

*Let's go now,
Hold me, don't lean on me
Wait for me, don't stop
The climb will become easy
There is no time that can come to an end*

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ACTING AS THERAPEUTIC SUPPORT IN
PARKINSON'S DISEASE.
A FIELD EXPERIMENT

PhD THESIS

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ABSTRACT

Key words: Parkinson's disease, non-motor symptoms, acting therapy, rehabilitation.

In the past, the clinical approach to Parkinson's disease focussed primarily on motor symptoms, whereas the current trend emphasises the importance of non-motor symptoms, thus moving towards a more complex type of assistance aimed at enhancing each patient's residual ability and, as far as possible, at rehabilitating their impaired daily activities. So, there is a growing amount of artistic activities that appear to positively influence the patients' emotional and relational sphere as well as their and their family's quality of life (QoL).

Over a period of 8 months, a group of patients with a moderate form of idiopathic Parkinson's disease, on stable L-dopa and L-dopa antagonists, together with a few family members, took part in a weekly theatre workshop culminating in a show given to the public. The patients were evaluated both before and at the end of the eight-month workshop using eight Assessment Scales indicating the state of progression of the disease (H&Y, UPDRS, PDQ8, PDSS, NMSS, FES, GFQ and MMSE). The results of these assessments were then compared to verify if the theatre workshop had had any influence and if so to what extent. The result analysis showed that modest improvements were associated with movement parameters, while parameters regarding memory, attention and concentration, quality of sleep and especially relational aspects were affected in a statistically significant manner, allowing us to say that the patients' quality of life (QoL) clearly improved thanks to acting.

LIST OF ABBREVIATIONS

DLB: Dementia with Lewy Bodies

DSM-IV: Diagnostic Statistic Manual

FES: Falls Efficacy Scale

GFQ: Gait and Falls Questionnaire

H&Y: Hoehn and Yahr Scale

HRQoL: Health Related Quality of Life

IRCCS: Private Health and Research Clinics

LD: Levodopa

MMSE: Minimal Mental State Examination

NMSS: Non-Motor Symptoms Scale (S: Severity, F: Frequency)

PD: Parkinson's disease

PDQ39: Parkinson's disease Quality of Life Questionnaire (39 questions)

PDQ8: Parkinson's disease Quality of Life Questionnaire (8 questions)

PDSS: Parkinson's disease Sleep Scale

SD: Standard Deviation

UPDRS: Parkinson's disease Rating Scale

Introduction

Parkinson's disease is a neurodegenerative pathology of the Central nervous System with a slow but progressive evolution involving certain functions such as movement and balance control. It belongs to a group of pathologies known as "Movement Disorders" and after Alzheimer's is the most common.

The disease is found in all racial groups all over the world: it affects both sexes, but with slightly more male sufferers. It is an illness of the pre-senile and senile age group showing a progression of 15 – 20 years: it usually starts around the age of 58-60, but approximately 5% of patients show a juvenile onset between the ages of 21-40; it is, however, extremely rare before the age of 20; above the age of 60 about 1-2% of the population have this disease, whereas after the age of 85 the percentage increases to 3-5%. ⁽¹⁾

According to the UNO there are about 4million people worldwide with this pathology and with greater life expectancy and an aging population it is expected that this number will have doubled by 2040.

The symptoms of Parkinson's disease have been known for thousands of years: the first descriptions of this illness were found in a 5,000 year old Indian medical treatise and in a Chinese document dating back to 2,500 years ago. The name is, however, linked to the 19th century London apothecary and surgeon, James Parkinson, who was the first person to give an accurate description of the symptoms of this disease in his famous treatise, "An Essay on the Shaking Palsy". ⁽²⁾

It causes serious motor, cognitive and psychiatric disability causing heavy expenditure due to patient hospitalisation for the complications caused by the disease (falls, psychosis, infections). Parkinson's disease determines both motor and non-motor symptoms, the latter, now recognised as an essential component of this multisystem pathology, may appear a few years before or after diagnosis, but will progressively take precedence over the motor symptoms, gradually confining patients to within the four walls of their home. It is characterised by apathy and a

reduction in activities with patients relying totally on their families for care as well as assistance. Patients gradually lose their independence, so their health, personal and social quality of life result seriously impaired. Pharmacological, surgical and rehabilitative therapies have been demonstrated effective, but despite the evident improvement in their motor symptoms, patients refer that, owing to pharmacologically and surgically resistant motor and non-motor symptoms, their quality of life deteriorates. This together with an increase in ever more specific medical aids has doubtlessly created a new scenario compared to as few as 10 years ago. As this disease is a chronically progressive illness, characterised by early and advanced phases with their relative symptomatology, a differentiation in goals has come about. In contrast to the past this disease is now considered for the whole of its duration, above all by looking at the non-motor aspects as well as all the functional systems involved, where symptoms such as depression, loss of sense of smell and sleep disorders have actually become markers for the disease. Whereas before the clinical approach essentially focussed on motor symptomatology, nowadays it concentrates on a more complex form of assistance tending to increase each patient's residual abilities and to rehabilitate, whenever possible, their impaired daily activities making life fun and improving social relationships.

Evaluations of the cognitive deficit linked to this pathology as well as its repercussions on patients' independence, individual and family relationship dynamics, and, last but not least, increased National Health Service expenditure, have laid the foundations for new experimental approaches, which, together with innovations in pharmacology, surgery and physiotherapy promote an innovative and more complete approach to the problems of Parkinson's sufferers. These workshop approaches, whose worth is still being examined, use the Arts such as music, singing, dance and theatre, aiming to improve the patient's and their family's quality of life. It has been calculated that this approach, which complements therapy may well save between 20-40% in health expenditure (medicines, doctor's visits). Lifestyle changes also aid caregivers and family members in preserving their own efficiency. Within the last ten years in Italy this kind of experimentation has brought about the

creation of permanent centres, which are both research centres as well as a real help for Parkinson's sufferers. Amongst the many, the IRCSS Neuromed in Pozzilli together with Parkinzone Onlus has shown how acting is an extremely effective "recreational" resource in this kind of pathology. This kind of activity appears to train the patient to develop new motor automatisms, reduce his sedentary lifestyle as well as meet his psychological needs: emotional control through an exchange between heart and head, drive and motivation towards a goal and interaction with others.⁽³⁾

Although this work has been inspired by previous theatre experiences, the author has decided to try a different kind of approach. Apart from the specific symptomatology and therapies used and with absolutely no therapeutic ambition, this workshop has basically aimed at valorising each single personality in the group, not only from a physical but also psychological, emotional and affective point of view: by looking at the person as a whole, and not at their "being ill", so as to enhance their expressive and creative skills, share their human condition as a life resource in order to develop communicative forms linked to interaction, reciprocity and co-sharing.

The aim of this work has been to evaluate if and which aspects of Parkinson's disease are modified through acting and especially to:

- ❖ evaluate the efficacy of acting on a group of fluctuating symptoms to pharmacological therapy: language, gait and balance;
- ❖ evaluate the efficacy of acting on non-motor symptoms: anxiety, depression, and impulse control disorder;
- ❖ evaluate the efficacy of acting on the patient and caregiver's psychosocial wellbeing.

1. Parkinson's Disease

Parkinson's disease is a pathology of the central nervous system. From an anatomopathological point of view it is characterised by the degeneration of neurones in the pars compacta of the substantia nigra in the ventral mesencephalon and other pigmented brainstem nuclei, such as the locus coeruleus and the vagus motor nucleus. The structures involved in Parkinson's disease are to be found in the deep areas of the brain, known as base ganglions (caudate, putamen and pale nuclei), which take part in the

correct execution of movements. The substantia nigra neurones produce a neurotransmitter, i.e. a chemical substance that transmits messages to neurones in other parts of the brain: the neurotransmitter at issue, called dopamine, is responsible for activating the circuit controlling movement. When there is a reduction of at least 50% in dopaminergic neurones, the receptors, or terminals situated in the striated area of the brain, are not being sufficiently stimulated. Parkinson's Disease manifests itself when the brain's production of dopamine consistently drops (over 60% cell loss compared to onset)⁽¹⁾. Seen under the microscope, inside the sick substantia nigra dopamine neurones one can see spherical corpuscles called Lewy bodies. These are mainly made up of alpha-synuclein and are considered a specific characteristic of Parkinson's disease, thus including this disease in a larger group of synucleinopathies. These are differentiated depending on what areas of the Lewy bodies are involved, varying from the cortex (dementia), the substantia nigra and cerulean locus (Parkinson's Disease) or the nervous systems feeding the internal organs (multisystem atrophy with the autonomous nervous system being compromised). At present research is being carried out to discover why these neurones get smaller and then die. There are many factors contributing to the development of the disease, among which genetics, considering that some noted mutations are associated with Parkinson's disease and that roughly 20% patients have familiarity with the disease. It is estimated that people with Parkinson's disease familiarity have a slightly greater chance of developing the disease than the general population. Toxic factors are also involved, some job related: there is a greater risk of contracting the disease after exposure to toxins such as certain pesticides or hydrocarbon solvents (e.g. trichloroethylene) and in certain jobs, such as welders who get greater exposure to heavy metals (iron, zinc, copper), but exposure to cigarette smoke probably reduces the likelihood of Parkinson's disease.⁽²⁾ The duration of the pre-clinical phase, or time that elapses between the onset of neurone degeneration and the onset of motor symptoms is unknown, but some studies think it may be about 5 years. Parkinson's Disease is one of the commonest cases of neurological disability, but is only one of the Parkinson syndromes or parkinsonisms. Parkinsonism is actually a general term used for both Parkinson's disease and for all the syndromes with similar symptoms.

1.1. Motor symptoms

The main motor symptoms of Parkinson's disease are: bradikinesia, rigidity, tremor at rest and in a more advanced stage postural instability and loss of balance. These symptoms appear asymmetrically (one side of the body is more involved than the other) and at onset often go unnoticed as their appearance is subtle, inconstant and the disease progresses slowly. Occasionally family and friends notice that "something is not quite right" and encourage the patient to see his doctor.

1.1.1. Akinesia/bradikinesia

Semeiotics defines akinesia as difficulty in making a spontaneous movement and bradikinesia as slowness in executing the movement (speed, scale and rhythm are all altered): basically they are the two sides of the same coin (Fahn, 1990). Akinesia almost always represents the most noticeable PD symptom getting progressively worse and manifesting itself differently according to which part of the body is involved. Since akinesia is the basic clinical signal when diagnosing PD, a patient with shaking only when resting cannot be strictly classified as having Parkinson's: akinesia must be present in one of its different expressions (Gibb and Lees, 1989) among which we note:

- ❖ facial hyponymy or "facies figee", i.e. reduced facial expressivity due to a reduction in the spontaneous facial expressions which normally accompany varying emotional states,
- ❖ a blank stare owing to a reduction in blinking,
- ❖ palilalia, or monotonous speech, as in a whispered and altered automatic repetition of syllables and phrases,
- ❖ dysarthria is often an extremely debilitating symptom from a social point of view, but can be partly helped with logopedia,
- ❖ loss in spontaneous movements (sitting down, crossing one's legs, gesticulating),
- ❖ micrographia (tiny illegible writing)
- ❖ paligrafiya (repeatedly writing short syllables and phrases).

Moreover, the patient finds it particularly difficult to carry out sequential motor tasks, such as alternating hand movements (flipping his hand over); complex movements, such as buttoning up a shirt, and delicate manual movements result impaired, less ample and become more tiring, so that when repeated they gradually become imperceptible.

Signals of the presence of bradikinesia are also difficulty in changing position, such as getting out of a car, turning over in bed or even putting on a jacket or a coat. There is a characteristic reduction in gait with the arms swinging less when walking and with one side more accentuated than the other, which is one of the clearest signals at onset; when the patient starts walking, his rhythm is slow with short steps and his limbs tend to drag. Occasionally what is known as “festination” is present: the patient leans forward and accelerates as though chasing his own barycentre, so that he appears to be taking part in a walking race and has difficulty in coming to a stop. A few years into the disease one may see paradox akinesia, or freezing: this is difficulty in starting to walk and swiftly change direction. Patients affected find particular difficulty in navigating narrow passages and getting to their destination (often coming to a full stop before reaching their chair or bed). They refer to feeling their feet “stuck” to the ground: this phenomenon comes on suddenly, but is transitory, yet it can cause total blockage in gait (Gladi and coll., 1992). Freezing is unknown when climbing the stairs or walking in water.

1.1.2. Rigidity

This is an involuntary increase in muscle tone. Rigidity, or Parkinson’s hypertonicity, is characterised by its plasticity and regular distribution across the gravity and antigravity muscles. At the onset of the disease rigidity may be light or even absent, in the latter case it may be verified by making the patient move the unaffected limb (Froment’s signal). A consequence of parkinsonian rigidity are the head and trunk slightly bent forward in a typical parkinsonian stance defined

“camptocormia” or bent posture, or even a postural attitude called the Pisa Syndrome in which the trunk leans to one side. Rigidity may sometimes be the first sign of Parkinson’s disease: many patients however are unaware of it whilst referring an ill-defined feeling of awkwardness. As in the other symptoms there is a frequent one-sidedness at onset that may be found in the limbs, neck and trunk. The reduction in the swinging of the arms when walking is a sign of rigidity and is associated with slowness in moving, but this may vary during the day under the influence of medicine, mood and emotive stress. It is not always clear how much rigidity contributes to the PD patient’s motor impairment as some seriously rigid patients have a relatively well-conserved motor function. One may presume, then, that concomitant akinesia plays a greater role of the rigidity when determining the degree of total disability in each single case.

1.1.3. Tremor

This symptom, even though not present in all patients, is often the first to show itself and is the best-known and most recognisable sign of PD. 70% of patients have tremors at onset (Hughes and coll., 1993), yet contrary to general belief, this is not actually the disease’s most disabling symptom. The patient usually becomes aware of tremor in the distal segments of an upper limb, first in the thumb and index finger and then in the other fingers of the same hand. The tremor will then affect the lower limb on the same side; only occasionally will the shaking start in the lower limb and then move to the upper. From a semiotic point of view, parkinsonian shaking is a rhythmic oscillating movement of the fingers with a frequency of between 4-7 cycles/sec, typically reproducing the gesture of “counting pills or money”. It is shaking when at rest and is highly visible when the patient is upright with his arms loosely hanging by his sides and tends to disappear when the arm is being used for something: a postural component of the shaking may remain present especially a few years into the disease. Patients occasionally complain of internal shaking, but with unclear objective signals as this sensation can only be noted by

the patient but not by an external observer. Although the tremor will become bilateral during the progression of the disease, there will always be a certain asymmetry. In the later stages of the illness it may be extended to other parts of the body, such as the jaw, lips, tongue and the roots of the upper and lower limbs. Parkinsonian tremors are particularly noticeable under stress and disappear when sleeping.

1.1.4. Postural instability (PI)

This is one of the most impairing PD characteristics, occurring later on in the illness, usually after the appearance of non-motor symptoms. It is mainly due to a dysfunction in the straightening postural reflectors, combined with various other factors including akinesia and rigidity: despite their tendency to lean forward, PD patients easily fall over backwards, with only the lightest push. Axial rigidity contributes to PD patients' poor stability as a response to the body's oscillation backwards (Horak et al., 2013).⁽³⁾ Apart from diminished postural reflexes, other factors also appear to contribute to PD patients' instability: orthostatic hypotension, age-rated sensorial changes, and a reduced capacity to integrate visual vestibular and proprioceptive stimuli. This postural instability causes motor impairment, difficulty in walking, inability to live independently at home and is also the main cause of frequent falls with a risk factor of 38/100 PD patients, out of which 13% fall more than once a week (Koller et al., 2010).⁽⁴⁾ These falls can have negative consequences, such as soft tissue lesions, hip fractures and the fear of falling. As the illness progresses, both postural instability, which does not respond to a specific pharmacological therapy and fear worsen making PD patients even more sedentary.

1.1.5. Gait impairment

This is what most clearly determines functional disability in a PD patient, strongly influencing his quality of life. It not always directly linked to upper limb bradikinesia, so that there are patients with extremely slow movements whose balance and capacity when starting to walk and turning are conserved and patients whose gait is extremely altered despite the good conservation of their limbs' fine motility.

1.1.6. Other motor symptoms

Matched eye movements are usually conserved in PD contrarily to what has been observed in other parkinsonian forms such as progressive supranuclear palsy and corticobasal degeneration. A limitation in looking up is not uncommon in elderly PD patients, whereas downward looking paralysis makes one suspect another diagnosis.

- ❖ A characteristic PD signal is the nasal-palpebral reflex, when the forehead is repeatedly tapped with the index finger (Meyerson's signal): with the movement of the stimulus the reflex normally weakens and tends to disappear.
- ❖ Osteo-tendon reflexes are unmodified in PD: they may decrease due to hypertonicity, but when hypertonicity is not marked they may result lively or even accentuated.
- ❖ The plantar reflex is always flexed.
- ❖ Somatic sensitivity may be involved, but only subjectively (paresthesia, dysesthesia, muscular cramps).

- ❖ Typical PD clinical motor symptoms (rigidity, bradikinesia, etc.) appear during the third and fourth stage with the involvement of the substantia nigra and other deep mesencephalon and pros-encephalon nuclei.

1.2. Non-motor symptoms

In PD there may also be non-motor phenomena starting many years before the appearance of the motor symptoms. They are often to be found in the early stages of the disease but their maximum presence is in the advanced stages. The most frequent non-motor symptoms are vegetative disturbances (altered internal organ functions), smell, sleep, mood and cognitive function disturbances, tiredness and pain.

1.2.1. Vegetative disturbances

Especially in the advanced stages and in older patients there are frequent and occasionally clinically important internal organ disorders, the most important being cardio-vascular. The following are included:

- ❖ orthostatic hypotension, i.e. a drop of more than 30mm Hg in systolic artery pressure when changing from a horizontal to an erect position, with consequent dizziness, lipothymia, and in the worst case syncope. Orthostatic hypotension is often asymptomatic and is particularly frequent in elderly patients after a heavy meal and in hot weather. One must not forget that PD drugs can often make pre-existing orthostatic hypotension worse;
- ❖ cardiac arrhythmias: rare but may appear as a side effect of dopamine agonists (e.g. tachycardia and extra systoles);

- ❖ livedo reticularis: a characteristic purple skin colouring which not infrequently appears during amantadine treatment, especially in women. This is harmless and needs no further investigation;
- ❖ extremity oedema: this appears especially in the later stages and is probably due to immobility.

Gastrointestinal symptoms are also very common, including nausea and hyper-salivation or sialorrhoea, which is caused, not by an increase in saliva production by the salivary glands, but to the pharynx muscles' difficulty in swallowing. Problems linked to swallowing (dysphagia) may appear later on in the illness. Swallowing is a fairly complex automatic movement involving the throat and tongue muscles, which must be coordinated in order to push the food from the mouth into the oesophagus; when this movement is compromised the patient may feel as though food has stuck in his gullet. This difficulty is more often referred to drinking, but solid food can also become dangerous when liquids, or indeed solids, are aspirated into the airways where they may cause pneumonia "ab ingestis" or "from aspiration". Then, there are disorders linked to sphincter functions (constipation, bladder hyper-reflex with sudden urination and occasional urinary incontinence in over 50% of cases) and sexual functions: male impotence is a frequent signal (up to 60% of cases) and may have a multi-factor genesis. This disorder is particularly noticeable in younger patients and needs to be properly treated. Finally we must note oily secretions giving the skin a greasy sheen and sweating. This is often severely increased, usually with no correlation to time of taking drugs and for which there is no specific drug treatment.

1.2.2. Sensorial, psychic and cognitive disorders

There is a vast range of non-motor disorders from neuro-psychiatric symptoms (including depression, confusion and dementia) to sleep linked symptoms, including excessive daytime drowsiness, restless legs syndrome and insomnia. Some people also suffer from pain, weight loss or increase or sight and sense of

smell impairment. The number of each individual's non-motor symptoms increases with age and the length and gravity of PD: these disorders may characterise both the early and advanced stages of the disease, with a significant impact on the quality of life when correlated to the patient's state of health (HRQoL) and may necessitate a stay in hospital thus increasing the cost of the illness. As has been said, some of the non-motor symptoms may develop years before the motor ones, i.e. before PD is diagnosed. ⁽⁵⁾ Braak and coll.'s post mortem studies ⁽⁶⁾ suggest that the manifestation of non-motor symptoms may reflect a 6 stage progression of the disease, parallel to localising "induction sites" in the brain, according to a foreseeable topographic sequence starting from the substantia nigra where dopamine is produced. According to this hypothesis, still under debate today, the early stages of the disease are associated with a deterioration in the sense of smell: this deficit starting many years before the appearance of motor symptoms, involves as many as 90% of PD sufferers and continues over time remaining unvaried with pharmacological therapy. The second stage reflects the progression of pathological processes in the lower encephalic trunk nuclei, i.e. the key areas mediating non-motor symptoms such as sense of smell, sleep control, depression and cognitive functions, pain, constipation and control of the autonomous central system.

Sleep disorders are frequent and may involve up to 70% of patients, at onset and during the illness. There are many different manifestations, depending on the underlying pathology and the drugs used including:

- ❖ night-time insomnia with difficulty in getting to sleep, early awakening or repeatedly waking up during the night, frequently due to rigidity or bradikinesia or the recurrent need to urinate (nycturia);
- ❖ excessive daytime drowsiness, often unrelated to night-time insomnia, may strongly influence the patient's QoL making certain light tasks (reading, driving or social activities) difficult;
- ❖ REM Behaviour Disorder (RBD) may be present during the REM sleep phase. During this sleep phase muscles are normally atonic, but people with this disorder are usually agitated when dreaming. Motor

manifestations are vocalisations and arm gestures (fighting, boxing, kicking) making it appear that the patient is interacting with his dream. This disorder can be a nuisance for the person sleeping next to the patient, as they risk being hit, but the patient is also at risk of hitting objects near the bed and hurting himself. This disorder may also be present many years before the onset of PD motor symptoms;

- ❖ Restless Legs Syndrome (RLS) making some patients feel uncomfortable together with an urge to move their legs continually. This disorder appears and intensifies in the evening and at night;
- ❖ apathy is frequently present and is often (around 20% of cases) associated with depression. Patients complain of being in a state of emotional indifference, with a marked lack of interest or desire to do anything;
- ❖ anxiety is a very common symptom, referred by patients as a sense of apprehension, fear or worry. Anxiety may precede motor symptoms by many years and is also associated with vegetative, somatic and cognitive symptoms. Its evolution may vary together with motor fluctuations, which complicate therapy after several years' treatment. Anxiety is particularly present during the "off" motor block phases;
- ❖ depression is common in every stage of PD and may often appear several years before the onset of motor symptoms. It is not always easy to diagnose, as some of its symptoms overlap with PD, such as fatigue, hyponymy, and apathy. Depression may appear with deflected moods, fatigue, sleep disorders, appetite changes, memory disorders. There are two etiological hypotheses as regards depression in Parkinson's patients: a "reactive" one when the illness with its consequent impairment is diagnosed and an "endogenic biochemical" one, based on the changes involving the dopamine and serotonin-energy system, which may be extremely serious (Mayeux 1990). As regards the reactive hypothesis, two incidence peaks have been described: an early one when the patient is first diagnosed and the second during Stage IV on the Hoehn and Yahr

Scale, when the patient is no longer independent and needs assistance. It has also been noted that depression is more common in bradikinesia-rigid forms of the illness compared to shaking and is frequently correlated to clinical variations in the pathology (off phases). In the DSM-IV a new diagnostic category has been added to the voice “mood disorder owing to a general medical condition”, confirming the gravity and importance of depression in PD patients. It is essential that depression in a PD patient must be recognised and properly treated, not only because of its recent inclusion in risk factors causing a more rapid progression of the disease, but also because treating depression may also improve motor symptoms;

- ❖ compulsive obsessive behaviour disorders, or repeated behaviour aiming at gratification and pleasure, such as over-eating, gambling, shopping, hyper-sexuality or internet-dependence. These may appear in a relatively small number of patients, especially when under the effect of dopamine drugs. Only rarely do psychotic symptoms such as hallucinations or delirium appear;
- ❖ PD dementia has often been defined as subcortical dementia for the preponderance of visual-spatial and dis-executive disorders compared to mnemonic and language ones. These alterations are generally referred to the frontal lobes’ characteristic functions and may be interpreted in the light of the connexions between base ganglions and the front cortex;
- ❖ cognitive functions involved are attention, visual-spatial abilities and executive functions (as in planning abilities and the capacity to change from one strategy to another). Cognitive disorders can be seen in every stage of the illness, but especially in the advanced stages and in elderly patients. When encountered in the early stages of the disease (i.e. within one year of the onset of motor symptoms) one may speak of Dementia with Lewy Bodies (DLB), where it is possible to observe visual hallucinations and fluctuations in cognitive performance;

- ❖ apathy, anhedonia, feelings of guilt and impotence, remorse and sadness, loss of self-esteem and initiative, mnemonic difficulties, lack of concentration and wisdom are unfortunately frequently found in Parkinson's patients together with the symptomatology that often accompanies depression – i.e. anxiety, panic attacks and agitation.

Relative evaluation scales (HRQoL) or “the patients’ own perception and evaluation of the importance the disease and its consequences have had on their lives” show that they are more frequently affected by depression and comorbidity (roughly 50%). Psychological adaptation to the effects of PD has greater effect than the seriousness of the illness on many aspects of HRQoL, which together with mood and personal independence result influenced by the disorder. That is why merely treating the patient’s motor symptoms cannot be the only concern. Goals related to the patients’ relationship with their partner and family appear to be of the utmost importance and those activities promoting their quality of life and preventing its decline are imperative for their influence on mood and HRQoL. Managing non-motor symptoms becomes ever more important also as regards the increase in life expectancy: hence the need for early diagnosis and a correct evaluation of non-motor symptoms, which were frequently under-valued in the past, either because greater stress was placed on motor symptoms, or, strange as it may seem, patients rarely refer non-motor symptoms because they are either too embarrassed or because they ignore their relationship with the disease itself. To increase PD sufferers’ wellbeing it would be a good idea to promote those activities, which improve the trunk’s axial alignment, the dimension and quality of social relationships and generally encourage social interaction. ⁽⁷⁾

1.3 Progress of the disease

The disease develops chronically owing to the progressive anatomico-pathological lesions present but may reap remarkable benefits from pharmacotherapy, surgery and rehabilitation, thus delaying or diminishing impairment. Initial symptoms are often unilateral and may stay so for a long time (Hemi Parkinson's). After several years the degree of impairment will vary greatly from patient to patient and its extent can only partially be predicted. Several authors have tried to identify the factors responsible for this wide spectrum in its development. Zetuský and coll. ⁽⁸⁾ believe that classifying PD patients on the basis of the predominance of tremor or balance and walking disorders may not only have semiological but also prognostic value. Shaking forms are characterised by shaking, rigidity, low bradikinesia, although gait is usually well preserved and with long-term minor functional impairment (Hershey and coll., 1991); cognitive disorders are also rare, onset tends to be earlier and there is frequent familiarity. Contrary to popular credence, among those factors influencing long term PD prognosis, there is no reduction in the efficacy of Levodopa (LD) therapy. Patients with idiopathic PD continue to respond to LD even after 15-20 years after the onset of symptoms, although in a different way, possibly with serious motor fluctuations ⁽⁹⁾ frequently associated with various kinds of dyskinesia and show psychiatric or vegetative side effects, but will still continue to clearly improve after a single dose of the drug. The main prognostic factors negatively influencing long-term PD are freezing of gait, balance disorders, depression, vegetative symptoms and drug psychoses. These prognostic factors are generally independent from the effect of drugs and may depend on alterations in neurotransmitter pathways other than dopamine ones. The presence of cognitive disorders is particularly important: slowness in conceiving ideas and in replying to verbal stimulation, known as bradyphrenia, is relatively common (Lees and Smith 1983); however there is true dementia in approximately 10-15% of all cases, increasing in late onset patients (Gibb, 1989). This group of patients is particularly susceptible to infections, especially urinary and respiratory and

death is often due to infective complications. PD cognitive disorders rarely improve with dopaminergic therapy, which at times may even make the situation worse. Moreover the appearance psychiatric drug induced side effects (visual hallucinations, confused mental states and alterations in the sleep-wake patterns) in themselves represent a risk factor for the onset of dementia and are thus associated with an increase in mortality. To conclude, there is an enormous variability in long-term functional PD prognosis yet there is no way the disease's evolution can be exactly predicted: the presence or absence of certain symptoms, especially if present at onset, may however allow a general prediction. Generally speaking, however, as PD is a slowly evolving chronic disease, in which motor, vegetative, behavioural and cognitive functions influence the quality of life, with suitable treatment life expectancy may be considered only slightly lower than the general population's.

2. ART AND PARKINSON'S

“Our tests, our approaches [...] only show us deficits, they do not show us power, they show us puzzles and schemes when we need to see music, narration, play or a living creature behaving spontaneously in his own natural way.”

Oliver Sacks

As has already been stated there have been interesting changes in the therapeutic approach towards PD as in the global vision of health care. Alongside traditional pharmacotherapy, surgery and rehabilitation a “holistic” approach to the disease has arisen. This has probably come about as greater attention has been paid to non-motor symptoms, which do not respond well to traditional therapies, but also to a new attitude in Western medicine, which is starting to contrast rigidity and excessive attention to technical details.

Even though both techno-scientific medicine and Western pharmacology have given us commendable results, they have their economic limitation in their over-heavy expenditure and ethic limitation in quality of life plus a lack in democracy in patient care. Treatment is beginning to be considered from the point of view of medical humanity, where with its with medical protocols whose success is based on a techno-scientific dimension, a new practice is taking shape: here treatment's symbolic component together with all its actors take centre stage in the therapeutic process: patient, physician, caregiver and community ⁽¹⁾. Pioneers have tried experimenting new support procedures in this multidisciplinary perspective, which, while retaining their experimental status, may well become functional tools complementing treatment. Traditional rehab programmes in the field of motor disorders have generally aimed at recuperating or preserving certain cognitive and motor functions; today, however, they aim to tackle the patient's depression and isolation while improving family and interpersonal relationships,

life style and in general those negative characteristics affecting both patients and family members, which tend to occur later on in the disease. Art Therapy ⁽²⁾ draws on a variety of theoretical approaches. It consists in a set of techniques and methodologies using artistic activities (music, dance, theatre) as therapy while aiming to recuperate and help the person grow emotionally, affectively and relationally. Artistic expression, from drawing and painting to body movement, offer pre-logical structures capable of developing suitable symbolic and language skills to communicate internal experiences. Art Therapy used to treat PD mood disorders is based on two peculiar characteristics: the Parkinson's patient's response to the medium of art and the group's situation in the sittings' setting. In 1994 at the European Parkinson's Disease Association AGM in Glasgow, the German neurologist Johannes Lakke read a paper on "Art and Parkinson's Disease" in which he evaluated the creative levels in artists with PD, both before and after diagnosis. The results of his research confirmed that there was no impoverishment in the original creativity of those artists who had developed the illness, despite the considerable motor impairment caused by the disease. The patients studied did, however, find it harder to express themselves through language and painting rather than use their own creativity to communicate. The British Art Therapist, Diane Waller, declares, "the Parkinson's sufferer is 'consumed' by the artistic process", meaning that the intensity of these patients' creative investment is enormous. As confirmation of her thesis, Waller gives a memorable quote from one of her patients, "When I draw I forget Mr Parkinson and Mr Parkinson forgets about me..." ⁽³⁾ Art Therapy helps patients activate skills to elaborate their personal experience and transmit it creatively to others. The artistic process actually consists in recuperating one's own creativity, in that it is a life force, and may also favour the expression of emotions, which the patient is otherwise unable to express verbally. It may also lower tension and anxiety, bolster self esteem and personal identity and may make the patient more aware of emotions conveyed by sensorial experiences and improve his relationship with both himself and others. By using a tool which respects the patient's personal defences, facilitates and is capable of activating sensitive

pleasure, it give the patients taking part considerable psychological relief. Manipulating different artistic materials reactivates corporal memories, as these are linked to primary relationships capable of arousing sensations, which the disease has cancelled. Furthermore the group situation of sharing, mirroring each other and confrontation is another strong point in Art Therapy. Being part of a group is actually a fundamental element in treating depression, as the American psychiatrist Irving Yalom described when he pinpointed certain therapeutic factors pertaining to group therapy. These satisfy the solicitations concerning the treatment of mood disorders connected to PD, especially the Parkinson patient's tendency to isolate himself in order to hide his disability. Sharing and mirroring in group therapy, including the realisation that the patient is not alone in his suffering, create hope and immediate relief for all those taking part in art workshops ⁽⁴⁾. Art has also got a strongly preventative component: just think of the high incidence of dementia cases among people with a low cultural background compared to professionals or people who work in an artistic environment.

2.1.Music and Parkinson's

Music Therapy, or "using music to favour the individual's physical, psychological and emotive integration" is widely used in a series of contexts from hospitals to rehab centres and may be used with every age group and for various treatments. There are few references to Music Therapy as treatment in literature, but it has been used as a kind of therapy for many different illnesses, as thanks to its evocative but at the same time regressive value (unless hearing is utterly compromised) it really may be experienced and appreciated by seriously physically or cognitively impaired patients. The powerful impact of rhythm on motor functions strongly suggests that music's temporal structure is the basic element connecting music to motor behaviour, even though the audio-motor bases

are still unknown today. In literature one may find several references to the relationship between music and neurone activity, e.g. there is a body of evidence suggesting that music activates various areas of the limbic system, such as the amygdala and the cingulate gyrus (Menon V. and coll., Neuroimage 2005). Blood and al. showed there are different neurone responses to different kinds of music, e.g. the frontal lobes are first activated while listening to pleasant music, whereas the temporals are activated when listening to unpleasant music ⁽⁵⁾. Numerous neurotransmitters and other biochemical mediators are involved in the perceptive and emotive processes of music in the brain. Dopamine, for instance, might well be involved in the enjoyment of music, as it has been demonstrated that this neurotransmitter is released by the “ventral striate” and in the ventral tegmental area in subjects listening to enjoyable music ⁽⁶⁾. Moreover, musical stimulation induces the release of endorphines and cannabinoids (Blood et al., 2001). When speaking of music we are referring to all its elements: pitch, intensity, tempo, timbre, tonal memory and rhythm. Tempo and rhythm are music’s most important subjective elements. One of the most interesting discoveries may be the proof that the interaction between the rhythm of hearing and its physical response may successfully be used in rehabilitating physically impaired patients ⁽⁷⁾. Music, in all of its expressions, is actually one of the strategies used in rehabilitating Parkinson’s patients: from vocal exercises to singing, from rhythmic and free body movements to active music, including collective creation. As has already been said, PD patients move slowly, but are able to reach almost normal speed with ample movements with the help of external stimuli. Music may give out auditory signals appertaining to the supplementary motor area through the thalamus, or the pre-motor cortex through the cerebellum. This phenomenon can be explained because external signals can access cortical circuits through the non-lemniscal system, thus by-passing Parkinson’s sufferers’ dysfunctional base ganglions ⁽⁸⁾; another experimental laboratory practice is Rhythmic Auditory Stimulation (RAS), which has been used like a pacemaker ⁽⁹⁾. Researchers from the University of Munster have discovered that music is a successful stimulus for some Parkinson’s symptoms, in particular for gait and muscular rigidity in that it

slows them down ⁽¹⁰⁾. Amongst the most significant references in literature from a motor point of view, regarding the positive effects music has produced in Parkinson's patients, indicate reduced bradikinesia ⁽¹¹⁾, with a consequent improvement in the amplitude of stride, speed and rhythm. Masayuki S. and coll., from the Mie University School of Medicine in Tsu have demonstrated that when PD patients walk while singing their gait may improve thanks to the tune's beat acting on the base ganglions (Masayuki S., *European Neurology*, 2008) ⁽¹²⁾. Thus Music Therapy results successful on motor, affective and behaviour functions with predictable consequences on the QoL ⁽¹³⁾. Singing Therapy results are, however, less striking, although they do act on speech intonation and speed, indirectly influencing posture and facial mimicry. On the emotional side, both music and singing have demonstrated a general improvement, as socialisation, integration and self-awareness have all had positive repercussions on PD patients' social and relational life. These therapies' limitation lies in that both the improvements in the motor system and the emotive/affective sphere disappear as soon as two months after stopping therapy.

2.2 Dance and Parkinson's

There is a fairly recent use of the systematic form of the potential therapeutic use of dance together with the development of psycho-body therapies using more or less structured body movements with different goals. Dance, whether individual or partnered, is seen as a highly successful way of tackling PD sufferers' motor and behaviour problems, as it includes the basic elements of balance and adapting to one's surroundings, whilst at the same time being both engaging and fun ⁽¹⁴⁾. The improvement dancing brings to locomotion, balance and motor functions has been tested in the laboratory ⁽¹⁵⁾. Laboratory experiments have shown that elderly people usually prefer dancing as it's more fun than traditional gym exercises, and that in turn favours greater participation and motivation ⁽¹⁶⁾. Among the dances the most beneficial are partnered, especially the

waltz, foxtrot and tango. If we put aside social-cultural preferences linked to musical and choral traditions they imply the presence of a partner and music and need posture control, the ability to start and stop movement, twist and move close to another person ⁽¹⁷⁾. Among short term effects are decreased rigidity, followed by improved hand movements, finger grip and facial expressivity. On the whole going dancing over a period of several years improves functional mobility, balance, postural stability, gait and the legs' reaction compared to a group of same age non-dancers ⁽¹⁸⁾. Moreover, among elderly people taking part in dance programmes there is increased motivation towards wellbeing, correlated behaviour and what is especially important is the beneficial effect on the patients' and their caregivers' QoL ⁽¹⁹⁾. There are different explanations as to this improvement including external stimuli, coming either from the music or from the partner, as well as the movements each dance entails. The Argentinian Tango turns out to be especially beneficial ⁽²⁰⁾: its worth has been evaluated in both short and long term effects, and also in relation to medium to advanced stage PD. The tango can improve walking backwards; facilitate problem solving and improvising movement, as well as improving a compromised axial posture, which greatly influences the PD patient's HRQoL ⁽²¹⁾. Significant improvements have been registered in the Berg Balance Scale after dancing the tango, unlike after traditional gym exercises, as well as in the Up and Go test, which evaluates the risk of falls in over 65 year-old patients ⁽²²⁾. Questionnaires have revealed social benefits, in corporal sensations, mobility and daily life skills as well as in the patient's and caregiver's QoL (the PDQ-39 showed QoL improvements). Significant interactions between time, mobility and social support have also been registered. HRQoL in general and HRQoL linked to mobility and social support have showed improvements linked to the tango, independently from the greater or lesser time the patient has been dancing the tango, even though the mechanisms underlying these improvements still have to be made clear. Neither depression nor cognitive skills were measured, even though highest levels of depression, anxiety and stress (all significantly associated with the more serious self-referred social support problems) improved only with the tango and not with the other partnered

dances. The diminished availability of dopamine transport in the anterior putamen is linked to depression and anxiety symptoms, yet tango dance steps have demonstrated their ability to selectively activate the putamen; the lack of improvement in social support in the other partnered dance groups is unaccountable, seeing as they, too, involve family members and support volunteers. Dance programmes may well have multidimensional effects on self-esteem. Beyond the limitations of the numeric sample analysed (for obvious testing reasons) the following seem points to have been relatively overlooked:

- a) the carryover effect, or permanent benefits of dancing;
- b) which programme best favours retaining these benefits (i.e. how often and how long each session should ideally be).

2.3 The Theatre and Parkinson's

The links between medicine and theatre go back a long way and there are many deliberate references in literature to this reciprocity: just think of doctor playwrights such as Molière and Chekov, Strindberg and Buchner, or even the theatre's favouring the semantics of disease, from "Dr Shaw's dilemma", to Pirandello's "Uomo dal fiore in bocca" or even Artaud's visionary theories and poetry ⁽²³⁾, where he compares the theatre to a plague epidemic capable of revealing man's profundity beyond his rationality. Some health professionals are beginning to consider the theatre an efficient tool and different theatrical methodologies (from the theatre of the oppressed to social and community theatres) work together with traditional therapies, with the result that they act as functional techniques in treating the disease. At present the only theatre experience with PD patients in literature is Italian: the IRCCS Neuromed at Pozzilli in Isernia together with Parkinzone onlus. About ten years ago the neurologist Nicola Modugno had a brainwave, believing that acting might aid Parkinson's patients to develop new motor automatisms, reactivate simulation brain areas (notoriously poor functioners in these patients), control their

expressive skills and control “negative” emotions such as anxiety or fear. A team of neurologists, physiotherapists, psychologists, theatre actors and directors took part in the study, which aimed at getting patients to have a comfortable relationship with their illness while developing new skills in the presence of a pathology with consequences, and last, but not least among the side-effects was to use the theatre, the place par excellence for exhibitionists, to favour the patients’ acceptance of their “state”, thus overcoming their embarrassment at showing themselves in public just as in daily life. Modugno and coll.’s work ⁽²⁴⁾ tested over a continuous period of 3 years a group of 20 patients with a moderate form of idiopathic PD, under stable pharmacological treatment and with no serious sensorial problems. The patients, divided into 2 groups, the first treated merely with physiotherapy, the second also with the theatre workshop, were evaluated at the start of each year using 5 International Rating Scales: the UPDRS, Schwab and England, PDQ39, Epworth Sleepiness and Hamilton Depression Tests. At the end of each year, unlike the control group, in each Scale the theatre group showed progressive improvements that were proportional to the time spent acting. Acting probably favours a cerebral plasticity allowing a partial reactivation of the compromised neurone circuits. This was a pilot study, with evident limits linked to the low number of patients tested, as well as the moderate and not advanced stage of the disease. Despite many operators from both the public hospital and university sector’s scepticism, the success of acting as a rehabilitation resource complementing traditional therapies has opened the doors to new initiatives wanting to boost the results and efficacy of physiotherapy and close the gap between the effects of pharmacological and surgical therapy and the conquest of a better QoL. Although it must be emphasised that Art Therapies are complementary to physio–kinesitherapy, one must stress the only the continuous use of both will justify their value and success.

3. THE PROJECT “RI PASSI IN SCENA”

3.1. MATERIALS AND METHODS

The experimental protocol was created in order to compare the results of the Evaluation Scale, indicating the state of the disease’s progression, to see if the theatre workshop had influenced the patients and if so, how.

3.2. SUBJECTS

Ten patients from the Centro Parkinson dell’U.O. di riabilitazione della C.d.C. “Villa dei Gerani” in Catania took part in the theatre workshop. The experimental protocol had initially foreseen a control group of similar patients for the duration and severity of their illness, but treated only pharmacologically and with rehabilitation, but the subjects’ lack of homogeneity made this group unfeasible.

The criteria for the inclusion of PD patients were:

- 1) having an idiopathic form of Parkinson’s (stage 2-4 Hoehn and Yahr);
- 2) ages between 55 and 85;
- 3) illness duration over 5 years;
- 4) absence of dementia according to the DSM-IV with a MMSE < 24 score;
- 5) stable drug therapy with L-dopa and L-dopa antagonists.

Each patient was aware he/she was taking part in a study.

The theatre workshop started in the first half of October 2012 and finished at the beginning of June 2013. The workshop was a weekly three-hour session, with the caregivers also spontaneously taking part, plus two professional actors. The

workshop ended with a show called “Il Tempo della Pazienza” (Time to be Patient) which went on in front of a large audience. During the period of the workshop one of the subjects was unable to continue owing to fracturing his hip in a fall, hence his data are not included in this work. The subjects were monitored in June 2012 (T0) and again in June 2013 (T1).

3.3. CLINICAL EVALUATION

The subjects were monitored with clinical observations and interviews with a neurologist and his team using some widely used Scales in studying PD:

- ❖ Hoehn and Yahr: this evaluates the disease’s advance in 5 stages (1=unilateral disease → 5= the patient bedridden or in a wheelchair);
- ❖ UPDRS – third part –Movement Disorder Society Task Force on Rating Scales for Parkinson’s Disease, 2003.

The UPDRS was created in 1987 in order to give a standard PD evaluation, as up to then this had been made difficult with the many scales used, all subject to different operator interpretations.

It is made up of 4 parts, and is completed by the examiner when interviewing the patient. The 3rd section uses 14 questions in which motility is evaluated both by the interview and by an objective examination of the patient, with a score from 0-56.

- ❖ Parkinson’s Disease Quality of Life (PDQoL) is a patient administered questionnaire, made up of 8 questions regarding 8 different domains (1 – mobility, 2 – daily activities, 3 – emotional wellbeing, 4 – stigmas, 5 – social support, 6 – cognitivity, 7 – communication, 8 –feelings of embarrassment caused by the body). Each patient is asked to think about his health and general wellbeing and consider how often during the last few months he has experienced certain events (e.g. difficulty in getting around in public places). He is asked to indicate the frequency of each

event, choosing from among 5 alternatives (Likert Scale): never / rarely / sometimes / often / always or is unable to do anything.

- ❖ Parkinson's Disease Sleep Scale (PDSS): quantifies PD sleep disorders using a Visual Analogical Scale for each of the 15 characteristics commonly associated with these disorders.
- ❖ Non-Motor Symptoms Questionnaire (NMSS) is used to evaluate the frequency (F) and seriousness (S) of Parkinson's non-motor symptoms. The patient completes the questionnaire, answering 30 qualitative questions, divided into 9 domains including the main non-motor PD symptoms.
- ❖ Falls Efficacy Scale (FES) (Harada, 1995) is a questionnaire to evaluate how afraid the patient is of falling when carrying out activities requiring postural control and balance. It contains 16 questions and the subject must indicate whether he does the activity confidently or insecurely. On a scale of 1-10, a low score indicates a high level of confidence, whereas a high score indicates insecurity. A score of 70 or more shows the subject is afraid of falling.
- ❖ Gait and Falls Questionnaire (GFQ) is a scale to evaluate gait and falls.
- ❖ Minimal Mental State Examination (MMSE) (Folstein et al., 1975) evaluates intellectual efficacy and presence of cognitive deterioration. The total score is between 10 and 30. A score equalling or lower than 18 indicates cognitive skills are seriously compromised; a score from 18-24 indicates light to moderate deterioration, 25 is borderline, whereas 26-30 is cognitive normality. The indications are, however, suggestive in that there are factors linked to the subject's age and education.

3.4. Theatre Workshop Content

The theatre workshops held by the Neon Cultural Association of Catania aimed to highlight each patient's own resources, beginning with their lives and not their pathology, except where the illness itself was a resource to be exploited. This is why the workshop was decidedly recreational and not in the least therapeutical, except that it produced a new openly expressed and shared condition.

3.5. Workshop Methodology

The group was given a guiding hand in creating situations/atmospheres through verbalised images and suggestions. Both single and collective action was developed and body signals were made to interact "circularly" with sounds, music and voices and the subjects were helped to explore each participant's nuances and emotional experience; moreover each member, protagonist in his own research and discovery, gave form to all his imagined elements and expressed or unexpressed desires, whilst offering himself to the others as a common resource. The workshop was developed with the help of some passages taken from José Saramago. The accent was placed on the theme of Time, as narrated by the author, and on Beauty fully expressed by the workshop members in a creative process in which each, in an ever-deeper awareness of their use of time and scenic space, expressed to the best of their abilities their own imaginary reality. The process brought every participant to a full interaction that was guided by the director, in which every single characteristic - from physical to illness-related, age, character nuances, strengths and fragilities (both expressed and unexpressed), awkwardnesses, desires, fears, enthusiasms, talents, experiences etc. all became indispensable catalysts in developing and making *the group's entity* grow together with the theatrical activities.

3.6. Statistical Analysis

The patients' basal clinical characteristics were referred as mean \pm standard deviation (SD). The normal distribution of the sample was verified using the Kolmogorov-Smirnov model. To evaluate the efficacy of the theatre workshop we used a variation analysis (ANOVA) with repeated measurements at 1 way, with "time" (2 levels: basal – T0, after 8 months – T1) as a variability factor within the subjects. The effects were considered statistically valid for values of $p < 0.05$.

3.7. Results

A recap of the data resulting from the clinical evaluation showed that the only real statistically significant differences between pre and post workshop were to be found in PDQ8 (T0 9.22/ T1 4.33), NMSS_S (T0 17.22/T1 8.22) and NMSS-F (T0 17.33/t1 10.33) (Fig.1).

The Hoehn and Yahr Scale shows a slight reduction (T0 1.78/T1 1.50), as does UPDRS (T0 27.11/T1 21.00) and the same trend may be seen in FES (T0 9.44/T1 9.11), GFQ (T0 6.33/T1 4.33), MMSE (T0 27.62/T1 28.09) and PDSS (T0 17.56/T1 22.00). The tables show statistical significance is particularly high in PDQ8 ($p = 0.00905$), whereas in NMSS_F it is slightly lower ($p = 0.01788$) as in NMSS_S ($p = 0.02512$). As regards the subjects' answers to PDQ8 at the end of the experiment, there is a global reduction in the frequency of the episodes in the 8 domains, especially in 4-Stigma (social embarrassment created by PD), 5-Social Support (support received from family members) and also 6-Cognitive (concentration, memory when reading and general cognitive activity).

As regards NMSS, the subjects' answers to the 30 questions showed a reduction both in the frequency (F) and in the severity (S) of their general symptoms, especially in the domains: 1- Cardiovascular, including falls; 2-Sleep/Tiredness; 3-Mood/Cognitivity; 5-Attention/Memory.

The analysis of the results shows the theatre workshops brought about modest improvements in strictly motor parameters or in the evaluation scales, such as FES or GFQ, concerning respectively balance, ambulation and falls, but it is probable that these aspects need to be monitored over a longer period of time. On the other hand parameters regarding Memory, Attention Span and Concentration, Sleep Quality and above all relational aspects such as Stigma, Social Support and Mood all react positively and statistically significantly to acting.

The above data allow us to state that the patients' QoL has clearly improved thanks to acting. To support and confirm the above, we carried out a series of short structured interviews not only to the patients but also the caregivers who supplied us with further feedback (see attached video).

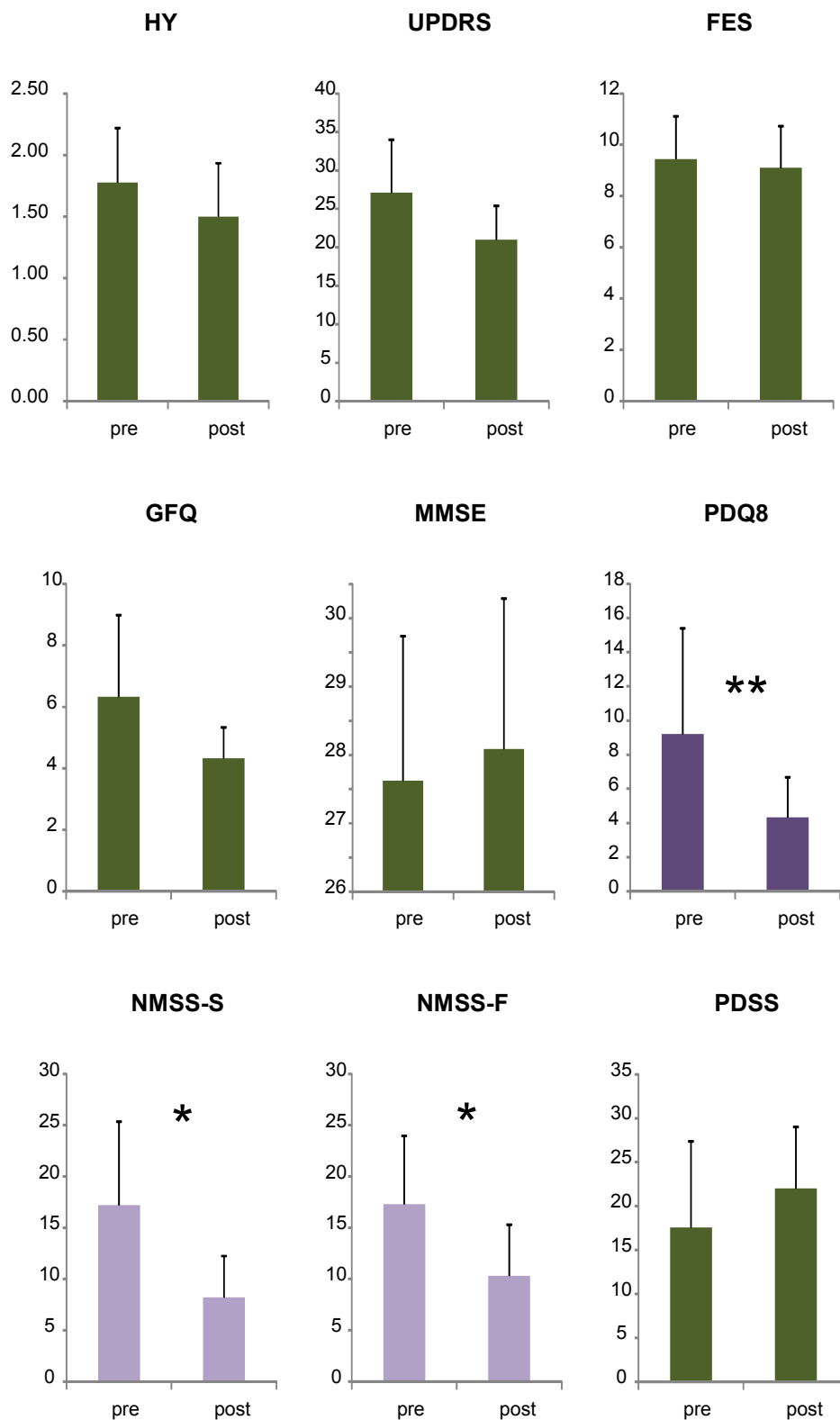


Figure1. Summary of statistical analysis with Mean and Standard Deviation for each parameter..

** p<0,01; * p< 0,05

4. DISCUSSION

The main characteristic of Parkinson's patients is their great difficulty in facing up to an illness which does not damage, or at least not significantly damage, their cognitive functions, but which does compromise their independence thanks to a series of difficulties which gradually become more serious and more impairing. Besides accepting his illness, a PD sufferer needs to learn to live with it without hiding away. Since this is the most delicate and challenging aspect of PD, the patient's relationships may deteriorate and become unsatisfying both within and without the family. Furthermore the patient often has a sedentary or fairly inactive lifestyle, tending to withdraw away from others and into himself; at times this is made worse by the malfunctioning of the prefrontal brain areas, which in turn makes both his daily routine and his relationship with family and non-family members deteriorate. At the same time, family or caregivers may feel frustrated or depressed, as they are unable to understand the patient's real need, and then may have difficulty in reacting to stress thus compromising their own self esteem, especially in their family and social roles.

In the classical world, health care involved "salus", or man's whole health, and so any means, including theatre, which is still considered an integrating therapy in India ⁽²⁵⁾, was considered pertinent and effective.

As time went by in the West a gradual differentiation of knowledge has come about. If, on the one hand this has allowed man to gain significant scientific knowledge, on the other it has caused a crisis in the community and the affirmation of the individual as the basis of a society which has become both individual-centric and lacking in solidarity: from the Greek chorus to the contemporary monologue, from the community to the individual.

Consequently and parallely, the incomprehension between medical operator and patient has been further weighed down by the basic incommunicability between the medic's professional approach and the patient's urgent need for an emotional approach requiring treatment, understanding, bonding, being listened to and

respect. A recent Scottish survey has revealed that one in four patients is unsatisfied with his relationship with his doctor, the information he is given and how he is supposed to put it into practice in his daily routine. To a certain extent the health profession might be defined “aphasic” as where life becomes dramatic, it is vital to ensure good communication for this is the first therapeutic element. A patient needs room, not only functionally but as a space where he can bring his whole self-made up of emotions, sentiments, thoughts and history ⁽²⁶⁾. Today the idea of health is undergoing a change, including prevention and promoting wellbeing while underlining not only the patient’s rights but also his “attention-seeking” as an element in the positive outcome of his treatment. Activating a person’s deepest resources, which belong to his culture as well as to his psychic and affective make-up, is an essential part of the healing process, without which external therapy is seriously weakened ⁽²⁷⁾. Theatre is both the most ancient and complex of art forms, since it is the only one to use all the expressive languages and codes and also the only one in which technological innovations count for little.

Compared to other body “techniques”, acting trains the body’s intentional and communicative expressivity: acting is defined as relationships, doing something together, listening, “taking part in the game”, opening up towards others and empathy, so in a theatre group one’s own individuality becomes a resource, not a limitation. Illness has “Pirandellian” ⁽²⁸⁾ power to block a person in a role, either as a patient or a sick person, so that his multi-faceted identity disappears ⁽²⁹⁾, yet in the “as though” of acting he is able to quit his own role and take on another. Journeying in the theatre means going beyond the knowledge of his own self, where his body becomes a connexion of the physical with the emotional: the deeper the actor connects with his own emotions, the better he learns to know them and share them, and in sharing he creates a circle of trust where each member of the group is indispensable for the others. In this climate of openness it is possible to explore, shed one’s fears and prejudices and find new ways of being together with oneself and others.

In this project's theatre workshop we need to stress its two distinguishing characteristics, which make this one not better, but different from Nicola Modugno's ⁽³⁰⁾: the first is the kind of activity used, far-removed from traditional theatre, yet favouring and facilitating the patients' participation, as they frequently refuse to take part, saying "*I have never acted*", thinking that acting consists merely in reciting memorised passages or taking on a character's role, so they feel inadequate and not up to it. Another innovative element was the caregivers' active participation in the theatre workshop. This is often underrated, if not even entirely ignored by the medical profession, who come into contact with their patients once a month and are either unable to imagine or underestimate how difficult it is to manage the patient in their daily domestic routine and also how much the family is burdened by the pathology's non-motor aspects.

The caregivers spontaneously decided to become involved in the project and this greatly helped the patients who were delighted to share this recreational activity with their loved ones; at the same time their caregivers/family members were affected both directly and indirectly during the sessions and in the days following the workshops by the climate of wellbeing created. Finally, and this is important, over the period of the workshop a climate of solidarity and support was created, especially between the wives which has continued even though the project is over ⁽³¹⁾.

If, then, there can be no doubt as to the motor and non-motor benefits Art Therapy generally brings to PD patients, acting would appear to extend its efficacy both in temporal terms as it retains the benefits for longer, and from a relational point of view, as it involves both family and social contexts.

4.1. Limitations of the theatre project

This project must doubtlessly be considered from an "experimental" point of view, as it presents a few objective limitations. First of all, the few subjects taking

part and the relatively brief time of observation; secondly, the lack of a control group made up of patients comparable for duration and severity of the disease, but treated exclusively pharmacologically and with rehabilitation; finally the lack of post hoc results, i.e. after a certain period of time after the theatre experiment had finished. It must be stressed that there is considerable difficulty in involving or getting either public or private health organisations to take part in ventures or projects like this one, owing to their resistance or scepticism regarding what is considered “non traditional”. From a purely scientific point of view, this limitation is definitely linked to the fact that the workshops involved patients with a moderate form of Parkinson’s, thus it is not possible to postulate what results would have emerged from a group of advanced stage PD patients.

5. CONCLUSION

Clinical attention usually focuses on PD motor symptoms, while the non-motor ones are either underrated or ignored, so this type of approach creates discordance between keeping motor disorders under check and the patient’s general and progressive awkwardness. The benefits of traditional therapy, such as physio-, occupational or art therapy, are limited by the fact that they are only temporary. The experimental data related in this study allow us to state that acting, together with pharmaco- and physio- therapy, directly improve the patient’s QoL from a non-motor point of view and their emotional and relational state, but also indirectly in the family and caregivers’ QoL. Promoting a more creative and socio-affective gratifying way of experiencing the disease, giving voice and body to all that that goes “beyond” the illness could well become a different and innovative way of managing PD.

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- ❖ Prof.ssa Tomarchio for giving me the opportunity to grow both personally and professionally.

NOTES

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