

The dialogic life-death in care delivery to adolescents with cancer¹

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This study aims to understand the experience of adolescents with cancer, family and the health team regarding death in the healthcare context, in the light of Edgar Morin's proposed theoretical framework of complexity. Participants were 12 adolescents, 14 relatives and 25 health professionals. The interview was used for data collection. The discussion of data was guided by the dialogic life-death in the context of care to adolescents with cancer. It was observed that the singularity in the way the adolescent experiences time and faces death and the possibility that the family will lose a loved one may not be in accordance with the care the health team offers, considering structural, organizational and affective aspects. It is not enough for the team just to rationally make choices on the use of diagnostic-therapeutic devices, in line with predefined moments in the disease. Instead, a contextualized and sensitive understanding of each situation is needed.

Descriptors: Adolescent; Neoplasms; Death.

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A dialógica vida/morte no cuidado do adolescente com câncer

Neste estudo o objetivo foi compreender a experiência dos adolescentes com câncer, familiares e equipe de saúde relacionada à morte no contexto do cuidado de saúde, à luz do referencial teórico da complexidade, proposto por Edgar Morin. Participaram 12 adolescentes, 14 familiares e 25 profissionais de saúde. A entrevista foi utilizada como recurso para a coleta de dados. A discussão dos dados empíricos foi conduzida pela dialógica vida/morte no contexto do cuidado do adolescente com câncer. Observou-se que a singularidade no modo de viver o tempo e enfrentar a morte pelo adolescente e a possibilidade da perda do ente querido pela família pode não estar em sintonia com o cuidado oferecido pela equipe de saúde, considerando aspectos de ordem estrutural, organizacional e afetivos. Não basta à equipe apenas, racionalmente, realizar escolhas quanto ao uso dos dispositivos diagnósticos e terapêuticos, conforme momentos predefinidos da doença, sendo necessária a compreensão contextualizada e sensível de cada situação.

Descritores: Adolescente; Neoplasias; Morte.

La dialógica vida-muerte en el cuidado al adolescente con cáncer

El estudio objetivó comprender la experiencia de los adolescentes con cáncer, de los familiares y del equipo de salud relacionada a la muerte en el contexto del cuidado de salud, bajo el marco teórico de la complejidad propuesto por Edgar Morin. Participaron 12 adolescentes, 14 familiares y 25 profesionales de salud. La entrevista fue utilizada como recurso para la recolección de datos. La discusión de los datos empíricos fue conducida por el discurso dialógico vida-muerte en el contexto del cuidado del adolescente con cáncer. Se observó que la singularidad en el modo de vivir el tiempo y enfrentar la muerte por el adolescente y la posibilidad de la pérdida del ente querido por la familia puede no estar en sintonía con el cuidado ofrecido por el equipo de salud, considerando aspectos de orden estructural, organizacional y afectivo. No le basta al equipo apenas racionalmente realizar elecciones en cuanto al uso de los dispositivos diagnósticos-terapéuticos, conforme momentos predefinidos de la enfermedad, siendo necesaria la comprensión contextualizada y sensible de cada situación.

Descritores: Adolescente; Neoplasias, Muerte.

Introduction

Child-juvenile cancer corresponds to 2 to 3% of all malign tumors⁽¹⁾ but, although rare, it represents the first cause of death by illness in this population⁽²⁾ and is therefore a health problem in Brazil and around the world.

Despite the impact of new therapeutic approaches developed in recent decades and the expansion of health policies for early diagnosis and treatment access at specialized centers, which enhanced cure possibilities for child and adolescent cancer, death is still present in the context of care to adolescents with cancer⁽³⁾.

Some studies have appointed the need to reflect on this theme in the context of health care, as its presence

is noteworthy in health professionals' daily reality⁽⁴⁻⁵⁾.

Thus, the goal of this study is to understand the experience of adolescents with cancer, their relatives and the health team related to death in the context of health care, in the light of Edgar Morin's proposed theoretical framework of complexity⁽⁶⁻¹¹⁾.

Theoretical framework

To develop this research, the experience of adolescents with cancer, their relatives and the health team related to death in the context of health care will

be analyzed from Edgar Morin's proposed perspective of Complex Thinking. The author defends the need to look at the multiple dimensions of the study phenomenon, i.e. the distinct parts that join in the composition of the phenomenon need to be considered in their context, bearing contradictions in a dialogic perspective⁽⁶⁻⁸⁾. To interpret the study phenomenon, conceptions that author developed about death will be used⁽⁹⁻¹³⁾.

Death is not the enemy of life, as it is integrated in life and permits its regeneration. It is the mortal enemy of the individual-subject though, exterminates his/her existence and introduces contradiction, sadness and horror in his/her heart. Contradiction between the subject's egocentrism, who is everything for himself, but who also knows he is a being for death, predestined to nothing, becomes the source of the most profound human anguish, that is, the certainty of his annihilation, accompanied by the uncertainty of its time^(11,13).

Awareness of death as the destruction of individuality, by the human being, emerges at the age of six to eight years and makes death present across the lifetime and not only at the moment of its event, inexorably separating us from animality. At the same time as human death bears the awareness of individual annihilation, it also contains a refusal of this annihilation, expressed as early as in archaic societies through myths and rites of survival after death as a pair (survival as a phantom, spectrum) or as rebirth in a new being and, even for those who do not believe in the possibility of life after death, this is a reason for suffering and anguish. It is certain that ways to accept and incorporate death are diverse and depend on cultures, but one cannot eradicate the human mental unity in view of death⁽¹¹⁻¹³⁾.

Obsession with survival, sometimes to the detriment of one's own life, shows man's concern with preserving his individuality beyond death. Thus, the emotion, feeling or awareness of losing one's individuality is the horror of death. This is a feeling of rupture, a traumatic feeling, awareness of a void that opens up where individual wholeness had existed until then. It is the assertion of individuality that globally and dialectically orients the awareness of death, the trauma of death and the belief in immortality. This is a dialectic relation, as awareness of death evokes the trauma of death, which evokes immortality. Departing from the trauma of death, awareness of death and the appeal on immortality gain reality, because the force of aspiring to immortality is a function of the awareness and trauma of death. This triple dialectic data, generically called human consciousness, is exactly the implication of individuality⁽¹²⁾.

Although we know death, are "traumatized" by it, distanced from our dead loved ones and certain of our death, we live blind to death, considering that our relatives, friends and we ourselves would never have to die. Ideas of death are distanced when we adhere to vital activities. Human life contains a significant part of lack of concern with death, which is often absent from the field of awareness which, adhering to the present, eliminates anything that is not the present. That is why daily reality is hardly marked by death: it is a life involved in habits, work and activities. It is only when the "I" looks at death or at oneself that it regresses⁽¹²⁾.

At first, disease situations cause a rupture in daily activities and, at the same time, open up the possibility to look at oneself and at death, which becomes more present. Thus, it makes sense to understand how death is experienced in the context of care delivery to adolescents with cancer, seeking support for the construction of care practices that respond to the needs of the singular subjects who go through this situation.

Method

This qualitative study was developed in line with the theoretical framework of complexity, as mentioned above. The development of this research from the perspective of complex thinking demands coherence between this framework and the methodological trajectory. Therefore, some essential aspects should be highlighted that supported this trajectory, in the choice of participants, the data collection techniques used and the analysis of the experiences of the subjects involved in care delivery to adolescents with cancer. Thus, the principles of the theoretical framework of complexity - dialogic, recursive and holographic - conduct the methodological trajectory. The dialogic principle involves composing antagonistic but complementary ideas. The recursive, operating differently from the cause-and-effect logic, permits constituting the interconnections that configure the study phenomenon. The holographic permits the distinction among the parts, without losing the notion of the whole and, at the same time, the acknowledgement of the whole incorporating the parts, without dissolving these in a whole that does not identify their differences, i.e. the whole is at the same time larger and smaller than the sum of its parts⁽⁶⁻⁸⁾.

In compliance with National Health Council Resolution 196/96 on guidelines for research involving human beings⁽¹⁴⁾, approval for this study was obtained from the Institutional Review Board of the institution

where this study was accomplished (HCRP Process No 2604/2008).

Study participants were twelve adolescents (between 12 and 18 years old), attended at the Pediatric Onco-Hematology Service of the University of São Paulo at Ribeirão Preto Medical School *Hospital das Clínicas* (HCRMPP-USP), male and female, with different diagnoses (leukemias – Acute Lymphoid Leukemia and Acute Myeloid Leukemia; non-Hodgkin Lymphoma; bone tumors – Osteosarcoma and Ewing's Sarcoma; central nervous system tumors – Germ Cell Tumors and Primitive Neuroepithelial Tumor; Desmoplastic Small Cell Tumor) and in different phases of the diagnostic and therapeutic process (diagnosis, treatment, relapse, advanced stage of the disease and survival), 14 relatives (two fathers, nine mothers and three siblings), besides 25 health team members (eight physicians, five nurses, six nursing auxiliaries, two social workers, two psychologists, one nutritionist and one occupational therapist).

The family members were selected in the attempt to have those relatives participate who accompanied the adolescent's illness period more closely, generally the mother, although other members were also included, which were considered important during this process and which the adolescents appointed.

The health team at the Pediatric Onco-Hematology Sector comprises physicians, nurses and nursing auxiliaries, psychologist, social workers, occupational therapist and nutritionists. To select team members, as nursing professionals are more numerous, we prioritized members in closer contact with this service, whether as a result of individual preference or the work schedule, in the belief that they could contribute to the achievement of the study goals. As for the physicians, the participation of representatives from each category (faculty, physician and resident) was guaranteed. In the remaining professional categories, all team members participated in the study.

Data were collected through interviews with the adolescents, their relatives and professionals. With the adolescents, we used questions focusing on aspects related to their experiences in the course of the disease and treatment (*"Tell me what your life has been like since you have become ill"; "In your daily life, have you been through situations you consider difficult? Which? Tell me about them"*). Interviews with the relatives were aimed at capturing their experiences with regard to the situation they experienced in this process, initially using the following guiding question: *"Tell me what your life has been like, in taking care of your child/sibling, since*

he started to present the symptoms of the disease". To interview the professionals, the following guiding question was used: *"Tell me what your experience has been like in care delivery to adolescents with cancer"*. The interviews with the adolescents, relatives and professionals took place between May 25th 2008 and January 22nd 2009, totaling 51 recorded interviews.

Comprehensive data analysis was accomplished in the attempt to preserving their multidimensional nature, considering the distinct perspectives involved in the study context and acknowledging the complexity of the whole. All recorded material was transcribed and, then, each of the interviews was read several times, looking for significant points based on the research aim. Next, data for the different subjects were related and articulated in view of diversities and integrated into the study context, seeking foundations in Edgar Morin's ideas on complexity. To present the interview excerpts, the letter A was used to identify the adolescents; FM, FF and FS for the relatives (mother, father and siblings, respectively). Professionals were identified using the letter P, followed by the identification of their professional category: M (physician), N (nurse), NA (nursing auxiliary), SW (social worker), P (psychologist) and OT (occupational therapist). In this study, the dialogic life-death in care delivery to adolescents with cancer conducts the discussion of empirical data.

Results and Discussion

In the context of this study, the adolescents do not clearly express the death that surrounds them. It does emerge in their own and their relatives' reports though, in submission to situations of intense suffering during treatment, as a form of distancing death, as well as in feelings of concern with and fear of relapse, which even adolescents who had already finished treatment expressed, as exemplified in the following report of an adolescent who had already been considered cured: *When the day comes to go to the hospital I get kind of upset, I can't sleep, I already get scared, so that, when I get an examination, who does the examination or the physician who stays there to write the report, I have to talk to one of them, I ask if they saw something. Before they talk to calm me down, I can't, then I leave more at ease. (A)*

Reports by mothers of adolescents who have not finished treatment yet also focus on concern with the result of examinations done to check to evolution of the disease and treatment results, demonstrating that fear and constant surveillance, even after the end of

treatment, will always be part of their lives: *We will always be concerned, we will always be alert to her disease, because she's an adolescent, but when she's 50, 60 years old, we'll always to the test, a check-up, that's for the rest of her life.* (FM)

In addition, any symptom the adolescent presents, even if unrelated to the disease, is associated with a possible relapse: *C. was having a very strong headache, I brought her in for some tests, thanks God there was nothing, it was all normal. When that headache came up I already got concerned, I got concerned with any pain she felt. But thanks God it was just a scare.* (FM)

The concerns with relapse expressed in the adolescents and family members' reports can be associated with decreased chances of cure and with a possible death. According to the psychologist, relapse is a moment of great frustration, not only for adolescents and families, but also for the entire team, precisely because of this association with the proximity of death. *When the adolescent has to cope with relapse, he's not the only one frustrated, so is the team. Although we initially consider this possibility, although cure possibilities are present, so is the possibility of relapse, so it's frustrating for the team as well. (...) We recognize that situation as a greater risk, in which death is approaching...* (PP)

The triple anthropological data about awareness of death, i.e. awareness of a rupture, trauma and aspiration on immortality reveals human individuals' fundamental inadaptation to death. This inadaptation is relative though, considering that, if it were absolute, man would not support the idea of death and would die of it. Thus, individuals' participations in the world also enhance possible adaptations to deal with the trauma of death, composing a dialectic complex of human adaptation-inadaptation to death⁽¹²⁾.

This adaptation-inadaptation complex of human individuals to death is present in the context of this study, related to the adolescents and their families as well as the professionals, from different perspectives and essentially represented by the techno-science and religiosity dimensions. These reveal human inadaptation to death and, at the same time, enhance adaptation, with a view to calming the trauma of death, by seeking either therapeutic resources based on the advances of techno-science or spiritual resources, based on religious beliefs, always working to defeat death, which becomes more evident in case of relapse and when the disease worsens, but can be perceived across the disease trajectory.

Although the adolescents' suffering because of relapse situations is underlined in the relatives and

professionals' reports, the adolescents' testimonies not only highlighted feelings of impotence and frustration, but also demonstrate greater strength with regard to the moment of the initial diagnosis, with a view to facing the challenge that is once again imposed and seeking therapeutic resources that permit distancing the presence of death, even if this is a remote possibility and they are aware of this: *This is my third relapse, what can I do? I have to fight until I win. When the doctors talked about the new relapse, I say, mom, lift your head. You're always with me, but I'm the one who is going through all this again.* (A)

This coping posture the adolescent assumes is also in line with the professionals' posture, who attempt to invest in cure at that moment, but equally looking at the adolescent's quality of life, as the chances of cure decrease and, therefore, the risk of death increases. The psychologist highlights this disagreement between the care the adolescents want and what the team delivers, as they intensely invest in their own vitality, so that acceptance of death is postponed as much as possible: *I perceive that the team delivers very different care throughout this process. In case of relapse, we will look much more at how we can enhance this adolescent's quality of life and at the same time offer care that, if it works out, can offer a possibility of cure. (...) I see that the adolescents fight much more, and this entails difficulties in the collision of forces with the team because, at the same time as the adolescent seeks care from the team, seeks curative care, we have something else to offer him and I think that this disagreement is the most relevant fact in care for the adolescent who experiences a situation of terminality.* (PP)

Although the dialectic complex of adaptation-inadaptation to death is characteristic of humans, as subjects who are part of their own experience, it concretely configures their form of adaptation-inadaptation. Hence, in the disease experience, mainly in the relapse phase, inadapted to death, the adolescents continue seeking a possible adaptation in techno-science resources, making their existence acceptable to themselves, although permanently permeated by the awareness of their own death.

In the perspective of complex thinking, death is the mortal enemy of the individual-subject. Self-awareness related to awareness of time gives rise to the awareness of living in time and the need to cope with death. The adolescent's experience seems to show that he starts to experience time urgently and coping with death is intensely present. In many situations, the singularity in the way of experiencing time and facing death may not be in tune with the care the health team offers⁽¹¹⁻¹²⁾.

In other words, when acknowledging that the techno-science resources available until then ran out, the health team starts a movement of dealing with a possible loss. Thus, while the adolescents imprint a sense of urgency on their experiences, health professionals move in the attempt to accept death. Anyway, it is the other, the adolescent who, as a subject, can signal the "tone" of his care, even in this short time period, as he experiences the possibility of death itself and the anguish of facing the certainty of death, even if its time remains uncertain.

This situation of urgency the adolescents experience makes them get involved in daily activities, filling their time, considering that death hardly marks daily life⁽¹²⁾. Some professionals highlight the need the adolescents experience to plan and put their goals in practice in the near future. It is as if their awareness of the proximity of death entailed a greater focus on the life that remains, with a view to concluding their existential plan: *J. was an example, she fought death until the end. She actually managed to accomplish herself, she managed to put some projects in practice, despite experiencing the terminality situation, dealing with the perspective of a nearby death, she managed to take care of her own life until the last sigh. That was very determining in her experience and in the experience of many adolescents our service attended.* (PP)

In care delivery to adolescents, dealing with situations that involve death may also be related with the dialogic relation between egocentrism and altruism: both adolescents and health professionals will be exercising the dimension of egocentrism, to the extent that they attempt to preserve themselves, even through different routes, in the confrontation with death? To what extent are health professionals able to be solidary with the adolescents from the perspective of building up care with them that does not annul them, that does not force them to accept a condition that confronts them with the possibility of their own annihilation? Also, to what extent do they need to help them acknowledge the moment they experienced without ceasing to be sensitive to the adolescents' pain and needs?

These inquiries approach health professionals to difficult ethical dilemmas that reveal some challenges, considering advances in the diagnostic-therapeutic process of child-juvenile cancer, which offer new possibilities in the fight against death, but may also mean the extension of the disease and suffering.

In this respect, some challenges should be emphasized which professionals face, related to scientific advances and available technology to postpone

death. One of these challenges refers to the definition of when exclusively palliative care⁽¹⁵⁾ is indicated to the adolescent, according to the following report: *But that's really a problem. How far can you go? How far can you extend the patient's life... that's a severe issue, to what point are you extending survival with quality, to what point are you extending suffering?* (PM)

Although the possibility of constructing palliative care indicates the health team's concern with offering a possible quality of life and comfort to adolescents beyond possibilities of cure, it lacks further depth in discussions about some aspects, for adolescents to be considered as subjects in their complex existential condition. To give an example, at many times, relieving pain as much as possible may mean decreasing the adolescent's awareness, which neither adolescents nor relatives accept sometimes, as this state withdraws the living condition, even if limited.

Thus, while the team's actions work towards avoiding any pain, which is legitimate, the families and adolescents may want to avoid certain devices (to give an example, drugs that relieve pain but exert sedative effects), as they clutch on to lines, as thin as they may be, to maintain contact between the adolescents and themselves, other people and everything around them, which is also legitimate.

This implies incorporating existential dimensions among health professionals, and mainly constructing a solidary dialogue with adolescents and relatives, acknowledging that, in some situations, they are not able to make certain decisions, even if that astonishes professionals. We can only say no to the other person's pain if we significantly understand what pain means to that person at the moment he is experiencing, which may even mean maintaining physical pain to preserve contact with the people around them. For the adolescents and families, this contact may mean the presence of life. One of the professionals associates the use of sedation, in a way, with an anticipation of death: *Often you wait a long time before sedating... Even before being sedated, he knows what's going to happen. And, to a certain extent that's good, you being sedated, because then you no longer see the person, you, kind of, end up leaving at that moment... you are no longer able to talk, you can't do anything anymore...* (PNA)

The acceptance of death only starts to become real when the clinical condition actually worsens. This perspective is expressed by the psychologist and corroborated by the report of two adolescents, who relate the moment the clinical condition worsens with

the moment when, in a way, they conquer the fear of death and consider the option of giving up treatment: *I think that a turning point is contact with clinical worsening, when the adolescent becomes aware that the team as a therapeutic resource has reached the final limit and I think that is the moment of moving on to a phase of further acknowledgement that that reality is happening.* (PP)

Finally, I wasn't afraid anymore, because I was already that bad, you know? Feeling so bad that, for me, if I left the suffering would end. Because not only I, everyone was suffering... (A)

Because I got really bad, I wanted to give up, I didn't want to continue, it's a lot of suffering. (A)

Returning to the adaptation-inadaptation complex of human individuals to death⁽¹²⁾, besides the technoscience dimension, religiosity is another dimension representing this complex in the context of the present study.

Myth strengthens man by masking the lack of understanding about his destiny and by completing the void of death. Myth and rite make it easier to cope with anguish and death, allowing individuals to be withdrawn from uncertainty, void and anguish and inserting them into a new order, in a community. In the same sense, religious faith as a profound force involves the human spirit in safety, trust and hope. Through religions, man fears death less. It should be highlighted that large religions continue over time, while others are revitalized. In addition, many sects and practices that deal with human anguish become widespread⁽¹¹⁻¹²⁾.

Thus, although religion, mythology and magic have entailed obstacles for man, in view of their excesses, they allow human beings to face their tragedies, feeling safer and more comfortable towards existential anguish⁽¹¹⁻¹²⁾. All study participants focus on religiosity as an important resource in coping with the illness process of adolescents with cancer. *My faith was the most important. I never gave up believing, that was the most important.* (A)

I think that God is the only one who's there beside us when we are tired. His divine breath makes us continue. (FM)

It was complicated. But we got a lot of strength from God. (FS)

And I was asking God, because I don't fail easily but, during her final chemotherapy sessions I was failing. (FF)

Even in view of failures, the religious dimension permits keeping up hope in cure and, at the same time, when hope is no longer possible, also enhances the acceptance of death: *He was going to start working during the day and studying at night, he was all cheerful. But God didn't want it, what can you do? (...) Have faith and hope in God's will.* (FM)

This perspective is also present in one physician's report who emphasizes this aspect. Even without any specific belief, she encourages family members to use the religious dimension when the chances of cure run out: *Thy get very attached to religion. (...) And then you have to agree, because it's the only thing that, at bottom, ends up helping to overcome this terminal phase. (...) I say, may God be with you, I don't have a lot of conviction, but I say it, because that's good for them.* (PM)

The family members' acceptance of death is probably related with belief in immortality, which supposes the subject's survival after death. This comforts the family, which overcomes the idea of the loved one's annihilation. Returning to the triple dialectic data^(8,10), the human attitude towards death paradoxically implies the rational awareness that originates a mental trauma and the assertion of life after death through beliefs that mitigate that trauma.

From the complexity perspective, we consider that religion can represent an important source of support for adolescents and relatives. Thus, while humanity has historically found support to face death in science and religion, each person individually, mainly in the most borderline situations of life and death, can find a meaning for adversities and strengths to cope with them⁽¹²⁾.

Some professionals also emphasize religiosity as a source of resources to support their own professional activities, granting them strength to deal with the suffering they experience at work. It should be highlighted that, among these, most are nursing team members: *How do you deal with all that? Only God can give us strength, we're not here at random.* (PN)

Another mandatory question related to death, in the disease trajectory, refers to adolescents who get cured and start to live with the death of friends whose treatment does not evolve well. While, at the moment of the diagnosis, the adolescents question "Why did it happen to me?", when they lose a friend submitted to the same treatment as they underwent, the feeling of inconformity emerges in the sense of questioning "Why did I survive?": *Today the feeling of being free is very strong. It's just that I go there today and see people, I found out that M. died, you know when you can't accept something? Because I'm so well and they left, if the suffering was the same and they are not here today. It's very sad!* (A)

In these situations, the surviving adolescents feel a "bottomless pain"⁽⁸⁾ with regard to the death of loved ones. Thus, not only the families of the adolescents who die suffer, but also the friends who experience the

disease situation. It should be highlighted that, for them, this can be a peculiar moment, because they do not only feel pain due to the loss of their friend, but also, as they significantly identify with him, they can anticipate, in some case, the possibility of unwanted outcomes for themselves.

Identification also appears in the reports of adolescents' mothers who have contact with other adolescents under treatment and their relatives: *With all the suffering that happened there, which we saw, (...) the other children, the mothers losing their children, it was very difficult.* (FM)

Death more intensely mobilizes rationality, affection and myth, characteristics of humans. In view of death, humans are divided between rational awareness of death, including the idea of individual annihilation, the disruptions deriving from this awareness, intensified by the intense pain the death of loved ones causes and the overcoming of this death through confidence in individual survival, guaranteed by their beliefs which, although they do not deny reality, can make it bearable. The anguish of death is experienced as the anguish of existence, which can be repressed through affective participations, but cannot be totally eliminated⁽¹¹⁾.

Final considerations

Throughout the study, it is observed that the adolescents make little mention of the possibility of death. This situation is related to the idea that death leaves little mark on daily reality. This feeling of annihilation, which emerges through the possibility of death, spans adolescent care. In some situations, after the initial phase of the disease, in which adolescents attempt to adapt themselves to the new condition and to treatment, in which a possible cure is more significantly present, the health team and adolescents are to a certain extent "in tune" with the use of available technical devices. In other words, adolescents, relatives and the team as if it were agree that they need to face death. In other situations, like when the worsening of an adolescent's clinical situation is found, the team changes the focus from the use of cure-oriented techno-science to the relief of suffering, which is not always sufficient for the adolescent, who continues in a kind of "urgency to live", experiencing the uncertainty of his "final moment", nor for the family, which does not bear the idea of their loved one's annihilation.

These situations may indicate that it is not enough for the team to rationally make choices on the use of

diagnostic-therapeutic devices, in accordance with predefined moments in the disease, demanding the contextualized and sensitive understanding of each situation.

Making decisions on the adolescent's treatment and care modes takes the team closer to the complex condition of the human being, which entails ethical, but also existential implications, confronting professionals with their own finiteness. Confrontation with one's own finiteness can approximate the health team, the adolescent and his relatives, who experience the pain of a probable loss.

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