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REFLECTIVE ANALYSIS ARTICLE

PAIN AND SUFFERING IN CHRONIC DISEASE: REFLECTION FROM THE "DEATH OF IVAN ILYICH"

DOR E SOFRIMENTO NA DOENÇA CRÔNICA: REFLEXÃO A PARTIR DA "MORTE DE IVAN ILITCH"

DOLOR Y SUFRIMIENTO EN LA ENFERMEDAD CRÓNICA: REFLEXIÓN A PARTIR DE LA "MUERTE DE IVAN ILITCH"

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ABSTRACT

Objective: to reflect on the romance by Leo Tolstoy "The Death of Ivan Ilyich" and current health policies relevant to the individual's disease process. **Method:** this is a descriptive and reflective study on the relevance of current health policies on health and the individual disease process in connection with the work of Leo Tolstoy and current literature, located through electronic search in PubMed/Medline, Lilacs and Scielo database. **Results:** the study was to meet regulatory arising from current laws of the current Health System based in the universality, equity and Completeness of Health Care, which could influence the direction of care management. **Conclusion:** care management, through contemporary health policy would be welcomed by Ivan Ilyich, and the principles of universality, integrality and equity in health care would provide an adequate and humane care. **Descriptors:** Knowledge; Nursing; Nursing Care; Health Management.

RESUMO

Objetivo: refletir sobre a novela de Léon Tostói "A Morte de Ivan Ilitch" e as políticas de saúde atuais pertinentes ao processo de adoecimento do indivíduo. **Método:** trata-se de um estudo descritivo e reflexivo acerca da pertinência das políticas de saúde atuais no processo de saúde e doença do indivíduo, em contexto com a obra de Léon Tostói e a literatura atual, localizada por meio de busca eletrônica na Pubmed/Medline, Lilacs e no banco de dados Scielo. **Resultados:** o estudo conduziu ao encontro de normativas oriundas das leis atuais do Sistema Único de Saúde vigente embasadas na Universalidade, Equidade e Integralidade da Atenção à saúde, que poderiam influir no direcionamento da gestão do cuidado. **Conclusão:** a gestão do cuidado, através da política de saúde contemporânea, seria bem recebida por Ivan Ilitch, e os princípios da Universalidade, Integralidade e Equidade na assistência médica proporcionariam um atendimento adequado e humanizado. **Descritores:** Conhecimento; Enfermagem; Cuidados de Enfermagem; Gestão em Saúde.

RESUMEN

Objetivo: reflexionar sobre la novela de Léon Tolstói "La Muerte de Ivan Ilich" y las políticas de salud actuales pertinentes al proceso de enfermarse del individuo. **Método:** se trata de un estudio descriptivo y reflexivo acerca de la pertinencia de las políticas de salud actuales en el proceso de salud y enfermedad del individuo, en contexto con la obra de Léon Tolstói y la literatura actual, localizada por medio de búsqueda electrónica en Pubmed/Medline, Lilacs y en el banco de datos Scielo. **Resultados:** el estudio fue AL encuentro de normativas de las leyes actuales del Sistema Único de Salud vigente basadas en la Universalidad, Equidad e Integralidad de la Atención a la salud, que podrían influir en el direccionamiento de la gestión del cuidado. **Conclusión:** la gestión del cuidado, a través de la política de salud contemporánea sería bien recibida por Ivan Ilich, y los principios de la Universalidad, Integralidad y Equidad en la asistencia médica proporcionarían un atendimento adecuado y humanizado. **Descritores:** Conocimiento; Enfermería; Cuidados de Enfermería; Gestión en Salud.

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INTRODUCTION

Leo Tolstoy was recognized as one of the greatest writers of the story, the romance *The Death of Ivan Ilyich* is among his many acclaimed works as *War and Peace* (1965 - 1869) *Anna Karerina* (1875-1877). The author throughout his life experiences a series of spiritual transformations that lead to new ways of living, seeking the understanding of oneself, in a covert society by political and ecclesiastical authority. He devoted his life in communion with nature seeking self-sufficiency. He died at 82 years old in 1910 with some of his works published posthumously.¹

In the romance *The Death of Ivan Ilyich*, Tolstoy describes a time when bourgeois life benefited from the higher classes allowing social, policies benefits and access to health care. Ivan Ilyich had all the access to medical consultations and monitoring of professional seeking a diagnosis for his illness, and a financial condition favoring him because he lived in a time when health policy was not universal and had no concern with chronic diseases, only with the prevention and control of infectious diseases to preserve the health of the masses that moved to the production of goods, determined by the capitalist economy of the market, where the focus of medical care was the poor who represented the workforce.²

The Death of Ivan Ilyich tells the story of a judge, Counsel of the Appeal Court, who dies at forty-five years old affected by a chronic disease, and having a deep social and family decay experience to discover and feel the illness, perceiving as a person useless and haunted by stories of his past, by his degrading and progressive physical pain of their present and fear of an end.

The romance passes from the childhood to youth of the character, to become man and provider of a family not showing as an enthusiast or a lover for life or for those around him. He worked, received friends and ignored the bad mood of his wife and so follows no major events until a stranger like that sometimes felt in the mouth evolves into a sickly background irritability and later confirmed the presence of a disease that will turn his life in an endless suffering during his trajectory to rendezvous with death. The reading of the story exposes the profound suffering experienced by Ivan Ilyich, crucial point and the object of our analysis.

OBJECTIVE

- To reflect on the romance "*The Death of Ivan Ilyich*" by Leon Tolstoy and current health policies and its relevance in the individual disease process.

MÉTHOD

It is a descriptive and reflective study on the relevance of current health policies on the health and the individual disease process, in context with the depicted in the work of Leo Tolstoy "*The Death of Ivan Ilyich*." For the preparation of this reflection, it was decided to exhaustive reading of that work of Leo Tolstoy, in addition to literature review related to current health policies and the process of health and disease in papers located through electronic search on Pubmed/Medline, Lilacs and Scielo database.

The study enabled the creation of three guiding points of reflection. For the creation of these points, it was observed and reflected on the main themes in the literature, by analyzing titles and article summaries, as follows: The different dimensions of suffering, political strategies for conducting health-disease process: easing suffering and management of the health-disease process: handling of physical pain and care to reduce suffering.

REFLEXIVE ANÁLISIS

- **The different dimensions of suffering**

In the romance *The Death of Ivan Ilyich*, the central character is a middle-class judge and bourgeois life, that after developing a chronic disease manifested by pain in the lower abdomen on the right side, which throughout the story is growing and so intense to the point to deprive him of work, social and family life, making him a totally dependent man and without the autonomy that accompanied him for the youth. It will find support and comfort in the back of his social status, in the person of Guerássim servant.

Suffering is in the human condition itself, when being confronted with the anguish of his finitude. To understand the suffering and define it, it is essential to draw on different looks to reflect on this phenomenon, seeking explanations in philosophy, anthropology, psychology and related fields. Using these approaches to reality, linking with education and principles of citizenship in a cultural and social context, it is possible to reason about it.³

The importance and the meaning given to get sick are related with the life experiences

of each individual, and this process is highlighted as social actors of the person, the family and the health professional, embedded in a social, political, economic and culture context at any given time and space.

In the same way that at the time lived by the character, where the care was centered in the hegemonic model of health care, biomedical model (characterized by a clinical approach centered on individual care and doctor's figure). It is necessary to articulate the interventions of different nature so that it is possible to meet human multi-dimensions. Looking at the health-disease process and care directions within macros and micro-contexts socially determined and under the aegis of subjective and cultural dimensions are crucial for the compression of this process⁴.

Ivan Ilyich did not only lose the functional capacity of his body, Ivan Ilyich lost his independence and freedom. He did no longer perform his daily work, share moments with his family, live with his friends, decide his fate. Ivan waited and waited for death, plunged into a grief so terrifying, empty and lonely.

Thus, what is comforting in this sad suffering of the story is the hosting to a supporting character, the only one who was able to ease his suffering, Guerássim steward, that nowadays would be called caregiver.

The relationship of health professionals with the client/patient is also a meeting of cultures, with values, different knowledge and practices and it is committed intervention, ethical and responsible, which can expand and extrapolate limits the actions of the biomedical model, this subjective look beyond what it is seen, referring to the anthropological approach, whose concern with the issues of health and disease has been present in ethnographic studies for a long time.

We believe that Gerássim experienced some of these ethical conflicts to see Ivan Ilyich, his boss, languishing before the positioning of the family of the suffering of that sick man, the indifference of friends, of his infinite loneliness. In daily work, different situations seem to reverberate suffering and anguish for us nurses. Power relationships predominantly bureaucratic, cold and technologic⁵.

The work is not about the character of Guerássim's suffering, it is up to us to awaken to this reality, and the health-disease process surrounded by a number of actors. Following this thought, we returned to the family, and

the family of Ivan Ilyich. Only his youngest son suffered. At the time did he cry on the edge of his father's bed, as described in the novel? How do families support or behave experiencing in their homes the suffering of a patient before a disease process such as Ivan Ilyich?

Over time, there has been some concern in studying this phenomenon, but more in the context of the patient's suffering and pain, and not from the perspective of family caregiver. Today, there are an increase of families caregivers, and faced with this reality, it seems fair then to ask whether these families do not go through a transition experiences during periods of suffering⁶.

The disease of one of the family members will entail disruption in everyday life and of the family, leading to changes in the daily routine and sometimes the establishment of a family crisis. The impact of diagnosing a disease affects not only the person but also the family⁷.

The way each nurse faces crisis situations, especially the suffering, reflects their individuality while being unique and network connections while being relational⁸.

The disease of the character mirrors the experience of many, which is not restricted only to disability and physical impairment, but also to aspects of health policies and what they bring benefits to the people and the community. Thus, each involved in this process of health and disease manifests differently their feelings towards the experience. Therefore, it is up to the health professional and the political to support and alleviate this collective suffering using the resources that are at its disposal to do so.

• Political strategies for conducting of health-disease processes: easing the suffering

The current universal health policy in Brazil today has a range of thoughtless scope for the time that goes the story of Ivan Ilyich and mainly on the health and illness process.

The scenario where the romance happens lacks of resources and strategies to minimize the harmful effects caused by chronic/degenerative diseases such as today. Faced with this character, patient, stricken by a serious, progressive, chronic illness, having limited resources to control pain, watched the Cartesian biomedical molds that prevailed at the time, and within a family structure which deprived him of adequate home support, relying on the generosity of his room cleaner to assuage his deep suffering, it would be advised to reflect on the fact that some public

health policies currently in effect would be advisable to use.

When transporting the character Ivan Ilyich to contemporary, he would have the right to receive care recommended by the Unified Health System (SUS), anchored on the principles of: Universality, Equity and Integrality of Health Care. Besides it is plausible that the character could use a private care plan by his economic possibilities. He had this support on his fingertips, but Would the humane care be preserved? Would he have adequate care? Thus, one might suspect that, in general, what happened back then, compared to today, is little different when it comes to the care of the sick, because even with the density technical knowledge we have, we work mechanically, disciplined by the “technical” medical.

Nowadays, what we would have to offer to Ivan Ilyich would be palliative care services that have a structured policy of provision, with access from the creation of a Technical Chamber of Pain Control and Palliative Care created by decree number 3150 of the Ministry of Health on December 12, 2006⁹, to establish national guidelines for the care of pain and palliative care, complemented by the creation of a Technical Chamber on Terminality Life in the Federal Council of Medicine, in 2006, adopted resolution 1805 06¹⁰, providing for orthothanasia (natural death of the patient) in Brazil, putting into focus the need to define such care as an area of knowledge and recognize the practice of Palliative Medicine, which is a set of care practices to the incurable patient which aims to provide dignity and reduction of suffering. This care, guaranteed by all national health and budget policies, as well as in the curricula of health professionals would benefit our character.

Ivan in his family life acted harshly, and his attitudes are the result of the same action of the medical part received in the course of his visits, but under no circumstances are to discuss family relationships, but rather focus on the rights that we have received a humanized and quality care, as well as having the clarification of the health professional about his condition, which appears in the National Humanization Policy 2004¹¹, and has as one of its objectives, promoting quality of care, as well as the hosting, although this feeling should be born of human relationships, and not be politically imposed, but it would be useful to promote quality of care, as well as host to citizens, so from this perspective, humanization is closely related to palliative care, as throughout life that care must be

humanized. Considering the feelings of Ivan, facing a difficult process of acceptance, this confrontation would be more serene.

From this point of discussion, the particularities of the multidisciplinary team forward to palliative care and humanization, training in health is going through a moment of concern for the social aspects, characterized by the application of a social responsibility of the health professional, contrary to the merely biological and mechanistic aspects that developed after World War II¹².

In the dimension of care, assistance and humanization in relevance to our point of reflection on the Death of Ivan Ilyich, we can consider that for decades the public health is faced with the emergence of chronic diseases. However, public policies and health still demonstrate unpreparedness for dealing with them, in the preparation of health professionals involved, or dispensed technologies. In this context, palliative care appears as a way to alleviate the suffering of the affected patient.

♦ Management of the health-disease process: handling of physical pain and care to reduce the suffering

At one point of the romance, it is noticed that the pain in the lower abdomen of Ivan Ilyich increases strongly, possibly the result of a hit on a furniture of his new home. At first, the pain was mild and transient, but over time, it has become persistent and unbearable, affecting the life of Ivan Ilyich. We wondering if the beating caused him the illness, and Ivan Ilych was stricken by an incurable disease, but in fact, it is worth reflecting not on the start of the character disease process, but diving to experienced deep suffering.

Thus, Ivan Ilyich presents complications in all aspects of his life, such as weight loss, physical stress, lack of proper adherence to treatment, difficult relationship with his family, the perception of the fragility of life and the anguish of living and die. Over history, we see the intensification of Ivan's suffering, his refusal to his physical picture and his poor relationship with his family and doctor.

Throughout this passage from the book, Leo Tolstoy put the character in the social position of the patient, creating a context of intense suffering and expulsion of his daily activities such as work and friends. The character loses complete control of his health and his life, becoming a slave to a physical pain and a pain in the soul.

With the description of the author, we can clearly see how the suffering of the character is intense, as he feels fragile and distressed because of the physical pain and the feeling of helplessness and loneliness.

Such perceptions of the pain brought by the author of this book appear to be present today in the lives of individuals. Also, there are restlessness of reason for a person to go through moments of pain and suffering. In this sense, the phenomenon of pain accompanies the history of humanity and of medicine. Very old reports demonstrate the concern not only to understand the painful phenomenon but finding resources to treat it and manage it effectively¹³.

Thus, the subjective nature of pain hinders to define, and even historically understood and explained in mythical form, mystical or religious. Thus, the pain and suffering can be inseparable, being socially prominent as punishments for purification and salvation of the soul.¹⁴

Thus, the physical pain is a biological issue, but its perception and experience are culturally constructed, that is they are personal, every individual can live it and feel it differently.¹⁵

The pain can be seen as complex and subjective sensations resulting from decoded pulses that reach the nervous system promoting interaction with stored information and emotional activities. Therefore, the pain is fundamentally what the person says and feels, being able to be assessed by means of communication, thus becoming able to define appropriate strategies to alleviate it. In evaluating the pain, it becomes indispensable knowledge of the clinical history, based on personal background, the painful experience and drug habits, psychosocial assessment of the current condition and history of pain.¹⁶

In this sense, pain relief follows not only a pharmacological approach, but also a psychosocial component. It is important pharmacological action of drugs on the pain, and that cannot be devalued, but there are other interventions that can be used combined pharmacological strategies that respect and is the field of nursing, aimed at reducing anxiety and consequently the own pain. Among these strategies, there is therapeutic touch, progressive relaxation, imagery, biofeedback and the suggestion¹⁶.

Another focus of pain presented in the book of Leo Tolstoy is the suffering of the soul, as already mentioned above, when the author describes the anguish of loneliness,

spiritual suffering and helplessness of Ivan Ilyich.

Suffering is broader than the pain, because the pain causes essentially reduced quality of life, as a negative response, induced by fear, anxiety, stress, losses and other psychological aspects. The pain requires a physical and existential explanation when not understood, interfering with a person's life leading to frustration, anxiety and depression. In this case, suffering is the tragic consequence of the lack of understanding of the meaning of pain. Suffering is often associated or confused with pain due to historical, religious and cultural roots.¹⁵

The suffering evokes compassion, which is empathy transformed into joint action, not only in a soporific exclamation consciousness as the expression "what a pity" or "what a pain"¹⁷.

Thus, similarity between physical pain and spiritual pain is that the suffering of the soul is the negative emotion of life itself, because we can suffer without pain and having pain without suffering. Thus, the suffering of the soul is not the pain, but can be stressed by it. The suffering of the soul is manifested by the abandonment, the rejection, loneliness.¹⁵

In this sense, loneliness is not regarded as a symptom, but it is defined as something that separates the social ties of the subjects. It is considered, as well as the impossibility of establishing a bond with other people.¹⁸ All these negative feelings of suffering and abandonment are mentioned by the author, during the life of Ivan Ilyich disease.

The spiritual psychosocial distress can be seen as a threat to the patient for the meaning of life, loss of control, the weakening of interpersonal relationships. This is because the process of dying favors isolation, helplessness, hopelessness with life. Thus, an appropriate strategy for dealing with the psycho-social-spiritual suffering must be developed to face this reality.¹⁷

Thus, the remedy may perhaps make greater effect in terms of healing, it is the quality of the relationship established between patient and caregivers and patients and their families. It lies in the heart of the therapeutic relationship between caregiver and patient care of the relationship and sense needs, as well as a real communication and honest¹⁹.

Other appropriate care to the patient who is suffering is trying to respect the patient's integrity as a human being, to ensure that the patient kept free of pain, having worthy moments that receive continuous care and is

not abandoned, having autonomy to decide whether to refuse or accept the therapies that prolong the process of dying, which is heard all the time as a person in his fears, feelings, thoughts, values, beliefs and hopes, and having the option to die wherever he wants.¹⁷

In many critical situations, the disease brings suffering and intolerable pain without prospects. This is the reason why people opt for euthanasia as a way to shorten the life intentionally avoiding suffering and pain.¹⁷

Therefore, the care of the pain and suffering of the soul is the key to rescue the dignity of the human person in a critical context, as when they are met with the professional efficiency, it can lead to an improvement of the individual's quality of life. It is believed that in front of generating scenarios of suffering, it is possible to implement assistance policies and care aimed at the dignity of the sick human being.^{17,21}

Ivan Ilyich was wounded in many ways, not being graced by health policies that would ensure his human dignity through comprehensive care shared by the professional working team and a formal organization of care and recovery of their integrity as human beings.

CONCLUSION

The book exposes the profound suffering experienced by Ivan Ilyich and his political, social, economic and family breakdown in his itinerary during the disease process, the loss of functional capacity of his physical body, and especially of his human dignity. The seemingly satisfactory financial life allowed him to receive care in health, lack of family and social support did dive into deep suffering, tempered by care of his room cleaner, who provided more worthy moments to his waiting for death.

Guerássim, nurse or servant? Professional without specific training, this determinant for service quality in contemporary times, then where are created humanization policies which try to ensure that health professionals are able to deal with the care of daily clashes and without these Gerássim attributes he achieved his goal, preserving the dignity of the patient.

This reading allows further about the possibilities of promoting acceptance and enlarge our vision of the importance of the practical application of regulations provided in the form of laws that could have been adopted and implemented mitigating the suffering of people in the same way the character Ivan Ilyich.

Thus, what leads to reflection is to care management through contemporary health policy would be welcomed by Ivan Ilyich, his family and those who surrounded him, and the principles of universality, integrality and equity of health care in health and disease process would provide the patient with adequate and humane care. Therefore, to reflect on the importance of promoting discussions on the management of contemporary health policies and their effectiveness allows to find the search for ways of human dignity after transit through the pain and suffering during the process of illness and death, and if these are really effective or slightly differ from the time the novel passes.

In addition to the critical value of a health policy, the human condition portrayed by Tolstoy transcends times and leads to the criticality of the health system, especially when conceived as a set of relationships aimed at results consistent with a social conception of health. Thus, depending on how a society sees what health is, is it better to build the profile of care. But the biggest lesson of the death of Ivan Ilyich, and what is critical to the health policy is the importance of how a society conceives life and death, a big challenging for either specific policy.

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