

Reading as a loving care
A bibliotherapy path with the elderly of Policlinico Italia

The ethnographic experience exposed in this paper consists in an experiment of reading therapy with a small group of elderly people affected by senile dementia. The project's idea came from the personal experience of a doctor whose mother suffered from Alzheimer disease. Reading to her some poems she used to appreciate, he discovered that she could come back to a state of lucidity. He then decided to test the effects of reading sessions on hospitalized patients of a geriatric clinic in Rome.

The Agency of Public Health of Lazio Region, the Policlinico Italia, and the Sapienza University, where I was finishing my master in Anthropology of Medicine, organized the project "Reading as a loving care". This project was to become the topic of my thesis dissertation.

The selection of patients was made on the basis of their mental-state level. The main doctor of the clinic chose patients who had a medium-low level of dementia (tested by using *Mini-Mental State Examination*). Before starting the reading therapy, which consisted in 10 private sessions of 30 minutes each, I met each patient in order to understand if there actually was an interest in participating in the activity, as personal motivation was a fundamental starting point for the outcome of the intervention.

This preliminary meeting was also important for the selection of books to propose to the patients, as the reader (me, in this case), filled a socio-demographic card and discussed with the patient his/her literary preferences. Finding the "correct" book, the one that is evocative for the patient, was equally fundamental for the success of the activity. As J. C. Hynes states, it is important to *know the patient, for the patient himself is the determining factor in book selection*¹.

Since the project was carried out according to a twofold perspective - the biomedical and the anthropological - it comprised different targets and outcome evaluation systems. Even if it was a non-pharmacological intervention, and it tried to overcome the biological reductionism of official medicine, a biomedical focus influenced both its principal purpose and the methods utilized to test the experiment's effectiveness.

The object of the project as elaborated in the original proposal of the Lazio Health Team, was to enhance the cognitive performance of the patients affected by a progressive neuronal degeneration. From the perspective of medical anthropology, a mere cognitive improvement does not signify a successful intervention if it is not accompanied by an enhancement of the patient's emotive-psychic state. Moreover, any improvement was evaluated considering the

¹ Jo Catherine Hynes, *Library Work with Brain Damaged Patients. A new mode of bibliotherapy*, Bulletin of the Medical Library Association, 60 (2), p. 333.

patient's feedback, while little importance was given to the results of the quantitative tests performed before and after the reading sessions by the clinic neurologist.

The fieldwork I conducted with these 13 patients can be overall defined as "ethnography of reading". Nonetheless, given that stories and poems (more generally, words) have an evocative power on people, the readings I proposed never remained sterile, but often worked as the basis on which the patients could draw their inspiration to tell about their life narratives or illness narratives.

In two cases, with Bruno and with Italo, this creative process of intermingling between the real and the imaginary, and between written and oral narrations, revealed itself to be very particular.

Bruno is an 88 year old man, hospitalized for two years. His legs are still good, but his eyes are almost blind. He can still go up and down the stairs of the clinic, remembering the Dolomites where he grew up.

In the first meeting with him, I shifted from the role of reader to that of listener, as he told me with great passion the story of his life: his enrolment in the army, the confinement in a prison camp, his brother's suicide after joining the S.S...

I was quite disoriented, trying to understand which kind of book could be most appropriate. Chance helped me, as in a newspaper kiosk I found a recently published diary of a member of the Italian alpine troops who fought in the same areas as Bruno.

The correspondences between this soldier's story and Bruno's were so frequent that sometimes I started a line of the diary and Bruno could complete its sense. There was similarity not just of landscape descriptions, but also of thoughts or impressions similarity.

As I read about interminable train trips for transferring the armies across the Russian plains Bruno tells me about the blankets of sunflowers, which the book's author mentions two lines later; as I read about the "General Winter" that slaughtered its victims mercilessly, Bruno's eyes fill with tears. I can feel a strong emotion too, my voice breaks, but for me is just an empathetic reaction, whereas he really lived it.

I start to doubt about the appropriateness of my choice. Wouldn't it be too difficult for him to go back to those days? I finally ask Bruno, proposing to him some other literary genres. Instead he is determined to continue, because he wants to know what happened to the author. And, moreover, he explicitly tells me that *these are things it's good to get off your chest now and then*.

Some reflections about the mechanism of interaction between written literary story and the patient's real life story follow.

The **identification** with the main character of the story, a frequent process of reading, is helped by the great parallels between the author's experience and the patient's. This identification favours a **cathartic process**, allowing Bruno to live again those difficult experiences in a protected setting, where he is sure to be listened to. It is possible to speak of catharsis because, as neuroscience explains, for our brain listening to a story is almost the same as living it. The brain doesn't distinguish between a lived and an imagined experience, but arouses the same hormonal/emotional reaction in the body.

Byron Good, talking about the "theory of the reader's answer", states that narration has, *per se*, intersubjective qualities: it is built for being transmitted or shared and it always implies the presence of another who could be real or imaginary. The other, that is the recipient of the reading, receives the content and gives it a sense, just by listening to it or by elaborating it in a real or fantastic discussion. In the specific case of Bruno, the other is double: the author of the diary and the reader, me. Bruno commits his story to me, but he imaginarily links it to the story of his unknown comrade. The testimony of a companion gives validation to his story and strengthens the sense of solidarity for a shared destiny.

Italo is a 93 year old man, graduated in medicine; he worked as a pharmacist and he coordinated a hospital camp in Libya during the second world war. In his case history there is no room for his interesting life, because too many physical-emotional problems are recorded: depressive syndrome for 30 years, Parkinson's disease for 10 years, thigh bone fracture...

He doesn't show a lot of interest in the readings, he often closes his eyes and drifts away, and above all he takes everything as a starting point to go back to the war days, and to start telling me long and intricate stories, interrupted only by a sentence: *I've lost the thread...*

Italo had written a diary during his years in Libya. I had understood that this diary had been stolen, but one day he told me that he had a copy in his room. The use of that document during our reading sessions was a turning point in the quality of our meetings, concerning not only our relation but also his level of attention and participation. We had found the key, the "book" that allows to reach the person. One's own diary, that can be defined the book of one's life, has a great potential in doing so.

Italo found himself in a bizarre situation: he could listen through a girl's voice the story of the most meaningful days of his life, that he had written himself. There was very little about war in those pages, whereas there were a lot of his feelings. For example, there was the description of a wonderful dusk, and then of a dawn admired during his voyage from Naples to Tripoli on a military ship (*While you read, I can still see it in my mind*, he told me).

This case shows clearly how the **appropriate instrument** can act upon the state of the patient; and to which extent the cognitive and the emotional level are intertwined. When I read him stories that couldn't reach him, stories that didn't

resonate with him, Italo looked asleep, distracted, sad. Finding his diary, we found the **thread** he used to lose so frequently, a thread that is not just that of remembering the order of the discourse and organizing it coherently, but is also an emotional thread, the one that linked him to his **meaningful experiences**.

When I read him his pages, his expression changed, his eyes became vivid, he was present and he didn't lose a single word of the story. The positive emotional involvement connected to the listening of such a meaningful story activated cognitive abilities, restoring Italo's lucidity and serenity.

As observed by Oliver Sacks, *each of us is a singular narrative, which is constructed continually, unconsciously, by, through, and in us. To be ourselves we must have ourselves - possess, if need be re-possess, our life-stories. We must "recollect" ourselves, recollect the inner drama, the narrative of ourselves. A man needs such a narrative, a continuous inner narrative, to maintain his identity, his self*².

Elderly people who live in geriatric clinics deal every day almost with a double challenge, one imposed by their physical-mental state and the other by the impact of institutionalization on their well-being. The pain or the confusion of dementia from one side, and the weakening of their social and affective networks from the other, contribute to strengthen the sense of loneliness and the non-sense of their present life.

The reading therapy counters this process by offering three fundamental resources:

1. a cognitive-emotional stimulation
2. a relational-socializing stimulation
3. a re-signification or a re-appropriation of the story of one's life, through the help of a literary text and in the presence of a reader/listener.

² Oliver Sacks, *The man who mistook his wife for a hat*, Harper Perennial, 1990, p.57.