

* **New writings and mediations in health**

"Os desafios do cuidado a portadores de Alzheimer"

DOI: 10.3395/receis.v6i1.577en

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Alzheimer

MUDANÇAS NA COMUNICAÇÃO
E NO COMPORTAMENTO



DOCUMENTÁRIO 26 minutos

DVD NTSC – English Subtitled / Subtitulos Español

Synopsis

Alzheimer's Disease is a degenerative neurological disease, progressive and irreversible, which affects the whole family, it significantly changes the family dynamic and brings a strong emotional impact, especially for those who assume the role of caregiver. In order to try to clarify some of the uncertainties surrounding the family during the course of the disease, this documentary presents basic information about changes in communication and behavior, which are the factors of greatest impact and disruption in the family.

Technical Specifications

Video: **"Alzheimer: mudanças na comunicação e no comportamento"**

Direction, Screenplay e Executive Production: Thereza Jessouroun

Consulting: Maria Aparecida Guimarães e Maria de Lourdes Ferreira (APAZ)

Co-Production: Fiocruz , Kinofilmes Produções e APAZ-Associação de Parentes e Amigos de

Pessoas com Alzheimer, Doenças Similares e Idosos Dependentes

Sponsor: SMSDC - Secretaria Municipal de Saúde e Defesa Civil do Rio de Janeiro

Distribution: VideoSaúde-Distribuidora da Fiocruz, APAZ, Kinofilmes, Selo Fiocruz Vídeo e Editora da Fiocruz

Duration: 26 minutes. / Production Year: 2011

This new and recent documentary, released at the end of 2011, is the second written, directed and produced by Thereza Jessouroun on Alzheimer's disease. It is a 26 minutes DVD, co-produced by Associação de Parentes e Amigos de Pessoas com Alzheimer, Doenças Similares e Idosos Dependentes (APAZ), with the head office in Rio de Janeiro, and by VídeoSaúde - distributor of Fiocruz, with the support of Secretaria Municipal de Saúde e Defesa Civil do Rio de Janeiro - SMSDC.

The filmmaker Thereza Jessouroun, director of several important documentaries focused on social issues and about woman, but generally repelled by society, ended up having their own personal and family history deeply marked by Alzheimer's disease: her own mother had this disease. Trying at the same time to exorcise and give social visibility to this so painful experience, Jessouroun released in 2007 the documentary *Clarita*, counting with sensitivity and courage the challenges of living this with the mother, which this author also summarized and recommended with enthusiasm in a recent article in this same journal (Vasconcelos, 2010). It seems that not only personal concerns did not calm down, as also the documentary mobilized other social actors who work with the disease, asking to a repetition, Jessouroun has accepted the challenge and this time has produced a not biographical film, that focus to systematize more rigorously the professional experience and care of these actors, but with the same level of sensitivity and empathy with the theme.

This documentary of Jessouroun presents a set of testimonials from professionals, some passages with a narrator (the actress Inez Viana) and illustrative fast episodes with people that are suffering with this disease. All these scenes are filmed without photographic and scenic resources or perspectives of artificial camera, which enhances even more the human experience and the content being spoken, but without taking away the merit of Dante Belutti, by its photograph and operation of the camera always careful and with substantial technical rigor. The screenplay and the edition are precise, with good balance in the distribution of time, balancing the emphasis given to each topic, without unnecessarily elaborating them.

The documentary was developed based on statements of well known neurologists and psychiatrists, such as José Luis Cavalcanti and Jerson Lacks, who throughout the film have narrative and informational appearances of concrete illustrative cases of people with the disease and their family members, supported by APAZ. We cannot forget to recognize the courage of these families that prioritized the greater cause of the public utility and have embraced the mission, even if it meant a public exposure of their relatives that have the disease. All of them have been identified and received proper gratitude in final credits.

The documentary created a synthetic vision, but didactic and broad, of the most important issues involved in the disease and the strategies of its treatment and care. It provides basic information about their neurological characteristics, their initial signs and symptoms, and especially about its impact on family and caregivers. The screenplay of Jessouroun tries to follow the time line in the evolution of the cases, exposing the unfolding of diagnosis confirmation, treatment planning and especially home care, explicitly alerting about the need of shared care, to avoid an only person responsible for home care. In the follow-up, this is the slow and progressive evolution of the disease and its phases, and the increasing dependence of care from third parties, necessarily generating a stunning for family members and caregivers, who on the other hand they need to recognize their right for a healthy personal and familiar life. It also sensitively deals with some most common feelings of the family, such as guilt, showing how people affected, if well cared, are happy and cannot notice the supposed suffering generated by the health condition. In addition, the film is extremely useful to provide tips, at the same time simple and valuable, on how to deal with the most frequently challenges in daily life, such as the spatial disorientation, the possibility of losing themselves in the city, losing the notion of personal identity, communication difficulties, the possibility of discomforts and aggression with caregivers, the catastrophic reactions, the problems in food and hygiene, etc. The documentary does not forget to remember the importance of regular medical follow-up, focusing on the development of the situation and the necessary changes in medication.

In this new work, Thereza Jessouroun can even overcome a small lapse of her previous film, when she implicitly presented, from the experience with her mother, a vision of the disease as if it were only a linear loss in direction of blunting. Now, she maintains a much more multifaceted conception of the disease process, recognizing the different forms of expression, communication and contact with a subjectivity in constant change, which needs to be understood in its own characteristics and differentiated phases. Then, communication may include body touch, massage,

music, singing, etc. This has a fundamental importance in the relationship and in caring, and Jessouroun calls the attention to caregivers to be attentive to these different forms of expression and communication with people who have the disease.



In this direction, the film mobilizes all actors of the film to provide maximum tenderness and care of these people, but without neglecting the needs of caregivers and family members. For that reason, group therapy is recommended as an effective alternative of shared talk about earlier family conflicts, about rescuing the bond with the sick person and the challenges of care, in the mold that are already offered at APAZ.



From the above, I have no doubt that the documentary is an important arrangement and extremely useful in education, health, ideal format to be widely published in the media and be appropriate for the training and continuing education of professionals, technicians and assistants, and mainly of family members and caregivers in the domestic setting.

However, this assessment cannot fail to raise a complex and multifaceted thematic in which this work of Thereza Jessouroun is virtually silent. In my view, the analysis of this topic should complement the reflection from the documentary, when used in health education, and especially in the planning and implementation of public programs and policies of patients with Alzheimer.

We can start this debate by saying that Jessouroun presents in her film an **implicit naturalized vision of family, gender relations in caring and care availability in the domestic setting**, which correspond no more to the occupation profile, work, changes in family structures and other demographic trends that occur in the country, nor to the advances in critical social sciences and feminist studies and gender, in which Thereza Jessouroun certainly has great sympathy. The model of a typical family, with stable conjugal relations, with family members ready and available to take care of one of its members each time needing more care, or able to pay for services of professional caretakers, seems more consistent with certain sectors of the traditional middle classes and social elites when compared to most of the segments of our population.

So, it is worth briefly reviewing some of the **major demographic trends that pervades Brazilian society**, in order to understand the great "hole" of current provision of care in the domestic setting for dependents, or elderly. Given the narrowness of the space in this article, we are not reviewing quantitative indicators, which are available in recent data released by Instituto Brasileiro de Geografia (IBGE) 2, referring to the results of census carried out in 2010:

a) We're witnessing in the country an acceleration of the demographic transition, with the increase of life expectancy associated with a decline in birth rate, with consequent aging and **increase in the number of elderly in the population**, with **proportional growth in the prevalence of chronic degenerative diseases (including Alzheimer) and the demand for informal home care**, formal social in health and social care for the elderly population, without the necessary growth of public provision of these services, that would be those available to the majority of the population.

b) There is a growing participation of women in the labor **market**, already occupying more than half of the labor force in the country, with the **reduction of the availability for provision of informal care within families and in the neighborhood** (usually women - wives, mothers, daughters, daughters in law-- who take care) (Finch and Grove, 1983; Balbo, 1987; Rose, 2003). This happens without necessary compensation in male culture related to home care by men,

creating an increasing demand for social services, educational and health care, which is also not compensated by public offering these services.

c) We witness in the country a **greater diversity of sexual and household arrangements**, new reproductive technologies and family planning, changes in gender roles and sexual identities, strong individualization process, with increasing rates of marital separation and births outside marital unions. The **new marital ties tend to be more volatile**, or "liquid", as it is called by the well-known sociologist Bauman (2004, 2007 and 2008), generating **not so much compromise with the partner and their children**, particularly in situations that require long-term investment, or more intensive attention/care, improving conditions that create neglect and/or domestic violence situations. There is a **significant increase in the number of single-parent families headed and taken care exclusively by women**, with high average of total hours per week of domestic and productive work. In Brazil, this type of home arrangement reaches today about a third of families, but it is even more diffuse in popular social groups. On the other hand, there is not a significant reversal in gender identities in care taking, which could encourage men to assume the role of caregivers in the family in a more massive and compromised way. Thus, in this context, women and the few men caregivers tend to become exhausted, without time and mood for taking care to the family with some sort of dependence. In Brazil, such families tend to have higher rates of social vulnerability and neglect and domestic violence episodes, which nowadays are already perpetrated by women. In parallel, there is also a significant growth in the number of people who live alone (one person households), particularly older women, what compose a situation for social and existential increasing vulnerability in cases of dementias, generating new and growing demands to the social security system.

In short, at least for the purpose of this discussion, we can try to summarize this situation by saying that we have in Brazil, on one hand, a very significant increase in the number of elderly people and in prevalence of dementias, including Alzheimer, and on another, home arrangement, cultures of gender and family ties that present increasingly adverse conditions for the taking care of dependents in the domestic setting. This happens in a context of neoliberal policies that generate a clear disinvestment in social policies, particularly in health and social welfare, which in another more favorable conjuncture could in theory partially make up for the trends mentioned above. This situation primarily affects the majority of popular classes in the country, who have difficulties of accessing private medical care, home care programs or the hiring of home care employees, strategies used by middle classes and social elites. **In contexts such as these, a volunteer, naturalized and not contextualized plea to production of more care and attention to our elders, without considering the conditions of producing them, actually ends up increasing the burden on caregivers, usually women (which are the ones that actually care), increasing even more the gender exploration.** It is necessary to remember that this process of exploitation has a very low degree of social visibility, because they occur in the private setting of homes, and is sustained by psychological, ethical and religious interpellation, and therefore, its ambiguities, conflicts and repressed rages cause on caregivers, in addition to the greater burden of work and sacrifice of their projects in personal life, a high level of self-guilt, of more stress and mental suffering, particularly of depression.

The implications of this reflection for the services directed to patients with Alzheimer's disease are numerous, but I would like to draw the attention to a fundamental aspect, the support to families and caregivers. In my view, group psychotherapy, as shown in the documentary, has its importance, but is insufficient. Restricting to its offering reveals a concept that difficulties and obstacles to the provision of care would be only reasons of our family and psychic conflicts, which need to be rethought to redeem our bonds with sickened people. This situation seems to be stuck to this naturalized idea and psychologist accentually about the reasons and blocks to our ethical obligations of taking care of the family, ignoring the demographic and political-social context and gender relations that pervade the so many lessons that could be touch about the production of care in the domestic setting. Effective responses to these challenges for all the population implicate in several integral, inter-sectorial and interdisciplinary initiatives in the field of public health, social welfare, education, culture, etc. , and especially, in the current context of disinvestment in these public policies, the achievement of this range of services and programs will require a great battle of the actors and social movements interested in health needs of the elderly and several kinds of patients with special needs.

We can also point out some **consequences of this reflection to the associations of individuals with chronic diseases**, such as APAZ. There are several kinds of associations like this in the country, as shown in recent research (Vasconcelos, 2008; Vasconcelos and Braz, 2010), but usually the independent associations, not related to public services, are created and maintained by families of traditional middle classes, who have economic and cultural resources, and some free time to find the resources and support the organization and its activities, most of the times for the members of their own families and closer community. Thus, these associations tend to have some difficulty in perceiving the more extensive needs and the point of view of popular classes, related to the production of care in a context of difficult access to services like public health, education, and social welfare, of more fragile and volatile family arrangements, and

an more expanded agenda of arrangements and social struggles necessary for the effective support to family and caregivers of the majority of the population of the country. However, there are some examples of this type of associations in the country (Vasconcelos, 2008) that are overcoming these limitations, demonstrating that can grow in their level of social and political awareness and move on to the plead of needs and struggles related to the interests of the majority of the population, as well as actively participate on arrangements of social control, as the district, municipal, state and even national councils of these policies.

These criticisms do not take away the great merit of the initiative of Thereza Jessouroun and the work of APAZ, as I mentioned above. We only propose that, in peripheral and semi- peripheral societies as the Brazilian, any appeal to the better home care today, as demonstrated by Jessouroun, either in documentaries or in any education arrangement in health, or in the planning and management of programs and services, should be followed by a reflection on the themes listed above. And there is no way to discuss them, without summoning all the ones who have compassion for the Other, to join the necessary social struggles that we have to engage, in the achievement of an integral and effective assistance in health, education and social welfare of public nature.

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Web Sites

Associação de Parentes e Amigos de Pessoas com Alzheimer, Doenças Similares e Idosos Dependentes (APAZ) -
<<http://www.apaz.org.br>>

Kinofilmes (Thereza Jessouroun) - E-mail: kinofilmes@uol.com.br

Editora da Fiocruz / Selo Fiocruz Vídeo - <<http://www.fiocruz.br/editora>>

VideoSaúde – Distribuidora da Fiocruz - <<http://www.fiocruz/videosaude>> / E-mail: videosaude@icict.fiocruz.br

Notes

1. Available at: http://www.censo2010.ibge.gov.br/resultados_do_censo2010.php

Received: 23/02/2011

Accepted: 23/03/2012