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THE EVALUATION OF WELL-BEING AND DISTRESS IN PATIENTS WITH PARKINSON'S DISEASE AND IN THEIR CAREGIVERS

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ABSTRACT

Studies on Parkinson's Disease (PD) traditionally focused on psychological symptoms and distress reported by patients and by their caregivers. However, they may sometimes experience also positive psychological changes and develop new existential resources that may help them to better face the illness.Within this perspective, only few investigations explored PD patients and their caregivers. The aim of this Phd thesis was to investigate well-being and distress in patients with PD and in their caregivers with four studies (two cross-sectional and comparative and two longitudinal).

Methods: 54 patients with PD, and 60 controls were recruited together with 50 caregivers of PD patients and 70 caregivers of controls. All participants completed questionnaires to measure both well-being dimensions and distress. In addition, a physician collected PD patients' clinical data. A six month follow-up was performed. In study 1 and study 2 patients were compared to their respective controls. Studies 3 and 4 with a longitudinal design examined the predictors of the psychological adaptation to PD of patients and of their caregivers, respectively.

Results: In study 1, patients reported more distress and less life satisfaction but more well-being than controls. In study 2, caregivers reported more distress and less well-being than their controls. In studies 3 and 4 it was found that the presence of well-being at the first evaluation together with the level of disability and caregiver burden (for patients and caregivers, respectively) were found to predict the level of adaptation to the illness at the second evaluation.

Conclusions: although PD patients and their caregivers may exhibit impaired levels of well-being and distress, in the long term those who report higher levels of psychological resources can experience a better adaptation to the illness. The importance of considering psychological resources when evaluating PD patients' and their caregivers psychological functioning is suggested.

CHAPTER 1

PARKINSON’S DISEASE AND POSITIVE PSYCHOLOGICAL FUNCTIONING

1.1 Etiology, clinical features and main treatments

Parkinson’s disease (PD) is one of the most common neurodegenerative disorders, with a prevalence generally estimated at 0.3% of the entire population in industrialized countries. It is an age-related disease, and its prevalence increases with age, reaching 1% in people over 60 years of age and 2% in individuals older than 80 years old (Pazzaglia, 2009). The likelihood of suffering from PD seems to be increased for men compared to women, although not all studies confirm this tendency (de Lau and Breteler, 2006).

PD's aetiology is still unclear, and although it tends to be a sporadic disease, some familiar variations may exist and several possible genetic correlates were found. It primarily affects the neurons located in the substantia nigra, responsible for the production of dopamine neurontrasmitters. Thus, its typical motor symptoms are related to the death of dopamine-generating cells in the substantia nigra, and more specifically in the ventral part of the pars compacta. By the time of death, this region of the brain has lost up to 70% of its neurons compared with the same region in healthy individuals (Davie, 2008). From this neutrotransmitter depletion may develop four main symptoms: bradykinesia (or akinesia, or hypokinesia), tremor at rest, rigidity, and postural instability. In addition, flexed posture and freezing (motor blocks) are typical symptoms of PD. Moreover, PD is characterized not only by motor symptoms but also by many non-motor and mixed forms of symptoms (Jankovic, 2008). Patients could thus manifest loss of sense of smell, constipation, orthostatic hypotension, sleep and mood disorders (Cronin-Golomb, 2013). Other important non-motor symptoms are represented by bladder problems, sexual problems, excessive saliva, weight loss or gain, vision and dental problems, fatigue and loss of energy and skin problems (Parkinson's Disease Foundation, n.d.). These problems together with the chronicity and progressive nature of the illness itself may seriously hamper patients’ physical and mental health (Cronin-Golomb, 2013).

PD is a chronic illness but different types of treatments are available for reducing impairments, disability and slow down its course. First, medications may aid patients managing symptoms, preserving functionality and health-related quality of life. The first choice treatment includes levodopa (L-dopa) (Connoly and Lang, 2014). The vast majority of patients take a polytherapy in which L-dopa is often included. In addition, patients have to often take dopamine agonists, anticholinergics, MAO-B inhibitors, COMT inhibitors and other types of medications. L-dopa can reduce the motor symptoms, certain cognitive deficits and depressive symptoms (Turjansky and Lloyd, 2005). However, treatment based on L-dopa should be delayed as much as it is possible in PD patients. This is the case of the younger PD patients who usually need long-term pharmacological treatments. In fact, unfortunately, long-term L-dopa treatments could determine side effects such as motor complications (dyskinesia and fluctuation of movement), anxiety, mood fluctuation, psychosis, mania, addictions, compulsive behaviors and impulse control disorders (such as gambling, compulsive sex, buying or eating, punding) (Turjansky and Lloyd, 2005). Accordingly, replacement therapy may also activate central dopaminergic pathways connected to the brain’s reward system and implicated in the process of addictions. In these cases, patients may exhibit a “hedonistic homeostatic dysregulation”, that is a neuropsychological behavioral disorder associated with substance abuse (Giovannoni et al., 2000).

Beyond the pharmacological treatments, other types of interventions could be applicable. Thalamic deep brain stimulation may contribute to improve the main motor signs (including tremor, bradykinesia, and rigidity), problems in gait and posture, and L-dopa-related complications. However, also in this case side effects may emerge, such as paresthesia, headache, dysarthria, paresis, gait disturbance, and ataxia. More important side effects are those concerning the risk of hemorrhage or infection, risk of mechanical failure, the frequent follow-up visits, and the economic costs of the device and battery replacements (Miocinovic, 2013).

In addition, physical therapy represents an essential ingredient of the PD treatment. It may improve the functional autonomy and reduce the secondary complications. Physical therapy particularly should be tailored to individual’s specific physical characteristics, lifestyle, and personal interests (Morris, Martin, and Schenkman, 2010; Tomlinson et al., 2013; van der Marck et al., 2009).

Finally dance movement therapy, by combining physical exercises together with emotional, cognitive and social activities may improve quality of life and alleviate some symptoms (McGill et al., 2014).

1.2 Psychological symptoms and disorders

Historically, studies on PD adopted a neuropsychiatric and neurological perspective. They focused on PD related problems, deficits, psychological symptoms and physical impairments. Non-motor symptoms such as psychological symptoms, cognitive and sleep problems may manifest in an early stage of PD. Depression could be one of the first manifestations of PD and lead clinicians to misunderstand the real diagnosis. These symptoms may be related to the reduction of dopamine, to the dosage of the medical treatment or they could represent a psychological reaction to the diagnosis (Lieberman, 2011).

The most frequent neuropsychiatric symptoms include depression, anxiety, apathy, psychosis, delirium, dementia and impulse control disorders (Park and Stacy, 2009; Thobois et al., 2017).

All of these psychological symptoms may impair patients and caregiver’ quality of life, their level of motor functioning and disability, and reduce their motivation in participating to rehabilitation and physical therapy programs (Walsh and Bennet, 2001; Prediger et al., 2012). Identifying the relative contributions of these psychological symptoms and of their neural pathways in PD patients could provide new information for the development of better therapeutic strategies for PD patients (Wen et al., 2016).

1.2.1 Depressive symptoms and mood disorders

Depressive problems in PD are reported by about 40–50% of patients (Marsh, 2013; Price et al., 2011), representing a higher prevalence compared to that one of the general population.

Studies found that it could be associated with the chronic disability but could also be related to the (very early) neurological degeneration of PD. Sometimes, depression is a risk factor for PD itself (Lieberman, 2006). Pontone et al. (2016) found that being female and less educated, having a lower intake of dopamine agonists, and having more motor fluctuations represent risk factors for depression in PD patients. Furthermore, depression is associated with a long-term adverse impact on daily functioning in PD. Moreover, depression was found to be positively related to the levels of physical disability and motor functioning measured with Hoehn and Yahr Scale (Hoehn and Yahr, 1967), a longer treatment with L-dopa, and the presence of more PD motor symptoms, such as tremor, gait instability, and dyskinesia (Piccini et al., 2012). Other studies found that depressed PD patients tend to exhibit a more rapid deterioration of cognitive and motor functions along time, compared with non-depressed individuals (Burn, 2002). Depression may be related to deficits in serotonergic and dopamine neurotransmitter (Cummings and Masterman, 1999). In fact, patients with PD show lower serotonin metabolite 5-hydroxindoleacetic acid compared to healthy controls and also to PD patients without comorbid depression.

1.2.2 Apathy

Another similar core symptom of PD is represented by apathy and it is strictly related to the progression of the illness (Martinez-Horta et al., 2013; Thobois et al., 2017). Apathy seems to be secondary to PD neurological changes rather than the result of the psychological distress and limitations associated with the physical disability (Butterfield et al., 2010). It could be often confused with depression (Bogart, 2010). However, while certain symptoms are common to both apathy and depression (such as decreased interest, psychomotor retardation, fatigue, excessive sleep, poor insight), and while the two syndromes may coexist, each of them has its own specific features. For example, depression is characterized by the negative view of the self and of the events whereas apathy implies a lack of responsiveness to both negative and positive events (Kirsch-Darrow et al., 2011). Moreover, apathy and depression determine different effects on cognitive and executive functioning.

Finally, concerning their independence, while apathy and depression rates are highly correlated in PD, apathy is not a significant predictor of quality of life, while depression is (Jones et al., 2014). From a neuro-anatomical point of view, apathy seems to be linked to striatal-dopamine depletion (Jones et al., 2014), specific brain regions involved with motivation, initiation, and motor functioning (Cummings, 1993).

1.2.3 Anxious symptoms and anxiety disorders

From 6 to 60% of patients who suffer from PD could also report anxiety symptoms or disorders (Broen et al., 2016; Zhu et al., 2017). Generalized anxiety disorder was the most reported disorders (14%), followed by social phobia (13.8%), anxiety not otherwise specified (13.3%), and specific phobia (13.0%). Panic disorder with or without phobia was experienced by 6.8% of PD patients. The most reported (>25%) PD-specific anxiety symptoms are distress, worry, fear, agitation, embarrassment, and social withdrawal due to motor symptoms and PD medication complications (Dissanayaka et al., 2016).

Anxiety may be associated with autonomic symptoms, motor fluctuations, severity and frequency of symptoms, staging of the disease, and PD onset and duration (Sagna et al., 2014). However, although systematic review and meta-analysis confirm that anxiety is very common, it is often under-recognized since there are not enough sensitive tools for identifying anxiety in PD.

Concerning anxiety neuroanatomy, Lauterbach et al. (2003) hypothesized two specific relations: generalized anxiety seems to be related to reduced pallidal inhibition of thalamofrontotemporal projections, whereas panic attacks to locus coeruleus dysfunction.

1.2.4 Psychotic symptoms

Psychotic symptoms could be other frequent impairments of PD. They can occur in more than 20% of patients. They are often characterized by vivid dreams, nightmares, illusions, delusions and mostly by visual hallucinations (Levin et al., 2016). Delusions, disorganized thinking and paranoid thoughts can in general regard spousal infidelity and in this case they can severely interfere with the care of the patients (Zahodne and Fernandez, 2008). While the use of anti-PD medications (particularly dopamine receptor agonists) is the most widely identified risk factor, other factors such as older age, disease severity and duration, (up to 70 % of the patients with a disease duration of 20 years or more), sleep disturbance, cognitive impairment, dementia and/or depression have also been reported by the literature (Levin et al., 2016; Zahodne and Fernandez, 2008). To the onset of psychosis can contribute both drug treatment, and other illness-related neuropathological processes.

Literature review documented the existence of multiple subtypes of PD psychosis, which are linked to dysfunction in the neurotransmitter systems of dopamine, serotonin and acetylcholine. Dysfunction of each of these systems is characterized by different clinical features and correlates, varied long-term treatment response and prognosis (Factor et al., 2017). In particular, deposition of toxic alpha-synuclein–containing Lewy bodies in the cerebral cortex that may disrupt both serotonin and dopamine neurotransmission alterations, with upregulation and overstimulation of cortical serotonin 5HT2A receptors and excessive release of dopamine in mesolimbic brain circuits have been documented (Harding et al., 2002; Stahl, 2016). These clinical phenomena are one of the main predictors of nursing home placement. In fact they represent an important source of burden for caregivers, who are usually old and with their age-related problems. Furthermore, when these psychotic symptoms increase, neurologists tend to reduce the dosage of the anti-parkinsonian medication, and this may further worsen the functional impairment (Aarsland et al., 2000). Therefore, an early identification of risk factors and of neuroanatomical correlates are most important measures against psychosis in PD patients.

1.2.5 Impulse control disorders

Chronic PD treatment with dopaminergic medications can be related to numerous unexpected behaviours including impulse control disorders or behavioural addictions (Lieberman, 2011; Voon et al., 2017; Weintraub et al., 2010, 2013). These problems may include compulsive gambling, buying, sexual behaviors, and eating and can affect up to 14% of people with PD taking dopamine agonists (Voon et al., 2017). Their impact on personal (e.g, gaining weight), familial (e.g, infidelity, hyper-sexuality), social, and financial well-being (e.g, debts) is very dangerous both for patients and for their caregivers. Despite the fact that dopaminergic medication could be related to impulse control disorders, these drug-induced problems should be considered also in interaction with the neurobiology of PD and with individuals' susceptibility (Rossi et al., 2017; Voon et al., 2017).

Thus, it is important to inform patients and their relatives about these phenomena and their clinical assessment with a careful monitor of the dopamine dosage is fundamental (Weintraub, 2008).

1.2.6 Somatization

Lipowski (1988) conceived somatization as a “specific individual tendency to experience and communicate somatic symptoms in response to psychopathological distress and to seek medical help for it” and suggested that somatic symptoms can be experienced also during the course of a physical illness. Based on this definition, Carrozzino et al. (2017) performed a systematic review of studies investigating the somatization among PD patients. Authors found that the prevalence of somatization may range from 7.0% to 66.7% (Carrozzino et al., 2017). In particular, Bugalho et al. (2012) found that 24 out of the 36 PD patients of their sample experienced pathological levels of somatization symptoms. Similarly, An Italian investigation performed by Siri and colleagues (2010) documented among 486 PD patients devoid of cognitive impairments, somatization, was reported by nearly half of them, especially among female patients.

Concerning somatoform disorders, Onofrj et al. (2010) reported that they occurred in almost the 7.0% of their sample of 412 patients with PD. Furthermore may significantly predict, they patients’ cognitive impairment. In a subsequent investigation, Onofrj et al. (2011) reported patients’ more frequent somatic complaints. In particular, nausea, intolerable gastric pain, burping and retching, confusion, sensation of empty head, dizziness with normal orthostatic blood pressure, hyper-somnolence or insomnia were reported.

Moreover, functional psychogenic movement disorders were reported by PD patients before being diagnosed with PD (Gaig et al., 2006; Pareés et al., 2013a) or were reported as underlying functional psychogenic movement disorders during PD (Baik and Lee, 2012).

However, Carrozzino et al. (2017) suggest that future studies should better investigate that these somatic symptoms by replacing the clinically inadequate diagnostic label of psychogenic parkinsonism with the psychosomatic concept of persistent somatization as conceived by the Diagnostic Criteria for Psychosomatic Research (Carrozzino et al., 2017).

1.3 Studies on patients and caregivers' quality of life

In 1946 the World Health Organization defined health as "a state of complete physical, mental and social well-being and not merely as the absence of disease or infirmity" (WHO, 1946).

This definition of health paved the way to a wider and more comprehensive perspective of investigation for psychological studies. For example, in 1977 Engel proposed his biopsychosocial model, which suggests to consider individuals not only in terms of their biological functioning but as a combination of biological, psychological (thoughts, emotions and behaviors) and social (economical, environmental and cultural) factors. Taken together, these dimensions of functioning play an important role in influencing human beings both in their health and illness conditions (Engel, 1977).

Under this umbrella, when investigating a clinical condition, all of these dimensions should be taken into account together.

Later on, Antonovsky (1979) coined the term "salutogenesis", aimed at propose and opposite term to that of "pathogenesis". According to this perspective, it was more important to focus on individuals' resources and capacity to create health than the classic focus on risks, ill/health, and disease. Thus, clinicians were invited to not only to examine the illness but also to identify and foster the possible protective factors of health.

With these broader definitions of health, studies of patients and caregivers' quality of life (QoL) and health-related quality of life (HRQoL) began to spread out. Different concepts were proposed for these two terms but in general, QoL is considered a measure of the general satisfaction of an individual with his or her life in relation with his or her goals (World Health Organization Quality of Life Group, 1993). Similarly, HRQoL is used in clinical settings and indicates the measure in which physical and psychological symptoms affect QoL (Leplege and Hunt, 1997).

These concepts have been investigated also within PD patients and their caregivers.

Peto and colleagues (1995) developed a specific measure for measuring the impact of PD on patients' quality of life, the Parkinson's Disease Questionnaire (PDQ-39). This measure is one of the most widely used and include the measurement of many dimensions of physical, cognitive, psychological and social functioning of PD patients. In particular, PDQ39 encompasses the following subscales: mobility, activities of daily living, emotional well-being, stigma, social support, cognitions, communication and bodily discomfort. In addition, authors developed the caregiver version, the Parkinson's Disease Questionnaire, PDQ29 item, caregiver version (Jenkinson et al., 2012). The development and validation of a quality of life measure for the carers of people with Parkinson's disease (the PDQ-Carer) for measuring caregivers' quality of life with four subscales (social and personal activities, anxiety and depression, self-care, and stress). These tools represent the most widely used for investigating both PD patients and their caregivers' quality of life (Marinus et al., 2002; Jenkinson et al., 2012).

Suzukamo and colleagues (2006) explored found HRQoL in relation to the severity of PD. They found that impairments of PD are strictly related to HRQoL. However, the most important predictor of HRQoL is represented by patients' ability to adjust to the illness.

Leroi et al. (2011) aimed at studying the effects of apathy and impulse control disorders on disability and HRQoL in individuals with PD (35 with impulse control disorders, 26 with apathy and 38 with neither behavioural complication. Authors found that both groups with behavioral complications IACOMO!(apathy and impulsivity) reported reduced HRQoL. Variation in HRQoL resulted to be explained by higher levels of impulsivity, depression, dopaminergic load, motor complications, working memory problems and younger age at onset.

Alvarado-Bolaños et al. (2015) investigated the prevalence of psychological problems in 492 patients suffering from PD and their effect on QoL (measured with PDQ39). They found that both the presence and severity of neuropsychiatric symptoms (mood/apathy alterations) significantly affected patients’ QoL.

Recently, Navarta-Sánchez et al. (2016) investigated the roles of social conditions and personal attitudes PD patients and their informal caregivers’ QoL. For patients, the main predictor of psychosocial adjustment and QoL was PD severity. Moreover, psychosocial adjustment was significantly related to QoL in patients and caregivers. For caregivers, coping and benefit finding resulted to be other predictors of QoL.

Corallo et al. (2017) investigated PD patients and their caregivers’ QoL and its predictors. Authors found that patients’ cognitive status was a significant predictor of most of the QoL subscales both in patients and in caregivers. Patients’ clinical conditions also significantly affected all of the 36-item Short Form Health Survey subscales. Furthermore, the clinical condition of the patient associated with physical functioning, bodily pain, vitality, and social role functioning. Thus, authors suggested considering the relationship between PD patients QoL and the perceived burden of their caregivers in order to develop interventions for treating their distress.

1.3.1 Caregiver burden in Parkinson’s Disease

As the PD progresses, patients need increasingly more and more assistance in their everyday life. The so-called “informal caregivers” often deliver this assistance (Grün et al., 2016). Informal caregivers provide patient’s phsyical, social and psychological support. In the majority of cases, spouses are the relatives who become caregivers (Glozman, 2004). In particular, this happens for caregivers of a disabled older man. Conversely, for women, her adult child usually takes the responsibility (Glozman, 2004). However, he/she generally has to manage various activities and responsibilities such as those related to family and those related to job.

Caregivers of people with PD have to daily face many obstacles (Tan et al., 2012). They may experience financial burdens (for the medical costs, reduced work hours, loss of employment, etc.), the lack of support from friends and family members, the feeling of not being appreciated enough and the strain of having competing role responsibilities, like having to take care of an elderly parent or a child (Tan et al., 2012). Caregivers might also feel guilty when leaving their sick relative alone or to someone else's care. They might end up excluding leisure time or holidays, and experiencing a sense of being trapped in their role (Tan et al., 2012).

Caregiving for patients with chronic medical illness is associated with significant mental health problems, and mortality, compared to non-caregiver populations (Allen et al., 2017; Cassidy, 2013; Pinquart and Sörensen, 2003; Potier et al., 2017).

In fact, caregiving is a physically and emotionally burdensome and life-changing role that may progressively impoverish the caregiver's social network, and contribute to the disorganization of the family dynamics (Grün et al., 2016).

The strain that characterizes caregiving is particularly evident also within those individuals who assist their relatives who suffer from PD. Partners of patients with PD are usually very willing to take on the role of informal carer, but often are not enough prepared for what will expect to them. Given the progressive and chronic nature of PD. caring may be provided over a long period of time. This may have detrimental effects on the caregiver's quality of life, on his sleep, grief, social isolation, worry and depression (Turney and Kushner, 2017).

Moreover, caregivers have a higher risk of suffering from depressive disorders compared to other family members (Abendroth, Lutz & Young, 2012; Schrag et al., 2004, 2006). Dotchin et al. (2014) documented that caregivers of PD patients may experience more caregiver burden compared to caregivers of individuals with dementia, especially when PD patients are in more advanced phase of illness. Other risk factors concerning caregiver burden (in aging individuals) are represented by the female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver (Adelman et al., 2014). Furthermore, some authors documented that elder spouses are more likely to experience higher levels of stress (Tan et al., 2012; Glozman, 2004; Pinquart and Sörensen, 2007). This must be considered when investigating PD since it is an age-related illness. PD in fact mainly affects aging individuals and in turn their partners that provide them assistance (Mosley et al., 2017).

Furthermore, caregiver burden is strictly associated with patients' mental and physical health (Carter et al., 1998; Schrag et al., 2006). Some factors in fact may amplify the level of burden (Mosley et al., 2017). For example, caregiver burden (or strain) is related to the severity and to the stage of the disease and to neuropsychiatric symptoms. Among non-motor symptoms, patients' depression, hallucinations, or confusion are the most important predictor of caregiver strain and depression, especially in the early phases of the disease (Carter et al., 2008; D'Amelio et al., 2009). Conversely, Schmotz et al. (2017) compared caregivers of patients with late-stage idiopathic PD with caregivers of patients with late-stage progressive supranuclear palsy. He found that caregivers of both groups reported high psychological burden and symptoms of depression. However, differently from previous evidence, authors found no significant influence of motor impairment, cognitive dysfunction, and depressive symptoms of the patient on the burden of the caregiver.

This caregiver burden should be considered together with other risk or protective factors (Abendroth et al., 2012). Every type of PD present a different course and a diverse type of manifestation of the symptoms. Psychological resources (e.g., functional coping strategies, spirituality, well-being, etc.) and social factors (e.g., friends, collaborative relatives, etc.) may also intervene to moderate the caregivers' adaptation to the illness and quality of life (Abendroth et al., 2012).

In conclusion, when considering PD, it is fundamental to include caregiver-burden among the problems associated with PD in order to improve both patient and caregiver lives.

Failure to recognize and manage caregiver burden may lead to burnout and premature institutionalization of the person with PD (Mosley et al., 2017).

1.4 Positive Psychology and chronic medical illness

Historically, the mission of psychology was to treat mental illness and psychological symptoms. Although with the OMS's definition of health and the development of measures concerning QoL and HRQoL the focus of the assessment started shifting, these measures (QoL/HRQoL) limited the investigation of well-being to the subjective reactions to the symptoms experienced and to their effects on their functioning.

Later on, with the development and the growth of positive psychology the need to understand individuals and community's resources began to emerge (Gable and Haidt, 2005).

The mission of Positive Psychology was defined as the scientific study of the strengths that aid individuals and communities to thrive and flourish. Accordingly, people want to live meaningful and fulfilling lives, to cultivate their virtues and strengths, and to enhance their positive moments and experiences of love, work, and play.

Positive psychology does not exclude sufferance and psychological disorders. Conversely, it suggests to take into account both distress and well-being/resources when considering human psychological functioning. Its message is to focus on the positive experiences, traits and virtues rather than on model focused on the illness (Seligman and Csikszentmihalyi, 2000). Within this perspective, human beings should be considered as individuals with inner resources, personal strengths, and positive virtues.

The main topics of positive psychology are positive emotions, positive traits and positive institutions with the aim of to going beyond the curing of mental illness by identifying and nurturing the strengths that enable individuals and communities to thrive. The ultimate aim is to aid individuals to ameliorate their well-being, nurture their happiness and deal with their psychological sufferance (Seligman & Csikszentmihalyi, 2000).

The applications of Positive psychology are numerous. Their theories have been applied in the study of successful and positive aging (Kales, 2014) and in various acute and chronic medical conditions (Barskova and Oesterreich, 2009).

In particular, within this new perspective of positive psychology, more detailed definitions of well-being were proposed and dimensions concerning positive psychological functioning, such as life satisfaction, post-traumatic growth, gratitude and other positive resources have been investigated (Ryff, 2014; Hefferon et al., 2009; Barskova and Oesterreich, 2009).

Under this umbrella, many studies observed how, also in patients who suffer from chronic medical conditions, resources as Posttraumatic Growth (PTG, Tedeschi and Calhoun 1995, 1996 2004), gratitude (McCullough, Kilpatrick, Emmons, and Larson, 2001), and spirituality (Lawler-Row and Elliot, 2015), might associate with a better psychological adaptation to the illness. This occurs both in patients and in their caregivers (Barskova and Oesterreich 2009; Wood, Froh, and Geraghty, 2010; Cassidy, 2013). Furthermore, positive psychological functioning resulted to be related to psychological and subjective well-being. In turn, these two factors resulted to positively influence biological parameters involved in aging processes, protecting both psychological and physical health (Chida and Steptoe, 2008; Ryff et al., 2004; Ryff, 2014; Steptoe et al., 2015; Wood et al., 2008a, 2008b; 2010).

1.4.1 Subjective well-being

Hedonic, or subjective well-being (HWB/SWB) is composed of a cognitive dimension (life satisfaction, LS), and an affective one (the presence of high positive affects and low negative affects) (Diener, 1984).

HWB was found to predict better physical and psychological health in patients and caregivers of patients with various types of medical illness (Fianco et al., 2015; Ostir, Markides, Peek, and Goodwin, 2000; Tsenkova, Love, Singer, and Ryff, 2008; Gil et al., 2004; Devins, Mann, Mandin, and Leonard, 1990; Levy, Lee, Bagley, and Lippman, 1988; Krause, Sternberg, Lottes, and Maides, 1997; Moskowitz, Epel, and Acree, 2008; Ickovics et al., 2006). These benefits are mediated by the protective effect of positive emotions on the immune system (Ickovics et al., 2006; Steptoe, Deaton, and Stone, 2015) and on coping strategies (Burns et al., 2008).

1.4.2 Psychological well-being

The concepts of eudaimonic well-being (EWB) or psychological well-being (PWB) mainly concern those personal and interpersonal characteristics that could help individuals to achieve an optimal level of functioning in their daily life (Ryff, 1989, 2014). Ryff (1989) developed a model by integrating developmental, clinical, theories, mental health perspectives, that encompasses six main dimensions: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth. Later on, other dimensions were considered as parts of PWB, such as the sense of autonomy, competence and relatedness (Ryan and Deci, 2000).

PWB was found to protect against psychological and physical illness both in patients and in caregivers (Anum and Dasti, 2016; Buchman, Barnes, and Bennet, 2010; Friedman and Ryff, 2012; Kim, Sun, Park, and Peterson, 2013a; Ryff, 2014; Ryff et al., 2004; Boyle, Barnes, Buchman, and Bennet, 2009; Kim, Sun, Park, and Peterson, 2013b; Spurlock, 2005).

1.4.3 Post-traumatic growth

After experiencing a potentially traumatic event, such as receiving a diagnosis of life-threatening or chronic illnesses, people may develop not only psychological symptoms but also, sometimes, positive changes (Joseph and Hefferon, 2013; Tedeschi and Calhoun, 1995). They might include enhanced self-perception (e.g., improved recognition of strengths and acceptance of weaknesses), social relationships (e.g., increased empathy and compassion), and positive changes in life philosophies and spirituality (e.g., increased appreciation of life) (Joseph and Hefferon, 2013; Tedeschi and Calhoun, 1995). These dimensions have been grouped under the broad umbrella of PTG or other similar concepts, such as benefit finding

(Affleck and Tennen, 1996). Studies within this field found that, although PTG shows controversial associations with distress, it may protect the psychological and physical adaptation to the illness (Barskova and Osterreich, 2009; Dunigan, Carr, and Steel, 2007; Helgeson, Reynolds, and Tomich, 2006; Kremer and Ironson, 2014a; Ruini et al., 2013).

1.4.4 Spirituality

Religion and spirituality are protective for physical (Krause, Emmons, and Ironson, 2015; Kremer, Ironson, de Deugd, and Mangra, 2014b; McIntosh et al., 2011; Mills et al., 2015) and psychological health outcomes, both in terms of distress and well-being particularly in older adults with chronic medical conditions (Lawler-Row and Elliot, 2015; Jackson and Bergeman, 2011; Krause, 2010; Yoon and Lee, 2004).

1.4.5 Gratitude

In psychological research, gratitude was conceptualized as an emotion (Emmons and McCullough, 2003), a moral affect (McCullough, Kilpatrick, Emmons, and Larson, 2001), or as a trait of personality which lead individuals to notice and appreciate the positive in the world; Wood et al., 2010). Gratitude was found to be associated with HWB and PWB and to protect physical health (Emmons and McCullough, 2003; Park, Peterson, and Seligman, 2004; Seligman et al., 2005; Killen and Macaskill, 2014; Wood et al., 2010). In medical settings also, gratitude may be a protective factor. Particularly, in people with chronic illnesses, pain (Ruini, 2017; Sirois and Wood, 2017), and breast cancer (Ruini and Vescovelli, 2013).

1.5 Well-being and positive psychological resources in patients with Parkinson's Disease and in their caregivers

The beneficial buffering effect of well-being and positive psychological functioning has been largely documented for oncological and cardiovascular diseases, up to date (Barskova and Oesterreich, 2009; Hefferon Grealy, & Mutrie, 2009; Kampman, Hefferon, Wilson, & Beale, 2015; Ruini & Vescovelli, 2013; Ruini et al., 2013; Ryff et al., 2004; Ryff, 2014; Scrignaro, Barni, & Magrin, 2011; Wood et al., 2010). As briefly illustrated in the previous section, only little research investigated the roles of these positive dimensions of psychological functioning in patients with neurological disorders (Barak and Achiron, 2009). The majority of such studies involved patients with multiple sclerosis (Barskova and Oesterreich, 2009).

Among neurological disorders, PD has several disabling consequences that imply progressive loss of personal autonomy and modifications in life styles, in relationships and self-identity (Dural et al., 2003; Birgersson and Edberg, 2004). PD patients need to adapt to these progressive changes, and the process of adaptation may lead patients and their caregivers to experience a personal journey of growth, and resilience. In turn, growth and resilience may facilitate their psychological adaptation to the illness itself (Dural et al., 2003; Birgersson and Edberg, 2004; Pacchetti et al., 2000; Simpson et al., 2006; Weintraub et al., 2006; Gustafsson et al., 2015; Rosengren et al., 2016; Rosqvist et al., 2016; Cubì-Molla et al., 2014; Hammarlund et al., 2014; Kang and Ellis-Hill, 2015; Pusswald et al., 2012; Koch et al., 2016; Sheehy et al., 2017; Mavandadi et al., 2014; Navarta-Sanchez et al., 2016; McCabe and O'Connor, 2012; Bingham and Habermann, 2006; Giaquinto et al., 2010; Iwamoto et al., 2011; Kèri and Kelemen, 2016; Habermann et al. 2013; Hodgson et al., 2004; Petrican et al., 2014; Parveen and Morrison, 2012; Tan et al., 2012). Thus, PD may have a twofold impact on patients and on their caregivers: it may negatively influence individuals' well-being and quality of life, but it may also trigger processes of growth and resilience, as it was found for other chronic conditions. The negative impact has been widely documented by previous literature (see Paragraph 1.1-1.3). However, the positive impact of the illness has received little attention, so far. Thus, the aim of the following paragraph will be to summarize and discuss the primary studies (quantitative, qualitative, empirical and observational), which investigated hedonic well-being, psychological well-being, post-traumatic growth, resilience, gratitude and spirituality in patients suffering from PD.

1.5.1 Subjective well-being and Parkinson’s Disease

Pacchetti et al. (2000) tested the efficacy of music therapy (MT) on motor and emotional functioning in 32 patients with PD. Participants were randomly assigned to two groups: one group participated to weekly sessions of Music Therapy (MT - choral singing, voice exercise, rhythmic, free body movements, and active music) the other group was assigned to weekly sessions of Physical Therapy (PT - passive stretching exercises, specific motor tasks for improving balance and gait). Patients were evaluated with the Unified Parkinson’s Disease Rating Scale (UPDRS) (Martinez-Martin et al., 1994) the Happiness Measure (Fordyce, 1988), and the Parkinson’s Disease Quality of Life Questionnaire (PDQL) (de Boer et al., 1996). Results showed that MT improved motor functioning, especially bradykinesia (measured with UPDRS). Furthermore, MT determined an improvement in emotional functioning both after each MT session and throughout the entire study period. However, when the effect of MT was measured at 2-month follow-up, happiness values returned to baseline levels. On the other hand, PT reduced rigidity in participants, but it showed scarce influence on mood state. Authors attributed the beneficial effect on emotional variables yielded by MT because of its different emotional impact on patients. This impact depended on its significant sensory stimulation and personal interaction during the music sessions. Hence authors recommend considering the important role played by MT in rehabilitation programs for its emotional ingredients that could facilitate movements in PD patients.

Simpson et al. (2006) investigated the relationships between social support and positive affect in 34 PD patients. Social support was measured with open-ended questions and with the subscale of PDQ39 (Peto et al., 1995). Participants completed also the Positive and Negative Affect Schedule (PANAS) (Watson et al., 1988), the Depression Anxiety and Stress Scales (Lovibond et al., 1995) and the Emotional well-being scale of PDQ39 (Peto et al., 1995). Authors found that higher levels of positive affect were related to more quantitative measures of social support, such as more children, and a greater number of close relationships. Conversely, lower levels of satisfaction with social support associated with higher depression, anxiety and stress. According to this investigation, the complexity of these relationships should be considered when implementing interventions for treating psychological distress and promoting happiness in PD. Authors affirmed that the development and encouragement of activities to improve social network and to preserve PD patients' self-esteem is fundamental for maintaining their well-being.

Weintraub et al. (2006) investigated the daily affective experiences of 24 patients with PD and their relation with daily events and motor symptoms. Patients and a comparison group of 23 healthy individuals completed the Lawton's Positive and Negative Affect rating scale (Lawton et al., 1995) for measuring daily affect and they recorded significant positive and negative events. Patients' clinical status was investigated with UPDRS (Martinez-Martin et al., 1994) and with a self-report questionnaire of PD symptoms. All these data were collected for 4 consecutive weeks. Patients with PD reported significantly less positive and more negative affect than controls over time. There were similar associations between negative events and affect in both groups. Although patients reported fewer positive events than controls, they reported an improvement in affect in response to them. Regarding self-reported PD symptoms, only increasing severity of motor symptoms was independently related with worse affect. Authors concluded that patients do not demonstrate anhedonia in response to positive life events, as expected by the effect of the illness on dopamine. Thus, rehabilitation interventions that favor daily engagement in positive experiences and improve positive affect might be implemented also in these patients.

Dural et al. (2003) investigated the relationships between motor and musculoskeletal impairments and LS in 48 patients with PD. Life Satisfaction Index (Neugarten et al., 1961) together with UPDRS (Martinez-Martin et al., 1994) and other specific measures for detecting impairments in PD were used. Motor and musculoskeletal impairments resulted to be related to the severity of disability. Bradykinesia and musculoskeletal impairments appeared negatively associated with LS. In light of these findings, authors suggest that an ideal rehabilitation program of patients with PD should focus on improving motor impairments such as bradykinesia as well as musculoskeletal impairments even in the early stages of the disease. Moreover, preserving motor and musculoskeletal functioning may help preserving PD patients' LS.

Gustafsson et al. (2015) investigated the relationships between LS and work employment in 1.432 individuals with PD and 1.135 matched controls of working-aged individuals. In this study LS was measured using 4 domains (life as a whole, employment situation, financial situation, and leisure) from the Life Satisfaction Questionnaire 11 (LiSat-11) (Fugl-Meyer et al., 2002). Employers with PD were those who reported lower LS and reduced likelihood of employment. Among them, those who experienced more social support (support received from other employees and from company health services) reported a greater likelihood of employment. However, a working situation balanced with individuals' competences resulted to be more difficult to achieve for people with PD, and they more frequently experienced work demands that exceeded their capacity, compared to controls. Thus, employees with PD resulted to have an impaired work inclusion, and this fact could relate to lower LS. Authors concluded that the opportunity to remain active and to experience greater LS could be favored by improving the work environment and the social support network of patients with PD.

Rosengren et al. (2016) investigated relationships between LS and other measures of distress and positive functioning in 80 persons with mild to moderate PD. Patients completed the Satisfaction With Life Scale (Diener et al., 1985), the Sense of Coherence scale (SOC-13) (Eriksson et al., 2007), the Reintegration to Normal Living Index (Wood-Dauphinee et al., 1998), and the Geriatric Depression Scale (Gottfries et al., 1997). They found that patients were able to remain generally satisfied with their lives, but LS may decrease as the disease progresses. Furthermore, a strong positive association emerged between LS, acceptance and adaptability to the illness (measured with SOC-13) (Eriksson et al., 2007). SOC is a well-established measure for positive coping strategies that usually is directly related to a better adaptation to medical and psychiatric illnesses in clinical populations. This is the first study that examines the correlations between SOC and LS in PD patients. Authors suggested to promote these protective factors (SOC and LS) through specific rehabilitation programs in order to help patients with PD to better understand, face and accept problems related to their illness.

Rosqvist et al. (2016) aimed at exploring the possible psychological and physical correlates of LS in 251 individuals with earlier and longer stage of PD. Patients underwent an extensive assessment consisting of LiSat-11 (Fugl-Meyer et al., 2002), Parkinson’s Disease Activities of Daily Living Scale (Hobson et al. 2001), UPDRS (Martinez-Martin et al., 1994), General Self-Efficacy (Nilsson et al., 2015) and Geriatric Depression Scale (Yesavage and Sheikh, 1986). In the whole sample, when controlling for age and gender, LS was negatively associated with depressive symptoms and positively associated with self-efficacy. Furthermore, other (weaker) predictors of LS were represented by the need of help with activities of daily living, walking difficulties, number of non-motor symptoms, motor symptoms, pain, PD severity, freezing episodes, and fluctuations. In patients with longer stages of PD, LS was inversely related to motor symptoms (e.g., walking difficulties), to non-motor symptoms (e.g., number of non-motor symptoms, fatigue, etc.) and directly related to personal factor (e.g., self-efficacy). This is the first research that documents an important link between LS and mental health in PD patients, with higher levels of LS associated with lower depressive and psychosomatic symptoms (such as fatigue) and vice versa. Furthermore, associations between LS and motor functioning also emerged. Authors recommended taking into account the reciprocal relationships among these variables when implementing interventions for improving mental health of patients with PD.

Cubí-Mollá et al. (2014) compared traditional measures of HRQoL with measures of SWB for measuring QoL and well-being in 199 patients with PD. They used the EuroQol five-dimensional questionnaire instrument (EQ-5D) (The EuroQoL Group, 1990). SWB was measured with four questions taken from the Integrated Household Survey (Dolan and Metcalfe, 2011). They found that the EQ-5D failed to capture important well-being aspects related to SWB and to the illness. Dimensions such as “having someone to count on in times of difficulty” or “trust in one’s community” are not included by the measures of health used by health care decision-making. Indeed, these factors, measured by SWB index, could help to understand how patients with PD living with a caregiver could experience higher SWB than those living alone. Since measures such as EQ-5D cannot capture them, authors of this research suggested that SWB index should be considered as a complement to conventional and too generic measures of HRQoL for evaluating patients suffering from serious chronic illnesses as PD.

Petrican et al. (2014) studied the relationship between the SWB (measured with Subjective well-being scales, Diener, 1984) of 37 individuals with PD and their partners and their ability to identify each other's emotions and compared them with healthy couples. In the healthy control couples, they found no effect of emotion identification on hedonic balance, but that ability to identify positive emotional states was associated with more life satisfaction. In couples in which one partner suffered from PD, authors found that the healthy spouses were more accurate in identifying positive emotions such as happiness, but less accurate in identifying negative emotions such as sadness than healthy couples. As the PD progresses, both tendencies got weaker. Furthermore, authors found on all of the couples no effect of the ability to identify emotional states on hedonic balance. In couples with a PD partner, satisfaction with life increased with spousal ability to identify negative emotions, specifically sadness. This effect got stronger with more years from PD symptoms onset. This study indicated that, for people with PD, the primary caregiver's ability to understand his/her assisted negative emotions may have a protective role for preserving a better hedonic balance.

1.5.2 Psychological well-being and Parkinson’s Disease

Hammarlund et al. (2014) interviewed 11 persons with PD with two open questions concerning the psychological and physical impact of preserving the ability to walk (in terms of experiences, aspects and the perceived significance) and their functional coping strategies. Participants had to report their level of mobility and PD symptoms. From the qualitative investigations, the ability to walk resulted to produce a multifaceted impact on patients. Such impact could be summarized in five main categories: changed walking ability, emotional reactions, strategies to manage the impact of walking difficulties, social consequences, independence and integrity. Authors observed particular relationships among these categories: emotional reactions to physical symptoms were modulated by coping strategies, that, in turn, played a role in facing the social consequences and independence/integrity. Particularly, the ability to remain active in daily life and to play a role and contribute to society favoured physical, psychological and emotional benefits. Conversely, walking difficulties negatively influenced participants' self-concept. In conclusions, despite the disabilities of PD, when these patients can walk and contribute to their social world, their sense of identity, autonomy, and purpose appeared to be maintained. Therapies should thus address not only walking and mobility *per se,* but also consider each individuals' emotional and psychological factors.

Similarly, Kang and Ellis-Hill (2015) asked 8 people with PD with duration of illness from 2 to 16 years what they considered as living successfully with PD and to rate its level. The meaning of successful living was considered as maintaining either the usual state of health or a readjusted state of health, maintaining skills in daily activities. Particularly, 5 of the participants (in the early stages of the disease) described successful living as the ability to live the usual life as they did before PD. Moreover, they compared their current life with their pre-illness life. They attributed the successful living mainly to effective medication, personal effort, or relatively mild symptoms, and to the fact that their usual routines and physical appearance had not changed much. Further, they mentioned the importance of maintaining social roles and activities that were abandoned when symptoms manifested (e.g., driving a car). On the other hand, participants also felt successful when they re-adjusted their state of health, and developed a sense of confidence in facing PD. Another aspect of this "readjusted state of health" pertained to the sense of acceptance of the illness and its difficulties. Particularly, sharing information about the illness helped participants both to better understand the situation and to deal with social stigma and isolation. In fact, two of the participants who had lived with PD the longest scored their level of success the highest and linked it to the maintenance of physical independence and psychosocial contribution to other individuals' lives. These skills fostered their sense of identity and dignity. These two participants also reported a strong sense of persistence in coping with the most stressful and painful moments of symptom exacerbation. Moreover, as strategies to gain sense of control, participants mentioned the importance of maintaining a positive mindset, which was protective against negative moments and related to more positive relations. Adequate social comparison with other ill people and the support of family and friends were also helpful factors. Finally, most of the patients participated to social activities such as physical activity, walking, poetry and painting, which were experienced as beneficial for both physical and emotional well-being. This study highlighted how maintaining an active role, feeling confidence and a sense of contribution to others' lives and to society as well as engaging in meaningful, fulfilling and pleasant activities might protect patients' mental health and quality of life and should be considered by care plans.

Using a quantitative methodology, Pusswald et al. (2012) examined the correlations among well-being and depression in 51 patients suffering from PD. Patients were compared with 59 individuals suffering from other chronic non-neurological diseases. Patients participated to an extensive medical routine examination including a cognitive evaluation with MMSE (Folstein et al., 1975) and a neurological assessment with UPDRS (Martinez-Martin et al., 1994). Furthermore, patients completed the PDQ-39 (Peto et al., 1995), a measure of PD patients physical, emotional, and psychosocial quality of life (the higher the score the more impaired is QoL). All participants completed Psychological Well-being Scales (PWBS) (Ryff, 1989), SOC (Eriksson et al., 2007), Geriatric Depression Scale (Bach et al., 1995), and a measure of coping style. Patients reported significantly lower levels of well-being and higher levels of depression compared to controls. Particularly, patients reported lower levels of environmental mastery, self-acceptance, personal growth and sense of coherence. When investigating motor functioning with UPDRS, negative correlations with some dimensions of well-being as personal growth, purpose in life. Authors concluded that the relationship between well-being and severity of disease is particularly important when examining PD course. Their combined assessment may help clinicians to better depict profiles of patients’ resources and to tailor psychological treatments to their specific needs.

Koch et al. (2016) aimed to assess the feasibility of a single Argentine Tango intervention in 34 PD patients in terms of well-being, body self-efficacy, outcome expectations, and experienced beauty. Patients completed the Heidelberg State Inventory (Koch et al., 2007) as a measure of well-being and the Body Self-Efficacy Scale (Fuchs and Koch, 2014) before and after the intervention. Furthermore, a subgroup of patients completed the Therapeutic Factors of Arts Therapies in PD related to the Aesthetic Experience (Mergheim, 2015) that includes positive emotions as beauty, flow, happiness, pleasure/joy, etc. The intervention determined an improvement in well-being, in body self-efficacy, and in health condition. Participants also reported an increased perception of beauty in their movements and increased feelings of happiness, pleasure and joy. Authors suggested that the aesthetic experience provided by tango, may represent an important therapeutic factor that could be added to well-established physical therapy. However, this hypothesis should be tested in future controlled studies.

More recently, Smith and Shaw (2017) investigated the psychological experiences and the opportunities of well-being of family members of patients with PD by using an interpretative phenomenological analysis (IPA; Smith et al. 2009) in nine PD patients and their partners. Four main themes emerged from analysis: “It’s more than just an illness”, which concerns the existential changes related to the diagnosis such as doubts and myths about the illness, the experience of receiving the diagnosis as a bombshell, and the possible disruption of self. Then, another theme was “Like a bird with a broken wing”, which refers to the need to adapt to increasing loss of physical autonomy and increasing physical disability through embodied agency and self-reparatory actions; In addition, there is “Being together with PD”, which regards the kinship within couples, the sense of connectedness and the sense of duty. Finally, the theme “Carpe diem” concerns the significance of time, the sense of uncertainty about the future with the efforts to make new meanings. Authors suggested that partners shared the impact of PD and tried to make meaning of the illness together. Interventions should provide emotional support for the threats to self-identity and for helping patients and their spouses to increase their relational sense of agency. Moreover, interventions should provide help for bodily changes in order to give patients and caregivers more opportunities for well-being.

1.5.3 Post-traumatic growth and Parkinson's Disease

Sheehy (2017) interviewed 20 patients with PD through a semi-structured interview, with questions concerning their decision to join a physical activity program, their ability to exercise, challenges or difficulties with participation, their perceptions of social relationships, support and social environment, and changes experienced as a result of being part of the program. By using a qualitative analysis (Smith et al., 2009) authors found that seeing other people in worse conditions who could overcome physical challenges, increased patients' hope to be able to overcome the same challenges. This mechanism indicated a shift in their focus from controlling the disease itself to control their physical abilities, an area amenable of improvement. Such shift helped them to rebuild a more positive identity. Another theme that emerged was humor. Joking about the symptoms helped participants to reframe them as normal and reduced their anxiety about the public display. Thus, a new, more positive, realized sense of self after PD onset emerged from this qualitative study.

Mavandadi and colleagues (2014) analyzed the impact of benefit finding through the Benefit Finding Scale (Antoni et al., 2001) on marital quality of 25 married couples, with one member with PD. Both patients and caregivers completed Patient Health Questionnaire (Kroenke et al., 2001), Spielberger's State Anxiety Scale (Spielberger et al., 1983), the Satisfaction with Life Scale (Pavot et al., 1991), and the 12-item negative exchanges subscale of the Positive and Negative Social Exchanges scale (Newsom et al., 2003). Patients and their spouses perceived the best marital quality when their spouse reported finding benefits as a consequence of dealing with the illness. Additionally, the perceived marital quality was associated with higher benefit finding. Authors hypothesized that the perception of benefits might have influenced marital quality both through a direct effect and through other mechanisms including better adjustment, fewer depressive symptoms, improved personal skills and resources. Finally, married couple considered the possibility that the experience of growing together through adversity led them to construct a shared view of their life circumstances as coherent and meaningful. This fact, in turn, could have endowed them with better adjustment and marital functioning. Thus, even within couples with one member suffering from PD, relationships could be enhanced and partners could find benefits, despite the experience of burden and distress.

Navarta-Sanchez et al. (2016) examined psychosocial adjustment and quality of life determinants of 91 PD patients and their caregivers. Patients completed Parkinson's Disease Questionnaire (PDQ-39) (Peto et al., 1995), the Benefit Finding Scale (Antoni et al., 2001), the Psychosocial Adjustment to Illness Scale Self-Report (Derogatis, 1986), and the Hoen and Yahr scale (1967). Although patients and caregivers reported more than half of the benefits included in the scale, benefit finding was found to be a predictor of QoL only in caregivers but not in patients. Thus, multidisciplinary interventions aimed at improving PD patients' QoL should differentiate according to the specific needs and difficulties of each population (patients vs caregivers).

Parveen and Morrison (2012) examined the predictors of gains (intended as positive changes) in 123 caregivers of people with various medical diagnoses in different time periods (time 1 = baseline; time 2 = 3 months from baseline; time 3 = 9 months from baseline). The most common diagnosis consisted of PD (n=38). Authors observed that at different time points there were different processes of changes and different predictors. First, authors documented that caregiver positive changes were found to remain stable over time. This was surprising considering the huge amount of literature showing the potential progressive increase of gains and positive changes with more years after the initial stress (such as receiving a diagnosis of a chronic illness) (Janoff-Bulman and Frantz, 1997). However, gains themselves did not change whereas predictors did. While a greater understanding of the illness was found to be a significant predictor of caregiver gains at time 2, it did not remain predictive of positive changes at time 3. Authors proposed that understanding the illness might be a necessary condition for caregivers to start perceiving benefits. Although the number of caregiving tasks was not predictive of gains, spending more time with their assisted them emerged as predictive of high caregiver gains at time 3. Intuitively, this seems to indicate that more time spent providing care provides more chances to find benefit in the activity. The use of active coping strategies was associated with more perceived gains at time 2, while increased use of self-distraction and denial were strong predictors of time 3 gains. This seems to indicate that active coping strategies are more successful earlier in the course of the disease, while at later stages, when caregiving becomes a more pervasive activity, the ability to "disconnect" from the role might be more beneficial.

When considering caregiving, Habermann et al. (2013) performed a qualitative exploration of the experience of adult children caring for parents with neurodegenerative disorders (n=8, 24% of the sample consisted of caregivers of patients with PD). A majority of participants (including all of those whose parent suffered from PD) attributed their positive experiences to their relationship with their ill parent. From the qualitative analysis, the following three different categories were found. First, “spending and enjoying time together” in which it emerged that caregivers enjoyed spending time with their parent and at the same time seeing their parent enjoying the time together, regardless of the type of activity. Secondly, “appreciating each other and becoming closer” in which caregivers reported to appreciate the possibility to take care for their parent. This appreciation related to the sense of gratitude that the parent manifested. Moreover, it was associated with the fact that caregivers experienced a sort of deepening of their relationship with their parent or an improvement of family bonds, not only between themselves and ill parent but also between the ill parent and their own children. Finally, the third theme was represented by “returning and giving back care”. With this category, many of the caregivers reported to be willing and happy for being able to provide care for their parent like their parent did for them when they were younger, an act that was described as “return[ing] the favor”. Finally, caregivers who had positive experiences in caregiving such as those related to gratitude, they also experienced fewer feelings of being overwhelmed or distressed by their stressful situation.

In another qualitative analysis (Tan et al., 2012), examined the psychological experience of 21 caregivers of patients with PD. In particular, 11 sub-themes were identified, which were organized into four key themes. First, “coping and adaptation” pertains to the coping strategies and tasks they had to deal with such as fears, anxiety and worries concerning their assisted health condition. Secondly, “challenges of caregiving” refers to the main challenges that the caregivers face as the disease progressed, such as financial burdens and long-term complications. Third, “effects of caregiving on the caregivers”. Within this theme, it emerged that 17 out of 21 caregivers of people with PD had adapted positively to changed social situations and that caregiving had provided them with satisfaction and improved family bonds. Two of them, who were caring for their spouses but experience a non-satisfying marital relationship, found that the disease had provided them opportunities to strengthen their relationship through adopting a different perspective and learning patience. Finally, the theme “need for better caregiver support” revealed the needs of caregivers for more information about how to manage PD and more support. The progressive impairment of PD patients was found to be related to caregiver burden and to their emotional well-being. Thus, the study suggested the importance of providing caregivers with support and formal education for reducing their burden even at the early stage of the illness (Tan et al., 2012).

Hodgson et al. (2004) performed a phenomenological investigation with 10 couples in which one member suffered from PD. Five main themes emerged from the analysis, “content about their relationship and disease history”, “their couple relationship”, “the impact of PD on the self and others”, “their connection with resources” and “strategies for survival”. Although the focus of the study was not primarily positive functioning, authors found that in the majority of the couples examined, (8 out of 10) PD determined a positive impact. In fact, many couples mentioned how living with PD reaffirmed their commitment to one another, and in some cases it appeared to have saved a doomed relationship. One caregiver even went as far as calling PD "a blessing in that respect”.

1.5.4 Spirituality, gratitude and Parkinson's Disease

Birgersson and Edberg (2004) examined the characteristics and sources of social support (spirituality and religion included) in 6 individuals with PD and their caregivers. What emerged from the qualitative analysis was that the support was mainly directed to the person who suffers from PD. Conversely, partners reported to experience poor support. Two overall main themes emerged in the whole sample: "being in the light" or "being in the shade of support". The first category was associated with feeling of being satisfied for patients, whereas it was related to the feeling of receiving attention for caregivers. "Being in the shade" meant feeling humiliated for patients and being neglected for the carers. While patients felt themselves to be in the light, their partners mainly were in the shade of the support. Nonetheless, the majority of the six couples reported religion and spirituality as sources of support. A feeling of community with God or Mother Nature instilled them with feelings of strengths and confidence in "carrying on". Although, this research focused on the role of support, it emerged that religiosity may represent one of the most important source of support.

Another qualitative study (Bingham and Habermann, 2006) examined the role of spirituality in defining and managing the daily experiences of 27 individuals with PD and their partners or son. Five categories corresponding to functional coping religious/spiritual strategies emerged from the analysis: 1) Believing that faith and religious beliefs assisted them in dealing with the challenges and difficulties of the illness; 2) Providing purpose and meaning by believing that God had a reason or purpose for the disease, and this helped them to better accept its consequences; 3) Establishing a connection with God by praying, which represented a way to communicate desires and to receive guidance in facing the disease; 4) Establishing a connection with other friends who provided them support in their church particularly for family members. Conversely, patients were often unable to attend church and mostly found support within their families; 5) Feeling a sense of gratitude, hope, and of being blessed for being still able to attend church or to take care of the patients. These aspects helped patients to focus on their resources rather than on their limitations. Authors concluded that spirituality influenced the day-to-day management of the illness and also the families' sense of confidence in facing the possible future consequences of the illness. This study highlighted the importance of religion for coping with the illness, favouring patients’ psychological adaptation to it, and helping them to discover and focus on their positive resources and emotions.

Giaquinto et al. (2010) compared religious and spiritual beliefs in 83 Christian individuals with PD, 79 hypertensive individuals not affected by PD and 88 healthy controls. Participants completed the Royal Free Interview for religious and spiritual beliefs (King et al., 1995), and UPDRS (Martinez-Martin et al., 1994), together with MMSE (Folstein et al., 1975), PD participants and controls did not differ on religiosity and spirituality. Among patients with PD, levels of religiosity and spirituality were unrelated to the severity of the disease, depression and age, and were higher among women. Thus, religious/spiritual beliefs appeared to be generally maintained in PD in spite of the disease severity. However, differently from other medical conditions (Lucette et al., 2016), spirituality did not seem to play a protective role for depression in this sample of individuals, maybe because these patients have not a recovery trend, although drugs can alleviate symptoms. Moreover, in PD, depression could be sustained not only by psychological factors but also by organic factors (frontal dysfunction) (McNamara et al., 2003) and by poorer cognitive functioning (Klepac et al., 2008). Therefore, future studies should better clarify the possible beneficial effect of religious and spiritual coping for psychological health of PD patients.

Iwamoto et al. (2011) performed a study on self-transcendence, a personality trait related to the experience of spirituality and to mental and physical health (Norberg et al., 2015), in 44 individuals suffering from various chronic illnesses, including PD. Patients were compared to a healthy sample of 1854 individuals and completed the Self-Transcendence Scale (Nakamura, 1998), the WHO-Subjective Inventory (Sell and Nagapal, 1992) and the Mini-International Neuropsychiatric Interview (Sheehan et al., 1997). Participants were grouped in five category based on area/system that was affected by their illness. The “system group were: neural/muscle system (PD included), digestive system, immunity/blood system, visual system, and bone/joint system. All disease groups reported higher self-transcendence than the control group, particularly the neural/muscle system group.

Furthermore, self-transcendence positively correlated to subjective well-being. Findings suggested that, by experiencing a life-changing disease and its challenges, patients with PD may develop or foster their self-transcendence. In turn, this may lead them to experience a sense of positivity despite the physical and mental suffering.

The investigation of Kéri and Kelemen (2016) started from an opposite perspective: patients with PD may show decline in their spirituality because of the illness. They examined hypo-religiosity in 28 newly diagnosed, never-medicated patients with PD and 30 matched healthy control individuals. Participants completed the Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) (Masters, 2013), the Stolz's index of Christian religiosity (Stolz, 2009), and the Francis Scale of Attitude to Christianity (Francis, 1989). Their clinical symptoms were evaluated with UPDRS (Martinez-Martin et al., 1994), Hamilton Depression Rating Scale (Williams, 2001), and Hamilton Anxiety Rating Scale (Maier et al., 1988). While patients reported lower spirituality on the BMMRS compared to controls, beliefs and attitudes related to their Christian religion appeared unchanged. Thus, the state of the disease was related with reduced spirituality, but not when considering Christian faith and its religious practices. These results suggested that dissociation between general spirituality and traditional religious faith could exist for PD patients. Authors claimed that results are in accordance with the separate file hypothesis. It suggests that disease processes may influence general aspects of spirituality, religious/existential goal attribution, feelings of meaning and purpose, and practices/rituals, but the belief, symbol, and practice systems of the self-identified religion are less changed.

McGwin (2011) examined the relationship between trait gratitude and social, psychological, and physical distress in people with PD. Trait gratitude was assessed with the Gratitude Questionnaire 6 (GQ-6; McCullough, Emmons, and Tsang, 2002). Participants with high levels of trait gratitude had lower levels of social distress, but no association was found between gratitude and physical or psychological distress. This study supports the idea that gratitude is a social construct, and as such can help improve or maintain good social relations. As for its possible link with psychological and physical distress, the author suggests that it might have been obfuscated by the small sample size (McGwin, 2011).

1.6 Conclusions

PD represents can determine significant levels of impairments and disability in physical, psychological and social functioning. Given its progressive neurodegenerative nature, it affects also those family members. It imposes them a great burden and force them to take new roles with the risk of experiencing high levels of emotional distress. Thus, also their mental and physical health could be impaired by such an event. While historically, studies adopted a neuropsychiatric perspective focusing on PD impairments, disability and negative consequences, with the growth of Positive Psychology, the perspective has been broadening. Studies on PD Well-being and positive psychological resources such as post-traumatic growth, spirituality and gratitude were examined in patients and caregivers suffering from PD.

CHAPTER 2

WELL-BEING, QUALITY OF LIFE AND DISTRESS IN PARKINSON’S DISEASE: A COMPARATIVE ANALYSIS

2.1 Introduction

Studies on people suffering from Parkinson’ Disease (PD) were mainly based on a neurological and psychiatric perspective, which focused on patients’ psychological problems (Peters et al., 2011; Sagna et al., 2014; Starkstein et al., 2015; Wee et al., 2016). With the World Health Organization’s definition of health (1948) as "a state of complete physical, mental and social well-being", the focus of the studies in medical settings started shifting towards well-being. However, such a concept has been vastly misinterpreted as a lack of symptoms. Within this perspective the initial investigations measured well-being with instruments concerning health related quality of life or coping strategy, and they showed that these dimensions are impaired in PD patients due to the illness related consequences (Fereshtehnejad et al., 2014; Hurt et al., 2011; Peters et al., 2011; Martinez-Martin et al., 2015). The recent development of positive psychology allowed a broader perspective on the relationship between well-being and distress (Gable and Haidt, 2005; Seligman et al., 2005). First of all, more detailed definitions of well-being were proposed. Two main perspectives on well-being have been developed: one investigating subjective well-being (SWB; Diener, 1984) and another investigating psychological well-being (PWB; Ryff, 1989). SWB refers to individuals’ cognitive and affective evaluation of their lives. In particular, SWB comprises three facets: a general cognitive evaluation of life as being good (life satisfaction), the experience of positive emotions, and few negative emotions. The concept of PWB mainly concerns those personal and interpersonal characteristics that could help individuals thrive and achieve an optimal level of functioning in their life (Ryff, 1989, 2014). Within this umbrella, Ryff (1989) developed a model that encompasses six main dimensions: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth. Both SWB and PWB associated with better mental health and psychological adaptation to chronic illnesses (Barskova and Oesterreich, 2009; Wood et al., 2010). Furthermore, these two variables were found to positively influence biological parameters involved in aging processes. Thus, SWB and PWB are considered protective factors for both psychological and physical health (Ruini et al., 2013; Ryff et al., 2004, 2014; Wood et al., 2010).

However, sparse research has explored these dimensions in patients with PD (Cubí-Mollá et al., 2014; Dural et al., 2003; Gustafsson et al., 2015; Kang and Ellis-Hill, 2015; Pusswald et al., 2012; Rosengren et al., 2016). The few available studies showed statistically significant correlations between psychological well-being and life satisfaction and the preservation of motor skills and autonomy. Furthermore, psychological well-being and life satisfaction were found to play a protective role for PD patients mental health when facing illness-related struggles (Kang and Ellis-Hill, 2015; Gustafsson et al., 2015; Pusswald et al., 2012; Rosengren et al., 2016; Rosqvist et al. 2016; Weintraub et al., 2004). However, only few investigations compared the levels of well-being of PD patients to those of healthy controls (Gustafsson et al., 2015; Pusswald et al., 2012; Weintraub et al., 2004). These existing studies found that patients reported more impaired levels of psychological well-being and life satisfaction compared to controls.

Another limitation of previous literature on this issue, concerns the fact that the majority of investigations are pilot experience with a qualitative methodology of assessment. Although numerous self-report questionnaires to measure PWB (Brandel et al., 2017) are available, only few have been applied to investigate well-being in neurological disorders (Bassi et al., 2016; Brandel et al., 2017; Pusswald et al., 2012). Thus, most information on PD patients' well-being derives from interviews or other qualitative measures. Despite their clinical usefulness, qualitative measures could provide only descriptive information with scarce scientific reliability.

In order to address these criticisms, the present investigation aims at measuring quality of life, well-being (life satisfaction, psychological well-being) and distress in patients with PD using standardized and reliable questionnaires. This patient population may be of particular interest because of their deficits in recognizing emotions, compared to healthy controls (Kan et al., 2002; Wagenbreth et al., 2016). In addition, apathy is considered a core symptom of PD and was found to be related to dopamine depletion or to a negative emotional consequence of disability and activity restriction (Cronin-Golomb, 2013; Jankovic, 2008). Given the important role played by well-being and positive emotions on the adaptation to chronic illness and the peculiarity of PD, we aimed to compare PD patients with a sample of individuals matched for socio-demographical variables. Thus, we recruited a control group reporting general health problems related to the normal aging process and devoid of neurodegenerative illness.

It was hypothesized that patients with PD would report lower levels of well-being (both psychological well-being and life satisfaction), lower levels of quality of life and higher levels of distress compared to controls.

2.2 Methods

2.2.1. Participants

For the purpose of the study, 113 individuals were consecutively recruited (53 patients with PD and 60 controls). (For more details see figure 2.1 – flowchart). PD patients were recruited from a rehabilitation outpatient clinic in Northern Italy where they were involved in physical rehabilitation programs. Inclusion criteria for the present research were as follows: diagnosis of PD (established by previous neurological examination based on specific clinical criteria and neurological tests); Hoehn and Yahr stage < 4; Mini Mental State Examination (MMSE; Folstein et al., 1983) > 24; absence of any psychiatric disease or any other type of cognitive deterioration, as established by an initial psychiatric screening performed by a registered clinical psychologist. No one (n=53) refused to participate but three patients were excluded: one because of a score on the MMSE of 20, and two because they showed severe symptoms of depression

Individuals in the control group (CG) were referred to the study protocol consecutively by their general practitioners who collaborated to the recruitment process for this research. Their medical centers were located in Northern Italy. In order to be included in the study protocol, participants had to meet the following criteria: age range = 50-85 years; MMSE (Folstein et al., 1983) > 24; absence of any psychiatric disease or any other type of cognitive deterioration; absence of a neurodegenerative and neurological chronic illness as evaluated by their general practitioners.

After explaining the study aim and procedure, participants in both groups accepted on a voluntary basis. Among the CG, 7 participants withdrew from the study due to personal and organizational impediments. All participants gave their written consent to participate in this study.

The Ethics Committee of the rehabilitation center approved the study protocol.

2.2.2 Measures

2.2.2.1 Clinical measures for PD patients

All PD patients underwent a routine medical examination concerning their neurological status, onset of symptoms, duration of illness, and measurement of motor disability with the *Unified Parkinson Disease Rating Scale* (UPDRS; Martinez-Martin et al., 1994).

Their functional status was evaluated with the *Hoehn and Yahr's scale* (1967). An assessment of cognitive functioning was performed using the MMSE (Folstein et al., 1983). Furthermore, all patients were assessed on their regular dopaminergic medication. The majority of patients was on treatment with dopamine (see table 2.1 for mean dosage) and adjuvant drug therapy. Only 3 patients were not taking dopamine.

2.2.2.2. Psychological measures for all participants

PD patients and controls were compared on the following self-report questionnaires:

The *Psychological Well-Being Scales* (PWB) (Ryff, 1989) which is a 42 item self-rating inventory that covers the 6 areas of psychological well-being: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self- acceptance. Subjects respond with a six-point format ranging from "strongly disagree" to "strongly agree". Responses to negatively scored items are reversed in the final scoring on the dimension assessed. The Italian version of PWB scales has satisfactory test-retest reliability (ranging between .81 and .88 in a six-week interval) (Ruini et al., 2003) and is inversely related to measures of psychological distress (Kellner, 1987). In the present study the Cronbach's Alpha was 0.677 (total scale).

The *Symptom Questionnaire* (SQ; Kellner, 1987) is a 92-item self-rating scale that yields 4 scales of distress (anxiety, depression, somatization and hostility-irritability) and 4 associated scales of well-being (relaxation, contentment, physical well-being and friendliness). Each symptom scale score may range from 0 to 17; each well-being scale scores from 0 to 6. The SQ was previously validated in an Italian population and has been found to be a sensitive instrument to detect changes in clinical trials, showing good split-half reliability (Fava et al., 1983; Kellner, 1987). In the present study the Cronbach's Alpha for the SQ total was 0.959.

Two single item scales were used to measure quality of life and life satisfaction:

The *Quality of life (QoL) scale* in which a general question was used to investigate quality of life: “How would you rate your quality of life?”. Participants have to respond on a Likert scale from 4 “excellent” to 0 “very poor”. This item was derived from Psychosocial Index (Sonino and Fava, 1998). This tool measures both distress and quality of life and has been largely applied in many clinical and medical settings (Sonino and Fava, 1998).

For *Life Satisfaction* (LS; *Personal Wellbeing Index*; International Wellbeing Group, 2013), a general question was used to investigate satisfaction with life: “Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?”. Participants had to respond on a Likert scale from 0 “No satisfaction at all” to 10 “Completely satisfied”. According to its manual the Personal Wellbeing Index could investigate life satisfaction in various life domains (e.g., employment, family, living conditions, etc.) or it could be used as a global evaluation using a single item. This latter modality is reliable and valid for research purpose (International Wellbeing Group, 2013).

2.2.3 Data analyses

The design of the study is cross-sectional and comparative.

Descriptive statistics were calculated for the whole sample by performing *t* tests for independent samples and chi square test. Differences between the PD group and CG in LS, PWBS, QoL and SQ were analyzed by running two separate univariate analyses (for LS and QoL) and two separate multivariate analyses (for PWB, SQ). The partial eta-squared (η_p^2) as a measure of effect size was calculated considering a value of 0.1 as a large effect, a value of 0.04 as a medium effect and a value of 0.01 as a small effect (Huberty, 2002).

Three regression analyses were performed in the whole sample to test if socio-demographic factors (age, gender, marital status, employment) and group condition (patients suffering from PD vs healthy controls) significantly predicted individuals’ PWB total score, LS and QoL. Furthermore, three separate regression analyses have been calculated in the PD group only, with the purpose of evaluating the role of socio-demographic (age, marital status) and clinical variables (function (UPDRS), MMSE score, psychotropic medication (dopamine levels)) in influencing PWB tot, LS, and QoL.

The level of significance was set at $p < 0.05$. The Statistical Package for the Social Sciences (SPSS, Version 23) was used for analyses.

2.3 Results

Table 2.1 shows the descriptive statistics of the whole sample and of the two subgroups (PD and CG). Among PD patients, 15 were women (30%) and 35 were men (70%), aged 70.6 ± 7.5 (age range = 52-84 years), and the mean years of formal education were 10.0 ± 4.2. Mean PD duration was 6.4 ± 5.3, mean total score at UPDRS (Martinez-Martin *et al.,* 1994) was 56.9 ± 35.0.

The control group (CG), matched for socio-demographic variables, consisted of 53 individuals. Thirty seven were men (70%) and 16 were women (30%), aged 69.0 ± 8.7 years (age range = 57-84 years). They reported the following conditions: 12 (22.6%) orthopedic and rheumatic problems, 5 (9.4%) cardiovascular or nephrological or pneumological problems, 5 (9.4%) urological problems, 4 (7.5%) gastroenterological problems, 4 (7.5%) deficits in hearing and sight, 3 (5.7%) viral and infective illness, 2 (3.8%) endocrine problems, 2 (3.8%) gynecological problems, and 16 (30.2%) reported minor psychological distress such as anxiety symptoms, bereavement, and work burnout.

No significant differences in the mean age ($t = 0.84$; $p = 0.399$) and in social characteristics emerged between patients and controls.

Patients reported significantly lower scores in LS and in quality of life compared to controls ($F = 13.77$, $p = 0.000$; $F = 10.184$, $p = 0.002$, respectively), with a small effect size (0.12 and 0.09 respectively) (Table 2.2).

Concerning PWB, PD patients reported significantly higher levels of environmental mastery ($F = 29.05$, $p = 0.001$), personal growth ($F = 241.21$, $p = 0.001$), purpose in life ($F = 431.00$, $p = 0.001$), self-acceptance ($F = 42.72$, p =0 0.001), PWB total score ($F = 56.61$, $p = 0.001$) and lower levels of autonomy ($F = 8.66$, $p = 0.004$) compared to controls. Effect sizes for the statistically significant scales range from 0.08 (autonomy) to 0.81 (purpose in life) (Table 2.2).

Regarding SQ, significant differences emerged for all its subscales. PD patients reported higher levels of anxiety ($F = 22.90$, $p = 0.001$), depression ($F = 28.40$, $p = 0.001$), somatic symptoms ($F = 36.46$, $p = 0.001$), hostility-irritability ($F = 6.48$, $p = 0.012$), relaxation ($F = 9.22$, $p = 0.003$), contentment ($F = 27.46$, $p <$

0.001), physical well-being (F = 94.83, $p < 0.001$), and friendliness (F = 6.53, p = 0.012). Effect sizes ranged from 0.06 (hostility-irritability) to 0.48 (physical well-being) (Table 2.2).

The first linear regression models in the total sample with PWB total score as dependent variable revealed that variables included in the models explained 37.9 % of the variance ($F_{5,97}$ = 11.818, $p < 0.001$). Particularly, only group condition significantly predicted PWB total score (β = -0.554, $p < 0.001$). The second regression analysis (LS as dependent variable) found that the model explained 14.0% of the variance ($F_{5,97}$ = 3.162, p = 0.013). It was found that group condition significantly predicted LS (β = 0.352, p = 0.002). Finally, the third regression analysis (QoL as dependent variable) found that the model explained 13.6% of the variance ($F_{5,97}$ = 3.053, p = 0.013). It was found that marital status and group condition significantly predicted QoL (β = -0.212, p = 0.031, β = 0.298, p = 0.007, respectively) (see Table 2.3).

Three regression analyses were additionally performed in the PD group only. The first one (PWB total score as dependent variable) indicated that variables included in the models explained 38.3% of the variance ($F_{5,41}$ = 5.084, p = 0.001). Age and UPDRS total score significantly predicted PWB total score (β = 0.314 , p = 0.024, β = -0.664, $p < 0.001$, respectively). The second regression analysis (LS as dependent variable) resulted to be non-significant ($F_{5,41}$ = 1.427, p = 0.235). Finally, the third regression analysis (QoL as dependent variable) found that the model explained 23.5% of the variance ($F_{5,41}$ = 2.525, p = 0.044). It was found that marital status significantly predicted QoL (β = -0.325, p = 0.022), as did UPDRS total score (β = -0.359, p = 0.048) (see Table 2.4).

2.4 Discussion

The aim of this study was to measure psychological well-being, life satisfaction, quality of life and distress in patients with PD and to compare them with a population of aging individuals reporting various physical conditions, excluding neurodegenerative diseases.

The results partially disconfirmed initial hypotheses. In fact, PD patients reported lower levels of satisfaction with life, quality of life and higher levels of distress as expected. However, they also showed higher levels of psychological well-being compared to the CG.

Concerning life satisfaction, results are in line with studies on other PD populations (Dural et al., 2003; Gustafsson et al., 2015; Rosengren et al., 2016). These studies showed that patients suffering from neurodegenerative disorders like PD could experience low satisfaction with life when compared to healthy controls (Gustafsson et al., 2015). Additionally, typical symptoms of PD such as bradykinesia and musculoskeletal impairments could hamper patients' physical autonomy and their opportunity of remaining employed (Gustafsson et al., 2015). These progressive impairments in physical and professional autonomy could consequently affect LS. Furthermore, LS was found to decrease as the disease progresses (Rosengren et al., 2016). Thus, the clinical condition and the progressive loss of physical autonomy of our patients could explain their lower levels of LS, compared to aging individuals matched for sociodemographic variables.

Regarding psychological well-being, our findings disconfirmed our hypothesis based on previous investigations where PD patients were found to report impairments in psychological well-being when compared to controls (Pusswald et al., 2012). Conversely, our PD patients reported higher levels of well-being compared to controls. Particularly, patients reported higher levels of environmental mastery, self-acceptance, purpose in life, and personal growth. This data are interesting considering the associations between PWB and motor functioning. Pusswald et al. (2012) documented a negative correlation between PWB and motor functioning in PD patients. This negative correlation was confirmed in our sample of PD patients with the regression analysis revealing that PWB scores were negatively predicted by UPDRS scores. However, contrarily from Pusswald et al. (2012), our PD patients reported higher PWB in almost all dimensions when compared to controls and the regression analysis showed that being in the PD group was the only significant predictor of PWB total score. These controversies might be explained by the fact that Pusswald et al. (2012) used the 18-item version of the PWB that received some criticisms for its poor psychometric properties (Ryff, 2014). Thus, the use of a longer version (42 items) of the questionnaire might have detected the peculiar differences between patients and controls with more sensitivity. Alternatively, our sample might differ from the one of Pusswald et al. (2012). For instance, the control group in Pusswald et al.'s (2012) study comprised of individuals with essential hypertension or diabetes mellitus type 2, whereas our control group included a larger variety of clinical conditions. Future studies are needed to resolve such controversial finding.

Concerning psychological distress, our PD patients reported higher levels of anxiety, depression, somatic symptoms and hostility, compared to controls. These results confirm previous investigation comparing PD and healthy subjects (Duncan et al., 2014; Pusswald et al., 2012) and they highlight the importance of considering psychological distress in PD patients. Unfortunately, mood and anxiety disorders are often unrecognized and untreated in PD patients and this comorbidity greatly exacerbates PD symptoms (Sagna et al., 2014).

Moreover, PD patients reported a worse quality of life compared to controls. This data is in line with previous findings documenting how PD may hamper patients' quality of life (Fereshtehnejad et al., 2014; Hurt et al., 2011; Martinez-Martin et al., 2015; Peters et al., 2011; Sagna et al., 2014). This construct is significantly related to the level of psychosocial functioning, mobility limitations, and to non-motor symptoms (van Uem et al., 2016). In addition, in our regression analysis we found that marital status could also influence QoL in PD.

Other results worth mentioning are those concerning the correlates of PWB, LS and QoL in the subsample of PD patients. In a series of regressive analyses, we found that older patients with lower levels of functional impairment (UPDRS) tended to experience higher PWB levels. The positive association between age and PWB disconfirms previous literature (Ryff, 2014) and future studies could better investigate the peculiarity of PWB in PD patients.

Similarly, QoL in this sample resulted in being negatively predicted by UPDRS and marital status. Thus, those patients who are married and who reported lower functional impairments in UPDRS reported higher levels of quality of life.

Both results are in line with previous studies documenting that being married and reporting lower impairments at UPDRS represent protective factors for PD patients' quality of life (Andreadou et al., 2011; Behari et al., 2005).

In conclusion, the present investigation provides confirmation to previous literature documenting the presence of depression, anxiety and a poor quality of life in PD patients when compared to controls. However, our study adds important new findings on this patient population by documenting the presence/preservation of dimensions of psychological well-being, which are considered important protective factors for both mental and physical health (Ryff, 2014). Other investigations documented that those patients with severe, chronic and life-threatening illnesses, such as cancer, neurodegenerative diseases, and cardiovascular disease might experience the coexistence of psychological distress and well-being, particularly in its existential dimensions (i.e. purpose in life, personal growth, self-acceptance). These well-being dimensions result in a better adaptation to the illness itself (Ryff, 2014). According to our findings this phenomenon could be observed in PD patients as well. Moreover, it highlights that the relationship between well-being and severity of disease is particularly important when examining PD course. The combined assessment of well-being and distress, through appropriate and sensitive quantitative measures, may help clinicians better capture profiles of patient problems and resources to enable tailored treatments to their specific needs.

2.1 *Socio-demographic and clinical characteristics of the sample*

	Patients (N=50)		Controls (N=53)		
	M	DS	M	DS	t
Age	70.6	7.5	69	8.7	0.84
	N	%	N	%	χ2
Gender					0.002
Men	35	70.0%	37	69.8%	
Women	15	30.0%	16	30.2%	
Employment					**0.420***
Retired	46	92.0%	32	60.4%	
Unemployed	1	2.0%	2	3.8%	
Current employed	3	6.0%	19	35.8%	
Educational level					0.101
5 years	14	28.0%	14	26.4%	
8 years	12	24.0%	9	17.0%	
13 years	19	38.0%	23	43.4%	
> 18 years	5	10.0%	7	13.2%	
Marital status					0.118
Unmarried	3	6.0%	4	7.5%	
Married	38	76.0%	39	73.6%	
Divorced	4	8.0%	2	3.8%	
Widow	5	10.0%	8	15.1%	
UPDRS total score	56.9	35.0	/	/	
MMSE	28.6	1.5	/	/	
Psychotropic med. (Dopamine)	402.0 mg/day	203.1 mg/day	/	/	

Note. *p≤0.05, **p≤0.01; UPDRS=Unified Parkinson Disease Rating Scale; MMSE=Mini Mental State Examination.

Table 2.2 *Differences between patients and controls in LS, QoL, PWB, and SQ*

	Patients	Controls	Total sample	F	η^2
	M (DS)	M (DS)	M (DS)		
LS	6.8 (2.0)	8.0 (1.4)	7.4 (1.8)	**13.77****	0.120
QoL	2.3 (1.1)	2.8 (0.6)	2.6 (0.9)	**10.184****	0.092
PWB					
Autonomy	31.6 (8.6)	35.8 (5.6)	33.8 (7.5)	**8.66****	0.079
Environmental mastery	39.0 (2.2)	34.9 (5.0)	36.9 (4.4)	**29.05****	0.223
Personal growth	45.5 (2.3)	32.0 (5.7)	38.6 (8.1)	**241.21****	0.705
Positive relations	34.4 (8.6)	36.0 (4.5)	35.2 (6.8)	1.57	0.015
Purpose in life	44.2 (1.7)	30.9 (4.2)	37.4 (7.4)	**431.00****	0.810
Self-acceptance	39.9 (2.0)	34.5 (5.4)	37.1 (4.9)	**42.72****	0.297
PWB Total	234.6(18.7)	204.2(22.0)	219.0(25.4)	**56.61****	0.359
SQ					
Anxiety	5.4 (3.9)	2.2 (2.8)	3.8 (3.8)	**22.90****	0.182
Depression	5.1 (4.0)	1.7 (2.2)	3.4 (3.6)	**28.40****	0.261
Somatic symptoms	7.0 (4.1)	2.8 (2.8)	4.9 (4.1)	**36.46****	0.390
Hostility-irritability	4.1 (3.7)	2.3 (3.3)	3.2 (3.6)	**6.48****	0.075
Relaxation	4.0 (1.7)	4.9 (1.3)	4.5 (1.6)	**9.217****	0.084
Contentment	3.2 (1.9)	4.9 (1.3)	4.5 (1.6)	**27.456****	0.214
Physical well-being	1.0 (1.0)	3.8 (1.8)	2.4 (2.1)	**94.831****	0.484
Friendliness	5.1 (1.1)	5.5 (0.8)	5.3 (1.0)	**6.533****	0.061

Note. *p≤0.05, **p≤0.01; LS=Life Satisfaction; QoL =Quality of Life; PWB=Psychological Well-Being Scales; SQ=Symptom Questionnaire.

Table 2.3

Regression Models Predicting PWB total score, LS, and QoL in the total sample (N=103)

	PWB Total score				*LS*				*QoL*			
	Model 1		*Model 2*		*Model 1*		*Model 2*		*Model 1*		*Model 2*	
	β	p	β	p	β	p	β	p	β	p	β	p
Age	-0.024	0.821	0.064	0.489	0.175	0.119	0.120	0.269	0.076	0.492	0.029	0.790
Gender	-0.091	0.347	-0.070	0.399	0.044	0.664	0.031	0.751	0.015	0.886	0.003	0.974
Marital status	-0.048	0.613	-0.052	0.525	-0.089	0.380	-0.087	0.371	-0.214	0.035	-0.212	0.031
Employment	-0.387	<0.0001	-0.081	0.437	0.209	0.062	0.014	0.909	0.191	0.083	0.026	0.831
Group			-0.554	**<0.0001**			0.352	**0.002**			0.298	**0.007**
R^2	0.149		0.379		0.047		0.140		0.069		0.136	
R^2 change	0.149		0.229		0.047		0.093		0.060		0.067	
F value	4.298	0.003	11.818	<0.0001	1.219	0.308	3.162	0.011	1.826	0.130	3.053	0.013

Note. PD=Parkinson’s Disease; PWB=Psychological Well-Being Scales; LS=Life Satisfaction; QoL=Quality of Life; For gender: 1=men, 2=women; marital status: 1=married, 2=not married (unmarried, divorced, widow); Employment: 1=unemployed/retired, 2=employed; Group: 1=patients, 2=controls. R^2 change for Model 1 indicates variance explained by socio-demographic factors (age, marital status and employment). R^2 for Model indicates variance explained by group condition (patients vs controls), after controlling for socio-demographic factors.

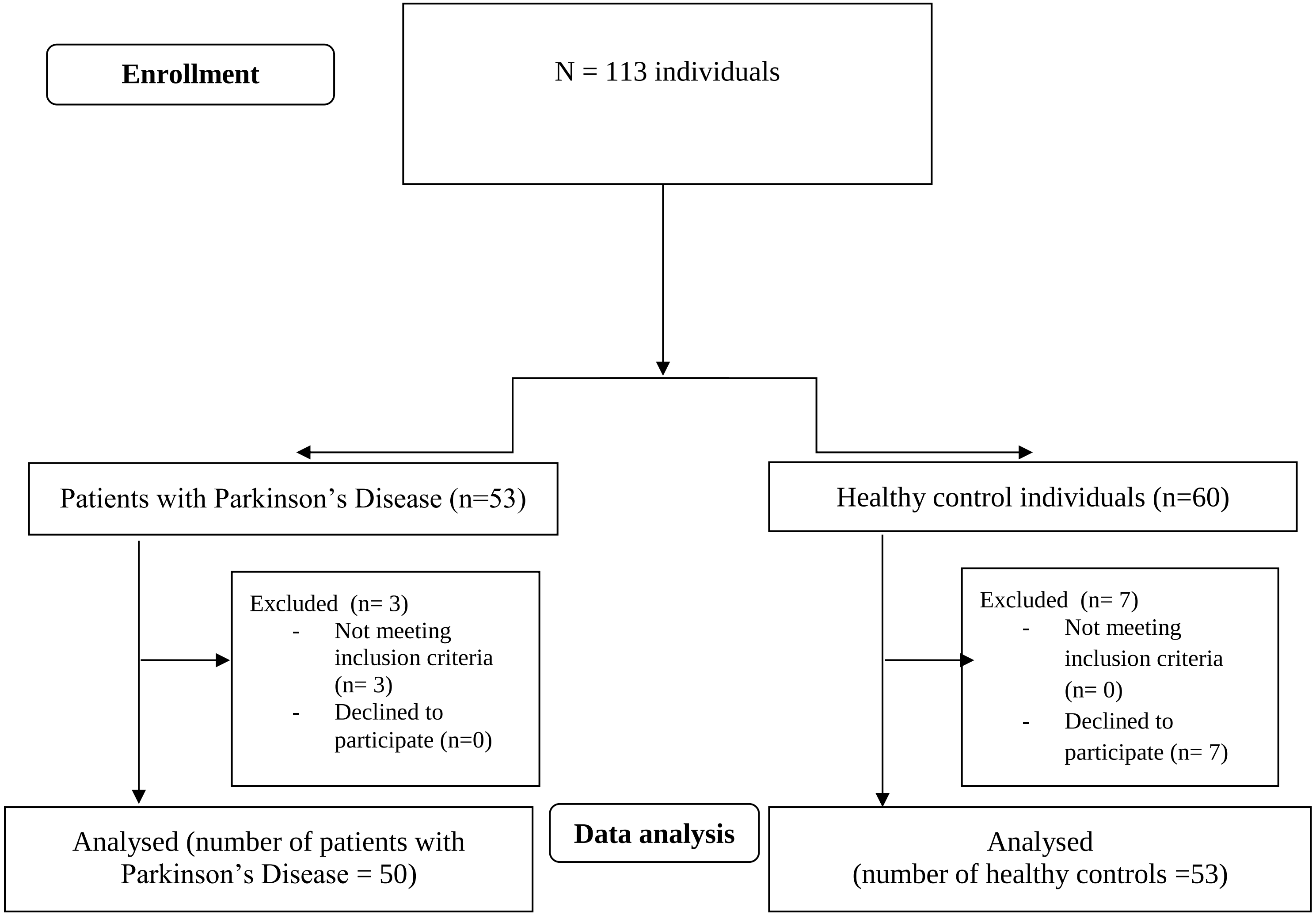
Table 2.4

Regression Models Predicting PWB total score, LS, and QoL in PD patients (n=50)

	PWB Total score				*LS*				*QoL*			
	Model 1		*Model 2*		*Model 1*		*Model 2*		*Model 1*		*Model 2*	
	β	p	β	p	β	p	β	p	β	p	β	p
Age	0.262	0.078	0.314	0.024	0.220	0.143	0.271	0.093	0.215	0.128	0.265	0.084
Marital status	0.054	0.715	0.047	0.708	-0.010	0.949	-0.022	0.883	-0.318	0.027	-0.325	**0.022**
UPDRS			-0.664	**<.0001**			-0.406	**0.035**			-0.359	**0.048**
MMSE			-0.027	0.842			-0.002	0.989			0.024	0.874
Dopamine level			0.194	0.238			0.238	0.217			0.177	0.333
R^2	0.071		0.383		0.049		0.148		0.153		0.235	
R^2 change	0.071		0.312		0.049		0.100		0.153		0.082	
F value	1.670	0.200	5.084	0.001	1.123	0.334	1.427	0.235	3.983	0.026	2.525	0.044

Note. PD=Parkinson's Disease; UPDRS=Unified Parkinson Disease Rating Scale; MMSE=Mini Mental State Examination. For marital status: 1=married, 2=not married (unmarried, divorced, widow). R^2 change for Model 1 indicates variance explained by socio-demographic factors (age and marital status). R^2 for Model indicates variance explained by UPDRS, MMSE, psychotropic medication (dopamine levels), after controlling for socio-demographic factors.

Figure 2.1 Research flow chart



CHAPTER 3

WELL-BEING AND DISTRESS IN CAREGIVERS OF PATIENTS WITH PARKINSON’S DISEASE: A COMPARATIVE ANALYSIS

3.1 Introduction

Since PD has a progressive and chronic nature, patients need increasing levels of assistance. Their caregivers, whose health is important per se but also because it is strictly connected with those of their assisted, play a central role. Thus, the identification of vulnerabilities could offer a better support both to patients and to their caregivers and family system (Glozman, 2004; Mosley, Moodie, and Dissanayaka, 2017) (see chapter 1 for a more detailed definition of caregivers and their burden).

Traditionally, studies on caregivers of PD patients have focused on their difficulties, obstacles, and on the burden associated with the assistance (Tan et al., 2012; Glozman, 2004). They have to redefine their social, familial and professional roles with the risk of experiencing a fail in all the fronts (Glozman, 2004). Caregiver burden is positively associated with the stage of PD. In the later stages of the disease, caregivers’ worries, tensions, distress, anxiety and depression increase, in particular in those who live a more disadvantage economic condition (Carter et al., 1998; Lageman et al., 2015).

Only more recently, with the growth of Positive Psychology, research started focusing on resources, protective factors, and even on the possible positive consequences of the caregiving activity (Fianco et al., 2015). Concepts such as those of positive emotions (Petrican et al., 2014), post-traumatic growth (PTGI; Tedeschi and Calhoun 1995; Habermann et al., 2013; Hodgson et al., 2004; Mavandadi et al., 2014; Parveen and Morrison, 2012; Tan et al., 2012), and spirituality (Bingham and

Habermann, 2006; Birgersson and Edberg, 2004) could be experienced also by PD caregivers. When experienced, these psychological resources could relate to a better psychological adaptation to the illness (Barskova and Oesterreich 2009; Wood et al., 2010) and to well-being that is protective for caregivers' mental and physical health (Cassidy, 2013; Corallo et al., 2017; Rosenberg, et al., 2013).

Although very promising, these results are pilot experiences that involved small sample of caregivers of patients with PD. Second, they did not include a control group. Finally, they often used only qualitative methodology, that could provide rich information but may suffer from a risk of bias and their results are not always generalizable.

The aims of this study were:

1) to compare the levels of distress and well-being in a sample of caregivers of patients with Parkinson's Disease with those of a socio-demographic matched sample of control caregivers of individuals with non-neurological diseases but who need daily assistance for their age-related health problems. This could help to identify possible differences related to the specific condition of providing care for Parkinson patients;

2) to investigate the possible correlates of high levels of caregiver burden (in order to identify a group of vulnerable caregivers);

3) to compare the levels of distress and well-being of caregivers with high levels of caregiver burden with those of caregivers with low caregiver burden (regardless of the illness of their assisted) in order to highlight possible differences related to the burden they have to face.

In line with previous findings with other types of caregivers, it was hypothesized that caregivers of patients with PD would report lower levels of well-being (both psychological well-being and life satisfaction), lower levels of quality of life, higher levels of distress but higher levels of psychological resources (as post-traumatic growth and gratitude), compared to controls.

Then, it was also hypothesized that impaired levels of well-being and higher levels of depression would correlate to higher levels of caregiver burden.

Finally, it was hypothesized that caregivers with higher caregiver burden would exhibit lower levels of well-being (both psychological and life satisfaction), lower levels of quality of life, higher distress and higher psychological resources (as post-traumatic growth and gratitude), when compared to those with lower caregiver burden.

3.2 Methods

3.2.1 Participants

The initial sample included 116 caregivers: 46 caregivers of patients with PD (CG_{PD}) and 70 caregivers of healthy individuals as controls (CG_C) (see figure 3.1 for flow chart).

In the CG_{PD} group, no one (*n* = 46) refused to participate. In the control condition, according to inclusion/exclusion criteria, 8 individuals out of the 70 individuals approached were excluded because they referred they did not provide any kind of assistance to their relatives; furthermore, 12 were excluded because their relatives suffered from a neurological or a neurodegenerative disease. Since these illnesses share the same level of caregiver burden of PD patients' caregivers, they could not have represented the good control group and were excluded (Aneshensel et al., 1995, Hogdson et al., 2004).

Forty-six consecutive CG_{PD} were recruited in a rehabilitation outpatient clinic in Northern Italy where they used to carry their relatives enrolled into a physical rehabilitation program. Inclusion criteria for the present research were as follows: assisting someone with a diagnosis of PD; absence of any psychiatric disease or any other type of cognitive deterioration, as established by an initial psychiatric screening performed by a clinical psychologist; age 18-85 years old. The final CG_{PD} sample consisted of 36 women (78.3%) and 10 men (21.7%), aged 60.7 ± 13.3 (age range = 33-84 years), mean years of formal education were 11.5 ± 4.7 and mean years of assistance were 6.1 ± 5.2.

The CG_C group, matched for socio-demographic variables, consisted of 50 individuals. Thirty-two were women (64%) and 18 were men (36%), aged 59.18 ± 10.63 (age range = 45-85 years), mean years of formal education were 10.76 ± 4.23 and mean years of assistance were 8.84 ± 10.30. They were recruited in leisure/recreational centers for older adults. Considering the peculiarities of these aging populations, participants in the CG_C group were interviewed with questions concerning their relatives' health (mental and physical) status and were excluded when he/she suffered from a neurodegenerative and neurological chronic illnesses or reported the presence of serious health problems (such as oncological disease). Controls reported to assist a relative suffering from non-serious mixed forms of health problems such as cardiovascular or endocrine diseases, problems in sight or hearing (e.g., diabetes, hypertension, etc.). Inclusion criteria for the CG_C were as follows: assisting someone with an illness other than PD or other than a neurodegenerative/neurological condition; absence of any psychiatric disease or any other type of cognitive deterioration, as established by an initial psychiatric screening performed by a clinical psychologist; age 18-85 years old.

After explaining the study aim and procedure, participants in both groups were asked to participate and accepted on a voluntary basis.

3.2.2 Procedure

CG_{PD} and CG_C were interviewed individually, at the rehabilitation outpatient clinic and in leisure/recreational centers for older adults, respectively. Interviews generally lasted around one hour and half although for some participants this time was significantly extended.

3.2.3 Measures

All caregivers completed the following self-report questionnaires:

Psychological Well-Being Scales (PWB) (Ryff, 1989) is a 42 item self-rating inventory that covers the 6 areas of psychological well-being: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self- acceptance. We have also calculated a total PWB score by adding together the scores of the six dimensions. Subjects respond with a six-point format ranging from "strongly disagree" to "strongly agree". Responses to negatively scored items are reversed in the final scoring on the dimension assessed. The Italian version of PWB scales has satisfactory test-retest reliability (ranging between .81 and .88 in a six-week interval) (Ruini et al., 2003) and is inversely related to measures of psychological distress (Kellner, 1987). In the present study, for $CG_{PD,}$ $\alpha = 0.738$ for autonomy subscale, $\alpha = 0.792$ for environmental mastery, $\alpha = 0.452$ for personal growth, $\alpha = 0.551$ for positive relations with others, $\alpha = 0.667$ for purpose in life, $\alpha = 0.792$ for self-acceptance and $\alpha = 0.847$ for PWB total scale. For CG_{C} , $\alpha = 0.782$ for autonomy subscale, $\alpha = 0.602$ for environmental mastery, $\alpha = 0.470$ for personal growth, $\alpha = 0.583$ for positive relations with others, $\alpha = 0.450$ for purpose in life, $\alpha = 0.73$ for self-acceptance and $\alpha = 0.819$ for PWB total scale.

Life Satisfaction (LS; Personal Wellbeing Index; International Wellbeing Group, 2013), a general question was used to investigate satisfaction with life: “Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?”. Participants had to respond on a Likert scale from 0 “No satisfaction at all” to 10 “Completely satisfied”. According to its manual, the Personal Wellbeing Index could investigate life satisfaction in various life domains (e.g., employment, family, living conditions, etc.) or it could be used as a global evaluation using a single item. This latter modality is reliable and valid for research purpose (International Wellbeing Group, 2013).

Gratitude Questionnaire-6 (GQ-6; McCullough et al., 2002) has 6 items rated on a 7-point Likert scale where 1 = ‘‘strongly disagree’’ and 7 = ‘‘strongly agree’’. The items measure gratitude intensity (‘‘I feel thankful for what I have experienced in life’’; ‘‘If I had to list everything that I felt thankful for, it would be a very long list’’). Responses to negatively scored items are reversed in the final total scoring.

The GQ-6 score can range from 6 to 42. The GQ-6 displayed excellent psychometric properties and has been shown to explain unique associations with relevant constructs even after controlling for higher-order personality traits (e.g., Big Five) and social desirability (McCullough et al. 2002). Additionally, the GQ-6 exhibited only moderate negative relations with indexes of anxiety and depression (r's = -0.41 and -0.36, respectively) in previous studies in populations with medical illness (Ruini and Vescovelli, 2013). In the present study, $\alpha = 0.785$ for CG_{PD} , and $\alpha = 0.714$ for CG_C.

Positive Life Changes (PLC; Anand-Kumar et al., 2014). This questionnaire was adapted from the Positive Effect of Transplantation Scale (PET; Anand-Kumar et al., 2014), which was developed in order to investigate the degree and the nature of positive psychological changes after organ transplantation. PLC yields a total score and three subscales scores: (1) life philosophy, (2) gratitude, (3) health perception. The content of its items was then adapted for caregivers and caregiving in general (e.g., "the illness of the person who I assist has made me realize how precious life is", "I am very grateful to the team that assist my relative"). Participants were instructed to rate on a five-point Likert-type scale (1 = strongly agree, 2 = agree, 3 = uncertain, 4 = disagree and 5 = strongly disagree) the extent to which they agreed with each statement. When scoring, all items were reverse coded, so that higher scores represented more positive effects. It has adequate validity and internal consistency for the total scale. It is possible to use both its total scale and subscale scores. In the presents study, for $CG_{PD,}$ $\alpha = 0.877$ for life philosophy subscale, $\alpha = 0.681$ for gratitude subscale, $\alpha = 0.903$ for health perception subscale, $\alpha = 0.909$ for PLC total scale. For CG_C $\alpha = 0.875$ for life philosophy subscale, $\alpha = 0.758$ for gratitude subscale, $\alpha = 0.875$ for health perception subscale, and $\alpha = 0.928$ for PLC total scale.

Post-traumatic Growth Inventory (PTGI; Tedeschi and Calhoun 1996). This scale has been developed to explore how individuals, who have to cope with the aftermath of a trauma, are successful in reconstructing or strengthening their perceptions of self, others, and the meaning of events. The PTGI has 21 items rated on a 6-point Likert scale, ranging from 0 = ‘‘I did not experience this change as a result of my crisis’’ to 5 = ‘‘I experienced this change to a very great degree as a result of my crisis’’. PTGI yields a total score and five subscales scores: (1) relations with others (7 items); (2) new possibilities (5 items); (3) personal strengths (4 items); (4) spiritual changes (2 items); and (5) appreciation of life (3 items). The scale has good internal consistency and acceptable test–retest reliability (Tedeschi and Calhoun, 1996). In previous study with medical populations (e.g., cancer patients) and controls, PTGI showed good psychometric properties (Cordova et al., 2001; Ruini, Vescovelli, and Albieri, 2014). For the present study, for $CG_{PD,}$ $\alpha = 0.923$ for relations, $\alpha = 0.868$ for new possibilities, $\alpha = 0.840$ for personal strengths, $\alpha = 0.874$ for spirituality, $\alpha = 0.753$ for appreciation of life, $\alpha = 0.960$ for PTG total scale. For $CG_{C,}$ $\alpha = 0.815$ for relations, $\alpha = 0.786$ for new possibilities, $\alpha = 0.761$ for personal strengths, $\alpha = 0.909$ for spirituality, $\alpha = 0.800$ for appreciation of life, $\alpha = 0.934$ for PTG total scale.

Psychosocial Index (PSI; Sonino and Fava, 1998) is a self-rating scale including 52 items; 37 items (questions 1–29 and 44–51) were derived from Kellner’s Screening List for Psychosocial Problems (SLP). Items 30–37 were derived from Wheatley Stress Profile. They were added to the list of life events included in the SLP to provide an appraisal of daily, work and interpersonal stress. The tool can provide a first-line, comprehensive assessment of stress, well-being, distress, illness behavior, and quality of life (Piolanti et al., 2016). The rating of stress, thus, attempts to provide an integration of both perceived and objective stress, life events and daily stress, yielding a clinimetric definition of allostatic load (Fava et al., 2010). Some questions of the PSI involve specific responses; most require a yes/ no answer, while others are rated on a Likert 0–3 scale (from ‘‘not at all’’ to ‘‘a great deal’’). In the original validation study internal consistency coefficients were 0.88 for stress subscale, 0.89 for psychological distress, and 0.90 for abnormal illness behaviour (Sonino and Fava, 1998). In the present study for $CG_{PD,}$ $\alpha = 0.890$ for distress subscale, $\alpha = 0.597$ for abnormal illness behavior, $\alpha = 0.428$ for stress, $\alpha = 0.707$ for well-being, and $\alpha = 0.856$ for PSI total scale. For CG_{C}, $\alpha = 0.915$ for distress subscale, $\alpha = 0.765$ for abnormal illness behavior, $\alpha = 0.581$ for stress, $\alpha = 0.676$ for well-being, and $\alpha = 0.911$ for PSI total scale.

Symptom Questionnaire (SQ; Kellner, 1987) is a 92-item self-rating scale that yields 4 scales of distress (anxiety, depression, somatization and hostility-irritability) and 4 associated scales of well-being (relaxation, contentment, physical well-being and friendliness). Each symptom scale score may range from 0 to 17; each well-being scale scores from 0 to 6. The SQ was previously validated in an Italian population and has been found to be a sensitive instrument to detect changes in clinical trials, showing good split-half reliability (Fava et al., 1983; Kellner, 1987). In the present study for CG_{PD}, $\alpha = 0.850$ for anxiety total scale, $\alpha = 0.820$ for depression total scale, $\alpha = 0.849$ for somatic symptoms total scale, and $\alpha = 0.782$ for hostility-irritability total scale. For $CG_{C,}$ $\alpha = 0.862$ for anxiety total scale, $\alpha = 0.820$ for depression total scale, $\alpha = 0.849$ for somatic symptoms total scale, and $\alpha = 0.782$ for hostility-irritability total scale.

For the evaluation of caregiver burden, caregivers completed the following questionnaires:

Parkinson' Disease Questionnaire 29 item carer-version (PDQ29; Jenkinson et al., 2012; completed by caregivers of PD patients) is a 29-item questionnaire encompassing four dimensions of quality of life (social and personal activities, anxiety and depression, self-care, and strain). These four domains could be summed to provide a single summary index score (Morley et al., 2013). Caregivers could select one answer from the range of Never (0), Occasionally (1), Sometimes (2), Often (3), Always (4). Internal consistency reliability was found to be high for all domains (Cronbach's alphas range from 0.86 to 0.92) in the original validation study (Jenkinson et al., 2012). In the present study for $CG_{PD,}$ $\alpha = 0.953$ for personal and social activities, $\alpha = 0.910$ for anxiety and depression, $\alpha = 0.905$ for self-care, $\alpha = 0.880$ for stress, and $\alpha = 0.976$ for PDQ29 total scale.

Zarit Burden Interview (ZBI; Chattat et al., 2011; completed by controls) is a self-report questionnaire for measuring caregiver burden. The original version consists of 29 item (Zarit et al., 1980), whereas for the study, the 22-item version was used. Items are rated on a Likert scale from 0 (never) to 4 (almost always). The final score is given by the sum of the score of each item. Total score may range from 0-20 (low burden), to 21-40 (moderate burden), to > 40 (high burden). This questionnaire allows identifying groups of vulnerable caregivers (score between 24-26). It has a good convergent validity and high internal consistency (Chattat et al., 2011; Lai, 2007; Zarit et al., 1980). In the present study, for $CG_{C,}$ $\alpha = 0.835$.

The former questionnaire (PDQ29) provides the most appropriate evaluation of Parkinson's caregiver burden; the latter questionnaire (ZBI) is one of the most used instrument for measuring general caregiver burden. The two questionnaires were then merged into a single measure of caregiver burden (see statistical analyses).

3.2.4 Statistical Analyses

Demographic characteristics of samples were compared using the $\chi 2$ tests and general linear model in the case of age, years of assistance and years of education.
In order to have a measure of caregiver burden, ZBI and PDQ29 scores were standardized and a new variable defined as "caregiver burden" was computed
Differences between CG_{PD} and CG_{C} in PWBS, LS, PLC, GQ, PTG, PSI, SQ, and ZBI/PDQ29 were analyzed by running seven univariate analyses (for LS, PWBS total score, PLC total score, PTGI total score, PSI total score, PSI QoL and ZBI/PDQ29) and five separate multivariate analyses (for PWBS, PLC, PTG, PSI, SQ subscales).

A four-step regression analysis was performed (method enter) in the whole sample of caregivers to test if socio-demographic factors (gender, age, marital status, employment, years of education), type of assistance-related variables (years of assistance, group condition CG_{PD} vs CG_{C}), PWBS dimensions and SQ depression significantly predicted caregivers' ZBI/PDQ29.

Finally, the median value of standardized caregiver burden - ZBI/PDQ29 -

(median = -0.44) was calculated and used for dividing the whole caregiver sample into two groups: (1) High levels of caregiver burden (HCGB) whose score was higher than -0.43 (at ZBI/PDQ29) and (2) caregivers with low levels of caregiver burden (LCGB) whose score was lower than -0.44 (at ZBI/PDQ29). Chi square and Anova were used to compare HCGB and LCGB with regard to group assignment and socio-demographic variables. Between-group comparisons on PWB, LS, GQ, PLC, PTGI, PSI and SQ scales were conducted using the Analysis of Variance for each questionnaire, with the group variable as a fixed factor.

In the evaluation of estimates, conclusions were based on both statistical significance (significant level set at $p < 0.05$) and standardized measures of effect, with Cohen's d of 0.2 considered small, 0.5 medium and 0.8 large, and Pearson's r of 0.10 small, 0.30 medium and 0.50 large (Cohen, 1988). The Statistical Package for the Social Sciences (SPSS, Version 23.0) was used for analyses.

3.2.5 Ethical considerations

The investigation conforms to the principles outlined in the Declaration of Helsinki and all participants agreed to voluntarily take part in the study and signed informed consent. The project was approved by the Ethical Commette of the rehabilitation outpatient clinic (for the recruitment of caregivers of PD patients) and of the leisure/recreational centers for older adults (for the recruitment of controls).

3.3 Results

Descriptive statistics of the whole sample and of the two subgroups (PD and CG) are displayed in table 3.1. No significant differences in the mean age and in social characteristics emerged between patients and controls, except for the employment.

Concerning PWB, a one-way ANOVA showed that CG_C reported significantly higher levels of PWB total score ($F_{1,93}$ = 4.128, p = 0.045) (Table 3.2). Then, a one-way MANOVA resulted to be non-significant for group assignment (Wilks' λ = 0.946, $F_{6,88}$ = 0.839, p = 0.543, partial eta squared = 0.054). However, the univariate main effects were examined and significant univariate main effects for group were found for environmental mastery ($F_{6,88}$ = 4.957, p = 0.028), with CG_{PD} reporting lower scores. Differences did not emerge for the other subscales (see Table 3.2).

At the univariate test, CG_{PD} reported significantly lower scores in LS ($F_{1,94}$ = 4.326, p = 0.040) than CG_C (Table 3.2). On the other hand, at the univariate test no differences appeared for quality of life between CG_{PD} and $CG_{C.}$

When investigating GQ, a one-way ANOVA showed no group differences ($F_{1,93}$ = 0.518, p = 0.473) (Table 3.2).

For PLC total score, a one-way ANOVA revealed a group difference ($F_{1,94}$ = 10.633, p = 0.002), with CG_C reporting higher levels (Table 3.2). Concerning PLC subscales, a one-way MANOVA revealed a significant multivariate main effect for group assignment (Wilks' λ = 0.860, $F_{3,92}$ = 4.988, p = 0.003, partial eta squared = 0.140). Significant univariate main effects for group were obtained for life philosophy ($F_{1,94}$ = 9.269, p = 0.003) and for health perception subscales ($F_{1,94}$ = 14.462, p < 0.001) with CG_{PD} reporting lower scores. Univariate main effect was not found for gratitude ($F_{1,94}$ = 3.742, p = 0.056) (Table 3.2).

At PTG total score, a one-way ANOVA highlighted a significant group effect ($F_{1,94}$ = 12.108, p = 0.001) and CG_C reported significant higher levels of this dimension. When investigating PTG subscales, a one-way MANOVA revealed a significant multivariate main effect for group (Wilks' λ = 0.847, $F_{5,90}$= 3.251, p = 0.010, partial eta squared = 0.153). Given the significance of the overall test, the univariate main effects were examined. Significant univariate main effects for group were obtained for relations ($F_{1,94}$ = 8.903, p = 0.004), new possibilities ($F_{1,94}$ = 11.053, p = 0.001), personal strengths ($F_{1,94}$ = 8.998, p = 0.003) and appreciation of life ($F_{1,94}$ = 16.674, $p < 0.001$), with CG_C reporting higher scores. These differences were not found for spirituality ($F_{1,94}$ = 3.092, $p = 0.082$) (Table 3.2).

At PSI total score, a one-way ANOVA showed no significant differences between CG_{PD} and CG_C ($F_{1,94}$ = 0.024, $p = 0.877$) (Table 3.3).

For PSI subscales, a one-way MANOVA revealed a significant multivariate main effect for group (Wilks' λ = 0.890, $F_{4,91}$ = 2.801, $p = 0.030$, partial eta squared = 0.110). When observing the univariate main effects, significant univariate main effects for group were obtained only for well-being subscale ($F_{1,94}$ = 4.194, p = 0.043), with CG_C reporting higher levels (Table 3.3).

Regarding SQ, a one-way MANOVA found no significant multivariate main effect for group (Wilks' λ = 0.919, $F_{4,91}$ = 2.007, $p = 0.100$, partial eta squared = 0.081). When examining univariate main effects for group, these emerged only for depression (F = 4.094, $p = 0.046$), with CG_C reporting lower scores (Table 3.3).

Regarding the regression analysis performed in the total sample with ZBI/PDQ29 standardized score as dependent variable revealed that variables included in the models explained 48.2% of the variance ($F_{14,80}$ = 5.313, $p < .001$) (Table 3.4). Particularly, age (β = 0.279, $p = 0.047$), PWB environmental mastery (β = -0.366, $p = 0.024$), PWB personal growth (β = 0.345, $p = 0.011$), and SQ depression (β = 0.387, $p = 0.002$), significantly predicted ZBI/PDQ29 total score (Table 3.4).

Finally, using the median value of ZBI/PDQ29 total score (median = -0.44) the whole caregiver sample was divided into 2 groups: (1) HCGB (n = 49, 51.0 %); (2) LCGB (n = 47, 49.0%).

Socio-demographic characteristics of the two groups are displayed in Table 3.5. No variable resulted to be significantly different in the two groups.

At multivariate tests, a one-way MANOVA revealed a significant multivariate main effect for group (Wilks' λ = 0.732, $F_{3,88}$ = 5.369, $p < 0.001$, partial eta squared = 0.268). Given the significance of the overall test, the univariate main effects were examined. Significant univariate main effects for group were obtained for PWB autonomy ($F_{3,88}$ = 4.068, $p = 0.047$), environmental mastery ($F_{3,88}$ = 25.602, $p < 0.001$), positive relations ($F_{3,88}$ = 4.484, $p = 0.037$), purpose in life ($F_{3,88}$

= 6.541, $p = 0.012$), self-acceptance ($F_{3,88} = 18.208$, $p < 0.001$), and total scale ($F_{3,88} = 17.085$, $p < 0.001$) (Table 3.6).

Two separate one-way ANOVA showed a univariate main effect for LS ($F_{1,95} = 7.446$, $p = 0.008$) and gratitude ($F_{1,94} = 8.607$, $p = 0.004$) (Table 3.6).

Concerning PLC, a one-way MANOVA found no significant multivariate main effect for group (Wilks' $\lambda = 0.957$, $F_{3,92} = 1.365$, $p = 0.259$, partial eta squared = 0.043). Univariate main effects were examined resulting to be not significant (Table 3.6).

Similarly, for PTG, a one-way MANOVA found no significant multivariate main effect for group (Wilks' $\lambda = 0.989$, $F_{5,90} = 0.208$, $p = 0.958$, partial eta squared = 0.011) and univariate main effects were not significant (Table 3.6).

At PSI, a one-way MANOVA revealed a significant multivariate main effect for group (Wilks' $\lambda = 0.656$, $F_{5,90} = 9.437$, $p < 0.001$, partial eta squared = 0.344). Significant univariate main effects for group were obtained for PSI QoL ($F_{5,90} = 31.779$, $p < 0.001$), distress ($F_{5,90} = 19.886$, $p < 0.001$), abnormal illness behavior ($F_{5,90} = 7.019$, $p = 0.009$), stress ($F_{5,90} = 9.048$, $p = 0.003$), well-being ($F_{5,90} = 38.715$, < 0.001) and PSI total scale ($F_{5,90} = 22.570$, $p < 0.001$) (Table 3.7) .

Concerning SQ, a one-way MANOVA revealed a significant multivariate main effect for group (Wilks' $\lambda = 0.795$, $F_{4,91} = 5.872$, $p < 0.001$, partial eta squared = 0.344). Given the significance of the overall test, the univariate main effects were examined. Significant univariate main effects for group were obtained for SQ anxiety ($F_{4,91} = 19.841$, $p < 0.001$), depression ($F_{4,91} = 22.501$, $p < 0.001$), somatic symptoms ($F_{4,91} = 10.770$, $p = 0.001$), and hostility-irritability stress ($F_{4,91} = 8.938$, $p = 0.004$) (Table 3.7) .

3.4 Discussion

The aim of this study was to compare the levels of distress and well-being in a sample of caregivers of patients with Parkinson's Disease with those of a socio-demographic matched sample of control caregivers of individuals with non-neurological diseases but who need daily assistance for their age-related health problems.

Results confirmed our initial hypothesis, concerning well-being. In fact, caregivers of PD patients reported lower levels of psychological well-being in PWB total scale, when compared to caregivers of individuals with different illnesses.
Psychological well-being has been scarcely investigated in PD caregiver populations. The only few studies reporting well-being used questionnaires concerning quality of life or measured the lack of symptoms (O'Reilly et al., 1996) or adopted a qualitative methodology (Smith and Shaw, 2017). Smith and Shaw (2017) found that PD caregivers could experience well-being only through the management of challenges and the ability to adapt to their partners' body changes and loss of autonomy. However, this study did not measure well-being with psychometric tools.

The only investigations that adopted a quantitative methodology focused on other types of neurodegenerative illnesses, such as Multiple Sclerosis (MS) (Bassi et al., 2016; Ghasemi et al., 2015). Bassi et al. (2016) found that PWB of caregivers of MS patients was negatively associated with negative emotional response to the illness. Conversely, caregivers' PWB increased with a better understanding of the illness, and in caregivers that felt the course of the illness could be controlled. Thus, although MS (like PD) is not curable, a clear understanding and confidence about the effectiveness of the treatment may help caregivers to gain a sense of control, and consequently to promote their well-being (Bassi et al., 2016).

Ghasemi et al. (2015) found that PWB of caregivers of MS patients was higher than PWB mean scores (in the general population) and higher than PWB scores of their relatives suffering from MS. However, these patient and caregiver populations were younger than ours, and their result could be in line with previous finding on the relationship between age and PWB (higher PWB in younger individuals) (Ryff, 2014).

The result concerning differences in LS showed that caregivers of PD patients reported lower levels of LS compared to their controls. To our knowledge, only one previous investigation (Petrican et al., 2014) evaluated LS among partners of PD patients. Authors found that LS was associated with a greater ability in identifying negative vs positive emotions. Unfortunately, in the present study we did not include the evaluation of this ability. However, negative emotions measured at the SQ resulted higher in caregivers of PD patients, when compared to controls.

In other neurological conditions, Bassi et al. (2016) found that LS was lower for caregivers of patients with MS with a more negative emotional reaction to the illness. LS increased in those caregivers who believed that the health condition could be ameliorated, and in caregivers of patients who were more able in making sense of their illness. Thus, maybe the unpredictable nature of MS (like PD) and its progressive symptoms may explain both a difficulty in making sense and may determine impairments in well-being.

Concerning the existential dimensions of well-being (gratitude, post-traumatic growth and positive life changes), our hypothesis was not confirmed. In fact, our caregivers of PD patients were found to report lower levels of positive psychological changes when compared to their controls and these two groups did not differ in terms of gratitude levels. Few existing literature on these dimensions is available in caregivers of PD patients. In fact, previous studies mainly considered patients and caregivers but did not compare caregivers of PD patients with other types of caregivers. For example, Mavandadi et al. (2014) explored finding benefits in relation to marital quality in PD patients and documented their positive contribution for a better adjustment, fewer depressive symptoms, improved personal skills and resources.

Like Mavandadi et al. (2014), other authors found that although PD is very disabling and burdensome, relationships could be enhanced and caregivers of PD patients could find benefits associated with their improved QoL (Haberman et al., 2013; Hodgson et al., 2004; Navarta-Sanchez et al., 2016; Tan et al., 2012). The perception of benefits in caregivers is related to different factors according to the life stage and the years from PD onset. However, Parveen and Morrison (2012) found that positive changes are quite stable over time within their PD population. Furthermore, they found that if initially a clear understanding of the illness was connected to the experience of positive changes, predictors of later positive changes were ethnicity, amount of caregiving, and an increase in self-distraction and denial as coping strategies. This finding could explain the results of our study where PD caregivers experienced lower levels of psychological changes when compared to controls. Our caregivers, in fact, reported less years of assistance compared to those of Parveen and Morrison’s sample (6.1 years vs 9.9 years, respectively).

Thus, our PD caregivers are still in an earlier phase of illness adaptation, they may lack information and support and therefore their opportunity to experience positive changes could be hampered. Furthermore, it was found that the longer is the time since the illness diagnosis, the greater are the positive changes experienced (Helgeson et al., 2006). Only future research with a longitudinal design could better clarify this result.

Thus, caregivers of PD patients seem to report less psychological resources (both in terms of well-being and psychological growth) when compared to other caregivers of patients who suffer from different illnesses. Possible explanations of these results may be that also caregiving for other types of illness such as cardiovascular and endocrinological problems, may be associated with the experience of resources such as increased post-traumatic growth and spirituality (Hamama and Sharon, 2013; Kim and Schulz, 2008; Koerner, Shirai, and Pedroza, 2013).

Concerning distress, our studies are in line with previous investigations, which documented a higher prevalence of depression in caregivers of PD patients when compared to other type of caregivers (Abendroth, Lutz, and Young, 2012; Dotchin et al., 2014; Schrag et al., 2004, 2006).

In conclusion, our caregivers of PD patients seem to be more vulnerable both in terms of psychological resources (well-being and posttraumatic growth) and in terms of distress.

These results could be related to the fact that control caregivers were recruited at leisure/recreational centers, which are characterized by associative and social activities (e.g., arts and crafts activities, play cards, dance, etc.). These activities may be related to greater social networks, to more sources of social support and positive relationships. These variables were found to be related to more well-being, post-traumatic growth (Hefferon et al., 2009; Ryff, 2014) and to a more positive aging (Kales, 2014). The possibility to have moments of discussion, to share emotions, problems and information may help these caregivers to better deal with their situations (Ozanne et al., 2012). Conversely, caregivers of PD patients reported a sense of social isolation and few possibilities of engaging in leisure activities. Similarly, Abendroth et al. (2012) documented serious limitations of social, professional and leisure activities in caregivers of PD patients. Authors suggested that these limitations may affect the opportunity to experience new existential resources or processes of psychological growth in these caregivers (Abendroth et al., 2012).

The second hypothesis of our investigation postulated that impaired levels of well-being and higher depression would correlate to higher levels of caregiver burden. The regressive analysis confirmed that in our total sample caregiver burden was predicted by age, well-being and depression (see Table 3.4). This result is in line with previous findings performed with other type of caregiver populations (Anum and Dasti, 2016; Burton et al., 2012; Spurlock, 2005). In particular, we found a direct relation between age and caregiver burden that confirms previous literature since older caregivers are more susceptible to feel overload for their own age-related problems than the younger ones (Glozman, 2004; Tan et al., 2012). Then, higher caregiver burden resulted to be predicted by impaired levels of environmental mastery. To our knowledge this is the first investigation concerning the measurement of PWB (with PWB scales) and caregiver burden in a PD caregiver population. The concept of environmental mastery refers to individuals' ability to choose or change environments according to someone's needs with specific activities. Since it implies individuals' active participation, and mastery of the environment, it could be argued that those caregivers possessing this skill may be more able to deal with the illness-related changes and challenges (Navarta-Sanchez et al., 2016).

Previous studies found that caregivers may experience empowering processes and take control of their circumstances and environment through the act of caregiving, and this influences the way caregivers view themselves. Caregiver mastery is defined as the "positive view of one's ability and ongoing behavior during the caregiving process" (Lawton et al., 1989, p. 62). Thus, it is possible that the higher is the environmental mastery in caregivers, the lower is the burden because of the sense of control and self-efficacy that caregivers gain from providing care.

Furthermore, the regression analysis revealed that another dimension of well-being, which predicted caregiver burden, is represented by personal growth. It emerged that the higher was the burden, the higher was the personal growth. Apparently, this could be a counterintuitive finding. However, previous literature on posttraumatic growth documented that the higher is the distress, the higher is the personal growth experienced (Barskova and Oesterreich, 2009; Hefferon et al., 2009; Ruini et al., 2013, 2016). In fact, Ruini et al. (2016) observed that PTG could coexist with distress. In this way, it is possible that our caregivers can better recognize a sense of growth from their efforts in dealing with the difficulties related to the assistance of their relatives (Hefferon et al., 2009; Barskova and Oesterreich, 2009; Ruini et al., 2013). Finally, from our regression, it emerged that another predictor of higher caregiver burden was represented by depression (see Table 3.4). This data confirms previous literature (Adelman et al., 2014).

The third hypothesis of our research postulated that caregivers with higher caregiver burden would exhibit lower levels of well-being (both psychological and life satisfaction), lower levels of quality of life, higher distress and higher psychological resources (as post-traumatic growth and gratitude).

In order to test such hypothesis, we divided our whole sample in two groups according to their levels of caregiver burden and our hypothesis was confirmed. First, what emerged was that those individuals in the HCGB were not necessarily those who assisted PD patients (Table 3.5). Rather, groups did not differ in terms of the type of the illness they provided assistance for. This result could be explained by what Garlo et al. (2010) documented. In fact, authors compared caregivers of patients with cancer, heart failure and chronic obstructive pulmonary disease and found that their caregiver burden did not differ in terms of intensity. Moreover, high burden was associated with the caregiver’s report of need for greater help with daily tasks, but not with the characteristics of patients’ conditions, such as symptoms or functional disability. Burton et al. (2012) found similar results, documenting few differences in caregiver burden according to the diagnosis of their assisted. These data suggest that burden could be conceived as related to the caregiver’s ability to adapt to the caregiving role, rather than to their assisted’s clinical conditions.

In any case, caregivers with higher levels of caregiver burden reported higher psychological distress (stress, abnormal illness behavior, anxiety, depression, hostility-irritability, somatic symptoms) and lower levels of both psychological and life satisfaction in the present research. This result was partially in line with research performed on other types of caregivers (Fianco et al., 2015). In fact, Fianco et al. (2015) documented that caregivers of children with neuromotor and cognitive disabilities with higher perceived burden reported higher levels of depression, lower life satisfaction and lower resilience than caregivers perceiving low burden. However, at the same time, Fianco et al. (2015) found that the best predictor of perceived burden was represented by life satisfaction, followed by resilience. Differently from our findings, depression did not emerge as a predictor.

Moreover, we observed that those caregivers with lower caregiver burden experienced higher levels of gratitude, when compared to those with higher caregiver burden. This result is interesting considering the implications of gratitude for mental and physical health (Wood et al., 2008a, 2008b, 2010). To our knowledge, it is the first quantitative study examining the relationship between caregiver burden and gratitude in caregivers of PD patients. From a qualitative investigation, Habermann et al. (2013) documented the important role of gratitude also among PD caregivers. In fact, authors (Habermann et al., 2013) highlighted that caregivers who reported feelings of gratitude related to their caregiving experiences reported fewer feelings of being overwhelmed or distressed.

In conclusion, concerning differences among caregivers with high versus low caregiver burden, caregivers with high caregiver burden are more vulnerable both in terms of distress and psychological resources independently from the type of illness they provide assistance for.

The study presented some limitations related to its preliminary nature and cross-sectional design. Only a longitudinal design with larger samples of caregivers may allow investigating burden and well-being and their changes along time. Moreover, only self-report measures were used. These tools are more valid and sensitive, however they could be integrated with qualitative measures. In fact, although interviews may suffer from a higher risk of bias, at the same time, they can better represent the psychological experiences of caregiver populations both in terms of distress and psychological resources.

Thus, despite the limitations, it could be argued that when investigating caregiver burden it is fundamental to consider also the measurement of well-being dimensions (Ryff, 2014). A sensitive identification of conditions of vulnerabilities together with the identification of personal resources may help researchers and clinicians to implement interventions addressed at fostering skills and competencies such as environmental mastery that could buffer from caregiver burden.

Table 3.1

Socio-demographic characteristics of the sample (N=96)

	PD Caregivers (n=46) M (DS) / N (%)		Controls (n=50) M (DS) / N (%)		F/ χ2
Age	60.74	13.3	59.18	10.6	0.406
Years of education	11.5	4.7	10.8	4.2	0.736
Years of assistance	6.1	5.2	8.8	10.3	2.582
Gender					2.358
Men	10	21.7%	18	36.0%	
Women	36	78.3%	32	64.0%	
Employment					5.734
Retired	27	58.7%	27	54.0%	
Current employed	19	41.3%	23	46.0%	
Marital status					.276
Unmarried	9	19.6%	12	24.0%	
Married	37	80.4%	38	76.0%	

Note. *p≤0.05, **p≤0.01; PD=Parkinson’s Disease

Table 3.2

Differences between caregivers of patients with PD and caregivers of control in PWBS, LS, GQ, PLC, and PTG

	PD Caregivers (n=46) M/DS	Controls (n=50) M/DS	Total sample (N=90) M/DS	F	Cohen's *d*
PWB					
Autonomy	32.7 (6.1)	34.8 (6.9)	33.8 (6.6)	2.620	0.32
Environmental mastery	30.3 (7.4)	33.4 (6.1)	31.9 (6.9)	4.957*	0.50
Personal growth	31.7 (5.2)	33.0 (5.8)	32.4 (5.6)	1.401	0.24
Positive relations	34.6 (5.1)	35.6 (5.3)	35.2 (5.2)	0.904	0.19
Purpose in life	28.0 (6.5)	29.2 (6.1)	28.7 (6.3)	0.818	0.19
Self-acceptance	30.8 (7.6)	33.7 (7.1)	32.3 (7.4)	3.727	0.40
PWB Total	188.0 (28.9)	199.7 (27.2)	194.2 (28.5)	**4.128***	0.41
LS	6.9 (1.8)	7.6 (1.5)	7.3 (1.6)	**4.326***	0.43
GQ	32.0 (7.0)	31.0 (5.7)	31.5 (6.3)	0.518	0.16
PLC					
Life philosophy	17.8 (4.7)	20.4 (3.6)	19.2 (4.3)	**9.269****	0.63
Gratitude	15.0 (2.9)	16.2 (2.8)	15.6 (2.9)	3.742	0.43
Health perception	10.3 (2.8)	12.3 (2.2)	11.3 (2.7)	**14.462****	0.80
PLC Total	43.2 (9.2)	48.9 (8.0)	46.1 (9.0)	**10.633****	0.67
PTG					
Relations	14.2 (10.0)	19.4 (6.9)	16.9 (8.9)	**8.903****	0.62
New possibilities	7.8 (6.1)	11.9 (5.7)	9.9 (6.2)	**11.053****	0.70
Personal strengths	8.5 (5.5)	11.5 (4.3)	10.1 (5.1)	**8.998****	0.62
Spirituality	3.1 (3.2)	4.3 (3.5)	3.7 (3.4)	3.092	0.36
Appreciation of life	5.6 (4.2)	8.9 (3.6)	7.3 (4.2)	**16.674****	0.90
PTG Total	39.3 (26.1)	55.9 (20.7)	47.9 (24.8)	**12.108****	0.71

Note. *p≤0.05, **p≤0.01; PWB=Psychological Well-Being Scales; LS=Life Satisfaction; GQ=Gratitude Questionnaire; PLC=Positive Life Changes; PTG=Posttraumatic Growth inventory.

Table 3.3

Differences between caregivers of patients with PD and caregivers of control in PSI, ZBI/PDQ29, and SQ

	PD Caregivers (n=46) M (DS)	Controls (n=50) M (DS)	Total sample (N=90) M (DS)	F	Cohen's *d*
PSI					
Distress	8.6 (7.1)	8.2 (7.6)	8.4 (7.4)	0.052	0.05
AIB	0.5 (0.7)	0.9 (1.6)	0.7 (1.3)	2.736	0.32
Stress	1.7 (1.4)	1.9 (1.8)	1.8 (1.6)	0.398	0.12
Well-being	6.9 (2.0)	7.6 (1.7)	7.3 (1.9)	**4.194***	0.38
QoL	2.3 (0.7)	2.5 (0.7)	2.4 (0.7)	1.690	0.29
PSI total	10.7 (7.8)	11.0 (9.8)	10.9 (8.8)	1.145	0.03
ZBI/PDQ29	0.0061 (1.0)	0.000 (1.0)	0.0029 (1.0)	0.001	0.00
SQ					
Anxiety	6.8 (6.0)	4.8 (4.5)	5.8 (5.3)	3.405	0.38
Depression	6.0 (5.0)	4.2 (3.7)	5.1 (4.4)	4.094*	0.42
Somatic symptoms	7.8 (5.5)	7.6 (6.0)	7.7 (5.8)	0.036	0.04
Hostility-irritability	3.9 (4.2)	3.7 (3.4)	3.8 (3.7)	0.110	0.18

Note. *p≤0.05, **p≤0.01; PD=Parkinson's Disease; PSI=Psychosocial Index; AIB=Abnormal Illness Behavior; QoL=Quality of Life; SQ=Symptom Questionnaire; ZBI=Zarit Burnout Inventory; PDQ29=Parkinson's Disease Questionnaire – caregiver version; ZBI and PDQ29 scores were standardized and combined in order to be comparable.

Table 3.4

Regression Models Predicting caregiver burden (ZBI/PDQ29) in the total sample of caregivers (N=96)

	Model 1		*Model 2*		*Model 3*		*Model 4*	
	β	p	β	p	β	p	β	p
Gender	0.204	0.048	0.215	0.038	-0.12	0.900	-0.028	0.761
Age	0.379	0.014	0.457	0.004	0.268	0.070	**0.279**	**0.047**
Marital status	0.087	0.419	0.079	0.461	0.064	0.509	0.074	0.417
Employment	0.180	0.244	0.204	0.183	0.096	0.481	0.174	0.187
Years of education	0.061	0.608	0.065	0.585	0.091	0.404	0.034	0.743
Years of assistance			-0.222	0.037	-0.057	0.575	-0.040	0.681
Group			-0.074	0.475	-0.129	0.155	-0.149	0.085
PWB autonomy					0.051	0.678	-0.023	0.849
PWB environmental mastery					-0.497	0.003	**-0.366**	**0.024**
PWB personal growth					0.367	0.011	**0.345**	**0.011**
PWB positive relations					0.085	0.476	0.131	0.247
PWB purpose in life					-0.286	0.014	-0.200	0.076
PWB self-acceptance					-0.213	0.208	-0.094	0.564
SQ depression							**0.387**	**0.002**
R^2	0.101		0.147		0.412		0.482	
R^2 change	0.101		0.045		0.265		0.070	
F value	2.009	0.085	2.138	0.048	4.366	<0.0001	5.313	<0.0001

Note. ZBI=Zarit Burnout Inventory; PDQ29=Parkinson's Disease Questionnaire – caregiver version. ZBI and PDQ29 scores were standardized and combined in order to be comparable. PWB=Psychological Well-Being Scales; SQ=Symptom Questionnaire For gender: 1=men, 2=women; marital status: 1=married, 2=not married (unmarried, divorced, widow); employment: 1=unemployed/retired, 2=employed; Group: 1=Caregivers Controls, 2=Caregivers of patients with Parkinson's Disease. R^2 change for Model 1 indicates variance explained by socio-demographic factors (age). R^2 change for Model 2 indicates variance explained by condition of assistance-related variables (years of assistance) after controlling for socio-demographic factors. R^2 change for Model 3 indicates variance explained by PWB subscales after controlling for socio-demographic factors and condition of assistance-related variables. R^2 for Model 4 indicates variance explained by depression, after controlling for socio-demographic factors, condition of assistance-related variables, and PWB subscales.

Table 3.5

Socio-demographic differences between caregivers with high levels of caregiver burden (PDQ29/ZBI) and caregivers with low levels of caregiver burden

	HCGB (N=49) M (DS) / N (%)		LCGB (N=47) M (DS) / N (%)		F/ χ2
Age	61.7	11.8	58.0	11.9	2.327
Years of education	11.4	4.6	10.9	4.3	0.371
Years of assistance	6.2	7.2	8.9	9.2	2.630
Type of caregiving					1.027
Controls	28	57.1%	22	46.8%	
Parkinson	21	42.9%	25	53.2%	
Gender					0.337
Men	13	26.5%	15	31.9%	
Women	36	73.5%	32	68.1%	
Employment					0.414
Unemployed	26	53.1%	28	59.6%	
Employed	23	46.9%	19	40.4%	
Marital status					0.019
Unmarried	10	21.3%	11	22.4%	
Married	37	78.7%	38	77.6%	
Children					0.472
Yes	42	85.7%	37	80.4%	
No	7	14.3%	9	19.6%	

Note. *$p \leq 0.05$, **$p \leq 0.01$; PD=Parkinson’s Disease; HCGB=High caregiver burden; LCGB=Low caregiver burden. ZBI=Zarit Burnout Inventory; PDQ29=Parkinson’s Disease Questionnaire – caregiver version. ZBI and PDQ29 scores were standardized and combined in order to be comparable.

Table 3.6

Differences between caregivers with high levels of caregiver burden (n=49, PDQ29/ZBI) and caregivers with low levels of caregiver burden (n=47, PDQ29/ZBI) in PWBS, LS, GQ, PLC, and PTG

	HCGB (M/SD)	LCGB (M/SD)	Total sample (M/SD)	F	Cohen's *d*
PWB					
Autonomy	32.5 (6.5)	35.2 (6.5)	33.8 (6.6)	**4.068***	0.42
Environmental mastery	28.8 (6.7)	35.2 (5.4)	31.9 (6.9)	**25.602****	1.06
Personal growth	31.5 (5.6)	33.3 (5.4)	32.4 (5.6)	2.743	0.33
Positive relations	34.1 (5.4)	36.3 (4.8)	35.2 (5.2)	**4.484***	0.43
Purpose in life	27.1 (6.4)	30.3 (5.9)	28.7 (6.3)	**6.541****	0.52
Self-acceptance	29.4 (7.8)	35.4 (5.5)	32.3 (7.4)	**18.208****	0.90
PWB Total	183.4 (28.0)	205.7 (24.4)	194.2 (28.5)	**17.085****	0.90
LS	6.8 (1.6)	7.7 (1.5)	7.3 (1.6)	**7.446****	0.59
GQ	29.7 (6.7)	33.3 (5.2)	31.5 (6.3)	**8.607****	0.61
PLC					
Life philosophy	18.7 (4.6)	19.7 (4.0)	19.2 (4.3)	1.348	0.23
Gratitude	15.6 (3.2)	15.6 (2.7)	15.6 (2.9)	0.000	0.00
Health perception	10.9 (3.1)	11.7 (2.2)	11.3 (2.7)	2.136	0.30
PLC Total	45.2 (10.0)	47.1 (7.8)	46.1 (9.0)	1.005	0.21
PTG					
Relations	17.0 (7.6)	16.8 (10.2)	16.9 (8.9)	0.016	0.02
New possibilities	10.3 (6.0)	9.6 (6.5)	9.9 (6.2)	0.312	0.11
Personal strengths	10.2 (4.7)	10.0 (5.6)	10.1 (5.1)	0.056	0.04
Spirituality	3.6 (3.3)	3.8 (4.6)	3.7 (3.4)	0.136	0.05
Appreciation of life	7.5 (3.7)	7.1 (3.6)	7.3 (4.2)	0.222	0.11
PTG Total	48.6 (21.3)	47.3 (28.1)	47.9 (24.8)	0.069	0.05

Note. *p≤0.05, **p≤0.01; PWB=Psychological Well-Being Scales; LS=Life Satisfaction; GQ=Gratitude Questionnaire; PLC=Positive Life Changes; PTG=Posttraumatic Growth inventory; HCGB=High caregiver burden; LCGB=Low caregiver burden; ZBI=Zarit Burnout Inventory; PDQ29=Parkinson's Disease Questionnaire – caregiver version. ZBI and PDQ29 scores were standardized and combined in order to be comparable.

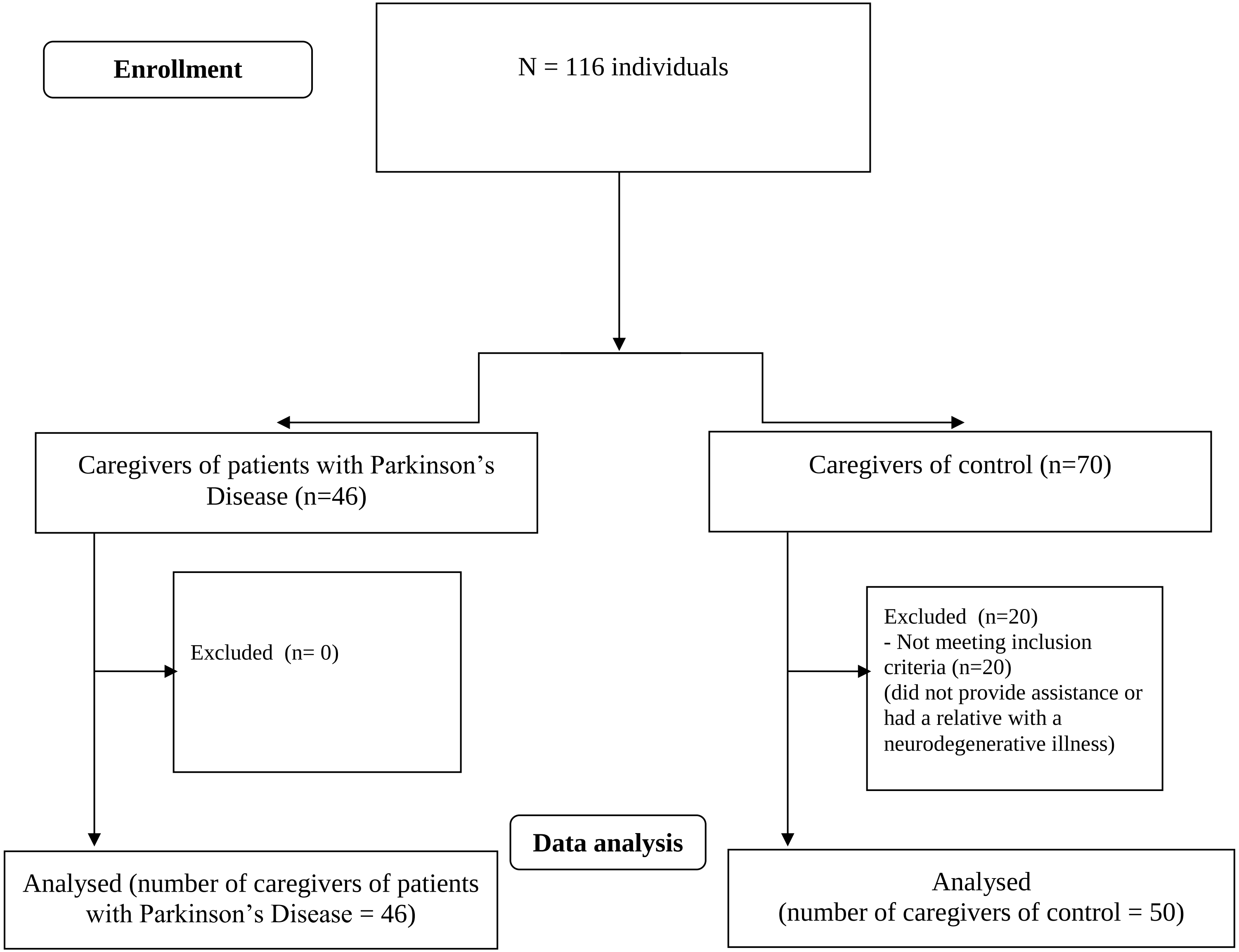
Table 3.7

Differences between caregivers of patients with PD and caregivers of control in PSI and SQ

	HCGB (M/SD)	LCGB (M/SD)	Total sample (M/SD)	F	Cohen's *d*
PSI					
Distress	11.4 (8.3)	5.3 (4.5)	8.4 (7.4)	**19.886****	0.92
AIB	1.0 (1.6)	0.4 (0.7)	0.7 (1.3)	**7.019****	0.49
Stress	2.2 (1.6)	1.3 (1.4)	1.8 (1.6)	**9.048****	0.60
Well-being	6.3 (2.0)	8.3 (1.0)	7.3 (1.9)	**38.715****	1.27
QoL	2.1 (0.7)	2.7 (0.5)	2.4 (0.7)	**31.779****	0.99
PSI total	14.7 (10.0)	6.9 (5.2)	10.9 (8.8)	**22.570****	0.98
SQ					
Anxiety	7.9 (5.9)	3.5 (3.5)	5.8 (5.3)	**19.841****	0.91
Depression	7.0 (5.0)	3.1 (2.6)	5.1 (4.4)	**22.501****	0.98
Somatic symptoms	9.5 (6.2)	5.8 (4.6)	7.7 (5.8)	**10.770****	0.68
Hostility-irritability	4.9 (4.0)	2.7 (3.1)	3.8 (3.7)	**8.938****	0.61

Note. *p≤0.05, **p≤0.01; PD=Parkinson's Disease; PSI=Psychosocial Index; AIB=Abnormal Illness Behavior; QoL=Quality of Life; SQ=Symptom Questionnaire; ZBI=Zarit Burnout Inventory; PDQ29=Parkinson's Disease Questionnaire – caregiver version; HCGB=High caregiver burden; LCGB=Low caregiver burden.

Figure 3.1. Research flow chart



CHAPTER 4

THE LONGITUDINAL EVALUATION OF PSYCHOLOGICAL FUNCTIONING OF PATIENTS WITH PARKINSON'S DISEASE AND THEIR CAREGIVERS

4.1 Introduction

Only few studies investigated the psychological functioning of patients with Parkinson's Disease (PD) and of their caregivers following a longitudinal design (Lwi et al., 2017; Pontone et al., 2016; Wee et al., 2016). The majority of such studies focused only on patients and caregivers' distress, neglecting the evaluation of their resources and their possible protective role in the psychological adaptation to the illness (for both caregivers and patients) and in the medical outcome (for patients).

In fact, for other types of patient populations, it emerged that the presence of well-being and of psychological resources such as gratitude and growth could favor a better psychological adaptation to a medical illness (Barskova and Oesterreich, 2009; Helgeson et al., 2006; Hefferon et al., 2009; Ryff, 2014; Wood et al., 2010).

Within PD populations, the few existing studies mainly included patients, neglecting their caregivers and neglecting the evaluation of the possible effect of psychological resources in terms of PD evolution and medical outcome.

Pacchetti et al. (2000) provided one of the first longitudinal study. Authors documented that PD patients' levels of happiness are amenable of improvement when they participate to music therapy. However, happiness values may return to baseline levels when the music therapy is interrupted. This result is interesting considering the implications of happiness and positive emotions for mental and physical health (Ryff, 2014; Fredrickson et al., 2013, 2017) that in this case was measured both with Unified Parkinson Disease Rating Scale (Martinez-Martin et al., 1994) and Parkinson Disease Questionnaire Quality of Life questionnaire (de Boer et al., 1996).

Weintraub et al. (2006) compared the daily affective experiences of 24 patients with PD with those of healthy individuals for 4 consecutive weeks. Patients with PD reported significantly less positive and more negative affect than controls over time. However, while patients experienced fewer positive events than controls, at the same time, they reported a positive improvement in affect in response to them. This result may indicate that they do not suffer from anhedonia in response to positive life events, as expected by the effect of PD on dopamine levels. Thus, authors concluded that rehabilitation interventions that favor daily engagement in positive experiences and improve positive affect might be implemented also in these patients.

Petrican et al. (2014) investigated the relationship between the satisfaction with life and the ability to identify emotions in 37 couples in which one member suffered from PD. The healthy spouses were more accurate in identifying happiness, but less accurate in recognizing negative emotions than healthy controls. Furthermore, authors found that satisfaction with life increased with spousal ability to identify negative emotions, this happened in particular with more years from PD symptoms onset. This study indicated that, for people with PD, the primary caregiver's ability to understand the patient's negative emotions may help maintain a better couple hedonic balance.

More recently, Koch et al. (2016) showed that a single Argentine Tango intervention in 34 PD patients was able to improve well-being, body self-efficacy, and perception of beauty in their movements and feelings of happiness, pleasure and joy. Thus, authors highlighted that psychological well-being may be improved by Tango and represent a protective factor for patients’ mental and physical health.

Concerning PD caregiver population, Parveen and Morrison (2012) studied the predictors of positive changes in 123 caregivers of people with various diagnoses (caregivers of PD patients *n* = 38). They highlighted that understanding the illness might be a necessary condition for caregivers to start perceiving benefits. Furthermore, they found that while active coping strategies are more successful in the initial course of the disease, at later stages, when caregiving becomes a more pervasive activity, the ability to "disconnect" from the role might be more beneficial. Despite these interesting preliminary results, they represent explorative studies, with no replication yet, to our knowledge examined the longitudinal changes of psychological resources and their impact on patients' medical outcome and quality of life and on caregivers' burden/quality of life. In fact the few existing experiences focused on positive emotions, such as happiness (Pacchetti et al., 2000; Weintraub et al., 2006; Petrican et al., 2014) or used only qualitative or non-standardized measures for measuring the eudaimonic dimensions of well-being (Koch et al., 2016; Parveen and Morrison, 2012).

Thus, we performed a longitudinal study in order to investigate psychological functioning of patients with PD and their caregivers in terms of well-being (hedonic, eudaimonic, and positive psychological resources such as gratitude and post-traumatic growth) and distress through two studies (one focused on PD patients and another focused on their caregivers).

4.1.2 Aims Study 1

- To observe possible longitudinal differences between patients at T1 (first assessment) and T2 (second assessment) in terms of psychological symptoms, well-being and disability.
- To identify groups of patients with lower levels of well-being and higher levels of distress (and vice versa). The former will be categorized as vulnerable individuals.
- To identify the role of protective factors for a better psychological adaptation to the illness (in terms of UPDRS/PDQ39/SQ) through the longitudinal design and a cluster analysis.

Given the chronic and progressive nature of PD, it was hypothesized that patients' level of functioning, disability and psychological distress would have remained the same or slightly worsen between T1 (first assessment) and T2 (second assessment).

Concerning the second hypothesis, it was hypothesized that those patients with higher levels of hedonic and eudaimonic well-being would have been less vulnerable by exhibiting more psychological resources, less psychological distress, and less functional disability, when compared to those with lower hedonic and eudaimonic well-being.

Finally, it was hypothesized that those individuals that at T1 experienced more hedonic and eudaimonic well-being would have reported a better psychological adaptation to the illness (in terms of PDQ39) at T2.

4.1.2.1 Methods

4.1.2.1.1 Participants and procedure

Pre-post measurements were collected from 42 patients. The remaining 12 (non-completers) did not participate to the second assessment (T2) because of various reasons: three of them died; the other nine patients reported that they were not able to take part to the research for health problems of family impediments (see figure flowchart 4.1). Among completers, thirteen were women (31%) and 29 were men (69%), aged 70.12 ± 7.3 (age range = 52-84 years), mean years of formal education were 10.9 ± 4.2 and mean years from diagnosis 6.0 ± 4.7. Mean total score at UPDRS (Martinez-Martin *et al.*, 1994) was 60.2 ± 33.1.

They were recruited in a rehabilitation outpatient clinic in Northern Italy (see study 1, chapter 2) where they were involved in physical rehabilitation programs. The recruitment process started in November 2014 and ended in May 2017. Between T1 and T2 (6 months), patients participated to the routine physical activities that are prescribed by the regional health system guidelines for PD (Adapted Physical Activity).

After explaining the study aim and procedure again, participants accepted on a voluntary basis. All of them gave their written consent to participate in this study. The Ethics Committee of the rehabilitation center approved the study protocol.

4.1.2.1.2 Measures

All patients completed the following self-report questionnaires:

Psychological Well-Being Scales (PWB) (Ryff, 1989) is a 42 item self-rating inventory that covers the 6 areas of psychological well-being: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self- acceptance. We have also calculated a total PWB score by adding together the scores of the six dimensions. Subjects respond with a six-point format ranging from "strongly disagree" to "strongly agree". Responses to negatively scored items are reversed in the final scoring on the dimension assessed. The Italian version of PWB scales has satisfactory test-retest reliability (ranging between .81 and .88 in a six-week interval) (Ruini *et al.*, 2003) and is inversely related to measures of psychological distress (Kellner, 1987). In the present study, Cronbach's alpha for the PWBS total score was 0.827. Cronbach's alpha for the PWBS subscales was as follows: α = 0.630 for autonomy subscale, α = 0.753 for environmental mastery, α = 0.727 for personal growth, α = 0.676 for positive relations with others, α = 0.461 for purpose in life, and α = 0.743 for self-acceptance.

Life Satisfaction (LS; Personal Wellbeing Index; International Wellbeing Group, 2013), a general question was used to investigate satisfaction with life: "Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?". Participants had to respond on a Likert scale from 0 "No satisfaction at all" to 10 "Completely satisfied". According to its manual, the Personal Wellbeing Index could investigate life satisfaction in various life domains (e.g., employment, family, living conditions, etc.) or it could be used as a global evaluation using a single item. This latter modality is reliable and valid for research purpose (International Wellbeing Group, 2013).

Gratitude Questionnaire-6 (GQ-6; McCullough et al., 2002) has 6 items rated on a 7-point Likert scale where 1 = ‘‘strongly disagree’’ and 7 = ‘‘strongly agree’’. The items measure gratitude intensity (‘‘I feel thankful for what I have experienced in life’’; ‘‘If I had to list everything that I felt thankful for, it would be a very long list’’). Responses to negatively scored items are reversed in the final total scoring. The GQ-6 score can range from 6 to 42. The GQ-6 displayed excellent psychometric properties and has been shown to explain unique associations with relevant constructs even after controlling for higher-order personality traits (e.g., Big Five) and social desirability (McCullough et al. 2002). Additionally, the GQ-6 exhibited only moderate negative relations with indexes of anxiety and depression (Pearson's r = -0.41 and -0.36, respectively) in previous studies in populations with medical illness (Ruini and Vescovelli, 2013). In the present study, α = 0.785.

Positive Life Changes (PLC; Anand-Kumar et al., 2014). This questionnaire was adapted from the Positive Effect of Transplantation Scale (PET; Anand-Kumar et al., 2014), which was developed in order to investigate the degree and the nature of positive psychological changes after organ transplantation. It consists of 12 item derived from organ recipient interviews. The content of its items was then adapted for patients (e.g., “the illness made me realize how precious life is”, “I am very grateful to the team that assist me”). Participants were instructed to rate on a five-point Likert-type scale (1=strongly agree, 2=agree, 3= uncertain, 4 = disagree and 5 = strongly disagree) the extent to which they agreed with each statement. When scoring, all items were reverse coded, so that higher scores represented more positive effects. It has adequate validity and internal consistency for the total scale. It is possible to use both its total scale and subscale scores. In the present study, Cronbach's alpha for the PLC total score was 0.880. Cronbach's alpha for the PLC subscales was as follows: α = 0.900 for life philosophy subscale, α = 0.679 for gratitude subscale, and α = 0.738 for health perception subscale.

Post-traumatic Growth Inventory (PTGI; Tedeschi and Calhoun 1996). This scale has been developed to explore how individuals, who have to cope with the aftermath of trauma, are successful in reconstructing or strengthening their perceptions of self, others, and the meaning of events. The PTGI has 21 items rated on a 6-point Likert scale, ranging from 0 = ‘‘I did not experience this change as a result of my crisis’’ to 5 = ‘‘I experienced this change to a very great degree as a result of my crisis’’. PTGI yields a total score and five subscales scores: (1) relations with others (7 items); (2) new possibilities (5 items); (3) personal strengths (4 items); (4) spiritual changes (2 items); and (5) appreciation of life (3 items). The scale has good internal consistency and acceptable test–retest reliability (Tedeschi and Calhoun, 1996). In previous study with medical populations (e.g., cancer patients) and controls, PTGI showed good psychometric properties (Cordova et al., 2001; Ruini, Vescovelli, & Albieri, 2014). In the present study, Cronbach’s alpha for the PTGI total score was 0.951. Cronbach’s alpha for the PTGI subscales was as follows: $\alpha = 0.825$ for relations, $\alpha = 0.885$ for new possibilities, $\alpha = 0.815$ for personal strengths, $\alpha = 0.819$ for spirituality, $\alpha = 0.782$ for appreciation of life.

Psychosocial Index (PSI; Sonino and Fava, 1998) is a self-rating scale including 52 items; 37 items (questions 1–29 and 44–51) were derived from Kellner’s Screening List for Psychosocial Problems (SLP). Items 30–37 were derived from Wheatley Stress Profile. They were added to the list of life events included in the SLP to provide an appraisal of daily, work and interpersonal stress. The tool can provide a first-line, comprehensive assessment of stress, well-being, distress, illness behavior, and quality of life (Piolanti et al., 2016). In particular, the rating of stress, thus, attempts to provide an integration of both perceived and objective stress, life events and daily stress, yielding a clinimetric definition of allostatic load (Fava et al., 2010). Some questions of the PSI involve specific responses; most require a yes/ no answer, while others are rated on a Likert 0–3 scale (from ‘‘not at all’’ to ‘‘a great deal’’). In the original validation study, internal consistency coefficients were 0.88 for stress subscale, 0.89 for psychological distress, and 0.90 for abnormal illness behaviour (Sonino and Fava, 1998). In the present study, Cronbach’s alpha for the PSI total score was 0.813. Cronbach’s alpha for the PSI subscales was as follows: α = 0.824 for distress subscale, α = 0.413 for abnormal illness behavior, α = 0.429 for stress, and α = 0.336 for well-being.

Symptom Questionnaire (SQ; Kellner, 1987) is a 92-item self-rating scale that yields 4 scales of distress (anxiety, depression, somatization and hostility-irritability) and 4 associated scales of well-being (relaxation, contentment, physical well-being and friendliness). Each symptom scale score may range from 0 to 17; each well-being scale scores from 0 to 6. The SQ was previously validated in an Italian population and has been found to be a sensitive instrument to detect changes in clinical trials, showing good split-half reliability (Fava et al., 1983; Kellner, 1987). In the present study, Cronbach's alpha SQ total subscales was as follows: α = 0.858 for anxiety total scale, α = 0.881 for depression total scale, α = 0.843 for somatic symptoms total scale, and α = 0.845 for hostility-irritability total scale.

Parkinson' Disease Questionnaire 39 item (PDQ39; Jenkinson et al., 1997) is a 39-item questionnaire encompassing the following eight dimensions: mobility, activities of daily living, emotions, stigma, social support, cognitions, communications, and bodily discomfort. Patients could select one answer from the range - Never (0); Occasionally (1); Sometimes (2); Often (3); Always (4). The scores of the eight domains are summed to produce a single index score that was previously found to be both internally reliable and valid. Internal consistency reliability was found to be high also for the various domains (Cronbach's alphas range from 0.86 to 0.92). In the present study, Cronbach's alpha for the PDQ39 total scale was 0.908. Cronbach's alpha for the PDQ39 subscales was as follows: α = 0.880 for mobility, α = 0.847 for activities of daily living, α = 0.855 for emotions, α = 0.713 for stigma, α = 0.596 for social support, α = 0.651 for cognition, α = 0.676 for communications, α = 0.557 for bodily discomfort.

4.1.2.1.3 Statistical analyses

Demographic characteristics of patients who completed the assessment with those who did not were compared using the $\chi 2$ tests and general linear model in the case of age, years from diagnosis and years of education.

Differences between T1 (first assessment) and T2 (6 month after the first assessment) in PWBS total scale, LS, PLC total scale, GQ total scale, PTG total scale, PSI total scale, SQ total scales, PDQ39 total scale, and UPDRS total scale were computed by running univariate analyses repeated measures in the sample of completers.

In order to examine the protective role of hedonic and eudaimonic well-being, a cluster analysis with k-means method was performed. For establishing the number of clusters, we relied on the theoretical model of well-being proposed by Keyes, Shmotkin and Ryff (2002). Keyes et al. (2002) described a typological model of optimal well-being based on cross-classification of levels of hedonic and eudaimonic well-being. The on-diagonal types include those individuals with consistent levels, either low or high, in both types of well-being. The off-diagonal types include those individuals that are characterized by disparate levels, where hedonic well-being is high and eudaimonic well-being is low or vice versa. Although hedonic (HeWB) and eudaimonic well-being (EWB) may complement each other in the on-diagonal types, they may compensate for each other in the off-diagonal types. Among these four types, we excluded the off-diagonal types of well-being (high EWB/low HeWB vs low EWB/high HeWB) because Keyes et al. (2002) documented that these groups were largely dependent on socio-demographic factors (age and education). Considering that our sample is small and homogenous, we decided to consider only the following two on-diagonal types of well-being: low EWB/low HeWB (Low Well-Being – LWB) and high EWB/high HeWB (High Well-Being, HWB).

Then, Chi square and Anova were used to compare the two clusters of patients (LWB vs HWB) with regard to group assignment and socio-demographic variables. Between-group comparisons on PWB, LS, GQ, PLC, PTGI, PSI, SQ, PDQ39, and UPDRS scales were calculated using the Analysis of Variance for each questionnaire, with the cluster variable as a fixed factor.

Finally, a three step regression analysis was performed (method enter) in the whole sample of patients to test if socio-demographic factors (age, gender, marital status), type of illness-related variables (years from diagnosis, initial levels of PDQ39 total scores), and the two clusters (LWB/HWB) significantly predicted patients PDQ39 total score at post-test (T2).

In the evaluation of estimates, conclusions were based on both statistical significance (significant level set at $p < 0.05$) and standardized measures of effect, with Cohen's d of 0.2 considered small, 0.5 medium and 0.8 large, and Pearson's *r* of 0.10 small, 0.30 medium and 0.50 large (Cohen, 1988). The Statistical Package for the Social Sciences (SPSS, Version 23.0) was used for analyses.

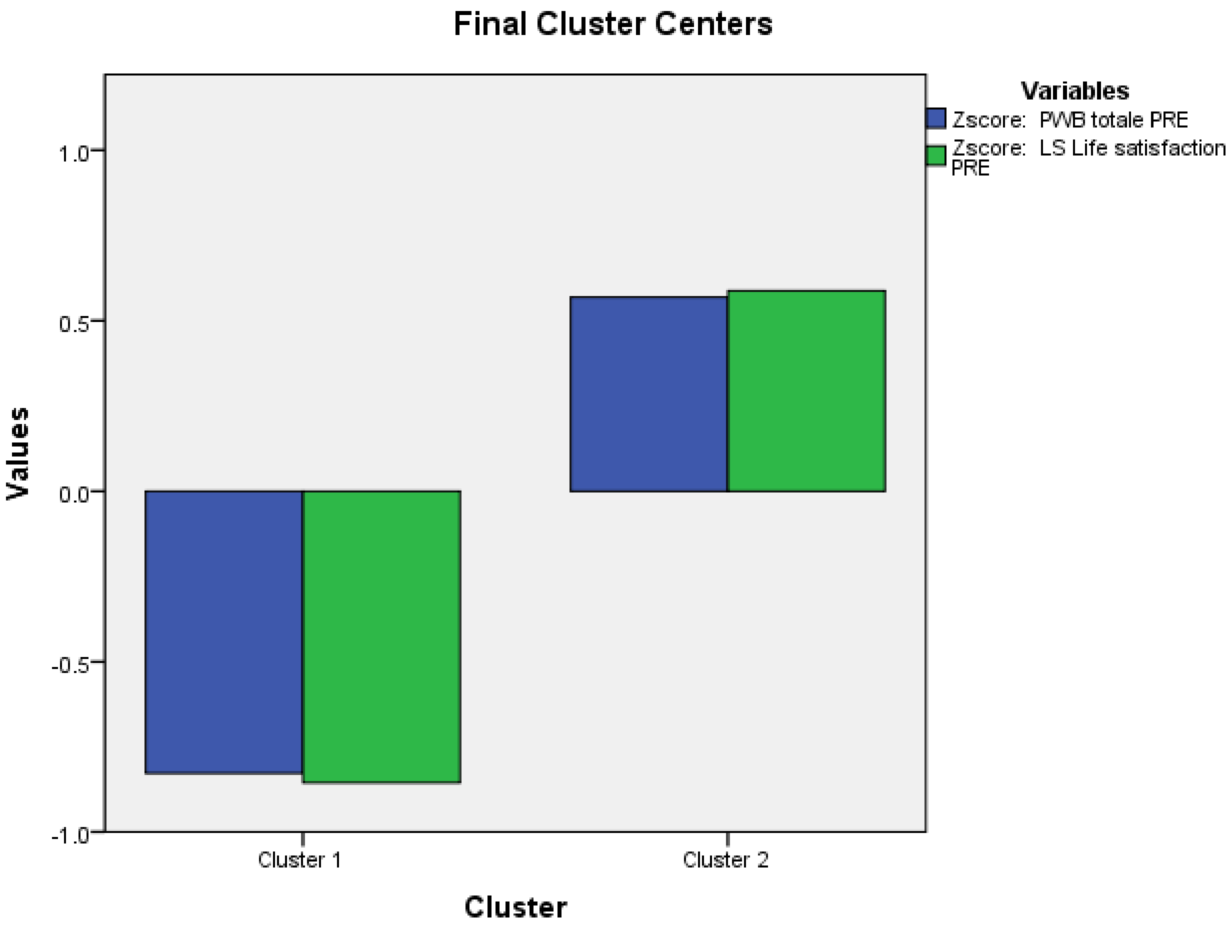
4.1.2.2 Results

No differences on socio-demographic variables were found between patients who completed the assessment and patients who did not, except for the PDQ39 scores. In particular, completers reported lower levels of PDQ39 total scores compared to non-completers ($F_{1,52} = 4.145$, $p = 0.047$) (Table 4.1).

Differences between T1 (first assessment) and T2 (6 month after the first assessment) in PWBS total scale, LS, PLC total scale, GQ total scale, PTG total scale, PSI total scale, SQ total scales, PDQ39 total scale, and UPDRS total scale were computed by running univariate analyses repeated measures (Table 4.2). In the second assessment, significant improvements were found on PSI total score ($F_{(1,41)} = 16.436$, $p < 0.001$, multivariate partial eta square = 0.286), on SQ anxiety total scale ($F_{(1,40)} = 3.959$, $p = 0.053$, multivariate partial eta square = 0.090), on SQ somatization total scale ($F_{(1,40)} = 5.911$, $p = 0.020$, multivariate partial eta square = 0.129), on UPDRS total score ($F_{(1,41)} = 14.635$, $p < 0.001$, multivariate partial eta square = 0.283), and on PDQ39 total score ($F_{(1,41)} = 232.301$, $p < 0.001$, multivariate partial eta square = 0.850 (Table 4.2). No significant differences on hedonic and eudaimonic well-being, gratitude and other positive psychological dimensions emerged between T1 and T2 (Table 4.2).

In order to examine the protective role of hedonic and eudaimonic well-being, a analysis with k-means method was performed based on completers' initial levels of hedonic and eudaimonic well-being. After 5 iterations, two clusters were identified as homogenous in their internal characteristics and highly differentiated between them. A multivariate analysis of variance found significant differences according to the cluster in PWBS standardized scores ($F_{1,52} = 47.961$; $p < 0.001$), and LS standardized scores ($F_{1,52} = 54.627$, $p < 0.001$). The model with two clusters explains 48% of the variance in PWBS scores, and 51.2% of variance in LS scores. The first cluster included individuals with low levels of hedonic and eudaimonic well-being (LWB), whereas the second cluster included individuals with high levels of hedonic and eudaimonic well-being (HWB).

Figure 4.2



Twenty-two individuals (40.7%) resulted to belong to the first cluster, with low levels of PWB and low levels of LS (LWB), whereas 32 individuals (59.3%) to the second cluster, with high levels of PWB and LS (HWB).

Socio-demographic characteristics of the two clusters are displayed in table 4.3. Chi square and univariate analysis of variance showed that the two clusters did not differ in terms of any socio-demographic variable, except for the presence of children. In particular, all the members of the HWB cluster reported to have children ($F_{1,54}$ = 4.620, p = 0.032).

In terms of psychological characteristics, many differences emerged between the two clusters. Beyond differences in terms of PWB scores and LS, differences emerged for GQ ($F_{1,52}$ = 4.421, p = 0.04), with those in the first cluster reporting lower levels of gratitude (Table 4.4).

Moreover, concerning PSI, a one-way MANOVA revealed a significant multivariate main effect for cluster (Wilks' λ = 0.735, F = 3.453, p = 0.010, partial eta squared = 0.265). Therefore, the univariate main effects were examined and significant univariate main effects for cluster were found in PSI distress ($F_{1,53}$ = 10.137, p = 0.002), well-being ($F_{1,53}$ = 12.324, p = 0.001), and quality of life ($F_{1,53}$ = 5.067, p = 0.029) (Table 4.5). In particular, those individuals in the HWB cluster reported lower distress, higher well-being and quality of life. An univariate analysis of variance revealed differences in PSI total score ($F_{1,53}$ = 9.728, p = 0.003), according to group, with those in the LWB cluster reporting higher distress scores, when compared to those in the HWB cluster (Table 4.5).

In addition, concerning SQ, a one-way MANOVA revealed a significant multivariate main effect for cluster (Wilks' λ = 0.646, F = 6.720, p < 0.001, partial eta squared = 0.354). Therefore, the univariate main effects were examined and significant univariate main effects for cluster were found in anxiety ($F_{1,52}$ = 18.447, p < 0.001), depression ($F_{1,52}$ = 24.433, p < 0.001), and hostility-irritability ($F_{1,52}$ = 6.745, p = 0.012), with those in the HWB cluster reporting lower distress scores, when compared to those in the LWB cluster. Finally, according to an univariate analysis of variance, the two cluster differed according to PDQ39 total score ($F_{1,52}$ = 7.076, p = 0.010) (Table 4.5).

Finally, the regression model in the total sample with PDQ39 total score at post test (T2) as dependent variable revealed that variables included in the models explained 54.9% of the variance ($F_{6,35}$ = 7.110, p < 0.001). Particularly, it was found that PDQ39 initial scores and the cluster (LWB/HWB) significantly predicted

PDQ39 total score at post-test ($\beta = 0.530$, $p = 0.001$, $\beta = -0.297$, $p = 0.034$, respectively) (Table 4.6). In particular, those individuals. In particular, higher levels of well-being were found to be predictive of a better outcome of PD.

4.1.2.3 Discussion

The aim of the study was to evaluate the longitudinal trajectory of patients with PD in terms of well-being, distress and disability. Secondarily, this longitudinal assessment would allow to identify subgroups of patients with low levels of well-being and more distress (vulnerable patients) or vice versa with high levels of well-being and less distress. It was hypothesized that the latter group would have a better adaptation to the illness over the course of time.

Furthermore, the study hypothesized that the level of patients' functioning and disability would have remained the same o slightly worsen between T1 (first assessment) and T2 (second assessment). Findings showed improvement for stress, anxiety, functional status and medical outcome (measured with UPDRS and PDQ39 respectively). Conversely, no improvements between T1 and T2 were found for hedonic and eudaimonic well-being and other positive protective resources. Despite the chronic and progressive nature of PD, the improvement of these physical dimensions can be explained by the fact that the majority of these PD patients (32 out of 42) came to the rehabilitation center for participating to a two 1-hour weekly session of physical activity program performed in a group format. Abbruzzese et al. (2016) showed that rehabilitation must be considered an adjuvant ingredient to medical treatments (drugs/surgery) for PD patients to improve physical functioning and reduce secondary complications. Since physical exercise has the potential for fostering synapsis and neurotransmission and patients' motor learning, it can be very helpful for both maintaining and sometimes improving patients' motor functioning and physical autonomy. Recent studies and review documented that physical activity can positively impact not only motor symptoms and physical disability but also PD non-motor symptoms such as depression, apathy, fatigue, sleep, and cognition (Abbruzzese et al., 2016; Cusso et al., 2016; Shu et al., 2014; Wu et al., 2017). In light of these findings, the improvements reported by our patients at the second assessment could find a proper explanation.

Moreover, the non-significant changes in well-being and positive psychological resources are partially in line with previous literature documenting that PWB and PTG tend to remain stable over time (Parveen and Morrison, 2012; Ryff, 2014). Furthermore, our patients were not involved in specific interventions/activities addressed at promoting well-being and positive psychological functioning.

Concerning the second hypothesis, we hypothesized that those patients with higher levels of hedonic and eudaimonic well-being would have been less vulnerable by exhibiting more psychological resources, less psychological distress, and less functional disability, when compared to those with lower hedonic and eudaimonic well-being. The results confirmed this hypothesis showing that those patients with more well-being (hedonic and eudaimonic) reported less psychological symptoms (distress, anxiety, depression, hostility-irritability), more psychological resources such as gratitude and a better medical outcome (PDQ39) and quality of life. Our hypothesis was based on studies documenting the protective role of eudaimonic and hedonic well-being for mental and physical health of healthy individuals and patients with various types of medical illness (Ryff, 2014; Steptoe et al., 2009; Ruini et al., 2013) including PD (Barak and Achiron, 2009; Dural et al., 2003; Birgersson and Edberg, 2004; Pacchetti et al., 2000; Simpson et al., 2006; Weintraub et al., 2006; Gustafsson et al., 2015; Rosengren et al., 2016; Rosqvist et al., 2016; Cubì-Molla et al., 2014; Hammarlund et al., 2014; Kang and Ellis-Hill, 2015; Pusswald et al., 2012; Koch et al., 2016, see chapter 1 for more details).

In this study, for the first time we combined an indicator of hedonic well-being with an indicator of psychological well-being (Keyes et al., 2002) for clustering a PD patient population.

Importantly, the present study found that the two clusters did not differ in terms of socio-demographic characteristics, with the sole exception of the presence of children. All of those patients in the HWB cluster reported to have children. This data found evidence in previous research documenting that the presence of children could be associated with improvements in eudaimonic well-being (Ryff, 2014). However, this relationship may be influenced and may change according to some variables. For example, the experience of positive moments with adult children may determine higher levels of eudaimonic well-being (An and Cooney, 2006). Similarly, Bassi et al. (2017) showed that women experienced an increase in their levels of self-acceptance and personal growth after becoming mothers.

Concerning the relationship between the presence of children and hedonic well-being, literature found that the presence of children may determine enduring positive effects on life satisfaction according to variables such as culture, economic costs, parents' employment arrangements (Pollmann-Schult, 2014; Vanassche et al., 2013). However, it must be acknowledged that also the opposite relation was found in literature: the presence of well-being may induce adults to have more children (Kim and Hicks, 2016). Even if our result are descriptive and we could no formulate final conclusion, we could only affirm that among all of the socio-demographic variables, the presence of children is the only one that differentiate those individuals with high versus low hedonic and eudaimonic well-being. Thus, PD patients without children may represent a vulnerable population. Further studies could provide more details to this association.

As expected, those individuals in the HWB cluster reported greater eudaimonic well-being in all of the PWBS dimensions. Furthermore, patients in the HWB cluster exhibited higher levels of gratitude. This was the first study documenting that also in PD patients well-being and gratitude are strictly related and higher well-being may be associated with higher gratitude or vice versa. This result has been found for other types of illness so far, but not for PD yet. This finding have important clinical implications considering the benefits of gratitude for mental and physical health (Eaton et al., 2014; Huffman et al., 2016; Ruini and Vescovelli, 2013; Sirois and Wood, 2017; Wood et al., 2010).

Moreover, those individuals with higher hedonic and eudaimonic well-being were found to report higher quality of life. This result was in line with previous finding showing the positive correlation between well-being and QoL (Cubì-Mollà et al., 2016; Pacchetti et al., 2000; Simpson et al., 2006; Rosengren et al., 2016;

Rosqvist et al., 2016). However, to our knowledge this was the first study that combined indicators of hedonic and eudaimonic well-being in relation to QoL in PD patients (Cubì-Mollà et al., 2016; Pacchetti et al., 2000; Simpson et al., 2006; Rosengren et al., 2016; Rosqvist et al., 2016).

Concerning distress, our findings highlighted that those PD patients with higher well-being, reported also lower symptomatology (stress, anxiety, depression, and hostility-irritability). This, again, confirms previous literature showing the important role of hedonic well-being for mental health (see chapter 1). However, to our knowledge, except for the study of Pusswald et al. (2012), this is the first one documenting the contribution of eudaimonic well-being (measured with standardized tools) for buffering psychological symptomatology among PD patients.

In addition, it emerged that the combination of hedonic and eudaimonic well-being may be associated also with lower physical impairments also in terms of functional disability (UPDRS) and adaptation to the illness (measured with PDQ39). This was the first study documenting such a relationship within a PD population. Given the neurodegenerative and progressive nature of PD, this finding has important implications as it may suggest that well-being may play a role in influencing the adaptation to the illness and the level of disability.

As a result, hedonic and eudaimonic well-being when combined together may provide a protection against psychological distress and disability also in this patient population.

Finally, our regressive model further confirmed the last hypothesis on the possible predictors of a better psychological adaptation to the illness.After controlling for socio-demographic factors, the main predictors of a better condition of health/quality of life in the long term (PDQ39) were represented by both the initial levels of PDQ39 and by cluster membership (high hedonic and eudaimonic well-being). Conversely, those individuals with more initial impairments in their health (PDQ39) and in their levels of well-being, could be more vulnerable and suffer from a worse condition of health in the long term.

To our knowledge, this research is the first longitudinal experience documenting the protective role of hedonic and eudaimonic well-being against the progressive loss of functioning and independence that characterize PD.

The protective role of well-being was documented by previous literature, both when referring to dimensions of eudaimonic well-being (Ryff, 2014) and of hedonic well-being (Chida and Steptoe, 2008; Steptoe et al., 2009, 2015). However, to our knowledge their combined role in protecting mental health was never investigate in individuals with PD with a longitudinal design.

Given its preliminary nature, the study presents some limitations. First of all, the sample was composed of self-selected individuals suffering from PD who were homogenous from a cultural and ethnic point of view. Secondly, the sample was small and more individuals could make the findings more generalizable. Moreover, only self-report questionnaires were used. Future studies should fill this gap and measure the protective role of hedonic and eudaimonic well-being in buffering PD patients' mental and physical health by monitoring their health condition also in terms of biological and neuroanatomical correlates.

4.1.3 Aims Study 2

- To observe possible longitudinal differences between caregivers at T1 (first assessment) and T2 (second assessment).
- To identify groups of caregivers with lower levels of well-being and higher levels of distress (and vice versa). The former will be categorized as vulnerable caregivers..
- To identify the role of protective factors for a better psychological adaptation to the illness of caregivers (in terms of PDQ29) through the longitudinal design and cluster analysis.

Concerning the first hypothesis, it was hypothesized that caregivers' psychological functioning and caregiver burden would have remained the same or worsen between at T1 (first assessment) and T2 (second assessment). Our caregivers came to the rehabilitation center only for carrying their assisted, and were not involved in any specific activity.

Concerning the second aim, it was hypothesized that those caregivers with higher levels of hedonic and eudaimonic well-being and lower levels of caregiver burden would have been less vulnerable by exhibiting more psychological resources, less psychological distress and symptomatology, when compared to those with lower hedonic and eudaimonic well-being and higher caregiver burden.

Finally, it was hypothesized that those individuals that at T1 experienced more hedonic and eudaimonic well-being would have reported a better psychological adaptation to the illness of their assisted (in terms of lower caregiver burden) at T2.

4.1.3.1 Methods

4.1.3.1.1 Participants and procedure

Thirty-eight caregivers of patients with Parkinson's Disease (CG_{PD}) completed the batteries (see chapter 3 and figure 4.2). The remaining 12 did not participate to the assessment because of various reasons: three were caregivers of PD patients who had died; the other nine caregivers reported that they were not able to take part to the research for health problems of family impediments. They were recruited in a rehabilitation outpatient clinic in Northern Italy (see study 2, chapter 3) where they used to come to carry their relatives with PD for physical rehabilitation programs.

Twenty-nine were women (76.3%) and 9 were men (23.7%), aged 59.6 ± 14.3 (age range = 45-85 years), mean years of formal education were 12.0 ± 4.6 and mean years of assistance 5.6 ± 4.4.

After explaining the study aim and procedure, participants accepted on a voluntary basis. All of them gave their written consent to participate in this study.
The Ethics Committee of the rehabilitation center approved the study protocol.

4.1.3.1.2 Measures

All caregivers completed the following self-report questionnaires:

Psychological Well-Being Scales (PWB) (Ryff, 1989) is a 42 item self-rating inventory that covers the 6 areas of psychological well-being: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self- acceptance. We have also calculated a total PWB score by adding together the scores of the six dimensions. Subjects respond with a six-point format ranging from "strongly disagree" to "strongly agree". Responses to negatively scored items are reversed in the final scoring on the dimension assessed. The Italian version of PWB scales has satisfactory test-retest reliability (ranging between .81 and .88 in a six-week interval) (Ruini *et al.,* 2003) and is inversely related to measures of psychological distress (Kellner, 1987). In the present study, $\alpha = 0.738$ for autonomy subscale, $\alpha = 0.792$ for environmental mastery, $\alpha = 0.452$ for personal growth, $\alpha = 0.551$ for positive relations with others, $\alpha = 0.667$ for purpose in life, $\alpha = 0.792$ for self-acceptance and $\alpha = 0.847$ for PWB total scale.

Life Satisfaction (LS; Personal Wellbeing Index; International Wellbeing Group, 2013), a general question was used to investigate satisfaction with life: “Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?”. Participants had to respond on a Likert scale from 0 “No satisfaction at all” to 10 “Completely satisfied”. According to its manual, the Personal Wellbeing Index could investigate life satisfaction in various life domains (e.g., employment, family, living conditions, etc.) or it could be used as a global evaluation using a single item. This latter modality is reliable and valid for research purpose (International Wellbeing Group, 2013).

Gratitude Questionnaire-6 (GQ-6; McCullough et al., 2002) has 6 items rated on a 7-point Likert scale where 1 = ‘‘strongly disagree’’ and 7 = ‘‘strongly agree’’. The items measure gratitude intensity (‘‘I feel thankful for what I have experienced in life’’; ‘‘If I had to list everything that I felt thankful for, it would be a very long list''). Responses to negatively scored items are reversed in the final total scoring. The GQ-6 score can range from 6 to 42. The GQ-6 displayed excellent psychometric properties and has been shown to explain unique associations with relevant constructs even after controlling for higher-order personality traits (e.g., Big Five) and social desirability (McCullough et al. 2002). Additionally, the GQ-6 exhibited only moderate negative relations with indexes of anxiety and depression (r's = -0.41 and -0.36, respectively) in previous studies in populations with medical illness (Ruini and Vescovelli, 2013). In the present study, $\alpha = 0.785$ for CG_{PD}.

Positive Life Changes (PLC; Anand-Kumar et al., 2014). This questionnaire was adapted from the Positive Effect of Transplantation Scale (PET; Anand-Kumar et al., 2014), which was developed in order to investigate the degree and the nature of positive psychological changes after organ transplantation. It consists of 12 item derived from organ recipient interviews. The content of its items was then adapted for caregivers and caregiving in general (e.g., the illness of the person who I assist has made me realize how precious life is, I am very grateful to the team that assist my relative). Participants were instructed to rate on a five-point Likert-type scale (1 = strongly agree, 2 = agree, 3 = uncertain, 4 = disagree and 5 = strongly disagree) the extent to which they agreed with each statement. When scoring, all items were reverse coded, so that higher scores represented more positive effects. It has adequate validity and internal consistency for the total scale. It is possible to use both its total scale and subscale scores. In the presents study, $\alpha = 0.877$ for life philosophy subscale, $\alpha = 0.681$ for gratitude subscale, $\alpha = 0.903$ for health perception subscale, $\alpha = 0.909$ for PLC total scale.

Post-traumatic Growth Inventory (PTGI; Tedeschi and Calhoun 1996). This scale has been developed to explore how individuals, who have to cope with the aftermath of trauma, are successful in reconstructing or strengthening their perceptions of self, others, and the meaning of events. The PTGI has 21 items rated on a 6-point Likert scale, ranging from 0 = ''I did not experience this change as a result of my crisis'' to 5 = ''I experienced this change to a very great degree as a result of my crisis''. PTGI yields a total score and five subscales scores: (1) relations with others (7 items); (2) new possibilities (5 items); (3) personal strengths (4 items); (4) spiritual changes (2 items); and (5) appreciation of life (3 items). The scale has good internal consistency and acceptable test–retest reliability (Tedeschi and Calhoun, 1996). In previous study with medical populations (e.g., cancer patients) and controls, PTGI showed good psychometric properties (Cordova et al., 2001; Ruini, Vescovelli, and Albieri, 2014). For the present study, $\alpha = 0.923$ for relations, $\alpha = 0.868$ for new possibilities, $\alpha = 0.840$ for personal strengths, $\alpha = 0.874$ for spirituality, $\alpha = 0.753$ for appreciation of life, $\alpha = 0.960$ for PTG total scale.

Psychosocial Index (PSI; Sonino and Fava, 1998) is a self-rating scale including 52 items; 37 items (questions 1–29 and 44–51) were derived from Kellner's Screening List for Psychosocial Problems (SLP). Items 30–37 were derived from Wheatley Stress Profile. They were added to the list of life events included in the SLP to provide an appraisal of daily, work and interpersonal stress. The tool can provide a first-line, comprehensive assessment of stress, well-being, distress, illness behavior, and quality of life (Piolanti et al., 2016). In particular, the rating of stress, thus, attempts to provide an integration of both perceived and objective stress, life events and daily stress, yielding a clinimetric definition of allostatic load (Fava et al., 2010). Some questions of the PSI involve specific responses; most require a yes/ no answer, while others are rated on a Likert 0–3 scale (from ‘‘not at all’’ to ‘‘a great deal’’). In the original validation study, internal consistency coefficients were 0.88 for stress subscale, 0.89 for psychological distress, and 0.90 for abnormal illness behaviour (Sonino and Fava, 1998). In the present study, $\alpha = 0.890$ for distress subscale, $\alpha = 0.597$ for abnormal illness behavior, $\alpha = 0.428$ for stress, $\alpha = 0.707$ for well-being, and $\alpha = 0.856$ for PSI total scale.

Symptom Questionnaire (SQ; Kellner, 1987) is a 92-item self-rating scale that yields 4 scales of distress (anxiety, depression, somatization and hostility-irritability) and 4 associated scales of well-being (relaxation, contentment, physical well-being and friendliness). Each symptom scale score may range from 0 to 17; each well-being scale scores from 0 to 6. The SQ was previously validated in an Italian population and has been found to be a sensitive instrument to detect changes in clinical trials, showing good split-half reliability (Fava et al., 1983; Kellner, 1987). In the present study, $\alpha = 0.850$ for anxiety total scale, $\alpha = 0.820$ for depression total scale, $\alpha = 0.849$ for somatic symptoms total scale, and $\alpha = 0.782$ for hostility-irritability total scale.

Parkinson' Disease Questionnaire 29 item carer-version (PDQ29; Jenkinson et al., 2012) completed by caregivers of PD patients) is a 29-item questionnaire encompassing four dimensions of quality of life (social and personal activities, anxiety and depression, self-care, and strain). These four domains are summed to provide a single summary index score (Morley et al., 2013). Caregivers could select one answer from the range - Never (0); Occasionally (1); Sometimes (2); Often (3); Always (4). Internal consistency reliability was found to be high for all domains (Cronbach's alphas range from 0.86 to 0.92). In the present study, $\alpha = 0.953$ for personal and social activities, $\alpha = 0.910$ for anxiety and depression, $\alpha = 0.905$ for self-care, $\alpha = 0.880$ for stress, and $\alpha = 0.976$ for PDQ29 total scale.

4.1.3.1.3 Statistical analyses

Demographic characteristics of CG_{PD} who completed the assessment were compared with those CG_{PD} who did not using the $\chi2$ tests and general linear model in the case of age, years of assistance and years of education.

Differences between T1 (first assessment) and T2 (6 month after the first assessment) in PWBS, LS, PLC, GQ, PTG, PSI, SQ, and PDQ29 were computed by running seven univariate analyses repeated measures (for LS, PWBS total score, PLC total score, PTGI total score, PSI total score, PSI QoL and PDQ29) and five separate multivariate analyses repeated measures (for PWBS, PLC, PTG, PSI, SQ subscales).

In order to examine the protective role of hedonic and eudaimonic well-being, a cluster analysis with k-means method was performed. For establishing the number of clusters, we relied on the theoretical model of well-being proposed by Keyes, Shmotkin and Ryff (2002). Keyes et al. (2002) described a typological model of optimal well-being based on cross-classification of levels of hedonic and eudaimonic well-being. The on-diagonal types include those individuals with consistent levels, either low or high, in both types of well-being. The off-diagonal types include those individuals that are characterized by disparate levels, where hedonic well-being is high and eudaimonic well-being is low or vice versa. Although hedonic (HeWB) and eudaimonic well-being (EWB) may complement each other in the on-diagonal types, they may compensate for each other in the off-diagonal types. Among these four types, we excluded the off-diagonal types of well-being (high EWB/low HeWB vs low EWB/high HeWB) because Keyes et al. (2002) documented that these groups were largely dependent on socio-demographic factors (age and education). Considering that our sample is small and homogenous, we decided to consider only the following two on-diagonal types of well-being: low EWB/low HeWB (Low Well-Being) and high EWB/high HeWB (High Well-Being). Moreover, we included the measure of caregiver burden (PDQ29) because of its association with hedonic and eudaimonic well-being (Ryff, 2014). Thus we considered two clusters: Low Well-Being and High caregiver burden (LWB) and High Well-being and Low caregiver burden (HWB).

Then, Chi square and Anova were used to compare the two clusters of patients (LWB vs HWB) with regard to group assignment and socio-demographic variables. Between-group comparisons on PWB, LS, GQ, PLC, PTGI, PSI, SQ, PDQ29, and patients' PDQ39 initial score were calculated using the Analysis of Variance for each questionnaire, with the cluster variable as a fixed factor.

Finally, a three step regression analysis was performed (method enter) in the whole sample of caregivers to test if socio-demographic factors (age, gender, marital status), assistance related variables (years of assistance and patient's PDQ39 total score at T2), and the two clusters (LWB/HWB) significantly predicted caregivers' PDQ29 total score at post-test (T2).

In the evaluation of estimates, conclusions were based on both statistical significance (significant level set at $p < 0.05$) and standardized measures of effect, with Cohen's *d* of 0.2 considered small, 0.5 medium and 0.8 large, and Pearson's *r* of

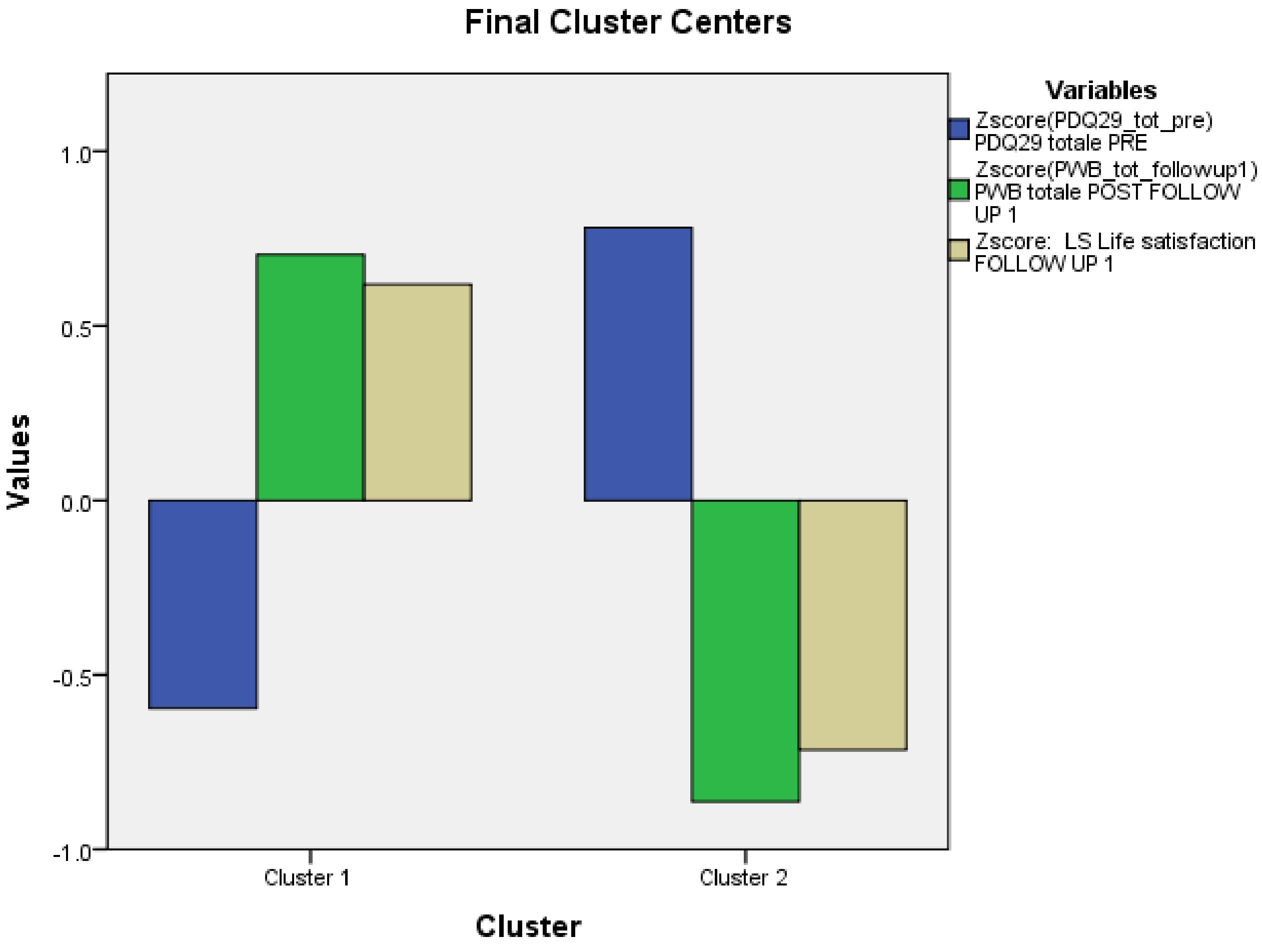
0.10 small, 0.30 medium and 0.50 large (Cohen, 1988). The Statistical Package for the Social Sciences (SPSS, Version 23.0) was used for analyses.

4.1.3.2 Results

No differences on socio-demographic variables were found between caregivers who completed the assessment and caregivers who did not (Table 4.7) Univariate analyses repeated measures found no significant difference between T1 (first assessment) and T2 (6 month after the first assessment) in all of the questionnaire total scales, except for PSI total scale (Table 4.8). There was a significant effect for time on PSI total score ($F_{1,37}$ = 3.960, p = 0.054, partial eta square = 0.097).

In order to examine the protective role of hedonic (LS) and eudaimonic well-being (PWBS) together with the role of caregiver burden (PDQ29), an analysis with k-means method was performed. Following Keyes et al.'s model (2002), after 3 iterations, two clusters were identified as homogenous in their internal characteristics and highly differentiated between them. In particular, a multivariate analysis of variance found significant differences according to the cluster in PDQ29 standardized scores ($F_{1,47}$ = 43.568; $p < 0.001$), in PWBS standardized scores ($F_{1,47}$ = 76.413; $p < 0.001$), and LS standardized scores ($F_{1,52}$ = 38.315, $p < 0.001$). The model with two clusters explains 48.1% of the variance in PDQ29 scores, 61.9% of variance in PWBS scores, and 44.9% of variance in LS scores. The first cluster included individuals with low levels of caregiver burden (PDQ29) and high levels of hedonic and eudaimonic well-being (HWB), whereas the second cluster included individuals with high levels of caregiver burden (PDQ29) and low levels of hedonic and eudaimonic well-being (LWB) (See figure 4.4)

Figure 4.3



Twenty-seven individuals (55.1%) resulted to belong to the first cluster, with low levels of PDQ29 and high levels of PWBS and LS, whereas 22 individuals (44.9%) to the second cluster, with high levels of PDQ29 and low levels of PWB and LS.

Socio-demographic characteristics of the two clusters are displayed in table 4.9. Chi square and univariate analysis of variance showed that the two clusters did not differ in terms of any socio-demographic variable, except for the age. In particular, all the members of the HWB (low PDQ29, and high PWB and LS) are younger ($F_{1,54} = 4.620$, $p = 0.032$), compared to those of the LWB (high PDQ29, and low PWB and LS).

In terms of psychological characteristics, many differences emerged between the two clusters. Beyond differences in terms of PWB, LS, and PDQ29 scores, differences emerged for GQ ($F_{1,47} = 27.060$, $p < 0.001$), with those in the first cluster reporting higher levels of gratitude (Table 4.10). Moreover, concerning PLC, a one-way MANOVA revealed a significant multivariate main effect for cluster (Wilks' $\lambda = 0.766$, $F_{3,45} = 4.572$, $p = 0.007$, partial eta squared = 0.234). Therefore, the univariate main effects were examined and significant univariate main effects for group were found for PLC life philosophy ($F_{1,47} = 8.770$, $p = 0.005$), PLC health perception ($F_{1,47} = 6.760$, $p = 0.012$), and PLC total scores ($F_{1,47} = 5.422$, $p = 0.024$), with those in the HWB cluster reporting higher scores, when compared to those in the LWB group. Differences did not emerge for PLC gratitude subscale (Table 4.10).

When examining differences on PSI total score, a one-way univariate ANOVA revealed a significant univariate effect for cluster ($F_{1,47} = 36.211$, $p < 0.001$). Moreover, when considering PSI subscales, one-way MANOVA revealed a significant multivariate main effect for cluster (Wilks' $\lambda = 0.426$, $F_{5,43} = 11.607$, $p < 0.001$, partial eta squared = 0.574). Therefore, the univariate main effects were examined and significant univariate main effects for group were found for quality of life ($F_{1,47} = 26.857$, $p < 0.001$), distress ($F_{1,47} = 32.722$, $p < 0.001$), and well-being ($F_{1,47} = 37.845$, $p < 0.001$), with those in the HWB cluster reporting higher scores, when compared to those in the LWB group.

Finally, concerning SQ, a one-way MANOVA revealed a significant multivariate main effect for cluster (Wilks' $\lambda = 0.159$, $F_{4,44} = 58.255$, $p < 0.001$, partial eta squared = 0.841). Therefore, the univariate main effects were examined and significant univariate main effects for group were found for anxiety ($F_{1,47} = 27.426$, $p < 0.001$), depression ($F_{1,47} = 37.666$, $p < 0.001$), somatization ($F_{1,47} = 29.537$, $p < 0.001$), and hostility-irritability ($F_{1,47} = 6.321$, $p = 0.015$), with those in the HWB cluster reporting higher scores, when compared to those in the LWB group. Differences did not emerge for initial PDQ39 patients' score (Table 4.11).

Finally, the regression model in the total sample with PDQ29 total score at post test (T2) as dependent variable revealed that variables included in the models explained

69.2% of the variance ($F_{6,30} = 11.232$, $p = 0.001$). It was found that PDQ39 total score at T2 and cluster membership were the only significant predictors of PDQ29 at post-test ($\beta = 0.520$, $p < 0.001$, $\beta = 0.428$, $p = 0.001$, respectively) (Table 4.12). In particular, those individuals whose assisted reported higher PD symptoms (as measured with PDQ39 scores at T2) and belonged to the LWB cluster (initial lower levels of eudaimonic (PWB) and hedonic well-being (LS) and higher caregiver burden (PDQ29)), were found to report a higher caregiver burden after 6 months.

4.1.3.3 Discussion

The aim of the study was to evaluate the longitudinal trajectory of caregivers of patients with PD in terms of well-being, distress and caregiver burden. Secondarily, this longitudinal assessment would allow to identify subgroups of caregivers with low levels of well-being and more distress (vulnerable caregivers) or vice versa with high levels of well-being and less distress. It was hypothesized that the latter group would have a better adaptation to the caregiver condition over the course of time.

Our longitudinal study documented that there were no significant differences in both caregivers' well-being and distress from T1 and T2, with the sole exception of psychological distress (PSI) that slightly improved at the second assessment.

More interesting results were found with the cluster analysis. Caregivers were grouped according to their levels of caregiver burden and their levels of hedonic and eudaimonic well-being (HWB vs LWB). Caregivers in these two groups differed only in terms of age, with those in the HWB being younger (see Table 4.9). A possible explanation could rely on the fact that the majority of variance of the cluster was explained by PWB (68%). Previous literature documented that PWB tends to decline as age progresses (Ryff, 2014). Furthermore, caregiver burden tends to increase with age (Glozman, 2004; Tan et al., 2012). Thus, the combination of well-being impairments and caregiver burden could identify a subgroup of caregivers who are more vulnerable (those 22 included in the LWB cluster). In fact, caregivers with initial higher levels of hedonic and eudaimonic well-being and lower levels of caregiver burden were found to report not only a better quality of life, and more self-acceptance, autonomy, purpose in life, positive relations, personal growth and environmental mastery, but also more existential resources such as those related to gratitude and positive changes in life philosophy (see Tables 4.10 and 4.11).

Furthermore, our results showed that PD caregivers with higher well-being and lower caregiver burden experienced also lower distress, anxiety, depression, somatization and hostility, when compared to those with lower well-being and higher burden (see Table 4.11). Thus, their mental health appeared to be less vulnerable compared to that one of the other group (with low well-being and high burden). The negative relationship between well-being and distress was previously documented by many studies among caregivers (Cassidy, 2013; Bassi et al., 2016; Fianco et al., 2015; Rosenberg et al., 2013; Ryff, 2014).but only few of them focused on caregiving in PD (Mavandadi et al., 2014; Navarta-Sanchez et al., 2016).

In conclusion, a first observation emerging from our findings concerns the more vulnerable subgroup of PD caregivers. This subgroup (belonging to the LWB cluster) is characterized by being older and not by other socio-demographic or assistance related variables (i.e., years of assistance and severity of symptoms of their assisted - see Table 4.11).

Finally, the longitudinal analysis, revealed that cluster membership had a significant effect also on caregiver burden at T2. Tt was hypothesized that those individuals that at T1 experienced more hedonic and eudaimonic well-being would have reported a better psychological adaptation to the illness (in terms of lower caregiver burden) at T2. This result was confirmed by our regressive analysis showing that cluster membership and patient’s symptoms at T2 (measured with PDQ39) were the only predictors of caregiver burden, after controlling for any other socio-demographic factors and assistance-related variables (see Table 4.12).

Previous studies documented that PD caregiver burden was associated with the use of active coping strategies and a clear understanding of illness characteristics (Parveen and Morrison, 2012). These protective resources may be similar to the eudaimonic well-being dimensions of environmental mastery (active coping strategies) or to self-acceptance (understanding of the illness) that are reported by our caregiver population. However, future studies are needed as Parveen and Morrison (2012) explored caregivers' resources only with a qualitative design with a heterogeneous population in terms of their medical illness. Conversely, our sample consisted of caregivers of patients suffering “only” from PD. A larger sample and a longer follow-up would allow a more generalizability of our findings.

Despite these limitations, this is the first study that examined the combined role of eudaimonic and hedonic well-being together with caregiver burden in the long-term trajectories of Parkinson caregivers..

Table 4.1. *Socio-demographic and clinical characteristics of PD patients completers and PD patients non-completers*

	Completers (N=42) M (DS) / N (%)		Non-completers (N=12) M (DS) / N (%)		F/ $\chi 2$
Age	70.12	7.3	72.0	7.6	0.604
Years of education	10.9	4.2	8.4	4.7	3.178
Years from diagnosis	6.0	4.7	8.1	6.3	1.589
MMSE	28.9	1.3	28.1	2.6	1.845
UPDRS total	54.9	30.0	79.6	40.8	**5.233***
PDQ39 total	258.7	110.0	336.7	139.9	**4.145***
Gender					0.159
Men	29	69.0%	9	74.0%	
Women	13	31.0%	3	25.0%	
Marital status					2.612
Unmarried	8	19.0%	5	41.7%	
Married	34	81.0%	7	58.3%	
Children					0.908
Yes	39	92.9%	12	100%	
No	3	7.1%	0	/	

Note. *p≤0.05, **p≤0.01; PD=Parkinson’s Disease; MMSE=Mini Mental State Examination; UPDRS=Unified Parkinson Disease Rating Scale; PDQ39= Parkinson's Disease Questionnaire.

Table 4.2. *Differences in total scale between T1 and T2*

	T1 M (DS)	T2 M (DS)	F	Cohen's *d*
PWB	183.7 (27.2)	186.2 (26.1)	0.727	0.09
QoL	2.4 (0.9)	2.4 (0.9)	0.000	0
LS	6.9 (1.9)	7.1 (1.8)	1.662	0.11
GQ	31.7 (5.0)	31.7 (5.3)	0.001	0
PLC total	46.9 (7.9)	47.7 (8.2)	0.403	0.10
PTG total	59.1 (23.7)	60.2 (20.7)	0.139	0.05
PSI total	14.4 (7.2)	10.6 (7.1)	**16.436****	0.53
SQ anxiety	6.5 (4.5)	5.3 (4.7)	**3.959***	0.26
SQ depression	6.9 (4.6)	6.4 (4.6)	0.857	0.11
SQ somatization	11.8 (4.2)	10.3 (4.5)	**5.911***	0.34
SQ hostility-irritability	4.4 (3.8)	4.3 (5.1)	0.034	0.02
PDQ39 total	259.7 (110.0)	189.1 (101.2)	**24.087****	0.67
UPDRS total	54.0 (29.3)	42.1 (25.8)	**14.635****	0.43

Note. *$p \leq 0.05$, **$p \leq 0.01$; PWB=Psychological Well-Being Scales; QoL=Quality of Life; LS=Life Satisfaction; GQ=Gratitude Questionnaire; PLC=Positive Life Changes; PTG=Posttraumatic Growth inventory; PSI=Psychosocial Index; SQ=Symptom Questionnaire.

Table 4.3 *Socio-demographic differences between PD patients with low well-being (LWB - low PWBS/low LS) and PD patients with high well-being (HWB - high PWBS/high LS)*

	LWB (n=22) M (DS) / N (%)	HWB (n=32) M (DS) / N (%)	F/ $\chi 2$
Age	70.5 (1.6)	70.6 (1.3)	0.005
Years of education	10.6 (4.0)	10.2 (4.7)	0.134
Years from diagnosis	5.2 (3.8)	7.3 (5.8)	2.131
Gender			0.099
Men	16 (72.7%)	22 (68.8%)	
Women	6 (27.3%)	10 (31.3%)	
Marital status			0.208
Unmarried	16 (72.7%)	25 (78.1%)	
Married	6 (27.3%)	7 (21.9%)	
Children			4.620*
Yes	19 (86.4%)	32 (100.0%)	
No	3 (13.6%)	/	
Completers			0.351
Yes	18 (81.8%)	24 (75.0%)	
No	4 (18.2%)	8 (25.0%)	

Note. $*p \leq 0.05$, $**p \leq 0.01$; PD=Parkinson’s Disease; LWB=Low well-being; HWB=High well-being. PWBS=Psychological well-being scale; LS=Life satisfaction. PWBS and LS scores were standardized and combined in a cluster.

Table 4.4. *Differences between PD patients with low well-being (LWB - low PWBS/low LS) and PD patients with high well-being (HWB - high PWBS/high LS) in PWBS, LS, GQ, PLC, and PTG*

	LWB (M/SD)	HWB (M/SD)	Total sample (M/SD)	F	Cohen's *d*
PWB					
Autonomy	29.7 (5.8)	34.5 (4.2)	32.5 (5.4)	__12.583**__	1.00
Environmental mastery	25.0 (6.4)	33.2 (4.9)	29.8 (6.8)	__28.374**__	1.50
Personal growth	25.8 (6.3)	32.5 (5.5)	29.8 (6.7)	__17.366__**	1.17
Positive relations	30.6 (6.0)	35.0 (4.7)	33.2 (5.6)	__9.105**__	0.85
Purpose in life	23.6 (5.3)	29.0 (4.9)	26.8 (5.6)	__14.422**__	1.09
Self-acceptance	25.1 (6.3)	34.0 (5.0)	30.4 (7.1)	__33.096**__	1.63
PWB Total	159.8 (20.3)	198.2 (19.8)	182.5 (27.5)	__47.961**__	1.96
LS	5.1 (1.8)	8.0 (1.1)	6.8 (2.0)	__54.627**__	2.05
GQ	28.2 (6.7)	32.5 (4.9)	31.2 (5.9)	__4.421*__	0.77
PLC					
Life philosophy	18.9 (5.6)	19.9 (4.8)	19.5 (5.1)	0.459	0.20
Gratitude	17.1 (2.4)	17.3 (3.2)	17.2 (2.9)	0.056	0.07
Health perception	9.7 (3.5)	10.3 (2.9)	10.1 (3.1)	0.573	0.19
PLC Total	45.7 (9.9)	47.5 (8.8)	46.8 (9.2)	0.503	0.20
PTG					
Relations	21.1 (9.4)	21.7 (7.2)	21.4 (8.1)	0.069	0.02
New possibilities	13.1 (8.4)	11.4 (6.7)	12.1 (7.4)	0.673	0.23
Personal strengths	10.1 (6.4)	10.5 (5.1)	10.3 (5.6)	0.067	0.07
Spirituality	4.4 (3.8)	5.2 (3.8)	4.9 (3.8)	0.595	0.21
Appreciation of life	7.9 (5.1)	8.7 (4.1)	8.4 (4.5)	0.423	0.18
PTG Total	56.6 (30.7)	57.5 (23.4)	57.1 (26.3)	0.016	0.03

Note. $*p \leq 0.05$, $**p \leq 0.01$; PWB=Psychological Well-Being Scales; LS=Life Satisfaction; GQ=Gratitude Questionnaire; PLC=Positive Life Changes; PTG=Posttraumatic Growth inventory. LWB=Low well-being; HWB=High well-being. PWBS=Psychological well-being scale; LS=Life satisfaction. PWBS and LS scores were standardized and combined in a cluster.

Table 4.5 *Differences between PD patients with low well-being (LWB - low PWBS/low LS) and PD patients with high well-being (HWB - high PWBS/high LS) in PSI and SQ*

	LWB (M/SD)	HWB (M/SD)	Total sample (M/SD)	F	Cohen's *d*
PSI					
Distress	15.9 (7.7)	10.3 (5.3)	12.6 (6.9)	**10.137****	0.90
AIB	0.9 (1.1)	0.8 (1.1)	0.8 (1.1)	0.028	0.10
Stress	1.9 (1.4)	1.3 (1.5)	1.5 (1.5)	2.468	0.42
Well-being	5.7 (1.6)	7.3 (1.6)	6.6 (1.8)	**12.324****	1.02
QoL	1.9 (1.2)	2.5 (0.8)	2.3 (1.0)	**5.067***	0.62
PSI total	18.7 (8.9)	12.4 (5.9)	15.0 (7.8)	**9.728****	0.88
SQ					
Anxiety	10.3 (5.8)	5.1 (3.0)	7.2 (5.0)	**18.447****	1.21
Depression	11.3 (5.3)	5.2 (3.7)	7.7 (5.4)	**24.433****	1.41
Somatic symptoms	13.1 (5.1)	11.6 (4.1)	12.2 (4.6)	1.504	0.34
Hostility-irritability	6.6 (4.1)	3.7 (4.0)	4.9 (4.3)	**6.745****	0.56
UPDRS total pre	64.5 (7.4)	57.5 (6.0)	60.2 (33.1)	0.529	1.10
PDQ39 total pre	325.8 (123.3)	241.8 (107.3)	276.0 (120.4)	**7.076****	0.80
MMSE pre	28.4 (2.0)	28.9 (1.49)	28.7 (1.7)	1.101	0.30

Note. *p≤0.05, **p≤0.01; PD=Parkinson's Disease; PSI=Psychosocial Index; AIB=Abnormal Illness Behavior; QoL=Quality of Life; SQ=Symptom Questionnaire; ZBI=Zarit Burnout Inventory; MMSE=Mini Mental State Examination; UPDRS=Unified Parkinson Disease Rating Scale; PDQ39= Parkinson's Disease Questionnaire.

LWB=Low well-being; HWB=High well-being. PWBS=Psychological well-being scale; LS=Life satisfaction. PWBS and LS scores were standardized and combined in a cluster.

Table 4.6

Regression Models Predicting PDQ39 total score at post test in patients (N=42)

	Model 1		*Model 2*		*Model 3*	
	β	*p*	*β*	*p*	*β*	*p*
Age	0.020	0.900	0.203	0.129	0.189	0.136
Gender	0.134	0.414	0.043	0.727	0.056	0.633
Marital status	0.088	0.585	0.254	0.046	0.205	0.096
Years from diagnosis			0.171	0.192	0.203	0.108
PDQ39 total scores pre			0.691	<0.001	**0.530**	**0.001**
Cluster (low wb vs high wb)					**-0.297**	**0.034**
R^2	0.028		0.486		0.549	
R^2 change	0.028		0.458		0.063	
F value	0.370	0.775	6.818	<0.001	7.110	<0.001

Note. PDQ39=Parkinson’s Disease Questionnaire – patient version. For gender: 1=men, 2=women; marital status: 1=married, 2=not married (unmarried, divorced, widow); cluster: 1=low psychological well-being and low life satisfaction, 2=high psychological well-being and high life satisfaction. R^2 change for Model 1 indicates variance explained by socio-demographic factors (age, gender, marital status). R^2 change for Model 2 indicates variance explained by illness-related variables (years from diagnosis and PDQ39 total initial scores) after controlling for socio-demographic factors. R^2 change for Model 3 indicates variance explained by cluster (low psychological well-being and low life satisfaction VS high psychological well-being and high life satisfaction) after controlling for socio-demographic factors and illness-related variables.

Figure 4.1. Research flow chart

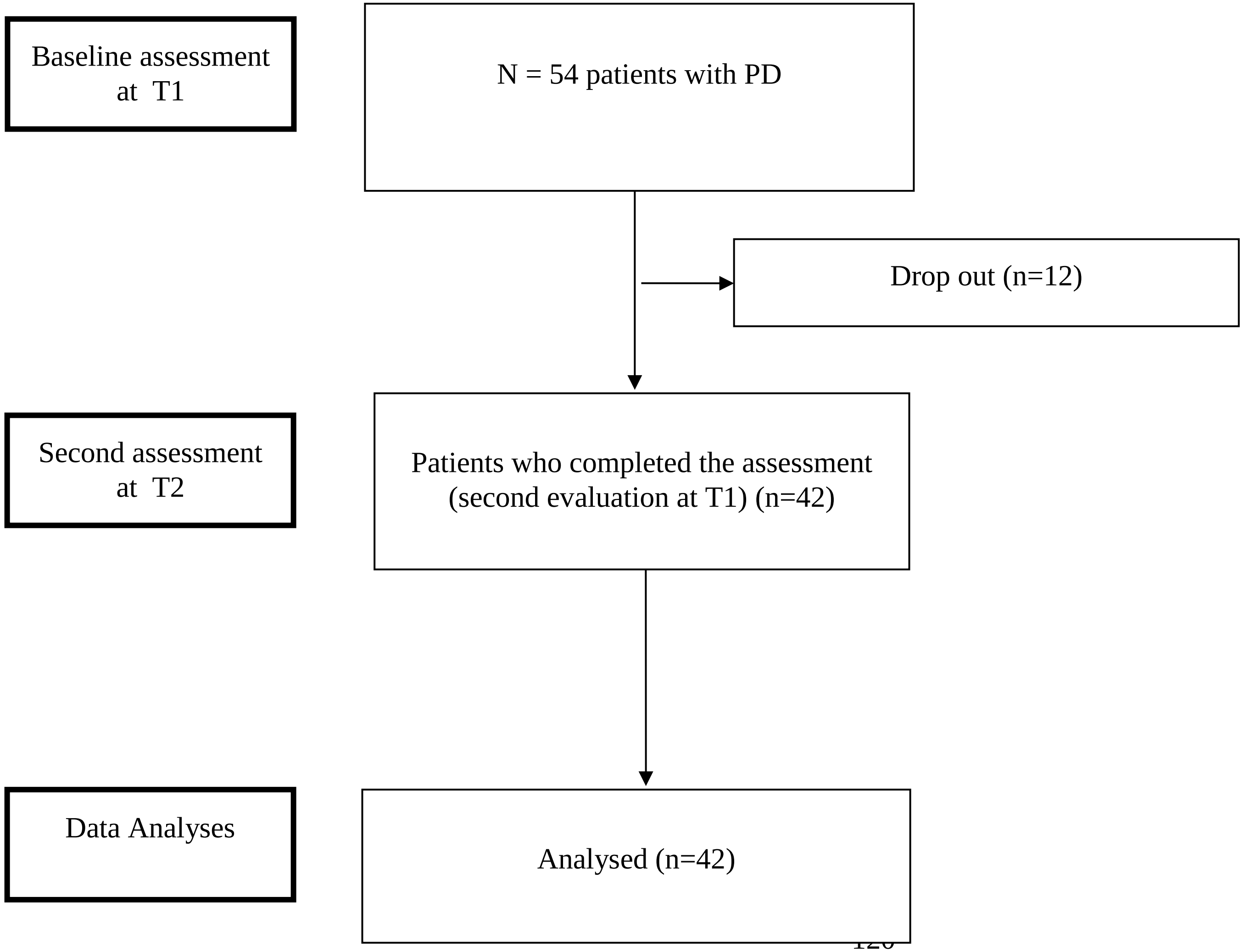


Table 4.7 *Socio-demographic of caregivers of PD patients completers and caregivers non-completers*

	Completers (N=38) M (DS) / N (%)		Non-completers (N=12) M (DS) / N (%)		F/ χ2
Age	59.6	14.3	64.7	12.6	1.193
Years of education	12.0	4.6	10.8	5.0	0.599
Years of assistance	5.6	4.4	7.7	6.5	1.466
Gender					0.009
Men	9	23.7%	3	25.0%	
Women	29	76.3%	9	75.0%	
Employment					0.261
Employed	15	41.7%	4	33.3%	
Not-employed	21	58.3%	8	66.7%	
Marital status					0.247
Unmarried	7	18.4%	3	25.0%	
Married	31	81.6%	9	75.0%	
Children					0.001
Yes	31	83.8%	10	83.3%	
No	6	16.2%	2	16.7%	

Note. $*p \leq 0.05$, $**p \leq 0.01$

Table 4.8 *Differences in total scale between T1 and T2 among caregivers*

	T1 M (DS)	T2 M (DS)	F	Cohen's *d*
PWB total	186.8 (26.6)	183.1 (30.7)	0.999	0.13
QoL	2.4 (0.6)	2.4 (0.8)	0.000	0
LS	6.6 (1.7)	6.6 (1.7)	0.127	0
GQ	32.1 (6.1)	31.4 (6.5)	0.944	0.11
PLC total	44.5 (8.7)	45.1 (9.1)	0.190	0.07
PTG total	37.6 (27.0)	38.1 (25.9)	0.031	0.02
PSI total	10.8 (7.8)	9.3 (6.2)	**3.960***	0.21
SQ anxiety	6.3 (5.9)	5.5 (4.8)	0.946	0.15
SQ depression	5.9 (4.7)	5.3 (4.0)	1.427	0.14
SQ somatization	7.4 (5.7)	7.7 (5.8)	0.123	0.05
SQ hostility-irritability	3.2 (3.9)	2.9 (3.5)	0.225	0.08
PDQ29 total	108.4 (99.4)	96.7 (86.4)	1.431	0.23

Note. $*p \leq 0.05$, $**p \leq 0.01$; PWB=Psychological Well-Being Scales; QoL=Quality of Life; LS=Life Satisfaction; GQ=Gratitude Questionnaire; PLC=Positive Life Changes; PTG=Posttraumatic Growth inventory; PSI=Psychosocial Index; SQ=Symptom Questionnaire; PDQ29=Parkinson's Disease Questionnaire – carer version.

Table 4.9

Socio-demographic differences between caregivers with high well-being/low caregiver burden (HWB, n=27) and caregivers with low well-being/high caregiver burden (LWB, n=22)

	HWB M (DS) / N (%)	LWB M (DS) / N (%)	F/ χ2
Age	56.6 (13.6)	65.8 (12.4)	**6.050***
Years of education	11.7 (4.8)	11.9 (4.5)	0.024
Years of assistance	7.0 (5.1)	5.3 (5.0)	1.519
Gender			
Men	8 (29.6%)	4 (18.2%)	0.859
Women	19 (70.4%)	18 (81.8%)	
Marital status			3.148
Married	19 (70.4%)	20 (90.9%)	
Unmarried	8 (29.6%)	2 (9.1%)	
Employment			3.032
Employed	14 (51.9%)	6 (27.3%)	
Unemployed	13 (48.1%)	16 (72.7%)	
Children			2.291
Yes	20 (74.1%)	20 (90.9%)	
No	7 (25.9%)	2 (9.1%)	
Completers			0.067
Yes	20 (74.1%)	17 (77.3%)	
No	7 (25.9%)	5 (22.7%)	

Note. *p≤0.05, **p≤0.01; HWB=high psychological well-being, high life satisfaction, low caregiver burden (PDQ29); LWB=low psychological well-being, low life satisfaction, high caregiver burden. PWBS=Psychological well-being scale; LS=Life satisfaction; PDQ29= Parkinson’s Disease Questionnaire – carer version. PWBS, LS and PDQ29 scores were standardized and combined in a cluster.

Table 4.10

Differences between caregivers with high well-being/low caregiver burden (HWB, n=27) and caregivers with low well-being/high caregiver burden (LWB, n=22) in PWBS, LS, GQ, PLC, and PTG

	HWB (M/SD)	LWB (M/SD)	Total sample (M/SD)	F	Cohen's *d*
PWB					
Autonomy	34.9 (4.3)	29.7 (6.4)	32.6 (5.9)	**11.740****	0.92
Environmental mastery	34.8 (5.3)	24.4 (4.3)	30.1 (7.2)	**54.050****	2.18
Personal growth	34.1 (4.5)	28.0 (3.9)	31.4 (5.2)	**24.848****	1.47
Positive relations	36.5 (4.1)	31.6 (4.8)	34.3 (5.0)	**14.747****	1.13
Purpose in life	30.6 (5.5)	23.9 (6.0)	27.6 (6.6)	**16.971****	1.19
Self-acceptance	35.6 (4.6)	24.7 (5.2)	30.7 (7.3)	**60.440****	2.28
PWB Total	206.6 (19.3)	162.3 (15.4)	186.7 (28.3)	**76.413****	2.56
LS	7.9 (1.3)	5.5 (1.4)	6.8 (1.8)	**38.315****	1.82
GQ	35.4 (4.4)	27.2 (6.8)	31.7 (6.8)	**27.060****	1.49
PLC					
Life philosophy	19.6 (3.9)	16.0 (4.6)	18.0 (4.6)	**8.770****	0.87
Gratitude	15.3 (2.8)	15.2 (3.1)	15.3 (2.9)	0.033	0.03
Health perception	11.4 (2.4)	9.4 (3.0)	10.5 (2.8)	**6.760****	0.76
PLC total scores	46.3 (7.9)	40.5 (9.4)	43.7 (9.0)	**5.422***	0.69
PTG					
Relations	15.1 (10.7)	14.0 (8.2)	14.6 (9.6)	0.147	0.11
New possibilities	8.3 (6.4)	7.8 (5.7)	8.1 (6.0)	0.086	0.08
Personal strengths	9.4 (5.5)	8.0 (4.8)	8.8 (5.2)	0.781	0.27
Spirituality	3.0 (3.4)	3.5 (3.2)	3.2 (3.3)	0.310	0.15
Appreciation of life	6.0 (4.4)	5.4 (3.6)	5.7 (4.0)	0.335	0.15
PTG Total	41.8 (27.8)	38.8 (21.8)	40.5 (25.1)	0.175	0.12

Note. *p≤0.05, **p≤0.01; HWB=high Psychological Well-being (PWBS), high Life Satisfaction (LS), low caregiver burden (PDQ29); LWB=low psychological well-being, low life satisfaction, high caregiver burden. PWBS=Psychological well-being scale; LS=Life satisfaction; PDQ29= Parkinson's Disease Questionnaire – carer version. PWBS, LS and PDQ29 scores were standardized and combined in a cluster. GQ=Gratitude Questionnaire; PLC=Positive Life Changes; PTG=Posttraumatic Growth inventory.

Table 4.11

Differences between caregivers with high well-being/low caregiver burden (HWB, n=27) and caregivers with low well-being/high caregiver burden (LWB, n=22) in PSI and SQ

	HWB (M/SD)	LWB (M/SD)	Total sample (M/SD)	F	Cohen's *d*
PSI					
Distress	4.6 (4.0)	13.6 (6.9)	8.6 (7.1)	**10.606****	1.67
AIB	0.4 (0.6)	0.8 (1.1)	0.6 (0.9)	0.926	0.47
Stress	1.5 (1.3)	2.2 (1.6)	1.8 (1.5)	1.304	0.50
Well-being	8.1 (1.2)	5.5 (1.8)	6.9 (2.0)	**15.689****	1.77
QoL	2.7 (0.5)	1.8 (0.7)	2.3 (0.7)	**61.179****	1.54
PSI total	6.5 (4.6)	16.6 (7.1)	11.0 (7.7)	**11.689****	1.76
SQ					
Anxiety	3.4 (3.9)	10.5 (5.5)	6.6 (5.8)	**27.426****	1.55
Depression	3.3 (2.9)	9.7 (4.4)	6.1 (4.8)	**37.666****	1.79
Somatic symptoms	4.9 (4.0)	11.9 (5.0)	8.0 (5.6)	**29.537****	1.60
Hostility-irritability	2.4 (3.1)	5.3 (4.7)	3.7 (4.1)	**6.321***	1.80
PDQ29					
Personal/social activities	13.9 (13.6)	46.2 (28.5)	28.4 (26.8)	**27.320****	1.53
Anxiety-depression	19.4 (11.8)	55.0 (23.3)	35.4 (25.2)	**48.282****	2.03
Self-care	7.0 (6.8)	42.3 (29.8)	22.9 (27.0)	**35.548****	1.75
Stress	16.8 (12.0)	51.2 (25.6)	32.2 (25.8)	**38.488****	1.82
Total score	56.9 (35.3)	194.5 (101.2)	118.7 (99.6)	**43.568****	1.94
PDQ39[a]	273.9 (103.4)	275.4 (132.3)	275.0 (116.0)	0.002	0.01

Note. *p≤0.05, **p≤0.01; HWB=high Psychological Well-being (PWBS), high Life Satisfaction (LS), low caregiver burden (PDQ29); LWB=low psychological well-being, low life satisfaction, high caregiver burden. PWBS=Psychological well-being scale; LS=Life satisfaction; PDQ29= Parkinson's Disease Questionnaire – carer version. PWBS, LS and PDQ29 scores were standardized and combined in a cluster. PSI=Psychosocial Index; AIB=Abnormal Illness Behavior; QoL=Quality of Life; SQ=Symptom Questionnaire; PDQ39=Parkinson's Disease Questionnaire, patient version.

[a] Values refer to the scores reported by each patient, coupled with his/her respective caregiver.

Table 4.12

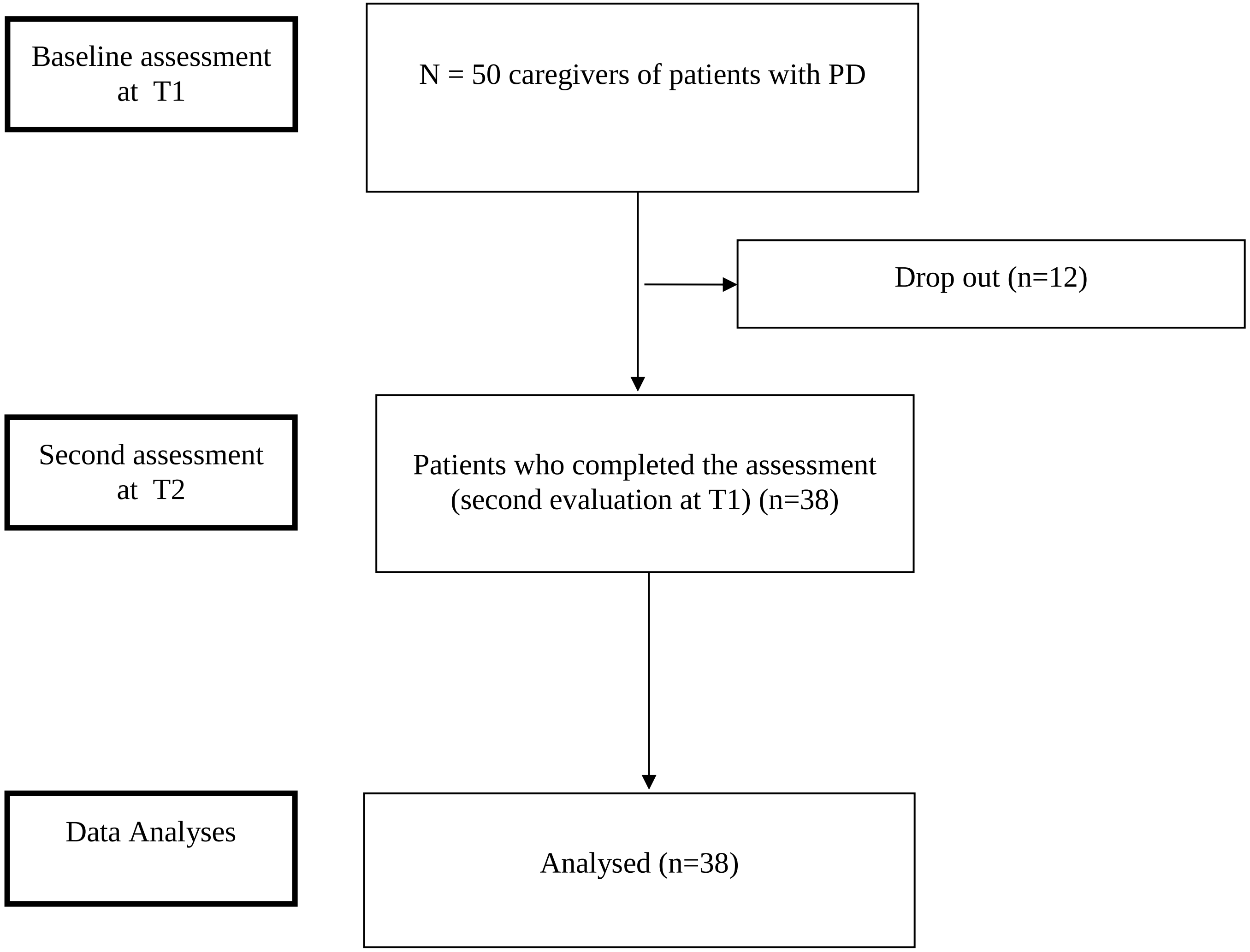
Regression Models Predicting PDQ29 total score at post test in caregivers who completed the assessment (n=38)

	Model 1		*Model 2*		*Model 3*	
	β	p	β	p	β	p
Age	0.210	0.358	0.221	0.189	0.080	0.585
Gender	0.259	0.135	0.231	0.073	0.178	0.103
Marital status	0.008	0.971	-0.052	0.767	-0.051	0.729
Years of assistance			-0.368	0.007	-0.220	0.065
PDQ39 tot post[a]			0.631	<0.001	**0.520**	**<0.001**
Cluster (high well-being/low PDQ29 vs low well-being/high PDQ29)					**0.428**	**0.001**
R^2	0.112		0.553		0.692	
R^2 change	0.112		0.441		0.139	
F value	1.393	0.262	7.679	<0.001	11.232	<0.001

Note. PDQ29=Parkinson's Disease Questionnaire – carer version; PDQ39=Parkinson's Disease Questionnaire, patient version. [a] Values refer to the scores reported by each patient, coupled with his/her respective caregiver.

For gender: 1=men, 2=women; marital status: 1=married, 2=not married (unmarried, divorced, widow); cluster: 1=high psychological well-being, high life satisfaction, low caregiver burden 2=low psychological well-being, low life satisfaction, high caregiver burden. R^2 change for Model 1 indicates variance explained by socio-demographic factors (age, gender, marital status). R^2 change for Model 2 indicates variance explained by assistance-related variables (years of assistance and PDQ29 total initial scores) after controlling for socio-demographic factors. R^2 change for Model 3 indicates variance explained by cluster (high psychological well-being, high life satisfaction, low caregiver burden VS low psychological well-being, low life satisfaction, high caregiver burden) after controlling for socio-demographic factors and assistance-related variables.

Figure 4.2. Research flow chart



CHAPTER 5

GENERAL CONCLUSIONS AND CLINICAL IMPLICATIONS

PD due to its neurodegenerative and progressive nature is associated to numerous types of impairments at physical, psychological and social level. PD may determine motor (tremors, slowed movement, crippling muscle stiffness and impairments of posture and balance) and non-motor symptoms such as mood disorders, anxiety, somatization, hallucinations, sleep disturbances, sexual and bladder problems. The most common and efficacious treatment is represented by the administration of L-dopa, which may reduce or control motor symptoms. However, pharmacological treatments may lose efficacy over time, and they may produce very disabling side effects (e.g., impulse control disorders, etc.). Other possible treatments are represented by surgery and by physical rehabilitation programs. Physical activities, in particular were found to be essential for preserving motor functioning, autonomy and quality of life. Unfortunately, patients may also suffer not only from primary psychological symptoms/disorders (related to the illness) but also they may develop symptomatology as a psychological reaction to the diagnosis and its related impairments. PD patients may tend to isolate themselves from social activities/bonds because of their problems in physical autonomy but also because of the visibility of their symptoms. For example, the stiffness of their facial muscles may induce them to experience embarrassment and may make them appear emotionless and uncommunicative. This can increase social isolation and also negatively influence their compliance to medical treatments or participation to physical programs.

In addition, PD may impact not only patients who suffer from it but also their caregivers. They are often forced to take new roles and responsibilities, and this may lead them to experience a great physical, psychological and economic burden. These increasing levels of burden are often related to the increasing loss of independence of patients that progressively needs more and more levels of assistance and support (physical, psychological and support). Moreover, they often are not involved in specific supportive intervention or training that could provide them with useful interventions and strategies to better deal with their stressful situation. Thus, mental and physical health of PD informal caregivers can often be impaired, representing a risk factor for themselves and also for their patients' adaptation to the illness.

These disabling consequences have represented the focus of psychiatric and psychological studies for many years. However, with the growth of positive psychology, the perspective began to broaden. Although investigating distress and problems, research within medical settings started taken into consideration the evaluation of psychological resources and protective factors such as hedonic and eudaimonic well-being, psychological growth, and gratitude. The longitudinal exploration of these psychological resources in PD patients and in their caregivers was the aim of the present Phd research project.

To the best of our knowledge, this is the first study investigating the important role of hedonic and eudaimonic well-being in patients with PD and their caregivers after controlling for socio-demographic and clinical variables (for patients: level of dopamine and level of disability, for caregivers: assistance-related variables) with standardized tools with well-established psychometric properties and through a longitudinal design.

In line with previous preliminary qualitative findings this research documented that individuals suffering from PD, although sometimes may have deficits in recognizing emotions and suffer from apathy, compared to healthy controls (Cronin-Golomb, 2013; Jankovic, 2008; Kan et al., 2002; Wagenbreth et al., 2016), can exhibit an intact ability to experience other dimensions of psychological well-being.

With the first study (chapter 2), in line with previous literature, we documented that patients reported more psychological symptoms, more impaired quality of life and life satisfaction when compared to matched controls. However, we observed that our patients experienced higher levels of eudaimonic well-being in all the dimensions except for autonomy, compared to controls. In addition, after controlling for socio-demographic and clinical variables, we found that older patients with lower levels of functional impairment (UPDRS) tended to experience higher PWB levels. Similarly, QoL in this sample resulted in being negatively predicted by UPDRS and marital status. Thus, those patients who are married and who reported lower functional impairments in UPDRS reported higher levels of quality of life.

In conclusion, this first study documented that the coexistence of well-being and distress could be experienced also by PD patients. Therefore, the research suggests that it is important to consider not only symptomatology and disability, but also psychological dimensions of well-being when assessing PD populations.

The presence of dimensions of psychological well-being is fundamental. In fact its protective role for both mental and physical health of other patient populations has been largely demonstrated (Ryff, 2014). These well-being dimensions result in a better adaptation to the illness itself (Ryff, 2014). Thus the combined assessment of well-being and distress, through appropriate and sensitive quantitative measures, may help clinicians better capture profiles of patients' problems and resources to enable tailored treatments to their specific needs.

With the second investigation (chapter 3) we documented that caregivers of PD patients experienced more impairments both in terms of distress, depression and in terms of positive dimensions of psychological functioning. In fact, they reported less eudaimonic and hedonic well-being, and less positive psychological changes compared to matched controls. These greater levels of psychological resources were found among caregivers of patients suffering from generic illnesses/illnesses related to their physiological aging process. Furthermore, these two groups did not differ in terms of caregiver burden. Considering the descriptive nature of this first analysis, a regression analysis was performed and showed that the main predictors of caregiver burden consisted of environmental mastery, personal growth and levels of depression. In particular, it emerged that lower levels of environmental mastery, higher levels of psychological growth and higher symptoms of depression are predictive of higher caregiver burden. Thus the positive association between growth and burden was not expected, in light of previous finding documenting the protective role of eudaimonic well-being for caregiver burden (Ryff, 2014). A possible explanation could derive from literature on the concept of post-traumatic growth. Hefferon et al. (2009) documented that the higher is the distress, the higher could be the growth (Hefferon et al., 2009). Psychological growth tend to be experienced as the struggles and the challenges increase in dealing with a stressful event. This could be the case of our caregivers. The more distressing the caregiving is, the higher is the opportunity to find new sources of meanings and growth. Finally, we documented that although those caregivers with higher levels of caregiver burden did not differ from those caregivers with lower levels of caregiver burden in terms of socio-demographic characteristics, the first group was found to be more vulnerable, when compared to the second one. In particular, they reported more symptomatology and less psychological resources both hedonic and eudaimonic, both more practical (e.g., environmental mastery) and more existential (e.g., gratitude, purpose in life, etc.). This is the first study documenting the relationships between caregiver burden and dimensions of positive psychological functioning. Given the protective role of these resources, these results must be considered when implementing interventions for helping groups of caregivers who suffer from burdensome condition of assistance. In line with our findings, we suggest that interventions should be more focused on improving dimensions of well-being, rather than targeting psychological distress (that could trigger existential growth). The diffusion of positive psychology could provide a useful field for planning and applying such positive interventions (Ruini, 2017b).

Finally, with the third longitudinal study (chapter 4) we aimed at investigating the possible protective role of hedonic and eudaimonic well-being for both patients and caregivers' adaptation to the illness over a six-month period. This research consisted of two separate studies.

The first one, focused on patients, showed that those patients who participated to both of the assessments, after six months showed improvements in symptomatology and in their motor and physical functioning (measured with UPDRS and PDQ39). Since in this time frame PD patients participated to physical activities, our result could be linked to the beneficial effect of exercise for preserving/maintaining and even ameliorating their level of disability. Finally, we documented that those patients with initial higher levels of both hedonic and eudaimonic well-being and lower levels of disability were found to report a better adaptation to the illness in terms of lower levels of disability/higher illness related quality of life after six months.

With the second study involving PD caregivers, we found similar results. Those who completed questionnaires also for the second evaluation were found to report no changes, except for the dimension of stress (compared to the initial assessment).

Furthermore, we clusterized the sample in groups of PD caregivers with high well-being and low caregiver burden and caregivers with low well-being and high caregiver burden. We observed that those individuals in the first group reported more psychological resources and positive changes (e.g., gratitude, positive changes in life philosophy) and less distress, when compared to the other group. Even more interesting results emerged when investigating the longitudinal functioning of caregivers. In fact, it was found that the only predictors of caregiver burden consisted of the cluster membership and their assisted's levels of symptoms (measured with PDQ39), after controlling for socio-demographic factors. In other words, those caregivers with higher initial levels of hedonic and eudaimonic well-being and lower caregiver burden and whose patients exhibited less disability, were found to experience lower caregiver burden in the long term.

In conclusion, also in Parkinson, the combination of hedonic and eudaimonic well-being was found to be protective for both patients and their caregivers' mental health.

These data may have various implications. First, they confirmed the coexistence of psychological distress and well-being, particularly in its existential dimensions (i.e. purpose in life, personal growth, self-acceptance) also in this severe, chronic and life-threatening illness. Thus, findings suggest the importance of increasing the percentage of individuals with optimal levels of well-being also among PD populations (both patients and caregivers).

This goal could be achieved by implementing psychosocial interventions (e.g., positive interventions) addressed at fostering the combined presence of hedonic and eudaimonic well-being (Friedman et al., 2017) and at reducing the burden related to providing assistance.

Recently, a specific program for promoting eudaimonic well-being in community dwellers resulted to be effective in increasing their levels of life satisfaction as well (Friedman et al., 2017). This was a USA pilot experience, but its larger implementation at international levels may yield promising results. Secondly, the implementation of similar positive psychosocial interventions may be particularly important for vulnerable older adults such as those with poorer mental health and those who daily provide a demanding assistance to one of their family members.

Considering the increased life expectancy all over the world, the maintenance/promotion of optimal mental health in older age should be viewed as a primary goal for welfare providers and/or policy makers (Jeste and Depp, 2010). Our investigation seems to suggest that addressing depression and alleviating caregiver burden may constitute key ingredients for promoting optimal well-being in older age. Future studies are needed to confirm these valuable findings.

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