

This section welcomes submissions addressing literature as a means to explore ethical issues arising in healthcare. "Literature" will be understood broadly, including fiction and creative nonfiction, illness narratives, drama, and poetry; film studies might be considered if the films are adaptations from a literary work. Topics include in-depth analysis of literary works as well as theoretical contributions, discussions, and commentary about narrative approaches to disease and medicine, the way literature shapes the relationship between patients and healthcare professionals, the role of speculative fiction as a testing ground for future scenarios in healthcare, and so on. Articles discussing the uses of literature for bioethics education and outreach will be particularly appreciated. Research on literature not originally written in English will be considered as long as it has also been published in translation. Submissions should include an abstract and should conform to the CQ Guidelines for Contributors. To submit an article or discuss a suitable topic, write to Antonio Casado da Rocha at antonio.casado@ehu.es.

## Narrative Autonomy

### *Three Literary Models of Healthcare in the End of Life*

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**Abstract:** This article proposes a concept of narrative autonomy to supplement existing accounts in healthcare ethics. This is done by means of a comparison between three end-of-life scenarios: Tolstoy's *The Death of Ivan Ilyich* and two related contemporary stories by Lorrie Moore and Bernhard Schlink, which explore some problems arising when extremely individualistic notions of patient autonomy are put into practice. It is argued that the best model for palliative care is a cooperative one in which patient autonomy is understood as essentially social, and that involves decisional, executive, informational, and narrative dimensions.

**Keywords:** patient autonomy; narrative; bioethics; palliative care; Tolstoy

What do we learn by reading fictional stories about terminally ill patients? One need not assume that narrative approaches to medicine have any privileged epistemic status or therapeutic virtue to argue that they can contribute

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to bioethics education, both classroom based and online.<sup>1,2</sup> A few chosen literary narratives can provide an accessible way to grasp the different bioethical cultures of a society in a particular time. And certain films and short stories are specially suited, in size and thematic range, to discuss ethical dilemmas at the end of life that might otherwise go unnoticed by healthcare professionals.

In this article, I examine existing models of healthcare relationships at the end of life by looking at three literary narratives by L. Tolstoy, L. Moore, and B. Schlink.<sup>3,4,5</sup> The three stories are very different in style and background, but all of them involve cancer patients (a nineteenth-century Russian, a twentieth-century American, and a twenty-first-century German), their caregivers, and the different strategies deployed by them in order to cope with their illness. Tolstoy's *The Death of Ivan Ilyich* is the classic reference, and it still sparks debate; Moore's and Schlink's narratives are rich in allusions to it and provide an illuminating contrast. They are, of course, written in very different times, but by putting them together, we get an overview of the historical development of healthcare ethics until today. Thus the three stories help us describe three different models of relationship: a professional-centered one, a patient-centered one, and a cooperative one.

These stories have not ever been comparatively examined before. After a brief contrast, I argue that only the model underlying Schlink's narrative aligns with international standards in contemporary bioethics, because only such a dialogical, cooperative model shows authentic respect for autonomy. To explain this, I provide a new definition and discussion of *narrative autonomy*, a concept that has not yet been discussed in the bioethical literature, and

that might supplement existing accounts of the multiple dimensions of patient autonomy.

### *The Death of Ivan Ilyich and Its "Sequels"*

At the first Cambridge Consortium for Bioethics Education, held in New York in April 2010, participants were asked to submit three to five of their favorite bioethics readings. Their responses comprise more than 80 references (some entries received several mentions), but the one and only reading mentioned that is from literature is *The Death of Ivan Ilyich*.<sup>6</sup>

This should come as no surprise; mentions of this novella are frequent in the medical humanities. There is an ongoing debate about its lesson concerning the end of life,<sup>7</sup> and leading authors in narrative medicine, such as Rita Charon, recommend it as an example of how the study of literature can help doctors to understand what happens in patients' lives, by portraying the regret of the dying man who realizes how empty his life has been.<sup>8</sup> Followers of narrative medicine argue that healthcare professionals "discover from close reading of and reflection on Tolstoy's classic not only that their patients suffer, but that we all fear death."<sup>9</sup> Charon herself has created "narrative oncology" groups in an effort to decrease staff burnout among members of an interdisciplinary team by developing means of coping with defeat and suffering that involve narrative activities that sharpen and intensify their members' attention on the patient.<sup>10</sup> After all, some patients could still feel very much like Ivan Ilyich: a recent study compared Tolstoy's narrative with that of a contemporary patient, and the latter revealed naïve cancer perceptions ("every treatment option should be tried") and no discussion of death.<sup>11</sup>

This looks very much like the scenario Tolstoy described at the beginning of his narrative, which could be one of the reasons why it has generated not only an academic literature but also literary responses, as we will see now.

In the story, which was published in 1886, Tolstoy introduced Ivan Ilyich as a 45-year-old Russian man who is dying of an unknown cause. Ilyich had set out as a lawyer with high hopes but ended up with a life of social conformity. Doctors, family, and friends provide no help in response to his growing anxiety and existential distress. His loneliness is only relieved by the care provided by a servant. He dies after three days of painful agony and several months of complex psychological turmoil.

Almost a century later, in 1984, Lorrie Moore published her story "Go like This," in which we get a first-person narrative account from Liz, a middle-aged American writer of stories for children who is dying of an unspecified cancer. After surgery and chemotherapy, knowing that the remaining therapeutic options will be futile, she plans a medically assisted suicide, which she performs after throwing a party for family and friends.

More recently, Bernhard Schlink (author of *The Reader*, a novel turned into a well-known film) published "The Last Summer" in his 2012 collection *Summer Lies*. In this story, we get to know Thomas Wellmer, a recently retired German philosophy professor. He has bone cancer but has not disclosed this to his family, with whom he intends to spend the summer at their holiday home. He plans to commit suicide when the pain becomes unbearable, but his wife finds out, and he has to reconsider his plan.

There is a degree of interconnection in the three narratives that makes it easier to use them together. The narrator of Moore's short story draws at

least two explicit analogies between her situation and that of Ivan Ilyich. On the other hand, Schlink is a judge (just like Ivan Ilyich), and many passages have a distinct Tolstoyan flavor.<sup>12</sup> (Philip Roth also uses *The Death of Ivan Ilyich* as a subtext for his novels *Everyman* and *The Anatomy Lesson*, but here I focus only on short stories.)

### Looking at the Narratives through the Triad

All cases are somehow reconstructed, but when we find them enveloped by a literary narrative, the nature of their construal is important to understanding them. In order to analyze the three narratives within a common framework, I use the triadic distinction between disease, illness, and sickness, which has become commonplace in the philosophy of medicine since first introduced in 1968 to analyze concepts of health. The triad refers to the spheres of physical, psychological, and social well-being present in the 1948 definition of health by the World Health Organization: calling-for-action perspectives on negative bodily processes, states, or events, as conceived of by the medical profession, by the very person who feels ill, or by society's institutions.<sup>13</sup> Thus the triadic approach distinguishes between *disease* (the condition as considered by the medical profession), *illness* (the condition from the subjective experience of the patient), and *sickness* (the condition from the perspective of society's institutions).

### *The Patient Perspective*

Although the narrator initially declares that "Ivan Ilyich's life had been straightforward, ordinary and dreadful in the extreme,"<sup>14</sup> as the story unfolds he is more sympathetic toward the main character. It is hard not to be, because this narrative "stands as one of the most effective *memento mori* statements in

world literature"; according to Anthony Briggs in his 2008 introduction, the reason is that "Tolstoy warms to his man as he dies."<sup>15</sup> Other authors agree that in the novella "there is extreme suffering, intense agony; but finally, as death approaches, fear recedes."<sup>16</sup> But more even than physical pain, a big part of the suffering is caused by the "constant tranquillisation about death" described by Martin Heidegger in *Being and Time*, when he writes of the "evasion of death" that dominates everydayness.<sup>17</sup> In Tolstoy's words, "Ivan Ilyich's worst torment was the lying—the lie, which was somehow maintained by them all, that he wasn't dying, he was only ill, and all he had to do was keep calm and follow doctor's orders and then something good would emerge." As a consequence of this lie, what gave Ilyich most suffering was the lack of sympathy.<sup>18</sup>

Unlike Ilyich, the narrator in "Go like This" knows the name of the disease that is killing her, and because Liz is a writer, she is ready to give us a full report in vivid detail. Her experience is devastating, something that the narrative conveys by means of a style that is as poetic as it is desperate: "A month ago I was told I have cancer. . . . It had spread through my body like a clumsy uninvited guest who is obese and eats too much, still finding, filling rooms." She tries to remain normal while mourning for her devastated body: "It is ravaged, paved over, mowed down by the train tracks and parking lots of the Surgical Way." At times she feels more dead than alive, as if her social death has arrived before the biological one: "I am something putrid . . . something incorrect."<sup>19</sup>

The narrative shows Liz's almost schizoid personality, determined on the surface but desperate inside. This is something known in the nursing literature, in which the dynamics between suffering in private and enduring in

public have been described.<sup>20</sup> From the outside, Liz is a strong, modern woman who decides to commit suicide on Bastille Day, "a choice of symbol and expedience." She does not want to let cancer ruin her life and that of her family. She tells her friends that it is a rational choice, but if Ilyich's suffering was about the lie, for Liz, her suffering involves the small response that her decision provokes. After the conversation with her husband in which she tells him about her wish to die, they "never truly discussed it, never truly."<sup>21</sup>

In "The Last Summer," the lie comes from the patient—not from the others, as in the previous stories. The central character in Schlink's narrative is very different from that of Moore's, yet the initial situation is very much the same: a terminally ill cancer patient decides to commit an idealized suicide. Both Liz and Thomas are writers, and they both are described as essentially rational. Unlike Ivan Ilyich, Thomas is not particularly interested in the medical perspective (disease): "He didn't want to be one of those sick people who know everything about their illness, who research on the Internet and in books and conversations and embarrass their doctors."<sup>22</sup>

Illness for Thomas is about having a last opportunity to get closer to happiness, to what really matters to him, and this is what we see in the narrative: he remembers a few stories from the past, he improves his relationship with family and friends after years of distancing caused by his professional commitments (just like Ivan Ilyich), and he gets carried away by music—and by pain management, because pain has become an invasive and threatening presence: "Wherever he felt, the pain was waiting for him, saying, I live here now. This is my home." In a crisis, pain "annihilated his desire, his sensations, his mind, and made him his creature,

unable to escape its grip or even to long for it to stop."<sup>23</sup>

### *The Caregiver Perspective*

According to Heidegger, seen from the perspective of the patient, illness is a source of disruption and collapse,<sup>24</sup> something that defies describing, and that might be the reason why Ivan Ilyich simply calls his pain "It." However, healthcare professionals appropriate his diagnosis; for some, Ilyich "appears to have hepatocellular carcinoma," whereas others associate it with the concept of "total pain" as developed by Cicely Saunders and the hospice movement.<sup>25,26</sup> Both readings fit well with the story, but we should be careful when imposing a diagnosis on a fictional character, as it might well be an act of medicalization that detracts from other interpretations of the story. Indeed, there is no direct evidence that Ilyich has cancer; the fact that oncologists appropriate his diagnosis is just their way of making Tolstoy's story of relevance to them.<sup>27</sup>

One of the best features of *The Death of Ivan Ilyich* lies in its depiction of the interaction between patient and doctor. Granted, Tolstoy's opinion of the medical profession is not good—it is indeed as bad as his opinion about the courts, and Tolstoy plays with the analogies between both professions. Disease here (as in the *House, M.D.* television series) is not about a personal relationship with the patient, but a mere balancing of probabilities: "Such-and-such demonstrates that in your inside there is such-and-such, but if this is not confirmed by our tests on this-and-that then you will need to go on to such-and-such." (Fortunately, Ilyich is not only taken care of by professionals. There is an informal caregiver, Gerasim the manservant, the only one who did understand Ilyich and was sorry for him.)<sup>28</sup>

As for "Go like This," initially the attitude of Liz's doctor is to follow the beaten track of paternalism, but unlike Ivan Ilyich, she is not willing to be patronized. Then the doctor "was taken aback, vaguely annoyed. Ad lib unpleasantries, my, my. He did not have lines for this." From that moment on he treats her with cold, defensive professionalism, with "the glare one gives a fractious child who is not going to get ice cream," and resorts to statistics: "Women have survived much greater damage than you have suffered, much worse odds, worse pain than this."<sup>29</sup> Once Liz expresses her decision to die, he disappears from the narrative.

Similarly, there isn't much to tell about the caregiver perspective in "The Last Summer," because Thomas decides to be his own "angel of death," and therefore the caregiver is practically absent in this narrative. A doctor gives him a prescription for morphine, which is handed to him in the pharmacy "with a glass of water and a sad smile."<sup>30</sup>

### *The Social Perspective*

According to Heidegger, inauthenticity toward death is the *das Man* attitude of neglecting and dismissing it: death is seen as something that only happens to "them."<sup>31</sup> That is the departing point for Tolstoy: at Ilyich's funeral, a colleague of his fears that something like that could happen to him but rejects the feeling as something inconvenient. Ilyich's relationship with his wife and daughter is also representative of Heidegger's description of death as "a social inconvenience, if not a downright tactlessness"<sup>32</sup> that stands in the way of the plans of the living. The social perspective over sickness is also understood in terms of fault and blame. On the day of the funeral, the daughter looked to a friend, "gloomy, assertive, almost truculent . . . in a

way that suggested he was to blame for something." "What have we done wrong?" she asked her mother. "Anyone would think it was our fault. I'm sorry for Papa, but why do we have to suffer?"<sup>33</sup>

In "Go like This" we see a wholly different situation. Patients expect to be informed by their doctors, and decision-making moves toward the patient. However, when Liz tells her friends about her suicide plans, it seems "as if they had already known before and had nothing but clinically prepared affirmations," convinced as always of Liz's sound-mindedness. "You have obviously thought this out," says a friend. "You have our love and our support, Liz." But she quietly remarks that this friend "seems to speak for everyone, even without conferring. . . . There appears to be no dissent."<sup>34</sup> In this central moment, the narrator summarizes most of the story: everyone speaks for everyone, but without really discussing things. This is yet another instance of Heidegger's "constant tranquillisation about death"<sup>35</sup> provided by the "them" self.

"The Last Summer" seems to be heading toward the same end as Moore's narrative. Thomas is able to lead a normal life and control the pain with morphine, but one night when he gets home, he discovers that his wife has found the "cocktail" he had stored away. She feels betrayed and angry. When he replies that he thought it "a good way to say goodbye," she says: "You're not saying goodbye to me, you're saying goodbye to yourself, and you want me there to act as a sort of movie extra."<sup>36</sup>

After learning that he was making all those decisions without them, his family is ready to leave him alone. After their departure from the holiday home, he realizes he cannot cope without his wife—not because he cannot perform daily routines; initially he can take care of himself and is functionally autonomous. But he realizes that he had

imagined an unrealistic picture of the close future, one in which time itself would do the decisionmaking, as it were. Thomas then goes through a sort of mourning period. He cannot cope, gets drunk, and has an accident at home. Then, at the most dramatic point of the narrative, he writes and sends to his wife a letter in which he acknowledges that in everything he had done in his life, he had drawn on the fact that he had her at his side. Therefore, he realizes that he will not be able to make his decision without her and proposes a new arrangement: "When things can't go on, we'll decide together that they can't go on."<sup>37</sup>

### Discussion: Underlying Models in Healthcare

An examination of these interconnected narratives provides a lively account of the development of the main paradigms in healthcare ethics. Ivan's narrative illustrates the received view of medical paternalism. Liz's is about the reaction against paternalism and the defense of patient autonomy, which was brought about by the rise of bioethics in the second half of the twentieth century. In turn, Thomas's narrative can be read as a postbioethics attempt to redescribe patient autonomy in more realistic terms, avoiding the individualistic extreme that might ultimately lead to patient abandonment.

Tolstoy's narrative is set in a model of interaction now known as benevolent paternalism, which was hegemonic in nursing and medical practice at least since the Hippocratic tradition; this hegemony has only recently been questioned. Moore's story is a disturbing twentieth-century response to Tolstoy's. Accordingly, the underlying model is the most radical theoretical alternative to medical paternalism, a model based primarily on patient autonomy, loosely

understood as patients having a right to control what is done to them. It is their lives and bodies that are at stake; they should have the final authority to decide what is done, and not the doctor or the nurse. In this model, the role of healthcare professionals should primarily be to provide the medical information on which patients can base their choices.<sup>38</sup>

It is important to note that, although the principle of respect for autonomy is considered by many authors in bioethics to have paramount importance,<sup>39</sup> it is not hegemonic. In practice, paternalism might remain present in many places in Europe as well as in America. Liz's narrative suggests that patients have to actively resist paternalism if they want to be autonomous. However, if Tolstoy's story provides no role model we can follow today, neither does Moore, whose story remains unreliable "as a model for the practice of suicide."<sup>40</sup> Although Liz's suicide is inspired by the real case of artist Jo Roman,<sup>41</sup> Moore provides many clues in the narrative that suggest that this is not a model she wants to endorse. Thus her story summarizes the dangers of conceiving autonomy in purely individualistic terms.

The extremely paternalist and autonomist models are both unrealistic. In one, only the doctor knows, and in the other, only the patient; each in a different way is monological. Much current work in bioethics is about how to implement a third model that accommodates the best of the previous ones (beneficence and respect for autonomy) while avoiding the dangers of giving too much weight to one or the other principle. One of those alternatives is the cooperative model of interaction in healthcare relationships described by Árnason,<sup>42</sup> which is explicitly designed in terms of communication. Based on the conviction that conversations between patient and caregivers

are the optimal way to reach the objectives of healthcare, this model promotes dialogue and authentic conversations (not Heidegger's "idle talk") between the main agents in the healthcare relationship: the patient, the caregivers, and other agents in their social background.

Although the starting point for Schlink's narrative is similar to that of Moore's, with patient autonomy as the underlying model, the cooperative third model is arguably the destination point this narrative is moving toward, when at the end of "The Last Summer" Thomas needs to communicate with his wife to make and execute his final decision.

### Conclusion: Four Dimensions of Patient Autonomy

In the last decade, several bioethics scholars<sup>43,44,45</sup> have independently argued for an expansion of the concept of patient autonomy to include not only the ability to make informed therapeutic choices (decisional autonomy) but also executive autonomy—the capacity to execute complex self-care and management tasks—and informational autonomy—the personal management of health-related information, such as the right to give or withhold it freely and without pressure.

Are these dimensions of autonomy present in our three narratives? Until now I have stressed the genealogical connections and similarities between Ivan, Liz, and Thomas, but there is a crucial difference in their stories concerning these dimensions of patient autonomy. Thomas is autonomous in all three dimensions—he decides to commit suicide (decisional autonomy) and is able both to carry out his decision (executive autonomy) and to hide it from others (informational autonomy). However, he feels something is missing; like Liz and Ivan, illness isolates him. But of all three stories, only this

one is open ended: after Thomas's crisis, we do not know whether his wife is going to answer his letter, and if so, how. But this new situation, no matter how dynamic and uncertain, is much more acceptable to contemporary ethical standards in healthcare—such as those in the 2005 UNESCO Declaration on Bioethics and Human Rights (articles 5 and 18.2)—than the ones described by Tolstoy and Moore.

The dialogue required by the UNESCO declaration might explain why Schlink's narrative is more acceptable to us. As we have seen, Tolstoy's and Moore's narratives are monological: decision-making is centered either in the professional or in the patient, but there is no real dialogue between them. This is mainly because the "evasion of death" described by Heidegger causes the telling of a lie that in turn prevents the enactment of an authentic autonomy. Because of the lie, Ivan is clearly a victim of medical paternalism. And, although Liz exerts a lot of decision-making power, it does not seem to be authentic (for instance, she performs her suicide out of a sense of duty, just when she discovers how to finish a children's story on which she had been working for years). If, as readers, we are sympathetic to Schlink's open-ended narrative, it is because it promises authentic respect for autonomy. This involves not only the three dimensions mentioned but also an extra one, which I will call here *narrative autonomy*. It involves recognizing that when we say that an agent is autonomous, we predicate not only a constitutive property (its separate identity or self) but also an interactive one (its relationship to others).

The concept of narrative autonomy as such has not yet been fully developed in healthcare ethics, but it is an emerging one that deserves more research and application. I propose the following definition for it: persons are

narratively autonomous when they are able to interact with others on the basis of a shared story that links past and future. This is done by means of narratives, artifacts conveying the story of a person to achieve a sense of "inner time" that Hurwitz describes as a connection of "ideas and memories of past experiences" with present ones,<sup>46</sup> similar to what is achieved at the end of Thomas's story. Therefore, narrative autonomy requires a connection between the patient's environment or audience and his or her own sense of time. This temporal aspect helps us distinguish the decisional (or synchronic) dimension of autonomy from the executive (or diachronic) one. Thus *decisional* autonomy is the present capacity of patients to make healthcare decisions, whereas *executive* autonomy is the capacity to implement those decisions over time in self-care practices; both are constitutive in the sense that they are properties of patients in relation to themselves. On the other hand, we also have two interactive dimensions of autonomy, involving how patients enact those practices in relation to others: *informational* autonomy (the capacity to manage their health information in the present moment) and *narrative* autonomy (the capacity of patients to develop a shared story linking their past and future).

All patients are "written" about by doctors and healthcare professionals who (re)create clinical notes, stories, or cases. This is an important part of their job, and they employ degrees of narrative competence to do that, as Charon and other scholars have stressed. But patients can "do" narrative oncology, too. They can write stories besides the clinical one, first-person accounts of their illness that supplement the medical concept of disease. This narrative dimension of autonomy integrates the perspectives of the



patient, the caregiver, and society, in a model of healthcare interaction that is dialogical and cooperative. Together with the decisional, informational, and executive dimensions, the narrative dimension provides a new, more comprehensive account of patient autonomy.

Notes

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