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*AM J HOSP PALLIAT CARE* 2013 30: 507 originally published online 11 July 2012

DOI: 10.1177/1049909112452626

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# How Tolstoy and Solzhenitsyn Define Life and Death in Cancer: Patient Perceptions in Oncology

American Journal of Hospice & Palliative Medicine®  
30(5) 507-511  
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DOI: 10.1177/1049909112452626  
ajhpm.sagepub.com  


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## Abstract

**Reason for the study:** Clinicians use conserving care in their therapeutic decisions. Discussing death as part of the treatment influences patient's perception and their acceptance of death. We compare 2 literary patients' perceptions of cancer and death (Solzhenitsyn's *Cancer Ward* and Tolstoy's *The Death of Ivan Ilyich*), with a contemporary patient perception. **Results:** The patient interview revealed naive cancer perceptions: every treatment option should be tried. In Solzhenitsyn's novel, the main character finds a goal in love; Tolstoy conceptualizes death as a solution for patients' moral issues. **Conclusions:** Tolstoy's novel shows death as an honest prospect. Solzhenitsyn's novel shows the opposite: the prospect of love and life helps the protagonist patient psychologically through his disease. The patient interview revealed no discussion of death at all.

## Keywords

medical humanities, biopsychosocial, cancer, death, literature and medicine, patient perception

## Introduction

Patients suffering from cancer have always been treated thoroughly and exhaustively. Unsurprisingly, discussion of death is something most patients with cancer are keen to avoid for as long as possible. The possibility of dying of cancer is often only mentioned at the end of treatment, as medical professionals feel their priority is to try and cure the patient. Research is scarce about whether patients want to discuss the prospect of death earlier in the treatment trajectory. However, discussing death in the process of seeking the best treatment can perhaps give a patient a more honest and balanced perception of the illness, its treatment, and course. Continuing aggressive, and perhaps desperate, curative treatment, despite an infaust prognosis, can lead to a situation with a substantially reduced quality of life in the patient's final few weeks. "Top priority of patients in this phase is, in addition to avoiding suffering, being with family, being mentally aware, and not becoming a burden to others. Medical technology and care have given many ways to prolong life, but should not create a new difficulty for mankind: how to die."<sup>1</sup>

In this article, we sketch a biopsychosocial picture of living with (and dying from) cancer. In addition to biomedical knowledge, biopsychosocial knowledge may be helpful in furthering the understanding of suffering. This in turn may lead to more humane (medical) care for patients and also to a more dignified death.

Lev Tolstoy (1828-1910) is a well-known Russian writer; his work is famous for having a moral message regarding life,

of which his novel *Resurrection* is a good example. In his novel *The Death of Ivan Ilych*, the main character, Ivan, spends his final weeks reflecting on his spoiled life. Ivan Ilyich is a patient who appears to have hepatocellular carcinoma. Tolstoy proposes death as a solution to this suffering: death as a solution to both the disease and a morally weak life. "It was nearing the end of the third day, an hour before his death. (. . .) This was the very moment when Ivan Ilyich had fallen through and seen a light, and it was revealed to him that his life had not been what it should have been, but that it could still be put right. (. . .) Where was death? There was no fear whatsoever, because there was no death. Instead of death there was light"<sup>2(p104-105)</sup> Ivan understands his condition and begins to reflect on his life, in the light of death. His life seems wasted to him due to the choices he made and the life he lived which was light, "easy going" and comfortable.

Solzhenitsyn (1918-2008), in his major novel *Cancer Ward*, gives a detailed description of different perceptions of cancer in different patients with cancer. The main character, Oleg Kostoglotov, reflects and meditates on life as he enters the cancer

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ward, and he continues to do so during his treatment. Despair and anxiety are the main emotions in his mind when entering the cancer ward, whereas it is interest in the outside world and enthusiasm about life that characterize his feelings when he leaves the cancer hospital.<sup>3</sup>

Our analysis of patients' accounts and narratives of literary figures in novels or other forms of art expressions falls within the context of medical humanities. This relatively recent field of research, teaching, and clinical care is defined by Brody as:

... a field of medicine, which combines art and literature with medical practice. This field seeks to educate future health professionals who adopt a more critical and reflective stance toward their work and toward the knowledge that informs it. The narratives remind us that the conceptions of the humanities are linked to ways of living our lives and addressing problems in the real world.<sup>4</sup>

Medical humanities aim at giving a better insight and perception into how patients make sense of their illness and its treatment and of their suffering. Literature (novels and poems) can be used to provide a perspective on this. Patient stories can be understood in a medical humanities perspective by studying novels, poems, movies, paintings, opera, and can also help medical professionals to better understand what the patient is going through. Both novels and the patient interview in this article also aim to do so. Our approach may be instrumental in helping medical professionals to communicate in a better way in the process of helping a patient with cancer, particularly psychologically.<sup>5</sup> Reflection on treatment cannot be ignored as part of the dialogue between the physician and the patient. Reflection can give an honest evaluation about quality of life and about the patient's prospect. Reading literature gives the physician an instrument in dealing with patients' feelings because literature describes these feelings. By reading about this, patients' problems and sufferings can be better understood.

In both novels, we see 2 characters reflecting on living with cancer. Death takes a serious place in these reflections. Studying this literature can give a context to the narrative of a contemporary patient. Both literary works can be used to teach health care providers about medicine and clinical care as some people may feel that "the creative work of a genius expresses what they feel, better than they themselves could express it."<sup>6</sup>

## Methods

This article discusses and compares 3 different perceptions about cancer. One perception is from an actual patient suffering from small-cell lung carcinoma, and 2 perceptions are from patients with cancer in works in Russian literature.

A.T. is a 67-year-old male patient with small-cell lung carcinoma. Before his retirement, he was a civil engineer. He was interviewed in his home in June 2011. The interviewer recorded the interview. A.T. is well known to the interviewer as they were friends.

A.T.'s medical history started in March 2009, when the patient was 65 years old, with pain in his lower back. After investigations and many tests in several hospitals, A.T. was diagnosed with small-cell lung carcinoma. A protocol of radiation therapy and chemotherapy was started. Recovering from his third chemotherapy, at the time of the interview, A.T. was waiting to get his fourth and final treatment the following week.

The novel *The Death of Ivan Ilyich* was published in 1886. We focus on Ivan Ilyich and his perception of both life and his suffering. The novel *Cancer Ward* by Solzhenitsyn was published in 1967. Although at least 2 main characters are presented in the novel, we focus on Oleg Kostoglotov and his struggle for love, which feeds his perception of his cancer during his stay in the cancer ward.

We have selected quotes from both novels and then compared and contrasted these quotes with excerpts from the patient interview. In addition, we used current research literature on psychosocial issues in cancer care and dying in order to put the 3 narratives in perspective.

## Results

### First Perception, Interview AT

"In March 2009 this disease story started with lower back pain. My general practitioner prescribed me with antibiotics, which I thought was strange. I mean, lower back pain . . . ?" A.T. has critically followed every medical decision step by step. "After this did not work out well, I was sent to different hospitals for a CT scan, X thorax, PET scan and some biopsies via a bronchoscopy but the only results were from the X thorax." A "spot" on the X-thorax was seen, and from this a diagnosis of lung cancer was concluded; biopsies were taken to differentiate among the various forms of lung cancer. After several biopsies, finally a result came. "My daughter looked up all the information on lung cancer on the Internet, because she wanted to help and support me. She made a summary of all the different forms, and below that, she wrote: 'And you can have small-cell lung carcinoma, but when you are diagnosed with that form, you can forget about being cured.' It was small cell lung carcinoma. Due to this sentence I was sadly surprised that it was exactly this form of lung cancer, the worst form of lung cancer you could get."

Fifteen years ago, A.T. quit smoking. "Smoking cannot be the cause of my disease. When you quit fifteen years ago, the risk you develop lung cancer is the same as when you are a non-smoker." A.T. sees the cause of his disease as arbitrary. "The same can happen to you (referring to the interviewer). The cause is always arbitrary and that's the most unjust aspect, the arbitrary cause". In A.T.'s own opinion, there is no specific reason why he was diagnosed with this type of cancer.

In the end, the diagnosis was "limited small-cell lung carcinoma," and A.T. then started radiation therapy at a special clinic. "The adverse effects to my oesophagus were devastating, a terrible burning feeling when food was passing through

it. At that time I could only eat fluid food. This disease was affecting more and more of my daily life and my freedom. This made me frustrated because I really enjoy a good meal. Now the disease is quite far advanced, these things are going really badly.”

“I am happy with the professional help I get in Holland. Doctors are very professional in communicating, especially the younger ones. I got a second opinion in Houston, USA, and there they were impressed with my professional help here. Death can be avoided because this cancer can be fought adequately with chemotherapy. Also with my wife’s and family’s help, I am able to fight this disease now. I am still not suffering from severe pain, but when it comes, I will then have to fight this disease on my own.” And how is daily life, considering these circumstances? “I say everything is well, considering the circumstances. But frankly, it is miserable. Fortunately I can rely on my wife and adult children; they balance my emotions and counteract my sorrow. They still make it worthwhile to fight this disease, despite the fact that I lose the pleasure and quality in the things I do.” Currently A.T. is resting in preparation for his final chemotherapy course. “I take each day as it comes. I expect no more than that. In the near future my wife and I are planning to travel around some countries in Europe. I am not depressed, but suffering from this disease does distress me. I live day by day. Nothing in this was ever expected. We recently bought a new house, and were aiming to concentrate on this house as a purpose, and not on this disease.”

During the whole interview, A.T. seemed rational, realistic but very denying. He has read *The Emperor of All Maladies* by Siddharta Mukherjee. “Reading this book gives me a thorough overview on medical science. It surprises me. They could have known a lot more about my disease. Could I have been cured? And now, what will my end be like? Will I be able to die suddenly, like my parents did, who died from a heart attack? I fear pain, it can make me suffer. Shall suffering make me wish for a speedy death? I don’t know.” And while saying this, A.T. looks at his wife who is crying.

### Second Perception, Ivan Ilyich

“The fact that Ivan Ilyich sometimes complained of a strange taste in his mouth and a funny feeling in his left side didn’t count as ill health. But as it happened this funny feeling began to get worse and turned into, if not pain exactly, a constant dragging sensation in his side, which put him in a bad mood”.<sup>2(p41)</sup> With this description, Ivan Ilyich’s disease starts. This description may be suggestive of any form of cancer.

The unpleasant, dull feeling becomes a daily companion. It affects the brightness of Ivan Ilyich’s mind and humor. “He was made to wait, the doctor was full of his own importance—an attitude he was familiar with because it was one that he himself assumed in court—then came all the tapping and listening, the questions with predetermined and obviously superfluous answers, the knowing look that seemed to say, “Just place yourself in our hands and we’ll sort it out, we know what we’re doing, there’s no doubt about it, we can

sort things out the same way as we would for anyone you care to name”.<sup>2(p43)</sup>

All Ivan Ilyich wants to know is whether it is a dangerous condition or not. “As far as Ivan Ilyich was concerned there was only one question that mattered: Is this condition life-threatening or not? But the doctor treated this question as irrelevant, and ignored it”.<sup>2(p43)</sup> This question becomes reality: it becomes a symptom of the disease itself. “The pain in his side went on wearing him down and seemed to be getting worse, nagging incessantly, while the taste in his mouth got more and more peculiar and he began to think that his breath smelt awful, and his appetite and strength fell away. The time for fooling himself was over: something new and dreadful was going on inside Ivan Ilyich, something significant, more significant than anything in his whole life. This was what tormented Ivan Ilyich more than anything”,<sup>2(p48-49)</sup> and so on.

Ivan is more and more convinced about the seriousness of his condition. “Ivan Ilyich could see that he was dying, and he was in constant despair. In the depths of his soul Ivan Ilyich knew he was dying but, not only could he not get used to the idea, he didn’t understand it, couldn’t understand it all”.<sup>2(p61)</sup> . . . “When I’m dead, what happens then? Nothing happens. So where shall I be when I’m no longer here? Is this really death? No I won’t have it”.<sup>2(p57)</sup>

Ivan Ilyich is suffering more and more. Pain fights his being. Pain and suffering fight his existence and lived life. “And in his imagination he started to run through the best times of his happy life. But what was strange was that all the best times of his happy life no longer seemed anything like what they had been before. (. . .) It’s not possible that life could have been as senseless and sickening as this. And if it has really been as sickening and senseless as this why do I have to die, and die in agony? There’s something wrong. Maybe I didn’t live as I should have done? came the sudden thought”.<sup>2(p90)</sup>

Ivan Ilyich starts living life in imagination. His critical analysis of life makes him suffer. A moral weakness is what he sees, because he has lived his life in a shallow and materialistic way. In such a situation, death can almost be a pleasant solution, as a relief from both his reflection and his pain. “He resisted like a condemned man resisting his executioner, knowing that he is not going to be spared, and with every minute that passed he sensed that despite all fighting and struggling he was getting nearer to the thing that terrified him. He sensed that the pain came from being thrust into that black hole and, what was worse, not being able to get through. What was preventing him from getting through was his insistence that his life had been a good one. This vindication of his lifestyle was holding him down, preventing him from moving on, and causing him the greatest suffering”.<sup>2(p103)</sup> After realizing this, he has realized something what he never did before. “What death? There was no fear whatsoever, because there was no death. Instead of death there was light”.<sup>2(p105)</sup>

Death is a pleasant escape after the knowledge that Ivan Ilyich gained. This insight helps him through death, although his death turned out to be a terrible event for his wife and children.

### Third Perception, Oleg Kostoglotov

*Cancer Ward*'s main character Oleg Kostoglotov has stomach cancer. As a former prisoner of a labor camp, he is determined to live, however. "Though his life promised him nothing that the people of this great town called good and struggled to acquire: neither apartment, property, social success nor money, there were other joys, sufficient in themselves, which he had not forgotten how to value . . . the right to rest on Sunday; the right to bathe in the river . . . And among them was the right to talk to women".<sup>3(p167)</sup> Kostoglotov is very concerned about his health. He wants to know about every medical decision step by step. "One fool can ask enough questions to keep a hundred wise men too busy to answer them all"<sup>3(book 2, p356)</sup> and "When they used X rays to destroy cells did they know, approximately even, what percentage of healthy cells as compared to diseased ones would be destroyed?"<sup>3(p365)</sup>

Due to his medication Kostoglotov becomes impotent. He suffers from that. Future life is taken from him. "First my own life was taken from me, and now I am being deprived even of the right . . . to perpetuate myself. I'll be the worst sort of cripple! What use will I be to anyone? An object of men's pity—or charity?"<sup>3(book 2, p359)</sup> Oleg Kostoglotov is nursed by a doctor with whom he falls in love. This feeling becomes a motivation for life. "He felt like saying something quite simple and friendly to her, something like 'Let's shake hands on it.' Then he would take her hand and—'my God, it's wonderful just talking to you!' His right arm was under the needle, though".<sup>3(p362)</sup>

Disease affects his behavior which in turn affects his possibilities in showing affection. But this restriction keeps him motivated to live.

After his treatment, Kostoglotov is able to leave the cancer ward. "Kostoglotov was in a hurry to leave, afraid something might crop up to detain him".<sup>3(p518)</sup> He immediately starts searching for the doctor he fell in love with. "His one joy would be to go and lie at her feet like a dog, like a miserable beaten cur, to lie on the floor and breathe on her feet like a cur. That would be happiness greater than anything he could imagine".<sup>3(p544)</sup> But in the end, Kostoglotov remembers he is now a cripple, in a figurative sense. He thinks his love would not be complete enough due to the treatment he got and that his resulting impotence would make him less valuable. He leaves the doctor a note and travels on cherishing the feeling of love. Facing life alone, with just this feeling is enough.

### Discussion

Comparing these 3 perceptions, we see similarities between the perceptions of A.T. and Oleg Kostoglotov. Family plays an import role in coping in A.T.'s situation. A.T.'s perception is rational and sober. He sees treatment as a remedy to continue and live life. Treatment is life. In *Cancer Ward*, treatment means suffering.<sup>7</sup> Unplanned, as cancer always is, and not welcome in his retirement, A.T. seems to be disappointed in his fate. Pleasure in life is interrupted. A.T. does not blame his

disease for its arbitrary nature. This time of suffering focuses his view on his family and his type of cancer. He has read *The Emperor of All Maladies* by Siddhartha Mukerjee.

On the other hand, disease and death gives Ivan Ilyich a serious reflection on his life. The miserable shallowness of this life is a judgment he can only see in the light of death. The moral weakness of it makes him aware of death as a solution. The only remark about death A.T. got from his doctor during his treatment was that he would not survive in the coming 5 years. Despite the horror of the event, the prospect of death can perhaps deepen a patient's life. It can, on the other hand, increase psychological stress, but the honest approach will prevent the process of trying to delay the inevitable. A.T. got social support from his wife and children. His family gives him the emotional balance to prepare psychologically for death. However, anticipation from the physician comes with an approach that ignores futile treatments despite the fact that the prosperous society we live in demands a longer life. Ivan Ilyich on the other hand is frustrated in his anticipation of death due to the shallowness he sees, when he thinks of death.

Kostoglotov takes his suffering as part of life. As a prisoner and slave in labor camp, he was used to the gloomy state his life was in. Love is a sparkle, a glowing light, in which he deepened his life. A.T. also took this approach and is comforted by his family and grandchildren. However, his story shows only increased concern about how to be cured. What is the best treatment? Who are the best doctors? Unlike Ivan Ilyich, death does not give a different insight into the rationalistic approach A.T. has toward cancer. But on the other hand, such a rationalistic approach has helped A.T. to come to grips with his prognosis.

Both novels are novels of reassessment.<sup>7</sup> Ivan Ilyich finds this in reflection and communication with his servant Gerasim, and Oleg Kostoglotov in love and communication with his doctor Vera. A.T. finds reassessment in his wife, family, and deepening on how to cure the disease and how to encourage a process of cure.

Cancer immediately focuses the patient to think about death, it induces different perceptions from patient to patient. A.T. focuses on curing the disease, he focuses on the process of curing. Curing is his hope. But when it does not go this way, this can evoke depression and a gloomy state of life, with no chance for anticipation of death. It can hasten the desire for death while in the mean time A.T. has not had the chance—that Ivan Ilyich did have—to come to grips with life itself.

This case study has a few limitations. Our sample is small, and the selection of the 2 novels and a patient is somewhat arbitrary. Nevertheless, our study may help inspire others in doing similar exercises. Nurses seem particularly well placed, given their access to patients, to replicate our study, with patients suffering from cancer—or any illness for that matter.

Medical professionals might be interested in these results because they give an insight into patient perceptions. It also gives insight into the way medical professionals could discuss (unnecessary) treatment. One important advantage is that this case study includes comparisons between perceptions from literature and the perception of a contemporary patient. The



patient interview gives a good example of a modern perception and is compared with literary patient perceptions in an earlier stage of medical science. Our findings can be utilized in further research about discussing death, not only in oncology treatment but also in other fields of medical care. Future research might consider studying larger samples, using alternative theoretical approaches, and examining additional themes (eg, coping, symptom perception, doctor-patient communication).

A clinical implication of our study relates to the suggestion that mentioning and discussing death in the consulting room may help a medical professional choose between stopping the treatment, and accept death as an imminent part of life, or continuing the treatment. "Society attributes to physicians the role of being responsible for conquering and overcoming death. The physician thus becomes omnipotent. Within this context, and in the presence of incurable diseases, the physician is faced with his inability to deal with these irreversible conditions. Consciously or unconsciously, the physician must face his own limitations, which can be frustrating."<sup>8</sup> Mentioning death and discussing death can protect elderly patients when they have to make this (shared) decision, especially when considering the balance between benefit and harm. Additionally, discussing death is a worthy and humanistic approach for physicians when communicating the discontinuation of anticancer treatment or in general.<sup>9</sup> Patients can expect an honest carer who seeks no unnecessary treatment. A carer who is perhaps more focused on improving their quality of life. This can in turn help a patient sustain a better quality of life in their final phase of life. Finally, discussing death can be a helpful tool when training students for cases in which they have to deliver bad news.<sup>4</sup> In general, when continuing treatment is no longer of any benefit, discussing death and quality of life can help both medical professionals and patients to avoid further treatment which would only reduce quality of life in the palliative stage of disease.

### Acknowledgment

The authors would like to thank Donald Freeke in correcting the manuscript for English language.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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