



Università
Ca' Foscari
Venezia

Corso di Laurea magistrale (*ordinamento ex D.M. 270/2004*) in Scienze del Linguaggio

Tesi di Laurea

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Psychosocial impact of aphasia: a study on sixteen aphasics

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2012 / 2013

To my auntie Gio',
for the last missed hug.

Contents

Acknowledgements.....	4
Abstract.....	5
Introduction	6
1. Aphasia.....	8
1.1 Classification of aphasias.....	8
1.2 Other models and new perspectives of study.....	16
2. Rehabilitation of aphasia.....	18
2.1 Traditional approaches in aphasia rehabilitation	19
2.2 From the pragmatic approaches to the social approaches.....	26
3. Psychosocial consequences of aphasia	30
3.1 The caregiver	35
4. The study: material and methodology.....	37
4.1 Subjects description.....	39
4.2 Problems encountered.....	41
4.3 General data analysis.....	42
4.4 Broca aphasics compared to amnesic aphasics.....	50
4.5 Qualitative content analysis of data.....	52
4.6 Questionnaire for caregivers: material and methodology	72
4.7 Different perspectives between PWA and their caregivers	72
5. Discussion.....	75
Conclusions and final remarks.....	79
Appendix	81
Bibliography.....	98

Acknowledgements

First of all I'd like to thank Gianfranco Denes, who gave me the opportunity to develop this research and inspired me with his interest in the quality of life of aphasic patients, Doretta Pontara, who made me love the internship experience and introduced me to her patients and Rosanna Trentin who helped me in the elaboration of the interview, enriching my work with good advices. Big thanks go to all the informants and their relatives, for being helpful and for teaching me things I will never forget. Many thanks go to Giorgia, who made me understand that nothing is impossible and supported me everyday during these long months, being my North Star. Thanks to Mike, who gave me a very special gift: "an unlimited free english shop for the rest of my life". Thanks to all my friends who are a second family to me: Cristina, Elena, Kristi, Francesco, Clelia, Eleonora, Prandina, Chiara, Francesca. Thanks to Fedino, my sweetheart, who constantly helped me with her precious advices and her strong empathy; to Amerigo, who shared with me sofa, chips and chat; to all my Venetian flatmates and to Alice and Anna, my lovely friends, from the time we played with Barbies until today. Special thanks go to Paolo for his infinite patience and for being a benchmark in my life, inspiring me with his determination and his love for life; to my parents for their sacrifices and love, especially to my mum and my aunt Giusy for being a constant and fundamental presence in my life; to my sister who hosted me in Turin and inspired me with her free spirit; to Sara and Roberto who gave me the biggest gift in the world: Lorenzo's smile.

Abstract

This thesis project investigates the experience of aphasics in relation to different aspects of their everyday life: the interaction with doctors, the speech therapy, the participation to a self-help group, the relation with family and friends, the changes experienced in the professional life and in the use of leisure time. Furthermore this study analyzes the divergences of perspectives between people with aphasia and their relatives and/or caregivers about relevant factors in the life after stroke. These data were collected through the administration of an interview to sixteen people with aphasia in the chronic stage and a questionnaire for their relatives.

The thesis presents different approaches to aphasia rehabilitation and in particular pragmatic and social approaches, which are based on the social and personal consequences of aphasia with a particular attention on the perspectives of people with aphasia and on adaptations rather than impairments. Social approaches are considered more efficient in order to improve the quality of life of people with aphasia. Moreover the thesis discusses the importance of communication in our life, the role of the caregiver and the change in the social life participation of people with aphasia with reference to the preexistent literature.

From the data emerged that the loss of language affected all the aspects of aphasics' life situation and as a consequence people with aphasia expressed the need of rebuilding their identity and bridging the gap between their past and present life, a process that may be faced only with the support of specialists.

Introduction

This thesis aims to describe the experiences of sixteen people with chronic aphasia in relation to different aspects of their life after the onset of the disorder, identifying how aphasia affects everyday life. The data was collected through an interview that investigated several fundamental aspects in aphasics' life: the interaction with doctors, the speech therapy, the participation to a self-help group, the relation with family and friends, the changes experienced in the professional life and in the use of leisure time.

First we are going to present the definition and classification of aphasias showing also an overview on the linguistic aspects connected to the disorder and conclude by showing that every kind of categorization is always a simplification.

In the second chapter we will describe different approaches to aphasia rehabilitation, from traditional models, whose main object is the rehabilitation of linguistic abilities (Basso, 2005) to pragmatic and social approaches (or consequence-based approaches), which are models based on disabling social barriers and moving from the concept of social agentivity (Kagan, 1999-2001; Holland, Hopper, 2002). In this section we will underline the importance of individualizing the rehabilitative approach in order to satisfy the different needs of people with aphasia and as a consequence improve their quality of life.

In chapter three we will discuss the psychosocial consequences of aphasia and the role of the caregiver especially with reference to the work of Parr et

al. (1998) and Blom Johansson (2012).

In chapter four we will present the study conducted on sixteen people with aphasia (PWA). A qualitative analysis of the relevant contents that emerged from the interviews was fundamental to individualize some aspects of the psychosocial impact of aphasia as the change in relationships and interactions with family and friends, the adaptation to a new condition and the necessity for a new identity.

A second questionnaire was proposed to caregivers and relatives in order to point out possible divergences between them and people with aphasia on relevant aspects of the life after stroke.

1. Aphasia

The word “Aphasia” is derived from the greek word “aphatos” (ἀφατος, ἀ- + φημι), meaning “speechless”. Aphasia is a disorder consequent to a vascular or traumatic lesion of the brain; usually the left hemisphere. This damage leads to the loss of the ability to communicate through language.

Damasio (1992) defined aphasia as “a disturbance of the comprehension and formulation of language caused by dysfunction in specific brain regions. It results from a breakdown of the two-way translation that establishes a correspondence between thoughts and language”. Aphasia is most often caused by stroke. Other possible causes are head trauma and brain tumor, infections, and neurodegenerative diseases (Blom Johansson, 2012).

Anna Basso (2005) explained that aphasia could simply be defined as “a total or partial loss of language”. This general definition excludes evolutionary delays of language, disorder of communication in demented subjects and disorders tied to deficiency of peripheral organs. The word “loss” leave out all the disorders connected to the acquisition of language.

1.1 Classification of aphasias

The study of aphasias started in 1861 when Paul Broca, a french anthropologist, described a type of aphasia showing the famous case of the patient named “Tan”. The patient's disorder was characterized by two

elements: a localization of the lesion in the left hemisphere of the brain and a series of symptoms resulting in the language disruption.

In 1865, after the study of eight cases of aphasia, Broca declared "*nous parlons avec l'emisphere gauche*" ("We speak with the left hemisphere"). Broca's contribution to the study of aphasias was very relevant as he discovered that the localization is related to the lobes and convolutions and stated that the right and left hemispheres have different functions. Broca's most important finding was the relation between a specific center of brain and articulate speech (Basso, 2003).

Wernicke (1874) confuted the hypothesis of a unique centre of language. He proposed that the neurological basis of language relied on different centers inside the left hemisphere and interconnected one center for production. The two centers communicated through a bundle of fibers. This model was confirmed by pathology: the disintegration of the motor-verbal centre led to Broca's aphasia, while the consequence of the destruction of the audio-verbal centre was a sensory aphasia, characterized by a disorder of comprehension. Wernicke proposed also the existence of another type of aphasia, called "conduction aphasia". The conduction aphasia is the result of the communication's interruption between the two centers.

Ludwig Lichtheim in 1885 changed and elaborated the language's scheme proposed eleven years before by Carl Wernicke. He introduced a new area: the concepts centre, connected to the center of auditory images (comprehension) and with the center of motor images (production). Lichtheim's model was not only a representation of the language centers in the brain but led to a formulation of hypotheses about the types of aphasia

that a patient could suffer from. This model was criticized because of two reasons: he did not consider the process of naming and he did not localized the concepts centre.

Geschwind (1965), a neoassociationist, identified the process of naming as a process depending on the possibility of forming a series of cortical associations between different modalities: visual, tactile, auditory. He described the angular gyrus as a big area of association and asserted that its lesion could cause a particular form of aphasia: anomia, characterized by a specific deficit in the oral and written denomination (Denes, 1999).

On the basis of Wernicke-Geschwind's model there were seven types of aphasias:

- Global aphasia
- Broca's aphasia
- Wernicke's aphasia
- Conduction aphasia
- Anomic aphasia
- Transcortical motory aphasia
- Transcortical sensory aphasia

Goodglass and Kaplan (1972) proposed a new classification of aphasias discerning fluent aphasias from non-fluent aphasias. Fluent aphasias are

characterized by an oral production composed by long sequence of words, normally articulated but with severe lexical difficulties.

Non-Fluent aphasias are characterized by a disorder in oral production, resulting in difficulties at the production level, in the concatenation of articulatory movements and of grammatical sequences. The spontaneous discourse is not well articulated and interruptions are frequent, words are often not syntactically tied (Denes, 2009).

The eight aphasias resulting from Goodglass and Kaplan's classification are categorized on the basis of quantitative alterations: the discourse is reduced in the former four syndromes and fluent in the other four.

Non-fluent aphasias:

Global Aphasia

It is the most severe clinical form. The patient speaks in a fragmentary way. The discourse is mainly constituted by syllabic fragments and/or stereotypies. In some cases the discourse could be totally absent with a very compromised hearing comprehension.

This type of aphasia is due to an injury involving the majority of language's areas of the left cerebral hemisphere.

Broca's Aphasia

The main characteristic of this syndrome is agrammatism. Agrammatism is characterized by a reduction and simplification of grammatical structures. Sometimes the order of sentences is altered. The verbal comprehension is

good. At closer analysis, however, there are problems with the comprehension of complex grammatical sentences. The repetition of words or sentences is very compromised. The injury involves the Broca area, situated in the frontal lobe of the left hemisphere. This aphasic syndrome is often associated with a paralysis of the right side of the body (hemiparesis or right hemiplegia).

Transcortical motor aphasia

The disorder consists in a dissociation between language and non-verbal thought and as a consequence an inability of translating thoughts in words. Subjects with transcortical motor aphasia have a preserved comprehension of spoken and written language, they can read and write without any problems. The spontaneous discourse is reduced, non fluent, characterized by difficulties in starting to speak and a compromised repetition.

Mixed transcortical aphasia

It's a quite rare and severe clinical form. Subjects with mixed transcortical aphasia do not present a spontaneous discourse and the comprehension is compromised.

Fluent aphasias:

Wernicke's aphasia

The verbal expression is fluent with numerous phonemic paraphasias, neologism and serious alterations of production. Denomination is quite compromised. The verbal comprehension and the repetition are extremely poor. Sometimes subjects with Wernicke's aphasia are not aware of their

unintelligible production. The written production is qualitative similar to the oral one and as much compromised.

This kind of aphasia is frequently associated with blindness of the right visual hemifield.

Conduction aphasia

Patients show a fluent discourse with phonemic paraphasias. The hearing comprehension is good, while the repetition is particularly compromised. This type of aphasia is characterized by frequent anomias and by *conduites d'approche* (spontaneous corrections with progressive approach to the phonemic or semantic target). The deficit could be so severe that subjects do not repeat or read correctly single words.

This kind of aphasia is quite rare and it represents only the 5 per cent of aphasias.

Transcortical sensory aphasia

Patients present a fluent discourse with phonemic and semantic deficit and substantial damages in the denomination.

The hearing comprehension is compromised, while the repetition is relatively preserved. This type of aphasia is very infrequent (less of the 5 per cent of aphasias).

Anomic (or amnesic) aphasia

Anomia is the more recurring manifestation in this form of aphasia. Phonemic and verbal paraphasias are infrequent. Patients show a fluent spontaneous discourse, informative and grammatically correct.

Comprehension and repetition are commonly preserved.

Linguistic Analysis

The qualitative alterations of the discourse involve a series of symptoms concerning the phonological, semantic or syntactic level. The main qualitative alterations are described with the following technical terms:

Agrammatism. A disorder characterized by omission of articles, connection words, auxiliaries and inflections, which leads to the reduction of the grammatical structure of the sentence to a rudimentary form, often limited to the production of sentences composed by one or two words.

Paragrammatism. A disorder consisting in mistakes of genre and in the wrong choice of prepositions.

Anomia. This term indicates the delayed or missed recalling of a word essential to define an object, an activity or quality. Generally, in substitution of the word, a circumlocution or *passe-partout* elements could be produced.

Stereotypies. Words or elements *passe-partout* that appear often, but although the absence of informative content, set in the context of sentences properly.

Semantic paraphasias. Substitution of a word with another word which does not express the desired meaning, but preserves a semantic relation with the target word.

Phonemic paraphasias. The term indicates the substitution of the sound of a

word or its omission, transposition or addition with consequent modification of the phonemic form of the word.

Verbal paraphasias. Production of words that are improper in the context's subject and without any phonemic resemblance or semantic relation with the target word.

Neologism. Production of words impossible to recognize.

Circumlocution. Substitutive strategy that often goes with anomia; the lexical element is not recovered and it is substituted by a syntagm or a proposition which describes the meaning of this element.

Conduite d'approaches. Production of phonemic variation of the target word with the intent of approaching the target word.

Echolalia. Tendency of the subject to repeat what the interlocutor has produced.

Perseveration. This term indicates the involuntary repetition of syllables, words or syntagms.

Articulatory Apraxia. Disorder of phonetic production and of the sequence of language's sounds. The disorder is not correlated to a paresis of the articulatory's muscles or other motor coordination deficits.

Phonemic or verbal slang. Alteration of discourse at a phonemic, lexical and syntactic level with consequent impossibility to recognize words.

1.2 Other models and new perspectives of study

Luria (1970), a soviet neuropsychologist, described language as a complex functional system. He theorized a cooperation of several regions of the brain in the structuring of language. The anterior part of the cerebral cortex checks and plans the motor behavior, the posterior part organizes the receptive aspects and the limbic system deals with attention and surveillance.

On the basis of these considerations Luria provided a model with the inclusion of four types of aphasias: motor, sensory, dynamic and semantic aphasias. He distinguished two forms of motor aphasias: afferent motor aphasia, where the pronunciation of sounds is compromised and efferent motor aphasia, characterized by loss of the smoothness of oral production and perseveration.

Sensory aphasia includes two forms: auditory aphasia, where the comprehension of single sounds is compromised and amnestic aphasia characterized by a semantic comprehension compromised, but the analysis and discrimination of sounds is preserved.

Dynamic aphasia is characterized by the compromised capability of introducing a conversation spontaneously and semantic aphasia is defined by a compromised comprehension of the relation between concepts and complex grammatical constructions.

Damasio (1966) established that concept are localized in different area of the perisylvian motor and sensory cortex. In the process of acquisition of

meaning, words are presented together with the correspondent stimuli (visual, tactile, olfactory, etc.). The final representation of a word is composed by different neuronal aggregates corresponding to different modalities of presentation of stimuli associated with this word.

Roman Jakobson (1964) proposed the existence of two process for the elaboration of language: the process of selection and the process of combination. The process of selection allows the choice of the linguistic unity (phoneme or word), whereas the process of combination combines the linguistic unity with other ones belonging to the same level. Therefore Jakobson considered the aphasic syndromes the results of specific compromised processes.

In the late 1970 it was clear that language was not represented in a unique area of the cerebral cortex and that it was necessary a neurological and functional organization with specific neurological sites for the treatment of the various components of the language system.

Besides, the neurological model based on the existence of three processes (comprehension, production and conceptualization) was obsolete because it did not take into consideration the different domains of phonology, syntax and semantic. With the new techniques of neuroimaging a new “anatomy of language” was introduced, with more elaborated models (Denes, 2009).

For example subcortical aphasia were discovered only in the XX century as a result of the introduction of these new techniques, as CAT (computed axial tomography) and NMR (nuclear magnetic resonance), which proved that lesions of deep structures could produce disorder of languages (Basso, 2005).

Cases of subcortical aphasias are uncommon. These types of aphasia are

characterized by reduced production, sometimes dysarthria, and there is no evidence of verbal apraxia, *conduites d'approache* or slang. Comprehension is relatively good, writing sometimes is more compromised than oral production.

The observation of aphasic subjects has put in evidence the fact that subject classified into the same aphasic syndrome could be very different and every kind of classification for this reason is always a simplification.

The cognitive neuropsychology led to a new method of study of aphasias: not only the study of syndromes and their relations with specific cerebral area but an examination of pathology's data to make interferences on the normal cognitive structure (Basso, 2005).

The results obtained through the anatomo-clinical method integrated with the data of morphological and functional neuroimaging together with the applications of principles and methods of cognitive psychology led to an incredible development of researches (Denes, 2009).

In this thesis we will not discuss these thematics because of we need only to have an idea of the classification of aphasias and their symptoms.

2. Rehabilitation of aphasia

The rehabilitation is an active process with a precise target: the greatest increase of functional independency and quality of life of patients.

There is a lot of concern about aphasia, but it is important to know what

being aphasic means. "Having a stroke-induced aphasia probably means that the individual has other stroke-related symptoms as well, such as motor, sensory, or cognitive impairments which affect the everyday life" (Bloom J., 2012). The guidelines on rehabilitation, proposed by the ministry of Health (2011), underline the central role of the patient and relatives. The rehabilitation's aim is to grant to the patient a real sense of wellness and not a mere re-education (Flosi, Consolmagno, 2013).

There are basically two categories of approaches in aphasia rehabilitation: Impairment-based therapies and Communication-based therapies.

The target of the first one is to improve language functions and consist of processes in which the clinician directly stimulates specific listening, speaking, reading and writing skills.

Communication-based (also called consequence-based) therapies are intended to enhance communication by any means and encourage support from caregivers. These therapies often consist of more natural interactions involving real life communicative challenges. In the next section we will describe these two categories with a particular attention on communication-based therapies with reference to Pragmatic and Social Approaches.

2.1 Traditional approaches in aphasia rehabilitation

Anna Basso (2005) described five main approaches in the aphasia's rehabilitation: the Stimulation Approach, the Behavioral Approach, the Pragmatic Approach, the Neurolinguistic Approach and the Neoassociationist

Approach.

The Stimulation Approach is based on the assertion that aphasia is a unitary disorder. The direct consequence of this hypothesis is the use of the same type of therapeutic approach for every patients.

This type of approach is based on the assumption that language is not lost, but inaccessible. Two processes occurring in patients with aphasia demonstrate the validity of this assertion: the automatic-voluntary dissociation and the variability of answers. Concerning the phenomenon of automatic-involuntary dissociation, the aphasic subject can produce sentences or words in certain situations, but not in other ones. It is famous the case described by Alajouanine, a neurologist, who depicted the situation in which him asked to a woman with aphasia her daughter's name and she could not answer and then talking to her daughter she said: "Voilà Jacqueline, que je ne sais même plus dire ton nom" ("Jacqueline, I can't even say your name!").

The phenomenon of variability of answers is demonstrated by the fact that the performance improves when facilitations are provided. For example aphasics subjects reported a better performance in tasks involving the completion of stories than in spontaneous discourse.

Schuell (1953) proposed a rehabilitative treatment consisting in an auditive stimulation and the possibility of repeating the same stimulus several times before asking the subject for the answer. Stimuli are effective only when subjects answer without an excessive effort.

Although the Stimulation Approach was widely used and nowadays several rehabilitators are inspired by Schuell's theories, currently it is impossible to

assume that language is a global function, not analyzable in independent components and the aphasic disorder cannot be considered a unique disorder. Brain damages could have different outcomes and it is possible to experience several selective impairments as deficit in reading, writing or lexical impediments (Basso, 2005).

The Behavioral Approach is based on the study of rehabilitative techniques based on “operant conditioning” and “programmed instruction”. The aim of this approach is to individuate the patient's desired behavior and programming different stages to reach it. This approach is more rigorous than Schuell's one and it is applied in a standardized way. The method is criticized for the lacking attention on contents and the aphasic deficit.

Until the 1970 aphasia rehabilitation was only based on the impairment level: the object was to reestablish the linguistic abilities through the use of specific linguistic tasks (Bloom J., 2009).

In 1970s Sarno and Holland introduced the concept of functional communication: a communication, which focused on natural contexts. This term underlines the primary goal of a PWA (People With Aphasia): the development of an efficient way of communicate in the different situations of everyday life.

As a consequence in 1970 the importance of the pragmatic aspect of language was recognized. Pragmatic linguistics examines the use of language; what is relevant is the relation between language and the global situation in which language is used. Communication has a key role: the ability to communicate of people with aphasia is more developed than their ability of express themselves through language. A pragmatic approach must be focused on a

qualitative description and judgment of the use of residual communicative abilities in situations of clinic interaction and the degree of pertinence of communicative behaviors, on a verbal and non-verbal level into daily actions. The “Promoting Aphasics’ Communicative Effectiveness” (PACE) is the most known method of rehabilitation based on the improvement of communicative capability through the development of communicative strategies and the continuous exchange of information between the therapist and the aphasic subject.

This approach is identified by the following principles:

- the patient and the therapist participate to the exchange in equal measure (“equal participation”)
- the interaction is based on an exchange of new information (“new information”)
- the patient can choose any informative channel (“free choice of channels”)
- the feedback is provided by the therapist, it is based on the success of the message conveyed by the patient and it shares the same characteristics of a feedback in a normal conversation (“natural feedback”)

This treatment has an important limit: it does not take into account possible differences between an aphasic subject and another one. Another limit is the fact that the aphasic subject has only to describe what he has seen and it is not a common situation in an ordinary conversation between two people.

The Neurolinguistic Approach is focused on the target of regaining linguistic capabilities over the communicative ones. The therapy requires the use of metalinguistic tasks; aphasic subjects take explicit decisions on phonological,

graphical, lexical, and grammatical structure (Huber, Springer, Willmes, 1993). The treatment's aim is the subjects' acknowledgment of compromised linguistic units and the construction of an individualized therapeutic course.

The method consists in the use of a technique called "deblocking". The deblocking is the process in which the needed answer is obtained in an accessible modality (ex. repetition) to unlock the "blocked" modality (ex. spontaneous production). After the deblocking, the answer can be reached also in the modality that was stopped. The effect achieved is limited in time (Giachero, 2006).

Another version of this approach is REST (Reduced Syntax Therapy); its aim is to facilitate the use of simplified structures as the one used in everyday life by "normal" subjects. Wilk and Paradis (1993) confuted this type of approach asserting that there are not systematic applications of a specific linguistic theory to a rehabilitative program for aphasic patients. In conclusion, linguistics is not able to offer learning strategies that can be useful for aphasic subjects (Basso, 2005).

The Neoassociationist Approach derived from the one based on stimulation; compared to the other methods it shows a more meticulous methodology, the introduction of some linguistic principles and a more accurate analysis of aphasic disorders. Ducarne (1986), a neoassociationist representative, outlined a method in which the linguistic behavior of the aphasic subject is analyzed and the goal is to restore the lost knowledge through the study of the most favorable context of communication for people with aphasia.

Ducarne gave also an important role in the rehabilitation process to the family of patients: patients have to do exercises at home, helped by their

relatives.

In 1970 the cognitive neuropsychology led to a change in the study of aphasia: the attention shifted on the nature of cognitive mechanisms. Cognitive neuropsychology is based on three principles:

- modularity: a cognitive function is the result of a series of subcomponents functionally independent
- universality: the cognitive functional structure has no individual variations
- transparency: when one or more components are compromised, the others continue to function

The innovation for treatments is evident: "If a cognitive function (such as naming, for instance) consists of a series of independent components that can be separately damaged and no re-organization is possible, a detailed diagnosis will locate the damage and the therapy will be specifically directed to that component and not to unspecified naming disorders" (Basso, Forber, Boller 2011). Such model-based treatment approach focus on intervening at an impairment level for a client's deficits (Rajinder, 2011).

In the following table the various approaches to aphasia rehabilitation are summarized with their theoretical underpinnings. The table shows also the Social or Consequences-based Approach that we will discuss in the next section.

Stimulation Approach Simulation of inaccessible language mainly through comprehension exercises that vary only according to the severity of the aphasic disorder.	Holistic School Language is a complex, indivisible psychological function, a property of the total brain. Aphasia can only vary in severity; in aphasia, language is not lost but inaccessible
Behavior Modification Approach Applies to aphasia therapy the principles of operant conditioning and programmed instruction. Shaping and fading are the most important techniques. Stresses methodology.	Operant Conditioning Human behavior is determined by external stimuli; verbal behavior is not qualitatively different from other behaviors. Only external stimuli and responses can be studied scientifically.
Pragmatic Approach The main goal of therapy is to restore communicative competence by whatever means: language, gestures, mimic, drawing, and so forth.	Pragmatics Stresses communication and studies the use of language in context. Views aphasia as a communication disorder.
Neurolinguistic Approach Scattered and rather vague suggestions to base therapy on linguistic principles. Principles of Chomsky's competence-performance dichotomy and transformation grammar have been used.	Neurolinguistics Analyzes in terms of a linguistic theory the language impairments that follow brain damage.
Neoassociationist or Syndromic Approach Therapy is still mainly based on stimulation, but more attention is given to the level of the linguistic disorder (phonemic, lexical, or syntactic) and therapy varies according to the type of aphasia. Much research on aphasia therapy effectiveness.	Neoassociationism Language is the sum of a number of faculties- comprehension, production, reading, writing. Damage to different areas of the brain differently affects verbal behavior.
Cognitive Neuropsychological or Impairment-based Approach	Cognitive Neuropsychology Language consists of a series of

<p>Therapy targets the "damaged" sub-component(s) of language, as inferred from a model of normal language processing.</p>	<p>independent subcomponents that perform different functions and interact with other parts of the system. Impaired language performance is explained in terms of damage to one or more of the sub-components in a model of normal language processing.</p>
<p>Social or Consequences-based Approach Therapy aims to reduce whatever barriers prevent aphasic people from using language and communication to participate in life.</p>	<p>Social Consequences Aphasia, with its effects on both language and communication, results in barriers to an individual's ability to participate in life.</p>

(Basso, Forber, Boller 2011)

2.2 From the pragmatic approaches to the social approaches

We now want to focus our attention on pragmatic approaches, as these therapies are the first ones more person-oriented. We have previously described the pragmatic approach PACE and now we will discuss briefly the principles of this category of approaches.

The Royal College of Speech and Language Therapists (RCSLT, 2009) individualized the therapeutic objectives followed by the pragmatic approaches:

- the reduction of the communicative disability ensuring the maximum use of residual ability (intervention on activities)

- allow the participation according to individual preferences and circumstances, the development of social abilities and confidence, promotion of independency and capability of taking decisions, reduction of isolation and increase of social integration (intervention on participation)
- increase of the sense of wealth and quality of life (intervention on quality of life)

The pragmatic models share some principles with the ICF (International Classification of Functioning, Disability and Health, 2001), “a framework for conceptualizing health and the consequence of disease” (Kagan, 2008). The ICF classification involves activities and participation in its program with a particular focus on communication, domestic life, interactions and interpersonal relations, social life.

Also the guidelines of SPREAD (Stroke prevention and Educational Awareness Diffusion, 2010) inserted among the main targets the “promotion of strategies of balance in order to pass the disorder of communication” and the “training of relatives to the most efficient modalities of communication”. The focus is now on the involvement of the patients and families in the process of rehabilitation, but pragmatic approaches do not seem to take sufficient account of the personal experiences of living with aphasia (Simmons-Mackie, 1998).

The pressure for a new category of approaches has arisen from people with aphasia and their relatives. The interviews with aphasic subjects revealed situations of “discrimination, social isolation, exclusion from work, education and leisure pursuits and limited community support and benefits (Worral, Frattali, 2000). The Social Approaches move exactly from the concept of

social agentivity. The managing of language can be damaged involving the interpersonal aspect and the consequences can be (Giachero, 2006):

- a sense of frustration and difficulties expressing thoughts
- difficulties obtaining adequate answers from interlocutors on a linguistic, behavioral, cognitive and affective level
- an excessive supply from relatives and interlocutors and a consequent feeling of impotence and dependence
- an evanescent independency of the subject
- the interlocutor may think that the subject has a mental deficit and not or not only a linguistic disorder and as a consequence the subject starts to doubt about himself feeling ashamed and depressed
- progressive impoverishment of social relations and consequent affective and cognitive disorders

The damage can involve also the intra-personal aspect and in this case the impairment is generalized. It concerns a reduced ability of using communication as a support to the thoughts, for example in the construction and managing of external narrative and action plan.

In social models the communication is designed to meet dual goals of social interaction and transaction of messages in order to get over aphasia's damages. Communication is considered as a flexible, dynamic, multidimensional activity and as a consequence authentic, relevant natural contexts are emphasized. The core of social approaches are the social and personal consequences of aphasia through a particular attention on the perspectives of people with aphasia and on adaptations rather than

impairments.

A social model involves the “societal perspective” that views disability in terms of societal barriers and restrictions and do not focus on the inability to carry out normal activities. Basically it is important to reduce the social consequences of aphasia and for this reason Social Approaches are also called “Consequence-based approaches”. The idea is that “a social approach to aphasia involves a shift in thinking that moves from working solely on the impairment of the individual, to examining the role of the environment and society in creating barriers to life participation” (Kagan, 1999).

Examples of these approaches are “Supporting conversation with Aphasia” (SCA) (Kagan, 1999; Kagan et al., 2001) and “Conversational Coaching Approach” (CC) (Holland 1991, Hopper et al., 2002).

The underlying principles of the SCA model and the CC are that aphasia hides competence, that is normally revealed in conversations, resulting in a reduction of communicative access that has a negative incidence on the quality of life. The competence of subjects with aphasia can be uncovered by a trained conversation partner. “Acknowledging competence can be accomplished by, for example, using an appropriate tone and verbal support in such a way that the conversation sounds natural and adult” (Blom Johansson, 2012). These approaches consist in handling conversations with a trained partner who manages the use of techniques of supported conversation in order to acknowledge and reveal the competence of people with aphasia. These models include the use of verbal facilitative conversation strategies (as simple vocabulary and yes/no questions) as well as non-verbal ones (as facial expressions and drawings) and “continuous clinician feedback

to improve communicative interactions between clients with aphasia and their spouses, family members, caregivers or volunteer communication partners" (Rajinder, 2011).

Another example of Social Approach is the Reciprocal Scaffolding Treatment (RST), described by Avent and Austermann (2003). It is an approach based on an apprenticeship model. The communication skills are entrenched in activities that are relevant and meaningful to the subject with aphasia. The PWA acts the part of an instructor in a domain of expertise, "while benefiting from scaffolding and support of linguistic and communication abilities" (Hinckley, 2009).

In this chapter we have described the traditional approaches to rehabilitation of aphasia focusing our attention on the principles of pragmatic and social approaches. It is essential to remember that "people with aphasia represent a clinically heterogenous population and it is clear that aphasia manifests differently among affected individuals" (Rajinder, 2011). As a consequence clinician and researchers have to choose from the various approaches to individualize the intervention.

3. Psychosocial consequences of aphasia

Aphasia has a negative impact on the spectrum of social experience, as we have previously seen, and different psychosocial problems can arise from internal and external factors (Worral, Holland, 2003). Indeed experiencing a limitation in the ability of communicate results in "considerable activity

limitation and participation restriction in all life domains: close relationships, social life, occupational life, recreational life, and the possibility of being an active citizen" (Blom, Johansson, 2012).

Lomas et al. (1989) described communication as a tool with four intentions: it is fundamental to meet basic needs, it is necessary to give and get help, it is used to accomplish activities in everyday life through exchanges of information and it has a social nature that allow all the types of interactions between people. In general terms we can affirm that communication is an essential human need and the reduced access to communication "is a challenge to all relationships" (Blom, Johansson, 2012).

PWA can incur into different types of disabling barriers: environmental (linguistic and physical), structural, aptitude and informational barriers (Parr et al. 1998). Aphasics need an appropriate physical environment to express himself/herself. The interaction with another person can be significantly impaired in comparison with non aphasics, for example, by noises or other types of distractors. Concerning the linguistic environment it is important to interact with aphasic people using an accessible language, characterized by simplicity and a calm and slow tone. Structural barriers are identified by inadequate or not available resources and services for PWA as consultancy services or social services. The access to work can be limited too, for example because of long meeting at a hectic pace, that are not appropriate situations for people with aphasia. Attitudinal barriers are the results of the reactions of others and their judgements: from compassion to prejudice. The general lack of knowledge about aphasia provokes discomfort in people who meet PWA and quite often aphasia is wrongly associated with cognitive deficits. The

informational barriers result in a limitation of access to information experienced by PWA in different occasions.

The time is a central factor for people with aphasia and can constitute a considerable barrier. "The rapid rhythm and tempo of everyday life make few allowances for a calmer, slower, more deliberate form of interpersonal communication" (Pound, Hewitt, 1993). A slower rhythm for PWA is not a choice, but the unique accessible pace. They need additional time to find words, think about how to express ideas, elaborate answers and managing decisions and choices. The conversation with PWA implies an effort on the interlocutor's side: he/she has to learn communicative facilitative strategies in order to use an accessible language. "Different temporal conventions in communication demand a lot of those who have aphasia and those who do not" (Parr, Paterson, Pound, 2003).

The impact of aphasia is fully realized when PWA return home from hospital and start to attempt the reintegration into their social surroundings. Leaving the hospital is a significative event and it is usually accompanied by a sense of relief as a signal that the process of curing is started and the recovery may have a positive outcome. For PWA, quite often, however, the returning home is the moment when they understand that their life would never be the same, they have to face the limitation imposed by the everyday reality. The optimistic feelings for the end of the convalescence are soon replaced by the awareness of their new condition that is often cause of anger, frustration and depression. (Parr et al., 1998). Managing daily activities as doing shopping and chat with neighbours can become difficult operations for PWA because communication is always involved. Furthermore being at home means

starting again to organise time that is no more occupied by hospital life activities. PWA may have a great amount of leisure time and do not know how to employ it. Living with aphasia obstructs the planning and organization of time, because of the loss of autonomy and the fear for the external world experienced by PWA. Moreover aphasia has a negative impact on professional and free time activities. Hobbies and interests of the life before aphasia may come to an end or completely change (Parr et al., 1998). The psychosocial consequences result in low self-esteem and frustration. PWA, realizing their life is dramatically changed, feel the need to reconstruct their identity. It is a process that involves reconceptualizing all the aspects of life: the self-identity, the relationships and daily activities (Brumfit, 1993). PWA have to "forget" their identity before stroke or to learn to live with it avoiding to make comparisons between the two identities. Accepting the new impaired image of themselves is a long and grievous process. Sometimes the feelings of shame and depression for their new condition bring PWA to situation of isolation resulting in avoiding any kind of interaction. For PWA it is often easier to manage social isolation than to deal with failure and frustration. The segregation can be a bidirectional process in someway: friends, peers and relatives may feel discomfort with the person's impairment and do not know how to interact with them. Meaningful interactions are based on social acceptance and the individual has to be considered a valid conversational partner (Lubinski, 2001).

Concerning the family dimension PWA may experience an exclusion from decisions and discussions as their relative tend to consider him/she no more able to solve problems and deal with domestic matters. A similar situation can occur in the professional life and PWA may be relegated to a lower

position as a consequence of their impairments or have to quit their job. Of course every single case is different, indeed a person who has reached the retirement age, for example, can anticipate the advantages of a fully matured retirement without being upset about the new condition. On the other side someone who has just undertaken a career and is very attached to his/her profession considers the return to work as a priority. In any case leaving the job is not an easy decision: for the majority of people it means losing social relationships, personal interests, prestige. The people's attitude towards life is always a fundamental variable and in the case of PWA an optimistic attitude can result in behaviors of adaptations and appreciation of life to the fullest that may be central for a successful recovery.

Blom Johansson (2012) points out that "although people with aphasia often have been excluded from studies concerning quality of life or depression, it has been concluded that they have significantly lower quality of life than people without brain damage and a higher degree of distress than people with stroke without aphasia". The communicative disability generated by aphasia has different significant implications on the social, professional and family life of affected subjects as it institutes a "rift" between the individual and the world of interactions, establishing a social barrier as we have previously seen. In conclusion aphasia brings several changes in the life of an individual and determines an alteration of the self-perception and the self-perception in the world. This negative effect is especially due to an altered ability of externalize representations (realized through language), that allow to give sense to an events flow and to interact with others, causing a break of the identity and invalidating the need of rebuilding and giving meanings to the own self (Code, Hermann, 2003).

After the dramatic event PWA are evidently exposed to a high amount of stress, due to the extent and severity of their physical, cognitive and psychosocial disabilities. Eventually as Strauss et al. (1984) state very accurately aphasia do not affect only the individuals, but involves all the social surrounding of PWA and especially the caregiver, figure that we will identified in the next paragraph.

3.1 The caregiver

In this section we will discuss about the figure of "caregiver". The term "caregiver" is used with reference to the people who take care of subjects affected by illnesses or disabilities. The word "caregiver" could be ambiguous because it seems to imply a nursing role that may not be present and at the same time the term "relative" is too limited because the care for aphasics can involve friends or other people important to the people with aphasia (Blom Johansson, 2012). For this reason in literature the term "Significant other" is widely used to include all the people involved in the process of taking care of subjects with aphasia. When a person suffers from aphasia life changes drastically and the change affects not only him or her but also his/her family and friends, what we have defined "Significant others". The significant others have to face several transformations in their life. For example stroke survivors and their spouses may experience role changes, a different perception of themselves, and as a consequence changes in the dynamic of relationships. Some partners may have to quit their job in order to take care of their relatives and modify their life style according to the new economic

situation. Couples who live with aphasia have to support and help the ill partner without losing respect and consideration for each other, they have to restore balance in their life and not being overwhelmed by the negative impact of aphasia. A type of dysfunction in relationships arises when “there is a discrepancy between the stroke survivor's abilities and family expectations” (Kitzmüller et al., 2012). PWA may feel contradictory feelings for their caregivers: from a sense of guilt for the partner efforts to resentful feeling for the unattended expectations of the partner. Furthermore the caregiver can establish a model of protection and support or create on the contrary situations of oppression and intrusiveness resulting in speaking for the PWA, taking decisions for him/her, substituting him/her in all the daily activities. PWA cannot control the caregivers' behavior because of their communication disability and as a consequence they may feel totally powerless. Therefore a central aspect is the creation of a dependency-relation: caregivers may feel resentful for their sacrifices and also guilty for not doing enough for them; on the other hand PWA may experience frustration for their inability to be independents, but also irritated by the overprotective attitude of significant others.

Several studies have shown that significant others risk to develop depression, anguish, sleep disorders, a low quality of life and health problems often due to high level of stress (Berg, Palomaki et al., 2005; Scholte, Richter et al., 2006; Ski, O'Connell, 2007) with consequent reduction of efficacy in the everyday assistance. For this reason it is important to involve caregivers in the process of rehabilitation and to offer adequate information and support to prepare them to face life with aphasia. The National Aphasia Association has edited the “Caregiver's Bill of Rights” making a list of the fundamental

rights of caregivers as “protect individuality” and “take care of myself”. Caregivers (or significant others) have to try to keep social contacts, their interests and world of interactions in order to be able of taking care of a PWA. A condition of isolation may be cause of a relationship break or other negative situations that can only further damage caregivers and PWA.

4. The study: material and methodology

The idea of an interview on the psychosocial impact of aphasia is connected to an experience of internship in the Venetian U.L.L.S. 12, district of rehabilitation, where it was possible to follow the activities of a speech therapist with some patients with aphasia.

The interview structure is shaped on the patient's course from the day of the trauma to the return to home and the everyday life. The interview is constituted by different types of questions: closed-questions, open-questions and multiple-choice questions. The semi-structured interview was conducted between a single participant and a presenter.

An interview guide (see Appendix A) has been proposed with the awareness of the importance of expressive freedom for every participant for a better comprehension of the dynamics of the patient's past events.

The selected people accepted to be interviewed and expressed their consensus. Every interview was recorded and transcribed in order to analyze the contents in an accurate way. Reading candidates case histories was fundamental to know how to conduct the interview and to apply different

strategies of communication with every participant.

The interview was conducted following some important conversational parameters. Anna Basso in a booklet promoted by A.I.T.A. (Associazione Italiani Afasici) describes the guidelines of an interaction with aphasic people:

- it is important to speak with them in a direct way, looking in their eyes and sometimes using gestures that recall what we are saying (example: while we say food we can point out the mouth);
- it is better to use closed questions and for this reason in the study we find closed and multiple-choice questions;
- you have to advise when the subject changes in order to make the conversation easier;
- it is important to use short sentences and simple vocabulary;
- when they are speaking it is essential to listen accurately and to try to understand the intention of their words, even when you encounter non-words;
- time is essential: if you speak quickly aphasic people may be confused;
- you have to encourage aphasic people to use gestures or others mean of communication, as drawing, but supporting always the use of words;

The themes raised by the interview are:

- the convalescence in hospital and the comprehension of the tragic event;
- emotions connected to the tragic event;
- the rehabilitation and its benefits;
- the relationship with relatives and friends;
- the self-help group;
- the job and free time;

The interview follows the phases of the life of a patient after the stroke and following the chronological order of events was important to allow the participants recalling the moments of their lives in a better way.

Another questionnaire was proposed to the subjects relatives in order to analyze the different perceptions about the disease and their reactions to the new situation. The questionnaire will be described in section 4.6.

4.1 Subjects description

The interviews were conducted in a comfortable setting, when it was possible in the department of rehabilitation after the sessions of self-help group and in some cases at PWA's home. The privacy was guaranteed and the

participants consented the recording of their answers.

To select the candidates we availed ourselves of the collaboration of the Venetian U.L.L.S. 12, an operative unity of speech therapy, where it was possible to consult case histories thanks to the supervision of the speech therapist of the department.

The parameters of inclusion of the participants were:

- subjects with fluent or non-fluent aphasia;
- the end of the period of rehabilitation (chronic cases);

Sixteen participants have been selected for this study. Six subjects suffered from non-fluent aphasia, ten from fluent aphasia. The average age was sixty-seven years old (min. 45- max. 81). Six out of sixteen subjects suffered from right hemiplegia and two subjects suffered from hemiparesis. Four were women and twelve men. The average distance from the time of the stroke was from 1 year to 26 years.

The subjects description is summarized in the following table.

Subjects description

Subject	Sex	Age	Education	Job	Type of Aphasia	Time passed from stroke	Caregiver
LF	F	79	12 years	Retired	Broca, Fonemic disintegration, hemiplegia	9 years (age 70)	Son
BG	M	78	11 years	Retired	Amnesic aphasia	10 years (age 68)	Son
RB	M	68	8 years	Retired	Wernicke's aphasia	11 years (age 57)	Daughter
SC	M	67	10 years	Banker	Broca's aphasia, articulatory difficulties	8 years (age 59)	Daughter
LZ	M	65	14 years	Accountant	Broca's aphasia, hemiplegia	14 years (age 51)	Wife
MM	M	56	8 years	Technician	Amnesic aphasia	1 year (age 55)	Wife
RF	M	67	8 years	Laboratory technician	Amnesic aphasia, hemiplegia	9 years (age 56)	Daughter
RI	M	61	8 years	Taxi driver	Broca's aphasia	11 years (age 50)	Wife
EP	F	78	12 years	Retailer	Amnesic aphasia	3 years (age 75)	Son
GB	M	65	8 years	Employee	Broca's aphasia	21 years (age 44)	Wife
MP	F	81	13 years	Musician	Wernicke's aphasia	16 years (age 65)	Daughter
PC	M	78	18 years	Employee	Amnesic aphasia, hemiplegia	26 years (age 52)	Wife
TL	F	68	12 years	Teacher	Global aphasia, hemiplegia	16 years (age 52)	Husband
CP	M	45	13 years	Surveyor	Global aphasia, hemiplegia	15 years (age 30)	Mother
EV	M	48	8 years	Bricklayer	Amnesic aphasia, alexia, agraphia and hemiparesis	16 years (age 32)	Mother
FD	M	51	8 years	Innkeeper	Amnesic aphasia, hemiparesis	17 years (age 34)	/

4.2 Problems encountered

The problems we encountered conducting the interview with subjects with aphasia were various. Firstly there were obvious problems of comprehension, in some cases it was not possible to get a coherent answer

from the participants. When the subjects did not answer coherently to the questions we gave them the necessary time to express themselves and when they did not understand, the question was repeated or reformulated.

A comprehension problem occurred especially with one participant who suffered from a severe Wernicke's aphasia. In this specific case we had also to contain his discourse because he had a tendency to be verbose and to go off topic. Some subjects had articulatory difficulties and for this reason it was not always possible to understand their discourse. The subjects had not been pressed to repeat the answers because this pressure could cause a sense of frustration. Several subjects preferred to use dialectal expressions and this was another critical factor for the correct transposition of the interviews.

One participant with severe aphasia (Global aphasia) did not answer to the majority of questions because her husband substitutes for her and as a consequence it was not possible to conduct a standard interview because of this intervention.

A question was removed from the interview because of its redundancy.

Another problem was the tiredness of the participants and as a consequence the difficulty in paying attention, possibly due to the length of the interview and the emotional complexity of the themes discussed.

4.3 General data analysis

In this section a general data analysis will be presented with quantitative outcomes divided into the relevant thematic emerged from the interviews.

The convalescence in hospital and the rehabilitation (speech therapy)

The first question of the interview revealed that almost all the participants experienced strange feelings and discomfort when the stroke occurred.

The feelings reported by the subjects were the following (organized in a decrescent order):

- strange feelings
- discomfort
- confusion
- fear
- anguish
- tiredness
- shock

The memory of the traumatic event was intact for the majority of aphasic people (63%), only four (25%) did not recall it and two (12%) did not answer coherently.

In 50% of the cases doctors explained clearly the situation, in the patients' opinion, 32% answered negatively, two (12%) reported they understood what happened only later (presumably because of aphasia) and one patient (6%) did not answer coherently. Even if doctors were clear only six people at the time were able to understand completely their condition, one patient did

not realize he was aphasic.

With reference to the convalescence in the hospital eleven people (69%) had a positive recovery, 19% had a negative one, one person (6%) did not remember at all the time spent in the structure and one subject (6%) did not answer the question.

The patients who had a negative recovery justify their judgement pointing out a problem: a lacking of consideration of themselves consisting of doctors who addressed only their relatives (67%). One patient (33%) reported that doctors had no time to listen and to try to understand him.

With reference to rehabilitation 82% of aphasics judged the speech therapy very useful. Two patients (12%) judged it quite useful and one patient (6%) did not understand the need of therapy, because he did not realize he suffered from aphasia.

Eight people (51%) showed an optimistic attitude towards healing, 25% a pessimistic attitude, one aphasic (6%) was not aware of his condition and one patient (6%) said he did not develop a particular attitude (he behaved as always). One patient (6%) was optimistic in the beginning then demoralized and in the end he had to adapt himself to the new situation. On the contrary one patient (6%) was hesitant in the beginning and only after improvements he changed attitude in a positive way. For nine aphasics (56%) the rehabilitation lasted the right time, while for five people (32%) the rehabilitation was of short duration. For one patient (6%) the rehabilitation lasted too long and one patient (6%) did not know how to evaluate the duration. Eventually seven aphasics (44%) were greatly satisfied with the rehabilitation, eight patients (50%) were sufficiently satisfied, while only one

(6%) was not convinced of its effectiveness.

Post rehabilitation and self-help group

50% of the informants did exercises supported by their relatives at home to improve the speaking, three people (19%) did not because they did not believe in the effectiveness. Five aphasics (31%) did not do exercises because of the lack of time of their relatives.

All subjects reported a collaborative attitude towards daily exercising at home with their relatives. The part of the group (50%) who did exercises found it very useful.

Eleven participants (69%) reported an improvement in their communicative abilities after the period of rehabilitation, while five (31%) of them did not. In 90% of the cases relatives and friends were aware of the improvements as well.

82% of the subjects followed the self-help group, only three aphasics (18%) did not, because they did not feel the need in one case (33%) and in two cases (67%) the therapy was not proposed. Everyone confirmed the effectiveness of the self-help group, however six people (38%) abandoned it for the following reasons:

- because of the hemiplegia they found hard to attend the therapy (50%);
- they were satisfied with their social relationships (33%);

- the environment made them feel sad (17%);

Family

50% of the informants preferred to spend time with their families, 38% with aphasics following the self-help group and friends. One informant (6%) reported to prefer to use the computer instead of spending time with other people. Only one person (6%) found himself at ease with anyone.

82% of aphasics reported that they have always been respected by their relatives. Only one person (6%) had a negative experience (he was not more involved in decisions and his relatives did not give to him the time to express opinions). Two people (12%) did not answer this question.

62% of the informants did not feel like a burden for their relatives, while six people (38%) did. The reason of their feeling was the perception of the tiredness of the family and complaining of relatives about the situation (67%). Two people (33%) did not answer coherently.

43% of the informants needed a lot of attention (even after years from the traumatic event), while the residual 57% did not. The answer of the family to these needs was very positive in 72% of cases. One participant (14%) was quite satisfied with the support of his family. One informant (14%) did not answer.

43% of participants reported that the relationship with their relatives did not change at all after the traumatic event, 19% reported a little change (they felt a little sorrow), 13% said their relationship was quite changed (they suffered quite a lot) and another 13% reported a big change (with a lot of suffering).

Two participants (12%) did not answer coherently the question. 37% of the participants who saw their family relationship changed said that with the passing of time they suffered less and less, while the other 37% continued to suffer for this reason (two people not so much, while one subject reported to suffer a lot). Two subjects (26%) did not answer the question. Eventually 76% of participants considered their family as a remarkable support. One participant (6%) considered his family a sufficient support, while two people (12%) did not consider their families as an aid. One person (6%) did not answer the question.

Job and free time

68% of the informants had a job when the traumatic event occurred, the other 32% did not work. 28% of participants kept their jobs, while 36% had to quit working and another 36% had to change their job.

71% reported it was hard to start again working for different reasons (they could indicate one or more answers):

- because of problems of communication (100%)
- the tasks were too hard (40%)
- for physical problems (20%)
- the relationship with peers was difficult (60%)

58% of the participants who kept working felt a sensation of happiness. One informant (14%) felt more self-confident, another one (14%) was scared, while one participant (14%) did not like the new job.

Two participants (50%) who had to quit their job felt a sensation of anger and grief. For one person(25%) leaving the job was a relief because he was tired after thirty years of hard work. One person (25%) did not answer the question.

75% of the informants succeeded in having a pleasant free time, the residual 25% did not. 43% of the participants were quite satisfied with their free time, 25% were not so satisfied and 32% were very satisfied with their daily activities.

Informants who had a job at the time of the stroke in 27% of cases reported a great suffering for the changes occurred, 18% reported a considerable grief while 37% felt only a little sorrow. Two people (18%) did not answer coherently to the question.

50% of participants suffered only a little for the changes in their free time. The 19% reported a considerable grief, while 25% felt only a little sorrow. One person (6%) did not answer the question.

Friends

50% of the participants did not spend time with their friends anymore while the other 50% kept spending time with them.

The subjects who did not spend time with their friends anymore reported these reasons:

- friends abandoned me (12%)
- I prefer spending time with people with aphasia (25%)

- it was my fault, I lived in isolation and as a consequence they left me alone (25%)
- because they felt discomfort for my problem of communication (12%)
- I just did not recognize people (12%)
- friends did not care about illness (12%)

The subjects who kept spending time with their friends stated that there were less occasions of meeting in 38% of cases. The reason of this change was “aphasia” for all the participants. The other 62% reported the same frequency of meeting.

44% of the subjects reported that they did not show a negative attitude towards friends, 26% felt embarrassed for the problems of communication and as a consequence often avoided to speak, 12% of subjects felt angry at themselves for their inadequacy, one person (6%) felt angry with his friends because they did not understand him, while one subject (6%) reported that friends were not sensitive and patients. One participant (6%) did not answer the question. 32% of the subjects lost important friendships, while 62% of participants kept their relationships. One person (6%) did not answer the question.

Eventually 44% of aphasics did not suffer at all for changes in their relation with friends, 19% felt a little sorrow and another 19% felt a considerable grief. Two people (12%) reported to have suffered a lot for this reason. One subject (6%) did not answer the question. With the passing of time only the two people who suffered a lot for changes in the relation of friendships

reported that they continue to suffer.

31% of aphasics found in their friendships a sufficient support. 19% of subjects considered their friends a great support, another 19% considered them a little support. 25% did not believe at all in the aid of friends. One person (6%) did not answer the question.

4.4 Broca aphasics compared to amnesic aphasics

In this section we will discuss briefly the answers that characterized the group of subjects with Broca aphasia, pointing out the differences with the group of subjects with amnesic aphasia, because the majority of the subjects suffered from these two types of aphasia. Among the 16 participants there were five people with Broca aphasia (two of them suffered from hemiplegia too) and seven with amnesic aphasia (four of them suffered from motor deficit: two from hemiplegia and the other two from hemiparesis).

Concerning the speech therapy two people out of five were satisfied with their results, while two informants were quite satisfied but retained they needed more time. One informant was not convinced of the speech therapy's effectiveness and showed a pessimistic attitude towards healing. Comparing the results with subjects with amnesic aphasia we have found that six out of seven PWA were satisfied with the speech therapy, while one informant retained he needed more time. For the amnesic aphasia group the speech therapy seemed to be more successful.

Concerning the need of attention three out of five people with Broca aphasia reported they needed a lot of attention while the other two did not. It is

important to outline that two of the people who needed attention suffered from hemiplegia. In the amnesic aphasia's group only two people out of seven stated to need a lot of attention, one of them suffered from hemiplegia and the other one from hemiparesis. Also in this case people with amnesic aphasia showed a more positive condition than the ones with Broca aphasia.

Only one out of five Broca aphasics was satisfied with his free time as he could yet go biking and running and did what he loved most. The other four Broca aphasics were not satisfied with their free time (two of them suffered from hemiplegia). They listed among their leisure activities only watching television and using the computer. On the contrary only two amnesic aphasics reported dissatisfaction with their spare time (one of them suffered from hemiplegia and the other one from hemiparesis), the other five subjects described a positive situation. Therefore from the interviews emerged that amnesic aphasics seemed to enjoy their free time, while Broca aphasics did not.

Two out of five Broca aphasics (one suffered from hemiplegia) reported they spent their time mostly using pc despite that the questionnaire did not include this as an option among the multiple answers (family, friends, self-help group). One informant answered that he divided his time between all the category of people cited in the question. Two other informants reported to spend their time with PWA following the self-help group and as the self-help group occurs only one time a week we can conclude that their social interactions were very poor. Amnesic aphasics described a better situation about social interaction as five of them spent their time mainly with family and the two other with friends.

Eventually three out of five Broca aphasics did not report improvements in

their communicative abilities after the period of rehabilitation, while five out of seven amnesic aphasics did. In conclusion we can affirm that from the interviews emerged that the amnesic aphasics reported more positive outcomes concerning the discussed thematics. These results may be due to the fact that Broca aphasia is more severe than amnesic aphasia and as a consequence communicative abilities are more impaired and can influence deeply the quality of life of PWA.

4.5 Qualitative content analysis of data

In this section we will extrapolate from the sixteen interviews some relevant thematics concerning the life of people with aphasia in relation to their deficit, to other people and to everyday life. The qualitative analysis starts from the experience of convalescence in hospital and it deals with the thematic touched by the interview, the ones we have previously seen in the general data analysis and other that emerged only through the qualitative analysis.

What has happened? The need of information and consideration

The relevant data about the time spent in the hospital by the subjects, described in some cases a situation in which the patient was not understood by doctors and the hospital employees. The negative experience can be more negative when the patient is able to understand what happened in some way but he can't express himself and he feels like no one considers him anymore.

One subject described his feelings with these words:

"Che non mi lasciassero tempo a spiegarmi come era stato quell'incidente, un po' messo là in un cantun"

In some cases aphasics explained that it was difficult to manage a conversation with them and they justified doctors' behaviour.

"Perchè io la bocca non ho eeee io eh parlavo bene e dopo no no niente da fare"

Other subjects found it very hard to understand what happened to them. They felt that even doctors did not understand their problems and the complexity of the disorder. A patient described a situation in which a doctor asked him to write realizing only later he could not do it because of aphasia. In this specific case the lack of knowledge may be due to the fact that the subject's stroke occurred in 1992, twenty one years ago, when aphasia was a quite unknown disorder and doctors did not know how to treat it.

"Non savea neanche loro quello che o vuo mi. Perchè dopo sette otto giorni mi fa: -ti non ti parli- ma se me gaveva fatto portare na penna da casa e non savea scrivere"

The fact that their disorder was quite unknown was something that worried and surprised people with aphasia.

"Tanti eh mmmh eeh studiati eeh eeh anche anche hanno fatto eh mmh accadamia non sanno non sa sanno sa no niente"

"E e quasi tutti i miei amici non sanno eh non sanno eh capire come che come come è successo un ictus come"

Some patients expressed their need of more information about aphasia and the process of rehabilitation. A number of subjects who were able to understand what happened to them, because their aphasia was not severe, suffered for the lack of time and patience shown by the hospital employees.

"Spiegato...Mica tanto..Si afasia mancanza di parola e basta"

"-Ti devi prendere una logopedista-, -Ma chi è?- non me l'hanno spiegato"

Other negative experiences in the hospital were related to the prognosis of doctors who did not leave any possibility of returning to normal life, despite that these statements were done too early to be taken into consideration. These statements influenced deeply the patients' attitudes to rehabilitation, they were overwhelmed by pessimistic feelings.

"Il dottore...mi dava per morto"

"I medici hanno detto che resto così, non c'è niente da fare di me, sgarbati"

In the majority of cases it was impossible for subjects with aphasia to understand their condition, although doctors and hospital employees were competent and tried to explain the situation adequately. The impossibility to understand in this case was due to the severity of aphasia that compromised the comprehension.

"Una sensazione strana, che i medici spiegavano e io non capivo, si capivo e non capivo eee...i medici mi spiegavano la sensazione a me io li guardavo e dicevo tra me e me -che cos'è questa roba, che mi stavo ben qua-"

"Non avevo capito, però i medici lo sapevano I medici"

Speech therapy: different attitudes and feelings

Concerning rehabilitation, the patients' attitude towards the speech therapy were various and influenced by the severity of aphasia. One patient with a severe deficit considered the logotherapy quite useless. He decided to quit rehabilitation, because there were not improvements and he felt tired and discouraged. This reaction was probably consequent to the doctor's pessimistic prognosis.

"Riabilitazione...poco no basta me son smonato"

Other people with aphasia considered the period of rehabilitation too long because with the passing of time there were not the expected improvements and as a consequence they felt frustrated for the neglected expectations.

"Forse troppo forse perché non lo so mi aspettavo qualcosa di più nel tempo, però insomma..."

One subject highlighted the importance of being followed by the right speech therapist. The interviews revealed the necessity of a peaceful atmosphere in which aphasics are free to take their time, speak slowly, far from the everyday confusion and speed.

"Era violenta questa logopedista e non capivo niente, non capivo niente"

Someone found it very hard to follow the therapy because of physical problems (hemiplegia, hemiparesis) and others because they needed to work, to return as soon as possible to an ordinary life. In some cases this necessity was based on economic factors, while in others it was only the strong desire for normality.

"Io non parlavo non parlavo, sono andata al Lido dove c'era una logopedista,

"ma non ce la facevo a camminare non ce la facevo..."

"riabilitazione durata anca 3 anni di più era giusto avevo il lavoro mi"

"si però sono costretto di andare per lavoro, per un altro lavoro, perché c'è mmh mmh c'è la mia moglie ha lavorato mezza giornata e io come faccio a a...ho eh una pensione minima per accompagnamento però però è troppo povero eeeh"

One subject had an impatient attitude towards the course of therapy. He thought that there was a limited time in which he could recover his abilities to speak, write, understand and after that period every effort was useless. The attitude of this subject was influenced by a doctor who explained to him that aphasia treatments have to be supplied within a critical time and after that fixed time speech therapy is quite useless.

"- quello che si impara subito bene, più si sposta nel tempo più...- quella è una grande verità"

One patient observed the importance of finding an autonomous dimension in which he could rely on his resources without any therapists. He criticized an approach of rehabilitation in which the patient become too therapist-dependent. He was 34 years old when the stroke and aphasia occurred and his priority was to become again independent as soon as possible.

"essere la persona che un po' alla volta un po' alla volta si mette nei termini giusti a fare delle belle cose, innanzitutto siete voi che aiutate, però il distacco, lasciatemi perdere tra parentesi, adesso faccio io da solo che con il tuo aiuto deve essere una circostanza"

To the contrary several subjects felt like the therapy ended suddenly and

they had to move alone in the world, they in some way feel abandoned, without adequate instruments to face interactions with other people. In some cases, even when families supported their relatives helping them in the practice of speaking and writing, they expressed the need of a professional figure.

"Bisogna dì eh mi mi secondo mi che mi voeva de più"

"Avrei preferito fare esercizi con la terapista"

Feelings like anger and frustration are common during the therapy especially for patients with a severe deficit in comprehension. One subject with Wernicke aphasia stated he did not realize for at least one year what happened to him and for this reason he was always angry as he did not comprehend the necessity of rehabilitation.

"Io non lo sapevo, mi arrabbiavo e basta, cominciavo a scrivere, mettere il nome..."

The self-help group

The self-help group is an occasion of meeting for patients with aphasia, the therapist and volunteers of the Association A.I.T.A (Associazione Italiana Afasici). During the internship we had the opportunity to follow these meetings in the Venetian district of rehabilitation. The self-help group consists in the collaboration between operators and aphasics in doing language activities, speaking about themselves, their problems and opinions and secondly sharing moments of life and hobbies together. Some of the patients interviewed expressed their opinions about this service.

Three subjects considered the self-help group very useful but they could not continue to follow it because of physical problems:

"Non ce la facevo più a camminare, facevo fatica, ho trovato tante belle persone, brave persone"

Other subjects felt contradictory sensations: on the one hand the self-help group was an occasion to meet people with the same disorder and as a consequence to share feelings and experiences in an empathic environment. On the other hand the pressure for a “normal” life and the rejection of situations in which the condition of disability is emphasized represented a strong limit. One informant explained clearly this condition. He was 34 years old when the stroke occurred and the self-help group's participants were mainly elderly people and as a consequence he felt out of place.

"bella perché eravamo insieme però non potevamo starci insieme per tutta la vita, però bella, per un momento, e dopo un po' il lavoro un po'... un po' tante cose... tipo diciamo già l'A.I.T.A. è in una situazione un po' nell'ospedale..."

The self-help group was an important benchmark for some subjects with severe aphasia, representing a world of interactions and stimuli they could not find in everyday life, because they lived alone or with a nurse. They felt free to make mistakes and cooperated to find a way to express themselves. For one subject the concept of solidarity and sharing aphasia were very important values in order to face difficulties due to his disorder.

"Si perchè stare fermi a casa non vuol dire niente"

"Lì si parla, si parla"

"noi che abbiamo questo ictus nostro dobbiamo fare le cose assieme, cercare

con calma di sviluppare le cose, perché sennò non esiste, se si arrabbia di qualcosa se va via e il cervello non parte, invece quello con calma, se si sbaglia qualcosa, si dice 'hai sbagliato troppo', 'hai ragione' però andiamo, riprendiamo"

The self-help group in some way can constitute a barrier for sociality, indeed some subjects isolated themselves in this protected environment avoiding other occasions of interactions. Two participants for example reported to spend their time only with PWA of the self-help group, this may be due to the fact that they lived alone and were affected by severe aphasia.

In some circumstances people with aphasia can enjoy the self-help group as an occasion to be helpful for other people, this was especially the case of a subject with mild aphasia.

"certe volte mi tiro la parola io per far ridere non so roba, sennò ogni tanto musetti e basta..."

Considering the data collected there are two ways of looking at the self-help group for the subjects interviewed:

- it can be an experience limited in time, a fundamental step preceding the return of the subject to the "normal" life.
- it constitutes a world of interactions, friendships, stimuli and with the passing of time it is considered as a pleasant hobby for the subjects who decide to continue to follow it for the rest of their life, involving also their families in the activities of the association.

The family

Concerning the relationship with family the situations of the subjects interviewed are very different depending especially on the severity of the deficit. We will discuss this thematic also in another section in relation to the data collected from the questionnaire for caregivers. The people with mild aphasia reported, in almost all cases, a positive situation with their relatives, because they were not dependent on them and continued to lead an autonomous life.

"no assolutamente vivo per conto mio vado a trovarli con la macchina di qua e di là..."

Sometimes people with aphasia return too early to a normal life and they are considered autonomous by their families when they are not yet. The rejection of their limits drives aphasic subjects to carry out a lot of activities even if it is too stressful for them.

"non sono autonomo però passo dalla parte da autonomo anche se non sono autonomo"

"perché servo a casa sennò i fioi xe morti porto a scuola mattina e dopo preparo il mangiar...Un afasico forse xe meglio solo perché sempre tutti ha bisogno di mi anca solo è meglio però non posso"

A number of subjects with severe aphasia and motor deficits felt like a burden to their families. They relied completely on relatives and in some cases were anguished by questions about their future. This was especially the case of a subject with elderly parents as caregivers, his relationship ended in

a break up because his wife considered his new condition unbearable. Another informant experienced the same situation with his partner, but he did not want to talk about it.

"per esempio come faccio a lavarmi fare la doccia con una mano, come faccio a farmi da mangiare con, metà riesco e metà no.."

"esempio come farò a vivere da solo punto di domanda?"

"...ricapitolando è andata via e ho pensato perché o costretta a fare la vita di di dili costretta a fare una vita tante una vita tante decisioni tante sofferenze tante"

Subjects with aphasia may confine themselves at home, avoiding any kind of interactions with the external world. This is a negative aspect not only for them but also for the significant others who become the only benchmark in their life and as a consequence they experience a situation of isolation too.

"Se non ci fossero loro sarei perso"

Furthermore from the interviews emerged that the role of caregiver was primarily covered by the spouses of PWA, while sons often could not take care of their parents. Sons of widowed PWA frequently decide to hire a nurse in order to take care of them. This solution may be cause of suffering and loneliness.

"I fioi pensa a robe sue"

"il problema che insomma no ma dico non li vedo proprio tanto perché sono fuori però sono sempre in contatto..."

"Io solo badante, solo badante"

Friends

As we have previously seen in chapter 3 the psychosocial consequences of aphasia result especially in a reduction of the social life participation of PWA. Several participants described situations in which their friends had not enough time or patience to respect their need of time to express concepts and ideas, showing lack of sensitivity.

"Gli altri non interessa niente, ti xe come solo gli altri non interessa niente, no gente in fretta...magari ti cominci un discorso no ha tempo aspetar"

"si si magari siamo in 3 mi no posso far le frasi lunghe lunghe come prima...ti fa poche parole e dopo.."

"sente 'pe pe pe pe', gli amici hanno bisogno di...non c'è sensibilità, gli amici no"

A considerable number of the PWA interviewed needed to change friendships, to spend time with someone able to understand their condition. They realized only after the stroke that their relationship were not as solid as they thought before the tragic event. In several cases friends were frightened by aphasia and its consequences and felt discomfort in the interactions with PWA.

"non interessa niente, na proforma gli amici no xe amici con il cuore"

"come prima no no no, dopo ti cambi gente adesso so coi corridori e ti fai amicizie fora.."

"con gli amici un taglio"

"quando ho avuto il malanno non mi dicevano niente, si sono allontanati e chiaramente allontanandosi loro io che dovevo cambiarmi ho cambiato...ho degli amici amici, ho mia moglie..."

Several informants affirmed that they decided to keep in contact with friends only through phone calls because they felt embarrassed for their communication impairment and in some cases they suffered from inferiority complex due to the break of their professional career. Other PWA who were limited by physical disability did not consider the possibility of being helped and sustained by friends, because they were too busy with their life.

"Mah amici io come ripeto ne ho avuti pochi quei veri amici ti telefonano anche se ormai non mi sento"

"Ho rimasto amicizia a per telefono e però ho mmh penso pe i lavoro e e alcuni amici hanno fatto Mmh eh in proprio geometri architetti ingegneri, io ho pensato lascerò stare ci sentiamo per telefono e poi basta"

"Amici un sostegno? No assolutamente, come sono ridotto..."

One informant pointed out that it was particularly difficult to reestablish contacts with his colleagues because they were only interested about work and business and showed a particular lack of sensitivity toward his problems and his new condition. In this case the informant suffered particularly for the lack of support from his colleagues, because he considered them friends and his life was based on the professional dimension as his work was a passion for him and something to be proud of.

"Per lavoro conoscevo tutti i direttori di banca, ma sono amici quelli che tu sei per loro un numero, non per te. Quando non sei più al livello, tu sei niente. Ho

visto veramente la differenza tra gli amici amici e quelli.... Sul lavoro dato un colpo taglio questi via e questi invece, ho dato un taglio netto”

One informant preferred to spend time with other PWA or other people who were gravely ill because he believed it was impossible for “normal” people to understand his situation and to manage a meaningful conversation with him, while people who have faced diseases were more sensitive and closer to him. It is a phenomenon also connected to a change of value in the life of PWA. Some PWA are no longer interested in money, wealth or other material things, but develop other interests as volunteering.

“Perché io ho bisogno di parlare con la gente con le persone di come me come o come afasici o come in ospedale, come SLA...amici diversi che hanno avuto un ma-ma lati. Il cuore è tanto forte per e i amici di quelli che che di una volta come si dice..manca sensibilità”

One informant reported that the only way to interact with friends was to be mediated by his wife. The dependence on a caregiver with the role of “interpreter” in interactions may be experienced as a strong limitation. In this case the subject considered the mediation of his wife fundamental as he was not able to express himself properly.

“quando vede i suoi amici come si sente? Angela via angela (angela la aiuta con la comunicazione?) si”

The interviews revealed that elderly PWA did not feel the same need of maintaining relationships with friends: in some cases they preferred staying at home alone or spend their time with family.

“ho avuto tanti amici però purtroppo sono anziani e sono anche morti, è che

adesso ho bisogno anche di star tranquilla”

“salutare, esco magari vedo ste persone che adesso riconoscono anche loro si fermano parlano con me, niente di più”

On the contrary some participants described a positive situation with their friends, especially childhood friends who were considered in several cases an important point of reference. One informant stated he considered his friends as a second family.

“Gli amici sono amici, gli amici come la famiglia sono amici”

Adapting to a new life: different attitudes

Several subjects explained their need of rebuilding their identity and adapting to their new condition as a grievous process which involved also the family. Everything is changed: any activities of the everyday life requires the adaptation to a new rhythm and the change affect also the significant others.

“perché ero tutto diverso, mi è molto difficile pensare..perché io sono, io siamo sono, sempre di corsa, invece al rallentatore..per esempio devo andare a tagliare i capelli, deve essere una macchina, mia moglie mi possa accompagnare”

One patient reported he just acted as he was not aphasic. He started to be passive in conversations, relations, avoiding any kind of direct interactions. This is an example of a negative reaction to aphasia: the withdrawal from society. This type of reaction in this case may be related to the fact that the subject lived with his family despite his advanced age (48 years) and he did not have a satisfying social life.

"Pur essendo attivo ero molto passivo, con i miei parlavo come... non fosse mai successo niente"

Some PWA showed an optimistic attitude: they recognized their limits and they succeeded in adapting themselves to a new life, trying to enjoy life to the fullest. Of course this positive attitude was more common when there was a stimulating social surrounding and when there were not severe motor deficits and as a consequence PWA could look after their own personal interests, activities and hobbies.

"Mi so samurai, mi no no come prima"

"Sto ictus per me è una parte che xe ferma, è solo fatica di dire la parola giusta"

"Adesso e xe passati 8 anni e dopo ti adatti sennò ti xe morto. Aie tanti afasici xe no morti, ci vuole stimoli sennò tanti non ha il carattere duro. Perché come prima basta, è un'altra vita"

The constant comparison with other people and with the life before stroke may lead to a sensation of frustration, due to high expectations resulting in disappointment, as we can see through the following informant's words. He used a scale number to express his impossibility to achieve the prefixed targets.

"Mi sentivo più dipendente per certe cose, ho sofferto sì, tra parentesi se tutti gli altri sono a 10 io sono a 9 perché vorrei essere a 10, ma sono a 9, un po' l'afasia, un po' la voglia di acquisire un po' la... però non sono mai a 10, devo arrivarcì"

Job

Following the onset of aphasia and the correlated disorders three participants had to quit their job, while three others had to leave it, sometimes experiencing grievous situations. PWA who went back to work (three people) had to face several problems, realizing the start of a new professional life.

One informant spoke about the fear he experienced when he returned to work: he could not answer the phone without feeling insecure, he did not know how to say things and was overwhelmed by frustration and the sensation of not being up to the tasks he had to carry out. After a period of time when he was able to resume his normal activities he realized he worked even better than before the stroke, maybe because the pressure of returning to normality had a positive impact on him.

"All'inizio no perché quando suonava il telefono non volevo nemmeno rispondere, però dopo insomma cioè...però dopo aver ripreso aver continuato così e veder che ho imparato nuovi programmi che mi sono stati sottoposti insomma, tutto"

"...riuscito a continuare il lavoro di prima forse meglio di prima"

Working is a primary need for some informants. After the stroke the biggest desire for some aphasics is restarting to work as soon as possible and this pressure sometimes is a source of frustration or on the contrary may become one of their strengths to face their new condition with more determination as we can see from the words of this informant:

"Ma no una sofferenza no, solo una voglia di poter, come si può dire, la voglia di

poter riprendere come prima”

For some PWA leaving a job may be an occasion to have less responsibilities in a difficult moment of their life, for others changing profession means quit a job they love and this may be cause of deep sorrow.

From the interviews emerged that leaving a job is always a grievous moment, independently from the kind of activity (from a musician to a bricklayer). Sometimes the professional activity is strictly connected to the PWAs' passions and interests and as a consequence the loss may be more unsustainable. The perception of not being socially useful often resulted in feelings of depression.

“No solo il lavoro che faccio non mi piace diciamo, però per...andando avanti ci si abitua a fare anche. Fare il muratore mi piaceva, non posso più farlo”

“È stata una roba orrenda, qui nel cervello io ero una maestra di musica, facevo concerti, avevo una ventina anche di più anche 30 allievi nella sala qui, non ricordo più assolu della musica assolu è scappa.., la musica è andata via ecco”

“Il mio cruccio è stato proprio, è stato imposto, questo mi resta qui. Ero al telefono con mia moglie dopo dieci giorni 'ma come va?' 'ho capito, vada...' questo mi ha dato dolore, al lavoro dicono 'nessuno è ind..., nessuno è impossibile no, nessuno è indispensabile”

One informant reported that he was not able to interact with their peers and as a consequence he experienced isolation and was reluctant to going to work.

“Per il posto di lavoro eh neanca un ciao non mi esprimo ben con gli altri”

On the contrary one informant said that the support of colleagues was

fundamental because they helped him to carry out various activities from answering the phone and writing emails to more demanding tasks.

"Primo momento se stà dificil, dopo col colleghe che avea me davan na man eeeh parlavo al telefono spesso eeeeeh"

PWA who did not have to quit their job felt more self-confident and considered their life more meaningful, because staying home made them feel they had no purpose in their life. One informant felt shame for his limits, but never the less he experienced also self-esteem improvements and happiness.

"Come autostima perché essere a casa e non sapere come...essendo al lavoro mi veniva tutto più facile"

"Provare autostima ero felice si, ho provato anche vergogna per dei limiti che ho, il discorso del 9, eh perché tutte queste cose che riguardano l'autostima mi dà il mezzo in meno che non ci arrivo mai, però..."

"no vergogna no eeeh, andavo a lavorare, normale, sono stato felice"

Free time

Concerning the free time several male participants reported they were no longer able to do some activities like sports, because of physical problems. Watching television and surfing the net became for some PWA the only amusement. Two informants listed among the activities they cannot do anymore "reading a book", as it is an activity that requires a great amount of concentration.

"Attività non posso farle, sono innamorato del calcio, seguo il Milan, speriamo"

"Televisione eeh televisione qua e programmi...basta"

"passo il tempo con il computer"

"me sero che faseva l'allenatore de una squadra di pulcini e o dovuo smettere"

"facevo delle cose anche corsa così e dopo con questo con quello del braccio non ho più.. allora vado fuori alla mattina, nel tempo che vado a camminare...a Mazzorbo"

"A me piacerebbe leggere tanto e non ci riesco non ci riesco perchè prendo i libri li guardo e mi tornano in mente un po' ma non...non è che posso leggere tanto ecco, sfoglio i libri così tanto per ricordare ma non..."

One informant said the social network Facebook was a way for him to connect with people and to share his experiences with other PWA and people affected by other diseases. He considered people he has known on the social network as friends.

"...come si dice, allora. Sono iscritto sul Facebook perciò ho 120 amici diversi che hanno avuto un ma malati"

One informant said that his idea of free time was completely changed after the stroke in a positive way, because he tried not to waste his time anymore and to enjoy what he could do despite the illness. This type of reaction may be due to the new perspective on time's consideration after illness: time was fleeting and he wanted to enjoy it at his best.

"Sono cambiato totalmente io, è cambiata la mia idea nel passarlo, ascoltato determinato tipo di musica e ne ascolto ben altra, vado a mostre adesso che non andavo, è cambiato, è sempre lo stesso tempo ho dato solo la possibilità di cambiarlo, cambiarlo in bene. Nel male riusciamo a farlo cambiare in bene. Andavo al cinema quasi sempre, da quella volta non sono più andato al cinema,

perché è stupido andare al cinema quando hai due ore di tempo libero”

Another informant said he was busier than before the stroke occurred, because he started to develop new interests mainly based on disability.

“Allora adesso pieno di impegni di prima, più di prima. È interessante, sono parte di tre società. Una a Venezia, Aita. Un'altra per la macchina, Società di si chiama Anglat, guida disabili e l'altra privato faccio parte di eeee come viaggiare come hanno fatto hanno fatto raccontato due o tre volte un libro e siamo andati a visitare dei posti dei paesi di viaggiare”

Two informants, both women, talked of their spare time in terms of housework. They seemed satisfied with their free time because they could keep their house clean and managing their home duties. This idea of free time may be connected to their sex, the advanced age and to the fact that they lived alone.

“sono contenta si perchè riesco a fare tante cose, guardo se c'è qualcosa che non va, delle volte dico anche alle signore bisogna far questo bisogna far quello poi mi faccio la lavastoviglie tanto si fa presto poi mi faccio anche la la lavatrice mi metto eeeh poi cerco di mettere in ordine secondo piacere, così mi passo il tempo facendo così lavoretti”

“In bagno seduta ho messo a posto asciugamani che c'erano insomma ho fatto ho fatto, erano nuovi ma avevo bisogno di metterli dentro, attaccarli. Io ho sempre cose da fare”

One informant reported that despite his advanced age and illness he practiced sports even more than before the stroke. This may be also a reaction to the condition of disability, in order to prove he could do anything exactly as before.

"No va beh prima avevo 50 anni adesso 60 anni, xe no vecio perché corro anche ben però 60 anni xe pochi fa robe mie il massimo gli sport sempre il massimo"

4.6 Questionnaire for caregivers: material and methodology

With regard to the questionnaire proposed to the subjects' caregiver, the methodology was different. The questionnaire is constituted only by multiple-choice questions and they completed it autonomously. The questionnaire was anonymous; the relatives had only to indicate the name of their family member with aphasia, their age, sex and profession. This second questionnaire follows some of the questions proposed for subjects with aphasia in order to consider the effects of the disease from the point of view of the caregiver. One questionnaire was not filled in because one informant did not want to involve his relatives. We will discuss the data that emerged from this questionnaire in the next section.

4.7 Different perspectives between PWA and their caregivers

Discussing the question about the perception of being respected by the caregiver in three cases emerged a discordance between the caregivers and PWA's statements. Three subjects with aphasia reported they were always respected by their relatives while the caregivers answered they did not respect them mainly for lack of patience. In only one case emerged the opposite situation: a subject felt not to be respected for a lack of

consideration and patience, while the family member retained he was always respectful. In the first case these results may be influenced by reasons of pride, as it could be difficult to admit to be not respected by your family and in the second case from the interview emerged a general self-pitying attitude.

Four out of sixteen caregivers reported they retained their relatives had never felt to be a burden to them, while PWA perceived to be a burden. Among these informants there was one woman who was hemiplegic and lived with a nurse and another one who lived alone, they were both widowed and this fact confirms that it is uncommon for sons and daughters to take care of their parents directly. In this case the discordance may be explained by the fact that the two PWA had only their sons as a point of reference and did not want to interfere with their lives (they stated their relatives were always tired and impatient). Furthermore the two subjects in question reported they did not consider their family as a support, this consideration may be associated with their feeling of loneliness and their isolation.

The other two lived with their wife, one reported he felt like a burden only for a period and then he started to be autonomous, the other subject suffered from hemiplegia and reported that his relative was always tired.

In three cases caregivers retained that the PWA perceived to be a burden for them, while they answered in a different way. Two of the PWA in question suffered from hemiplegia and this may be the reason why caregivers answered in that way. The third subject suffered from Wernicke aphasia, he did not realize completely his condition and as a consequence it was impossible for him to perceive to be a load.

The caregivers' expectations resulted to be higher than the aphasics' ones

with regard to the rehabilitation and to the general quality of life of their relatives. These unattended expectations about the speech therapy may be the consequence of disinformation on aphasia as from the questionnaire emerged a lack of knowledge and communication with doctors. Caregivers have to be aware that improvements in communication may appear after a long time or may not.

Three caregivers reported that in their opinion the period of rehabilitation would have been longer while the PWA sustained it lasted for the right time. These results may be due to the fact that the vocabulary and communication strategies of these subjects were very poor and as a consequence caregivers were not satisfied with the speech therapy's outcomes. On the contrary subjects with aphasia were convinced of their positions: a patient stated that there was a critical time in which the speech therapy could be useful and after that period it was not effective, another patient decided to quit speech therapy because he did not see improvements and the last one just stated that it was not necessary to prolong the period of rehabilitation. The three subjects had in common a sense of frustration and the realization that there were no more improvements in communication abilities.

Eventually four caregivers reported that in their opinion the PWA interviewed preferred to spend their time with family, while the subjects answered differently. In two cases they answered they preferred to spend time with PWA attending the self-help group, another subject reported he chose to spend time surfing the net, while the other PWA spent time preferably with colleagues and friends. Some of the caregivers interviewed tended to consider themselves as the unique point of reference for their

relatives, while PWA tried to find an autonomous dimension. Some PWA felt their relatives did not totally comprehend their situation and favored other types of interactions.

5. Discussion

The total or partial loss of language ability and consequently a significant part of the ability to communicate was a devastating loss to the informants, which affected all aspects of their life situations. The inability to speak caused the informants deep frustration, no longer being able to express their thoughts, opinions, knowledge and personality as they did before the stroke. As reported by Kitzmüller (2012) the dimensions mainly affected by aphasia were: communication, relationships, identity.

The first theme that emerged from the interviews was the need of more information on aphasia. The demand for information concerned not only PWA but also their caregivers, they expressed the need of improvements in knowledge and skills regarding aphasia by health care workers.

Informants in several cases found very difficult to immediately understand what happened to them and the possible disorder's consequences. According to Parr (1998) PWA need to continuously receive information, in the short-run, medium-run and long-run. At the same time health care providers should be careful with premature prognosis which may have damaging consequence on PWA's course of rehabilitation as reported by Anderson and Marlett (2004). From the interviews emerged that specialists' opinions influenced deeply PWA's attitude towards healing. Moreover from the

qualitative content analysis resulted that almost all the informants were satisfied with the participation to the self-help group, but in some cases this activity was not proposed or PWA could not reach the structure because of motor deficits. The National Health Service should provide more services to aphasics and their family and the healthcare structures have to be distributed homogeneously throughout the territory. Specialists should individuate the more appropriate approach to rehabilitation for aphasic patients and suggest any alternative opportunity and aid available to them. In addition PWA and caregivers should be aware of the improvements achievable through speech therapy without refuting themselves in false expectations that may be damaging. Evans et al. (1994) reported that family dysfunction often derives from the gap between what the ill person can still do and what is expected of the person by his family.

A second thematic arose from the study: informants sought to regain their former role as active participants in society and to reconstruct their identity. Bloom (2012) stated that psychological support may be needed to help people with aphasia cope with the strong feelings of loss, frustration and fear. From the interviews emerged that even after several years since the onset of aphasia PWA continued to make comparisons with their life before stroke and show "yearning for their previous language ability" (Blom, 2012). The rebuilding of identity and bridging the gap between the past and the present life are passages that require the intervention of a specialist and for this reason a person with aphasia should take into consideration the support of a psychologist. According to Anderson and Marlett (2004) health care workers' communication should be improved in order to sustain stroke survivors and their families' renegotiations of identity and to help them rebuilding their life

narratives to include the impact of aphasia. For some informants the longing for "normality" had a paralysing effect in the sense that they could not accept the present situation. For others this longing in combination with an urgent need to express themselves seemed to create innovativeness and a strong fighting spirit, which helped them deal with their communication difficulties. Psychologists could represent a guide also in cases where PWA limited their interactions to ill people, stating the fact that other people could not comprehend their situations. The interviewed in some cases identified themselves with aphasia, having lost their identity and their social role after the stroke. Paterson et al. (1999) in their study guided the participants to the process of separation of the self from illness. Participants went beyond body's limitations focusing on future and thus viewing the projection of themselves and their possible future life. The study succeeded in motivating participants and highlighted the importance of preserving hope in order to avoid feelings of frustration and anger.

A positive outcome was the fact that despite of aphasia and in some cases motor deficits nobody lived in a nursing home, although there were cases of PWA with motor deficits who had to live with elderly parents. The cases in question sometimes were characterized by economic discomfort that could be solved with the provision of specific subventions, especially to avoid situations in which a PWA is forced to quit speech therapy in order to come back to work. Furthermore support from specialists should be recommended also to caregivers, especially when they are considered by the relative with aphasia the only benchmark in their life and as a consequence they feel the pressure of responsibility, no longer being able to lead a "normal" social life. Some participants, especially the ones who lived alone, experienced situation

of isolation consequent to the interruption of interactions with friends and colleagues and to the limited contact with their relatives. Parr's results (2007) show that in some cases social exclusion is experienced as the most grievous effect of aphasia and this problem is determined mainly by the behaviour of relatives and caregivers, but also by lack of voluntary services, institutions and communities. Health care workers should be a support against aphasics' isolation teaching to family members and friends how to communicate with PWA and thus helping them to maintain supportive relationships. Some informants reported marginalization not only in relationships but also in the professional domain. Parr (2007) stated that PWA are exposed to social exclusion in various situations and as a consequence they experience negative effects on identity and personhood.

The study pointed out that health care workers should provide more information about aphasia to PWA and their relatives in order to prepare them to face aphasia's psychosocial impact. Moreover caregivers have to be involved in the process of rehabilitation to be aware of the communicative abilities of their relatives and to know how to find proper strategies to communicate with PWA. Eventually both aphasics and their caregivers should take into consideration a psychological support.

This study did not reach statistical significance, because of the sample's small size and heterogeneity. For this reason it was not possible to make generalizations, but only to analyze the collected data with reference to the literature. Moreover the semi-structured interview should be rebuilt in order to be a more adequate tool of investigation.

Conclusions and final remarks

This thesis describes the experiences of sixteen people with aphasia recorded in the chronic stage, focusing on various aspects of their everyday life in order to individuate the disorder's effects and to analyze their social participation and quality of life. We found that communication impairments influenced all the life situation of aphasics resulting in reduction of interactions and social life participation.

From the discussion on the data emerged that PWA may need a constant support from specialists and psychologists to face the psychosocial impact of the disorder and to regain their active role in society as suggested by Bloom (2012). The "loss of identity" was the main thematic reported by this study, as almost all the informants experienced a self transformation, which affected deeply their psychological balance, creating a gap between the life before and after stroke. As suggested by Paterson et al. (1999) people with aphasia have to separate the self from the illness and this process requires the intervention of a specialist.

A second thematic was represented by aphasics and caregivers' need of information. As reported by Parr (1998) health care workers should be prepared to represent a point of reference to aphasics and their caregivers in providing information about possible therapies and their effectiveness. Moreover they have to encourage supportive relationship and interactions, teaching to aphasics' friends and relatives how to communicate with them in order to avoid situation of isolation. Eventually we found that caregivers experienced feelings of frustration due to unattended expectations about the

speech therapy and the condition of life of their relatives. We suggested that caregivers have to be involved in the process of rehabilitation and may need also a psychological support to be able to sustain their relatives and at the same time to preserve themselves from a life of deprivations and consequent feelings of depression and frustration.

The sample size was too small and heterogenous to allow generalizations and this work did not reach statistical significance. Moreover the interview and the questionnaire have to be reshaped to investigate in a better way the psychosocial impact of aphasia, taking into consideration more aspects connected to the quality of life and highlighting other possible divergences between aphasics and their caregivers. However we retained it was important to conduct this kind of study because there is little literature in Italy about the psychosocial impact of aphasia as the majority of studies concerns aphasia's linguistic deficits.

Appendix

A. Semi-structured interview to PWA

La qualità della vita di una persona afasica

Buongiorno, la ringrazio molto per la sua collaborazione. Le farò alcune domande riguardo la sua vita da quando è diventato afasico. Le chiedo di rispondere in modo accurato e sincero. Le informazioni che mi fornirà saranno usate per una piccola indagine sulla qualità della vita di una persona afasica, le sue emozioni e il suo inserimento sociale. Tutti i dati personali saranno tutelati dalla privacy, resteranno quindi strettamente confidenziali.

Età

Scolarità

Data inizio afasia

Tipo di afasia

Periodo della riabilitazione

Tempo trascorso dalla fine della riabilitazione

Gravità di deficit di comunicazione e di conoscenza della malattia

Deficit motorio (lieve o grave)

1. Riesce a ricordare l'evento traumatico?

Qual è stata la sensazione più forte in quel momento?

- paura
- confusione
- angoscia

2. I medici le hanno spiegato chiaramente la situazione?

Quindi aveva capito cosa le era successo?

Come si è sentito in ospedale?

- aiutato
- rispettato
- trascurato

Se non si è trovato bene in ospedale qual è il motivo?

- non mi consideravano, parlavano solo con i miei famigliari
- non mi lasciavano il tempo per capire e parlare
- si comportavano come se avessi dei problemi mentali

3. La riabilitazione è stata utile?

- no
- poco
- abbastanza

- molto

Il suo atteggiamento nei confronti della guarigione era:

- ottimista
- pessimista
- ero impaziente, volevo vedere subito dei miglioramenti

La riabilitazione secondo lei è durata:

- il tempo necessario
- troppo poco
- troppo a lungo

Nel complesso è soddisfatto della riabilitazione?

- no
- poco
- abbastanza
- molto

A casa i suoi famigliari l'hanno aiutato a fare esercizi per migliorare la sua condizione?

(Se sì) è stato utile?

Quando faceva esercizi a casa era:

- collaborativo
- sfiduciato
- impaziente
- ottimista
- mi stancavo subito
- preferivo fare gli esercizi con la terapista

(Se no) perché secondo lei i suoi famigliari non l'hanno aiutata?

- non avevano tempo
- per mancanza di pazienza
- pensavano che gli esercizi non fossero utili
- non si sentivano capaci di farlo

Ci sono stati miglioramenti anche dopo la riabilitazione?

(Se sì) se n'è accorto solo lei o anche famigliari e amici?

È migliorata la capacità di:

- parlare
- capire

- relazionarmi con gli altri

4. Ha seguito il gruppo di auto mutuo aiuto?

(Se sì) pensa che sia stata utile?

(Se non) ha seguito il gruppo qual è il motivo?

- desideravo parlare con persone che comunicano normalmente
- rifiuto della mia situazione, non volevo identificarmi con gli altri
- paura di vedere se gli altri migliorano o no
- tristezza per il tipo di ambiente
- sono soddisfatto delle mie relazioni sociali, non ne ho sentito il bisogno

5. Adesso a casa si sente bene?

Preferisce stare con:

- la famiglia
- gli amici
- il gruppo

Si è sempre sentito rispettato dai suoi familiari?

(Se no) in che modo non si è sentito rispettato?

- non mi danno il tempo necessario per parlare
- parlano di me come se non ci fossi
- mi trattano come un bambino
- non vengo coinvolto nelle decisioni

Si è mai sentito un peso per i suoi famigliari?

Se sì, si ricorda qualche occasione in particolare?

- no, è solo una mia impressione
- ho visto spesso i miei famigliari stanchi
- li ho sentiti lamentarsi della situazione, se sì di cosa in particolare?

Ha ancora bisogno di molte attenzioni?

(Se sì) come reagiscono i suoi famigliari a questi bisogni?

- sono sempre disponibili e pazienti
- a volte ci sono state reazioni aggressive e di rifiuto
- cercano di aiutarmi, ma qualche volta sono troppo invadenti

Quanto ha sofferto subito dopo il trauma per i cambiamenti nei rapporti con i famigliari? (da 1 a 5)

E ora quanto soffre per questi cambiamenti? (da 1 a 5)

Quanto considera i famigliari un sostegno? (da 1 a 5)

6. Quando ha avuto l'ictus lavorava?

Se la risposta è sì:

Ha continuato il lavoro di prima?

Ha cambiato lavoro?

Ha smesso del tutto?

È stato difficile ricominciare a lavorare?

(Se sì) perché?

- è difficile il rapporto umano con i colleghi. Si lamentano di alcune mie mancanze. Quali?
- per i problemi di comunicazione
- per problemi fisici, mi stanco più facilmente
- per la difficoltà dei compiti

Tornare al lavoro le ha fatto provare:

- felicità
- autostima
- vergogna per certi miei limiti

- frustrazione
- paura

Se la risposta è no (ha abbandonato il lavoro) cosa ha provato?

- rabbia
- sollievo
- dolore
- invidia per gli altri
- noia

Attualmente riesce a praticare le attività che ama nel tempo libero?

È complessivamente soddisfatto del suo tempo libero?

(Se sì) quanto?

- poco
- abbastanza
- molto

Quanto ha sofferto per i cambiamenti nel lavoro? (da 1 a 5)

Quanto ha sofferto per i cambiamenti nella gestione del suo tempo libero? (da 1 a 5)

7. Ha continuato a frequentare gli amici di sempre?

(Se no) perché?

- per colpa mia, mi sono isolato
- perché loro si sentivano a disagio, non riuscivano a comunicare con me
- preferisco frequentare persone nuove, che non ricordano come ero prima
- preferisco frequentare persone afasiche, nella mia stessa situazione

Se frequenta gli amici di sempre sono diminuite le occasioni per incontrarsi?

(Se sì) pensa che sia a causa della malattia?

Pensa di aver avuto delle reazioni negative con i suoi amici in certe occasioni?

(Se sì) che tipo di reazioni?

- rabbia, perché non mi capiscono
- invidia per le loro vite
- imbarazzo per le difficoltà di comunicazione

Ha perso rapporti a cui tiene?

Quando vede i suoi amici come si sente?

- in imbarazzo per le difficoltà di comunicazione

- felice
- mi arrabbio quando non riesco a partecipare a certe conversazioni
- mi sento diverso, soffro il confronto con loro

Quanto ha sofferto subito dopo il trauma per i cambiamenti nei rapporti di amicizia? (da 1 a 5)

E quanto soffre per questi cambiamenti ora? (da 1 a 5)

Quanto sente il sostegno dei suoi amici? (da 1 a 5)

B. Questionnaire for caregivers

Valutazione della qualità della vita di una persona afasica

Chiedo la sua gentile collaborazione per un'indagine che ha lo scopo di comprendere quali siano le sensazioni e i bisogni di una persona afasica, come riesce a reinserirsi nel tessuto sociale dopo l'evento traumatico e quali siano gli aspetti della vita che più incidono sulla sua sofferenza così come sul suo benessere.

Le chiedo di rispondere alle domande in modo accurato e sincero.

Le garantisco la riservatezza di tutti i dati che ci fornirà così come la sua privacy.

Non le chiedo di inserire il suo nome, ma solo il suo sesso, l'età e la professione

(nel caso fosse in pensione indichi la professione che svolgeva prima). Inoltre le chiedo di indicare il nome del suo familiare.

La ringrazio per la collaborazione.

Sesso: M F

Data di nascita:

Professione:

Nome e cognome del familiare:

1. Qual è stata la sua prima reazione all'evento traumatico? (metta una crocetta, può scegliere anche più di una risposta)

- paura
- confusione
- angoscia
- dolore
- rabbia

Quale pensa che sia stata la reazione del suo familiare? (anche più di una risposta)

- paura

- confusione
- angoscia
- smarrimento

I medici le sono sembrati chiari riguardo la situazione?

- no
- abbastanza
- molto

Il suo famigliare è stato assistito:

- male
- discretamente
- molto bene

2. Pensa che la riabilitazione sia stata utile?

- no
- poco
- abbastanza
- molto

Nei confronti dei metodi usati era:

- scettico

- fiducioso
- non sapevo valutare se fossero validi o meno

Pensa che il suo famigliare fosse soddisfatto della riabilitazione?

- no
- poco
- abbastanza
- molto

Pensa che sia durata:

- il tempo necessario
- troppo poco
- troppo a lungo

E lei è soddisfatto della riabilitazione?

- no
- poco
- abbastanza
- molto

Dopo la riabilitazione ha aiutato il suo famigliare a svolgere attività per recuperare la facoltà di parlare?

- sì

- no
- raramente

Se no perché?

- per mancanza di tempo
- per mancanza di pazienza
- ero scettico riguardo l'utilità degli esercizi
- non mi sentivo capace di farlo

Se l'ha aiutato a fare esercizi come ha trovato l'atteggiamento del suo familiare?
(anche più di una risposta)

- collaborativo
- sfiduciato
- impaziente
- ottimista
- si stancava subito

Ci sono stati miglioramenti anche dopo il periodo di riabilitazione?

- sì
- no

Se sì è migliorata la capacità di (anche più di una risposta):

- parlare
- capire
- relazionarsi con gli altri

3. Il suo famigliare ha seguito il gruppo di auto mutuo aiuto?

Se sì pensa che sia stato:

- inutile
- abbastanza utile
- molto utile

Se non ha seguito il gruppo quale pensa sia stato il motivo principale?

- desiderio del famigliare di parlare con persone che comunicano normalmente
- rifiuto della propria situazione, non volersi identificare con gli altri
- paura di vedere se gli altri migliorano o no
- tristezza per il tipo di ambiente
- è soddisfatto delle sue relazioni sociali, non ne ha sentito il bisogno

4. In questi anni (dal momento del trauma) ha trovato l'atteggiamento del suo famigliare:

- Combattivo
- Rassegnato
- Ottimista

- Pessimista

Pensa di aver sempre mostrato rispetto nei confronti del suo familiare?

- sì
- no

Se la risposta è no in che modo pensa di avergli mancato di rispetto?

- per mancanza di pazienza
- l'ho trattato come un bambino
- l'ho escluso da tutte le decisioni
- a volte ho parlato di lui come se non ci fosse

Il suo atteggiamento rispetto alla guarigione era:

- ottimista
- pessimista
- impaziente rispetto ai miglioramenti

Pensa che il suo familiare si sia sentito un peso?

- sì
- no

Se sì quale pensa sia il motivo?

- credo che mi abbia visto spesso stanco

- mi sono lamentato per questioni di mancanza di tempo per me
- è lui/lei che si è sempre sentito in colpa

Ritiene che il suo famigliare si senta meglio:

- con la sua famiglia
- con il gruppo
- con i suoi amici

È soddisfatto dell'attuale situazione del suo famigliare?

- no
- poco
- abbastanza
- molto

Pensa che il suo famigliare sia soddisfatto della vita che conduce?

- no
- poco
- abbastanza
- molto

Grazie per la collaborazione

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