

## FROM HALLUCINATION IN THE CLINIC TO THE HALLUCINATORY VISION OF THE IMAGE: AN ETHNOGRAPHIC JOURNEY

DOI

[https://dx.doi.org/10.11606/  
issn.2525-3123.gis.2019.146843](https://dx.doi.org/10.11606/issn.2525-3123.gis.2019.146843)

ORCID

<http://orcid.org/0000-0002-7735-6174>

**DANIELA FERIANI<sup>1</sup>**

Universidade de São Paulo, São Paulo, SP,  
Brazil, 05508-010 - fla@usp.br

### ABSTRACT

Following the threads that compose Alzheimer's disease, including the lines of flight, became the trajectory shaping the course of my doctoral research. In this article, I demonstrate this ethnographic journey through the lines and images with which I wove the disease as a field of experiences and disputes, in which it manifests as a diagnosis, a mode of subjectivity and an aesthetic simultaneously. From medical consultations to deliriums, from medicine to shamanism and the viewpoint of those with dementia, the images opened me up to other ways of seeing and narrating the disease. Along this journey, an ethnographic proposal emerged. What did Alzheimer's disease reveal to me about doing anthropology – and vice-versa? How did the passage between living the disease and telling others about it help me envisage my own passage between living the field and its re-telling? Since as Alzheimer's disease was gradually being composed, so too was an ethnography.

### KEYWORDS

Ethnography; image;  
Alzheimer's disease;  
haunting; experience.

---

1. Article developed during a scholarship granted by Fundação de Amparo à Pesquisa do Estado de São Paulo (Fapesp 2017/14740-7)



FIGURE 1  
Dandelion. Photo:  
Daniela Feriani.

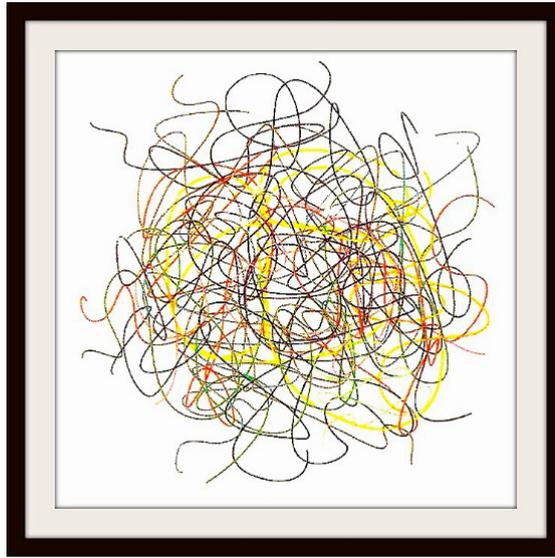


FIGURE 2  
Meshwork, in  
the book *Lines*.  
Ingold, 2007.

For the inhabitant, the line of his walking is a way of knowing. Likewise the line of writing is, for him, a way of remembering. In both cases, knowledge is integrated along a path of movement.  
(Ingold, 2007)

“It’s like the threads are slowly unravelling”. This is how the coordinator of the Brazilian Alzheimer’s Association (ABRAZ) began talking about the disease to a group of family carers. Reassembling the threads of the disease, composing and dissolving them, has likewise been formative of my own ethnographic journey.

Over the course of the research, I became more and more interested in the accounts and scenes that escaped the more institutional dynamics. Although my field site began at ABRAZ in the support group meetings and the neurology and geriatric psychiatry wards, accompanying medical appointments in a university hospital, the wish to witness more subjective scenes and accounts led me in search of other spaces. If the everyday is fundamental to the constitution of the disease by means of the clues left in domestic activities, I felt that researching these more informal spaces would allow me to weave more threads into the tangle.

Leaving the medical clinics and the ABRAZ meetings, therefore, I would visit the homes of people diagnosed with dementia. I heard Rosa explain to her husband how to dress. “No, *nego*, it’s not like that. That’s a shirt, not a pair of trousers. You’re supposed to wear it on your arms, not your legs”. I saw Célia become alarmed with the monkey from the soap opera about to invade her living room. I waited with Olga for her mother – dead the past 20 years – to arrive back to a home Olga said was

not her own. I talked with João for hours, moving between memories, deliriums and mathematical calculations. I laughed with Arthur's implacable humour and cried with him when he became overwhelmed by the beauty of life.<sup>2</sup>

In this quest to compose Alzheimer's disease, some images cropped up again and again. Finding their way to me through narratives, scenes and gestures witnessed in the field, or via photographic essays, videos and actions produced by awareness-raising campaigns, or in the blogs and artworks of people with dementia, I began to collate them under names like *dandelion*, *house* and *mirror-face*<sup>3</sup>. Based on these images, I designed a research itinerary, superimposing questions, subjects, spaces and times. My wish here is to recount how these images – or metaphors – displaced my way of thinking and doing ethnography and opened me to other ways of seeing and narrating the disease. As this involves showing a path, the relations through which I passed will be mobilized to compose this trajectory, like threads being pulled but which, for now, I shall not dwell on specifically. By proposing to show a flux, I shall leave the pauses for other moments. If I run the risk of passing over some questions without capturing their density, it is, therefore, with the intention of allowing the movement of the research to become more clearly visible.

The *dandelion* – whose seed-head is formed by numerous filaments that when blown by the wind or a person's breath, are released and float away – is frequently used in informational material on Alzheimer's disease, whose most (im)potent image is one of dissolution. It is no accident that sites, pamphlets and leaflets frequently use it to speak of the irreversibility of dementia processes.<sup>4</sup>

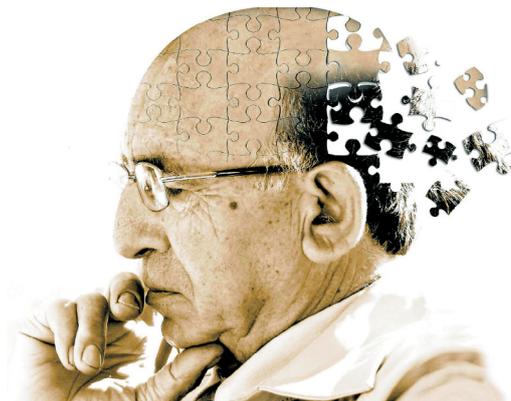
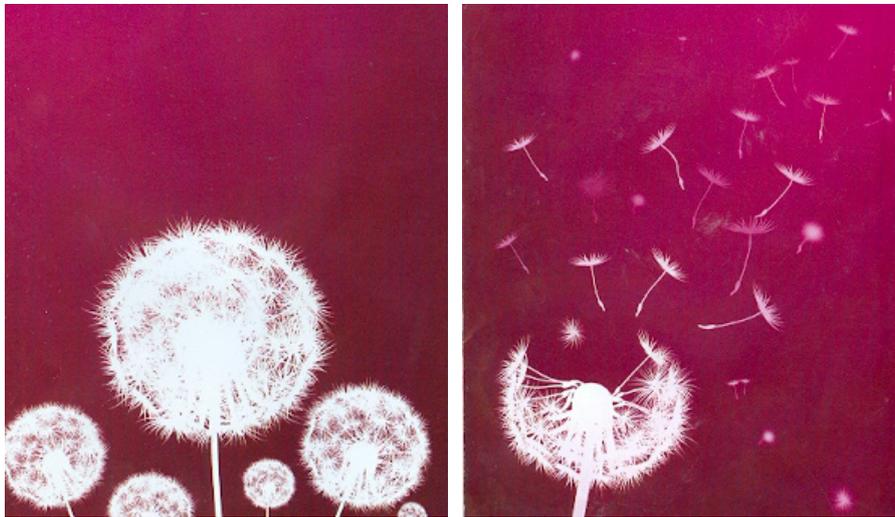
---

2. The people with whom I interacted in the research are mostly from underprivileged classes, users of Brazil's national health system (*Sistema Único de Saúde*: SUS). The carers are family members, mainly spouses and children. The patients were diagnosed with Alzheimer's disease at different stages – initial (light), moderate and serious. I met them while they were attending medical appointments at a university hospital and at meetings of the ABRAZ support group (focused on the carers since the patients cannot take part). It was in these spaces that I was able to approach these families and obtain the contacts to accompany them more closely through home visits.

3. These include images produced by family carers and specialists (such as photographers, filmmakers, ABRAZ volunteers, and myself, as researcher) and those produced by the people with dementia. My attempt has been to assemble these images and produce various compositions in an endeavour to see and take them as a visual thought of the disease.

4. I have preferred to speak of dementia and/or a dementia process because the diagnosis of Alzheimer's disease (the most common type of dementia) is extremely complex and always refers to a probability – “probable Alzheimer's disease” in the expression used by doctors – since a definitive diagnosis, which may still entail some degree of uncertainty, can only be made through necropsic examination of the brain. Furthermore, the boundaries and nuances between various types of dementia (Alzheimer's, frontotemporal, vascular and Lewy body dementias) are tenuous, uncertain, susceptible to reformulation and thus controversy. For a deeper discussion of diagnosis, see Feriani (2017a).

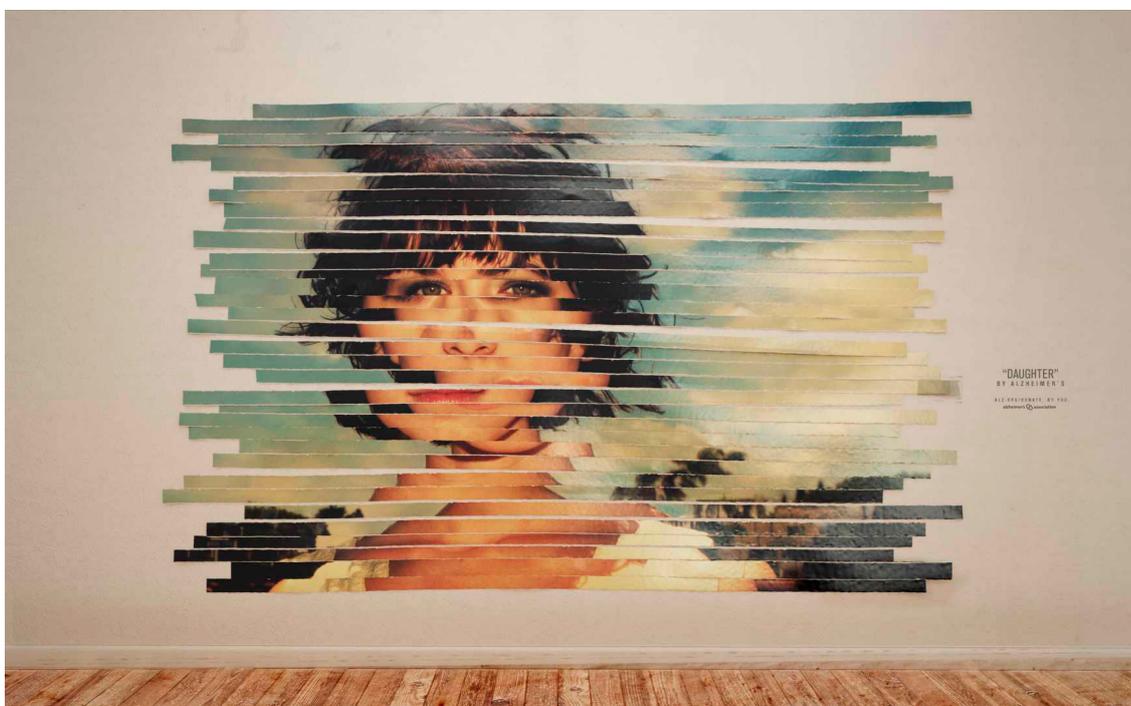
FIGURES 3 and 4  
Leaflet of  
the Brazilian  
Alzheimer's  
Association  
(ABRAz).



FIGURES 5-7  
Images found  
on news sites  
on Alzheimer's  
disease.



What is the potential for dissolution?



FIGURES 8-10  
'Alzheimer'  
exhibition,  
organized by the  
Alzheimer Disease  
International  
(ADI) / EUA.

I took the metaphor of dissolution seriously as a way to think about both the composition of Alzheimer's disease and the composition of my own research and writing trajectory. I took the dandelion seed head, with its overlapping and vulnerable filaments, which sometimes separate, sometimes cluster, as the entanglement of the theme and ethnography that I aimed to produce: an intersection of fields, relations and subjects in a transversal movement of folding and unfolding, containing and overflowing.

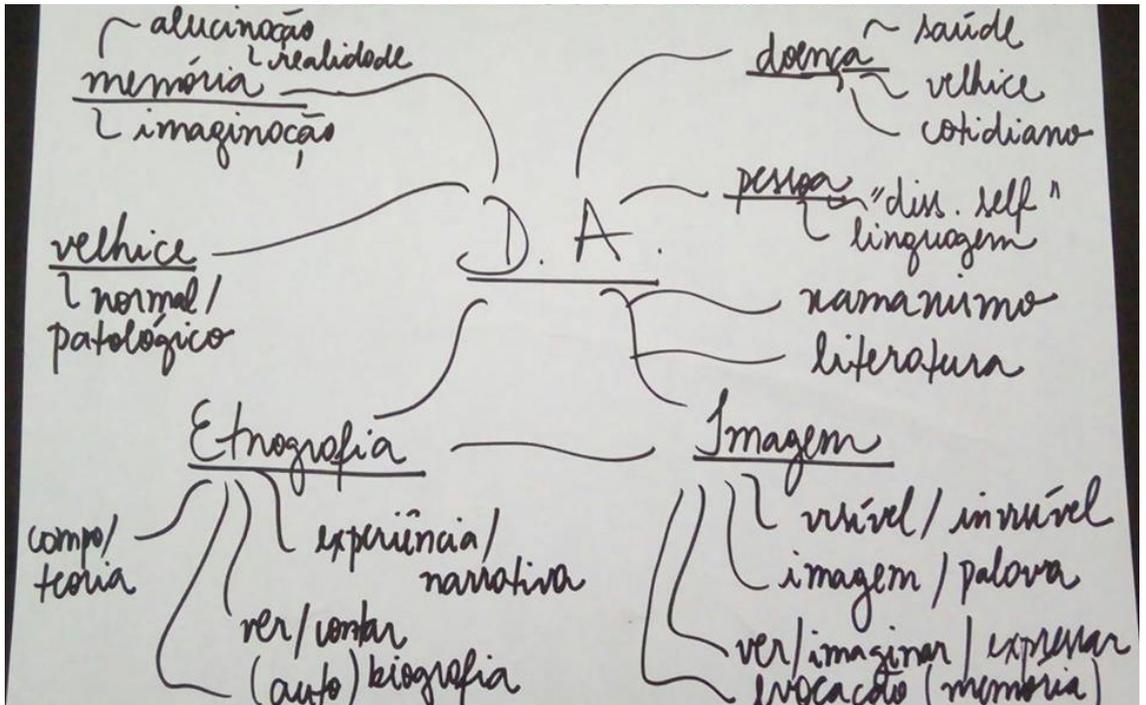


FIGURE 11  
network of neurons, in  
<http://www.rzagabe.com/2014/11/03/an-introduction-to-artificial-neural-networks.html>;

FIGURE 12  
dandelion. Photo:  
Daniela Feriani;

FIGURE 13  
Ingold, 2007.

FIGURE 14  
meshwork  
of research.

The key images of Alzheimer’s disease – the network of neurons (*Figure 11*) and the dandelion (*Figure 12*) – juxtaposed with the meshwork of Tim Ingold (*Figure 13*) led me to look to the movement of the research itself, to the efficacy of form, and thus to see and design my own ethnographic journey, my own meshwork (*Figure 14*), with the main filaments – or concepts – that I wished to relate.

If the *dandelion* led me to follow a map of lines to compose the disease and the ethnography, *home* and *mirror-face* persuaded me to introduce the pauses needed to contemplate the gestures, the lines of flight, the contours and blurring.

*Home* contains a relationship composed of care, disease and memory. This image derives from one of the main complaints of family carers – the ill person wishes “to go home,” referring to their childhood home while not recognizing the place where they now live as their own. Setting out from this fact, I looked to comprehend the place occupied by the family in caring for the disease as measured and excessive, dosed and out of control: while the family carer is fundamental to achieving a diagnosis by providing the necessary information and acting as the doctors’ thermometer when it comes to managing symptoms and medications, he or she also presents medical professionals with other demands that exceed their competence, such as conflicts between relatives, situations of violence and abuse, and disagreements concerning the process of negotiating what the patient is or is not permitted.

*Home* also shows the importance of gathering up everyday traces and clues in order to compose both memory (Feriani 2017b) and a diagnosis of Alzheimer’s disease (Feriani 2017a). It is by delving into the everyday life of the patient by means of scenes and accounts described by carers that doctors and residents can ascertain the extent to which a patient ‘not remembering’ is related to ‘being unable to do things.’ Taking a bath, eating, answering the phone, dressing and cooking become scenes that need to be recorded, dedicated, collated, as though it were necessary to retain them, safeguard them, so that they can become normal and possible. While these activities may seem banal and virtually imperceptible, they acquire an extraordinary dimension for those unable to perform them or at least encounter difficulties in doing so: Kris is unable to turn on the washing machine; Joe is terrified because the food in the fridge is going to attack him; Odalina uses lime instead of tapioca flour to make biscuits and washing-up liquid to cook; Guilherme uses a shirt as though it were a pair of trousers; Olga no longer knows how to make coffee; José took a shower while still dressed – another time, he tried to bathe using water from the lavatory bowl.



FIGURE 15  
Susan Falzone<sup>5</sup>.



FIGURE 16  
Alejandro Kirchuk<sup>6</sup>.



FIGURE 17  
Fausto Podavini<sup>7</sup>.



FIGURE 18  
Fausto Podavini.



FIGURE 19  
Susan Falzone.

The power of the image is such that another element to feature strongly is the mirror. Not recognizing oneself when staring in the mirror is taken by doctors as one of the most feared symptoms of the disease, the so-called “dissolution of the self.”<sup>8</sup> Family carers tell of people who talk to their own reflection, invite their mirror image for a walk, become frightened believing that a stranger has invaded their home. These are tragicomic scenes: at the same time as they show the horror of the disease, they provoke laughter from those who witness them.

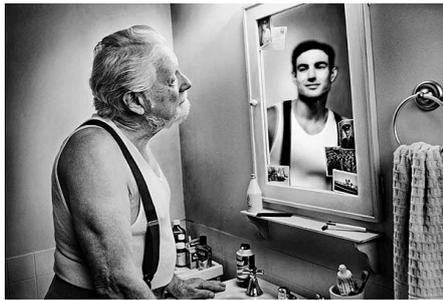
In 2010, a pharmaceutical lab used this theme during a launch campaign for a new drug for delaying memory loss, recommended for the light and moderate phases of Alzheimer’s disease. *Reflections* was the name given to the photographic essay by Tom Hussey.

5. Essay “Grace” in which Susan Falzone photographs the everyday life of her aunt with Alzheimer’s disease. Available at: <https://bit.ly/1kQFD1a>.

6. Essay “La noche que me quieras” in which Alejandro Kirchuk photographs the everyday life of his grandmother with Alzheimer’s disease. Available at: <https://bbc.in/2TCVCAE>

7. Essay “Mirella” in which Fausto Podavini photographs the everyday life of a couple – the man with Alzheimer’s disease, the woman as carer. Available at: <https://bit.ly/2FwSPKj>

8. An expression used by doctors and residents from the neurology ward studied.



FIGURES 20-23  
*Reflections*,  
Tom Hussey.

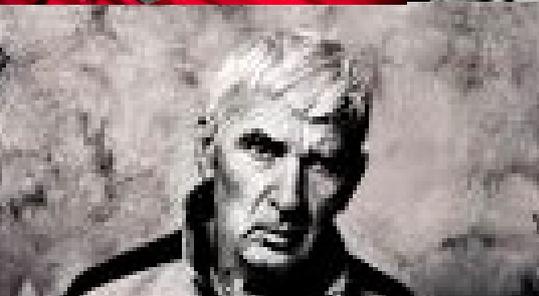
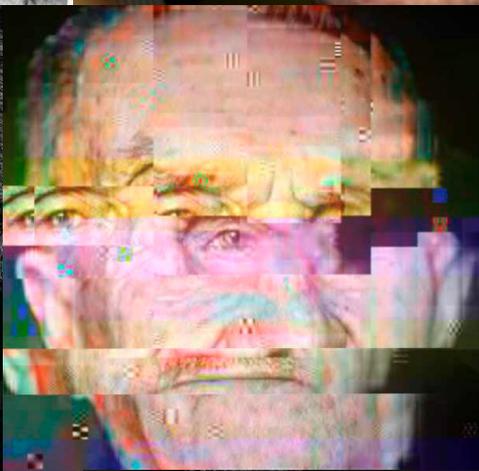
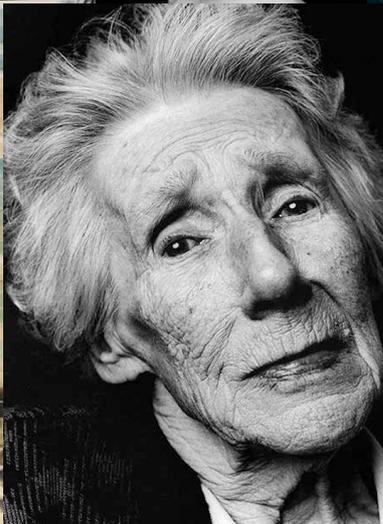
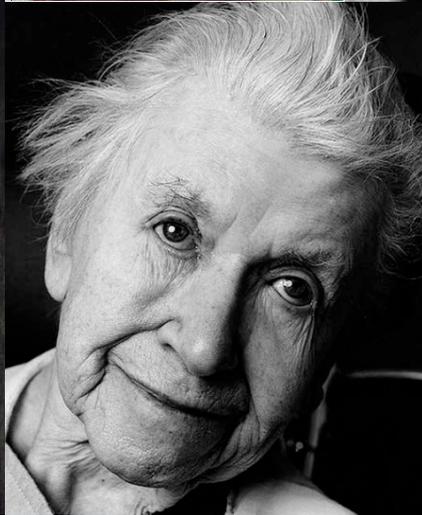
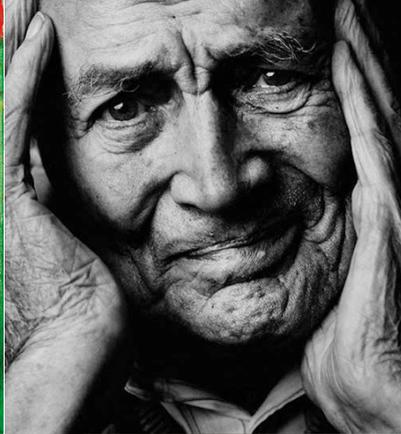
The mirror is both an object/thing and a metaphor for speaking of the fractality, dissolution and confusion caused by the disease. As Kopenawa and Albert (2013, 63) shows, “they are not mirrors to look at oneself, they are mirrors that shine”. And by shining, they obscure sight, as in the case of Jimmie, who became terrified on looking in the mirror and not seeing himself (Sacks 1985).<sup>9</sup>

#### HOW TO NOT SEE? AND, ON SEEING, WHAT TO DO WITH IMAGES?

The river that curved  
around the back of our house  
was the image of  
a soft glass that curved  
around the back of our house.  
Later a man passed by  
and said: this curve  
that the river makes around the back  
of your house is called an inlet.  
It was no longer the image  
of a glass snake that  
curved around the back of the house.  
It was an inlet.  
I think the name impoverished the image.  
(Manoel de Barros)

<sup>9</sup> I explore this discussion of the mirror, the notion of the person and the relation with shamanism in another article (in press).





How not to see these faces, gestures, looks, noses, hands? How not to hear how much they cry out and express?

These images burn, signal a crisis, a symptom. They reveal not a lack of meaning but an excess: “[...] the image burns with memory, which means that it burns whatever, even when it has become no more than ash: a way of stating its essential vocation for survival, in spite of everything” (Didi-Huberman 2012b, 216).

The discourse of the ‘dissolution of the self’ coexists with a large number of faces.<sup>10</sup> If the neurosciences elect the brain as the concept-image of the notion of the person, the counter-narrative of Alzheimer’s disease elects the face – the face as an interior-exterior fold, an inside-outside, a head-body.<sup>11</sup> The impression is that, despite the loss of memory, narrative and the world, what remains is the face, with its expressions, gestures, nuances, distortions, erasures, symptoms, as though it tells what can no longer be told through words. The face as an agent of perception interconnecting the head (brain) and body to compose an alternative notion of person to the biomedical model.

*Mirror-face* explores the notion of person that shifts during the oscillations between denying or potentializing dissolution. In other words, the biomedical expression ‘dissolution of the self’ is linked to a conception of personhood based on cognition, the individual and autonomy. When we turn to other contexts like indigenous and/or ‘non-western’ societies, this expression makes no sense because another notion of person is in play. Alzheimer’s disease oscillates, then, between an epidemic, an evil, a terror – in societies in which the notion of the person is based on memory and cognition – and invisibility, absence or tolerance, when the person is composed by a field of relations.<sup>12</sup>

10. Almost 70% of the images encountered are faces/portraits.

11. By counter-narrative I mean everything that surpasses the biomedical discourse of the ‘dissolution of self,’ including the photographic essays, videos and campaign actions designed to raise awareness about the disease, the accounts of family carers, the scenes witnessed over the course of field research, the blogs and artworks of people with dementia. Although these situations contain the idea of a loss of the person and the notion of reality, this process unfolds ambiguously with endeavours to show that, in spite of everything, the person remains, primarily by means of the body, affects, gestures, behaviours. Even for biomedicine, the ‘dissolution of the self’ coexists with a series of recommendations that contradict or at least problematize the process, such as maintaining autonomy for as long as possible and the importance of cognitive stimulation through physical activities, including occupational therapy, leisure pursuits such as walks, family lunches and so on. However, although the brain for the neurosciences is increasingly related to the environment and the body – especially the heart – it remains the privileged place for thought and for the notion of personhood in scientific and biomedical conceptions.

12. Aware of the risks and making the necessary mediations, this dialogue with other contexts such as shamanism – a phenomenon that also deals with disease, death, illness and altered states of consciousness – is pursued in an attempt to discover other reference points from which to think notions of personhood, illness, memory and reality beyond the bounds of biomedical discourse, thereby composing a counterpoint that is “good to think” what may be at stake in taking Alzheimer’s disease as “the disease of the twenty-first century.” I discuss these points in detail in another article (in press).

Alzheimer's disease has already been associated with 'an evil' due to its threat to neoliberal values such as autonomy, individuality, independence, self-care (Robbins 2008, Burke 2015, Wearing 2015, Goldman 2015). Fabio Landa, a medical doctor and social scientist with studies in psychology and psychoanalysis, shows how the French philosopher Emmanuel Levinas engages in a critique of the notion of autonomy as a pillar of western thought, highlighting the place that the Face assumes in his work, focusing particularly on the extermination of the Jews in Europe during the Second World War. According to Landa, Levinas takes the Face as the surplus to any possible description, the most vulnerable part of the human body, the most denuded and exposed to violence: "[...] perceiving a Face, according to Levinas, involves an enchantment that leaves no time to see, like before an image, a picture" (Landa 2003, 117). Thus, "accommodating a Face undermines the certainties that each of us tries to acquire over the other and over ourselves" (Ibid., 118).

Similarly, in my own research on Alzheimer's disease, choosing a Face is a counterpoint to a diagnosis, assuming, like Levinas, the irreducibility of alterity rather than the 'dissolution of the self.' Perhaps the growing production of images on Alzheimer's disease – such as films, novels, photographic essays, theatre plays, blogs, art exhibitions – is an attempt to accommodate these faces, perceiving them in their vulnerability, violence, rapture, as any other; in sum, an attempt for us to see ourselves in them.

As mirrors of ourselves, we see, through the backwards reflection, the "irreducible alterity of the other" (Landa 2003) so that, traversing this "world beyond" of dementia, we come to distrust our own certainties and points of reference. For the family carers, this implies a transformation so large that some begin to feel the effects of the disease, such as a sense of dissolution, disorientation, forgetting, confusion, madness and strangeness, and also the need to reinvent their everyday life, language and face.

What is language without the face?

The face is not an envelope exterior to the person who speaks, thinks, or feels. The form of the signifier in language, even its units, would remain indeterminate if the potential listener did not use the face of the speaker to guide his or her choices ('Hey, he seems angry...'; 'He couldn't say it...'; 'You see my face when I'm talking to you...'; 'look at me carefully...'). [...] The face constructs the wall that the signifier needs in order to bounce off of; it constitutes the wall of the signifier, the frame or screen. The face digs the hole that subjectification needs in order to break through; it constitutes the black hole of subjectivity as consciousness or passion, the camera, the third eye. (Deleuze and Guattari 1987, 167-168).

Faces constitute contexts of enunciation; they define the positions of subjects. Language can only be comprehended because it has the face as a wall off which the signifier can bounce. “Choices are guided by faces, elements are organized around faces: a common grammar is never separable from a facial education” (Ibid., 179).

What is the face without language? The relationship between image and name proved fundamental over the course of composing Alzheimer’s disease and the people who live it. If residents and doctors pursued this relation in order to attempt a precise diagnosis and family carers in order to comprehend and manage the disease, people with dementia also set off on the same quest: for them, naming the experience of the disease meant naming themselves. In a campaign called ‘Still’ on the social network Facebook, the Alzheimer Society of Ireland published photos of people with the diseases holding a sign on which was written “still (*name of the person*)” or “still (insistently) (*name of the person*).”

Inspired by the work of Roy Wagner, Dulley (2015) shows how a certain form of naming is linked to a specific conception of difference, the relationship between naming and alterity being the general problem of anthropology. The name is a way of fixing a reference point in a potentially infinite range of relations and this designation is always relational. Turning to Derrida, she discusses how the act of naming establishes a difference not only between names, on one hand, and the name and thing, on the other, but also between the thing and itself, calling attention to the instability of the name, its movements and tensions.

For Wagner (1989), there are two ways of seeing names: 1) Names as points of reference or codes, representing the things named (the order of homology) and 2) Names as a relationship between the name and the thing named (the order of metaphor, analogy). Adopting the second way – which I also attempted to do in my research –, the author shows how the name is a symbol that stands for itself, an organizing principle whose meaning resides in the analogies that it establishes, not in its referents. Names are conceived, then, as expanded metaphors since they establish relations of relations – concepts and images participate in an analogical thought. In this sense, to claim a name and a face is to position oneself within a field of relations, to have a place of speech, to create a context of enunciation. In the ‘backwards world’ of dementia, where everything is possible and fleeting, claiming a face is perhaps how the mortal line of the disease becomes folded.

## A DEMENTED POINT OF VIEW, OR HOW TO SEE BLURS AND FIREFLIES



FIGURES 24 and 25  
Photos: Fábio  
Messias.

*Mirror-face* took me closer and closer to the demented point of view, the endogenous images, the deliria, the disease's lines of flight. For Deleuze, it is by folding the mortal line of disease that a mode of subjectification, a possibility of life in the space between, a becoming, can be composed. The fold is the "potential for metamorphosis" (Deleuze 1995).

That's what subjectification is about: bringing a curve into the line, making it turn back on itself, or making force impinge on itself. So we get ways of living with what would otherwise be unendurable. What Foucault says is that we can only avoid death and madness if we make existing into a 'way,' an 'art.' (Ibid., 113).

Folding the line of flight constitutes the subject at the margin of established knowledge and powers, especially for the socially excluded – the complaint, here, has a great poetic and historical importance in this process. It comprises a lifestyle, the composition of an aesthetic and an ethic that take shape in the capacity to see and say – for Deleuze (1995), this is the crucial question: what are we capable of seeing and saying? Or, as Didi-Huberman (2011) asks, are we actually capable of seeing fireflies?

Because these people are feeling, saying, painting, writing, dancing, singing. Metaphors, words, gestures, images, noises, lacunas, things, spirits and ghosts all appear, they haunt, they become heard. They narrate the loss of narration or other narrative possibilities. They invent a life, a face, a language.

Along with the comments, gestures, complaints, refusals and desires encountered over the course of the research, there are the blogs of Kris and Joe, and the artworks of William Utermohlen and Carolus Horn.

Joe from the US decided to write his story and his day-to-day life with the disease on a blog, begun in 2006, two years after his diagnosis. "Welcome to my world," he invites us. "It is like not having to wear glasses now; my eyes say you can see stupid, my brain says where your glasses are?"

What is really a pain is looking for my glasses that I do not need. [...] The birds, clouds, trees and such all take on a new meaning in the world we are thrust into” (Potocny 2006). The posts alternate between moments of lucidity and confusion. Comparing his mind to a sponge, Joe says that he forgets where he left objects, forgets to eat, or take his medicines, or sleep, or what he was going to say in the middle of a phrase, or while writing the blog.

For Joe, the disease created ‘other world’: ‘Joeland,’ a ‘World of Dementia,’ ‘Neverland,’ ‘Mr. Alzheimer’s,’ ‘Alzheimer’s land,’ ‘dream land’ are some of the expressions he uses. At some moments, he sees himself between two different realities, split, confused. “I was in a state of in betweenness, between here and there. I finally started eating but with my fingers and slowly got back to where I should be”; “I live in a multiple of realities, unlike you I never know when I will pop in or out of any of them” (Ibid.).

In this ‘dream land’, dream and reality – “whatever you call it” or “this shitty reality I call life” – merge: he awakens, hears voices, and is unable to distinguish in what state he is, feeling like a captive of his own mind, body and home. On the other hand, Joe likes to create situations in his brain and to see how the parts play with them. He considers this more interesting than the mental games recommended by his doctors, carers and relatives. He believes that he has always done this, but now perceives his brain to be more visual - “Find myself more and more drawing inside myself” (Ibid.), not knowing whether it is because of the disease or because of the way he found of dealing with it.

In comparing himself to a book where the cover may be good but the actual content bad, Joe invites us to read him without losing his peculiar characteristics – ripped up, marked, meaningless, folded with bits missing. He says he has invented a new language, calling it ‘Joenese,’ ‘dementiaese’ and ‘soap box.’ Like Catarina, living in a “continuous redefinition of herself – Catarina, Catakina, Catioki, Catkine, Catkina” -, “capable of exploring new modes of self-evaluation and renewing her sense of dignity” (Biehl 2008, 444), Joe also lives a process of writing-becoming that invents a possibility of life – Joe, Joenese, Joeland.

My conversation with others is getting more difficult and less, oh what the hell, speak able cannot think of the right wording. That is becoming harder, finding the words that fit we play guessing games with me as to what I am trying to say, I guess I am refining my language, joenese, to a more pure form, which I do not understand.

[...]

In just regular conversation I get all mixed up, use the wrong words, words sort of dribble out of my mouth and I forget in the middle of things what it is we are talking about. (Potocny op. cit.).

Kris also writes a blog. From the United States like Joe, she was diagnosed with Alzheimer's disease at the age of 46. She began the blog in 2003, the same year of her diagnosis. Both Joe and Kris see themselves as spokespeople for the disease and engage in several activities for this purpose, such as congresses and lectures in various parts of the world.

Feelings of confusion, puzzlement, cloudiness and disorientation are constant. Haze (or mist, fog), mazes, journeys, storms are recurrent imagery to recount the experience of living with the illness. On these days (what she calls 'foggy days'), Kris is unable to read an article, find a cartoon funny, cook (she writes that her 'fog' self tries to cook but, despite knowing all the ingredients and what needs to be done, she is simply unable to do so).

In some situations, Kris says she has panic attacks, normally when she cannot perform some activity she considers 'normal', like being unable to turn on the washing machine, not knowing how to tidy up the craft-work room, burning the cookies in the oven, forgetting how to make coffee, not knowing how to buy things at the shopping mall, getting lost in her own home, being unable to switch off the electric toothbrush. In these moments, she perceives that the thought is in her brain, but she is unable to translate it into action. "It's like the instructions are written in a foreign language" (Bakowski 2003).

Finding it difficult to find words - "my word problems" (Ibid.) -, Kris, like Joe, also notes that her brain is more visual. Rather than thoughts appearing as words, she now sees them as images, a 'storyboard,' which, for her, makes everything more difficult because she must convert these images into words again in order to be able to say them, to communicate them. Regardless, she recognizes this to be a new way of seeing the world.

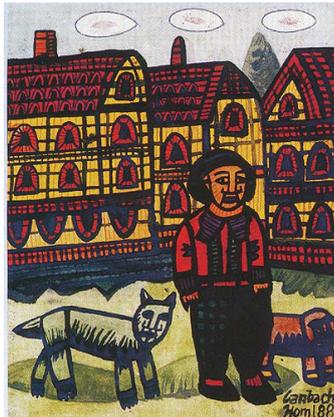
I realized then that the way I 'see' things in my brain has changed. I used to 'see' things with words – if I had a thought I was trying to say or get a point across it was words that I was forming in my brain and almost reading them back in order to explain something or even with a regular conversation. Now, I see more images in my mind rather than words. This makes it more difficult for me because I then have to convert those images to words and then get it out of my mouth! How simple is that? Not that simple for me. Last night I had this whole storyboard of images in my mind with this story I was going to tell my husband. I couldn't get it out – I couldn't put the words to the images and make it come out. I'm sure this sounds strange to most of you reading this, but I can't figure out another way to say it. (Ibid.).

The “problem with words” makes it difficult to write the blog and makes Kris ask herself to whom, ultimately, she is writing.

I have started this post many times and didn't finish it. I was afraid that those of you that read this blog will think I am writing about you – and then I realized that the people I am going to write about probably don't read this blog so it doesn't matter anyway! So, if you are reading this – it isn't about you. (Ibid.).

A paradox of writing, a problem of representation: Kris wants to communicate mainly with the people who, like her, have Alzheimer's disease, but recognizes that they will be unable to read her posts. So the blog is about someone different to the one who reads it: “...if you are reading this – it isn't about you.” The difficulty of communicating with people is a recurrent topic and leads us to question – as Joe also does – whose the problem ultimately is: the sick or those who are incapable of understanding them.

While Kris and Joe write blogs, the German Carolus Horn (1921–1992), diagnosed at the age of 58, and the American William Utermohlen (1933–2007), diagnosed at the age of 61, painted pictures as the disease took its course.



FIGURES 26–33  
Pictures by  
Carolus Horn over  
the evolution  
of Alzheimer's  
disease.



FIGURES 34–42  
Self-portraits  
by William  
Utermohlen over  
the evolution  
of Alzheimer's  
disease<sup>13</sup>.

The paintings by Utermohlen and Carolus compose a constellation of gestures, expressions, highlights and shadows in the undulating rhythm of disease and memory, like a game of presence and absence, a possibility – like the blogs of Joe and Kris – for entangling narrative and experience through imagery.

<sup>13</sup>. Available at: <https://bit.ly/2YrspCA>. Consulted 23/02/2014.

Between *sopros* and *assombros* (puffs of air and shadows)<sup>14</sup>, these ‘demented authors’ write and paint sensations, perceptions, by means of a special kind of narrative: as Taussig (2011) say about writing the field notebook – or the diary in general – it involves a direct translation of experience to the page (or screen), usually in a rushed, abbreviated and urgent manner. They also participate in the tragic described by Taussig: each word seems to multiply the distance between narrative and experience, language and world; writing, as an epitome of consciousness, ends up obliterating the reality that the writer wishes to communicate, pushing it further and further out of reach. The paradox of this type of writing becomes greater still in a dementia process in which words fall silent over time and the distance between word and author – or the latter’s world – begins to verge on the abysmal: “I think about what I am going to write and then I just can’t get the words to go from my head to the page” (Bakowski 2003).

When the perception of what is seen/lived is so strange – like Joe’s astonishment on seeing the food in the fridge wanting to attack him, Célia’s terror because the monkey was about to invade the living room, the dismay of failing to recognize relatives and not recognizing oneself in the mirror, and so many other situations that I lived over the course of my research – then seeing starts to doubt itself and must find another way of seeing-narrating. And so images proliferate as a way of reinventing connections and possible worlds.

Wagner (1995) invites us to be suspicious of our ability to communicate, to express our intentions, given that we cannot know them directly but only through knowledge of other people’s intentions. It amounts, therefore, to a bluff, a mismatch between meaning and saying and what others understand this saying to mean. There exists an ambiguity, an enigma surrounding intentionality and spontaneity, which become hidden and mediated in a relation field. As occurs with humour and metaphor, intention can play tricks, a ruse, a joke, it can cheat and invert meaning, twist perspectives; it may speak indirectly and refuse the verbal and the categorical. Like photography, the intention, for Wagner, is concealed, obscure, treacherous, it feigns to be like the ‘I’ known from the portrait when it appears so little like it – like the sick person who looks in the mirror and does not recognize herself. It has, then, a touch of revelation, apparition, wonder. For Wagner, these traps, erasures and bluffs of language, rather than making it unviable, also narrate, tell

---

14. TN: The Portuguese word *assombro* has a wide range of meanings difficult to capture in translation: astonishment, admiration, awe, terror, as well as soul, ghost, closely associated with the verb *assombrar*, to scare, haunt, astonish, fill with dread. Here the term is translated by its root etymology, *sombra*, shadow, which also evokes the idea of ghostly blurring explored in the article. *Sopro* means breath, exhalation, a blow of air and here recall the puffs of air blowing away the dandelion seeds.

important things. If, ultimately, we are all unreliable narrators, the question is why some of us are less unreliable than others.<sup>15</sup>

For Course (2012), language is a problematic, strange and paradoxical phenomenon: while we can only know ourselves and create through it, and while it is through language that authority and social relations are constituted, it has an excessive force that removes our control. The surplus meaning may be both a bad intention and a quality endemic to discourse itself. The language thus becomes agency itself, an act, a movement, not merely an appropriation on the part of a subject.

Language as an act and a movement, which constitutes an authority at the same time as it escapes the control of those who possess it, allows us to see the dislocations, overlaps and tensions in the composition of Alzheimer's disease which overflows the medical field to invade other areas, subjects, references.

While Taussig (2011) speaks of opening language and Cesarino (2011a) of twisting it, Deleuze (1997, lv) compares it to delirium, to "invent a new language within language, a foreign language, as it were". To make language delirious is to fabulate, to experience it as a becoming, "driving words from one end of the universe to the other" (p. lv), creating "a witch's line that escapes the dominant system" (p. 5) and removing it from "its usual furrows" (p. 5), "inventing a people who are missing" (p. 4). What are the blogs and paintings if not an attempt to create a line of flight, search for a meaning beyond meaning, constitute a community of people with Alzheimer's disease? To invent a people is to invent a possibility of life.

For Deleuze, delirium, in literature – and I would add in art and shamanism – is a passage, becoming, health. "But when delirium falls back into the *clinical state*, words no longer open out onto anything, we no longer hear or see anything through them except a night whose history, colors, and songs have been lost" (Ibid., lv). Delirium, when it leaves literature to fall back into life, is no longer health but sickness, no longer a passage of life but a "stopping of the process" (p. 3). It is not fabrication but confabulation. Just as thinking madness is not an experience of madness but of thought – it only becomes madness in the collapse (Deleuze 1995) – so too delirium, in literature, is a sign. Like memory, delirium, in the clinic, loses its polysemy, becoming a pathology.

But when someone with Alzheimer's disease traces a line of flight by writing a blog, painting a picture, making a joke, being ironic, delirium becomes both a sign and a pathology, critique and clinic. Unlike the

---

15. The term 'unreliable narrator' was coined in 1961 by the US literary critic Wayne C. Booth in *The Rhetoric of Fiction*. Some attempts at classification were made, including the mad, the mentally ill, the naive and the liar as unreliable narrators. Since then, many writers and authors have joined the discussion, questioning the extent to which a narrator, any, can be considered reliable.

writer who returns to 'normality' after the ritual or writing, though, it seems that this return does not exist for anyone in a dementia process. "All of us need to take little holidays from our frontal lobes – the tragedy is when, through grave illness or injury, there is no return from holiday" writes the neurologist Oliver Sacks (1995, n.p).<sup>16</sup>

We need to ask, though, what this 'no return' means when it comes to a disease in which moments of lucidity and dementia alternate. As in shamanic ritual, in which the near unconsciousness of the shaman allows him to see more (Taussig 2011), it involves the fold or paradoxical relation between consciousness and unconsciousness – much more than any separation or opposition. If we are constantly drifting between different states of consciousness – in dreams, diseases, uses of hallucinogens, rituals – what, then, does being conscious, "returning to normality," actually mean? After all, as one neurologist said, "no one is demented all the time."

In this mirror-face-language composite, the 'dissolution of the self' depends on who is looking, towards whom and from where: the blurred, out-of-focus vision may be our own, the 'non-sick' looking at the 'sick'; them looking at ourselves, family and friends, and them looking at themselves. Based on the positioning of the capacity to see, hear and say within a field of relations and contexts of enunciation – whether in a medical consultation, an ABRAZ meeting, in the living room, as an author of a blog or a work of art, or in a shamanic ritual – the dissolution may be a pathological symptom, a sign or a mode of subjectification.

The 'dissolution of the self' and the loss of cognitive functions caused by the disease may be expressions of 'defacialization' (as a becoming, both as a 'non-person' in some contexts/discourses and a 'multiple person' in others) and facialization (with the election of some faces as more 'normal' and 'health' than others or with the attempt to hold on to a face to say that, despite everything, the person remains). Ears, noses, eyes and hands compose a gallery of multiple faces, fragmented, composite, a kind of "formula of pathos"<sup>17</sup> – faces against the Face. In sum, other faces are possible, "...here, cutting edges of deterritorialization become operative and lines of deterritorialization positive and absolute, forming strange new becomings, new polyvocalities" (Deleuze and Guattari 1987, 191).

Other faces, other mirrors, other languages. If the face blurs and the mirror shatters, language, in Alzheimer's disease, also opens up, distorts, raves, burns by means of metaphor, the image, the body, in a fold

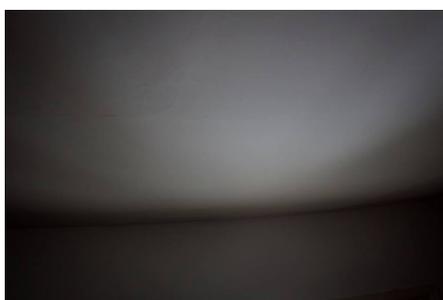
16. As one neurologist said to me, the frontal lobe is responsible for our humanity, including compliance with social rules and control of 'primitive instincts' like sexuality, and critical judgment.

17. The expression "formula of pathos" (*pathosformel*) is used by Aby Warburg to describe, principally, a series of gestures, expressions, bodily forms that have survived in paintings and portraits since the Renaissance. This expression is recuperated and discussed by Didi-Huberman (2013a) in his proposal for an 'anthropology of gestures.'

between dementia and lucidity, memory and forgetting, routine and creativity, terror and humour. A language that twists in order to, distancing itself from meaning, extrapolating the ordinary, connect the poetic function and the referential function, making this difference ambiguous, composite (Cesarino 2011a).

The everyday becomes haunted; real and surreal, memory and hallucination, literal and metaphoric overlap, as when Guilherme used his flip-flop to change the TV channel.<sup>18</sup> In an ‘upside-down world’ with other reference points – including the very notion of reality – a language-becoming, incomprehensible to some, becomes necessary, which, even when it uses the verbal extends beyond it, generating other aesthetic expressions.<sup>19</sup>

#### TOWARDS A HAUNTED ETHNOGRAPHY



It was only a glimpse [...].  
But it belongs to a set  
of images which have  
mesmerised me ever since.  
(Marilyn Strathern,  
*The ethnographic effect*)



FIGURES 43–47  
Photos: Fábio  
Messias.

18. Or again: the literal is a metaphor that became obviated (Wagner 1989) – the metaphor of the metaphor that obviates the referent or when the metaphor becomes the referent itself, like Hamlet who reveals the truth by pretending to be mad, revealing the truth via its acting out as the theatre; or like, in my own research, the everyday that becomes absurd, surreal, verging on the absurd, and the apparently most banal domestic activities turn frighteningly mysterious.

19. The ever-expanding production of films, novels, autobiographies, theatre plays, music, photographs, blogs and exhibitions on the disease would seem to attest to this.

The folds that accompanied the research also made my experience as an anthropologist. I also found myself immersed between terror and humour, routine and creativity, person and dissolution, memory and invention, the flashes of light, the trails, the contours and the chaos of a tangled mass. I was haunted too, intoxicated by the innumerable scenes that I saw, heard, imagined, assembled over the course of this composite formed by this ethnography, as research-writing, field-theory, experience-narrative.

Olga, with pink lipstick and slippers, earrings, necklace and rings, and a diaper, who welcomed me like a good hostess, offering coffee she was unable to make, who danced with aplomb in the medical appointment, but was unable to follow the conversation in the house that she said was not hers, who gave me excellent advice while she waited for her mother, dead for twenty years. Guilherme, who lay the television flat so that the people would not fall out and wore a shirt as though it were a pair of trousers. Célia's distressed hand clutching a cloth because the monkey from the soap opera was going to enter the living room. José, who ate dog food and was no longer able to finish a phrase; Dr. P, who mistook his wife's head for a hat (Sacks 1985); Jimmie, who believed he was 19 years old when he was 40 (Ibid.); Jussara, who invited her mirror image to go out for a walk. Eyes that shine, become frightened, fade; rushed hands, silent hands, confident hands; the laughter, the jokes, the complaints, the crying, the requests – glimpses that persist, images that mesmerize: a phrase, a gesture, a scene, a fragment. If the processes of dementia unfurl between puffs of air and shadows, the ethnography was affected by them too – I also had my ghosts.<sup>20</sup>

Aware that writing, as an “epitome of consciousness,” is flawed when it comes to expressing experience, with words opening up an abyss between subject and world – or between language and the world –, Taussig (2011) invites us to incorporate the images, astonishments, mysteries and gestures perceived over the course of the research. Hallucination – like an image, an apparition – functions as an analogy to think shamanism, ethnography, field notebooks; it opens language, deforms sight to see more and further – a squinting, arduous sight, a slow motion sight.

The image as spirit, vision, prophecy (Kopenawa & Albert 2015) involves an act of seeing in which, more than narrating, it evokes and expresses; the image is thus more gestural than discursive in kind – which proved to be of fundamental importance in relation to the dementia process.

---

20. This haunting feeling also resides in studying something that may happen – like old age and Alzheimer's disease. Great-grandparents, grandparents and other relatives had the disease and, although a hereditary cause is not proven, the fear – especially of my father, who has already referred to this many times – is real.

If it is in the darkness of night that shamanic visions shine, as it is for the fireflies, how to see, in the middle of the fog of the disease, the flashes, the apparitions? In a disease “whose threads gradually unravel,” what can images do in this context of lapses and collapses? What do they show when words fall silent?<sup>21</sup>

Images allowed me to see Alzheimer’s disease in another way. By perceiving and incorporating the photographs, videos, blogs, Facebook pages, art, humour, gestures, scenes, metaphors, shadows, I was able to listen to people in a dementia process, hear the unspoken, and see what normally passes unseen when faced with a disease like this. Rather than taking as given the ‘dissolution of the self,’ memory loss, the absence of language, I showed how the dissolution can be dissolved or potentialized, how memory becomes corporeal and overlaps with invention, and finally how language, rather than simply – or just – disappearing, opens up, twists, raves, burns.

Opening up language (Taussig), ripping up the image (Didi-Huberman), breaking the thing (Foucault, Deleuze), searching for unexpected associations, perceiving similarities where, in the first contact, there are none. My attempt, then, was to relate Alzheimer’s disease and shamanism – and also literature – as a “creative meeting of references” (Cesarino 2011b), in a kind of writing-delirium in which the dissimilar are connected in order to see what cannot be seen with the naked eye.<sup>22</sup> Imagination here is transversal knowledge, the intrinsic power of the assemblage that makes similarities appear where none had been presumed, inventing analogies between more distant and heterogenous analogies (Didi-Huberman 2013b).<sup>23</sup> It was the lesson that Lévi-Strauss said he had learned from surrealism. This is what Alzheimer’s disease, in its everyday surrealism, revealed to me.

If the composition of the disease revealed an experience and an aesthetic across the traversed fields and subjects, the ethnography was also composed in this double dimension: as experience and aesthetic.<sup>24</sup> For this to happen, it was necessary to inhabit the knot, become a line: choosing what to reveal and what to conceal, what to remember,

---

21. My thanks to Fabiana Bruno especially for this and other questions relating to the research images.

22. The relation between shamanism and literature (such as *Alice’s Adventures in Wonderland* by Lewis Carroll) is explored in an attempt to think the other-becoming of the disease, the space of metamorphosis of an ‘upside-down world.’ I discuss these relations in “Doença de Alzheimer e xamanismo: diálogos (im)possíveis” (in press).

23. As Strathern (1999, 260) writes, “relations are what make people ‘see’ anything at all”. Or again: “writing only works [...] as an imaginative re-creation of some of the effects of fieldwork itself” (p. 1).

24. Here I take aesthetics as sensory, imagetic, intuitive thought (Bruno 2009), a theory of the qualities of feeling (Freud 2006), a reflection on metaphors and sensory codes (Cesarino 2011a).

forget and imagine, transiting between facts and deliria and wandering through many places – from medical wards to congresses, from congresses to ABRAZ, from ABRAZ to the family homes, from the homes to the blogs, from the blogs to Facebook pages, photographs, videos.<sup>25</sup>

By assembling the ethnography through images revealed to me by the field – *dandelion*, *home*, *mirror-face* – I sought to show how they act as a presence (Severi 2009), rather than as a representation, or Walter Benjamin's 'dialectical images,' by presenting a field of relations, located between dementia and lucidity, routine and creativity, person and 'dissolution and self,' terror and humour, memory and hallucination, sickness and old age, normal and pathological, and perceiving which poles shone and which faded according to the situations and subjects, in a constant figure-ground reversal, light and shadow, like the night and the firefly, the dandelion and the puff of air, the mirror and the haunting.

"I swear I saw this," writes Taussig (2011) after glimpsing a woman – or what he thought to be a woman – sewing a man – or what he thought was a man – into a sack by the side of a tunnel. Still unable to believe what he had seen, Taussig sketches the scene to picture it one more time. For him, the field notebook, like the image and the shaman's song, is an act of testimony, a combination between seeing, speaking and committing. The testimony is a discourse that takes the position of the 'I' – *I swear I saw this*. The 'I' of this phrase, in my own research, could be the I of the anthropologist who composes an ethnography, the I of the family member providing care, the I of the person with dementia experiencing the disease. Each of them, in their own way and with different objectives, sought and composed a name for the experience that they lived and/or are living. For the residents, doctors and ABRAZ team too, the name proved fundamental to making a diagnosis, determining a form of treatment and managing the disease. Is it old age or disease? Is it disease or tantrum? Memory or hallucination?

Faced by the haunted and nebulous everyday life of the disease – and the ethnography – each of the subjects situated in this complex cartography of connections and disconnections needed to claim, create and reinvent a speech, dislocating notions of disease, personhood, memory and reality in an assemblage somewhere between experience and aesthetics. If, for the poet Manoel de Barros, the name impoverished the image, it was up to the image to twist, open and split the name.

---

25. These were the lines that I chose to follow, aware that others were left out and would have taken me along other paths, such as laboratories and the pharmaceutical industry, the market and courses for carers, public policies, legislation and so on. Some lines, though running into them, ended up not being pursued, despite my interest, including the films and autobiographies, which will remain for a future journey.

Images are fireflies. Against the apocalyptic pessimism of the filmmaker Pier Paolo Pasolini and the philosopher Giorgio Agamben, who decreed the destruction of experience, the end of human beings, living communities and the culture of resistance in the fact of the terror of wars, the rise of fascism, the dictatorship of industry and consumerism, and the society of control,<sup>26</sup> Didi-Huberman (2018) argues for the survival of fireflies – that is, the flashes, resistances, desires and insurrections that surface in the dark of the night, the dance of the fireflies, “this moment of grace that resists in the world of terror...” (p. 9), however fleeting and fragile it may be. For him, decreeing the end of fireflies due to the blinding light of power – as Pasolini does – is to “see nothing but the black night or the blinding glare of the spotlights [...]. To see only the *whole*. And thus not to see space – though it may be interstitial, intermittent, nomadic, improbably located – of openings, of possibilities, of flashes, *in spite of all*” (p. 18). Fireflies only disappear, then, when we cease to follow them.

Didi-Huberman follows them, sees the flashes of counterpower, and shows that “...*experience is indestructible*, even when it may well become reduced to survivals and clandestine moments, to simple glimmers in the night” (Ibid., 80), even in such sombre settings – or precisely because of them: “...the fireflies’ living dance plays out precisely in the heart of shadows” (p. 27). It is in the darkness, terror and despair that flashes of light can be seen, revealing “firefly-words” and “firefly-images” against the “spotlight-words”, as the witnesses of trauma, the war survivors, the Warsaw ghetto newspapers, the chronicles of insurrection, the photographs of the gas chamber prisoner. The collapse of experience is also an experience and transformation does not mean destruction.

While Alzheimer’s disease has been associated with the crisis in memory of modern times, the impoverishment of narrative and experience, the blogs, paintings, comments, gestures and faces of the people with dementia, the metaphors and images are the flashes in this black night, a night that also has its fireflies – an eye that shines, a hand that holds a cover, the drips of water after the shower, the coffee stain in a cup, a kept photo, a joke, a language that is invented, a painting, a complaint, a walk, a dance, a song, a laugh, a cry, a refusal, a desire. And these flashes also compose an experience, a memory, a knowledge, even though it is a disease that gradually erases them.

---

26. An important reference for these authors is Walter Benjamin, especially “Experience and poverty” and “The storyteller.” Didi-Huberman shows, however, that Benjamin speaks of a decline in experience, not its destruction, as well as glimpsing the potentiality, the flashes and openings that can emerge, something absent from the apocalyptic vision of Pasolini and Agamben.

It is not a question of denying the terror of the disease but of seeing it beyond this horizon. See beyond, see more, see fireflies: see the potentiality of blur, of dissolution. See that, in the middle of fog, Joe uses humour and invents words when they seemed lost; Kris perceives his brain becoming more visual; Dr. P listens to music to do his everyday tasks; Jimmie goes to mass for guidance; Rebecca keeps herself alive and coherent in the theatre; William Utermohlen and Carolus Horn paint pictures. And so many others who make comments, tell jokes, disagree, move about, in flashes of desire, thought, knowledge. If there are reasons for being pessimistic, “it’s more necessary than ever to open our eyes in the night, to move around without rest, to set out again in search of fireflies” (Ibid., 23).

If it is possible to see fireflies in the dark, the twisted faces seen in the mirror backwards show us the importance too of seeing the blurs – the blurred vision, a gaze that loses itself, a speech that is left unspoken, a body that does not move, the bathroom that is not found, the portrait and the mirror that reveal ghosts, the washing machine that can no longer be switched on, the coffee, the shower, the food that can no longer be made. To see the fireflies and the smudges is to see the glimpses that allow, amid the losses, the constellation of an experience to emerge, a narrative, a memory, a legacy. “Although they skim just above the ground, moving so slowly, emitting such a weak light, don’t the fireflies draw, strictly speaking, just such a constellation?” (Ibid, 30).

\*\*\*

For Lévi-Strauss (1991, 4), research with myths revealed an aesthetic experience, all the more stimulating because

these myths appear first of all as puzzles. They tell stories without head or tail, full of absurd incidents. One has to ‘hatch’ the myth for days, weeks, sometimes months, before suddenly a spark bursts out, and in some inexplicable detail in another myth, so that by thus expedient they can be brought together as a unity. Each detail in itself need mean nothing; it is in their differential relationships that their intelligibility is found.

Like myths for Lévi-Strauss, and Alzheimer’s disease for myself, ethnography can take on the fluidity of a “soup of enigmas” as Aby Warburg referred to his own style: a “shapeless mass, without head or tail, a thought always averse to being ‘cut,’ that is, to defining for itself a beginning and an end” (Didi-Huberman 2013a, 29). “How to navigate in a knot of problems?” (p. 37).

“In fact, it involves experiencing in oneself a displacement of the point of view: displacing one’s own position as a subject in order to be able

to offer a way to displace the definition of the object”, Didi-Huberman writes (Ibid., 37) apropos Warburg’s voyage to the indigenous societies of New Mexico, showing how the search to not know led him to collect the details, traces, collapses and intervals as important vehicles of uncertainty and disorientation. Much the same applies to ethnography and Alzheimer’s disease: the traces of the everyday point to mysteries, enigmas, puzzlements – in Alzheimer’s disease, it is the details of the day-to-day that reveal what the patients no longer know or are no longer able to do. It is by pursuing this not knowing, excavating cracks, traversing lacunas, gathering uncertainties, that the diagnosis – and, ultimately, life with dementia – is slowly assembled.

Ethnography as an experience of displacement and the suspension of knowing led me in other directions, to create alternative paths, like opening the field beyond biomedicine, the potentiality of images, the connection between shamanism and literature, the inclusion of the patients as research subjects. Moving among the threads of the ethnographic tangle by means of a transversal movement of folding and overlapping was important to maintain the complexity and nebulosity that surround Alzheimer’s disease as something mysterious and slippery, an obscurity as epistemological as it is ontological (Taussig 1993).

The creation of a world apart – the world of dementia – at the same time as it requires boundary strategies, like “avoiding confronting it head on”, being creative, good-humoured, also involves something of the impassable, an alterity marked by other times, spaces, references. If this encounter of worlds transposes the problem of interpretation and translation to ethnography and shamanism, Alzheimer’s disease also participates in the same via the sick person who needs to learn to transit between these worlds, via the task of the family carer and doctor of being able to see and hear these people, and via the endeavour of the anthropologist who writes to you.<sup>27</sup> The problem of translation shifts between a world of dementia and a world of non-dementia, between dementia and shamanism, between dementia and ethnography or performance and writing (how to pass from what we observe, see and hear to what we write).<sup>28</sup>

---

27. As Strathern (1988, 312) warns us: “The anthropologist’s efforts at communication are hampered by his or her very subject matter; and indeed if they are not, if there are no hesitations, then something is wrong”.

28. Taussig speaks of witnessing as the relationship between seeing, writing and committing. For him, the field notebook is the place of encounter of these dimensions. The question he explores is: what is lost in the passage from the field notebook to the writing of the book? This exploration of the relation between field and writing also appears in Strathern (2014). In this journey, both Taussig and Strathern reveal the hauntings of research.

Approaching Alzheimer's disease as a problem of translation also led me to become aware of the moments when the object is named and the consequences of this naming, describing the process of constituting names, their distancing and overlapping, relating them to contexts and showing permanence and transformations. What mattered most was to display these connections, inhabit the entanglement rather than interpret and analyse it. Rather than asking what Alzheimer's disease is, my objective was to explore what it (dis)connects.

For people with dementia, the crisis in representation can be seen in the difficulty in communicating, like the "problem with words," the blog "that was not made for you," the increasingly abstract pictures of William Utermohlen and Carolus Horn. The difficulties and failures of this search for language end up opening language up: the faces, gestures, noises, silences, lacunas, metaphors, puffs of air and shadows need to be seen, heard, witnessed. Images enter as potentialities of expression: images twist words, create new contexts of enunciation, distort official discourses, offer other worlds and forms of recognition.

The mirror as refraction and divergence is a good image-concept, reference-metaphor, for the proposal of a haunted ethnography: not seeing oneself in the reflected image means suspending knowing so as to enter the world of the other, move through other references, in a back-to-front world, in a field of strangeness, disorientation and dissolution of the subject, in order to take the native thought seriously (Viveiros de Castro 2002) and translate it without flattening out the differences.

This is what Didi-Huberman (2012a) does: rather than discarding the blur in the photograph taken by a prisoner for being aesthetically too crude to include in an exhibition, he saw its potentiality, the blur as something important in itself, a witness to the absurdity and peril of war.<sup>29</sup> The blur, like the dissolution of Alzheimer's disease, is what remains when we attempt to perceive an uncertain reality, imagine the unimaginable, represent the unrepresentable, experience what has no wish to be experienced. Only those capable of seeing deep in the fog are capable of seeing the blur, those who have opened up their gaze, who have turned the making of the image into an act, a question, a tension.

---

29. Following the discovery of four photographs taken by a prisoner in a gas chamber, which showed, from inside a cell, fragments of the outside world, like a patch of ground, the sky, a tree, one of them, taken to be a blur, was ignored in the subsequent exhibition due as aesthetically non-viable. Didi-Huberman (2012a) argues, however, that we must consider the photograph of the blur precisely because it shows the context of imprisonment and the horror in which it was produced. In this sense, being "only a blur" says much.



Ethnography is an exercise in looking in which the invisible is more important than the visible – how to see language where they say there is none, see the person amid the ‘dissolution of the self.’ For Severi (2011), the chimera is this act of looking to gather different fragments in order to compose an image by means of a movement of perception and projection, order and salience – which, for the author, constitutes the mnemonic process. The chimera is thus an assemblage, a connection of dissimilar elements in which the organizing principle is plurality and contiguity (the ‘and’ or the ‘between’ rather than the ‘or’). As a plural representation of heterogenic parts, the chimera does not represent the beings but the possible relations or those imagined as such between them, just as my proposal was not to represent Alzheimer’s disease but the relations – possible or imagined as such – that compose it.

Ethnography may also be a chimera, made in a movement of containing and overflowing, selecting and projecting, a mixture of different times and specialities, a plurality that activates its invisible parts. By crisscrossing the fields, subjects and questions and exploring different lines, languages and images, I also gathered a collection of fragments that could be assembled in diverse ways. In this sense, “ethnography is a form of controlled invention” (Cesarino 2013, 6; Strathern 1998).

My ethnography began with medical consultations and ended up in delirium: from hallucination as a pathology, I opened myself to the hallucinatory viewing of the image; from the neuroimages of the MRI scans, I turned to the mental/endogenous images of people with dementia. Going beyond medicine to fall into the demented point of view was my way of crossing the looking glass, tracing a line of flight towards the disease. In this Deleuzian fold between clinic and critique, aesthetics is the twisting of classification, the refraction of the biomedical discourse, the potentiality of dissolution.

Dissolution – and everything that it contains and overflows, folds and unfolds – is also a good image for ethnography. By exploring what is contained and overflows in Alzheimer’s disease, I perceived that, more than an ‘becoming-other’ in dementia, the disease itself is a becoming, composed of fragments of heterogenic and multiple experiences, a process in continual movement that points, amid fogs, to inexhaustible directions. I was only able to see and walk along this tangled path by seeing and walking along the ethnography too as a line that composes it. It was also necessary, therefore, to explore what is contained and overflows in/from ethnography, in a movement of extension and distension, an incomplete sewing, with loose knots and threads that gradually unravel, and pauses, to see blurs and fireflies.

#### BIBLIOGRAPHY

- Bakowski, Kris. 2003. *Dealing with Alzheimer's Blog*. 24 dez. 2003. Disponível em: <https://bit.ly/2OvPyiM>. Access in: 26 mar. 2019.
- Biehl, João. 2008. Antropologia do devir: psicofármacos – abandono social – desejo. *Revista de Antropologia*. São Paulo, USP, vol. 51 n. 02.
- Bruno, Fabiana. 2009. *Fotobiografia: por uma metodologia da estética em antropologia*. Tese de doutorado, Instituto de Artes, Universidade Estadual de Campinas, Campinas.
- Burke, Lucy. 2015. The locus of our dis-ease: Narratives of family life in the age of Alzheimer’s. In Swinnen, Aagje & Schweda, Mark (eds.). *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*. Aging Studies, vol.6. Germany: Transcript Verlag, Bielefeld, p. 23-42.
- Cesarino, Pedro de Niemeyer. 2011a. *Oniska: poética do xamanismo na Amazônia*. São Paulo: Perspectivas.
- \_\_\_\_\_. 2011b. Mito, antropologia e teatro: entrevista com o antropólogo Pedro Cesarino, por Beatriz Labate. *Avisos psicodélicos*, 2 feb. 2011. Disponível em: <https://bit.ly/2JEstvv>.
- \_\_\_\_\_. 2013. O curador como etnógrafo, o etnógrafo como curador. Entrevista com Pedro Cesarino. *Máquina de escrever*. São Paulo: Capacete Entretenimentos. Disponível em: <https://bit.ly/2TxX8KD>.
- Course, Magnus. 2012. The birth of the word. Language, force, and Mapuche ritual authority. *HAU: Journal of Ethnographic Theory*, vol. 2, nº. 1: 1-26.
- Deleuze, Gilles. 1992. *Conversações*. São Paulo: Editora 34.
- \_\_\_\_\_. 2011. A literatura e a vida. In *Crítica e clínica*. Gilles Deleuze, 11-16. São Paulo: Editora 34.
- Deleuze, Gilles e Félix Guattari. 1996. Ano zero – rostidade. *Mil platôs: capitalismo e esquizofrenia*, vol. 3. Gilles Deleuze e Félix Guattari, 28-57. São Paulo: Editora 34.
- Didi-Huberman, Georges. 2011. *Sobrevivência dos vaga-lumes*. Belo Horizonte: Editora UFMG.
- \_\_\_\_\_. 2012a. *Imagens apesar de tudo*. Portugal: KKYM.
- \_\_\_\_\_. 2012b. Quando as imagens tocam o real. *Pós*, vol. 2, nº. 4: 204-219.
- \_\_\_\_\_. 2013a. *A imagem sobrevivente: história da arte e tempo dos fantasmas segundo Aby Warburg*. Rio de Janeiro: Contraponto.

- \_\_\_\_\_. 2013b. Disparates. "Ler o que nunca foi escrito". In *Atlas ou a Gaia Ciência Inquieta*. Georges Didi-Huberman, 9-70. Lisboa: KKYM.
- Dulley, Iracema. 2015. *Os nomes dos outros: etnografia e diferença em Roy Wagner*. São Paulo: Humanitas, Fapesp.
- Feriani, Daniela. 2017a. Pistas de um cotidiano assombrado: a saga do diagnóstico na doença de Alzheimer. *Ponto Urbe*, vol. 20, nº. 1.
- \_\_\_\_\_. 2017b. Rastros da memória na doença de Alzheimer: entre a invenção e a alucinação. *Revista de Antropologia da USP*, vol. 60, nº. 2: 532-561.
- Freud, Sigmund. 2006. O estranho. In *Obras psicológicas completas*, vol. 17. Sigmund Freud. Rio de Janeiro: Imago.
- Goldman, Marlene. 2015. Purging the world of the Whore and the horror. Gothic and apocalyptic portrayals of dementia in Canadian fiction. In Swinnen, Aagje & Schweda, Mark (eds.). *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*. Aging Studies, vol.6. Germany: Transcript Verlag, Bielefeld, p. 69-88.
- Ingold, Tim. 2007. *Lines: a brief history*. London, New York: Routledge.
- Kopenawa, Davi e Bruce Albert. 2015. *A queda do céu: palavras de um xamã yanomami*. São Paulo: Companhia das Letras.
- Landa, Fábio. 2003. E. Lévinas e N. Abraham: um encadernamento a partir da Shoah. O estatuto ético do terceiro na constituição do simbólico em psicanálise. In *História, memória, literatura: o testemunho na era das catástrofes*, org. Márcio Seligmann-Silva, 111-122. Campinas: Editora da Unicamp.
- Lévi-Strauss, Claude. 2005. *De perto e de longe*. São Paulo: Cosac Naify.
- Potocny, Joe. 2006. *Living with Alzheimer's*. 25 set. 2006. Disponível em: <https://bit.ly/2FAMf70>. Acess in: 25 mar. 2019.
- Robbins, Jessica C. 2008. "Older americans" and Alzheimer's disease: citizenship and subjectivity in contested time. University of Michigan.
- Sacks, Oliver. 1997. *O homem que confundiu sua mulher com um chapéu*. São Paulo: Companhia das Letras.
- \_\_\_\_\_. 2006. *Um antropólogo em Marte: sete histórias paradoxais*. São Paulo: Companhia das Letras.
- Severi, Carlo. 2009. A palavra emprestada ou como falam as imagens. *Revista de Antropologia*, vol. 52, nº. 2: 459-505.
- \_\_\_\_\_. 2011. L'espace chimérique: perception et projection dans les actes de regard. *Gradhiva*, nº. 13: 8-47. Available in: <https://bit.ly/2JF294b>.
- Strathern, Marilyn. 2006. *O gênero da dádiva: problemas com as mulheres e problemas com a sociedade na Melanésia*. Campinas: Editora da Unicamp.
- \_\_\_\_\_. 2014. O efeito etnográfico. In *O efeito etnográfico e outros ensaios*, ed. Florencia Ferrari, 345-405. Tradução de Iracema Dulley, Jamille Pinheiro e Luísa Valentini. São Paulo: Cosac Naify.
- Taussig, Michael. 1993. *Xamanismo, colonialismo e o homem selvagem: um estudo sobre o terror e a cura*. São Paulo: Paz e Terra.
- \_\_\_\_\_. 2011. *I swear I saw this: drawings in fieldwork notebooks, namely my own*. Chicago: University Of Chicago Press.
- Viveiros de Castro, Eduardo. 2002. O nativo relativo. *Mana* 8 (1), 113-148.

Wagner, Roy. 1989. *Symbols that stand for themselves*. Chicago: University of Chicago Press.

\_\_\_\_\_. 1995. Hazarding intent. Why Sogo left Hweabi. In *Other intentions: cultural contexts and the attribution of inner states*, ed. Lawrence Rosen, 163-175. Santa Fe: School of American Research Press.

Wearing, Sadie. 2015. Deconstructing the American family. Figures of parents with dementia in Jonathan Franzen's *The Corrections* and A.M. Homes' *May We Be Forgiven*. In Swinnen, Aagje & Schweda, Mark (eds.). *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*. Aging Studies, vol.6. Germany: Transcript Verlag, Bielefeld, p. 43-68.

#### LIST OF FIGURES - FACES

First page – p.11 (from left to right):

Line 1: 1. Self-portrait by William Utermohlen; 2. 'Alzheimer' series by Alex ten Napel; 3. First diagnosed patient. Photo by Rudolph in the patient records; 4. Photo: Alex ten Napel.

Line 2: 1. Photo: Alejandro Kirchuk; 2. Photo: Susan Falzone; 3. Self-portrait by William Utermohlen; 4. Photo: Alex ten Napel.

Line 3: 1. Photo: Alex ten Napel; 2. Self-portrait by William Utermohlen; 3. Photo: Alex ten Napel; 4. Self-portrait by William Utermohlen

Line 4: 1. Photo: Susan Falzone; 2. Photo: Alex ten Napel; 3. Self-portrait by William Utermohlen; 4. Photo: Alex ten Napel

Line 5: All images by Alex ten Napel.

Second page – p. 12 (from left to right):

Line 1: 1. Photo: Alex ten Napel; 2. Self-portrait by William Utermohlen; 3. Photo: Alex ten Napel; 4. Self-portrait by William Utermohlen

Line 2: 1. Photo: Susan Falzone; 2. Photo: Alex ten Napel; 3. Photo: Susan Falzone; 4. Photo: Alex ten Napel

Line 3: 1. 'Alzheimer' exhibition organized by Alzheimer Disease International (ADI / USA) (detail); 2. Photo: Alex ten Napel; 3. Photo: Susan Falzone

Line 4: 1. Photo: Susan Falzone (detail); 2. Photo: Alex ten Napel; 3. 'Alzheimer' exhibition, USA (detail); 4. Photo: Alex ten Napel.

Line 5: 1. Photo: Fausto Podavini (detail); 2. Photo: Alex ten Napel (detail); 3. Photo: Alex ten Napel (detail); 4. Photo: Fábio Messias (detail).

\* All the images are available on the internet, in Google images and/or on indicated sites, including:

1. William Utermohlen:  
[www.hypeness.com.br/2014/01/pintor-com-alzheimer-faz-auto-retratos-registrando-o-avanco-de-sua-doenca;](http://www.hypeness.com.br/2014/01/pintor-com-alzheimer-faz-auto-retratos-registrando-o-avanco-de-sua-doenca;)

2. Alex ten Napel:  
[http://www.alextennapel.nl/;](http://www.alextennapel.nl/)

3. Primeira paciente diagnosticada:  
<http://www.alzheimermed.com.br/biografia-alois-alzheimer/a-primeira-paciente-august-d;>

4. Alejandro Kirchuk:  
[http://www.bbc.com/portuguese/videos\\_e\\_fotos/2012/02/120214\\_galeria\\_alzheimer\\_pu.shtml;](http://www.bbc.com/portuguese/videos_e_fotos/2012/02/120214_galeria_alzheimer_pu.shtml;)

5. Susan Falzone:

<http://www.hypeness.com.br/2014/04/fotografo-capta-o-cotidiano-da-tia-com-alzheimer-em-serie-sombria-e-emocionante/>;

6. Fausto Podavini:

<http://www.hypeness.com.br/2013/05/projeto-fotografico-tocante-mostra-o-dia-a-dia-de-uma-esposa-cuidando-do-marido-com-alzheimer/>;

7. Fábio Messias: <http://cargocollective.com/fabiomessias/Essa-Luz-Sobre-o-Jardim>.

**DANIELA FERIANI** is postdoctoral fellowship in Anthropology at University of São Paulo (USP), PhD (2017) and Master (2009) by the State University of Campinas (Unicamp). She is a researcher in the Group of Visual Anthropology (GRAVI / USP) and the Anthropological Laboratory of Graphic and Image (La'grima / Unicamp). She studies the composition of Alzheimer's disease and other dementias as diagnosis, experience and aesthetics from autobiographies, blogs, photographic essays, videos, gestures and metaphors. E-mail: [danielaferiani@yahoo.com.br](mailto:danielaferiani@yahoo.com.br)

**Use license.** This article is licensed under the Creative Commons CC-BY License. With this license you can share, adapt, create for any purpose as long as you assign the work.

Received: 06/07/2018

Resubmitted: 12/20/2018

Accepted: 02/22/2019