

Bioethical reflection on the responsibility of caregivers of terminally ill patients

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Abstract

The present study was performed with the aim to know and describe the meanings about the end of life and the responsibility of the caregiver regarding the terminally patient, as well as to promote a reflection about the impasses that arise from these bioethical issues. As a qualitative-descriptive method and methodological guideline of the collective subject speech, 19 caregivers of terminal patients assisted at Samuel Libanio University Hospital in Pouso Alegre-MG were interviewed. From the research results it was possible to conclude that death still causes a lot of pain and sadness. It is in the context of bioethics that the caregiver takes the responsibility of taking care with great attention, compassion and solidarity, showing respect to human life and to the process of dying with dignity.

Key words: Terminal patient. Care takers. Bioethics.

Resumo

Reflexão bioética sobre a responsabilidade de cuidadores de pacientes terminais

O presente estudo foi realizado, tendo por objetivos conhecer e descrever os significados sobre a terminalidade da vida e responsabilidade do cuidador perante o paciente terminal e promover uma reflexão diante dos impasses advindos destas questões bioéticas. Como método qualitativo-descritivo e diretriz metodológica do discurso do sujeito coletivo, entrevistaram-se 19 cuidadores de pacientes terminais atendidos no Hospital das Clínicas Samuel Libânio da cidade de Pouso Alegre, Minas Gerais. A partir dos resultados da pesquisa concluiu-se que a morte causa muita tristeza e emoção. E é no contexto da bioética que o cuidador assume a responsabilidade de cuidar, desdobrando-se em desvelo, compaixão, e solidariedade e demonstrando respeito à vida humana e ao processo de morrer com dignidade.

Palavras-chave: Doente terminal. Cuidadores. Bioética.

Resumen

Reflexión sobre la responsabilidad de los cuidadores de pacientes con enfermedades terminales

Este estudio fue realizado y tendrá como objetivo descubrir y describir el significado sobre el carácter terminal de la vida y la responsabilidad del cuidador frente al paciente desahuciado y promover una reflexión sobre las cuestiones bioéticos que surgen. Como orientación fue usado el método cualitativo-descriptivo y directriz metodológica del discurso del sujeto colectivo, fueron entrevistados 19 cuidadores de pacientes con enfermedades terminales atendidos en el Hospital das Clínicas Samuel Libânio de la ciudad de Pouso Alegre, MG. A partir de los resultados de la investigación se concluyó que la muerte causa mucha tristeza y emoción. Y es en el contexto de la bioética que el cuidador asume la responsabilidad del cuidado, esmerándose en desvelo, compasión y solidaridad y demostrar respeto por la vida humana y por el proceso de morir con dignidad.

Palabras-clave: Enfermos terminales. Cuidadores. Bioética.

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The expression *termination of life* refers to the final stage of human life. According to Gutierrez ¹, it is when there is no possibility of rescue patient's health conditions and the possibility of near death seems to be inevitable and predictable. A patient is considered to be in terminal status when his/her illness, independently of the therapeutic measures adopted, will inexorably progress towards death ². It is in the very final stage of the illness when it is not possible to control it any longer that caregivers' role becomes instrumental ³.

Caring comes from Latin *cogitare* – to think, give attention, take into account ⁴. According to Boff ⁵, the term "care" conveys the meanings of devotion, solicitude, diligence, zeal, attention, good treatment with one another, indicating a relationship of respect. To take care implicates to put oneself on the other's shoes, be it in personal or social dimension. It is a way of being together, to the extent of special moments in life and social relations, as birth, promotion, health recovery and even death itself ⁶.

For Párraga Diaz ⁷, caregivers are those who are busy providing for self-care and attention needs to individuals who have a certain degree of dependence. The caregiver is the one who takes up the responsibility of caring, giving support or assisting any need of an individual being taken care of, aiming at improving his/her health. The act of taking care is an attitude of responsibility and the meaning of responsibility is linked to the ability of an individual to be accountable for his/her own actions or for the actions that concern personal and professional actions they take, with a view to assisting and caring ^{8,9}.

The *principle of responsibility* is the turning point of the whole of Jonas' reflection ¹⁰. For Jonas ¹¹, the effect of human being's actions must be compatible to the permanence of an authentic human life and that it should not endanger the indefinite continuity of mankind on Earth. To *live*, for him, is not to *just survive*, but to *live well*, according to values. In ethics of responsibility it is necessary to respect and preserve the right to be; therefore, the agent, the act and effect must not threaten future life. The concept of responsibility implicates the notion of respect, trespassing the traditional concept of individual right to become a zeal for the common good in relation to everything and everyone ¹⁰.

Mankind is the only one able to be held accountable for others. They are the guardians of other being's ends, since their existence is linked to them. The main goal of responsibility is life. It is a scream, a begging for the care and for its continuity ¹⁰. Transferring Jonas' parameter of responsibility to the dimension of health, ethics and care to the patient that has death as progn-

sis, keeps the relationship strict ¹². In this context, care would be minimal and universal ethical attitude that is able to extend one's existence and, above all, to improve one's life conditions, even in the short time they have left ¹³.

Feeling responsible is feeling in charge of a task, carrier of a mission. Responsibility is within our power as we feel responsible for the vulnerable and fragile ¹⁰. In this sense, this study's main goal was to know the meaning of termination of life for caregivers of terminal patients.

Method

This study was developed between March 2009 and May 2010, having as subjects caregivers of terminal patients admitted to the Samuel Libanio University Hospital of Pouso Alegre, Minas Gerais. In order to know and describe the meanings of termination of life and caregivers' responsibility as to terminal patients, a quality-descriptive approach was opted.

Sample comprised of 19 caregivers of terminal patients, with no restrictions regarding age, social class, race or level of instruction. Caregiver subjects were interviewed by means of two instruments: a set of semi-structured questions and a biosocial data questionnaire. Participation was voluntary, after reading and signing in the free and clarified consent term (TCLE) as per Resolution 196/96 of the Brazilian National Health Council. The study was approved by the Ethics Committee as research of the University of Vale do Sapucaí of Pouso Alegre (Univas).

The interviews investigated perceptions presented as to termination of life and caregivers' responsibility in face of terminal patients. As methodological referencing the social representation theory (TRS) was adopted and the analysis and presentation of results was based on the collective subject discourse (DSC), from which meaning was built out of the statements. DSC was written in first person, composed of key-expressions (ECH) that had the same central ideas (IC) and same anchoring (AC), thus following strictly this order:

1. Interviews were recorded on tape and transcribed and the two questions were analyzed separately;
2. For every answer, ECHs that revealed the essence of the discourse were identified;
3. From key-expressions of every answer, the ICs were sought after (linguistic expression that describes synthetically the sense of every discourse analyzed);
4. ICs with same sense were grouped;

5. DSC of each main idea was built on their respective ECH.

Results and discussion

The study sample was composed by 19 caregivers of terminal patients, being it 100% female with mean age of 52.1 years. The level of instruction varied, with majority at incomplete level of elementary schooling (42%). In relation to the professional activity, 31% of caregivers worked in other professional activities, as maids, general service helpers, teacher and secretary, besides being caregivers.

The results obtained with the semi-structured interview of caregivers' reports were grouped and analyzed as to the answer provided to the questions "For you, what is the meaning of termination of life?"; "In your opinion, what is your responsibility regarding the terminal patient?". The answer to each question was open, providing the caregiver with full freedom to answer the questions.

For the first question – *what does termination of life mean?* –, out of a rate of twenty-two main ideas nine were: very sad (7); God's will (5); natural passing (5); horrible (1); relief (1); no despair (1); fatal (1); rest (1); tough (1). The most frequent main idea was *very sad* (31%), followed by *God's will* (23%) and *natural passing* (23%). The least frequent ones were for main ideas like *horrible* (1%), *relief* (1%), *no despair* (1%), *fatal* (1%), *tough* (1%) and *rest* (1%). However, these main ideas were not mutually excluding and, in some cases, the same interviewee expressed more than one of them in their speech, being the most predominant main idea of each statement thoroughly analyzed, as Table 1 shows:

Table 1. Meaning of *termination of life* for caregivers of terminal patients

Main ideas	Subjects	Frequency
Very sad	2,3,4,9,11,13,16	7
God's will	1,6, 8, 14,17	5
Natural passing	6,12,15,18,19	5
Horrible	2	1
Relief	2	1
No despair	5	1
Fatal	7	1
Tough	19	1
Rest	10	1
Total		22

*Refers to the question: "For you, what is the meaning of termination of life?"

Daily and continuous care leads to the development of a very close relationship between caregiver and patient. When it concerns family, the bond becomes even stronger and the caregiver suffers with the illness of the one he/she takes care of, causing them to be taken by a mixture of feelings in face of this situation¹⁴. The feeling of sadness can be observed in the speech by the main idea of *very sad*, the most frequent one:

"I think it's horrible, lord, I don't want even to think about it, very sad. The end of life is sad. This end, I think that we who are taking care need to give more support and to be closer, because it's a phase, I don't know, it's very sad for us, isn't it? So we want the most we can help and to be there, I think it's important. It takes good care, because the end of life is sad. Every day that goes by we lose hope because suffering is greater. It all depends on me, so I think his end of life's been very sad for me because he is dear to me, you know, and we see him dying little by little. I think that termination of life is very sad, and because of that love, caring for a person who is in the end of life is important, because it's very, very sad the end of life".

For five caregivers the meaning of termination of life was identified as *God's will* – the second most frequent main idea. Faith in God is found as consolation in the discourses and allows caregivers to accept it better and to face imminent death:

"I see end of life as when God call it an end. The day God sets is really ended, there's nothing to do, there's nothing in the world that can do something without end of life, this is it. That's termination of life, we are born there's an age to be born, and we were born, sure we grow and one day will die. So at the time God sets for us we will die, there's a day to be born, which God allowed us to be born and there's the right day God allows us to die. I think a lot about death, keep thinking that we don't know what is set for us in the blink of an eye, then I think the following about death, it's how they say, when God wants it there's no way out, it is very painful but it's what we have to be sure about, it's death, it's the terminal phase. I accept everything the Lord does...".

Faith in God is a feeling rooted in our culture and, as showed the statements by the participants of this study, which supports the findings of Inocenti¹⁴, and it is as necessary as other confronting strategies. The need to gather outer forces so as to overcome distress and suffering by holding on to religion makes caregivers feel themselves to be protected by a superior being, which follow them and help them face obstacles¹⁴. In the Christian faith perspective there is the conviction that God is love, and where there is love there is

God. Thus, the existence gets support and turns into a tangible reality, for there would be an afterlife¹⁵. Still under the spiritual point of view, termination of life was defined as a *passing*, the end of matter, and the divine restart of the soul:

“Look, here’s what I think, it’s the most beautiful thing there is, you see having a life and then you letting it pass towards another life, it depends on your spirituality right? The faith you have. And I do feel she is leaving... But I want to hand her over to the hand of God with a lot of caring. That’s a complex question, isn’t it? It has some broad sense, because, you know, for the religious side we have always heard life is a passing and that we’ll pass from a phase to another better one. As I am a Catholic, I think we are here temporarily, but that life doesn’t end here, and that after this there’s another life, it doesn’t end here, just the body dies, the matter, but the spirit remains alive. Termination of life in my opinion is a passing from this life to another; it’s as if you were starting it all over again”.

For Zoboli¹⁶, spirituality is the relationship room where one expresses their desires of the heart, demands of reason, fragilities, strengths, the path taken, what supports them, their reasons for living and hoping. The spiritual dimension, when it regards the sense of living, opens the human beings for realities beyond their somatic and psychic structures and their historical-social configuration, attributing more meaning to chance and opening infinity

wide. By the perspective of spirituality, death is not the final event; it remains being part of life, being it intrinsically related to its preservation, resurrection and perpetuity¹⁵.

Observations regarding the first question enhanced the idea that all the various meanings and feelings aroused in relation to termination of life death were interlinked to aspects such as familiarity between patient and caregiver, religious beliefs and spirituality. Caregivers identified the process of dying and death as a feeling of sadness by the disability and limitation of the one being taken care of and by the perception of finitude of another – and, as a result, their own finitude.

Caregivers identified death as rest, a natural passing allowed by God’s will. This confronting strategy provides them with a less painful and overwhelming experience. There was also observed some ambiguity in the caregivers’ feelings: at times there is predominantly hope for a miracle of an unlikely cure, then there is the will of ending the suffering for the approaching of death and, as a result, both of them rest: caregiver and terminal patient.

The second question, which dealt with the caregiver’s responsibility in relation to the terminal patient, presented five main ideas: Care giving (7), full giving (5), care giving as retribution (3), tough (3) and obligation to give care (1). The most frequent main idea was care giving, accounting for 37%. Total frequency of main ideas was 19 (Table 2).

Table 2. Meaning of *responsibility* for caregivers of terminal patients

Main ideas	Subjects	Frequency
Care giving	1,9,11,12,15,16,17	7
Full giving	2,5,6,13,14	5
Care giving as retribution	3,7,19	3
Obligation to give care	4,8,10	3
Tough	18	1
Total		19

**Refers to the question: “In your opinion, what is your responsibility in regarding the terminal patient”.*

By analysis of the discourses of the second question, it was observed that commitment and responsibility taken by caring a terminal patient are surrounded by a number of meanings that encompass from the simple act of taking care, observing it as essentially linked to life, without which it does not continue, to the feelings of giving, retribution, obligation and the difficulty taking up so big a responsibility. For seven caregivers the responsibility

regarding the terminal patient resembled the idea of caring, being it the most frequent idea:

“It’s to look after him as he deserves. It’s cleanliness, hygiene and stuff. And to take care of him until God thinks I have to. Well, it’s a lot of responsibility, it takes good care, but then there’s a lot of responsibility, he was a very good husband to me, thank God, I’ve nothing to complain about. I have full responsi-

bility to take care of him, I'll do so till the end, until God says otherwise. Responsibility is giving medication, bathing. Because the one who is at the end of life has almost no more energy for nothing, so we have to do everything they need. This is what I feel responsible for, not to forget meal time, his bath, everything on the right time for him because even if I am supposed to take care of him and myself, this is what I feel.”

The intense feeling of giving was often found in the speeches analyzed, noting, yet, negligence of caregivers towards their own private lives so as to help the terminal patient: “It’s a huge responsibility; I hardly remember my own life. Fully responsible for him, with my body and soul, I give everything, even a part of me. It’s like if I were an only child and only protector too, because it’s all on me. I feel physically and mentally fragile, you know, emotionally it seems I am overwhelmed body and soul. I think the responsibility is to do the most we can, share it with the person who is ill, take care, zeal, let them happy, with a lot of peace and tranquility”.

It was also observed that the taking care by the children brings a strong feeling of retribution, the third most frequent main idea: “First, my mum took care of me, and now I have to take care of her, at the end of her life, which leaves only me. that’s it. I do it with all my love because she did it to me, I am very happy to take care of her. The responsibility, well, it’s not even responsibility, that’s what I am saying, she took care of me the whole life, I think it’s retribution, she took care of me since I was a child and even when I grew older, she was always there, then now I think I am doing what she would do for me, what she has always done for me”.

Braz’s study ¹⁷ on the matter shows how the spousal commitment, perceived as an obligation to take care opted by the spouses seems to be linked to the pact done at marriage. Bearing in mind the age of those social actors and the habits of then, such commitment firmed was understood as for the whole life – the action of taking care is seen as an ordinary consequence, intrinsic to marriage itself ¹⁷.

Hans Jonas proposes the principle of responsibility as an ethical principle for technological civilization. Ethics of responsibility is an area of knowledge that raises questions related to bioethics, that is, ethical values and biological facts for the survival of the ecosystem as a whole ¹⁸. For Jonas, the human being is a fundamental value. Even in face of their own precariousness and vulnerability, the human community is responsible for one’s totality, continu-

ity and future. We are, from the beginning, the aim of that responsibility. Mankind’s featuring difference is the fact that only they can have responsibility, and also have it for others like him. In that sense, Jonas states that in the existent human being there is a duty and an obligation in form of external responsibility ¹⁹.

There has also been observed in this study that the action of taking care was taken up by some caregivers as the fulfillment of a duty, an obligation, at the same time that the idea of reciprocity was verified by which taking care of the other implicates in (alleged) guarantee that somebody will give a hand in a moment of need. For the author, having some responsibility for somebody is something that indissociably belongs to the human being.

The human being is called on duty to take care and protect that which is under his/her responsibility, due to his/her capacity of feeling and reasoning, which lead him/her to understand care as a social commitment founded on the possibility of placing themselves on somebody’s shoes. Showing integrality, solidary and human behavior towards others is an ethical attitude that is indispensable for life in society, since in order to survive human beings depend on each other. To neglect the duty of taking care is as offence to life, the most precious “good” one can ever have.

The care for a human being must be present from being born until death ⁸. Caring turns into concern, value and sense of responsibility for everything. Caring is a renewed, daily, brave and spiritual exercise, whose real practice takes place in taking up every day’s things with consciousness and attention, being in every moment as a whole, with all feelings and attention ¹⁶.

Py ²¹ draws attention to the need of instructing family members in the specifics of caring and also about the feelings that emerge from the daily contact with the ill. The reflection is a proposal, an invitation for care giving relatives to think about the dependence-care relationship, about the approach of death – which also lead them to think about the perspective of their own odds of being ill and their own finitude.

Final remarks

By joining Hans Jonas’ principle of responsibility to matters regarding termination of life, we aimed at provoking an ethical reflection, especially

because, currently death is more and more seen as a process likely to be avoided. Denying death, at any cost, supported by technological achievements of medicine summarizes the feelings of failure and powerlessness of both medical team and caregivers who come across it²².

The analysis of the topic based on assumptions of bioethics of responsibility allowed observing the sense of humanity and solidarity towards a terminal patient are the constant adopted by their caregivers. The bioethical perspective of responsibility can be applied to the caregiver that does everything they can in order to show concern, compassion, solidarity and responsibility, to show respect for human life and to the process of dying with dignity²³. They are the ones to take up the responsibility of taking care and giving support, aiming at somebody's health improvement or just the relief of their suffering.

However, it was possible to observe that this is not an easy task. In each interview, by observing gestures, expressions and tears of caregivers we could summarize their difficulty dealing with the situation. Caregivers showed to be fragilized and extremely responsible for the one being taken care of,

turning a blind eye to their own personal life so as to help the other. It should be highlighted that the task of taking care of a terminal patient has a strong gender aspect, once women are the major responsible in the process of taking care, which is seen as a natural role to be played, given that this task is socially associated to the role of a mother²⁴.

It was possible to notice that death and the process of dying arise a number of feelings on those who work as caregivers: sadness, faith, pain, relief, insecurity, powerlessness, obligation and retribution. The way of dealing with these feelings and sensations is personal for every caregiver and also results from the sort of relationship they had with the one being taken care of.

Data collected allow us to consider, at last, that owing to the great physical and emotional wearing lived by the caregivers of terminal patients it is necessary for them to be provided with support by the health team, guidance and proper psychological follow-up, with a view to minimizing suffering and daily difficulties they come across concerning termination of life.

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Authors' participation in the paper

Amanda Furtado Proença, Claire Marie Pedroso Dias and Elisangela Pereira Gonçalves outlined the topic, performed bibliographical research, selection of sample, interview and its transcription, as well as the analysis of the results and writing of the paper. Adriana Rodrigues dos Anjos Mendonça was the advisor for this paper.

