhood alongside questions about what it is to be human, the work of palliative care staff thereby unsettle established ideas about the meaning of these categories, and potentially provide new ways to think about how we might live in, and indeed be part of, the world rather than in contrast to it (Braidotti 2016)—even in the last days of life.

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Notes

1. We use first names here to reflect our relationships with patients and clinicians.
2. This commitment to a so-called holistic approach clearly aligns with the more general shift to person-centered care in medicine. Palliative care staff are defined as having a more specialized skillset, better suited to address “complex” needs of patients at the end of life. If this complexity is deemed to have decreased substantially, patients can be referred back into the care of ward staff or community teams and GPs. Otherwise, the patients remain on the case load of the Specialist Palliative Care team until their death.
3. The fieldwork this article is based on was conducted pre-COVID. COVID-19 significantly increased the duration of an average intensive care unit stay, especially in the early waves of COVID-19 cases (see Rees et al. 2020; <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-020-01726-3>).

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