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The Self in the Alzheimer's patient as revealed through psycholinguistic-story based analysis

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Abstract

The World Alzheimer Report (2014) stated that 44 million people worldwide suffer from AD. Perhaps the worst effect of the disease is the loss of Self, which is based on the loss of identity and memory (Caddell & Clare, 2010). Research into the initial stages of the disease with the scope of developing some sort of 'salvage therapy' is rather scarce. This work reports research done from a psycho-linguistic point of view with the goal of identifying how Alzheimer's patients maintain the Self through narrative. Self-narrative may be effective in maintaining the Self in AD patients if begun in the preliminary stages of AD .The purpose of this study was to extend knowledge about how subjects with a probable AD diagnosis or in a medium-low phase maintain the continuity of Self. The use of narration with linguistic analysis was used. Various authors have considered the use of narrative therapy (England, 2010; Ramanthan, 1997; Hyman, 2011). The study was conducted on a group of 10 patients /7 females and 3 males) with ages ranging between 67-82 (average=73.70; DS=4.76), a medium-low education level (between 1 and 11 years of education) and a probable diagnosis of AD. Three interviews were conducted including neuropsychological tests. Interviews were recorded, transcribed according to Mergenthaler (1992) and analysed following the GT approach and using the textual analysis software of Atlas.ti. This research showed that the emotional aspects which give continuity to the patients' Self seem to be well conserved in their implicit memory. The analysis of the beginning phase of the disease and the way in which it progresses seems to be useful in the effort to understand the patient's psychic reaction to the diagnosis as well as how he or she reorganizes self-representation. It is also useful in observing how the subject's identity weave or self concept begins to deteriorate. Intervention protocols could be developed as well as a subsequent model to promote psychological health and efficacy of available traditional treatments. More research needs to be done in this area internationally, in order to test the universality of these results.

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1. Problem Statement

Alzheimer's Disease (AD) is currently one of the most significant health problems in the world. The World Alzheimer Report (2014) stated that 44 million people worldwide suffer from AD. This report states that the number of people affected will almost double by 2030 and more than triple by 2040. The cost is astounding: in 2010 the global cost was estimated at U.S.D. $604 billion (World Alzheimer Report, 2014).

1.1. Definition of AD/dementia

Dementia is not a new phenomenon. It has been associated with aging for centuries but only in the 20th century was it actually recognized as a disease (Orulv, 2008). It seems to have been considered a stigma (Ballenger, 2006) and even considered to be worthy of being executed as a witch (Lyman, 1989). In later centuries it was associated with the unavoidable aging process (Lyman, 1989) but the stigma continued. Alois Alzheimer identified the disease of "premature senility" in 1906, but it was linked to younger people and was called "presenile dementia" (Gubrium, 1986). By the 1970's dementia in older people was linked to Alzheimer's disease (Herskovits, 1995) and subsequently attributed to being a major cause of dementia in addition to vascular conditions. (Gaunt, Ohlander, & Schwarz, 1993). By the 1980's many Alzheimer's associations were encouraging research, policy changes and public awareness (Gaunt, Ohlander & Schwarz, 1993). These associations were instrumental in communicating the 'medicalization' of the disease to the general public and aided in reducing the stigma and fear attached to the disease. Numerous quantitative biomedical and neuropsychological studies have been conducted worldwide that have advanced knowledge of the physical aspects of AD/dementia but have created a pessimistic idea of the disease. This reduction of AD/dementia to a physical disease raised concern about the loss of the social aspects (Orulv, 2008). It was argued that the actual experience of the disease with its various social and psychological effects was being ignored. The fear was that the labeling of the disease itself would result in isolation and negativity thus creating a self-fulfilling prophecy (Dows,2000).

1.2. Effects

Perhaps the worst effect of the disease is the loss of Self, which is based on the loss of identity and memory (Caddell & Clare, 2010). Just how bad the disease is considered to be can be noted in the area of public discourse about the disease, from clinical reports to public information communications.

1.2.1. Public discourse

Orulv points out that in public discourse the disease is communicated as "brokenness and disintegration" and dementia sufferers are viewed as "somehow broken without any prospect of being mended (Orulv, 2008). Various sources of public communication depicted the condition as "a funeral without an end"," a loss of self", "a death before death", with sufferers being "shells of their former selves" (Herskovits, 1995; 152). The medical model has its limitations: it tends to reduce persons to their diagnosis. And this in turn imposes limits on their identities (Lyman, 1989). In addition to that the common view that there is nothing to do about the disease (Josephsson, 1994, 1996) made an AD/dementia diagnosis a death sentence. Fortunately in the 1990's researchers began to question the biomedical model and search for more person-oriented theories of diagnosis and treatment.

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1.3. Self narration to maintain identity

Various authors have considered the use of narrative therapy (England, 2010; Ramanthan, 1997; Hyman, 2011) as a method of maintaining identity in AD patients. Recent international research (Beard, 2004; Hyden & Orulv, 2009; Fargeau et al., 2010) showed that even patients in the most advanced stages of AD maintained a continuity of Self although they demonstrated difficulties in telling autobiographic stories. According to these authors, patients can conserve the Self through narration by using it as an organizer. Ramanathan (1997) and Mills (1997), both believe that the repetition of small "frozen" segments (verbal perseverations), even if apparently out of place, can say something important about the way a person gives meaning to his/her life, as well as show a link to basic meanings. Other studies and reviews (Mograbi et al., 2009, Gil et al., 2011) showed that personality modifications usually described by caregivers are actually not recognised by patients. Moreover, it was found out that the patient's self-evaluation corresponds to his/her personality before the illness, not in the present. This discovery confirmed that patients' anosognosia is caused by a kind of petrification of the "Self", a kind of "freezing" of the main personality characteristics of the person that were consolidated during the early adult years. Essentially, this memory deficit would force the patients to design a kind of adaptation strategy in order to keep control of themselves by appealing to an obsolete database of themselves.

2. Purpose of the Study

Research into the initial stages of the disease with the scope of developing some sort of 'salvage therapy' is rather scarce. This work reports research done from a psycholinguistic point of view with the goal of identifying how Alzheimer's patients maintain the Self through narrative. The purpose of this study was to extend knowledge about how subjects with a probable AD diagnosis or in a medium-low phase maintain the continuity of Self.

2.1. Self narration/narrative therapy

Narrative therapy is a type of therapy in which the patient tells his or her life story. It was introduced under that name in Australia during the '70's and '80's and subsequently became popular in the U.S. and Canada after the publication of the book Narrative Means to Therapeutic Ends (White and Epston, 1990). It is centered around "restorative and transformative justice and characterized by the client being allowed to define his or her own position in relation to the problem (White 2007). It is based on the idea that identity is found in the life story of the patient. Narrative therapy removes patients from their problems and transforms these problems into something external (externalization). Externalization makes it easier to understand the impact of problems on patients' lives.

The therapy is patient-centered and the therapist plays the role of an interviewer or investigator, asking questions to assist in externalization. The parts of Narrative Therapy that are most significant for Alzheimer's patient or persons with dementia are the elements of identity definition. Narrative therapy operates from the idea that narrative forms the identity of the patient; externalization helps the patient assess problems and their effects (White & Epston, 1990). As applied to Alzheimer's patients or dementia patients, this research attempts to demonstrate that by narrating their life stories somehow they may be able to hold on to their identities. Narrative therapy has been used in caring for patients with dementia (Williams & Keady, 2006, p 163) but the amount of published research about how it can be used in treating memory loss is somewhat scarce (England, 2012).

3. Methods

3.1. Hypotesis

The researchers' hypothesis is that patients with Alzheimer's develop a relative anosognosia mainly in regards to personality changes (Ruby et al., 2009). This is probably connected to a reduction of self-awareness and diminished capacities to understand the caregivers' perspective. This research attempts to construct a theory on the experience

of the Self in terms of continuity/discontinuity. The following hypothesis questions were asked in regards to subjects with a probable AD diagnosis/ a medium-low phase:

- What is the continuity of "Self" that is maintained by the patient?
- How do subjects use strategies to give continuity to "Self" ?
- How can the patient's quality of life be improved with this integration of the "Self"? (clinical usability; ethical value).

3.2. Subjects

The study was conducted on a group of 10 patients (7 females; 3 males), aged between 67 and 82 (average = 73.70; DS = 4.76), a medium-low education level (between 1 and 11 years of education), and a probable diagnosis of AD. The participant were recruited at several public Alzheimer care clinics in Sicily. Only patients with moderate deterioration were selected (i.e. with a score between 17 and 26 at MMSE; average = 23,1900; DS = 2,93994) and at least two MDB performances that were lower than cut-off scores (criterion necessary to hypothesize probable AD dementia). Moreover, all the subjects were diagnosed with cerebral atrophy at an initial phase, documented by a TC scanner.

The inclusion criteria chosen were:

- Presence of the first symptoms for at least 2 years
- Access to the health service no more than 6 months before
- Not undergoing pharmaceutical therapy
- No other neurological pathologies
- Light to moderate phase of the disease process, as shown by the score of the MMSE. The lowest cut-off to define a moderate insufficiency in this study was set at 17,70 out of 30. Subjects with a history of brain injury, aneurism, cerebrovascular disease with resulting language-communication problems, neurological abnormalities different from Alzheimer's, history of alcoholism or drug addiction, psychiatric diseases or longterm psychopharmacological drug use were excluded.

3.3. Assessment

All the patients with the potential AD diagnosis were assessed with the Mini Mental State Examination (MMSE) (Folstein, 1975), Mental Deterioration Battery (MDB) (Caltagirone et al., 1995) and the Milan Overall Dementia Assessment (MODA) (Brazzelli M. et al., 1994) in order to evaluate their cognitive state. We chose to administer only the first section of the MODA, which evaluates orientation and verbal and deferred memory (short story). That is because the spatial-temporal and personal-family orientation provides information in regards to the objective of this research, especially concerning the capacity of self-representation. Moreover, the short story was chosen to explore prose memory in a more focused way, which means the capacity to narrate semantic contents which are not necessarily personal. All the verbal memory techniques contribute to designing the memory as one of the functions necessary to comprehend language, and therefore semantic representation; which is the capacity of a subject to reconstruct the meaning of the information received. In this context, the short story helps us to investigate the process of signification of the contents stored in the memory. The delayed recall of those contents allows the testing of the permanence of the mnestic trace or its missing consolidation due to a cognitive deficit.

The research took into account the fact that "neuropsychological evaluation should not simply identify cognitive compromise but should also be able to comprehend it through qualitative analysis of its systematic mistakes, which is the determinant element to identify the specific form of cognitive deterioration." (Quattropani, 2008, p.39).

3.4. Clinical semi-structured interview

An important instrument of qualitative research is the qualitative interview, that is, the "extended" conversation between the researcher and the interviewed, through which the researcher tries to obtain as much information as possible on the topic. The interview regarding the Self Narrative given to selected participants was especially

designed ad hoc. It was composed of various parts which allowed the subject to reach an autobiographic structure (Quattropani, 2005).

The areas taken into consideration are: Personal Area, Family Area, Social Area, Professional Area, and the Areas concerning the past in regards to Symptomatology (Past Areas). The objective of the interview was to access the perspective of the subjects, to grasp their conceptual categories, interpretations of reality and the explanation of their actions (Corbetta, 1999). The interview was guided by the interviewer through flexible question, which allowed freedom of exposure to the patient and allowed the talk to be focused on thematic knots, avoiding the frustration of a totally de-structured stimulus. This kind of setting structure allowed the patient to "narrate him/herself", being free to make mistakes and meander, without being rebuked by a family member.

3.5. Procedure

An empirical methodology with a qualitative approach was adopted. All the subjects were examined individually. Three meetings were arranged for each subject. The first one focused on welcoming and collecting data of the anamnestic history of the subject. The second was designed to administer the neuropsychological battery of tests. Finally, the third one was dedicated to "Self-Narration". The data collection allowed the construction of a complex setting, where the researcher was included in the field research. The interviews were audio-recorded. The transcription was done according to the standardised transcription rules of psychotherapy sessions of Mergenthaler (1992). These rules are quite exhaustive and simple, hence, they allow a universal understanding of the transcribed text, facilitating the research and the data usability for the scientific community. Afterwards, the transcription was analysed following the GT (Grounded Theory) approach (Glaser & Strauss, 1967) and using the textual analysis software ATLAS.ti. (ATLAS.ti Scientific Software Development GmbH).

3.6. Textual qualitative analysis: Atlas.ti

ATLAS.ti is an instrument which is designed to reconstruct the theories behind the information under scrutiny (Chiarolanza & De Gregorio, 2007). The general approach is based on the constant use of the graphic interface which Muhr (2004) summarises with the VISE principle (acronym for Visualization, Integration, Serendipity , Exploration). The versatility of this instrument is due to the opportunity it gives to acquire audio and video files in a digital format which can be directly processed into Grounded Theory.

The decision to handwrite or not clearly depends on the objective of the research. ATLAS.ti suggests two main ways to organise the work: the textual level and the conceptual level. The first one is about segmentation and codification of the textual material, while the second one is about the construction of a theoretical model through linking the codes with the conceptual nets. After the first coding phase, the data is ready to be associated with macro-categories. In fact, the software can unify the codes with a similar semantic value. During the coding process, the program will automatically update a 'codes list' with a specific number of occurrences – i.e. the number of times a quote was associated to a specific code, while on the other hand, the programme will quantify the semantic density. Simultaneously, the codification phase with a higher level of abstraction (intermediate codification) can also be started, without the first phase being totally terminated (it can be reviewed later on). The categories are associated and gathered in code families. Through the code manager function it is possible to connect the codes as if they were knots of a net, indicating the typology of the link (associative, conflictual, accidental, part of...). ATLAS.ti adds rigour to the researcher's interpretative work, by employing the Query tool. This tool uses some interrogation operations (algorithm RPN, acronym for Reverse Polish Notation), verifies the existence of a relationship between the codes or the families of the codes (operandi), therefore identifying the logical, semantic and spatial quality of the relationship itself. The operators that are used to verify the relationships are: boolean operators (simple relationships), semantic operators (relationships within conceptual nets) and proximity operators (spatial relationships) (ibidem). As soon as the relationships between the codes and the families codes are investigated, it is possible to move on with a more precise organisation of the material, where the level of abstraction is increased.

Supercodes are subsequently identified. The program automatically defines a supercode by combining two codes together with the operator chosen to mark the quality of the relationship. This phase of individuation of the

supercodes allows the researchers to start the process of reasoning that will take them to the theoretical codification and the identification of the core categories. The supercodes represent some indicators that are used to illustrate the codes through two coordinates: properties and dimension. As prescribed by Strauss and Corbin (1998), properties indicate the general or specific feature of each code, while the dimension indicates the localization of the property over a continuum, a classification system articulates the organization of the emergent theory.

For the purpose of this research, the system of dimensional classification is the emotional density of the narration where the codes' properties are distributed. This is the emotional analysis of the narration – inspired by Carli and Paniccia's (2010) (AET) classification principles of emotional analysis of texts. They stated that some of the words gathered from the clinical interviews are highly emotionally dense and reveal unconscious elements which are essential to understand the subjective past of the person. This model agrees with Siegel's ideas (2001) on the role of implicit memory as the main organiser of the Self. For the purpose of this study, this model was chosen because of its classification system of the code properties. The code properties represent the continuity/discontinuity of the Self (perception of change/missing perception of change); while the dimension of the properties is due to the emotional awareness of self perceptions (from awareness to denial).

3.7. Linguistic Analysis

The transcriptions of ad hoc interviews were analysed with the intention of obtaining a direct picture of what the subjects were experiencing as revealed through their language. Errors, parentheses, conversation, digressions, hesitations, etc. were an integral part of the material. The aim was to provide clinical information on how to communicate and manage a diagnosis of AD and help maintain the integrity of the "Self", both for the patients themselves and their families.

4. Results

The main purpose of this study was to understand the subjective experience of Alzheimer's disease, in particular, to record the stories of these patients. The structure of the interview and the subsequent analysis of the transcribed material demonstrated the need to give shape to patients' stories, not only to answer the hypotheses proposed in the research design, but also to explore the possibility of an intervention through clinical psychology.

4.1. Initial codification

What seemed to emerge from the initially codified categories was the capacity of patients to represent themselves in an understandable way. This would suggest that it is possible to describe, negotiate and insert this representation into an interpersonal self-identity frame.
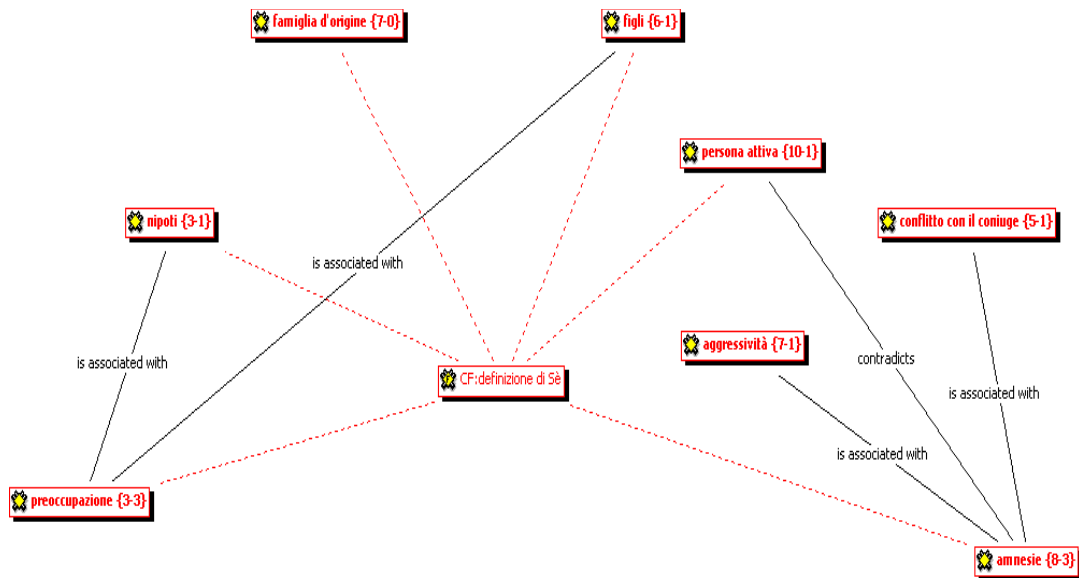
Fig. 1. Definition of the Self. Keys: (3-3) worry; (3-1) nieces and nephews; (7-0) family of origin; (6-1) children; (10.1) active person; (5-1) conjugal conflict;(8-3) amnesia; (7-1) aggression; CF definition of Self

The first output table (Fig. 1.) – which is the result of the semantic algorithm generated by the code "definition of the Self" shows that patients tend to define themselves first with their family. This demonstrates a strong continuity with the family. Fathers, mothers, uncles, aunts, siblings and other family members dominate the stories about the Self.

4.2. Intermediate codification

This codification phase, which is more substantial than the others, allows the correlation of the categories in relation to the different areas of the semi-structured interview. The process starts with the software matching all the codes with a similar semantic value (merging codes). Once the relation between codes and code families is established it is possible to refine the organization of the material which increases the level of theme abstraction.

Thus the individuation of the supercodes can be translated. The program automatically assigns the supercode name that represents the combination of two codes together with the operator chosen to mark the quality of the relation. The supercodes represent the indicators for showing the codes along two coordinates: property and dimension.

The UP semantic operator moves from the most simple indicators (in this case, "insomnia","nervousness", "aggressiveness") towards a higher level of abstraction that includes the preceeding (in this case,"preoccupation/worry").

At the same time the label "preoccupation/worry" demonstrates a spatial relationship of proximity (WITHIN) with the term "change". The operator WITHIN indicates that the term "change" is inside of the code "worry". Indeed, the narrative style, which was often full of anguish, showed preoccupation – which was also spontaneously expressed during the interview. Subjects focused their anxiousness on the future of their children and nieces and nephews. They also gave concrete motivations for such worries. Some showed apprehension for the economic situation and the social status of their family members, while some others demonstrated anxiety about their health.

The representation of Self would configure itself like a weave between personal and familiar aspects in which the emotive quality of the narration is associated with the experience of loss of the family of origin and worry for their own children (Fig. 2).
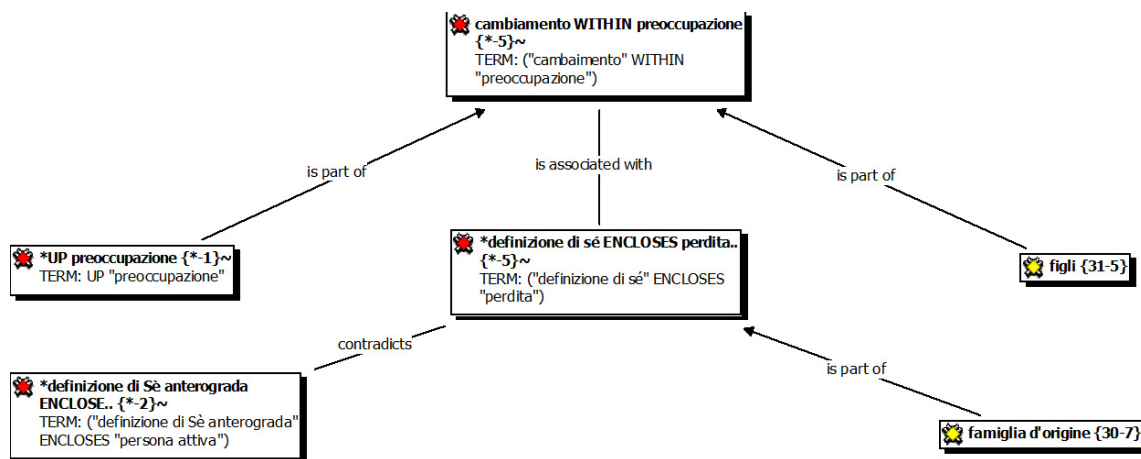
Fig. 2. Representation of Self

The change relative to the illness seems to be expressed by the reference to emotions aligned to the children and family of origin. When this externalization of life experience is not possible, the patients seem to go backwards in time referring to the Self before the illness.

Putting forth the analysis of the theoretical code phase we can affirm that the "family of origin" and "children" respectively make reference to a former dimension of the Self (filial) and a current dimension of the Self (parental) (Fig. 3).
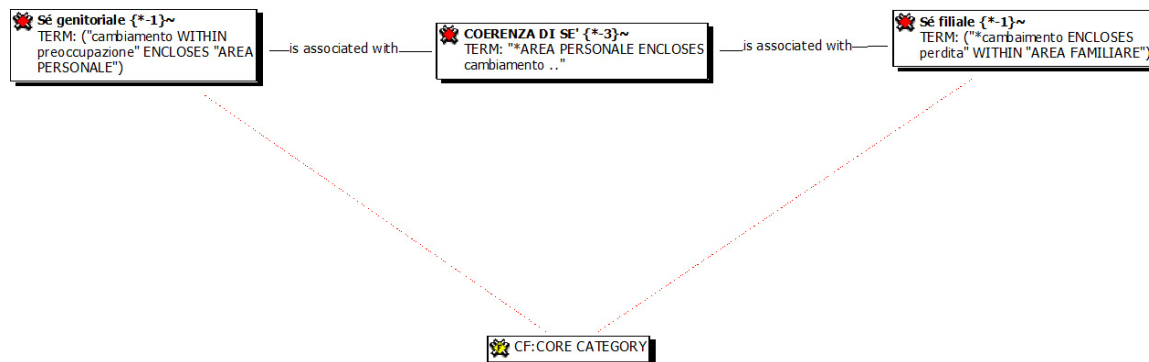
Fig. 3. Analysis of the theoretical code phase

It is true that, in accordance with the neuro-psychological literature, the AD subject tends to provide a self-definition that is not current and which does not agree with the relatives' description of his/her current condition. The results of this study do not contradict this hypothesis, but they do reduce its range: this conservation strategy which derives from the reorganization of the autobiographic memory is not the only one and does not seem to be constantly present.

4.3. Discussion

As it often happens in research (especially in qualitative research related to clinical psychology and psycholinguistics), the results lead to a reinterpretation of the research questions initially chosen, once more recalling the indissoluble circularity between data, results and hypotheses, which sets the ground for further research, a more in-depth analysis of the data collected and new unexplored perspectives.

The theory elaborated in this study pushes towards a new way of analysing the "Self" in the AD patient. Indeed, the literature available on the matter tries to clarify once and for all if the AD patient's Self can be considered in its integrity and coherence, or instead, if cerebral degeneration has irreparably deteriorated the fundamental structure of subjectivity, leading to a confirmation or non/confirmation of the patient's alienation. In reality, it is clear that the matter is falsified by the cognitive distortions, which in this context – both cultural and scientific – force us to reason through dichotomies, such as working/not working, normal/pathological, useful/useless and so on.

The researcher constantly fights in this difficult epistemological procedure, struggling to use meta-thinking with his/her research. For this study, there was a risk of falling into the categorical interpretative paradigm which would have placed the patients into that continuity/discontinuity of "the self" paradigm. Luckily, the qualitative approach which was embodied in the data (Grounded Theory), made it possible for the theory to emerge directly from the material. This way it was possible to understand, through the phase of theoretical codification, that the essential question to be answered was about what configuration the AD patient's Self-continuity took, and what representation the freezing of the self showed up in such patients.

From the elaborated theory it seems that both the Self-functioning modes are present in the analysed patients, and that none of the two would necessarily exclude the other. The patients of the clinical group studied showed in fact both aspects of continuity and discontinuity, depending on the assignment and the type of cognitive functions he/she needed to use to organize the story. In other words, when they were directly required to describe themselves, the answers provided seemed to provide a non-recent picture of the Self which was immersed in a previous professional identity and those competences possessed in the early-adult years. On the other hand, when the question was not direct, the patient was more free to organize the dialogue, stories about the perception of the change after the diagnosis seemed to emerge spontaneously.

The cursor guiding this awareness of the condition was the emotional density of the story: concern for the future of the loved ones was the main sign of a change in the personal way of feeling and thinking. Such a clear mind indicated a demarcation line, a break between the Self before and after the disease in the patients' stories. From this perspective, the subjects' Self continued to act as a temporal link, which integrated the autobiographic story. Furthermore, when patients were simply asked to tell their story, family stories and most of all sad events that happened a long time ago erroneously moved in time or felt like they were recent. This aspect could mean that the AD patient was a victim of his/her past and therefore incapable of living in the present. However, when looking at the implicit components of the story, what seemed to be the expression of an interruption of the Self-continuity was also the chance to manifest the pain for the loss of themselves and their own story--namely, the pain of forgetting themselves.

From this perspective and going back to the initial questions, we could say that the cerebral damage inevitably hits the identity landmarks (repere points), and this Self-disintegration emerges mainly when the patient is asked explicitly to describe him/herself as an individual, outside the social narrative context. Instead, when the subject organizes the narration freely, including the significant others in the self-description, the implicit memory preserves its identity-aggregating function, mainly working on the relational and emotional aspects of the story. To sum up, it is like the participants are saying that, until there is an internal interlocutor who reminds me who I am, I can be myself. These results intersect with the studies on autobiographic memory in two main points: the first point concerns investigation methods; indeed, the complexity of this function could be compromised if it was investigated merely through structural and standardized stimuli (Neisser, 1988). The second point is about the deeply social and relational nature of this psychological structure (Solms, Turnbull, 2004). Such feature seems to be essential in the AD patient's strategy of maintenance of the Self-continuity. In these regards, some studies on demented patients' narrative competence underline the importance of scaffolding (literally, scaffolding), namely the possibility of

building a story on the basis of structure dialogically negotiated with another interlocutor – preferably a patient's relative (Hyden & Orulv, 2009).

The conclusion at this point seems to be that, even if there are some aspects of discontinuity, it is not enough to identify a petrified Self in the AD patient; nor a mind that cannot "mentalize", as long as the patient can intercept his/her relationship – current or past - with loved ones and seem to be able to restore the coherence and constancy of the Self over time.

If it is true that the disease attacks the adult identity landmarks (repere points) – both professional and performance – the affection quotes connected to Self-representation and Self-desegregation, emerge in a figure and become mnestic aggregating tools. The current relationship – not just the historical one – with loved ones and the interactions with them become condensation knots of the identity. Indeed, the identity conservation strategies seem to be connected with an identity mainly with affective features. Given the fact that the individual identity is incessant in terms of "constancy of the Self" and "unchanged characteristics of the Self" is an ongoing work in process, it is constantly dialoguing with its affinities and its culture of origin (Napolitani, 1987). Then this aspect is not only conserved by Alzheimer patients, but it also becomes a necessary anchor to keep a relational framework where a person can place him/her/self.

5. Conclusion and Recommendations

The decision to conduct this research project was due to the scarce availability of neuropsychological and psychodynamically oriented studies on the subjective implications of this specific illness, especially in the Italian literature (Gabbard, 2005). There are very few studies that can clarify the relationship between "Self" and the awareness of the disease. The analysis of this particular segment of the initial phase of the disease – and how the disease progressively worsens – seemed useful to understand how the patient's psyche reacts to the diagnosis, and how he/she reorganises his/her self-representation, and finally, if and in which way the subject's identity weave begins to deteriorate. Such information could allow us to design an intervention protocol that takes the subjective processes and internal representations of the patients affected by AD into consideration. Consequently, a model could be created to promote their psychological health and increase the efficacy of available traditional treatments (both pharmacological and cognitive reactivation).

5.1. Implications

Such results bring up new questions about the possibility of clinical intervention with these patients. Clinical interventions using narration to facilitate communication What results could a longitudinal study on the AD patient's family system – which protracts though a longer time frame, from the appearance of first symptoms till the unavoidable fatal progression – produce? What benefits could we gain in terms of improvement of the quality of life and, perhaps, slowdown of the dementia?

Such studies are still scarce and inclined towards a positive relationship between relational quality and the course of the illness; insomuch that the institutionalization of the patient in an aseptic structure based on a medicine-culture seems to accelerate the exitus of the disease (Tamanza, 2001).

Certainly, in this study an important starting point for further studies emerged. The AD patient preserves a subjectivity, which he/she tries to defend strenuously from the first phases of the illness, the entire health system has the clinical and ethical obligation to support such capacity. Thus, it would seem that the possibility on the part of the patient to maintain an integration of Self depends on the intersubjective components of his own identity and his own family relationships.

5.2. Future paths

Simultaneously, new social and political policies should be promulgated to support families, often not ready to face such a painful and costly burden. Western culture itself should review its paradigms of interpretation of the world. It should not just focus all its energies on the simple effort to reject the ageing process and connected illnesses, but also try to restore the physiological ageing process as part of the natural and unavoidable human

condition. We conclude this study with the hope that future research will throw light on the possibilities of clinical intervention with AD patients, within a new cultural framework directed towards a humanization of the demented condition.

There is a long way to go. Even though recent research is gradually intensifying the interest for the life conditions of people with dementia, we are quite far from using pluri-professional clinical instruments that can guarantee a holistic approach to handling such diseases. This is the first study ever conducted in Italy that tries to understand a highly complex phenomenon, both for its ezio-pathogenic aspects as well as the ones concerning its handling and intervention. Hence, we tried to create an isomorphism between the complexity of the subject of study and the procedures and methodologies adopted to understand it, this was done not so much to give exhaustive and certain answers, but rather to provide research that escapes from reductionism and attempts to integrate clinical reasoning and rigorous explanation of methodologies used. It seems that clinical psychology cannot back out of the burdensome duty of illuminating and verbalizing what the world hides. It is hoped that the operatives and researchers who read this will recall the words of Spinoza when he said that "Intellectual knowledge is such only when it is also affective knowledge"(Spinoza, 1659). They should embrace this listening sensitivity and intercept the choked voice of AD patients, a chorus that is as vast as it is silent.

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