

## New writings and mediations in health

### Clarita

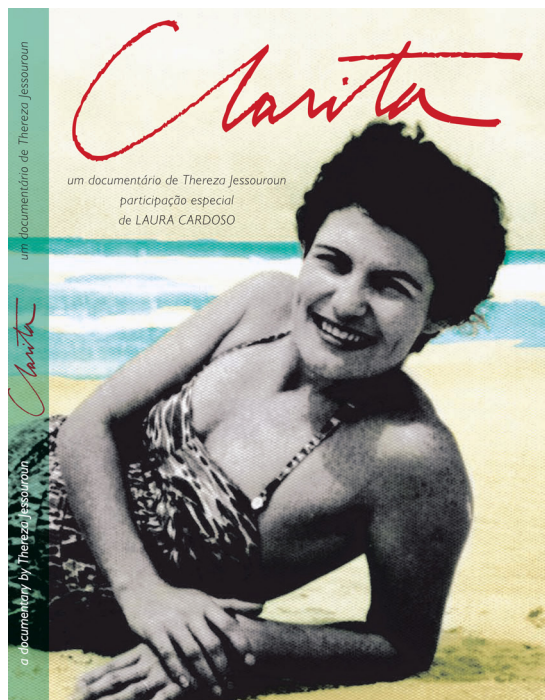
by Thereza Jessouroun

The multiple features of Alzheimer's disease for us, family members, caretakers, and professionals: comments on the documentary

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#### Synopsis

Narrated in the first person, and based on the director's mother story, an Alzheimer disease subject, the documentary presents reflections and questions about the meaning of life and the confrontation with death. The documentary alternates images filmed with her mother and reconstitutions made with the actress Laura Cardoso.

#### Technical Team

Direction, Script, Narration, and Executive Production: Thereza Jessouroun  
Special participation: Laura Cardoso  
Original track: Marcelo Alonso Neves  
On-line and Transfer to 35 mm: DIGITAL LINK

35 mm/beta digital/dvd

Sound: dolby stereo 5.1

Duration: 14'35"

Production year: 2007

#### Distribution

- Exhibited in the website: [www.portacurtas.com.br](http://www.portacurtas.com.br)
- Distributed by Programadora Brasil ([www.programadorabrasil.org.br](http://www.programadorabrasil.org.br)) to audio visual exhibition points (schools, universities, cinema clubs, culture centers, culture points) of non commercial circuits
- Individual acquisition through the e-mail: [kinofilmes@uol.com.br](mailto:kinofilmes@uol.com.br)

In this text, I intend to make some reflections about some topics risen by the sensitive and corageous report by Thereza Jessouroun about her mother Clarita, in the documentary under the same name. I wish to particularly emphasize our role as caretakers of our aged family members and as professionals that undertake the treatment of individuals suffering from diseases such as the Alzheimer.

Therefore, at first, I would like to put in perspective *our condition of caretakers inside the family*. In the picture, Thereza puts the finger in the wound, on the impact of this kind of disease to the relatives: the burden of caretaking and the alternation among irritation, impatience, revolt, doubts, the financial overload, the splits and destructuration of the family. Most of the times, in the invisibility of their homes, the women are the ones who feel more implied with the caretaking, who sacrifice their projects of life and who afford more effective dedication. In a still patriarchal society, the burden of the caretaking of the family falls almost always on mothers, wives and daughters. Specially in neoliberal societies which value only that which can be converted into goods; which only wants to see the young, good shape and active body; which labor's market absorbs only half of the economically active population, leaving a huge redundant part of it; and which invests each time less in effective social policies for the aged people, for women in general, for those considered improductive and for the support to the informal caretakers inside the family. Thus, in the perverse logic of this social order, it is better that this family caretaking remains socially invisible, that the daughters and wives take care heroically of their old relatives in silence, resigned; that the society and the State are not charged for a broad program that contemplates the needs of their old sick persons and their informal caretakers; or that the focus be put only in the active aged people, publicity able to maintain activities.

However, in this regard, Thereza did not shut up and had the courage to expose personally the reality of her mother Clarita, and to give a little more visibility to the drama she went through, by means of this documentary, turning herself into a voice for thousands of other daughters that live or lived similar situations. At the end of her movie, Thereza reminds us briefly the challenge arisen by the illness as "a matter of public health, mainly for the poorer people". From my side, I would say that it is also a matter of social care and of gender. Therefore, departing from this movie, it is up to us to amplify her courage and inquire: how the society and the Brazilian public managers are facing this reality which

must reach almost 20% of the 85 year old aged people? Which programs exist to recognize and effectively support the countless informal caretakers in the family, mainly women? Which resources and aid structures and mutual support these families and caretaking women can count on nowadays, in each city of this country?'

I think that, in this respect, the movie can have a very big impact on the brazilian society, mobilizing the various governmental, congress, third sector instances and the media, to discuss this topic and propose more effective measures and programs in the area.

At second, I would like to reflect on the *image we have of the Alzheimer disease*. In *Clarita*, Thereza lets us catch a glimpse of a certain ambiguity, which is not only hers, but which is shared by Medicine and the whole society. On one side, *the representation of deficits and progressive losses in linear progression*, as in its characterization of "alienation", "shut up for ever", "see nothing, feel nothing" etc. On the other side, the experience of crying on Clarita's shoulders, who surprisingly caresses her in an unexpected and perhaps the last manifestation of love. Thereza, here, possibly casually, exceeds the growing deficit image, to report to us the discovery of another way of communication with Clarita, more unexpected, and directly through the body.

From my side, through the experience generated in the psychiatric and anti insane asylum battle process in our country, of which I am an activist, I think that the initial stages of the Alzheimer disease thus encompass another look of the disease: *not only of an individual targeted in his growing and linear deficit, but of an individual marked by the difference, whose pathology imposes on him other forms of existing, being in the world and communicating. Therefore it is up to us to decode the phenomenon in its positivity, in its own phenomenology, as one of the entirely human possibilities of our existence, and in the same way, in each person, in the personal forms and in its radical singularity*. Many times, as Thereza found out, this communication occurs directly by the warmth of the body contact, other times by the touch of the hands, but also by the massage, or by the silent exchange of looks or still by singing together old tunes' rhymes or lullaby songs. I also remember another movie called 'Iris', directed by Richard Eyre, released in the U.S. in 2001 and in Brazil in 2002, which narrates the true story of novelist Iris Murdoch and her husband John Bayley, until the end of the writer's path as a writer, with the same Alzheimer disease. Perhaps helped by the personal position conquered by his wife, John

mobilized all his dedication to decoding Iris and her new forms of being in the world, to the maximum.

After that, and in the third position, I would like to recognize this limit: there is a stage, in which *the disease directs us inexorably to the finitude and death*. In this respect, Thereza once again points us the deep and sensitive way of her personal experience: this slow good-bye makes us think of “the terrible finitude of things”, “about the meaning of life” and “its insignificant certainties”. In this process with Clarita, she tells us, with her own words: “I became a better person and I reconciled with her”. Or still in respect of the unauthentic life we live: “we lose consciousness of the most important values, concerned with the predominant economical values, and in this way, like her, we do no more than merely surviving”. And she concludes: “it is because we die that life has value, that the gesture has a meaning”.

Here, Thereza Jessouroun shows us, with elegance, more of her personal path’s ending, in its positivity, without talking much about the intermediate phase, with its radicality, the pain and the abyss posed by this confrontation brought by the Alzheimer disease with the forthcoming human death: not only the beloved one’s, but our own, as a mirror of our finitude and future death. About this, I would like to bring to notice some reflections already expressed in another work of my authorship<sup>2</sup>, in which I discuss various features of this topic, mainly for us, Health professionals. Due to the size of this text, I will be able to address here only two or three ideas, which I consider the more essential to discuss this movie-documentary.

This experience of confrontation with death is so deep and radical that, when archeologists find traces of a ritual burial, they see the unmistakable sign which distinguishes the first hominids and their descendants. For the *Homo sapiens*, the rituals of burial show the permanent and universal concern of all our ancestors with death and with the dead people, which inspires fascination and horror. Their ritualization means, therefore, a symbolical attempt to domesticate it, to strip it from its violence and brutality, and change it to a “passage”.

The existentialist philosophy also presents its contributions to approach the topic of the affliction before death. In my opinion, it was the German philosopher Martin Heidegger who wrote the work of more impact on the subject: “Being and the time<sup>3</sup>”, published in 1926. In spite of the complexity of the author and his work, certainly with some very polemical aspects, it is possible to quickly indicate here some of the more essential parts of this book. For Heidegger, the human

being, thrown in the world unwillingly, is, in his life, alienated, craven and attached to the small day-to-day privileges, in summary, an unauthentic life. The affliction before death is, amongst human feelings, the one able to make relative these attachments and to lead man back to its entirety as a human being, to make him overcome the lack of meaning given by the immersion in the monotony and indifferentiation of the day-to-day life, to overcome the betrayals committed against ourselves and our existence projects, and promote the contact with and the knowledge of our deepest dimensions. According to him, the affliction reveals the human being as a being-to-death. Before this, there are two alternatives: escape again to forget its deepest dimensions through the return to day-to-day, or to initiate a process of overcoming it and seeking for self-knowledge, for transcendency of the day-to-day, as a being of multiple possibilities, in the path of a more authentic life. And in this path we are not alone, each one of us is a *being-with*, a *being-in-common*, sharing deep dimensions with other human beings. I do not know if Thereza knew this existentialist approach to death, but, doubtlessly, in her movie, she seems to have reached this same deep sage which Heidegger tells us about, and that is available in the work of the existentialists, to all who wish to go deeper in this trajectory.

On his turn, according to the founder of the analytical psychology, the Swiss Karl Gustav Jung, this process of search for a more authentic life is called *individuation*. The requirements of this process are done during all the life, but they are emphatically accentuated during the so-called *middle age crisis*, specially after 40 years of age, when the heroic impulses of youth and of the first stage of maturity tend to cool down, with the first signs of physical aging, and the inevitable more direct contacts with the signs of fragility and death in our parents and in ourselves. To those who live this experience of individuation in depth, *it is felt clearly as a symbolic death*, and it can also be represented by the image of the snakes which have to detach from their skin and leave it behind, in order to continue living and growing. It is an authentic *psychological rebirth*, which is represented in the various mythologies, such as the trip of the prophet Jonas to the bottom of the sea and into the whale’s stomach; Theseus entering the labyrinth and confronting the Minotaur; in the various deeper passage rites accompanied or induced by the shamans; and particularly, in the mythical images of the wounded healers, which are very suggestive to us, Health professionals. According to them, *our deepest ability to be*

*close to, to take care and to follow up people suffering from serious diseases or their families depends directly on our ability to recognize ourselves as also wounded, as also marked by this condition of affliction before death, which is one of the main inducers in our process of individuation and search for wisdom in our life.*

Let us examine an example of our culture. In the Yoruba tradition originated in Nigeria, but also African-Brazilian, the figure of *Omolu* is generally represented wearing a long straw cover that hides the various wounds provoked by the smallpox during childhood, as a result of his conflicts with his mother. They were also caused by the difficulties he went through when he left his house and looked for his own path through the world with scarce personal resources, facing hunger and thirst, while suffering people's rejection due to his wounds, during his first searches in small towns and villages. The wounds derived also from the fever, from the thorns and mosquito bites in his trajectory through the forests, where he started to live after the rejection in the cities. This experience in dealing with his own pain and illnesses gave him the capacity to be a healer, attending the calling of an interior voice. Thus carrying his healing outfits composed of various types of water, medicines, small calabashes of potions (*atós*), he started to visit the villages where he had been rejected, and where the inhabitants now begged for their healing and protection. He healed all the sick people and performed the ritual of protection, sweeping the pest out of the houses with his coconut fiber broom, the *xarará*. In the same way, he returned to his own house, healing his own parents.

I would like, in addition, to exemplify this figure of the *wounded healer*, using a case reported by the extraordinary American doctor and oncologist, specialist in treatment of patients without therapeutic possibilities, Doctor Elisabeth Kubler-Ross, who had various books published about the topic. In one of them<sup>4</sup>, the author draws our attention to the importance of the symbolic language in the communication with patients with serious diseases, particularly children.

According to the author, the question to be asked to individuals and their family at this stage is: "Must I tell them that they are about to die?" Actually, the more authentic question should be: "Will I be able to listen to them?" If this kind of person, for example, tells you: "I won't be here for your birthday in January", what would you do? You could say: "Don't say that. You will be fine". This statement will interrupt the communication between you and the person, because implicitly you are saying that you are not prepared to listen

to these people. This will literally silence them and cause them to feel very lonely. However, if you have already walked a minimum path of angst relating to death, and if you recognize your condition of wounded healer, then you can alternatively sit down together with them and say something like: "Would you like me to do anything for you...?" And then, simply stand by the person's side, open your heart with all attention and be able to fully and fearlessly listen to the person.

Therefore, in more depth, Thereza Jessouroun's documentary ends up whispering to us, Health professionals, a message which is at the same time deeply silent and a shout: the work with Alzheimer disease, the sensitive and humanized relationship with the individuals suffering from the illness, their families and caretakers, demands from us much more than a good graduation and professional willingness. It implies on us, in the deep of our *psyche*, and demands our recognition of our inexorable condition of both *doctors and wounded healers*. And exactly knowing how to silently deal with this human life unhealable scar, will make the difference in the treatment we can offer, as a person and as a professional.

## Notes

1. In the city of Rio de Janeiro, we have the Association of Relatives and Friends of Alzheimer Patients, Similar Diseases and Aid dependent Aged People (APAZ), which performs a work of mutual aid and education in the area. This kind of work and organization is vital to the process of experiences interchange, orientation, rights defense and empowerment of the relatives and, indirectly, of the ill individuals. For an appreciation of the outreach of this kind of work, refer to my book "The power which arises from pain and oppression: empowerment, its history, theories and strategies" (São Paulo, Paulus, 2003).
2. It is about the work called "Podemos ser curadores, mas sempre também feridos! Dor, envelhecimento e morte e suas implicações pessoais, políticas e sociais", published as a chapter of the book "A espiritualidade no trabalho em saúde", organized by my brother Eymard Mourão Vasconcelos, and published by Editora Hucitec, São Paulo, in 2006.
3. For a first and rapid touch with life and this author's thought, before starting to read this so important work, I suggest to the reader interested in getting started by the introduction done by Marilena Chauí to the book about Heidegger in the collection. *Os Pensadores*, published for the first time in the 1970s by Editora Abril Cultural, São Paulo.
4. KÜBLER-ROSS, E – *The tunnel and the light: essential reflections about life and death*. Campinas, Versus, 2003.

### Bibliographic references

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