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"Accompanied Only by My Thoughts": A Kantian Perspective on Autonomy at the End of Life

ANNA MAGDALENA ELSNER*
University of St. Gallen, St. Gallen, Switzerland

VANESSA RAMPTON*
ETH Zurich, Zurich, Switzerland

*Address correspondence to: Anna Magdalena Elsner, School of Humanities and Social Sciences, University of St. Gallen, Müller-Friedberg-Strasse 6-8, 9000 St. Gallen, Switzerland. Email: anna.elsner@unisg.ch

Within bioethics, Kant's conception of autonomy is often portrayed as excessively rationalistic, abstract, and individualistic, and, therefore, far removed from the reality of patients' needs. Drawing on recent contributions in Kantian philosophy, we argue that specific features of Kantian autonomy remain relevant for medical ethics and for patient experience. We use contemporary end-of-life illness narratives—a resource that has not been analyzed with respect to autonomy—and show how they illustrate important Kantian themes, namely, the duty to know oneself, the interest in elaborating universalizable principles, and the emphasis on ideals as points of orientation that guide behavior without ever being fully realized. As Kant does, the patient-authors discussed here perceive the end of life as a moment to reflect on the constitutive principles which have governed that life, thereby offering a privileged moment to pursue self-knowledge. We argue that bioethical conceptions of autonomy stand to gain if they revise their conception of Kantian moral philosophy as too formal, abstract, and detached from emotions and personal relationships to be helpfully applied.

KEYWORDS: *autonomy, bioethics, Diski, end of life, illness narratives, Judt, Kant, Kalanithi, Taylor*

> [T]here I lie: trussed, myopic, and motionless like a modern-day mummy, alone in my corporeal prison, accompanied for the rest of the night only by my thoughts.
>
> —Tony Judt

I. INTRODUCTION

Autonomy is a key concept in moral philosophy and has significantly shaped ideas about the ethical practice of Western medicine since the 1970s (Saad, 2018, 125). While different accounts of the concept exist, the most influential ones are J. S. Mill's conception of autonomy as the defense of a sphere of private choice, and Immanuel Kant's account of autonomy as fundamental for morality. According to Ruth Faden and Thomas Beauchamp, autonomy can be identified with several ideas, including "privacy, voluntariness, self-mastery, choosing freely, the freedom to choose, choosing one's own moral position and accepting responsibility for one's choices" (1986, 7). Respect for patient autonomy is taught to Western medical students as one of the four principles of medical ethics, along with justice, beneficence, and non-maleficence (Beauchamp and Childress, 2013, 101–49). In medical ethics, this

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principle is thought to be binding primarily on healthcare providers and has given rise to a range of practices such as the facilitation of choice, the doctrine of informed consent, respect for privacy, and assessments of mental competency (Faden and Beauchamp, 1986).

Yet how support for autonomy intersects with the moral life and sense of self of patients has been controversial. Following her own experience of illness, bioethicist Deborah Bowman (2017) reflected that attending properly to autonomy "is about much more than the provision of information and the facilitation of choice, although those are sound enactments of respecting autonomy." Various contributions from narrative ethics and care-focused feminist ethics have criticized mainstream conceptions of autonomy from different angles, with the shared aim of developing accounts of autonomy in line with the institutional, legal, and ethical requirements of medical practice, but that are better able to capture how patients conceive of their own self-realization. As a rule, these critiques of autonomy have argued that the concept, in both its Millian and Kantian incarnations, is excessively rationalistic, abstract, and individualistic, and therefore far removed from the reality of patients' needs. In particular, these concurring arguments have challenged the purported link between autonomy, self-knowledge, and self-realization, in favor of perspectives that valorize emotions, personal relationships, and the multiplicity of personal points of view.

This paper draws on recent contributions in Kantian philosophy, which provide substantial evidence that Kant's conception of autonomy is more flexible than some of its detractors suppose. By highlighting the more nuanced and integrated Kantian conceptions of human nature they present, we argue that specific features of Kantian autonomy remain relevant for medical ethics and for patient experience. We demonstrate this by drawing on contemporary end-of-life illness narratives which illustrate these important features of Kantian autonomy, namely, the duty to know oneself, the interest in elaborating universalizable principles, and the emphasis on ideals as points of orientation that guide behavior without ever being fully realized.[1] The four autobiographical narratives we scrutinize—*In Gratitude* (2016) by Jenny Diski, *The Memory Chalet* (2010a) by Tony Judt, *Dying: A Memoir* (2016) by Cory Taylor, and *When Breath Becomes Air* (2016) by Paul Kalanithi—are particularly suited for capturing autonomy from the point of view of patients, because the authors conceive of the act of writing as a reflective exercise linked to self-knowledge and self-realization. To explore notions of autonomy in these texts is to come to grips with the limitations of the idea that patients always can and should "choose" what happens to them in care. Yet, writing about moral agency at the end of life also shows that what we identify as specifically Kantian themes are often bound up with the most emotional and relational aspects of patient experience. As such, these intimate testimonies of terminal illness present an ideal vantage point to test the ways in which a revised Kantian view of selfhood can shed light on bioethics in the clinic.

In juxtaposing these narratives—a resource that has not been analyzed with respect to autonomy—with Kant's moral philosophy, our goal is not to suggest that the Kantian view is itself justified nor maps exactly the kind of autonomy the authors engage with in their writing. Neither do we want to argue against a widely held philosophical consensus that social relationships and practices profoundly influence the realization of autonomy. What we do want to suggest is that the three specific features of Kantian autonomy we discuss here can shed light on what autonomy means to these patient-authors dying of terminal illness. This includes the need for rational detachment from an ailing body and the identification of principles that transcend an individual perspective—features that are not prioritized in accounts of autonomy that have distanced themselves from Kant. Moreover, we argue that a revisionist reading of Kant offers a path to understanding the specific case of autonomy at the end of life that is not subject to the critique that autonomy fails to attend to individuals' lived experiences. Bioethical conceptions of autonomy, therefore, stand to gain if they were to revise their conception of Kantian moral philosophy as too formal, abstract, and detached from emotions and personal relationships to be helpfully applied.

II. FROM KANTIAN AUTONOMY TO PATIENT AUTONOMY AND BACK

Derived from the Greek *autos* (self) and *nomos* (rule, governance, or law), the word autonomy originally referred to the self-rule or self-legislation of independent city-states that followed the laws they had made themselves. Yet, while the term can be traced back to antiquity, it has no single philosophical meaning. Gerald Dworkin has pointed out that the word "autonomy" has been "used in an exceedingly

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broad fashion," and that it is not clear that there is a core meaning underlying descriptions of a person, a decision, the will, or a nation as autonomous (1988, 6).[2] That said, the most influential formulation of the concept is Immanuel Kant's, who provided an account of autonomy as a moral concept linked to self-governance; in Jerome B. Schneewind's words, Kant "invented the conception of morality as autonomy" which replaced earlier notions of morality as obedience (1998, 3–4).

Kant's conception of autonomy derives from his view of persons and of the essential features of human society. Kant had a certain pessimism regarding human nature, which he saw as prone to self-deceit, self-love (1998a, 4, 407), and marked by an antagonism he calls "unsociable sociability" (*ungesellige Geselligkeit*) (2009, 13), namely, a permanent antagonism between human beings. Moreover, Kant was skeptical about the possibility of practical self-knowledge, and believed that "[o]nly a few places on the vast *map* of our mind are *illuminated*" (2006, 24), and that we ultimately remain opaque to ourselves (1998a, 4, 407). Yet Kant's sense of the difficulty of obtaining morally relevant self-knowledge co-existed alongside his account of a duty to "know thyself" (1996, 6, 441), and his complex picture of agents as both limited and finite, as well as rational.

A crucial part of this picture is his desire to provide a stringent account of morality with reference to principles or values that cannot be reduced to individual desires and preferences embedded in actual situations. Moral autonomy, in Kant's view, implies the ability to abstract from one's own, biased point of view—including emotions and inclinations—and to subject oneself to universalizable moral principles. Kant presents his "Formula of Autonomy," "the idea of the will of every rational being as a will giving universal law" (1998a, 4, 432–3) as a formulation of the Categorical Imperative to "[a]ct only in accordance with that maxim through which you can at the same time will that it become a universal law" (1998a, 4, 421). Human will, thus conceived, is autonomous because it is capable of self-determination according to this freely chosen moral law ("ought," *das Sollen*) discoverable by reason.[3] His view of flawed, mutually antagonistic moral agents, combined with the existence of autonomy as a normative ideal, meant that Kant understood the human condition as a constant process of "incessant laboring and becoming," through which we try to improve ourselves (1998b, 6, 48). Importantly for our purposes, Kant singled out the end of life as a moment in which we can partially overcome our chronic opacity and self-deceit because we can look back over our life as a whole, consider our conduct, and infer what our constitutive practical principles have been (1998b, 6, 70–1).

Kant's depiction of autonomy is therefore, as Thomas Hill puts it, a "crucial part of the moral point of view from which specific principles can be assessed, not an ideal of living independently of others" (2013, 15). Conceptions of autonomy in the healthcare context, however, have strongly focused on the ability of patients to make decisions, and have therefore particularly stressed the importance of patients' *independence* in choosing between alternatives.[4] Concretely, this has been associated with practices such as "informed consent," and the patients' right to know everything about their diagnosis and prognosis, unless they specifically ask not to be informed. The desire to respect the competent person has been associated with the obligations of health professionals and others (e.g., family and friends) to help patients arrive at their own decisions (e.g., by providing information in a manner that can be understood), and to respect and follow those decisions regardless of their own views (Hope, 2004, 65). Onora O'Neill summarizes that, in contrast to Kant's depiction of autonomy as principled, the concept has "been understood as a matter of individual independence in and beyond bioethics for some decades" (2002, 24).

That these usages of autonomy and related views of human nature in the clinical context are "far away from its Kantian foundation" has been duly noted (Downie and Macnaughton, 2007, 43; see also Secker, 1999, 44; O'Neill, 2002, 30). At the same time, autonomy's association with Kantian philosophy has been seen as part of the problem.[5] A number of contributions argue that traditional approaches to "patient autonomy" that consider patients rational and morally responsible agents are excessively reductionist and leave out crucial dimensions that matter to patients. Care-based approaches to medical ethics have attempted to supplement older accounts of autonomy by relating them to trust and dependencies (Held, 2006). This has influenced the concept of "relational autonomy" (Mackenzie and Stoljar, 2000; Ells et al., 2011), which "recognizes relational experiences as an integral dimension of individuality" (Donchin, 2001, 367), and "family-centered approaches" that have sought to widen the scope of autonomy from the intellectual to the emotional (Igel and Lerner, 2016, 56). To attend properly to autonomy, Bowman (2017) has argued, is to "attend to all the different 'ways of being and knowing'

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that co-exist in a clinical consultation" which she associates with the interplay between "forensic rationality, insatiable questions and emotional response." Significantly for our purposes, the ethics of care was originally formulated, as John Paley puts it, "in opposition to a kind of moral theory that was regarded as essentially Kantian and, to a considerable extent, that opposition remains at the centre of current debate" (2002, 133; see also Friedman, 2000, 212). As understood by those arguing for relational concepts of autonomy in medicine, moral agency in Kant cannot accommodate social interconnectedness, embodiment, and the importance of emotions for moral judgement; rather, it is solely associated with a person's rational nature, capable of willing in accordance with the moral law (Donchin, 2001, 378).

Recent interpretations of Kant suggest that Kant's conception of autonomy and his view of human nature that grounds it are each more flexible than some of its detractors suppose. In what follows, we contend that specific elements of a common revisionist position can maintain Kantian autonomy's relevance for medical ethics. In particular, contributions by Marcia Baron, Barbara Herman, Christine Korsgaard, Onora O'Neill, Laura Papish, and others have shown that Kant's theory of practical rationality is much more complex than often portrayed in bioethics literature. These finding suggest (1) first, that Kant did not fully ignore that practical principles manifest themselves in embodied, finite, and social beings. Kant believed, for example, that human persons must acknowledge the duty of self-knowledge, but must also understand themselves as prone to self-deception and therefore capable of falling short of its demands. Self-cognition in this perspective is both key to moral understanding as well as grounded on a notion of the self that "relies on empirical conditions to gain moral insight, whose ethical progress is impossible in social isolation, and who is dependent on historically situated and culturally robust institutions" (Papish, 2018, 34; see also O'Neill, 1993; Korsgaard, 2009; Ware, 2009). (2) Furthermore, Kant's conception of autonomy need not be opposed to the view that emotions, as well as qualities such as empathy and nurturance, play a valid role in moral judgment. What is required is that emotions are approved from a reflective perspective (Christman, 1995, 27; see also Baron, 1999). In this vein, Marilyn Friedman interprets Kantian autonomy as follows:

> A person can realize autonomy while remaining dependent on others, caring for them intensely, taking ample account of the needs and desires of loved ones, cooperating with others in collective endeavours, or, on some accounts, even subordinating herself to others... so long as her choices to do so have been based on the right sort of self-reflection. (2000, 218)

(3) Kantian moral autonomy is flexible enough to allow for the fact that human interconnectedness and personal relationships may (and often do) *actively* contribute to an agent's practical rationality. Barbara Herman, for example, argues that the rules of moral salience that "structure an agent's perception of his situation so that what he perceives is a world with moral features" are "elements in a moral education" and are acquired from others (1993, 77). Christine Korsgaard has also emphasized the worth that Kant ascribed to friendship and its ties to morality, highlighting that one's own autonomy is in fact best realized if one's ends and actions "are chosen under the restrictions of a possible reciprocal relation—a kind of friendship—with everyone" (1992, 309). To be sure, this notion of friendship is clearly restrictive, because it holds only to the extent that relationships based on what Thomas Scanlon has called "mutual recognition" (1998, 162), namely, a reciprocal sharing of ends and reasons, entail mutual responsibility. Even if this clearly limits the specific forms of friendship that could be compatible with Kantian autonomy, these corrective contributions provide evidence, then, that Kantian autonomy can remain relevant for our embodied, emotional selves and can be connected to interpersonal relations. What Christman refers to as a "revised Kantian picture" (1995, 27) is crucial for our purposes, and yet still underdeveloped with respect to its ramifications for medical ethics. In what follows, we scrutinize several end-of-life narratives to illustrate how Kant's conception of autonomy need not be at odds with imperfect self-knowledge as well as valuing emotions and relationships, the importance of which has been emphasized by relational accounts of autonomy.

III. AUTONOMY AND END-OF-LIFE NARRATIVES

Our analysis of Kantian themes draws on four autobiographical texts, in which the authors describe their experience of living with different terminal diagnoses (melanoma, lung cancer, ALS) from

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different national healthcare perspectives (Australia, Great Britain, and the United States).[6] They can all be classified as "end-of-life memoirs," a sub-genre of the illness narrative or (auto)pathography that became more popular around the same time that bioethics emerged in the 1970s.[7] Both illness narratives and bioethics center on the patient, yet the former's focus on singular human experience sets it apart from traditional (bio)ethical reflections because illness narratives are uniformly "situational, emotional, [and] detailed" (Wiltshire, 1998, 184). This difference is also the reason that Wiltshire and others have described the genre as an "untapped resource for the pondering of medical ethics" (1998, 187). While these texts lack the abstraction and orderliness of bioethical case studies, they confront ethical issues as embedded within the fabric of "the turbulent and demanding conditions of medical crisis" (Wiltshire, 1998, 187). While narrative approaches to medical ethics have been taken into account in order to understand a patient's moral choices and elucidate ethical dilemmas (Charon and Montello, 2002; Montello, 2014), it has been argued that such approaches have yet to substantially engage with the experience of dying and terminal patients' understandings of autonomy (Kellehear, 2009), a gap which this paper aims to fill.

Before proceeding, it should be acknowledged that the terms "autonomy," "autonomous," and "autonomously" hardly figure in the texts we examine here. When they are used, they are associated with (1) physical independence—as when Judt, suffering from Lou Gehrig's disease, observes that: "[m]y legs, although they will lock when upright long enough to allow a nurse to transfer me from one chair to another, cannot bear my weight and only one of them has any autonomous movement left in it" (2010a, 16)—or (2) independence of (moral) action—as when Taylor refers to euthanasia as an option that allows her "to feel that my autonomy is still intact" (2016, 146).[8] In what follows, we are well aware that these authors do not appropriate the term autonomy. Yet authors of end-of-life memoirs seek to, as Berman has noted, "die in character," which he defines as striving toward "a consistency between the way we live and the way we die" (2012, 3). For Taylor, Diski, Kalanithi, and Judt, as for Kant, the end of life is presented as a moment to reflect on the constitutive practical principles that have governed that life, thereby offering a privileged moment to pursue self-knowledge. Our analysis of these experiences of terminal illness, therefore, highlights that the authors' heightened self-critical reflection, shaped by their broader views of human nature and society, aligns with Kantian aspects of the concept and is not entirely captured by the principle of "respect for patient autonomy," associated with the right to make one's own decisions.

Moral Self-Scrutiny

The experience of a finite body and an emotional crisis triggered by a terminal diagnosis underpin the four end-of-life narratives we analyze here. In all cases, the authors experience their illness and the transformation of their identity into someone dependent and unfamiliar as disorienting; Diski describes the state of confusion she now lives in as analogous to "peeping over the edge of the world while remembering you've left your spectacles on the kitchen table" (2016, 135). Kalanithi, for one, contrasts the experience of being a patient with his previous identity as a doctor, noting that "[a]s a doctor, I was an agent, a cause; as a patient, I was merely something to which things happened" (2016, 142). One motivation behind these four memoirs is the desire to document this confused and painful encounter with their authors' "new" selves, and to gain additional knowledge of them, descending into what Kant refers to as the "hell of self-cognition" (1996, 6, 441). Kant's observation, that "moral cognition of oneself, which seeks to penetrate into the depths (the abyss) of one's heart, which are quite difficult to fathom, is the beginning of all human wisdom" (1996, 6, 441) is a recurring theme in the texts examined here.

That this type of self-knowledge cannot be reduced to protecting a sphere in which patients can make independent choices is clear from how these authors portray institutionalized practices designed to respect patient autonomy. Taylor, for example, loses interest in managing medical details and taking treatment decisions, and increasingly yearns for a "state of unknowing" (2016, 146). Diski, in the terminal stages of inoperable lung cancer, comments on a similar phenomenon, namely, being struck by her own "lack of will even to investigate what was going on inside me" (2016, 116). While choice-making is often portrayed, including by physicians, as a meaningful opportunity for patients, this clashes with the actual experience of these patient-authors, who recount feeling abandoned rather than liberated. As a former neurosurgeon, Kalanithi comments on the limitations of practices

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surrounding conveying information to patients now that he himself is affected by illness. He writes: "[i]t occurred to me that my relationship with statistics changed as soon as I became [a patient]" (2016, 134).

This is not to say that freedom of choice, that is, the possibility to direct the course of medical care and adequate information, for example in statistical form, is misguided or unimportant for patients. Rather, in these accounts, as for Kant, making choices informed by whatever desires one happens to have at a given moment does not support self-realization. Not because choice is not what the authors want, but because a choice becomes supportive of autonomy if it is made by the self as an active agent, associated with the power to exercise control over one's own life. As Diski puts it:

> [It's] increasingly clear to me that there may be little to find out and that no one, Onc Doc, Onc Nurse, really knows very much, except in an academic way. Everything is presented to me statistically, as probabilities. I can't find the right question to break through that, to talk about the cancer that is me and mine, what it is, how it is, how it and I are with each other. (2016, 116)

Ultimately, she conceives of the type of "informed choice" offered by her doctor less as an expression of free will and more of a simulacrum of meaningful decision-making. As Diski writes: "I choose how to respond and behave, but a choice between doing this or that, being this or that, really isn't freedom of action, it's just picking one's way through an already drawn flow-chart" (2016, 10). Instead, she posits that if a medical choice is to be meaningful, it needs to be framed in a way that allows her to "put an end to uncertainty in [her] life" (Diski, 2016, 118). A meaningful choice could therefore never arise from weighing two kinds of uncertainty against each other, but would need to reflect her values, experiences, and ideals. "Onc Doc's skills are essentially statistical... But I'm not a statistic" writes Diski (2016, 150–1).

The real question, as she formulates it, concerns engaging with the metaphysical implications of her choice:

> how much do I want to be dependent on others for my everyday life, or, indeed, for finding a reason to stay alive a little while longer? Missing a few months of feeling awful, being dead, versus not missing those months of feeling awful. Dead, at least theoretically, is the less painful of the two options, assuming that dead equals not being at all. (Diski, 2016, 161–2)

Diski's remarks emphasize that she can only begin to confront her particular situation if she is able to examine and judge it from a vantage point that is paradoxically disconnected from it. The choices offered by her doctor do not reflect "the metaphysics, the memoiring" (2016, 150) that allows Diski to engage more closely with her present experience, albeit in a more rational manner. In line with Kant's depiction, autonomy in these texts has metaphysical implications, because it does not arise primarily from the self reacting to available options, but from the self discerning an internal point of view from which it can assess its principles. Judt observes that as his body grows less functional, obtaining self-knowledge gains in importance; "I was forced to think very hard about what it meant to be me, what it means to be a person who is only a brain ... I'm just a bunch of dead muscles thinking" (Judt, 2010b). One of the results of this is uncovering a dimension of selfhood through cognition. In response to the question "what does he think about?" Judt (2010b) answers: "I find myself thinking about what is the core me-ness in me. What's the core places, influences, events, pleasures or angers, turning points and so on. I'm trying to work out what it must mean now to be reduced to the essence of who I am." For Judt, terminal illness triggers a quest for the essential, moral self, which he associates with the substance of his own humanity.

Working this out and recording his thoughts for Judt, as for the other authors discussed here, becomes an active and organizing form of resistance. For Kant, autonomy entails abstracting from the present and situational; in the case of these authors, detaching themselves, albeit temporarily, from the sense of anguish and confusion of illness connected to their physical, corporeal existence is a highly valuable exercise. Judt, for example, finds "solace and recourse" in his thoughts (2010a, 18), which prove to him that he still has "an analytically disposed mind" (2010a, 14) and can be employed as a diversion "from the body in which [my mind] is encased' (2010a, 17–8). Indeed, the authors

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conceive of establishing order in their attitudes and beliefs, of "memoiring" and writing about dying, as an important part of their self-realization. Judt describes himself as constructing a memory palace, a "storehouse of infinitely reorganized and regrouped recollections," and characterizes it as a place of "extraordinary appeal" that he wants to "visit again and again" (2010a, 6–7). The success of this strategy to liberate his mind and his reason from the constraints of bodily, everyday existence is clear. He writes: "I am occasionally astonished, when I reflect upon the matter, at how readily I seem to get through, night after night, week after week, month after month, what was once an almost insufferable nocturnal ordeal" (Judt, 2010a, 19). Taylor, too, describes the very acts of thinking and of writing as a lifeline. She muses: "I don't know where I would be if I couldn't do this strange work. It has saved my life many times over the years, and it continues to do so now" (2016, 32). Part of the reason, as she explains, is that she writes in order to determine "herself" as an agent capable of shaping her decisions and "to banish the feeling of utter helplessness that threatens so often to overwhelm me" (Taylor, 2016, 146). The philosopher Beate Rössler has highlighted the important role that life-writing plays for self-knowledge and self-determination. In her treatise on autonomy, she argues that diaries "act as a scaffold, a support for a self-determined life" (2017, 188).[9] Rössler does not link this to autonomy in its Kantian mode, but we want to argue that this mode is particularly pertinent if the emphasis on self-knowledge is connected to a further Kantian theme in these narratives, namely, the interest of the authors in moral duty and universalizable principles.

Universalizability of Experiences

In her account of Kantian moral philosophy, O'Neill states that "if we are to act as morally worthy beings[,] we should not single ourselves out for special consideration or treatment" (1985, 172). These narratives are triggered by the subjective experience of dying and the specific circumstances that characterize the personal situation and particular health condition of each author. Yet they also aim to move beyond this by placing the authors' individual lives and deaths in broader contexts, thereby reclaiming dying as a universal experience of human persons. Mostly implicitly, but in some instances, also explicitly, these terminally ill patients take up the theme of the universalizability of their deaths. They do so by proposing that their own particular practical principles hold a universal relevance for those who shall read their stories. Judt, for example, highlights that his condition "leaves your mind clear to reflect upon past, present, and future" (2010a, 4). Taylor further states:

> You do reflect on your past when you're dying. You look for patterns and turning points and wonder if any of it is significant. You have the urge to relate the story of your life for your children so that you can set the record straight, and so that they can form some idea of where they came from. (2016, 25)

Even if Taylor is preoccupied with relating *her* particular experience and telling the story of *her* life, she also references the moral obligation to engage with the experience of dying beyond what it means for her personally. As she puts it: "For while my body is careering towards catastrophe, my mind is elsewhere, concentrated on this other, vital task, which is to tell you something meaningful before I go" (Taylor, 2016, 32–3). Now it is the interpersonal character of this obligation that motivates Taylor to write her memoir: "I am making a shape for my death, so that I, and others, can see it clearly" (2016, 32). Kalanithi, too, is motivated by the desire to capture the non-exotic, inevitable, and, therefore, universalizable aspects of dying. As he elucidates, what drives him to write is the notion that the reader "can get into these shoes, walk a bit, and say, 'So that's what it looks like from here ... sooner or later I'll be back here in my own shoes'" (Kalanithi, 2016, 215).

Judt, Kalanithi, Diski, and Taylor understand constructing a narrative on the broader implications of their death as confirming the importance of the relationships with others who are both affected by and affect their dying. Invariably, the authors comment on the extent to which their current physical condition has made them more reliant than ever on a network of supporters. Judt, for example, describes how his physical debilitation has made him "utterly and completely dependent upon the kindness of strangers (and anyone else)" (2010a, 16). Taylor draws attention to how the debilitation Judt describes feels like a change in generational roles: "I'm much like an infant now, with an infant's dependence" (2016, 110). Human relations and emotional dependencies are, as Kalanithi writes, fundamental for moral judgement, since they constitute "the bedrock of meaning" (2016, 142; see also

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31). He aptly remarks that "any major illness transforms a patient's—really, an entire family's—life" (Kalanithi, 2016, 240). Taylor offers one such example when describing how she comes to choose between medical treatments that entailed different risks. She writes:

> I didn't decide straightaway. I slept on it over the weekend … I remember lying in my bed, unable to sleep, silently discussing my options with Mum as if she could hear what I was thinking. (Taylor, 2016, 133)

In marked contrast to Kant, these authors cautiously abstain from formulating anything approximating a normative philosophical position. Yet their writing is concerned with incorporating their respect for others into their *own* actions, whereby they are implicitly answering the question of whether they had valid reasons for conducting their life the way they did. Taylor's statement suggests both the importance of approving of our actions from a position of reflection and, conversely, of the importance of others, as symbolized by the imaginary exchange with her mother.

This is further illustrated when she discusses assisted suicide, which she is considering. Given that assisted suicide is illegal in Australia (since the publication of Taylor's text, voluntary assisted dying laws have been passed in Australia), Taylor recounts that she has bought herself a Chinese euthanasia drug on the Internet in an attempt to feel in charge. Yet, owning the drug engages her in a mental exercise in which she reviews the ways in which taking the drug would impact the life of her husband Shin and her two sons; she writes: "I'm constrained by the thought of collateral damage, of the shock to my family, of the trauma to whoever was charged with putting out the flames, fishing out the body, scraping the brains off the pavement" (Taylor, 2016, 37). The purported freedom she associates with the drug is inseparable from moral obligation; as Kant emphasizes, obligations to others become a barrier to her doing "what she wants." The sort of universalizability that Kant aims for seems well beyond the reach of Taylor's "collateral damage," and yet, what holds Taylor back from opting for assisted suicide is deeply connected to her sense of the world beyond her. Taylor observes that her drug shall remain unused because of "some moral qualm," deriving from "the harm one can inadvertently do to others, by going rogue and acting alone" (2016, 15). She arrives at this conclusion by reflecting on the limitations of suicide as an act of independent judgment, because it is inherently constrained by her feelings of responsibility and moral obligation. A further potentially universalizable aspect of end-of-life is exemplified in another common theme in these narratives, which is the authors' simultaneous attachment to reason and awareness of the inadequacy of reason in the light of the incomprehensibility of illness. In attempting to convey the paradoxes of mortality, these authors often reference other literary works, what Berman has described as the "turning bookish" of the authors of narratives (2012, 1). Literary use of language and narrative forms are useful for the memoir authors because, as Kalanithi writes, they provide "a vocabulary with which to make sense of death, to find a way to begin defining myself and inching forward again" (2016, 148). He further observes that he feels that literature provides "the richest material for moral reflection," contrasting this with his "brief forays into the formal ethics of analytic philosophy [that] felt as dry as a bone, missing the messiness and weight of real human life" (Kalanithi, 2016, 31). Beckett and Nabokov offer Diski "genuine comfort" and "real solace" (Diski, 2016, 150), because they capture something incommunicable about human existence, "a brief crack of light between two eternities of darkness" (Nabokov, 1989, 19).

The engagement with literary works not only provides a means to feel connected with others through the shared experience of mortality, but it also represents a springboard for engaging with the incoherencies of mortality. Reading and commenting on other texts is a way for these authors to reassure themselves that they can still reason, which entails prescinding from their own situation. Engaging in this reflective distancing allows them to assess their own experience critically and thereby to assume a position of reflection reminiscent of Kant's. This entails engaging with their particular experience in abstract terms while acknowledging the inherent limitations of doing so. Taylor, for example, when trying to make sense of the fact that her body stores her past, shapes her present, and will define her future, turns to T.S. Eliot's poetry. Eliot's "Burnt Norton" (1936) particularly epitomizes her paradoxical experience of time as both "eternally present" and "unredeemable" (Taylor, 2016, 129). Eliot's description of "Time present and time past/Are both perhaps present in time future" expresses Taylor's intuition that life "is also simultaneous, all of our experiences existing in

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time together, in the flesh" (2016, 129). The irreconcilable dual nature of time is also accounted for by Kalanithi, who describes the moment he became aware of both the immediacy and the banality of his own mortality. Terminal illness means the proximity of death and thereby pushes these patient-authors to the limits of rationality and meaning, because, as Kalanithi puts it, "the shadow of death obscured the meaning of any action" (2016, 149). Diski echoes this when formulating the contradictory emotions triggered by the inevitability of her near death: "[s]o I think I'd better not be afraid, I'll always be afraid" (2016, 143). For Kalanithi, it is the literary absurd, fueled by the certainty of death, that provides him with particular solace. Specifically, the final words of Samuel Beckett's novel *The Unnamable* (1953) resound with his experience:

> I woke up in pain, facing another day—no project beyond breakfast seemed tenable. *I can't go on*, I thought, and immediately, its antiphon responded, completing Samuel Beckett's seven words … *I'll go on*. I got out of bed and took a step forward, repeating the phrase over and over: "I can't go on. I'll go on." (2016, 149)

Contradictory, yet ending on the affirmative "I'll go on," Beckett's words epitomize both the universal determination to overcome the absence of meaning in the face of death, and what these authors portray as a common struggle to do so, the topic of the next section.

Endless Striving Towards an Ideal

The importance of step-by-step moral reflection for self-knowledge has been noted by John Wiltshire, who observes that the patient-pathographer:

> attempts, in his or her journal, or retrospectively, to rescue the semblance of moral being. He or she strives to see what really happened, what it would have been right to do, what attitude it was proper to take up towards themselves or the sick person, in circumstances … in which all courses would have been, in some measure, wrong. (1998, 189)

Writing allows these authors to establish a connection with moral autonomy, because it converges with the Kantian account of our duty "only to strive for perfect virtue, and not a duty to attain it" (Wood, 1970, 77). In Allen Wood's depiction, Kant believes that "as rational creatures our condition must be one of... endless striving" (1999, 334). This aspect of Kantian autonomy finds a notable echo in the ways the authors of the memoirs describe not only their journey into self-scrutiny but also their depiction of a constant draw toward improvement, even in the face of catastrophic illness. In particular, it is acknowledging the value of process rather than outcome that provides these authors with solace.

Reflecting on a seeming call for unceasing improvement, Judt ponders why he associates his underproductivity (with regard to transcribing his memoirs) with feeling guilty. He asks:

> Who could do any better under the circumstances? The answer, of course, is "a better me" and it is surprising how often we ask that we be a better version of our present self—in the full knowledge of just how difficult it was getting this far. (Judt, 2010a, 10)

Judt's wonderment about this open-ended and constant pull recalls Kant's description of autonomy as an ideal that a person posits as a guide, and the duty of striving toward it, rather than its fixed result. In a similar vein, for Diski, the crucial point is that the process of reflecting on her life in writing is a call that goes beyond herself. "So I've got cancer. I'm writing" she concludes (Diski, 2016, 13).[10] And yet, she compares the very process of reflecting in writing to an eternal challenge that can never be completed:

> In my experience, writing doesn't get easier the more you do it. But there is a growth of confidence, not much, but a nugget, like a pearl, like a tumor. You learn that there is a process, and that it doesn't very much matter what you write, but how you do it. (Diski, 2016, 13)

The act of writing represents one way in which these authors not only acknowledge the value of a process as well as allows them to reflect back on how the struggle to achieve ideals shaped their lives prior

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to illness. Kalanithi, for one, posits that striving for the unattainable was what drew him to his chosen profession, neurosurgery, "with its unforgiving call to perfection" (2016, 71). Kalanithi's formulation of this striving is reminiscent of Kant's account of the demands of duty, particularly when Kalanithi describes the call to practice surgery as a "moral duty" (2016, 151) that comes with a "*responsibility*" (2016, 114), deriving from the inability to fully answer the call to perfection. Yet for Kalanithi, it is the striving toward an ideal, rather than the nature of the ideal itself, that retains particular importance. Describing how he conceives of the moral role of a neurosurgeon, he reflects on the importance of the symbolism of an asymptote, while acknowledging that the perfection toward which neurosurgeons strive is neither fixed nor obtainable. Kalanithi writes:

> [o]ur patients' lives and identities may be in our hands, yet death always wins. Even if you are perfect, the world isn't … You can't ever reach perfection, but you can believe in an asymptote toward which you are ceaselessly striving. (2016, 114–5)

Kalanithi's current vantage point as a patient provides him with a further insight which complements the Kantian one: an ideal need not be a fixed or permanent value as its content can change; all that is fixed is the status of the ideal within a given person's purview (Emerson, 2003, xi; see also Poole, 2003). Kalanithi observes that while his oncologist urges him to "find his values," "[t]he tricky part of illness is that, as you go through it, your values are constantly changing. You try to figure out what matters to you, and then you keep figuring it out" (2016, 160). He explains that finding meaning, a "struggle toward the capital-T Truth," is from the outset an impossible task, because all of us—whether doctor or patient, family member or someone else—are only ever able to grasp a part of the picture (Kalanithi, 2016, 172). For Kalanithi, "[h]uman knowledge is never contained in one person. It grows from the relationships we create between each other and still it is never complete" (2016, 172). Finding one's values is a process that does not happen in isolation, as it involves others. Nevertheless, it is also a constantly creative and open-ended project that can never be concluded as it continuously compares an ideal self, Judt's "better me," with the realities of lived experience.

This theme of a permanent disjunct between an ideal and a felt reality is also a Kantian one. Literary scholar Caryl Emerson has reflected on how Kantian-inspired moral philosophy provides the intellectual resources to bridge the gap between an ideal such as autonomy and the incoherencies we experience as part of our everyday existence. She writes:

> [L]iving by ideals is supremely realistic, since coherence or justice is at no point expected from the outside world or imposed upon it. External events, "what happens to us," can never be counted on to cohere for our benefit—that is not the way the world is made—but each individual can choose to be answerable for a coherent set of responses to events, which is what the ideal facilitates. In other words, positing ideals makes wholeness possible in my life. (Emerson, 2003, xii)

In Kalanithi's account, this is precisely what makes striving for an ideal meaningful, even if it also implies that there will always be a lack of conclusive answers for terminally ill patients. Kant noted that we strive to perfect ourselves morally and that this striving is bound to involve a constant struggle (1996, 6, 440). This seems particularly pertinent for the situations of grief, loss, extreme precarity, and unreasonableness described by the four authors examined here. Being oriented by ideals and the possibility of continuously moving towards them, rather than attaining them, become a necessary part of living with terminal illness.

IV. CONCLUSION

While Kant's view has been portrayed as unrealistic and impractical in the light of actual clinical situations, the aim of this paper was to show that Kant's conception of autonomy is relevant for medical ethics. As Kant does, the four patient-authors discussed here perceive the end of life as a moment to reflect on the constitutive principles that have governed that life, thereby offering a privileged moment to pursue self-knowledge. Moral self-scrutiny, identifying universalizable elements of human experience as well as continually striving toward an unattainable ideal are key characteristics of these

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exemplary patient perspectives on terminal illness, as well as constituting some of the central prerequisites of Kantian autonomy. While in these end-of-life narratives the more abstract and rational features of Kantian autonomy are connected to the emotional and embodied experiences of authors, recent work has demonstrated that Kantian autonomy is compatible with attributing moral significance to our social and emotional embeddedness. It might, therefore, be time for bioethical conceptions of autonomy to revisit their interpretation of Kantian moral philosophy as too detached from human reality.

These texts further highlight that patients conceive of self-realization in ways not entirely captured by the principle of "respect for patient autonomy," associated with the right to make one's own decisions. This insight, which aligns with other recent critiques of "patient autonomy," is not meant to diminish the practical significance of the principle itself, but rather to suggest that by updating their conceptual frameworks regarding what self-determination means for patients, clinicians will be able to engage in practices that better support the realization of autonomy. This seems particularly relevant, given that in some instances, as we have shown, indubitably important healthcare processes—such as offering choice and enabling informed decision-making—might be perfectly aligned with the principle of respect for patient autonomy but can be at odds with or even impair patients' sense of their own self-determination.

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NOTES

1 Jeffrey Berman coined the term "end-of-life memoirs" (2012, 11) to describe memoirs written by terminally ill patients.
2 Dworkin is the primary advocate of autonomy as a second-order concept referring to the capacity of persons to reflect critically on their first-order preferences and desires.
3 As these formulations suggest, autonomy is not a trait Kant ascribes to individuals or persons; rather, he has in mind autonomy of the will, of reason, of ethics, and of principles.
4 Beauchamp associates a new interest in autonomy with the birth of bioethics in the 1970s (2011, 516). See also Tauber (2001); Saad (2018) and Ramsey (1970).
5 For an analysis of the difference between the contemporary "Kantian understanding" and Kant's original, see Secker (1999).
6 Notable other examples of the genre, not taking into account non-English-speaking memoirs, include Riggs (2017); Hitchens (2012) and Lubbock (2012).
7 Literary scholarship has played an important role in situating the genre of the illness narrative within a larger framework of medical and social discourse (see Hunsaker Hawkins, 1993; Frank, 1995; Couser, 1997).
8 The use of autonomy in this second sense has affiliations with the Kantian position, even if, as we show below, it does not coincide with it entirely.
9 Rössler links autonomy and diary writing, proposing that the act of writing functions as "scaffolding" for (Millian) personal autonomy, because it involves self-critical reflection (2017, 188 e passim).
10 The intuitive response that engages these authors in the process of writing is, to varying degrees, also reflected in the fact that the narratives discussed here were not conceived as books from the outset, rather as a series of short interventions. They were first published serially (in the case of Diski and Judt) or posthumously as a book (in the case of Kalanithi). The opening line of Judt's memoir is: "The essays in this little book were never intended for publication" (2010a, xiii).

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